

The Canadian Congenital Heart Alliance – we're here for you!

In 2004, a group of adult congenital heart defect (CHD) patients attended a meeting at the Toronto General Hospital where we learned that the clinic, the largest and most prestigious in the world, was at risk of being closed due to lack of funding. The doctors and nurses there encouraged us to band together to advocate for ourselves because they said they couldn't do it alone. Until that evening none of us had a clue that our care was in jeopardy. Like most patients, none of us knew anyone else with a heart defect and besides our appointments and surgeries, didn't have much to do with the hospital. It was a real wake-up call!

Later that month four of us formed the Canadian Congenital Heart Alliance (CCHA), a registered non-profit organization made up of patients, their families and friends, and the medical community, to support and advocate on behalf of Canadians with CHD. While collecting information and statistics to create a brochure and website I learned that thanks to outstanding pediatric care there are now far more adult "survivors" than there are children (130,000 adults vs. 50,000 kids) and yet the medical system hasn't kept pace. While it was known that more and more children were surviving past 18 years of age, not much was done to prepare for what has been referred to as a "tsunami" of survivors. In the 1960s only about 20% of children survived to age 18 and now it is 98%. In fact there are more Canadians with CHD than there are with multiple sclerosis, HIV/AIDS, Parkinson's disease, cerebral palsy, or cystic fibrosis, and yet hardly anyone knows about it, and the funding just isn't there.

There are numerous children's support groups across the country (mostly raising money for pediatric hospitals) and several local adult groups but CCHA is the only national organization representing both children and adults with CHD. Our thinking is that although the medical system is divided into pediatric and adult care, CHD lasts a lifetime; while CHD patients can be repaired with surgeries, they are never fixed.

We have been focusing a lot of our energies on adult CHD because that's where the crisis is. After age 18 the standard of care largely evaporates; that's not to say it isn't very good, but there just isn't enough of it. There are too few centres in Canada with specially trained cardiologists and surgeons, and little incentive for young cardiologists to specialize. There are very few "soft services" available, like social workers and psychologists to deal with the psycho-social issues which plague patients who have struggled all of their lives with a life-threatening illness.

We would like to have more parents involved because they have a vested interest in their child's care and have the energy to help.

What we've done so far

Funding for an adult CHD research project

With a small executive committee and an advisory board we have accomplished several landmark events: we were finally successful in getting Heart & Stroke Ontario to provide, for the very first time, \$100,000 for an adult CHD research project. We have made a couple of strong allies there who are trying to help us though CHD is still not part of their mandate and may never be.

The Beat Retreat Camp

For the past two years we have run an adult weekend camp called the Beat Retreat. It provides adult patients the rare opportunity to get together to share stories, support, and the chance to have fun canoeing, rock wall climbing, playing volleyball, doing arts and crafts, and much more. For many, it's the first time they've been away to camp. In the future we hope to run a kid's camp because there is only one in all of Canada for kids with devices or who have had a heart transplant.

Website and online forum

We have a great website with lots of information including recent statistics, as well as an online forum/chat room for CHD parents, kids and adults to share information.

Awareness DVD

Last summer we created an awareness film called "Born with a Broken Heart" – you can see it on our website or on YouTube. So far it has over 1,800 views!

Attendance at CCS

For the past three years we have set up our booth at the Canadian Cardiovascular Society meeting to help make regular cardiologists more aware of CHD and the need for specialized care for their patients. We will be attending again this fall in Vancouver.

Education days, service clubs, and more

We have participated in pediatric family education days, talking to parents and kids, and we have spoken at several Rotary and Lion's clubs in Ontario, Quebec, and NS. We have also spoken to hundreds of cardiologists at regional meetings and have tried to get our brochure available in every centre. There is so much more we can do, but we're limited by funds, people power, and energy. Many of our members are struggling with major health issues.

Life, dental, and travel insurance without a medical

For most of us, getting life insurance was out of the question. Some patients manage to get coverage through work, but many are out of luck. CCHA is the only organization to offer life, dental, and travel insurance to patients with no medical. For contact information, visit the website and click on "Resource Centre".

Chapters

We have Ontario and Maritime chapters and possibly a chapter starting up in BC. Unfortunately, our Alberta chapter was discontinued but we're hoping to get another one going in the future. We're hoping more people take the initiative to set up chapters in their community and to fundraise so we can expand our programs and help more people.

If you would like to learn more about CCHA please visit our website at www.cchaforlife.org and if you'd like to get involved please email me at communications@cchaforlife.org.

Shelagh Ross

Vice-president and CHD patient