

Our names are Priyanka and Bren. We sit on the Board of Directors for the Canadian Congenital Heart Alliance (CCHA) and are children of a parent with congenital heart disease.



Our mother, at the age of 16, a provincial triathlete outside of Canada, learned she had to have a coarctation of the aorta repair. This is a congenital narrowing of the aorta that results in a variation of pressure in a given direction, usually located at or next to the site of insertion of the ductus arteriosus. This became a scary and terrifying experience to go through as a teenager without much access to resources about CHD, even though it is the 8th most common one. The repair used end-to-end anastomosis; cutting out the coarctation segment and sewing the remaining two ends of the aorta back together. This surgery was a success and she continued to live a healthy and active life, eventually becoming a teacher, immigrating to Canada, and marrying our father.

However, once becoming pregnant with Priyanka, her community cardiologist realized that her Aortic Stenosis had become greatly exacerbated by pregnancy and immediately referred her to Toronto General Hospital. Here a multi-disciplinary team evaluated our mother's pregnancy and realized that the stress of it was increasing her heart work by 50% above normal at her 4th month mark (this usually occurs at the end of the 6th month of pregnancy). Though the normal course of action in the early 90's was terminating the pregnancy, her team decided on a more ground-breaking method. They arranged for an aortic balloon valvuloplasty while our mother still had Priyanka in utero. This procedure is done by feeding a long catheter to your groin and into the aortic valve. There is a balloon at the tip of the catheter that is inflated to help dilate the valve, reducing stress on the heart, and helping our mother safely carry Priyanka to term.

Not only was the procedure a success and one of the first to be performed during pregnancy anywhere, our mother became a pioneer patient and helped shape what is now the University of Toronto Pregnancy and Heart Disease program. This is one of the world's largest and most respected programs dedicated to treating complications of pregnancy. Our mother remembers how scared she was but how safe she felt to be in a room full of the kindest doctors who took the time to explain exactly what was going on every step of the way.

Four years later, once she was strong enough, our mother persevered again by undergoing the Ross Procedure. This is known as the switch procedure or the pulmonary autograft, pulmonary allograft procedure. Here, the aortic valve is replaced with a patient's own pulmonary valve. Then, the pulmonary valve is replaced with a bioprosthetic valve. Once again she was successful in this surgery which aided in the healthy delivery of Bren another three years later.



Taking different turns in life, Priyanka pursued cardiology, while Bren pursued kinesiology, two realms that were, and continue to be, large parts of our mother's life. Today, our mother continues to live a healthy and active lifestyle, with yearly outpatient visits to her congenital cardiologist. In her spare time, she supports us in our aspirations in academia, as well as our passion to advocate to the CHD community, providing resources she once had limited access to. In essence, being a part of CCHA is a family endeavour, a way for us to use our experience, connect with and educate others of the chance to bring new life into the world, even with CHD.