C3G Natural History Study

Monica Hall, RN, BSN

C3G Clinical Research Coordinator C3G Family Meeting 2020.10.17

What does it mean when we say "Natural History"

- The natural development of the disease over a period of time
- The study of individuals in their environment, leaning more towards observational than experimental methods of a study
- It encompasses scientific research but is not limited to it

A systematic study of each unique individual, with a focus on the origin, evolution and interrelationships.

- Interrelationships The kidney has SO many functions:
 - maintaining ACID-base balance
 - maintaining WATER balance
 - ELECTROLYTE balance
 - TOXIN removal.
 - BLOOD pressure control
 - making ERYTHROPOIETIN
 - Vitamin D metabolism

- C3G can affect many body systems that alter:
 - mental clarity-memory
 - appetite-diet
 - emotional stability
 - physical symptoms

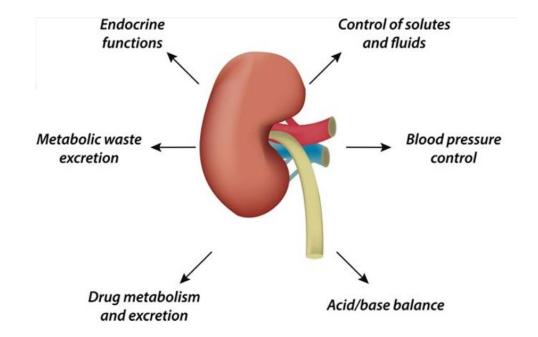
Fatigue – Inability to keep up with peers

Swelling/edema

Eye changes – Drusen

Altered bone balance, fractures, etc.

Blood pressure

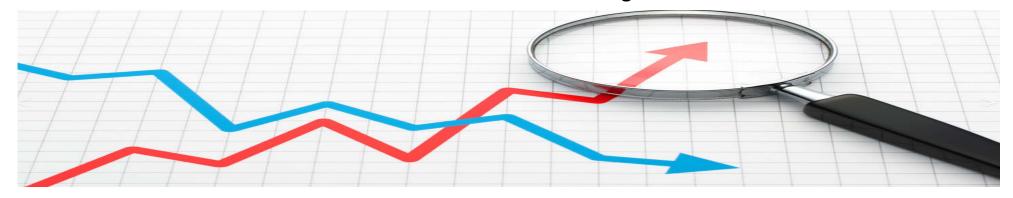


'Predicting' the course of C3G in a specific individual is very difficult due to:

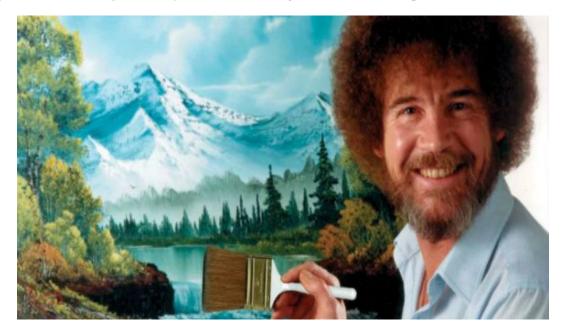
- the many functions of kidney
- the age each individual presents with disease
- the extent of kidney damage by the time of diagnosis
- the possibility of other underlying health concerns
- the potential genetic variants and/or
- known or unknown degree of complement dysregulation......

Inputting biomarkers, lab results & symptoms along a timeline in our database it allows us to:

- follow outcomes
- identify parameters and biomarkers that are predictive of outcome
- develop hypothesis
- enlist our statistician to assist with machine learning so we can LEARN from our data.



MORL's goal: to paint a *brighter picture* - by facilitating better outcomes for C3G patients.



While understanding the pathologic underpinnings of C3G is critical, without a better understanding of C3G disease course, there remains little hope of devising more effective treatment approaches and of fostering the development of targeted therapies. By understanding the natural history of this complex disease, we are better positioned to optimize the use of currently available treatment strategies, educate providers and families on best practice management approaches, and advise industry in the development of novel therapies.

How can we achieve our goal:

By studying individuals with C3G in their native kidneys and after transplantation.

What does persons Natural History of C3 Glomerulopathy look like?

~ Our Success Depends on the Participation of Everyone ~



HOW CAN YOU HELP? PLEASE CONTACT US!



Monica Hall, RN, BSN

C3G Clinical Research Coordinator 5292 Carver Biomedical Research Building

Phone: (319) 353-0905 Fax: (319) 384-9616

Pager 1622, Hospital Operator (319) 356-1615

Email: monica-hall@uiowa.edu



Lynn Vining, RN, MSN, CPHQ

C3G Clinical Research Assistant 5292 Carver Biomedical Research Building

Phone: (319) 335-8756 Fax: (319) 335-9890

Email: lynn-vining@uiowa.edu



Amy Weaver

C3G Admin Services Coordinator/Project Assistant 5296 Carver Biomedical Research Building Phone: (319) 335-6623

Fax: (319) 335-9890

Email: amy-weaver@uiowa.edu



THANK YOU!