



CANADIAN  
CONGENITAL  
HEART ALLIANCE

# CCHA 2020 ANNUAL GENERAL MEETING

June 24, 2020

# Agenda

Time	Item	Speaker
8:00	Welcome	Krista Vriend (President)
8:10	President's Report	Krista Vriend
8:30	Executive Director's Report	Allan Weatherall (Executive Director)
8:45	2019 AGM Minutes	Jennifer Michaud (Secretary)
8:50	CCHA Financial Report	Robbyn McLellan (Treasurer)
9:00	Board Elections	Jennifer Graham (Vice President)
9:20	New Business	Krista Vriend
9:30	Meeting Adjournment	Krista Vriend



# Welcome

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



# 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.





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# President's Report

# President's Report - Review

## 2019

- Beat Retreat to rejoin CCHA
- CHD Awareness Week and Heart Month
- Continuing research & advocacy
- Physical Activity Toolkit project

## 2020

- Partnerships with other CHD focused organizations
- CHD Awareness Week and Heart Month
- COVID-19 awareness & CHD impact
- Revisit strategy



# President's Report - Beat Retreat

Beat Retreat camp launched in 2009

- Happy to announce that the Beat Retreat has officially joined and is part of CCHA once again.
- Makes both organizations stronger and allows for expansion
- Focused Beat Retreat donations can now be made through CCHA to provide charitable tax receipts
- Migration of all communications and online presence under CCHA umbrella is underway.



# 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**
- Resources included in the toolkit intervention are:
  - Information on the importance of outdoor play
  - Heart rate monitoring information
  - How to choose safe activities
  - A searchable web site with an array of activity selections and programs
  - Tips on how to approach physical activity without fear
  - One on one kinesiology support
- 98 participants completed full 6 month study, 22 still actively participating
- Recruitment in Ottawa and London complete. Edmonton ongoing (currently on hold due to pandemic). Study completion date June 2021



# President's Report - Research

## 2019

- 2 collaborative papers with Ryerson University published
  - 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

## 2020

- Collaborative paper with CHEO RI Halo group published
  - Impacting child health outcomes in congenital heart disease: Cluster randomized controlled trial protocol of in-clinic physical activity counselling. *Contemporary Clinical Trials*



# President's Report - CHD Awareness Week & Heart Month

## 2019

- Faces of CHD Campaign
  - 14 stories. Kicked it off on Feb 7 with a collage of pictures
  - Everyday for CHD awareness week we posted a story then once a week. Intermingled this with CHD facts and donation posts. Stories were very well received.
  - Great engagement with reach over 5500 and 1100 engagements all through organic - better than some of our paid engagements.

## 2020

- Collaboration with 5 other CHD organizations to produce the Transition of Care Tip sheet and launched new Transition resources on website
  - CHD Facts were posted along with transitions stats and infographic.
  - Also called for donations



# President's Report - Partnerships

- Worked to develop partnerships with five (5) other CHD organizations in Canada, including:
  - Heart & Stroke
  - Fondation En Coeur
  - Braveheart Support Society
  - iHeartChange
  - Global ARCH
- Collaborated & co-Authored two key initiatives:
  - Transition Infographic for Heart Month
  - Two COVID-19 & CHD publications



# President's Report - 3-Year Strategy Pivot

- The COVID-19 pandemic has shifted the focus and outlook for CCHA.
  - This has created the need to revisit the remainder of our 3-year strategy and determine how the organization should pivot in this new environment.
- Current needs:
  - Fundamental changes globally may shift needs of our members
  - Work to ensure representation of diversity and inclusion across the organization
  - Fuller engagement of Professional Advisory Board
- Next Steps
  - The new board will assess and determine key priorities to set CCHA up for future success.





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# Executive Director's Report

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Since joining the CCHA in 2015 as a part-time Executive Director... I have learned so much about CHD...thank you.

There is one constant in health care...change. Through 2019 and into 2020 has been a time of adjustment for the Canadian Congenital Heart Alliance.



# Executive Director's Report - Administration

- Liaise with CCHA chapters in London and Eastern Ontario
- Continue to build relationships and partnerships with various organizations
  - Peter Munk Foundation - UHN
  - Health Partners (Ottawa)
  - Genetic Discrimination Act - House of Commons
  - PEMS '*Lost to Care*' CHD movie – USA
  - Riipen
  - Children's Healthcare Canada
  - McMaster University - Childhood Disability Research



# Executive Director's Report - Media

- Government - connected with MPs in House of Commons – statement for CHD Awareness during Heart Month
  - Liaised with Marilyn Gladu, MP (2019) and Robert Kitchen MP (2020)
- Media
  - Interviews with News 1310 (Ottawa); NewsTalk 1290 (London); My FM 94.1 (St. Thomas), CBC Radio One (London)
  - Developed 3 PSAs with Joe Bowen – still being played on radio
- On-going outreach and communication with various media channels
  - CTV network health reporter
  - CBC Newsworld
  - Globe and Mail
  - Toronto Star



# Executive Director's Report - Fundraising

- Connected - Grant Advance re: 'free' membership for one year
- Received 1 year RBC Future Launch grant - funding for Riipen - connecting post secondary students with industry projects
- Connected with TELUS re: potential coverage and support
- Several large donations and fundraisers
  - Celtic Football Club/Toronto re \$2,100 donation
  - Sarah Y Canada Helps fundraiser for Heart Month \$1,324
- Continue to monitor donations and send thank you letters to donors
- Continue to contact Foundations



# Executive Director's Report - Chapter reports

## Hearts of London/Middlesex - CCHA London Chapter

### February Heart Awareness:

- London City Hall and city buildings were lit 'red' for CHD awareness week
- Radio interviews - Fanshawe College radio, AM980 Radio in London, CTV London, high social media engagement

### Support Meetings

- February 5<sup>th</sup> – Guest speaker Dr. Cory Andersen. February 26<sup>th</sup> – Guest speaker Robert Haworth - new parents at both meetings, used Skype to enable adults from Sarnia to participate

### Additional items

- Looking to establish permanent signs in London paediatric and adult Cardiac clinics

\*\*\* Diagnosis folders and Support bags – in progress – to complete Fall 2020



# Executive Director's Report - Chapter reports

## Eastern Ontario Chapter

- Chapter struggling in 2019, conflicting schedules and priorities
- Meeting set for March 2020 - cancelled due to COVID-19
- Looking at options to restart Chapter and activities - via Zoom



# 2019 AGM Minutes



**CCHA**  
**ANNUAL GENERAL MEETING**  
**MINUTES**

July 10, 2019  
7:30-9:00pm  
[Sick Kids Hosp/Teleconference]

Allan Weatherall - Executive Director, Krista Vriend - President, Jennifer Graham - Vice President,  
Laura Philippe, Sarah McMillan, Matthew Main, Toby Cox

**Attendees:** Video/Teleconference - Robbyn McLellan - Treasurer, Meaghan Sharp, Jacqui Esler, Jennifer  
Michaud, Julie Spears, Bengy Mercier

**Recorder:** Jennifer Graham

## MINUTES

### 1. Welcome – Allan Weatherall

- Call to Order
- Quorum established
- Appointment of Recording Secretary – Jennifer Graham
- Proof of Notice of Meeting

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

- 1) Recap of 2018 Accomplishments
  - Completed Fearless Physical Activity Project with CHEO RI
  - Various Awareness and fundraising events and activities across Canada
    - o Walk of Life - Toronto & Ottawa Race Weekend
  - Conference and education participation
    - o ISACHD Symposium, Labatt Family Heart Centre Family Conference, BC PACH Education Day,
  - Completed 2019-2021 Strategic Planning session - rescheduled due to ON ice storm
- 2) 2019 Year to Date Accomplishments & Initiatives
  - Working towards Beat Retreat rejoining CCHA
  - Successful CHD Awareness Week and Heart Month - Faces of CHD campaign
  - Continuing research advocacy
- 3) Fearless Physical Activity
  - 2 year project in collaboration with CHEO RI, funded through Ontario Ministry of Tourism, Culture and Sport OSRCF Grant. The grant ~\$186,000 funded 31 family friendly, low cost physical activity events across Ontario in partnership with local recreation centre partners to help educate individuals and families with CHD of all ages learn to exercise without fear, barriers and limitations. CHD Clinics across Ontario also partnered with us in support
  - Project completed in June 2018.
  - Moved forward with evaluation of the materials and program through UofT research project. Involves 3 FPA sessions across Ontario this summer
  - Fearless resources and are available on CCHA website.
  - Looking to establish permanent program in Ontario and expand across Canada.
- 4) Physical Activity Toolkit
  - Research trial with CHEO RI to investigate the provision of physical activity counselling, resources and kinesiology support to children with CHD as part of routine CHD clinic care.
  - Over 100 participants enrolled in Ottawa, London and Edmonton. 47 children between 5-17 yo have completed the program.



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# CCHA Financial Report

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Statement of Operations & Changes in Net Assets		
Year Ended December 31	2019	2018
Total Revenues	\$ 12,769	\$ 80,931
Total Expenditures	\$ 16,192	\$ 93,131
Net Assets, beginning of year	\$ 23,283	\$ 35,483
Excess of Revenue over Expenditures	-\$ 3,423	\$ -12,200
Net Assets, end of year	\$ 19,860	\$ 23,283



# CCHA Financial Report

## Statement of Financial Position

December 31st	2019	2018
Total Assets	\$21,363	\$50,577
Total Liabilities	\$1,503	\$27,293
Net Assets, Unrestricted	\$19,860	\$23,283



# CCHA Financial Report - Movement

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

- Completed CCHA Notice to Reader Financial Statements 2019
- Appointment of Accountant/Auditor for 2020





# CCHA Board Elections

# Current CCHA Sitting Board of Directors

Board Member	Sitting Term	Position Status / Renewing
Krista Vriend, Sitting President	2017-2020	Not Renewing <b>X</b>
Jennifer Graham, Sitting Vice-President	2019-2022	
Robbyn McLellan, Sitting Treasurer	2020-2022	
Laura Philippe	2018-2021	
Jennifer Michaud, Secretary	2019-2022	
Christelle Savoy	2019-2022	
Sarah McMillan	2019-2022	
Karen LeComte	2019-2022	
Meaghan Sharp	2017-2020	Renewing
Bengy Mercier	2017-2020	Interim replacement
Vacant	2019-2022	



# Board Elections - Application Process

- Notice posted on May 26, application deadline June 5, 2020
- Published on website, social media and emailed to members
- 4 positions are open for the 2020-2023 Board Position
  - 2 are vacant
  - 1 is renewing
  - 1 was interim and recommend election to full-term on Board



# Board Elections - Selection Criteria

- Preferred Skills
  - Experience on a non-profit board
  - Fundraising/philanthropic experience
  - Accounting or legal experience
  - Strategic and operational expertise
  - 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 - Interview Process

- Interview Committee:
  - Krista Vriend
  - Robbyn McLellan
  - Allan Weatherall
  
- Committee interviewed all four applicants:
  - Anna Bailie - Ottawa, ON
  - Jacey Hughes – Bedford, NS
  - Stephanie Kalp – London, ON
  - Lauren Rea – Toronto, ON



# Board Elections - Recommended New Members

## Anna Bailey – Ottawa, ON

- Graduate of McGill and Queens University, Master and Bachelor degrees in science.
- Employed as a Senior Economist with the Economic Development and Corporate Finance Department with the Federal Department of Finance
- Diagnosed with CHD at age 13, which until then had been undetected

## Lauren Rea – Toronto, ON

- Graduate of the University of Guelph, currently student at George Brown College
- Employed as an Appeals Registrar, Appeals Services Division at the Workplace Safety and Insurance Board of Ontario
- Living with congenital heart disease (CHD)

## Jacey Hughes – Bedford, NS (honorary position)

- Graduate of University of Prince Edward Island – Charlottetown with a BSc in Kinesiology,
- Diploma in Massage Therapy from Northumberland Massage College in Halifax.
- Despite her CHD diagnosis - aortic stenosis - she has been actively involved in competitive hockey and as a swimming instructor for children with special needs.



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

## Meaghan Sharp - Thunder Bay

Meaghan is a CHD patient, and has called Canada home for the last 18 years. Born in Sydney , Australia, Meaghan is extremely passionate about ensuring CHD patients receive quality care continue in the pursuit of excellence in patient and family centered care. Meaghan is a Registered Nurse, and is currently the Director of Cardiovascular and Stroke Programs, at Thunder Bay Regional Health Sciences Centre. Meaghan has over 15 years of extensive management and leadership experience in health care. She has a clinical background in acute care, holds a Masters Degree in Nursing, and is currently enrolled in a Masters of Business Administration Program. Outside of her career, Meaghan is married and the mum of one child. She is passionate about fitness and has returned to competitive swimming in the Fall of 2017. Her inspiration for her return is her 13 year old daughter, who is an active competitive swimmer. Meaghan also adores gardening and fashion.

## Bengy Mercier - Montreal

Bengy is the mother of two kids, a little boy (January 2014) and a little girl (March 2018) born with Tetralogy of Fallot with absent pulmonary valve syndrome. She has a bachelor's degree in Computer Science, and she is currently working as an IT Analyst with experience in administration and project management work along with website development and social media. Bengy lives in Montreal and loves spending time and enjoying all the little moments with her husband and children, she likes to travel, to sing and to support people in need.



# Board Elections - Nominations

- In accordance with the CCHA by-laws, the individuals voted onto the Board will each begin three-year terms, regardless of time remaining on vacated terms.
- Recommended candidates:
  - Anna Bailie - Ottawa, ON
  - Lauran Rea – Toronto, ON
  - Jacey Hughes – Bedford, NS (honorary position)
- Recommended for re-election:
  - Meaghan Sharp - Thunder Bay, ON
  - Bengy Mercier - Montreal, QC



# Board Elections - 2020/2021 Board of Directors

- Anna Baillie
- Jennifer Graham
- Karen LeComte
- Robbyn McLellan
- Sarah McMillan
- Bengy Mercier
- Jennifer Michaud
- Laura Philippe
- Lauran Rea
- Christelle Roy
- Meaghan Sharp
- Jacey Hughes - Honourary





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**New Business**

**Meeting Adjournment**



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**Thank you!**