

Birt-Hogg-Dubé Newsletter

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You are receiving this email because you have expressed an interest in BHD. We hope you will enjoy this and future editions. If you do not wish to receive this newsletter, please see the end of the email for instructions.

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

The Second BHD Symposium 2010 is now less than a month away! Comprehensive details about the Symposium, including how to register and suitable accommodation can be found on the dedicated page www.BHDsyndrome.org/the-second-bhd-symposium. The full programme for the 'Researcher's Session' has been released and is an interesting mix of Clinical and Basic Research.

We are also excited to announce that a parallel 'Families session' has been planned to run alongside the day's scientific presentations. Families and individuals affected by BHD Syndrome are invited to attend and participate in patient-focussed sessions held by Joyce Graff and Lindsay Middleton (see *below*). The provisional 'Families Session' programme can be found [here](#).

In addition we have organised the day so attendees of the 'Families Session' will be able to listen to presentations regarding current clinical research projects in BHD Syndrome and hear from invited speakers:

Families Session Speakers:

Joyce Graff is currently the Executive Director of the VHL Alliance and we are pleased that she will be sharing her vast experiences with VHL disease (both as a patient advocate and founder of the VHL Alliance) to the BHD community.

Lindsay Middleton is a genetic counselor with the Urologic Oncology Branch, NCI, NIH, Bethesda, MD and a member of the National Society of Genetic Counselors. She will lead a session discussing topics of interest to patients and their families such as 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.

Second BHD Symposium Invited Speakers:

Dr. Berton Zbar has over 20 years experience in the field of renal cancer genetics and we are delighted that he has agreed to address the Symposium. Dr Zbar's will be presenting: "A personal view of renal cancer genetics: history and lessons". Before his retirement, Dr Zbar was chief of the Laboratory of Immunobiology at the Center for Cancer Research, NCI-Frederick, USA, where he and his colleagues have studied families affected with the BHD Syndrome as well as von Hippel-Lindau (VHL) syndrome, hereditary papillary renal carcinoma (HPRC), and Hereditary Leiomyoma and Renal Cell Carcinoma (HLRCC).

Dr Frank McCormack has agreed to talk about “LAM and BHD, similarities and differences”. Dr McCormack is an expert in the field of Lymphangiomyomatosis (LAM), a progressive lung disease that affects women almost exclusively and is characterized by the development of pulmonary cysts, which overtime obliterates lung function.

For those of you unable to attend the meeting in person we will be hosting a live blog on www.BHDSyndrome.org to provide a rundown of the day's highlights as they happen. More details will be released closer to the day.

PDF poster gallery?

What is BHD?

'What is BHD?' is the latest contribution to the 'Researchers' section of www.BHDSyndrome.org and provides a comprehensive scientific introduction to BHD Syndrome detailing the original classification of the disease and it's clinical manifestations, through to the identification of the *Folliculin* gene, all the way up to our current understanding of the cell biology underlying BHD Syndrome. 'What is BHD?' is an original document made up from review past and current published research in the field of BHD research.

A pdf file of 'What is BHD?' is also available to download [here](#) in the Researcher's section and also [here](#) in the Families section. Non-scientific individuals should consider that this text has been specifically composed for researchers but that it has been made available to everyone on www.BHDSyndrome.org as we realise that this kind of information may appeal to all.

Getting to know you!

In this instalment of 'Getting to know you' we're featuring Professor Eamonn Maher, from the University Of Birmingham, UK and the personal experiences of Wendy from Australia. The interviews can be found [here](#).

If you would like to participate in our 'Getting to know you!' feature, please contact us at contact@BHDSyndrome.org

If you would like to submit information or a topic for the next newsletter, please contact the editor at info@bhdsyndrome.org

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