

2015 ANNUAL REPORT



Message from the President and Executive Director

In Canada, approximately one in one-hundred children born has a CHD. As a result, upwards of 275,000 Canadians were born with CHD. About 2/3 are now adults; a dramatic change as decades ago few children survived to adulthood, whereas now over 90% do with changes to technology, treatments and identification.

In 2015, CCHA Directors adopted a three-year strategic plan with a focus upon; awareness building, sustainable fundraising - from a variety of sources so that the programs of CCHA can expand and grow - and on-going support for CHD patients and stakeholders.

The year 2015 has seen the Canadian Congenital Heart Alliance go through a metamorphosis as long-time volunteer; past CCHA president and 2015 Executive Director Shelagh Ross decided to lessen her active role. Her years of service, dedication and commitment to the advancement of the CCHA are to be commended. While she remains supportive in many ways, the Board of Directors elected to retain the services of a part-time Executive Director and Allan Weatherall was hired in August 2015. His background in many facets of non-profit administration - primarily in health care - was deemed very suitable to advance and support the Mission of CCHA.

We recognize that not all people with congenital heart defects require treatment. Some may only need to be observed and routinely visit a cardiologist. In other cases, surgery or a cardiac catheterization may be needed to reduce the effects of and/or repair the defect. Even when a defect is treated as a child, further conditions may develop that would benefit from additional medical treatment. Therefore, the need for advocacy, support and research has been increasing corresponding and dramatically too and the Canadian Congenital Heart Alliance role is to support them whenever possible. Unfortunately, many patients decide they do not need any follow-up and are lost to being seen maybe as they should and thus sometimes they are seen too late for effective treatment or support. One of the key efforts of CCHA is to deliver the message to those patients and family members that specialized care exists across Canada in many centres. We encourage them to obtain the care required to prevent new forthcoming health challenges.

In addition, CCHA chapters in the London, Ottawa and Vancouver areas have been very active with many locally based initiatives.

As we move into 2016 and beyond the journey continues for CHD patients, we will focus upon strengthening and growing programs critical in support of CCHA members and their families. The Canadian Congenital Heart Alliance will purposely be an advocate wherever possible. Thank you.

Eric Gonneau

President

Allan Weatherall

Executive Director

OUR BOARD

BOARD OF DIRECTORS

President

Eric Gonneau, MBA, P.Eng

Eric Gonneau is a CHD patient who owns and operates an engineering, design and construction company. Eric has been on various boards, most recently as president of a Kiwanis Club, a Director on a condominium board and a director with Big Brothers.

Vice-President

Krista Vriend, BComm

Krista is a CHD patient, with over 15 years of marketing experience in the financial industry. She is currently the Director of Global Marketing for Insurance for a big five bank.

Treasurer-Secretary

Denise Hackett, RD

Denise is a CHD patient, and registered dietician who has worked in several areas such Clinical Nutrition, Business/Industry, Pharmaceutical and Private Practice

Yvonne Balon, MN, RN

Stella Cockett, RN, BSN

Jack Colman, MD

Jennifer Graham, BSc (Hons)

Lea Legge, RN

Saad Minhas, LLB (Hons)

Executive Directors

Shelagh Ross (Jan-Aug)

Born with tetralogy of Fallot, Shelagh helped initiate CCHA in 2004 serving as vice president and president over the years.

Allan Weatherall (Sept-Dec)

Allan has over twenty-five years' experience in non-profit administration with professional accreditation in both fundraising and public relations. Allan has worked in hospital Foundations in Ottawa, Huntsville and St. Thomas.

MEDICAL ADVISORY BOARD

Derek G Human, BM, BCh, MRCP (UK), FRCPC

Pediatric & ACHD Cardiologist

BC Children's Hospital & St Paul's Hospital
Clinical Professor, Department of Pediatrics
University of British Columbia

Jonathan Windram, MBChB, MRCP (UK)

ACHD Cardiologist, Mazankowski Heart Centre
Assistant Professor of Medicine, University of Alberta

Jack M. Colman MD, FRCPC

Professor of Medicine, University of Toronto,
ACHD Cardiologist, Toronto Congenital Cardiac Centre
for Adults, Peter Munk Cardiac Centre, UHN and Mount
Sinai Hospital

Frederic Jacques MD, MSc, FRCSC

Instructor of Surgery, Laval University
Congenital Heart Surgeon, Institut universitaire de cardiologie
et de pneumologie de Quebec and CHU de Quebec

Ariane Marelli MD, MPH, FRCPC, FACC, FAHA

Professor of Medicine, McGill University
President CACH Network
Founder and Director of the McGill Adult Unit for Congenital Heart Disease
Associate Director of Research and Academic Affairs
Cardiology, McGill University Health Center

Najaf Nadeem, MB, BS, FRCPC

Associate Professor, Division of Cardiology
Dalhousie University
ACHD Interventional Cardiologist

Jasmine Grewal MD, FRCPC, FASE

Clinical Assistant Professor of Medicine, University of British Columbia
Director Cardiac Obstetrics
ACHD Cardiologist, Pacific Adult Congenital Heart (PACH) Program
St. Paul's Hospital, Vancouver

Gary Webb, MD

Director, Cincinnati Adolescent and Adult Congenital Heart Disease Program
Professor of Clinical Pediatrics and Internal Medicine, University of Cincinnati

Barbara Bailey RN (EC), MN, NP-Adult

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

Henry Kafka MD, FRCPC

ACHD Cardiologist, Queen's ACHD Clinic
Department of Medicine, Queen's University, Kingston

WHO WE ARE:

The Canadian Congenital Heart Alliance (CCHA) is a registered charity administered by a volunteer Board of Directors. It was founded in 2004 by a group of adult congenital heart defect survivors and their families as a registered charity. Its Board of Directors continues to consist primarily of those living with congenital heart defects (CHD) and is dedicated to promoting excellence in CHD care. It also supports patients – who have CHD as well as their families, friends, the medical community and aligned patient groups. With donations of money, time and resources the CCHA aims to improve the quality of life of patients with CHD. In addition, a Professional Advisory Committee supports CCHA activities. Several local chapters across Canada are actively functioning too and more are expected.

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 OBJECTIVES:

The objectives of the CCHA include the following:

- Raising awareness of congenital heart defects 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
- Raise money to achieve financial self-sufficiency and fund CCHA initiatives

What is a congenital heart defect?

Congenital heart defects (CHD) are the most common type of birth defect and can involve defects of the walls, valves, and/or the arteries and veins near the heart. These defects often disrupt or constrict the normal flow of blood through the heart and/or body, and can result in other complications with other organs. Approximately 1 in every 100 newborns have congenital heart defects, which can range from mild to severe. CHD is believed to happen because of incomplete or abnormal development of the fetus' heart during the very early weeks of pregnancy and often before the mother is aware that she is pregnant. Some are known to be associated with genetic disorders, such as Down syndrome, but the cause of most congenital heart defects is unknown. While they can't be prevented, there are many treatments for the defects and related health problems.

At one-time most of those born with CHD did not survive to adulthood ... today virtually 95% do survive well into adulthood. However, about half of them will require life-long monitoring and possibly specialized care.

PRESIDENT'S REPORT

FUNDRAISING "ENSURING WE HAVE THE FUNDS TO DO IT"

CP Has Heart donated \$10,000 for two Alberta Patient Conferences and the Beat Retreat
2nd annual Heart Warriors Walk in Abbotsford, BC on Feb 14 – raised \$3,200
Amber Deveraux in Marathon Ontario held an Easter Dance and raised \$3,300 for CCHA.
Raised over \$7,250 in annual Cardiac Foundation of Canada Walk of Life (50/50 split)
Actelion Donated \$2,000
Aviva Community Fund \$1000 Wildcard Prize.
Tides Canada Foundation \$5,860
TOTAL RAISED TO DATE IN 2015 = 39,686

MEMBER SUPPORT "HELPING OUR MEMBERS"

7th "Beat Retreat" camp: 27 patients & 7 Health Care Providers attended

AWARENESS "ADVOCATING FOR OUR CAUSE"

Spoke & participated at Sick Kids Labatt's Family Education Day for the 7th year (April)
Spoke at Cardiac Foundation Walk of Life (May)
Spoke at the 22nd International Symposium on ACHD in Toronto (June)
7th year attending the CCS in Toronto (funding provided by Heart and Stoke) (October)
Letter to Ontario Minister of Health regarding destruction of Patient Records after 33 years in
Attended a CHEO Cardiac Kid LIFFE research panel (October)
Spoke at the CHD "Heart to Heart" patient education days in Edmonton & Calgary

CURRENT & FUTURE ACTIVITIES

Hired our first Part Time Executive Director - Allan Weatherall (2015/2016)
Reviewed and Updated the Strategic Plan (2015/2016)
Patients conferences in spring 2016 – Vancouver – plans underway
Create monthly national newsletter (in partnership with other CHD orgs?)
Engage the medical advisory board
Speak at CHD events
Secure funding for more Beat Retreat camps and conferences
Host more meet and great seminars
Fundraise more \$\$

FINANCIAL REVIEW

2015

Canadian Congenital Heart Alliance Statement of Operations and Changes in Net Assets

Year ended December 31

	\$	5,860
Revenues		36,223
Grants		42,083
Donations		10,753
Expenditures		2,162
Administration		6,704
Advertising and Promotion		321
Programs		5,893
Bank Charges		2,592
Conferences		8,475
Insurance		<u>3,208</u>
Professional Fees		<u>40,108</u>
Office and General		<u>\$ 1,975</u>
Excess of revenues over expenditures (expenditures over revenues)		\$ 25,657
Net assets, beginning of year	\$	<u>1,975</u>
Excess of revenues over expenditures (expenditures over revenues)	\$	<u>27,632</u>
Net assets, end of year		



BRITISH COLUMBIA CHAPTER

What Has the BC Chapter Done in 2015:

- Attended the Growing up with Heart Disease Conference at BC Children's Hospital
- Conducted presentations with local businesses and support organizations
- Continued to build a working relationship/partnership with the Children's Heart Network
- Organized and held the 3rd Congenital Heart Warriors Walk



Looking to the Future of the BC Chapter:

- We would love to expand events. A family summer BBQ, social events for patients, a BC Beat Retreat Camp as funds allow.
- In order to expand, we need more dedicated and reliable volunteers to get involved.
- Areas we need help with are social media publications, event planning, grant writing and applications, business and donor requests, media submissions and awareness.
- If you are interested in getting involved and volunteering, please contact Julie Bard at BCHearts@cchaforlife.org

The Congenital Heart Warriors Walk

- First Year (2014) we had 106 participants with \$3,448.15 raised—one major business donor of \$1000
- Second Year (2015) we had 121 participants with \$3,075.00 raised—no major donors
- Third year (2016) we had 168 participants with \$3,996.00 raised—no major donors
- Support from local businesses is growing each year as well as support and awareness with the communities and its residents.



EASTERN ONTARIO CHAPTER

CCHA's Newest CHAPTER

The **Eastern Ontario Chapter** was established in August 2015 in an effort to bring opportunities for support and awareness to the CHD community in the Eastern Ontario region.

Our region includes the areas of Ottawa, Gatineau and Kingston. In our first year we established the roles of Chairperson: Brynne Campbell, Treasurer: Kat Biljan, Secretary: Katherine Hunter, and Kingston Representative: Paula Mooney. (Unfortunately Kat has stepped down from the role of treasurer this year)

Our group worked hard to establish connections within the community, including contacts at CHEO, University of Ottawa Heart Institute, and the Kingston CongenitaClinic. We also signed up for the Ottawa Race weekend which took place in May 2016. We also held an open house in October which was advertised at the local hospitals that was successful in getting the word out about our presence.

We have worked on establishing the chapter, and growing with new members to make sure we are a strong group that can contribute to the mission of CCHA.

LONDON CHAPTER

2015 was a full year for the London Chapter as continued to grow and expand.

In January, we had a meeting at library with a guest speaker – a cardiology resident

February was very busy as we had the 'heart campaign' and CHD awareness. London City Hall was lit in red and CHD families met with Mayor. The children saw the Mayor's office and chatted with them and noted that his wife has CHD. He committed to do in again next year.

We also had a display at the hospital on CHD awareness. We also collected DVDs for new DVD players for echo rooms in paediatric cardiology clinic. We also obtained heart stuffed animals given on behalf of our group to cardiology clinics and they were donated by Walmart.

In March, we had another meeting at Library and had open sharing

In September, McCormicks announced Hearts of London/Middlesex, CCHA would be the recipient of charity day in June 2016 with more that \$40 000 expected as a donation.

In November, we reorganized a display and received approximately \$575 as a donation recipient at Holiday Shop for Preschool of the Arts.

We greatly look forward to 2016 as we anticipate some wonderful things for 'Hearts of London'

The Beat Retreat 2015

Annual Beat Retreat brings ACHD patients and professionals together

More than 30 CHD patients and healthcare professional gathered on the shores of Moira Lake this past September for the 7th Annual Beat Retreat.

The retreat, sponsored by the CCHA, is a fun-filled, four-day annual learning and networking event for adult congenital heart disease (ACHD) patients. The event provides participants with a valuable opportunity to:

1. Share experiences with others who have a similar heart history.
2. Connect with an established peer support network.
3. Participate in a wide range of activities geared to their physical abilities.
4. Learn how to better manage their healthcare needs and cope with the psycho-social challenges of CHD.

Education is a key component of the retreat each year. This year's retreat included:

- an information session on the social work resources available to ACHD patients,
- a presentation on healthy eating habits for ACHD patients,
- an open question and answer session with healthcare professionals, and
- a presentation on the work-up process for heart transplants.

Because ACHD patients often face financial challenges because of their health issues, the CCHA subsidizes much of the event's cost.



"For the last couple of years, I have wanted to attend the Beat Retreat, however health problems and hospital stays prevented me from being there. I was finally able to be there this year, after having a heart transplant exactly one year prior to the Beat Retreat. Although my new heart does not have a congenital defect, I will always be a CHD survivor and I found it so amazing to be surrounded with people who actually understand a big part of my life that others can't. At the Beat Retreat, there is an immediate bond that is created and there are no explanations needed; we share similar experiences, fears, obstacles and medical procedures. All along the canoeing, archery, rock climbing, and snacks, there are so many "me too!" and "I totally get it!" conversations that go on between all the campers. What a fun and needed experience!"

~ Anne-Marie

"Leaving the country for the first time to attend the beat retreat not knowing anyone was a little scary, but the friendliness of everyone made it easy. Being able to be surrounded by people who understand you, what you've gone through, and how you feel is by far one of the best experiences in my life. You instantly feel at home and loved."

~ Valerie

"Every year I count down the days look forward to camp. Whether its out on the water, in the war canoe, on the climbing wall, working as a team to complete obstacles, out on the archery range, or just relaxing during meals, at campfire or boardgames The Beat Retreat is an amazing experience. This is my 7th year and it was great having so many new campers and making more CHD friends."

~ Jonathan

"The Beat Retreat is an incredible opportunity to not only experience camp but to meet others who share similar health challenges. You will make new friends while participating in a wealth of fun camp activities, enjoy a beautiful natural setting and learn how to maintain a healthy lifestyle through the numerous practitioners and experts over the four-day event. You won't experience this anywhere else."

~ Lisa

"As a first time camper I had no idea what to expect. What I got was the experience of a life time! Being surrounded by people who "get it" is so comforting and freeing. I cannot wait to see my new family next year."

~ Jennifer

CANADIAN CONGENITAL HEART ALLIANCE

C4-233 CROSS AVENUE P.O. BOX 233, OAKVILLE, ON L6J 2W9

EMAIL: INFO@CCHA4ORLIFE.ORG WWW.CCHA4ORLIFE.ORG TWITTER: [@CCHA4ORLIFE.ORG](https://twitter.com/CCHA4ORLIFE)