

# Aplastic Anemia & Myelodysplasia Association of Canada NEWSLETTER

## Chairperson's Message

They say good things come to those who wait. That must be the case with this beautiful summer weather. I hope you are all enjoying this season to the max. I can't help but recall that it was ten years ago this week (as I write this) that I entered the hospital for my bone marrow transplant. Hard to believe how fast time flies.

In my last message I mentioned that I would update you on our Nurses Education Program pilot project. I am happy to report that the first two Lunch and Learn sessions on MDS have now taken place with great success. The first one was held on June 22<sup>nd</sup> at the Kaye Edmonton Clinic with speaker Nicole Crisp, Nurse Practitioner at the University of Alberta Hospital. The second session was held on July 29<sup>th</sup> at the Sault Area Hospital with speaker Cindy Sheaves, Primary Care Nurse in the Algoma District Cancer Program. A big thank you to the dedicated individuals involved in organizing these events. Your contributions are very much appreciated. The feedback from the nurses was excellent, and we look forward to presenting more of these sessions, including one in conjunction with our Atlantic Regional Patient Education Day in St. John's on September 27<sup>th</sup>. As of this writing, there are 16 RNs registered for this session, and if you are in Newfoundland and know of any nurses who may be interested in learning more about MDS, please spread the word. If you are a nurse who is interested in attending this session (there is no charge to attend and lunch is provided), please contact us to register.

It is also time to make your travel plans for this fall's patient education days (if you haven't already). There is no fee to attend these events either but please contact us to pre-register:

- Atlantic Regional Patient Education Day: St. John's, September 26<sup>th</sup>
- British Columbia Patient Education Day: Vancouver, September 26<sup>th</sup>
- National Patient Education Day: Toronto, October 17<sup>th</sup>
- NRBDO Patient Education Day: Calgary, October 17<sup>th</sup>

This is also the time of year that your AAMAC directors budget for the upcoming fiscal year and thoughtfully consider the research grant requests we've received. I am happy to say that there is some great research being conducted related to bone marrow failure currently and we are excited about the progress that is being made.

And finally, on behalf of the board, I would like to welcome our new Patient Support Liaison for Southern Ontario, Darlene Edmonds. We look forward to Darlene's assistance and support with patient meetings in Ontario over the coming year.

Enjoy the rest of the summer,  
Jennifer Garvey  
AAMAC Chair

The Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) provides information about aplastic anemia (AA), myelodysplasia (also 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*

I hope all of you have tolerated the seriously hot summer, can't remember what green grass looks like. It will be a nice change to have rain without people grumbling about it!

The BC Group will be hosting an educational meeting on Sept 26 in Surrey. Details follow later in this newsletter. Our speakers should be able to provide information both about the diseases and about living with them. As we want support to be a big part of this day, we are planning a first: a patient panel where people can hear first hand what a diagnosis and treatment have meant to others and how they have learned to manage. The meeting is being held in Surrey to try and make it a bit easier for people from the Fraser Valley (FV) to attend. We also have something to discuss that seriously impacts some FV patients.

At the present time a patient from the FV might have to bypass their local hospital and their regional hospital and travel all the way into Vancouver to receive Vidaza® treatments. This involves a short treatment, 7 days in a row, a three week time off and then a repeat of the cycle. This continues for a minimum of 4-6 months and perhaps longer. We know of some patients who refuse this treatment due to the travel and/or expense and difficulties of temporarily relocating. We are hoping to find a way to help change the situation. In other parts of BC patients receive this treatment in their local or regional hospital, but in the Fraser Valley they must travel. We hope that some of the patients affected by this will share their stories.

If you or a family member have been offered Vidaza® and are affected by this, please contact us even if you are unable to attend the meeting. bc@aamac.ca or (604) 826-7222.

As always, please think about taking an AAMAC brochure in to your doctor or nurse. It is one of the best ways for new patients to find out about us.

*Janice Cook, BC Group Co-ordinator*

*Pamela Wishart, Assistant BC Group Co-ordinator*

# Atlantic Update

By Gwen Barry

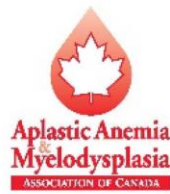
Atlantic Region will have a busy autumn. Two sessions have been organized on a variety of topics related to death and dying – each session will have guest speakers. The first session will be on Friday, September 11, 2015, from 1:30pm to 3:30pm, at the new Halifax Public Library on Spring Garden Road. It will be on the 2<sup>nd</sup> floor in the BMO room. The guest speaker will be Gradie Patrick from the QE II Health Sciences Centre, Halifax. She will be speaking on the subject of Living Wills and Powers of Attorney. AA, MDS and PNH patients and their families are welcome to attend. Please confirm your attendance in advance with Linda O'Brien at [linda74@eastlink.ca](mailto:linda74@eastlink.ca) or call 902-863-2959. This is a great opportunity to experience the amazing new Halifax Public Library. Later in the fall, a second session will be announced on another aspect of death and dying.

On Saturday, September 26, 2015, Atlantic Region will be hosting a Patient Education Day in St. John's, Newfoundland and Labrador (NL) for AA/MDS/PNH patients and their support person(s). There will be presentations on: An Overview of MDS, AA, and PNH; Iron Overload; the psycho-social aspects of these blood cancers; and Stem Cell Transplants. There will also be several testimonials.

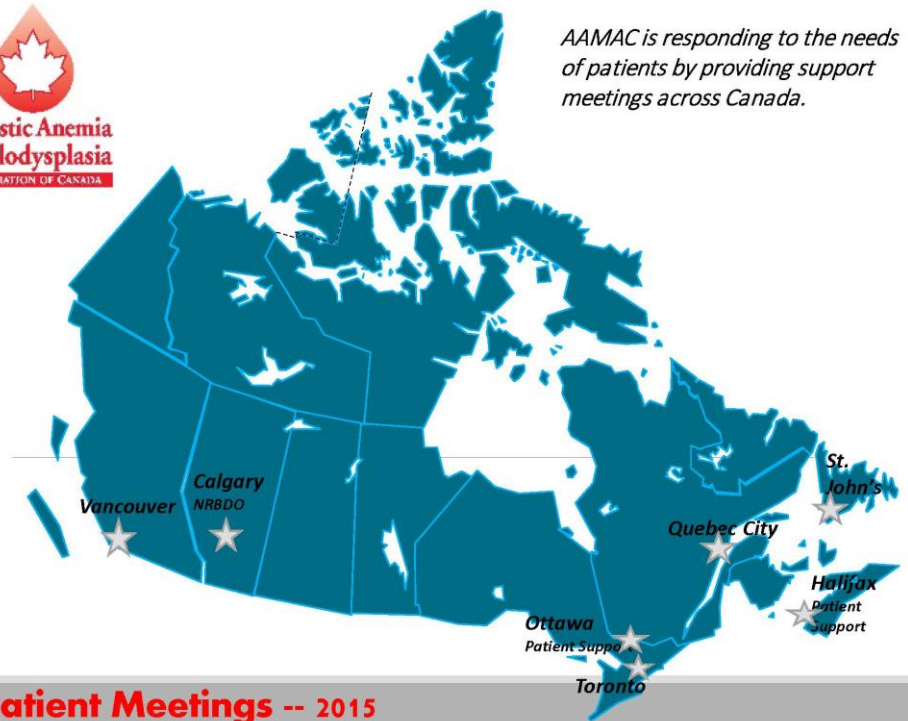
Travel bursaries are available for patients from NL (including one support person per patient).

Patients and their support person(s) from the four Atlantic Provinces are welcome to register, but only those from NL are eligible to apply for travel bursaries. The application form can be found in this issue of the AAMAC Newsletter. We look forward to seeing you there.

## Patient Education Days & Support Groups Across Canada



*AAMAC is responding to the needs of patients by providing support meetings across Canada.*



**Patient Meetings -- 2015**

AAMAC has organized four patient education sessions that span from coast to coast. Please visit [www.aamac.ca](http://www.aamac.ca) for full details.

Join the Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) for an opportunity to learn more about Aplastic Anemia (AA), Myelodysplasia (MDS) & Paroxysmal Nocturnal Hemoglobinuria (PNH).

The day will also include:

- A chance to meet others with bone marrow failure diseases;
- Informal discussions; and,
- Lunch is provided free of charge.

## Join AAMAC at the Patient Education Day closest to you:



### Toronto Patient Education Day

**WHEN:** Saturday, October 17, 2015  
8:00am to 4:30pm

**WHERE:** Novotel Toronto – North York  
3 Park Home Avenue, Toronto  
(Near 401 & Sheppard Avenue)

#### Experts conducting lectures:

\* Dr. Richard Wells      \* Daniela Fiorini, RD  
\* Dr. Karen Yee        \* Tammy de Gekker, Nurse Practitioner  
\* Cindy Murray, RN, NP

To register or for more information visit

**AAMAC.CA**

OR

Email/Call: [info@aamac.ca](mailto:info@aamac.ca) or 1-888-840-0039

*Special hotel rates available. Must be booked before  
September 18th. Call Novotel at (416) 733-2929.*



### BC Patient Education Day

**WHEN:** Saturday, September 26, 2015  
9:30am to 2:30pm

**WHERE:** The Sheraton Vancouver Guildford Hotel  
15269 104 Avenue, Surrey, BC  
Room: Green Timbers 1

#### Experts conducting lectures:

\* Dr. Armit Kahlon      \* Michelle Forman, RN, CON(C)

*Includes panel discussion of patients discussing their experiences,  
successes & living with bone marrow failure.*

To register or for more information visit

**AAMAC.CA**

OR

Email/Call: [info@aamac.ca](mailto:info@aamac.ca) or 1-888-840-0039



### Atlantic Region Patient Education Day

**WHEN:** Saturday, September 26, 2015  
8am to 3pm

**WHERE:** Delta St. John's Hotel & Conference Centre  
120 New Gower Street  
St. John's, Newfoundland

#### Experts conducting lectures:

\* Dr. Eve St-Hilaire      \* Dr. Colleen Walsh  
\* Dr. Richard Wells      \* Dr. Jacqueline Costello  
\* Dr. David Jones

To register or for more information visit

**AAMAC.CA**

OR

Email/Call: [info@aamac.ca](mailto:info@aamac.ca) or 1-888-840-0039

*Special hotel rates available. Call Delta St. John's at  
1-866-400-7450*



### Quebec City Patient Education Day

**Fall 2015**

More details to come...

Information will be posted on:  
**[www.aamac.ca](http://www.aamac.ca)**  
when available.

To register or for more information visit

**AAMAC.CA**

OR

Email/Call: [info@aamac.ca](mailto:info@aamac.ca) or 1-888-840-0039



# Nurses' Education Program

By Janice Cook

At AAMAC, we know how important nurses are to patients and their families as they undergo diagnosis and treatment for AA, MDS and PNH. Nurses provide expertise and clarity when a busy hematologist, oncologist or family doctor might not have time, make sense of hard to understand terms and health concerns that medical specialists discuss in a visit and reinforce specifics which you may have trouble remembering. Nurses care about your physical and emotional well-being, and are able to make suggestions that may improve the quality of your daily life.

Historically, nurses have been invited to attend AAMAC patient education days. Many have attended over the years. Recently they have requested more specific information to better support patients. This was the birth of the AAMAC Nurses' Education Program.

On June 22, the first pilot of the Nurses' Lunch and Learn Seminar, MDS, was presented by Nicole Crisp, RN, NP, of the University of Alberta Hospital, in Edmonton. The feedback received has encouraged us in our belief that this type of seminar is worth holding at other facilities. The second pilot was on July 29 at the Sault Area Hospital in Sault Ste Marie, Ontario, presented by Cindy Sheaves, RN, ONC.

The presentation that was created can be taught by other nurses to fit the audience, whether they be hematology nurses at a transplant facility, nurses who work at an outpatient clinic who infuse blood products or medications, medical or palliative care nurses who care for inpatients or nurses who work at a cancer center where many MDS patients are followed.

Our next challenge will be identifying nurse educators and specialists in other provinces and enlisting them to do presentations in their facilities.

If you know of nurses in your hospital or clinic who may be interested please have them contact AAMAC.

*Thanks to our sponsors and fundraisers who make AAMAC Education possible.*

## Meet Oliver Ferguson & Family



Melitta, Oliver, Scarlett & Rob Ferguson

*AAMAC first learned about Oliver's story in June of this year. We were honoured to provide gift items to assist in raising funds for Oliver and his family at the Canadian Tire Motorsport Park, IMSA Grand Prix race.*

*Included in this newsletter is a heartfelt story written by Oliver's father, Rob, detailing Oliver's journey with AA:*

When looking at Oliver, we see a beautiful, strong, vivacious five year old boy. What we don't see is that he has severe Aplastic Anemia. This was caused by short telomeres and suspected dyskeratosis congenita -- a genetic

disorder which mutates certain genes and causes a multitude of serious illnesses.

We *were* a very happy family. My wife Melitta, Oliver, Scarlett (our daughter), and myself. Like me, Oliver is a huge auto-racing fan and car enthusiast. For fun, our family went to NASCAR and sports car races. Oliver loved his pedal go-kart and would take it everywhere. Life was good.

In October 2014, my wife noticed Oliver was yellow. With a trip to the doctor we discovered his liver enzymes were >1000. Yikes! This was way too high as the normal level is no more than 40. Within a day, Oliver had undergone additional testing and his levels were getting higher. An ultrasound indicated two kidney stones and his liver enzymes now over 3000. He was admitted to Sick Kids Hospital immediately. This was the beginning of our horrifying journey.

After about 10 days, a biopsy was conducted when Oliver's enzyme levels hit 5100. The consensus was Autoimmune Hepatitis with a treatment of high-dose prednisone. We started the nasty drug. Thankfully, it worked. Oliver's enzymes started dropping almost immediately and we were sent home two days later. Unfortunately, Oliver suffered through every prednisone side effect. He had unbearable migraines, severe constant stomach pain, and debilitating back pain. He gained 18 pounds on his 49 pound frame and generally felt terrible!

During his five months on prednisone, we regularly went to the hospital for bloodwork. In December, they noticed a deficiency of Immunoglobulin G

and sent us to Immunology. They chalked it up to prednisone but after a couple months noticed his platelets and neutrophils were low and trending down. Oliver finished prednisone mid-March and had a bone marrow biopsy mid-April. We discovered, he was in complete bone marrow failure. Telomere tests revealed that he has short telomeres, and likely Dyskeratosis Congenita (DC) -- which is one of the rarest and worst possible diagnoses there could be. DC causes Aplastic Anemia (AA).

Oliver has toughed out 14 platelet transfusions, and 4 hemoglobin transfusions. His sister, Scarlett, now just over two years old, is a perfect 10/10 marrow match, however she may also carry DC as well. Her telomere tests showed some of her cell lines are low and both their DNA has been sent to University of Chicago for extensive genetic evaluation. Now we wait.

One of the worst parts about all of this, is that AA is so rare and no one knows what it is. It's an invisible disease that doesn't have the big lure of Cancer. Doctors are perplexed and people in general have never heard of AA. So, some people compare it to the time their kid had the flu. AA is certainly not the flu!

In the meantime, our lives have been turned upside down. Oliver was removed from school when we discovered he basically has no immune system. My wife can barely run her dog-grooming business, because of the constant hospital appointments. I got laid off 3 weeks before Oliver's initial hepatitis onset, and have not worked since. Not only because of all the appointments, but how do you work when the only thing on your mind is how to save your son's life?

Oliver has been unbelievably resilient. Faced with all kinds of pains and generally feeling worse than anyone can imagine, he almost always has a smile. And his smile lights up a room, if not a crowd of 60,000! Just this past month, Oliver was invited by Ron Fellows, a legendary racecar driver and owner of Canadian Tire Motorsport Park to be the Grand Marshal at its biggest event, the IMSA Grand Prix race. Oliver got a couple laps on track with Ron in a 2015 Corvette racecar and he gave an earth-shattering "Drivers, Start Your Engines!" command that people will talk about for years!



*Oliver at IMSA  
Grand Prix Race*

## Welcome Darlene!

Please help us welcome, Darlene Edmonds to the AAMAC team! Darlene has accepted a one year contract position as Regional Support Group Liaison Coordinator, Ontario.

Darlene has spent the last 20 years working with community partnership and local student nutrition programs across Ontario. She has worked closely with staff and volunteers, assisting with planning, and implementing workshops, training events and fundraisers.

Prior to the community work, Darlene was a program planner for the Senior Activation Maintenance Program in Hamilton.

In her spare time she teaches yoga and spends quality time with her three granddaughters.



*Darlene Edmonds*

We try to keep his life as normal as possible. Unfortunately Oliver cannot play in a park or indoor playground. Scarlett tries to play with him, but sometimes he just doesn't feel up to it. He gives her a hug, tells her he loves her, but just can't play right now.

It has been a frustrating journey, and we have found solace in support groups, as well as meeting and talking with other parents in similar situations.

We aren't sure where we are headed now, as we are still waiting for news on Scarlett's DNA. If she can, she will donate and hopefully, we will have TWO hero children to have the privilege of raising. This diagnosis has devastated our family, but it's also taught us to live day-by-day, and enjoy every moment we have together.

We have started a Facebook page called "Olliestrong" so people can meet our incredible little boy virtually, and raise awareness about AA and Dyskeratosis Congenita. Please feel free to like Ollie's Facebook page and get regular updates:  
<https://www.facebook.com/4Olliestrong?fref=ts>



# Join us in Calgary!

By Silvia Marchesin

The Network of Rare Blood Disorder Organizations (NRBDO) – Alberta is hosting an educational day on **Saturday, October 17, 2015** at the University of Calgary campus. The conference is intended for patients, family members and health professionals dealing with rare diseases such as aplastic anemia, MDS, and PNH.

Confirmed speakers include:

- **David Page**  
National Executive  
Director, Canadian  
Hemophilia Society
- **Dr. Dawn Goodyear**  
Co-Clinic  
Director, Southern Alberta  
Rare Blood and Bleeding  
Disorders Comprehensive  
Care Program - Adult  
Division
- **Dr. Nancy Marlett  
and Dr. Svetlana  
Shklarov**  
PACER Program (Patient  
and Community  
Engagement Research)  
University of Calgary

This **free** event will include an afternoon break-out session with presentations about bone marrow failure.

Our speaker during the afternoon will be:

- **Dr. Michelle Geddes**  
Clinical Assistant Professor, Dept of Medicine, University of  
Calgary

This is a unique opportunity to learn from local experts and to meet other patients with similar disorders. We hope to have a number of travel sponsorships available to out of town delegates who may need financial assistance with travel expenses to attend.

Registration will be open on September 1<sup>st</sup>, 2015, at:

[www.nrbdo.ca/alberta.html](http://www.nrbdo.ca/alberta.html)

SAVE THE DATE

The Network of Rare Blood Disorder Organizations - Alberta Presents

Getting Your Health in Working Order  
With Comprehensive Care



Rare Blood Disorders  
Education Day  
October 17, 2015  
8:00am - 4:30pm  
Calgary, AB

Porphyria  
Thalassemia  
Sickle Cell Disease  
Immunodeficiencies  
Hereditary Angioedema (HAE)  
Bone Marrow Failure (Aplastic Anemia, MDS, PNH)  
Hereditary Hemorrhagic Telangiectasia (HHT)  
Hemophilia and Inherited Bleeding Disorders

For more information visit  
[www.nrbdo.ca/regional-affiliates/alberta](http://www.nrbdo.ca/regional-affiliates/alberta)





# Transplantation Update



H. Joachim Deeg, MD, Professor of Medicine  
University of Washington and Fred Hutchinson  
Cancer Research Center

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AA&MDSIF recently spoke with Dr. Joachim Deeg of the Fred Hutchinson Cancer Center, about updates and changes in stem cell transplantation over the two years since his last interview with AA&MDSIF.

## Interview:

### Pre-transplant Conditioning

In my view, the major progress has been in reducing unacceptable toxicity from the regimens used to prepare patients for stem cell transplants regardless of who the donor is or the source of [stem cells](#) used. There has been a focus on the low or reduced intensity conditioning regimens. They are beneficial, but are also linked to higher relapse rates for [MDS](#).

With [aplastic anemia](#) patients, the effort always has been to have low-intensity regimens.

Unpublished data of the recently completed 03-01 study of the BMT/CDN, the results were quite remarkable. Using 97 aplastic anemia patients who received transplants from unrelated donors after having failed immunosuppressive therapy, this study was to answer the question is it possible to reduce or even completely avoid cyclophosphamide (Cytosan®) by instead using fludarabine, combining with ATG and low dose body radiation as the conditioning regimen, thereby reducing toxicity.

The results showed that this can work, but we can't completely omit cyclophosphamide because there was failure of [engraftment](#) when this drug was not used. However, smaller doses (50 or 100 mg per kg) of cyclophosphamide were shown to be useful when used with fludarabine, anti-thymocyte globulin (ATG), and low dose total body irradiation (TBI) resulting in a survival rate in excess of 90 percent. So clearly there's progress in this area.

As far as stem cell transplantation in MDS, the best results are with a regimen using treosulfan rather than busulfan in combination with fludarabine and with or without low dose TBI. We recently published data suggesting this regimen may be beneficial even for patients who have what we consider complex, high-risk [cytogenetics](#) ([monosomy 7](#) and others) which was the major cause of failure due to relapse in earlier studies.

The most recent data suggested that with treosulfan, higher-risk patients have an increased survival (in remission) probability of 65-70%, which if sustained, would be tremendous. We're currently doing some genetic studies in that context.

In patients with aplastic anemia, there are studies underway on a 3-Y randomization, now pruned down to 2, including using sirolimus, tacrolimus, and MMF as [GVHD](#) prophylaxis, although there are no results yet to show it reduces GVHD in related or unrelated donors.

[PNH](#) with prominent [hemolysis](#) is treated effectively, in most patients, with eculizumab Soliris and additional therapies are under investigation. However, for unresponsive patients, and patients who develop marrow failure or experience leukemic transformation, hematopoietic cell transplantation may offer curative therapy. Results are superior in patients transplanted for marrow failure, with survival rates similar to those observed in patients with aplastic anemia. Results are inferior in patients with severe hemolysis or thrombotic complications. Outcome tends to be better with [HLA](#)-matched related donors than with unrelated donors.

## Sources of Stem Cells

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Our view is that patients with non-malignant disease such as aplastic anemia, should receive stem cells from [bone marrow](#) rather than mobilized stem cells that are harvested from peripheral blood, because the incidence of GVHD is higher with peripheral blood.

In patients with clonal malignant disease like MDS, we typically use mobilized stem cells from peripheral blood with good success. I should emphasize that a randomized study using bone marrow vs. mobilized stem cells from unrelated donors really showed a 10 to 15% higher incidence of GVHD and no difference in survival. Since chronic GVHD is really an issue, the transplant community is trying to reassess who exactly should get stem cells from bone marrow and who should get them from peripheral blood.

At Hutchinson, we're looking at cord blood cells from [HLA](#) haploidentical donors only if we can't find an HLA matched related or unrelated donor. There are now studies on the relative benefit of HLA haploid identical versus cord blood and there are retrospective analyses that have already been presented comparing cord blood to matched unrelated donors and there may or not be significant differences. It has not been compared yet in a prospective fashion.

## Age Ceiling for Stem Cell Transplantation

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The maximum age for stem cell transplantation has been raised, but there's a note of caution here. As we treat older individuals, we are often dealing with other medical comorbid conditions that can interfere with the success of transplantation. Some published data suggest that age is not a factor, but this data on older patients in their late 60s or 70s is based on a selected population of patients – selected on the absence of comorbid conditions. So this can't be presumed to be the case with the general population in that age group.

I will add that even patients who are 70 may be doing well with an allogeneic transplant but if they develop problems, like GVHD and they are then treated with steroids, the post-transplant scenario may become more difficult. This is because older patients do not tolerate steroids with all its side effects as well as younger patients would. More study on assessing who in the older patient group is truly suited for stem cell transplantation is needed.

## Graft-Versus-Host Disease

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GVHD is still an issue, but can be less severe with lower intensity regimens. A new study is under design that uses [thymoglobulin](#) early in the pre-transplant conditioning, as early as nine days, and suggests that this may further enhance results. This is even when cord blood is the stem cell source or when HLA haploid (half matched) donor cells are used. Most of us agree that GVHD is still a major issue for those who have nonmalignant diseases where we do not expect any potential benefit from the graft versus host reaction, particularly in its chronic form. Whether additional, or early use of thymoglobulin is beneficial—we'll have to wait and see.

## Transplantation success rates

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It's not new data, but it's important -- we can see that results with unrelated donors are approaching or even equal to those with matched siblings for many of these indications.

In some indications, especially the reduced intensity regimen, from AML results with matched donors are somewhat higher/better than matched related presumably because of the graft vs. leukemia link. A CIBMTR study showed there was no significant advantage.

Originally published on 05/12/2015 - 12:40pm. Last updated on Thu, 05/14/2015 - 2:42pm

## Resources

At AAMAC, we're here to help. Please call or email the head office if you're in need of information or support. An information package can be mailed to you, or you can be connected with a peer to receive individualized support.

Reach us at: 1-888-840-0039 or [info@aamac.ca](mailto:info@aamac.ca).

**MDS information** is now available in many languages at [www.mds-foundation.org](http://www.mds-foundation.org). *The top right hand of the home page allows you to select a language. Once selected, the website is converted to the selected language.*

**100 Questions & Answers about Myelodysplastic Syndromes**, Second Edition is available for order. *These booklets are free and can be ordered from:* [jbutchko@mds-foundation.org](mailto:jbutchko@mds-foundation.org) or call 1-609-298-1035.

**Supporting Students with Bone Marrow Failure Diseases**, *A Guide for Parents & School Personnel* is a booklet that is available as a download at: <http://www.aamds.org/sites/default/files/SupportingStudentsGuide.pdf>

## Call for Directors & Volunteers

Have you ever considered volunteering as an AAMAC Board member or know someone you think might be interested?

Consider nominating yourself or someone else. AAMAC is currently in need of individuals with experience in finance, law and/or technology as well as those in the Prairie provinces, NB, PEI and NL. If you're interested, recommendations must be made to the committee at least 21 days before the annual general meeting in October. Contact [info@aamac.ca](mailto:info@aamac.ca) for more information.

We also welcome volunteers to assist with office duties or those who have personal experience with a specific bone marrow failure disease such as PNH, AA or MDS to take part in the Peer Support group. Please refer to [www.aamac.ca](http://www.aamac.ca) and complete the volunteer form found on the "Home" page and email the completed form to [info@aamac.ca](mailto:info@aamac.ca).