

Protein in your urine?

What you need to know about rare kidney diseases (RKD).



You're not alone in the fight against rare kidney disease.

What is NephCure?

A patient advocacy organization for those impacted by rare, protein-spilling kidney disease (RKD). We push RKD research and care forward while connecting patients, families, and caregivers to the resources and support they need.

Who does NephCure serve?

Those affected by:

- Nephrotic syndrome
- Focal segmental glomerulosclerosis (FSGS)
- IgA nephropathy (IgAN)
- Membranous nephropathy (MN)
- Minimal change disease (MCD)
- C3 glomerulopathy (C3G)
- Immune complex membranoproliferative glomerulonephritis (IC-MPGN)
- APOL1 kidney disease
- Other rare, protein-spilling kidney diseases

Questions You May Have

What are rare, protein-spilling kidney diseases?

Protein-spilling kidney diseases injure the filtering units in the kidney (called glomeruli) which allows protein, and sometimes blood, to “leak” out of the bloodstream and into the urine.

These rare kidney diseases (RKD) can happen without cause, be genetic, or have environmental causes.

Symptoms can include:



Swelling of the eyes, hands, feet, and abdomen (edema)



Low levels of albumin (protein) in the blood



High blood pressure (hypertension)



High levels of protein in the urine or foamy urine (proteinuria)



High cholesterol



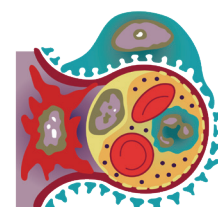
Blood in the urine (hematuria)



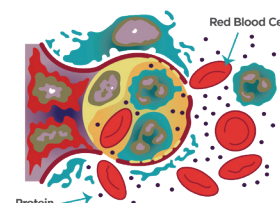
Fatigue

Proteinuria & Hematuria:

Normal kidney filters keep protein and red blood cells in the blood and eliminate waste into the urine.



When the kidney filters are not working, protein and sometimes blood leak into the urine.



■ How is RKD diagnosed?



Urinalysis

Most patients are initially diagnosed through a urinalysis which finds high levels of protein in their urine. Sometimes a kidney biopsy is required to understand the specific type of RKD you may have.



Kidney Biopsy

Levels of **protein spilling** can predict the likelihood of kidney disease getting worse.

**Less than
1 gram of
protein
per day**



Lower risk
of kidney
damage

**More than
1 gram of
protein
per day**

Higher risk
of kidney
damage

Goal: Stop or lower protein spillage in your urine, in order to prevent damage to your kidneys.

Genetic testing
plays an important role
in understanding your
disease and potential
treatment options.

■ Who is impacted by RKD?

RKD represents a broad umbrella of diseases that can impact individuals of any age, racial/ethnic background, and sex. Each individual, no matter the exact diagnosis, is often impacted differently. RKD disproportionately affects specific populations.

■ How do you treat RKD?

These diseases impact each patient differently and everyone has a unique journey. Some patients are treated with **prednisone (steroids)** first. Others try **blood pressure medication** to lower the protein spilling. If that fails to improve your symptoms, doctors may prescribe additional medications called **immunosuppressants or newly-approved medications** to help reduce or stop protein spilling.

Clinical trials are potential treatment options, too. Clinical trials are the key to better treatments. Your participation is needed to provide new, approved treatment for your rare kidney disease.

Ask your doctor about the best treatment options to stop or lower the protein in your urine.

■ Hope is on the horizon

Today, after more than two decades of groundbreaking research and the commitment of doctors, scientists, and patients like you, there are finally several FDA-approved therapies and medications, and more than 25 drugs to treat RKD being studied in clinical trials. Over the next few years, we are excited to see even more drugs approved to treat RKD!



**Hope is here—
new treatments for
your disease, beyond
steroids, are coming!**

NephCure offers patient navigation services that help patients and their families with healthcare access, insurance headaches, seeking a second opinion, access to medications, school support services, and more.



Scan the QR code or contact
info@nephcure.org to connect with help.

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