



CANADIAN  
CONGENITAL  
HEART ALLIANCE

# CCHA 2019 ANNUAL GENERAL MEETING

July 10, 2019

# Agenda

Time	Item	Speaker
7:30	Welcome	Allan Weatherall (Executive Director)
7:40	President's Report	Krista Vriend (President)
8:00	Executive Director's Report	Allan Weatherall
8:10	2018 AGM Minutes	Jennifer Graham (Vice President)
8:15	CCHA Financial Report	Robbyn McLellan (Treasurer)
8:30	Board Elections	Laura Philippe (Director)
8:45	New Business	Allan Weatherall
9:00	Meeting Adjournment	Allan Weatherall



# Welcome

- Call to order
- Determination of Quorum
- Appointment of Recording Secretary
- Proof of Notice of Meeting





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# President's Report

# President's Report - Review

## 2018

- Fearless Physical Activity
- Awareness/fundraising events and activities
- Conference and education participation
- 3-Year Strategy session and development

## 2019

- Beat Retreat to rejoin CCHA
- CHD Awareness Week and Heart Month
- Continuing research advocacy



# President's Report - Fearless Physical Activity

- 2 year joint project with CHEO completed September 30, 2018
- Resources and tools available on CCHA website
- Transitioning into a permanent program of CCHA
- Upcoming events
  - Toronto - Sunday July 14
  - Kingston - Tuesday July 16
  - Hamilton - Sunday July 21
- Next steps - expand program outside Ontario



# President's Report - Physical Activity Tool kit

How can we increase daily physical activity participation among children living with CHD?

- The trial investigates the provision of **physical activity counselling, resources** and **kinesiology** support to **children** living with congenital heart defects (**CHD**) as part of their routine clinical care. We will measure to see if this intervention **increases** the children's level of **physical activity**
- Some of the resources included in the toolkit intervention are:
  - Information on the importance of outdoor play
  - How to choose safe activities
  - A searchable web site with an array of activity selections and programs
  - One on one kinesiology support
  - Heart rate monitoring information
  - Healthy lifestyle history questionnaire
  - Tips on how to approach physical activity without fear
  - Use of a pedometer



# President's Report - Physical Activity Tool kit

**OVER THE LAST YEAR 100+ PARTICIPANTS HAVE ENROLLED  
IN THE PROJECT ACROSS THREE SITES.**

(Ottawa, London & Edmonton)

A total of 47 children between the ages of 5-17 have completed the project at this time.  
Recruitment is ongoing in hopes for additional participation.





# President's Report - Research

- Published 2 collaborative papers with Ryerson University
  - Historical Investigation of Medical Treatment for Adult Congenital Heart Disease: A Canadian Perspective published in *Congenital Heart Disease*
  - Continuity of care for adults living in the community who have been diagnosed with congenital heart disease published in *Primary Health Care*
- CCHA invited to join newly established Canadian Research Network for Adult Congenital Heart Disease Interventions (CRN-ACHDi) as pillar partner and collaborator



# President's Report - CHD Landscape in Canada

- CHD landscape across Canada is comprised of a small number (relative to the CHD population size) of specialized clinics servicing the healthcare needs of people living with CHD.
- Tremendous progress and advancements in CHD pediatric care over the last 50 years
- More individuals living well into adulthood and surviving with more complex conditions and needs
- A number of smaller, local CHD support organizations have formed to service the auxiliary needs of CHD patients
- Currently there is no:
  - unifying body across these smaller organization/networks to help share learnings and best practices
  - national voice to elevate/advocate for larger issues and concerns for CHD care
- Research/information remains siloed and regionally based, with little industry support

**With these significant gaps and needs being brought to light, there is a case to look at how CCHA can evolve as an organization with the purpose of being a unifying body connecting patient groups, research and the professional CHD community together.**



# President's Report - CHD Survey: Key Insights

- Social media, word of mouth and clinics are key awareness drivers while parents and patients are key persons interested in CCHA
- CCHA's website requires an overhaul with better Search Engine Optimization infrastructure to capture Canadian audiences
- Key Areas of focus and interest and where CCHA can add value are:
  - Awareness
  - Education
  - Advocacy and Support
  - Research
  - Fundraising



# President's Report - CHD Survey: Key Insights

- Top 3 Education Needs
  - Understand diagnosis and care needs
  - Transition of care
  - Lifestyle behavior
- Top 3 Desirable Events
  - Education
  - Social
  - Physical activity



# President's Report - The New Platform for CCHA

## **Mission:**

We advocate for and enrich the lives of people with CHD through awareness, education, research and support.

## **Vision:**

To be the leading voice for enriching the lives of Canadians with CHD.

## **Value Statement:**

Building a dedicated CHD community that fosters compassion, empowerment and collaboration.



# President's Report - 3-Year Strategy: Objectives

1. Become the go-to organization that connects CHD organizations across Canada.
2. Partner to build out CHD programs that will support and benefit the CHD community across Canada.
3. Advocate for and assist with the advancement and dissemination of CHD research to the CHD community across Canada.
4. Be a key resource and education partner for the CHD community
5. Develop sustainable fundraising programs and sources to support the above objectives.
6. Build a deeper awareness of CHD within the CHD community and the Canadian public at large.



# President's Report - 3-Year Strategy: Initiatives

1. Building a CHD organization network
2. Build awareness of CHD/CCHA
3. Explore CCHA rebranding
4. CCHA website refresh
5. Fundraising development
6. Membership & volunteer recruitment
7. Research collaboration
8. Program development & expansion



# President's Report - 3-Year Strategy: Next Steps

- Gut check strategy with new Board members
- Refine and prioritize initiatives
- Get to work!







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# Executive Director's Report

# Executive Director's Report

- Administration
- Media/Awareness
- Fundraising
- Chapter reports



# 2018 AGM Minutes



## CCHA ANNUAL GENERAL MEETING MINUTES

June 20, 2018  
7:00-9:00pm  
[Sick Kids Hosp/Teleconference]

**Attendees:**

Allan Weatherall, Jennifer Graham, Krista Vriend, Saad Minhas, Joanna Hunt, Farrukh Aman, Teleconference - Robbyn McLellan, Stella Cockett, Meaghan Sharp, Effie Slapnicar, Christina Ding, Jennifer M (EO), Jenna Yaraskavitch, Jennifer Silaghi, Heather Joe, Laura Phillippe, Shelagh Ross, Matthew Crichley, Alfredo, Roberta Leblanc, Shelley Chuter, RJM, Trish, Alfredo, Roberta LeBlanc, unknown (416-819-0612)

**Recorder:**

Joanna Hunt

### MINUTES

#### 1. Welcome – Allan Weatherall

- Call to Order
- Quorum established
- Appointment of Recording Secretary – Joanna Hunt
- Proof of Notice of Meeting

#### 2. President's Report – Krista Vriend

- 1) 3-year Strategic Plan objectives
  - Build Awareness of CCHA nationally
  - Establish a sustainable fundraising program
  - Provide ongoing support for CHD patients and stakeholders
- 2) Recap of 2017 Accomplishments
  - Professional Advisory Committee formed
  - Attended Canadian Cardiovascular Society conference in Vancouver
  - Engaged Provincial Health Ministries regarding patient record keeping and disability grants
  - Increased efforts on fundraising
    - Worked in conjunction with CHEO to secure ~\$200,000 Fearless Physical Activity program grant in 2016; project development and delivery in 2017
    - Walk of Life and Toronto & Ottawa race weekend events
  - Attended events including Labatt Family Heart Centre Family Conference, Edmonton Patient Education conference, Cardiac Kids BBQ, Sick Kids Transition Night
- 3) 2018 Year to Date Accomplishments & Initiatives
  - Finalized Chapter Guidelines for operations and conduct
  - Participated in numerous events including ISACHD Symposium, Labatt Family Heart Centre Family Conference, BC PACH Education Day, Walk of Life - Toronto & Ottawa Race Weekend
  - Completed Fearless Physical Activity Project events, project ends June 30, 2018
  - Strategic Planning session postponed - due to scheduling conflicts and ON ice storm



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# CCHA Financial Report

# CCHA Financial Report

<b>Statement of Operations &amp; Changes in Net Assets</b>		
<b>Year Ended December 31</b>	<b>2018</b>	<b>2017</b>
Total Revenues	\$ 80,931	\$ 149,456
Total Expenditures	\$ 93,131	\$ 146,630
Net Assets, beginning of year	\$ 35,483	\$ 35,657
Excess of Revenue over Expenditures	-\$ 12,200	\$ 2,826
Net Assets, end of year	\$ 23,283	\$ 35,483



# CCHA Financial Report

## Statement of Financial Position

December 31st	2018	2017
Total Assets	\$50,577	\$86,631
Total Liabilities	\$27,293	\$51,148
Net Assets, Unrestricted	\$23,283	\$35,483



# CCHA Financial Report

**CCHA Auditor: Jennifer Rade** Chartered Professional Accountant

- Completed CCHA Audited Financial Statements 2018
- Appointment of Auditor for 2018 & 2019





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# CCHA Board Elections



# Board Elections - Application Process

- Notice posted on May 10, application deadline May 17, 2019
- Published on website and social media
- Nine candidates applied for 2019-2021 Board Positions
  - Jacqui Esler – Calgary, AB
  - Steven Ibbotson - Three Hills, AB
  - Jennifer Lewis - Innisfil - *application withdrawn*
  - Sarah McMillan – Toronto, ON
  - Bengy Mercier – Montreal, QC
  - Jennifer Michaud – Calgary, AB
  - Christelle Roy – Calgary, AB
  - Jessica Sestito - Toronto, ON
  - Julie Spears – Toronto, ON



# Board Elections - Interview Process

- Eight Board positions are open, five of which are vacant
- Interview Committee: Krista Vriend, Laura Philippe, Allan Weatherall
- Nine applicants, seven of which were shortlisted
- Committee interviewed six applicants:
  - Jacqui Esler – Calgary
  - Sarah McMillan – Toronto
  - Bengy Mercier – Montreal
  - Jennifer Michaud – Calgary
  - Christelle Roy – Calgary
  - Julie Spears – Toronto



# Board Elections - Selection Criteria

- Preferred Skills
  - Experience on a non-profit board
  - Fundraising/philanthropic experience
  - Accounting or legal experience
  - Marketing/social media knowledge and experience
  - A direct CHD link
- Every elected Board Member should possess:
  - A passion for the CCHA mission
  - A willingness to dedicate time and expertise with a commitment to engaging others
  - An understanding and ability to be a consensus builder
- Additional Criteria
  - Geographic location - Leadership qualities - Time available - Knowledge of CCHA activities



# Board Elections - Recommended New Members

- Sarah McMillan – Toronto
- Jennifer Michaud – Calgary
- Christelle Roy – Calgary
- Julie Spears – Toronto
- Jacqui Esler – Calgary
- Bengy Mercier – Montreal (honorary member)



# Board Elections - Recommended New Members

## Sarah McMillan – Toronto

- CHD patient
- Works at UHN as a research coordinator
- Experience with grant and publication writing
- Masters in Social Work
- Fundraising experience

## Jennifer Michaud – Calgary

- CHD patient with recent surgery experience, transition experience
- Project management, social media, web experience
- Volunteered with Heart and Stroke Calgary



# Board Elections - Recommended New Members

## Christelle Roy – Calgary

- CHD patient
- Social media, design experience
- Fundraising experience
- Bilingual
- Worked for Ronald McDonald House Charities

## Julie Spears – Toronto

- CHD patient
- Administration roles in legal, education and financial industries
- Previous experience on a board of directors



# Recommended for Board of Directors

## Jacqui Esler –Calgary

- CHD patient
- Patient advisory working group for the Libin Cardiovascular Institute
- Heart Beats Children's Society Board Member at the Alberta Children's Hospital
- Executive Director of Calgary BIA

## Benjy Mercier – Montreal (Honorary Board member)

- IT background, administration and project management
- Experience/familiarity with website development, social media
- Bilingual
- One year old daughter has CHD



# Board Elections - Re-Elections (full 3-year term)

## Jennifer Graham - Toronto

Jennifer has been part of CCHA since 2006 and has served on the Board for many years and recently has Chaired the fundraising committee and served as Vice President. She graduated from Carleton University with a B.Sc. Hon in Biology and Psychology and brings healthcare project management and system development experience. She is a CHD patient.

## Karen LeComte – Vancouver

Karen came onto the Board during the last term and is up for election for a full three-year tenure. She is a Clinical Nurse Specialist with the Heart Centre at St. Paul's Hospital with a goal to support others and develop educational resources for patients and families. She will also be involved with the Professional Advisory Board of the CCHA.

## Robbyn McLellan - Guelph

Robbyn was born with a Congenital Heart Defect (TOF) and has sat on several Boards and HR Committees. She is a Human Resource Professional with over 24 years experience in a corporate environment, in various aspects of Human Resources Management. She is a graduate of both Lakehead University and Sheridan College. Robbyn has served as Treasurer for most of her time on the Board





# Board Elections - Nominations

- In accordance with the CCHA by-laws, the individuals voted onto the Board will each be on three-year terms, regardless of time remaining on vacancy terms.
- Recommended candidates:
  - Sarah McMillan – Toronto
  - Jennifer Michaud – Calgary
  - Christelle Roy – Calgary
  - Julie Spears – Toronto
  - Jacqui Esler – Calgary
- Recommended for re-election:
  - Jennifer Graham - Toronto
  - Karen LaComte - Vancouver
  - Robbyn McLellan - Guelph



# Board Elections - 2019/2020 Board of Directors

- Jacqui Esler
- Jennifer Graham
- Karen LeComte
- Robbyn McLellan
- Sarah McMillan
- Jennifer Michaud
- Laura Philippe
- Christelle Roy
- Meaghan Sharp
- Julie Spears
- Krista Vriend
- Benjy Mercier - Honorary





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**New Business**

**Meeting Adjournment**



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**Thank you!**