



CANADIAN
CONGENITAL
HEART ALLIANCE

CCHA 2022 ANNUAL GENERAL MEETING

December 13, 2022

Agenda

Time	Item	Speaker
7:30	Welcome	Allan Weatherall (Executive Director)
7:35	President's Report	Jennifer Graham (interim President/Vice President)
7:45	Executive Director's Report	Allan Weatherall
7:55	Strategic Plan	Anna Bailie (Secretary)
8:15	2021 AGM Minutes	Anna Bailie
8:20	CCHA Financial Report	Robbyn McLellan (Treasurer)
8:35	2022 Board Elections	Anna Bailie, Jacey Hughes, Priyanka Kugamoorthy
8:50	New Business	Jennifer Graham
9:00	Meeting Adjournment	Jennifer Graham



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

2021

- CHD Advocacy tools and video in collaboration with other CHD organizations
- Launched children's book 'Penelope goes for her Heart Checkup'
- Lit Canada Red for CHD Awareness Week and Heart month activities
- Began development of Strategic Planning 2023-2026

2022

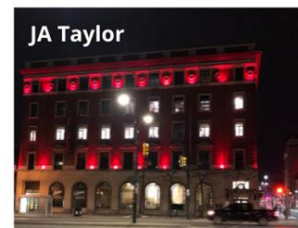
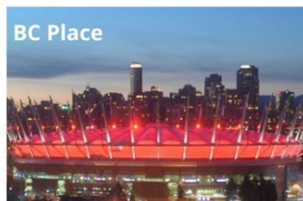
- Engaged 2 student teams from Laurentian University's MBA program and University Canada West's graduate management program to assist with development
- Invited a professional facilitator Tom Little (CMCS Consulting) to moderate 4 planning sessions with the board.



Mission – Awareness

CHD Awareness Week & Heart Month

2022 Light Canada Red



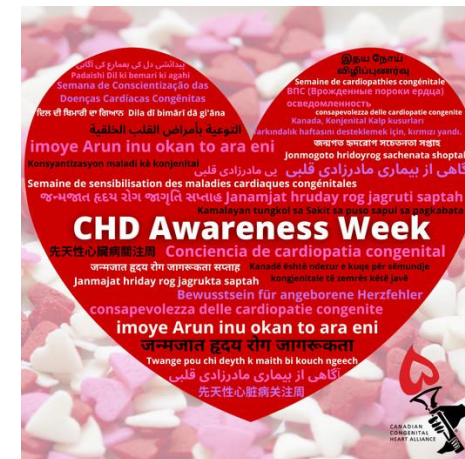
#CanadaLitRed4CHD campaign for CHD Awareness Week

- Edmonton High Level Bridge
- Vancouver BC Place Stadium
- Calgary Tower
- London City Hall
- London JA Taylor Building
- London and Toronto Canada Life building
- RBC Place London
- CN Tower
- Niagara Falls
- NL Government House
- Winnipeg sign
- Halifax City Hall



Collage - Lit Red 2022 (Social Media) V2(1).mp4

Promoted in 30 languages



Mission – Awareness

CHD Awareness Week & Heart Month

CHD Awareness Week proclamations

9 cities proclaim CHD Awareness week

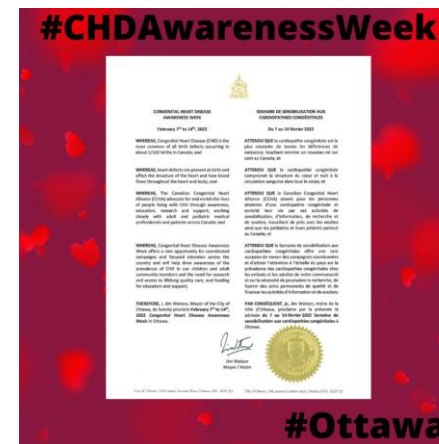
- Victoria
- Edmonton
- Calgary
- Regina
- Toronto
- Ottawa
- Fredricton
- Halifax
- St. John's

CHD Stories

- 4 stories shared – Alana, Pearl and Samatha (mom), Priyanka and Bren and Jamie and Vanessa (mom)Victoria
- 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



Stories of CHD

What gives you hope?

"Improving early detection. It was a shock when Pearl's CHD was diagnosed at 1 day old."

— Samantha, Pearl's mom



Histoires de CHD

Que'st-ce qui te donne de l'espoir?

"Améliorer la détection précoce. Ça fut un choc quand le CHD de Pearl a été diagnostiqué quand elle a eu une journée de vie."

— Samantha, la mere de Pearl



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Mission - Education

Developing 2 Transition video resources

- Partnered with Mohawk College's Digital Health program (Riipen) to create along with nurses from Sick Kids and BC PACH clinic
 - For teens going through the transition process
 - For parents/family of teens going through transition
- Objective is to support families through Transition process by sharing lived experiences
- Share questions or advice or experience through written submission or 30 sec video
- Working on French version in collaboration with Fondation En Coeur




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CONGENITAL HEART DISEASE TRANSITION RESOURCE VIDEO

Are you a teen or parent/caregiver with questions about transitioning from pediatric to adult care?
Want to share your experience to help others?

**WE ARE LOOKING FOR VOLUNTEERS TO TAKE PART
IN A CHD TRANSITION RESOURCE VIDEO**

VIDEO INFORMATION

- *Transition* is the process of moving young adults with medical conditions from pediatric to adult-oriented care
- Teens and their families can submit questions they have about the transition process
- Share your questions or experience transitioning from pediatric to adult care either by recording a 30-second video or in a secure form
- Recordings and post submissions will be compiled into a resource video for patients and families

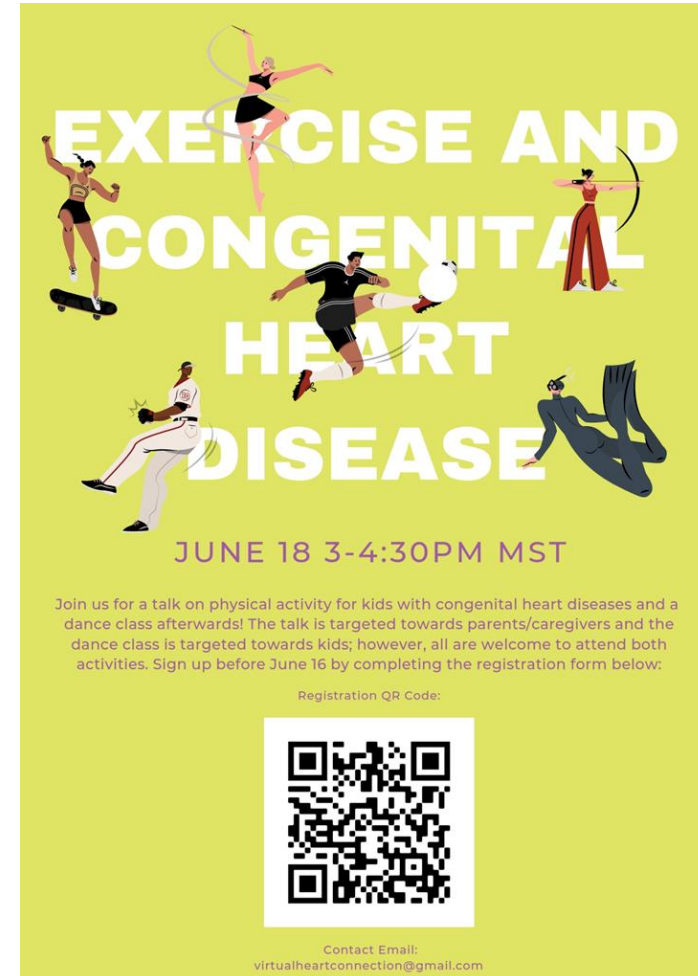
Please scan the QR code below if you are interested in participating.
If you have questions or need more information, contact infoecchaforlife.org



Mission - Education

Physical Activity and CHD virtual talk

- Partnered with Virtual Heart Connection to provide education for physical activity and CHD
 - Talk was geared toward parents/caregivers
 - Dance class was designed for kids
- Our BOD Brenaven Kugamoorthy was presenter in the physical activity talk




**EXERCISE AND
CONGENITAL
HEART
DISEASE**

JUNE 18 3-4:30PM MST

Join us for a talk on physical activity for kids with congenital heart diseases and a dance class afterwards! The talk is targeted towards parents/caregivers and the dance class is targeted towards kids; however, all are welcome to attend both activities. Sign up before June 16 by completing the registration form below:

Registration QR Code:



Contact Email:
virtualheartconnection@gmail.com



Mission – Research

CRN-ACHDi Inaugural Meeting

- CCHA 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
- 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.



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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*
- Ongoing 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

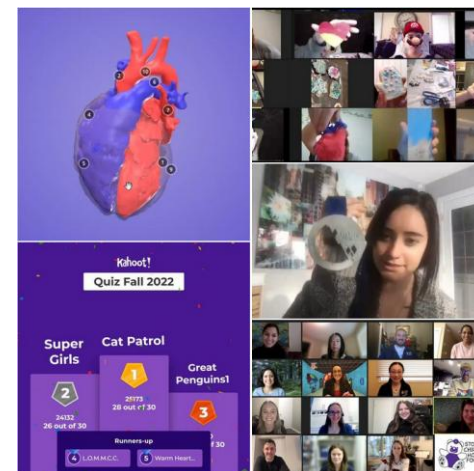
Beat Retreat Camp

- In person camp held September 2022 after 2 years of virtual camps
- 15 people attended and participated in camp activities and met new friends



Virtual Fontan Camp

- Partnering with Virtual Heart Connection to support and develop Fontan camp for kids 8-15 years
- February camp 33 kids
- November camp – 45 kids attended. 15 volunteers, 3 adult Fontan testimonies and 1 special guest



Mission - Advocacy

Partnered in 2 WCCHN Boost Competition pitches

- Virtual Heart Connection to support and develop pan-Canadian virtual Fontan camp for kids 8-15 years old across Canada
- 3D Heart Project is intended to use 3D heart models and digital 3D heart visualizations as teaching tools for patients, families and health care providers. CCHA will be a partner in dissemination of the open access learning resources



Building connections
..through online camps
..across Western Canada & beyond

SAVE THE DATE FOR THE:
1st Pan-Canadian Virtual Fontan Heart Camp
Saturday November 26, 2022

All children aged 8-15 years with a Fontan are invited to participate in this FREE, fun, online event!

Click here [Add me!](#) or scan code to be added to the mailing list:

[f](#) [@virtualheartconnection](#)
or click on the icon

More details to follow. Any questions?
Email: virtualheartconnection@gmail.com



3D Heart Project

WCCHN BOOSTUP PITCH
COMPETITION FINALISTS

FEB 8TH, 7:00PM (MST)





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Executive Director's Report

Executive Director's Report

- For the 2021-2022 year and into this current fiscal year
- Ongoing administrative support and initiatives



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
- *Penelope goes for her heart checkup* - support in production
 - i.e. Toronto Blue Jays endeavour
- Thank you to all donors ... via emails, letters, phone calls



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
- Still high lack of awareness for CHD overall



Executive Director's Report - Fundraising

- Investigated DMS (donor management systems)
 - Assisted with *Giving Tuesday*
- 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



Executive Director's Report - Chapter reports

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





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Strategic Plan

Strategic Plan – Pivot Strategy

2020

- The COVID-19 pandemic shifted the focus and outlook for CCHA.
 - This created the need to revisit the remainder of our 3-year strategy and determine how the organization should pivot in the new and uncertain environment.
- Priority 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
- Steps to success
 - The new board will assess and determine key priorities to set CCHA up for future success.



Strategic Plan – Pivot Strategy

2021 - 2022

- Due to large turnover in Board members in 2019 and 2020 (7/11) and the COVID-19 pandemic, a shift in focus and outlook was needed for CCHA:
 - Revisited the remainder of our 3-year strategy and determine how the organization should pivot in this new environment
 - In August and September 2020 the board reprioritized focus
 - Website
 - Fundraising
 - Education
 - Social Media
 - Awareness
- In late 2021 and into 2022 began to develop Strategic Plan for 2023-2026
 - Fundamental global changes may shift needs for our members
 - Work to ensure diversity and inclusion across the organizations and members
 - Fuller engagement of Professional Advisory Board



Strategic Plan – 2023-2026 Development

- Engaged 2 student teams from Laurentian University's MBA program and University Canada West's graduate management program to assist with development
- Invited a professional facilitator Tom Little (CMCS Consulting) to moderate 4 planning sessions with the board.
- October and November 2021 worked as team to determine priorities and goals
- Board reviewed student's final reports
- Board committee worked to develop draft Strategic plan over summer 2022 and Board revised and finalized in fall of 2022



Strategic Plan – 2023-2026 High-level

CCHA Mandate reviewed and remains unchanged

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.



Strategic Plan – 2023-2026 High-level

Overview

- CHD affects more than just the individual – as such CCHA also includes and engages families, friends and loved ones. CCHA also works closely and relies on the advice of medical practitioners, by way of (but not limited to) our Professional Advisory Board (PAB)
- Being the ones living with, or the loved ones living with CHD, the CCHA (including BOD, members, volunteers and partners) is best positioned to understand the most salient issues for Canadians with heart defects and to advocated for them, along with the rest of the CHD community. However, to do so, the CCHA needs to continue to work to raise awareness about CHD, deepen and expand our partnerships with the medical community and other researchers, and ensure we are best positioned to support others by acting to assure our own long term sustainability.



Strategic Plan – 2023-2026 High-level

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



Strategic Plan – 2023-2026 High-level

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

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

Deepening and Expanding our Partnerships

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



2021 AGM Minutes



CCHA ANNUAL GENERAL MEETING MINUTES

June 22, 2021
7:30-9:00pm ET
Teleconference

Attendees:	Allan Weatherall (Executive Director), Jennifer Graham (Vice President, Interim President), Robbyn McLellan (Treasurer), Jennifer Michaud (Secretary), Christelle Roy-Couillard, Bengy Mercier, Jacey Hughes, Priyanka Kuugamoorthy, Brenaven Kuugamoorthy, Lauren Rea
Guests:	Frances Knowles, Renee Charette
Secretary:	Jennifer Michaud (call recorded)

MINUTES

1. Welcome – Allan Weatherall, Jennifer Graham

- Attendance & Introductions
- Call to Order
- Quorum Established
- Appointment of Recording Secretary:
 - Jennifer Michaud
- Proof of Notice of Meeting
 - Provided on website and through emails to membership May 27, 2021 to AGM being called

2. The CCHA Mandate – Jennifer Graham

- Mission, Vision and Value Statement

3. Presidents Report – Jennifer Graham

- 2020
 - Partnerships with other organizations
 - Beat Retreat rejoin CCHA
 - Virtual camp in September 2020, and again in 2021
 - CHD Awareness Week and Heart Month
 - COVID-19 awareness & CHD impact, website resources
 - Revisited strategy (due in part to large board membership turnover)
- 2021
 - CHD Advocacy tools and video in collaboration with other CHD organizations
 - Launch children's book "Penelope goes for her heart checkup"
 - Lit Canada Red for CHD Awareness and Heart Month
 - Strategic Planning 2022-2025
- Education
 - Transition Resources – 2020 CHD Awareness Week, with 5 partnership organizations (Heart & Stroke, Fondation En Coeur, Braveheart Support Society, iHeartChange, Global ARCH)
 - COVID-19 Resources – 2020 spring, with partner organizations
 - Advocacy Tools – 2021 CHD Awareness Week, with partner organizations
 - Launched children's book: "Penelope goes for her heart checkup"
 - Internship (via Riipen) with UBC Okanagan students helped to create the book
 - Reviewed by pediatric child life specialists and nurses



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CCHA Financial Report

CCHA Financial Report

Statement of Operations & Changes in Net Assets		
Year Ended December 31	2021	2020
Total Revenues	\$19,027	\$19,865
Total Expenditures	\$18,906	\$13,395
Net Assets, beginning of year	\$26,330	\$19,860
Excess of Revenue over Expenditures	121	\$6,470
Net Assets, end of year	\$26,451	\$26,330



CCHA Financial Report

Statement of Financial Position

Year Ended December 31	2021	2020
Total Assets	\$27,954	\$27,832
Total Liabilities	\$1,503	\$1,503
Net Assets, Unrestricted	\$26,451	\$26,330



CCHA Financial Report - Movement

CCHA Auditor: Jennifer Rade Chartered Professional Accountant

- Completed CCHA Notice to Reader Financial Statements 2021
- Appointment of Accountant/Auditor for 2022





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CCHA Board Elections

Current CCHA Sitting Board of Directors

Board Member	Sitting Term	Position Status / Renewing
Jennifer Graham, Interim President/Vice President	2013-2022	Renewing
Robbyn McLellan, Treasurer	2016-2022	Not Renewing X
Jennifer Michaud, Secretary	2019-2022	Not Renewing X
Karen LeComte (PAB liaison)	2019-2022	Renewing
Anna Bailie	2020-2023	
Meaghan Sharp	2017-2023	
Bengy Mercier	2020-2023	
Lauren Rea	2020-2023	Resigned 7/22
Jacey Hughes	2021-2024	
Priyanka Kugamoorthy	2021-2024	
Brenaven Kugamoorthy	2021-2024	



Board Elections - Application Process

- Notice posted on May 6, application deadline October 30, 2022
- Published on website, social media and emailed to members
- 5 positions are open for the 2022-2025 Board Position
 - 2 are renewing
 - 2 are not renewing
 - 1 vacancy



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
 - Jacey Hughes
 - Priyanka Kugamoorthy
 - Allan Weatherall

- Committee interviewed all applicants:
 - Luxshikka Canthiya – Markham, ON
 - Amanda Fregonas – Ottawa, ON
 - Dr. Edythe Tham – Edmonton, AB
 - Elina Williams – Edmonton, AB



Board Elections - Recommended New Members

Luxshikka Canthiya – Markham, ON

- Cardiology Research Assistant at Toronto General Hospital, with an academic background in molecular biology and genetics.
- Volunteer background in clinical and academic settings, with an emphasis on being a mentor



Board Elections - Recommended New Members

Amanda Fregonas – Markham, ON

- Second year medical student at the University of Ottawa, born with CHD
- While a student at the University of Guelph, was a member and President (for one year) of the University's Oxfam Chapter, spearheading fundraising and educational events, while also managing the Chapter budget



Board Elections - Recommended New Members

Dr. Edythe Tham – Edmonton, AB

- Associate Professor, Division of Pediatric Cardiology & Diagnostic Imaging, and Director, Pediatric Cardiology Resident Program, Stollery Children's Hospital.
- More than 15 years of clinical experience working in pediatric and children's heart disease.
- Experienced volunteer in a number of settings, more recently establishing virtual camps for children with heart disease.



Board Elections - Recommended New Members

Elina Williams – Edmonton, AB

- Registered nurse with more than 17 years of pediatric congenital cardiology experience.
- Currently a program manager with the Western Canadian Children's Heart Network.



Board Elections - Elections

Jennifer Graham – Toronto, ON – Renewing board member

Jennifer has been part of CCHA since 2006 and has served on the Board since 2013 working in various roles and projects and is currently the interim 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 has CHD.

Karen LeComte – Vancouver, BC – Renewing board member

Karen 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 has been instrumental in developing resources such as our Transition pages, Heart Surgery Infographic, Transition video project and children's book Penelope goes for her heart checkup. She is also be involved with the Professional Advisory Board of the CCHA as the Liaison.



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:
 - **Luxshikka Canthiya** - Markham **Elina Williams** - Edmonton **Amanda Fregonas** - Ottawa
 - Recommended for re-election:
 - Jennifer Graham – Toronto, ON Karen LeComte – Vancouver, BC
 - Recommended for Honourary board position:
 - Dr. Edythe Tham - Edmonton



Board Elections - 2022/2023 Board of Directors

- Anna Baillie
- Luxshikka Canthiya
- Amanda Fregonas
- Jennifer Graham
- Jacey Hughes
- Brenaven Kugamoorthy
- Priyanka Kugamoorthy
- Karen LeComte
- Bengy Mercier
- Meaghan Sharp
- Elina Williams
- Dr. Edythe Tham - Honourary





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New Business

Meeting Adjournment

Engage and connect with CHD community!

www.cchaforlife.org



@cchaforlife





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Thank you!