

News from CureGN

June 2016

Sponsored by the National Institutes of Health (NIH)
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

Thank you for your time and contributions to CureGN. As you may be already aware, the CureGN study is a huge effort aimed to further the understanding of rare forms of kidney diseases, including minimal change disease (MCD), focal segmental glomerulosclerosis (FSGS), membranous nephropathy (MN) and IgA Nephropathy. Please find below some updates about this important, one-of-a-kind study.

The CureGN study is being performed jointly by 4 participating clinical centers (PCCs): The Midwest Pediatric Nephrology Consortium (MWPNC), Columbia University, University of North Carolina, and the University of Pennsylvania. Each center may have several enrolling sites. We would like to introduce you to each of our centers over the next several newsletters.

Columbia University Profile

In this newsletter we will introduce you to the Columbia University PCC.

The Columbia University PCC includes the Center for Glomerular Diseases at Columbia University Medical Center, as well as a pediatric subsite at the Gaslini Institute in Genoa, Italy. The Center for Glomerular Diseases was established to foster improved understanding, care, and outcomes for patients with glomerular diseases. The Center represents a collaborative effort of members of the Divisions of Nephrology and Renal Pathology at Columbia University. The clinical arm of the center includes 6 nephrologists whose practice is dedicated to patients with various types of glomerular disease, and who participate actively in local,

Enrollment

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Clinical research studies like CureGN depend on you!

As of 6/7/2016:

Total Enrolled: 1270

Totals by disease:

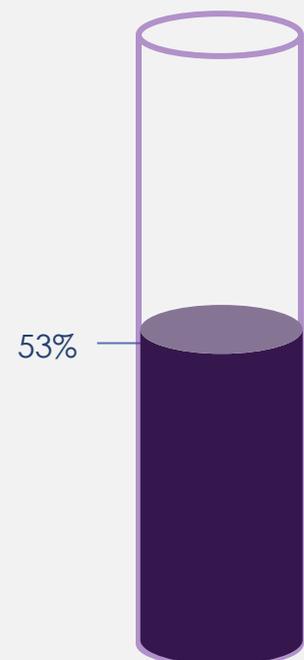
MCD: 265

FSGS: 318

MN: 229

IgA: 458

Goal: 2400





national and international research in these diseases, assisted by a team of 6 research coordinators. The Renal Pathology Division includes 6 full-time pathologists who process around 4000 renal biopsies yearly.

The Gaslini Institute is one of the 10 largest pediatric hospitals in Europe, with over 2,000 employees, and serves as a national and international referral center. It is the top-ranked Italian pediatric hospital for scientific productivity and international excellence. The pediatric nephrology division has 10 full time pediatric nephrologists and has made major contributions to the understanding of the genetics, biology and therapy of pediatric glomerular diseases.

To date, the Columbia PCC has successfully recruited over 300 patients to CureGN, with around 40 from Gaslini, making Columbia University by far the single site with the largest number of recruited patients and Gaslini near the top of the subsites.

Patient Profile - Columbia



Hello, my name is Julian Gomez. After high school, I experienced a big change in my weight, which caused me to feel very uncomfortable with myself. In the summer of 2013, I developed several blood clots throughout my body, and protein was found in my urine. I was then hospitalized several times during the year, and this caused me to miss several classes during my first and second years of college.

By the end of 2013, I was diagnosed with minimal change kidney disease; although I had a diagnosis, my condition was still unclear to the first team of doctors I was working with. I've had several procedures done since I've been diagnosed, and so far I've been doing well thanks to my second team of doctors at Columbia. They encourage me to eat healthier, stick to my medication regimen, and be a better person.

This experience has really changed my life. I have my ups and my downs just like anyone else living with a chronic condition, but if I focus on my health and listen to my doctor, I know I can overcome this disease that tried to take over my life. I know we can overcome this just like anything in life.



CureGN Disease Spotlight:

Minimal Change Disease (MCD)

Minimal change disease is the most common cause of nephrotic syndrome in young children and the third most common cause in adults. The disease is referred to as “minimal change” because the kidney looks normal under a regular microscope. The disease is only detected after a special electron microscope is used to look at the kidney biopsy to magnify it to detect subtle changes. While there are a variety of potential causes of minimal change disease, in most cases, the cause is unknown.

The symptoms of minimal change disease are non-specific and are the same in all forms of nephrotic syndrome. Symptoms include swelling (particularly around the eyelids in the morning, and feet and ankles later in the day), weight gain from holding on to fluid, decreased appetite, and a foamy appearance to the urine. In contrast to other forms of nephrotic syndrome, the symptoms of minimal change usually happen all of a sudden. Blood and urine tests provide the initial clues that the nephrotic syndrome has developed, but a diagnosis of minimal change disease can only be made after a kidney biopsy is performed. In young children, kidney biopsies may not be needed right away if minimal change disease is suspected.

Minimal change disease has the best outcomes of all the known conditions that lead to the nephrotic syndrome. Minimal change disease only very rarely progresses to kidney failure requiring dialysis or kidney transplantation. Most patients develop a complete remission of the disease after treatment with steroids. However, some patients relapse when steroids are stopped. Treatment options for patients whose disease frequently relapses or who become dependent on steroid therapy include rituximab, cyclophosphamide, cyclosporine, tacrolimus, and mycophenolate mofetil. Each of these therapies has different side effects, and all can increase the risk for infection. Treatments must be tailored to the individual patient and close consultation with a kidney doctor is needed to properly weigh the risks and benefits of each therapy.

NKN Contact Information

Have you received a call or e-mail from the NephCure Kidney Network patient registry? Participating in the NephCure Kidney Network patient registry is an active way to help fight Nephrotic Syndrome and provide researchers with the data they need to make new discoveries. You can learn more at www.nephcurekidneynetwork.org

Additional content can be found on our website CureGN.org or at Nephcure.org.