

	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
    - Walk of Life Toronto & Ottawa Race Weekend
  - Conference and education participation
    - 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.

- 5) Other ongoing research work
  - 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

## 6) CHD Landscape in Canada

- CHD landscape across Canada is comprised of a small number of specialized clinics servicing the healthcare needs of people living with CHD.
- Tremendous progress and advancements in CHD pediatric care over the last 50 years
- More individuals living well into adulthood and surviving with more complex conditions and needs
- A number of smaller, local CHD support organizations have formed to service the auxiliary needs of CHD patients
- Currently there is no:
  - unifying body across these smaller organization/networks to help share learnings and best practices
  - o national voice to elevate/advocate for larger issues and concerns for CHD care
  - Research/information remains siloed and regionally based, with little industry support

With these significant gaps and needs being brought to light, there is a case to look at how CCHA can evolve as an organization with the purpose of being a unifying body connecting patient groups, research and the professional CHD community together.

- 7) CCHA CHD Survey
  - Survey conducted June September 2018 through SM and members to generate member input into developing Strategic Plan
  - Social media, word of mouth and clinics are key awareness drivers while parents and individuals with CHD are key persons interested in CCHA
  - CCHA's website requires an overhaul with better Search Engine Optimization infrastructure to capture Canadian audiences
  - Key Areas of focus and interest and where CCHA can add value are:
    - o Awareness
    - o Education
    - Advocacy and Support
    - o Research
    - Fundraising
    - Top 3 Education Needs
      - Understand diagnosis and care needs
      - Transition of care
      - Lifestyle behavior
  - Top 3 Desirable Events
    - Education
    - o Social
    - Physical activity
- 8) Introduce 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.

- 9) 3-year Strategic Plan: Objectives
  - 1. Become the go-to organization that connects CHD organizations across Canada.
  - 2. Partner to build out CHD programs that will support and benefit the CHD community across Canada.
  - 3. Advocate for and assist with the advancement and dissemination of CHD research to the CHD community across Canada.
  - 4. Be a key resource and education partner for the CHD community
  - 5. Develop sustainable fundraising programs and sources to support the above objectives.
  - 6. Build a deeper awareness of CHD within the CHD community and the Canadian public at large.
- 10) 3-year Strategic Plan: Initiatives
  - 1. Building a CHD organization network
  - 2. Build awareness of CHD/CCHA
  - 3. Explore CCHA rebranding
  - 4. CCHA website refresh
  - 5. Fundraising development
  - 6. Membership & volunteer recruitment
  - 7. Research collaboration
  - 8. Program development & expansion
- 11) Next Steps
  - Gut check strategy with new Board members
  - Refine and prioritize initiatives
  - Get to work!

### 3. Executive Director's Report – Allan Weatherall

- Continue to work in 4 key areas
  - o Administration
    - Continue to make connections with corporations, allied health organziations and many levels of government to advocate on behalf of CCHA
  - o Media/Awareness
    - Liaise with Marilyn Gladu MP Sarnia re: statement read in House of Commons for Heart Month and organized a sit down meeting with her afterwards
    - Coordinated TVO The Agenda with Steve Pakin 30 minute interview
    - Organized creation of 3 PSAs with Joe Bowen still heard on radio stations
    - Involved in numerous other media interviews and connections
  - o Fundraising
    - Continue to reach out and connect with various corporations, foundations and businesses for support
- London Chapter
  - Fearless Physical Activity events very successful, enjoyed by everyone and would continue to support program. YMCA very supportive - indoor and outdoor events, fun, active and educational
  - Heart Month activities London City Hall and London City buildings were lit RED for CHD Awareness Week. Families met with London mayor for photo and office tour in support of CHD Awareness week - families loved it. Promoted on social media
  - o Guest speaker at February meeting PTSD, small group but great discussion
  - McCormicks Sharing Day charities supported by McCormicks came together to

- showcase research being done at LHSC and projects supported by donated funds
- $\circ$   $\;$  Continue to move ahead with creating Diagnosis folders and Surgery Support bags  $\;$
- Eastern Ontario Chapter update
  - o Ottawa Race Weekend raised over \$5000, booth at Health and Wellness Expo
  - o 2nd annual Bowl-a-thon 50+ bowlers, raised funds to send 2 kids to camp
  - Continued to support Fearless events
  - Held 1st BBQ at Mooney's Bay 25 attended. Face painting, games and line dancing, great event.
- BC Chapter
  - o Chapter temporarily inactive

# 4. 2018 AGM Minutes – Jennifer Graham

- Minutes posted on CCHA website June 24, 2019 for review
- Quorum established

Motion - to approve 2018 AGM minutes - moved by Robbyn McLellan, 2nd by Krista Vriend - approved

# 5. CCHA Financial Report – Robbyn McLellan

- 2018 Financial Overview reviewed audited statements were uploaded to website June 24, 2019 for review.
- Decrease in Revenue and Assets due to Fearless project completion

Motion - to approve hiring of new Accounting Firm Jennifer Rade for accounting services – moved by Jennifer Graham, 2nd by Meaghan Sharp - approved

Motion - to approve 2018 Financial Statements - moved by Krista Vriend, 2nd by Laura Philippe - approved

# 6. CCHA Board Elections – Krista Vriend

- Review of Application process (notice posted May 10, 2019; applications due May 17, 2019; notice posted on website and social media
- Eight open board positions, three current members renewing their terms
- 9 applicants, 7 shortlisted for interviews
- Interview committee composed of Executive Director (Allan Weatherall) and two board members (Krista Vriend, Laura Philippe)
- Review of preferred skills, mandatory criteria and other factors considered
- Credentials of short-listed candidates reviewed Jacqui Esler Calgary, Sarah McMillan -Toronto, Bengy Mercier - Montreal, Jennifer Michaud - Calgary, Christelle Roy - Calgary, Julie Spears - Toronto
- Recommended candidates:
  - Jennifer Graham (to be re-elected)
  - Robbyn McLellan (to be re-elected)
  - Karen LeComte (to be elected- had been interim board member)
  - Sarah McMillan (to be elected)
  - Jennifer Michaud (to be elected)
  - Christelle Roy (to be elected)
  - Julie Spears (to be elected)
  - Jacqui Esler (to be elected)
- Call for any other candidate nominations recommended Bengy Mercier be named Honourary Board member
- Motion re-elect Jennifer Graham to the Board of Directors moved by Meaghan Sharp, 2nd by Laura Philippe approved
- Motion re-elect Robbyn McLellan to the Board of Directors moved by Jennifer Graham, 2nd by Laura Philippe -

approved

- Motion elect Karen LeComte to the Board of Directors moved by Jennifer Graham, 2nd by Jennifer Michaud approved
- Motion elect Sarah McMillan to the Board of Directors moved by Laura Philippe, 2nd by Jennifer Graham approved
- Motion elect Jennifer Michaud to the Board of Directors moved by Jennifer Graham, 2nd by Meaghan Sharp approved
- Motion elect Christelle Roy to the Board of Directors moved by Sarah McMillan, 2nd by Laura Philippe approved
- Motion elect Julie Spears to the Board of Directors moved by Jennifer Mchaud, 2nd by Toby Cox approved
- Motion elect Jacqui Esler to the Board of Directors moved by Robbyn McLellan, 2nd by Matthew Main approved
- Motion name Bengy Mercier as an Honourary Board of Directors moved by Laura Philippe, 2nd by Christelle Roy - approved

### 7. New Business - Open

Thank you to Sick Kids for generously donating the room and AV equipment to conduct CCHA's AGM meeting.

We welcome any volunteers to get involved with CCHA on projects or committees.

#### 8. Adjourn

Motion - to adjourn the 2019 AGM at 8:55pm – moved by Laura Phillipe, 2nd by Robbyn McLellan - approved

#### Approved: