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