



# CCHA BOARD MEETING MINUTES

September 13, 2016  
7:30-9:00pm  
Teleconference

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**Attendees:** Krista Vriend - Chair, Eric Gonneau, Jennifer Graham, Allan Weatherall, Mark Myers, Joanna Hunt, Saad Minhas

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**Regrets:** Toby Cox, Stella Cockett, Jordan Hier,

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**Recorder:** Jennifer Graham

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## MINUTES

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### 1. Review & Approval of Agenda

No Agenda provided

### 2. Review & Approval of Minutes

Approval of July minutes - Moved - Jennifer, 2<sup>nd</sup> - Mark – Approved  
Approval of July Overview minutes - Moved - Jennifer, 2<sup>nd</sup> - Mark – Approved  
Approval of August minutes - Moved - Jennifer, 2<sup>nd</sup> - Mark – Approved  
Approval of August Overview minutes - Moved - Jennifer, 2<sup>nd</sup> - Mark – Approved

### 3. Fearless Physical Activity - Jennifer

Submitted to CHEO REB early August, expect to hear back early October. New partners in Sudbury (YMCA) and Thunder Bay (Canada Sports Complex). Government finally made announcement at end of August - communication sent to members. CHEO contract outstanding, to be reviewed for approval. Send draft version to Mark. Allan sent communication to various news networks across Canada, minimal uptake, only local in St. Thomas. MTCS only did media release, no publicity. Meeting with Dr. Longmuir, Allan, Eric and Jennifer - decided not to pay (\$700 min Canada Newswire) for wide media release, will wait until survey or announcement of event dates.

### 4. Treasurer's Report – Mark

Main bank balance approx \$30,285, expenses below income. Highest bank balance to date for 2016. Track average monthly income and expenses, milestone - 2 month trend of income exceeding expenses. Upcoming expenses include Beat Retreat.

OSRCF grant funds unchanged.

Q - Mark - inquire about disbursements for OSRCF grant funds. Jennifer - CHEO flexible with how we structure payments, currently do not have contract in place, to be reviewed.

Working with accountant on Audited Financial Statements.

Budget - being drafted.

### 5. Committees

#### Advocacy/Awareness Committee - Saad, Mark, Joanna

No update.

#### Membership Committee - Krista

- Committee meeting with Stella and Brynne, very productive. Follow up meeting pending. Some sections still outstanding and awaiting some feedback. Urgency to complete has dissipated. Expect to present guidelines at October board meeting and present to membership at AGM. Focus on pertinent sections to have completed at a minimum by AGM i.e. discussion about chapter budget and funds. Krista to discuss with chapter leaders and

put proposal forward next month - 2 options for chapter funding, board evaluate pros and cons of each and vote.

### **Fundraising Committee - Jennifer, Mark, Jordan**

- Montreal Grocery Bagging fundraiser - Jordan - postponed until February 11 & 12 for CHD Awareness week.
- Met with Gord Durnan (father of CHD patient), extensive fundraising and hospital board experience 30+ years. Allan connected with him over the years. Gave 5 key points with 2 areas of focus. Fundraising board discuss and felt that overwhelming for committee of 3 to tackle it all, will narrow focus to projects with significant cost benefit, less labour and resource intense. i.e. focus on annual end of year fundraising campaign, giving Tuesday - social media focused. Jennifer has contact willing to donate her time and social media expertise
- Pefferlaw District Lioness Club will have cheque presentation for yearlong charity drive on November 16th, minimum of \$10K has been raised. Asked that Jennifer and Krista attend presentation, will be held in Omemee, ON.

### **6. Professional Advisory Board (formerly MAB) - Stella**

No update. PAB concerns about CRA financial reporting with McCormick research funds been resolved.

### **7. Other updates**

#### **1. McCormicks - Allan**

In process of scheduling cheque presentation, Children's Health Foundation of London require written script and 2 weeks' notice prior. Tentative October 3 or 4. McCormick give CCHA cheque, CCHA then give cheque to Children's Health Foundation. Estimate \$54K from McCormick, \$40-\$45K to Dr. Norozi research project. Can submit event to local Snap'd newspaper.

**ACTION:** Allan to prepare speaking notes for cheque presentation. Allan prepare article for local Snap'd newspaper, Jennifer to post

#### **2. CCS Congress - Montreal, Oct 22-25 - Jennifer**

No HSF funding this year for booth (~\$3K). Awaiting if Jordan and/or Stella available to work booth, Stella offered to pay registration fees, asking if CCHA can cover flights and accommodation. TBD if PAB will be meeting. Estimated costs ~\$5K, additional costs of shipping booth and equipment if no one driving. Board agreed CCHA should attend. Krista available to attend part of conference, no accommodations needed. May be beneficial to send previous attendee to continue to build relationships. Mark and Joanna not available to attend, Eric, Allan and Jennifer available, Krista available partially. Sunday late afternoon CACHnet presentation. Board agrees 1 other board member to attend.

**ACTION:** Jennifer to make arrangements. Allan and Krista to coordinate materials for booth and update to materials

#### **3. Beat Retreat**

46 attendees, 38 campers, 6 medical staff. 3 guest educational speakers a) Danielle, social worker - TGH, b) Amanda, dietician - TGH, c) Anne-Marie, transplant patient. Any board member attending needs to submit application and medical form to participate in any activities - insurance waiver and liability. Eric plans to attend on Friday. Posted event in Quinte Snap'd newspaper, agreed to cover the event for us in article if we submit photos.

#### **4. Annual Report**

Materials compiled and submitted to Toby for design, hope to draft within week of Beat Retreat completion.

#### **5. Newsletter**

Saad sent template drafts to Mark, Krista, Jennifer and Jordan for quotes - group didn't receive. Toby offered to design for free.

#### **6. Chapter Updates**

London chapter very involved with McCormicks funding. Ottawa chapter been active lately - held 1st annual AGM earlier in month. BC no update.

#### **7. Board Recruitment**

Committee of Eric, Joanna, Jordan and Allan completed notification, posted on website. Allan sent to CHD clinics and several sites with CHD connections across Canada. To be promoted on social media - delay as was posted as pdf on website, not best practices for social media posting (uses data to download the document, hard to open and find). Jennifer to send out via mail chimp. Deadline October 10, 2016. 2 board vacancies and

Jennifer term ending

**ACTION:** Jennifer to mail to membership via mailchimp

#### **8. AGM**

Board agreed to hold 2016 AGM in Toronto. Location at Sick Kids available for no cost - look at site with improved AV system.

**ACTION:** Mark to investigate using facilities at his workplace

#### **9. Bill S201/Genetic Fairness**

Continue to receive updates and information from CGF organization

#### **10. Beat Retreat expansion**

Potential volunteer willing to organize Beat Retreat in Saskatoon, has support from ACHD clinic. Jennifer discussed requirements and logistics with her, she will draft a proposal. Julie Bard also planning to organize a BC Beat Retreat for spring 2018. Significant mentoring and support to organize and run - draft procedures to step by step to organize 'camp in a box'.

#### **11. Letter to MPP regarding medical records**

Letter sent to Dr. Erick Hoskins - Ontario Provincial Health minister, was directed to contact Ontario College of Physicians and Surgeons as well as Ontario Medical Association, regarding need to keep medical records beyond the 33 years. Amend to include a 'Call to Action'. Will be sending to other provinces as well

#### **12. CHEO Cardiac Kids LIFFE project**

Research group will be applying to CIHR for funding of the PA Tool kit project involving centers in Ontario and Alberta study. CCHA has agreed to collaborate on the project as co-PIs

#### **13. Ryerson Research project**

Ryerson received funding to begin their Congenital Heart Disease study, CCHA is collaborating on the project. Will be interviewing 4-5 patients and 1-2 family members. Looking to do group interview with board members from perspective of an advocacy group.

**ACTION:** Jennifer to contact board members to determine who interested in participating.

#### **8. Next Board Meetings:**

**October 11<sup>th</sup> @7:30 to 9:00** - Mark not able to attend

**November 8<sup>th</sup> @7:30 to 9:00**

**November 29<sup>th</sup> @7:30 to 9:00 - AGM**

**December 13<sup>th</sup> @7:30 to 9:00**

Meeting adjourned @ 9:10 pm