

**ANNUAL  
REPORT  
2 0 1 6**



**CANADIAN  
CONGENITAL  
HEART ALLIANCE**

## Who we Are:

The Canadian Congenital Heart Alliance (CCHA) is a registered charity run/coordinated by a volunteer Board of Directors. Founded in 2004 by a group of adult congenital heart disease survivors and their families, it is a registered charity with a Mission to improve the quality of life and health outcomes for individuals with congenital heart defects, through advocacy, raising awareness, education and advancing research.

The CCHA's Board of Directors continues to be comprised primarily of individuals who are themselves or have family members that are living with congenital heart disease (CHD). The board is dedicated to promoting excellence in CHD care and supporting 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 the CCHA mission. Furthermore, local chapters across Canada are actively functioning to support CHD in their communities and the organization supports expansions across other regions and communities.

## Objectives:

Our objectives include:

- Raising awareness of congenital heart defects and the CCHA within the congenital population, medical community, government, and public
- Provide support and education 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 disease (CHD) is the number one birth defect in Canada and worldwide. It 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 one in every one-hundred child born has CHD. About 2/3 of them are now adults; a dramatic change as decades ago few children survived to adulthood. Now almost 95% do with changes to technology, treatments and identification. As a result, upwards of 275,000 Canadians have CHD. However, about half of them will require life-long monitoring and specialized care.

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.

# MESSAGE FROM THE PRESIDENT AND EXECUTIVE DIRECTOR

In 2016, CCHA Directors continued with the implementation of a three-year strategic plan adopted in 2015. With a focus on; 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 also saw great strides with support from the Ontario government as we developed relationships through a successful grant for the Fearless Physical Activity program, in collaboration with the Children's Hospital of Eastern Ontario (CHEO) in Ottawa. There will be continued activity under this initiative to report in 2017. Other programs were supported in London, Ontario, through a wonderful donation from McCormicks Corporation.

It is very worthy of noting that the Medical Advisory Committee became the 'Professional Advisory Board' under Board Member Stella Cockett's direction in 2016 and has evolved throughout the year as they continued to support our endeavors.

We recognize that not all those with congenital heart defects may necessarily require lifelong specialized treatment. However, unfortunately, many are lost to follow up and are possibly not receiving proper care. With the advancements in medical treatment and people with CHD living longer lives, the need for advocacy, support and research has increased dramatically and the CCHA's role is to support them whenever possible. One of the key efforts of CCHA is to deliver the message to patients and family members that specialized care exists across Canada in many centres. Initiatives that were undertaken in 2016 aligned to this mandate included:

- CCHA became a partner with many other charities supporting Bill S201 - Genetic Non-Discrimination Act - to prohibit the use of genetic information as basis for discrimination. The Board unanimously supported it in March 2016 and participated with plans were to move it forward within the Canadian Parliament for adoption in 2017.
- Another successful Beat Retreat was held again in September. It is a fun-filled, four-day weekend for adults with congenital heart disease who can participate in a mix of traditional camp activities – all geared to physical ability and comfort level. It is also an opportunity to make new friends and learn from the experiences of other CHD patients and chat with healthcare professionals in a relaxed and informal setting. It was a weekend of fun, friends, firsts, and great food.
- In October 2016 the Canadian Pediatric Cardiology Association and Canadian Cardiovascular society introduced a Position Statement on Pulse Oximetry Screening in Newborns to Enhance Detection of Critical Congenital Heart Disease at the Canadian Cardiovascular Congress. CCHA and our PAB support this statement and look forward to seeing this initiative move forward in 2017.

In addition, CCHA chapters in the London, Eastern Ontario and British Columbia have been very active with many locally based initiatives that supported CCHA families and patients in those communities, raising both local awareness and funds for the organization. We look forward to seeing continued support in the years to come.

As we move into 2017 and beyond, the journey for both CCHA and the CHD patients, families and communities we support continues. With this in mind, we will be turning our focus towards strengthening and growing, awareness and membership, programs that are vital in supporting CCHA members and their families, and our fundraising endeavors. The Canadian Congenital Heart Alliance will knowingly be an advocate wherever possible for the CHD communities we support.

*Thank you.*



**Krista Vriend**  
President, 2017-18



**Allan Weatherall**  
Executive Director

# BOARD OF DIRECTORS 2015-16

Eric Gonneau - *President*

Krista Vriend - *Vice-President*

Jennifer Graham - *Secretary*

Mark Myers - *Treasurer*

Aaron Brown (*portion of year*)

Stella Cockett

Toby Cox

Denise Hackett (*portion of year*)

Jordan Hier

Joanna Hunt

Saad Minhas





# FINANCIAL REVIEW 2016

## Canadian Congenital Heart Alliance

### Statement of Operations and Changes in Net Assets

| Year ended December 31                      | 2016                   | 2015                   |
|---|------------------------|------------------------|
| <b>Revenues</b>                             |                        |                        |
| Grants                                      | \$ 557                 | \$ 5,860               |
| Donations                                   | 94,750                 | 31,408                 |
| Programs                                    |                        | 4,815                  |
|   | <hr/> 95,307           | <hr/> 42,083           |
| <b>Expenditures</b>                         |                        |                        |
| Administration                              | \$ 23,489              | \$ 18,952              |
| Advertising and promotion                   | 2,921                  | 2,162                  |
| Programs                                    | 6,835                  | 6,704                  |
| Bank charges                                | 189                    | 321                    |
| Conferences                                 | 7,372                  | 5,893                  |
| Donations                                   | 40,340                 |                        |
| Insurance                                   | 2,592                  | 2,592                  |
| Professional fees                           | 1,400                  | 1,250                  |
| Office and general                          | 3,942                  | 3,434                  |
|   | <hr/> 89,080           | <hr/> 41,308           |
| <b>Excess of revenues over expenditures</b> | <hr/> <b>\$ 6,227</b>  | <hr/> <b>\$ 775</b>    |
| Net assets, beginning of year               | \$ 26,432              | \$ 25,657              |
| Excess of revenue over expenditures         | <hr/> 6,227            | <hr/> 775              |
| <b>Net assets, end of year</b>              | <hr/> <b>\$ 32,659</b> | <hr/> <b>\$ 26,432</b> |



# FINANCIAL REVIEW 2016

## Statement of Financial Position

| Year ended December 31 | 2016              | 2015             |
|------------------------|-------------------|------------------|
| <b>Assets</b>          |                   |                  |
| Current                |                   |                  |
| Cash                   | \$ 150,096        | \$ 26,849        |
| HST receivable         | 1,820             | 2,049            |
|                        | <u>\$ 151,916</u> | <u>\$ 28,898</u> |
| <b>Liabilities</b>     |                   |                  |
| Current                |                   |                  |
| Payables and accruals  | 7,097             | 2,466            |
| Deferred revenue       | 112,160           |                  |
|                        | <u>117,437</u>    | <u>2,466</u>     |
| <b>Net Assets</b>      |                   |                  |
| Unrestricted           | 32,659            | 26,432           |
|                        | <u>\$ 151,916</u> | <u>\$ 28,898</u> |

## Statement of Cash Flows

| Year ended December 31                       | 2016              | 2015             |
|--|-------------------|------------------|
| Cash derived from (applied to)               |                   |                  |
| <b>Operating</b>                             |                   |                  |
| Excess of revenues over expenditures         | \$ 6,227          | \$ 775           |
| Change in non-cash operating working capital |                   |                  |
| HST receivable                               | 229               | 160              |
| Payables and accruals                        | 4,631             | 360              |
| Deferred revenue                             | 112,160           |                  |
|  | <u>123,247</u>    | <u>1,295</u>     |
| Net increase in cash                         | 123,247           | 1,295            |
| Cash, beginning of year                      | 26,849            | 25,554           |
| <b>Cash, end of year</b>                     | <u>\$ 150,096</u> | <u>\$ 26,849</u> |



# BRITISH COLUMBIA CHAPTER

## Warriors Walk 2016

Independent Grocer donated all the hot chocolate, granola bars and supplies. Boyd Auto Body the tents, PS system and volunteer help. Sun Hang Do Martial arts did another amazing warm up and fun demos. Plus, other businesses for draw donations.

Oh, we had one issue as the company that had donated the helium the last two years was not being able to this year, so we had to scramble to find someone. We worked out EZ Party doing it for us at cost. They even blew them all up (115 balloons) with fancy strings and weights which I thought was great for what we paid considering it was at cost and no more.

### For perspective on growth:

In **2014**, there were **106** participants with **\$3,448**  
*(with one major financial business sponsor of \$1,200.00)*

In **2015**, we had **121** participants with **\$3,075**  
without a major financial business sponsor.

In **2016**, there were **168** participants with **\$3,996**  
- without a major sponsor.

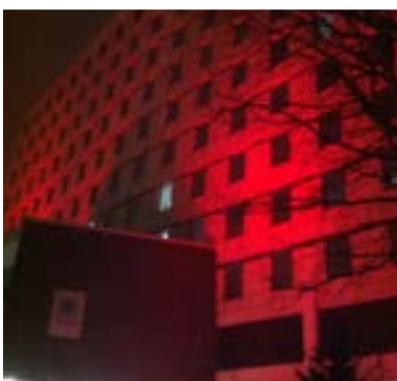




# LONDON CHAPTER

## What did we do in 2016?

- Promoted February CHD Awareness Week (7-14) and Day (14)
- City Hall, London Tourism and London Life buildings lit red
- Radio interview to educate on CHD awareness – CJBK radio
- Radio interview segment on Fanshawe radio and project for Fanshawe broadcasting student
- CHD Awareness week display at London Health Sciences Centre
- Gave out hearts to wear for CHD awareness
- Presented Stuffed Valentine Animals to Paediatric Cardiology on donated to us by Wal-Mart and Superstore (Loblaws) – this has been a huge success and gratefully appreciated by staff and children. A sticker with CCHA information is put on stuffie as added communication to families.
- Presented at 3 General Meetings for McCormick’s Canada to promote CCHA and C-Day initiative as McCormick’s C-Day local charity recipient
- February 9th – General Support Meeting
- April 26th – General Support Meeting
- May 24th – Support meeting – Guest speaker invited but unfortunately had to cancel – became support meeting
- June 4th – C-Day at McCormick’s – families came out, BBQ, and we were presented with a cheque for \$54,949.22
- Presented cheque at London Health Sciences Centre to Children’s Health Foundation alongside of McCormick’s representatives. Money to be used for research and family support.
- Purchased train table for pediatric Cardiology clinic waiting room
- Continued additional followers on Londonhearts twitter and Facebook accounts.



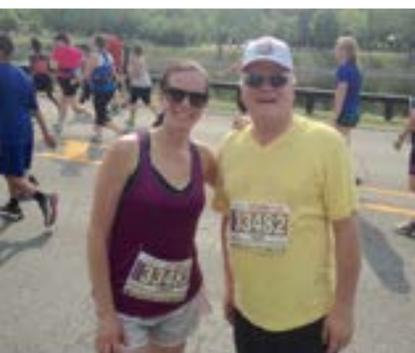


# EASTERN ONTARIO CHAPTER

EASTERN ONTARIO CHAPTER



The Eastern Ontario Chapter has made great strides in its efforts to form solid connections and relationships with local community groups and members. We welcomed five new members to the group, including Ricardo Garabatos who is now serving as Chapter treasurer, Jennifer Mulder who is working closely with Ricardo and taking over running the Chapter involvement in Ottawa Race Weekend and Sandra Zimmerman Mahoney, a heart mom who has been a wonderful asset and advocate for CHD, locally and nationally.



The 2016 Ottawa Race Weekend was a big success. We raised over \$5,500 and had team members in almost all the races! We are very excited to be participating as a charity again this year for a second time, and raising even more funds for CCHA. We will also be participating in their Health and Wellness fair next year to raise awareness on a local level.



Our Graduate Program Committee has been doing an excellent job working with the Children's Hospital of Eastern Ontario and the University of Ottawa Heart Institute to build on current patient transition programs, finding opportunities to assist the hospital staff in current protocol and prepare documents to help ease the patients into adult care. This is an ongoing collaboration between the local hospitals and CCHA.

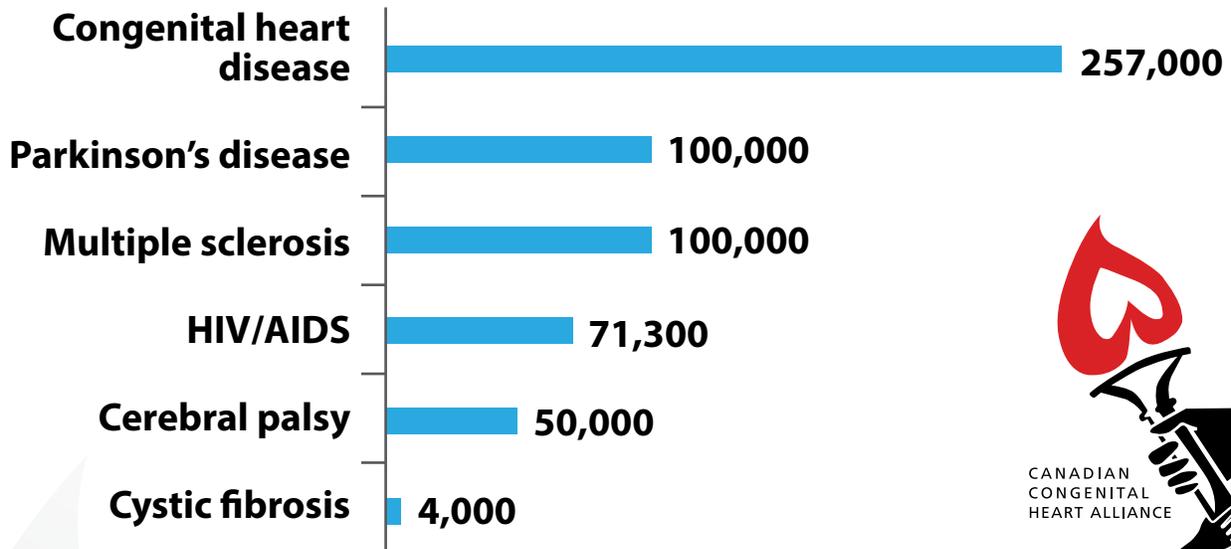


We have made some great connections with the local Ottawa Heart Support Group and Alumni Group that meets each month at the University of Ottawa Heart Institute. We built some strong connections between the Adult Congenital Clinic, CHEO and the Support Group. We are thrilled to say that we have had our first CHD focused night presented in partnership with the Ottawa Heart Support Group on November 21st. Dr. Gyaandeo Maharajh, currently Chief, Division of Cardiovascular Surgery at CHEO, presented "From Despair to Hope - The evolution of congenital cardiac surgery thru the advent of the arterial switch operation."

We are also working with CHEO to partner CCHA with their 2017 Cardiology camp hosted in partnership with the YMCA.

We are looking forward to another amazing year, furthering our community relationships and building upon our solid foundation.

# CANADIAN POPULATION DISEASE STATISTICS



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

## CHD Facts

- ♥ Congenital heart disease (CHD) world's leading birth defect (~1 in 100)
- ♥ Over 257,000 Canadian CHD patients (~180,000 are adults)
- ♥ Survival rate 2017 >95% 1960s ~20%
- ♥ More children die from CHD than all childhood cancers
- ♥ Patients with complex cases now surviving beyond age 18
- ♥ CHDs can be repaired, but not fixed. Many need multiple surgeries, interventions and medications throughout their lives



CANADIAN CONGENITAL HEART ALLIANCE

CCHAforlife | @CCHAforlife | [www.cchaforlife.org](http://www.cchaforlife.org)