



CCHA BOARD MEETING MINUTES

January 12, 2016
7:45-9:15pm
Teleconference

Attendees:	Eric Gonneau - Chair, Joanna Hunt, Stella Cockett, Mark Myers, Toby Cox, Jordan Hier, Jennifer Graham, Allan Weatherall, Krista Vriend, Saad Minhas, Aaron Brown,
Regrets:	<u>Karen LeCompte</u>
Recorder:	<u>Jennifer Graham</u>

MINUTES

1. Review & Approval of Agenda

Approval of Agenda - Moved - Eric, 2nd - Joanna – Approved
Eric added Annual report and board meeting times

2. Review & Approval of Minutes

Approval of December 15th minutes - Moved - Jennifer, 2nd - Joanna – Approved
Agreed to begin posting on website for members beginning in January 2016

3. Guest Presentation – Bev Heim-Myers – Canadian Coalition of Genetic Fairness

Bev is chair of Canadian Coalition of Genetic Fairness and CEO of Huntington Society of Canada.

- Genetic discrimination occurs when individuals treated unfairly due to actual or perceived differences in genetic information that may cause or increase the risk to a future disability or disorder.
- Many face discrimination based on predisposition or familiar potential for a genetic disease.
- Many required to prove they do not have disease through genetic testing prior to services being provided (i.e. insurance). Many refuse genetic testing for fear of genetic discrimination, job loss, inability to obtain insurance or medical benefits
 - o Hospital for Sick Children started a genetic study in 2013. Study offers whole genome sequencing or genetic testing for young babies who present with what could be genetic disease, research had allowed them to be treated with advanced treatment from an early age. 33% parents decline participation and therefore treatment due to concerns of genetic discrimination and future issues for themselves and other children in family.
 - o Two brothers at familial risk for Long QT Syndrome, one tested and treated at age 22, other age 24 declined genetic testing for fear of job discrimination
- Little evidence-based research published to date on genetic discrimination. Yvonne Bombard – ‘Beyond the patient: The broader impact of genetic discrimination among individuals at risk of Huntington disease’. Found 86% of HD population fear genetic discrimination, 50% have experienced genetic discrimination.
- Canada is only G7 country that does not protect genetic information. Canadian law permits insurers to require health information, including genetic testing information.
- Direct to consumer genetic testing companies can be unreliable or provide false results, no regulations around these testing companies
- Government of Canada Public Opinion research poll on genetic information and privacy: found 91% of Canadians feel insurance companies should not be allowed access to genetic information.
- Some progress since CCFGF started in 2008 with regards to laws and government:
 - o Genetic Fairness included in 2013 Throne speech
 - o 2015 Bill S201 tabled by Senator Bill Cowan, but was nullified when election called.
 - o Government tabled Bill C68 in 2015 – very weak protection for genetic fairness
 - o Senator Cowan again tabled Bill S201 last fall after the election finished, to be discussed in Senate

next week.

- Private member bills have been tabled in Ontario and Alberta
- Objectives are to educate Federal and Provincial government ministers and Canadians and increase awareness for genetic discrimination
- CCGF currently has 18 Member organizations. Membership fee of \$2,000 annually, but can be discussed.
- As an aside, HD Society has confidential board meeting minutes due to privacy issues or personal information discussed, but shares Board Meeting Overview for members.

4. Committee Assignments

By-laws do not require committees be established

Membership/Support – Krista Vriend – Chair, Toby, Stella

Goals: Review/revise chapter guidelines, host events, active chapters across country, expand Beat Retreat

Advocacy/Awareness – Saad Minhas – Chair, Joanne, Mark

Goals: Produce monthly/semi monthly newsletters, host 3 patient education conferences

Fundraising – Jennifer Graham - Chair, Jordan Hier, Mark Myers. Volunteer – Rachael Manion

Goals: Develop fundraising plan and budget

Administration – President – Eric Gonneau, Treasurer – Aaron Brown, Secretary – Jennifer Graham

5. Items arising from last meeting

1. Lengthening of record keeping beyond 33 years - Eric

Healthcare is provincial mandate in Canada, each province decides how long records must be maintained, each province different. Issue revolves around surgeries and chronic conditions. Received response to our letter from office of Dr. Hoskins - MPP Health Minister for Ontario, indicate that College of Physicians and Surgeons in Ontario set the guidelines. Awaiting direction from Ontario Medical Association, Allan to contact. BC has recently changed to lifetime records. Alberta and Manitoba have same issues.

2. Signing officers for bank account – Eric

Eric, Krista, Denise and Jennifer are current signing officers, Shelagh has been removed.

3. Strategic plan – Eric

Eric encouraged everyone to read and review the objectives for upcoming year.

4. Budget initialization – Eric

Will need to create a 2016 budget.

5. Grant applications/Rachel Manion – Allan/Jennifer

No new grant opportunities presented by Rachael. Will review each opportunity to determine effort, ROI, relevance and feasibility.

6. Christmas appeal fundraising campaign – Jennifer/Allan

Letter was mailed out to past donors last week of November; results for combined Christmas Appeal letter and Giving Tuesday campaign were significantly better than last year, but not as high as targeted. 20% of letters mailed from Past Donor List were returned unknown address or moved, unknown how old or current list was.

7. Website/Facebook/Twitter – Eric

Allan looking after Communications and Info email addresses. Currently 4-5 people have access to post on Facebook, 2 people with Twitter access. Jennifer and Shelagh currently main resources for both. Shelagh has agreed to train group on website: Mark, Jordan and Jennifer to learn.

8. Director Status – Eric

Denise has tentatively resigned.

9. BC PACH clinic – Stella

BC clinic hosting 1 day patient education conference on Saturday May 7th, 2016 - Unique Hearts, Unique Lives – Information on navigating adult life with CHD.

10. Update of Records to CRA – Eric/Allan

To be reviewed

11. GTA Chapter Application – Eric

Discussed at length by board during December 15th board meeting. Decision made not to approve the application. Board decided to revise the chapter guidelines.

6. Treasurer’s Report – Jennifer Graham

Main bank balance approx \$26,084.59 London account has \$192.85 , Sick Kids account has \$3.76.

Approval of Treasurer’s report for December - Moved - Jennifer, 2nd - Krista – Approved

Jennifer, Aaron, Eric, Krista to work on 2016 budget.

Jennifer interim Treasurer, work to transition role to Aaron.

7. Administrivia

- Krista in Vancouver this weekend, to meet with Stella. Krista will contact Stella to organize.
- Allan and Lisa meeting with McCormick on January 13th regarding their \$40,000+ donation. Will provide update next board meeting.
- Move Board calls to 7:30, confirm with Stella that ok.
- Ask all new board members to submit bio and picture to update BOD on website, returning board members can send any updates if they wish as well. Send info to Krista to ensure consistency.
- Jennifer to connect with Aaron to transition Treasurer role.
- Mark is collecting mail and forwarding to relevant individuals

8. Upcoming Events

Nothing to report

9. New/Other Business

Nothing to report

10. Next Board Meetings:

February 9th @7:30 to 9:00

March 8th @7:30 to 9:00

April 12th @7:30 to 9:00

May 10th @7:30 to 9:00

June 14th @7:30 to 9:00

July 12th @7:30 to 9:00

Meeting adjourned @ 9:30 pm