

Canadian Congenital Heart Alliance – 2011 Annual Report

President's message



In 2011, the CCHA hit the reset button. After four years as CCHA President, John MacEachern stepped down. During his tenure, John – a Tetralogy of Fallot patient who recently turned 70 – was a passionate and persistent ambassador for congenital heart defects (CHD). His energy and commitment was greatly appreciated and will be missed.

Having already served as CCHA Vice-President since the organization was launched in 2004, I was appointed by the CCHA Board of Directors to succeed John in October. In my new role, I look forward to picking up where John left off – building on the CCHA's many successes and taking the organization to the next level.

There were three other important changes at the Board level in 2011. Dr. Bill Williams and David Edgell were both elected to the Board by CCHA members in May, while Dr. Bob Lowrie stepped down in November to fulfill other commitments. I would like to thank Bob for his valued service and formally welcome Bill and David. Bill is a retired cardiovascular surgeon from Sick Kids Hospital, while David, also from Sick Kids Hospital, is a perfusionist (the person who manages the heart lung machine). Both men bring a wealth of experience to the Board table.

With new leadership and broader Board experience in place, the CCHA has taken the opportunity to “shift gears” and adopt a more strategic approach to fulfilling its mission.

CCHA is the only *national* organization that aims to improve the quality of life and health outcomes for all CHD patients – children and adults alike. However, our efforts as an organization have been hampered by the lack of a formal national network. We see the development of local chapters – that bring together patients, families and health professionals in a given region – as the best way to develop that network and create a unified, national voice for CHD patients. In 2011, we began laying the groundwork to make that happen.

In the fall of 2011, the Board set to work preparing draft guidelines for establishing Chapters and began holding preliminary discussions with key contacts in various regions. Our goal is to establish six formal chapters over the next two years – in B.C., Alberta, the Prairies, Ontario, Quebec and Nova Scotia.

The creation of chapters is a major strategic initiative, but it is by no means our only focus. In 2011, the CCHA moved forward with multiple initiatives aimed raising awareness and improving the quality of life and health outcomes for CHD patients. A comprehensive list of our many achievements can be found on page 2 of this report.

While much has been accomplished, there is even more to do...and we need your help. We need your help to spread the word. We need you to volunteer. And, if can, we need your financial assistance. Working together we can – and will – make a difference.

Shelagh Ross
President

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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, and the medical community. With your support, we aim to improve the quality of care for these patients, many of whom require lifelong expert care.

Score card – 2011

Following are highlights of CCHA's many achievements from 2011:

- Began laying the foundation for a national network of chapters***
We believe building a national network of chapters will help us better serve and represent the interests of CHD patients, families and health care professional from all regions of the country. In 2011, we drafted chapter guidelines and began preliminary discussions with individuals from across the country with the goal of establishing six chapters over the next two years.
- Hosted a three-day retreat for adult CHD patients***
Adult CHD patients often lead a more sedentary, dependant lifestyle – due to their medical condition, anxiety, a lack of confidence, financial hardship, and/or a lack of public understanding. The Beat Retreat works to change that by giving participants an opportunity to try new activities, explore the limits of their condition, build confidence in their physical abilities, and have fun – all in a controlled setting.
- Raised awareness through presentations to service groups***
Raising awareness of CHD issues continues to be top a priority for the CCHA. To that end, CCHA representatives made presentations to the Weston Lions Foundation and a Montreal Rotary group. Both presentations were well received.
- Participated in Sick Kid's 2nd Annual Heart Disease Family Education Day***
The CCHA is committed to helping CHD patients and families alike. In addition to working with the Sick Kid's planning committee, we also hosted a booth at the event, participated in a panel discussion, and presented the CCHA awareness film "Born with a Broken Heart".
- Hosted a booth at the Canadian Cardiovascular Congress in Vancouver***
The conference provides an important opportunity to reach out and inform healthcare professionals about the unique challenges of CHD patients. The vast majority of cardiologists lack the special training needed to treat complex CHD conditions. Our goal is to ensure they know how and where to access cardiologists specially trained to treat adult CHD patients. Thanks to the Heart & Stroke Foundation of Ontario for covering the cost of our booth.
- Launched a letter-writing campaign to have February 14 declared CHD Awareness Day in Ontario***
In 2009, we came close to having February 14th proclaimed Congenital Heart Defects Awareness Day in Ontario. Bill 178 made it all the way to second reading – with full party support – before falling off the order paper. In 2011, we began a campaign urging members to petition their MPPs to resurrect the bill – a step that would help raise the profile of CHD.
- Met with the Heart & Stroke Foundation of Canada to discuss opportunities for collaboration***
Members of the CCHA Board met with newly appointed Heart & Stroke Foundation Canada President Bobbe Wood to discuss CHD issues and explore opportunities for collaboration. We received assurances that CHD will remain on the radar as the HSF moves forward with their new strategic plan.
- Participated in the Cardiac Foundation of Canada's "Walk for Life"***
CCHA members, family and friends came together to raise more than \$6,000 in the Cardiac Foundation's Walk for Life. The proceeds were split between the Foundation and CCHA and used to support the programs of both organizations. Many congenital heart patients take advantage of the Foundation's rehab programs to exercise safely in a supervised setting.
- Updated the CCHA brochure***
To help raise awareness of CHD and the work of the CCHA, we updated our brochure and redistributed it to clinics and contacts across the country. Actelion Pharmaceuticals Canada Inc. donated money to cover printing costs for the new bilingual brochure, while Aileen Montesclaros at the McGill University Health Centre's MAUDE unit assisted with the French translation.

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 made it to adulthood. Today, about 90% of children born with CHD make it adulthood. Most, however, will require lifelong monitoring and specialized care.

Financial review – 2011

CANADIAN CONGENITAL HEART ALLIANCE
Statement of Operations and Changes in Fund Balance
December 31, 2011

	<u>2011</u>	<u>2010</u>
REVENUES	\$ 25,348	\$ 35,385
EXPENSES		
Amortization	1,127	1,127
Bank Charges	75	47
Conferences	6,464	7,945
Fund raising	31	19
Insurance	1,086	1,166
Office and general	2,056	4,597
Professional fees	1,163	536
Promotion	2,617	21,001
	<u>14,620</u>	<u>36,438</u>
EXCESS OF REVENUES OVER EXPENSES	10,728	(1,053)
Fund balance, beginning of year	<u>2,989</u>	<u>4,042</u>
FUND BALANCE December 31, 2011	<u>\$ 13,717</u>	<u>\$ 2,989</u>

Copies of the our 2011 Audited Financial Statements are available on the CCHA website at www.cchaforlife.org

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.

Our Board of Directors

The CCHA is governed by a Board of Directors. Directors are elected by the membership at the CCHA's Annual General Meeting. There are currently five members serving on the Board. Members serve for two year terms and terms are staggered to provide leadership continuity.

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

David Edgell – David 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 of the University of Toronto. He is a member of the Canadian Society of Clinical Perfusion and American Board of Cardiovascular Perfusion certified.

Shelagh Ross, President – Born in 1962 with Tetralogy of Fallot, Shelagh helped found the CCHA in 2004. Since then, she has worked on the CCHA Board, serving as vice president and now president. She holds an honours B.A. in English from the University of Toronto and works as a medical writer, editor and website manager.

Ted Thaler – Ted is a CHD patient (Tetralogy of Fallot) and is a communications consultant with Eckler Ltd. 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 – Bill is the Director of the Congenital Heart Surgeons' Society (CHSS) Data Center 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 congenital heart surgery, adult congenital surgery, hypertrophic cardiomyopathy, post-graduate teaching, and clinical outcomes research.

CCHA objectives

The objectives of the Canadian Congenital Heart Alliance (CCHA) include the following:

- ***Raising awareness of congenital heart defects (CHD) and the CCHA within the congenital population, medical community, government, and general public***
- ***Provide peer support, mentoring and outreach programs to patients and families***
- ***Advance congenital heart disease-related research***

Faces of CHD

