

MINUTES OF THE APRIL 19, 2018 CONFERENCE CALL
APLASTIC ANEMIA & MYELODYSPLASIA ASSOCIATION OF CANADA

Present: Cindy Anthony, Gwen Barry, Marilynne Convey, Vivian Do, Jennifer Garvey, Haydn Liang (Chair), Pam Wishart

Regrets: Ashley Oakes, Sanjeev Parmar, Jesse Praeger

1. Call to Order

Haydn called the meeting to order at 7:05 pm EST.

1.1. Approval of Agenda

Marilynne requested that Nurse Education be added to Other Business. Cindy requested that Review of the New Website be added to Other Business, and that the CBS Survey be added under 2. Motions Approved by Email. Haydn moved that the Agenda be approved with the changes, seconded by Pam. All were in favour.

1.2. Approval of Minutes of March 8, 2018 Conference Call

On the master of the minutes, the next meeting date is to be corrected. Under the Novartis Presentation, Paul Simpson's name is to be added. Vivian moved that the minutes be approved with these changes added, seconded by Pam.

2. Motions Approved by Email

The motions approved by email were the Pharma Policy, Marilynne Convey's appointment to the Board, and distribution of the CBS Survey.

3. Financial Update

Vivian reported that donations are significantly up from what was anticipated. We are awaiting \$40,000 from Alexion, and Celgene's grant is due in May. Pam noted that the changes that Vivian has made to the Financial Statements make it much easier to understand. See attached Financial Update.

4. Research Proposal Update (Grace Christou Project)

Cindy reported that Grace is finalizing her patient and medical personnel Surveys, with drop down menus, as suggested by several reviewers.

5. Executive Director's Report

Cindy met with Novartis this week, and would like to form a committee of interested AAMAC Board members to start to work on the coverage of Revelade in B.C. Marilynne, Pam, and Haydn, and well as Ashley will be participating. See attached Executive Director's Report.

6. Patient Education & Support Updates

Cindy reported that the planned meetings for Halifax, Ottawa, and Vancouver are progressing well. The Sickle Cell Anemia group are hosting a conference in Edmonton in November, and have invited other groups to host their own patient meetings as part of the larger conference. Fiona will be holding an AAMAC patient meeting as part of the larger conference. Cindy will be meeting with Claude Francoeur's wife Toshimi to retrieve material, and to see if Toshimi has any suggestions about a replacement for Claude as our Quebec Region Coordinator. See attached reports for Atlantic Region, BC Region, and Ontario Region.

7. Other Business

7.1. Nurse Education

Janice Cooke has brought Marilynne up to speed on the situation with development of Nurse Training Modules for AA and PNH. Marilynne has found a Nurse Educator, Rebecca St Jean, in Vancouver who has expressed an interest in assisting AAMAC with the development of these modules. Pam will provide Marilynne with a copy of the MDS Nurse Training Module, which could serve as an aid in development of the other modules.

7.2. Review of New AAMAC Website

Cindy reported that the new website is close to the launch stage, but needs someone who has not been involved in its development to proof read/review it. Pam has offered to review it. Haydn has also offered to help, if needed.

7.3. winmail.dat

With Carol's updated computer software, some Exel attachments sent by Carol by email are coming through with the winmail.dat file extension, and cannot be opened on Gwen's pc.

Action Item: Cindy will check with Carol to see if she can turn off winmail.dat, or if there is some other solution.

8. Adjournment

Gwen moved that the meeting be adjourned at 7:35 pm EST.

Next Conference Call: June 7, 2018 at 7:00 pm EST

Attachments

Agenda

Minutes of March 8, 2018 Conf. Call

Financial Report

Executive Director's Report

Update Atlantic Region

Update BC Region

Update Ontario Region