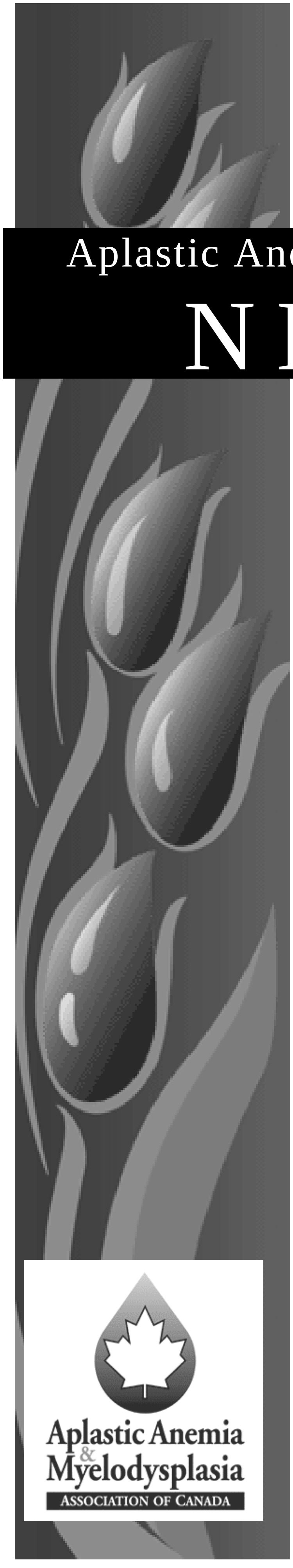

Education
Support
Research

Summer 2016

Aplastic Anemia & Myelodysplasia Association of Canada
NEWSLETTER

Message from the Vice Chair

April showers bring May flowers! That is certainly evident on the west coast of British Columbia. The tulips, daffodils and crocuses have bloomed, bears are newly awakened and dining on the salmon berries in my back yard and the air is rich with the sound of buzzing bees! By the looks of things a beautiful summer is on the way. And with the arrival of the warm weather comes the arrival of AAMAC's summer newsletter and with it the registration form for Education Day, to be held this year on October 15 in one of my favourite east coast cities - Moncton, New Brunswick. This is a great opportunity for you to visit the Maritimes, hear from a myriad of wonderful speakers and meet fellow patients, families, caregivers and medical professionals. Travel bursaries are available (applications can be found at www.aamac.ca) and group rates will be available at the Delta Beausejour Hotel. If you are unable to attend Education Day, select presentations will be available on the AAMAC website following the event.

In addition to AAMAC's annual Education Day, smaller patient support meetings take place throughout the year and across the country. Upcoming patient support meeting information can be found on the AAMAC website with confirmed events scheduled to be held in Hamilton and Toronto in the coming months. For those in BC, a patient support meeting is currently being planned for Kelowna and we will be posting more details in the coming weeks.

Throughout the year, AAMAC works tirelessly to advocate for AA, MDS and PNH patients. We do this by having representation on committees and attending meetings such as the Network of Rare Blood Disorders (NRBDO), Canadian Blood Services National Liaison Committee (CBS NLC), and the Canadian Organization of Rare Disorders (CORD). Additionally, when necessary, AAMAC advocates directly to government representatives.

We are able to work hard for patients, families and caregivers, as well as fund important research and programs such as nursing education, thanks to the support of our wonderful sponsors and donors. In March, AAMAC was grateful to receive a donation from Joe Laxton, made in honour of Mr. Herb Walton on the 50th birthday of Mr. Walton's twin sons, Andy and Larry. This generous donation was also matched by NA Engineering Associates Inc. Thank you to Debbie & Joe Laxton, Larry & Andy Walton, and NA Engineering Associates Inc. for your generous spirit!

Lastly, I'd like to extend a warm welcome to Haydn Liang, the newest member of AAMAC's Board of Directors. Haydn holds a PhD in Immunology and is a medical writer with Ogilvy CommonHealth in Toronto. In his short time on the Board he has proven to be a huge asset! Welcome Haydn.

Wishing you all a wonderful summer,
Ashley Oakes, Vice Chair, AAMAC Board of Directors

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.

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BC Update

By Janice Cook

Hi everyone. I hope that you are out enjoying the spring flowers and green grass and leaves before the heat of summer and water restrictions take care of that.

Gardening has been a hobby of mine since the late 70s, and I have now gardened in the three westernmost provinces. Each one has their challenges, but in the summer of 2004, while being actively treated for severe aplastic anemia, the challenges and disappointments were almost overwhelming. Gardening can be, after all, very labour intensive, and more so if you can barely climb a flight of stairs some days, and changing bed sheets is followed by a lay down resting period.

After finding out that I could develop fungal infections from working in the soil, being in the sun could cause skin problems as a reaction to medication, and mosquitoes carrying West Nile disease had surfaced in Canada, I sometimes wondered if it was worth it.

Well, I'd like to say it is worth all of the effort it takes to continue on with the activities that you most enjoy, and all the more so while you are sick.

Doing the things you enjoy the most is so important to your emotional and mental health that it is worth the adjustments and changes that you must make to accommodate your illness. So go ahead and invite some like-minded friends over to till the soil and plant, while you direct and put together a lunch. Then you have a party that's good for anyone's mood.

You don't have to dress up like a bee-keeper but do remember to cover up with hat, gloves and always closed shoes to prevent injury. Remember your immune system is compromised, so if you do get a cut or sliver, do proper first aid with soap and water and cover until healed. Check the wound every day after first washing your hands with soap and water. See a doctor right away if you have signs of infection that might include red streaking, swelling, drainage or increasing pain at the site (sorry but that's the nurse in me).

And if you can't garden yourself, enjoy other people's gardens, a garden centre, a gardening magazine or a show on TV that reminds you of all the natural beauty in the world. Of course if you don't like to garden I don't have any suggestions at all.

I recently had an email from a man who told me that he spent the winter snowboarding and teaching kids to snowboard. While this is pretty special to a lot of us, it was all the more incredible to hear that he had a stem cell transplant last April! So happy new birthday H.G. I hope your hematologist doesn't read this!

Thanks to Robin M, for bringing the Alliance program for Exjade to our attention. Please read about it elsewhere in this newsletter.

The pediatric meeting has been rescheduled for August 27. Please keep checking the website, emails, etc. for further information.

We plan to have a meeting in the fall in Kelowna, so please contact me at bc@aamac.ca if you want information but are not on the chapter email list. I am always happy to hear how you are doing.

Stop and smell the flowers.

Atlantic Region Update

By Gwen Barry

In February 2016, the Halifax Support Group met for lunch at the home of Jackie MacDonald. The guest speaker was Joyce Nifort, Wish Granting Manager, Make A Wish, Atlantic Provinces. At the meeting, the group also discussed media relations options and opportunities in AAMAC Atlantic Region.

One of our members, Dolores D'entremont, has been invited to speak about PNH and AAMAC on the local French radio station in Pubnico, Nova Scotia.

On May 7, 2016, the Halifax Support Group met for a Spring Luncheon and Social at the home of Jackie MacDonald.

As you will see elsewhere in this issue of the newsletter, AAMAC is holding another Patient Education Day in Atlantic Canada. This time it will be a New Brunswick - Prince Edward Island Education Day, to be held in Moncton, N.B. on Saturday, October 15, 2016. Patients from all of Atlantic Canada are welcome to attend, but travel bursaries will only be available for patients and their caregivers living in N.B. and PEI.

AA/MDS/PNH patients and their caregivers are also welcome to attend any of our local Halifax Support Group events. We can also provide educational material, and/or arrange a one-on-one conversation for you with another patient with a similar diagnosis. For further information, please contact Jackie MacDonald at rob.jack@ns.sympatico.ca or (902) 443-1615.

Ontario Chapter Update

By Darlene Edmonds, Regional Support Liaison, Ontario

We've had very successful patient support group meetings take place in Hamilton, Toronto and London. All of these groups have scheduled their next meetings for June, September and October 2016. (Hamilton's meeting took place May 7, 2016 prior to the newsletter being released.)

Please see the events section of this newsletter for upcoming meetings in Kitchener, Toronto and London.

These meetings provide a safe environment for patients, caregivers and health care providers to come together to learn and share. We can all learn from one another.

If you have a topic suggestion for a meeting, or if you've heard someone present that you were really impressed with, please share the details with the AAMAC office. Plans are already under way for future meetings so please send us topic ideas and speaker suggestions.

Wishing everyone a warm and sunny spring!

Annual Education Day Heads East to Moncton, N.B.

Join AAMAC for an opportunity to learn more about aplastic anemia, myelodysplasia (MDS) and PNH.

Our free annual Patient Education Day features presentations about bone marrow failure diseases by experts in the fields who provide valuable, disease-related information.

This year's event takes place Saturday, October 15, 2016 from 8 a.m. to 3 p.m. at the Delta Beausejour (Shediac BC room), 750 Main Street in Moncton, New Brunswick. Registration begins at 8 a.m. in the Upper Mezzanine.

Patients, family, and healthcare professionals living in Atlantic Canada are welcome to join us.

Presentations include:

- MDS, AA & PNH overview
- a panel discussion
- patients discussing their experiences, successes and living well with bone marrow failure
- what to expect with a stem cell transplant
- the psychosocial aspects of living with chronic diseases, and
- iron overload.

A full agenda is included in this newsletter.

Travel cost bursaries are available. They are limited to one patient and one support person per family.

To register or for more information visit aamac.ca or contact info@aamac.ca or 1 (888) 840-0039.

Special hotel rates available if booked before September 14. Call the Delta Beausejour at 1 (888) 890-3222 for information about rates.

Nova Scotia Girl Celebrates Second "Birthday"

This article was published in April 2016. It is reprinted courtesy of the "Cape Breton Post – TC Media."

By Julie Collins

Kaylee MacIntyre celebrates the second anniversary of her bone marrow transplant May 8, the same day the eight-year-old and her family leave for Disney World. "She is going to burst," said her mom Patricia MacIntyre. "The whole time she was sick, we used the wish as an incentive for Kaylee – to help her to get better. She did everything we asked of her. Now, her trip is only days away and she is that excited, it's wonderful."

Kaylee received her wish Tuesday during a special celebration at Scotiabank in Sydney Mines with officials from the Children's Wish Foundation.

"Kaylee was sick for a long time. Now, we get to celebrate as a family, something that is good. No doctors, no transfusions, it's just fun, fun, fun."

MacIntyre said her daughter can't wait to meet Cinderella and see the Disney castle and watch the fireworks. "Kaylee absolutely loves fireworks. She gets to spend time with Cinderella all by herself. She has no idea about it and is going to absolutely bust."

Kaylee had aplastic anemia, a condition that occurs when your body stops producing enough new blood cells. "She had severe aplastic anemia. Because she has a rare genetic makeup she was getting transfusions every few days for a couple of years until we found a donor," said her mom. "It was an anonymous donor, a 22-year-old female and we are so grateful."

After two years families can apply to make contact with donors. Her voice breaking, MacIntrye said she sent off an email about two weeks ago. "She helped save my baby, I really want to find her. Kaylee wants to meet her too."

Kaylee will be accompanied on her trip to Florida by her parents Patricia and Barry MacIntyre and her cousin Ashley Inder.

"Kaylee really is an old soul and is so appreciative of this gift," said her mom. "She is counting down the days."

Since her daughter got sick, MacIntyre joined the local Children's Wish Foundation volunteer team and also helped raise money for Kaylee's trip. "I will continue to volunteer with Children's Wish for many years to come. They are a great group of people."

Established in 1984, Children's Wish is a national non-profit organization dedicated to fulfilling a wish for children diagnosed with life-threatening illnesses. A wish can range from a personal computer or a home-theatre system, to travel or a meeting with a celebrity. "It truly takes a community that helps us grant wishes," said Cathy Sutherland, the foundation's development co-ordinator in Cape Breton. "We have 18 wish referrals just in Cape Breton right now, with new referrals coming in all the time."

Sutherland added that in Cape Breton five wishes have been filled since January.

Kaylee MacIntyre, front, enjoyed a special celebration hosted by Scotiabank in Sydney Mines after she received her wish for a trip to Disney World in Florida. Back, from left, Fred Tilley, principal of the Nova Scotia Community College Marconi Campus and co-chair of Exile Island Children's Wish fundraiser; Children's Wish Foundation volunteers Ann Edwards, Melissa MacGillivary, Cathy Stockly, Lydia Matthews, Ellen Ley, Scotiabank branch manager Sydney Mines; and Kaylee's parents Patricia and Barry MacIntyre.

Access to Stem Cell Transplant Issues

Many patients with bone marrow failure diseases rely on stem cell transplants from related or unrelated donors. For some, it is their only chance at a cure. As a result, we are extremely concerned about a lack of access to bone marrow and stem cell transplants for adults in Ontario and the impact of this situation on our members.

While there have been issues for some time, the situation has worsened. For example, we understand that Princess Margaret Hospital in Toronto is no longer accepting patient referrals for stem cell transplants due to resource limitations.

Other adult transplant centres in the province are also reported to have resource constraints and longer than standard waiting times for transplants. Currently adult transplants are only done in Ottawa, Toronto, Hamilton and London. (The London program does not include unrelated transplants.)

Media have reported that the province is offering to send hundreds of patients with various diseases for treatment in the United States to deal with the situation; however, only a small number of patients have been able to do so.

A letter to Cancer Care Ontario (CCO) penned by a number of Ontario transplant doctors in May 2015 about what they called a "critical infrastructure shortage" was recently posted on the Toronto Star's website. We encourage members to read it.

The letter indicated that some patients are undergoing unnecessary chemotherapy while on the transplant waiting list, that some patients are dying while they wait and that in some cases doctors don't tell patients that a stem cell transplant is an option because resources are not available.

The issue has gained increased attention due, in large part, to the late Laura Hillier, a Burlington-Ontario teenager who had a stem cell match but died at age 18 earlier this year while on a waiting transplant list in Hamilton. While waiting for a transplant, she worked to raise awareness about the situation. Since her passing, her parents have taken up her fight to ensure that what happened to her does not happen to others.

Although media have reported that in response the Ministry now plans to fund a new transplant centre at Sunnybrook Health Sciences Centre in the future, we remain concerned. AAMAC has requested a meeting with Ontario's Minister of Health and Long-term Care to discuss our concerns and work towards a solution. As of this printing we have not received a response aside from a confirmation that our request was received.

We have however met with Cancer Care Ontario about this situation. Currently we understand that CCO does not report how many patients may have passed away while waiting for a stem cell transplant. We are advocating for solutions including transparent reporting so that we can confirm that any changes to the system are truly improving the situation for patients.

We will continue these efforts and ask any patients, family members or health care providers who are aware of past, present or future resource concerns to let us know.

We would also be interested in hearing from you if you are aware of or become aware of any similar resource concerns in other parts of Canada.

We anticipate needing help to advocate for solutions that will resolve this very serious situation and welcome volunteer assistance. Please watch our website for more details or contact our office.

Even if you do not need a stem cell transplant yourself, as a patient with bone marrow failure, a family member, a friend, or a healthcare provider, we hope that you will join us in pursuing both short and long term solutions.

We thank local media including the Toronto Star for its attention to this situation and encourage members across the country to read the newspaper's coverage. We also thank our MSAC Chair, Dr. Richard Wells who shared his concerns with the media.

Canadian PNH Network

Do you have PNH? Patients with PNH can access resources including a list of Canadian centres and physicians with expertise in the disease from the Canadian PNH Network. Visit pnhnetwork.ca for detailed contact information and other resources.

Experts listed on the website include:

- Dr. Brian Leber, Hamilton Health Sciences Centre, Chedoke-McMaster Site, Hamilton, Ontario
- Dr. Christopher Patriquin, McMaster University Medical Centre, Hamilton Health Sciences, Hamilton, Ontario
- Dr. Danièle Marceau, CHU de Quebec L'Hôtel-Dieu de Québec, Québec, Québec
- Dr. Ian Chin-Yee, London Health Sciences Centre, Victoria Hospital, London, Ontario
- Dr. Karen Valentine, Foothills Hospital, Calgary, Alberta
- Dr. Kuljit Grewal, Health Sciences Centre General Hospital
- Dr. H. Bliss, Murphy Cancer Centre, St. John's, Newfoundland
- Dr. Loree Larratt, University of Alberta Hospital, Edmonton, Alberta
- Dr. Richard Wells, Sunnybrook Health Sciences Centre, Toronto, Ontario
- Dr. Stephen Caplan, Jewish General Hospital, Montreal, Quebec
- Dr. Sue Robinson, QE II HSC−Victoria General Building, Halifax, Nova Scotia
- Dr. Thomas Kiss, Hôpital Maisonneuve-Rosemont, Montreal, Quebec
- Dr. Thomas Nevill, Vancouver General Hospital, Vancouver, BC
- Professor D. Robert Sutherland, University Health Network (Description: PNH Network Member providing expertise on the standard of care for PNH diagnostics. For patient referrals in Toronto, please contact Dr. Richard Wells.)

Mark Your Calendars

Please also check local provincial updates for regional support group meetings and education events.

For further information about events, call the office toll-free at 1 (888) 840-0039 or contact info@aamac.ca.

Ottawa Meetings
This year's meetings take place on the following Wednesdays from 6 to 8 p.m. at the Maplesoft Centre at the Ottawa Regional Cancer Foundation, 1500 Alta Vista Drive: June 8, September 14, October 12 and November 9. Come out and meet other patients and families dealing with the same bone marrow failure diseases as yours. Share stories, compare notes, learn how others are coping and see how they are responding to treatments.

Kitchener "Kitchen Table Talk"
An Ontario patient support group meeting is planned to share and learn from one another on Saturday, June 18, 2016 from 10:30 a.m. to 12:30 p.m. at the Wellspring Grand River, 16 Andrew Street, #2 in Kitchener.

Pediatric and Adolescent Aplastic Anemia and Marrow Failure Meeting, BC
Join us Saturday, August 27, 2016 from 8:30 a.m. to 3:30 p.m. at the BC Children's Hospital and Child and Family Research Institute Auditorium 4480 Oak Street, Vancouver, BC Watch for registration information and the agenda on our website or contact our office.

Toronto Support Group Meeting
Join us on Saturday, September 17, 2016 from 10:30 a.m. to 12:30 p.m. at the Bloor Street United Church, 300 Bloor Street West in Toronto, Ontario. Cindy Murray, a nurse practitioner at Princess Margaret Cancer Centre, will speak about

Managing Common Side Effects of MDS treatments.

Annual Patient Education Day
Check out the article about this year's event in Moncton, N.B. on Saturday, October 15, 2016.

London Support Group Meeting
Join us on Saturday, October 29, 2016 for a "Kitchen Table Talk," a patient support group meeting to share and learn from one another. It takes place from 10 a.m. to noon at the Wellspring Cancer Support Centre, 382 Waterloo Street in London, Ontario.

Okanagan, BC Meeting
A meeting is being planned for the Fall of 2016 in the Okanagan area. If you are interested in participating or assisting with this meeting please contact Janice Cook, bc@aamac.ca or 1 (888) 840-0039.

News of Note

Nicola's Triathlon for Kids
This year's Nicola's Kids Triathlon takes place Sunday, June 12, 2016. The event is held in memory of Nicola Anne Tullio. Nicola's future was cut short by marrow failure. Her family and friends at YellowBalloon Projects hope to make Nicola's legacy a future free of such diseases.

All donations from this event will go to the SickKids Foundation to fight marrow failure and myelodysplasia (MDS). The eligible age for this annual event is up to 16 years old and registration is required. Teens not racing are invited to volunteer. The event takes place at 225 Duncan Mills & Bayview Glen School from noon to 6 p.m. Registration is $70 Individual or $140 for a relay squad. For more information, visit www.nicolastri.com.

Robin Roberts Highlights MDS
ABC's Good Morning America anchor and MDS survivor Robin Roberts filmed a Public Service Announcement (PSA) for the Aplastic Anemia and MDS International Foundation (AAMDSIF) as part of its annual Awareness Week. To view the PSA, visit aamds.org.

Taylor Swift Parody Raises Bone Marrow Donation Awareness
A writer and filmmaker in Los Angeles recorded a parody of singer Taylor Swift's video Bad Blood to raise awareness about the need for bone marrow donors. Called "Good Blood," Kevin McDevitt made the video after he went through a bone marrow transplant for both aplastic anemia and PNH. The video includes clips of aplastic anemia patients around the world. In March, Kevin celebrated his first "birthday" post transplant. To view his video and a blog about his experiences since diagnosis, visit www.kevmcdev.com.

Reuben Kincaid Remembered
If you're old enough to remember the television series The Partridge Family, you'll recognize the name of character Reuben Kincaid who managed the Partridge Family band. The actor and comedian who played him, Dave Madden, passed away in 2014 after living five years with MDS. His widow, writer Sandra Madden, has released a revised and edited edition of the book *Reuben on Wry: The Memoirs of Dave Madden* which includes a final chapter about his MDS journey. Each purchase of the book, *Reuben Kincaid Remembered*, will support the MDS Foundation. It's available on Amazon.

Thanks to Generous Supporters!
A generous donation was presented to AAMAC on Saturday, March 19 with a matching donation provided by NA Engineering Associates Inc.

A surprise birthday party was held for Andy & Larry Walton. These twins celebrated their 50th birthday at BTown Sound in Burlington. Many friends and family attended and enjoyed the great music of 3 Hour Tour.

A special moment was had when friend Joe Laxton announced that on behalf of the birthday guests and in honor of their father, Mr. Herb Walton, $500 would be donated to the Aplastic Anemia & Myelodysplasia Association of Canada. Mr. Walton has AA.

100% of this generous donation will help fund support, programs and services for those with AA, MDS and PNH.

The birthday party presentation was accepted by Darlene Edmonds, AAMAC's new staff person for Southern Ontario. The matching donation from Nick Aroutzidis, President & CEO of NA Engineering Associates Inc. was accepted by Carol Fazari from our office.

Many thanks to Debbie and Joe Laxton, Larry and Andy Walton, and NA Engineering Associates Inc. We couldn't do what we do without your support!

Medicine Programs

The pharmaceutical company Novartis offers patient support programs relevant to some of our members. For more information about the programs, please contact the numbers listed below or speak to your physician.

Program services include reimbursement navigation, financial assistance, patient education and support, information on community resources and pharmacy services.

The Alliance™ program relates to the hematology drugs Exjade® and Jadenu™. For information call 1 (855) 489-4362. inReach™ relates to the drug Revolade®. For information about it, call 1 (888) 475-4255.

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