News from CureGN

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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.

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

Newly Funded Study Allows CureGN Investigators to Look for Unknown Genetic Causes of Glomerular Diseases

By Dr. Krzysztof Kiryluk, MD

Recent genetic studies have identified several important factors in the onset of glomerular diseases. However, genetic studies with sufficient number of participants are still missing for most glomerular disease types. In addition, the existing genetic findings from prior studies require further study, including validating these findings in diverse populations and discovering the consequences of genetic variants on clinical outcomes. The newly funded genetic study based on the CureGN cohort will address the above challenges by aiming to discover, validate, and more precisely define known and new genetic susceptibility factors. This study will include a pioneering partnership with AstraZeneca and Columbia's Institute for Genomic Medicine to perform extensive genetic testing on 4,000 cases of glomerular disease, including the entire CureGN study, the largest prospective cohort of patients with glomerular disorders. This will be followed by international collaborative validation studies in more than 25,000 patients with biopsy-confirmed primary glomerular disorders. The investigative team, led by Dr. Kiryluk (Columbia University) and Dr. Kretzler (University of Michigan), expects that their findings will be critical in defining targets for new therapeutic interventions.

Enrollment

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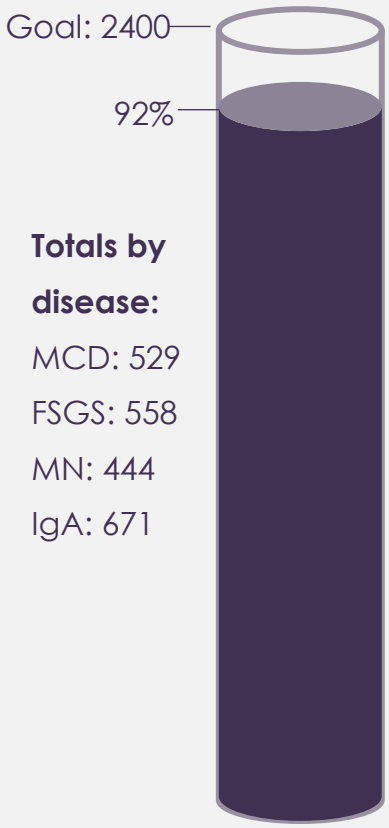
Clinical research studies like CureGN depend on you!

As of 07/23/2018:

Total Enrolled: 2202



Totals by disease:

MCD: 529

FSGS: 558

MN: 444

IgA: 671

The above study is an example of the value of DNA samples provided by CureGN patients. You can opt-in for DNA collection at any time during the study. Here are a few Q&A to help you make this decision.

Q. ***Why DNA is important for CureGN?***

A. DNA is important to understand the genes involved in any disease, including glomerular diseases. The genetic testing done in CureGN will help to determine whether there are certain genes that make some people more likely to develop kidney diseases, or whether there are genes that are expressed more in patients with or without specific symptoms or specific response to therapies. Ultimately, we hope to use this information to develop personalized treatments and new therapies.

Q. ***Will you hear back about your genetic results?***

A. If you decide to opt-in for DNA collection, you will also have the option to give us permission to contact you about the genetic results in case something that is relevant to your health is discovered. In this case, you will be informed by the CureGN team about the option of doing a confirmatory testing on a repeat blood sample in a clinically-certified laboratory.

Q. ***What is the limitation of a research-based genetic studies?***

A. CureGN is performing research-based genetic studies. Genetic research analyses take a long time and are performed across many years. The results may be meaningful to understanding a disease, even if they're not specifically meaningful to any one patient. If you are not informed about any genetic results, this does not necessarily mean that you don't have a genetic risk factor for a kidney or non-kidney-related condition. CureGN genetic studies do not substitute for commercial genetic testing your doctor may suggest to you or your family for any reasons.

Q. ***How will your privacy and genetic data be protected?***

A. Your samples are de-identified using a unique study code so that no personal identifier will be on the sample or any results generated by your DNA. Personal identifying information are only stored at your study site. If you want to have more details about our privacy protection policies, feel free to ask your site study team.

Q. ***Why I should opt-in for DNA collection?***

A. CureGN's final goal is to better understand the causes of your kidney disease, the response to therapy and the disease progression with the purpose of curing glomerular diseases. In order to achieve all of this, genetic analysis on your DNA is invaluable. Your choice matters!

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*** and click on the ***FOR PATIENTS*** page