

CureGN Patient and Family Fireside Chats

Patients and families involved in the CureGN study have been gathering. These online events were launched as a way for patients, families and CureGN researchers to meet up and discuss research findings from CureGN, educational topics related to kidney disease and health, and for patients to share their priorities for education and research related to kidney disease.



Highlights from the most recent fireside chats include:

- Research progress and publications focused on
 - Renal Complications in Pregnancy Preceding GN Diagnosis – Andrea Oliverio, MD
 - Infection-Related Acute Care Events among Patients with Glomerular Disease – Dorey Glenn, MD
 - Longitudinal Changes in health-related quality of life in primary glomerular disease – Shannon Murphy, MD
- Educational topic
 - Genetics in Glomerular Disease: What we know and what we are learning – Ali Gharavi, MD
- Suggestions from patients
 - Schedule more Fireside Chats!
 - Increase visibility of CureGN publications {these are on the CureGN website at [CureGN.org/publications](https://curegn.org/publications)}
 - Recommended future educational topics – healthy nutrition, long-term care of disease, weight management
 - Recommended future research emphasis – race differences, key findings from study, COVID and vaccines
 - Recommended communication and engagement approaches include allowing patient/family community members to sign up for direct communication about upcoming CureGN events, notifications, and links to new CureGN publications

Additional CureGN Resources and Information for Patients and Families



Accessing Publications: <https://curegn-org.webflow.io/publications>



CureGN Events: Upcoming Fireside Chats – November 18th and 20th; 6:00 – 7:30 PM ET
RSVP: <https://tinyurl.com/ChatRSVP>



CureGN Participant Dashboard: The CureGN dashboard can be accessed at curegndashboard.org. At the time of consent, the patient is notified that by providing their email address they will be sent a link to log in to the dashboard. On the dashboard they can view graphs of their Blood Pressure, Kidney Function (eGFR), Urine Protein (UPC), Urinalysis Protein (dipstick), and Patient Reported Quality of Life. Patients can view the study news feed that contains study information and updates. Lastly, patients can use the dashboard to contact the study team directly through the dashboard. [CureGNDashboard.org](https://curegndashboard.org)