



CCHA IS
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ANNUAL REPORT 2014



CANADIAN
CONGENITAL
HEART ALLIANCE

WHO WE ARE

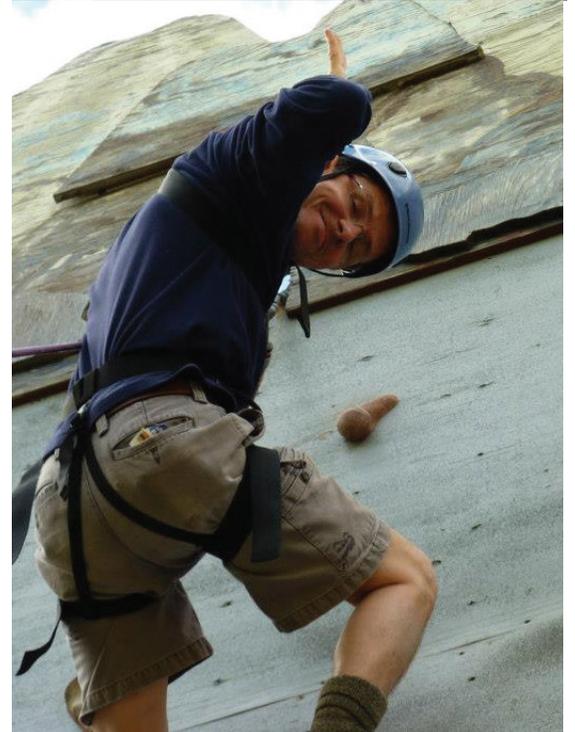
The Canadian Congenital Heart Alliance (CCHA) is a volunteer-run registered charitable organization made up of patients with a congenital heart defect, their friends, families, the medical community, and aligned patient groups. With your support, we aim to improve the quality of life for these patients, many of whom require lifelong expert care.

OUR MISSION

To improve the quality of life and health outcomes for individuals with congenital heart defects: by raising awareness; providing peer support and mentoring; advocacy; and advancing research.

WHAT IS A CONGENITAL HEART DEFECT?

A congenital heart defect (CHD) is a structural problem (or defect) in the heart that is present at birth. CHD was once considered a childhood disease since few patients survived to adulthood. Today, about 90% of children born with CHD survive into adulthood. About half, however, will require life-long monitoring and specialized care.



SURVIVAL RATE IMPROVES BUT MEANS NEED FOR ONGOING CARE AND SERVICES

According to a 2014 Canadian study, the number of adults with CHD has increased 70% from 10 years ago, thanks to outstanding medical care and research. This is not to say the problem is fixed! While most patients are surviving to adulthood not all remain fully healthy and functional. A significant percentage of patients do not fare well as they age, facing repeat procedures and surgeries, and even early mortality. The need for lifelong advocacy, support, and research has never been greater.

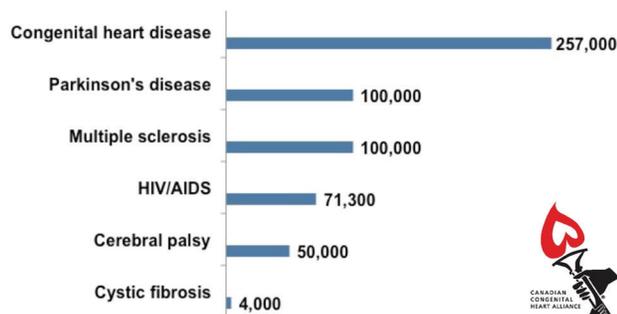
There are now an estimated 257,000 Canadians with CHD, and two-thirds are adults. About half of the patients will require ongoing specialized cardiology care, which is provided at the 15 specialized centres across Canada. Many will require re-operations, implantable devices (e.g. pacemakers and defibrillators), and costly medications. Unfortunately, only a fraction are now being followed; the rest are considered “lost to follow-up” – perhaps because they feel too well to consider themselves “heart patients”, or they think the distance to travel is too far, or they

don't know or have not been told they should be getting specialized care. Regardless of the reason, many patients end up being seen when it's too late to receive optimal care. Through our ongoing efforts, we are trying to make patients and their families aware that specialized care exists, and to encourage them to get the care they need as they age and face new health challenges.

Through our educational projects and presentations, peer support networks and camp, advocacy work, and research advancement, we are working hard to make sure patients and their families get the information and support they need throughout their journey with CHD.

One of our priorities for 2015 is to secure sufficient funding so that we can continue to grow and expand our programs. We will be initiating several fundraising campaigns in 2015, and we will be relying on our members and supporters to help us succeed. Thank you to all who have helped us to get this far!

CANADIAN POPULATION DISEASE STATISTICS



Sources: Canadian Congenital Heart Alliance, Parkinson Society of Canada, Multiple Sclerosis Society of Canada, Public Health Agency of Canada, Active Living Alliance, Cystic Fibrosis Canada

Shelagh Ross
CCHA past-president, and
2015 Executive Director





“When I grow up...
I will need the medical
system to be ready
for me”

Please support the
Canadian Congenital
Heart Alliance

cchaforlife.org



ANNUAL GENERAL MEETING & NEW BOARD OF DIRECTORS

Our AGM was held on December 2 at SickKids in Toronto and via web and tele-conference. We're delighted to welcome four new board members:

- Eric Gonneau** – President
- Krista Vriend** – Vice-president
- Denise Hackett** – Treasurer and Secretary
- Lea Legge**
- Saad Minhas** (honorary board member)

Shelagh Ross is now the Executive Director.

To read the complete board member bios please go to www.cchaforlife.org/board-directors



“As a professional I work with adults with congenital heart disease every day. I see their bravery and their positive outlook, I see the great successes of the treatments that have brought them to care, and I see the challenges that they face going forward. Patients and their families must build support networks and develop political strength to ensure the world becomes a better place for them as they grow and age. Thankfully, CCHA is here to provide that structure, and that is why I support them. I encourage you to support them too.”

~ Dr. Jack Colman, Cardiologist, Mount Sinai Hospital
and Peter Munk Cardiac Centre/UHN, and Toronto Congenital Cardiac Centre for Adults

FOUR NEW PATIENT EDUCATION DOCUMENTS

We have recently created four new educational documents for patients, based on publications produced by the Adult Congenital Heart Association in the U.S. They're informative and easy to read. Please go to www.cchaforlife.org/CHD Information/About Congenital Heart Defects/Patient education hand-outs.

- Tetralogy of Fallot
- Coarctation of the aorta
- Transposition of the great arteries after Mustard/Senning repair
- Pulmonary hypertension

NEW: CCHA FOR LIFE.ORG

Our brand new website launched in September! It's now more attractive and much easier for everyone to use! I'm happy to say that thanks to grants from the website company Pixel Sweatshop, and from the Children's Hospital of Eastern Ontario (to host their "Healthy Living in Kids with CHD"), 100% of the costs were covered.

If you haven't seen the new website, please take a few minutes to go through it because there's lots of great information.

Also, encourage your family, friends, colleagues, etc. to join CCHA (sign-up in at top right of website) in order to build our membership, because numbers count when trying to improve services and support for patients.

CHD PATIENTS ASK...

On the website under "CHD information" we've posted 31 questions that were asked by our Beat Retreat campers and answered by a team of nurse practitioners. For example:

- *Does having scar tissue at the top of the ventricles and between the pulmonary artery and aorta cause fatigue?*
- *Can beta-blockers make you feel sluggish?*
- *Can someone with a half heart (single ventricle) carry a baby to term?*

There's lots of great information here. Maybe the answer to your questions!



Q and A: Transposition of the Great Arteries after Mustard/Senning Repair

What is Transposition of the Great Arteries?
In transposition of the great arteries (TGA), the heart's two major arteries are reversed. The blue blood entering the heart gets pumped directly out to the body without going through the lungs. Blood coming from the lungs gets sent back to the lungs rather than out to the body. Babies born with TGA will die unless there is a hole between the two sides of the heart to allow some red blood to get out to the body. Many people with TGA are born with a ventricular septal defect (VSD) that allows this to happen. In others, doctors make a hole to keep them alive. Babies born with TGA almost always need surgery to help the heart work more normally. Two of these surgeries are the Mustard and the Senning repair (also called Mustard or Senning procedures). The main other surgeries are the arterial switch and Rastelli procedure.

What is a Mustard or Senning repair?
The Mustard and Senning repair are two similar operations for TGA. Each is named for the surgeon who first performed the operation. In both, the surgeon creates a two-way baffle in the top part of the heart. This baffle serves as a bridge between the two sides of the heart. In a Senning procedure, the surgeon uses the patient's own tissue to create the baffle. In the Mustard procedure, a synthetic material is used. Both are called "atrial switch procedures" because there is a baffle through the heart's top part, or atria, which allows the blood to reach the ventricles.

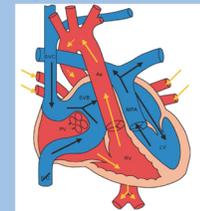
When and where were Mustard and Senning repairs first done?
Dr. Ake Senning of Sweden performed the first Senning procedure in 1957. Dr. William Mustard, from Canada, performed the first Mustard procedure in 1963. In general, the Senning was more common in Europe and the Mustard was more common in the United States and Canada.

Are the Mustard and Senning repairs still used?
Today's children born with TGA usually have an operation called an arterial switch. This operation was first developed in the late 1980s. In the arterial switch, the surgeon disconnects and reattaches the heart's arteries to create more normal blood flow. This means that Mustard and Senning patients are usually between 22 and 50 years old.

What kind of long-term problems do people with a Mustard or Senning repair experience?
There are three kinds of problems that people with a Mustard or Senning repair face: rhythm problems, baffle problems, and pump problems.

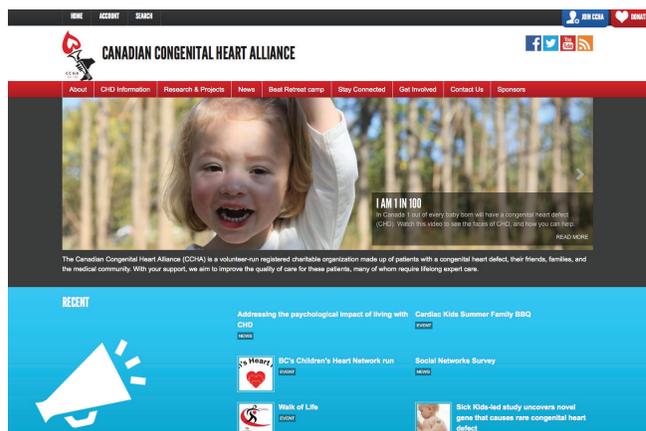
- **Rhythm problems:** Many TGA patients have inborn problems with the heart's electrical system. The scarring from previous surgery can also cause electrical problems. Sometimes the heart's "relay box," called the sinus node, is damaged. This can cause sick sinus syndrome, which makes the heart beat too slowly. Pacemakers are used to treat a too-slow heart. Up to 25% of Mustard/Senning patients have a pacemaker by adulthood. Other TGA patients experience heart rates that are too fast (tachycardia). This happens when a section of the heart's electrical system starts firing too quickly. Heart rhythm doctors now often use ablation to treat too-fast heart rates. The doctor first identifies the area of the heart that is misfiring. Then, this area is scarred to stop the fast heart rate. If the ablation is successful, further treatment may not be necessary. Medication can also be used to treat heart rhythm problems. If the problem is life-threatening, a defibrillator might be implanted. A defibrillator is a device that shocks the heart into a regular rhythm.

In this illustration of a heart with d-TGA that has had a Mustard/Senning repair, the blue blood flows through the two-way Systemic Venous Baffle (SVB) to the left ventricle. The blue blood is pumped to the lungs to get oxygen. The red oxygenated blood is directed through the Pulmonary Venous (PV) baffle to the right atrium and gets pumped by the right ventricle to the rest of the body.



KEY:
SVC – Superior Vena Cava
IVC – Inferior Vena Cava
SVB – Systemic Venous Baffle
LV – Left Ventricle
MPA – Main Pulmonary Artery
PV – Pulmonary Venous Baffle
RV – Right Ventricle
Ao – Aorta

Image courtesy of the Columbus Ohio Adult Congenital Heart Disease Program at Nationwide Children's Hospital Heart Center, Columbus, Ohio



The screenshot shows the CCHA website with a navigation bar, a featured article titled "I AM 1 IN 100" about a child with a congenital heart defect, and a "RECENT" section with articles like "Addressing the psychological impact of living with CHD" and "BC's Children's Heart Network run Social Networks Survey".



AWARENESS CAMPAIGNS

These are just two of the wonderful posters we created for CHD Awareness Day on February 14. Thank you to all who sent in photos!

WALKING...

CCHA raised over \$16,000 in the Cardiac Foundation of Canada Walk of Life in May, and we split the proceeds with them 50/50.

TALKING...

In addition to all of the materials we created, we were also invited to speak at a number of events, including the SickKids Family Education Day (for our 6th year), and the Canadian Cardiovascular Society Congress in Vancouver, where we continued our “Share the Care: Congenital Heart Patients Deserve It!” initiative, in an ongoing effort to educate community cardiologists about the need for specialized adult CHD care. We also attended the Cardiac Kids Family BBQ and spoke at Toronto SickKids nursing session, and have been invited back for a second year in April 2015.

CCHA BEAT RETREAT FILM

During our 2013 Beat Retreat, young filmmakers Adam Cunliffe and Kerry Noonan followed our campers’ activities to create a wonderful video, which we’ve been using to showcase our one-of-a-kind camp for adults with CHD. The Beat Retreat is the only camp of its kind in the world, and we’re very proud of it! You can watch the video at www.cchaforlife.org/multimedia/videos/beat-retreat-camp

“At SickKids we regularly offer patients and their families opportunities to learn and network from each other. A consistently well-attended session at any event has been an adult with CHD sharing their experience and offer support and encouragement to young families starting their journey. Seeing and hearing grown-ups who have very successful lives gives tangible and incredible hope to families that hospital staff can’t offer. The Canadian Congenital Heart Alliance has been a great resource for us!”

~ Jennifer Kilburn, Nurse,
The Labatt Family Heart Centre



6TH BEAT RETREAT CAMP

In September we ran our 6th annual Beat Retreat camp for adults with CHD. This year we had 30 campers, 3 nurse practitioners, and a psychologist to help answer questions and provide support (and join in the fun!). Our hope is to raise enough funds to be able to run camps in other provinces. Because really, it's a great thing! But instead of me telling you how great the camp was, here are a few testimonials:

"I wasn't sure what to expect. I loved every second of camp. As I drove away I just wanted to turn my car around and relive the weekend over again. I felt so welcome, like I was a long-lost cousin. Everyone has so much love for everyone! I can't wait for next year! It can't come fast enough."
~ Chelsea

"CCHA's Beat Retreat camp has been a wonderful connection to many young adults who like our daughter Shannon live with congenital heart disease. Through the power of the camp Shannon now has friends like her to share stories and support each other on this lifelong journey. Thank you!"
~ Gord and Dale Durnan

"What another awesome year, and to see our small original group to grow to over 30 is incredible! The best part of camp this year for me was meeting all the new folks and of course an awesome night of euchre! But more important was the welcoming by all the new faces - it's like coming home to my extended family. You guys did a great job!"
~ Doug

"At the age of 62 I stumbled across a Facebook page about tetralogy of Fallot, the birth defect I've lived with my whole life. Through that I found a posting about the Beat Retreat, a program run by the CCHA. At the Beat Retreat I was able to finally talk to others about our survival and difficulties we had faced growing up. When I hopped into the car on Thursday I was driving into uncharted waters. When I was driving home Sunday I felt like a member of a much larger family. Thank you guys, thank you Beat Retreat, and thank you CCHA!"
~ Bruce



CHAPTER UPDATE



CCHA chapter Hearts of London/Middlesex once again celebrated February 14 by having the London City Hall lit up in red. Lisa Wright, the London chapter leader, spoke at several events and ran networking meetings. She and volunteers also ran a successful garage sale fundraiser. Thank you Lisa!

The BC chapter, led by Julie Bard, was very active in its second year. Julie and volunteers ran the CCHA booth at the Children's Heart Network Christmas party as well as several community booths over the Christmas holiday to create awareness about CHD. Julie also presented at a local Kiwanis Club.

On February 14 the chapter ran its first annual Congenital Heart Warriors Walk in Abbotsford, BC, with over 100 participants, raising \$3200. Plans are underway for the 2nd annual walk this February, complete with online registration.

Julie also attended the Children's Heart Network Wine Gala where she managed to fit in some power networking! In October she helped CCHA's co-founder and board member Paula Andrade at the Canadian Cardiovascular Society Congress in Vancouver, manning the booth and spreading the CCHA word. Thank you Julie!

"The CCHA is a very important partner in patient care in the congenital heart disease world. So many patients have rare, even unique diagnoses, that it is essential for them to have the support of others with similar conditions, helping them navigate their course through the health care system.

The insights we as health care providers, get from our patients and organizations like CCHA, definitely help inform and improve the care we can offer. Thanks for your support in this work."

~ Derek G Human, BM, BCh, MRCP (UK), FRCPC, Head, Division of Cardiology,
BC Children's Hospital



"As a congenital heart patient, I have been grateful to the CCHA for providing the leadership for all of us living with this condition. As an organization dedicated to raising awareness, providing support and advocacy, the CCHA continues to have real impact on quality of life issues for all of us. As volunteers, their caring dedication has made a real difference to ensuring that our medical system is working for congenital hearts across Canada. It is for this reason that I make an annual donation and encourage others to support the CCHA."

~ Daniel Weinzweig

FINANCIAL REVIEW

STATEMENT OF FINANCIAL POSITION 2014

	2014
ASSETS	\$
CURRENT	
Cash	25,554
Commodity taxes recoverable	2,800
Prepaid expenses	2,038
	30,392
LIABILITIES	
CURRENT	
Accounts payable and accrued liabilities	0
	30,392
FUND BALANCE	
	30,392
INCOME	
Beat Retreat Camp	1,350
Fundraising Donations	11,626
Gift in Kind	500
Grants Received	7,352
Donations	124
- Memorium	6,357
- Online	1,909
- Personal	29,218
EXPENSES	
Events	720
Beat Retreat Camp	5,143
Bank Charges	207
Conferences	2,629
Fundraising	217
Insurance	566
Office & General	2,712
Administration (dedicated grant)	16,007
Professional fees	0
Postage & Telephone	549
Travel	113
Promotion	2,047
	30,909
EXCESS OF REVENUES OVER EXPENSES	-1,691
Fund balance, beginning of year	32,082
FUND BALANCE (Dec 31)	30,277





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Jennifer Graham, BSc (Hons)

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University of British Columbia

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Assistant Professor of Medicine, University of Alberta

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ACHD and Congenital Cardiovascular Surgical Nurse Practitioner
Toronto Congenital Cardiac Centre for Adults, Peter Munk Cardiac Centre, UHN

Henryk Kafka MD, FRCPC
ACHD Cardiologist, Queen's ACHD Clinic
Department of Medicine, Queen's University, Kingston

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