

ANNUAL REPORT 2012

CANADIAN
CONGENITAL
HEART ALLIANCE



PRESIDENT'S MESSAGE

Who we are

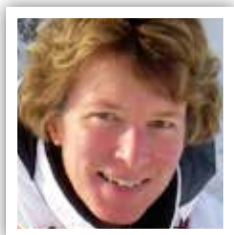
The Canadian Congenital Heart Alliance (CCHA) is a volunteer-run registered charitable organization made up of patients with a congenital heart defect, their friends, families, the medical community, and aligned patient groups. With your support, we aim to improve the quality of life for these patients,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



2012 WAS A YEAR FOR BUILDING CONNECTIONS: WITH PATIENTS, MEDICAL PROFESSIONALS, AND RELATED ORGANIZATIONS ACROSS THE COUNTRY.

Early in the year, the CCHA launched its “One Country, One Voice” initiative. This initiative focuses on making CCHA a truly national organization that represents all congenital heart defect (CHD) patients across Canada.

Thanks to a \$10,000 grant from The Medtronic Foundation, we were able to push ahead with that initiative – traveling across the country to connect with the medical community, build alliances with patient organizations, mobilize volunteers, and lay the groundwork for new chapters.

We believe that establishing a national network with a unified voice will enable us to better represent CHD patients and their families. Equally important, we believe it will give us more credibility in the eyes of government, media, and the medical community.

As part of our “One Country, One Voice” initiative, I visited the Alberta Children’s Hospital and the Peter Lougheed Hospital where we introduced the CCHA and stressed the importance of raising awareness. I also met with staff at the B.C. Children’s Hospital in Vancouver, and made a presentation to a group of patients at the Pacific Adult Congenital Heart Clinic.

In addition, I spoke at the “Heart Talk Conference” – an annual gathering for CHD kids and their parents, held at Camp Brigadoon in Nova Scotia. Finally, Paula Andrade, a CCHA co-founder and Board member, and I, visited the Children’s Hospital at London Health Sciences Centre where we met with staff and CHD family members who wanted to learn more about the CCHA. Paula also traveled to BC where she participated in the Children’s Heart

Network conference. There she had the opportunity to meet CHD patients and medical staff and told them about the CCHA and the work we're doing.

All of our travels and hard work are paying off:

- We're now on the radar of the various healthcare professionals we met during our travels.
- CCHA established an important alliance with the Braveheart Support Society, a Nova Scotia-based organization that provides support for families living with CHD.
- We've seen a marked increase in the number of patients and families who want to get actively involved in the CCHA.
- We now have a new chapter in London, run by three dynamic women – Lisa, Courtney, and Rebecca. This chapter has already placed defibrillators in schools and had February 14 declared CHD Awareness Day in London!

While "One Country, One Voice" was a top priority in 2012, it was certainly not our only priority. For example, we participated in a wide range of events – from education days to conferences – to raise awareness of CHD issues. We participated in ReACH, the "Healthy Lifestyles for Children with Complex Heart Problems" project, and we will be promoting the program and offering information on our website. We hosted the fourth annual Beat Retreat, a fun-filled four-day outreach program for adult CHD patients. And, we conducted a survey to get a better handle on the healthcare needs of adult CHD patients. (See page 4 for a more comprehensive list of our 2012 achievements.)

The CCHA also took steps to comply with new rules governing federally regulated not-for-profits. Specifically, we replaced our letters patent and our by-laws with new charter documents. While updating the bylaws, we took the opportunity to increase the size of our Board of Directors so it better reflects the

national scope of the organization. In the wake of this change, we welcomed five new members to the board: Stella Cockett from B.C., Angela Krizan and Yvonne Balon from Alberta, Yarrow Gillis from Nova Scotia, Debbie Decher from Quebec, and Dr. Jack Colman from Ontario. (See page 10 for brief bios on these individuals.)

While there is still an endless number of items on our "to do" list, we can look back on 2012 with a sense of pride. We accomplished a great deal in a short period of time – and that in itself is an achievement for an organization powered by volunteers. I want to thank each and every one of those volunteers for their hard work.

Looking forward, we'll continue to move ahead with "One Country, One Voice", cementing alliances and building a national network of chapters and volunteers. But we will also be putting together plans for educational sessions, holding our fifth annual Beat Retreat, revamping our website, and continuing to raise the profile of CHD in Canada – all with the end goal of ensuring CHD patients get the care and support they need. With your continued help and support, we can make it all happen.

I would like to take this opportunity to thank our wonderful and tireless accountant, John Parker, for donating his time and expertise to help us stay on track and grow as an organization. His help is very much appreciated.

Thank you very much for your interest in CCHA and your continued support.



Shelagh Ross



FOLLOWING ARE HIGHLIGHTS OF THE CCHA'S MANY ACHIEVEMENTS FROM 2012:

Received a \$10,000 Medtronic grant

In March 2012, we received a \$10,000 grant from The Medtronic Foundation to support our “One Country, One Voice” initiative. The money from this grant has been used to offset travel expenses related to “One Country, One Voice” and to provide materials and important seed money for chapter start-ups.

Held the 4th annual Beat Retreat for adult patients

This year, 23 adults made their way to Camp Quin-Mo-Lac (north of Belleville, Ontario) to benefit from four fun-filled days of friendship, personal challenge, and health awareness. That compared to just 12 attendees at our first retreat in 2009. A special thanks to CCHA volunteers Toby Cox and Ted Thaler, and special guests Qunyu Li and Laura-Lee Walter, for making this annual event such a huge success. For more information on the retreat, check out the CCHA website and/or the Beat Retreat Facebook page.

Participated in the “Walk for Life”

The CCHA fielded a 22-member team to participate in the Cardiac Health Foundation of Canada’s Walk for Life. The Foundation funds rehabilitation services often used by CHD patients. Our team of walkers successfully raised \$5,860 (half of which goes to the CCHA), earning us third place among corporate fundraising teams. The CCHA team was led by Jennifer Graham, a long-standing and tireless CCHA volunteer. Jennifer has been so successful at organizing this event that she was recently invited to join the Cardiac Health Foundation of Canada board. We are gearing up for this year’s walk on May 26 in Toronto – please visit our website for more information.

Conducted a patient survey

We conducted an e-survey of adult CHD patients to determine their needs and challenges. The survey found that while most patients are satisfied with the medical care they receive, there are some important areas where improvements could be made, notably psychosocial support, employment counselling, and professional advice regarding nutrition and exercise. The survey results are posted on the CCHA website under “Resources”. They were also presented at the 22nd International Symposium on ACHD and are analyzed in an article we hope will soon be published in a medical journal.

Presented at the International Symposium on Adult CHD

Building on the event’s theme, “Beyond Saving Lives”, we presented the results of our 2012 patient survey. The symposium provided a valuable opportunity to share with medical experts from the around the world the concerns and challenges faced by adult CHD patients.

Hosted a booth at the Canadian Cardiovascular Society Congress

We hosted a booth at the Canadian Cardiovascular Society (CSS) conference for the 5th straight year. The conference provides a valuable opportunity to connect with leading specialists in general cardiology and CHD care. Over the course of several days, we spoke to dozens of cardiologists and nurses about the importance of lifelong specialized care for CHD patients and explained the role of the CCHA. Once again, we thank the Heart & Stroke Foundation for inviting us to this important event.



Participated in ReACH

In June, the CCHA was invited to participate in ReACH, the Ottawa Children's Hospital "Healthy Lifestyles for Children with Complex Heart Problems" project. This planning and resource development project is aimed at enabling children with complex heart problems to lead healthy, active lives within their own community. The primary goal is to promote physical activity. As part of our participation effort, the CCHA will be adding a section to its website on healthy living.

Raised awareness at various educational events

Raising awareness of CHD issues continues to be a top priority for the CCHA. To that end, we participated in a wide range of events, including the Sick Kid's Heart Disease Family Education Day, the Lion's Foundation event for non-profits, the Nova Scotia Heart Talk Conference at Camp Brigadoon, the B.C. Children's Heart Network Conference, the Canadian Cardiovascular Society Congress, the International Symposium on Adult CHD, and the Pacific Adult Congenital Heart (PACH) clinic event in Vancouver.

Introduced two new scholarships

The CCHA introduced two new \$1,000 scholarships – one for a CHD patient in post-secondary studies and one for a student studying to work with CHD patients. We received so many excellent applications that we ended up providing two additional scholarships of \$500 each. We are hoping to have funds available to offer scholarships again in 2013. Congratulations to the recipients of our 2012 scholarships – Alec Morgana, Lauren Ryan, Lauren Fougner, and Kristy Popwell.

Collaborated with the Heart & Stroke Foundation

We continued to work with the Heart & Stroke Foundation to ensure that CHD received appropriate consideration as they reviewed and updated their strategic plan. We also continued to explore opportunities for collaboration between the two organizations.

Launched our "One Country, One Voice" initiative

We successfully launched our "One Country, One Voice" initiative. This initiative focuses on ensuring CCHA is a truly national organization representing all congenital heart defect (CHD) patients across Canada. During the year, we traveled from coast-to-coast meeting with patients and their families, healthcare officials, and other patient organizations. Along the way, we laid the groundwork for a national network of chapters, alliances, and volunteers.

Expanded our Board of Directors

To ensure the CCHA Board of Directors reflects the interests of all CHD patients – regardless of age or location – we added five new directors. The Board now has directors from British Columbia, Alberta, Ontario, Quebec, and Nova Scotia and has representatives from both the patient and medical communities.

Complied with new rules governing not-for-profits

We replaced the CCHA's letters patent and by-laws with updated charter documents to comply with new rules under the federal Not-for-profit Act. The new rules are designed to be more flexible and better suited to the needs of the not-for-profit sector.

INCREASED MEDIA RECOGNITION

During 2012, the CCHA continued its efforts to raise the profile of CHD by encouraging media coverage.

In recognition of CHD Awareness Day (an initiative of our London-Middlesex Chapter), the city of London lit up its city hall in red. This event attracted significant media coverage. To view some of that coverage, click on the links below:

www.thelondoner.ca/2013/02/14/city-hall-turns-red

www.londoncommunitynews.com/community-story/2076117-there-s-a-hole-in-their-hearts

Following the media coverage in London, Carly Weeks, a reporter from *The Globe and Mail*, contacted the CCHA looking to write a feature story on CHD. The story, which was published on February 19th, can be viewed at:

www.theglobeandmail.com/life/health-and-fitness/health/living-with-congenital-heart-disease-the-high-cost-of-survival/article8838469

In March 2013, *Chatelaine* magazine published a three-page article on CHD. The article, which focused on the importance of ensuring CHD patients receive life-long follow-up, included an interview with CCHA President Shelagh Ross:

www.cchaforlife.org/wp-content/uploads/2013/03/Chatelaine-CHD-article-March-2013.pdf





CHECKING THE PULSE OF CHD PATIENTS

IN FEBRUARY 2012, THE CCHA CONDUCTED A SURVEY OF ADULT CHD PATIENTS. THE PURPOSE OF THE SURVEY WAS THREE-FOLD. WE WANTED TO DETERMINE:

1. How the lives of CHD patients have been impacted by their heart defect,
2. What CHD patients think of the care they receive, and
3. What changes/additions are required to improve the quality of life and health outcomes for CHD patients.

The survey generated a large number of insightful comments from respondents. Following is a small sampling of those comments.

"My heart condition affects where I choose to live, where I choose to work, what I choose to study, where I feel comfortable vacationing, if I'll have children. It affects everything."

"I would love to have someone to talk to more about [the] fears and challenges I impose on myself. I would love to feel like my doctor doesn't see me as just a number and would spend more than 30 seconds with me once a year."

"I've never had a cardiologist ask/offer/refer me to a psychologist even when I clearly could have used one. I would love to have access."

"I worry about taking long trips to countries with poor health care and I try not to get into serious relationships because of fear of not being able to have children or dying early."

"I would never tell my employer for fear of my condition being used against me. Such as if I was to try and gain a job promotion."



The survey results are posted at <http://www.cchaforlife.org/resource-centre/ccha-patient-survey-2012-results.html>



FUN, FRIENDSHIPS, AND FIRSTS



EVERY YEAR FOR THE PAST FOUR YEARS, THE CCHA HAS HOSTED THE BEAT RETREAT – A FUN-FILLED LONG WEEKEND FOR ADULT CHD PATIENTS WITH A SPECIAL FOCUS ON FRIENDSHIP, FIRSTS, AND LEARNING.

The retreat provides “campers” with an opportunity to participate in a mix of traditional camp activities – all geared to their physical ability and comfort level. But just as important are the social and educational aspects of the weekend. Participants have an opportunity to learn from the experiences of other CHD patients, as well as from members of the medical community.

But don’t take our word for it. Here’s what some of our past “campers” had to say:

“As a new camper, the Beat Retreat is an amazing and life changing experience. The people you meet are all so wonderful and beautiful. The opportunity to ask questions and just chat about life experiences with others who have shared similar experiences is invaluable. The laughter, the support, and the people. The Beat Retreat is a weekend like no other. It’s not to be missed.”

– Brynn

“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

“My favorite part of this year’s camp was all of us sitting around a campfire, roasting gooey marshmallows for our s’mores, and listening to the stories, issues, and concerns we all share. Who better to empathize than other adults who have gone through or are going through similar issues?”

– Debbie

“I found it was a great opportunity to meet, interact and share stories with others, who like myself, have lived with cardiac challenges, setbacks and triumphs all of their lives. It was a great experience.”

– Wayne

“I thoroughly enjoyed experiencing the Beat Retreat. It was my first time camping and it proved to me that people with heart conditions can handle the outdoors, no problem. Never a dull moment – there was always something to do... be it low ropes, initiatives, rock climbing, yoga, canoeing, arts & crafts or hiking. The campfires were a blast. It’s always a great experience to connect with other people who have CHD and see what they have achieved in life. The Beat Retreat is a wonderful setting to forge new friendships.”

– Katherine



FINANCIAL REVIEW

STATEMENT OF FINANCIAL POSITION 2012

	<u>2012</u>	<u>2011</u>
	\$	\$
ASSETS		
CURRENT		
Cash	26,662	11,029
Commodity taxes recoverable	2,755	717
Prepaid expenses	<u>62</u>	<u>68</u>
	<u>29,479</u>	<u>11,814</u>
INTANGIBLE ASSETS		
Trademark	5,636	5,636
Less: accumulated amortization	<u>4,837</u>	<u>3,710</u>
	<u>799</u>	<u>1,926</u>
	<u>30,277</u>	<u>13,740</u>
LIABILITIES		
CURRENT		
Accounts payable and accrued liabilities	1,668	23
FUND BALANCE	<u>28,609</u>	<u>13,717</u>
	<u>30,277</u>	<u>13,740</u>

STATEMENT OF OPERATIONS AND CHANGES IN FUND BALANCE 2012

REVENUES	<u>51,791</u>	<u>25,348</u>
EXPENSES		
Amortization	1,127	1,127
Bank Charges	174	75
Conferences	10,402	6,464
Fund raising	51	31
Insurance	1,038	1,086
Office and general Administration (dedicated grant)	3,593	2,056
Professional fees	500	1,163
Education Grants	3,000	
Promotion	<u>3,430</u>	<u>2,617</u>
	<u>36,899</u>	<u>14,620</u>
EXCESS OF REVENUES OVER EXPENSES	14,892	10,728
Fund balance, beginning of year	<u>13,717</u>	<u>2,989</u>
FUND BALANCE December 31, 2012	<u>\$28,609</u>	<u>\$13,717</u>

OUR BOARD OF DIRECTORS

THE CCHA IS GOVERNED BY A 10-MEMBER BOARD OF DIRECTORS. DIRECTORS ARE VOLUNTEERS AND REPRESENT PATIENTS, PARENTS OF CHD KIDS, AND THE MEDICAL COMMUNITY. THE MEMBERS OF OUR BOARD (AS OF DECEMBER 31, 2012) ARE LISTED BELOW.

Paula Andrade is a CHD patient and is a founding member of the Canadian Congenital Heart Alliance. She is a registered nurse and worked at The Hospital for Sick Children for 11 years. Currently she works for the Workplace Safety and Insurance Board (WSIB) in Ontario educating small business employers about their health and safety responsibilities.

David Edgell is a Staff Perfusionist at The Hospital for Sick Children in Toronto and worked at the Montreal Children's Hospital in Perfusion and Experimental Surgery. David received his undergraduate degree from Harvard University and recently completed a Master's degree at the Joint Centre for Bioethics at the University of Toronto. He is a member of the Canadian Society of Clinical Perfusion and certified by the American Board of Cardiovascular Perfusion.

Ted Thaler is a CHD patient and is a communications consultant with Eckler Ltd. in Toronto. He holds an M.A. (Journalism) from the University of Western Ontario and an Honours B.A. (Political Science) from McMaster University.

Dr. Bill Williams is the Director of the Congenital Heart Surgeons' Society (CHSS) Data Centre and Emeritus Professor of Surgery, University of Toronto. He is also the former Division Chief of Cardiac Surgery at The Hospital for Sick Children in Toronto. His professional interests cover all aspects of pediatric and adult congenital heart surgery, hypertrophic cardiomyopathy, post-graduate teaching, and clinical outcomes research.

Yvonne Balon is a nurse clinician and has been at the Southern Alberta Adult Congenital Heart Clinic in Calgary since 1994. She graduated with a Bachelor of Nursing from Athabasca University and has a Masters of Nursing

from the University of Calgary with a focus on the psychological wellbeing of adults with CHD. She is a member of the Congenital Cardiac Care Associates Research Network, and the Nursing Education Program Approval Board for the College and Association of Registered Nurses of Alberta.

Stella Cockett is a nurse clinician at BC Children's Hospital where she has worked in cardiac sciences for over 20 years. As well as working on the cardiac unit, she has held positions as cardiac nurse educator and clinical instructor for the University of British Columbia. She currently coordinates the Cardiology Partnership Program which provides traveling clinics to 10 communities around BC and the Yukon.

Dr. Jack Colman is a past-president of the International Society for Adult Congenital Heart Disease (ISACHD). He is a staff cardiologist at Mount Sinai Hospital and at the Toronto Congenital Cardiac Centre

for Adults at University Health Network, where he was director of clinical services from 2004 to 2006. He has been a member of the Medical Advisory Board of the Canadian Marfan Association, and continues to be a member of the Medical Advisory Board of the Adult Congenital Heart Association (ACHA-USA).

Deborah Decher is a CHD patient living in Montreal. Deborah's work background is in education and quality assurance, and she is currently employed at Geep Inc. as a compliance manager.

Angela Krizan has 15 years of pediatric nursing experience including eight years in PICU and Critical Care Transport, two years as a Donor Coordinator with the Southern Alberta HOPE Program and one year as the Assistant Patient Care Manager of the PICU at Alberta Children's Hospital. Angela recently took over as the Coordinator for the Western Canadian Children's Heart Network.

Yarrow Gillis is a mother of two young children, one with a complex heart defect. Several years into their journey, Yarrow founded the Braveheart Support Society which endeavours to support those in Atlantic Canada living with the challenges of congenital heart disease, as well as raise overall awareness about the disease. Yarrow also works part-time with the IWK Health Centre as a Family Advisor.

President

Shelagh Ross is a CHD patient and is a founding member of the Canadian Congenital Heart Alliance. She has served on the CCHA Board since 2004 as vice president. She holds an honours B.A. in English from the University of Toronto, and works as the managing editor at K2 Animal Health Publishing.

THANK YOU TO OUR SPONSORS





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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!