**Can I Fly with BHD? Katty’s BHD Story
Interview by Senior Charity Officer Jazzmin Huber**

**Jazzmin**: Hello, my name is Jazzmin and I'm a charity officer at the BHD Foundation and Myrovlytis Trust. I'm going to be talking to Katty about her BHD diagnosis and the misinformation she received surrounding flying during her BHD Journey. It's really lovely to have you here today Katty. How are you?

**Katty:** I'm fine thank you. Hello!

**Jazzmin:** Fantastic. So let's start from the very beginning they say. So when and how were you diagnosed with BHD?

**Katty:** My brother had several lung collapses in his 20s, and then eventually he was having a scan and they noticed the skin tags on his face. There was a student there and they said, oh my God, that could be BHD. And so he was then tested and he was positive. And then myself and my mother and my other brother were tested and my father and it was me and my mom and my one brother. But one brother and my dad who are not. So how many pneumothoraxes had he had before that medical student spotted the skin bumps? They had quite an impact on his life over 20 years. About 20 years of lung collapses and they thought it was because he worked at a screen printers. He stopped and they didn't really know. But he kept presenting with these sort of random lung collapses and nobody really knew. He probably had a good five six seven, maybe more repeatedly.

**Jazzmin:** Well, it makes me feel a bit hopeful that maybe our younger generation of doctors may be a little bit more informed about it.

**Katty:** Yeah, the skin tags and the skin that's what they said. They put those two things together. I have got these bumps and I thought I've probably got it then and my mom's got the umps. And I was the GP with these pumps before I knew and I said, what are these? He's a skin special and he went, 'Oh, no nothing'. And my mum went and she was sent to the Dermatology Department at the hospital and they said oh no, you don't know nothing. Which seems rare because that's what I think everyone gets them. Most people have them.

**Jazzmin:** Yeah. It's one of the most common kind of symptoms of BHD these kind of slight bumps called fibrofolliculomas. And yeah, one of our key targets is the skin doctors, the dermatologist, because they're the ones who will see kind of those first signs potentially.

**Katty:** Yeah. That's why I think they should have known. I went for a lot of skin things. We've had a lot of skin things in family. So checks and nobody picked them up at all. Okay. So when you were first kind of diagnosed, what information were you given by your doctor? I was given.. They said that I've got an increase chance of kidney cancer, possibly an increased chance of bowel cancer if I've got in my family, which I do have. My mum's. Half brother, has had bowel cancer. Okay. Well, they're in Italy and they didn't want to be tested. So that was it. And that was it really. And then we were sent for a kidney scan and a lung scan and we repeatedly have the kidneys scans every year. The lungs we had one of those CT scans for the lungs and they measured all our cyst and things. Yeah, and that was it really.

**Jazzmin:** Did they give you any other lifestyle advice at all while you were there?

**Katty:** Well the lung specialist just said don't fly long haul, don't do impact Sports and don't scuba dive. Yeah, that was it really. And I tried and repeatedly called just for more information and they said they'd sign me off and that was it. I couldn't get any more so I did contact Guys and they couldn't really advise me and it was also the pandemic so there was COVID which is respiratory. So I understand that everyone was quite busy.

**Jazzmin:** Yeah, but still I can imagine that uncertainty was quite difficult at the time. Wanting more information and not being able to get it.

**Katty:** It was a bit and I know I wanted information as well on covid and it, because that's what I didn't know. And I didn't know whether my children might have it and so I didn't know how much more at risk we would be. We were eventually sent a letter saying to isolate from the doctor the GP, but that was through us contacting the GP and saying we're not sure where we should be with this. My brother worked in a sort of school University. So he should possibly have been. You know, eventually we got the letter saying that we're in a little higher category and we should isolate but we we weren't really sure what to expect from it and what my children again and my mom obviously, you know, it was quite an unsettling time, but nobody knew anyway.

**Jazzmin:** I think there was so much we were constantly learning during the pandemic every day the kind of advice was changing. So let alone being diagnosed with the rare condition during the pandemic on top of the pandemic.

**Katty:** It was a respiratory condition. That's the concern that and that, you know, nobody really know what was happening to people's lungs and we were sort of had these great big cysts on our lungs. Yeah. So yeah, so that's all really. The main thing for me was that I was told not to fly really apart from, she said don't do long-haul just short-haul, but I've been a travel artist and I've flown all over the world before. I've done everything. And I was planning on obviously after pandemic on doing that with the kids. So obviously suddenly I couldn't do any of that which is quite a big thing. That's what I was planning into my sort of as I get older, when the kids leave home. My aim was just to finish off the world I haven't seen. So yeah, so that was quite a big issue for me. And when I rang again, they just said don't you understand it's life threatening. Just don't fly. And they were quite off with me. And just said that's it. Don't fly, you know.

**Jazzmin:** To kind of come to you and say that's life-threatening that's quite scary language, they're using as well. It is.

**Katty:** They said don't you know, it's life threatening. I rang a couple of times and they said look, you know, this is all we can say it's life threatening don't. So obviously that and none of us, you know me the kids and every time I've flown. I've flown European as I'm half Italian. It's been quite anxiety inducing. Quite worried beforehand obviously, you know constantly aware of it for a month after. And actually I don't think I to be.

**Jazzmin:** I think this is the perfect opportunity to talk about kind of our discussions with the lung specialists. Because we've had a lot of people like you Katty coming to us and saying can I fly and there's been a few Papers written about flying and BHD and the general consensus is flying doesn't massively increase your risk of having a lung collapse (\*current research suggests that if 1000 people with BHD flew on a plane, 1 or 2 of them would have a lung collapse. Pleurodesis may reduce this risk\*). However, what the key thing here is if you do have a pneumothorax and you get on a plane It can make it worse because if you go up in a plane pressure gets greater and if you've got little collapse, you can imagine that pressure is pushing your lung down. So if you've already got a lung collapse and you get on a plane that is where the problem is. So the key thing our doctors are telling us is not that people with BHD shouldn't fly. They're saying people with BHD can fly wherever they like on as long as it's a pressurized plane to commercial plane. They can fly wherever they want for as long as they can unless you have any of the signs of a new pneumothorax before you get on a plane. So I think that is the key thing that if you don't have a pneumothorax and you'll know if you've got a pneumothorax, you might have some shoulder pain you'll feel breathless. So I think the key thing for anyone with BHD is before you're getting on the plane. Are you feeling breathless? Have you got any chest pain? If not go and enjoy your holiday or going enjoy your travels?

**Katty:** So could you go and get it checked?

**Jazzmin:** so if you were worried that you might have a collapsed lung the thing would be to probably go to.. well go to A&E and they would do a chest x-ray and the chest x-ray would be able to see if you had a lung collapse. It wouldn't be advised to do it routinely every time you were to fly because also you don't want to have loads of radiation exposure by having constant chest x-rays, but Yeah, if you did think you had a pneumothorax the key thing is to go and get a chest x-ray. to see if you had it or not, so I think the key thing here is you can fly and it's really hard for us to hear when people say, you know, you can't it's life-threatening and it's just it's your body you're being more in tuned with it than anyone else.

**Katty:** I've flown all over the world and I've done loads of flying before never had a problem and even it's probably the specialist just didn't know.

**Jazzmin**: Yeah, and I think that's the same they hear a rare condition that causes lung collapses and they know that if you've got lung collapse you shouldn't fly so they kind of think therefore if you've got BHD you shouldn't fly. Whereas they're missing out the step of only if you have a collapsed lung.

**Katty:** Yeah. So yeah, so that's brilliant for me.

**Jazzmin:** I'm just so sorry with the misinformation. It's something we're trying really hard to you know reduce.

**Katty:** Other thing that would have been really good is if they referred me to you when I first got diagnosed. I didn't I wasn't given anything. I was just sent off with the piece of paper saying I've got it. And that's it. And I did Google and I couldn't find. All I could find was sort of specific articles kind of in America or in Australia. And there was no where else. no one else. I didn't know anyone else. I couldn't find anyone else. You know, I had a kidney specialist. I had a kidney scan and there was something on it was fine and he had one other patient with it. So he had a slight insight into it. I've never met anyone else that's ever had a patient with it in all my scans and doctors.

**Jazzmin:** Yeah. So that was going to be my next question. What do you wish had been available to you and I'm guessing more information and potentially signposting to us?

**Katty:** Yeah, you're Symposium last week was brilliant for me. In learned so much more than you know, got to speak to Specialists who are fantastic. I got to hear all about it and it really made me feel stronger and once you know about something it's so much easier to manage. But yeah, so it's brilliant absolutely brilliant. And I think if anyone gets diagnosed if there's a way of diverting them to you, that'd be amazing.

**Jazzmin:** This is something we are trying to do and embed ourselves into the healthcare system to kind of get you know, little leaflets out so that when someone's diagnosed you can be given the leaflet which directs to us. It is challenging but we are in the process of looking into it and anyone who does come to us as doctors and we give them the leaflets to try and say if you see someone in the future, please direct to us.

**Katty:** And possibly the kidney departments as well because if they if they've never known. I've been for several kidney scans.

**Jazzmin:** So yeah 100% I think the kidneys the lungs and the skin doctors are our key targets. Yeah, whereas possible and so how do you manage your BHD now? Is it two years on since you were.

**Katty:** No It was more than that. It was 2019. So yeah, it's fine. I just have a kidney scan yearly. Um, the lungs are fine now I've got you. I'm aware of all the symptoms of a pneumothorax and the skin I'm still in the system of the Dermatology Department. So I every so often if I want to be seen and I can be seen. Yeah sort of once every year to three years. I think with covid everything's delayed. And I'm just watching the kids for signs of any of it because one's nearly 16. So potentially we get him tested just to see.

**Jazzmin:** How do your kids feel about it?

**Katty:** Well, I mean now they know they can fly, because before that restricted them and made their world quite different really. Even if they never go anywhere. It's just nice to know that you could yeah. Yeah, they're fine. They're fine. I think, I mean ideally hopefully they're tested and that's it. And then that would be the end of our family line. If they haven't got it because my brother doesn't have children so it would have gone away which would be lovely. Because you can't pass it on if they haven't got it.

**Jazzmin:** No, so you can only pass it on if you've got it. You've got a one and two chance of passing it on to your children.

**Katty:** Yeah, so that's all really and I'm just aware and things like traveling Insurance. That sort of stuff. And again, they can't ever find you on the insurance. They put you down as they put me down to something totally different, but I've told them what it is, you know? Yeah. So yeah, that's a tricky one actually insurance is a tricky one because they can never find you so find any sort of similar thing. So that that was a tricky, you know, that's the other thing that would probably be good if the insurance companies could realize that it's actually fine. Because they put down something really unrelated Hodgkin's lymphoma or something. That's totally different. Just very different.

**Jazzmin:** Yes. That's interesting to know because giving advice insurance we're not able to give that directly because it varies so much by country and people's medical backgrounds, but knowing that there's not even an option for BHD or something equivalent.

**Katty:** And actually my doctor when I first went to my doctor said I was going to take the test to be diagnosed one of my doctor said I wouldn't get insurance.

**Jazzmin:** You can get insurance with BHD which is the key thing. And also the reason you want to be diagnosed is so you can get that kidney screening. What advice would you give to someone now who's recently been diagnosed with the BHD knowing everything, you know?

**Katty:** Not to worry because I think I felt really really anxious when I first diagnosed and oh my God, that's it my lifes over. I'm gonna have a long collapse any minute that I felt really vulnerable and quite weak and my kidneys and It's actually it's actually fine. And you're monitored, you know, which is brilliant. So as long as you get the regular kidney scans, that's fantastic and the lungs as far as I understand you get your CT scan and that doesn't really change. You get to know baseline of where you are and that's all good. And the skin again. Got to get your skin checked anyway. I did have all my skin checks and I ended up having some moles removed, which is brilliant because I would not have gone otherwise. so, you know, it's a good thing. I mean as long as you've got the right people around you and the foundation support you with information. So yeah, so I would I wouldn't worry as much as I did.

**Jazzmin:** Thank you so much Katty! it's been and a pleasure to talk to you and I really hope you go on some wonderful holidays now.

**Katty**: Thank you so much and everyone. Yeah, it's fine!