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.

CureGN Presentations at ASN 2017

We are starting to learn valuable information from the data collected in the CureGN study. The CureGN study had five associated presentations at this year's American Society of Nephrology (ASN) meeting in New Orleans. Each of the lead authors provided us with a summary of their work.

Investigator Profile – Andrea Oliverio, MD

Andrea Oliverio, MD is currently a Clinical Lecturer and Research Fellow in the Division of Nephrology at the University of Michigan. She completed a dual residency in Internal Medicine and Pediatrics in 2015. She is currently pursuing a Master's degree in Health and Health Care Research through the Institute of Healthcare Policy and Innovation at the University of Michigan. Her research focuses on the reproductive health of women with CKD.

Renal Complications During Pregnancy Before and After Glomerulonephropathy Diagnosis – Andrea Oliverio, MD

In this study, we examined the pregnancy histories of women enrolled in CureGN. Women who reported a complication in one of their prior pregnancies (elevated creatinine, worsening blood pressure, protein in the urine, preeclampsia) had a shorter time between that pregnancy and diagnosis of their kidney disease when compared to women who had prior uncomplicated pregnancies. While we do not know the reason for this finding, it is possible that some types of kidney diseases (such as glomerulonephropathies or "GN" in this study) may go undiagnosed or misdiagnosed in pregnancy, that there may be some shared genetic risk factors between these pregnancy

Enrollment

Clinical research studies like CureGN depend on you!

As of 12/4/2017:

Total Enrolled: 1941

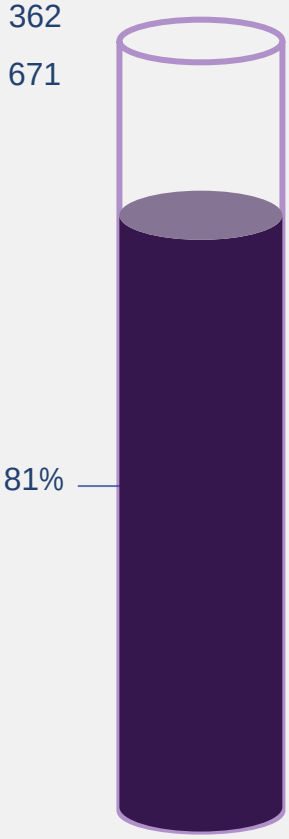
Totals by disease:

MCD: 441

FSGS: 487 Goal: 2400

MN: 362

IgA: 671



complications and GN, or that pregnancy complications may trigger GN in a woman predisposed to developing it. It also suggests that follow up after these pregnancy complications may be important for early identification and treatment of GN. In the future, the CureGN women's health working group hopes to study pregnancy outcomes after GN diagnosis in order to help women with these diagnoses make informed decisions about their reproductive health.

Cardiovascular Disease Risk Factors in Pediatric Glomerular Disease: An Early Analysis of the Cure Glomerulonephropathy (CureGN) Study – Isa Ashoor, MD

By studying the CureGN data, we found that children with nephrotic syndrome have a high burden of risk factors that may contribute to later onset of heart disease. For instance, about one fourth had high blood pressure, one third were obese, and more than a half of those tested had high cholesterol levels. These figures are a major call for action for us to do more to identify and treat those risk factors in children with nephrotic syndrome to reduce the risk of heart disease in the future.

Health Related Quality of Life (HRQOL) in Primary Glomerular Disease: The Initial CureGN Experience – Pietro Canetta, MD

We began to examine the quality of life measures reported by patients enrolled in the CureGN study. We have identified some of the factors most closely linked to quality of life. For example, the presence of edema (swelling of the legs or face) has major impact on many aspects of patients' quality of life, including anxiety, fatigue, sleep and mobility. Our findings are unique in that there has been very little work done in the past to examine quality of life in patients with glomerular diseases. We hope our results help guide clinicians and investigators to focus on the symptoms most important to patient well-being, and the factors that might influence these symptoms.

The Cure Glomerulonephropathy (CureGN) IgA Nephropathy and IgA Vasculitis Cohort – David Selewski, MD

By studying the CureGN data we found significant differences in the disease presentation and early disease course between children and adults with IgA Vasculitis (previously known as Henoch Schonlein Purpura, HSP) and IgA Nephropathy. For example, adults with both diagnoses had worse kidney function at the time of biopsy than children. Furthermore, there were significant differences in treatments between these two diseases with more IgAV patients receiving immunosuppression and corticosteroids than those with IgAN. Treatment of IgAV and IgAN has been difficult to guide due to a lack of clinical trials for HSP and IgAN and we hope that our research will change this.

The Cure Glomerulonephropathy (CureGN) IgA Nephropathy and IgA Vasculitis Pediatric Cohort - David Selewski, MD

This study looked at data for all pediatric patients with biopsy-confirmed IgA Nephropathy or IgA Vasculitis (previously known as Henoch Schonlein Purpura, HSP) enrolled in CureGN. There were differences between these two groups. For example, those with IgAV were younger at diagnosis and significantly more likely to receive immunosuppression and corticosteroids than those with IgAN. Participants will now be followed as part of CureGN to further define disease characteristics such as kidney disease progression, and response to therapy.

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