



CANADIAN
CONGENITAL
HEART ALLIANCE



AGM / AGA

ANNUAL GENERAL MEETING/
Assemblée Générale Annuelle

June 25, 2024

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

Agenda

Time	Item	Presenter
7:30	Land Acknowledgement	Priyanka Kugamoorthy (Vice-President)
7:33	Welcome	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	Amanda Fregonas (Secretary)
8:20	CCHA Financial Report	Bengy Mercier (Treasurer)
8:35	2024 Board Elections	Amanda Fregonas, Nathalie Lacoste-Hofmann, Allan Weatherall
8:50	New Business	Jennifer Graham
9:00	Meeting Adjournment	Jennifer Graham

Welcome

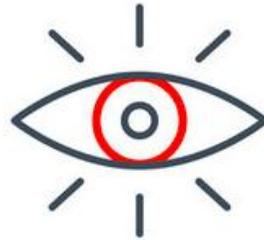
- Call to order
- Attendance
- Determination of Quorum
- Appointment of recording secretary
- Proof of Notice of Meeting

THE CCHA MANDATE



MISSION

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



VISION

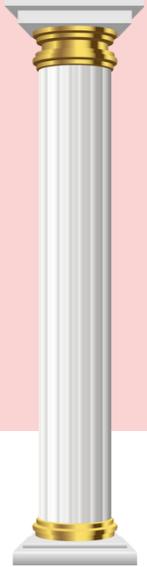
To be the leading voice for enriching the lives of Canadians with CHD



VALUES

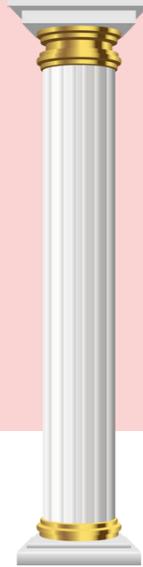
Building a dedicated CHD community that fosters compassion, empowerment and collaboration

EDUCATION



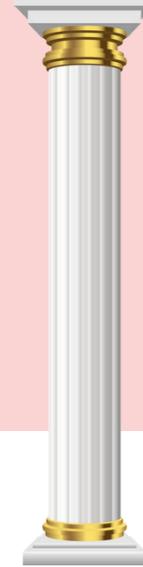
- Children's Book
- Mental Health Resources
- Transition Resources
- Advocacy Tools

AWARENESS



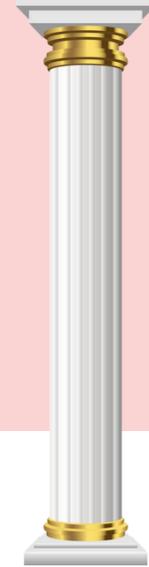
- Canada Lit Red for CHD Campaign
- CHD Awareness Week

SUPPORT



- Virtual Heart Camp
- Beat Retreat
- Fearless Physical Activity
- Personal Stories

RESEARCH



- Physical Activity Toolkit
- Partnerships
- Collaborations
- Letters of Support

ABOUT US

- Established in 2004
- CCHA is the only charity in Canada dedicated to supporting all Canadians living with CHD
- CCHA works closely with both pediatric and adult medical professionals across Canada to improve resources and care, raise awareness of CHD and the need for lifelong expert care
- Strive for partnerships and alliances to build and strengthen our network



President's Report



Review

2023

- Launched 'Penelope va chez le cardiologue' – French version and audiobook
- Returned to Instagram, launched #FunFactFriday
- Attended CCS in Montreal

2024

- Virtual Heart Connection Children's choir
- Launched a podcast
- Developing new website
- Launching physical activity resources for kids

Awareness

CHD Awareness Week/Heart Month



Landmarks lit red

- 17 landmarks across Canada
- 7 businesses show their support by lighting red for CHD Awareness Week

Statement in House of Commons Ryan Williams MP Bay of Quinte statement for CHD Awareness Week



Education

CCHA resources

- Mental Health Resources
- Transition Tools and Resources
- Endocarditis Prevention
- Advocacy Resources
- Fontan Education -> Canadian Fontan
- Healthy Living in Kids with CHD
- Fearless Physical Activity resources
- Link to find ACHD centres in Canada
- Pregnancy in Women with CHD
- Personal Stories
- CHD Unpacked: podcast



<https://youtu.be/GSqt88dTwjo>

Research

Completed 2 research Projects with CHEO HALO RI

- Fearless Physical Activity
- Toolkit project

Physical Activity resources for kids and families will be available on website next month



Fearless Physical Activity



You can do activities that make you breathe faster:

 **Vigorous dynamic** activities that make you breathe really hard and get your heart beating really fast, such as skipping, badminton, long distance running, soccer, tennis, cross-country skiing (classic style), field hockey, squash, orienteering, ultimate frisbee, swimming, ringette or racquetball.

Moderate dynamic activities that sometimes make you breathe hard or make your heart beat fast for short time such as baseball/softball, jogging, tag/hide-and-seek, table tennis, road hockey, volleyball, fencing, tap or jazz dance, in-line skating, soccer baseball, flag football, swimming, dodge ball, skateboarding, bike riding or ice skating.

Light dynamic activities that don't usually make you breathe hard such as walking, cooperative games, Ring around the Rosie, golf, billiards, bowling, croquet, cricket, throwing a Frisbee, curling, tai chi, riding a scooter, meditating, playing catch or playing on slides.

You can do activities that use your muscles to push or pull:

 **Vigorous static** activities that make you push really hard and usually make you hold your breath while you are pushing, such as canoeing and rowing, downhill skiing and snowboarding, wrestling, skateboarding, weight lifting, martial arts, gymnastics, windsurfing, horseback riding and jumping, or playing on monkey bars.

Moderate static activities that sometimes make you push so hard that you hold your breath, such as basketball, ice hockey, tobogganing, pushing a friend on the swing, hopscotch, lacrosse, ballet, cheerleading, bouncing on a trampoline, rock wall climbing, tether ball, archery, BMX or mountain biking, hiking, or yoga.

Light static activities where you don't usually need to push or hold your breath, such as walking, cooperative games, baseball/softball, gardening, table tennis, volleyball, shuffle board, badminton, tree climbing, soccer, billiards, bowling, cricket, curling, golf, tai chi, slides, swimming, bocce, tap and jazz dancing, cross-country skiing (classic style), field hockey, pony rides, geocaching, squash, or racquetball.

The activities above: CAN be played competitively
 Can NOT be played competitively

Comments: _____

For more information about physical activity for your child, contact your child's doctor or your clinic nurse

Name: _____ Date: _____ Provided by: _____

Support



CHD Stories

Highlighting CHD stories of strength and hope across Canada

Support



Beat Retreat camp
4 day weekend for adults (18+)
living with CHD



GO GO GO

Tough CHD Kids Club

Virtual Heart Camp
November 23, 2024
Ages 7-16

Interactive BINGO - Cookie decorating
Testimonies - Escape game - small groups and more!

Questions?
email: virtualheartconnection@gmail.com

Scan qr code to register
Hurry!
Space is limited to 80 kids

Early bird cost
\$10 until Oct 1
\$20 until registration
closes on Nov 1

CANADIAN CONGENITAL HEART ALLIANCE
ALLIANCE CANADIENNE DES CARDIOPATHIES CONGÉNITALES

VIRTUAL HEART CONNECTION

Virtual Heart Camp
1 day virtual camp for kids age 7-16

Projects

CHD Unpacked

- Podcast is a safe space to discuss well-being, lifestyle, psychosocial impacts and unique medical challenges faced by those living with CHD
- Episodes will feature physicians, researchers, and allied healthcare.



A Podcast About Living with
Congenital Heart Disease

Brought to you by the Canadian Congenital Heart Alliance



Episode 1 – Dr. Longmuir – CHD and exercise – June 7

Episode 2 – Dr. Silversides – Pregnancy and CHD – July 5

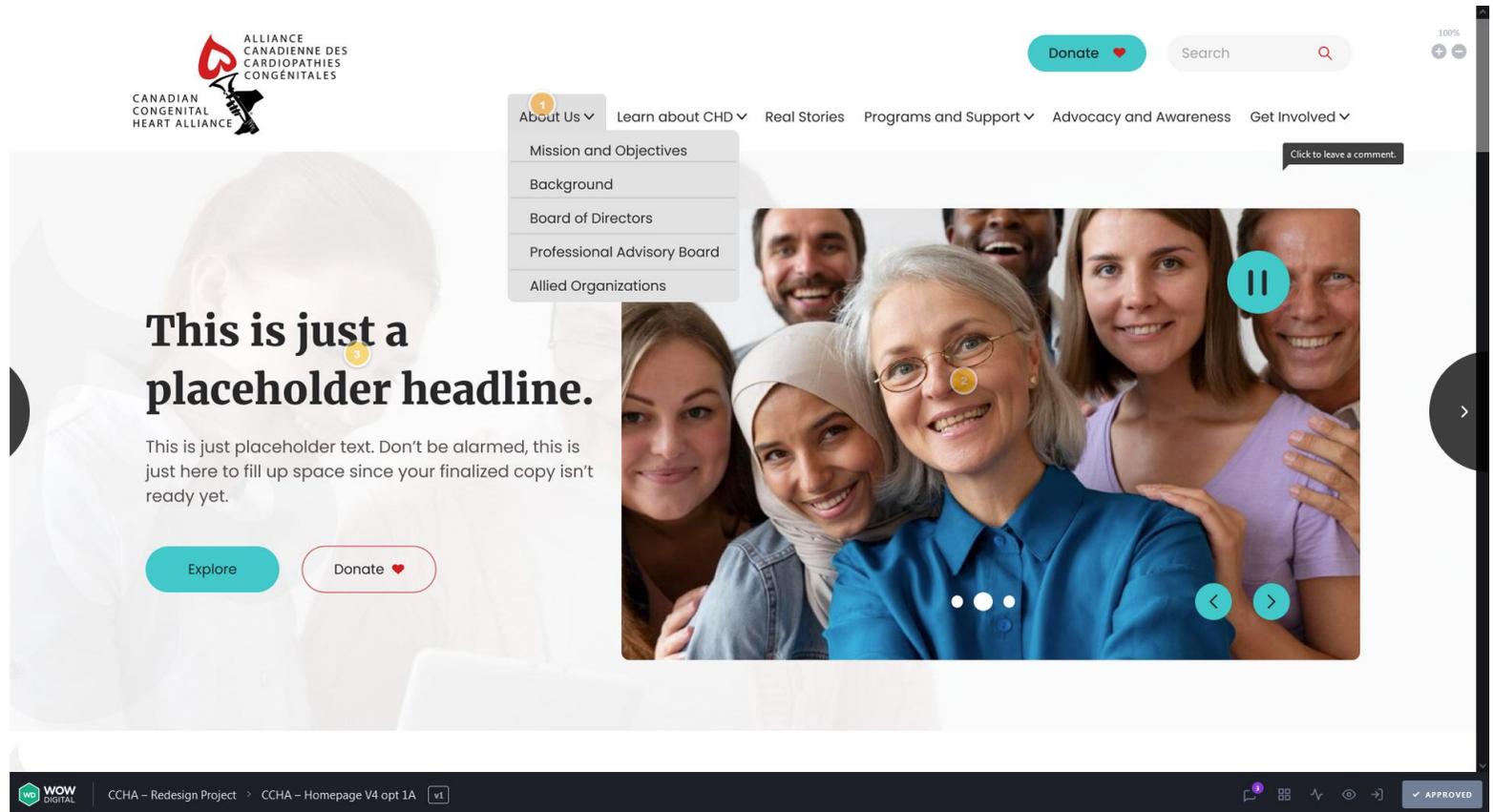
Episode 3 – Dr. Silversides – Contraception and family planning – July 19

Projects

CCHA Website

- Current website launched in 2014
- Update planned, however due to unforeseen and unfortunate circumstances, urgent need to build new website
- Working with WOW Digital to develop new website, to create the Go To resource for trusted CHD information and education.

CANADIAN CONGENITAL HEART ALLIANCE



<https://feedback.wowdigital.com/mockup/ccha-redesign-project/#/ccha-homepage-v4-opt-1a>



Strategic Plan 2023-2026

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

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

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

Get Involved!

- Raise CHD Awareness
 - Engage with us on social media, share your story
- Volunteer
 - Join our Social Media team
 - Create resources for CHD families and community
 - Event planning – social events, virtual events
- Fundraise or Donate
 - Bake or book sale, car wash, bowling or skate-a-thon, karaoke night
 - Fundraising toolkit – coming soon
 - Donate through the website or send cheque



Executive Director's Report

Overview

- For 2023 year - into 2024 - and into this current fiscal year
- Board support and information sourced that might be of interest
- Ongoing administrative support and initiatives
- Connected with Braveheart in Northern Ireland re: possible bilateral support
- Attended Canadian Cardiovascular Society Congress – Montreal

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
- Board support
- Ensures that thank you's are sent to all donors ... via emails, letters, phone calls

Media

Effort to liaise with various media outlets to tell the CHD and CCHA story

- 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
- Send out a media release – re: Lit RED campaign

Fundraising

- Assisted with Giving Tuesday and Year End fundraising campaigns, and other ongoing fundraising initiatives
- Presented to Rotary club in London
- Some success in some new areas - In Memoriam gifts - Monthly Donors

Chapters

London/Middlesex chapter

- Active during CHD Awareness Week – four city buildings lit red, seven businesses lit red in London
- Worked with student group from Western University to create CHD Awareness Week activities and publicity for chapter

Eastern Ontario and BC Chapter remain inactive

Minutes

2023 AGM Minutes



CCHA ANNUAL GENERAL MEETING MINUTES

June 19, 2023
7:30-9:00pm ET
Teleconference

Attendees:	Allan Weatherall (Executive Director), Jennifer Graham (interim President), Priyanka Kugamoorthy (Vice President) Bengy Mercier (Treasurer), Anna Bailie (Secretary), Brenavent Kugamoorthy, Dr. Edythe Tham
Guests:	Robbyn McLellan, Kristina, Claire Lellan,
Secretary:	Anna Bailie (call recorded)

MINUTES

1. Welcome – Allan Weatherall & Priyanka Kugamoorthy

- Agenda
- Call to Order
- Land Acknowledgement
- Quorum Established
- Appointment of Recording Secretary:
 - Anna Bailie
- Proof of Notice of Meeting
 - Provided on website and through emails to membership, on May 31, 2023 to AGM being called
- Overview of CCHA mandate, including mission, vision and value statement

2. President's Report – Jennifer Graham & Priyanka Kugamoorthy

- 2022-23 Highlights
 - Finalized and approved strategic plan
 - Collaborated with Virtual Heart Connection and 3D Heart Project
 - Ongoing work with college and university programs across Canada
 - Launched the French version of 'Penelope goes for her heart checkup'
 - Continued to grow the Canada Lit Red campaign
 - Four pillars: Awareness, Education, Research and Support/Confirmed Strategic Plan
- Mission: Awareness
 - Expanded the Canada Lit Red Campaign, added to the number of monuments lit red - across 9 cities
 - Continued to grow reach across each year since 2019, even though we had to start a new Instagram account this year
 - Got proclamations in 9 cities for 'CHD Awareness week'
 - Statement read in the House of Commons
 - Shared more stories of those with CHD
 - Also released posts in over 40 languages!
- Mission: Education

Finance Report



Financial Report

Statement of Operations & Changes in Net Assets

Year Ended December 31	2023	2022
Total Revenues	\$14,749.94	\$36,945
Total Expenditures	\$22,788.66	\$21,862
Net Assets, beginning of year	TBD	\$26,451
Excess of Revenue over Expenditures	TBD	\$15,083
Net Assets, end of year	TBD	\$41,534

Note

Notice to Reader - Full financials will be available this fall



Financial Report

Statement of Financial Position

Year Ended December 31	2023	2022
Total Assets	TBD	\$43,285
Total Liabilities	TBD	\$1,751
Net Assets, Unrestricted	TBD	\$41,534

Note

Notice to Reader - Full financials will be available this fall

Financial Report

CCHA Auditor

Jennifer Rade – Chartered Professional Accountant has become

Rade Barrington CPA

- To complete CCHA Notice to Reader Financial Statements in fall 2024
- Appointment of Accountant Auditor for 2024

Board Elections



Current Board of Directors

Board Member	Sitting Term	Position Status / Renewing
Jennifer Graham (President)	2013-2025	
Priyanka Kugamoorthy (Vice-President)	2021-2024	Renewing
Bengy Mercier (Treasurer)	2020-2026	
Amanda Fregonas (Secretary)	2022-2025	
Karen LeComte	2019-2025	Not Renewing X Moving to PAB Liaison
Brenaven Kugamoorthy	2021-2024	Renewing
Edythe Tham	2023-2026	
Elina Williams	2022-2025	
Nathalie Lacoste-Hoffman	2023-2024	(Honourary)
Katie Losenno	2023-2024	(Honourary)



Application Process

- Notice published on May 19, 2024, application deadline June 16, 2024
- Published on website, social media and newsletter
- Six positions are open for 2024-2027 Board Position
 - two are renewing
 - one not renewing (moving to PAB Liaison)
 - two honorary were moved to interim board members
 - one vacancy

Selection Criteria

Preferred Skills

- Experience on a non-profit board
- Fundraising/philanthropic experience and/or grant writing
- Communications and marketing
- Accounting or legal experience
- Strategic and operational experience
- A direct CHD link

Every elected board member should possess

- A passion for the CCHA mission and mandate
- 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

Interview Process

Interview Committee

- Allan Weatherall
- Amanda Fregonas
- Nathalie Lacoste-Hoffman

Board Candidates

Committee received three applications

- Claire Tempier
- Jackie Rosen
- Annabelle Williams

Committee interviewed two of three candidates

Board Candidates - New

Claire Tempier

- Lawyer – Immigration Legal Professional – refugee law for the Government of Canada
- Fully bilingual, multilingual
- Lives with CHD

Jackie Rosen

- Long time communications professional and freelance news writer/reporter
- Areas of expertise - disability, diversity and inclusion, health and research, politics, non-profit experience, Canadian media
- Lives with CHD

Board Candidates - Returning

Priyanka Kugamoorthy

- Doctor of Medicine (MD), Bachelor of Science (BSc) in Biological Sciences, University of Guelph
- Fellow of The Divisions of Cardiology at Peter Munk Cardiac Centre – University Health Network (Toronto General Hospital); Labatt Family Heart Centre, The Hospital for Sick Children; Translational Medicine Program, Peter Gilgan Centre for Research and Learning

Bren Kugamoorthy

- Kinesiology and Physical Education (KPE) - Honours Candidate – University of Toronto – St. George Campus
- A leader, governor and philanthropist with initiatives in University of Toronto community including hosting national conferences, academic events, working with special Olympic athletes, representing students on faculty committees. Notable positions: Head Coordinator for half a million dollar Kinesiology conference, Faculty Ambassador, Strength and Conditioning Coach for Varsity Blues, motionball

Board Candidates – Full Board role

Nathalie Lacoste-Hoffman

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

Katie Lynn Losenno

- 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

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 – new

- Claire Tempier
- Jackie Rosen (Honourary)

Recommended candidates – renewal

- Bren Kugamoorthy
- Priyanka Kugamoorthy

Recommended candidates – full board position

- Katie Lynn Losenno
- Nathalie Lacoste-Hoffman

2024/2025 CCHA Board of Directors

- Amanda Fregonas
- Bengy Mercier
- Bren Kugamoorthy
- Claire Tempier
- Edythe Tham
- Elina Williams
- Jennifer Graham
- Katie Lynn Losenno
- Nathalie Lacoste-Hoffman
- Priyanka Kugamoorthy
- Jackie Rosen (Honourary)

New Business

CANADIAN CONGENITAL HEART ALLIANCE



cchaforlife.org



[@cchaforlife](https://www.facebook.com/cchaforlife)



[@ccha4life](https://www.instagram.com/ccha4life)



[@cchaforlife](https://twitter.com/cchaforlife)



[@cchaforlife](https://www.youtube.com/cchaforlife)



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CONNECT WITH US!



Thank you!



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