



Uncover a cure for cancer

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Dear fellow BHD families:

My name is Jean Sohrakoff and I have BHD. In 1980, I had five pneumothoraces. I was lucky; the doctors didn't know what caused my collapsed lungs, but they did perform pleurodesis. Then, in 1977 my bilateral kidney tumors were discovered and I wasn't so lucky. One urologist wanted to remove both of my kidneys, and another insisted the tumors were all benign, so I waited. In 2008, my son had a near-death experience with a pneumothorax and my husband, surfing the internet, found a reference to BHD. I pursued the lead, and a few months later my son and I were at the NIH. A partial nephrectomy proved that my tumors were not benign, and the largest was nine centimeters long! I know that I would not be alive if not for the research published on the internet.

By banding together we can help ourselves, as well as the researchers and others who are trying to help us. John Solly and the Myrovitis Trust in the UK are doing a great job encouraging research on BHD throughout the world. With their help, we will someday have a medication to control BHD.

Meanwhile, as you know, there are lots of families dealing with a lot of medical issues. We all need encouragement, support, and empowerment. The VHL Family Alliance (VHLFA) has agreed to provide an environment where we can find one another, interact, and build an international network of patient support for Birt-Hogg-Dubé.

The VHL Family Alliance has built an extensive network of patient and family support for VHL. For the past few years, VHLFA has been hosting and coaching a group of people with HLRCC, helping them to build their own patient support network and a body of information to help them manage their health.

I would like to see us build a community of friends with BHD to support one another, and to build up a body of information to help us all stay healthy. As one example, if my son had known that he was at risk for a spontaneous pneumothorax, he would not have gone deep sea diving in Mexico! Understanding our risks, and learning to manage them, we should all be able to stay healthier longer.



An active support network will also give us a way to hear about the latest in research, and about any clinical trials that may be open to enrolling participants. It's those clinical trials that will lead us to the drug we all wish for.

I have volunteered to help lead the charge. Won't you join us? It will take a team of people to make all this happen!

Please come join the conversation at <http://vhl.inspire.com>. You can create a free private account, with a username as public or private as you choose, and ask whatever you wish. In these early days we are hosted by the VHLFA, alongside people with VHL, HLRCC, and BHD, giving us a supportive community even on day one.

I look forward to speaking with you on Inspire, and with your help, building a strong and effective worldwide community of friends, learning to manage BHD.

Sincerely,



Jean Sohrakoff

P.S. my username on Inspire is Jean9b7 ... what's yours?
Feel free to call me at 800-767-4845, ext 725,
or write to me at bhd@vhl.org