



CCHA BOARD MEETING MINUTES

June 21, 2016
7:30-9:00pm
Teleconference

Attendees: Eric Gonneau - Chair, Stella Cockett, Jordan Hier, Allan Weatherall, Joanna Hunt, Mark Myers, Jennifer Graham

Regrets: Saad Minhas, Krista Vriend, Toby Cox,

Recorder: Jennifer Graham

MINUTES

1. Review & Approval of Agenda

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

2. Review & Approval of Minutes

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

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

3. Items arising from last meeting

1. Annual Report

Eric to review. Looking for photos and financials. Past Annual Reports have not include Audited Financial statements but yearend financial report. Eric to review by week and distribute to board for review.

2. Update of records to CRA for directors - Mark, Eric

Eric had been updating directors list with Industry Canada. CRA director list has not been updated.

ACTION: Mark to work with accountant to complete and submit updated director list for CRA.

3. Online documents - Jennifer and Joanna

Jennifer has set up online document repository for CCHA board members, through Dropbox.

4. CASL regulations - Krista

Krista to look into, Allan also researching.

5. Criminal record check

Confirm that mandating policies of dual signature and posting bank statements online are in place to ensure integrity and safeguard organization.

4. ED Report - Allan

1. Media connections and list

Obtained media contacts including National contacts from various contacts.

2. McCormicks

McCormick 'C-Day' was held Saturday June 4th, Allan and Lisa attended on behalf of CCHA. Raised approximately \$55,000.

3. MP/MPP meeting

Allan and Eric have conference call meeting this week with Brian Roe - AB, recommended by office of Federal Minister of Health - Jane Philpott to inform about work CCHA is doing, possible funding opportunities.

4. Bill S201/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 passed 2nd reading and is on hold for summer.

5. Newborn screening efforts

Email circulated regarding the issue. Stella reported update from Dr. Derek Human of BC Children's Hospital and

also on PAB.

MOTION: put issue on hold until after CCS meeting in October and assign to PAB for review and next steps with respect to upcoming letter to be issued by CCS. Stella moved, 2nd - Joanna - Approved

5. Treasurer's Report – Mark

Main bank balance approx \$22,245.50 London and Sick Kids accounts had minimal activity.

Also provided November and December 2015 as well as 2015 Annual financial statements from accountant.

Approval of Treasurer's report for April - Moved - Jennifer, 2nd - Joanna – Approved

Approval of Treasurer's report for May - Moved - Jennifer, 2nd - Joanna – Approved

6. Committees

Advocacy/Awareness Committee - Mark and Joanna

Federal Minister of Health declined to meet with CCHA, referred to Dr. Brian Roe - AB as resource.

Joanna to draft letter to Ontario College of Physicians regarding 33 year records project.

Newsletter (Mark) – Saad to review draft content and outline of newsletter. Jordan offered to provide publishing and design for newsletter.

Brochure reprint - delayed as printer has gone into receivership, starting over with new printer.

Membership Committee - Stella

Chapter guidelines still in review.

Membership list - 10 years of history of email addresses for members.

Fundraising Committee - Jennifer

McCormick's raised ~\$55,000.

Ottawa Marathon - 15 team members, raised \$5,500. Unknown when funds to be delivered

Walk of Life - 28 team members, raised \$12,800.

Montreal Grocery Bagging fundraiser - Jordan - Postponed until September.

100 men/100 women - Allan attended 100 men in London and St. Thomas. Lisa to attend 100 women in London. Also a children's version.

Puckstoppers - Allan waiting to hear date of book launch.

7. Professional Advisory Board (formerly MAB) - Stella

Meeting has yet to be organized.

8. New/Other Business

1. AGM initial planning and board recruitment

AGM held late November - early December. 2 vacant board positions, Jennifer's term expires.

AGM meeting - discuss locations to be held in Canada. Board agree to continue to hold in Toronto.

2. Upcoming events/activities

Nothing upcoming over the summer.

3. Website updates

Received email from member suggesting website include information about government programs and funds that may be applicable to CCHA members (e.g. RDSP, CRA Disability Tax Credit, ODSP and other provincial equivalents). Board agrees to provide high-level explanation/information about programs and hyperlinks to relevant website for each program, for both provincial programs and national programs.

4. Other

Look into scholarship information and programs.

9. Next Board Meetings:

July 12th @7:30 to 9:00

August 9th @7:30 to 9:00 - Krista not available to attend

September 13th @7:30 to 9:00 - Stella, Toby not available to attend

Meeting adjourned @ 9:43 pm