Neph Cure for Rare Kidney Disease

PRESENTED TO FDA MARCH 2, 2026

Focal Segmental Glomerulosclerosis (FSGS) Community Petition

Food and Drug Administration:
Allow individuals with focal segmental glomerulosclerosis (FSGS) access to sparsentan

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NephCure's Mission:

To ensure that all individuals with rare, protein-spilling kidney disease have equitable access to the care and treatments that offer them the best kidney health outcome possible.

Community Letter

Dear FDA: Allow Individuals with focal segmental glomerulosclerosis (FSGS) Access to sparsentan

We, the members of the focal segmental glomerulosclerosis (FSGS) patient, caregiver, and advocacy community, write to you at a pivotal moment in history addressing our disease.

After decades of failed clinical drug development programs, we continue to rely on a limited number of severe, off-label medications with unpredictable efficacy and safety. We continue to face debilitating disease burden and progression, and all too often, recurrence of disease even after kidney transplantation. We continue to have more questions than answers about what our future, and the future for our children, holds with this complex and variable disease.

Our community, including the researchers, doctors, and many others who have devoted their lives to finding answers for this disease, have finally reached a critical moment in our combined efforts: the decision point regarding the first drug to complete a phase 3 study for FSGS. Through the DUPLEX study, sparsentan demonstrated profound and sustained reductions in proteinuria in a population with no FDA-approved treatment options.

As a crucial player in our journey to conquer FSGS, we want to acknowledge and thank the FDA for its longstanding and meaningful commitment to patients with rare kidney diseases. We recognize the agency's thoughtful research stewardship, scientific rigor and efficiency, and emphasis on incorporating the patient voice into regulatory decision-making. This commitment has given our community hope during years when progress felt out of reach.

Why are we coming to you now? Because despite the collective community's passionate efforts, time is running out for people living with FSGS.

Background on Focal Segmental Glomerulosclerosis (FSGS)

FSGS is a devastating, heterogeneous, and often episodic disease that remains one of the leading individual causes of kidney failure in both children and adults, accounting for up to 11% of the adult kidney transplant population and 15% of kidney failure in children. For people with FSGS, receiving a kidney transplant does not mean a cure: the disease reoccurs after transplant approximately 50% of the time, forcing patients back on dialysis indefinitely. Although designated as a rare disease, its burden is profound and lifelong, and it affects individuals of all racial and ethnic backgrounds. Most patients are diagnosed in childhood, adolescence, or early adulthood—years that should be defined by education, career development, and family formation, not dialysis, transplantation, and chronic immunosuppression.

For decades, FSGS patients have had no approved medicines and few meaningful options for treatment. Current clinical management relies heavily on off-label immunosuppressive drugs that often provide limited benefit while imposing significant short- and long-term toxicity. Many patients endure cycles of remission and relapse that unpredictably derail their lives; others progress rapidly to kidney failure within just one to two years of diagnosis. Both paths carry extraordinary physical, emotional, and financial costs.

Against this backdrop, sparsentan represents a long-awaited inflection point.

Proteinuria: Statistically Significant and Meaningful to Patients' Lived Experience

The DUPLEX trial demonstrated statistically significant, profound, and sustained proteinuria reduction against an active comparator—using pre-specified and prospectively collected data points. While the eGFR endpoint was not met, subsequent insights from the groundbreaking PARASOL (Proteinuria and GFR as Clinical Trial Endpoints in Focal Segmental Glomerulosclerosis) initiative clarified and confirmed that change in eGFR over two years in an inclusive population (such that enrolled in DUPLEX) may not capture a protective therapeutic effect in a rare disease trial.

Proteinuria reduction, by contrast, has emerged through rigorous research, patient data, and regulatory dialogue as a meaningful and appropriate endpoint in FSGS studies. Patients themselves have emphasized reduction of proteinuria as the leading clinical trial outcome that they felt was most important to their experience with FSGS, higher even than eGFR, through opportunities like the 2020 Externally Led Patient-Focused Drug Development Meeting on FSGS. Had the field known a decade ago what PARASOL has now conclusively validated, proteinuria reduction would likely have been selected as the primary study endpoint from the beginning.

Importantly, the DUPLEX trial was conducted during the COVID-19 pandemic and still achieved a 91% retention rate—an extraordinary outcome for any rare kidney disease trial, and particularly for one as complex as FSGS. This study recruited patients from the broad spectrum of FSGS diagnoses, including individuals with disease caused by genetic variants. In addition, families and community members advocated for pediatric inclusion, and this study remains one of the few in pivotal kidney disease studies to include participants as young as eight years of age. Patients participated, remained enrolled, and adhered because we are acutely aware of the stakes.

Rationale for Approval

Since the phase 3 program for sparsentan began, as many as half of all individuals with FSGS and unmitigated nephrotic-range proteinuria have likely progressed to kidney failure. For FSGS patients, delay represents not caution, but loss: loss of kidney function, independence, opportunity, and in some cases, life itself.

As patients, we live with the daily realities behind the endpoints and statistics. We are young adults forced to abandon schooling or careers, children who endure dialysis, repeated transplants, and prolonged hospitalizations before adulthood, and families navigating life with constant uncertainty. The cumulative burden of dialysis, transplant failure, and potentially life-altering side effects from unstudied treatments shape our willingness to accept uncertainty and risk in exchange for the possibility of preserving our kidney function and gaining time.

We ask for the opportunity to access the first therapy successfully studied and shown to meaningfully reduce proteinuria in FSGS. We are prepared to use this treatment responsibly, in partnership with our healthcare providers, and discontinue use if clinical benefit is not achieved.

The FDA has emphasized the importance of incorporating the patient voice, particularly in rare diseases with no approved therapies and high disease burden. The 21st Century Cures Act and the FDA's patient-focused drug development initiatives recognize that patients are uniquely positioned to contextualize benefit, risk, and unmet need. We respectfully ask that our voices be fully considered in the evaluation of sparsentan for FSGS.

As you deliberate, we ask that you remember us. We are the patients behind the data—those who enrolled, those who sacrificed, and those who today would give anything for five to ten more years before dialysis. For some, that time means finishing school or starting families; for many, it simply means living with hope and a future measured in years and decades rather than months.

We ask that our community not be penalized for the inherent variability of this disease nor for the diversity of clinical experiences it produces. We have stepped forward repeatedly and with urgency to participate in research and advance the field. We ask that our contributions not be made in vain. With innovation rapidly advancing across other kidney diseases, FSGS patients are waiting for the same progress to reach us—and not be held back due to the complexity of our disease.

Based on the totality of evidence from DUPLEX, the insights provided by PARASOL, and the severe, longstanding unmet needs of the FSGS community, we respectfully and urgently request that sparsentan be allowed to move forward as the first FDA-approved therapy for FSGS. We hope that this will be the first step of many in the development of a full range of novel therapeutics that will be needed to safely and effectively treat the full range of our experiences with FSGS.

We remain deeply grateful for your dedication to patients with rare kidney diseases and for your thoughtful consideration of this petition.

Sincerely,

NephCure on behalf of the FSGS Patient, Caregiver, and Advocacy Community

Background

On January 21, 2026, NephCure convened a virtual FSGS Town Hall to provide information around the U.S. Food and Drug Administration's (FDA) regulatory decision-making process, and in particular, potential implications of the FDA's review of sparsentan for focal segmental glomerulosclerosis (FSGS). The initial PDUFA date for this drug was January 13, 2026; on this date, the FDA issued a major amendment to the supplemental New Drug Application, extending the target action date to April 13, 2026.

During this Town Hall, expert physicians with extensive clinical and research experience in FSGS explained what the FDA's decision could mean for individuals and families living with FSGS, and how their voices and experiences, particularly in rare diseases, can and should be included in the regulatory decision-making process.

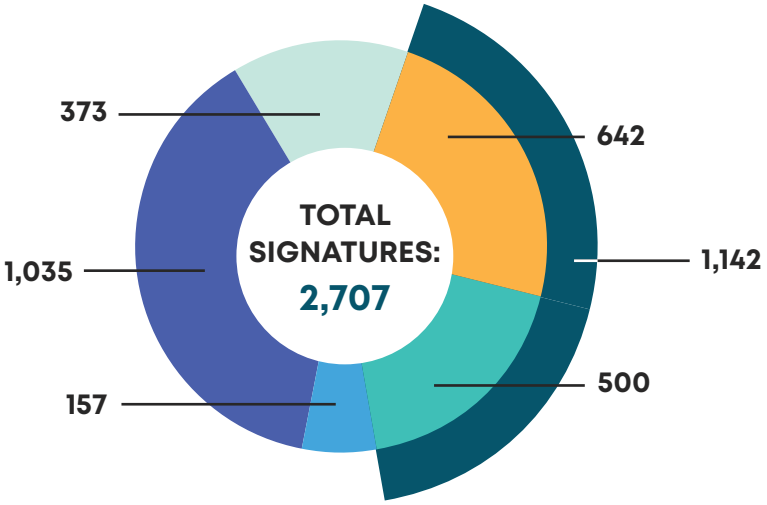
Following the Town Hall, NephCure issued a public Call to Action in the form of a community sign-on letter, launched on February 6, 2026, which invited individuals to share their lived experiences and perspectives and to formally express support regarding the approval of sparsentan for FSGS. The sign-on period remained open for two weeks, through February 20, 2026. The letter specifically invited participants to share experiences related to living with FSGS, participating in associated clinical trials, receiving sparsentan through trials or other access pathways, and navigating the physical, emotional, and financial burdens of the disease.

The sign-on letter was broadly disseminated through NephCure's communication channels, including website, email lists, SMS lists, and social media platforms, to ensure that individuals across the FSGS, and other rare, protein-spilling kidney disease, community had the opportunity to participate. Through this outreach, NephCure sought to capture a diverse and representative set of voices reflecting the real-world impact of FSGS and the urgent need for additional treatment options.

In total, we heard from **2,707** individuals, including **1,142** individuals living with FSGS and parents and caregivers of someone who has FSGS, **157** healthcare providers and researchers, **373** patients, parents or family members of someone who has been diagnosed with another rare kidney disease, and **1,034** friends of the FSGS community, advocates, or volunteers.

Signatures Breakdown

- **Living with FSGS***
- **A parent or family member of someone who has FSGS***
- A healthcare provider or researcher
- A friend to the FSGS community, an advocate, or supporter
- A patient, parent, or family member of someone diagnosed with another rare kidney disease
- **An individual living with, a parent, or family member of someone who has FSGS**



Responses were overwhelmingly from within the United States, with approximately **92%** of respondents representing the FDA's primary constituency. While input was also received from individuals across 18 countries outside the U.S., the findings are strongly reflective of the experiences and unmet needs of the U.S. FSGS community.

Signatures by Countries

The respondents represent patients across chronic kidney disease stages, ages, and treatment experiences, including those who have participated in sparsentan clinical trials and those who continue to face progressive kidney function loss without access to approved therapies.

Through written comments and statements, community members shared personal stories of disease progression, treatment uncertainty, clinical trial participation, and the everyday realities of living with or caring for someone with FSGS. We received **1,046** total written comments from individuals living with FSGS and parents or caregivers of someone who has FSGS, as well as **127** comments from healthcare providers and researchers.

Patient Story

Nicholas A.

Diagnosed at 17, Nicholas faced a severe case of FSGS that caused his skin to tear from the pressure of 40 liters of excess fluid. His journey included an emergency transition to dialysis, a life-threatening seizure, and a three-day coma, all while trying to maintain his education. Though Nicholas eventually received a transplant, his younger brother tragically passed away from the same disease, underscoring the desperate need for more effective treatments to prevent such catastrophic outcomes.

These perspectives underscore both the profound burden of FSGS and the hope represented by therapies that may slow disease progression and preserve kidney function.

In addition, the National Kidney Foundation (NKF), submitted a letter of support, writing on behalf of FSGS patients they represent and joining NephCure in making the request of the FDA to allow individuals with FSGS access to sparsentan.

The enclosed materials reflect the collective voice of the FSGS community and underscore the urgency felt by patients and families for timely access to therapies that may meaningfully impact disease progression. NephCure respectfully submits this packet to the FDA to ensure that these perspectives are considered alongside clinical and regulatory data as part of the decision-making process regarding sparsentan for the treatment of FSGS.

Patient Story

Hannah G.

Diagnosed at age six, Hannah battles steroid-resistant FSGS alongside a complex array of respiratory and immune complications that have resulted in multiple emergency hospitalizations. Her journey highlights the reality of current treatments; a high-dose steroid regimen not only failed to reduce her massive protein loss but triggered a cascade of severe side effects, including heart palpitations, an enlarged liver, and a fourfold increase in proteinuria. Hannah's family remains in a state of constant fear, navigating a lack of definitive answers and the use of harsh immunosuppressants to save her kidneys without further compromising her fragile health at such a young age.

Response Form

Time is critical for people living with FSGS. Sign the community letter urging the FDA to allow access to sparsentan and ensure patient voices are heard at this critical moment.

By completing the form, I acknowledge that I have read and understand the full contents of this letter and agree to be included as a sign-on supporter.

Name* _____ _____

First Name Last Initial

Country* _____

I am...*

- ☐ Living with FSGS
- ☐ A parent or family member of someone who has FSGS
- ☐ A patient, parent, or family member of someone who has been diagnosed with another rare kidney disease
- ☐ A healthcare provider or researcher
- ☐ A friend to the FSGS community, an advocate, or a volunteer

If you or someone you know has or had focal segmental glomerulosclerosis (FSGS), please respond to the question below, with specific examples if possible. How would the availability of sparsentan, potentially the first ever FDA-approved drug for FSGS, impact you or your family member? If you or your family member participated in the DUET, DUPLEX, or EPPIK studies, please feel free to share your experience or observations.*

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Comments

From Someone Living with FSGS

Question: If you or someone you know has or had focal segmental glomerulosclerosis (FSGS), please respond to the question below, with specific examples if possible. How would the availability of sparsentan, potentially the first ever FDA-approved drug for FSGS, impact you or your family member? If you or your family member participated in the DUET, DUPLEX, or EPPIK studies, please feel free to share your experience or observations.

Comments have been reviewed. Those deemed inappropriate or not providing relevant perspective have been removed.

Harlan J.	The impact is life extension to be with your family hopefully without dialysis.
Andrew S.	This drug would help me out. FSGS was responsible fo my kidneys failing. Anything that we can do to help prevent or cure kidney failure will be something that will always support
Julie L.	I'd like up know more. I'm on dialysis and am trying to get on the transplant list. I'd love to try this new potential drug for FSGS.
Marie Janelle T.	It would mean not having to live with dialysis or a kidney transplant later on in life. Dialysis is life saving but also comes with so many risks and complications. Kidney transplant suppresses the immune system and can reduce a person's quality of life. Not to mention the amount of medications that have various side effects. The fear of keeping healthy and hoping that rejection never happens. Medical trauma would be less. I have lived with FSGS and Alport Syndrome for a long time. It has brought financial troubles, depression, OCD, and altered our way of life. It has postponed my dreams of becoming a mother and accomplishing my career goals. It led me to renal failure. I can't emphasize enough how treating FSGS and maintaining healthy kidneys will be a gift to those who can still save their kidneys.
Kimberly H.	I have nephrotic syndrome with glommulearitus fsgs. Two transplants dialysis diagnosed 38 years ago. Not genetic
Joyce F.	Yes
Don L.	Make life better
Melissa N.	My mother and I are diagnosed with FSGS and anything to help our condition would be life altering to not need dialysis. I have two daughters who may find out when they are older that they have FSGS and if there was something to stop the progression of this disease it would be amazing!
Lisa P.	I didn't have FSGS originally, it was already in my deceased doner transplanted kidney. My kidney failure was due to type 1.5 diabetes. My husband was originally diagnosed with FSGS from his initial kidney biopsy. Sparsentan would help me keep my kidney healthy, so I don't have to go back on dialysis. I can continue to be an elementary school teacher.
Katrina B.	I've already had a transplant due to FSGs. My son was born with kidney disease and has FSGS. He visits the hospital in Boston every three months for his kidney disease. A transplant is in his future.

Comments

From Someone Living with FSGS

Christopher P.	I was diagnosed with FSGS in 2011 after a kidney biopsy, which was performed due to a diagnosis of high-blood pressure a year earlier. Despite this I was able to put off needing a transplant until 2018. Meanwhile my wife, who is diabetic, had her kidney fail on Thanksgiving day 2019 and had to do dialysis for nearly five years. Her 2024 transplanted kidney unfortunately came with an FSGS diagnosis from the previous deceased donor. If sparsentan works for FSGS it would be a great benefit to my wife and I.
Karen W.	I have FSGS, along with 8 other family members. I have watched my mother and three aunts all receive transplants and end up on dialysis and eventually pass away. My two uncles are currently on dialysis and have never been transplanted and my older sister was diagnosed with FSGS a year and a half ago. I was transplanted in 2007 and my creatinine level is slowly creeping back up. I worry about my two sons and two nieces also being diagnosed one day. If there is anything to help this horrible disease we need it. The wait for a transplant is long and being immunocompromised the rest of your life has it's challenges, not to mention is not healthy for our bodies.
Kelsie H.	It would provide me the opportunity to have a treatment option that does cause immunosuppression. Immunosuppression comes with many risks and long term negative effects.
Kristal H.	The implementation of this drug may help reduce or delay the need for dialysis or transplant in people with FSGS.
Glenda F.	The availability of this new medication would improve my life and keep me off of dialysis. It would help me to live a longer healthy life
Charlotte M.	I am 10 years in remission from FSGS, and the road to reaching normal kidney functions as a middle school student completely destroyed my confidence and trust in medicine. My experience consisted of multiple trial and error stages of different types of medication at different doses, with side effects a young child couldn't understand. I hope future kids with fsgs don't have to go through such uncertainty
Christy C.	Hi, I found out in 2017 that I have a solo kidney and it has FSGS stage 3B. I'm on blood pressure medicine to try to keep it stable. No cure they say until I hit stage five.
Samantha C.	I was diagnosed 7 months ago and we have been unable to find treatment that works for me. After many hospitalizations, recurrent AKIs, and a whole list of complications and side effects from many medications, having another option to try would be helpful when we are quickly running through the list of typical medications that have either not worked or made me worse.
Kristie G.	Research has always been crucial for this disease, and with the addition of new and advanced drugs, we can hope that more people will find long term relief. I have had FSGS/Nephrotic Syndrome for 22 years. I feel as though this step is a pivotal first step in showing more awareness to this disease, and getting treatment that many desperately need.
Gilbert W.	Transplant failed due to FSGS
Jake S.	I currently have FSGS. I am in tacrolimus which is not good for my body long term. This new drug would create a safer option for me. I need this badly, please.

Comments

From Someone Living with FSGS

Mary H.	Sparsentan would give hope for successful treatment of FSGS
Jonathan B.	well i am on dialysis for 8 years. guess it's too late to help me
Kristian G.	Having a medication that treats FSGS would help me not spill so much protein in my urine. Which would help my kidneys repair themselves a little bit or at least slow the progression of the disease. Having a medication that treats your disease is so important.
Susan P.	2 years ago I had a kidney transplant from a living donor. FSGS is reoccurring now. I live with fear of needing to be on dialysis again. A new treatment for this rare kidney disease would give me hope for a better future. I would have less stress and sleep better at night.
Sally C.	It would be great!
Tashara G.	Possibly would have helped me not go into kidney failure and had to get a transplant. Would love others who have not made it to the stages I have be treated and have another outcome for them.
Amber I.	Any medicine to help curb damage from FSGS would be wonderful.
Lillian C.	I was blessed with a kidney transplant. But until I received one, dialysis was not only brutal for me, but for my family. My son stood by me, held off in pursuing his dream, to be my caregiver. He saw when I was at my worst, he saw me be 1/2 of the person I was. But after transplant I thought I would be my old self (before diagnosis) but these anti rejection meds are no joke. 6 weeks after transplant all the energy I had was gone. My bones ached and I was weak and tired all the time. I wish, and I hope there is another option that can improve our quality of life. Or even better cure ckd with fsgs.
Lori M.	I have tried other treatments but have yet to reach remission. Sparsentan may be the answer we're looking for.
Michael J.	It would lower the protein in my kidneys allowing my native Kidneys to last longer
Rakeem W.	It would change my life if it works because the thing have Impacted my life and a cure would mean the world to me
Mary H.	Dealing with alot of issues before during and after kidney transplant I am being mentored weekly was able to come off dialysis Dec 26th had my transplant July 19th
TRACY W.	I have had two kidney transplants since 2002. It would change my life forever.
Heidi S.	It would have prevented me from having to endure dialysis and then a kidney transplant.
Grace-Ann D.	This would be life changing. If this drug could replace the current immunosuppressants that I take and be specific to helping with the FSGS diagnosis, it would change my life

Comments

From Someone Living with FSGS

Jeremy J.	I have not participated in any studies but i have been living with stage 3-4 FSGS since November of 2020. I believe a medication specifically designed for the treatment of FSGS would be very beneficial to my quality of life.
Margaret H.	It would allow me more treatment options.
Monica L.	When I was diagnosed with fsgs, they tried the usual meds & nothing worked. My kidneys quickly failed and I needed a transplant. A new medication would help keep the fsgs away. It was so scary to take so many medications that do not work for fsgs so having one that may would be a huge relief.
Chris B.	This drug is much needed for people with this dreaded disease the sooner the better
Darryl M.	I had FSGS and Membrane Neuropathy. I had a kidney transplant 03/18/2022. I'm praying the disease does not comeback.
Leah W.	It may simply allow me to LIVE.

"My name is David. I live with focal segmental glomerulosclerosis, and I do home hemodialysis every other day.

This disease has stolen dreams. It has prevented dreaming at times. It has made me question what I could do and who I could become. And the truth is, every patient's life and story is different. No two journeys look the same.

I have considered transplant, but the fear of recurrence is real. That is the reality many of us live with.

For years, treatment felt like we were borrowing medications meant for other diseases and hoping they would slow it down. Hoping for time.

The potential availability of sparsentan, possibly the first FDA approved drug specifically for FSGS, represents something bigger. It means future patients may have a treatment built for their specific disease. Something designed to slow progression before dialysis becomes the only option.

Progress matters.

Real treatment matters.

Hope matters."

- David R.

Comments

From Someone Living with FSGS

Paul S.	Fsg surviver, found when I was 16, went on dialysis at 50, transplanted at 60 now 6.5 years post
Keith B.	Would help anyone who lives with FSGS live a better life hopefully not on dialysis.
Melissa G.	I have been back on Dialysis for 10 Years I would be So Thankful to have the Availability of a different Treatment. Thank you
Francisco D.	Life changing
Teresa R.	It would have prolonged me having to have a renal transplant.
James W.	I am doing everything I possibly can to avoid dialysis. Unfortunately this disease has proven to be extremely difficult to manage.
Casey S.	I need something to help my kidneys fsgs I'm currently on dialysis.
Gavin T.	Having the opportunity to help extend the life of my native kidneys will allow me to have more time with my wife and kids and hopefully avoid potential complications that comes with either dialysis or transplant.
JEFF D.	A succesful teatment for FSGS would extend my life and make the quality of life better by avoiding or delaying end stage kidney disease. I currently take imunosuppresants that have significant risks if nothing else to catching many illnesses such as COVID that could also have severe consequences
Allison B.	FSGS is a very rare disease but when you have it, it impacts your life so dramatically. I am a working mom of three, runner, vegetarian, healthy and was diagnosed w idiopathic FSGS. Needless to say, my life was rocked. Swollen, 20-30 pounds of extra fluid, GFR to 45%, it was awful. Luckily after about two years of unsuccessful treatment, I found docs at Mayo Clinic who found gazyva to treat me. More options available would impact so many people.
Michael G.	A welcome miracle!
Brooks B.	a new FDA approved drug for FSGS would make my life as a teenager living with FSGS much easier and more stress-free, the current treatment side effects are very hard to live with at first, and this would be monumental
Sylvia B.	I am living with FSGS. I have been given 14 more months before my second kidney will be consumed. I am on the transplant list but because of so many antibodies in my blood it does not look like I will get a living donor in time. I have decided not to do dialysis at this time.
Margaret G.	Gives me HOPE to potentially to delay or even halt my stage 4 FSGS CKD from progressing to end stage kidney failure.
Wil P.	I'm the on living with FSGS and would like any improvement to the treatment of this disease and improve future outcomes

Comments

From Someone Living with FSGS

Chimezie M.	This would provide a medication that would help me manage my disease offensively, as opposed to just playing defense by managing BP and immune response with drugs like Valsartan and immunosuppressants.
Jess S.	Will save lives everyday!!!
Whitney W.	It could potentially save my life
Sara R.	Feel like there is nothing available to help. Imagine also living with the idea of being hopeless and this condition is going to kill you
Mike L.	Anything to improve quality of life.
Algenia H.	I'm sure it would help. I know very little about FSGS as I've just learned of this diagnosis. I haven't participated in any studies.
Florencia V.	Id love to find a Targeted medicine for fsgs before is too late for me
Ian C.	It would be great to get some relief
Mesha W.	Hopefully save my life
Mindi W.	Any treatment could significantly improve our lives. Especially given the fact that FSGS is recurrent even after kidney transplantation. I have been living on machines for 15 years waiting for something to improve my quality of life.
Janelle J.	It might make my life easier and transplants might stick vs rejection
Phillip C.	I am in a study currently. People with kidney disease need hope. Some hope. Please help us
Genoveva V.	I am currently living with FSGS. I was diagnosed 23 years ago. In the years since diagnosis I have only gone into remission once. A medication such as Spasentan, that is specifically for patients with FSGS would be so helpful to those of us living with this disease. It might mean the difference between a normal day and a symptomatic day. On symptomatic days I feel horrible fatigue, pain, and swelling. Most days are symptomatic days. Can you imagine for a moment what that must be like for me and others? Please make this drug available to all with FSGS to ensure that we have a greater chance of having normal days or at the very least less symptomatic days. The drugs that we currently have prescribed do little to help many of the symptoms we experience with this disease.
Ella F.	I am an 18 year old college student , FSGS has taken both my natural kidneys left me to dialysis and a transplant. I drug that can slow the progession, reach remission or better yet cure --what a welcome this would be to all of us with the dreadful disease. Thank you
Kelley R.	Just knowing a specific treatment is there for me should I need it already makes a world of difference.

Comments

From Someone Living with FSGS

Leslie O.	Currently have a kidney transplant so wouldn't need it at this time.
Dhruvika D.	It could be big relief and life changing for someone struggling with fsgs and uncertainty of the future I hold .
Amy R.	Would help me live a more normal life.
Carol K.	I am stage 4 with FSGS. Anything that could keep me from dialysis would be great. I am willing to participate in trials.
Jessica W.	Please help us live a more normal lifestyle
Stacy J.	I have been living with this for 17 years been on haemodialysis for 7. If th8s can help me I would be very grateful.
Shelly F.	It might save my kidney
Joni R.	Find a cure . Would it be covered by health care or kidney foundation?
Christine C.	It would relieve me of the stress I have of being worried that eventually I may have to go on dialyses or even try to get a kidney transplant. Being in hospital (for the third time) was stressful (with our strained health care system) for me and more perhaps than for most as I don't have family members in this part of the country to visit me. Two times, while in hospital, despite walking in the hallways to try and stay strong I became very weak and required physio. I think also of the repercusions to our health care system as it has to take care of me when I flare up and also in other ways. Also, daily I have my medication routine of prednisone, amlodipine and ramipril amongst other things.
Amardeep D.	I have lived with FSGS for over 25 years. During which time I have been home hemo dialysis for almost 23 of those years. I had a failed transplant due to aggressive nature of my FSGS returning within days after transplant. I have refrained from being transplanted again as there no real treatment for dealing with my FSGS. This disease has taken much from me in this life. Most of which I cannot begin to explain in this letter. But a treatment for FSGS would allow me to be transplanted and live a normal life again.
Ann S.	There are limited treatment options for FSGS and having access to new and novel drugs that slow progression and reduce symptoms and side effects would significantly improve quality of life for many patients. Maintaining higher levels of renal function is whole body protective. This new medication can help preserve kidney function for FSGS patients with better efficacy than any other drug that is currently used. This also means possibly fewer transplant needs and increased life span.
Jacqueline C.	If it works, it could be life changing.
Pamela S.	I only have one working kidney and it is consumed by fsgs so it it failing fast. Please help.
Isabel V.	Tremendously

Comments

From Someone Living with FSGS

Natalie D.	I was diagnosed with FSGS 6 years ago. I have been on numerous different medications in an attempt to lower protein spill and preserve as much kidney function as possible. They each come with their own unsavory side effects that greatly affect quality of life. The treatments have all been very expensive causing a financial burden for so many. If this medication can help just some of us with FSGS it is a win. Having FDA approved treatment brings more awareness and hopefully more affordable treatment recognized by insurance companies. It is disheartening to be told there really isn't a good option. Basically trying to buy more time until the inevitable dialysis or transplant. I don't know anyone who wouldn't want to try an approved option that could potentially slow or stop the progression of this disease. I don't want to just survive. I want to thrive and have the quality of life that allows me to participate and be present for my son and granddaughter for as long as possible. An FDA approved medication is hope for thousands of people, young and old, to live with an improved quality of life. My understanding is the trials have shown some positive results and if it will help even a few achieve quality of life or even remission then it is worth it.
Lawrence C.	Avoid dialysis
Meagan M.	Hello, I was diagnosed in 2020 with FSGS. When the disease was at its worst, I had over 40 lbs of fluid. I was hospitalized for a week for iv diuresis. Being able to lessen the protein loss with sparsentan would mean living with less swelling and fluid retention, more energy, better response to medications (since some medications are proteins), better cholesterol (able to get off statin), more stale hormone levels (hormones are also proteins). This disease affects every aspect of my life. Better control of proteinuria means better control of symptoms which results in a better quality of life. Please approve this medication. This community and those with FSGS desperately need a better treatment option.
Kendall T.	After 8 years of continuous prednisone wreaking havoc on my body I am in desperate need of an alternative option. Please!
Tia S.	Omg this would be amazing if it actually works and stops the protein from coming out of my kidneys! No more swelling and I would feel so much better!
Gina G.	Tried steroids, cellcept, rituximab infusions still spilling tons of protein for almost 20 years on and off remission. Hoping for something that will finally help.
Paul S.	It would be amazing, tho I am 6.5 years post kidney transplant
Sharon N.	The availability of Sparsentan may help prolong Kidney function and delay the need for dialysis, which will allow me to continue to be of service to my family and community.
Sara H.	To be able to have a treatment specific for FSGs, rather than treat with drugs not designed to treat FSGS, but rather control filtering to decrease damage would be amazing. Taking medications that have consequences and side effects, not targeted for the actual disease you have, is frustrating and disappointing. and ultimately a band-aide not a solution.
Andrea S.	Prayers to saving my transplanted kidney

Comments

From Someone Living with FSGS

Lisa L.	If Sparsentan works and has minimal side effects, it would vastly improve my life. I've been on PD dialysis for 8 years and still trying to get on the kidney transplant list. I'm a divorced, single mother of 5 children and 2 grands. This would mean, whenever I do receive a kidney transplant, I'll have a greater chance of the FSGS not destroying the new kidney and I can finally be free of this horrible disease. It would give me my life back. FSGS has robbed me of quality of life.
Sharon R.	I even lost my transplant due to fsgs! I'm currently waiting on my second transplant and it would be really nice if I don't lose this one I'm preparing to get to fsgs also.
Eugene M.	I am currently on immunosuppressants and I am unsure how safe this is for my body long term. I believe that a drug that was made specifically for FSGS would ease the mental strain I have. The diagnosis itself was quite depressing. I would live my day to day life much happier with treatment that didn't lower my immune system and gave me a true shot at living close to a normal life.
Jenn T.	It could be life-changing. I've lived with this disease for over 20 years now. I've had 2 transplants, with FSGS recurring in both.
Nikki C.	I am currently on dialysis due to secondary FSGS.i have been waiting for 7 years for a transplant. My FSGS was diagnosed 20 years ago. With a medication targeted for my disease I may have been able to not go on dialysis. I am also worried about FSGS reoccurring in a new kidney once I get one.
Faith S.	I want to be able to live more of a physically healthy life.
Onaje R.	Peace of mind
Windy W.	I was diagnosed with FSGS back in 2016 and had a kidney transplant in 2019. I feel if this drug was in question I am pretty sure it would have made a difference in my life as well before the transplant.
Ramond G.	I am not sure how it would impact me. I have not did much research on this, as this is my first time hearing about. My nephrologist says there is such clinical trials going on for.
Katie T.	I fear that my child or grandchildren may be affected by FSGS just like me.
Regina W.	I have had FSGS since since 2003. I am at the stage where they've tried all the treatments on me and now its maintained what function I have left. Thei treatment can potentially prolong my kidneys ao I could avoid dialysis and/or transplant.
Susan B.	I have been on 5 different medications that have not helped control my FSGS. We have been attempting to get Sparsenten covered by insurance, but they wont approve it since it is not approved by the FDA.
Lindsey J.	Improve quality of life and reduce fears about the future
Sally C.	Hope it would help with some of the symptoms

Comments

From Someone Living with FSGS

George W.	It would give more life with less pain and suffering. A renewed purpose would be instilled in me. It would give me hope to move forward with my life instead of just waiting to see what happens. I would become a more productive citizen.
Lawrence C.	Keep me off of dialysis
Miranda W.	An FDA approved medication would lessen the affects of steroids along with the affects of active FSGS which would result in a much easier remission process for patients already going through so much physically.
Aleta G.	Sparsentan has helped reduce my proteinuria levels from nephrotic range and my labs have been fairly stable for the last few months. It would be nice to know that this drug will continue to be available to me There is always the worry of it not being accessible to me long term.
Shanice Y.	Living with tags since age 23 on dialysis 2 transplants willing to find and support anything that can help
Jeremy C.	Having to be on dialysis is cumbersome, having access to a medication that will help with FSGS, could allow a transplant to last longer. I'm hoping to get a transplant in 2027 after I retire.
Tawana D.	I have FSGS, dedicated medication specifically for FSGS will improve my quality of life.
Leanne C.	It may allow me to stop taking my immune supression and live a more normal Like.
Tara G.	I want any option to slow this down possible!
Jennette M.	It would not have an impact on me at all; because I would NOT TAKE ANY OTHER DRUG. I've been doing VERY WELL maintaining my health, and my labs and diet.
Jeremy W.	Longer life without a transplant.
Zachary L.	I think anything would help for this rare disease there really isn't anything specifically for it
Andrew B.	I have tried many other treatments with no real success and am still in nephrotic syndrome. More recognition from the FDA means I can get better to see my daughter grow up.
Kent B.	I've had FSGS for almost 50 years now never have. I had an opportunity like this. I sure wish I had had it. It may still be able to be used for me if I begin to lose my kidney transplant.
Maria B.	It will save my life
Chelsea b.	I was part of the duplex trial and it was the only medication that worked for me. I was out of options and was so glad to find this trial and a new medication to try

Comments

From Someone Living with FSGS

Leilah S.	I was diagnosed with minimal change/FSGS at 18. It wasn't until after a suicide attempt that I had the tools to cope with the reality that even after a transplanted kidney the disease could come back. To know that a cure is possible means [for me] no longer living with the mental anguish that I will have this disease forever; because even transplant isn't a cure. I'm now 37 years old living with a ten year old kidney transplant. But, unfortunately there may come a day when I return to dialysis and if my FSGS returns- with a cure, at least I'd have a fighting chance. I've endured 15 surgeries, 3 seizures, and a medically induced coma. 5 years of dialysis. And now 9 years of monthly Nulojix IV infusions. I pray with a cure not another person experiences what I have over the past 18 years. I credit and dedicate my success as an FDA Panelist (Organ Transplantation) 2016, Harvard Speaker, National Kidney Foundation International Coalition Representative, World Kidney Day Congressional Record Feature, Mentor, Speaker, Author of "The Gift of Disappointment: A Memoir" to my therapist.

"Living with kidney disease has changed every part of my life—physically, emotionally, and financially. Dialysis is not just a treatment; it is something that takes hours from my days, limits my independence, and affects my ability to work, travel, and plan for the future. The emotional toll of living with uncertainty and chronic illness is just as heavy as the physical burden.

The availability of a medication like sparsentan, especially as a potential first FDA-approved treatment specifically for FSGS, would represent hope. Hope for slowing disease progression, preserving kidney function longer, and possibly delaying or preventing the need for dialysis or transplant. For patients and families, that kind of hope is life-changing. It means more time with loved ones, more stability, and a better quality of life.

Even for those of us already on dialysis, new treatments signal that the medical community is still fighting for us—that our lives and futures matter. Access to innovative therapies could mean fewer people experiencing the hardship that so many kidney patients face every day.

For families, the impact is just as profound. Kidney disease affects not only the patient but everyone who loves and supports them. A treatment that slows progression or improves outcomes would reduce emotional stress, financial strain, and caregiver burden.

Because of this, the availability and accessibility of sparsentan would mean more than a new medication—it would mean possibility, dignity, and hope for the kidney disease community."

- Elizabeth L.

Comments

From Someone Living with FSGS

Alice A.	Approval of this medicine for FSGS would provide a targeted treatment that can improve patients' quality of life, reduce serious complications, and lower healthcare costs
Debra S.	I have been waiting since 2018 to have this drug as an option for me and hopefully get off prednisone and tacrolimus. Thank you
Ann Marie C.	Hoping it would improve quality of life and reduce the flare ups that can take years to recover from.
Casey S.	A potential treatment for FSGS would literally change lives.
Kirsten U.	I was diagnosed in 1989. I've been living decades of misery and torture because of this disease. I've experienced breast cancer and double mastectomy and it was a footnote on my medical rap sheet in comparison to years of sickness, exhaustion, over 5 years of dialysis, 3 kidney transplants, all while trying to juggle work to pay for it all and raise 2 beautiful children with my husband of now 31 years. Please, if this 3rd transplant gets attacked by this disease or Gail's I will need some hope and help from this medication! THANK YOU!
Liron T.	Pilspri did magic to me in less then one month decrease my protein from 5 mg in to 1 mg !!
Anne B.	Approving sparsenten as an fda approved drug for fsgs would be a huge step towards better care for the rare kidney disease community.
Jane B.	I think it could be beneficial for many who are dealing with FSGS. As the disease is very patient specific and every patient has a different treatment plan and response to treatments/remission and relapse.
Jacob P.	Right now, living with FSGS can feel like being stuck in limbo. You do the right things, you take medications, you adjust your life, and then you wait for the next set of numbers to tell you whether you are stable or sliding. Having sparsentan available would change that. It would give patients and families a concrete option and a reason to believe progression is not inevitable. For me, that is not theoretical. I am a father of a young son, and the biggest fear hanging over my family is whether I will be there for him in the way he deserves as he grows up. A potential first approved treatment would reduce the constant background dread of dialysis, transplant, and the possibility of relying on loved ones for a donor. It would also help me be more present in my life, not living mentally in worst case scenarios. Approving a therapy for FSGS would also send a clear message that this community matters and that innovation in rare kidney diseases is worth pursuing.
Kevin B. F.	Could save my life.
Rebecca B.	I have FSGS and they have never been able to find a treatment that would help me. I just received a kidney transplant and it's starting to come back already.

Comments

From Someone Living with FSGS

John B.	Knowing there are more treatment options and life saving medications available mean the world to patients like me. I have had FSGS for 18 years with limited avenues for treatment and have talked to many peers who have not been as fortunate as I am. Some have had multiple transplants or dialysis which leads to a number of complications and even less life enjoyment. Having more ways to prolong or avoid these outcomes, let alone death, can only be a good thing.
Zachary L.	I think anything would help for this rare disease there really isn't anything specifically for it
Louise M.	I will need another transplant in the future having these treatments may mean I will not lose my transplant to fsgs it returned aggressively in first transplant
Henry S.	It would be fantastic!
Jodi B.	It would save me from dialysis and kidney transplant and I could enjoy my life!
Tracy W.	It could make a huge difference in my life and the quality of my life. Being able to enjoy the rest of my life would be incredible. Thank you!!
Sabrina W.	I have been blessed to get a new kidney, transplant due to FSGS. Unfortunately, FSGS is affecting my new kidney and I have to have plasma pheresis treatments to help control the kidney spilling protein. So, yes a treatment for this disease would be a tremendous blessing to fighting this disease! No. I have not participated in the studies listed but would like to have an intervention to slow down or stop FSGS destroying the filters of the kidneys causing them to spill protein and for people now finding out they have the disease to stop the progression and hopefully a cure! The FSGS community need this drug to help the current and future community.
Meghan R.	Having no success with the treatment of my fsgs, having a new drug approved would give me potential hope!
Dylan P.	Would mean the world to our quality life!
Allyson G.	The medication I am currently on is not safe to be on long term so I will need to find a new medication soon and we are trying to find a medication that is safe and affordable.
Elizabeth G.	We need hope, access to medications that show improvement in some can be a game changer. We also need world wide approval. Thank you.
Frank A.	I would go into remission and my kidneys would be saved.

Comments

From Someone Living with FSGS

Ashley J.	As someone living with FSGS, the potential availability of sparsentan would represent a meaningful advancement in treatment. Many individuals with FSGS rely on non–disease-specific therapies that can carry significant side effects and offer inconsistent control of the disease. A treatment specifically studied for FSGS could help reduce proteinuria, slow disease progression, and lessen reliance on broadly immunosuppressive medications, improving both stability and quality of life. FDA approval of a therapy for FSGS would also acknowledge the serious unmet needs of this rare kidney disease and provide long-overdue hope for patients and families.
Peter A.	I was diagnosed with FSGS over 20 years ago. Lately, my kidneys have been a little erratic and I have been spilling more protein than in the past so it's likely this drug could help slow that down
Brandon G.	Well it would certainly help if it was more available since it is very promising. Especially since it isn't in Canada but that starts with approval from the FDA in the states.
Pamela K.	I was in the DUET Study for 5 years. I believe it was working for me, and needs to be approved as soon as possible.
Daniel K.	When I was first diagnosed with FSGS I was spilling 28,000 mg of protein in 24hr collection studies…It took me over 5 years to reduce my spilling to a near normal level with the currently available treatments…The potential that Sparsentan has shown in the study information I have seen could have cut that time down and saved the function of my kidneys from the continued spilling I was dealing with…Please approve this med so that those of us still struggling with the damaging effects of FSGS can benefit from its treatment.
Eva F.	It would give me another treatment option after transplant. I've already had 2 transplants, and none of the treatments I've done got me to remission.
Brooke W.	I no longer have a functioning kidney and am completely dependent on dialysis after two previous kidney transplants. Living with FSGS has meant constant medical treatments, hospitalizations, and uncertainty about my future. I am currently trying to find a doctor willing to help me pursue a third transplant, but options are limited, and the physical and emotional toll on me and my family has been overwhelming. The availability of sparsentan would be incredibly meaningful because it represents the first treatment specifically for FSGS rather than just managing symptoms. If I am able to receive another transplant, a medication like this could help protect that kidney from the same disease process that caused my previous failures. For patients who still have native kidney function, it could mean delaying dialysis altogether. For people like me, it offers hope that future transplants could last longer and that others will not have to experience the same losses I have. This drug could change the trajectory of families affected by FSGS and give us a chance at longer, healthier, more stable lives.

Comments

From Someone Living with FSGS

Courtney G.	A FDA approved drug to help preserve my kidney function would be an answer to prayer. I have been rapidly losing kidney function over the past few years and feel helpless. I have been eating healthy and trying to do anything I can to remain healthy. I am terrified of the idea of getting a transplant and am currently dealing with a lot of emotional stress relating to that. The approval of a medication to reduce and help control my proteinurea would help me and so many other people dealing with FSGS. Thank you!
Saadiq F.	I did not participate in either of the studies mention but I have been living with FSGS for 31 years.
Michael B.	Living with FSGS
Susan D.	FSGS is an early death sentence. Any new treatment that might slow or stop progression of this disease would be a miracle.
Janis V.	I have lived with FSGS since I was 15. I am now 68. I had a transplant 19 years ago because of FSGS (a beautiful gift from my sister) but the disease recurred just a month after my transplant. I had several other treatments over the course of 3 years and have been in remission ever since, but having a more effective drug available for FSGS would be an incredible blessing.
Melissa M.	All of us need to stop or reduce protein spillage to help slow the progression of our disease. There's no cure but the least that can be done is approval of a medication to help. Please help us.
Melissa S.	My FSGS diagnosis was 27 years ago. I've tried so many medications, spent years on dialysis and had 3 transplants while waiting for an approved treatment. These high costs and loss of my ability to work should not be the future for new patients. We need an approved treatment now.
Breeana D.	Having the availability of any medication's, especially new medication's too help manage and slow the progression of FSGS would make a huge difference. The current available medication is minimal and there is a huge way to go to find new better and more treatment for this terrible disease
Jennifer P.	Knowing there is a treatment available for when I inevitably fall out of remission for FSGS would actually give me hope for longevity. The unknown is the worst part of this disease but that changes with a FDA-approved treatment. With this approval, I know I have hope! Please consider this approval carefully for all of us impacted by FSGS. Thank you for your time.
Shannon M.	This would help me after I receive my kidney transplant. This would allow me to take this medication to help make sure my FSGS doesn't attack my new kidney.
Pam S.	I have fsgs and my kidney is failing fast egfr at 30
Kadija B.	I have fsgs

Comments

From Someone Living with FSGS

Omar A.	Approval of an FSGS-specific treatment like sparsentan would make a big difference to my life - it would remove the uncertainty of not knowing whether the particular treatment I'm having will or won't work and give me the confidence that my disease is able to be managed long-term.
SHIRLEY S.	I feel that because this is a condition suffered by women, women of color that it's not getting love,time,care and finances. I humbly reached out to a doctor who studied FSGS extensively poured my heart out an he wouldn't even respond to say no I can't see you without insurance. I feel like no one cares.
Claire W.	I have been on Tacrolimus for over five years. I'm worried about the side effects I'm interested to hear more about sparsentan.
Thomas R.	Right now I feel like I'm being left to die, recurrent FSGS in 2016 and told I can't have another transplant. This feels like hope for the first something that genuinely would let me live again. This is so important, so vital for not only me but the countless others not only plagued by this horrid kidney disease but who have to see their friends and family also suffer with the impossibility to seek remedy and solution
Carla B.	As a patient living with FSGS, having an approved drug to treat this disease, would mean a lot to me and my family. I was diagnosed 17 years ago and have several family members who suffered CKD. Two family members succumbed to renal failure and two other family members finally received transplants after being on dialysis for years. Since my diagnosis, I have suffered from steroid-induced diabetes and avascular necrosis which caused me to need a bilateral hip replacement. Currently, my kidney functioning is at 31 percent. I fear every nephrology appointment that I will receive news that my kidneys have worsened. Have a drug that can reduce or slow down the progression of this disease, would allow me to live a longer, healthier life and be here for my fiancé, son, future grandchildren, and the rest of my family.
Hunter M.	It would be amazing to have an FDA approved treatment for an illness so rare
Mandy M.	It might help with m symptoms and improve quality of daily life.
Norman N.	Both my primary nephrologist and my FSGS specialist at the University of Washington medical center recommend that I try Sparsentan to treat my primary FSGS, as soon as it becomes available.
Marvin F.	I am on several medications currently, and my numbers are still slowly getting worse. I am ready to try something new, giving me hope for a better future. There are many folks in the same boat as me, just searching for answers.
John D.	Did not participate in clinical trials but it would help to have a treatment specifically for FSGS as opposed to taking different blood pressure meds.
Wendy A.	I am living with FSGS every day. This is a horrible disease. No explanation for cause, no definitive cure, drugs that have devastating side effects, relapse at every turn and no cure. It is a debilitating and demoralizing existence. This drug would offer a first hope to returning to a more normal life for the first time In years.

Comments

From Someone Living with FSGS

Ivan H.	I will keep the family together as I am the patriarch of the family and bread winner
Brian S.	It might have prevented both of my kidney transplants.
Kim M.	I am not finding a drug that is helping me with high protein. I would like to avoid dialysis and a kidney transplant if at all possible and feel like medication is a much better and more affordable option than both of those. Thank you for your attention.
Denise M.	Any medicine that would make my life easier would be wonderful
Alexis K.	Aftern2 failed transplants from recurrent FSGS this is a promising future for me and my family
Eric G.	Great
Mindy O.	I am affected greatly without having a reliable drug. No treatments have worked besides plasmapheresis twice a week. Quality of life is low.
Jackie O.	I have not had any specialty medicine for FSGS.
Jeremy R.	It would be life changing.
John P.	Would provide hope that my protein loss would lessen reducing further kidney damage. That means feeling better and reducing chances of living on dialysis, or even preventing a kidney transplant.

"Right now, living with FSGS can feel like being stuck in limbo. You do the right things, you take medications, you adjust your life, and then you wait for the next set of numbers to tell you whether you are stable or sliding. Having sparsentan available would change that. It would give patients and families a concrete option and a reason to believe progression is not inevitable.

For me, that is not theoretical. I am a father of a young son, and the biggest fear hanging over my family is whether I will be there for him in the way he deserves as he grows up. A potential first approved treatment would reduce the constant background dread of dialysis, transplant, and the possibility of relying on loved ones for a donor. It would also help me be more present in my life, not living mentally in worst case scenarios.

Approving a therapy for FSGS would also send a clear message that this community matters and that innovation in rare kidney diseases is worth pursuing."

- Jacob P.

Comments

From Someone Living with FSGS

Jose Paulo C.	It would mean that i have a chance of living a normal life
Norah F.	It would heavily impact my life as well as my fathers since we both have kidney problems due to FSGS.
Katlynn W.	Below I share the last two paragraphs of my appeal to Anthem, as they denied my request for coverage of this medication after I have exhausted all other available treatments with no relief and measured progress in my disease. Anthem again denied this request for coverage noting it was not medically necessary-as I slip closer to kidney failure. I respectfully request and plead with you that this medication be approved for use under my policy. While I understand the need to be measured and responsible while reviewing appeals, I also understand that without control of the high proteinuria, my case will ultimately end in kidney failure and the need for dialysis and transplantation. These costs will ultimately be exorbitant in comparison to the cost of Filspari under this program, and will further deteriorate my quality of life, and that of my family. I also recognize that recurrence of FSGS happens in more than half of all transplanted patients, further increasing long term costs and stress on the medical system. I am desperately trying to preserve my native kidney function, and find hope in the scientific literature which supports the use of Filspari to control proteinuria and preserve kidney function in FSGS. I am 36 years old, I have a young (3-year old, dinosaur-loving) son whose name is Jude, my greatest joy in my life has been that of being a mother. I am desperate to continue providing for and supporting my son and family, contributing to society and my career, and being healthy enough to show up physically every day for my son and husband. With chronic kidney disease and nephrotic syndrome to level at which I experience it, even making dinner each night can be difficult, tiring and painful. My son deserves a mom that can not only show up daily by cooking meals, helping at bath time and reading books at bedtime, but he also deserves a mom that can accompany him to the park, on field trips, have enough health and energy to make holidays special, and join him on family vacations. I beg you to reconsider authorization of this drug, not only for my health, but for that of my family and son.
Vishwanath K.	The availability of sparsentan will enable me to hopefully live long enough to walk my daughters to the aisle. They are currently 2 years and newborn.

Comments

From Someone Living with FSGS

Alicia H.	I have been living with focal segmental glomerulosclerosis (FSGS) for more than eight years, and in that time I have never reached full remission. My disease has been persistent despite trying the currently available treatment options. At this point, there are no remaining medications for me to try outside of therapies that are still awaiting FDA approval. Living with FSGS is not just "having a kidney condition." It affects nearly every part of my daily life. I live with constant uncertainty — never knowing if my labs will suddenly worsen, if swelling will flare, or if my kidney function will drop further. I have experienced repeated cycles of hope when starting a treatment, followed by disappointment when proteinuria remained high or side effects became unmanageable. Long-term steroid exposure and other immunosuppressive therapies have taken a toll physically and emotionally, yet my disease has remained active. Because I have not achieved remission, I continue to carry a high risk of progression toward kidney failure. That reality shapes every decision I make — from work and finances to family planning and long-term life goals. It is difficult to fully plan for the future when dialysis or transplant is a looming possibility. The mental burden is heavy: the constant monitoring, the lab draws, the waiting for results, and the fear each time numbers change. The availability of sparsentan would represent something I have not had in eight years: a treatment specifically approved for FSGS and designed to address the proteinuria that drives kidney damage. Right now, many of us are treated with medications never developed specifically for this disease, often with limited effectiveness and significant side effects. Having an FDA-approved therapy would mean: • A real chance at better proteinuria control, which could slow progression and help preserve my kidney function longer • Hope for disease stability, instead of feeling like I am just delaying the inevitable • Reduced reliance on broad immunosuppression, which carries serious long-term risks • Emotional relief from knowing there is a therapy developed with FSGS patients in mind For patients like me who have exhausted other options, this is not about convenience — it is about time. More time before dialysis. More time with functioning kidneys. More time to live a normal life without constant crisis management. FSGS is a rare disease, and that can make patients feel overlooked. The approval of sparsentan would send a powerful message that our disease matters and that targeted innovation for rare kidney diseases is possible. For me personally, it would mean renewed hope after years of plateaued progress, and the possibility of finally moving closer to remission rather than simply trying not to decline.
Juli M.	Having a drug approved specifically for FSGS patients would mean everything to our community. For far too long, we have been forced to rely on treatments that were never designed for us, especially steroids that cause serious and lasting harm. We deserve better. We deserve a therapy that actually targets FSGS, instead of years of trial and error and unnecessary suffering. This drug represents hope, dignity, and the chance for a better quality of life for every person living with FSGS. It is finally time to address a critical unmet medical need.
Robert G.	It would be the first drug that directly dealing with the actual symptoms.

Comments

From Someone Living with FSGS

Victoria S.	It would help catch FSG earlier and without side effects from previous medication's, that really have an effect on their body
Christine W.	If the drug was available at the time that I was first diagnosed, this could have made a big difference on preventing further decline of my kidney functions. The decline of my kidney functions resulted with me having a transplant. I was fortunate to have a living donor transplant, however, if I had a drug that could've prevented me from having to put another person at risk of their own kidney decline. This would've been very beneficial and I feel that if the FDA can approve medication for FSGS or other rare kidney diseases that would prevent anyone from experiencing dialysis or transplantation, we would probably be able to educate our providers as well as patients and family members.
Shawn O.	We've never been on these medications
Lacey S.	When I was first diagnosed with FSGS in 2018, there was a lot of uncertainty in my treatment plan and outcome. The doctors had to just use steroids as a first course of action, which I had tons of side effects from and gained a ton of weight. They also did not slow down the progression of my disease, and I entered kidney failure 6 years later. I am very lucky to have received a transplant in 2025, but I know there is a chance the FSGS will recur. The availability of an FDA approved drug for FSGS would give me a peace of mind about my future health, and help countless other people with this rare disease, who have so far had to deal with so much uncertainty.
Christopher M.	I am a 57 year old male living with FSGS for 10 years. I tried many drugs with no success and then I decided to enter the Duplex Trial. Well the drug Filspari from Travere has saved my kidneys. In 5 years on this drug my proteinuria has been reduced from 6 grams down to 1 gram and has kept my GFR stable. It has literally saved my kidneys and my life. Forever grateful
Bailey F.	I was diagnosed with FSGS in 2021 and since then I've tried 7 different courses of treatment, each failing to reduce my proteinuria. An FDA-approved drug for FSGS not only increases accessibility to a treatment approach that may help people like me go into remission, but it also continues the momentum within research around FSGS.
Olivia K.	I feel like I would have a better quality of life with a drug with has less side effects like sparsetan compared to other first line of drugs like tacrolimus.
Pamela M.	I would've been able to skip taking Prenisone. I now have to deal with steroid induced glaucoma and diabetes. I'm also steroid dependent.
Michelle W.	The availability of sparsentan would be life-changing. FSGS is a rare, unpredictable disease with very limited treatment options, many of which come with significant side effects and uncertainty. Having a targeted therapy that directly addresses proteinuria — one of the most critical drivers of disease progression — offers real hope not just for slowing kidney damage, but for preserving quality of life. For patients and families living with FSGS, an FDA-approved treatment would represent validation, progress, and the possibility of stability in a disease that often feels anything but stable.

Comments

From Someone Living with FSGS

Cheryl G.	It would certainly impact my life to have a definitive treatment that would allow me to improve or at least maintain my current kidney function and perhaps continue to keep my own kidneys for the remainder of my life.
Stefanie D.	I was diagnosed with FSGS in 2007 after a kidney biopsy. My goal is to stay healthy enough to see my young daughters through adulthood. Taking care of myself through diet and lifestyle changes and taking blood pressure meds has been the most my doctors have been able to do to maintain my kidney function, as there is no dedicated medication to treat FSGS and the continued scarring of my kidney due to proteinuria. Having access to a medication that can reduce or eliminate proteinuria would prevent future damage of my kidneys and allow me to maintain my kidney function, avoid degrading to the point of dialysis / transplant, and allow me to enjoy my remaining years in stable health with my family.
Shyam A.	I am living with FSGS with stage III renal impairment. My kidney function is deteriorating gradually. This medicine will help me to slow down the progression of kidney impairment.

Comments

From Someone Living with FSGS

Marc C.	As a kidney transplant recipient whose kidneys failure was caused by focal segmental glomerulosclerosis (FSGS), I offer this perspective based on lived experience with the disease and it consequences. FSGS is not a condition that slowly and predictably progresses with ample opportunities for intervention. in my case, and in the experience of many patients I have met through advocacy and care networks, the disease advanced rapidly, with limited therapeutic options beyond supportive care. At the time of my diagnosis and progression, dialysis was not a "treatment for FSGS, it was the consequence of having no disease modifying treatment available. Had an FDA-Approval therapy such as sparsentan been available earlier in my disease course, it is reasonable to believe that my trajectory could have been materially different. the ability to meaningfully reduce proteinuria and potentially slow kidney function declinemay have delayed or prevent progression the end stage kidney disease. even a delay of years would have had profound implications: preserving kidney function longe, avoiding dialysis initiation, maintain employment and insurance stability, and reducing the physical and psychological toll associated with kidney failure. Dialysis is often described as a life-sustaining therapy, but for patients with FSGS it represents a failure of upstream treatment options. Dialysis does not treat the underlying disease, does not halt systemic complications, and significantly diminishes quality of life. For many patients, it becomes a bridge to transplantation, if they are fortunate enough to be eligible and to receive an organ. In my own experience, transplantation required extensive planning, financial resources, and acceptance at multiple transplant centers, along with the ever-present fear of disease recurrence. The availability of sparsentan as a targeted therapy for FSGS would fundamentally change how patients and clinicians approach this disease. Instead of reactive management focused on managing decline, it would introduce a proactive option aimed at altering the disease course itself. This is especially critical for younger patients, working-age adults, and families facing the long-term burden of chronic kidney disease. While I did not personally participate in the DUET, DUPLEX, or EPPIK studies, I have followed their progress closely as a patient advocate. The willingness of patients and families to participate in these trials reflects the desperation created by the absence of approved therapies. Their contributions should be viewed in the context of an unmet medical need that has existed for decades. In summary, the potential approval of sparsentan represents more than a new medication, it represents the possibility of preventing dialysis, delaying or avoiding transplantation, and preserving quality of life for individuals with FSGS. For patients like me, it is not an abstract advancement; it is the difference between having options and having none. Thank you for considering the patient perspective in your evaluation.
Nelly N.	It will make life so easy and great to navigate

Comments

From Someone Living with FSGS

Raquel F.	The availability of sparsentan as a potential FDA-approved treatment for FSGS would bring meaningful hope and impact. Current treatment options are limited and often involve medications with significant side effects that do not always stop disease progression. A treatment specifically developed for FSGS could help reduce proteinuria and slow kidney damage, potentially delaying or preventing the need for dialysis or transplant. This would greatly improve quality of life and reduce stress and uncertainty for patients and families. While I did not participate in the DUET, DUPLEX, or EPPIK studies, the research behind these trials is encouraging and offers hope for better treatment options for those living with FSGS.
Rebecca O.	I am on experimental sparsentan and it is the first thing to get me in remission after fighting this disease for 12 years. Having access to this drug will continue to protect my kidneys and prolong the health of my native kidneys, pushing off dialysis as long as possible. I'm a single mom with two children who needs to work to support my family and dialysis would be a huge burden for my family.
LaToisha D.	Having access to this medication will help me personally as I have the APOL1 gene with the collapsing variant and I'm looking forward to medication to become available to treat FSGS specifically. I have not participated in studies as I have been newly diagnosed since October 2025
Susanne C.	I did not participate
Cathy L.	I am in remission now but never know when that could change. I need options and hope!
Patty R.	Need meds that will work
nikita k.	it would be life changing for myself and many others
Mindy E.	It has the potential to be life changing
Jennie P.	It might keep me from needing dialysis.
Shannon M.	The availability of sparsentan would make sure that once I have a kidney transplant taking this would help me know lose my kidney.
M E.	Iam a urosurgeon & I discovered that I had FSGS at 2011 while I was 45 y , now my kidneys status reaches stage 3 CKD & I am in need for this drug .
Avram A.	I would hopefully get my life back, be able to spend quality time with my wife and two children. I would hopefully be pain free, or the pain would be reduced so I can enjoy every day. Be able to work and support my family.
Evelyn C.	Well I trust that there is something to reverse this I'm only 28 and I believe in my soul this can work. thank you I don't know what else to say but I want to start a family and I going to share this with everyone I know
Darielle P.	These studies could prevent many young people from having their lives derailed by FSGS.

Comments

From Someone Living with FSGS

Amanda L.	I was diagnosed with fsgs at 19, before finishing college, before exploring my life & dreaming of what I could've fit into this lifetime. Devastating is an understatement. After nearly a year on dialysis and several failed kidney donor applications from friends and family I had my younger sister donate one of her kidneys to me at 21. Lived again like I hadn't experienced fsgs thanks to my one and only sister/family member who shared my blood type. 10 years later fsgs took over her kidney forcing me back in dialysis again. My mental health took a nose dive and worthlessness took over. I waited for about a year for a cadaver and I felt I have been took lucky as far as fsgs patients go. I know this is a reoccuring disease but if it could be slowed or prevented it would save so many lives, from kidney failure related issues or mental health.
Ramesh K.	Hello, i am living with FSGS since 1988, almost 38 years. Since then i am taking lisinopril. I am happy that new drugs is going to approve soon by FDA for fsgs. what i need to do get this drugs and how.please let me know. My email rkoirala03@yahoo.com
Sherrell H.	The availability of sparsentan would save my kidneys thereby prolonging my life
Kristie R.	I had a kidney transplant 3 yrs ago but lived with Fsgs my whole life. This would (ve) helped me extremely throughout my life!!!
Windy W.	I was diagnosed with FSGS and had a kidney Transplant in 2019. Not sure how it would affect me.
Marilou A.	I was diagnosed with FSGS while pregnant with my daughter. After failed treatments (prednisone, cyclosporine) it took it's course and ended having to be an dialysis. Thankfully I was able to get a kidney transplant. If there would have been better treatment for it I wouldn't have had to go through all the trials and errors and suffered so much. Now there could be a possibility that my daughter might have FSGS and I wouldn't want her to go through what I went through.
Susan M.	I'm currently in remission but will require an immunosuppressant to stay there. Because my immune system is compromised, I live a fairly isolated life trying to stay healthy and safe. Since Sparsentan is not an immunosuppressant it would be life changing. In addition, having FDA approval for it would make insurance easier to navigate - I've been declined treatment for medications with fewer side effects than prednisone because there are no FDA approved treatments for FSGS. Right now I live in fear of a relapse and what my safe and affordable options will be if one happens.
Keith H.	Not exactly sure if the drug would help me as I was diagnosed over twenty years ago. I had a transplant, thanks to the generosity of my brother, and the transplant has since failed. I have been on dialysis for two years now and it a tough way to live. Anything that could be done to help other patients recover their kidney function should be attempted. Thanks, Keith
Vickie L.	Because it can be hereditary, it can prevent future family members from long term dialysis.
Marco T.	Sparsentan would give me, someone with FSGS hope for a better quality of life.

Comments

From Someone Living with FSGS

Thomas M.	Might save you from Dialysis or Transplant.. I was lucky renovating to get a Transplant where millions will not have a chance at that…
Kimberly P.	The improvement of life overall how grand or small would be better with a medication that can help cure or even just reduce the excruciating and debilitating course of FSGS. Please we need this.
Jill H.	I have had 3 transplants with FSGS returning each time. Sparsentan could extend the life of my current transplanted kidney by reducing proteinuria. This would prevent me from needing to rely on dialysis in the future. Dialysis is a horrible quality of life.
francisco P.	I have Fsgs I hope for a cure I wanna be able to live a long life to be able to see my kids grow
Tracy S.	It would impact me by possibly increasing my kidney function.
Vanessa T.	I am 18 & was diagnosed with FSGS 1 year ago. On the old treatments, my kidney function was still declining. Now I am part of a trial for the new drug & My kidney function has improved!!! It started improving the very first month I took it! It has continued to improve each month! Please approve Sparsentan so that might have a chance at Remission! For the first time, I feel hopeful! Thank you, Vanessa
Leigh B.	It may have extended the life of my kidneys and delayed the need for a transplant.
Megan T.	I've lived with stage 3 chronic kidney disease caused by fsgs for 16 years. Any improvement or longevity provided by a medication is a win. Maybe I will live long enough and be well enough to see my daughter grow up and have a family of her own.
Katherine R.	Another possibility to help manage FSGS in the future.
Ana O.	I could have a chance at remission and to avoid dialysis and needing an eventual transplant. Also, a better quality and quantity of life.
Karen K.	No other medications have been effective for my fsgs. I've been on epic amounts of prednisone many times, cyclosporine, MMF, rituximaub, candesarten and forxia. While I'm not as sick as I once was, I live with edema and fatigue, not to mention the anxiety of knowing I could get worse and there are no treatments that have put me in remission. A new med that is actually effective for fsgs would be a game changer for me and my family. I have 7 year old twins and I fear fsgs could reduce the time I have with them. Thank you, K.
Douglas g.	It would impact my life greatly
Maureen R.	Might help to slow down my progression of FGN

Comments

From Someone Living with FSGS

Maureen R.	Hopefully would slow down my kidney failure
Michele B.	I guess if this was an option for me, maybe it could've saved my kidneys.
Robert G.	This would be life changing and could improve my chances of a successful transplant. My 1st one failed because my fsgs came back.
Angelia L.	I was diagnosed with FSGS collapsing approximately 3 1/2 years ago. My treatment options have been prednisone and cyclosporine. Both of these drugs have had significant side effects to my health. Having the availability of a new drug could be life altering for people living with FSGS. Some of the side effects that I have endured due to the medicines I have had to take include double cataract surgery for steroid induced cataracts, development of osteopenia, skin cancer, as well as other side effects, such as weight gain, hair, loss, etc. People living with FSGS deserve better options. Thank you so much For your time.
Michele C.	Dear Review Committee at the U.S. Food and Drug Administration, I am writing as someone living with focal segmental glomerulosclerosis (FSGS). This disease affects every part of my life, from constant monitoring and medications to the constant uncertainty about my kidney function and long-term future. For the past 10 years, my immune system has been suppressed due to treatment with Prograf. Living in a chronically immunosuppressed state is frightening, especially with ongoing strains of COVID-19 and seasonal influenza still circulating. Everyday situations that others may not think twice about can carry serious risks for me. The long-term effects of immune suppression weigh heavily on my physical and emotional well-being. An approval of sparsentan for FSGS would mean more than just access to another medication. It would represent hope for reducing proteinuria and potentially slowing disease progression without further suppressing my immune system. For patients like me, having an additional targeted treatment option could lessen dependence on immunosuppressive therapies and provide renewed optimism about our future. Thank you for your thoughtful review and for considering the real-world impact your decision has on individuals and families living with FSGS. Sincerely, A patient living with FSGS
Sabreena S.	It would mean another option to manage my minimal change disease. It would be hopeful for a different long term solution and quality of life care.
Kelly M.	I am already a transplant recipient but my initially cause of kidney disease was FSGS. I am definitely interested in any progress in medicine that could help the disease slow down progression.

Comments

From Someone Living with FSGS

Christopher W.	The approval of Sparsentan would truly be life-saving to so many patients living with FSGS that have no available treatments for lowering their proteinuria. Most patients sit and wait idly by while their numbers decrease, and they face the eventuality of dialysis and transplant. Having a drug finally approved that gives these patients the hope of staving off or even avoiding dialysis or transplant is a godsend
Rebecca C.	Survivor since 2011. Medication would extend my life
Lynette S.	It would give me great joy to live a healthier lifestyle.
Jennifer A.	It could prevent further damage of the kidneys and prolong life or prevent the need for dialysis.
Juanisha S.	Having this medication will improve the patient and their family life. There are a lot of side effects having FSGS and if it's a medication that will help us please, allow us to get this medication.
Jessica C.	I would love to have the opportunity of trying something that could potentially help FSGS.
Eric B.	I would live a normal life I'm 43 years old with 3 kids a wife and have be sick for 10 years one transplant and I still have fsgs 135 plasma treatments and no luck
Rochel S.	I can finally feel normal like everyone else :(
Jonathan R.	Sparsentan would help me manage my proteinuria.

Comments

From Someone Living with FSGS

Shonda G.	Approving this drug would hopefully give me a better quality of life. I take 23 meds right now to try to manage my primary FSGS and the symptoms it causes, it's exhausting many drugs come with side effects. Please help us who struggle with this disease.
Kelly R.	I was born with primary FSGS and went through two transplants as a pediatric patient. Then again as an adult. The years of on and off dialysis and Immunosuppresive meds have left immense damage to my body. I am forever grateful to my donors but the idea that, without a true cure, I will eventually face dialysis again is frightening. Not to mention the "what-ifs" about a future cancer diagnosis as a result of my anti rejection meds. Help those of us with FSGS face the possibility of a life with a cure.
Vanessa B.	It would be life changing
Lisa M.	I lost the fight with FSGS, and was lucky enough to be receive a kidney transplant 4 years ago. However, I still live with the knowledge that FSGS often recurs in transplanted kidneys, which could lead me down the road to end stage renal disease and another transplant in the future. There are no real treatments for FSGS now, and anything that can help slow progression or solve the issue will help those of us with FSGS live healthier lives—and perhaps, reduce the number of us that end up needing dialysis or transplant to survive.
Kostadin S.	If there was a drug that can help me, that would be great, I am already on my 4th kidney transplant and the FSGS comes back right away in thr transplant kidney. People need this.
Javier T.	As a patient with FSGS not having a treatment is heart breaking, there is not much that I can do to get better, it feels like I am just waiting to die
Lindsy G.	I was diagnosed with FSGS 19 years ago and have been living with the disease since I was a teenager. I have participated in 4 clinical trials over the years and have tried a number of treatments, living with an extremely high level of uncertainty for decades. Living with a disease that has no cure is one thing, but decades with no FDA approved treatment is another. FSGS is an unpredictable disease that is not well understood, and while no drug is a panacea, patients deserve every treatment option available to them since the clinical approaches to FSGS are just as variable from person to person as the disease itself. Patients deserve better than this and I understand the importance of robust data you want to see. That said, if you are paying attention to anything about this disease, you will know that being unpredictable and inconsistent is the hallmark of this disease. There has been *no* change in this field *this century*. I do not understand why living in this reality is not enough, and you're asking this population to explain why we deserve the first ever approved treatment? What are we doing here?
Tiffany L.	The availability of additional drugs like sparsentan in the market can improve lifestyles and independence of FSGS patients by enabling us to have access to a treatment that is designed for our specific disease. We are currently subject to the side effects of taking other treatments off label and it significantly impacts our overall well being.

Comments

From Someone Living with FSGS

Barbara K.	I have been through the entire scope of treatment options already existing with no treatment providing long lasting remission. I am presently in remission but once I am no longer, I have no options for treatment left other than dialysis. This new treatment would give me hope of a treatment that may work and may extend my life without dialysis.
Johnny S.	It would drastically increase the outlook I have on life. This would be the blessing we all need.
Catherine T.	save my kidneys
Dana T.	It would give me hope.
lisana a.	i have been with fsgs since i was 2, no medicine seems to work much
Luis F.	It would depend on what the drug does. Will it get me off dialysis?
Debra S.	I had always wanted to participate in the studies of sparsentan, but was told that since I was prescribed prednisone I was not a candidate. I am looking forward to being able to take sparsentan and get off all the other drugs I currently am.
Steve K.	My original kidneys were destroyed by FSGS and I had to start dialysis 7 years ago. A year later I was fortunate enough to get a transplant. Now my transplant has been ruined by FSGS. I'm back on dialysis and worried going through all this again while still having FSGS. My wife was my first donor and now I live with the tough that I destroyed and wasted her kidney.
Jacqueline M.	It could help halt or slow down gags so I can live my life to the fullest
Wayne S.	We have been using drugs that are meant for other deases and are helping some. Would be great to have a drugs that is meant for just FSGS instead of experimenting to find a drug that will help
Kimberly D.	I've already had to get a transplant ..but this would have been helpful before …and maybe it will help my transplanted kidney
daniela c.	I have focal segmental glomerulosclerosis (FSGS), but I did not participate in the DUET, DUPLEX, or EPPIK studies. The availability of sparsentan would give me hope for better disease control and improved quality of life.
Rhonda K.	Need help !!!!
Pamela C.	Never have to go back on dialysis.
Elizabeth G.	Slowing the progression of the disease, as there is currently no cure - Reducing the need for intense medications like prednisone, especially for young patients - Mitigating side effects and weight gain - Providing more than one trusted treatment option

Comments

From Someone Living with FSGS

Pamela C.	I would have loved to have this medicine available to me.
Jennifer M.	I had a kidney transplant because my FSGS ruined my native kidneys. I may still have it, and which case it would ruin my transplanted kidney as well.
Jennifer B.	Having this medicine , eliminates all worry and wonder when my kidneys are going to stop working. My future plans for my life would definitely change, for the better. I've prayed for this for the last 10 years. Please help us save our kidneys.
John D.	Do not know about this medication. If it's available and effective I would be happy to try. Right now I'm taking high blood pressure medication and farxiga for help with my fsgs.
Tara G.	Potentially saving my kidneys in the long term
Gary M.	I participated in the Duplex study and my doctor believes that sparsentan has helped me. There is nothing else to take to try and limit the progress of FSGS. You have to give approval as we need some hope against this condition.
Jonathan W.	I'm currently on seven medications, most of which are related to maintaining my quality of life due to the symptoms caused by FSGS. If sparsentan became available for use to treat FSGS, I would be able to cut down the number of medications I take to only a few, saving myself money and lessening the risk of medication side effects for the rest of my life.
Christine W.	This would have been very helpful if it were available when I first was diagnosed and possibly not had to experience ESRD and receive a transplant. This drug would greatly improve the lives of patients and family members who live along side this disease. Please approve to help reduce the impact of dialysis and transplantation, let alone the cost savings it would improve.
Eva H.	Have not participated
Michael W.	Please help keep people off of dialysis as long as you can. FSGS is aggressive so every day matters. Help preserve quality of life. Help give people hope. It's not just for the patient it's for the family as well.
Marvin F.	The hope that sparsentan could give me less side effects and a chance of a longer life is immeasurable. The greatest joy a grandparent has is being present to watch their grandkids grow up. That is the hope that sparsentan gives me. Thank you.
Jennifer G.	I was a participant in the Duplex study.
John P.	Would reduce my proteinuria, reducing further damage to my kidneys, allowing me to live life longer without dialysis or a transplant. Please help!
Olivia K.	Improve quality of life

Comments

From Someone Living with FSGS

Scarlett S.	Currently in remission from a year of steroids and immunosuppressant - a very tough year for me and my family. And I was a lucky one where this treatment worked. Having an approved treatment would give me a peace of mind knowing if I had a flare up - there would be a treatment that would allow me to continue to live a normal life.
Ebony J.	I am a suffer. I'm actually in the hospital as I sign this. I have not participated in any study.
Eric R.	12 years of FSGS no end in sight, please find a cure or at very least a treatment to truly keep from progressing to end stage renal failure, so many people with FSGS truly hope for a day like this to come
Nora R.	I might get a transplant prior dialysis and be able to care for my disabled child, continue my career versus just hang in while turning down well paid f/tt career employment, for another decade, if sparsenten was available. Life for two people versus a slow death and suffering.
Sally C.	Hopefully it would prevent me from having dialysis
Leon L.	Have been living with Primary FSGS since 2020. I have never been in remission despite many different treatments from a Dr that was trained at the Mayo specializing in FSGS. I am running out of options. Please held me along with many others that are in the same situation as I am. Thank you Leon
Dolores S.	Very impactful
Thien D.	I currently have fsgs and my doctor say there is no cure, if there is a possible cure I am excited and looking forward to it
Ashley K.	Having more options available to treat FSGS would benefit so many living with this disease. This drug gives hope to those that don't have other options.
Sarah S.	Just the simple hope that there has been an advancement like this is amazing. Rare disease don't get break throughs often and those of us living with something that has no cure and can suddenly turn into complete kidney failure is terrifying. I'm only 33, and I can't guarantee that I'll always be around for my son. That is a devastating reality. If there is something that can potentially prolong my time with him, that is worth everything.
Marcus M.	A relief
Marquetta A.	I was diagnosed at 18. I am 49 now. My renal function has gone down to 11% to 21%. Quality of life is challenged. Help could save and change lives.
Allethia F.	I would be able to live without fear of my transplanted kidney failing. I would be taking a drug specifically for my condition. I would be able to life a full time life.
Allison S.	I've tried almost every available medication that's been an option for me and my current health. I'm steroid resistant and none of the other immunosuppressants I've tried have made a difference. Sparsentan offers me so much hope for the future of FSGS for myself and the other people living with it.

Comments

From Someone Living with FSGS

Casey S.	I'm a disabled vet with heart problems and dialysis
Amy P.	To help control proteinuria and prolong the path to end stage kidney failure leading to better quality of life.
Julie J.	Could possibly prevent need for dialysis or at least extend kidney function
Macy C.	This medication would change my life, I struggle with swelling, fatigue, blood clots, etc all from this disease. We go to dr appts upon dr appts and still get no answers. This medication would change so many lives for the better. We finally want to be seen.
Joshua W.	I believe my doctor just recommended me for the new sparsentain trials. Hoping to see what good comes from a new medication.
Elizabeth C.	Primary FSGS is a life-altering diagnosis that forces patients and families into difficult treatment decisions, often involving high-dose steroids and immunosuppressive therapies with significant side effects. My wife has undergone treatment with prednisone and rituximab — therapies that carry real risks and require careful monitoring. Even when these treatments work, relapse remains a constant concern. The availability of an FDA-approved therapy specifically indicated for FSGS would provide patients and physicians with a targeted option designed for this disease rather than relying solely on broad immunosuppression.
Stormy G.	I have been living with FSGS for 17 years and to find a cure and avoid transplant would be a miracle.
Patrick D.	a treatment for FSGS would extend the life of my transplant and keep me off dialysis- saving the american tax payer a great deal. it will give me more time with my family.
Jennifer C.	Give me hope for future without dialysis
Sandra M.	The symptoms of this are horrible, especially when you can't take anything for them! Please help with the medication, so myself and a lot of other's will potentially not suffer as we are now! Thank you!
Renea M.	It would be amazing to have a new drug that could possibly help FSGS
Carrie L.	I am living with FSGS and had a transplant if I can prevent that for someone else with this medication that would be amazing
Frank A.	I have been living with this chronic disease since 2009. Please help save my life!
Farnaz F.	I'd love to have a treatment for FSGS so that my new transplant kidney will last me the rest of my life and not carry on FSGS
Marquisha W.	How do I get housing authority to stop discriminating against me and follow my stake in property while actually considering my disability?

Comments

From Someone Living with FSGS

Jessica D.	It would impact me by giving me one option for medication instead of taking multiple pills in a day.
Debbie b.	Swelling is the worst I have iga with fsgs
Dustin O.	Just need info about this treatment
Carolyn D.	Improve longevity and quality of life.
Melissa N.	My family could hopefully not need a kidney transplant
Pamela K.	I was in the Duet study when it first came out. Was in it about 5 years. The medicine slowed my FSGS down. It should pass so other people can have the same chance I had.
LELAND B.	This new drug could be a life saver!
Pam S.	I live in fear everyday that something I've eaten will send me over the edge of kidney failure.
Regina W.	New treatments means saving my kidneys, delaying dialysis, delaying a transplant. Give my parents the time that I won't have without these new treatments
Brent B.	Help
Carol K.	I'm 73 with stage 4 kidney disease. The past year I have dropped my EGFR from 35 to 23. I'm not getting any younger and I'm on a forced income. If I could find help for my kidneys, that would be great.

"A nephew, by marriage, of mine has suffered for several years from FSGS. He has endured years of dialysis and other treatments, and, after a suitable kidney donor was not found among family members, his father went so far as to donate a kidney of his own to go to another patient who was a match, for the purpose of moving him higher on the waiting list for a kidney from a matching donor.

Although Ben has finally received a donated kidney, he has suffered numerous complications and subsequent hospitalizations. His doctor believes that sparsentan may help his underlying condition and improve his quality of life, if only he can access it.

Please approve the use of sparsentan for FSGS, so that he and other patients suffering from this potentially fatal condition will have an opportunity to more effectively treat their FSGS."

- Kimberly B.

Comments

From Someone Living with FSGS

Scott H.	Sparsenten has the ability to own the progression of fsgs, delaying or possibly preventing the need for dialysis and transplant.
Russell G.	If it cures I'm in
Diane M.	I don't know if I have a specific example other than I suffered with proteinuria when I was first diagnosed. My doctors tried to stop it but there was no adequate treatment. This gives us hope for treatment, health, and personal/society economic stability.
Najeeb A.	It would be a life saver
Lyndsay A.	I have had proteinuria for most of my life. My brother has FSGS and progressed to transplant 13 years ago. My diagnosis of FSGS was confirmed in 2020. The disease has progressed more slowly than for my brother, but at 21 years old I struggle to keep my levels steady. So far, Lisinopril, Vit D and Farxiga have slowed down progression a little. It's very important to me to have more medication options.
JUSTIN R.	I am desperate to find a medication combination that will postpone or eliminate the need for constant dialysis, transplant, or death.
Majella M.	If this drug could slow down the progression of FSGS it would be a great relief for me.
Suzanne M.	I currently have zero treatment options. Basically watch labs every couple of months and wait for it to be bad enough for dialysis. Because of my weight, I like won't be approved for kidney transplant either. It's time for more treatments to preserve what kidney function I have left!
NaYaN W.	May be beneficial.
Manon B.	Cela pourrait me sauver l vie à la prochaine crise
Mark M.	I await a breakthrough. This may be it.
Kendall T.	It would change my life as prednisone has destroyed my body. I NEED this. Don't make me wait another 10 years.
Shenita S.	It will save me from dialysis.
Kahil S.	As someone who was diagnosed with nephrotic syndrome at 2 and FSGS 6-8 years later, I have tried every form of treatment I could think of, all the way from forms of chemotherapy to cocktails of medications. My treatment plan now works but is still far from ideal. Having one, non immunosupressant, medication would change my life. No longer having to fear my ability to fight off infection would be just one of the many worries that would be lifted off my back
Joshua A.	Having sparsentan available could potentially be helpful for me and my family. It could provide an additional treatment option to manage FSGS and potentially improve day-to-day health outcomes.
Lauren M.	Never participated or was aware of the studies listed.

Comments

From Someone Living with FSGS

Robert S.	It would remove the constant feeling of FSGS returning at any moment. Living with FSGS is like living in a city with an active volcano - knowing that one day that volcano will be a volcano…
Sean S.	I was diagnosted with AR-FSGS in 2007. I am currently Stage 2 CKD and am hoping for FDA approvel in order to delay my progression for as long as possible to avoid dialysis or the need for a kidney transplant.
Willie M.	It would help me a lot if the drug works I'm 38 yrs old and want longevity and good health
Denise H.	Having a drug to treat FSGS would be incredible! I currently love knowing that in the future my life could be interrupted if my disease progresses. It's a scary feeling knowing and not knowing at the same time.
Jacob K.	My dad also has it.
Jill A.	I have been living with this since I was 14had a transplant now my transplant kidney has infected so im not happy
.Leon L.	I have reached remission with All other treatments. Have been battling FSGS since 2021. Thank you for any help I can get.
Russell G.	I am not in any studies
Robin W.	I was diagnosed with FSGS when I was 19, I'm now 46 & have to do PD every night
Katie S.	This would be life changing for me. I lost most of my 20s and 30s to FSGS. It would bring some relief to my days and could live normally
Marquetta A.	I know they are only trying it on kids. Bur as someone who was diagnosed at 18. With 60% of renal function already gone and down 80+ renal function gone. It is hard living with FSGS
Brenda K.	I am not sure if it would help me now as mine has progressed to end stage and dialysis but but would have been nice to have another treatment option as the 3 approved methods did not work for me.
Erica J.	I was just diagnosed with FSGS a few days ago after months of horrible fatigue, swelling, nausea, high blood pressure and headaches. I lost my other kidney a few years ago due to something completely unrelated. I am a single, fully self supporting mom putting two kids through college. I am 55 years old and must continue working for my health insurance and to save hopefully for retirement. A cure for this debilitating disorder would be life-changing for me and give me hope. It would help me to be more active in my son's lives and give them the mom. They deserve, as it's been very hard for me to be there for them with this disorder.
Beth R.	It could have possibly helped me sooner. Delaying or omitting completely dialysis and transplant.

Comments

From Someone Living with FSGS

Michael R.	Life on dialysis is expensive for everyone. Let's find a cure
Amber M.	My mom passed FSGS down to my 2 siblings and I and I passed it down to my 2 daughters. There was no medicines or cure other then dialysis and transplant. I think adding Sparsentan is a start to helping future people fight kidney disease longer. I lost my mom, sister and brother at a young age do to kidney disease.
Elizabeth C.	I have the disease (FSGS) and the doctors have not yet discovered what caused it, so I am waiting for treatment
Jaclyn C.	I have had two kidney transplants in less than 6 years and yet I still have FSGS. So this would greatly impact me and my family I have 4 young children who need their mom to be around as long as possible.
Casey S.	I'm a disabled veteran and I have fsgs and need help.
Peter M.	I have it.
Steven G.	I have had it for decades, and each year, a little worse. Di not want to go on machines
Cepriano L.	I have been diagnosed with Fsg and I'm starting to lose hope.
Laura P.	I am living with FSGS
Jose Paulo C.	it will definately improve our lives knowing that we have hope for cure
Angie G.	I haven't experienced this. I would love to be a part of the study if it will help.

Comments

From Someone Living with FSGS

Angie G.	I'm ready for sparsentan to put me in remission. I need this to happen now. I want to be around for my family.
Robert C.	This medicine would reduce the protein leakage and further damage.
Dorothy C.	Have FSGS
Brett W.	It would help very much.
David R.	I live with focal segmental glomerulosclerosis, and I do home hemodialysis every other day. This disease has stolen dreams. It has prevented dreaming at times. It has made me question what I could do and who I could become. And the truth is, every patient's life and story is different. No two journeys look the same. I have considered transplant, but the fear of recurrence is real. That is the reality many of us live with. For years, treatment felt like we were borrowing medications meant for other diseases and hoping they would slow it down. Hoping for time. The potential availability of sparsentan, possibly the first FDA approved drug specifically for FSGS, represents something bigger. It means future patients may have a treatment built for their specific disease. Something designed to slow progression before dialysis becomes the only option. Progress matters. Real treatment matters. Hope matters.
Linda B.	I was diagnosed with primary FSGS in April 2025. I'm steroid resistant and have also tried Tacrolimus with no results to reduce the amount of protein, never achieved remission or even partial remission. I'm currently trying to get approval for Rituximab but the insurance company has denied treatment. We are trying to appeal. We need FDA approval for Sparsentan. For people like me we don't have many options and need anything that will help to prolong kidney function, give us a chance to go into remission, and a chance at life. I have been very diligent with all treatment options and would love a chance to be given a drug that could possibly help. Thank you
Theresa B.	I was diagnosed with FSGS in 2009 and received transplant in 2024. My fear every day is the FSGS coming back. I would love to know if we're to happen that there would be a way to treat it.
Sean J.	It would obviously change my life and my families life to finally not have to worry everyday
Levi P.	I've been on dialysis for a long time, so I'm not sure if this drug could help me. If it could treat my FSGS and allow for another transplant, that would be good.
Ivan H.	Life!

Comments

From Someone Living with FSGS

Bethany S.	Most Doctors are guessing treatment possibilities with this disease. Having an approved drug that has been proven to help manage the disease well and is available across the community is huge.
Allan P.	It would make it easier for me to access a drug that can help lessen the impact FSGS has on my newly, 10 week post Transplant, Kidney, and help it not reject and or not go to stage five kidney failure
Brock W.	It would definitely help my kidneys with FSGS
Shad I.	Took the therapy
Sharron R.	As a kidney warrior living with FSGS, the availability of Sparsentan would have a profound impact on my family members that may be diagnosed with FSGS in the future. This drug would prevent the progression of the disease which may result in the need for dialysis.
Andi G.	I didn't try it because i got stable with Chinese mushrooms !
Nora D.	It would be a total blessing
Brenda T.	Was dx with CKD in May, 2010. Have vasilated Stage three, to Five, non-dialysis during Covid 2021, back to Stage ThreeB. High blood pressure caused.
Natalie L.	To have an approved drug for my disease would be Amazing. Kidney Disease can be so stressful and tiring.
Vickie W.	My nephrologist discourages participation in any trial studies, saying he took an oath to cause no harm. In my early 60's, I was originally diagnosed with idiomatic, steroid-resistant, Minimal Change Disease, but the last biopsy showed the progression to FSGS. I'm otherwise healthy, which works in my favor, but every treatment plan I've tried has had horrible side effects, with a lack of positive results, but a lingering new problem. For the last 3 years, I've just been "monitored" with no options left. Hard to believe that in this day & age, with the number of people dealing with kidney disease, that there is still no product that focuses on that cure.
Donny F.	It wouldn't affected much because I am end stage renal failure but for others who still have function I'd be happy for them.
Shane H.	It could lengthen my life
Matthew D.	It could add years to my life.
Brittany R.	As a young adult I have learned to live with fsgs. I have had fsgs for 20 years and have always had to experiment to stay in remission. I had a kidney transplant 6 years ago and I have had to heavily rely on plasmapheresis. This could be groundbreaking for people like me
Brooke M.	I have FSGS and would like a more effective treatment.

Comments

From Someone Living with FSGS

Ayanna P.	As someone who was diagnosed at 14, the approval of this medication could support with allowing me to maintain a sense of normalcy. At 31, I'm lucky but know that a medication like this could help me stay lucky.
Andrea B.	It would give me another option if the treatment I am taking stops working. Please give sparsentan FDA approval.
Michael L.	I have been living with FSGS for over 6 years. In that time I have participated in a clinical trial with zero results and been on several drug regimines that severely impacted my health and ability to enjoy day to day activity. Sparsentan is the first therapy that has hope in reducing protein spillage.
Jeff B.	Treating FSGS with treatment that is not an immunosuppressant I would imagine to be a FAR superior alternative to what I went through . At 51 years old, in great health and completely out of the blue, I was told I had perhaps 4 years to live if I did not treat my FSGS that had just cropped up. Not wanting to die, of course I submitted to treatment. My doctor apologized to me in advance. I was on high doses of prednisone and cyclosporine. This resulted in a severe case of pneumonia. The cyclosporine in higher doses that were attempted meant NO sleep. It also gave me a stutter and tremors. I could no longer write legibly. It was not sustainable. I am 6 feet tall and dropped to 155 lbs. This is what it took to get me to a GREAT outcome. I hit partial remission in three years. Two more years of lighter treatment got me to full remission, which has held for 11 years. I am understating how hard this was. The high doses of prednisone have had lingering health concerns now later in life. If sparsentan is as promising as it sounds, it could allow patients to skip a hard path through all this. I would also expect to see results that may happen very slowly in some patients. It took me five years to completely beat this. I consider myself lucky when meeting with other patients struggling with this for years.
Esther M.	I have been living with fsgs since 2005. I was a patient in the fsgs clinical trial called DUET. Sparsentan has put me into full remission and reduced protein spill to zero. I personally have not experienced any side effects. Even after so many years with fsgs (biopsy proven) I still have my native kidneys, have never been on dialysis and have not needed a transplant. All of the other so called treatments I tried caused many side effects and little effectiveness. I do hope the fda approves this drug for fsgs and thereby end the suffering and hopelessness of fsgs patients. Fsgs is a rare disease and it is not completely understood by the medical system to this day. I am living proof that a person can reclaim a normal life after a fsgs diagnosis. The reason is Sparsentan.
Tracy j.	It would help them enjoy a better quality of life….
Jorden A.	It would provide more viable options for our care
Camille L.	As an FSGS patient, I am limited in my treatment options. I am maxed out on my ARB medication, which means we have to increase the dose of my immunosupressant to achieve my target proteinurea reduction. With young children at home and constant exposure to germs, I am frequently and sometimes severely sick. Having access to sparsentan to replace my current ARB would hopefully permit me to reduce my immunosuppressant dose. Thank you for considering our diverse patient experiences in reviewing this important medication.

Comments

From Someone Living with FSGS

John R.	If it means less pain, fatigue, weariness, chills, etc., I'm all for it.
Regina W.	It would mean less stress overall
María Alejandrina S.	Para los niños nefroticos
Brieanne H.	It would be everything.
Jennifer C.	I was diagnosed with FSGS at the age of 22 and in the three and a half decades since, I have been on dialysis three times and had four kidney transplants. In all my years managing the uncertainty of FSGS, there has never been a FDA treatment indicated for FSGS. The availability of sparsentan would be the most life-changing, hopeful, uplifting development for patients like me. A game changer. I have remained hopeful and optimistic for so many years with FSGS as my constant companion. The FDA approval of this medication would create a better future for so many patients struggling to live full lives with FSGS. Thank you.
Denise b.	If I had never gotten FSGS my life would be so different. I was diagnosed at 5 year old in 1986.
Sandy A.	As a person who was diagnosed with FSGS and had a transplant ten years later. Any medication to help someone and/any new form of treatment would be new hope to an ill individual. Its a horrible feeling going to the doctor and being diagnosed with a disease and then asking questions and being told “We dont know”. Lets push for a change.
John H.	I'm currently on dialysis, and have received two kidney transplants, both of which failed due to FSGS. A cure would allow me to be eligible for another transplant, which would allow me to live a relatively normal life again, and be there for my son.
Isidro G.	Para que sea subvenciónado este medicamento para los nefríticos
Lidia D.	Para todos
Amanda G.	If I had a drug back in 2004 when I was diagnosed that was for fsgs I could have avoided horrible side effects from prednisone many years later and could have preserved my function so I could spend more time in high school than in the hospital. I wousknt have had to experiment with dangerous drugs not approved for fsgs just to see what works and have damage from those drugs years later

“The improvement of life overall how grand or small would be better with a medication that can help cure or even just reduce the excruciating and debilitating course of FSGS. Please we need this.”

- Kimberly P.

Comments

From Someone Living with FSGS

Harlan J.	Give them a better life, no Mrs suffering.
Elizabeth L.	Living with kidney disease has changed every part of my life—physically, emotionally, and financially. Dialysis is not just a treatment; it is something that takes hours from my days, limits my independence, and affects my ability to work, travel, and plan for the future. The emotional toll of living with uncertainty and chronic illness is just as heavy as the physical burden. The availability of a medication like sparsentan, especially as a potential first FDA-approved treatment specifically for FSGS, would represent hope. Hope for slowing disease progression, preserving kidney function longer, and possibly delaying or preventing the need for dialysis or transplant. For patients and families, that kind of hope is life-changing. It means more time with loved ones, more stability, and a better quality of life. Even for those of us already on dialysis, new treatments signal that the medical community is still fighting for us—that our lives and futures matter. Access to innovative therapies could mean fewer people experiencing the hardship that so many kidney patients face every day. For families, the impact is just as profound. Kidney disease affects not only the patient but everyone who loves and supports them. A treatment that slows progression or improves outcomes would reduce emotional stress, financial strain, and caregiver burden. Because of this, the availability and accessibility of sparsentan would mean more than a new medication—it would mean possibility, dignity, and hope for the kidney disease community.
Ashley F.	I have already had 2 kidney transplants and both times my FSGS has returned. I will not get a 3rd transplant until a new treatment is approved. As of now, I will continue on my 13 year journey of dialysis.
Ashley F.	I have already had 2 kidney transplants and both times my FSGS has returned. I will not get a 3rd transplant until a new treatment is approved. As of now, I will continue on my 13 year journey of dialysis.
Daphiny M.	I wouldn't be on dyalisis
Desarena M.	It would be the best thing ever for us, I had a transplant and it didn't work it could possibly help it not recur in another transplant
PAULA T.	As a patient diagnosed with FSGS in 2012, I believe this drug could have made a significant impact on my life. I have now been post-transplant for almost six years, and I would have liked the option of taking one medication to help preserve kidney function rather than progressing to the point of needing a transplant and lifelong transplant medications. Although I am grateful to be living without dialysis, I believe sparsentan could make a major difference for others by potentially slowing disease progression and offering a more affordable long-term option for patients.
Saadiq F.	It could make life better for those living with FSGS.

Comments

From Someone Living with FSGS

Lyle H.	To put it simply,if it is an effective treatment, it would save my life and give me my life back to make memories with my wife and children.
Leigh B.	I might not have had to undergo dialysis/transplant
Rebecca C.	When diagnosed in 2011, I was told 15 years is average life expectancy. I'm 80 years old and feel the effects of FSGS every day. I have hopes for a cure for all people with the diagnosis of FSGS.
Kristin M.	Having access to proper medications could keep me healthy for my small children!
Nora D.	It would be a life changing experience. Living with FSGS hasn't been an easy process.
Kimberly M.	I have FSGS. While in remission for the last 5 years, new treatment options would be so welcomed!!!

Comments

From Someone Living with FSGS

Ann H.	To start with there has been 7 family members that have had kidney failure. Starting with my dad's mom. In 1940 my dad's mom past away when my dad was only 8 years old. She was experiencing fatigue that kept her from keeping up with house chores. At the time she past, they did not have a specific name or disease name. She was 32.My dad's sister had flue symptoms in the mid 60's. She died in the hospital at the age of 32 leaving behind 6 young children. Those children came to live with us for awhile. I don't know their whereabouts and I don't know if or how many of them got figs. I would love to know tho. Then at the age of 17 my dad signed up for the army. This was about 1949. When he went for his physical he had high blood pressure so they gave him blood pressure medicine to last 2 weeks so he would pass his physical. My dad was told he had high blood pressure and kidney disease and started home dialysis at home. The first person in our city to do dialysis at home. He received his kidney transplant on Christmas 1976. His kidney transplant went good but he had 16 lbs of water on his heart. He had a coronary heart attack at the age of 44. He past away in the ambulance on the way to Madison Wi. He was brain dead for 1 week. I was 17, it hit me so hard. They didn't have a specific kidney disease name in the years he passed in 1977. Then came my turn. I was present they noticed I had kidney failure. They told me I would need a transplant or be in renal failure 2 years later. I was lucky enough to have a cousin who gave me a kidney on 4.1.1993. It lasted almost 30 years. I was told I had figs. This was the first time this kidney disease had a name. There must have been some research done. Also that it was a hereditary kidney disease. I have learned so much through the research by reading and also genetics testing. Over the years I have been on Prednisone, Neoral, immune, mycophenolate, mycohpenotic, Envarses, and taculimus. And yes I have had side affects such as hands shaking, skin cancers and sepsis, and infections. Aches and pains. My sister got figs. Received a kidney from hr husband. She passed from cancer at 53. Our daughter got fsgs. I don't remember what age, but she has been doing good since her transplant. Our son also got fsgs. Not sure what age, but hi transplant failed short of five years. He was given too high of taculimus and it ruined his kidney. He was doing peritoneal for about 5 years now doing in clinic dialysis. He is 42 now. They decided not to have children because of the gene hereditary factor. He had a severe problem of his white blood cell killing the red blood cells. Almost died 2 times. He has had over 40 blood transfusions to help. Still needs to get blood transfusions sometimes. It is a very very rare chromosome and immune problem. I have been going for chemo treatments. I have a very very rare protein ang some things that have to do with iga,I'm, something like that. It is something that is locally in my kidney. It is not cancer such as myeloma, but is treated pretty much the same. I have been going for treatment about 2 or so months and should be done around April. My results are doing very well. I am being treated by Dr Brunner at Madison clinic. And we have our daughter of 36 that does not show any signs of fsgs. Also my brother who is about 70 had to start dialysis. I am not sure why. He doesn't talk to me. Maybe age related. Lol or being grumpy lol. My 2nd transplant was 2.15.2020. I have learned that this protein, really RARE problem I doing treatment for I guess showed up about 2023. I have learned really so much and always researching about kidneys. I'm very grateful that I have been given 35 plus years of life. Without research, new medicines and keeping updates with Dr's we would be dieing and suffering horribly. I hated dialysis but most days of the 5 months I walked out saying out loud Thank God for these backup machines. I got horrible headaches from dialysis. No matter who or what age we are humans. WE WANT TO LIVE! life is a journey and along the way many things come up that we have to trust in the people who truly care. I love my family. I want to see them to have a normal life as possible. I have been married 44 years and thankful that We have the chance to celebrate many more because of people advocating new medicines that could help my children and others to live a longer life celebrating life together, with each other. I see people posting on Facebook how they are scared about "The unknown " I given my thoughts and what I have gone through, my experiences that I have been thanked for whatever the experience s. I hope those that are going through kidney situations, skin cancers, depression have helped those . As kidney recipients, kidney disease diagnosed, kidney rejection are one big community that care about each other and we care about all the medications you have developed for us. Also just noticed ...no i don't think I have done any of the studies. I do know that I had the genetics done. Thank You, Ann

Comments

From Someone Living with FSGS

Theresa J.	It would give us another chance at remission, if we fail other treatments.
Karla C.	It could be life changing for so many of us.
Amanda Y.	It would give me hope
nicholas a.	I have Fsgs and I am also a pharmacist. I lost my brother to the same disease. I constantly ponder how different our lives could have been if we were aware of drug trials for this disease left alone an actual option for treatment.
Alana E.	The availability of this medication would be life changing for my physical and mental health. My body is not responding to steroid treatment, but I have to remain on a high dosage of steroids until we find a treatment to get me into remission. The high dose of steroid is causing increased swelling which is making me not look like myself. Being unrecognizable to myself each day has been difficult.
Andrea P.	An approved treatment would increase access to medication. While my FSGS has been in remission for almost 30 years, knowing that there is a clear option gives me peace of mind. This particular medication did not exist for me, but I'm glad it does for others and for my future, if needed.
María Isabel F.	Deseando que se apruebe, seria maravilloso
Wendy C.	I am at the point of no options to treat my FSGS. I have tried every medication during the past 28 years with either horrible side effects (i.e. prednisone, cyclosporine, cyclophosphamide) or that have no impact on my disease (Acthar Gel, rituximab) to name a few. My kidneys continue to deteriorate and I may soon need a transplant or dialysis. I implore you to approve this medication to give people like me living every day with this horrible disease an opportunity for living a better life.
Jamal s.	The availability of any proven successful new study could mean me going back to performing on Broadway stages without a catheter or worry I don't have enough strength to get thru a performance. I miss performing it means a true lived life for me!
Aanisa W.	It would be me access to treatment
Mitchell D.	I would love to know more about sparsentan and to have more treatment options available. In my case, my condition didn't respond to prednisone or other common treatment methods. The only option for me that has worked has been rituximab infusions and I am worried that at some point my system may reject future infusions.
Frank D.	It would be great if it works.
Kristin P.	It could keep me from rejecting again since FSGS will eventually infect transplants and I lost my first transplant. This could potentially keep people from needing a transplant in the first place if it could treat or cure or even just slow down the progression of FSGS

Comments

From Someone Living with FSGS

Erica B.	I have lived with FSGS for 34 years. I've had reoccurrence in all four of my kidney transplants, and it's time for me to start looking for my fifth kidney, unfortunately I'm 84% resistant to the current antirejection medications which severely limits the possible success of a fifth transplant. I've always known that there's a chance that my lifespan would be shorter than my peers. That I wouldn't live long enough to watch nieces and nephews graduate or get married. I put my hope in current research and future treatments to give me a longer lifespan and time with my family and friends.
Amber F.	If I relapse again I will have an option!
Michelle P.	This medication would allow me to live a longer, healthier life and be an inspiration for others FSGS patients.
Samantha S.	I would be able to live a normal life.
Keayrshae H.	It will help me by maybe limiting my symptoms and reversing the effect on my kidneys
Daniella O.	It would be a miracle to see it come true!
Janelly C.	It would improve tremendously our lives providing me a better living more freedom of time and mind
Stuart B.	It would have greatly helped me to avoid the kidney function decline and eventually the kidney transplant that I needed.
bryan j.	I am a father of three young girls and have FSGS. I desperately need to be around for my daughters. I'm begging you to please make sparsentan available for me and others, thank you Dr Bryan Johnson
Bob H.	I don't know exactly what type of ckd I have. I have been on dialysis for about two years.
Reina P.	Better life expectancy without dialisis
Gwen B.	Thank God I'm in remission but it was a long road to get there at such a young age. I pray we can get better treatments than what I had so I hope this goes through for everyone else that needs to be in remission.
James C.	Could make for a better life/s.
Kevin M.	I am 42 years old and was diagnosed with FSGS when I was 15 years old. I reached ESRD and was placed on dialysis at 23 years of age. I was on dialysis for 14 months then received a kidney transplant. Me, my mother, grandmother, and uncle all had kidney failure and were all on dialysis at some point.
Michelle T.	Please make this medication available for people who have FSGS.

Comments

From a Parent or Family Member of Someone with FSGS

Azurlyn F.	Sparsentan would greatly impact my daughter's life in a positive way. She would have a chance at living a better life. One free of guessing if someone else's sickness will impact hers because her immune system is suppressed.
Angela R.	My daughter is 3 and she has kindey disease
Kent F.	I have Minimal Change disease and my daughter has FSGS and she received a kidney transplant last summer.
Stephanie R.	The availability of sparsentan would mean that my son would be able to be put on the transplant list again and be given some hope for the future of not having to rely on dialysis. He has an aggressive form of fsgs and nephrotic syndrome and this would give him some hope that he can be helped.
Kelsea G.	It would give us peace of mind that there are more options and kidney disease is not a death sentence.
Janna W.	My aunt has FAGS and having access to this drug could drastically improve her, her son's and husband's life. She's tried every treatment the doctors have recommended including chemotherapy. Getting access to this medication could mean being able to cook dinner for her family, being able to play at the park with her 4 year old son, she could be able to do things that most people including myself take for granted everyday.
Karen N.	As a mother of a child with FSGS, I have watched my daughter endure years of uncertainty, treatments, and hospital visits that ultimately led to a kidney transplant. No parent should have to wonder if their child's kidneys will fail or if their disease will come back. If a medication like sparsentan had been available earlier, it could have offered hope—hope to slow the disease, protect her kidneys, and possibly prevent the need for transplant. For families like mine, sparsentan represents more than a drug; it represents time, quality of life, and the chance for our children to grow up with fewer medical burdens. An FDA-approved treatment for FSGS would mean everything to parents who are fighting every day to protect their child's future.
Stephen P.	My young adult son lost his kidneys to FSGS. His transplanted kidney is now under attack from FSGS, which is causing protienuria. This further scars his new kidney. Drugs to reduce protienuria are desperately needed.
Constance P.	My niece has FSGS. After ongoing treatment without improvement using traditional therapy,her kidney disease is placing her at risk for need of dialysis .It is our hope that qualifying for this medication could prevent this.
Bea P.	Sending support.
Allison C.	My 15 year old cousin suffers from FSGS and like him, many patients with this condition are steroid and mediation resistant and many need additional options for treatment.
Alina B.	Help avoid full kidney failure and transplant.

Comments

From a Parent or Family Member of Someone with FSGS

Jessica C.	The availability of sparsentan would improve the quality of life for patients living with FSGS. The medication reduces the amount of protein the kidneys are leaking by allow the filters the time they need to repair or reduce the amount of scarring the protein spilling has causes. This medication has helped many during the clinical trials to reach remission! I would encourage the FDA to approve this medication so FSGS would finally have an approved medication on the market. My daughter has lived with FSGS since she was 3 years and had to receive a kidney transplant at age 12. Even after transplant this FSGS has still caused complications since transplant is still a treatment and not a cure. Feel free to contact me for more information at jessicacritzerfox@nephcurevolunteer.org or 703-328-4123. We live about an hour away from Washington, DC.
Gladys C.	The mother of my Great granddaughter is desperately looking for this help for her 3 year old.
Vicki L.	See my little granddaughter suffer like a warrior
Jacob B.	My son was in the EPPIK clinical trial. Once the trial ended he was no longer approved to continue taking the medication. insurance would not approve the medication due to it not being FDA approved for the treatment of FSGS even though my son had taken it for two years with great improvement and slowed progression. He was forced to change medications and start the process all over again as a child with steroid resistant FSGS CKD stage 2.
Coleen B.	Our grand daughter has FSGS it could be life changing!!!
Kimberlee M.	My husband is young. 37 years old. He's a doctor and a father of 4. He's also in kidney failure due to FSGS. He has so much life to live. We need answers and help.
Joseph B.	I think it would really help
Macy L.	It could give someone more time. We went from stage 3 to stage 5 kidney failure in 18 months.
Erin C.	This drug would help the future of my son in terms of relapses and his kidney disease.
Colton N.	It would help keep a child alive
alessandra b.	It would help my cousin tremendously. It'd help him maintain his symptoms and feel himself again.

Comments

From a Parent or Family Member of Someone with FSGS

Sara A.	My daughter, Cheyenne, was initially diagnosed with FSGS a couple weeks after her 2nd birthday. She is steroid resistant and has tried many things to help like Tacrolimus and Cellcept (that failed). She now has to do Rituximab infusions every 6 months, as well as take blood pressure, cholesterol, antibiotics, and other medications to keep her at a decent level. She has never reached full remission from her Nephrotic Syndrome she has dealt with since the beginning, which is causing the FSGS to progress. This could be life changing for our daughter. She is now 3 years old and cannot live a normal life due to being immunocompromised from the disease as well as all the medications she is needing. Please approve this for her.
Kayleigh S.	It would help my son who was diagnosed at 2, had a transplant at 4 and it instantly came back, who's now 11 be able to enjoy more of his childhood instead on of being on Perotineal dialysis. If we could take this disease for him we would in a heartbeat. He now has calcium deposits and we're worried about his heart.
Lauren M.	It will give him a chance to be able to live a life with no dialysis. No more suffering alone, and just a chance at living life.
Elyse H.	My daughter has fsgs and needs to get off tacro
Sandra C.	I would hope to use it to help my daughter who has FSGS
James N.	It could save my brother in laws life.
Stephanie N.	We just want a cure for our brother to be able to live his life freely!
Rocco M.	My son could probably be free to live a normal life instead of doing dialysis 3 times a week while waiting for his second transplant.
Gabriella M.	It would simply give my brother his entire life back. More than that, it would give my mom her life back after ten years of taking care of her sick son
Laura E.	This treatment could have potentially saved a 17 year olds life. He received a transplant, but it quickly failed. He passed away at 17 years old and never got that chance to truly live. He was on dialysis for years and sick most of his childhood. We lost one of the most important people in our lives. Please approve this so there is a chance that another family doesn't have to go through this.
Victoria P.	Sparsenten has the potential ro lengthen the viability of my brother recently donated kidney and enhance the quality and quantity of his life.
William B.	Hopefully, It would cure him
Clara B.	Hopefully it would put him in remission.
Elizabeth D.	What ever can help my grandson with FSGS.
Eliana R.	Mi hija actualmente no tiene un medicamento para tratar su enfermedad así que seria muy bueno que ese medicamento fuera aprobado

Comments

From a Parent or Family Member of Someone with FSGS

Jennifer S.	My family member wouldn't have to suffer with swelling and retaining fluid if he had a medication his body responded too.
Stephanie A.	It could be life changing!
Lisa Ann S.	It is hopeful that a potential cure is on the horizon. It would give such relief to know there might be a safe , full -proof option for my son.
Caroline S.	My daughter has FSGS. She is on cell cept treatment currently and has yet to go in remission.
Heidi C.	It would give us access to a therapy, we have struggled to manage this relentless disease for 15 years
Ryan R.	The trials have helped my cousin so much. And needs continued treatment.
Julie C.	It would give our son an opportunity to treat his rare kidney disease to avoid kidney failure and need for a transplant
Leah G.	It would buy my husband so much time to be approved for this medication, we know he's a good fit, but haven't been able to attempt the drug, waiting and praying for instance to cover it, losing precious time. We believe my husband could avoid dialysis entirely as a stage 4 FSGS patient, while he waits for his kidney transplant. Surely the cost of this medication far outweighs the cost of dialysis
Aimee E.	This could be life changing. My son has struggled with FSGS for years. We still haven't reached remission.
Elaine S.	It would be a life saver. My daughter is young and has family who want her healthy and to grow old.
Gabriella B.	This is important to me because there are no FDA-approved treatments for rare kidney conditions like my nephew's . This means that his parents frequently need to fight insurance for treatment, and there is no treatment that consistently works.
Whitney B.	My son participated in the EPPIK study which put him in a partial remission. Having this approved by the FDA would allow him to continue taking the medication through insurance. After the trial ended our insurance denied continued treatment and we were forced to put him on a new medication.
Julie C.	Please approve this treatment so my son has a chance at a normal life.
Laura F.	It would be amazing to have access to new treatments.
Jessica H.	My nephew and many patients like him are treatment and steroid resistant. We need more research.

Comments

From a Parent or Family Member of Someone with FSGS

Kristin C.	It would be great for the medical field to know where to start with medications for FSGS. If they know to try sparsentan early or at specific point tye patient will have more success with treatment. With FSGS early treatment is imperative.
Rose H.	My adult daughter has FSGS with no known cause. She was on dialysis for 20+ years and finally qualified for a transplant. Within a short time the doctors said the FSGS had returned. That was even before the kidney started working. Her doctors are doing anything and everything they can to keep it under control but we live in fear that it will eventually necessitate a return to living on dialysis. As she says, she has to enjoy each and every day this kidney works. In all the years she has had FSGS nothing has been discovered to stop it. Please help in any way possible.
Lisa F.	We need more help our children's current medication is rejected in their bodies over time. There is no more options. Please help
Kaitlyn N.	He is only 7 and it could allow him to function normally and feel better!
Catherine B.	It is important that there is representation for the families who have to go through fighting to get insurance to cover critical treatment
Kristy R.	No more taking tacrolimus everyday for my daughter who has been on meds since 2 years old. She is now 12.
Jeremy M.	Sparsentan could help our 4 year old son live longer with his current kidneys.
Laura J.	Being able to stop using steroids to treat FSGS would greatly improve overall health.
Yoreisi V.	My daughter passed away at 4yo All treatments only made her sicker and her heart failed
Jaclyn H.	If my daughter were able to benefit from sparsentan, it would mean so much more than access to another medication — it would mean the possibility of a healthier, fuller life. As her mother, I have seen how FSGS affects her physically, emotionally, and socially. The days when she feels weak, uncomfortable, or limited by her health are discouraging not only for her but for our whole family. Having a treatment like sparsentan available — potentially the first FDA-approved drug for FSGS — gives real hope. It could help protect her kidney function, reduce symptoms, and slow disease progression, all of which are critical to her well-being. It would mean the chance for her to participate in activities other children take for granted — planning for the future, and simply enjoying being a woman without the constant worry of her health. For our family, the availability of this treatment would be life-changing. It would lift some of the fear that comes with an unpredictable disease and give us hope that she can live as fully and vibrantly as possible. Having options matters — especially for a child who deserves the opportunity to thrive.
Norma M.	It would mean hope. It would mean that my son could avoid or prolong ever being on dialysis again. It would mean my son gets to keep his new kidney transplant.There is nothing for FSGS.

Comments

From a Parent or Family Member of Someone with FSGS

Deirdre W.	It has taken far too long for treatments for FSGS to be developed. Now is the time to make progress!
Kristen C.	The availability of sparsentan is not just a medical improvement for my family; it is the only hope we have left to save my son's new kidney. My son suffered significantly due to FSGS, eventually progressing to End-Stage Renal Disease (ESRD). Our journey before his recent transplant was traumatic and illustrates exactly why patients need better options to stop protein loss and kidney scarring. He spent over a year on Peritoneal Dialysis (PD), which was not a simple treatment but a daily battle. He suffered severe complications, including a hernia and catheter infections that hospitalized him. The limitations of current standard cares were terrifyingly obvious when he developed dangerous medical problems requiring emergency interventions. My son is currently battling a recurrence of FSGS in his transplanted kidney. We are terrified that we are losing the organ we fought so hard to get. Approving sparsentan would give us a desperate lifeline. We need a targeted therapy that can reduce proteinuria and protect his transplant now, before the damage is irreversible. We have followed the DUET and DUPLEX trials closely, and the reductions in proteinuria seen in those studies represent the specific kind of relief he needs to avoid returning to the nightmare of dialysis.
Margaret D.	Having a specific medication to treat FSGS would be very beneficial. Up to this point only symptoms can be treated. We removed lisinopril from my daughter's regimen and her protein spilling tripled. Steroids are no longer and option for her because of the severe side effects she experiences. When she has a relapse it can take a year or more to achieve remission.
Donna P.	All progress for FSGS helps. Need to find a cause!
Sarah G.	At this time, this drug is the last attempt at remission (either partial or full) for her.
Cameron S.	FSGS took my son's when he was 3 years old. A treatment could've potentially been life changing for him.
Kiyana C.	Help with treatment
Brenda G.	Steroid and medication resistance
Kenny H.	We need a treatment specific to this dies.
Leslie L.	My daughter has tried it and it put her into remission. It was the only drug that worked.
Adrianne P.	My son has already beat this terrible disease at age 15. He lived with steroid dependent FSGS for 8years with multiple drugs. After Rituximab, he finally went into remission once and for all. This does not happen for everyone, and new drugs need to be approved so kids can live normal lives again. My son is now 24!

Comments

From a Parent or Family Member of Someone with FSGS

Joanne F.	Sparsentan would greatly impact and improve my 21year old son's life. He has been living with FSGS since he was five years old and to finally have something to help slow down the progression of this terrible kidney disease would be a true blessing. We follow exactly what the doctors tell us to do but we desperately need more. We need medical intervention./medication to help him and other people living with FSGS. We desperately need help to slow down this damn disease, he and everyone else deserves the opportunity of having a better, healthier and longer life.
Heather R.	After failed attempts at other treatments, sparsentan would allow this FSGS course to slow down before total kidney failure.
Cynthia H.	People living with FSGS walk a tightrope with the available drug therapies. Some of these can also cause further damage to the kidneys. Access to a drug designed to specifically treat FSGS would be an amazing step forward for these patients.
Hafiz F.	Greatly
Angel R.	My son has experienced FSGS and had two failed transplants due to reoccurrence. No medication helped him. It would be great to see what new medications could help.
Anna R.	I can't put it any simpler than this. My son was diagnosed 3/2018 and dead by 6/24 because of how this disease ravaged his body. It's starts with the kidney disease and then in turn affects everything else in the body. There was never a cure for him this we knew but not to even have effective treatment is deplorable and cruel.
Williamettia S.	Lower the risk to remaining kidney to require transplant.
Sarah J.	It could help put my 14 year old daughter into remission.

Comments

From a Parent or Family Member of Someone with FSGS

Reegan E.	My daughter has tried several different treatments and has yet to go into remission spilling high levels of protein consistently. An approved treatment that may stop this would eliminate the constantly worrying. Maybe get things back to normal. She has lost her hair, lost the ability to play sports she loved, she doesn't feel herself with the side effects of th different regiments. But, we are hopeful there may be a light at the end of this tunnel.
Tara A.	My son and daughter have FSGS. He had a transplant 13 years ago. She is struggling to keep her proteinuria under control. So far a combination of Farxiga and lisinopril are helping a little. We would love to have another option to prevent renal failure.
Shabnam Q.	Mother of 2 daughters with FSGS. I passed away at age six after transplant complications. The CB older one is 35. Had 3 transplants already. 2nd lasted 20 years which was from me. 3rd was a swap who donated her a C kidney. It's been 8 years. Still going.
Christopher W.	My 9 year old granddaughter has to take basically chemotherapy to keep her kidneys from killing her. She has hypertension, has to watch her sodium intake, and her fluid intake to avoid swelling. This could change her life.
Trevor M.	Help my Mom
Kelsey F.	As the wife of someone who was diagnosed with FSGS one year ago, the availability of sparsentan would mean hope and stability for our young family. My husband is 37 and a new father. More than anything, he wants to be a loving, present, and healthy dad for our son. He dreams of having the energy to play with him, to be there for milestones big and small, and to feel confident about being around for the long term. This past year has been a mix of ups and downs. We welcomed our first child while also trying to understand and manage a life-changing diagnosis. The diagnosis of FSGS feels ubiquitous and unpredictable. It doesn't follow a clear path, and that uncertainty makes it harder to plan for the future or be fully be present in the moment with our family. There are good weeks and difficult setbacks, and the emotional toll on us all is heavy. Having an FDA-approved treatment specifically for FSGS would offer reassurance that there is a specific option for this disease, not just trial-and-error approaches. It would give our family hope that we can slow disease progression. It would give him a better chance at the long, healthy life he wants with his son. It would allow us to focus more on being parents and less on living in fear of what comes next. It would change everything.
JoAnne S.	Any medication at this point would be life-saving. My son is steroid resistant and medication resistant when it comes to FSGS. We are looking down the barrel of a kidney transplant, and we desperately need more options.
Julie W.	My granddaughter could have a better, healthier life.

Comments

From a Parent or Family Member of Someone with FSGS

Sam S.	No child should have to experience this disease as our granddaughter has been forced to. Having to daily take multiple doses of medication, which itself causes damage to her kidneys, plus causing hypertension in a small child that continues with her, even if her disease goes into remission, because her little kidneys are so damaged now. Our Prayers and education for all Americans into this disease and the beautiful children and families this disease attacks is desperately needed. We can find a cure, if this crippling disease of our children becomes known and addressed as every bit as destructive as any other major illness. These children are fighters, and they have to overcome insurmountable odds just to live a reasonably normal life. Pray for them all. And get the word out: FSGS is a nightmare for all the children it attacks. Let's put an end to this nightmare for them.
Rebecca K.	If the medication had been available sooner my daughter's kidneys may have functioned longer. She's 33 years old and is currently on dialysis after 16 years of fighting the disease.
Sharon S.	Not sure since my son is already on dialysis.
Katherine R.	I am the mom of a 2.5 year old who was diagnosed with FSGS just after his 2nd birthday. Seeing the effects that long term steroid use had on his young body makes me long for something with fewer side effects. Even the Tacrolimus that he takes now will cause kidney damage in the long term. Having a standard medication for FSGS would be such a relief for those dealing with this disease - even if it is just a starting point, at least there would be a standard treatment, for which there is currently none. We never thought we would have a child with a rare disease, but here we are, fighting to make his life as easy and healthy as possible.
Sophie M.	My son with diagnosed with FSGS and it took us years to find a treatment plan that worked for him. I'm hopeful we are close to finding a cure and once sparsentan is FDA approved Pediatric's will also be able to use.
Amy M.	Any treatment for FSGS is hope for a cure for my daughter.
Sam S.	My precious granddaughter was struck with FSGS at the age of only 18 months old. It has been traumatic for her and all of her family members, having to watch this child endure deadly medications in hopes of slowing down the progression of this horrible disease. FDA should allow any medication to come to market that proves beneficial to any child suffering with this condition. Please help these children live a normal life, and live a long life, full of joy and beauty, rather than pain and suffering.
Milton L.	Our 7 year old was diagnosed 4 years ago and has been on immunosuppressants since his diagnosis. Having access to a medicine that is not an immunosuppressant and higher rate of remission would be life changing for our family.
Jessica L.	Our 7 year old was diagnosed 4 years ago and has been on immunosuppressants since his diagnosis. Having access to a medicine that is not an immunosuppressant and higher rate of remission would be life changing for our family.
Chloe G.	She would not have to be on such strong steroids. An alternative treatment
Jenifer D.	I feel it will help her have a better quality of life.

Comments

From a Parent or Family Member of Someone with FSGS

Jake W.	My wife is suffering through the process of remission recently being diagnosed with FSGS and the only medication available to her is prednisone and I've seen first hand how that has no only affected her physically but mentally as well. I wish there was a medication that targeted her kidneys specifically without adding to everything she's already going through having FSGS.
Karen W.	The steroid treatment has been devastating to her. There needs to be a drug to treat this without steroids!
Robert W.	For my daughter in law.
lily f.	It would impact my family in a good way. My family member with FSGS would be able to go back to the things they love to do without a worry. It would be easier on her life.
Kylie F.	It would greatly impact how my sisters life would be the side affects of her medication now has made her gain weight and made it difficult to do everyday tasks. This medication would make it so much easier on her body.
Patricia R.	FSGS patients are in desperate need of a targeted treatment. As the only treatment, Immunosuppression is hard on the body and mind.
Rhonda V.	My husband has FSGS. Any kidney disease is incredibly hard on the patient and the family. Any type of medication to give a chance of prolonging life of the kidney is worth it. I see how my husband struggles. He is currently back on dialysis.
Jen P.	Any period not in remission slowly destroys your kidneys, waiting or praying for drug approvals is not the way to manage fsgs
Regina S.	It would be such a blessing to our granddaughter who is 9 living with FSGS!
Dan M.	Help my wife whom is diagnosed with FSGS. This disease has changed our lives.
Anna C.	My sister and many others wont have to suffer for so long with this awful disease
John W.	It would be a huge relief for my family
David M.	It might save my child's second kidney!!
Liliana D.	My son has been living with FSGS for almost a year now! This disease has significantly impacted his life and our family's life. We need treatment options and we need them NOW! The fact that Sparsentan is not an immunosuppressant and works directly on the kidneys is a huge deal, and it gives us hope that help is closer now than ever..
Jaimee W.	Having a safe, reliable treatment for those with FSGS will give comfort & peace of mind. Everyone deserved safe healthcare & treatment options available to them.
Leslie K.	My daughter's kidney disease has progressed, and she is currently on the last option of treatment.

Comments

From a Parent or Family Member of Someone with FSGS

Michelle M.	I would give me and my 12 year old whom has FSGS a better chance and a more normal life and less hospital stays.
Julie C.	This treatment will help my son have a fighting chance against FSGS.
Katy R.	My son has tried all available therapies so far. None have worked and he's in plasma aphersis twice a weeks to protect his kidneys until new treatments are available. He's 18 and has been on this treatment regimen for 18 months during his junior and senior year of high school. Having another drug option and giving him the ability to possibly obtain remission would give him the option of college, which he's not considering right now due to time commitment of treatment.
William M.	This drug is needed in order to preserve my niece's native kidney function. She has exhausted all other forms of treatment. This drug could put her in partial or total remission so she can avoid dialysis or kidney transplant which would cost considerably more than this drug. Please approve this drug so she can watch her 3 year old boy grow up. Thank you.
Margaret M.	This drug is needed in order to preserve my niece's native kidney function. She has exhausted all other forms of treatment. This drug could put her in partial or total remission so she can avoid dialysis or kidney transplant which would cost considerably more than this drug. Please approve this drug so she can watch her 3 year old boy grow up. Thank you.
Elise W.	My son died of FSGS in 2018 at the age of 17. If an FDA approved drug for FSGS had been available, he probably would still be alive today. Please prioritize FDA approved drugs for FSGS. It is so critically needed!
Krista K.	My son has had a transplant and is doing well but we wish there would have been meds that would have given him some hope before he had 2 tranplants and over 10 years of dialysis by age 21
Scott C.	My daughter has had two kidney transplants
Brittany D.	My sister was diagnosed with FSGS in 2009, when she was just 15 years old. Hearing that diagnosis was devastating, but what made it even harder was realizing no treatment options existed. We were told what the disease could take from her, but not given anything meaningful to fight it with. That lack of options left our family feeling powerless and completely out of control. The potential availability of sparsentan feels different. Having a medication that can meaningfully reduce protein loss could change the trajectory of this disease for people like my sister. For some, it could mean shifting FSGS from a life-threatening diagnosis to a chronic condition that can be managed and stabilized with treatment. Even having one FSGS-targeted option would have made an enormous difference for our family. Choice is empowering. Hope is empowering. For families living with FSGS, sparsentan represents both.

Comments

From a Parent or Family Member of Someone with FSGS

Raquel F.	am writing on behalf of my 7-year-old son, who has been diagnosed with focal segmental glomerulosclerosis (FSGS). He is currently being treated with immunosuppressive therapy (Tacrolimus). While this treatment is necessary, it has significantly weakened his immune system and has already led to hospitalization due to complications. Even common viral infections pose a serious risk to his health, as they can escalate rapidly because of his immunocompromised state. My son has been evaluated by several highly respected nephrologists across the country. Each of them has independently recommended Sparsentan as a more appropriate and promising treatment option for managing his FSGS and potentially reducing his dependence on long-term immunosuppression. Unfortunately, we were unable to enroll him in the clinical trials, and we are now anxiously awaiting FDA approval of this medication. Access to Sparsentan would represent a meaningful and potentially life-changing improvement in my son's treatment and quality of life. It could offer him a safer, more effective therapeutic option and provide our family with renewed hope for better disease management and long-term outcomes. Thank you for your time, consideration, and commitment to advancing treatments for children with rare and serious kidney diseases. We are deeply grateful for your work and respectfully ask that you consider the urgent needs of pediatric patients like my son.
Robert S. C.	it would give her a chance to live a normal life!
Lorie C.	It wil give her hope and the possibility of living a more normal life. No one should have to spend every day of their life worrying about not being there for their spouse and their children.
Maria E.	If sparsentan is available to those diagnosed with FSGS, my husband would be healthy and live a normal life like any other dads. Without sparsentan, he had to be hospitalized, undergo dialysis three times a week, and struggle so much everyday to continue to live. Please make sparsentan available NOW so families won't have to go through the hardship and uncertainties of having FSGS.
Marcie B.	More treatment options may prevent or slow the need for transplant/dialysis.
Kim H.	My daughter has FSGS and is receiving dialysis. While we are grateful for the treatment as it is life saving it is very time consuming and has some hard side effects. If there is a possibility she would be able to try
Olegna F.	As a parent of a child living with focal segmental glomerulosclerosis (FSGS), the potential approval of sparsentan would give our family real hope. Current treatments can be difficult, with significant side effects and inconsistent results, and it's hard watching your child go through that uncertainty. A targeted treatment that could reduce proteinuria and slow disease progression would mean fewer medical complications and a better quality of life for our child. It would also give families like ours reassurance that meaningful progress is being made in treating FSGS and helping children focus more on growing up and less on managing a chronic illness.
Sherry B.	Live a longer life without dialysis or transplant

Comments

From a Parent or Family Member of Someone with FSGS

Octavio H.	My son was diagnosed at 3 years old with nephrotic syndrome and did not responded to corticoid protocol. Then, a biopsy confirmed FSGS. His life and ours as parents changed completely. We are running out of medication alternatives after several relapses. Any new medication that can delay CKD is a light of hope for out little ones and adults living with FSGS
Hannah D.	This would help save my family member
Shubhi R.	FSGS is such a rare kidney disease impacting families along with the patients life. Getting the medicine approved by the FDA will give us hope. It will help Patients to live a better life.
Deb H.	A chance to not have to be on dialysis it's horrible life not having any treatments available to try
Richelle G.	This drug helps my sister maintain a healthy lifestyle so she can be around for her family and friends.
Mary S.	It would hopefully give my son hope to live a more normal life vs being tied to a machine
Janel F.	Steroids were so harsh on my daughter's body. Tapering off the steroids made her feel like she was going through withdrawal.
Kathleen R.	I hope it would extend my grandson's life expectancy. And others who have this disease.
Susan B.	With no clear drug for my son, he will continue to walking in the unknown if he will ever get remission.
Nicole J.	It would affect my family as it would finally provide a reliable treatment for his and and father of my children. All treatments he has tried have failed.
Jens C.	Offer a better solution than current drugs on the market. Perhaps with less side effects.
Ruth C.	Our teenage son is currently taking numerous off label medications to control the symptoms of FSGS. He takes 17 pills daily and has been having yearly Rituximab infusions. Our prayer for him is to reduce the amount of medications he has to take to control this disease and to have access to medication that is made specifically for FSGS. We are hopeful that patients with FSGS will have brighter futures with the approval of drugs that are made specifically to treat this disease.
Alex W.	It would change our daughter's life significantly. She was diagnosed in 2024 and has never been able to live a normal life again. The immunocompromised nature of her current meds has kept her and the family home bound. The quality of life would greatly improved not being a immunocompromising medication
Joshua P.	It would help my cousin so much. She has felt with this for years and deserves a break.

Comments

From a Parent or Family Member of Someone with FSGS

Kathryn P.	I have a cousin who desperately needs sparsentan, as she battles with FSGS and has a 3 year old to take care of.
Melinda W.	This could possibly be life changing for my son and all the others who have FSGS.
Justin C.	Having access to a medication specifically designed to treat FSGS allows those afflicted with the disease to streamline their treatment and stop taking the myriad of other medications that are often hard on the body and have significant side effects. My son takes two types of anti rejections drugs, a blood pressure medication, a diabetic medication as well as annual drug infusions. Please allow this medication to be available for those that need it.
Savanna S.	I would like to see my little girl get off of Prograf and be able to live more normally.
Nina V.	Less worry if my son with special needs would need a transplant.
Rachael T.	Might be life saving
Elizabeth B.	My son is 22 years old at end stage renal failure. He is in desperate need of some type of treatment while he awaits a transplant.
Jacqueline S.	Our Daughter, Katlynn Wilber, Age 36, wife and Mother of an adorable 3 year old boy who is her life, has struggled with FSGS since her diagnosis in 2023. I have watched her navigate her life through times when she can barely walk and she is so exhausted and Ill most people would lie down and quite. The possibilities that this medication would bring her would be a life without dialysis and the possible looming of kidney implantation ahead of her. It would give her the opportunity to have a long life as a wife and mother. She has exhausted all other routes at this time and we are begging for consideration of this drug to be granted to her so that she may live a life that we all want for our children....One free of pain and illness
Jessica M.	This is vital to my sisters next step in her treatment. She is running out of time with this disease progressing and cannot get past insurance denials.
Jeff G.	This drug could have the potential to preserve my daughter's kidney function and provide a better quality of life.
Lloyd P.	I am Jake's father. From a family perspective, FSGS creates ongoing uncertainty and forces decisions and planning around lab results, medications, and risk. It is not just a medical diagnosis. It is a constant pressure on day-to-day life and long-term expectations. The availability of sparsentan would have a meaningful impact because it would represent a concrete treatment option for a disease with limited approved therapies. It would give Jake and our family more confidence that progression is not inevitable and that there are tools to fight back. It would also reduce the long-term fear that he may need dialysis or a transplant, including the worry that loved ones may one day be asked to consider living donation. An approval would also encourage further investment in FSGS research and treatment development. When thinking of my son having to deal with this on the heels of the birth of his first child. I wish that I had gotten FEGS not him. The advent and approval of Sparsentan would enable me to begin to replace despair with hope.

Comments

From a Parent or Family Member of Someone with FSGS

Josh W.	It would be wonderful if it was available
Amanda C.	My cousin has exhausted all other treatments and has been denied for this due to it not being cleared by FDA.
Jackie M.	A non-immunosuppressive medicine like this drug is crucial to patients with FSGS as being on immunosuppressive therapy drugs/cancer treatment, drugs for decades on end, compromises them and more ways than just immuno suppression it actually is a cancer, causing drug as well And a drug like Sparsentan Would eliminate the immune suppressing part and allow their bodies to be able to fight off infections. It will also help with kidney function and help against chronic leakage !!! This drug is a critically needed drug and needs to be approved quickly by the FDA!!!!
Christa K.	Could extend her life.
Joy J.	My son wasn't diagnosed until after his transplant almost 3 years ago. We were told that because of the FSGS, this will likely not be his last transplant. Treatments for this condition are sparse - a new drug would give so many much needed hope.
Tess S.	The options for treatment are diminishing. The expense is outrageous.
Mindy P.	I am Jake's mother, and watching your child live with FSGS is frightening in a way that is hard to describe. Even when things look stable, there is always uncertainty in the background. It affects how our family thinks, talks, and plans. It also affects Jake's ability to feel secure about his future, which affects all of us. If sparsentan becomes available, it would give our family something we do not have right now: an approved treatment option and a reason to believe we are not powerless. It would ease the constant fear of progression toward dialysis or transplant, and it would reduce the emotional burden on Jake and everyone who loves him. It would also send a message that the FSGS community matters and that developing treatments for this disease is worth the effort.
Julie P.	I am Jake's sister. FSGS has changed how our family thinks about the future. Even when things are calm, the uncertainty is always there. I see how much mental effort it takes for Jake to stay present and optimistic while still carrying fear about progression. If sparsentan were available, it would give my brother and our whole family real hope and a sense of agency. It would mean there is a path besides waiting and worrying. It would also help with the constant fear of dialysis and transplant, and the possibility that family members may someday need to step in as donors. I want Jake to be healthy and fully present for his child and for his life. An approved treatment for FSGS would change what feels possible for our family.

Comments

From a Parent or Family Member of Someone with FSGS

Chrystal H.	My daughter, Lauren, is living with focal segmental glomerulosclerosis (FSGS), and every day our family feels the weight of a disease with no FDA-approved treatment options. FSGS is not just a diagnosis for us — it is a constant presence that shapes Lauren's daily life, her energy, her confidence, and her future. The availability of sparsentan would mean hope where there has been uncertainty. Right now, our choices are limited to treatments that are often harsh, unpredictable, and not designed specifically for FSGS. We have watched Lauren navigate side effects, missed school days, and the emotional toll of not knowing what comes next. As a parent, it is heartbreaking to explain to your child that there is no approved medicine for what they are facing. Sparsentan represents the possibility of stability — a chance for Lauren to grow up with fewer disruptions, fewer hospital visits, and fewer fears about what her kidneys may look like in a year or five years.
Ricardo P.	There is no treatment for FSGS and watching my loved one go through trial and error. Medication's was very hard, especially since the medication's made her sick.
John S.	My Daughter went through it. I support every thing about. Needs to be recognized better.
Jenny R.	Please help to make this accessible for my loved one who truly needs this to be well, have quality of life and survive. This has provided them with hope and life.
Libby H.	It would give my niece more valuable time. She is so young and has a beautiful family that need her. She has exhausted all treatments to date.
Shannon S.	This is the last resort for my niece living with FSGS- at 36 years old with a 3yo son. Please- it is her last hope!
Danielle M.	My brother has been living with this since he was 17 and this treatment would have a significant impact on his quality of life.
Jan S.	My niece has this terrible disease, with her it was trial and error, and she could not continue with steroids which made her feel more sick.
Adam r.	would help with a better lease of life
Rebecca R.	My little brother has had this diesease since he was 17 years old. He has lived with it for over 12 years and it's not just the diesease it's the effects it also has on all his other organs. It's vital he gets treatment soon.
Rebecca C.	This would help to prolong or potentially put in remission my 36 year old cousin suffering with this horrible disease. She just wants to see her 3 year old grow up. She has exhausted all other treatment options. She faces dialysis and kidney transplant that are ultimately much more expensive than this course of treatment. Please approve this drug for her and countless others suffering from FSGS.

Comments

From a Parent or Family Member of Someone with FSGS

Suzie C.	It would give my son the chance to live life without the risks and issues associated with being immune suppressed with daily drugs and infusions for the last 17 years. It would also give him the opportunity of having a biological child of his own - without the birth defect risks Myfortic acid present. Praying every single day that sparsenten will be FDA approved soon , and he will be able to take this amazing new medication.
Cody H.	My cousin has struggled with this for almost her entire life. This would give her opportunity at something she's never had.
Don W.	After seeing what effort , mentally, physically, and just the plain unknowing of what our daughter is going to eat at practically every meal ….if this medication was approved , it hopefully could take much of the daily uncertainty away.
Lauren W.	It would save my cousins life!
Shannon M.	Having child with fsgs has changed our lives dramatically. There was no FDA approved mediations for our daughter & she went into kidney failure less than two years of being diagnosed with FSGS. If Sparsentan was available prior maybe she would not have been in kidney failure & need a transplant. So having this approval will give us HOPE for the many who suffer with this terrible RKD.
Emily G.	It would help slow down kidney damage so my sister could not be so worried about the future and the possibility of having to have a kidney transplant in the next few years.
Ellie M.	Improve her quality of life/ save her life.
Matthew B.	As a race we should do whatever possible to help protect and heal one another. No matter what form of assistance that may be.
Katie J.	My daughter has tried so many treatments and it's only gotten her to partial remission after transplant. She's had 2 and she's back on dialysis.
Marc S.	Please help my sister.
Rosa N.	My son was diagnosed 2 years ago has had different treatments. They start well but he stops responding to the mefications. If this is promising for this lets give our children a promise to life.
Cristobal M.	Anything that would make my wife's FSGS future any less daunting is worth pursuing.
Shawn N.	Hopefully increase the time someone would need to be starting dialysis. Increase the quality of life.
Melissa C.	Improve the quality of life.
Lisa M.	My daughter has fsgs.
Jill K.	Able to stay in remission with Tacrolimus.

Comments

From a Parent or Family Member of Someone with FSGS

Mary N.	My sister was diagnosed with FSGS 26 years ago. 3 transplants later she is currently in remission. She is an incredibly strong person and advocating for herself and others keeps her going.
Margaret P.	It was very difficult for my niece to get a treatment protocol.
Angela A.	This incurable disease needs treatments as each case may be resistant to drugs that are approved for treatment. The more drugs available the better
Amy P.	My daughter was diagnosed with FSGS 6 years ago at the age of 29. It's been a rollercoaster with her trying multiple medications. We've been waiting for Sparsentin to be approved for FSGS so that she can possibly live a somewhat "normal " life. Please approve this asap to allow FSGS patients access to this treatment
Esmeralda P.	The availability of sparsentan could reduce the amount of times we have to try different types of medications, hospital visits due to relapses, this would show that fsgs is being taken serious knowing there is a medication that could possibly be a positive for those dealing with fsgs, this would ease anxiety in parents/care takers even the patient themselves, this gives hope to our families!
Jenny S.	Not sure. My son has tried so many treatments that haven't worked and is on his way to a transplant.
Donald H.	For 8 years since my daughter was diagnosed with FSGS, there was no cure, this give long term help for her kidneys for her lifetime.
Heather P.	Anything to help preserve, the remaining function of his kidneys and reduce hospital inpatient stays to give him some type of quality of life would be very beneficial.
Mark W.	The availability of sparsentan would mean hope and relief for our family. Watching someone you love live with FSGS is incredibly difficult — the uncertainty, the limited treatment options, and the side effects that impact daily life take a real toll. A targeted, FDA-approved treatment would offer not only the possibility of slowing disease progression, but also peace of mind that there is finally a therapy designed specifically for this condition. For families, sparsentan represents progress, stability, and hope for a better quality of life for the people we love.
Andrea W.	Their doctor says it would help them!
Julia H.	My sister could focus more on raising her family, doing her job, and living her life rather than constantly worrying about her kidneys!
Lora H.	For 8yrs there has not been a treatment that worked. Approving this will give my family hope, quality of life!
PHILLIS W.	There is no treatment for this
Eftihia N.	My daughter is living with this rare kidney disease that had zero medications developed for it, until now. This medication will put FSGS on the FDAs radar and hopefully more medications will be developed/created to help those diagnosed with this awful disease.

Comments

From a Parent or Family Member of Someone with FSGS

Kathy W.	It would mean she could have a longer life ….it would mean everything as a parent that their child does not have to be denied a long life because of this disease
Christine M.	My 11 year old son with FSGS is currently taking Sparsentan, he began it in October as a last ditch effort to try and postpone him beginning dialysis. This medication has helped in slowing down the progression of his kidney failure. We have seen no adverse reactions to it, only benefits!
Lisa W.	The availability of sparsentan would bring real hope and relief to our family. Watching a loved one live with FSGS is incredibly difficult—the constant uncertainty, limited treatment options, and serious side effects take a profound toll on daily life. A targeted, FDA-approved therapy offers not only the possibility of slowing disease progression, but also the reassurance that there is finally a treatment designed specifically for this condition. For families like ours, sparsentan represents meaningful progress, greater stability, and hope for a better quality of life for those we love.
Kelly H.	My daughter has recurrent FSGS, meaning she did not respond to any available off-label therapies and her disease progressed to end-stage kidney disease, requiring dialysis and a kidney transplant at the age of five. Her disease returned in her transplanted kidney, and once again, available treatments failed. Sixteen years later, she is now 20 and has received a second kidney transplant. Her FSGS is currently in remission for reasons that remain unknown, and we live with the constant fear that when her disease relapses, we will again have no effective treatment to prevent the progression to kidney failure. Having an FDA-approved therapy like sparsentan available is essential. It offers a targeted treatment designed specifically for her disease, with limited side effects. Access to such a therapy is critical not only to prolong the life of her donated kidney but also to allow her to function and thrive with peace of mind and minimal treatment burden as she navigates young adulthood.
Jennifer G.	This would be a huge benefit for my daughter. She has tried several medications and none have put her into remission. I have heard a lot about this drug and would definitely want my daughter to try it.

"Sparsentan would greatly impact and improve my 21year old son's life. He has been living with FSGS since he was five years old and to finally have something to help slow down the progression of this terrible kidney disease would be a true blessing. We follow exactly what the doctors tell us to do but we desperately need more. We need medical intervention./ medication to help him and other people living with FSGS. We desperately need help to slow down this damn disease, he and everyone else deserves the opportunity of having a better, healthier and longer life."

- Joanne F.

Comments

From a Parent or Family Member of Someone with FSGS

Eliana R.	My immediate family member, my daughter, has focal segmental glomerulosclerosis (FSGS). Living with this disease has been extremely challenging, not only medically but emotionally, financially, and socially. She does not respond well to standard treatments and has been on immunosuppressive therapies that come with serious side effects. We live with constant uncertainty — worrying about relapses, progressive kidney damage, and the very real possibility of kidney failure and transplant in the future. The availability of sparsentan, as a potentially first FDA-approved treatment specifically for FSGS, would have a profound impact on our lives. Current treatment options are limited, often ineffective, and not designed specifically for this disease. A medication like sparsentan, developed to target the underlying mechanisms of FSGS and shown to reduce proteinuria, represents real hope — not just symptom management, but the possibility of slowing disease progression and preserving kidney function. For our family, sparsentan could mean fewer relapses, fewer hospital visits, and a better quality of life for my daughter. It could allow her to live more like a normal child, attend school consistently, and grow without the constant burden of aggressive treatments and their side effects. For me as a parent, it would mean hope — hope that her kidneys can be protected longer, hope that we may delay or even avoid dialysis or transplant, and hope that her future is not defined solely by this disease. Although we did not participate in the DUET, DUPLEX, or EPPIK studies, we closely follow advances in FSGS research. Knowing that clinical trials have shown meaningful reductions in proteinuria with sparsentan gives families like ours something we rarely have: cautious optimism. An FDA-approved treatment specifically for FSGS would be life-changing for our family and for so many others facing this rare and devastating condition.
Keri C.	Tremendous
Kathy R.	It would be wonderful if she didn't have FSGS. She had a transplant but she still has FSGS.
Richard G.	My daughter is an FSGS patient that had a transplant
Catherine C.	My son has been in remission for a couple of years. However, having an alternative to the harmful effects of steroids during his treatment would have been a godsend. The side sport term and long term side effects have been brutal.
Andrew M.	My mom has fsgs so I worry for her
Judith L.	it would greatly help my friend child who might have fsgs
Licia S.	My brother (1 transplant & currently on dialysis), my 2 sons (4 transplants) and myself all have Stage 4 FSGS. Never heard of the studies.
Tara K.	My son was diagnosed with FSGS at age 6 and underwent transplant H 10. He's currently 15. I don't know much about this truck, but if it is specific for FSGS, then it would be tremendous.

Comments

From a Parent or Family Member of Someone with FSGS

Emmaline M.	It will give my 13yr old son who has been struggling with this disease since the age of 3yrs a new life and live as a normal kid
Brenda M.	Many patients are waiting for a cure; my son is one of them. No matter how small the hope may be, I believe it would be worth it…
Michael M.	If it slows or stops the progress of the condition it would allow him to resume his engineering work and return to a fulfilling life with a future. Right now, and for the last three or more years, his days are entirely taken up dealing with the impact of FSGS, with dialysis, preparing for a kidney transplant and waiting for the call that a suitable match is available, and now recovering from that transplant knowing a functioning healthy kidney is only a stopgap.
Ben T.	My sister has FSGS & the new trial drug is helping her so much! Please approve this medicine!
Melissa G.	My son is 10 years old living with FSGS. Currently on a rejection medication and I would love to try something else.
Christy C.	HopeWill Foundation & Tampa Pig Jig was started for my son in law Will Wellman. Since diagnosed in 2008 with FSGS has had hope of a drug been and one day be off of dialysis.
Heidi M.	My son was diagnosed through a biopsy with FSGS in 2013 he had a good Nephrologist and was given infusions of Rituximab several times, but the medication didn't work...He went into ESRD and was on Dialysis for over 4 years 4 times a week, in 2025 he received a gift of life and was transplanted at Mayo Clinic in Phoenix, AZ, but we were informed before the surgery that FSGS may come back....we are hoping and praying that it doesn't happen....we are advocating for the first FDA-Approved drug for FSGS...to help so many people that suffered from this disease.
Sandee S.	No more experimental use of drugs to alleviate symptoms of this disease.
Ahmed E.	My wife has it and I don't want her to go through dialysis
Shirley H.	Positivity
Julie S.	My son was diagnosed when he was three and now 19. We have struggled four years to keep him in remission.
Adam E.	My mother had FSGS and has gone to multiple doctors and they could never find the reason. She has been struggling with it since her 20s, can't do religious fasting and it's just scary knowing her kidneys are only getting worse.
Lena M.	It would minimize lab testing for my son which depletes his iron levels each time we go, reduce anxiety for all of us, allow my son to lead a regular childhood not worry about what he can eat and how much liquid he can drink. Perhaps it would reduce the number of other autoimmune diseases he has.
Joanne C.	My granddaughter was diagnosed with fsgs at age 3. She's 20 now. We need to fund a cure.

Comments

From a Parent or Family Member of Someone with FSGS

Taylor W.	My husband has had FSGS and has been on dialysis for over 15 years. Having this drug on the market would make a transplant for him all the more possible. This isn't just a "nice to have" drug option for us. It could genuinely the difference between a limited life on dialysis or a long, recovered future with our family.
Tyler W.	My brother was diagnosed with FSGS over 15 years ago. Since his diagnosis there have been no majors changes to standards of care or new medications used for treating this poorly understood and cureless disease. It has been challenging for my brother and our family to see the years pass by with no new treatments coming to market. We have been following the progress closely with Sparsentan. It gives us so much hope to FINALLY see something potentially coming to market that could be truly life changing for my brother and so many others who suffer from this rare kidney disease. My brother has put off having another transplant (the disease relapsed in his first transplant) and has been on dialysis for the past 15 years because of the lack of effective treatments on the market. Having an effective, FDA approved medication for treating FSGS would enable him to move forward with a transplant knowing there is a medication available in the event he has a relapse. It is hard to express how life changing this could be for my brother. We are hopeful the FDA moves forward with approval!
Jennifer W.	It would be life changing in helping my brother survive. This medicine has given him hope.
Leslie J.	Both of my daughters are kidney transplant recipients and lost their native kidneys to FSGS.
Jennifer K.	It is difficult to determine the impact as my child is achieving good outcomes and is well managed on his current medications.
Karlene C.	We are thrilled that Sparsenten can be available for my 9-year old son who has FSGS. My son has been on so many medications that haven't been specifically designed for FSGS.
Jama G.	My son has FSGS. He is stable now on cellcept, but I am very worried what the future holds for him worh this disease. If this drug was approved for treatment of FSGS, it could mean keeping him stable longer, or even prolonging his life. He is almost to the point where cellcept is not working as well, and I worry about the next line of treatment frequently. This drug, just knowing its there as a back up, could give a ton of peace to my mind and his.
Marcy M.	It would make a huge difference.
Qingyi D.	Having an option such as Sparsentan to treat FSGS is like seeing light at the end of a long dark tunnel for patients with this disease. It will make the disease much more manageable for patients and families, and will make the diagnosis feel a little less painful.
Sarretta M.	For 17 years, since my daughter was 3 years old, we have lived without targeted treatments for FSGS and have had to rely on cancer drugs to help maintain some semblance of a normal life. All incremental progress that can protect our kids' kidneys from end stage renal disease and transplant give us hope to extend the quality of life for our kids. Thank you for hearing us!

Comments

From a Parent or Family Member of Someone with FSGS

Cathy M.	I am a parent of patient who had FSGS. She had a transplant 22 years ago. In the event that she would need another transplant. It would be extremely important to have a drug to help with having to worry about the disease returning again. And help all The patients going through this terrible disease that often leads to kidney failure and needing a kidney transplant. Thank you.
Randy C.	My grand daughter has been fighting FSGS for 12 years, with current treatments putting her life at risk.
Martha F.	Granddaughter failed several.
Susan F.	Please approve this medicine. A lot of people need help..
Diana A.	My 14 year old granddaughter has this. Any treatments to help, I'm all for.
Louis A.	My 14-year-old granddaughter has this disease, and any hope that a normal life would be wonderful for her.
Joshua J.	I believe this could be life changing and improve the quality of life. This will be instrumental in working towards a cure. Controlling this disease should be a priority.
Walter J.	It would give us HOPE.
Bruce M.	It would ease the burden of infusions multiple times a year and help with improving the lives of so many people.

Comments

From a Parent or Family Member of Someone with FSGS

Dana L.	So he would not relapse
Sara L.	It would make a difference if it worked for him.
Jessica J.	My son has been living with FSGS for 10 years. He is 11 years old. He has been taking tacrolimus immunosuppressant since he was 2. He has been hospitalized, missed school, taken a chemo infusion used to treat rheumatoid arthritis, In addition to various other ways it has affected our life. The opportunity to take a non-Immunosuppressant medication like Filspari would make a world of difference for us! The once daily pill would cut down his need for twice a day medication also, and hopefully eliminate the need for the chemo infusion which kills his immune system completely. He would not have to endure more needles, time away from school, and potential health risks due to a compromised immune system. It is very important to our family that this drug passes the FDA approval and we can begin administering it as soon as possible! Thank you for your consideration.
Coleene V.	My son died at age 26 from complications of FSGS and other conditions.
Lisa C.	It would help them live a much better life.
Breanna W.	My 7 year old niece could play with a friend, go to school, go out to eat with her family. She has been in isolation for 2 years following her diagnosis. Which, in turn, her parents, her two brothers also need to be in isolation. This is no way for a child and her family to live.
Joyce F.	Help prevent relapse after transplant.
Amanda Y.	We would worry significantly less about relapse
Kerry S.	My wife has been waiting for this drug to be available for years. I hope she will be able to have access to this drug
Valerie S.	My niece has FSGS who is 8. I think a lot about all the kid activities/life experiences she can not partake in due to her suppressed immune system. I also have only gotten to see her a few times outside since her diagnosis a few years ago due to her suppressed immune system. It is heartbreaking to miss so much of her life and want more than anything to have her be able to see her and watch her be a kid.
Rosie K.	Our son has had several relapses and steroids did not always help. Any medication to help battle FSGS would benefit many people

"There is no treatment for FSGS and watching my loved one go through trial and error. Medication's was very hard, especially since the medication's made her sick."

- Ricardo P.

Comments

From a Parent or Family Member of Someone with FSGS

Paul T.	Our Story regarding FSGS and our most recent email to NHS England. Good evening, To whom it may concern, As a very concerned and desperate father, I am writing further to my wife's email below regarding our daughter, Zoe. Zoe is now 22 years old and has suffered from nephrotic syndrome since the age of 9. Following a kidney biopsy at Newcastle RVI in 2012, she was diagnosed with minimal change disease and began treatment with immunosuppressants. Despite high doses of steroids and other medications, she only ever achieved partial remission. A second biopsy was then recommended, and we received the devastating news that Zoe had developed steroid-resistant FSGS. We were subsequently referred to Professor Moin Saleem at Bristol Children's Hospital. After speaking with him, he recommended starting Rituximab infusions. He explained that if Zoe responded, her condition could be considered immune-driven, giving her natural kidneys a better prognosis. If she did not respond, her condition was more likely genetic, and in that case a future transplant would be less likely to be affected by FSGS. We left that consultation feeling hopeful for the first time, how wrong we were. When Zoe turned 18, her care was transferred to the Newcastle Freeman Hospital. After discussions involving visiting consultants from the United States and representatives from a pharmaceutical company, Zoe was accepted onto the Duplex study. We do not know whether she received the trial drug or a placebo, but her proteinuria did appear to decrease and her kidney function, though impaired, seemed to stabilise for a time. The following paragraph reflects our personal opinion, though we understand others may disagree. As Zoe was considered clinically vulnerable during the COVID-19 pandemic, she received three doses of the AstraZeneca vaccine (Vaxzevria/Covishield). Shortly afterward, her remaining kidney function declined rapidly, her proteinuria increased significantly, and she was advised that a kidney transplant was now necessary. She began peritoneal dialysis and, after an episode of peritonitis, was transferred to haemodialysis three times per week. I underwent extensive testing and was found to be a compatible donor. I donated my kidney to Zoe in November 2023. That Christmas was the happiest and most normal our family had enjoyed in years. Tragically, our joy was short-lived. At a consultation in January 2024, we were told that Zoe's protein leak was rising again, the FSGS was attacking her transplanted kidney. She had a neckline reinserted and began plasmapheresis twice a week. After a fistula was formed in her arm, treatment continued via the fistula, and the neckline was removed. The treatment did initially reduce her proteinuria, and the frequency was reduced to once per week, but this resulted in her levels rising again. After further surgery to unblock the fistula, she has now returned to treatment twice weekly. At a recent consultation at the Freeman Hospital, my wife asked whether Zoe could be referred to a centre offering LDL apheresis. The response she received was deeply distressing: "We don't have that here, but if you want to seek an opinion elsewhere, feel free." We are terrified that unless we pursue this ourselves, our caring, beautiful daughter is sleepwalking toward renal failure for the second time in her short life and we genuinely fear what will happen to her next. We have been greatly encouraged by the story of Kitty Srabski and her remarkable progress following her transplant and subsequent LDL apheresis treatment, her case is strikingly similar to Zoe's. This has given us a glimmer of hope. We are absolutely desperate to give Zoe the chance of a normal life. She has endured more setbacks than any young woman should, and we would be eternally grateful if you would consider her for assessment and potential treatment. Thank you for your time, and we sincerely hope to hear from you soon. Kindest regards, Paul & Kath Thompson God bless Nephcure and hope our story assists you in your fight for better outcomes for FSGS patients and their families and friends because this disease is truly devastating and is non discretionary.

Comments

From a Parent or Family Member of Someone with FSGS

Jackie M.	Anything that will reduce proteinuria, give a partial or full remission thus reducing stress on kidneys needs to be made available to our kidney loves!!! My daughter is only 26 and has had some serious relapses in the 24 years since diagnosis. Her Nephrologist is just waiting for Sparsentan to be available so that my daughter will immediately be prescribed this. My only other hope is that insurance doesn't make her pay a small fortune in order to help save her life!
Michele H.	Help is urgently needed
Deborah W.	My eight year old granddaughter has had FSGS for two years. Her treatment means she is severely immunosuppressed. This has severely limited our contact with her, and her family's contacts with relatives, friends and the rest of society. They have missed weddings, funerals, birthdays and a host of other activities, with no end in sight. She and her siblings are homeschooled due to her vulnerability. Sparsentan may help alleviate some of this burden, and give her time for further advances in treatment. This drug has the potential to help many patients and families facing decades of hardship and loss.
Michael W.	My eight year old granddaughter has suffered with FSGS for roughly two years. Her treatment has been by trial and error, with no clear course. A targeted drug would give us all hope for the future. The entire family has suffered severe disruption due to FSGS. Family visits and activities are severely curtailed due to her immune compromised condition. Her mother homeschools her and her siblings for the same reason. The whole family's social interactions are limited. The possibility of some relief from this situation is heartening.
Rebecca G.	My nephew (14y) is in remission but has been taking 5 daily medications since he was 18 months old. Sparsentan is hope. Hope to never be on dialysis or need a kidney transplant.
Emily F.	It would give my 11 year old hope for effective treatment. We suffer constantly as a family emotionally and financially because of the constant stress of this disease
Betty V.	Grandson diagnosed with FSGS when he was 22. Now 25 and engaged to be married. I so want him to enjoy a healthy long life with his wife to be.
Ashley J.	It would be life changing! My daughter was diagnosed a week before her 2nd birthday and rediagnosed at 6 and is now 16. We have spent so much time in and out of hospitals and doctors treating the symptoms. She has been held back in school for missing school and has suffered with bullies because of the steroid puff and weight gain during a relapse. I was super excited when a doctor said that new treatments were coming out.
Mandee B.	My son has been living with FSGS since he was two years old. He has never lived a "normal life". Anything which will give him hope for a brighter future is considered golden. Please help families like mine.
Susy L.	It would help other patients who are not able to take or don't respond well to other treatments.

Comments

From a Parent or Family Member of Someone with FSGS

Ruby T.	My son was diagnosed recently along with Lupus Nephritis. Dream job, good relationship, already paid half of his new truck off in a year. He had just turned 20, on top of the world. Now he is back home , not able to work his trade and we are providing for him. His body is slowly taking all his proud moments away.
Nancy E.	Keep off steroids and better quality of life
Alice S.	Praying for them to be relive of pain
Scot E.	To keep our family member off steroids and to improve her quality of life
Michele N.	This could greatly improve their quality of life! With multiple failed kidney transplants and being on dialysis, this option could help the future golf all involved
Michael C.	To have an FDA approved medication for FSGS would be a life-changing moment for our family. For the whole of our journey with my son's FSGS, we have been throwing proverbial darts to try to just manage the disease, hoping that one of the many off-label medications would get him into remission (or if not one, any combination to prolong his health). If sparsentan were to be approved, not only would it be the very first bespoke, targeted medication that my son can use, but it would mean the door opens for potentially more medications to address different aspects of this disease and ultimately, a cure.
Beverly V.	Anything that would help with making life easier for FSGS patients would be greatly appreciated.
Danielle D.	My son was diagnosed with nephrotic syndrome
Angela K.	Hoping for this to be effective and available to all who need it.
Priyanka S.	Will help everybody so much
Danielle D.	It will help my child who suffers from Nephrotic syndrome
Kamal B.	The availability will help find a cure
Jacob H.	So I know very little about this drug and haven't personally done research on it. However the loved one of mine who has FSGA seems very optimistic about this drug providing stability to her condition.
Richard G.	My daughter has FSGS and needed a transplant at 11 years old. We need meds to help stop this
Robert B.	My nephew has been hospitalized repeatedly for this and this drug could save his life.
Samantha A.	If this was something where she only had to take one medication instead of all the meds she currently takes and it's effective (she's 8 years old) she would be very happy!
Jennifer F.	My family member has been baking this since he was 5 years old

Comments

From a Parent or Family Member of Someone with FSGS

Denise M.	Live a long happy life!!
Robert R.	Could possibly prevent further relapses and hospital stays
Heather D.	It would make my Aunts life easier and fuller to have treatment
Lliani G.	If the drug works to combat FSGS it would help a young, bright, amazing boy lead a much better life. Him and many others who are dealing with this disease.
Walda H.	I think the drug would really help in the treatment to get my family member back into remission.
RosaLisa L.	The approval and availability of this treatment for FSGS wound greatly improve the lives of those struggling to combat the disease and who are fighting to keep their kidney function. It would ultimately reduce the number of people waiting for a kidney donation and give those who have received a kidney with the hope that if it returns, they can combat it. My best friend is waiting now 5 year for a donation after FSGS took his kidney function away and if this treatment was available to him at diagnosis, he would have had a better quality of life and would have been able to enjoy his children as they are growing up.
Rochelle S.	New treatments that are effective are needed
Lisa S.	new treatments are needed
Debbie P.	A family member has this disease and fights every so often to find an additional or new drug to treat it. If a new drug has been created, seems only right to make it available to those who so critically need it.
Maria C.	I am the mother of a 10 yrs child with recurrent FSGS. We participated in the Duplex study. We would do anything to get a disease specific medication for our warriors
Jill K.	At some point my son who is medicine dependent will at some point need alternative treatment options. He is 10 years into his journey mow at 25 years old.
Nicole R.	Impact their quality of life
Sarah E.	A treatment would have possibly allowed my husband to skip dialysis and transplant which both interrupted truly living life. They completely take over every aspect of your day to day life. Granted--they are life saving measures we are extremely grateful for, but treatment prior to those stages would be life changing.
Gene A.	It would be a game changer
Stephen M.	The availability of Sparsentan would provide my wife with the ability to heal. She is on a multitude of drugs which do not focus on FSGS and having Sparsentan would change her life dramatically. Additionally, Sparsentan could reduce her symptoms related to proteinuria which would improve her quality of life! Please help us get this medication readily available!

Comments

From a Parent or Family Member of Someone with FSGS

Dawn P.	An option to manage the condition
Jaclyn L.	It would give people hope.
Angela S.	My son is only 27 years old. Any advancement by the FDA to help cure FSGS and other kidney diseases would be groundbreaking! Let's not let the red tape get in the way. PLEASE!
Ravinder S.	As someone with two family members affected by nephrotic syndrome — minimal change disease and FSGS — and with no known cure available, I strongly support FDA approval of this drug.
Kristine A.	My granddaughter was diagnosed 12 years ago at 2 years old. She has received prednisone, anti rejection drugs, been on a kidney diet and a year ago received a kidney transplant that was rejected. She is now on dialysis. Any research on new treatments for this disease will be a welcome addition.
Zafar G.	This drug could help them live longer healthier lives
Rachel C.	He wouldn't have to take so many pills and possibly back to remission.
Chiquita J.	This will allow my daughter to feel hopeful that her diagnosis can be managed better or even be cured.
Mary M.	Access to this drug will help my cousin reclaim his life and not be sidelined by painful and lengthy medical emergencies and hospital stays.
Georgia K.	It is medicine that he needs.
Taylor L.	This would help my nephew with his rare kidney disease.
Margaret M.	Two of my young cousins have FSGS and one has kidney failure and has been on dialysis and in and out of the hospital for a few years, before and after a kidney transplant. This medicine could prevent the same for my cousin who's still in college, and help up the odds for my cousin who's struggling to survive.
Terry H.	My son had FSGS and lost kidney function within one year of diagnosis. He died after 4 years of fighting this disease. With proper treatment, he may still be alive. He passed at 22 years old.
Danielle G.	I have a family member that will need this medicine for his FSGS treatment!
Coral G.	My daughter was diagnosed at 13 years old. She has been in and out of hospitals since. After her first transplant at 19 FSGS came back in 2 days. She has 10 bad days for every one good day. Her eyes are failing and her digestive system is trash after years of medication. With multiple chronic illnesses it is hard to keep a job but she has to work to afford quality care. I want her to live past her 40th birthday. I don't want others to suffer like she has.
Chrisanta T.	This would provide my cousins husband a healthier and more fulfilling life to spend with his family and friends.

Comments

From a Parent or Family Member of Someone with FSGS

Ayrolyn K.	We are past this point and on to transplant. Thanks!
Harold G.	My son had FSGS and was cured with Plasmapheresis
Jess W.	Having a drug that is specifically studied for and approved for on-label use would be amazing to treat FSGS while we work for and wait for a cure.
Angelique P.	My family member is currently in remission luckily; however the disease can become active again and treatment options are needed for those that have not been able to enter remission.
SURINDER G.	Better quality of life
Amrita C.	Two of our Nephews are living with FSGS and we approve FDA support.
Dev N.	Sparsentan hopefully will strengthen my grandson's immune system which will make us associate with them more physically, instead of them isolating themselves for often falling ill.
Alysia F.	I'm not sure if the treatment would help my brother at this point as he has been on dialysis for over 20 years now but to know that another kid doesn't have to go what he's gone through in his life would be enough
Saira B.	As someone with two family members affected by nephrotic syndrome — minimal change disease and FSGS — and with no known cure available, we strongly support FDA approval of this drug.
Kameswararao M.	Hello. My son m gagan is suffering from FSGS since 6 &1/2 years. He was diagnosed when he was 1 &1/2year now he turn to 9years. I am eagerly looking for cure and my son lead normal life like other children
Debbie R.	To be cured
Manjit D.	Two of my nephews are living with nephrotic syndrome — minimal change disease and FSGS. With no known cure, we strongly support FDA approval of this treatment.
Sabrina D.	Two of my nephews are living with nephrotic syndrome — minimal change disease and FSGS. With no known cure, we strongly support FDA approval of this treatment.
Armaan B.	Make their life a lot easier.
Carla B.	Our nephew has FSGS who could use the benefits of this drug
Inder D.	Keep up the good work!
Vince B.	It would be a huge benefit to my 2 nephews who have been living with FSGS since they were young boys.

Comments

From a Parent or Family Member of Someone with FSGS

Amy G.	As someone with two family members affected by nephrotic syndrome — minimal change disease and FSGS — and with no known cure available, I strongly support FDA approval of this drug.
Bemi J.	It would give them access to my nephews
Noor G.	It would give my family member the chance to live a longer and healthier life.
Kundan B.	My cousin's two sons are affected, and I know that it would help them accomplish their education goals, and live full lives without medical setbacks.
Zorawar Biri S.	Thanks for doing this
Balbir S.	Both of the boys of our son have this disease which was very traumatic for the family. Now we see light at the of the tunnel.
Mira N.	Both my cousins have been on medication for Nephrotic Syndrome and FSGS since young childhood and all of us have watched the despair, anxiety, and heartbreak that both cousins and their parents have experienced with the ups and downs of the diseases. It is so hard to watch the slow loss of hope over finding treatments that last and the fear that they could lose their lives- that being said- we will never know how it feels to be the one experiencing this first-hand. Finding new potential solutions and new avenues for this disease and having the support of doctors, research, and funding is restorative both to their corporeal bodies but also to their hopefulness and spirit to live.
Kimberly M.	My cousin has had two transplants n my daughter lives with this disease
Manrita S.	Lifelong impact of having to be on highly toxic medications since age 4. Expectation of a short lifespan. New treatment would be life changing for patient and family . Thank you
Scott D.	My SO has FSGS
Tej S.	both of my children have Nephrotic syndrome with the elder son having FSGS. there are currently no cures and the only medication we have is extremely strong, immunosuppressants. we desperately need more research and more medication options to treat this chronic disease, especially in children.
Chris B.	My cousin is 45 years old and has been suffering with this terrible disease for many years now. He has had every treatment possible. He has even had a live kidney transplant from his father but nothing will stop this terrible disease. Please allow access to Sparsentan in order to help save the lives of people suffering with FSGS.
Martha B.	My nephew is 45 years old and has been suffering with this terrible disease for many years now. He has had every treatment possible. He has even had a live kidney transplant from his father but nothing will stop this terrible disease. There is nothing left to try and save his life as well as the lives of so many others suffering with FSGS. Please, you must allow access to Sparsentan for these critically ill people.

Comments

From a Parent or Family Member of Someone with FSGS

Christopher B.	Please approve Sparsentan for FSGS treatment.
Michelle Q.	Everyone deserves to live a healthy life. This could ensure better quality of life for so many people.
Laurie D.	My daughter was diagnosed at 3 with nephrotic syndrome and now is fsgs. 10 years later and she hasn't been protein free in a few years. We have had many MANY hospitalizations over the last 3 years and we just wish we had more options and answers.
Marie-Paule C.	It's fantastic to finally have something FDA approved for FSGS. I think it's too late for my son to benefit from it. But, I know patients who have benefited and there are others who need it and will benefit form it.
Tamra L.	Maybe he won't get it again after a second transplant.
Thomas S.	A possible cure fir this terrible disease.
Edith S.	It could cure this horrible and debilitating disease.
Laurie M.	My cousin has FSGS.
Alice B.	Improve the quality of life
Timothy M.	It would give her a chance to live.
Daniel S.	Cousin with liver damage due to FSGS
Andrea B.	FDA approval might allow my family member to access this treatment through insurance, making it accessible to them.
Elana C.	Would make her daily life more livable.
Brittany S.	The availability of this drug could help so many people who live with this disease.
Sophia C.	It could save his life
Jeffrey B.	My 45-year-old nephew has FSGS and had waited for years to be at a stage for transplant. His father donated a kidney (different blood type) and a few months later my nephew received a transplant. He has had complications with FSGS. This drug has passed Phase 3 trials and needs to be approved by FDA immediately. Thank you.
Kathy M.	We need a cure for this debilitating disease, but before a cure is found more options for these patients. Please approve this much anticipated new drug.
Margaret R	Help my nephew get his life back! He has been in pain for over 6 years

Comments

From a Parent or Family Member of Someone with FSGS

Richard B.	It could give him a longer and healthier life
Thomas M.	Reduced reliance in invasive surgeries and continued strain on the availability of donor kidneys.
John B.	Ben B., my nephew has been hospitalized twice for about 14 days since his transplant. The blood cleansing was intense and he now has inflation. Sparsentan can aleviate his symptoms and pain.
David B.	My nephew has been living with (FSGS),and has suffered grueling side effects with current treatments for several years. The potential availability of sparsentan is more than just a new prescription—it represents a fundamental shift in his quality of life and outlook on the future. His nephrologist and team of doctors are optimistic this treatment will help.
Jean B.	Our nephew has been living with (FSGS),and has suffered grueling side effects with current treatments for several years. The potential availability of sparsentan is more than just a new prescription—it represents a fundamental shift in his quality of life and outlook on the future.
Meredith G.	Having a medicine that will enable my family member to live a normal life as they possibly can by using this medication and not be dependent upon others or constant dialysis is important to me and my family. Anyone who suffers from long term disease would want a treatment that would allow them to lead a normal life without pain or constant medical treatment.
Joyce B.	I am a close friend who has family member (son) that had a kidney transplant three months ago and is facing complications. Doctors recommended this drug in the past but insurance would not cover it.
Carl L.	i have a nephew who has FSGS and is trying to keep his kidney.
Misty G.	The medication just eliminate some of my fathers symptoms and allow him to live a longer life.
Miranda P.	My father has FSGS. He has tried multiple meds. He will do better for a little bit then get worse again. This medicine would be a chance to stay better. Anything thy could help
Joy L.	My husband has been fighting this horrible incurable disease, FSGS. We have exhausted all the treatments and he has never reached remission. Thank you for all your help.
Emily D.	My cousin has been hospitalized on and off for years and we believe this may be his only hope.
Paul B.	My nephew with FSGS is having post-transplant issues and his nephrologist says sparsentan would help him.

Comments

From a Parent or Family Member of Someone with FSGS

Nikki B.	My daughter has FSGS and is currently in remission. She has been on all of the meds available to get her into remission. When she relapses a new option in medication could be the difference in her living a productive, full life versus fighting the disease and not being able to work and be a productive member of her community. This medication could help life changing for those fighting FSGS.
Daniel B.	My brother has fsgs and this would help him live a much better life
Ian G.	It would be wonderful to have more treatment options for fsgs
Elizabeth J.	My brother was diagnosed with FSGS at the age of 12. He lost kidney function, his senior year of high school and had three kidney Transplants. After each transplant, the FSGS reoccurred, destroying the transplanted kidneys within two years, putting him back onto full-time dialysis. I was one of the kidney donors, for his second transplant. We have been actively working and praying for a cure. My brother has been on full time dialysis for over 20 years of his life, and I'm afraid that without a cure, he may not have much longer. Please approve this drug for my brother who is now an adult, and all the children suffering with FSGS and other rare kidney diseases that they can have a chance for a cure.
BLANCA B.	My 13-year-old great-granddaughter suffers from a kidney disease called Nephrotic Syndrome, in her case complicated. I pray that you can implement this medication so that you can improve the quality of life of these children and all people with kidney diseases.
Pablo M.	My 13-year-old niece suffers from complicated Nephrotic Syndrome that leads her to receive different treatments and not an improvement of the disease. The implementation of this medication will not only mean that you have more options but will also improve the quality of life of many people who suffer from FSGS and associated kidney diseases.
Cristina M.	My 13-year-old niece suffers from Nephrotic Syndrome that is difficult to manage with different treatments that are still effective and that have an impact on her quality of life. We pray that you can implement this medication that will provide more options for all those people living with this disease and other associated ones.
Pablo M.	I am the grandfather of a 13-year-old girl with a Nephrotic Syndrome that is difficult to manage and possible FSGS. We are witnesses to the improvement in the quality of life of many children living with this disease and the options that this medication would mean for our granddaughter and for all those patients, family members, professionals who live with associated kidney diseases.
Ignacio A.	Soy padre de una niña de 13 años con un Síndrome Nefrótico de difícil manejo y posible GEFS. Actualmente con diferentes tratamientos inmunosupresores. Con la implantación de esta medicación habría más opciones para el futuro de nuestra hija y para el resto de niñas y niños que padecen esta enfermedad o enfermedades renales asociadas.

Comments

From a Parent or Family Member of Someone with FSGS

Debra j.	This could offer my son hope from further progression of FSGS. Allowing him to reach his dreams of becoming a mechanic or law enforcement officer!
Lori B.	Life changing
Ruth L.	My daughter has FSGS and has had two transplants. I would hope that the FDA will approve this drug which could provide hope for patients suffering with FSGS.
Kirsten B.	It would give my son more treatment options and hopefully a better quality of life.
Aggie G.	It would abe another treatment that hopefully can help my son to potentially provide a better future which is difficult to navigate now. It means one step closer to a cure. It's means so much more
Stephanie P.	My family member has been living with FSGS and progressive kidney disease, and the impact has been profound. This diagnosis affects far more than lab numbers. It affects daily life, long term planning, employment stability, mental health, and family dynamics. We have watched kidney function decline over time despite careful medical management. Elevated proteinuria, rising PTH, chronic fatigue, pain, sleep disruption, and uncertainty about the future have become part of everyday life. The fear of dialysis or transplant is not theoretical. It is a looming reality that shapes every decision we make. The availability of sparsentan as a potential FDA approved treatment specifically for FSGS would represent hope where there has historically been very little. Currently, treatment options are limited, often off label, and not targeted to this disease. A medication designed to reduce proteinuria and slow progression could meaningfully delay kidney failure, extend time before dialysis or transplant, and preserve quality of life. For families like ours, even a few additional years of stable kidney function would be life changing. It would mean more time working, more time with family, and less psychological burden. It would shift the experience from reactive crisis management to proactive disease control. FSGS patients deserve a therapy that acknowledges the seriousness of this disease and offers a real chance at slowing its progression. Access to sparsentan would not just change numbers on a lab report. It would change the trajectory of our lives.
Amy J.	My daughter is recently diagnosed and we can't get her into remission. Its heartbreaking the uncertainty and impacts all the family. Never knowing if or when things will get better, or worse
Lisa Cimino !.	My daughter reached ESRD before sparsentan was available.

Comments

From a Parent or Family Member of Someone with FSGS

Kristine A.	I don't know what this is but anything that shows promise helping this debilitating health issue should be considered
Stephanie L.	It is critically important that this, the first ever medication to target FSGS be available to the patient population. Our son has FSGS and was a part of the DUET study.
María del Pilar S.	It would improve the quality of life of these patients.
Carol B.	My son had a kidney transplant and is battling fsgs in the new kidney. He absolutely needs this new medication.
Jen R.	It would impact her life greatly so she would be on the road to recovery!
Mary Jo R.	My niece would live longer
Donna V.	I am for any research or potential treatment/cure for FSGS. Our then 25 yr old son who suffered from FSGS received a living donor transplant in 2023 and doing well.
John M.	It would help if this drug were available.
Dana G.	All meds we have tried were trial and error and not FDA approved for FSGS. It would be amazing to have. And that works.
Abby D.	My Aunt has been suffering for years with FSGS and could have really benefitted from this drug, but was unable to get it in time after her last transplant. I would want this opportunity to be available for all!
Susan M.	My family member would be able to live free of hooking up for dialysis, she could finally feel healthy physically and mentally. Approving this medication would give her and others with FSGS hope and not just i Was just Hope in this medicine but hope for more options becoming available. She started this journey as a teenager and still has plenty of life to live and enjoy with all of us who love her.
Kayla L.	This could save my dear friend's life. She can not make it through another kidney transplant with all her other complications. She needs this to live!
Lorraine L.	It may save her kidney
Courtney P.	FSGS is such a tough disease to live with. My husband has been living with it for 25 years. This would help so many people.
Caitlin M.	Loved one has already had a kidney transplant and would not survive another one.
Therese M.	Anything that could cure my daughter I am for!!

Comments

From a Parent or Family Member of Someone with FSGS

Michael L.	An FDA approved drug for FSGS would be life altering and life changing for our son Matthew who was diagnosed with FSGS 19.5 years ago when he was 2.5 years old. It would give us hope that he could live a long, normal healthy life. Thank you, love the Levines
Gina K.	Please
Alex S.	My aunt was diagnosed at 16. This would make a tremendous impact.
Joseph B.	Our son had kidney failure caused by FSGS. He has received a donor kidney, but FSGS is endangering the new kidney. Sparsentan could save his new kidney and his life.
Christine M.	Year after year, I keep getting my hopes up that there will be a solution to the soon but after my second traumatizing transplant, my hope is starting to dwindle away. I need this medication or else I won't survive after my next transplant.
Maggie A.	Had my sister been able to receive this drug after her second transplant she most likely would not be on dialysis again! Please make this available!
Peg I.	This could be life saving!
Sandra M.	If she could have received this more expediently after her last transplant, maybe she wouldn't have needed dialysis so quickly.
Mary K.	This would be a game changer please please approve
Colleen G.	hi , it will change lives!!
Ann W.	It would be such a relief to have an approved medication to assist my daughter in fighting FSGS. She is 16 and was diagnosed at 8 years old. she has been on different regimens for 8 years. please approve !
KD S.	This has been devastating for our family in many ways. Approval of this drug would be extremely beneficial for so many people. Please consider this. What if it were someone you love? Thank you for your consideration.
Carla C.	My sweet little cousin Madi's life has been saved the past 4 years while she has participated in trials for this drug.
Jim D.	This would be LIFE CHANGING for all children afflicted with this hideous disease. Please approve this ASAP !
Carly P.	This new drug could save someone a lifetime of trauma and treatments. Kidney transplants don't always work and a medicine to potentially cure before reaching that point is crucial!

Comments

From a Parent or Family Member of Someone with FSGS

Elsa R.	My daughter was diagnosed with FSGS at the age of seven and had taken numerous medications to slow the progression of the disease. Unfortunately, at the age of 17 she received a kidney transplant and eventually will need another soon due to the toxicity of one of her medications. Sparsentan would be a possibility of delaying another transplant.
Phyllis P.	It would help protect the donor kidney.
Michael S.	FSGS is an awful disease that does not enable a person to live a "normal" life. Any cure and/or more effective treatment of this disease would be life changing for many
Anita W.	It would help with recovery!
Karen H.	It would provide another option in treatment
Lori M.	I'm hoping it may lead to putting my grandson into remission so he can get another transplant. He had one at the age of 4 and it was back within a day. He's been in dialysis since 2021 and could use some good news for once.
Brandy e.	My daughter already had a transplant !!she had fsgs from the age of 13 had dialysis from 19-26 when she had her transplant I prayed for a treatment so I'm happy this may be it for those who suffer from fsgs
Kyle W.	My nephew has battled for over 13 years with frequent treatments of steroids and chemo infusions with their terrible side affects because there is no good drug specific to treat FSGS.
Scott P.	As the drug trial appears to show success in reducing protein in urine, this would positively impact the patient.
Sonya C.	It would help treat and possible prevent a FSGS patient from going on dialysis. My daughter was 12 when she was dx with FSGS and I feel it could if saved her kidney if FDA were available. She's had kidney transplant 5 years ago but her FSGS returned and having to go back on dialysis. It's a horrible disease
Hollie W.	It would help a lot!
Joyce J.	My family member was diagnosed as a toddler after several months of testing and inpatient hospital stay. Today, as a high achieving college student, dialysis is a big part of life. If improved treatment had been available during initial stages, today's life could be much different.
Elizabeth S.	Our son has failed on all the medications currently available to treat FSGS. We need more approved options to treat FSGS to ensure my child and others have a chance to live a long, healthy life.
Julie B.	It would help my sister manage her symptoms of FSGS.

Comments

From a Parent or Family Member of Someone with FSGS

Colette W.	My husband is 44 years old and was recently diagnosed with FSGS. With affordable and available medication my husband might not have to go on dialysis as early or at all. Our dream is to watch our teen son grow up and be there for him. Without FDA approved medication this will not be possible for him and many others in the world. RKD is important. Please approve this drug for the use of individuals with FSGS.
Cody Y.	My sister participated in the studies and the medication would help her.
Laura D.	My sister has had two kidney transplants. She is on dialysis for the third time in her life. Having the availability to have sparsentan immediately after her 2nd transplant may have made the difference of saving that new kidney. She is now back on dialysis. Please make this drug available for people to have a chance at life.
Kim D.	My daughter with FSGs has not had this treatment. She was treated with Rituxan and is currently in remission
Tiffany S.	This will improve the quality of my moms life she has been living with fsgs for 10 years now
Matt S.	This would greatly improve my wife's life if we could get this new drug approves. She deals with swelling daily and has for the last 10 years
Leah S.	It would help my mother from swelling up and spilling protein . It will greatly improve her life
Joni Y.	My daughter has been living with the disease and raising two small children. It is progressing and requires substantial mitigating treatments. This medication could alter her life and her children's.
Kristie K.	Yes it would. My daughter was diagnosed at 2 years old and is still struggling at 22.
Janet H.	Our granddaughter is very precious to our family and we hope to have her around for many years to come. Please approve sparsentan for FSGS.
Iara Y.	My sister was diagnosed with this as she was pregnant with her first child. She had to experience many different treatments with various negative side effects. The treatments still did very little to help her to stop the increasing kidney damage. Having a drug specifically to treat this disease could give her and others hope and hopefully others won't have tong through the unknown of trying so may other things.
Tiffaney F.	It could potentially keep my daughter from needing a kidney transplant!
Michael A.	My sister is suffering from this disease and already had 2 transplants. I hope this treatment can give her back a normal day to day life.
Sue R.	My child had a kidney transplant a couple years ago and had to go through plasmaphoresis due to signs of FSGS post transplant. It would be great to see more treatment options if we start seeing signs of FSGS affecting the new kidney.

Comments

From a Parent or Family Member of Someone with FSGS

Terry B.	Nephew patient, FSGS
Wade Y.	This brings the patient great comfort and hope that they may live a normal and healthy life.
Priscilla O.	Saved a young girl who a number if times was declining and near death and she now a thriving teen.
Farrah Y.	My sister-in-law's quality of life would be greatly improved by this medication.
Charles d.	Not now!
Maria Rita B.	The availability of sparsentan would have a significant impact on our family. My son has FSGS, and until now, treatment options have felt limited and often focused on managing symptoms rather than targeting the disease itself. He has been exposed to medications with challenging side effects, and as a parent, it's been incredibly hard to watch him cope with fatigue, hospital appointments and the uncertainty about his future kidney health. Knowing that sparsentan could be the first FDA-approved treatment specifically for FSGS gives us real hope. A medication designed for this condition, rather than used off-label, would provide reassurance that his treatment is based on solid evidence for FSGS. If sparsentan helps reduce his proteinuria, it could slow the progression of kidney damage and potentially delay or prevent the need for dialysis or a transplant later in life. Beyond the medical benefits, the emotional impact would be huge. It would ease some of the constant anxiety we live with as a family and allow our son to focus more on being a child rather than a patient. Having an approved treatment option would also make discussions with doctors clearer and more hopeful, giving us a sense that progress is finally being made for children with this rare condition.
Alec L.	My partner has FSGS.
Jennifer M.	New treatment for FSGS or Nephrotic syndrome means not relying on harsh drug such as prednisone. This is currently the only first in line treatment for nephrotic syndrome and one we hope never to take again.
Gina V.	My healthy son was diagnosed with FSGS completely out of the blue just a month shy of his 13th birthday, and spent months in and out of the hospital while they tried to keep him healthy. Edema caused him to balloon to 170 lbs from his normal weight of 140 and stretch marks across his midsection and legs will forever remind him of how sick he was at one point in time. Thankfully, he is remission with a daily dose of tacrolimus, but we know that that same medication can also cause kidney damage over time. We may be on borrowed time, as are many kids with FSGS using off-label treatments to keep them as healthy as possible for as long as possible. We hope that a drug specifically for this terrible disease can give hope to these children for a healthy future.
JOSÉ MARIA L.	Para reducir la proteinuria de su Síndrome Nefrótico Infantil. Lleva 2 años sin remisión

Comments

From a Parent or Family Member of Someone with FSGS

Michael M.	All possible treatment options for the disease need to be on the table as their are no FDA approved remedies.
Jen V.	Many people with FSGS currently cycle through steroids and off-label or supportive therapies (like blood pressure medications), with mixed or limited success. An FDA-approved drug would represent a treatment specifically studied for this disease, offering new hope for patients who have struggled with proteinuria and kidney decline.
Pamela K.	It would greatly benefit my great nephew.
Julie R.	He passed away in 2023. I only wish something could of helped him
Kristen F.	Our friends daughter is affected by this and having this medication would help her in so many ways. It's sad when young children are suffering
Carmen F.	I donated my kidney to my brother. He has FSGS. May this treatment help others with this condition.
Maria M.	It would provide hope.
David M.	It is a chance to help her get healthier and live a longer life. She's a teenager and the thought of her not living a long and beautiful life is devastating.
Maria G.	If it could put her into remission from spilling protein her natural kidneys may last forever and we can avoid dialysis or a transplant.
Iosune C.	The availability of sparsentan would have a significant impact on our family. My son has FSGS, and until now, treatment options have felt limited and often focused on managing symptoms rather than targeting the disease itself. He has been exposed to medications with challenging side effects, and as a parent, it's been incredibly hard to watch him cope with fatigue, hospital appointments and the uncertainty about his future kidney health. Knowing that sparsentan could be the first FDA-approved treatment specifically for FSGS gives us real hope. A medication designed for this condition, rather than used off-label, would provide reassurance that his treatment is based on solid evidence for FSGS. If sparsentan helps reduce his proteinuria, it could slow the progression of kidney damage and potentially delay or prevent the need for dialysis or a transplant later in life. Beyond the medical benefits, the emotional impact would be huge. It would ease some of the constant anxiety we live with as a family and allow our son to focus more on being a child rather than a patient. Having an approved treatment option would also make discussions with doctors clearer and more hopeful, giving us a sense that progress is finally being made for children with this rare condition.
Kelly H.	Sparsentan could potentially keep my loved one from losing his transplanted kidney due to reoccurring FSGS. If approved it would keep him off life long dialysis.
Kevin M.	It would extend the life of my wife who is the mother of our 2-year old son Calvin McCarthy.

Comments

From a Parent or Family Member of Someone with FSGS

Reba j.	Still a lot to be learned about FSGS
Concepción R.	A member of my family suffers this desease. He's a child and he can't stay with people for season because of virus. When he gets flu or cough he gets worse of the desease and he often has to go to the hospital. He hardly ever go to the school for this reason. Going to school is really important to have a properly growth.
Maria L.	The availability of sparsentan would have a significant impact on our family.
José L.	The availability of sparsentan would be very significant for my niece, as currently treatment for focal segmental glomerulosclerosis (FSGS) is primarily limited to medications that control blood pressure and reduce proteinuria, but there are no approved options specifically for this disease. Having access to sparsentan, potentially the first FDA-approved drug for FSGS, would represent hope for a more targeted treatment that could slow disease progression and improve quality of life.
Sandra S.	Essentially is of the utmost importance
Lu E.	We need more help with people with GFR PATIENTS
Nuria V.	Amiga de enferma con glomeruloesclerosis
Monica M.	please
Elsa A.	Hay mucha gente que lo necesita
Laura R.	No, but muy son has FSGS.
Virginia S.	Es para una niña de 13 años que lleva con la enfadad bastante tiempo
Verónica C.	Mi son
Jennifer H.	My nephew has FSGS. His dad donated a kidney a few years ago, but it is currently at 24% function and he will need another one eventually. A drug for the condition may prolong his life.
Acenet B.	My husband is 31 years old and was diagnosed with FSGS in December 2024. Since then, my husband's GFR has continued to decrease, proteinuria has continued to increase, albumin levels have continued around 1.6 causing my husband to be swollen most of the time, even on diuretics. My husband has been on Lupkunis, Acthar, CellCept, has been doing Albumin infusions every other week to hopefully help his levels. However, he has not really improved. My husband's nephrologist and ourselves have high hopes for Filspari, and would sincerely believe it could help my husband and many others with FSGS. The availability of this medication could not only potentially help my husband reach remission, but could also hopefully remove my husband from the CellCept medication, as we would truly like to have a baby in the near future.
lina r.	It will improve his quiality of life and delay transplant

Comments

From a Parent or Family Member of Someone with FSGS

Christine F.	We had the opportunity of being in the duplex study for my daughter who has FSGS. We enrolled back when the age limit was lowered for the study which then made it possible to enroll. My daughter didnt respond to the other meds which made her very sick and she had no quality of life. Fighting for her to join the study was life changing. The closest facility for the study was 4.5 hours away one way. We made this trip for years as this drug brought her into remission. She gained her health back and was able to finally experience life as a kid with a better quality of life. My daughter is 15 now and we were in the study and extended open label for just over 4 years. We are anxiously waiting for approval for the drug as it put her in remission with little side effects. We are forever grateful for the quality of care she received in the study and for it giving her a chance to feel better. There are patients out their that need this drug and a chance it offers to help them battle FSGS.
Tina M.	My husband was diagnosed with FSGS, a rare kidney disease, in 2022 at age 42. It started with swelling in his ankles, and was soon followed by swelling in his abdomen, and then massive swelling all over his body. He became unrecognizable from the protein spilling, which caused the swelling. He had been a varsity high school athlete in soccer and basketball, and maintained a physically demanding job after college. The swift transformation to his swollen state was crushing. He had no energy, became bedridden for most of the day, and was sometimes unable to get out of the bed on his own. Frighteningly, his initial nephrologist was so outside of his depth dealing with the rare disease. My husband was put on a standard protocol of immunosuppressant drugs and steroids, and the swelling only accelerated. We were terrified that we would lose him. In 2023, we were able to move him to a different hospital that was a leader in glomular research, and a different doctor who was more specialized in glomular disease. My husband became inpatient at this hospital for 11 weeks, during which time he lost 50 lbs in water as the swelling was reduced. Currently, he continues to be a warrior against the FSGS. After close to 2 years of dialysis, he received a kidney transplant in 2025. However, the FSGS quickly returned, resulting in him staying at the hospital for 6 weeks after his transplant. During this time, he endured 5 different surgeries for various issues. He is currently being treated with a therapy approved by the FDA under a Humanitarian Device Exemption. The hope that keeps us all going is the miraculous discovery happening in science and the fearless and life-saving work happening at the hospitals. More research into this rare disease, plus new therapies like Spartensan are desperately needed.
Leah R.	It would be another tool to prolong transplant needs or increase longevity of transplant potential
Kyle K.	It would have possibly prevented the need for a kidney transplant, alleviating the pool of donors for someone else.
Laura S.	Patients and Doctors need more options to treat this devastating disease. With FDA approval, another option becomes available whereas without approval the door is closed in your face.

Comments

From a Parent or Family Member of Someone with FSGS

Rhonda M.	FSGS is not only hard on the person who has it, but also hard on the family members who watch what they go through, especially during flare ups. Things such as edema, nausea, stomach pain, muscle cramps, dizziness, trouble walking and lots more. It affects your quality of life and any medication that can help relieve some of these symptom to make their lives a little bit easier is a great help!
Bobbi c.	My son when he was 7. Transplant
Kelly H.	It would make a young girl's life easier and better
Jessica S.	My daughter is 15 and she has had nephrotic syndrome since before she turned 2. Originally we were told it was MCD but in 2022-2023 we were told that it had swapped to FSGS. She has done Ritux treatments twice and done well with them each time. I just wish there was a cure as we have been told that she will need a transplant at some point in the future.
Lisa L.	To have an actual treatment would help so many people and children. Instead of just trying different medications that help symptoms. These kids go through so much.
Paula B.	familiar de 14 años con globuloesclerosis
Joanne G.	My 21 year old son was diagnosed with fsgs two years ago. He would greatly benefit from the availability of sparsentan. Thank you.
lLydia A.	The availability of sparsentan would have a significant impact on our family. My son has FSGS, and until now, treatment options have felt limited and often focused on managing symptoms rather than targeting the disease itself. He has been exposed to medications with challenging side effects, and as a parent, it's been incredibly hard to watch him cope with fatigue, hospital appointments and the uncertainty about his future kidney health. Knowing that sparsentan could be the first FDA-approved treatment specifically for FSGS gives us real hope. A medication designed for this condition, rather than used off-label, would provide reassurance that his treatment is based on solid evidence for FSGS. If sparsentan helps reduce his proteinuria, it could slow the progression of kidney damage and potentially delay or prevent the need for dialysis or a transplant later in life.
Jose Manuel H.	Necesitamos para los niños con sindrome nefrotico.
Dacil Á.	Necesitamos sparsentan para nuestro hijo con síndrome nefrotico
Jack L.	The availability of sparsentan would give my nephew hope as there are no other drugs available to help him.
M° victoria F.	Nieta de 14 años con gloruroesclerosis

Comments

From a Parent or Family Member of Someone with FSGS

Leonardo S.	My niece has nephrotic syndrome with significant loss of kidney function. This medication could mean that she would not need to undergo a transplant and suffer the subsequent side effects.
Toni M.	Help my dear fiend
Ann A.	Daughter
María S.	My niece has nephrotic syndrome with significant loss of kidney function. This medication could mean that she would not need to undergo a transplant and suffer the subsequent side effects.
Ann A.	Daughter
Silvia S.	My 13-year-old daughter is resistant to all medications, and this could be the one that gives us a break.
Soraya P.	Soy madre de un niño con síndrome nefrotico
María Mercedes G.	Mi sobrina de 13 años necesita este medicamento, de lo contrario necesitará diálisis e incluso transplante de riñón. Es urgente.
Madison F.	My cousin is affected by this disease, and access to this medication would greatly impact her life.
Ana R.	Los estudios revelan que esta medicación tiene buenos resultados en las patologias nefroticas
Victor V.	Yo pienso que ese tratamiento irá bien
Juanma G.	It Will improve the wsy of living of patients
John S.	Without a viable treatment plan approved by the FDA, we are concerned our son will lose his kidney in the future and have to rely upon dialysis to survive. Drugs such as sparsentan give us hope that his kidney disease can be managed and dialysis avoided.
Lynda C.	There is nothing now!
Amanda C.	My nephew needs this
Sarah M.	Having access to medications that benefit FSGS patients becomes life changing - not only for the patients but for the caregivers too. Having a medication that is FDA approved also allows for better access to it for other countries when the see it is FDA approved

Comments

From a Parent or Family Member of Someone with FSGS

Rainah V.	My little brother has had another flare up and been in the hospital for over a week on different IV medications and steroids.
María Jose L.	I would feel relieved.
María Jesús L.	This medication would improve the quality of life of my 13-year-old daughter with FSGS, who is currently experiencing pleural effusion due to massive protein loss in her urine. With this medication, we would gain time, the progression of the disease would be slower, and it would also help reduce hospital admissions.It is a matter of humanity. We feel helpless in the face of this disease. Please consider this support not only for patients with FSGS but also for the kidney disease community. Thank you and blessings.
Peyton Z.	My husband has FSGS and has been battling it for a few years now. We have children so on top of this horrible disease he also works hard in the oilfield everyday. This could possibly help him in SO many way!
Juan José E.	My 23 year-old daughter suffers from FSGS. Nothing has worked in the last 3 years: she's steroid resistant, and no treatment has made her get any better at all. We truly believe this may give her a break before her kidney function starts reducing. It's a hope for us.
Katie W.	My family member, who is a child, is in the hospital currently and needs a cure!
Scott P.	Having Sparsentan approved by the FDA for FSGS would be life-changing. My wife was diagnosed with FSGS. The FDA's approval of Sparsentan for FSGS would bring a transformative change to our lives. Since my wife's diagnosis, we have dedicated more energy to fighting our insurance company than to tackling her illness or cherishing the moments we have together. It's time to prioritize patients over paperwork and give hope to those in need. Having an FDA-approved treatment would guarantee my wife would receive the treatment that she needs to live, and no one should ever be denied the chance to live.
Tristen C.	Please for the sake of the patients!!!!
Cassie S.	The availability of a non-Immunosuppressant option would be life changing. I want my child to have the full capability of his immune system when facing everyday viruses. Especially as a school student.
Dane K.	This would be life changing for those with fsgs. It would also save so much money for families and everyone in dialysis and other medication costs.
Matthew G.	Sparsentan as the first FDA approved treatment for FSGS would be life changing. Watching loved one suffer relentless proteinuria, swelling, fatigue, and the fear of dialysis or transplant has broken our hearts. Trials like DUPLEX offered real hope with better protein reduction and remission rates. Approval could slow disease progression, preserve kidney function, ease symptoms, and give us more precious time together restoring hope, reducing anxiety, and letting us imagine a healthier future. We're praying for this breakthrough.
Joshua J.	I'd would be enormous towards control of this condition.

Comments

From a Parent or Family Member of Someone with FSGS

Jo An J.	The availability of sparsentan would give Hope to our son who has been living with FSGS. This is a very serious disease that has impacted our whole family. We keep Hoping and praying for something to cure him. This is the most promising drug we have heard of for this disease. I urge this to be FDA approved for FSGS
Laura F.	Sparsentan shows promise of being the first treatment that may actually get my daughter in remission after 5 years of living with this life-altering disease and trying all other treatments to date without success. It is my hope that this drug becomes available and easily accessible to all patients who suffer from this disease.
Arlene O.	This medication could help my cousin and many others live longer, productive lives without fear of impending kidney failure or the need for dialysis or transplant. A 46-year-oldfather of 2 that I know was amazingly fortunate in receiving a kidney from a live donor - after fearing impending dialysis and uncertainty about future ability to work. His employer also has kidney disease.
Angela M.	Kindly make this drug available to all if it can help anyone it's worth it!!!!!
Lindsay R.	My cousins 8 year old son has this
Brian M.	When our son Pete was diagnosed with FSGS 15 years ago, we went through years of treatments - medicines we were told were doing harm to his kidneys, but with the potential upside of fighting off the long term decline of his kidney function. Nothing worked and we eventually ran out of options. Any possibility of a drug specifically tailored to FSGS would suddenly give us a path and more hope than we've ever had before.
Sarah C.	I was asked tobsign this for my cousins child. She is a toddler dealing with this disease. Any new treatment would help them tremendously.
Monica b.	A lot.
Kathy B.	Help my little 8 year grandson.

"Sparsentan shows promise of being the first treatment that may actually get my daughter in remission after 5 years of living with this life-altering disease and trying all other treatments to date without success. It is my hope that this drug becomes available and easily accessible to all patients who suffer from this disease."

- Laura F.

Comments

From a Parent or Family Member of Someone with FSGS

Diego M.	Dear FDA, as the parent of a 7-year-old patient I've experienced first-hand the devastations that FSGS brings. My son used to be a happy, energic and sociable kid. But a lot has changed since his FSGS diagnose. We are lucky that he responded to some of the existing off-label treatments, but not without toxic side effects. Being severely immunosuppressed our kid is now made fun of for wearing masks everywhere he goes, he avoids social settings and turned into a reclusive screen dependent kid. We found the best possible professionals on this disease around the globe and flew him there. Many spoke about Sparsentan, its strong evidence of positive results in the phase 3 study and how it could be a great fit for his case. The idea of a medication that reduces his proteinuria without the immunosuppressive side effects would mean so much to our kid and our family. I fully understand the FDA is committed to ensuring everyone's well-being and therefore requires strict protocols. But the evidence is strong, proteinuria is our key metric and our community has endured many years of devastation. We are committed to trying this medication responsibly, with strict medical supervision, and discontinuing it in case of insufficient results. I would ask you to please grant my son and other FSGS patients access to Sparsentan - it could be life changing for us all. Best Regards Diego M
Kamesh M.	My son Gagan 9years old Date of birth-(15-10-2016) He was diagnosed with FSGS when he was 1.5years old Searching and waiting for better treatment for cure
Sharyl H.	There are NO medications that work for ALL FSGS patients. If sparsentan can help some more patients achieve remission, that couldn't reach remission on the other few medications available, then it should be added to the doctor's list of possible medications to talk to patients about.
Troy P.	Grandson was in EPPIK for 2 years without FDA approval insurance will not cover the medication for treatment of FSGS.
Patty P.	Without FDA approval there is no insurance coverage and my grandson was in the EPPIK trial for two years.
Martha Jo S.	My daughter was in the Duet study. It definitely helped her make it longer until she ultimately needed a kidney transplant. It gives hope to a disease that has no cure. She was a healthy 23 year old when she was diagnosed.
Dakota A.	My 3 year old daughter was diagnosed with FSGS and this drug becoming available coukd be life changing for her.
Judy T.	It could help
Jamie F.	We need a cure.

Comments

From a Parent or Family Member of Someone with FSGS

Cassie W.	This could be something my niece could take that would potentially put her into remission.
Kaitlin W.	For our family, sparsentan could mean fewer hospital visits, less fear about the future, and the ability to plan life with more confidence. It represents progress, validation of the FSGS community's experiences, and hope for better long-term outcomes for patients who have waited far too long for a dedicated treatment option.
Audra L.	My daughter had this horrible disease. We lost her June 27 2022.
Tracy S.	My 3 year old granddaughter has it and it would help with the progression
Treasure W.	Please pass the FDA treatment for FSGS.
stephanie D.	We can cure
Jo Anna B.	The availability of a medication to keep my son alive seems like a dream. Why? In this era of medical advancement, this is expected and needed.
Amanda B.	Would like to know more information on this
Ashlee H.	I would have loved to have had this option when my son was diagnosed when he was 2 years old in 2008. We had many years of trying many different medications. If this medication would have worked from the beginning, it would have made my son's life that much more manageable and happy.
Deborah C.	My mother was misdiagnosed for 18 months and treated him properly before she was diagnosed with FSGS. She went through dialysis, a double kidney transplant, dialysis again before she passed in 2001.

Comments

From a Parent or Family Member of Someone with FSGS

John S.	My sister has focal segmental glomerulosclerosis, and watching her live with this disease has been incredibly difficult for our entire family. FSGS brings constant uncertainty about kidney function, disease progression, and whether current treatments are actually slowing damage or just managing symptoms. Most of the available options have been off label medications like steroids or immunosuppressants, which often come with serious side effects and no guarantee of long term benefit. The availability of sparsentan as a potential FDA approved treatment for FSGS would have a profound impact on my sister and on our family. For the first time, there would be a medication specifically studied and developed for this disease rather than relying on treatments borrowed from other conditions. The possibility of reducing proteinuria and slowing kidney damage could mean preserving her kidney function longer and delaying or preventing dialysis or transplant. Even small improvements or delays in progression would make a meaningful difference in her quality of life and ability to plan for the future. As a family member, the emotional toll of FSGS is significant. We worry constantly about what the future holds and how quickly the disease may progress. Knowing that an approved treatment exists would provide hope and a sense of stability that we do not currently have. It would help ease some of the fear that comes with watching someone you love live with a rare and serious kidney disease. My sister did not participate in the DUET, DUPLEX, or EPPIK studies, but following the progress of these trials has been encouraging. Seeing research focused specifically on FSGS and showing promising results has given our family optimism that real advances are finally being made. Overall, sparsentan would represent more than a new medication. It would be a critical step forward for people living with FSGS and for the families who support them every day.
Tara T.	My daughter Vanessa, who is a young healthy Athlete, was diagnosed 1 year ago @ 17 years old with FSGS. The 2 standard 'protocol' immunosuppressant drugs were not doing enough for her to go into remission. In fact, the 2nd line of treatment had her kidney function declining rapidly! Now, she is in a TRIAL taking the NEW FSGS Drug for 4 months & her kidney function is improving! In fact, her protein numbers both started getting better even 1 month into the trial! Now, 4 months in, we are very excited that she might have a chance to go into remission!! We want her to get to bra kid & finish High School & live a healthy life as long as possible before having to be faced with a transplant! As a mom, I'm pleading with you to make this New FSGS DRUG available to everyone living with FSGS disease! They all deserve a chance to be better & a Drug that actually is working!! Thank you, Tara Trevey Lubbock, TX
Amanda C.	My nephew needs it. Thats all I know.

Comments

From a Healthcare Provider or Researcher

Debra K.	It would enable them to have a better quality of life
Ruthann O.	Supporter of FDA approval.
Alyssa B.	Seeing my friend live with FSGS has shown me how hard it is to manage a chronic kidney disease with so few treatment options. They've had to deal with ongoing uncertainty, side effects from current medications, and constant worry about their long term kidney health. Having access to a medication like sparsentan could mean better disease control, fewer complications, and more peace of mind for them and their family. It could reduce the risk of progression to kidney failure and improve their quality of life. For our friend group, it would mean less fear about the future and more hope.
Stacy F.	My friends and also patients of ours got diagnosed. I would love nothing more than this to be preventable in the future.
Elaina S.	Save lives
Lori S.	This would take many people off the transplant list as well as treatment for a disease that only had two options prior to the invention of this new medication.
Alyssa M.	Would help reduce hospitalizations for those with the disease.
Melissa K.	Sparsenten should be made avialable and covered by insurance to help people with FSGS who have failed with alternative treatment methods.
Agnes F.	Patients lives matter.
Regina M.	It will give people quality of life
Shirley S.	I am aware of the neccesity of treatment options for kidney disease because I am a licensed patient care technician. Please approve this possible treatment.
Maya D.	Support pts and families who take part in studies
Ashley T.	This treatment could reduce the number of people on dialysis, in turn reducing the number of people waiting for transplants. Improving transplant likelihood for patients with untreatable causes of CKD/ESRD.
Debra G.	As a healthcare worker I understand how important it is to have the research and the Monies to be able to help these people with this rare disease.

Comments

From a Healthcare Provider or Researcher

Sandra G.	I am a retired pediatric nurse who has worked with children with FSGS. There is a huge need for new drugs to help these children.
Kathleen M.	I'm a retired RN
Evelyn Y.	They need a cure.
Annie S.	Just interested as a retired RN.
Tara N.	This is such a needed option to continue offering the most life changing care for patients who previously had few options.
Gale G.	As a pediatric nephrologist I cared for many children with FSGS. There has not yet been a drug for this.
Ruthie W.	It would help people live fuller lives at home.
Laurie K.	She needs it to help preserve what renal function she has.
Deborah E.	It would help immensely
Furwa H.	I am a registered dietitian who would love to see more options for CKD and FSGS
Patrick M.	The data speaks towards a therapy.
Aditya B.	Decrease the chance of ESRD and thus the associated morbidity and mortality
Denise P.	My friend has had FSGS for over 5 years. She deserves this drug to be approved to give her a greater quality of life and a hope to know she will have years to spend with her family.
Omaima D.	We need treatment options
Jessica C.	I am a MD who sees the necessity for a treatment option for my patients who suffer from FSGS. This would be a huge disservice to overlook the potential in Filspari to allow an effective treatment option for my patients
Jennifer M.	We need to try something. Medical advancements only happen when we try something new/different. Let's hope this is it.
Sunny L.	Sparsentan would save so many lives, and bring peace to so many people living with FSGS.
George B.	The availability of sparsentan could potentially make a major impact on patients with FSGS.

Comments

From a Healthcare Provider or Researcher

John S.	Approval of this drug would provide the first FDA-approved drug for FSGS based on the largest FSGS RCT yet executed. The Parasol data support the validity of proteinuria reduction as a valid surrogate endpoint kidney failure-free survival.
Rajeev R.	Having new therapeutic options for patients suffering from diseases that cause protein in the urine and are not controlled with current FDA approved medications is critical to slow progression of kidney disease. Ultimately it will save the system money by reducing the number of patients on dialysis.
Frederick K.	FSGS is a devastating chronic kidney condition with no effective treatment. It may appear in infancy and continue throughout the patient's lifecourse. This new therapy offers a glimmer of hope to those afflicted with the condition.
Ashraf E.	I have been managing patients with FSGS for the past 20 years. I travel the journey with them from diagnosis till they reach end stage kidney disease, some get transplant and some not and death happens premature and early. There is great loss to the individual, the families and the society at large. Any medication that can change the trajectory should be approved and adopted.
Maya D.	As a pediatric nephrology social worker and a health social work educator, i have seen how devastating FSGS can be. It is vital to bring safe new treatnents forward to help affected young people and adults live longer healthier lives.
Jason L.	Very much
Marie D.	As a healthcare provider, I can speak to this from the perspective of both clinical practice and what I see families go through. Focal segmental glomerulosclerosis (FSGS) is a challenging and often devastating diagnosis. Many patients both adults and adolescents—present with significant proteinuria, edema, fatigue, and progressive decline in kidney function.
Raymond H.	New treatments for FSGS are desperately needed.
Tej M.	This would be an additional tool to treat FSGS
Jayanthi C.	FSGS is a disease characterized by heavy proteinuria and considerable morbidity. Deceasing proteinuria slows down progression of the disease and modify the course of this devastating disease.
Bradley D.	FSGS is a devastating disease for pediatric patients, both due to the lack of widely effective approved therapies, and the high rate of recurrence after kidney transplantation. We need a variety of therapeutic options to be commercially available for patients with FSGS, and sparsentan can lead that pipeline.

Comments

From a Healthcare Provider or Researcher

Howard T.	I have taken care of pediatric patients who have benefited from receiving sparsentan as participants in the DUPLEX trial
Brad R.	Have been treating patients with sparsentan when i can get it through insurance and it works well at lowering proteinuria very quickly. For many patients this is the only drug that i have used that lowers proteinuria
Alessia F.	All patients with FSGS would have a replacement of ACEi/ARB with sparsentan
Rasheed G.	Sparsentan will slow the progression of kidney disease in patients living with FSGS.
Duncan J.	Studies with sparsentan have been consistently favorable, and for the benefit of patients, I urge approval for the indication of FSGS
Katherine T.	I was an investigator on the DUPLEX trial and observed first hand how kidney function was preserved in study participants with FSGS. I encourage you to help make sparsentan available to this group of patients in desperate need of effective treatments.
Diego A.	A a Pediatric Nephrologist treating Children with FSGS, it is crucial to have access to spansertan for childen with this condition.
John D M.	As a Kidney Specialist, treating patients with FSGS, the FDA-approval and availability of Sparsentan will significantly benefit the treatment of patients with the rare kidney disease FSGS.
Scott M.	It will improve outcomes for my patients
Rahul M.	FSGS is a glomerular disease with poor treatment options which often invariably leads to dialysis. A new medication would open the door to improved QOL for these patients.
Suneel U.	I am a PI of the DUPLEX trial and have seen the impact of sparsentan on my patient's condition--providing a layer of renal protection (mediated by reduction in proteinuria) that we could not achieve with previously available therapies. I would strongly encourage the FDA to consider approval for sparsentan given the high unmet need and the clinical data demonstrating impact in proteinuria reduction to levels established to be consistent with long-term renal protection.
Guillermo H.	Even the most recalcitrant form of nephrotic syndrome, a 5 yo with congenital FSGS has had significant reduction of proteinuria leading to normalization of serum albumin and more than 50% reduction of proteinuria with only use of progressive doses of Sparsentan. Please note this effect is single drug effect! Patients with FSGS deserve the right to obtain treatment with Sparsentan
Agnieszka S.	I treat patients who would benefit from sparsentan.

Comments

From a Healthcare Provider or Researcher

Amy M.	FSGS is a progressive disease and I have little to offer my patients who are resistant to immunosuppressive therapy. Having access to sparsentan for my patients could give them hope and alleviate some degree of the angst they suffer in knowing they could develop kidney failure. We need treatments for this rare, chronic, progressive disease.
Michael E.	We have so few therapies for FSGS. Sparsentan shows efficacy in this population and is an important first step for therapy.
Dechu P.	Will make a big difference in controlling proteinuria and slowing progression to ESKD
Jacob N.	The availability and ability to prescribe these medications is a step towards curing kidney disease. Any and all efforts to slow progression will improve care and quality of life. Not to mention slowing progression will save resources and provide a way towards fiscal responsibility of the healthcare system.
Dorothy L.	We are Advocates for Responsible Care and Advocates on behalf of patients.
Rita E.	It would improve quality of life
Beth C.	I feel that this drug has the potential to prevent mor damage to the kidneys and improve quality of life for the victims of this disease.
Christine H.	Justice for victims
Crystal M.	It has been frustrating as a healthcare provider to be unable to provide more aggressive treatment to my FSGS patients to slow or prevent monitor the demise of their kidneys. The delay in the availability of this medication will inhibit the ability to potentially save kidneys, prevent dialysis or maybe even save lives. I have three patients with FSGS that are already on max RAASi and SGLT2i with persistent nephrotic range proteinuria. We need new treatment.
Ali P.	Signing on behalf of GlomCon
Pamela G.	Any drug that can possibly cure or help a disease must be made available to anyone that needs or wants it.
Jing M.	I am a nephrologist. I would like to know if sparsentan would be approved for FSGS indication.
Navreen P.	Help improve longevity of someone who has nephrotic syndrome
Shweta S.	sparsentan would be very helpful in our pediatric and young adult patients to reduce proteinuria in our patient with FSGS, particularly those who have had a steroid resistant/dependent course and genetic forms of FSGS to slow down proteinuria and frequent admissions for edema
Alamjit V.	My nephew has FSGS and would potentially benefit from the availability of sparsentan.
Philip S.	Research!

Comments

From a Healthcare Provider or Researcher

Michael M.	I have a number of pediatric patients with genetic FSGS where immunosuppressive therapy is ineffective. Sparsentan could be extremely helpful in treating these patients and decreasing the number of admissions that they have to manage edema and to delay the progression to ESKD.
Christopher K.	There is a need for further treatment for FSGS. Already approved for IgA with quite a bit of safety data. I particular, we are discovering more and more people with Alport syndrome and this will provide the first treatment for it.
America P.	Praying for a cure, and total healing.
David R.	Sparsentan is appropriate treatment for FSGS and approval by the FDA is indicated
Patsy M.	I am a retired nurse who is supporting this cause to improve the lives of people living with FSGS.
Sandra A.	I am a pediatric nephrologist and have had several patients with FSGS show response to sparsentan after exhausting other treatments. They have achieved both partial remission and full remission. We have not had any pediatric patient stop the drug due to adverse effects and it has shown some benefit in all of our patients treated. Treatment options for FSGS are extremely limited. For children, lack of response to treatment means less time with kidney function, often leading to prolonged dialysis until their disease is burned out. Prolonged dialysis time is directly associated with shorter duration of life and lower quality of life for children with kidney disease.
Gabriel C.	As a provider, I anticipate this will benefit a lot of patients who otherwise have limited therapeutic options and will hopefully help mitigating proteinuria and slow the progression of kidney disease.
William L.	Patients need access to this medication.
Faris H.	I have many patients who have reached renal failure due to Focal Segmental Glomerulosclerosis
Swati A.	Limited options for patients with FSGS.. Sparsentan could help in reducing proteinuria significantly
Paul R.	No one should have to live with this. If there is something out there that can help improve these individuals lives then they should have the ability to get access to this medication.
Ayaa Z.	As a provider, it's very promising to help patient remains off dialysis for as long as possible.
Dawn m.	It could help
Benito V.	I am a Healthcare provider and the elusive treatment for fsgs truly has palpable effects in patients and a source of frustration. Availability.of thr drug Will mitigate this and address important clinical.questions and patient outcomes

Comments

From a Healthcare Provider or Researcher

Neeraja T.	Sparsentan marks an important advance in FSGS management as the first FDA-approved, disease-specific therapy. The clinical development program demonstrated substantial and durable antiproteinuric effects and favorable trends in preserving kidney function compared with ARB alone.the drug is a valuable addition to the therapeutic armamentarium for patients with FSGS and persistent proteinuria. Implementation into clinical practice will require thoughtful patient selection, close follow-up, and integration with existing supportive and immunomodulatory treatments.
Brian R.	As a nephrologist, the lack of treatment options for patients with FSGS has been frustrating. With a focus on proteinuria (and specifically urine albuminuria) as a major marker of rapidly progressive disease, I am eagerly anticipating the use of DEARA medications for my patients.
Veronica M.	I am a dialysis nurse, so let's help these patients from ever having to experience being connected to a dialysis machine.
Usha P.	Add options to rx regiment For secondary and genetic Versions of FSGS
Luis V.	Sparsentan Would directly help my patients living with FSGS, nephrotic syndrome and worsening CKD by reducing their protein burden. The duplex trial clearly showed a significant proteinuria reduction in patients with FSGS. Please help me take care of my patients by approving the use of Sparsentan in patients with FSGS.
Ashte C.	I have dozens of patients with FSGS and progressive CKD despite max-dose RAAS inhibition, and they desperately need better therapy. The approval of sparsentan for FSGS would finally give my patients a better option to lower proteinuria and save as many nephrons as possible.
Katarina S.	There are not many options for steroid resistant FSGS. I have patients with persistent proteinuria who have had terrible side effects from steroids, calcineurin inhibitors, and rituximab. Having a dual acting drug that decreases protein levels would improve their lives. We need to work on podocytopathies, not constant immunosuppression.

"As a provider, I anticipate this will benefit a lot of patients who otherwise have limited therapeutic options and will hopefully help mitigating proteinuria and slow the progression of kidney disease."

- Gabriel C.

Comments

From a Healthcare Provider or Researcher

Molly F.	I am a pediatric nurse practitioner, providing care to children with renal conditions in Massachusetts. I currently provide care to a 15-year-old patient who was recently diagnosed with FSGS in November 2025 and continues to struggle with fluid overload, nephrotic range proteinuria, and hypoalbuminemia. She requires 1 to 2 infusions for albumin replacement and diuresis a week, and each infusion requires over 2.5 hours of travel to our clinic. Over the three months that she has lived with this condition, it has had an enormous impact on her family, her mental health, her school attendance, and her ability to live like other kids her age. The financial strain on the family has been significant. The Impact that a treatment for FSGS could have on just this family would be astronomical. Even though it will likely not cure her condition, it will provide an enormous Amount of support for her kidneys, her family, and her mental health. Please, please consider Approval of this medication. FSGS is a devastating chronic condition and our patients deserve more than the limited options they have for treatment and disease management.
Elaine S K.	Over several decades since I was a pediatric resident, I have cared for and watched too many children and young adults suffer from and die from the complications of FSGS. It is a cruel disease that may even dash the hopes of a better life after transplant. We desperately need therapies that will provide better days and years ahead for our patients and their families.
Jefffrey K.	As retired nephrologist (30+yr in practice and active in FSGS research at the NIH) I saw many patients take a series of medications for FSGS. Many, if not most, patients, progressed to ESKD. We need to expand the list of medications that we can use to slow or halt this disease, which compromises quality of life and shortens lifespans.
Rafael V.	can be life saving as no current treatment for fsgs
Frederick K.	An extremely timely therapy that slows the progression of CKD and lowers the proteinuria.
Rakesh G.	Early adoption of the drug for my FSGS patients upon FDA approval.
Kevin M.	Sparsentan works. I have participated in DUET, DUPLEX and EPPIK.
James D.	I have cared for many patients with FSGS. The emotional and physical toll significant proteinuria has on a patient can be severe. Sparsentan can help with patients proteinuria which can help with these effects of FSGS. For this reason, I would encourage the approval of sparsentan to help address an unmet need for patients with FSGS.
Reza Z.	I have many patients I care for that are suffering from FSGS and don't have adequate therapy.
Jai R.	I was the site PI for the DUET and DUPLEX trials with many pts experiencing significant reduction in proteinuria on sparsentan. Luckily, they were able to get off-label sparsentan, and it would be difficult to manage these patients otherwise

Comments

From a Healthcare Provider or Researcher

Taewoo L.	I am a nephrologist who prescribed Sparsentan for one of my patient with Biopsy-proven FSGS. Improved proteinuria significantly
Wayne K.	I participated as PI on DUPLEX trial and witnessed the improvement in proteinuria and benfit to my patients with FSGS who have had nothing other than conservative management to treat their diseae. Sparsentan would be a true gamechanger for patients with FSGS, providing a treatment that is superior to ACE/ARB and would assist with slowing progression of disease.
Laura M.	I have been involved in the clinical trials for sparsentan as a principal investigator, and have seen its effect firsthand in many of my pediatric patients living with this very difficult condition. Having a potential first-ever FDA-approved therapy for FSGS would be profoundly meaningful—not only as a clinician, but for the patients and families who have struggled for years with limited treatment options and a high burden of disease. For those who participated in DUET, DUPLEX, or EPPIK, I witnessed how access to sparsentan offered a sense of hope, stability, and in many cases, tangible improvement. Seeing patients respond—sometimes for the first time in their treatment journey—reinforced how impactful this therapy could be if made widely available. The availability of sparsentan would represent more than a new medication; it would be a long-awaited advancement for families living with FSGS and a critical step forward in changing the trajectory of this challenging disease.
Laura D.	Sparsentan could change the course of the disease progression and prevent ESRD.
Joseph F.	Approval of sparsentan for FSGS, including pediatric patients, would represent a major advance in the care for these patients.
Sherry W.	It would impact the patients I care for because currently there is not an approved treatment to slow progression and help these patients
VICKI S.	As a healthcare provider FSGS is a serious, often progressive disease characterized by scarring (sclerosis) in scattered parts (segments) of the kidney's filtering units (glomeruli), leading to nephrotic syndrome, heavy protein loss in urine, and, frequently, chronic kidney failure. Despite its rarity, FSGS is among the leading causes of kidney failure in the US and drives more patients to kidney failure within 10 years.
Nikki U.	Pediatric Clinical Research Coordinator working with pediatric patients with various kidney disease diagnoses.
Alex M.	Approval of sparsentan for the treatment of patients with FSGS would provide a treatment option that reduces proteinuria to slow disease progression. This would significantly improve the lives of many patients with FSGS in whom current therapies are insufficient to prevent progression to kidney failure
Karen H.	Without research people will die
Margaret C.	Mother in law had disease many years ago

Comments

From a Healthcare Provider or Researcher

Corina N.	It would give hope to many of my patients.
Neha P.	Sparsentan would be the first approved therapy for FSGS and has the potential to slow the progression of chronic kidney disease, helping to delay or prevent the need for chronic dialysis in children. This is especially important because long-term dialysis significantly increases the risk of cardiovascular complications in pediatric patients and is associated with a markedly reduced life expectancy, often averaging only around 30-40 years.
Wacharee s.	It is wonderful and we are waiting for all patients who are almost all with FSGS who will loose the kidney function at their early life.
Kathy L.	These patients need to have the care they need.
Myda K.	I have patients with FSGS and proteinuria, and there are no therapeutic options for them. It is sad to watch them deteriorate without additional nephrotection that exists
Omaima D.	I need more options for my patients to prevent this progressive disease
Andrew S.	How soon until pediatric trials?
Scott W.	I was site investigator for the DUPLEX and EPPIK studies in Texas, before I moved to Canada. I saw how scared my patients were with FSGS and their families, when they realized how few FDA-approved options there are for children with FSGS. Then there was a glimmer of hope when I could offer them screening for potential enrollment in a clinical trial. I saw my pediatric patients on these trials reading the results published on the DUET study and hoping that they too could experience the same benefits on reducing their proteinuria, being able to liberate their fluid restrictions, and potentially delaying or preventing their kidney from failing.
Dawn C.	I am an adult Nephrologist and was site PI for the DUPLEX study. I saw my patient improve in the study and hope she can continue the treatment she has been on for 5+ years. Her kidney function has stabilized and she experienced >50% reduction in proteinuria.
Sreedhar M.	There are no good medications for FSGS, this will be a huge step forward
Stacey A.	One of my research have it.
Gisela. A. F.	Well, my brother had kidney failure. I couldn't get no kidney and died.
Sameera G.	I believe everyone deserves treatment

Signatures

From Someone Living with FSGS

Harlan J.
Andrew S.
Julie L.
Marie Janelle T.
Kimberly H.
Joyce F.
Don L.
Melissa N.
Lisa P.
Katrina B.
Christopher P.
Karen W.
Kelsie H.
Robyn G.
Kristal H.
Gary K.
Patty R.
Nikita K.
Mindy E.
Jennie P.
Shannon M.
M. E.
Avram A.
Evelyn C.
Darielle P.
Amanda L.
Ramesh K.
Sherrell H.
Kristie R.
Windy W.
Marilou A.
Susan M.
Keith H.
Vickie L.
Marco T.
Thomas M.
Kimberly P.
Jill H.
Francisco P.
Tracy S.
Vanessa T.

Leigh B.
Megan T.
Katherine R.
Ana O.
Karen K.
Douglas G.
Maureen R.
Maureen R.
Kevin C.
Michele B.
Robert G.
Angelia L.
Michele C.
Sabreena S.
Kelly M.
Christopher W.
Rebecca C.
Lynette S.
Jennifer A.
Juanisha S.
Jessica C.
Eric B.
Rochel S.
Jonathan R.
Shonda G.
Kelly R.
Vanessa B.
Lisa M.
Jim L.
Kostadin S.
Javier T.
Lindsy G.
Tiffany L.
Barbara K.
Johnny S.
Catherine T.
Dana T.
Lisana A.
Luis F.
Debra S.
Steve K.

Jacqueline M.
Wayne S.
Kimberly D.
Daniela C.
Rhonda K.
Pamela C.
Elizabeth G.
Pamela C.
Jennifer M.
Jennifer B.
John D.
Tara G.
Gary M.
Jonathan W.
Christine W.
Eva H.
Michael W.
Marvin F.
Jennifer G.
John P.
Olivia K.
Scarlett S.
Ebony J.
Eric R.
Dilli T.
Nora R.
Sally C.
Leon L.
Dolores S.
Thien D.
Ashley K.
Abdul N.
Brian S.
Sarah S.
Marcus M.
Marquetta A.
Allethia F.
Allison S.
Casey S.
Amy P.
Julie J.

Macy C.
Joshua W.
Elizabeth C.
Stormy G.
Patrick D.
Jennifer C.
Sandra M.
Renea M.
Carrie L.
Frank A.
Eric G.
Farnaz F.
Marquisha W.
Jessica D.
Debbie b.
Dustin O.
Carolyn D.
Kadija B.
Melissa N.
Pamela K.
Leland B.
Saadiq F.
Pam S.
Regina W.
Brent B.
Carol K.
Allethia L.
Scott H.
Russell G.
Diane M.
Najeeb A.
Ben D.
Lyndsay A.
Justin R.
Majella M.
Suzanne M.
NaYaN W.
Manon B.
Mark M.
Kendall T.
Shenita S.

Kahil S.
Joshua A.
Lauren M.
Robert S.
Sean S.
Willie M.
Denise H.
Jacob K.
Jill A.
Leon L.
Russell G.
Robin W.
Katie S.
Marquetta A.
Patsy J.
Brenda K.
Erica J.
Beth R.
Michael R.
Joseph L.
Amber M.
Elizabeth C.
Jaclyn C.
Casey S.
Peter M.
Steven G.
Cepriano L.
Laura P.
Jose Paulo C.
Angie G.
Robert C.
Dorothy C.
Brett W.
David R.
Linda B.
Theresa B.
Sean J.
Levi P.
Ivan H.
Bethany S.
Allan P.

Signatures

From Someone Living with FSGS

Brock W.
Shad L.
Sharron R.
Bill A.
Andi G.
Nora D.
Brenda T.
Natalie L.
Vickie W.
Donny F.
Shane H.
Matthew D.
Brittany R.
Brooke M.
Ayanna P.
Andrea B.
Karen Z.
Marquita M.
Michael L.
Jeff B.
Esther M.
Tracy j.
Jorden A.
Camille L.
John R.
Regina W.
María Alejandrina S.
Brieanne H.
Jennifer C.
Denise B.
Sandy A.
Henry S.
John H.
Isidro G.
Lidia D.
Amanda G.
Harlan J.
Elizabeth L.
Ashley F.
Ashley F.
Daphiny M.

Desarena M.
PAULA T.
Saadiq F.
Lyle H.
Leigh B.
Rebecca C.
Kristin M.
Nora D.
Kimberly M.
Ann H.
Theresa J.
Karla C.
Amanda Y.
Nicholas A.
Alana E.
Andrea P.
María Isabel F.
Wendy C.
Jamal s.
Aanisa W.
Mitchell D.
Frank D.
Kristin P.
Erica B.
Amber F.
Michelle P.
Samantha S.
Keayrshae H.
Daniella O.
Janelly C.
Stuart B.
bryan j.
Bob H.
Reina P.
Gwen B.
James C.
Kevin M.
Michelle T.
Glenda F.
Charlotte M.
Christy C.

Samantha C.
Kristie G.
Gilbert W.
Jake S.
Mary H.
Jonathan B.
Eugenio M.
Kristian G.
Susan P.
Tom D.
Sally C.
Felicia W.
Tashara G.
Amber I.
Lillian C.
Lori M.
Michael J.
Rakeem W.
Mary H.
Tracy W.
Heidi S.
Grace-Ann D.
Jeremy J.
Margaret H.
Monica L.
Chris B.
Darryl M.
Leah W.
Paul S.
Keith B.
Melissa G.
Francisco D.
Teresa R.
James W.
Casey S.
Gavin T.
Jeff D.
Allison B.
Cinthia F.
Michael G.
Brooks B.

Sylvia B.
Margaret G.
Wil P.
Chimezie M.
Jess S.
Whitney W.
Sara R.
Mike L.
Algenia H.
Florencia V.
Ian C.
Mesha W.
Mindi W.
Janelle J.
Phillip C.
Genoveva V.
Ella F.
Kelley R.
Leslie O.
Dhruvika D.
Amy R.
Carol K.
Jessica W.
Stacy J.
Shelly F.
Joni R.
Christine C.
Amardeep D.
Ann S.
Jacqueline C.
Pamela S.
Isabel V.

Natalie D.
Lawrence C.
Meagan M.
Kendall T.
Tia S.
Gina G.
Paul S.
Sharon N.
Sara H.
Andrea S.
Lisa L.
Sharon R.
Eugene M.
Jenn T.
Nikki C.
Faith S.
Onaje R.
Windy W.
Ramond G.
Katie T.
Regina W.
Susan B.
Lindsey J.
Sally C.
George W.
Lawrence C.
Miranda W.
David W.
Aleta G.
Shanice Y.
Jeremy C.

Signatures

From Someone Living with FSGS

Tawana D.
Leanne C.
Tara G.
Shumphert H.
Jennette M.
Jeremy W.
Zachary L.
Andrew B.
Kent B.
Maria B.
Chelsea b.
Leilah S.
Alice A.
Debra S.
Ann Marie C.
Casey S.
Kirsten U.
Liron T.
Anne B.
Jane B.
Jacob P.
Michael M.

Kevin B. F.
Rebecca B.
John B.
Zachary L.
Louise M.
Henry S.
Jodi B.
Tracy W.
Sabrina W.
Meghan R.
Dylan P.
Allyson G.
Timothy M.
Elizabeth G.
Frank A.
Ashley J.
Peter A.
Brandon G.
Pamela K.
Tariq R.
Daniel K.
Eva F.

Brooke W.
Courtney G.
Saadiq F.
Michael B.
Susan D.
Janis V.
Melissa M.
Melissa S.
Breeana D.
Jennifer P.
Shannon M.
Pam S.
Kadija B.
Catherine T.
Omar A.
Shrley S.
Claire W.
Thomas R.
Carla B.
Hunter M.
Mandy M.
Norman N.

Marvin F.
John D.
Wendy A.
Ivan H.
Brian S.
Kim M.
Denise M.
Alexis K.
Eric G.
Mindy O.
Jackie O.
Jeremy R.
John P.
José Paulo C.
Norah F.
Katlynn W.
Vishwanath K.
Alicia H.
Juli M.
Robert G.
Victoria S.
Christine W.

Shawn O.
Lacey S.
Christopher M.
Bailey F.
Olivia K.
Pamela M.
Michelle W.
Cheryl G.
Stefanie D.
Shyam A.
Marc C.
Nelly N.
Raquel F.
Rebecca O.
LaToisha D.
Susanne C.
Cathy L.

"As a patient diagnosed with FSGS in 2012, I believe this drug could have made a significant impact on my life. I have now been post-transplant for almost six years, and I would have liked the option of taking one medication to help preserve kidney function rather than progressing to the point of needing a transplant and lifelong transplant medications. Although I am grateful to be living without dialysis, I believe sparsentan could make a major difference for others by potentially slowing disease progression and offering a more affordable long-term option for patients."

- Paula T.

Signatures

From a Parent or Family Member of Someone Who Has FSGS

Azurlyn F.
Angela R.
Kent F.
D. T.
Stephanie R.
Kelsea G.
Janna W.
Karen N.
Teresa B.
Keri C.
Kathy R.
Richard G.
Catherine C.
Andrew M.
Judith L.
Licia S.
Tara K.
Md Mizanur Rahman J.
Emmaline M.
Brenda M.
Michael M.
Connie P.
Ben T.
Melissa G.
Christy C.
HEIDI M.
Sandee S.
Zain E.
Amy F.
Ahmed E.
Shirley H.
Julie S.
Adam E.
Lena M.
Joanne C.
Taylor W.
Tyler W.
Charlie C.
Jennifer W.
Vivian K.
Emily W.

Leslie J.
Jennifer K.
Karlene C.
Jama G.
Marcy M.
Qingyi D.
Sarretta M.
Cathy M.
Randy C.
Martha F.
Susan F.
Diana A.
Louis A.
Joshua J.
Walter J.
Bruce M.
Dana L.
Sara L.
Jessica J.
Coleene V.
Lisa C.
Breanna W.
Joyce F.
Amanda Y.
Kerry S.
Valerie S.
Rosie K.
Paul T.
Jackie M.
Michele H.
Deborah W.
Michael W.
Rebecca G.
Emily F.
Betty V.
Ashley J.
Mandee B.
Susy L.
Ruby T.
Nancy E.
Alice S.

Scot E.
Michele N.
Michael C.
Mary K.
Beverly V.
Danielle D.
Cynthia G.
Angela K.
Priyanka S.
Danielle D.
Kismat D.
Kamal B.
Jacob H.
Richard G.
Robert B.
Mikenna H.
Samantha A.
Jennifer F.
Denise M.
Robert R.
Heather D.
Lliani G.
Walda H.
Britney Q.
RosaLisa L.
Rochelle S.
Lisa S.
Debbie P.
Maria C.
Jill K.
Nicole R.
Sarah E.
Gene A.
Courtney B.
Stephen M.
Dawn P.
Jaclyn L.
Angela S.
Ravinder S.
Kristine A.
Zafar G.

Rachel C.
Chiquita J.
Mary M.
Georgia K.
Taylor L.
Margaret M.
Terry H.
Danielle G.
Coral G.
Chrisanta T.
Ayrolyn K.
Harold G.
Jess W.
Angelique P.
Alyse Z.
Surinder G.
Amrita C.
Dev N.
Carmella P.
Alysia F.
Saira B.
Kameswararao M.
Debbie R.
Rachel H.
Jaspinder G.
Manjit D.
Sabrina D.

Armaan B.
Carla B.
Sonia D.
Inder D.
Vince B.
Amy G.
Harjinder S.
Karen G.
Bemi J.
Sunny G.
Kiron D.
Hargunvir S.
Noor G.
Kundan B.
Hargunvir S.
Zorawar Biri S.
Balbir S.
Parminder A.
Mira N.
Kimberly M.
Manrita S.
Scott D.
Tej S.
Chris B.
Matthew B.
Dominique W.
Martha B.

Signatures

From a Parent or Family Member of Someone Who Has FSGS

Christopher B.
Michelle Q.
Laurie D.
Marie-Paule C.
Tamra L.
Martha L.
Thomas S.
Edith S.
Laurie M.
Alice B.
Timothy M.
Daniel S.
Andrea B.
Elana C.
Brittany S.
Sophia C.
Jeffrey B.
Kathy M.
Margaret R.
Richard B.
Thomas M.
John B.
David B.
Jean B.
Meredith G.
Joyce B.
Carl L.
Misty G.
Miranda P.
Joy L.
Emily D.
Paul B.
Nikki B.
Daniel B.
Ian G.
Elizabeth J.
Blanca B.
Pablo M.
Cristina M.
Pablo M.
Ignacio A.

Debra J.
Lori B.
Ruth L.
Kirsten B.
Aggie G.
Stephanie P.
Amy J.
Lisa Cimino !.
Markesha S.
Kristine A.
Stephanie L.
María del Pilar S.
Carol B.
Jen R.
Mary Jo R.
Donna V.
John M.
Dana G.
Abby D.
Susan M.
Kayla L.
Lorraine L.
Courtney P.
Caitlin M.
Therese M.
Michael L.
Gina K.
Alex S.
Joseph B.
Christine M.
Maggie A.
Peg I.
Sandra M.
Mary K.
Colleen G.
Ann W.
KD S.
Carla C.
Jim D.
Carly P.
Elsa R.

Phyllis P.
Michael S.
Anita W.
Karen H.
Lori M.
Brandy E.
Kyle W.
Scott P.
Sonya C.
Hollie W.
Juan Jesus V.
Joyce J.
Elizabeth S.
Julie B.
Colette W.
Cody Y.
Laura D.
Kim D.
Tiffany S.
Matt S.
Leah S.
Dylan S.
Joni Y.
Kristie K.
Janet H.
Lara Y.
Tiffaney F.
Michael A.
Sue R.
Terry B.
Wade Y.
Priscilla O.
Farrah Y.
Charles D.
Maria Rita B.
Alec L.
Jennifer M.
Gina V.
José Maria L.
Michael M.
Drew D.

Jen V.
Pamela K.
Julie R.
Kristen F.
Carmen F.
Maria M.
David M.
Maria G.
Iosune C.
Kelly H.
Kevin M.
Reba j.
Concepción R.
Iker Daniel M.
Marta S.
Leticia S.
Maria L.
José L.
Sandra S.
Lu E.
Nuria V.
MONICA M.
Elsa A.
Laura R.
Virginia S.
Verónica C.
Jennifer H.
Acenet B.
Lina R.
Christine F.
Beatriz N.
Tina M.
Leah R.
Kyle K.
Laura S.
Rhonda M.
Bobbi c.
Kelly H.
Jessica S.
Lisa L.
Paula B.

Yolanda G.
Patricia S.
Joanne G.
Lydia A.
Darlene M.
Darlene M.
Jose Manuel H.
Sonia yadira D.
Paula S.
Dacil Á.
Jose G.
Jack L.
M° victoria F.
Josegny M.
Leonardo S.
Gloria S.
Toni M.
Ann A.
María S.
Ann A.
Silvia S.
Soraya P.
María Mercedes G.
Maria y.
Madison F.
Carlos D.
Ana R.
Pilar G.
Victor V.
Natalia L.
Juanma G.
John S.
Lynda C.
Amanda C.
Sarah M.
Rainah V.
María Jose L.
María Jesús L.
Peyton Z.
Juan José E.
Katie W.

Signatures

From a Parent or Family Member of Someone Who Has FSGS

Scott P.
Tristen C.
Cassie S.
Dane K.
Matthew G.
Joshua J.
Jo An J.
Laura F.
Arlene O.
Angela M.
Lindsay R.
Brian M.
Sarah C.
Monica b.
Kathy B.
Diego M.
Kamesh M.
Sharyl H.
Troy P.
Patty P.
Martha Jo S.
Dakota A.
Judy T.
Jamie F.
Julia M.
Cassie W.
Kaitlin W.
Audra L.

Tracy S.
Treasure W.
Stephanie D.
Jo Anna B.
Amanda B.
Ashlee H.
Deborah C.
John S.
Tara T.
Amanda C.
Gladys C.
Vicki L.
Jacob B.
Coleen B.
Kimberlee M.
Joseph B.
Macy L.
Erin C.
Colton N.
Alessandra B.
Sara A.
Kayleigh S.
Lauren M.
Elyse H.
Sandra C.
Laura V.
Gillian V.
James N.
Stephanie N.

Rocco M.
Gabriella M.
Laura E.
Victoria P.
William B.
Clara B.
Elizabeth D.
Eliana R.
Jennifer S.
Stephanie A.
Lisa Ann S.
Caroline S.
Heidi C.
Ryan R.
Julie C.
Leah G.
Aimee E.
Elaine S.
Gabriella B.
Whitney B.
Julie C.
Laura F.
Jessica H.
Kristin C.
Rose H.
Lisa F.
Kaitlyn N.
Catherine B.
Kristy R.
Jeremy M.
Laura J.
Yoreisi V.
Jaclyn H.
Norma M.
Deirdre W.
Kristen C.
Margaret D.
Donna P.
Sarah G.
Cameron S.
Kiyana C.

Brenda G.
Kenny H.
Leslie L.
Adrianne P.
Joanne F.
Eric F.
Heather R.
Cynthia H.
Cindy C.
Hafiz F.
Angel R.
Anna R.
Williamettia S.
Sarah J.
Reegan E.
Tara A.
Shabnam Q.
Christopher W.
Trevor M.
Kelsey F.
JoAnne S.
Julie W.
Sam S.
Rebecca K.
Sharon S.
Katherine R.
Sophie M.
Joanne H.
Amy M.
Sam S.
Tara S.
Milton L.
Jessica L.
Chloe G.
Jenifer D.
Jake W.
Karen W.
Robert W.
Lily F.
Kylie F.
Patricia R.

Rhonda V.
Jen P.
Regina S.
Dan M.
Anna C.
John W.
David M.
Liliana D.
Jaimee W.
Leslie K.
Michelle M.
Julie C.
Katy R.
William M.
Margaret M.
Elise W.
Krista K.
Scott C.
Brittany D.
John C.
Raquel F.
Robert S. C.
Jennifer B.
Lorie C.
Maria E.
Marcie B.
Kim H.
Crystle M.
Olegna F.
Sherry B.
Octavio H.
Hannah D.
Shubhi R.
Deb H.
Richelle G.
Mary S.
Janel F.
Kathleen R.
Susan B.
Nicole J.
Jens C.

Signatures

From a Parent or Family Member of Someone Who Has FSGS

Ruth C.
Alex W.
Joshua P.
Elizabeth A.
Kathryn P.
Melinda W.
Justin C.
Savanna S.
Nina V.
Rachael T.
Elizabeth B.
Jacqueline S.
Jessica M.
Jeff G.
Lloyd P.

Josh W.
Amanda C.
Jackie M.
Christa K.
Joy J.
Tess S.
Mindy P.
Julie P.
Shelley J.
Chrystal H.
Ricardo P.
John S.
Jenny R.
Libby H.
Shannon S.

Danielle M.
Jan S.
Adam R.
Rebecca R.
Rebecca C.
Suzie C.
Cody H.
Don W.
Lauren W.
Shannon M.
Emily G.
Ellie M.
Matthew B.
Robin C.
Katie J.

Marc S.
Rosa N.
Renee C.
Cristobal M.
Shawn N.
Melissa C.
Lisa M.
Jill K.
Mary N.
Margaret P.
Angela A.
Amy P.
Esmeralda P.
Vivian K.
Jenny S.

Donald H.
Heather P.
Mark W.
Andrea W.
Julia H.
Lora H.
Phillis W.
Eftihia N.
Kathy W.
Christine M.
Lisa W.
Kelly H.
Jennifer G.
Eliana R.

"My son has been living with FSGS for 10 years. He is 11 years old. He has been taking tacrolimus immunosuppressant since he was 2. He has been hospitalized, missed school, taken a chemo infusion used to treat rheumatoid arthritis, In addition to various other ways it has affected our life. The opportunity to take a non-Immunosuppressant medication like Filspari would make a world of difference for us! The once daily pill would cut down his need for twice a day medication also, and hopefully eliminate the need for the chemo infusion which kills his immune system completely. He would not have to endure more needles, time away from school, and potential health risks due to a compromised immune system. It is very important to our family that this drug passes the FDA approval and we can begin administering it as soon as possible! Thank you for your consideration."

- Jessica J.

Signatures

From a Healthcare Provider or Researcher

Debra K.
Ruthann O.
Alyssa B.
Jessica C.
Jennifer M.
Maria B.
Sunny L.
Danielle R.
George B.
John S.
Rajeev R.
Frederick K.
Ashraf E.
Sahar K.
Teresa B.
Maya D.
Jason L.
Michelle C.
Marie D.
Raymond H.
Tej M.
Jayanthi C.
Hollie D.
Bradley D.
Howard T.
Brad R.
Alessia F.
Susan G.
Rasheed G.
Duncan J.
Katherine T.
Diego A.
John D M.
Scott M.
Rahul M.
Suneel U.
Guillermo H.

Agnieszka S.
Amy M.
Michael E.
Dechu P.
Jacob N.
Constance P.
Dorothy L.
Rita E.
Beth C.
Christine H.
Crystal M.
Ali P.
Pamela G.
Arun R.
Edgar L.
Jing M.
Navreen P.
Shweta S.
Alamjit V.
Alyssa G.
Philip S.
Michael M.
Christopher K.
America P.
David R.
Patsy M.
Sandra A.
Gabriel C.
William L.
Faris H.
Swati A.
Paul R.
Ayaa Z.
Dawn M.
Benito V.
Neeraja T.
Brian R.

Veronica M.
Usha P.
Luis V.
Ashte C.
Katarina S.
Molly F.
Elaine S K.
Jefffrey K.
Rafael V.
Frederick K.
Rakesh G.
Kevin M.
James D.
Reza Z.
Jai R.
Corey C.
Taewoo L.
Wayne K.
Michelle T.
Laura M.
Laura D.
Cecelia L.
Joseph F.
Rhonda H.
Sherry W.
VICKI S.
Nikki U.
Alex M.
Karen H.
Margaret C.
Corina N.
Neha P.
Wacharee s.
Kathy L.
Myda K.
Elena M.
Omaima D.

Andrew S.
Devanshi B.
Scott W.
Dawn C.
Sreedhar M.
Stacey A.
Natti F.
Marie M.
Gisela. A. F.
James V.
Sameera G.
Mindy H.
Stacy F.
Renae F.
Jillian M.
Julie S.
Elaina S.
Lori S.
Jackie S.
Alexis C.
Alyssa M.
Melissa K.
Agnes F.
Michelle B.
Regina M.

Shirley S.
Maya D.
Ashley T.
Debra G.
Tina K.
Linda B.
Sandra G.
Patricia M.
Kathleen M.
Evelyn Y.
Annie S.
Tara N.
Gale G.
Ruthie W.
Laurie K.
Franci V.
Deborah E.
Furwa H.
Patrick M.
Aditya B.
Denise P.
Omaima D.

Signatures

From a friend to the FSGS community, an advocate, or a volunteer

George C.
Margaret A.
JoAnn H.
Courtney P.
Sarah L.
Sharon S.
Lee D.
Treva L.
Liz S.
Karen S.
Linda M.
Sam S.
Shay B.
Dixie P.
Pamela R.
Catherine C.
Sonya S.
Lindsay D.
Andrew C.
Melissa G.
Linda S.
David C.
Tammy H.
Carol H.
Charlotte G.
Jehna H.
Jason S.
Marissa A.
Craig W.
Virginia M.
Liz W.
Kristene D.
Jeanna L.
Kim V.
James C.
Erica D.
Alma S.
Amy S.
Grace C.

Euphrates D. C.
Andrew S.
Josh T.
Kelly L S.
Martha A G.
Michael D.
Nav S.
Margarita V.
Kay G.
Laura A.
David F.
Nicolette M.
Teresa E.
Joan W.
Jacynthe D.
Keri M.
Lorin B.
Monica K.
Annie C.
Chelsea A.
Susan D.
Tiffany L.
Angela B.
Teresa M.
Mona S.
Sheri W.
Lisa S.
Richard C.
Alexandra V.
Jenna R.
Michel D.
Suzanne U.
Lashonda W.
Cindy N.
Jesse C.
Carrie D.
Kelsey R.
Kelley L.
Gavin N.

Momodou C.
Lauren B.
Shelli B.
Christine T.
Shana G.
Lynn M.
Ann D.
Diana J.
Hollie B.
Gail S.
Katy F.
Julie C.
Amy W.
Kathleen C.
Abby G.
J D.
Robert C.
Catherine H.
Tess C.
John B.
Nicholas N.
Margaret S.
Suzanne B.
Dorothy L.
Jenifer W.
Janet M.
Joe K.
Savannah F.
Veronica S.
Lisa R.
Lee Ann P.
Laurence S.
Janaina O.
Robyn d.
Richard N.
AJ G.
Linda B.
Amanda S.
Mary B.

Donna S.
Mary B.
Tricia F.
Kathy B.
Bonnie L.
Abbie G.
Maura F.
Elizabeth C.
Melissa N.
Marlene S.
Peter W.
Pete W.
Maria M.
Amy M.
Rashi R.
Bill N.
Melissa F.
Katie M.
Judy R.
Richard j P.
Alisa S.
Zlata S.
Loren E.
Robert S.
Jill Z.
Deborah F.
Shannon G.
Juliette S.
Joanna R.
Kristin B.
Brandon H.
terrianne t.
Nancy M.
Bryan S.
Debbie S.
Jennifer T.
Beth A.
Holly A.
Amanda B.

Karen S.
Virginia S.
Katina L.
Marisa L.
Nicole M.
Helen B.
Heather G.
Bruce D.
Jason K.
Karyn P.
Laurie C.
Paula W.
Maria W.
Annie T.
Rachel M.
Julia P.
Eric H.
Corinne S.
Tracey A.
Theresa J.
Pat S.
Jennifer I.
John C.
Jennifer L.
Shari S.
Grace P.
Mariann D.
Sheryl L.
Susie D.
Donna M.
Stephanie G.
Dorothy L.
Angela M.
Jennifer S.
Debbie H.
Howard C.
Rosemary R.
Anna N.
Cindy E.

Signatures

From a friend to the FSGS community, an advocate, or a volunteer

Denae W.
Jaimee L.
Cindy M.
Pamela M.
FaithAnn Y.
William S.
Michele P.
Ashley A.
Guy T.
Sheridan V.
Janet O.
Pamela R.
Sophie D.
Paul F.
Diana M.
Cindy F.
Tina N.
Rebecca B.
Lisa R.
Rita D.
Sandra S.
Theresa E.
Katherine B.
Kaye E.
Jamie C.
Shirley H.
Charles B.

Sarah H.
Brittainy R.
Kimberly H.
Shawnda H.
Janet B.
Kara S.
Becky D.
Rebecca P.
Emily B.
Monica K.
Niki f.
Allison W.
Brittney Z.
Brooke N.
Eric G.
Deb A.
Andrea T.
Vinny W.
Raeanna L.
Amy Elizabeth A.
Roxanne E.
Carlina F.
Julie L.
Lynn P.
Tamara B.
Beverly H.
Jody I.

Carrie D.
Stef J.
Sandra G.
Pamela K.
Kerri B.
Jane D.
Rob D.
Jessica W.
Rakesh D.
Stacy M.
Bethany A.
Kate D.
Bonnie K.
Debbie B.
Angela A.
Trisha T.
Amanda J.
Greg C.
Linda F.
Ken O.
Christopher G.
Ruki S.
Linda M.
Kenneth H.
Vinna S.
Richard D.
Lynn C.
Carolyn A.
Manraj S.
C S.
Kathlen J.
Keaton J.
Carol K.
Philip S.
Shannon B.
Henry D.
Sydney V.
Tom N.
Sangeeta G.

Megan H.
MaTheresa R.
Sanjay L.
Karishma K.
Nimerta S.
Candice B.
Samant V.
Preet V.
Rick D.
Michael S.
Tracey G.
Raechel K.
Maryann M.
Maryann M.
Debra M.
Jenn S.
Leandra T.
Teena W.
Heather G.
Jo N.
Vicki M.
Mark T.
Ryan B.
Marvin J.
Abeljose M.
Roxanne M.
Aisling B.
Stephanie A.
Fonda Y.
Debbie M.
Kelly L.
Christina T.
Timothy L.
Margaret J.
Kevin G.
Kiki G.
Jennifer E.
David M.
Denise T.

Donna B.
Amber R.
Joanna R.
Heather T.
Cari C.
Carol B.
Christopher P.
Debra H.
Kim D.
Jennifer C.
Judith T.
Ame H.
Karis J.
Jenny Z.
Rachael M.
Karina T.
Alyssa P.
Kathleen L.
Janet H.
Scott B.
Susan D.
Jennifer S.
Susan C.
Godelieve G.
Roberto G.
Laurel O.
Kathryn S.
Hunter T.
Kas E.
Jacqueline B.
Monica K.
Jeff L.
Danny R.
Alberta G.
Patricia C.
Gayle K.
Jeralyn H.
Miguel S.
Cheryl Y.

Signatures

From a friend to the FSGS community, an advocate, or a volunteer

Marissa W.
Dawn E.
Patrice S.
Terri B.
Diana C.
Karen H.
Kathryn B.
Joan T.
Janet P.
David H.
Nate O.
Nicole N.
Jessica H.
Heather G.
Diane M.
Melody D H.
Stacey B.
Jessica A.
Hunter T.
Donna M. P.
Helen B.
Steve M.
Toni D.
Lori S.
Janice F.
Royce B.
Valle A.
Chad W.
Norine M.
Larissa H.
Jessica J.
Georgette R.
Serena T.
Kelley C.
Bridget M.
Matthew M.
Carmen O.
Mark T.
Kathleen G.

Susan K.
Danielle B.
Tiffany R.
Angelica M.
Jerry L.
Phillip W.
Eileen D.
Peggy &.
Hunter T.
Dale W.
Lauren R.
Christine K.
Kayla M.
Spencer E.
Lexy P.
Sonya H.
Robert E.
Peggy F.
Olga D.
Janine S.
Donna Maria H.
Tracy M.
Mary M.
Suz E.
Ruben T.
Janice b.
Delfina C.
Lisa H.
Kim Y.
Lorelei S.
Paul P.
Tara M.
Jessica M.
Elizabeth T.
Robert C.
Geralyn M.
Lori R.
Olivia M.
Rolf T.

Melissa H.
Lois R.
Christopher R.
Anne C.
Linda M.
Tara R.
Madeline B.
Brian G.
Pamela G.
Jill T.
Teena W.
Esther A.
Jillian C.
Penny J.
Jackie B.
Kimberly S.
Carla S.
Geri B.
Tina G.
Natashia C.
Erin C.
Darron D.
Henry G.
Madeline M.
Marchelle S.
Gail Y.
Chloe' C.
Elizabeth T.
Teresa W.
Leslie G.
Grace M.
Robert S.
Christiena S.
Nancy M.
Zena B.
Jennifer E.
Fritzi D.
Kathy B.
Mackenzie U.

Myriam A.
Jane S.
Soline D.
Kelly C.
Judy S.
Michele F.
Natasha N.
Julianna P.
Elberta B.
Kim E.
Tamiko L.
Michele M.
Jennifer B.
Dan K.
Nycole R.
Laurie M.
Shanna S.
William M.
Judith E.
Robin M.
Therese L.
Casey C.
Melissa V.
Connie N.
Denna W.
Beth O.
Sars R.
Jenny H.
Beka N.
Patricia P.
Cynthia S.
Stephen S.
Tyla G.
Margarita A.
Rion L.
Shaye R.
Emalie A.
Lisa M.
Richard L.

Maite V.
Monique B.
Stephanie S.
Erica W.
Alene S.
Olivia M.
Andrea B.
Hannah J.
Nancy G.
Sara C.
Bonnie H.
Sandy S.
Jamie K.
Judy J.
Charlene S.
Christina B.
Sharon R.
Lisa L.
Lauren C.
Stephanie K.
Vanessa V.
Maura G.
Vickie R.
Lydia M.
Kayla H.
Joan L.
Maresa F.
Mariona F.
Melisa M.
Joyce S.
Cathy S.
Jill M.
Chandelle K.
Olaia D.
Pam M.
Elizabeth L.
Mackenzie D.
Dar H.
Bridget D.

Signatures

From a friend to the FSGS community, an advocate, or a volunteer

Marty B.
Tianna L.
Rae H.
Lise A.
Debbie M.
Robert H.
Maria jose F.
Karen S.
Katherine G.
Maria Teresa L.
Julia W.
Reva J.
Tracy S.
Clara María L.
Melody G.
Soraya S.
Sandra S.
Shele H.
Carmen B.
Shain G.
Jackie Z.
Jeane C.
Olivia M.
Tamara J.
Dora A.
Michelle T.
Courtney S.
Michele O.
Margaret H.
Deborah B.
Linda G.
Amanda C.
Joanna K.
Connie N.
Brooke M.
Wilma G.
Jessica W.
Kathy H.
Kim P.

Ann L.
Debbie F.
Eric P.
JoAnna W.
Katie Jane M.
Stephen M.
Anne L.
Patrick M.
Mayra S.
Sharon S.
Rachel G.
Gretchen H.
Maya S.
Marquis W.
Amanda G.
Morgan T.
Rae M.
Shannon M.
Morales A.
Kaitlyn M.
Alonso S.
Susana S.
Maria H.
Laura L.
Shannon T.
Sheila B.
David B.
Mariah F.
Arlene S.
Kathy M.
Susan M.
Jahayra F.
Sue M.
Judit O.
Mary Sue S.
Christian G.
Stephanie C.
Harold L.
Jill B.

Laura V.
Christian A.
Tricia W.
Emmalee M.
Crystal K.
Vanessa T.
Meghan G.
Courtney B.
Cory D.
Elizabeth P.
Janice T.
Alison G.
John M.
Julie Ann H.
April B.
Sara F.
Angela S.
Tyler T.
Louise B.
Thomas H.
Hailey S.
Jo N.
Barbara B.
Mandy C.
Gabriela S.
Tahnisha M.
George C.
Luisa B.
Katherine L.
Jakob K.
Teresa N.
Emalie A.
Charday F.
Crystal P.
Robert A.
Kaitlyn S.
Gwen M.
Melody G.
Al S.

Hugh T.
Lea F.
Tessa E.
Katie C.
Ashley Q.
Brianna B.
Pamela E.
Kelly B.
Breanna O.
Kylie S.
Stacy M.
Alexandria S.
Jill F.
Jennifer S.
Mackenzie K.
Anna C.
John C.
Andrew N.
Anna O.
Cathy D.
Alyssa S.
Samantha S.

Katie W.
Jarvis T.
Kim S.
Erika R.
Rita H.
Ana S.
Kerri S.
Cheryl B.
Lorri Q.
Cari B.
Brittany A.
Rebecca R.
Jeana C.
Laura D.
Ruth F.
Aalon C.
Rebecca V.
Chandelle K.
Bethany J.
Dulce P.
Adrian S.
Laurie B.

Signatures

From a friend to the FSGS community, an advocate, or a volunteer

Emalie A.
Ms B.
Jolane L.
Bianca N.
Lindsay M.
Jaime A.
Trinity C.
Elizabeth A.
Miranda L.
Michelle W.
Art S.
Cynthia K.
Cindy E.
Tommy T.
Brandy T.
Andrea A.
Adam T.
Marisol J.
Victoria S.
Rochelle R.
Amanda Z.
Rachel H.
Olivia R.
Liza S.
Brea C.
Nicole O.
Cahill K.

Clarissa A.
Allison L.
Peyton C.
Jordan F.
Nanette S.
Kathi K.
Monica M.
Alex G.
Jordan E.
Shaye C.
Lori S.
Diane C.
Rosemary W.
Annjanet C.
Jeanette D.
Martina D.
Cathy D.
Melinda P.
Rachel B.
Susan G.
Kim H.
Kristen K.
Colleen E.

Halene H.
Toy B.
Amanda G.
Cynthia W.
K I.
Rachel K.
Margaret B.
Lana B.
Jennifer B.
Abigail V.
Rocco L.
Jane R.
Evelyn W.
Morgan L.
Layann B.
Jessica F.
Rhianna S.
Khushboo P.
Jinx H.
Amanda M.
Arlene S.
Wayne T.
Maria K.
Devon V.
Tammie C.
Shannon M.
Brea A.
Salima S.
Arlene K.
Kate A.
Angelina G.
Mary P.
Melissa M.
Stela B.
Annette H.
Jennifer M.
Melodie M.
Michele L.
Melissa D.

Colleen S.
Pamela G.
Jean W.
Bryan S.
Bonnie W.
Virginia A.
Dawnette B.
Barbara S.
Art S.
LaTasha M.
Tierney F.
Nikki H.
Amanda J.
Marian S.
Helene B.
Donna G.
Nyree Z.
Luisa B.
Thomas R.
Katt L.
Kaela B.
Sophia G.
Vivien B.
Jenny C.
Anne L.
Lorrie S.
Melissa D.
Keitha J.
Kristen Y.
Connie K.
Amanda G.
Carol F.
Claudia R.
Sarah L.
Kyle H.
Ronak M.
Mark N.
Sheila M.
Paulette A.

Megann L.
Darron D.
Vivian M.
Esmeralda R.
Amanda C.
Erica S.
Edward S.
Tracey B.
Mariah P.
Lauri L.
Gaylynn A.
Ann L.
Jeffrey S.
Sharon M.
Amber S.
Paul C.
Jen B.
Baylee M.
Daniel S.
Kerry B.
Lisa R.
Jenny P.
Jeannie B.
Alexandra C.
Susannah H.
Linda R.
Tamia M.
Walter S.
Linda U.
Taylor C.
Catherine B.
Patricia K.
Leslie H.
Michael L.
William H.
Kathryn C.
Huyen L.
Codie M.
Stacey Z.

Signatures

From a friend to the FSGS community, an advocate, or a volunteer

Fran D.
Vickey C.
Meredith G.
Shelia B.
Aaron S.
Christina N.
Judith E.
Donna W.
Lisa V.
Diane S.
Joanne C.
Johnmichael R.
Michelle G.
Joyce W.
Elayne S.
Kristen W.
Kelly M.
Samantha C.
Karen B.
Ethan N.
Mario B.
David C.
Star S.
Cassie C.
Bryan T.
Jim A.
Henry K.
Leslie M.
Julie P.
Rebecca D.
Steve W.
Eileen L.

Vida D.
Heather W.
Mark T.
Karen M.
Mateo K.
Karishma K.
Susan B.
Lisa J.
Pam S.
Anna S.
Janet S.
Colleen K.
James P.
Priscilla N.
Lynn K.
Kathy T.
Amaya C.
Mary G.
Rafaela P.
Luela S.
Ashlyn A.
Heather M.
Gwendolyn S.
Lori C.
Kaylyn A.
Terry Q.
Virginia C.
Amy B.
Kelly P.
Doris M.
Karen G.
Regina D.

Peggy L.
Gina G.
Michelle L.
Christine M.
Jenifer O.
Amy A.
Teresa H.
Jim V.
Jennifer S.
Carrie n.
Kari A.
Amanda W.
Miriam M.
Penny C.
Marlene W.
Nancy W.
Quirine T.
Carol T.
Patricia Bryn F.
Carla A.
Hannah G.
Melanie G.
Jessica B.
Mckenzie A.
Jordyn B.
Rhonda B.
Kimberly K.
Brittany C.
Kelly I.
Jennifer J.
Emily M.
Andrew G.

Angela M.
Shawn M.
Judy W.
Vicki D.
Amber B.
Rob L.
Samantha S.
Tina F.
Megan H.
Lindsey S.
Jessica J.
Jennifer W.
Colleen A.
Olivia D.
Andy R.
Peter R.
Kelsey B.
Caroline J.
Jen S.
Sean B.
Erin D.
Sheena C.
Kathleen J.
Kristin R.
J. S.
Nikki S.
Andrea D.
Cory D.
Ronda E.
JP M.
Becky G.
David F.

Jenelle F.
Shealagh C.
Emily N.
Carrie S.
Katrina O.
Liz K.
Angela M.
Rich M.
Michelle M.
Sharon W.
James C.
Tony W.
Angela J.
Heather H.
Kathy L.
Stephen P.
Bea P.
Allison C.
Alina B.
Jessica C.
Alexander F.
Colleen K.
Kristen K.
Jessica O.
Lisa H.
Marlene W.
Nicole C.
Tracey D.

Signatures

From a Patient, Parent or Family Member of Someone Who has Been Diagnosed with Another Rare Kidney Disease

Meladie J.
Nora R.
Chanin C.
Jennifer R.
Rita L.
Beth Ann F.
Ann V.
Oliver B.
Sarah Jean G.
Mary M.
Balraj G.
Yolanda M.
Matt W.
Anita M.
Brenda P.
Lucille C.
Alessio B.
Signe R.
Emilia F.
Claudia A.
Rusty Romero R.
Frederick L.
Judy B.
Jessica B.
Maureen R.
Johnny W.
Ryan H.

Elizabeth M.
Brenda W.
Freda S.
Nakesha T.
Melissa L.
Donna S.
Maureen C.
Vida D.
Tony W.
Karen B.
Leti L.
Jennifer T.
Ashtyn P.
Buffy J.
Thaddeus M.
Rosalie D.
Pamela Y.
Damaris N.
Maranda V.
William S.
Andrew W.
Eleanor B.
Georgann Smith S.
Laura M.
Clarisa P.
Allison M.
Kristen H.

Audrina T.
Christine C.
Alexander G.
Tina B.
Kortlynn A.
Christina C.
Sally R.
Malkia W.
Haley W.
Amjer R.
Beth Ann F.
Dana L.
Lisa P.
Raquel P.
Karen C.
Anthony P.
Kerry M.
Lorraine W.
Sheila D.
Courtney G.
Wanning W.
Johnny W.
Thomas P.
Anne Marie P.
Mallory H.
Michelle M.
Cristen S.
Andrew C.
Jacob J.
Jared H.
Brianna H.
TerriAnn T.
Livino R.
Michie Z.
Carson l.
Nora M.
John Paul P.
Aissa N.
Brandon O.

Sukhreet B.
Amrita B.
Donna B.
Ana P.
Lucky J.
Puneet B.
Kiyana C.
Simran B.
Keerat D.
Yasmin R.
Jessica G.
Madhu J.
Meena S.
Jaideep L.
Sonia F.
Cassandra P.
Kylee B.
Linda R.
Carolina L.
Shannon C.
Mitzi V.
Christopher G.
Kimberly B.
Wanda B.
Debbie H.
Devan B.
Angela C.
Elvira W.
Maria Nieves G.
Beatriz M.
Michael L.
Amy B.
Angelica S.
Michael W.
Maureen K.
Penelope C.
Brian M.
Jennifer K.
Suzanne M.

Hailey S.
Suzanne M.
Dawnette B.
Sandra S.
Elizabeth A. G.
Montse G.
Byron W.
Sarah M.
Danielle B.
Sara C.
Maureen R.
Jason B.
Nissa Z.
David Y.
Raymond B.
Kyla H.
Gary H.
Betty L.
Susan C.
Baleigh M.
Becky G.
Gina B.
Teresa M.
Lindsay P.
Erma R.
Maria S.
rachel e.
Megan N.
Sandra H.
Nancy S.
Katie M.
Julia M.
Jessica O.
Christina W.
Tom B.
John W.
Amanda H.
María Eugenia M.
Izaskun M.

Signatures

From a Patient, Parent or Family Member of Someone Who has Been Diagnosed with Another Rare Kidney Disease

Gloria B.
Robin P.
Jennifer s.
Jessica C.
Steve M.
Jamie A.
James J.
Katherine L K.
Diane M.
Maria S.
Matthew S.
Donna D.
Lauren K.
Leland B.
Kelly M.
Barbara O.
Deborah Z.
Karen B.
Kathy A.
Anthony D.
Ashley S.
Mike F.
Deborah W.
Mary McLaughlin R.
Eva Maria S.
Kristin H.
Kiani S.
Kate K.
Regina M.
Veleda O.
Angela M.
Jennifer P.
Tamara A.
Porfirio A.
Esperanza D.
Ashley D.
Adoración C.
Oscar B.
Sílvia L.

Marta P.
Jordan B.
Julia R.
Intza Z.
Machuca Gonzalez J.
Yolanda A.
Shannon Y.
Amy S.
Lisa R.
Patricia W.
Lizette G.
Amanda R.
Rebecca S.
Vir D.
Vicki F.
Carolina U.
Kim D.
Roxanna A.
Maria O.
Lauren P.
Carlos L.
Rebeca P.
Melanie B.
Janis C.
Ana G.
Laura S.
Brenda W.
Brenda W.
Silvia P.
Juan M.
Marta E.
Luis L.
Carme S.
Frida S.
Tina K.
Tom L.
Annmarie K.
Sanchez-Moreno P.
Verónica P.

Felipe Rodríguez S.
Brenda W.
Lauren H.
Melissa L.
Danielle O.
Vivian G.
Nicole E.
Jenn B.
Kristi R.
Averil C.
Carla C.
Amanda M.
Kathy T.
Andrew K.
Brenda S.
Marvin J.
Katie G.
Denise H.
Kristin B.
Sabrina M.
Carolyn Y.
Alicia G.
Chad M.
Tricia H.
Daryl M.
Cassie M.
Donny C.
Julie C.
Chelsea O.
Fawn A.
Suzette V.
Sanya J.
Shannon B.
Adelina P.
Sharon P.
Rickie B.
Deborah B.
Michelle Z.
Holly V.

Jacqueline S.
Heather M.
Angelica B.
Kimberly H.
Julie B.
Sam S.
Patricia R.
CaryAnn T.
John W.
Xiaofei D.
Jessie H.
Cara M.
Brenda C.
Yatu S.
Viral D.
Grissell L.
Diane M.
Jessie D.
Ashley W.
Jeanne F.
Patti C.
Kirsten M.
Christopher K.
Abigail K.
Linda I.
Rebecca M.
Emily B.
Ramona I.
Brittany M.
Patricia A.
Liz S.
Valerie M.
Jamacian C.
Patty F.
Howard E.
Stacy D.
Danielle R.
Shelli D.
Gisela F.

Pat G.
Victor E.
Anais H.
Susan L.
Brittany T.
Alexander S.
Julisha U.
Lorraine M.
Hannah W.
Miranda L.
Sharon B.
Shanita L.
Lauren B.
Laszlo T.
Judith S.
Celine A.
Angela M.
Thomas K.
Megan S.
Amber S.
Jessica C.
Joann D.
Kristen H.
Andrea S.
Althea A. B.
Karen T.
Nancy M.
Megan H.
David M.
Larry M.
Johnny W.
Barbara L.
Crystal M.
Dixon S.
Meladie J.
Dawn D.

Letter of Support from National Kidney Foundation

NATIONAL KIDNEY FOUNDATION®

30 E. 33rd Street
New York, NY 10016
212.889.2210

February 18, 2026

The Honorable Dr. Martin A. Makary
Commissioner of Food and Drugs
U.S. Food and Drug Administration
10903 New Hampshire Avenue
Silver Spring, MD 20993

cc: Dr. Tracy Beth Høeg, *Acting Director, Center for Drug Evaluation and Research (CDER), U.S. Food and Drug Administration*
Dr. Aliza Thompson, *Director of the Division of Cardiology and Nephrology, Center for Drug Evaluation and Research (CDER), U.S. Food and Drug Administration*

Re: Ensuring patient access to sparsentan for focal segmental glomerulosclerosis (FSGS)

Dear Commissioner Makary,

On behalf of the National Kidney Foundation (NKF) and the thousands of Americans living with FSGS, we write to express our support for FDA approval of sparsentan for the treatment of FSGS and urge the FDA to consider the patient voice in the approval decision.

FSGS is a devastating form of kidney disease that affects both children and adults and frequently progresses to kidney failure (ESRD). Importantly, there are currently no FDA-approved drugs specifically for the treatment of idiopathic/primary FSGS or APOL1-mediated FSGS. Presently, patients often rely on off-label immunosuppressive regimens with significant toxicity and inconsistent efficacy. Many patients ultimately progress to ESRD requiring either dialysis or transplant to survive. Even if transplant is achieved, people living with FSGS face disease recurrence.

Sparsentan is already FDA-approved for the treatment of IgA nephropathy (IgAN), reflecting prior agency determination of its safety and efficacy profile within a glomerular disease population. In FSGS, the benefit–risk calculus must appropriately account for the severity of disease, limited alternatives, and the patient community's willingness to accept uncertainty in exchange for the possibility of delaying kidney failure.

NKF and our clinical membership have reviewed the sparsentan data for FSGS in detail. At NKF's 2025 Spring Clinical Meeting, findings from the DUPLEX trial on sparsentan were presented.[1] The DUPLEX data demonstrated that patients achieved partial or complete remission of proteinuria earlier and more frequently with

[1] Tumlin, J. (2025). Patients in DUPLEX Achieved Partial or Complete Remission of Proteinuria Earlier and More Often With Sparsentan vs Irbesartan: Implications for Slowing Progression to Kidney Failure in Focal Segmental Glomerulosclerosis. 2025 Spring Clinical Meetings, National Kidney Foundation. https://cme.kidney.org/spa/app/resource/r649-2025-spring-clinical-meetings/event/home/posters/abstracts?abstractId=7678

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sparsentan compared to irbesartan.[2] In a disease characterized by persistent proteinuria and progressive loss of kidney function, reduction and remission of proteinuria are clinically meaningful outcomes that patients and clinicians prioritize. The demonstrated proteinuria effects are important in the context of a rare, heterogeneous disease with high unmet need. The DUPLEX trial showed no significant difference in eGFR slope between sparsentan and irbesartan at 108 weeks in FSGS patients, despite sparsentan's superior proteinuria reduction. However, several nuanced findings suggest kidney protective effects that warrant consideration. In a prespecified sensitivity analysis excluding measurements after initiation or intensification of immunosuppressive treatments, the chronic eGFR slope (week 6-108) favored sparsentan with a difference of 2.[1]

ml/min/1.73 m²/year (95% CI 0.1 to 4.1), suggesting that differential use of immunosuppression in the irbesartan group may have diluted between-group differences. While not statistically significant, exploratory analyses showed consistent trends favoring sparsentan. The composite endpoint of ≥50% eGFR reduction, kidney failure, or renal death occurred in 11.4% of sparsentan patients vs. 16.6% of irbesartan patients.[3]

We also emphasize the importance of incorporating patient experience data into regulatory decision-making. The FSGS community has articulated the daily burden of uncontrolled proteinuria, relapse cycles, hospitalizations, dialysis, and transplant uncertainty.[4] In rare diseases such as FSGS, where large trials are challenging and timelines are long, FDA's Patient-Focused Drug Development framework plays a critical role in ensuring that regulatory decisions reflect what matters most to patients.

The kidney community has few therapeutic advances in FSGS despite decades of need. Timely regulatory action would represent meaningful progress for patients and families facing a lifelong, progressive disease without approved treatment options.

We appreciate FDA's commitment to rigorous, science-based, and patient-centered review and would welcome the opportunity to further discuss the FSGS unmet need landscape and the clinical implications of the DUPLEX findings.

Sincerely,

Joseph A Vassalotti, MD
Chief Medical Officer, National Kidney Foundation

[2] Rheault MN, Alpers CE, Barratt J, et al. Sparsentan versus irbesartan in focal segmental glomerulosclerosis. N Engl J Med 2023;389:2436-2445.

[3] Ibid.

[4] National Kidney Foundation & NephCure Kidney International. (2021). The Voice of the Patient: Externally Led Patient-Focused Drug Development meeting on primary focal segmental glomerulosclerosis (FSGS) (Report date: September 10, 2021). https://www.kidney.org/sites/default/files/elpfdd_fsgs_vop_20210910.pdf

What is focal segmental glomerulosclerosis (FSGS)?

Overview

FSGS is a chronic, serious kidney condition and a common cause of end stage kidney disease in both children and adults, accounting for approximately 10% of kidney failure in children.[1,2]

The term FSGS describes a pattern of scarring that is seen on a kidney biopsy, rather than one uniform disease. It can result from a number of underlying causes that damage the kidney's filtration barrier.

FSGS is categorized into four subtypes:[3]

- Primary
- Genetic
- Secondary
- Undetermined Cause

While these subtypes appear similar on a biopsy slide, each has a distinct pathogenesis. This heterogeneity complicates diagnosis, clinical management, and research design.

PRESENTATION AND PROGNOSIS

More than 70% of patients present with nephrotic syndrome, which includes proteinuria as well as edema, fatigue, and loss of appetite. Hypertension is also common and can be severe.[4]

FSGS generally results in progressive loss of kidney function. Outcomes vary, but patients who do not respond to therapy often progress to end-stage kidney disease within 6–8 years, or sooner in severe cases. Treatment success is largely defined by the degree and duration of proteinuria reduction, outcomes which are associated with improved kidney survival.[4,5]

After receiving a kidney transplant, FSGS reoccurs in about one-third of patients.[6] Genetic forms of FSGS tend to progress more aggressively and are typically resistant to immunosuppressive therapy, though recurrence risk after transplant is lower.[7,8]

Patient Story

Davis S.

Diagnosed at age 12 after sudden, extreme swelling, Davis was quickly identified as steroid-resistant, a transition that led to a more specific and daunting diagnosis of FSGS. Despite a complex, two-year regimen of immunosuppressants and blood pressure medications, he remains in only a "partial remission," continuously spilling significant amounts of protein that threaten his long-term kidney viability. His journey has been marked by secondary complications like anemia and a decline to Stage 2 renal failure, highlighting the urgent need for more effective therapies that can achieve full remission and protect the native kidneys of pediatric patients.

EPIDEMIOLOGY

FSGS is most frequently diagnosed between the ages of 18-45, though it can impact individuals of any age. In the United States, there are approximately 40,000-70,000 cases of FSGS, with an increasing incidence of between 6,000-9,000 new cases reported each year.[9.10.11.12.13]

Males are 1.5-2 times more likely to be affected than females,[4],[14] and incidence is 3-7 times higher in Black than white individuals, due in part to genetic variants that increase susceptibility to kidney injury.

BURDEN OF DISEASE

There are currently no FDA-approved treatments for FSGS. Most patients are treated with immunosuppressive therapy,which has a variable response rate among primary FSGS patients and poor/no response among patients with genetic forms.

A recent study of primary FSGS patients found that only 55% achieved complete or partial remission with immunosuppressive therapy.[15] Over an average follow-up of 4 years, 39% of all patients progressed to kidney failure, and 27% of patients died.

Due in part to the life stages that are impacted by FSGS, its high comorbidity burden, and the high likelihood of kidney failure and subsequent need for dialysis and transplantation, FSGS is associated with a high clinical and economic burden. Studies have estimated that FSGS patients have an average total medical cost of between 7-14 times the cost of non-FSGS patients.[16] In addition, those with nephrotic range proteinuria had nearly twice the cost of non-nephrotic FSGS patients.[17]

These data underscore the inadequacy of current treatments to prevent disease progression and the profound unmet need in FSGS. More effective therapies that can alter the course of disease and reduce its significant clinical and economic impact are urgently needed.

Endnotes

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