The cost of not treating rare kidney disease is leaving families like mine in an impossible chronic state of constant medical interventions, consuming upwards of 20 medications, a plethora of co-morbidities, and severely decreased quality of life, both physically and economically. **We deserve better**.

Kelly Helm mother of 11-year old Macy, an FSGS patient since 2009

We Deserve Better.

Revolutionizing Rare Kidney Disease

A community call to action











Introduction

The rare kidney disease community finds itself at an inflection point.

Until very recently, clinical trials in kidney disease were virtually nonexistent. While other chronic and acute diseases saw significant leaps in innovation, kidney disease treatment innovation was stagnant. Among medical specialties, nephrology ranks last in clinical trial participation and trial completion.¹ While the advent of dialysis in the 1940s was a milestone achievement, there was little to no innovation for kidney disease treatments in the following 80 years. Rare progressive kidney diseases like focal segmental glomerulosclerosis (FSGS), Berger's disease (IgA Nephropathy or IgAN), and Alport Syndrome continue to lack Food and Drug Administration (FDA) approved treatments. As a result, these chronic kidney diseases (CKD) have been overlooked and underdiagnosed, despite being causes of declining kidney function that can quickly progress to end-stage renal disease (ESRD), also known as endstage kidney disease (ESKD).

Families impacted by rare kidney diseases live in uncertainty and fear. These diseases

are largely "invisible," meaning patients suffer in isolation and face criticism from others who minimize their illness with comments like, "Can't you just get a transplant?" or "You don't look sick." On top of being rare, many of these kidney diseases are chronic, complex conditions plagued by rollercoaster cycles of

Can't you just get a transplant? You don't look sick...

remission and relapse. As with many rare diseases, the timeline from first symptoms to diagnosis can be protracted, with many patients taking years to receive a formal diagnosis and medical care. Patients and families experience difficulty finding a nephrology expert well-versed in their conditions, causing a delay that can initiate a rapid progression to kidney failure. Once seemingly healthy individuals guickly find themselves preparing for dialysis and must put their futures on hold due to their illness. As many patients will attest, the physical complications are often rivaled by the overwhelming psychosocial challenges brought on by rare and chronic kidney disease.

The toll of rare kidney disease to the healthcare system is dramatic. In particular:



The rare kidney disease community finds itself at an inflection point. The flexibility of regulatory bodies has started a wave of clinical work as companies invest in the development of treatment options. Motivated patient communities are active and engaged in multi-stakeholder initiatives to connect patients to clinical research opportunities and address the day-to-day challenges that prevent families from getting the quality care they need. For example, the Kidney Health Initiative, a partnership of the FDA and the American Society of Nephrology, has been a strong champion for including kidney patients, especially those with rare diseases, in both clinical trials and medical innovation. The momentum is palpable, but key changes are necessary in U.S. healthcare policy to save more lives and drive down costs.

Executive Summary

Rare Kidney Disease on the National Agenda

In the summer of 2019, the White House announced "Advancing American Kidney Health," an executive order (EO) that called for revolutionizing how people with chronic kidney disease and kidney failure are diagnosed and treated.⁷ The EO directed the U.S. Department of Health and Human Services (HHS) to take immediate action and recognized the overdue need for innovation and novel therapies in nephrology. Novel therapies in rare kidney disease will help HHS meet two of its important goals: reducing the risk of kidney failure and improving access to person-centered treatment options. Moreover, the advancement of science in rare kidney disease will have inevitable ripple effects that will help improve the care and treatment for the 37 million Americans with chronic kidney disease.⁸

In the months following the release of the Advancing American Kidney Health initiative, leaders in the rare kidney disease community met with policymakers in Congress and HHS to discuss the advances in clinical work in rare nephrology and its potential to revolutionize kidney care. Based on feedback received, NephCure Kidney International and Retrophin, in partnership with the American Association of Kidney Patients, agreed to host a groundbreaking policy roundtable on rare kidney disease in September 2020 titled, "Revolutionizing Kidney Care Through Novel Therapies in Rare Nephrology: Dawn of a New Era in Rare Kidney Disease Treatment."

Policy Roundtable with HHS and Congress

Capitalizing on the traction from the executive order, 40 people convened in August and September 2020 to begin a dialogue on key issues impacting the rare kidney disease community. Joining these workgroup discussions were patients, healthcare providers, diversity health organizations, diagnostic companies, biotechnology manufacturers, payers, and rare disease organizations, among others. The diverse participants exchanged ideas and contributed their unique perspectives in this first-ever forum to bring together both the nephrology and rare disease communities. The workgroups considered three topics:

- Costs of Not Treating Rare Kidney Disease
- Promises and Challenges of Innovation in Rare Kidney Disease Treatments
- Addressing Diversity in Rare Kidney Disease

Each workgroup explored policy issues and potential solutions under each topic. On September 23, 2020, select workgroup leaders reported their findings before an online, nationwide audience, including leaders from HHS and five members of Congress. The event was also livestreamed to the public.

Overall, five summary recommendations were made:

Increased rare kidney disease awareness is essential and should be part of our national strategy to reduce kidney failure. Rare kidney disease awareness and education need to be dramatically increased to ensure the value of innovation is understood and prioritized. Future kidney health education efforts by the federal and state governments and partners should include information on rare kidney diseases.

Significant reductions in the time to diagnosis for rare kidney patients would yield dramatic improvements in health outcomes. Diagnosis of rare kidney disease needs significant improvement through enhanced tools and protocols, potentially incorporating genetic testing.

Identifying and meeting the needs of communities of color living with rare kidney disease is a necessity. Diverse patients need access to community-level information and platforms to connect with healthcare providers and build trust, to communicate with each other for peer support, and to elevate their voices with policymakers and regulators.

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Healthcare providers, including nephrologists, need more education on treating and serving patients with rare kidney disease. Nephrologists and other providersincluding those in the primary care setting and those serving communities of color-need more education on rare kidney diseases to create a standard of care and reduce variable outcomes.

Access to specialists and patient advocates will help preserve kidney function. Patients need earlier access to specialists and designated patient advocates, and providers must be comfortable having hard conversations about disease progression and steroids.

Call to Action

These five recommendations are a call to action, taking the first step toward advocating for public and private policy changes that will impact and improve the lives of everyone living with rare kidney disease.

"We deserve better." A Better Future for Rare Kidney Disease Families

CURRENT REALITY

Negligible

results in

awareness of

rare kidney diseases

preventable, poor

health outcomes

RECOMMENDATION & ACTION STEPS

Increase rare kidney disease awareness as part of our national strategy to reduce kidney failure

- Designate regional centers of excellence for rare
- kidney disease Prioritize public awareness of the challenges of living with rare kidney disease • Boost research of rare kidney diseases, including quality
- of life
- Early and ongoing patient education with mental health emphasis

THE BETTER FUTURE

Widespread awareness, compassion, and appreciation for the burden of rare kidney diseases on patients and society, translating into action and positive health outcomes. Innovation sparks systematic change throughout all chronic kidney disease.

Diagnostic delays result in exasperating patient odysseys with negative physical and emotional health outcomes

Significantly reduce time to diagnosis for rare kidney patients

- Incorporate new diagnostic technologies and enhanced approaches with existing
- technologies-particularly genetic testing Improve and develop new diagnostic clinical protocols
- Boost research of genotype-phenotype and disease progression

New diagnostic protocols and technologies are implemented that detect rare kidney disease much earlier. A standard of care is common practice, saving money and improving quality of life.



Communities of color with rare kidney disease disproportionately suffer due to greater prevalence amplified by health disparities

Identify and meet the needs of communities of color Build trust through long-term commitment at the community level

- Elevate in federal health equity initiatives Incent nephrologists to serve communities of color
- Build targeted early detection and referral programs Empower rare kidney families to voice perspectives
- Conduct research on efficacy of care plans in communities of color
- · Boost medical education resources specifically for families of color
- Funders should direct public and private rare kidney researchers to include diverse populations in genomic studies • Expand access and coverage of public and private insurance
- Price novel therapies reasonably, including out-of-pocket costs
- Maintain access to telehealth services and out-of-state providers

Patients in communities of color are receiving culturally competent care so that no disparity exists within the rare kidney disease patient population.



Diagnosis and treatment of rare kidney disease is haphazard, with few protocols and no standard of care

Develop protocols and educate providers on treating patients with rare kidney disease

- Accelerate rare kidney disease education of primary care clinicians and continuing education for nephrologists, particularly for those serving communities of color
- Develop clinical protocols and guidelines for rare kidney diseases

Patient quality of life and overall health outcomes are significantly improved because treatment pathways and protocols have been developed, standardized, and are being taught to and utilized by healthcare providers.



Rare kidney disease patients suffer unnecessarily without access to specialists and advocates

Improve access to specialists and patient advocates

- Incent faster access to nephrologists and rare kidney disease experts, including out-of-state specialists
- Provide reimbursement for preserving kidney function • Enhance patient and provider communication tools for
- use in disease progression discussions with families and caregivers
- Ensure early access to professional rare kidney patient advocates

The "rare kidney function cliff" crumbles because patients and their families have better outcomes, achieved through access to knowledgeable specialists and patient advocates to help them personally navigate their rare kidney journey.

1.

Increased rare kidney disease awareness is essential and should be part of our national strategy to reduce kidney failure.



Rare kidney disease awareness and education need to be dramatically increased to ensure the value of innovation is understood and prioritized. Future kidney health education efforts by the federal and state governments and partners should include information on rare kidney diseases.

Summary

All workgroups identified the urgent need for greater awareness of rare kidney diseases and related health education initiatives. The urgency was fueled by the negative outcomes associated with a lack of understanding: diagnostic challenges, barriers to quality care, and public misperception of disease risks. The lack of awareness led to personal anxiety and mental health issues for patients, which had a concurrent effect on physical health and well-being. Patients and providers, including diversity health representatives, also felt strongly that the government could take a leading role and fill critical gaps in research, both into general rare kidney disease and quality of life issues that are not captured in traditional clinical work. Participants also noted that without proper awareness, the importance of treatments would not be adequately understood and prioritized.





Federal government, patients, providers, and payers should unite in designating regional centers of excellence for rare kidney diseases in treatment, regulatory decision making, and research.

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The federal and state governments should partner with the rare disease and nephrology communities to increase public awareness of the challenges of living with rare kidney disease.

• At a minimum, future kidney health education efforts by the federal and state governments and partners should include information on rare kidney diseases.

Research on all rare kidney diseases, including glomerular diseases, should be considerably increased at the National Institutes of Health (NIH) and other federal agencies. In addition, research should be conducted on improvements in quality of life that are not incorporated into most clinical trials.

- Policymakers and regulators should never use Quality Adjusted Life Years (QALYs) to make decisions regarding the patient experience of people living with rare kidney disease.
- **4.** Gaps in mental and emotional health for rare kidney disease families must be filled with peer support, patient education, and medical information through public and private collaborative efforts at the federal, state, and local levels where feasible.
- **5.** Public-private partnerships should boost early and ongoing patient education, including critical renal diet and lifestyle choices which promote kidney health.

2.

Significant reductions in the time to diagnosis for rare kidney patients would yield dramatic improvements in health outcomes.



Diagnosis of rare kidney disease needs significant improvement through enhanced tools and protocols, including genetic testing when clinically appropriate.

Summary

Patients and providers communicated loud and clear that diagnostic challenges were a ubiquitous barrier that impacted all aspects of rare kidney disease. Frustration with delayed and variable diagnosis was noted on both sides of the patient-provider relationship, and all noted the negative impacts on treatment, care, and quality of life. Some proposed ideas focused on remediating existing gaps, specifically that routine and inexpensive testing such as urinalysis could help identify people with rare kidney disease much earlier; in this case, protocols are lacking. Moreover, patients and providers regularly mentioned that newer technologies such as genetic testing could help dramatically reduce the rare kidney disease diagnostic odyssey, but face acceptance issues and coverage challenges.



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Federal agencies should partner with the nephrology, life sciences, rare disease, and diagnostics communities to ensure earlier diagnosis of rare kidney diseases through new technologies or enhanced approaches with existing technologies. Mechanistic, non-invasive diagnostic testing should be the goal.

 As feasible and when clinically appropriate, genetic testing and counseling should become a diagnostic standard for rare kidney diseases. In particular, integrating identification of the APOL1 gene into a diagnostic protocol could have significant impacts for Black Americans.

The federal government, medical societies, and patient advocates should partner to improve diagnosis through new protocols.

 Urinalysis should become routine again in certain situations, followed by a 24-hour urine test, followed by genetic testing as feasible and clinically appropriate.

Further research by the NIH should be conducted and disseminated regarding the correlation between genotype-phenotype and disease progression, as it is critical to determining the right path of treatment. From my perspective as a patient and caregiver, genetic testing is an important opportunity in these ways: it's less invasive than biopsy; gives an accurate diagnosis that also provides mutation type; avoids potential of being treated improperly with counter-beneficial treatments such as steroids, which may help with some CKD patients but be detrimental to Alport patients; and it also supports important research.

Lisa Bonebrake

Executive Director, Alport Syndrome Foundation | Alport Syndrome patient, mother of an Alport Syndrome patient The nephrology community must identify and meet the needs of communities of color.



Diverse patients need access to community-level information and platforms to connect with healthcare providers and build trust, to communicate with each other for peer support, and to elevate their voices with policymakers and regulators.

Summary

Black Americans and other Americans of color have a higher prevalence of rare kidney disease than white Americans.

- Black Americans comprise 13.2% of the United States population but represent more than 35% of all patients in the U.S. receiving dialysis for kidney failure.⁹
- Chronic kidney disease and FSGS disproportionally affect Black Americans at rates at least 4x and 5x greater than white Americans.¹⁰
- In particular, a variation on the apolipoprotein L1 gene (APOL1) often found in people of African descent is thought to be associated with one of the most severe forms of kidney disease, and its presence significantly reduces the efficacy of already limited treatment options. Approximately onethird of FSGS cases in the United States in Black Americans are thought to be associated with APOL1 variants.¹¹

Because of the genetic predisposition and barriers to quality care experienced by people of color, thousands of people are at risk of being excluded from any innovations in treatments unless meaningful action is taken to address their unique needs. Workgroup members identified that timely identification and accessibility to expert care is generally limited in the best of scenarios, often resulting in painful and debilitating journeys to dialysis and transplantation. Reversing this accepted paradigm will require addressing challenges communities of color face finding trusted specialists with sufficient expertise to develop a treatment path. Patients indicated that clinical markers were often overlooked or dismissed as related to other issues. Peer support and community-level resources are necessary for education and support, with the goals of earlier detection and referral to a qualified provider.



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Action Steps

To build trust, government and industry must make long-term, community-level commitments to people of color living with rare kidney diseases through a series of urgent initiatives.

- Ongoing federal health equity initiatives should include people living with rare kidney disease.
- Congress should enact incentives for nephrologists who specialize in cultural competency and serve communities of color.
- The Centers for Medicare and Medicaid Services (CMS), the Health Resources and Services Administration (HRSA), and/or other federal and state agencies should partner with medical

societies and industry to build programs to help improve earlier detection and referral to trusted specialists specifically for community of color living with rare kidney disease.

- HHS, including CMS and the FDA, and the NIH should partner with community-level advocates and industry to empower rare families living with rare kidney disease with platforms to voice their perspectives directly with policymakers and regulators.
 - Regulatory pathways should include data for outcomes measures that show a significant positive impact on

Genetic link to rare kidney disease and people of African decent

Abnormalities with a person's APOL1 gene put the person at increased risk for rare kidney disease and historically results in a quicker progression to total loss of kidney function. Individuals with two abnormalities will lose kidney function nearly twice as fast, within 16.5 years versus 30 years. These individuals are more likely to be African Americans because one of the gene variants for APOL1 is often found in Americans of West African or Caribbean descent.¹²

health outcomes in communities of color.

- NIH, CMS, HRSA, and the Centers for Medicare and Medicaid Innovation (CMMI) should conduct research on the efficacy of rare kidney disease care plans in communities of color which include social determinants of health, such as transportation, employment, childcare, food, etc.
- 2. The federal and state governments, in partnership with industry and community health organizations, should boost medical education resources specifically for families of color living with rare kidney disease. The goal of this information should be to help communities of color advocate for themselves, their family members, and their communities. Kidney disease and rare kidney disease should be demystified, and communications should emphasize "life, not death."
- **3.** Funders should direct public and private researchers to include diverse populations in rare kidney disease genomic research studies.
- 4. Access and health insurance coverage, both public and private, must be maintained and expanded, and pricing and out-of-pocket costs for novel therapies must be reasonable.
- 5. Access to telehealth and out-of-state providers must be maintained.

Rare disease patients will always have the greatest power in moving the needle on public policy as it pertains to them. By providing spaces for rare patients to voice their stories and perspectives, we can see the needle moved for policymakers and regulators. Institutionally, working with healthcare providers and government health agencies to connect with diverse patient populations is a great way of ensuring that patient voices can affect change.

Adrian Palau-Tejeda

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Diversity and Inclusion Fellow, EveryLife Foundation for Rare Diseases

4.

Healthcare providers, including nephrologists, need more education and protocols on treating and serving patients with rare kidney disease.



Nephrologists and other providers need more education on rare kidney diseases, particularly those serving communities of color, to create a standard of care and reduce variable outcomes.

Summary

The diagnostic and treatment odyssey of people living with rare kidney disease is varied but uniformly troubling. Workgroup members identified the lack of provider education on rare nephrology as a major driver of diagnostic and treatment odysseys for both patients and providers. Providers also cited the challenges in diagnosing and knowing how to treat these diseases. Furthermore, medical training specifically for providers serving communities of color was identified as a critical need. Across the board, the need for rare kidney disease education was cited at both the primary care and specialist levels. Nephrologists need a standard of care to reduce variable outcomes.

I knew my selection of my [nephrologist] was going to be a life or death decision.

Daniel Keaveney FSGS patient

Understanding the process and that there is no standard guideline for care is hard. Each center from state to state varies, so if you have one that is not well educated or involved in the battle, you are fighting on your own against doctors' egos to just have some guality of standard of care.

Christine Floto Mother of an FSGS patient

Government, medical societies, and industry should partner to accelerate training of nephrologists, including those serving communities of color.

- Focusing on the next generation of providers will help build trust and ensure that innovation reaches all patients.
- Providers must not separate the science of medicine from the reality of care delivery, instead taking a more holistic view of opportunities and challenges of optimizing care with novel therapies.
- Patient organizations should work with nephrology medical societies to develop protocols and clear guidelines to develop a standard of care and reduce variable quality.
 - Government, medical societies, and industry should partner to accelerate primary care clinicians' (MDs, PAs, NPs) rare kidney disease education with a focus on early diagnosis, referral, and treatment. Continuing education in nephrology, including rare nephrology, should be initiated.
 - Too many adults are diagnosed by a garden
 - variety nephrologist and if they don't respond
 - to steroids they are merely monitored once or
 - twice a year until their kidneys begin to fail, at
 - which time the nephrologist treats with dialysis.
 - They are never educated on second-line medications
 - that could stop or slow the progress of their disease. [Additionally,]
 - different doctors tend to use different approaches.

Kelly Helm

Assistant Director, Patient Advocacy, NephCure Kidney International | mother of an FSGS patient



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Access to specialists and patient advocates will help preserve kidney function.



Patients need earlier access to specialists and designated patient advocates, and providers need to be comfortable having hard conversations about disease progression and steroids.

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Summary

Beyond diagnostic tools and provider education, the workgroups identified payer barriers to specialists as a key issue. Access to specialists was particularly important because focusing on early diagnosis and referrals could help avoid the "kidney function cliff," where rare kidney disease patients rapidly progress from a functioning organ to ESKD in a matter of months. Frustration was noted by patients and providers alike at the unwillingness of some providers to engage in frank discussions about both disease progression and the disadvantages of steroid use. Finally, patients also cited the challenges of living with rare kidney disease and the need for a designated patient advocate. Clinicians echoed the value of a patient advocate in achieving quality care.

As a physician, I take care of many children and adolescents with rare kidney diseases. Often, pediatric nephrologists need to become the primary care physician for these patients. Primary pediatricians are often unable to manage the complexities of some kidney diseases, and nephrologists often coordinate care among other specialists. If a child with rare kidney disease is fortunate enough to gain access to a "complex care clinic" or a "patient advocate," they tend to have better outcomes. But these resources are scarce.

Scott E. Wenderfer, MD, PhD

Professor, Pediatrics, Renal Section, Baylor College of Medicine

Congress should enact incentives to ensure that rare kidney disease patients receive faster access to nephrology experts, including out-ofstate specialists.

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Congress and payers should implement alternative reimbursement models which support preserving kidney function, including:

- Changing payment structures for dialysis or opportunities for valuebased payment that emphasize preserving kidney function
- Ensuring reimbursement and additional time for patient discussions on rare kidney disease
- 3. The federal government, payers, industry, and patient groups should collaborate to ensure that rare kidney disease patients have a professional advocate to help them manage the complexity of their lives (i.e., designated patient advocates, social workers, care coordinators, case managers, etc.).
 - Providers agreed that, from a clinical perspective, patient advocates improve care by helping navigate the multitude of medical interventions, insurance and medication hassles, and obtaining proper services including emotional and mental well-being supports
 - Manufacturer pricing of novel therapies must not create real formulary issues that inhibit access, nor should formulary decisions be based solely on Quality Adjusted Life Years (QALYs) data and absent patient quality of life concerns and data including Patient Preference Insights (PPI) and Patient Reported Outcomes (PRO)
- 4. Providers should sensitively engage in difficult disease progression discussions with patients, including:
 - Unpleasant, often devastating side effects of steroids and other treatments
 - Impact on quality of life when assessing effectiveness of treatments
 - Patient and caregivers' emotional needs and access to mental health services

Workgroup Participants

Thanks to the workgroup members who gave so much of their personal time in August and September 2020. Your valuable contributions significantly shaped the recommendations in this report.

Costs of Not Treating Rare Kidney Disease

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- Kelly Helm

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- Lauren Lee
- Chris Porter

- **Moderators**
- Chris Porter
- Josh Tarnoff

Moderators

Richard Knight

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Opinions of workgroup members are personal and do not represent the views of their employer. Workgroups were not asked to endorse these recommendations.

Endnotes

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Resource List

Community Resources

- Alport Syndrome FoundationAmerican Association of Kidney PatientsAmerican Society of NephrologyAmerican Society of Transplant SurgeonsAmerican Society of TransplantationBlack Health MattersEveryLife Foundation for Rare DiseasesHarmony 4 Hope
- IGA Nephropathy Foundation Kidney Health Gateway Kidney Health Initiative National Organization for Rare Diseases NephCure Kidney International Renal Pathology Society Retrophin

Government

Administration

Advancing Americans Kidney Health Vision Document

Executive Order on Advancing American Kidney Health

HHS Office of Assistant Secretary for Planning and Evaluation: Advancing American Kidney Health: 2020 Progress Report

Kidney Precision Medicine Project

National Institute of Diabetes and Digestive and Kidney Diseases

Congress

Congressional Black Caucus

Rare Disease Congressional Caucus