



2021 Canadian Women's Heart Health Summit

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Lori Constable-Smolcic

Woman with Lived Experience
Toronto, ON

Biography

Lori Constable-Smolcic is a Congenital Heart Disease (CHD) survivor, warrior and advocate with a degree in Nursing and a certificate in Smoking Cessation. I have worked over 20 years in various healthcare roles at Trillium Health Partners and currently work in the Cardiac Surgery Database department.

Born with severe complex CHD in 1972 in Toronto. My defects are Atrial Septal Defect (ASD), Ventricular Septal Defect (VSD), Atrioventricular Septal Defect (AVSD), and Cleft Mitral Valve Defect. Back then the chances of dying from CHD as a child was 50/50, and if you lived to adulthood you were a miracle. I've had three open heart surgeries (OHS), just had my seventh defibrillator (AICD)/Permanent Pacemaker (PPM) surgery, one cardiac ablation, multiple cardioversions, and live with acute on chronic right sided heart failure and pulmonary Hypertension in which a heart transplant may be required. Additionally, CHD runs down the generational line in my family history in both males and females. Therefore, I believe I have a unique opportunity to bring expertise to this Structural Heart Disease (SHD) group from a patient, a family member, and a healthcare professional point of view.

Once I turned eighteen and went over to Toronto General Hospital (TGH) for my adult congenital cardiac care I realized how little patient support, funding, and expertise was there for or available to us. It was disturbing how many patients were lost in transition as they lived outside of the only Adult Congenital Cardiac Clinic (ACCC) in Ontario; how many patients were told they were fixed and didn't need follow up care; how many patients felt lost/frightened going from being coddled to being told that you're responsible for your health; how many patients knew very little about their condition; how women with CHD were brushed off with some of their symptom complaints; how many patients and their families didn't have a support network; how there were at one time only two allocated beds on the cardiac floor for CHD patients to use but nothing on the floor that was geared to them; and how many patients felt that the government, the health care system, and that organizations such as the Heart and Stroke didn't care about them now as they were adults. These are true patient testimonies

Womensheartsummit.ca

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that the Canadian Congenital Heart Alliance (CCHA), The Beat Retreat, and patient advocates such as myself have gathered and brought to our healthcare professionals over the years.

For these reasons is why I became a nurse, why I keep advocating for CHD, why I speak up for those patients whom feel forgotten, why I am a member of CCHA, why I co-chair the Beat Retreat, and why I help contribute as a member to the Heart & Stroke SHD Council.