

# Birt-Hogg-Dubé Newsletter

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*This is the first quarterly BHD newsletter. 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.*

## **Inaugural BHD Symposium**

The Inaugural BHD Symposium was held in Roskilde, Denmark, on 3rd September. There were 47 attendees. More details to follow, but initial feedback suggests that the Symposium was well received: we hope it has provided an opportunity for BHD researchers to meet and find out about each other's research as well as stimulating new ideas. The abstracts of the talks and posters have been published on Pubmed <<http://www.ncbi.nlm.nih.gov/pubmed/18704757>> .

## **FLCN antibodies**

New anti-FLCN antibodies are being created by Dr Arnim Pause at McGill University, Canada.

Funded by the Myrovlytis Trust, these antibodies will be available to the research community before publication. The intention is that making sufficient quantities of high quality antibody freely available will facilitate BHD research.

## **New mouse model of BHD**

Dr Teh's lab at Van Andel Research Institute, Michigan, has just published a kidney-specific BHD knockout mouse model <<http://www.ncbi.nlm.nih.gov/pubmed/18974783>> . This adds to the useful and growing number of animal models available: Baba M. *et al.*, 2008 <<http://www.ncbi.nlm.nih.gov/pubmed/18182616>> ; Arnim Pause's unpublished model <<http://www.myrovlytistrust.org/news.aspx#mouse>> ; rat (see below); Lingaas F. *et al.*, 2003 <<http://www.ncbi.nlm.nih.gov/pubmed/14532326>> .

## **The Nihon rat model of BHD is now accessible**

Some BHD researchers have had difficulty accessing the Nihon Rat (Okimoto *et al.*, PNAS, 2004 <<http://www.ncbi.nlm.nih.gov/pubmed/14769940>> ). The authors now have permission from the company handling the animals to send them. If you would like access to this animal, please contact Kazuo Okimoto ([kazuo-okimoto@ds-pharma.co.jp](mailto:kazuo-okimoto@ds-pharma.co.jp)) directly. If you do not receive a timely response please email the Myrovlytis Trust ([info@myrovlytistrust.org](mailto:info@myrovlytistrust.org)) to ensure that the animals are made available to the BHD research community to facilitate BHD research.

## **Update for Patients**

The Inaugural BHD Symposium brought together leading experts in BHD from around the world. It was agreed that written guidelines for treatment and follow up would be really useful to patients in every country. In general, the discussion focused on the need for CT scan or MRIs in following potential kidney tumors, as ultrasound does not pick up all BHD kidney lesions. It's important that those affected by BHD are familiar with the symptoms of lung collapses (spontaneous pneumothoraces), and how to get treatment. There is currently no known treatment to permanently remove fibrofolliculomas or trichodiscomas, the skin lesions associated with BHD.

For more information about the BHD syndrome, or to join a discussion forum, see the new website that is a joint project between the Myrovlytis Trust and the Birt-Hogg-Dubé Family Alliance. [www.bhdsyndrome.org](http://www.bhdsyndrome.org) <<http://www.bhdsyndrome.org>>

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

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