

The Second BHD Symposium, April 22nd 2010, Washington DC, USA.

Families Session Provisional Programme

The day has been designed so that attendees have sessions specifically addressed to their needs as well as intersecting with the 'Scientific Session' at clinically relevant talks (indicated by a 'tick').

Time	Topic	Speaker	Joint session for Families & Researchers
07:30	Breakfast		✓
08:30	Registration		✓
09:00	Introduction	Dr Laura Schmidt	✓
09:10	A personal view of renal cancer genetics: history and lessons	Dr Berton Zbar	✓
09:55	Patient Advocacy in BHD Syndrome: Joyce Graff is currently the Executive Director of the VHL Alliance. She will be sharing her vast experiences both as a patient advocate and founder of the VHL Alliance.	Mrs Joyce Graff	
10:25	Coffee Break		✓
11:05	Living with BHD Syndrome: a host of topics will be discussed including <ul style="list-style-type: none"> • what services are available at the NIH; • familial communication; • when to get genetic testing; • how to tell your children they are at risk for BHD; • recommended screening guidelines and; • health insurance concerns about genetic testing. 	Ms Lindsay Middleton	
12:20	LAM and BHD, similarities and differences	Dr Frank McCormack	✓
13:05	Lunch		✓
14:05	Living with Rare Cancer - a family's perspective	Mrs Joyce Graff	✓
14:35	Investigation of the Birt-Hogg-Dubé tumour suppressor gene (FLCN) in familial and sporadic colorectal cancer	Mr Mike Nahorski	✓
14:50	Topical rapamycin to treat fibrofolliculomas in Birt-Hogg-Dubé syndrome	Dr Lieke Gijzen	✓
15:05	Diagnostic criteria, and recommendations for screening and surveillance of patients with BHDS: a North American perspective	Dr Jorge Toro	✓
15:20	Therapeutic targeting of the loss of the BHD suppressor gene	Dr Xiaohong Lu	✓
15:35	Evaluation and follow-up of 54 families with suspected Birt-Hogg-Dubé syndrome; a multi-center study in the Netherlands	Dr A.C. Houweling	✓
15:50	Coffee Break		✓
16:20	Round table discussion with clinicians and scientists.		✓
18:30	Dinner		✓