ANNUAL REPORT 2013

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.

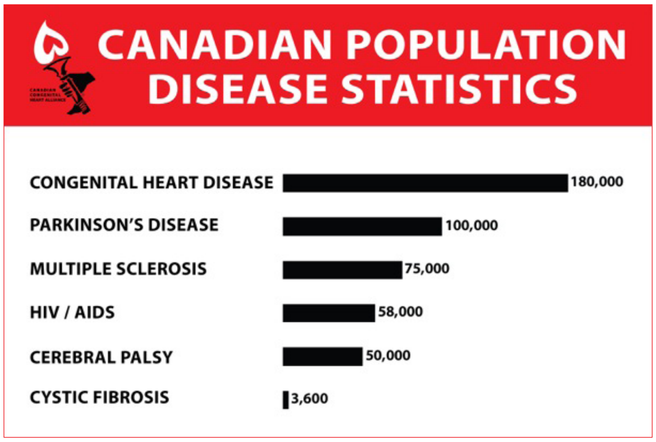
What is a congenital heart defect?

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 95% of children born with CHD survive into adulthood. About half, however, will require life-long monitoring and specialized care.

2013 marks the eve of CCHA's 10th anniversary! While the past nine years have gone by quickly, all in all raising awareness about CHD has been a lot of hard work, accomplished by a small group of dedicated volunteers. To move to the next level we need to create strong partnerships with allied organizations and industry to help make our goals a reality. With a rapidly growing population of CHD "survivors", *now* is the time to act.

Despite the progress we've made, one of our ongoing challenges is that most people equate heart disease with old age, obesity, lack of exercise, and smoking. Trying to change that mindset is our challenge. If they think of CHD at all, they associate it with something that happens to babies. But the fact is, most babies are surviving. Fifty years ago only about 20% of kids survived to age 18, but thanks to outstanding medical advancements, now about 90-95% will become adults. This is wonderful news, but it means that more and more children with really complex heart defects are now becoming adults with really complex heart defects. This not only puts a huge strain on patients and their families, but also on a medical system that hasn't kept pace. There are now more than 180,000 Canadians with heart defects, many requiring lifelong expert care. In fact there are more Canadians with CHD than many more "popular" and well-known diseases, and awareness and support of CHD falls short of the need.

As the only organization in Canada that advocates for and supports Canadians with CHD and their families, it is up to us to ensure that we get the care and support that we need...throughout our lives. This means raising awareness about CHD and making sure there are enough specially-trained medical professionals to care for us, enough support staff, enough dedicated hospital beds, etc. We also want to make sure that when we go to our family doctors or end up in the emergency department, those medical professionals know how to treat us or whom to refer us to. Last but not least, we want to find the 77% of patients lost to follow-up, to make sure they get the care they need to live long healthy lives.


CANADIAN POPULATION DISEASE STATISTICS

At this point, we are still volunteers working on a shoestring budget, with a post office box we call home. To get to the next level, we need the financial and moral support of the community, allied organizations like the Heart and Stroke Foundation of Canada, and industry.

We will continue to raise awareness about CHD among patients, their families, and the medical community to help ensure we get the care we need. We want to develop more programs to provide peer support, mentoring, and outreach to CHD patients and their families. We also want to focus on promoting CHD-related research. We have done so much already with so little. Just imagine what we could accomplish with a bit more! That being said, we wouldn't be here at all without the support we've received over the years from patients, families, the medical community, and our wonderful sponsors!

Thank you to all who have helped us along the way. Your support – moral, financial, and volunteerism – are all very much appreciated.

Shelagh Ross
CCHA president

FOLLOWING ARE HIGHLIGHTS OF THE CCHA'S MANY ACHIEVEMENTS FROM 2013:

"SHARE THE CARE" INITIATIVE

At this year's Canadian Cardiovascular Congress in Montreal in October we launched our "Share the Care" message, directed at community cardiologists and GPs to educate and remind them to refer their adult CHD patients to one of the 15 specialty centres across Canada. We provided a laminated information sheet with contact information (www.cchaforlife.org/posters-brochures), along with a coffee mug with the website address. Then in early December we attended Heart and Stroke's Clinical Update meeting, for GPs and nurses, and spread the message to them. We were somewhat dismayed to find that nearly none knew anything about adult CHD programs in Canada and the 15 specialty CHD centres, and the vast majority only thought of CHD in terms of children. There is still a lot of educating to do!

CCHA GOES ON THE ROAD

Earlier in the year CCHA spoke at the International Symposium for Adults with Congenital Heart Disease, in Washington State, followed by an invitation to attend a tetralogy of Fallot conference in Marseille, France. It was heartening to discover that although CCHA is still experiencing growing pains, we were applauded by European patient organizations and cardiologists for being well organized and well run! Wow!

WALKING AND TALKING

In addition to these larger conferences, we attended the Sick Kids Family Education Day for our 5th year, and Gabrielle's Ride, to support pediatric CHD and stroke. We also participated in the Cardiac Foundation of Canada's (CHFC) Walk of Life, raising over $15,000 (we split the proceeds 50/50 with them), making us the 1st place corporate fundraising team! Thanks go to the 57 CCHA participants who all helped to make the day a big success.

CHEO KIDS AND HEALTHY LIVING PROJECT

CCHA has also been involved with the Children's Hospital of Eastern Ontario's Cardiac Kids Quality of Life research project, to promote healthy living for kids with CHD. More information can be found on our website.

STRATEGIC PLAN MEETING

In May, CCHA board members met for 2 days in Toronto, and aided by a talented facilitator, drafted an updated Strategic Plan. To read the plan, and other important CCHA documents, visit www.cchaforlife.org/governance-documents.

NEW CCHA BROCHURES

Thanks to a grant from Actelion Pharmaceuticals Canada Inc., and permission from the Adult Congenital Heart Association in the U.S. to adapt their material, we were able to publish two new brochures for our members – one for kids with CHD and one for adults. If you are a healthcare professional and would like some brochures for your clinic, please email info@cchaforlife.org.


When your Child
has a Heart Defect
Planning Ahead for
Lifelong Heart Health

CCHA IN THE PRESS

We received some great press coverage this year, thanks in large part to CCHA's London, Ontario chapter leader Lisa Wright, and colleagues, who got February 14th declared Congenital Heart Disease Awareness Day in London-Middlesex. As well, CCHA member and Beat Retreat camp founder Toby Cox was featured in a Globe and Mail article about the high cost of survival, and an article about CHD and CCHA was featured in the April issue of Chatelaine magazine. To read the articles visit www.cchaforlife.org/media.

5TH BEAT RETREAT CAMP

In September we ran our 5th annual Beat Retreat camp for adults with CHD. This year we had 28 campers, 2 nurse practitioners, and a psychologist from the Toronto adult CHD clinic. As usual, the camp was a huge success, and with funding and support, we hope to offer similar camps in other provinces in the future. We are delighted to have had the expertise of two young filmmakers to make a documentary about the camp – thank you Adam and Kerry! Please visit www.cchaforlife.org/multimedia/videos/beat-retreat-camp to watch the video.

AGM & GIVING TUESDAY

On December 3 we held our annual general meeting, welcoming three new board members: Jennifer Graham, Adrian Rose, and Aubyn Baker.

On the same day we celebrated Giving Tuesday, an initiative that encourages Canadians to give to a charity of their choice. To celebrate the day, talented CCHA member Laurie Haughton, mom of a CHD son, created a “1 in 100” video which we used to promote the CHD story. You can watch the video by going to www.cchaforlife.org/multimedia/videos/i-am-1-100. *Note, due to music copyright laws, the video can only be viewed using a computer, not on mobile devices. Another life lesson for CCHA!

BC chapter leader Julie Bard and helpers have made a big impact in their first year: Julie has spoken to several community groups, has met with the Children's Heart Network, and is organizing the first ever "Congenital Heart Disease Warrior Walk" on February 15th in Abbotsford, BC! As well, the Mayors of Chilliwack and Abbotsford declared February 14 CHD Awareness Day!

Hearts of London/Middlesex began its first year having February 14th recognized as Congenital Heart Defect Awareness Day. Lisa Wright (chapter Chairperson) spoke in City Council chambers to explain CHD and the need for more awareness. Red hearts were worn on all council members' lapels and throughout the city. Lisa also spoke at City Hall alongside Liz Burrill, Nurse Practitioner from Paediatric Cardiology, Children's Hospital, London Health Sciences Centre. City Hall was lit up on the exterior in red from the 13th evening all through February 14th in recognition of those with CHD!

On February 14th, Lisa's daughter's school raised $480 selling candy grams and presented it to Paediatric Cardiology with a huge valentine in the atrium of the hospital. The funds will be used to help pay for home monitoring equipment for children with CHD. Heart-shaped balloons and cake were given to patients on behalf of Hearts of London and CCHA.

The chapter will continue to promote Feb. 14th as CHD Awareness Day and is looking forward to starting to put together Heart Care bags for families travelling from the London area to Toronto for surgeries and other interventions.

FUTURE PLANS

Our plans include launching our new website, as well as a regular e-newsletter; expanding funding partnerships; developing patient education material, including a Q&A section for the website; creating an article for *Canadian Family Physician*; expanding the patient story section of the website; creating an official medical advisory board; continuing to develop fundraising events; expanding our social media reach; and furthering partnerships with stakeholders.

STATEMENT OF FINANCIAL POSITION 2013

	2013 $	2012 $
ASSETS		
CURRENT		
Cash	26,791	26,662
Commodity taxes recoverable	3,688	2,755
Prepaid expenses	2,604	62
	33,083	29,479
INTANGIBLE ASSETS		
Trademark	5,636	5,636
Less: accumulated amortization	5,636	4,837
	-	799
	33,083	30,277
LIABILITIES		
CURRENT		
Accounts payable and accrued liabilities	1,000	1,668
FUND BALANCE	32,083	28,609
	33,083	30,277

STATEMENT OF OPERATIONS AND CHANGES IN FUND BALANCE 2013

REVENUES	52,599	51,791
EXPENSES		
Amortization	799	1,127
Bank Charges	212	174
Conferences	14,933	10,402
Fund raising	39	51
Insurance	1,044	1,038
Office and general	2,490	3,593
Administration (dedicated grant)	18,113	13,585
Professional fees	3,224	500
Education Grants	-	3,000
Promotion	8,271	3,430
	49,126	36,899
EXCESS OF REVENUES OVER EXPENSES	3,474	14,892
Fund balance, beginning of year	28,609	13,717
FUND BALANCE December 31, 2013	$32,083	$28,609

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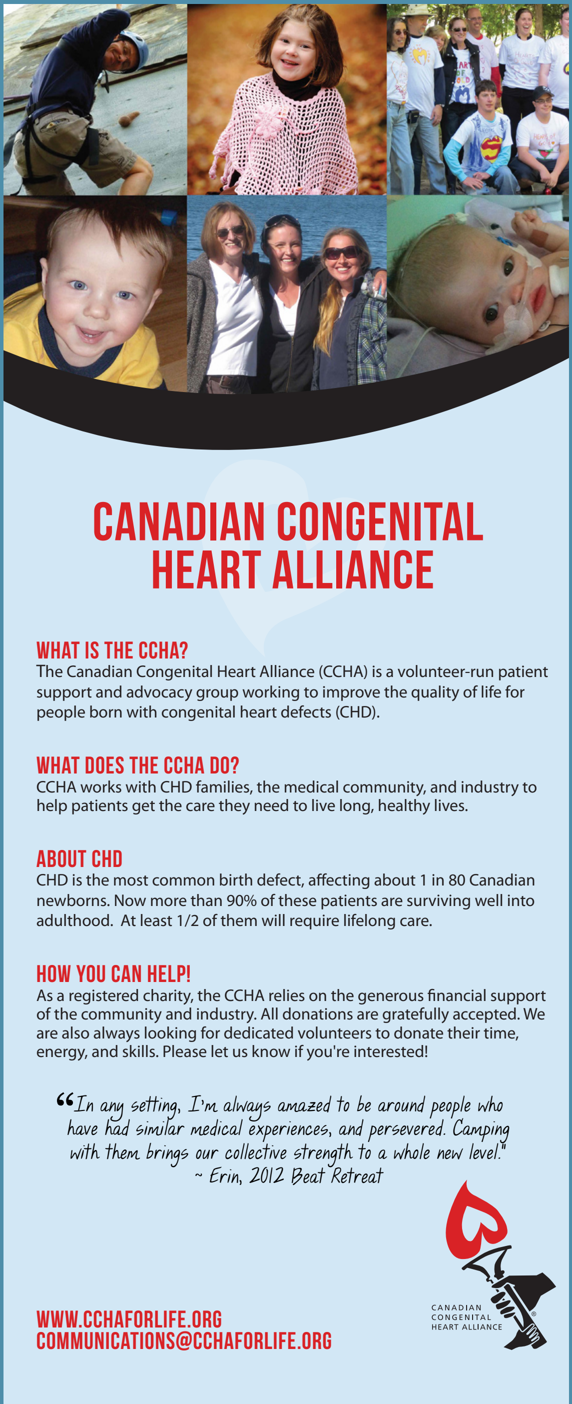

CANADIAN CONGENITAL HEART ALLIANCE

WHAT IS THE CCHA?

The Canadian Congenital Heart Alliance (CCHA) is a volunteer-run patient support and advocacy group working to improve the quality of life for people born with congenital heart defects (CHD).

WHAT DOES THE CCHA DO?

CCHA works with CHD families, the medical community, and industry to help patients get the care they need to live long, healthy lives.

ABOUT CHD

CHD is the most common birth defect, affecting about 1 in 80 Canadian newborns. Now more than 90% of these patients are surviving well into adulthood. At least 1/2 of them will require lifelong care.

HOW YOU CAN HELP!

As a registered charity, the CCHA relies on the generous financial support of the community and industry. All donations are gratefully accepted. We are also always looking for dedicated volunteers to donate their time, energy, and skills. Please let us know if you're interested!

> *"In any setting, I'm always amazed to be around people who have had similar medical experiences, and persevered. Camping with them brings our collective strength to a whole new level."*
> *~ Erin, 2012 Beat Retreat*

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WWW.CCHAFORLIFE.ORG
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WE NEED YOUR HELP! AS A REGISTERED CHARITY, THE CCHA RELIES ON THE GENEROUS FINANCIAL SUPPORT OF THE COMMUNITY AND INDUSTRY. ALL DONATIONS ARE GRATEFULLY ACCEPTED.

THANK YOU...FROM THE BOTTOM OF OUR HEARTS!

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