

CANADIAN
CONGENITAL
HEART ALLIANCE



CCHA 2021 ANNUAL GENERAL MEETING

June 22, 2021

Agenda

Time	Item	Speaker
7:30	Welcome	Allan Weatherall (Executive Director)
7:40	President's Report	Jennifer Graham (Vice President and interim President)
8:00	Executive Director's Report	Allan Weatherall
8:15	2020 AGM Minutes	Jennifer Michaud (Secretary)
8:20	CCHA Financial Report	Robbyn McLellan (Treasurer)
8:30	2021 Board Elections	Christelle Roy-Coulliard
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

President's Report - Review

2020

- Partnerships with other organizations
- Beat Retreat rejoin CCHA
- CHD Awareness Week and Heart Month
- COVID-19 awareness & CHD impact, website resources
- Revisit strategy

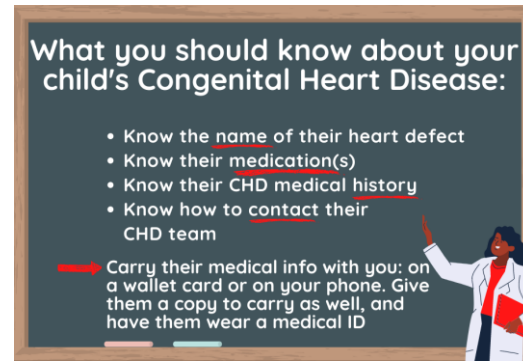
2021

- 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



President's Report - Education

2021 Advocacy tools



Collaborated with 5 organizations to create CHD Educational Resources

Fondation En Coeur, Braveheart Support Society, GlobalArch, IHeartChange and H&S

2020 Transition Resources

Congenital heart disease transition of care tip sheet

Do you know...

- CHD is the most common birth defect in pregnancy.
- Many people with CHD require lifelong expert medical care and struggle with both physical and mental health challenges.
- There are now more adults with CHD than children, thanks to medical and surgical advances.

Making the transition to adult congenital heart disease care

Transition is a process that begins in childhood and continues through early adulthood. The transition from pediatric to adult congenital heart disease care is a process that begins in childhood and continues through early adulthood. The transition from pediatric to adult congenital heart disease care is a process that begins in childhood and continues through early adulthood.

Where will I be transferred to?

Simple	Examples	Who should you ask about your heart?
Simple	Religious conversion, religious conversion, religious conversion	From simple to complex, the adult congenital heart disease team should be involved in your care. They might refer you to a general cardiologist or a specialist congenital heart disease team with adult expertise.
Intermediate	Complex congenital heart disease, complex congenital heart disease, complex congenital heart disease	From simple to complex, the adult congenital heart disease team should be involved in your care. They might refer you to a general cardiologist or a specialist congenital heart disease team with adult expertise.
Complex	Complex congenital heart disease, complex congenital heart disease, complex congenital heart disease	From simple to complex, the adult congenital heart disease team should be involved in your care. They might refer you to a general cardiologist or a specialist congenital heart disease team with adult expertise.



Steps to take for a successful transition

- 1. Talk to your healthcare team about transitioning to adult care and next steps.
 - 2. If you need to choose a different primary healthcare provider, ask your cardiologist if they can recommend a provider who has experience with CHD patients.
 - 3. Keep your health passport with you. This is a summary of your medical information including your name and phone number of your cardiologist, your diagnosis and surgical history, and medications.
 - 4. Ask questions. Learn about your condition.
 - 5. Know that feelings such as fear or stress are normal for some people. It's good to talk about your concerns and feelings with people you trust, including your healthcare team.
- Other actions you can take:**
- Learn about your heart condition and steps to make a successful transition. Visit heartandstroke.ca/heartandstroke/congenital-heart-disease/.
 - Know that you can find support and resources for CHD patients at heartandstroke.ca/heartandstroke/congenital-heart-disease/.
 - Join heart & stroke's Facebook group to share community support, heart health tips, and support the power of community.
 - Find a support group such as Braveheart Support Society or Fondation En Coeur on Facebook.
 - Share your stories on social media using #CHDawareness and #CHDawareness.



COVID -19 Resources

TIPS FOR PEOPLE LIVING WITH CONGENITAL HEART DISEASE TO MANAGE YOUR HEALTH DURING THE COVID-19 PANDEMIC

We are still learning how COVID-19 affects people. Some children and adults living with congenital heart disease (CHD) may be at higher risk for more severe symptoms and complications due to COVID-19. We have prepared some tips for managing your health during this challenging time.

- Continue medications**
Continue all regular medications unless your doctor tells you otherwise. Keep your medication supply current and ask if your pharmacy offers home delivery.
- Ask about virtual care**
If an upcoming appointment, test or surgery can be safely postponed, your doctor will confirm that with you. For care that is deemed necessary, ask your health team about the safest way to do so, be it in-person or via phone or video.
- Stay connected and supported**
Stay connected with family and friends for support. Join an online community like [Heart & Stroke Braveheart Support Society](http://Heart&Stroke.BraveheartSupportSociety.com) or [Fondation En Coeur](http://FondationEnCoeur.ca) to find support from people in similar health situations.
- Contact your health team**
If any symptoms of your condition worsen, or if new symptoms develop, contact your health team to discuss. If you develop COVID-19 symptoms, immediately and isolate and then contact your health team to discuss.
- Practice distancing and hygiene**
Follow the guidelines from the [Public Health Agency of Canada](http://PublicHealthAgencyofCanada.ca) and your public health authority to reduce your risk of contracting COVID-19.
- An emergency is always an emergency**
Dial 9-1-1 immediately if you become blue or breathless, or are experiencing signs of heart attack or stroke.

Visit our partner websites for more information and support.



TIPS FOR PEOPLE LIVING WITH CONGENITAL HEART DISEASE TO MANAGE YOUR HEALTH DURING THE COVID-19 PANDEMIC

We are still learning how COVID-19 affects people. Some children and adults living with congenital heart disease (CHD) may be at higher risk for more severe symptoms and complications due to COVID-19, specifically those living with the following conditions:

- Complex defects
e.g. single ventricle, cyanotic heart defects and double-outlet ventricle
- Significant valvular disease (e.g. severely leaky valve)
- Low oxygen levels or living blue (cyanotic symptoms)
- Heart failure or reduced heart strength (cardiomyopathy)
- High blood pressure in the lungs (pulmonary hypertension)
- Other health conditions
e.g. chronic kidney disease, diabetes, or chronic lung disease
- Heart transplantation or recent heart surgery
- Heart rhythm problems (arrhythmias)

Visit our partner websites for more information and support.



President's Report - Education

Penelope goes for her heart checkup



Launched children's book

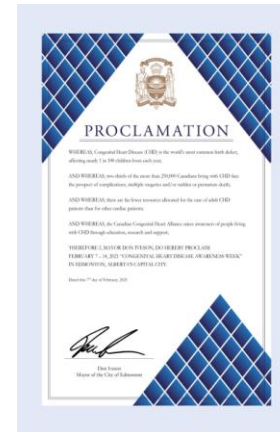
- Created by Sydney and Avery – 2 UBC Okanagan students
- Possible through student virtual internship with Riipen
- Story and information created from input from parents with young CHD children
- Reviewed by 2 nurses, and 2 pediatric child life specialists
- Illustrated by Kristen Foster



President's Report - Advocacy



Campaign to light Canada Red for CHD Awareness



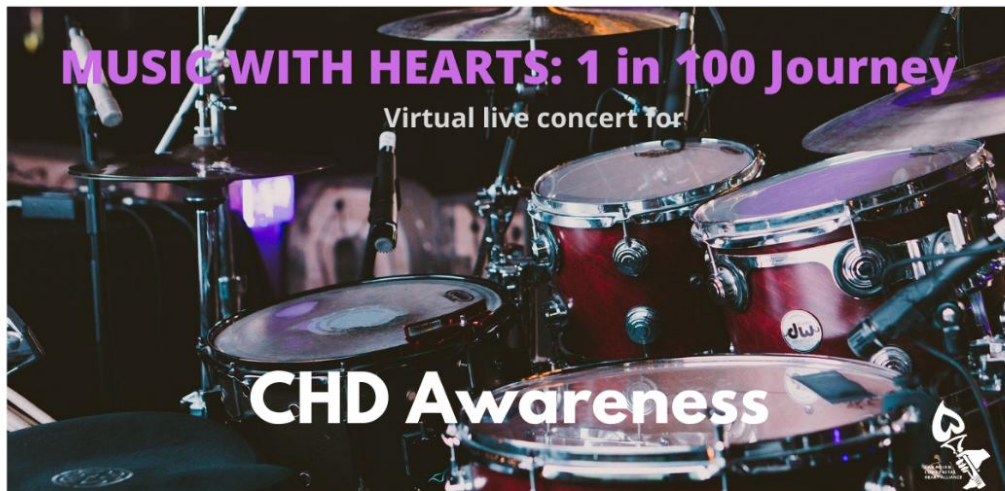
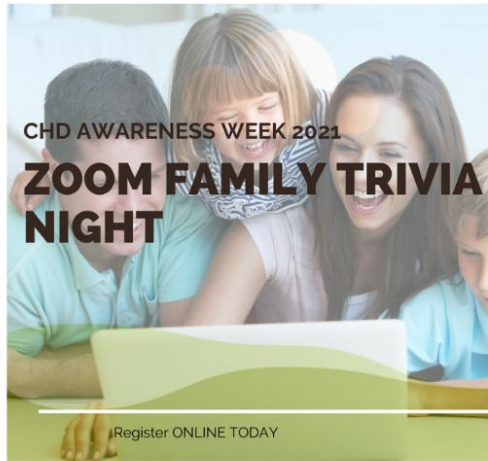
CHD Awareness Week
proclaimed in Calgary,
Edmonton and
Chestermere AB

Statement by Karen Vecchio,
Member of Parliament (Elgin-
London-Middlesex) recognizing
CHD Awareness Week in House
of Commons



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President's Report - CHD Awareness Week & Heart Month



Heart Month events

- 3 events:
 - Family Trivia Night
 - Online Scavenger Hunt
 - Music with Hearts: 1 in 100 Journey live virtual concert for CHD Awareness
- Huge thanks for Jen M and Michelle M for organizing
- Great events and attendance



President's Report – 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.



President's Report – 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



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
- Presented at 2020 Patients Redefining the Future of Health Care in Canada Summit
 - Part of working group authored the Declaration of Personal Health Rights in Canada
 - <https://saveyourskin.ca/wp-content/uploads/Declaration-EN.pdf>
- Presented at IFA Expert Meeting | Pneumonia vaccination in at risk groups. A Canadian perspective



President's Report - 3-Year Strategy Pivot

- Due to large turnover in Board members in 2019 and 2020 (7/11) and the COVID-19 pandemic, created a need to shift focus and outlook for CCHA:
 - Resulted in a need to revisit 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
- Next Steps: Strategic Planning for 2022-2025
 - 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



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Executive Director's Report

Executive Director's Report

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

There is one constant in health care...change. However, none of us anticipated what COVID brought and how it affected everything.



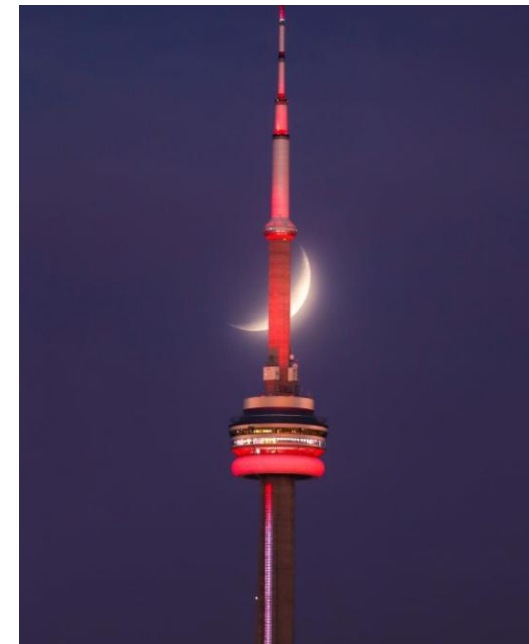
Executive Director's Report - Administration

- Monitored donations – responded and thanked donors accordingly
- Involved with many day-to-day functions
- Contacted MPs office re: statement in House of Commons for CHD Awareness Week
- Liaised with CCHA chapters in London and Eastern Ontario
- Always looking for opportunities to promote CCHA
- Spoke initially with Christy Jermias at Riipen Onboarding re: marketing or communications ideas with post-secondary institutions
- Contacted McMaster and Dalhousie Universities re: cooperative initiatives
 - SKIP 'solution for kids in pain' – work together



Executive Director's Report - Media

- Contacted media – Globe and Mail, CTV, CBC, Global TV and Toronto Star
 - Potential CHD/CCHA stories (Ken Shaw, Avis Favro, Heather Hiscox, Andre Picard)
- However... for the last 18 months primary focus has been on COVID-19 pandemic
- Q3 and Q4 2021 – continue to seek CHD/CCHA stories
- February 14 ... Light Canada red for CHD Awareness



Executive Director's Report - Fundraising

- Monitored Canada Helps donations – responded and thanked donors accordingly
- 2021 – studied and reviewed ‘donor management systems’ (with committee) – decision postponed until September
- Continued initiatives with companies/foundations re: sponsorship/donations
- Continued contact with HealthPartners – re: government workers donations
- Always looking for opportunities - #1 rule is asking



Executive Director's Report - Chapter reports

Hearts of London/Middlesex - CCHA London Chapter

Due to COVID all activities came to almost a virtual standstill



February Heart Awareness:

- London City Hall and city buildings were lit 'red' for CHD awareness week
- Interviews e.g. 980 and 1290 radio London, CTV2 London

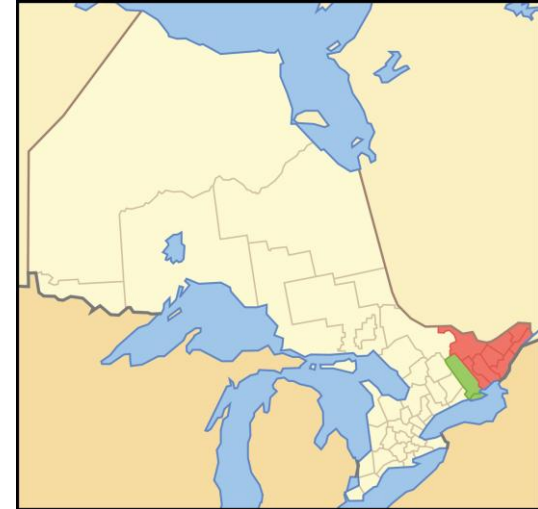


Executive Director's Report - Chapter reports

Eastern Ontario Chapter

Due to COVID all activities came to almost a virtual standstill

- 2020 – planning was underway until COVID stopped all activities
- 2021 – chapter lead has stepped down - review chapter future steps



Thank you to Jennifer Mulder for her work in leading the Eastern Ontario chapter



2020 AGM Minutes



CCHA ANNUAL GENERAL MEETING MINUTES

June 24, 2020
8:00-9:30pm ET
Teleconference

Attendees:	Allan Weatherall (Executive Director), Krista Vriend (President), Jennifer Graham (Vice President), Robbyn McLellan (Treasurer), Jennifer Michaud (Secretary), Christelle Roy, Laura Philippe, Bengy Mercier, Sarah McMillan, Karen LeComte, Meaghan Sharp, Jacey Hughes, Anna Bailie, Lauren Rea, Jennifer Rade (Accountant), Jasmine Grewal (PAB), Erwin Oechslin (PAB)
Secretary:	Jennifer Michaud (call recorded)

MINUTES

1. Welcome – Krista Vriend

- Call to Order
- Quorum Established
- Appointment of Recording Secretary:
 - Jennifer Michaud
- Proof of Notice of Meeting
 - Provided on website and through emails to membership 30 days prior to AGM being called, along with nominations

2. Presidents Report – Krista Vriend

- Mission, Vision and Value Statement reminder
- 2019
 - Beat Retreat to rejoin CCHA
 - Focused BR donations can now be made through CCHA for charitable tax receipts
 - Will be migrating all comms and online presence under CCHA umbrella
 - Due to COVID-19, Beat Retreat 2020 will be virtual
 - CHD Awareness Week and Heart Month
 - Faces of CHD Campaign
 - 14 stories featured
 - High engagement: Reach over 5500 and Engagement of 1100 all through organic
 - Continuing research and advocacy
 - 2 collaborative papers with Ryerson University
 - CCHA invited to join newly established Canadian Research Network for Adult Congenital Heart Disease Interventions (CRN-ACHDi)
 - 2020 Collaborative paper with CHEO RI Halo group
 - Physical Activity Toolkit
 - Recruitment for study in Ottawa and London is complete, but Edmonton was delayed due to pandemic – expected completion is June 2021
- 2020
 - Partnerships with other CHD focused organizations
 - Heart & Stroke



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CCHA Financial Report

CCHA Financial Report

Statement of Operations & Changes in Net Assets		
Year Ended December 31	2020	2019
Total Revenues	\$19,865	\$12,769
Total Expenditures	\$13,395	\$16,192
Net Assets, beginning of year	\$19,860	\$23,283
Excess of Revenue over Expenditures	\$6,470	(\$3,423)
Net Assets, end of year	\$26,330	\$19,860



CCHA Financial Report

Statement of Financial Position

December 31st	2020	2019
Total Assets	\$27,832	\$21,363
Total Liabilities	\$1,503	\$1,503
Net Assets, Unrestricted	\$26,363	\$21,363



CCHA Financial Report - Movement

CCHA Auditor: Jennifer Rade Chartered Professional Accountant

- Completed CCHA Notice to Reader Financial Statements 2020
- Appointment of Accountant/Auditor for 2021



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CCHA Board Elections

Current CCHA Sitting Board of Directors

Board Member	Sitting Term	Position Status / Renewing
Jennifer Graham, Vice-President & interim President	2013-2022	
Robbyn McLellan, Treasurer	2016-2022	
Jennifer Michaud, Secretary	2019-2022	
Karen LeComte (PAB liaison)	2019-2022	
Anna Bailie	2020-2023	
Jacey Hughes		Interim replacement
Bengy Mercier	2020-2023	
Laura Philippe	2018-2021	Not Renewing X
Lauren Rea	2020-2023	
Christelle Roy-Coulliard	2019-2022	Move to Honourary
Meaghan Sharp	2017-2023	



Board Elections - Application Process

- Notice posted on May 21, application deadline May 31, 2021
- Published on website, social media and emailed to members
- 3 positions are open for the 2021-2024 Board Position
 - 1 is interim replacement for vacancy
 - 1 is not renewing
 - 1 has requested to step down to fill Honourary Board position



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:
 - Christelle Roy-Coulliard
 - Karen LeComte
 - Allan Weatherall
- Committee interviewed all applicants:
 - Priyanka Kugamoorthy – Markam, ON
 - Brenaven Kugamoorthy – Markham, ON



Board Elections - Recommended New Members

Priyanka Kugamoorthy – Markham, ON

- Doctor of Medicine (MD) , St. Vincent and the Grenadines (ASU) College of Medicine
- 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
- A lifelong advocate for enriching the lives of people living with CHD
- Sister to Brenaven



Board Elections - Recommended New Members

Brenaven Kugamoorthy – Markham, ON

- Kinesiology and Physical Education (KPE) - Honours Candidate – University of Toronto – St. George Campus
- A lifelong advocate for enriching the lives of people living with CHD by designing workouts and exercise programs based on exercise science through ongoing research projects with the Kinesiology and Physical Education Faculty at University of Toronto
- International athlete – basketball
- 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 committee
- Connection to CHD through mother requiring novel cardiac procedure
- Brother to Priyanka



Board Elections - Elections

Jacey Hughes – Bedford NS – Honourary to full board member

Jacey was born with Congenital Heart Disease. She completed her BSc in Kinesiology at the University of Prince Edward Island and received her diploma in Registered Massage Therapy at ICT Northumberland College. Jacey now works as a Registered Massage Therapist and kinesiologist in Halifax, Nova Scotia. Throughout her school years and into university, she played competitive hockey, a swimming instructor for children with special needs and continues to be a physically active person. She was brought up with a positive outlook on life and that anything is possible and is excited to be a part of CCHA.

Christelle Roy-Coulliard – Calgary (move to Honourary board member)

Christelle is a CHD patient with ALCAPA. She is an experienced communications professional with a background in administration and digital marketing. Previously she held positions in the nonprofit sector, namely with Ronald McDonald House Charities and the Humane Society. Over the years she has volunteered with organizations like Canadian Blood Services, the Heart and Stroke Foundation, and the United Way. Prior to this she completed a Bachelor's degree in Communication Studies and obtained a Graduate Certificate in Public Relations while working in her college's Marketing department. She is passionate about bringing people together, building community and promoting wellness. In her spare time she enjoys reading, watching documentaries, managing Facebook groups and travelling.



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:
 - Priyanka Kugamoorthy – Markham ON
 - Brenaven Kugamoorthy – Markham ON
 - Jacey Hughes – Bedford, NS (current interim board member to fill vacancy in Nov 2020 – was honorary board member)
- Recommended for realignment:
 - Christelle Roy-Coulliard – step down from Board position to Honourary board member



Board Elections - 2021/2022 Board of Directors

- Anna Baillie
- Jennifer Graham
- Jacey Hughes
- Priyanka Kugamoorthy
- Brenaven Kugamoorthy
- Karen LeComte
- Robbyn McLellan
- Bengy Mercier
- Jennifer Michaud
- Luran Rea
- Meaghan Sharp
- Christelle Roy-Coulliard - Honourary



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New Business

Meeting Adjournment

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Thank you!