

# News from CureGN

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

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## Transfer Success Story

Hello, my name is Jackie. I'm a first year medical student at Rutgers, Robert Wood Johnson Medical School. I was diagnosed with IgA Nephropathy when I was 17 years old, just before starting college. This was a little scary for me, as I was going to attend the University of Michigan and didn't know how I would be able to handle the disease being so far away from my parents, who were in New Jersey.



Luckily, I was able to find amazing nephrologists, who helped me along my journey. While there, they introduced me to the CureGN study, aimed at helping rare forms of kidney disease, such as the one I have. I was very happy to be able to participate in such a promising project. When college was over however, I had to figure out how I was going to transfer

from this CureGN site to another one. Luckily, the research coordinator at Michigan helped connect me to those at Columbia University, which is where I was going to be throughout my gap year before medical school. I found this transition very easy, as I was assured that I would still be able to get the proper care needed for my disease, while also still being able to participate in the study. Overall, I'm very grateful to be involved in the CureGN project and urge those that are moving/relocating to ask their coordinators information about CureGN sites near them".

Moving? You can continue to participate in **CureGN!**



Ask your study coordinator about the options available to you. With **70 CureGN study sites**, there may be one in your new backyard.

To view a map of all CureGN study sites, visit [CureGN.org](http://CureGN.org) and click on the **FOR PATIENTS** page

## Enrollment

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**Clinical research studies like CureGN depend on you!**

**As of 12/3/2018:**

**Total Enrolled: 2284**

Goal: 2400

95%

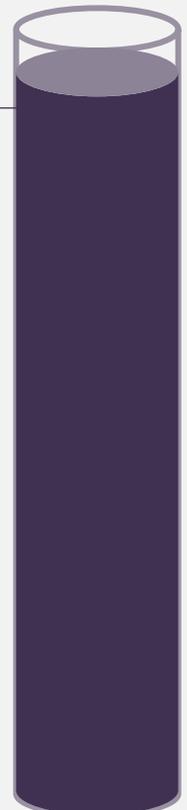
**Totals by disease:**

MCD: 547

FSGS: 590

MN: 475

IgA: 672



## What is the PRO and why we ask you to fill it out at each visit?

As a participant in CureGN, you by now have become familiar with the questionnaires about your quality of life: your mood, sleep quality, fatigue levels, general impressions of your physical and mental health, and the types of activities that you're enjoying. You are also probably familiar with the little figurine on



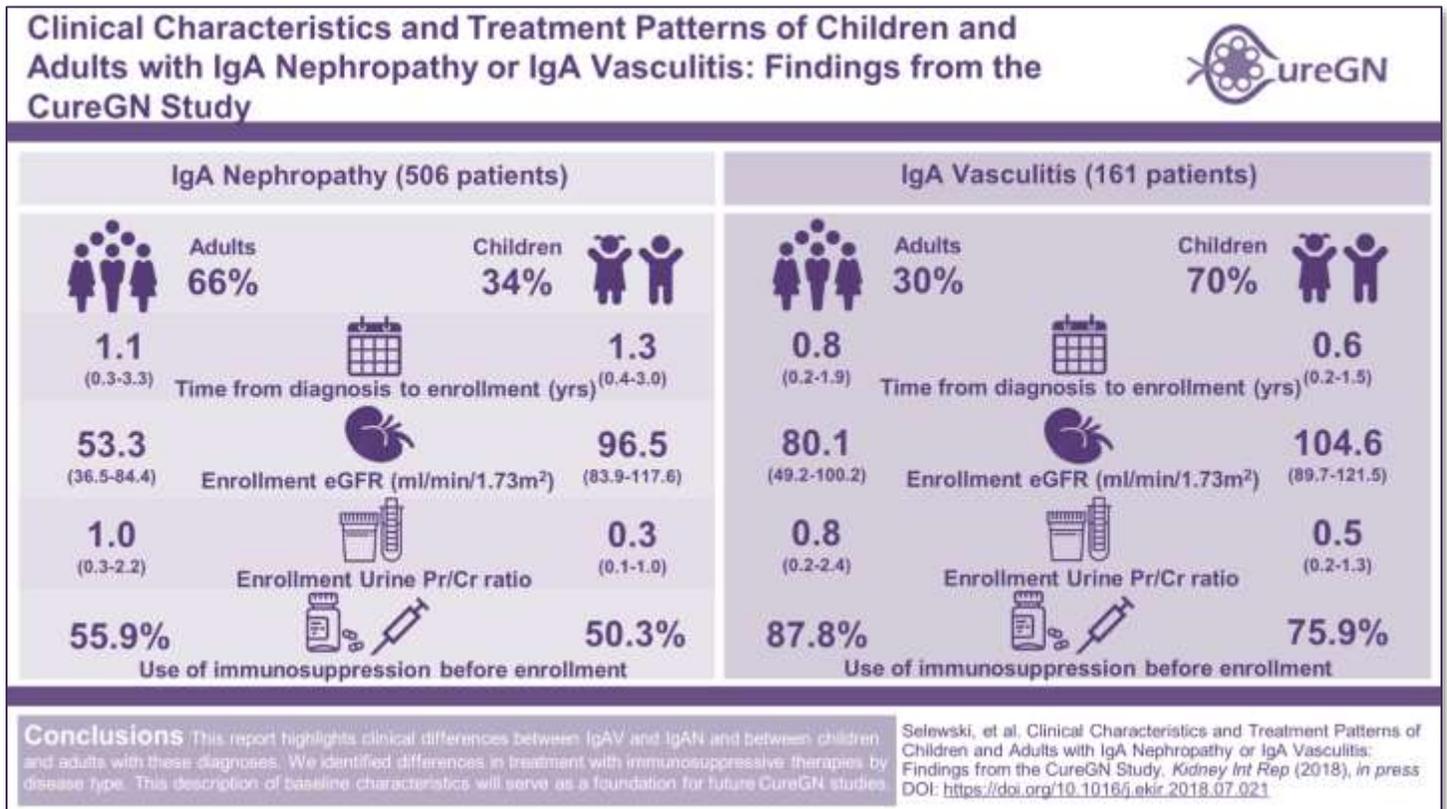
which we ask you to rate any location and amount of edema, or swelling, that you may be experiencing. These types of questions are known as “patient reported outcomes,” (PRO) and they are an important part of modern research studies because they try to capture, in a measurable and quantifiable way, the experience of disease and what aspects of a patient’s life is most affected by the disease (or its treatments). CureGN was expressly designed to capture these outcomes, in part because in the past there has been very little research into what aspects of the glomerular disease experience are most meaningful to patients. A large group of CureGN investigators is studying this data, and we have just had our first paper accepted into a prestigious journal, *Kidney International*, addressing this topic. The paper is entitled, “Health-related quality of life in glomerular disease: a report from the CureGN study,” and examines the quality-of-life outcomes measured among all CureGN participants (both adults and children) at their entry into the study. We tried to understand what were the major factors related to poor reported quality of life, among the various measured domains (e.g. fatigue, anxiety, mobility, sleep, etc.).

## What has CureGN discovered thanks to your responses/How has CureGN used your responses to improve knowledge in glomerular diseases?

We discovered that self-reported edema (the amount of edema marked off on the figurine) had the strongest and most reliable correlation with quality of life among all the factors measured. Sex, weight, and GFR had some associations with quality-of-life as well, but they were not as strong. Edema seemed to be more important than urine protein levels, immunosuppressive medications, age, race and a host of other variables. The findings are intriguing, and we think this will be a landmark study for researchers who want to find ways to help people tolerate the symptoms and effects of glomerular disease in their daily life. Within CureGN, we will be continuing to study quality-of-life measures as they change over time, during disease flares or quiet periods, and in relation to different medications. We are thrilled that this research has been recognized to be important by the larger nephrology community. Most importantly, studies like this cannot be done without the cooperation and involvement of our patients, so thanks to all our participants and keep up the responses!

## First research paper about the CureGN IgA nephropathy/IgA vasculitis cohort published:

Dr. David Selewski and a number of other CureGN investigators recently published a research paper describing all of the patients in CureGN with IgA nephropathy and IgA Vasculitis (previously known as Henoch Schonlein purpura nephritis). They compared the differences between children and adults with each of these diagnoses. The researchers found that children with IgA nephropathy had better kidney function (higher eGFR) and lower urine protein to creatinine ratio at enrollment in the study compared to adults. They found that about half of both children and adults with IgA nephropathy had been treated with immune suppressing medications before enrollment in CureGN. Both adults and children with IgA vasculitis were more likely to be treated with immune suppressing medications compared to those with IgA nephropathy. The information in this research paper will lay the groundwork for future studies of patients with IgA nephropathy and IgA vasculitis in CureGN.



**Thank you for your time and contributions to  
CureGN.**