

## Dense Deposit Disease Program

### Friday August 15th

19:00-19:30 Cheese and Wine Reception

19:30 Dinner

### Saturday August 16th

#### Focus on DDD – Setting the scene

Moderator: Sean Tully

08:00-08:05	Opening Remarks	Sean and Hope Tully
08:05-08:15	Purpose and Objectives	Richard Smith
08:15-08:30	Epidemiology – The MPGN Database	Lynne Lanning
08:30-08:45	What we do and do not know about the activation and control of complement C3	Seppo Meri
08:45-09:00	The key functional aspects of the factor H protein family	Paul Barlow

#### Interactive Session One: The pathology of DDD

Moderator: Terry Cook

09:00-09:15	The Histopathological spectrum of DDD	Patrick Walker
09:15-09:30	What do the human GBM deposits in DDD contain?	Sanjeev Sethi
09:30-09:45	What do the GBM deposits in the factor H-deficient mouse model contain and what does that tell us about the pathogenesis of DDD?	Matthew Pickering
9:45-10:45 (60 mins)	Group Discussion: The pathology of DDD (1) Important paradoxes in the literature (2) Insights and comments (3) Unanswered questions (4) Immediate research objectives	Moderator: Terry Cook

10:45-11:0  
(15 minutes) Coffee break

#### Interactive Session Two: The response of the kidney to the dense deposit

Moderator: David Salant

11:00-11:15	The mesangial cell response in DDD: injurious or reparative?	Patrick Walker
11:15-11:30	Are proteoglycans important in the pathophysiology of DDD?	Johan van der Vlag
11:30-11:45	Are the podocytes important in DDD?	Sue Quaggin
11:45-12:00	How Reversible is DDD? – insights from human and animal studies	Jessy Alexander

12:00-13:00 (60 mins) Group Discussion: The response of the kidney to the dense deposit Moderator: David Salant

- (1) Insights and comments
- (2) Unanswered questions
- (3) Immediate research objectives

13:00-14:00 (60 minutes) Lunch break

Interactive Session Three: Complement and DDD  
Moderator: TBA

14:00-14:15	Factor H and related proteins in DDD	Peter Zipfel
14:15-14:30	CR1 – is this important in DDD?	John Atkinson
14:30-14:45	The Terminal Pathway in DDD	Sakari Jokiranta
14:45-15:00	Is C3NeF nephritogenic or an epiphenomenon? Is depletion of C3NeF in DDD patients a worthwhile goal?	Michael Braun
15:00-16:00 (60 mins)	Group Discussion: Complement and DDD	Moderator: Richard Quigg

- (1) Insights and comments
- (2) Unanswered questions
- (3) Immediate research objectives

16:00-16:15 (15 minutes) Tea break

Interactive Session Four: The genetics of DDD  
Moderator: Santiago Rodriguez de Cordoba

16:15-16:30	The Genetics of DDD	Richard Smith
16:30-16:45	Does the genetic basis of atypical hemolytic uremic syndrome help us to understand DDD?	Santiago Rodriguez de Cordoba
16:45-17:00	The Genetics of AMD – What applies to DDD?	Greg Hageman
17:00-18:00 (60 mins)	Group Discussion: The genetics of DDD	Moderator: Santiago Rodriguez de Cordoba

- (1) Insights and comments
- (2) Unanswered questions
- (3) Immediate research objectives

19:00 Dinner

Sunday August 17th

Interactive Session Five: Therapeutic options in DDD  
Moderator: Ron Taylor

07:30-7:45	Targeting C3 and C5 in DDD	Josh Thurman
07:45-08:00	Can factor H therapy be used to treat DDD?	Greg Hageman
08:00-08:15	Can Compstatin be used in DDD?	John Lambris
08:15-08:30	Can C3Neph be a consequence of dysregulating mutations?	Paul Morgan
08:30-08:45	Fusion proteins with promise	Richard Smith
08:45-09:00	Scavenging C3 breakdown products as a treatment for DDD	Ron Taylor
09:00-09:15	Other therapeutic strategies for DDD - are heparanase inhibitors an option	Vicki Levidiotis
9:15-10:00 (45 mins)	Group Discussion: Therapeutic Options in DDD  (1) Insights and comments  (2) Unanswered questions  (3) Immediate research objectives	Moderator: Seppo Meri

10:00-10:15  
(15 minutes) Coffee break

**Interactive Session Six: Clinical trials in DDD**  
Moderator: Gerard Appel

10:15-10:30	Designing a Clinical Trial for a Rare Disease – Points to Consider	Richard Smith
10:30-10:45	Trail Design and Monitoring Efficacy – Defining Primary Efficacy Endpoints	Marina Noris
10:45-11:00	Enrollment in Europe	Tim Goodship
11:00-11:15	Enrollment in North America	Christoph Licht
11:15-11:30	Is On-Line Global Enrollment Feasible?	David Salant
11:30-12:30 (60 mins)	Group Discussion: Clinical trials in DDD  (1) Insights and comments  (2) Unanswered questions  (3) Immediate research objectives	Moderator: Gerard Appel

12:30-13:30  
(60 minutes) Lunch break

**Focus on DDD – Moving forward**  
Moderator: Michael Braun

13:30-14:30 (60 minutes)	Group Discussion:  Can we define the immediate research and therapeutic priorities?	
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**Closing of Meeting**

14:30-14:45 Closing Remarks – Sean Tully