



**NEPHCURE**  
Kidney International

Saving Kidneys • Saving Lives

# *Nephrotic Syndrome and Children*





**Abigail, Age 7**  
Nephrotic Syndrome  
Boca Raton, FL

Abigail has been diagnosed with Nephrotic Syndrome for just over a year. In that time, she's relapsed once and spent 16 weeks on steroids—a harsh immunosuppressant used to “reset” the body's immune system. Due to the severe side effects of taking this kind of drug, Abigail has suffered intense mood swings and weight gain and is at an increased risk for infections.

*NKI donor funds are invested in research to understand why some patients, like Abigail, relapse when taken off from steroids.*

**Aaron, Age 16 (pictured with Abigail)**  
Nephrotic Syndrome  
Miami, FL

Aaron was diagnosed when he was 2 years old. He's had numerous relapses and biopsies. When he was 9, his medication stopped draining the excess fluid from his body, and his blood pressure was irregular. He was rushed to the ER. After 5 days in the hospital, they fixed the dosage, and Aaron was able to come home.

*NKI donor funds support the largest long-term study ever undertaken to understand early childhood onset in patients like Aaron.*



**Landon, Age 3**  
Nephrotic Syndrome  
Orlando, FL

Landon had just celebrated his 2nd birthday when he became swollen. Within 24 hours he was diagnosed with Nephrotic Syndrome. He went through 5 relapses in a year and is considered steroid dependent. Symptoms of long term steroid use include stunted growth, brittle bones and fractures, cataracts, high blood pressure, and thin skin, bruising and slower wound healing.

*NKI donor funds work to increase the number of drugs in the FDA pipeline so kids like Landon have access to the newest, most effective treatments.*

## NEPHROTIC SYNDROME OVERVIEW

Nephrotic Syndrome is not a disease itself, but a collection of signs and symptoms. It occurs when glomeruli of the kidney are damaged, and protein normally kept in plasma begins leaking into urine in large amounts (proteinuria). This leads to edema, or swelling, typically around the eyes, feet, and hands.

Other symptoms include weight gain from excess water, high blood pressure and cholesterol, and an increased risk for thrombotic events and infections. These often end in renal failure, leaving patients on dialysis and in need of a kidney transplant.

Nephrotic Syndrome is a rare disease syndrome, with prevalence in the United States of around 2.7 cases per 100,000 children. Yet, according to the United States Renal Data System, **it is the second leading cause of pediatric End Stage Renal Disease, responsible for up to 20% of kidney failure in children.**

## FOCAL SEGMENTAL GLOMERULOSCLEROSIS (FSGS)

One of the most common causes of Nephrotic Syndrome is FSGS, a disease which causes serious scarring in the kidney. The damaged kidney filters allow protein to leak into the urine, and prolonged leakage can lead to kidney damage and failure.

**FSGS is the leading single-disease cause of kidney failure in children.** In addition, African Americans are 5 times more likely to have FSGS in comparison with the general population, meaning about 1 in 12 African Americans will get FSGS in their lifetime. The causes of FSGS are unknown and there is currently no cure.

## DIALYSIS, MORTALITY, AND HOSPITALIZATION RATES

Almost 35 percent of children with ESRD are re-hospitalized within 30 days of their first discharge. This rate has not changed in a decade.

Children at ESRD must undergo dialysis or receive a kidney transplant. Tragically, despite improvements in survival on dialysis over the years, children on dialysis have mortality rates 30 times higher than their peers without ESRD.

And unfortunately, transplants are not always a solution for this population, as **FSGS returns in 30-50% of patients who receive a transplanted kidney.**

## OUR MISSION

NephCure Kidney International is the only organization committed exclusively to support research seeking the cause of the potentially debilitating kidney disease Focal Segmental Glomerulosclerosis (FSGS) and the diseases that cause Nephrotic Syndrome, improve treatment, and find a cure.

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