

News from CureGN

January 2021

Patient Impact



Cure Glomerulonephropathy (CureGN) is a multi-center study designed to enroll 2400 adult and pediatric patients with four main glomerular diseases: IgA nephropathy (IgAN), Minimal Change Disease (MCD), Focal Segmental Glomerulosclerosis (FSGS), and Membranous Nephropathy (MN). The National Institutes of Health (NIH) funds this study, so 66 sites in the United States, Canada, Poland, and Italy can look for patients with these rare diseases. By the end of the first 5 years of funding, CureGN1 had been very successful in recruiting the target number of patients needed.

What is new in CureGN2?

As we launch CureGN2, the second funded phase of the study, our attention is going to shift to retention. This means we want all participants to continue participating in the study for at least the next 5 years. We listened to your feedback, comments, and suggestions and changed the study protocol for CureGN2. In CureGN2, the study schedule will be more flexible, so more study visits and clinic visits can happen together when possible. After enrollment, patients will have only one required in-person visit per year. All other visits can be done remotely through phone, email, or video conference depending on your clinical center. If you agree to participate in this study, you will receive text messages on a monthly basis to collect information about your symptoms, kidney medications, and major health related events. Also, pediatric patients will not have to get blood draws as often as in CureGN1. All these listed changes should reduce the burden of participating in the study.

We also want to increase your engagement in the study: We will give participants access to a personalized CureGN online account where you can see some of your clinical and lab data collected over time. We will be sending you newsletters with study updates more frequently. We also want to invite you to participate in the patient advisory council (PAC), so you can give feedback about the study.

Changes to CureGN 2 based on your feedback:

Visit schedule reduced to 1 required in-person visit/year



Remote visits via phone, email, or text message



Personalized dashboards to review your own data



Reduced blood volume for children



If you are interested in being a member of the PAC, please email CureGN-Admin@arborresearch.org or call 734-232-4830.

We want to better understand glomerular diseases to be able to treat them more effectively. Our success is your success. We need you to join us on this journey, and we look forward to another 5 years of working together!