**Married on a Mountain with a Collapsed Lung**

**A Personal Story of BHD**

**Film Transcript**

Hi, my name is Joanna Hawley-McBride. I am a social media content creator and small business mentor and I have Birt-Hogg-Dubé syndrome (BHD). I was diagnosed with BHD in March 2020 after having my first pneumothorax in September 2019 and it is a wild story because I did not expect my lung to collapse literally on my wedding day.

I knew my wedding would be a big deal to me, but I didn't imagine it would make such a big change in my life, right away. We got married on top of a mountain here in Washington state called slate Peak and it's about 7,500 feet in elevation. We basically got all of our friends and family together and drove from Seattle to the mountain had our wedding up at the top of the mountain caravanned down and had an amazing party that evening. The entire time I was kind of complaining about having shoulder pain in my right shoulder and I really thought it was just the stress. I thought the breathlessness that I was experiencing was just the excitement and the anxiety and just all of the feelings of it being my wedding day.

We came back to Seattle on that following Monday. Then on that Wednesday, I went to a spin class in the morning, an hour-long very intense spin class and it was the hardest spin class of my life. Afterwards, I was walking home and I had to stop repeatedly to catch my breath. I felt light-headed, dizzy and I was like something isn't right? My husband wanted to go sailing that evening and I texted him and I was like, you know, I kind of have some chest pains. I don't feel right something is off. So he came home and we were talking and of course, me being me I posted about it on social media. We had a family members, at the time, fiancé message me and say get a chest x-ray stat. Literally, she said that.

So of course I made an appointment the next day to see my primary care physician. She listened to my chest, listened to my breathing and she's like, you know, just to be safe, let's get a chest x-ray. And so I walk over from my doctor's office to the hospital to get the chest x-ray. They were all in the same block in Seattle. And I get the x-ray done and I was like, you know, it's really early in the morning. I haven't had a chance to go to the bathroom as frequently do you guys mind if I use the bathroom? I see that there's one here in the x-ray room and they're like, yeah sure go for it. And so I'm in there and I hear a commotion and I'm like, oh what's going on? So I come out and there is a man with a wheelchair and he says I need you to stay very calm. I need you to sit in this wheelchair. You need to stay calm your right lung has collapsed and we are taking you to the emergency room right now. So they literally wield me from the x-ray wing across the entrance and directly into the emergency room. They already had a doctor waiting for me and they put in a chest tube probably within like 20 to 30 minutes of me having been admitted.

There were signs that my heart was in distress and at that point I was transferred to a different hospital where I stayed for five days. In that time I had surgery where they use the sugar to fix my lung back to...I went to school for art, I'm not very scientific. But this is the best of my knowledge that I understand.

So my right lung was fixed and then I was discharged and I had a few months of recovery. I experience some nerve tenderness here in my chest. They said that was a result of potentially the chest tube.

It honestly just scared me and as somebody who was extremely active in rock climbing and being at high elevations and I travel a lot especially before the covid pandemic, to be told, you know, stay home, stay at like sea level, don't travel was sobering. Around that same time, my mum who works at NIH fortunately mentioned that she had her genes mapped and they found markers for something called Birt-Hogg-Dubé. And so in tandem with me meeting with my amazing pulmonologist, he ordered a genetic test on me based on this information from my mum.

So just in wrangling with insurance and all of that it took a few months for me to even just be able to take the test which is why I didn't find out about the official diagnosis until about March or April basically at the start of lockdown.

So in terms of managing these days, I live my life fully. I mean we actually were very inspired after my diagnosis to sell our home in the city and buy a home, a cabin in the mountains in the North Cascade Mountains of Washington state and really just live life in the area where we spend all of our time anyway and just kind of you know, the whole cliche of live life to the fullest and just kind of jump in. So we were inspired by my diagnosis to do that.

Day to day really isn't that different for me. I wear an Apple watch sometimes and that helps to monitor my oxygen levels. I also like that I can initiate an emergency phone call if I need to and it kind of gives me a little added layer of feeling a little safer, especially since we live in such a remote area. I haven't travelled since the start of the pandemic so I can't attest to you know, getting on a plane since my diagnosis, but I'm very eager to travel as soon as I personally feel safe again. I've spent tons of time in the mountains, since my diagnosis, and have not had any troubles.

I see my amazing pulmonologist, Dr Papas about twice a year. So basically we do the lung function tests, and he orders my MRI to check out my kidneys. He has put in a referral for me to go to the dermatologist. I have not experienced too many of the fibrofolliculomas on my face. But, I think they're starting to come in. So I just kind of want to get started on that and make sure that I, you know, keep up with it, especially given that part of my career is being on camera, taking photos that sort of thing. I also have my kidney screened once a year with an MRI just to make sure that everything is looking good there.

A big part of why I wanted to share my story is because I really had no idea what a pneumothorax was, what it felt like, what to look for the symptoms. None of that. I had no idea. I thought it was just some crazy thing that you saw randomly on like Gray's Anatomy or like in a movie. And so I think just even, just building awareness for people first of all that there are these rare genetic conditions that can affect you via pneumothorax or you know bumps on your face, whatever. Just raising concerns like that, I think will help people feel a little bit less alone. I know when I was first diagnosed I didn't know anybody who had it and I felt pretty alone not really knowing you know, who can I talk to about this, who can really understand what it means to have a chest tube and that special type of hell that I really had no idea existed. And just sort of navigating those feelings of the unknown. So my hope in sharing my story is that people won't feel as alone, especially if you don't fit the typical look and persona of somebody who has a pneumothorax.

My advice to others with BHD is to really research your doctors and try to find the best care that you can given your budget, your insurance, your location. I'm so blessed that I have an incredible pulmonologist who really works with me in managing the condition and researching it. He has one other patient who has the condition and so I feel very comfortable trusting him. And if I'm feeling off he is always really fast to order an x-ray for me so I can make sure that everything is okay.

In the future. I am hoping to just spend more time here in the mountains, climbing, hiking, swimming in Alpine Lakes, even though they're really cold. I'm excited to travel again. We haven't actually been on our honeymoon yet. So I'm very excited for us to finally get to do that as soon as we feel comfortable doing so and travelling so in the future. Hopefully, I'll be you know, living my life the way that I was pre-pandemic.