



C3 Glomerulopathy 14th Family Conference

October 3-5, 2019 • University of Iowa



Friday, October 4th

6:00 PM Dinner at One-Twenty-Six Restaurant 126 E. Washington, Iowa City, IA 52240

Saturday, October 5th

Atrium - Medical Education Research Facility (MERF)

375 Newton Rd., Iowa City, IA 52242

| | |
|---------|---------------------------|
| 7:00 AM | Blood Draws |
| | Sign in and Coffee |

Welcome and Updates

| | |
|---------|--|
| 8:00 AM | Welcome / Greeting from Kidneeds Lynne Lanning |
|---------|--|

| | |
|---------|--|
| 8:15 AM | Greater Cedar Rapids Community Foundation – a fundraising resource for Kidneeds Michelle Beisker, Susan Willey |
|---------|--|

Understanding C3G

| | |
|---------|---|
| 8:30 AM | The Kidney Biopsy – The cornerstone of the diagnosis of C3G Danniele Holanda <i>Learning objectives</i> <ul style="list-style-type: none"> To understand the anatomy of the kidney and glomerulus To understand how a diagnosis of C3G is made To understand that kidney biopsies can change over time To understand PIGN and MGRS and their relationship to C3G |
|---------|---|

| | |
|---------|--|
| 8:50 AM | Predicting the Future – Testing the complement system to piece together a complex puzzle Richard Smith <i>Learning objectives</i> <ul style="list-style-type: none"> To understand normal and abnormal complement activity To understand the role of genetic testing in C3G To understand how dysregulation of the alternative complement pathway leads to C3G To understand that occasionally dysregulation of the lectin pathway occurs |
|---------|--|

| | |
|---------|--|
| 9:10 AM | Current Care – What does that mean? Carla Nester <i>Learning objectives</i> <ul style="list-style-type: none"> To understand that initial therapy is only supportive treatment To understand when MMF should be started To understand the pros and cons of steroids To understand when a person with C3G might be eligible for a clinical trial |
|---------|--|



C3 Glomerulopathy 14th Family Conference

October 3-5, 2019 • University of Iowa



| | |
|---|---|
| 9:30 AM | Transplantation or Dialysis – What is the right choice? Christie Thomas <i>Learning objectives</i> <ul style="list-style-type: none">• To understand the pros and cons of transplantation vs dialysis• To understand the steps in preparing for a transplant• To understand whether there is an ideal protocol if you move forward right now• To understand that chronic dialysis is a viable and acceptable option |
| 9:50 AM | The Eye and C3G Ian Han <i>Learning objectives</i> <ul style="list-style-type: none">• To understand the basic anatomy of the eye• To understand how C3G affects the eye and what a patient would notice• To understand how the eye changes can be treated |
| 10:10 AM | Break |
| Living with C3G | |
| 10:30 AM | Living with a Chronic Disease Emily Kroska <i>Learning objectives</i> <ul style="list-style-type: none">• Accepting there will be depression, anger and fear• Learning to make the changes without becoming overwhelmed• Knowing that you can feel like yourself again as you adapt and learn how to fit your 'chronic disease' into your life• Knowing you have to give yourself time to learn how to take care of your “new” self |
| 10:50 AM | Living Donors: The highs and the lows Lynne Lanning and Pieter Hogeveen |
| 11:00 AM | The Natural History Study Monica Hall |
| Advances in Complement Therapies for C3G | |
| 11:10 AM | The FDA and Clinical Trials Elizabeth Durmowicz <i>Learning objectives</i> <ul style="list-style-type: none">• What does it mean when a pharmaceutical company has been “endorsed” by the FDA to conduct a clinical trial?• Can the FDA know if a drug will have any effect?• How does the FDA try to protect the patients in clinical trials? |



C3 Glomerulopathy 14th Family Conference

October 3-5, 2019 • University of Iowa



| | |
|---|---|
| 11:30 AM | <p>Drugs Currently in Clinical Trials – What’s a patient to do? Carla Nester</p> <p><i>Learning objectives</i></p> <ul style="list-style-type: none"> • To be familiar with the currently available trials • To understand that the trials are designed differently • To understand the drugs target different parts of the complement system |
| 11:50 AM | <p>The National Kidney Foundation and C3G David Feldman</p> <p><i>Learning objectives</i></p> <ul style="list-style-type: none"> • To review the initiatives by the NKF to support the C3G community |
| 12:00 PM | Eat and Greet with the MORL |
| Living with C3G: Experiences from patients just like you | |
| 1:00 PM | <p>My experience with transplantation Jenna Smith and/or Matt Jones</p> |
| 1:10 PM | <p>My experience on Eculizumab Lindsey Fuller</p> |
| 1:20 PM | <p>My experience in a clinical trial Brian Primozych</p> |
| 1:30 PM | <p>My experience with dialysis Sarah Jandick-Hiniker</p> |
| The International C3G Community | |
| 1:45 PM | <p>An update from Italy Fabrizio Spoletì</p> |
| Poster Session | |
| 2:00 PM | <p><i>Learning objectives</i></p> <ul style="list-style-type: none"> • To become familiar with the on-going research in the MORL |
| Poster 1 | <p>Monitoring Renal Complement Activity in Patients with C3 Glomerulopathy: Kristofer May</p> |
| Poster 2 | <p>In vitro modeling of the glycomatrix to study kinetics of C3 convertase: Sofiya Pisarenka</p> |
| Poster 3 | <p>Post-Liver Transplant C3G with Highly Elevated Factor H Autoantibody: Renee Goodfellow</p> |
| Poster 4 | <p>Role of Renin in C3 Glomerulopathy: Bertha Martin</p> |



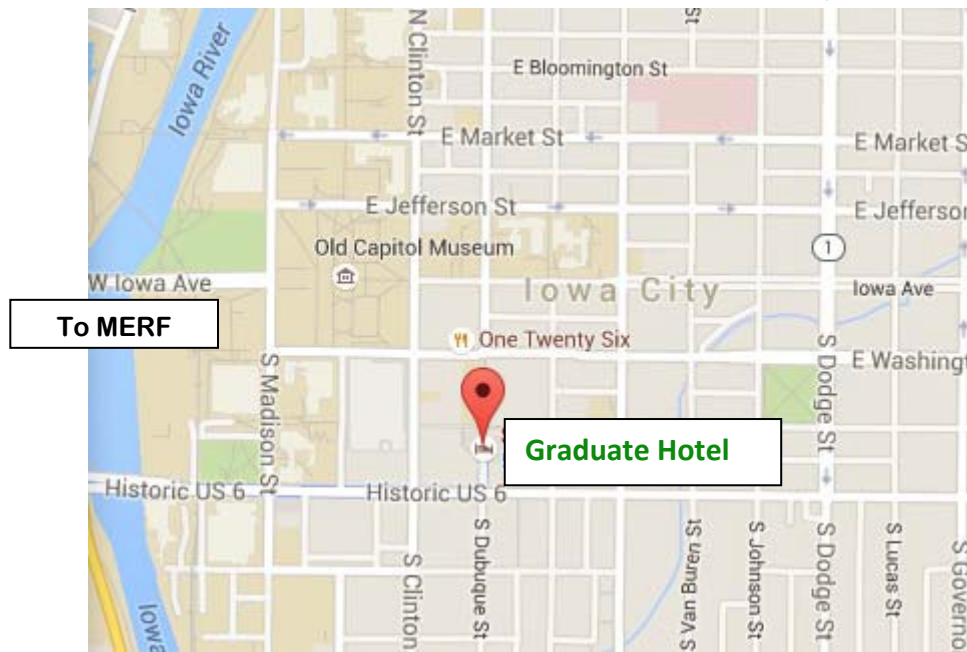
C3 Glomerulopathy 14th Family Conference

October 3-5, 2019 • University of Iowa



| | |
|--------------------------|--|
| Poster 5 | Longitudinal Complement Biomarker Trend in C3 Glomerulopathy Monica Hall |
| Poster 6 | Genetics and the Glycometrix Jill Hauer |
| 2:20 PM | Q & A |
| 2:30 PM | Break |
| Breakout Sessions | |
| 2:45 PM | Patients Only Facilitator – Sarah Jandick-Hiniker, Jenna Smith and/or Matt Jones |
| | Non-Patients Facilitator – Carolyn & Ed Harris |
| 4:00 PM | Reconvene and adjourn |
| 6:30 PM | Family Dinner at the Jones' |

Directions from Sheraton Hotel to Newton Parking Ramp



- Head south on S Dubuque St toward E Burlington St/Historic US 6 (Pulling out of parking ramp)
- Turn right onto E Burlington St/Historic US 6 at stop light
- Turn right onto S Madison St (Second stop light)
- Turn left onto W Iowa Ave (First stop light)
- Continue onto Newton Rd
- Parking ramp will be on the right (you have to drive by the structure before turning into the entrance)



To get to the conference, walk up the sidewalk to the west side of MERF and follow the signs to come into the building.

We will have the hotel shuttle drop people off in front of MERF.