



Dense Deposit Disease Family Conference

Friday and Saturday - October 28 and 29, 2011

Friday, October 28

6:00 PM Conference dinner – to be arranged

Saturday, October 29

9:00 AM Coffee and sign in

9:10 AM Welcome
[Lynne Lanning]

9:15 AM The history of DDD and what we now know about its pathophysiology
[Richard Smith]

9:45 AM The epidemiology of DDD – who gets it and what happens when they do?
[Lynne Lanning]

10:00 AM Adults with DDD – how they present and a flow chart of treatment options – following Druesen, hypertension and high cholesterol; the role of plasmapheresis; issues with pregnancy
[Christie Thomas]

10:30 AM **Break**

10:45 AM Children with DDD – how they present and a flow chart of treatment options – following growth: bone disease and parathyroid issues; anemia, volume overload and cardiac damage
[Carla Nester]

11:15 AM Genetics and biomarkers – how genetics might influence the disease course and why biomarkers are likely to be important
[Richard Smith]

- 11:45 AM** Dialysis – PD and in-center or home hemodialysis – how to choose; sclerosing encapsulating peritonitis – what is it and what should you know about it?
[TBA]
- 12:15 PM** **Lunch**
- 1:00 PM** Transplantation - special considerations for the DDD patient.- recurrent disease, what it means and what to do
[Christie Thomas]
- 1:30 PM** Eculizumab and TP10 – new treatments on the horizon
[Carla Nester]
- 2:00 PM** Financial considerations of DDD; establishing a special-needs trust
[TBA and Lynne Lanning]
- 2:30 PM** Concluding remarks
[Lynne Lanning]
- 2:45 PM** Family Meeting
- a. Address fundraising issues
 - b. Research participation
 - c. Lobbying or political involvement
 - d. Improving service and coordination of effort for better networking-website improvement
- 6:00 PM** Family dinner – to be arranged