



CANADIAN
CONGENITAL
HEART ALLIANCE

CCHA 2023 ANNUAL GENERAL MEETING

June 19, 2023

Agenda

Time	Item	Speaker
7:30	Land Acknowledgement & Welcome	Priyanka Kugamoorthy (Vice-President) Allan Weatherall (Executive Director)
7:35	President's Report	Jennifer Graham (President) / Priyanka Kugamoorthy
7:45	Executive Director's Report	Allan Weatherall
8:15	2022 AGM Minutes	Anna Bailie (Secretary)
8:20	CCHA Financial Report	Robbyn McLellan (Treasurer)
8:35	2023 Board Elections	Priyanka Kugamoorthy, Anna Bailie, Allan Weatherall
8:50	New Business	Jennifer Graham
9:00	Meeting Adjournment	Jennifer Graham



Ohenten Kariwatekwen

- Canadian Congenital Heart Alliance respectfully recognizes and acknowledges the traditional and ancestral land of the First Nations, Inuit, and Métis peoples across Turtle Island on which today's Annual General Meeting operates.
- ***Ohenten Kariwatekwen***: The words spoken before all others.
- Turtle Island is home to:
 - 634 different First Nations communities
 - 53 Inuit Communities
 - 8 Métis Settlements

Welcome

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



The CCHA Mandate

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

Review

2022

- Finalized and approved 2023-2026 Strategic Plan
- Collaborated with Virtual Heart Connection for Virtual Fontan camps and WCCHN Boost UP competition submission
- Collaborated with 3D Heart project for submission to WCCHN Boost UP
- Ongoing work on projects with college and university programs across Canada

2023

- Launched French version children's book 'Penelope goes for her Heart Checkup'; audiobooks in progress
- Continued growth and expansion of CHDAW 'Canada Lit Red' campaign



Mission – Awareness

CHD Awareness Week (CHDAW) & Heart Month

2023 #CanadaLitRed4CHD



[#CanadaLitRed4CHD](https://www.instagram.com/CanadaLitRed4CHD) campaign for CHDAW

- Edmonton High Level Bridge
- Vancouver BC Place Stadium
- Calgary Tower
- Fredericton City Hall
- London City Hall
- London JA Taylor Building
- London and Toronto Canada Life building
- LHSC - Women's Heart Health Institute
- RBC Place London



Mission – Awareness

CHD Awareness Week (CHDAW) & Heart Month

2023 #CanadaLitRed4CHD



[#CanadaLitRed4CHD](#) campaign for CHDAW

- CN Tower
- Ottawa Sign
- Niagara Falls
- NL Government House
- Tour de Montreal
- Winnipeg sign
- Halifax City Hall
- St. John's City Hall
- St. Thomas - Jumbo Statue



Mission – Awareness

CHD Awareness Week (CHDAW) & Heart Month

CHD Awareness Week proclamations

9 cities proclaim CHD Awareness week

- Victoria Edmonton Calgary
- Regina Toronto Ottawa
- Fredericton Halifax St. Thomas

CHD Stories

- 9 stories shared – Jamie & Vanessa (mom), Andraya, Maddox and mom, Davita, Priyanka and Bren, Veronique, Jackson and mom, Alex, and Meghan
- Stories shared in English and French

CHD Statement in House of Commons

- Statement by Ryan Williams, Member of Parliament (Bay of Quinte) recognizing CHD Awareness Week in House of Commons

PROCLAMATION
CONGENITAL HEART DISEASE AWARENESS WEEK
FEBRUARY 7-14, 2023

WHEREAS: More than 50 percent of all children born with CHD will require at least one invasive surgery in their lifetime; and

WHEREAS: Survival of children with CHD has greatly improved thanks to advances in medical technology, but for some, CHD means lifelong cardiac care; and

WHEREAS: With more patients reaching adulthood continued efforts in fundraising and research is required to ensure access to ongoing care and support.

THEREFORE: I, Kate Rogers, Mayor of the City of Fredericton, do hereby proclaim that February 7-14, 2023, shall be known as "Congenital Heart Disease Awareness Week" in Fredericton.

Kate Rogers
MAYOR

• CHD STORIES •
“ Having your child diagnosed with CHD was a very tough thing to hear, but it's truly amazing what our doctors can do these days. ”
Maddox's Mom

LES HISTOIRES DE MALADIES CARDIAQUES CONGÉNITALES
“ Avoir votre enfant diagnostiqué avec une cardiopathie congénitale était une chose très difficile à entendre, mais c'est vraiment incroyable ce que nos médecins peuvent faire de nos jours. ”
La mère de Maddox



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Mission – Awareness

CHD Awareness Week & Heart Month

Promoted Awareness and created individual social posts in over 30 languages!



Mission - Education

Pénélope va chez le cardiologue

- Launched French Penelope book for 2023 CHDAW, EN launched in February 2021
- Currently EN and FR available as Flipbook or for download on CCHA website
- FR audio book is completed and EN is in progress
- Next steps
 - Provide pediatric clinics across Canada with hard copy
 - Have physical copies available for purchase
 - Translate into more languages



Mission - Education

Transition video resources

- Objective is to support families through Transition process by sharing lived experiences and advice
- Working on French version in collaboration with Fondation En Coeur

YouTube shorts

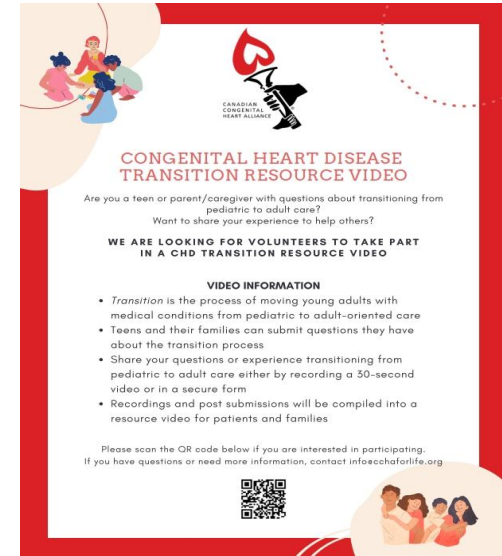
- Short 60 sec videos about CHD defects, diagnosis, terms and more

Fearless Physical Activity events

- Create virtual and in person physical activity events, to educate and improve activity level for those living with CHD

CHD stories

- Continue to expand and share our stories of people and families living with CHD



Mission – Research

CRN-ACHDi Inaugural Meeting

- October 16, 2022: **CRN-ACHDi** held its first network meeting
 - included congenital investigators and research team members from across Canada
 - CCHA invited to speak about our organization and our ongoing activities. Also participated alongside other network members in discussion of future studies and network activities.
- CCHA was invited to join the **Canadian Research Network for Adult Congenital Heart Disease Interventions (CRN-ACHDi)** as a pillar partner in 2019 - the first Canadian national ACHD research network to bring together researchers, patients and caregivers, providers and decision makers to improve patient care through collaborative, innovative and highly translational research



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Mission – Research Partnerships and Collaboration

Co-Principle Investigators

- Collaborative paper with CHEO RI Halo group published March 2020
 - Impacting child health outcomes in congenital heart disease: Cluster randomized controlled trial protocol of in-clinic physical activity counselling. *Contemporary Clinical Trials*
- Finalizing research project with CHEO RI Halo group
 - Impacting Child Physical and Mental Health Outcomes in Congenital Heart Disease: A Randomized, Controlled, Multi-Centre Trial of Enhanced Physical Activity Support in Clinical Care to Decrease the Burden of Disease and Treatment-Related Morbidity

Collaborations/Partners

- Dr. Jasmine Grewal and St. Pauls Hospital, Vancouver BC
 - Bridging the Gap: Screening for Fontan Associated Liver Disease (FALD) study
- Dr. Tieghan Killackey and Dr. Ahola Kohut, Sick Kids Hospital, Toronto ON
 - Virtual peer-to-peer mentoring for adolescents with Congenital Heart Disease: An Implementation study.



Mission – Research Letters of Support

Letters of Support

- Dr. Luke Eckersley and Stollery Children’s Hospital, Edmonton AB
 - Multi-modality validation of neonatal pre-operative hemodynamic findings in hypoplastic left heart syndrome
- Dr. Kevin Harris, UBC and BC Children’s Hospital, Vancouver BC
 - A Feasibility Study: Physical Activity Counselling for Children with Congenital Heart Disease (CHD)
- Dr. Suzanne Fredericks, Lind Alliance and Ryerson University, Toronto ON
 - Study of research priorities of patient, caregivers and clinicians related to heart surgery
- Dr. Andrew Mackie and Dr. Jennifer Conway, Edmonton AB
 - Tackling access to care with virtual technology in pediatric heart disease – multi-project study



Mission - Support

Beat Retreat Camp

- 14th annual camp schedule for September 7-10
- Registration forms available on CCHA website
- Opportunity to participate in camp activities, learn, make new friends and build network of support



Virtual Fontan Camp

- 3rd annual camp scheduled for November 4
- Bilingual camp, open across Canada to kids ages 7-15
- Registration forms available on CCHA website
- Opportunity to connect with other kids with Fontan, learn and share in fun activities and costume party!



Mission - Advocacy

Ottawa Heart to Heart Event

- Organized by Board member Amanda Fregonas with support from Anna Bailie, and in collaboration with Pediatric Interest Group at University of Ottawa
- Event designed for medical students, Dr. Susan Lee – CHEO and NP Joanne Morin – Ottawa Heart Institute presented, along with Jennifer Mulder who shared her journey living with CHD

Sick Kids Advanced Pediatric Cardiology Nursing presentation

- Lori CS and Jennifer G share their journey living with CHD and importance of including people and families with CHD in creating resources

Fun Fact Friday and Educational media

- Educational videos and images shared on social media to learn about CHD defects, terms, medical tests and other important information



20th Anniversary

CCHA is turning 20 in 2024!

- CCHA was founded in 2004
- Next year CCHA will be celebrating its 20th anniversary

What's happening?

- More advocacy and awareness campaigns
- Larger scale Heart Month and CHDAW campaigns
- Collaborations with other organizations on more projects
- Stay tuned - more details to come!

CHEERS
TO 20
YEARS!



Strategic Plan – 2023-2026 High-level

Overview

- The Strategic Plan was approved at the 2022 AGM

Challenges

- Awareness
- Partnerships
- Financial sustainability and governance

Opportunities

- CCHA has unique niche mandates as only organization in Canada supports individuals with CHD throughout lifespan and are valuable partner to offer wealth of information and programs
- CCHA has been established 19 years with continuity and passionate and resourceful Board with varied experiences living with CHD
- Seen as reliable and accurate source of CHD information, resources and support
- Established partnerships and positive reputation with medical community
- Do not conduct research, therefore able to connect, advocate and support CHD research and provide non-biased, patient-centered view on CHD



Strategic Plan – 2023-2026 High-level

Priorities

Connecting with People

- Growth through social media
- Website development
- Improve community communications
- Create educational and advocacy resources and tools
- Improve Diversity and Inclusion by expanding languages
- Expand events and programs

Priorities

Growing and Sustaining CCHA

- Grow and diversify fundraising activities and opportunities
- Explore new revenue streams
- Further develop and strengthen our Stewardship platform
- Ensure sustainable approach to CCHA's governance and leadership



Strategic Plan – 2023-2026 High-level

Priorities

Deepening and Expanding our Partnerships

- Assess existing partnerships
- Connect and establish new partnerships/collaborations
- Engage and expand research support and partnerships
- Engage and build on our Professional Advisory Board
- Enhance work with CHD clinics



Strategic Plan – 2023-2026 High-level

KPIs (Key Performance Indicators)

Connecting with People

- Increasing social media and membership by 10% year over year

Growing and Sustaining CCHA

- Contribute to or support at least three research projects per year

Deepening and Expanding our Partnerships

- Increase donations 5% year over year, and directing resources to activities that will support fulfilment of our vision and mission





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Executive Director's Report

Executive Director's Report

- For the 2022 year (and into 2023) and into this current fiscal year
- Ongoing administrative support and initiatives
- Board support and information sourced that might be of interest



Executive Director's Report - Administration

- Each week time is spent on monitoring emails from wide variety of sources
- Support for ongoing activities - i.e Light Canada Red, CHD Day, MP statement
- Board recruitment process
- Thank you to all donors ... via emails, letters, phone calls
- Confirmed more sites for "Canada Lit Red" campaign
- Met with Anna Bailie and Leanne Lang (Ottawa Heart Institute) in Ottawa



Executive Director's Report - Media

- Endeavour to liaise with various media outlets
 - i.e. Globe and Mail, W5, Quirks and Quarks (CBC)
- Still a challenge to get 'the news hook' for media to be interested
- Secured a statement in the House of Commons recognizing CHD Awareness Week for 7th year
- Created press release championing 'Canada Lit Red' campaign to media, excited to have several articles in Canadian press



Executive Director's Report - Fundraising

- Assisted with Giving Tuesday and other fundraising initiatives
- Some success in some new areas
 - *special events (i.e. Kitchener)
 - *Transfer of stocks
 - *In Memoriam gifts
 - *Monthly Donors
- Better financial position through enhanced fundraising success
- Prepared thank you letters (i.e. monthly donors, corporate donations)
- Further contact with Health Partners (Ottawa) re: federal employee donations



Executive Director's Report - Chapter reports

The Chapters in Eastern Ontario and London have been inactive due to COVID19 challenges.



2022 AGM Minutes



CCHA ANNUAL GENERAL MEETING MINUTES

December 13, 2022
7:30-9:00pm ET
Teleconference

Attendees:	Allan Weatherall (Executive Director), Jennifer Graham (Vice President, interim President), Robbyn McLellan (Treasurer), Anna Bailie (Secretary), Bengy Mercier, Jacey Hughes, Priyanka Kugamoorthy, Brenaven Kugamoorthy,
Guests:	Edith Tham, Elina Williams and Luxshika Canthiya
Secretary:	Anna Bailie (call recorded)

MINUTES

1. Welcome – Allan Weatherall, Jennifer Graham

- Attendance & Introductions
- Call to Order
- Quorum Established
- Appointment of Recording Secretary:
 - Anna Bailie
- Proof of Notice of Meeting
 - Provided on website and through emails to membership November 30, 2022 to AGM being called

2. Presidents Report – Jennifer Graham

- 2021-22 Highlights
 - Advocacy during CHD Awareness Week, especially the well-received Light Canada Red, proclamation in the house of commons,
 - Writing a new Strategic Plan
- Education
 - Development of informational documents and created transition materials
 - Participated in learning opportunities
 - Brenaven Kugamoorthy presented on the importance of physical activity – looking to develop a new project in collaboration with the Blue Jays/Sick Kids
- Research Partnerships and Collaborations
 - Priyanka Kugamoorthy presents on our research activities, including a recent presentation at the inaugural CRN-ACHDi Inaugural Meeting, importance of patients participating and being an active part of studies
 - Also supporting research at CHEO, in Vancouver and at SickKids, and also indicating support for other research projects by providing letters
- Support
 - Collaborated with 5 other CHD organizations in Canada, including Heart & Stroke, Fondation En Coeur, Braveheart Support Society, iHeartChange, Global ARCH
 - Continued our support for the Beat Retreat, in person again in September 2022, also supporting a virtual Fontan camp run by Dr. Tham, which had more than 30 and 40 participants in February and November



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CCHA Financial Report

CCHA Financial Report

Statement of Operations & Changes in Net Assets		
Year Ended December 31	2022	2021
Total Revenues	\$36,945	\$19,027
Total Expenditures	\$21,862	\$18,906
Net Assets, beginning of year	\$26,451	\$26,330
Excess of Revenue over Expenditures	\$15,083	\$121
Net Assets, end of year	\$41,534	\$26,451



CCHA Financial Report

Statement of Financial Position

Year Ended December 31	2022	2021
Total Assets	\$43,285	\$27,954
Total Liabilities	\$1,751	\$1,503
Net Assets, Unrestricted	\$41,534	\$26,451



CCHA Financial Report - Movement

CCHA Auditor: Jennifer Rade Chartered Professional Accountant

- Completed CCHA Notice to Reader Financial Statements 2022
- Appointment of Accountant/Auditor for 2023





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CCHA Board Elections

Current CCHA Sitting Board of Directors

Board Member	Sitting Term	Position Status / Renewing
Jennifer Graham (President)	2013-2025	
Priyanka Kugamoorthy (Vice-President)	2021-2024	
Bengy Mercier (Treasurer)	2020-2023	Renewing
Anna Bailie (Secretary)	2020-2023	Not Renewing X
Karen LeComte (PAB liaison)	2019-2025	
Luxshikka Canthiya	2022-2025	
Amanda Fregonas	2022-2025	
Jacey Hughes	2021-2024	Not Renewing X
Brenaven Kugamoorthy	2021-2024	
Meaghan Sharp	2017-2023	Not Renewing X
Elina Williams	2022-2025	
Edythe Tham (Honourary)	2022-2023	



Board Elections - Application Process

- Notice posted on May 6, 2023, application deadline June 4, 2023
- Published on website, social media, emailed to members, LinkedIn, Charity Village
- 4 positions are open for the 2023-2026 Board Position
 - 1 is renewing
 - 3 are not renewing
 - 3 vacancies



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:
 - Anna Bailie
 - Priyanka Kugamoorthy
 - Allan Weatherall



Board Elections - Interview Process

- Committee received 21 applications, including:
 - Javid A – ON
 - Mahir A – ON
 - Lee B – ON
 - Villeury B – QC
 - Zebalda B – ON
 - Ali K – external applicant
 - Sylvie L – ON
 - Christine M – ON
 - Joe M – ON
 - Sunnaiyakam M – ON
 - Malcolm P – ON
 - Erika R – AB
 - Sarah R – PEI
 - Shivani S – external applicant
 - Frank V – QC
- Eight applicants were invited to interview (only six were completed due to one withdrawal and one cancellation)



Board Elections - Recommended New Members

Davita Friedland – AB

- LNP working at an Indigenous Wellness Centre
- Born with CHD, active in social media fora for those with CHD

Rick Harland – AB

- Consultant with significant fundraising, marketing and strategic planning background
- Family member with CHD



Board Elections - Recommended New Members

George Jiri – ON

- Detective Constable with significant community volunteer experience
- Family member with CHD

Nathalie Lacoste-Hofmann – ON

- Retired teacher with 30+ years experience, including organizing school events
- Born with CHD, Heart Transplant Recipient



Board Elections - Recommended New Members

Katie Losseno – ON

- Pediatric cardiologist finishing fellowship and soon to establish own practice who has led wellness committees
- Born with CHD and has networked with those with similar defects

Jacqueline Wang – ON

- Paralegal with significant regulatory and legal experience, including within the health field
- Shared personal experience with their healthcare journey



Board Elections - Elections

Bengy Mercier – Montreal, Quebec – Renewing board member

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. 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. Entering her 2nd term as a board member, Bengy has greatly pushed the Penelope children's book initiative forward with the french translation and creation of the FR audiobook, along with contributions to various other projects .

Edythe Tham – Edmonton, AB – Honorary to Electing board member

Edythe Tham is a staff Cardiologist at the Stollery Children's Hospital, University of Alberta specializing in cardiac imaging, namely echocardiography and cardiac MRI. Her research interests are in novel imaging techniques to evaluate cardiac function. She is also a dedicated volunteer in the field of pediatric cardiology, supporting a number of projects for children, families, and healthcare professionals. She is the founder of the [Virtual Heart Connection](#) (a series of virtual day camps online for children with a Fontan) and organized the first Congenital Heart Family Picnic in July 2022.



Board Elections - Nominations

- In accordance with CCHA By-Laws, the individuals voted onto the Board will each begin three-year terms, regardless of time remaining on vacated terms.
 - Recommended candidates:
 - **Edythe Tham** – Alberta
 - **Rick Harland** – Alberta
 - **George Jiri** – Ontario
 - Recommended for re-election:
 - **Bengy Mercier** – Quebec



Board Elections - 2023/2024 Board of Directors

- Luxshikka Canthiya
- Amanda Fregonas
- Jennifer Graham
- Rick Harland
- George Jiri
- Brenaven Kugamoorthy
- Priyanka Kugamoorthy
- Karen LeComte
- Bengy Mercier
- Edythe Tham
- Elina Williams





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New Business

Meeting Adjournment

Engage and connect with CHD community!

www.cchaforlife.org



@cchaforlife





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Thank you!