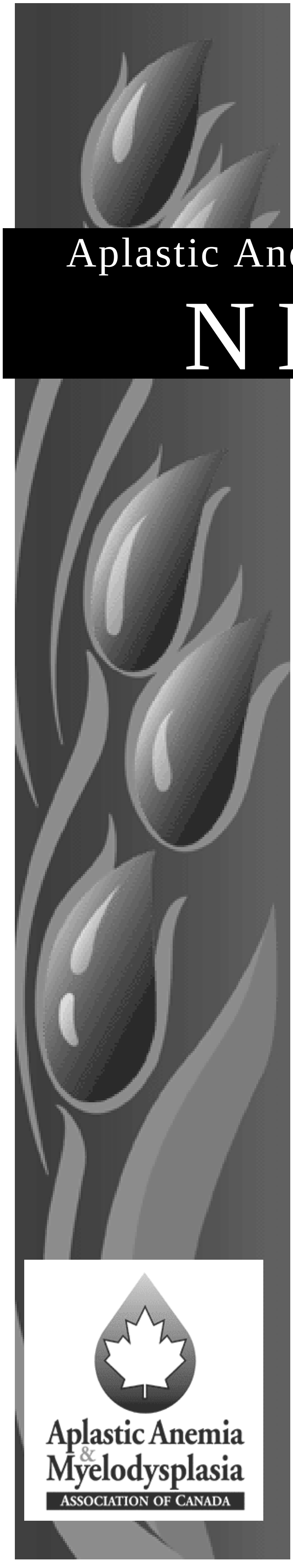

Education
Support
Research

Fall 2016

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

Message from the Chair

I hope everyone is enjoying a relaxing and fun-filled summer with family and friends. It's nice to have some downtime before we get back to our fall activities.

AAMAC will be kicking off the fall season with Patient Education Day in Moncton on Saturday, October 15. This is the first time we've held Education Day in the picture province and, after hosting education programs in Nova Scotia (Halifax) and Newfoundland and Labrador (St. John's), we are very excited to be coming to another Atlantic province, New Brunswick.

You will see from the attached agenda that we have excellent speakers scheduled to present on a variety of topics and I hope many of you will be able to join us. There is no fee to attend, but we ask that you pre-register. The registration form is included with this newsletter.

In addition to patient education sessions, there will also be a Lunch and Learn session for nurses. As always, we will be uploading selected presentations to our website after the event for those of you who are not able to join us. We will let you know about other upcoming educational opportunities across the country as we continue through the year.

While we are in Moncton, we will also hold our annual general meeting, so this message will be my last one as Chair of AAMAC, as my two-year term comes to an end. It has been a pleasure to chair AAMAC's board and I look forward to continuing to serve as your Past Chair and welcoming Ashley Oakes as our new Chair. She's going to do a wonderful job.

I would like to thank all of our board members, our Medical and Scientific Advisory Committee and our other volunteers who contribute so much to the success of AAMAC. And I would also like to thank our staff members for all their hard work, expertise, and dedication. They are the best!

Finally, I would like to take this opportunity to thank our sponsors and donors for their financial support. They make all the things we do possible.

I invite you to like us on Facebook, follow us on Twitter, and visit our website for more information on how you can become involved with AAMAC.

Enjoy the rest of this newsletter, and enjoy the rest of your summer!

All the best,

Jennifer Garvey
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 all from beautiful, hot BC. It is too hot today to be outside but I never want to complain about the sun. It makes me think of all the things that can be done when it's too hot, cold, rainy, windy…

It's so easy to find an excuse not to participate in things but that is exactly what people need to avoid when they are dealing with an illness that makes them fatigued, or necessitates avoiding crowds and activities that put them at risk for infection or injury. Bored, lonely people are more easily prone to depression, and depression can be so difficult to stop once it takes hold. It's also hard on a caregiver to watch this happen to someone they care about.

I'm a firm believer in the fact that a person's mood has a role to play in their general health and it's a well-known fact that mild exercise is one of the easiest and best treatments for depression. It is usually best not to overdo activity. Do it early in the day before fatigue is too great, and perhaps limit activities to every second or third day or whatever feels best.

Like most things it is individual, but if you are transfusion dependent, take advantage of the boost in your oxygen carrying red cells after a transfusion and plan your activity to follow that.

Enjoyment is the goal here, if you feel better you will enjoy the activity better.

Thinking about all the special activities that go on in the summer and the reasons why some are not good for an immune suppressed or anemic patient made me think of alternatives. For instance, if you enjoy the Farmer's Market, go when you are rested, early before it's too hot, take a hat or umbrella, and forgo the sampling that is often offered. Instead take your produce home, wash it well and then store it at the proper temperature until using. Don't eat things that are past their prime, and this might be the time to avoid homemade dressings or sauces and things that aren't sealed. If you are unsure consult the Government of Canada Food Safe Guidelines about things to avoid.

Food poisoning is nasty in someone healthy, and more serious in someone with a limited immune system. That's why you may be advised to avoid buffet dinners, or potluck dinners, unless everyone is aware that all foods you eat must be properly prepared and stored before serving.

You can still enjoy a picnic, just choose the food items carefully and use a cooler and ice to maintain a safe temperature. By the time you read this picnic season may be over but the food precautions need to be maintained.

If the weather is not to your liking for outside activities, now is the time to invite a friend over for a visit.

Sometimes people might seem to avoid you, but often if they hear you have a disease that makes it easy for you to catch an infection, they are afraid of making you sick, or are just unsure of what to do.

The best thing to do is tell them what you need – such as visits from healthy people, who don't have a sore throat, or the sniffles. Or ask them to do an errand on the way ov or bring some cookies or a game to play.

Whatever it was that drew you to each other in the first place is still a part of your friendship and just needs a bit of adjusting.

Instead of a golf or tennis date, have them over to watch a game on TV. Instead of going to the movies, make popcorn and watch something together in your home. You can still talk about books with the book club even if you haven't read it as fully as you did before. This might be the perfect time to ask a grandchild to help you set up your computer or tablet so you understand it better, and can use it more fully. You could ask them take down those dusty old photo albums and go through them together and discard all the ones you no longer need, then send them off to the library or home to scan the important ones and make albums with them. Remember the days when we saved every blurred photo of everything and everyone? I'll bet many of us have a few of those around that could be purged.

Another thing you can get someone to do is to bookmark your favourite websites including the AAMAC webpage and also the AAMDSIF page. There are lots of informative teaching webinars, archived education day sessions, as well as current trends in our bone marrow failure diseases that you can learn about here. This might be especially helpful if you have treatment decisions to make or understand more fully.

I finally must apologize to the Okanagan people as I haven't been able to find a speaker for a fall meeting so nothing is booked yet. After talking with one of you, we would like to try to get together for lunch, as a small group did a few years ago. I'll contact everyone in September and see if we can find a date and place that will work for everyone. If you are newly diagnosed and live in BC, please contact me at bc@aamac.ca so that I can include you in upcoming plans.

Take care everyone.

Atlantic Region Update

By Gwen Barry

Survivorship BBQ in St. John's Newfoundland
Local interests in the Newfoundland and Labrador stem cell transplant community are organizing their first-ever Stem Cell Transplant Survivorship BBQ by invitation for patients of that province who have had a stem cell transplant. I will be attending as a representative of AAMAC, and am pleased to do so. This event is being held August 28 and I will tell you about it in the next issue of the newsletter.

Halifax area support group
AA, MDS, and PNH patients and their support persons living in the greater Halifax area meet four or five times a year, sometimes with a guest speaker, and sometimes just socially to provide moral support to each other.

You are welcome to attend to compare notes, or just to be among others who have gone through similar experiences.

If you wish to be notified of upcoming meetings please contact me, AAMAC Coordinator, Atlantic Region at (902) 864-8872 or gwenb@eastlink.ca. Alternately, arrangements can be made for you to speak to another person with a similar diagnosis to your own.

Ontario Chapter Update

By Darlene Edmonds, Regional Support Liaison, Ontario

Over the summer I've been booking some exciting patient support group meetings for the South Western region. I hope we'll see many of you joining us at the upcoming meetings.

Please see the events section for upcoming dates. 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 or a 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.

Enjoy the rest of the summer and I look forward to meeting you at one of the upcoming patient support meetings. Please continue to watch the website for future webinars.

Annual Education Day in New Brunswick Nears

By Gwen Barry

This is a reminder that the Annual Patient Education Day will be held in Moncton, NB on Saturday, October 15, 2016 at the Delta Beausejour Conference Centre. The event is free for AA, MDS, and PNH patients, their support persons and healthcare providers.

There are a limited number of travel sponsorships available to a maximum of $500. If you require financial assistance to attend Education Day, please indicate this on the registration form. The purpose of the sponsorship is to help patients and families from outside of the Moncton area attend. We will let you know as soon as possible if your sponsorship is approved. An expense claim will be provided and must be accompanied by receipts.

If booking an overnight room at the Delta Beausejour, please mention AAMAC as a discount rate has been arranged for participants.

Further information and the Registration Form can be found elsewhere in this issue of ths newsletter.

This is an opportunity to learn more about these diseases and about treatments on the horizon. I have attended many of these Education Days over the years, and I learn something new every time I attend. Advances in treatment, and better understanding of these disorders is on-going, especially the genetic aspects of them.

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.

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

BC Research Highlighted

This article was originally published by the University of British Columbia in June and is reprinted with permission. Dr. Kirk Schultz is a member of AAMAC's Medical and Scientific Advisory Committee.

Dr. Schultz

A potential early warning sign of transplant rejection

Faculty of Medicine scientists have identified a protein that could be used to diagnose chronic graft-versus-host disease (cGvHD), a serious, long-term complication that affects some patients after a blood and bone marrow transplant.

cGvHD occurs when immune cells in donated blood and marrow cells recognize the recipient's cells as foreign and launch an immune attack against them. CGvHD can damage the skin, liver, lungs and digestive tract, leading to greater risk for cardiovascular disease, diabetes, obesity, and endocrine (hormone) abnormalities. Early diagnosis is key to preventing the life-long impact of cGvHD, but currently no such test exists.

"If we can diagnose it earlier and better, then treatments can be used to stop it before it becomes a chronic, disabling disease," says principal investigator Kirk Schultz, a Professor in the Department of Pediatrics and a scientist at BC Children's Hospital. "A child with leukemia can be cured with a blood and marrow transplant but then has to suffer a life-long disease, cGvHD, which causes a major decrease in their life expectancy and quality of life."

In the study, published in the journal *Blood*, researchers compared blood samples from two groups of adult patients, 170 who developed cGvHD and 180 who did not. They analyzed the samples to identify proteins in the blood that could be an early sign of the disease, finding elevated levels of the inflammatory protein CXCL10. This protein appears to impact a patient's normal immune cells, preventing the body from fighting cGvHD.

Over 1,500 children and adults receive a blood and marrow transplant each year in Canada, often because it's the only effective treatment for some forms of leukemia. CGvHD affects approximately 30 to 50 per cent of blood and bone marrow transplant recipients.

Although testing a transplant patient for this protein could provide the early diagnosis physicians urgently need, further study is necessary before a diagnostic test for cGvHD can be put into clinical use.

This research was made possible by support from BC Children's Hospital Foundation, Canadian Institutes of Health Research, CIHR/Wyeth Clinical Research Chair in Transplantation. The study was carried out through the Chronic GvHD Consortium, which is funded through the Rare Diseases Clinical Research Network (RDCRN), an initiative of the Office of Rare Diseases Research (ORDR), National Center for Advancing Translational Sciences (NCATS) and the National Cancer Institute.

Ontario Teen Meets German Donor

By Mandy Marciniak

This article originally appeared in the Kingston Heritage in May and is reprinted courtesy of the Kingston, Ontario newspaper.

In 2013, Kingston teen Mackenzie Curran was diagnosed with myelodysplastic syndrome (MDS), a bone marrow failure that can lead to leukemia. She needed a bone marrow transplant and luckily, in November of 2013, an anonymous donor was found.

"I was really lucky to find a match so quickly because the MDS was progressing much faster than it should have," she explained. "I was at the top of the list and normally it takes six months to a year to find a match, but they found one for me in three months." Curran had surgery soon after a donor was found and now, she is grateful to be healthy again.

While her donor was anonymous, Curran filled out paperwork to learn the identity of the person who saved her life; luckily her donor did too, but there was still a lot of waiting until they could contact each other.

"I had to wait two years to find out who my donor was," she said. "In North America you have to wait one year, but in Germany you have to wait two years. We knew that it wasn't someone from Canada or the U.S. after one year."

Mackenzie pictured with donor Alexander. Photo by: Miv Photography in Ottawa.

Curran's donor was Alexander Türk from Germany and after corresponding for a while, Curran's family decided to fly him to Canada. Türk arrived on May 18 in Ottawa to a crowd of welcoming Canadians, including an emotional Curran.

"I was very excited and I am really grateful to Mackenzie and her family for giving me the opportunity to come to meet her in person," said Türk.

"It was very emotional for both of us," added Curran.

The duo spent some time in Ottawa following Türk's arrival and even met Prime Minister Justin Trudeau, but Türk joked that meeting Mackenzie was still better.

"I liked meeting Mackenzie more than the prime minister," he said "I didn't know him before."

Curran and Türk have also been trying to raise awareness wherever they go and on May 27, they held a Canadian Blood Services stem cell event at Holy Cross Catholic Secondary School, Mackenzie's old school.

The event asked students to do cheekswabs and register to be part of the donor registry in Canada and worldwide in the hopes of making more matches. Curran was also encouraging more male donors to come out.

"Males statistically have a better patient outcome and patients tend to do better if they have a male donor in the age range of 17 to 35," she explained. "Males also typically have more cells to give and their cells tend to have less chance of rejection. We are also looking for ethnically diverse donors too."

Curran hopes that her story can inspire others and she hopes that by bringing Alexander to Canada she can also show people how easy it is to save a life. "Alex tells a story about not even needing pain medication the day after the surgery and I think people are really surprised to hear that. They think it is scary to be a donor and painful," she said. "Hopefully people will see our story and how easy it was for him and be inspired."

Tourism Ottawa and Ottawa Biplane Adventures organized a special flight for Mackenzie and Alexander during his visit.

For more information about how to become a donor visit www.blood.ca.

Editor's note: If you haven't seen it already, visit AAMAC's Facebook page to see video footage of Mackenzie and Alexander meeting for the first time. AAMAC wishes Mackenzie all the best as she heads off to university this fall to study nursing!

Saskatchewan Family Encourages Blood Donations

By Ashley Martin

This article originally appeard in the Regiona Leader-Post on July 29, 2016 and is reprinted with permission of the newspaper and the Honoway family.

Lincoln Honoway is a vibrant three-year-old. He's happy, loves playing with his cousins, and doesn't even mind the hospital.

"He's an awesome kid, he looks forward to those hospital visits, which I never can figure out," said his mom, Erica Honoway.

In February, her always-healthy little boy started looking pale, with dark circles under his eyes and mysterious bruises.

Doctors thought Lincoln might have leukemia. In March, he was diagnosed with aplastic anemia.

It's a rare disorder — about two in a million people have it — and in Lincoln's case, it could be fatal. "His bone marrow has shut down," said Honoway. "He doesn't produce basically any red cells, white cells or platelets on his own."

Blood transfusions are keeping him going for now, but he needs a bone marrow transplant to survive — it'll reset his system. He has an appointment scheduled for Aug. 22 at the Alberta Children's Hospital in Calgary, as long as his backup donor doesn't cancel as the primary donor did.

An anonymous donor could save little Lincoln's life. And that's why the Honoways — Erica, husband Ryan, and the rest of their family — want to help grow the OneMatch donor registry.

"The more people you have on these registries, the better chance you have of finding a match. It can be one in a million to try to find someone," said Honoway.

"There are only a few people in the world that seem to match each of us, so the more of us that we can get on the registry, the better our chances of finding bone marrow donors for the people who are in need."

Bone marrow donors have to fit the age range of 17 to 35. So when the Craven Country Jamboree rolled around, sister-in-law Haley Ryan worked with Canadian Blood Services to set up a donor registration booth; 100 people signed up.

"I call them angels," said Honoway. "These people that are willing to save someone else's life is pretty special. I always think of what it would feel like to get that phone call that you are the one chosen to save somebody's life. It would be amazing."

Since Lincoln got sick, Honoway has encouraged her friends and family to donate blood.

"You think it'll never be you who's going to need it and I would have said the same thing. I had four perfectly healthy kids a few months ago and would have never dreamt I'd be needing this," said Honoway.

"Someone else's blood and someone else's platelets saved his life. I can't help but want to do that for someone else."

Lincoln Honoway pictured with his mother Erica. Photo: Michael Bell, Regina Leader-Post.

To learn more about OneMatch, visit blood.ca

Blood Donor Criteria Update

Thousands more people may now be eligible to donate blood thanks to recent changes to a number of Canadian Blood Services' (CBS') deferral policies and donor restrictions. According to CBS, the changes are an important step being taken to broaden the pool of eligible donors in the country. This year alone, about 100,000 new blood donors are needed to support the national blood supply.

The following notable changes are now in effect across the country:

- The upper age limit for donating has been eliminated. Further, donors over the age of 71 no longer need to have their physician fill out an assessment form before donating blood.
- Donors who have a history of most cancers (such as breast cancer, thyroid cancer, and prostate cancer) will now be eligible to donate if they have been cancer free for five years. This change does not apply to those with a history of hematological cancers (such as lymphomas, leukemia or melanoma).
- Donors who have recently received most vaccines, such as a flu shot, will no longer need to wait two days before donating blood.
- Donors who were born in or lived in some African countries (Central African Republic, Chad, Congo, Equatorial Guinea, Gabon, Niger, and Nigeria) are now eligible to donate blood. HIV testing performed on blood donors can now detect HIV strains found in these countries.
- Geographic deferrals affecting Western Europe have been revised based on scientific evidence that indicates the risk of variant Creutzfeldt-Jakob Disease (vCJD), or mad cow disease, has decreased since January 2008. Donors who spent five years or more in Western Europe since 1980 are deferred from donating blood, but we are now including an end date of 2007. Donors who reached the five-year limit in Western Europe after 2007 will now be eligible to donate blood.

"Canadian Blood Services regularly reviews the criteria used to determine if someone is eligible to donate blood, including geographic and age restrictions based on new scientific information," says Dr. Mindy Goldman, medical director of donor and clinical services with Canadian Blood Services. "These restrictions are no longer necessary. We estimate that about 3,000 people who try to donate each year but cannot will now be eligible to donate due to these changes."

Canadian Blood Services hopes that these changes will contribute to bringing more donors to clinics, enabling more Canadians to save lives.

The complete policy changes are available at www.blood.ca/en/blood/recent-changes-donation-criteria.

Canadian Blood Services also recently announced that Health Canada has approved its request to reduce the blood donation waiting period for men who have sex with men from five years to one year. The change took effect on August 15. Héma-Québec, Québec's blood operator, made the change at the same time.

"This is an exciting, incremental step forward in updating our blood donation criteria based on the latest scientific evidence," said Dr. Graham Sher, chief executive officer, Canadian Blood Services about the MSM decision.

"Canadian Blood Services is dedicated to being as minimally restrictive as possible, while also maintaining the safety of the blood supply."

Canadian Blood Services and Héma-Québec both submitted applications to Health Canada to change the eligibility criteria near the end of March. This change was based on scientific evidence and supported by input from stakeholders.

Canadian Blood Services is exploring the possibility of moving toward behaviour-based screening. We are working with researchers, the LGBTQ community, patient groups and other stakeholders to determine how best to gather the scientific evidence required to determine future changes to the eligibility criteria.

AAMAC participates in the National Liaison Committee as a patient representative.

CBS has indicated that its first priority continues to be safety, as patients bear 100 per cent of the risk associated with changes to our eligibility criteria.

In February, in response to the recent global outbreak of the Zika virus, Canadian Blood Services indicatged that anyone who has travelled outside of Canada, the continental United States and Europe will now be temporarily ineligible to give blood for three weeks.

Donors who were turned away in the past due to the former restrictions but would like to return are invited to visit a clinic or call 1-888-2DONATE to book an appointment.

Canadian Blood Services is currently updating its digital systems and online bookings are temporarily unavailable for some of these donors. New donors who have never been screened before are invited to book an appointment online, call 1-888-2DONATE, or visit a clinic.

Canadians can visit blood.ca or download the GiveBlood app to discover multiple ways they can give life, assess their eligibility and to book an appointment.

To learn more, visit blood.ca.

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: 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.

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.

Kitchener Support Group Meeting
A patient support group meeting is an opportunity for sharing and learning from one another. Topic to be determined. Wednesday November 9, 2016 from 6:30 to 8:30 p.m. at Wellspring Grand River, 16 Andrew Street, #2 in Kitchener, Ontario. A light dinner will be served.

London Support Group Meeting
Join us Saturday, October 29, 2016 from 10 a.m. to noon at Wellspring Cancer Support Centre, 382 Waterloo Street in London, Ontario for Talking about Iron and Iron Overload with Dr. Cyrus Hsia MD, FRCPC, HBSc.

Hamilton Support Group Meeting
Join us Saturday, November 5, 2016 from 10:30 a.m. to 12:30 p.m. at Wellwood, 501 Sanatorium Road in Hamilton, Ontario. Topic to be determined. Please mark this date in your calendar.

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

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

News of Note

Marrowforums Celebrates a Decade of Support
Congratulations to Ruth and Neil Cuadra who began a private online discussion forum for AA, MDS and PNH patients 10 years ago. "Marrowforums enabled them to remain anonymous and have discussions in a commercial-free environment that was both safe and free," said Kathleen Weis, CEO of the AAMDS International Foundation, in an email to members. "The idea may have been inspired by AAMDSIF, but it was shaped by their own experiences.

"In 1996, Ruth was told that she had aplastic anemia. When treatment didn't normalize her blood counts, it was discovered that she actually had MDS. A successful bone marrow transplant from an unrelated donor saved her life.

"The Cuadras had learned the hard way how crucial it is for patients to build community, and with that in mind, www.Marrowforums.org was born. The site averages nearly 100,000 page views a month."

AAMAC would like to extend our

sincere thanks to Ruth and her husband Neil for continuing to volunteer in support of other patients and families through Marrowforums and an earlier listserv.

If you haven't checked it out yet, visit www.Marrowforums.org.

A First for Young MDS Survivor

Congratulations to Jayden Roll who became the first child honoured at the annual Israel Cancer Research Fund Montreal Gala in June. The seven-year-old received a bone marrow transplant for MDS.

The event was headlined by singer Robin Thicke with proceeds funding an Israeli researcher in pediatric oncology at the Montreal Children's hospital.

Founded in 1975, ICRF is a non-profit organization consisting of physicians, scientists and volunteers who are dedicated to supporting innovative cancer research in Israel and locally in Montreal at the McGill Translational Centre in association with the Jewish General Hospital.

Charity Launches Fashionable Hospital Gowns for Teens

"Teens are unique. Why should their hospital gowns be any different?" That's a question asked by the Starlight Children's Foundation in partnership with RETHINK as part of a new initiative called WARD + ROBES.

It involves designers creating unique hospital gowns for teenagers. It was launched recently at the Children's Hospital of Eastern Ontario.

If you're a teen or know a teen who might be interested, visit starlightcanada.org.

Actress Recognized by 2016 Queen's Birthday Honours

Speaking of Starlight, British actress Emma Samms was among those recognized for their achievements in the health and social care sector in the 2016 Queen's Birthday Honours awards. Samms co-founded the Starlight Children's Foundation in 1982 to support seriously ill and terminally ill children as a tribute to her brother. He lost his battle with aplastic anemia at age 8. Today, the charity operates in countries including Canada.

Professionally, Samms is perhaps best known for her role as Holly Sutton in the soap opera General Hospital. She has also appeared on Dynasty.

Free online courses available

AAMDS International Foundation offers online courses – with one type for patients and families and another designed for health professionals.

Its Online Academy includes dozens of classes for patients and family including basic disease information, treatment options and wellness topics such as nutrition.

Please just keep in mind that treatment options may and some disease-related measurements differ between Canada and the United States. As always, please also discuss any information with your health care team before making changes because everyone's situation is different.

Webcasts and online learning modules are also available for physicians and some are accredited for continuing medical education requirements.

Visit aamds.org to view the courses and other educational resources including many in different languages.

Did you know?

The play Matilda the Musical which closes its Toronto run at the Princess of Wales Theatre on September 4 has an MDS connection. The play is based on the books of author Roald Dahl who passed away in 1990 after a battle with MDS.

Dahl is best-known for his classic children's books which also include Charlie and the Chocolate Factory, James and the Giant Peach, and Fantastic Mr. Fox.

This September 13 marks what would have been Dahl's 100th birthday. The day is celebrated annually around the world as Roald Dahl Day.

Electronic Newsletter

Did you know that you can receive this newsletter directly in your email box? Contact the office if you'd like to switch from a paper copy to an electronic one. Doing so will also help AAMAC save printing and postage costs, freeing up these funds for its support of patient education and research.

Congratulations Grandma!

AAMAC's Executive Director Cindy Anthony recently became a grandmother for the first time with the arrival of grandson Bowen. We wish the best to Cindy and her family – especially this little guy.

Share Your Milestone

Do you have a special occasion to celebrate? We're always on the lookout for patient celebrations to share in the newsletter! If you have a bone marrow transplant anniversary, a graduation, birth of a child or some other special occasion to celebrate, let us know and we'll share it with other patients and their families.