



Faces of CHD | Amanda's Story



Meet Amanda C of Victoria, BC

Age 35

CHD Diagnosis: ASD, VSD and Transposition of Greater Arteries (TGA)

I never really thought about my heart condition as a child and my mom and I never let it hold me back. I had surgery at 3 and 6 months, but my sister says I was never able to run until after my open heart surgery at 5 years old. It wasn't until I was a teenager and was watching a tv show where they showed someone having open heart surgery that it really hit me, it was eye opening what I had been through and the brevity of it.

One of my biggest challenges has been not fully understanding my condition and the implications for my health. I've had some memory loss/trauma from the surgeries so didn't remember it for a long time. But I've been lucky, I've had amazing care and a great support system. Living in Victoria, there isn't an ACHD doctor here on the island and travelling to Vancouver for annual appointments are costly and require day off work. I've been lucky in that I've been able to keep my cardiologist from when I was younger and living in Edmonton. Now I schedule my annual check ups when I go home to visit family. If something urgent comes up, then I see a pediatric CHD cardiologist in Victoria along with my family Dr., we all work together and I have great healthcare team taking care of me.

Looking into the future, I am concerned about pregnancy. I have been given the ok by my cardiologist, but I am still apprehensive. My cardiologist is great and we have very frank and honest discussions. Their advice is to live life and not let my CHD hold me back.

My advice for anyone transitioning into adult CHD care is to not be afraid. Be open to options (like seeing a paediatric cardiologist or surgeon if that's what's available) and do your research before your appointments, ask questions. Also, don't be afraid to ask for a second opinion.

Financial security is one of the most important things to ensure I have the best medical care in the future. If you find a job with benefits, take it!

I really try to live my life to the fullest. I travelled to Paris - I never thought I would see the magic of that city! I also have tried to face my fears - high up in the trees on an aerial obstacle course that is amazingly fun and challenging.

