A conversation with Jamie

I found out about Huntington's disease when I was quite young. Apparently, a neighbour told us, but I don't remember. It wasn't really a spoken subject in our house. So, we weren't sure what was wrong with Granddad when he started getting symptomatic. He was just a bit of a funny guy and we didn't know why.
We weren't told that my mum was gene positive as well. We also didn't know that our uncle was gene positive. We didn't know that it was hereditary.

When I was around 12 years old, my parents separated, and Huntington's Victoria got involved. Our family was given a worker and she gave us practically all the information that we needed to know. I found out then that it was hereditary and that we were all at risk of having this disease.

I remember being told a lot that I was a lot like my mum, and we'd been told that she was gene positive. So, it was very, very daunting and very scary leading up to 18 and knowing that I was able to get tested then.

Before I was 18, I left my family. I left my friends and I just started fresh in a regional area. I didn't know anyone. I didn't have a job. I picked up work pretty quick but stayed very isolated. I didn't want anyone to know what I was going through. I didn't want anyone to know that my mum was sick. I didn't really want to deal with it. I was pretty naive at that point.

I spent a bit of time talking to my middle sister. I told her just before I was going to go and get tested. I wasn't ready. I was still 18, just very young and didn't have a lot of support behind me at that time. So, I spoke to my sister about wanting to go get tested. And I arranged to meet a genetic counsellor.

I didn't know what the process was going to be. I don't even remember how I actually organised it all. It was about ten years ago now. My sister told my grandma that I was going to go and get tested and she contacted me. And she was very adamant that she was going to come along. But I didn't really think I wanted her there or anyone there. I didn't know how much of a big decision it was to go and get tested. I didn't know the repercussions of it.

I remember sitting down with this counsellor. I didn't know anything about him. He didn't know anything about me. We went through one session, and he got the genogram on my family, wanted to know who was sick. I actually didn't know much of the information at all – Grandma jumped in and put in all that information for me, and I realised how widespread it

was at that point. I learned a lot on that day. I had to go back for a second counselling session and I don't remember that one at all.

I had to go to the Royal Children's Hospital to go get tested. They sent the Starlight Foundation clowns in because I was terrified of needles and my grandma was laughing at me for acting like a sook. They only took a little bit of blood and they told me it would be up to seven weeks wait, I think, for the results. They gave me a fair bit of information on that day. And again, I don't remember a lot.

I went home and just worked and pretended like nothing was going on. Then when I came back [to the hospital], they asked me if I knew what I was going to do if I was positive or what I was going to do if I was negative. I was adamant that I was positive. I thought, that's it, I've got it. And then they told me that I was gene negative, and I didn't really know what to do. My grandma cried. I think I was confused. And yeah, I think they offered me more counselling after that and I declined. I thought, no, that's it, I'm fine. But I'd made a lot of mistakes when I was younger. Thinking, living my life as though I was going to be gene positive.

So, I hit this point at 18 when I found out that I was gene negative and I had this long and fruitful life that I could live without getting sick. And I thought, what have I done? I'd got myself in a lot of trouble. I'd isolated myself from a lot of my friends and family. It was hard. I felt very alone after that. I didn't really deal well with my results. I feel like I shouldn't have got [the test] so young and I shouldn't have left my family. It was such a hard thing, and I just didn't know how hard it was going to be. I had my mind set on being gene positive and that didn't work out.

I should've been more open-minded about what my results could have been. I should have asked my family for help. I should have told people more about what was going on rather than just hiding it behind drinking and getting in trouble. Nobody knew anything. I didn't want anyone to know anything. I spent a long time running away from it all. By the time that I was old enough to accept my gene status, I had a lot of rebuilding to do. I now know how important it is to have support behind you. Whether it's Huntingtons Victoria or your family or your friends, every little person helps, makes a big difference.