

Myrovlytis Trust

November 2009

Dear Sir or Madam,

Re: UK Patient Group for BHD Syndrome

I am writing from the Myrovlytis Trust to see if you might be interested in a UK patient group for BHD Syndrome.

The Myrovlytis Trust (www.MyrovlytisTrust.org) is a medical research charity, founded in London in late 2007. We fund basic scientific research into BHD Syndrome at universities across the world. Additionally, we are funding a small clinical trial in the Netherlands for the fibrofolliculomas, we run www.BHDSyndrome.org, and we are currently organising the Second BHD Symposium.

Why have a group?

- There has been a patient group based in the United States, called the Birt Hogg Dubé Family Alliance. They have been around for several years and the Trust has worked closely with them – for example, to develop www.BHDSyndrome.org, and to organise the Inaugural BHD Symposium in 2008. The BHD Family Alliance has recently become less active and, although it works with patients from around the world, is based in the USA. Therefore, we are exploring the idea of a UK-based patient group for BHD Syndrome.
- We think that a ‘patient voice’ for BHD Syndrome would be very useful, not only to provide a patient’s perspective, but also to enable people affected by BHD syndrome to ask each other questions and provide support.

What might it involve?

- That would be up to you. Many new groups start informally by connecting to other people through email or phone calls. The BHD website contains a discussion forum that’s open to everyone – www.BHDSyndrome.org/forum.

If you would like to be involved in a UK patient group for BHD Syndrome, or if you are interested in finding out more, please do not hesitate to contact us directly – phone, email, or via the BHDSyndrome.org forum. We look forward to hearing from you.

Yours faithfully,

John Solly

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