



CCHA BOARD MEETING MINUTES

May 17, 2016
7:30-9:00pm
Teleconference

Attendees: Eric Gonneau - Chair, Mark Myers, Jennifer Graham, Jordan Hier, Toby Cox, Allan Weatherall, Krista Vriend

Regrets: Joanna Hunt, Stella Cockett, Saad Minhas,

Recorder: Jennifer Graham

MINUTES

1. Review & Approval of Agenda

Approval of Agenda - Moved - Eric, 2nd - Mark – Approved

Allan proposed Consent agenda format - items circulated approx 5-7 days in advance for review

2. Review & Approval of Minutes

Approval of April minutes - Moved - Jennifer, 2nd - Toby – Approved

Approval of April Overview minutes - Moved - Jennifer, 2nd - Toby – Approved

3. Items arising from last meeting

1. U of T nursing presentation - Eric

Eric and Lori C-S presented on April 13. Used Shelagh's past presentation.

2. Labatt Family Health Education conference - Jennifer and Joanna

Had CCHA booth and information set up for the day. Event on April 23, 2016, Jennifer and Joanna attended, was successful. Had 10-15 people sign up to join CCHA.

3. Transition Night - Jennifer and Joanna

Held on May 12 at Sick Kids hospital. Approximately 15-20 patients and their family members. Sick Kids had one of their speakers cancel last minute - recent transition grad - CCHA was able to find a member as a replacement for the event - Sana, who gave a great presentation. Jennifer and Joanna also presented, had several questions after the TGH tour - insurance and Beat Retreat.

4. BC PACH clinic conference - Stella, Jennifer

BC clinic hosted - Unique Hearts, Unique Lives – Information on navigating adult life with CHD; 1 day patient education conference on Saturday May 7th, 2016. Conference was filled to capacity, ~ 130 people attending. Combined a Transition session into conference day as well. Jennifer and Julie gave joint presentation. Evaluations were very favourable with several great comments about CCHA presentation. ~ 50 people signed up to join CCHA

5. Update of records to CRA CRA for directors - Eric

Eric confirmed that CRA information updated in February. Aaron remaining on record.

ACTION: Eric to update CRA records to remove Aaron. - Update remains outstanding, Eric to complete for next meeting

6. Annual report - Allan

Need photographs for various sections of Annual Report and Financial Statements as of 2015 fiscal year end.

4. ED Report - Allan

1. McCormicks

McCormick 'C-Day' scheduled for Saturday June 4th. Expected will raise \$40,000 - \$60,000 for CCHA. Allan and Lisa to attend on behalf of CCHA, attend the BBQ. Look at CCHA bring cake.

McCormick will be donating funds to CCHA, CCHA will be providing grant to Dr. Norozi (University of Western Ontario/London Children's Hospital), to conduct research project, therefore within CCHA guidelines. 2 pieces of

equipment needed for research \$24,000 and \$12-16,000. Any remaining funds beyond research project, will be used by London Chapter to develop kits for parents/patients travelling to Sick Kids for cardiac surgery (with expectation to be expanded across the country).

Q - Jennifer - Can you provide pictures on day of event to post on social media? Allan agreed

2. MP/MPP meeting

Allan working to organize meetings with various members of federal and provincial government.

Advocacy committee to pursue the issue regarding keeping of records beyond 33 years (or timeline in each province) with each Provincial Health minister as well as letter to President/Chair of medical association/board in each province.

3. Genetic Fairness

Bill S201 brought before the Senate Standing Committee on Human Rights by Senator Cowan on February 17, 2016. Bill originated in Senate, currently in House of Commons. Bill intended to prohibit discriminate on the basis of genetics and genetic information is to be protected. Canada is the only country of the G7 countries that does not have genetic fairness legislation in place. Consider sending communication to CCHA members asking them to submit letter (form letter) to MP to support the Bill S210.

4. Media

Allan working to get CHD attention or story into media. Looking for the right issue/hook.

5. Bill S201

See #3 Genetic Fairness above.

6. Newborn screening efforts

Movement underway to have O2 saturation monitors included as part of screening process for newborns to pick up CHD. Experts feel that will more accurately detect CHD and reduce cases where its missed in newborns. Currently most large hospital centers are following this practice, it's the smaller towns and hospitals that have yet to adopt this as standard practice.

5. Treasurer's Report – Mark

Revamped format of Treasurer's report, each bank account detailed and separated out.

Main bank balance approx \$21,463.35 London and Sick Kids accounts had minimal activity.

Mark provided trending on financial activity.

2016 Budget remains outstanding - Mark and Eric to discuss.

6. Committees

Advocacy/Awareness Committee - Mark

Joanna to draft letter to Ontario College of Physicians regarding 33 year records project, to be finalized and sent to review in upcoming weeks. Will then amend and send to each provincial organizations?

Q - Jennifer - Should PAB be engaged before sending letter? Agreed that PAB should be involved with review of draft letter.

Joanna presented to Ajax Seniors Group - contacted through FB. Organizer was part of group Jennifer and Krista presented to at Pefferlaw Lioness Group last October. Presentation very well received, lots of interest and questions.

Newsletter (Mark) – meeting with Saad this week. Still looking for content from rest of board. Include articles from Professional Advisory Board (formerly MAB). Content to include clinic info, healthy living tips, historical perspective, new innovations and medical breakthroughs. Can summarize any online content and embed link in the newsletter.

Website modifications - Mark and Jordan working on website updates.

Now officially member of CGF - Allan to connect with Bev H-M to see how organizations can best work together.

Looking at Awareness campaign towards and promotional items towards end of summer in conjunction with other committees.

Rachael looking into Newborn Screening issue - committee of provincial health ministers looking at conditions to be screened for. CGF has list, Advocacy committee to review for any CHD conditions are missing.

Membership Committee - Krista

Chapter guidelines still in review. Having difficulty scheduling committee meetings.

Fundraising Committee - Jennifer

Puckstoppers - Allan to meet later this week. Expect to put link to his website on CCHA site, and need to confirm that CCHA website like on his website. Book release set for June or July.

Ottawa Marathon - currently 11 team members, raised \$3567

Walk of Life - Team CCHA currently have 16 team members, raised \$2995. Goal this year is \$20,000 and 50 team members, we are keeping 75% of money raised. Prize from MLSE

Water bottle ~ \$350 for 250 - giveaway for Ottawa Marathon, Walk of Life etc

Jordan met with grocery store manager - scheduled for June 25/26th. Directly after St. Jean Baptiste day, so store will be extra busy that weekend. Looking for 9-12 volunteers.

Jordan met with co-founder/president Christina Ding of Hearts 4 heart (www.heart4heart.ca) children's charity - nationwide charity that started in Montreal by McGill University students, chapters across Canada and 2 in US. Strictly raise funds for children around the world needing CHD surgery for Gift of Life to sponsor operations. Look at ways to collaborate for events and fundraising. Will have her meet with executive and attend BOD meeting in upcoming months.

Jennifer spoke with contact for Pefferlaw Lioness Club at Sick Kids Family Education Day - her and her daughter presented couple months after Krista and Jennifer, successful night including a \$5000 cheque. Project has currently raised over \$10,000 for CCHA, cheque presentation to be in October/November.

Allan attending 100 guys meeting on June 21st, Lisa attending 100 women in London approx same date. Also a children's version - Lisa's daughter may be interested.

7. Professional Advisory Board (formerly MAB) - Stella

Looking at organizing a meeting. Dr. Jasmine Grewal - Chair looking for assistance with organizing and minutes for the meeting. Allan and Jennifer both offered to help.

Will connect with rest of PAB for content for CCHA newsletter. Assistance with review of letter to provincial Ministers for Health

8. Administrivia

Nothing to report

9. Upcoming Events

Nothing to report

10. New/Other Business

1. Online documents

Document repository currently set up, testing underway with Mark.

2. CASL regulations

Advocacy committee to review to determine requirements for CCHA.

3. Criminal record check

Should this be a requirement for CCHA board members - especially signing authorities. Alternate option is to provide copies of actual bank statements. Valid for 3 years, only shows past convictions.

Board agrees to choose posting monthly online bank statements as well as dual signature policy. May be necessary down the road if research grant approved.

11. Next Board Meetings:

June 14th @7:30 to 9:00

July 12th @7:30 to 9:00

August 9th @7:30 to 9:00

September 13th @7:30 to 9:00

Meeting adjourned @ 9:03 pm