

# News from CureGN

July 2020

## The Value of Community

In these trying times, all those working on the CureGN study remain committed to our goal of advancing the understanding of IgA nephropathy, FSGS, Membranous Nephropathy, and Minimal Change kidney diseases, while supporting scientific progress for our entire CureGN patient community. As always, your input is invaluable to us in the pursuit of these goals. Due to the pandemic, we are working to lessen any burden that this study may place on its participants. As a result, the study visit schedule will now be based on an every four-month system during years one through three. However, visits for those in their fourth year of participation and beyond will have study visits scheduled every six months, in this new five-year period. We hope that changing our visit scheduling system will lighten the load for some participants who may be feeling overwhelmed right now.

### What does CureGN look like today?

- Just over 2,400 patients have joined the CureGN study.
- 20 scientific papers and presentations have been generated
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- 26 Research Projects are underway that depend on the CureGN information and banked specimens.

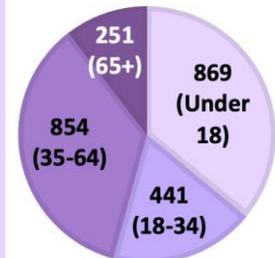
### We heard your feedback: What's new for CureGN starting summer 2020?

- The study is providing more opportunities for video calls and virtual visits in response to the COVID-19 pandemic
- Study blood draw volumes will be smaller
- Study patients will be invited to use a personalized web-based dashboard to see their own information and study updates

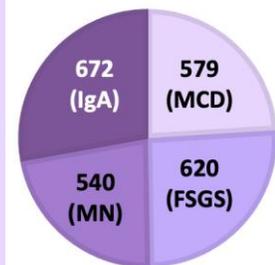


### Number of Participants in our CureGN Patient Community

BY AGE



BY DISEASE



### Spring CureGN Consortium Meeting

CureGN consortium patient representatives, study coordinators, and investigators met virtually in April 2020 to share the study's progress and to launch the next 5 years of the CureGN study.

Interested in more involvement?

If you would like to join the CureGN Patient Advisory Council, please contact your local study coordinator or email:

[CureGN-admin@arborresearch.org](mailto:CureGN-admin@arborresearch.org)

### Why is your continued participation so important?

CureGN is a cohort study. A cohort is a group of people who all share an identifier or an identifying factor. One way to think of a cohort is like a library full of books. Each book contains the story of one person's disease, and investigators are able to "check out" information from the library to do their research. The CureGN cohort was designed to help understand the causes of disease, the responses to therapy, the disease progression, and ultimately to help reach the goal of curing glomerulonephropathy.

This information collected from a cohort over time is important, as it can be used to answer many research questions, including those that were not thought of when the study first started. This means that information from your study visits (in person or by telephone), and measurements from the blood and urine samples you have provided, keep the door open for numerous research studies. Your ongoing contribution, for many years, is important, so that the research captures and represents what is happening to everyone in the study with as few "gaps" in the data as possible. Keeping everyone in the cohort also ensures that the research results are as meaningful as possible to others with the disease, including those not in the CureGN cohort.



Are you moving? Please make sure to contact your coordinator about transferring to another CureGN site.

### What can you do?... Stay Engaged!

- We will be getting in touch with you about your progress from your local treatment providers. Please stay tuned for a letter documenting how we will do that.
- Virtual CureGN study visits should be occurring every 4 to 6 months. If you haven't heard from your coordinator, then you are welcome to call them.
- You can always reach out to your Nephrologist or CureGN study coordinator if you have questions or something changes in your life like if you plan to move or have new contact information.
- When the time is right, a return to in-person annual visits will be very important.

### COVID-19 Information:

- You will be receiving calls, so we can learn how the current COVID-19 pandemic may be affecting you.
- Check out these great resources and feel free to share them with our CureGN patient community:
  - CDC website: [cdc.gov](https://www.cdc.gov)
  - NKF website: [kidney.org](https://www.kidney.org)
  - NephCure: [nephcure.org/recent-news](https://www.nephcure.org/recent-news)
- Please contact your CureGN study coordinator if you have questions or any updates such as new contact information
- When the time is right, a return to in-person annual visits will be very important.