C3G Natural History Study

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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!

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THANK YOU!