

Birt-Hogg-Dubé Newsletter

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You are receiving this email because you have expressed an interest in BHD syndrome. 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.

BHDSyndrome.org Update

Mid-June saw the relaunch of <http://www.BHDSyndrome.org> with the aim of making it THE primary resource for patients, families and researches alike.

The updated researcher's section now contains a whole host of new resources including a brand new BHD literature archive. This downloadable excel file includes the majority of past and present BHD related publications, summarised for convenience and all hyper-linked to source journals so that the original publication is never more than a click of your mouse away! Let us take the stress out of your literature searches - we will update the archive regularly so that it is constantly up-to-date: go to www.BHDSyndrome.org now and download your copy!

Since the current version is in the *beta* test stage we'd also welcome your feedback. So if you do have any ideas on how we could improve the resources, please leave a comment on our forum, or alternatively reply to this email.

FLCN Mutation Database

The folliculin (FLCN) variation database <http://www.lovd.nl/flcn>, curated by Dr. Derek Lim, (European Birt-Hogg-Dube Consortium, University of Birmingham School of Medicine, UK), has been recognized by the Human Genome Variation Society and is hosted by Leiden Open Variation Database.

The database contains a comprehensive listing of published FLCN mutations, as well as unpublished data, and submitting new findings is greatly encouraged.

BHD UK Patient Group

If you are interested in finding other BHD families in your area or in your country, we would like to help. At the moment, only a few hundred families worldwide have been diagnosed as having BHD syndrome. We believe there are many more families who have the syndrome and are not aware of it.

Many new groups start informally by connecting to other people through email or phone calls. Our website, www.BHDSyndrome.org, contains a discussion forum that is open to groups from different countries, or to people who speak different languages, who wish or meet each other online and to talk about their experiences with BHD.

If you have any questions, please email us at info@bhdsyndrome.org.

BHD Symposium - Watch This Space!

Planning for the next BHD Symposium is currently underway and is preliminarily scheduled for April 2010 in Washington DC, USA. More information will be issued when plans are finalised.

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Myrovlytis Trust Birt-Hogg-Dubé Family Alliance