University of Iowa C3 Glomerulopathy Natural History Study

The University of Iowa, Molecular Otolaryngology and Renal Research Laboratories (MORL) are one of the largest and most robust laboratories in the world. We are focused on the research of the ultra-rare complement- mediated kidney diseases, DDD and C3GN, known together as C3 Glomerulopathy, or C3G for short.

What is C3G?



- C3G is very rare.
- About 1 in 1,000,000 people have C3G.
- It may strike at any age.
- People with C3G are very likely to get permanent kidney failure.
- The disease may come back after a kidney transplant.

Unfortunately, when a person is diagnosed with C3G, there is no way to know who will do well and who will do poorly. This is due to a lack of knowledge of the natural history of the disease. There needs to be a better definition and understanding of what happens when a person gets C3G. This knowledge will help doctors decide who needs treatment. It will also help predict how effective different treatments are.

Our study aims to collect clinical data on 400 people. We will pair this data with:

- Biomarkers of disease (blood and urine samples)
- Genetic variations in specific genes
- Pathology (kidney biopsy slides)

This study will be the largest natural history study on C3G using the largest C3G database in the world.

Our study goals are to:

- Create a C3G database for patient-related information.
- Collect data on each person (such as medical history, family history, etc).
- Receive blood and urine samples from people with C3G for biomarker and genetic testing.
- Collect, interpret, and store kidney biopsy slides.
- Evaluate all complement pathway biomarkers and genetic data.
- Use the newest statistical methods and machine learning to compare patient clinical information with biomarker and genetic data and the kidney biopsy.
- Share discoveries with other doctors and scientists through:
    - Scientific journals
    - Seminar presentations
    - Conferences (local, national, international)
- Be available to treating doctors to assist in the care of their patients.
- Link people to clinical trials.
- Offer people access to new medicines and innovative treatments by acting as a hub site for complement drug trials.

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For our study, we will:

- Need you to sign and agree to be in the study.
- Ask for your biopsy slides/images to be mailed to us. This is to verify your C3G diagnosis.
- Ask that you have kidney biomarker labs (blood samples) drawn every 6 months and shipped to our lab. We will also review your medical records for routine kidney function labs and will enter results into our database.
- Ask that you get renal genetic testing. This is done only one time.
- Ask for medical updates. We will aim to update your kidney medications and medical history in our database every 6 months and when you are ill.

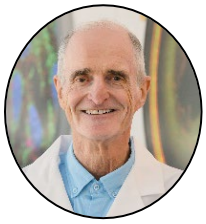
If you would like to join our C3G Natural History Study:

Please reach out to Rebecca Franklin, RN with questions by calling (319) 467-4824 or email: rebecca-a-franklin@uiowa.edu.



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