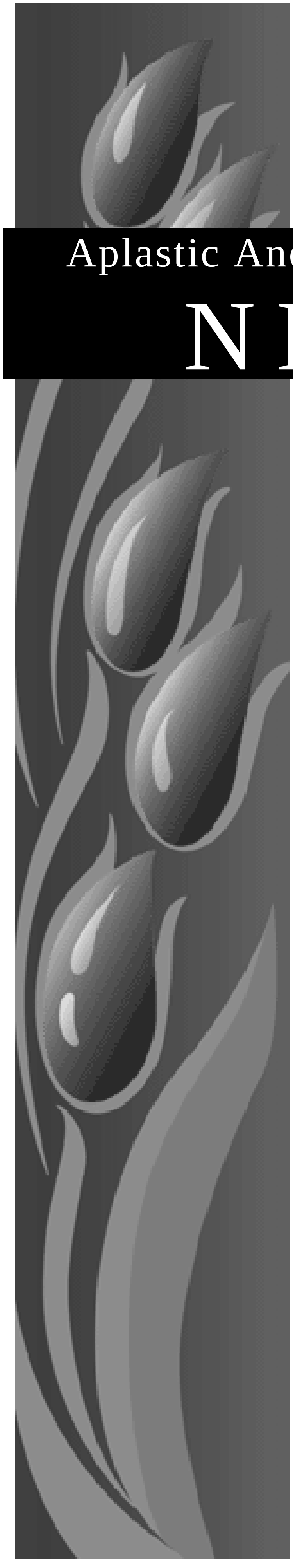

Education
Support
Research

Spring 2018

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

Message from the Chair

Happy New Year and I hope that 2018 has gotten off to a good start!

In the coming year, AAMAC will hold patient support group meetings across the country! These meetings ensure we are working vigorously towards our mission to provide a seamless support network for every Canadian patient, family member, friend, and concerned healthcare provider dealing with aplastic anemia, myelodysplasia (myelodysplastic syndrome or MDS) and paroxysmal nocturnal hemoglobinuria (PNH).

In addition to holding patient support group meetings and our annual patient education day, held in the fall, AAMAC board members and our Executive Director represent our patients, families and caregivers through our involvement with the Canadian Blood Services National Liaison Committee, the Network of Rare Blood Disorder Organizations, and the Canadian Organization for Rare Disorders. This work ensures we stay on top of the latest developments that impact our patient population and ensure we are advocating for patients families and caregivers across the country.

AAMAC's annual patient education day will be held at in Ottawa on October 13, 2018 so please mark your calendars. We look forward to distributing more details in the coming months.

As always, please contact our office (by emailing info@aamac.ca or by calling the office at 1 (888) 840-0039) if you would like to volunteer, if you are in need of support, or if you would like us to mail you educational and support material. All material and support services are available in English and French.

Sincerely,

Ashley Oakes
Chair of the Board
AAMAC

AAMAC ACAAM
Aplastic Anemia & Myelodysplasia
ASSOCIATION OF CANADA
ASSOCIATION CANADIENNE
de l'anémie aplasique et de la myélodysplasie

The Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) provides information about aplastic anemia (AA), myelodysplasia (also called myelodysplastic syndrome or MDS) and paroxysmal nocturnal hemoglobinuria (PNH) to the public; operates a nationwide support network for patients, families and medical professionals; supports Canadian Blood Services blood programs and OneMatch Stem Cell and Marrow Network; and raises funds for medical research.

The Aplastic Anemia & Myelodysplasia Association of Canada Newsletter is published 4 times a year. The contents are not intended to provide medical advice, which should be obtained from a qualified health professional. No part of this publication may be used or reprinted without written permission. For submissions, inquiries or comments, please contact us at:

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Atlantic Region Update

By Gwen Barry

On November 30, 2017, the Halifax Support Group held its annual Christmas gathering at the home of Dolores d'Entremont. The event was well attended. We had a round table of sharing our experiences, which was hopefully helpful to a new aplastic anemia patient who attended.

The Atlantic Region of AAMAC will host an Education Day for AA/MDS/PNH patients and their caregivers/support persons in Halifax on Saturday, May 5, 2018. While travel bursaries (up to $500 per family) will only be available for residents of Nova Scotia, patients from elsewhere are welcome to attend.

Further details and the registration form are included with this issue of the newsletter.

In addition to learning about these disorders from hematologist guest speakers, it is an opportunity to meet with others who share your diagnosis, and your concerns. Hope to see you there.

AAMAC is Hiring

Our vision is to support all Canadians and their families and friends through diagnosis, treatment and remission stages of these diseases.

We have openings for two Regional Support Group Liaison positions – one in Alberta and one in B.C.

The roles report to the Executive Director, will be based in Alberta and B.C., and assist with planning, promoting and attending patient support groups.

Duties:
- Plan meetings in cities TBD
- Arrange for venue and refreshments
- Prepare flyers and promote the meetings in hospitals, other institutions
- Prepare information about meetings for Facebook and AAMAC's newsletter
- Under the direction of the Executive Director arrange for speakers for the meetings
- Work with existing volunteers to attend hospital clinics

Qualifications:
- Excellent communication skills
- Knowledge of MDS, PNH and Aplastic Anemia an asset
- Strong organizational, project and time management skills
- Computer skills – Microsoft programs such as Word, Excel and PowerPoint
- Ability to work independently and with minimal direction
- Excellent advocacy skills and proven experience with the medical community and/or community networks
- Experience and training in community development/capacity building approaches
- Driver's license and use of vehicle

Terms and conditions: One (1) year contract

Pay Range: $20 to $25 per hour – number of hours TBD and hours will vary on a monthly basis. Time and Activity reports will be submitted to Executive Director on the last day of each month. Travel within province will be required and all travel costs will be reimbursed by AAMAC.

The successful candidates will be required to maintain a home office in Alberta or B.C. with appropriate computer and communications equipment.

Please forward resume to: Cindy Anthony, Executive Director at cindyanthony@aamac.ca.

Ontario Update

By Darlene Edmonds, Ontario Support Coordinator

I'd like to wish everyone all the very best in 2018. Within the scope of my position with AAMAC, I've been assisting with the planning and implementing of the patient support group meetings being held in London, Kitchener, Hamilton, Toronto and Oshawa.

If you and/or your family have any suggestions of topics or speakers please drop me an email. I'd love to hear from you. I can be reached at ontariosupport@aamac.ca.

Dates and venues have been booked for the Spring. I encourage you, family members and/or friends to attend the meetings. Everyone has something to share and these meetings are a great way to connect and support one another.

Make a plan to attend a spring meeting in your area.

- **Kitchener:** Saturday, April 7, 2018 from 10:30 a.m. to 12:30 p.m. at Hopespring Cancer Support Centre, 475 King Street North at the back entrance of the Inn of Waterloo
  Topic: TBD
- **Toronto:** Saturday, April 14, 2018 from 8:30 a.m. to 5:30 p.m. Marrow Failure & Myelodysplasia Patient and Family Conference (See details about this event at the Hospital for Sick Children in this newsletter.)
- **Oshawa**: Saturday, April 21, 2018 from 10:30 a.m. to noon at a new location – Simcoe Street United Church, 66 Simcoe Street South
  Speaker: Pamela West, Nurse Practitioner in Oncology & Supportive Care
  Topic: Quality of Life When Dealing with a Chronic Disease
- **London:** Saturday, April 28, 2018 from 10:30 a.m. to noon at the Wellspring Cancer Support Centre in the YMCA at 382 Waterloo Street
  Topic: TBD
- **Hamilton:** Saturday, May 5, 2018 from 10 a.m. to 11:30 a.m. at Wellwood, 501 Sanatorium Road
  Topic: TBD

I look forward to reconnecting with many of you at the upcoming meetings. Follow us on Facebook and Twitter for updates. Happy winter and looking forward to the Spring.

Catherine Knoll is also organizing **Ottawa** support group meetings in 2018 on March 14, April 11, May 9, June 13, September 12, and November 14. Meetings take place at the Maplesoft Centre, Ottawa Regional Cancer Centre, 1500 Alta Vista Drive from 6 to 8 p.m. There will also be an Ottawa Patient Education Day on October 13 so mark your calendar and watch for details in the future.

AAMAC Grant Supports Alberta Nurse Practioner

AAMAC has long supported a Canadian Nurses Foundation (CNF) grant and recently received the following update from the CNF about the 2016-2017 Aplastic Anemia and Myelodysplasia Nursing Grant recipient, Derek Rothe.

We share the following letter from the CNF's Director of Development, Annette Martin and thank all the AAMAC donors who made this grant possible.

"CNF is so thankful for AAMAC's support since 2000 in providing an annual $5,000 scholarship for students focusing their research in the field of hematology or oncology – we wanted to share with you the impact of your recent support!

"Thanks to your support, Derek recently completed his Masters in Nursing at the University of Alberta. Derek's thesis included research in cardiac rehabilitation in lymphoma patients who have been treated with bone marrow transplant and chemotherapy. As part of his studies, he submitted abstracts and poster presentations at national conferences such as Canadian Conference on Lymphoproliferative Disorders (CCOLD) and Canadian Association of Nurses in Oncology (CANO), as well as a global cardio-oncology summit in London, UK.

"Currently Derek is applying for nurse practitioner employment in oncology and is optimistic about his future. Moving forward he plans on remaining involved with University of Alberta research projects while he dedicates the next few years to developing his new Nurse Practitioner practice.

"Derek is so thankful for your support – in his own words, *'Receiving a CNF award is an important moment in a person's career. There is a validation that comes with receiving the Aplastic Anemia and Myelodysplasia Nursing Grant, and the confidence that comes with knowing that my passions, and vision for the future of nursing practice is worth investing in. Thank you."*

"On behalf of the entire CNF team, it is a real pleasure working with you and AAMAC. We look forward to our continued partnership. Thank you again for your generosity."

Thanks Mom! Give Life Call for Volunteers

thanks mom! give life 2018

Thanks Mom Give Life 2018 campaign looking for volunteers across Canada! Mother's Day is coming up and what better way to honour her than by helping to Give Life to others as she gave life to you! "Mothers have given us life, and we, in turn, can give life to others!"

This is the theme of the Thanks Mom Give Life 2018 campaign. AAMAC patients, their family members and friends know about all too well and how blood, cord blood, adult stem cells can save lives. This year's campaign (the fifth one since 2006) will be held May 5 and 6, 2018 at Guildford Town Centre in Surrey, British Columbia. We are also partnering with BC Transplant to raise awareness about registering as a potential organ/tissue donor. There are four ways to give life: blood, adult stem cell, cord blood and organ/tissue.

This year, we also hope to have other volunteer groups across Canada join us in this general public awareness event to educate Canadians about the vital importance of Canadian Blood Services and how to give life while honouring Mom along the way!

We are especially looking for any volunteers in Brampton, Ontario. If you or anyone you know is interested in doing a campaign or helping out, please let us know ASAP! Your efforts and enthusiasm are much appreciated! Graphics and posters are available and we can also add your event to our social media and website. All we need is you!

For further information, see web links below or please contact Eileen Sue at info@thanksmom.org. Eileen is a Canadian Blood Services volunteer and family member of an aplastic anemia patient who has now recovered.

Please also let everyone know about Thanks Mom Give Life 2018 through your social media!
www.thanksmom.org
facebook.com/thanks.mom.drive/
instagram.com/thanksmom.givelife/
twitter.com/ThxMomStemCell

News of Note

Thank You Volunteers!
This April, Canada celebrates volunteers who make the work of organizations like AAMAC possible. We thank each and every one of our volunteers for the value they bring to the organization and people with bone marrow failure diseases! We also thank all those family members and friends who volunteer in other ways including as blood and stem cell donors.

New Office Location
AAMAC's national office has moved. Our new address is 2201 King Road, Unit #4, King City, Ontario, L7B 1G2. Phone numbers are the same.

MDS Alliance Update
AAMAC's Executive Director, Cindy Anthony, recently concluded her two-year term as the Chair of the MDS Alliance. She remains on the steering committee of six founding countries in this growing organization. For information about the Alliance, visit www.mds-alliance.org.

Ontario Funds Medication for People Under Age 25
According to the Government of Ontario, starting January 1, 2018, OHIP+ will cover all drugs and drug products currently reimbursed through the Ontario Drug Benefit program.

For more information including about other medications visit www.ontario.ca/OHIPplus. Information about OHIP+ for healthcare professionals is at health.gov.on.ca/en/pro/programs/drugs/ohipplus/.

Rare Disease Day: February 28
Visit rarediseaseday.org or raredisorders.ca for details about plans around the world to mark Rare Disease Day this year.

SickKids

2018 Marrow Failure and Myelodysplasia Patient and Family Conference

Saturday April 14, 2018 - 8:30 a.m. to 5:30 p.m.

SickKids Peter Gilgan Centre for Research and Learning
Salter Auditorium, 3rd Floor, 686 Bay Street, Toronto

We are pleased to invite you to this an interactive meeting. It is an ideal opportunity to learn, network with other families and meet experts in the field.

This meeting is for patients and families with bone marrow failure disorders and myelodysplastic syndromes (MDS), physicians, other health-care workers, fellows, residents and all others who are interested in the field. Adult patients who have or suspected to have familial or inherited types of bone marrow failure syndromes are also invited.

Conference agenda

Overview and new developments related to the conditions and their treatments; transition of paediatric patients to care in adult centres; information about Canadian treatment centres and support groups; raising awareness; new research to understand the diseases and develop new treatments in Canada and abroad.

Speaker list

Physicians, scientists, research students, nurses, social workers, genetic counsellor, patient and family representatives (speaker list will be announced prior to conference).

Bone marrow failure and myelodysplastic disorders

• Aplastic anemia • Fanconi anemia • Shwachman-Diamond syndrome • Diamond Blackfan anemia • Dyskeratosis congenita • Cyclic neutropenia • Kostmann and severe congenital neutropenia • Congenital amegakaryocytic thrombocytopenia • Glycogen storage disease type Ib • Barth's syndrome • Benign familial neutropenia • Myelokathexis • Thrombocytopenia with absent radii • Familial thrombocytopenias • Dyserythropoietic anemia with thrombocytopenia • Familial thrombocytopenia with leukemia predisposition to leukemia • Congenital hair hypoplasia • Pearson disease • Sideroblastic anemia • Myelodysplastic syndromes (de novo MDS, familial MDS and therapy-related MDS) • other classified and non-classified bone marrow failure syndromes

Children are welcome!
Children's activities and education sessions
hosted by Camp Quality volunteers.

The conference is free!
Lunch and refreshments included. Parking discounts available.

For details and to register at no charge, please contact:

Connie Grillo, Marrow Failure and Myelodysplasia Program
416-813-5977 or connie.grillo@sickkids.ca

Note: number of participants is limited by the conference facilities. Early registration is recommended!

Sponsors (TBA)