

Birt-Hogg-Dubé Newsletter

March 2009

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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.

BHD support groups

We encourage everyone who is interested in getting in touch with other BHD families to consider being part of, or starting, a support group. This support group could be as simple as 'meeting' online via emails to our discussion forum. Depending on the distance, you may find other BHD families in our area. We'd like to do anything we can to help people get together. We'd be happy to help you look at ways to make this happen, whether you want to set up a group on your own, or as part of the BHD Family Alliance. Because our numbers are small, groups may be small to start with. Look for more information on our website!

BHD discussed at American Society of Clinical Oncology Genitourinary meeting

Dr. Laura Schmidt of the NCI presented information about BHD. She mentioned that nearly 100% of those affected by BHD have fibrofolliculomas. Statistics show that there is a 50 fold increased risk for having spontaneous pneumothoraces in BHD families, and a seven fold increased risk of having kidney lesions. 30% of those with BHD will develop kidney lesions, usually after the age of 50. The BHD gene test detects cases of BHD with about 90% accuracy.

BHD Forum

The BHD discussion Forum at www.bhdsyndrome.org is currently under construction. We will let you know as soon as it is ready for postings!

It runs in the family- BHD

Date / Time: April 2nd 2009 3:00 PM

Cathy Sherman of the Birt-Hogg-Dubé Syndrome Family Alliance talks with Joyce about how her family learned why so many members were getting kidney cancer, and how they formed a group to support one another and find answers.

Call-in Number: +1 (347) 237-4358

For more information, see www.blogtalkradio.com/powerful-patient.

Drug Repurposing Grants

Up to four one-year grants, each of \$25,000 USD, are available for projects "that can have a direct and significant impact on the BHD patient population within the next 12-24 months". These grants are part of the Rare Genetic Disease Pilot Grant Programme, created by the Myrovlytis Trust and Partnership for Cures (www.4cures.org). More information available at www.MyrovlytisTrust.org/news.aspx and at www.4cures.org/home/birt_hogg_dube_syndrome. Please consider applying, and/or passing this information on to others you think might be interested.

Travel Grants

The Myrovlytis Trust has travel grants available to support research into BHD syndrome. See www.MyrovlytisTrust.org/tg.aspx.

New mouse model

The Henske lab, formerly at the Fox Chase Cancer Center in Philadelphia, USA and now at the Brigham and Women's Hospital in Boston, USA, has just published a new mouse model of BHD syndrome in the journal *Oncogene* (Hartman TR et al., 2009, PMID 19234517) www.ncbi.nlm.nih.gov/pubmed/19234517.

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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Myrovlytis Trust Birt-Hogg-Dubé Family Alliance

