
FSGS is the second leading cause of kidney failure in children...

1-866-NephCure
www.NephCure.org

NephCure

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GLOBAL INITIATIVE

NephCure has joined a global consortium dedicated to sharing ideas, combining strengths and supporting one another as we strive to find a cure.

More information is available at: www.NephCureInternational.org

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www.nephcure.org

MISSION POSSIBLE

T.H.E
NEPHCURE
FOUNDATION


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Our Stories

LINDSEY
We first noticed that something was wrong in August 2005 during a Mets game. Lindsey's face, arms and legs appeared swollen and she seemed to have difficulty walking. After calling her pediatrician, we took her to an emergency room where she was diagnosed with Nephrotic Syndrome. At the time of her diagnosis, her protein levels were critically low and she was at risk of a seizure. Several weeks later Lindsey was diagnosed with peritonitis, a potentially fatal bacterial condition. Lindsey was diagnosed with FSGS. Jim and Pam, Lindsey's parents

KIM
At the age of 35, I charged through each day like the Energizer® Bunny. In 1998, I had trouble keeping food down, significant weight loss, and sheer exhaustion. The diagnosis from my doctor was unexpected. My FSGS had almost progressed to End Stage Renal Disease. I recently received my second kidney transplant after my first one had failed. I am not depressed; I figure these are just challenges in my life, but this kidney disease does not define my life, it is not who I am. I am more than that.

SAGE
After spending three days at Children's Hospital, Sage was diagnosed with Minimal Change Nephrotic Syndrome. Sage has been dependent on steroids that have long-term effects and also weaken her immune system. Seeing those kids on the Nephrology floor has left a lasting impression. We see life differently. Life is too short and this journey has opened our eyes. The Nephcure Foundation is our support and reminds us we are not alone.

Nephrotic Syndrome & FSGS

Nephrotic Syndrome (NS) occurs when there is a malfunction in the kidney’s tiny filtering vessels (glomeruli) causing valuable protein in the blood to leak into the urine (proteinuria). This leakage causes fluid to accumulate in the body and prolonged leakage has been shown to cause kidney failure.

Focal Segmental Glomerulosclerosis (FSGS) is a disease that attacks the kidney’s filtering vessels (glomeruli) causing serious scarring. FSGS is one of the many causes of Nephrotic Syndrome.

Our Mission

The NephCure Foundation is the only organization committed exclusively to support research seeking the cause of two potentially devastating kidney diseases, Nephrotic Syndrome and FSGS, improve treatment and find a cure.

Our Commitment

• Fund research around the globe that will continue to move us closer to improved treatment and a cure.
• Be the primary source of information on Nephrotic Syndrome and FSGS.
• Lead the charge for legislative action to provide more federal funding for research.
• Work to attract researchers to this field.
• Educate the public and raise awareness about Nephrotic Syndrome & FSGS.

What We Support

Research into Nephrotic Syndrome and FSGS. As in solving a 1000-piece jigsaw puzzle, scientific research involves trial and error until the right pieces fit together and the final image emerges. NephCure’s research philosophy: The more scientists working on the NS/FSGS puzzle, the sooner we will see our final image—a cure.

Education about Nephrotic Syndrome & FSGS. We raise awareness of NS/FSGS among the general public and educate patient families, empowering all to join in our quest for more research, more funding and more progress against these devastating conditions.

Research & Advances

A collaborative scientific infrastructure without expensive bricks and mortar, NephCure’s Virtual Research Center is a global network of researchers and medical professionals who use different 21st century communication channels to share their efforts to identify a cause of NS and FSGS, establish effective treatment and find a cure.

The Research Center’s primary goals are to
• Advance research.
• Attract young researchers to the field of glomerular disease.
• Complement the efforts of the National Institutes of Health.
• Attract young researchers to the field of glomerular disease.

NephCure Funding serves as a priming pump to get young kidney researchers started in the field.

Visit the center at www.vrc-ncf.org

Quick Facts

• An estimated 6,000 people are diagnosed with FSGS every year. (defined as a diagnosis of FSGS or Minimal Change Disease).
• The Nephrotic Syndrome disease group, at end stage renal disease, has an annual cost to Americans of more than $3 billion.
• Currently there are more people nationwide suffering from FSGS than Cystic Fibrosis.
• An estimated 75% of Nephrotic Syndrome patients will relapse following treatment.
• There are currently no FDA approved drugs to treat FSGS.

Our Stories

LINDSEY
Kim, diagnosed with FSGS define my life, it is not who I am. I am more than that.

MATTHEW
For a period of time, three-year-old Matthew woke up in the mornings with swollen eyes. A urine analysis showed a high level of protein in the urine. We were told that Matthew may have kidney failure and to pull him out of school immediately. A kidney biopsy revealed that Matthew had the “worst kind of kidney disease, FSGS.” Matthew is now five years old. He has tried many drugs, however, he has never been in remission. We continue to pray everyday that a cure will be discovered and our little boy will be cured. We have teamed up with The NephCure Foundation to help provide hope for the other “Matthews” out there.

- Dana and Michael, Matthew’s parents

Our Stories

SAGE
Sage has been dependent on steroids that have long-term effects and also weaken her immune system. Seeing those kids on the Nephrology floor has left a lasting impression. We see life differently. Life is too short and this journey has opened our eyes. The Nephcure Foundation is our support and reminds us we are not alone.

- Josh and Cori, Sage’s parents

Be An Advocate

You are the voice of all patients and families faced with the challenges of Nephrotic Syndrome & FSGS. When you speak up for vital research funding or advocate for public policies that bolster the fight against these devastating diseases—people will listen. Together, we form a nationwide network of people dedicated to finding the cause and cure for Nephrotic Syndrome and FSGS.

To become an advocate please contact: info@nephcure.org or call 866.NEPHCURE.