

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

President's Message

When I tell newly diagnosed patients about our charity, they're often surprised to discover that the vast majority of our efforts are carried out by volunteers and that most donations come from individuals. A small but dedicated group of Canadians from all walks of life – many patients themselves – make it possible for us to fund research projects, provide patient support, deliver educational programs like the upcoming Education Day this October, promote blood and stem cell donation and advocate for access to new treatment options.

With a focus on rare or uncommon diseases like aplastic anemia, myelodysplastic syndrome (MDS) and paroxysmal nocturnal hemoglobinuria (PNH), our volunteer and financial resources are somewhat limited as a result of the small community that forms the basis for our organization. One way we make the most of those resources is to collaborate with others who share common goals.

In this issue you will see terrific examples of that collaboration at work – from two research grants being offered by AAMAC and the Canadian Institutes of Health Research, support groups held in donated hospital and Canadian Blood Services spaces and increased access to eculizumab (Soliris®) and azacitidine (Vidaza®) through provincial advocacy efforts. As we pass the halfway point in the year I look forward to further collaboration with these and other groups on exciting projects including the new *Life Beyond Limits* initiative described in this newsletter.

With collaboration comes a great deal of coordination and so I was extremely pleased that the Board of Directors approved a new part-time Executive Director position to help the organization meet growing patient needs in the future. I would like to take this opportunity to thank John Doherty who has for the past several months been assisting us with this and other projects on an interim basis. John has a wealth of knowledge about charities and is well-suited to guide the Association into this next stage. I look forward to introducing you to our permanent part-time Executive Director later this year.

In the meantime, I hope to meet many BC patients, family members and health care providers at October's Education Day in Vancouver. The event also includes our Annual General Meeting, which attendees are most welcome to join if they wish. This will be the first time the free day-long event will be held in BC and I encourage you to attend. It is always a worthwhile day of updates about each disease and provides opportunities to talk with others affected by the diseases.

Enjoy a happy and healthy summer and fall.

Chris Meyer, President



The Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC): provides information about aplastic anemia, myelodysplasia and 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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Alberta Chapter Update

By Silvia Marchesin

A number of initiatives are moving forward in Alberta.

First, Dr. Loree Larratt has kindly agreed to do a presentation about aplastic anemia, PNH and treatment options to interested nurses in Edmonton in late September. We had a similar presentation last fall on MDS and it was well attended. Details on the date and location will be posted at the University of Alberta hospital hematology and outpatient units. We have received funding to specifically assist in nursing education and so hope to have several training opportunities in 2011 and 2012.

Second, the local Network of Rare Blood Disorders Organization (NRBDO) group will meet again in the fall to discuss what initiatives we can work together on. Right now the group consists of representatives from the sickle cell, hemophilia, porphyria, and immune deficiencies communities along with an AAMAC representative. Last spring we organized a mini-conference in Edmonton that was very successful. Currently, we are considering smaller events such as presentations that might be of interest to numerous patient groups. This will allow us to leverage the presenter's time and also learn from each other. We welcome your ideas on topics of interest, and projects that might apply to more than one group.

We continue to need volunteers to run the chapter. Specifically we need volunteers to:

- Keep hospitals stocked with AAMAC brochures
- Post notices about upcoming webinars in local hospitals (AAMAC is planning numerous cross-country webinars in the future), and
- Coordinate the chapter.

If you are interested in supporting the local chapter by volunteering, please contact Silvia at smarchesin@shaw.ca.

BC Chapter Update

By Janice Cook and Pam Wishart



Attending the Thanks Mom! stem cell drive are (from left to right): Lisa Scholman, Shevonne Twamley, Janice Cook, Melissa Cook and Eileen Sue. Missing are Xiomira Godinez and Paul Sue.

The "Thanks Mom! Multi-Ethnic Stem Cell Drive" was held in Vancouver the day before Mother's Day and was organized by BC Chapter member Eileen Sue. As well as Eileen and her husband Paul, AAMAC had five members and friends out to help with pre-screening and assist members of the public who had many questions about the process. Thanks to Xiomira Godinez, Melissa Cook, Shevonne Twamley and Lisa Scholman for the time you spent training and assisting. Janice's daughter Melissa presented her with a Mother's Day card printed specially for the event that showed that she has now registered as a potential donor. What better gift could a mom ask for?

This is what Eileen had to say about the Drive:

This Thanks Mom had a great result for a general public awareness event and community drive!

We should be proud of the more than 400 new registrants for OneMatch (we were told 427 total) as well as countless others that were reached because of our combined efforts! The Thanks Mom Multi-Ethnic Stem Cell Drive was a success on many levels because:

1. It was the first multi-ethnic stem cell campaign that was a community event.

2. We did not have a specific patient appeal (which always draws in more people).
3. It was not a campus event (which is situated where the target population is and results in more registrants).
4. Most of us have never done such an event before!!
5. We had a great diversity of ages and backgrounds of volunteers who were engaged and enthusiastic.

6. There was solid media coverage both in mainstream as well as ethnic media including TV, radio, newspapers (see the "In the News" link on the www.thanksmom.org website).

We can learn from this experience and take the lessons forward as our legacy is handed over to next generation! Young people can be equipped to take it forward to reach their peers because we have laid a solid foundation for them. Thanks Mom 2011 was a catalytic event and like planting a seed, we may not know the fruits of our labour until years later. We don't know how people were affected or touched by our efforts but we can take pride in that fact that all the volunteers did a great job!!

Ontario Chapter Update

By Andy May

Congratulations to all who supported, volunteered at and attended this year's dinner, dance and fundraiser, Spring Swing 2011. This was our biggest event to date with 351 people in attendance. As a result of your generosity a total of \$46,300 was raised. Let's try and make next year's event bigger and better!

I would like to mention and thank the core group of dedicated volunteers who make this event happen. I can tell you that countless hours are spent in preparation for the silent auction up to and even into the first hour of our event. Once the first silent auction

table closes it is nonstop cashing out the rest of the evening for the cash out team. Everyone did a fantastic job.



Having fun at the Spring Swing! From left to right: Andy May, Lois Henderson, Chris Meyer, Janice Cook, Rolla Bahsious, Silvia Marchesin and Stan Chmelyk.

This year's event was held at the Woodbine Banquet Hall and Conference Centre in Rexdale, Ontario, an elegant and great facility providing delicious food and a filling menu. We hope to return next year. Entertainment was provided by the Classic Connexions Band. Once the music started the dance floor was packed.



AAMAC volunteers Bill and Caroline Laughlin enjoying Spring Swing.

This event is a success because of you, the participants, patients, past and present, family members and friends or just friends of friends wanting to support each other.

On a personal note I was thrilled to see 68 police officers in attendance. Officers attending were from the following: the Toronto Police Service, 31 Division "E" platoon, 13 Division, 22 Division, 23 Division, 41 Division, TPS Auxiliary Police, TPS Mounted Unit, TPS Homicide Squad, Orangeville Police Service, Peel Regional Police Service, Ontario Provincial Police and the Royal Canadian Mounted Police. We even had two brave firefighters from York

and Toronto!

On behalf of the board at AAMAC I send out a big "Thank You" to our event sponsors, Celgene, Novartis and Alexion. Your continued support is appreciated by all of us representing the organization.

Lastly, AAMAC is run by volunteers. We appreciate anyone who wishes to donate some time to volunteer during events etc. If you would like to volunteer please contact our head office and indicate your interest at info@aamac.ca.

Atlantic Chapter Update

By Robert MacDonald

Since the last newsletter, activities in the Atlantic Chapter have been relatively quiet. The chapter met on a social basis in early June. A lunch and discussion focused around future plans and activities. I attended National Blood Donor Week, promoted by Canadian Blood Services. Brochures, information and lifesavers were passed out to the blood donors.

The Chapter plans a summer picnic for August. Future plans for the Fall will be worked out over the coming months.

If you are an AA, MDS, PNH survivor, caregiver for someone with these disorders or just an individual who just wants to be involved you're most welcome to contact the Chapter with your interest and information. All interested can contact the Chapter by calling (902) 443-1615 or rob.jack@ns.sympatico.ca.

AAMAC and CIHR Offer \$550,000 in Research Funds

By Chris Meyer

One of the Aplastic Anemia and Myelodysplasia Association of Canada's goals is to fund research into our bone marrow failure diseases. In partnership with the Canadian

Institutes of Health Research (CIHR), through the Small Health Organization Partnership Program (SHOPP), the Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) is pleased to announce two new Fellowship research grants to a maximum of \$550,000 in total.

The application deadline is October 3, 2011 with decisions expected to be made in April 2012.

We would like to thank our donors for their ongoing support which makes this significant funding possible. We will report back once the recipients of the funding are selected.

The funding will be available for applications that are determined to be relevant to one of the following research priority areas:

- Aplastic anemia
- Myelodysplastic syndrome
- Paroxysmal nocturnal hemoglobinuria
- Hematology
- Bone marrow failure

Applicants must be willing to devote the greater portion of their total effort to research closely related to aplastic anemia (AA), myelodysplasia/myelodysplastic syndrome (MDS), or paroxysmal nocturnal hemoglobinuria (PNH) under the direction of a sponsor with a research program closely related to bone marrow failure diseases.

Relatedness to AA/MDS/PNH is interpreted in a broad sense. Investigators in such areas as biochemistry, microbiology, molecular biology, immunology, or other areas will be acceptable if the proposed research is related in a significant way to AA/MDS/PNH.

The maximum amount awarded for a single award is \$55,000 per year for up to five years. We anticipate that two awards will be offered.

Specific requirements are as follows.

- This Priority Announcement will require the completion of a Relevance Form.

- The award must be held in Canada.
- Applicants must have a M.D., Ph.D. or equivalent degree and must conduct their proposed research under a sponsor who holds a formal appointment at the sponsoring institution.
- The research may not be carried out at a private sector for profit laboratory.
- Award recipients are asked to submit a report after the project's completion upon request from AAMAC.

For research questions on CIHR funding guidelines, how to apply, and the peer review process contact:

Priority Announcement Program
Delivery Team, Canadian Institutes of Health Research
(613) 941-3485
Fax: (613) 954-1800
PA-AP@cihr-irsc.gc.ca

If you are experiencing technical difficulties with a ResearchNet account or the e-Submission process contact:

CIHR ResearchNet Support
Canadian Institutes of Health Research
(613) 941-9080
support@researchnet-recherchenet.ca

For questions about this initiative and research objectives you may also contact:

Small Health Organizations
Partnership Program, Canadian
Institutes of Health Research
Fax: (613) 954-1800
pce.pec@cihr-irsc.gc.ca

We thank all applying researchers for their interest in bone marrow failure diseases!



CIHR IRSC
Canadian Institutes of Health Research Instituts de recherche en santé du Canada

Life Beyond Limits

A global public health initiative to raise awareness of myelodysplastic syndromes called MDS Life Beyond Limits is looking to hear the stories of people who have been affected by an MDS diagnosis.

MDS Life Beyond Limits was launched in response to evidence that suggests there are significant differences in the standards of treatment of MDS patients – particularly older MDS patients. The campaign, which is being supported by a coalition of MDS advocacy groups including AAMAC and the AAMDSIF, aims to raise awareness of MDS and highlight inequalities in treatment based on age. The campaign further aims to change the perceptions of healthcare professionals and to educate patients and their caregivers about the disease to ensure all MDS patients are getting the best care and treatment possible.

The stories submitted will be featured on the campaign website www.mdslifebeyonlimits.org to help raise awareness of MDS and bring attention to the need for equal access to treatment. More importantly, your story may provide comfort to other MDS patients and empower them to become better advocates for their health. Further, if you are interested, you could be considered to be photographed by world-renowned photographer, Ed Kashi, for a global photography exhibit about MDS.

The campaign wants to hear from ordinary people about how they are living their daily lives with MDS. How has MDS has affected your life? How were you diagnosed? How are you continuing to live life despite limitations/obstacles caused by your MDS diagnosis, or alternatively, what obstacles would you like to overcome? What goals do you have?

Please note:

- You do not have to have an extraordinary story to be considered for this campaign. The

campaign would like to hear from average people who are relatable and continue to live life to the fullest despite having MDS.

- You may share your story even if you do not wish to be considered for the photography portion of the campaign.

There are several ways you can get involved:

1. Go the following link to submit your story through the website: www.mdslifebeyondlimits.org/share-your-story/patient-story-form/
2. Go to www.mdslifebeyondlimits.org and sign up for campaign updates and join the community.

For questions about the campaign or AAMAC's involvement please contact Chris Meyer at chris_meyer@sympatico.ca.

Patient Education Day in Vancouver October 22, 2011

By Pam Wishart and Janice Cook

Plans for AAMAC's 6th Annual Education Day 2011 are well underway. It will be held October 22 at the Sheraton Vancouver Airport Hotel in Richmond, at 7551 Westminster Highway. Information about the location can be found at www.sheraton.com/vancouverairport. This free event runs from 8 a.m. to 4:30 p.m. and includes breakfast, lunch and parking. So far we have confirmed a number of speakers. We are pleased to feature local experts who will speak on AA, MDS, PNH, current treatments and management, iron overload and chelation, pediatric bone marrow failure and treatments, and stem cell research. Confirmed speakers include:

- Dr. Michael Barnett, The Leukemia/Bone Marrow Transplant Program of BC
- Dr. Allen Eaves, Stemcell Technologies Inc. and member of AAMAC's Medical and Scientific Advisory Committee

- Dr. Tom Nevill, The Leukemia/Bone Marrow Transplant Program of BC
- Dr. Kirk Schultz, BC Children's Hospital and member of AAMAC's Medical and Scientific Advisory Committee
- Dr. John Shepherd, The Leukemia/Bone Marrow Transplant Program of BC

We also will have presentations from patients with AA, MDS and PNH, as well as a presentation from Bill Laughlin about his participation in the Canadian Organization of Rare Disorders' Arctic Quest.

We encourage patients, their families, friends and all others interested in learning more about bone marrow failure come out to hear and meet local hematologists and others with an interest in bone marrow failure and its treatment. We also encourage interested health professionals to register and attend.

Remember, although free, you must register to attend. We encourage you to register as soon as possible, particularly if you require a travel subsidy, as they are limited.

We look forward to meeting you in beautiful Vancouver!

NRBDO Wins TEAM Award

By Silvia Marchesin and Janice Cook

The Network of Rare Blood Disorder Organizations (NRBDO) is a coalition of patient groups that share the common goal of raising awareness of and creating standards of care for those who require the transfusion or infusion of blood products to treat their disease, and in many cases to survive. Under the guidance of the Canadian Hemophilia Society, we are learning about creating positive changes within our groups, and advocating to governments for equitable treatment across Canada.

The members of NRBDO work, advocate, and lobby together in a coordinated fashion on key issues to

secure and maintain patient access to comprehensive care while empowering patients who have rare blood disorders.



The TEAM Award was accepted on behalf of NRBDO by Riyad Elbard, chair of the Thalassemia Foundation of Canada (holding the plaque) and past AAMAC president, Silvia Marchesin (seated front left). They are pictured here with NRBDO volunteers.

With the support and knowledge gained from fellow NRBDO groups, new partnerships and patient organizations are being formed and valuable lessons learned that will enable small groups to work even more effectively for the patients they represent.

The NRBDO's name was put forward to receive The Excellence in Advocacy Medal (TEAM) award which is sponsored by Celgene Corporation. Every year AAMAC recommends someone who has worked to advocate for patients, whether it be access to medications, or any other type of advocacy. Given the work that the NRBDO has done over the years to empower patient organizations, and to help move patient agendas such as comprehensive care forward, this is appropriate recognition.

The TEAM award is comprised of a plaque recognizing the advocacy work and a \$5,000 donation to AAMAC. Even though it's a national award, it has been presented at Spring Swing for the last few years.

On June 4, member groups of the NRBDO were meeting in Toronto and took advantage of this to attend the Spring Swing dinner, dance and silent auction.

The award was accepted on behalf of the NRBDO by current Chair Riyad Elbard of the Thalassemia Foundation of Canada and past chair Silvia

Marchesin of AAMAC.

The Board of Directors of AAMAC has voted unanimously to give the full dollar amount of the award to the NRBD, to enable the continuation of the valuable work being done.

Fabulous News Regarding Soliris Funding

By Silvia Marchesin

Eculizumab (Soliris®) was approved by Health Canada for the treatment of paroxysmal nocturnal hemoglobinuria (PNH) in January 2009. It is the first and only treatment specifically for this bone marrow disease and has been a miracle drug for numerous patients. Until now, only patients with third party insurance coverage have been able to obtain this expensive and life-saving medication.

However, we are very pleased to announce that in late July, at the meeting of the Premiers in Vancouver (the Council of the Federation), a decision was made to fund Soliris. This recent decision is extremely good news for the remaining PNH patients who might benefit from Soliris.

The story about this first appeared in the July 22 edition of the Toronto Star. It stated:

After years of negotiations, Canada's premiers have agreed to band together to bulk-buy the drug Soliris, which is used to combat a rare blood disease.

"This is an important step forward for all of us," Ontario Premier Dalton McGuinty told the Star.

"Soliris has the reputation of being the most expensive drug in the world. It's over \$400,000 annually for a patient," said McGuinty.

"There are all kinds of drugs like that out there and we'll be called upon to find ways to fund them.

"It's one drug and in the grand scheme of

things it can appear to be paltry but for the very first time we've brought 13 provinces and territories together and we've agreed that when we combine our buying power and our negotiating strength we can do something that benefits all of us."

The entire article is available on the Star's website.

AAMAC commends the provincial/territorial governments of Canada for their decision to provide public access to Soliris. At the time of print, we have not been able to confirm that each province and territory has indeed signed the agreement for funding, but we believe this will be the case shortly. Ontario has approved the funding and access is based on guidelines similar to those used in Australia.

Many PNH patient and physician advocates have approached their provincial governments over the past two-plus years to encourage public funding of Soliris. AAMAC board members, along with members of our Medical and Scientific Advisory Committee met with the governments of Ontario and Alberta. We thank them sincerely for meeting with us and for responding to the needs of PNH patients. We would like to thank Dr. Larratt and Dr. Wells for supporting our efforts. As well, AAMAC would like to recognize the hard work of the Canadian Association of PNH Patients which was actively involved in advocating for Soliris funding. Finally we recognize the efforts of individual patients and physicians that helped move this agenda along.

Mourning Gai Thomas

By Robert MacDonald

Gai Thomas, the founder and principal force behind the Atlantic Chapter, passed away unexpectedly on July 28, 2011. Gai represented all the attributes required of a true dedicated volunteer. She was forceful, convincing, articulate and sometimes feisty in her approach. She was able to

accomplish things and bring people onside to support her efforts.

Gai, despite the ravages of Graft Versus Host Disease (GVHD) from two previous transplants, one for lymphoma and one for MDS, was active and keen up to the last week of her life. In fact, two weeks before her untimely death she was worried and concerned about the state of our display in the hematology clinic at the QEII hospital, Halifax, Nova Scotia.

In recent years, Gai kept a schedule of activities including travel which took her as far afield to her country of birth, Australia. In fact, Gai was eagerly anticipating a return visit to Australia this coming winter.

Aside from AAMAC, Gai had a long career in health education and occupational health and safety. She received the first award of Excellence from the Occupational Health Nurses Association of Nova Scotia, later named the Gai Thomas Award of Excellence. She was also very involved with Girl Guides, the arts and her church.

Gai will be greatly missed by the chapter members for her power of persuasion, her ability to approach and involve people and her eagerness to pursue new ideas.

Rest in Peace, Gai. Your memory and accomplishments will live on.

New AAMAC Videos About MDS

By Chris Meyer

AAMAC is pleased to announce that we have produced a new informational video in both English and French for MDS patients interested in finding out more about azacitidine (Vidaza).

The videos include general information about Vidaza, not medical advice. Patients should speak to their doctor about treatment options appropriate for them and the information in the video.

The videos will be available to doctors across Canada on request by DVD or can be shared with patients for viewing on our website with a simple password.

The videos were developed in collaboration with and with the generous contributions of: Dr. Dick Wells, the Chair of AAMAC's Medical and Scientific Advisory Committee and the co-director of the Myelodysplastic Syndromes Program at the Sunnybrook Health Sciences Centre Odette Cancer Centre in Toronto, Cindy Murray, MN, NP at the Princess Margaret Hospital in Toronto, Dr. Luigina Mollica at Maisonneuve-Rosemont Hospital in Montreal, and Lucie Laporte, an oncology clinical nurse at Charles-LeMoine Hospital in Quebec.

We would also like to thank Celgene for its support of these videos and Past President Stan Chmelyk who worked very hard to get this project off the ground.

Please contact Chris at chris_meyer@sympatico.ca or (416) 994-6712 for further information. If you are a doctor and wish to request a copy of the DVD or password for your office, please contact info@aamac.ca.

Calling all Marrow Movers!

By Susan McVeigh

Now that the intense heat of July has passed, it's time to go for a walk after dinner and get ready for our upcoming 5K Charity Challenge walk as part of the Scotiabank Toronto Waterfront Marathon.

It's a relaxed, family-friendly event, and a great opportunity for family and friends to come out and have fun together, while experiencing the excitement and energy of a road race.

When: NEW DATE AND TIME!
OCTOBER 16, 12: 30 PM—proposed start time.

Where: Fabulous, scenic Waterfront

5K course, starting at Canadian National Exhibition grounds, and going point-to-point from inside the Princes' Gates to Nathan Phillips Square Finish line. □ How do I register: <http://www.torontowaterfrontmarathon.com/en/charity.htm>.

How do I raise funds: you can collect pledges both online through your own fundraising page as part of the Charity Challenge, or simply by collecting pledges.

Training: The Running Room offers learn to walk and learn to run clinics leading up to the race, but for a 5k walk, simply getting outside a few times a week is enough! It should take approximately an hour to complete the walk. Strollers are OK; no pets except for service animals.

Time together + a walk along the waterfront + fundraising for AAMAC = a great event you should be part of! Call or email me with any questions at susanbmcveigh@hotmail.com or (416) 251-9552.

Dance For Life Fundraiser a Success!

By Janice Cook

Lisa Ross is a wonderful AAMAC volunteer from Victoria. She is currently being treated for PNH and will be one of the patient speakers at Patient Education Day in October. The following is a letter she sent following an amazing fundraiser event held in Victoria in June.

Hi all!!!! I just wanted to let you know how the dance went. First of all I want to thank you all for the help getting me the supplies, and all of the things we needed to make is such a HUGE SUCCESS! We had an ABSOLUTE BLAST! It was an incredible night, and my brother's band, Old School, was so amazing and will be donating their time every year! We packed the place with 300 people, and the music rocked!!! Some of my old classmates, who are now magicians, donated their performances and worked the crowd for the first hour. I had a good cry, because I was so excited about ALL the people that came to show their support, and have a great time! My

whole family was involved in helping out. My dad Rick was the MC, my brother Mike's band rocked the block, my mom Sue and Auntie Shawn took tickets at the door, my teammates/extended family from Team Phoenix, Liz, Bev, and Debbie, helped with the raffles, Wanda took pictures, and of course my wonderful boyfriend Doug helped me sell raffle tickets, and helped me with the announcing of the prizes. We also gave out the AAMAC shirts that you so wonderfully donated, and everyone who got one wore it all night! We raised \$6,200 IN TOTAL!!!! We raised \$3,000 from the ticket sales, and another \$2,900 at the dance with raffles, along with three donations of \$100. It was just awesome! Everyone who came said they can't wait until next year! Thank you so much for everything, and I am so proud to be a part of this organization.

*Take Care,
Lisa*

News of Note

MDS Treatment Added to Two Provincial Formularies

AAMAC applauds the governments of Saskatchewan and Manitoba for adding azacitidine (Vidaza®) to their provincial formularies, which is the list of medications the government will pay for. This summer they joined BC, Alberta, Ontario, Quebec and Nova Scotia in making the treatment available to MDS patients who meet certain medical criteria. Vidaza is also available on a "case by case" basis in Newfoundland.

New Ontario Support Group Planned

We are currently looking at starting a support group for patients in the Kitchener-Waterloo area with an initial meeting to gauge interest being considered for October. If you would be interested in attending, helping out or finding out more, please contact Chris Meyer at (416) 994-6712 or chris_meyer@sympatico.ca. Details of the meeting including date and location will be posted on www.aamac.ca.

New Research Confirms Horse ATG More Effective than Rabbit ATG

A study published in the August 4, 2011 New England Journal of Medicine compared the effectiveness of horse vs. rabbit antithymocyte globulin (ATG) for the treatment of severe aplastic anemia. Conducted by researchers at the National Institutes of Health (NIH), this study examined the results of 120 severe aplastic anemia patients ranging in age from two to 77 who received either the horse ATG (Atgam®) or rabbit ATG (Thymoglobulin®). Investigators found that horse ATG significantly outperformed rabbit ATG as a first line therapy for aplastic anemia.

For more information, and to read AAMDSIF's interview with the study's investigator to find out more on what this means for patients, please visit www.aamds.org. For questions related to your own treatment, please speak to your doctor.

Mark Your Calendars

CORD's Orphan Drugs & Rare Diseases Conference September 15-16, 2011, Toronto, ON: The Canadian Organization for Rare Disorders (CORD) will be holding a two-day conference this fall. On the first day, CORD will focus on how to implement the proposed Canadian Orphan Drug Regulations and on the second day, CORD examines sustainable solutions for a Canadian Drug Plan for Rare Diseases. For more information please visit: www.raredisorders.ca or call 1(877) 302-7273.

Patient Education Day, October 22

Please see the article and flyer in this newsletter for details and check our website for updates over the fall.

Regular Monthly Toronto Support Group Meeting, Toronto, ON

Returning this fall is our regular Toronto support group meeting the second Saturday of each month from

2 to 4 p.m. at Canadian Blood Services, 67 College Street. Please call us for details. Come out and meet other patients and families dealing with the same bone marrow failure disease as yours. Share stories, compare notes, learn how others are coping and see how they are responding to treatments. Share as much or as little as you are comfortable with in an informal setting. For more information or to RSVP please contact Stan Chmelyk by phone at (905) 457-9858 or email stan_c@primus.ca. We hope to see you there.

Monthly Ottawa Support Group Meetings, Ottawa, ON

The AAMAC Ottawa support group meets on the second Saturday of every month at the Ottawa General Hospital, 501 Smyth Road, Room 5100. Meetings are from 3 to 5 p.m. and are open to all patients, their families and supporters. For more information, please don't hesitate to contact Bob Ross at aamac.ottawa@gmail.com or by phone at (613) 882-2416.

Regular Monthly Halifax Support Group Meeting

We normally meet on the last Wednesday of every month from 3 to 5 p.m. at the Atlantica Hotel, Robie St. We advise you to call ahead to confirm the meeting: (902) 443-1615 or email rob.jack@ns.sympatico.ca. We welcome anyone who has an interest in our association.

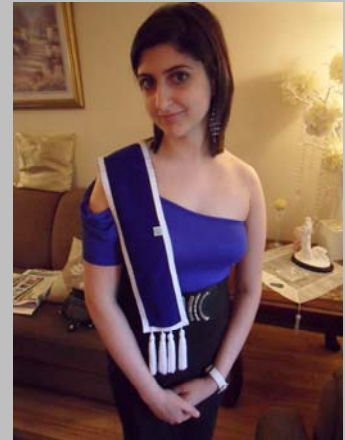
Last AAMDSIF Regional Conferences in 2011

This year the Aplastic Anemia & MDS International Foundation organized free regional day-long conferences instead of one large multi-day annual conference featuring experts in all three diseases.

One of the final regional events this year takes place close to Canada in Minneapolis on September 24, 2011. The event includes a pediatric issues question and answer session for parents. Space is limited and advance registration is required. For details, visit www.aamds.org.

Our Members' Milestones!

MDS Survivor Rana Bahsous graduates college!



Rana Bahsous on her graduation day

AAMAC would like to congratulate Rana Bahsous, on her college graduation this past June. Rana completed her Advanced Diploma in Visual and Creative Arts at Sheridan Institute of Technology and Advanced Learning.

Rana was diagnosed with Myelodysplastic Syndrome and underwent a successful bone marrow transplant in 2000. She recently donated one of her many beautiful sculptures to AAMAC's silent auction at the annual Spring Swing.

Rana plans to return to Sheridan for a post-graduate certificate in Special Effects Make-up Props and Prosthetics this fall.

Congratulations, Rana!

At AAMAC, we believe that it's important to celebrate our members' triumphs despite battling with bone marrow failure. If you would like to share you or your family member's milestone with our newsletter readers, please contact our newsletter editor, Rolla Bahsous at rolla.aamac@gmail.com. Thank you!