

Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC)  
MINUTES of the 16 OCTOBER 2016 ABM – MONCTON

**Present:** Gwen Barry (Secretary), Janice Cook, Claude Francoeur, Jennifer Garvey, Haydn Liang, Ashley Oakes (Chair), Pam Wishart. Staff: Cindy Anthony, Carol Fazari.

**Regrets:** Sanjeev Parmar

### **1. Call to Order**

Ashley called the meeting to order at 9:30 am.

#### **1.1. Approval of Agenda**

Cindy requested that NAC re Blood and Blood Products be added to the Agenda under Item 9. Claude requested that Goal Setting be added to the minutes under 12. Other Business. With the following additions, Jennifer moved that the Agenda be approved, seconded by Pam. All were in favour - motion carried.

#### **1.2. Approval of Minutes of Aug. 25, 2016 Conference Call**

Haydn moved that the minutes of Aug 25, 2016 be approved, seconded by Janice. All were in favour – motion carried.

### **2. Grant Update – Nursing Scholarship**

Gwen moved that the Nursing Scholarship be continued for another three years, finishing in 2019-2020. Jennifer seconded the motion. All were in favour – motion carried.

**Action Item: Cindy agreed to send the Directors a copy of the criteria for AAMAC's Nursing Scholarship.**

### **3. Board of Director Roles for 2016-17**

The following persons agreed to hold the following positions:

Vice Chair: Haydn Liang

Secretary: Gwen Barry

NRBDO Reps: Janice Cook and Haydn Liang

CBS NLC Rep: Ashley Oakes

Treasurer: To be determined

Nominating Committee: Cindy Anthony and Gwen Barry

Governance Committee: Cindy Anthony, Claude Francoeur, and Jennifer Garvey

MSAC Liaison: Cindy Anthony, Gwen Barry, and Haydn Liang

Grants: Pam Wishart and Haydn Liang

Jennifer moved that the above appointments be approved, seconded by Haydn. All were in favour – motion carried.

It was agreed that we not establish a Fund Raising Committee at this time. Ashley has agreed to lend her expertise in this area, should any ad hoc needs arise.

### **4. Staff Reports**

#### **4.1. Regional Support Liaison**

See attached Update – Regional Support Liaison – D. Edmonds

#### **4.2. Executive Director**

Cindy informed the Board that AAMAC has been selected to partner with Celgene on the live tweet on MDS Awareness Day. AAMAC's Twitter account is AAMAC1989. Also see attached 'Update Report – Executive Director.'

**Action Item: Ashley and Cindy will investigate creating an AAMAC Planned Giving Document, to be included with the next Annual AAMAC Letter to patients, members and supporters.**

## 5. Office Administration

Carol informed the Board that AAMAC that SUMAC is fully operational for our contact/patient data base. Input took many months. It is important for Regional Coordinators to inform Carol of any changes to our Regional contact information, including corrections, additions, and deletions. The Board expressed their appreciation for Carol's valuable contribution to AAMAC. Also see attachments: Update: Office Processing – C. Fazari, and Patient Contact Information Form.

**Action Item: Carol will send the Regional Coordinators the current Contact reports by province.**

**Action Item: In future, as Carol receives a new patient/supporter's contact info for addition to SUMAC, she will notify the appropriate Regional Coordinator.**

**Action Item: Carol will add a title to the Patient Contact Information Form.**

## 6. Coffee Break

## 7. Bilingual Logo

The Board was given two proposed bilingual logos for discussion.

**Action Item: Cindy will provide the Board with an actual size draft logo, using the fading blood drop, for further consideration.**

## 8. Financial Matters

### 8.1. Budget 2016-17

Claude expressed concern about our shortage of future revenue, coupled with increasing costs. It was agreed that this could be balanced out by issuing fewer, if any, Research Grants in 2017-18, and in part by fundraising through such events as the Scotia Bank Charity Walk/Run in various regions. Also see attached 2015-16 Audit Report.

**Action Item: Cindy will investigate the process/details of getting AAMAC included in the Scotia Bank Charity Event, and on what date it is to be held next, so Regions can make plans to participate.**

### 8.2. Financial Report on Investments

See attached reports: Wood-Gundy Asset – Return Contribution and Wood-Gundy Performance Review.

### 8.3. Treasurer Update

**Action Item: Cindy will send a thank you card and flowers to our past Treasurer, Anna Chamrai.**

### 9.1. NRBDO - PMPRB

Haydn briefed the Board on the role of the Patented Medical Prices Review Board (PMPRB), and on the type of input that they are seeking from relevant organizations. NRBDO is developing a position for input to PMPRB, which we have not seen as yet. The deadline for submissions is October 24, 2016. Essentially the Board feels that we have insufficient expertise on which to base a position, but that AAMAC would like to at least provide PMPRB with our general views on the matter, separate from what NRBDO may submit. Jennifer moved that AAMAC produce its own submission, seconded by Janice. Gwen moved that if we receive a copy of the NRBDO submission by October 21, that it be distributed to the Board for quick review and a decision on whether AAMAC wishes to also sign on to the NRBDO submission. The motion was seconded by Ashley. All were in favour – motion carried. Also see attachments: PMPRB Haydn's Presentation, and PMPRB Discussion Paper.

**Action Item: Jennifer will produce a draft of an AAMAC submission to PMPRB, for quick distribution to the Board for approval in time for the Oct 24 deadline.**

### **10.1. National Liaison Committee (NLC) for CBS**

Ashley briefed the Board on the NLC meeting of Sept 12-13, 2016, concerning issues about the plasma supply in Canada, and the need for an AAMAC position on the matter. Action on an AAMAC position has been deferred.

**Action Item: Ashley will provide the Board with a report on the upcoming meeting of October 2016 in Ottawa.**

### **10.2. National Advisory Committee (NAC) on Blood and Blood Products**

Ashley provided the Board with information on NAC's proposed recommendations re irradiated blood products. The deadline for stakeholder feedback/concerns is October 28. The Board felt that they had insufficient expertise to comment fully on NAC's recommendations.

**Action Item: Ashley will provide Cindy with the concerns of Board members, and Cindy will ask MSAC what they suggest that AAMAC's position should be, from which Ashley can draft a submission to NAC for the Boards review before Oct 28.**

## **11. Patient Education Discussion**

### **11.1. Patient Education Day – Vancouver 2017**

The Board has decided on the dates of Sept 30 for Education Day and the AGM in Vancouver, followed by the ABM on Oct 1<sup>st</sup>, if this turns out to be feasible for the guest speakers. Janice suggested that the One Match video would be very suitable for use at the Vancouver Education Day.

### **11.2. Other Education Days**

A mini Education Day in Quebec City may be feasible for 2017. There will also be a lunch and learn session on MDS for Registered Nurses in Halifax in 2016-17.

### **11.3. Review of Education Day – Moncton Oct 25 2016**

The Board's initial observations were that the speakers were all quite good, and that the question period after each presentation was invaluable. However, the lack of a microphone made it hard for a few people to hear some of the presenters from the back of the room. And also that it was difficult for the group to hear participant's questions after each presentation. Gwen suggested that the Evaluation Sheet completed by attendees at the end of the days sessions be expanded to include an evaluation on each presenter in terms of relevance, and quality, as well as some evaluation of sound and sight issues with each presentation.

**Action Item: Ashley will add a Review of the Education Day Evaluation Form as an item for the December 2016 Conference Call, with the blank form to be provided to the Board members by Cindy or Carol.**

## **12. Other Business – Goal Setting**

This has been deferred to the next Conference Call of 8 December 2016.

## **13. Adjournment**

Gwen moved that the meeting be adjourned. All were in favour – motion carried at 2pm.

The next meeting will be on 8 Dec. 2016 by Conference Call at 7pm EST.

## **Attachments**

<u>Agenda Item</u>	<u>Title of Attachment</u>
1.1.	Agenda for ABM Oct 16, 2016
1.2.	Draft #2 Minutes of Aug. 25 2016 Conference Call
2.	Nursing Award 2016
2.	Nursing Scholarships Summary
4.1.	UPDATE – D. Edmonds
4.2.	UPDATE – Executive Director
5.	UPDATE - C. Fazari – Office Processing
5.	UPDATE – C. Fazari – Patient Contact Information Form
8.1.	Audited Financial Statement 2015-16
8.2.	Wood-Gundy Asset – Return Attribution
8.2.	Wood-Gundy Performance Review
9.1.	PMPRB Haydn’s Presentation
9.1.	PMPRB Discussion Paper
10.2.	CBS NAC on Blood and Blood Products – Draft
10.2.	CBS NLC on Blood and Blood Products – Letter

## **Parked Items**

AAMAC’s Goals

Review of Education Day Evaluation Form

Draft Planned Giving Document for Board Review

Bilingual Logo

Grants Policy Development (from Oct 18, 2015) (Discussions were held over the course of 2015-16, but insufficient information has thus far been available on which to finalize a Grants Policy)

Scotia Bank Charity Walk/Run

## **NOTES:**

Oct 16, 2016 AGM Draft #2 Minutes (Moncton) approved at Dec 8, 2016 Conference Call.

Final version, and attachments distributed to all Board Directors, Cindy, and Carol on Dec 9, 2016.