

CANADIAN GLOMERULONEPHRITIS REGISTRY (CGNR)



RESEARCH QUESTION

Can we build a collaborative national platform to understand the natural history of GN across Canada and create resources to better understand both the biology of GN and the patient experience with these diseases?



PROJECT GOAL

The overarching goal of establishing this resource is to build a national effort to develop precise, personalized, patient-centred treatment strategies for patients with GN and to bolster GN-focused collaborative research capacity in Canada. This will be accomplished by creating a rigorous protocol to follow patients with GN across Canada using a new web-based clinical registry and federated biobank.



POPULATION

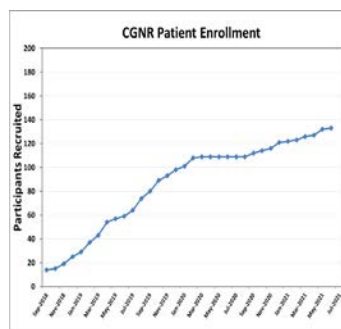
Eligible male and female subjects with biopsy-proven diagnoses of GN, aged 18-80 years, will be followed during the course of the study.



Our team consists of nephrologists, researchers, clinical and data managers, and patient partners. Each site has an invested and dedicated team working to recruit and follow patients. Weekly updates within the study teams and monthly data checks ensure accountability and data quality.

BACKGROUND

Glomerulonephritis (GN) is a group of rare diseases (<5 per 250,000 population) yet is a leading cause of kidney failure. There are few treatments for these conditions and no cures. Patients with GN need better access to new therapies to improve wellbeing and prevent kidney failure.



KNOWLEDGE NUGGETS

- ▶ Built web-based tools for the follow-up of patients with GN from across Canada
- ▶ Enrolled patients from west to east coast Canada, engaged centers not previously involved in GN research networks
- ▶ Though patient engagement we have refined our research priorities and protocols and placed more value on studying the patient experience
- ▶ Built a rich dataset describing the experience of patients with GN across Canada
- ▶ Next steps: boost enrollment, improve access to knowledge about GN and clinical trials across Canada

Biopsy diagnosis	N=134
FSGS	12.8%
MCD	15.0%
MGN	27.1%
IgAN	39.1%
MPGN	5.3%
Age	46 yrs
24hr proteinuria	4.4 g/d
Serum creatinine	110 umol/L
Serum albumin	31 g/L



Canadian
Glomerulonephritis
Registry



CGNR by the numbers

10	>30	5	134	295	1185
Research Centres	Team Members	Kidney Diseases	Patients	Visits	Biologic samples



PROJECT TIMELINE

