

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

President's Message

As the new President of the Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC), it's my privilege to thank Stan Chmelyk for his contributions as President during the past two years. Always full of hope and focused on the needs of patients, Stan exemplifies what the Association is all about. He advocated for new or continued provincial funding for medication, knowing that many patients are not eligible for a bone marrow transplant as he was. Stan also focused a great deal of effort on increasing the support available to patients. He re-established a regular support group meeting in Toronto, worked very hard with other volunteers to establish a successful support group in our nation's capital and made headway towards our goal of support groups in Quebec and Manitoba.

I asked Stan to deliver the closing remarks at our annual Education Day in Ottawa – a role that traditionally falls to the current President. Although I took a fair bit of teasing from Stan for delegating one of my first duties, it was worth it. Ending his term on such a high note in the city where he helped set up a new support group and had received a successful transplant for MDS was wonderfully fitting.

I clearly have big shoes to fill – not just Stan's but those of Past President Silvia Marchesin who also returns to the Board. I am extremely fortunate to benefit from their guidance. Stan has also offered to continue to lead our important advocacy work in his role as Past President.

(continued on the next page)

Education Day 2010 Draws 100 Participants

By: Bob Ross

We're very pleased to report that AAMAC's Annual Education Day, which took place for the first time in our Nation's capital on October 16th, was a resounding success! Nearly 100 delegates from across the country joined us at the Marriott Hotel in downtown Ottawa for an information-packed day. The theme this year was 'Living With Bone Marrow Failure', and the topics were chosen by patients from AAMAC's Ottawa Chapter to reflect the issues that patients with Aplastic Anemia, MDS, PNH, and other types of bone marrow failure must face every day.

The day began with Dr. Mitchell Sabloff, hematologist at the Ottawa General Hospital giving an excellent talk entitled 'Blood 101 – Introduction to Blood and Bone Marrow', after which he segued into an overview of bone marrow failure diseases.



Education Day committee:

(continued on next page)



**Aplastic Anemia
&
Myelodysplasia**
ASSOCIATION OF CANADA

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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President's Message Continued

This Association is fortunate to benefit from the contributions of an incredible group of volunteers across the country. Twelve of them serve on the Board of Directors. In addition to Stan, Silvia and me, your 2010/2011 Board includes: Pam Wishart, who serves as Board Secretary and Janice Cook who jointly coordinates our B.C. Chapter with Pam; Reanne Booker, a bone marrow transplantation nurse in Alberta; Doug Mylie, our Alberta Chapter coordinator; Andy May, our Ontario Chapter coordinator; Anna Chamrai, our Treasurer; Rolla Bahsous, our newsletter editor; Bob Ross, who leads our Ottawa support group; and Robert MacDonald who is our Atlantic Chapter coordinator. I thank each of them for their continuing efforts to help patients and their families. The vast majority of these individuals have a direct personal connection to a bone marrow failure disease which helps keep the association focused on the needs of patients.

Unfortunately, we were all very saddened that Trevor Thompson was not able to stand for re-election after losing a long and well-fought battle with bone marrow failure in September. Trevor was one of the first AAMAC volunteers I met after my late husband was diagnosed with MDS and I will always be personally grateful for his encouragement and support. (See the tribute to Trevor inside.) Volunteers make this organization possible – whether it's medical professionals including the expert members of our Medical and Scientific Advisory Committee or volunteers at local chapters. In fact, our part-time office administrator, Lois Henderson, whom many newsletter readers know, is currently the only paid person in the organization.

Volunteering with this exceptional group of people and meeting patients, family members and healthcare providers across the country has been a wonderful experience and I am

excited to serve patients in a new role. I hope that, if you are not already involved as a volunteer, you will consider joining us in some way.

Sincerely,
Chris Meyer

Education Day 2010 Continued

By Bob Ross

This was followed by Dr. John Storrington, Hematologist at the McGill University Health Centre, speaking about new and emerging drug treatments. Next we heard Dr. Edward Fitzgibbon, Medical Director of the Palliative Care Program at the Ottawa General, talking about his work and the relevance of palliative care programs in general. The morning ended with a patient tribute to Dr. Sabloff and nurses Carol Hua-Yung and Annie Wereley, who were each presented with beautiful framed photographs and plaques by Shibly Abela on behalf of AAMAC's Ottawa chapter support group. To see the gratitude these patients had for their caregivers was quite moving, and for many people in attendance this was the high point of the day. Just before breaking for lunch, we got to welcome Chris Meyer as AAMAC's new president during the annual general meeting. (Congratulations Chris!)



*AAMAC Board of Directors and
Administrative Assistant Lois Henderson*

The afternoon got off to a great start with Dr. Lothar Huebsch, director of the blood and marrow transplant program at the Ottawa General answering a very important question: Are you a transplant candidate? Dr. Robert Klaassen, Pediatric Hematologist and Oncologist at the

Children's Hospital of Eastern Ontario followed this with a very informative talk about pediatric bone marrow failure, and Dr. Melissa Forgie, Program Director for the Hematology Training Program at the University of Ottawa followed that with a detailed look at iron overload, something many patients have to deal with.

The day's closing talk was given by Annie Wereley and Carol Hua-Yung, both clinical nurse experts in hematology at the Medical Day Unit at the Ottawa General. Fittingly, their presentation was entitled 'Living With Bone Marrow Failure' and centered around the typical, ongoing issues patients have to grapple with, both in hospital and at home, from a nursing perspective.

There were also three poignant patient testimonials by Robert Kupferschmid from the Ottawa Chapter (MDS), 11-year-old Josée Ross (AA), and AAMAC Board member Silvia Marchesin (PNH). These were interspersed between the presentations and were very well received by everyone in attendance.

AAMAC would like to thank our Platinum sponsor Celgene Corporation, and Gold sponsors Novartis and Alexion Pharma Canada for their generous and ongoing support, as well as the organizing committee from the Ottawa Chapter for all the hard work they put into making Education Day 2010 the huge success that it was.

Look for videos of the presentations to be posted on the AAMAC website at www.aamac.ca soon. We hope to see you all next year in Vancouver!

Alberta Chapter Update

By Doug Mylie

The Alberta Chapter continues to support patients and families from across the province as well as from Saskatchewan and Manitoba.

The hospitals and Medical Support Staff do wonderful work in treating patients associated with Bone Marrow failure, however those that have been affected by these illnesses are often feeling alone and overwhelmed by the sudden impact they have on their lives and families. The volunteers with AAMAC understand these feelings and challenges from the perspective of the patient and family members and can offer the extra support that is needed during these times. One of the valuable opportunities in this area is the organizing of Patient and Family support group meetings, where we can get together and share our experiences and stories with others that are struggling with these issues.

The Alberta Chapter is looking to set up Support Groups to connect people in various locations. These groups would be open to any patient or family member to attend. They are traditionally smaller in size and are in a comfortable setting for those that attend. If you are at all interested in getting a group in your area started or would like more information please contact me at Alberta@aamac.ca.

Remember you are not alone and there are others that understand.

BC Chapter Update

By Janice Cook

Pam Wishart and I both attended our 5th Annual Patient Education Day in Ottawa and found it a well organized and very worthwhile learning day. The next day we attended our yearly board meeting, and our big news from that is that our fellow board members agree that it's time to bring Education Day out to the west coast! So get ready for next fall, we are full of ideas and beginning to put together a committee to bring it all together. We have many excellent hematologists in BC and hope to have some of them participate as speakers (maybe even yours). If you are interested in being a part of the planning group, please contact Pam or me at bc@aamac.ca or (604) 826-7222.

A few of us are getting together for a support group meeting in Langley on November 9. Give me a call if you would like to meet at a later time.

Ontario Chapter Update

By Andy May

I was not able to submit a summer report for personal reasons and therefore did not get to mention the outcome of AAMAC's Spring Swing 2010 which was held on May 15 of this year. This year's Spring Swing dinner and dance was another great success with a total of more than \$36,500 being raised from the silent auction along with very generous sponsorships from Celgene, Novartis, Alexion and Enbridge Gas Distribution. A big "Thank You" to all who dedicated their time to ensure this event was such a huge success. Thank you to our volunteers including co-chair Caroline Laughlin, Jeanette Rintoul, Victoria Fleming, Gordon Fleming, Carole Sanford, Stan Chmelyk, Mandy Chmelyk, Emily Deeb, Mikaela Gray, Jenny Pranger, Lois Henderson, David Sanford and Laura Sanford. A special thanks to the members of No Strings Attached who donated their performance in memory of Terry McEvoy.

This edition of the chapter update is all about a bunch of thank You's. Let's start with a big thank you to our outgoing President Stan Chmelyk. Stan has and does work very hard for this organization and I am proud to work alongside such a dedicated and compassionate man. I am ecstatic that Stan is continuing as a dedicated Director for AAMAC here in Ontario. We are thrilled to have Chris Meyer lead the way as our current President for the next term, thank you Chris. This national organization is blessed to have such a dedicated group of volunteer directors along with our office administrative assistant Lois Henderson, to you all thank you.

AAMAC's Marrow Movers once again showed their strength and commitment this past September in

participating in the Toronto Waterfront Marathon in downtown Toronto. To all who participated, thank you – the event was once again a huge success.

I was fortunate to attend the 2010 Toronto Police Homicide Police Golf Tournament in Ballantrae, Ontario with my wife Leah. Even though we thoroughly got soaked by rain, the event was a blast. I even managed to hit a few balls to the rough and a couple of balls to the lakes on the course. To Dave Ecklund, the organizers and everyone who participated, thank you. Proceeds of \$3,600.00 this year are devoted to AAMAC for education, research and support. Below is a photo of our foursome.



From left to right: Andy May, Leah Gilfoy, and Renata and Tim Loubikari.

AAMAC's Education Day held in Ottawa this year was once again a huge success. A big thank you to Bob Ross and Catherine Knoll from Ottawa, and to all the volunteers who made this event such a great achievement. I would also like to mention to all the attendees that your comments and input will only make future AAMAC Education Days just that much better. Thank you for attending.

Events like Education Day cost quite a lot to put on and we acknowledge and thank our sponsors, Alexion, Novartis and Celgene. Thank you for your continued support.

AAMAC is fortunate to have our current national promotional video being updated. This project is being donated by the participants and by James Burns. The production is well under way and is expected to be completed in January or February

2011. It takes a ton of time and professional equipment to finish a project like this. To the producer James Burns and his assistant director Caroline Laughlin, a big thank you.

I do not want to limit my thank you's to only those I have mentioned. Many people make our work in Ontario possible and I thank each of you.

I am changing my contact email address to andy@amayfamily.com please do not hesitate to contact me here.

Atlantic Chapter Update

By Gai Thomas

On Saturday October 23 our support group of 10 people met in Halifax and welcomed three new members. We were also happy to have our chairperson Robert and his wife, Jackie with us after their stay in Needham, Massachusetts for Robert's eye treatment at the Boston Foundation for Sight.

We started with a lively round table discussion and information sharing on the subject of coping with chronic illness presented by Janice Spencer, MSW, RSW, the social worker for the Queen Elizabeth II Health Sciences Centre hematology department. We each identified two of our main day-to-day challenges coping with bone marrow failure illnesses. Aside from most people experiencing fatigue, necessary reduction of activities, side effects from treatments for MDS, AA, PNH, and other health problems and dealing with losses, we added many individual challenges. These challenges included confusion and lack of understanding of available treatment, lack of acceptance and understanding of medical/technical aspects, fear of the unknown and unpredictability of the future, graft versus host disease (GVHD) problems following allogeneic donor transplants, the need to continually adjust and amend plans by rationing time and energy, and the need to re-think and amend ambitions/expectations etc.

It was quite an overwhelming litany but there was a great deal of social support among the members and Ms. Spencer gave us many good hints and topics to consider in the handouts she distributed. There was a lively discussion and humour around the table. Many thanks to Dolores and Linda for arranging the event and catering a delicious lunch.

Two of our members attended Education Day in Ottawa. They were impressed with the presentations and information received. During our next meeting they will share their experiences with us. During lunch, chapter business was discussed and future plans were made. We hope to see you at our November 27 meeting from 1 to 3 p.m. at the Dickson Building, QEII Victoria General site, 5th floor room 5513.

Remembering Trevor Thompson



The following is the eulogy given on behalf AAMAC honoring the life of one our Board members, the late Dr. Trevor Thompson. The ceremony was held in Kingston, Ontario on September 11, 2010.

My name is Stan Chmelyk and I am the President of the Aplastic Anemia and Myelodysplasia Association of Canada (or AAMAC for short). On behalf of the members of our organization I am speaking to you here today, to pay tribute to the life and career of a truly outstanding individual, Dr. Trevor Thompson.

After his diagnosis of aplastic anemia, Trevor volunteered with and then joined the board of our organization in 2004. AAMAC provides support and information to patients and families dealing with bone marrow failure diseases as well as funding research towards a cure. The organization was thrilled to welcome a physician with such a wealth of knowledge and such a long and successful career.

What struck me the first time I met Trevor was his positive attitude and amazing amount of energy. I was an MDS survivor, but I had a bone marrow transplant and was cured. Here Trevor, 30 years my senior, dealing with a life threatening disease, continuing his practice as a physician, and still finding energy and time to volunteer on our Board. He would stride purposefully with vigor when I walked with him and I would be huffing and puffing to keep up. He was always positive and supportive and I never heard a disparaging comment from him about anybody.

Trevor was not an outspoken man; however whenever he did speak, his comments were always very insightful, thoughtful and direct. He had a knack for identifying a problem and delivering a suitable solution that commanded everyone's attention.

Above all Trevor possessed a tremendous amount of character. He was a very kind and generous man who devoted his career, and indeed his life, to the care and wellbeing of others. I remember him relating to me an occasion when he was working in Africa and was treating a woman who experiencing a very difficult delivery. It was imperative that a caesarian section be performed to save this mother's life. Trevor said he had not performed surgery so he pulled out his text book and then simply went to work. I was astonished that someone would have that kind of courage and commented that I would not be able to attempt something like that. He looked me in the eye and said matter-of-factly "this woman was going to die." I realized that Trevor likely was not aware of the good he was

providing in the care of others. His work was not for personal gain or accolades – it was simply what he did and who he was. I cannot count the number of times our Board would be discussing some project and as a small charitable organization there would always be concern about maintaining costs. Invariably Trevor would offer to fund some of the expenditures personally. The offer would be politely refused but there was no doubt in anybody's mind that it was genuine and given without reservation.

Simply put, Trevor was a fine human being and the earth was blessed by his presence. On behalf of AAMAC, I would like to express our condolences to Trevor's lovely wife Patricia and to his family and friends. Our organization and patients were honored by Trevor's support and we will miss him. We will carry our fond memories forever.

Marrow Movers in the Medals!

By Chris Meyer

For the second year in a row, it was a wonderful Sunday as the Marrow Movers team walked a fun and sociable five kilometres from the Canadian National Exhibition grounds along Lake Ontario to city hall on September 26. We walked with purpose, raising awareness about bone marrow failure diseases and funds for the Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) in the Toronto Waterfront Marathon, Half Marathon and Five-kilometre Walk.

As we travelled the course along city streets that were closed for the event, it was great to hear encouragement from marathon volunteers with bullhorns as they tried to read our association's name off the banner we carried. For the most part they did quite well – even if they needed a bit of help with the pronunciation of "myelodysplasia" from time to time!

This year's amazing team not only raised awareness but an incredible

\$7,000 and counting thanks to the support of well over 100 generous donors who sponsored them!

Top fundraising honours went once again to Carole Sanford who walked in memory of her late husband Gord Sanford who served for several years as AAMAC's President. Also returning to the team this year was long-time volunteer Jeanette Rintoul accompanied by her friend Suzanne LeBlanc.

In addition, we were joined by a number of new friends including Rosemary Pauer who was one of the fastest walkers with MDS to cross the finish line that day! Newlyweds Amber Eisenhut-Bundle and Jonathan Bundle also joined the Marrow Movers for the first time. Amber has aplastic anemia and even being on crutches at the time of the walk could not keep her from participating – she rented a red scooter to match our team colours and crossed the finish line in style!



From left to right, Marrow Movers Carole Sanford, Rosemary Pauer, Suzanne LeBlanc, Chris Meyer, Jeanette Rintoul, Amber Eisenhut-Bundle and Jonathan Bundle show off their finisher medals at the end of the walk.

At the finish line walkers were each awarded a 2010 finisher medal as we arrived at the Nathan Phillips Square in time to see Kenya's Kenneth Mungara called on stage to be recognized for running the fastest marathon ever on Canadian soil. (Participants in the marathon and half marathon also received medals.)

In the finish area we also met up with team members from Nicole's Hope who raised an amazing \$2,500 for AAMAC! Peter Snodgrass, Chantal LeBlanc, Edie Bandel-Vandenberg and Andrea Bandel-Vandenberg each walked in memory of Peter's daughter

and Chantal's sister, Nicole Snodgrass, who died in May at the age of 35 due to complications related to aplastic anemia.

In addition to the five-kilometre walk, we were also very proud to have Marrow Movers participate in other parts of the event.

For the second year in a row volunteer Susan McVeigh and her friend Susan McDowell walked the half marathon in memory of Susan's father Gordon O'Halloran who had MDS.

We even had a runner participate on the team this year as Melanie Duguid completed her first marathon! Congratulations Melanie! Melanie ran in honour of her neighbour and daughter's playmate, four-year old James Rajaratnam who has aplastic anemia. James' parents Noelle and Romesh also raised funds and awareness as part of the Marrow Movers although unfortunately they could not attend the walk.

Also taking part was Remona Basur who read about the association in the list of official marathon charities and decided to raise funds from her five-kilometre run for the Association.

Fortunately, September 26 did not mark the end of the Marrow Movers for 2010. We were very pleased to receive a call from Judy Fernandes who was running in the Toronto International Half Marathon on October 17. She decided to encourage her friends and family to sponsor her with donations to AAMAC in memory of her father, Amro Fernandes, who died four years ago due to complications of MDS.

I would like to thank each and every Marrow Mover and the members of Nicole's Hope as well as the family and friends who sponsored their walk or run in celebration or in memory of someone. Each was a wonderful tribute and we are honoured that you selected the Association as the beneficiary of your efforts. Thanks to each walker, runner and sponsor, our small group made big strides this year. Your support will help Canadian

patients faced with bone marrow failure diseases.

Watch upcoming newsletters for plans for next year's walk which takes place on October 16, 2011. Please let me know if you would like to volunteer to help organize our team. There are also similar events across the country if you would like to consider organizing a team in another location next year.



Members of the Marrow Movers (in red) meet up with team members from Nicole's Hope – from left to right in purple are Peter Snodgrass, Edie Bandel-Vandenberg, Andrea Bandel-Vandenberg and Chantal LeBlanc.

Canadian Conference on Myelodysplastic Syndromes

By Janice Cook

On September 24 and 25, Cindy Van der Eijk (Bell) and I attended the Canadian Conference on Myelodysplastic Syndromes in Vancouver. In all, 156 people from all across Canada registered for the conference, which was an accredited group learning activity for hematologists. There were speakers from BC, Alberta, Ontario, Quebec, and Nova Scotia, six from the United States, one from the Netherlands and one from Italy. Some of the presenters have published their findings; many others have participated in clinical trials. About 30 nurses and pharmacists also attended with their own three-hour session and then joined the larger group. The sessions were all interesting, and included the most recent research and advances in treatment information available.

The nurses' session was presented by a nurse specialist from New York, and a pharmacist from Hamilton. They

presented background information on MDS and the International Prognostic Scoring System, and discussed treatment for iron overload, and new drug therapies for treating MDS. There was talk about quality of life surveys and discussion about the age discrimination that can exist for older patients. This is a serious issue as the median age at diagnosis is 73. The issue of co-morbidities makes a team approach helpful with older geriatric patients. The first study is being published which looked into co-morbidities and prognostics. The mantra "start slow, and go slow" is sometimes used in starting drug treatments in the elderly, and toxicities and drug interactions need to be monitored. We were told that in the United States, the frontline drug of choice for high risk MDS patients who are greater than 75 years of age is azacitadine (Vidaza®).

The doctors' sessions included information on pathophysiology, molecular research, clinical trials (both completed and ongoing), and of course new drug and treatment regimes. Some session titles were Canadian Clinical Research Initiatives in MDS, BC Programs in MDS, Progress and Challenges in MDS, Prognosis in MDS: Current Perspectives, Hypomethylating Agents in MDS, Role of Growth Factors in MDS, Clinical Relevance of Iron Overload in MDS, Controversies Surrounding Iron Chelation Therapy for MDS, MDS: A Canadian Perspective, and Optimizing Management of MDS in 2010. There was also a debate between Dr. Richard Wells (chair of our medical/scientific advisory committee), and Dr. Jochim Deeg of Seattle, titled "Cure Should be our only Goal for Eligible MDS Patients." Dr. Wells took the NO stance, citing quality of life and the fact that with advances in therapies today, some MDS patients can be offered actual treatments instead of just supportive care, as was the case just a few years ago. Cure can be possible in some instances, and for some, MDS may become a chronic condition. The importance of individualizing treatment plans was mentioned a number of times. This is

why your treatment plan may differ from someone else's.

I once heard a fellow board member comment on the difficulty of obtaining drugs to treat bone marrow failure diseases in Canada. Her comment was that Canada sometimes seems like a third world country. It was mentioned a number of times that some of the drugs shown to be useful in treating MDS are not yet available in Canada. (Special Access Forms to be filled out must drive a busy doctor crazy). We heard about the Bone Marrow Failure Syndrome Clinic in Vancouver (Dr. Tom Neville) and the plans for a National MDS Data Bank (Dr. Rena Buckstein from Toronto). We know that many Canadian MDS patients see well respected and knowledgeable hematologists and some have access to Centers of Excellence for their care. For others it may be missed diagnoses, possibly inadequate or outdated care. Your treatment may be dependant more on your postal code than on your needs. There are probably many more people with MDS in Canada than we currently know about. With organization and collaborative data banks of patients, perhaps more Canadian patients will be able to participate in clinical trials for new therapies. Then it will be up to us to help convince our governments to make these drugs accessible for all Canadians, regardless of where they live.

There was a very positive and exciting vibe at this conference. The number of ongoing research projects into MDS, and new knowledge of genetics, cell mutations and even acquired MDS following cancer treatment all seem to point to even more promising treatments in the future. I thank the conference organizers for graciously allowing me to represent AAMAC at this meeting by providing a display table to showcase what type of support and information we give to patients, how we support research into bone marrow failure, and provide pamphlets about us for them to distribute to their patients. I also met as many nurses and doctors as I could and encouraged them to hand out our

information to patients, as we know that we are only reaching small numbers of them. There are thought to be up to 500 patients in BC with myleodysplasia, but sadly we have only some on our current contact lists. If you meet patients at clinic, please let them know about the Association.

Canada Needs an Orphan Drug Policy

By Caroline Laughlin, Canadian Organization of Rare Disorders (CORD) Director

On September 30, 2010, 50 representatives of rare disorders from across Canada met with Members of Parliament (MPs) to encourage them to support a change to the Health Act. (All MPs were asked to speak to our delegates and 50 replied.) At these meetings we informed, educated and discussed how the federal government should be acting on new legislation to include access to medication for patients with rare disorders. There are three million people across Canada who do not have the same access to drugs as the rest of the population, including MPs. You may be one of them.

Canada is the only nation in the developed world which does not have an orphan drug policy. The United States has had an orphan drug policy since 1983 and the European Union has also implemented changes to its regulations to accommodate orphan drugs.

Many MPs supported Motion M426 by Don Bell in 2008 regarding this issue but have never inquired about its progress since. Some of these MPs were also on the Canada Health Committee and did not know that anything regarding orphan drugs was being discussed.

We heard that the government is working on broader drug regulation reforms and on how orphan drugs should be treated differently and incorporated into the regulatory framework. This may or may not include rare diseases. The last time that Health Canada analyzed the need

for an orphan drug policy was in 1996 and it concluded then that one was not necessary because the existing regulations were sufficient. Times are changing and we need one now.

At the meetings, each MP was asked to send letters to the Prime Minister and the Minister of Health to act on moving this motion forward in a timelier manner. We did offer to supply letters for them to send to said persons. Most did accept these suggestions. Of course, there were some who said that this is a provincial matter until we explained that the provinces cannot do anything until the federal government shows guidance.

Although it is discouraging to know that this government has done little or nothing to further the cause of orphan diseases, it was encouraging to me to see more patient groups on Parliament Hill and a greater movement forward to talk to more MPs.

The representatives all agreed to take back the same message to their own MP in their riding and to meet again in the very near future in Ottawa. Only by showing a strong front to the government will we get a definition of a rare disorder and a special access drug review for rare diseases.

You can help by contacting your MP to ask for a meeting to discuss the need for an Orphan Drug Policy that will assist you and others with rare disorders. For "how to write or meet your MP" assistance, contact me at wclaughlin@rogers.com.

2010 Aplastic Anemia/Myelodysplasia Nursing Grant Awarded:

By Reanne Booker

The Canadian Nurses Foundation (CNF) is a national non-profit charitable organization that was founded in 1962 by the Canadian Nurses Association. Through the support of nursing education and research, the association endeavors to promote health and quality care for Canadians. The CNF has more than

25 research partners throughout Canada and provides support to each province via scholarships for nurses at the baccalaureate, masters and doctoral levels.

AAMAC has supported a CNF nursing grant since 2000. The grant is awarded by the CNF to individuals pursuing graduate nursing studies who specialize in oncology/hematology or who have oncology/hematology as the focus of their research.

The 2010 AAMAC Nursing Grant Recipient is Ms. Margurite Wong, RN, BA, BSN (Hons). Ms Wong is a research nurse coordinator at the Complementary Medicine Education and Outcomes program (CAMEO) at the British Columbia Cancer Agency (BCCA) and community health nurse at the Vancouver Coastal Health Authority.

Ms. Wong brings a wealth of nursing experience to her current nursing roles, including her staff nurse roles in hospice and acute palliative care, the inpatient oncology unit, and most recently as an Education Resource Nurse, at the Vancouver Centre of the BCCA.

Currently, Ms. Wong is enrolled in the Master of Science (Nursing) program at the University of British Columbia. Her goal is to become a nurse researcher and educator to translate research evidence to clinical practice.

Upon learning that she was the recipient of the 2010 AAMAC Nursing Grant, Ms. Wong wrote to the Canadian Nurses Foundation to express her gratitude and commented, "...[the] generous support is helping [her] to fulfill [her] dream of becoming an oncology advanced practice nurse and educator." Ms. Wong's research will focus on exploring the current trend in complementary medicine (CAM) use and the CAM information and decision supportive needs of cancer patients.

Patient's Corner: Josee's Story

By: Josee

Hi, my name is Josee and in 2006, when I was six years old they told me I had aplastic anemia. Not fun. For a few days before that I was feeling really tired and sort of like you do when you have the flu. Then one day I had a really bad fever and little red spots all over my body, and that's when my mom brought me to CHEO (Children's Hospital of Eastern Ontario). I remember being really scared because I didn't know what was going to happen to me. They told my mom they had to keep me because they didn't know what I had at first. That's when everything just went crazy for me. That night my platelets were at 3. My reds were really low too, I can't remember exactly but I remember those two bags of blood. I got to be really familiar with those bags for the next two years.

After a few days when they found out I had AA, they started giving me cyclosporine and a bunch of other pills. But what I remember most was the cyclosporine. That stuff is AWFUL! When they showed me the size of the pill I was like "NO WAY I'm going to swallow that!" Plus it smelled like a skunk! So instead they said I could get it in a syringe and squirt it in my mouth. You think cyclo smells bad? Let me tell you it tastes worse! It makes Buckley's cough syrup seem like an ice cream sundae.

So after a few weeks of everyone having to fight me to get me to take my meds, I was ready to try taking the pill. And what worked best was...apple sauce! I would put all my pills - 18 of them - in a big spoon of apple sauce and swallow them in one shot! I tried other stuff besides apple sauce, like pudding and yogurt...I even tried ketchup once! Don't do that... trust me.

So, next thing I know I'm stuck in a room for like, four months in isolation. Lots of video games, but it got really hard and boring. That's when I had my first ATG treatment, and that was pretty bad. I felt like I was going to blow up! My mom and dad tell me I was tired and cranky all

the time, but I think I just slept through it all.

The Children's Wish Foundation said I could have a wish, so I wanted to ride a horse, but Dr. Klaassen said it was too dangerous and I'd have to get better first. So I started just thinking about getting better so I could get on a horse one day.

A few weeks later I started feeling a bit better and I was allowed to go to the playroom and have a bit of fun. I even had IV pole races down the hallway with another kid who was sick. We had a blast! The nurses let us, they were really nice. I think I had the nicest nurses you could ever ask for.

I have three necklaces that I made at CHEO made out of hundreds of beads. They're my Candlelighter beads. Every time I had a treatment or a procedure or something, I got a special bead, so every single one of those beads is for something I had to go through when I was sick. The red ones are blood transfusions, there are some for needles and pokes, some for when they put my picc line in and then took it out because it got infected. Some are for bone marrow biopsies...you know, when they punch a hole in your hip. I think I must have had like 10 million needles. I REALLY hated that.

Then I had a second ATG treatment and at first it didn't seem to go so well. I was able to go home for a few days but then I got really sick again. As soon as anyone would just touch me, it hurt so bad I screamed. So guess what... back to CHEO! I even had to go to Montreal because maybe I was going to get a bone marrow transplant. But it turns out I didn't need one. Dr. Klaassen and the other doctors did such a great job that they fixed me, and next thing you know my counts started climbing. Slowly but surely, I was getting better. Then guess what? I got my wish! My counts were good enough that Dr. Klaassen said I could ride a horse (I don't think he really liked the idea to tell you the truth).

Do you know how I felt when I got on that horse for the first time? I felt

GREAT! I felt like I was finally winning the fight! It was the best day of my whole life! I knew I would be OK that day.

The next couple of months my counts kept getting better and better. Then finally in September 2008....NO MORE CYCLO!! As a matter of fact....no more pills! Then at Christmas time that year, Dr. Klaassen said I was in remission. How cool is that! And look at me now, two years later and still in remission and feeling great! I beat the disease, and you can too.

Congratulations McMaster

Many patients who rely on blood transfusions and stem cell transplants were excited to hear news in November about promising research taking place at Ontario's McMaster University. The following news item, "McMaster scientists turn skin into blood," is posted at dailynews.mcmaster.ca along with a short video about the research. While it is still too early to know if this will one day help patients, we wish the research team all the best as they continue their efforts and we hope that one day in the future their efforts might lead to improved treatment options for bone marrow failure patients.

McMaster scientists turn skin into blood

In an important breakthrough, scientists at McMaster University have discovered how to make human blood from adult human skin.

The discovery, published in the prestigious science journal *Nature* on November 7, could mean that in the foreseeable future people needing blood for surgery, cancer treatment or treatment of other blood conditions like anemia will be able to have blood created from a patch of their own skin to provide transfusions.

A Story of Survival

Bob Kupferschmid

(My experience with a Bone Marrow Transplant has been very positive, I can't say that I am typical, I know several people whose ordeal with AA, MDS and BMT has been very hard. I expected the worst but just went one day at a time and in the end I think I was very lucky.)

I had MDS. I don't now. I underwent a blood stem cell transplant in March 2010 to treat my MDS. I was diagnosed in January 2008 which was not the most convenient time. I was due to go to South America on a six month project. My hematologist, Dr. Allan at the Ottawa General Hospital didn't think that was a very good idea. I had thrombocytopenia (low platelet count) and anemia (low red cell count). We arrived at a compromise and for six months I came back to Canada once a month for transfusions.

After 18 months of transfusions a second bone marrow biopsy indicated that the disease had progressed from one to two genetic abnormalities and my blast count was up close to 10%. Like anyone in this situation I was hopeful for a cure so in September 2009 we decided to pursue a bone marrow transplant (BMT).

None of my three siblings were a match so the search expanded into the International Bone Marrow Registry. Around this time I had four cycles of Vidaza which was very effective in eliminating any transfusion requirement. Then in January 2010 a match was found which was not perfect but considered to be very good. Once we agreed to use this unrelated donor (still unknown to me) there was about six weeks while the donor's arrangements were confirmed.

At the end of February I started 5 days of chemo at the BMT Unit at Ottawa General, then one day for radiation. On the 5th of March I received the transplant which consisted of a bag of stem cells delivered like a regular blood transfusion. At this point I was still feeling great; the chemo hadn't bothered me much, yet. I was still at home going into the hospital for a few hours daily.

Six days after the transplant the chemo reaction was such that I couldn't swallow so I was admitted to the hospital and given a feeding tube. After eight days of amazing treatment and support by the BMT staff my throat cleared up and I was feeling good enough to go home.

My transplant had been a 'reduced intensity' transplant meaning the pre-transplant chemo and radiation treatments were too low to eradicate 100% of my existing bone marrow. This reduces the risk of serious infection and allows for reduced amounts of immunosuppressive drugs. It also means that the donor stem cells must eradicate the remainder of my stem cells resulting in some Graft versus Host Disease (GVHD).

The next 5 months at home were restful and uneventful. My GVHD symptoms were moderate – skin rash and dry mouth (which I still have after 8 months). It took 3 months before I could actually taste food. After 5 months I started going back to my office desk job. I now feel healthy and eat well but I think I'll leave the overseas travel until next year.

I have to say that the organization and commitment of the Ottawa General BMT Unit was outstanding and I owe them a great debt of gratitude. Also to my wife Mary and daughters Denise and Lauren who helped keep my spirits up. Lastly, I want to express my deep gratitude to the "unknown donor" who unselfishly provided the gift of stem cells for my transplant.

Registering as a potential stem cell donor has never been easier with OneMatch

With Canadian Blood Services' OneMatch Stem Cell and Marrow Network it is easy and fast to register as a potential stem cell donor—from anywhere in Canada.

Now, registering is as simple and painless as brushing your teeth. In the seconds it takes to swab the inside of your cheek registrants could be steps closer to saving a life.

Visit www.onematch.ca for more information.

News of Note

November is Bone Marrow Awareness Month in Ontario

Members of Provincial Parliament in Ontario voted to make the month of November Bone Marrow Awareness Month. The new Act is intended to raise awareness of the need to increase the size of the volunteer donor pool in order to better the chances of finding a matching bone marrow donor for every patient in need of a transplant.

Information for Parents

The Aplastic Anemia & MDS International Foundation (AAMDSIF) has set up a new webpage at www.aamds.org for parents of pediatric patients. It provides tips, information, and resources that can help such as the booklet Supporting Students with Bone Marrow Failure Diseases: A Guide for Parents & School Personnel. Just visit the website, click on Support & Resources and then Parents of Pediatric Patients. The Foundation plans to include additional information, so check back regularly.

Mark Your Calendars

For the Love of Dance, Saturday, November 27, 2010, 7:30 to 10 p.m., Alumni Theatre, University of Ottawa (Jock Turcot University Centre), Ottawa, ON:

9th Annual Multi-Cultural Dance Showcase and Fundraiser. Showcasing the wonderful diversity that unites us all in our love of dance, this year's all-new show features Chinese, Persian, Columbian, Middle Eastern, Jazz, Ballroom and Circus dance styles, to name only a few! Tickets are \$15 and available at www.annabellydance.ca/events or through Safiya at safiyadancer@gmail.com. Proceeds will be donated at intermission to the Aplastic Anemia and Myelodysplasia Association of Canada.

Marrow Failure and Myelodysplastic Symposium, April 9, 2011, Hospital for Sick Children, Toronto, ON: Dr. Yigal Dror, a member of AAMAC's Medical and Scientific Advisory Committee, will hold information sessions at Sick Kids. All patients, families, and friends are welcome. Watch for details in the next newsletter or visit our website closer to the date.

Regular Monthly Toronto Support Group Meeting:

We now have a 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: 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. The dates through March 2011 are:

Saturday, November 20, 2010
Saturday, December 11, 2010
Saturday, January 8, 2011
Saturday, February 12, 2011
Saturday, March 12, 2011.

For more information, please don't hesitate to contact Bob Ross at amac.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.

Regular Leukemia and Myelodysplastic Syndrome Family Support Group Meetings, 4th Saturday of every month at 11 a.m. to 12:30 p.m., Vancouver General Hospital, Vancouver, BC:

This group is open to people diagnosed with leukemia, or myelodysplastic syndrome, as well as their families and friends. The group provides an opportunity for people affected by leukemia and MDS to get together and share their experiences and wisdom, and learn about these diseases through educational seminars. This mutual support group is not group therapy, however health care professionals working in cancer care facilitate it. The main goals of the group are to provide social, emotional and informational support to people living with leukemia and MDS.

Pre-registration for this free program is required. For more information or to register, please contact: Sharon Paulse, the Patient Services Manager at (604) 733-2873 ext 30 or sharon.paulse@lls.org.

Last Call for Angel Pendants

We have a limited number of angel pendant necklaces available for purchase from our office. This ongoing fundraising activity will come to a close when the remaining necklaces are sold. Order forms are available at www.aamac.ca or you can contact our office. Orders will be processed on a first-come, first-served basis.

Patient Tracker and 2011 Calendar

AAMAC is working with Novartis and Celgene to develop a small tracker and calendar for bone marrow failure patients. It will include room to keep track of your blood counts and other information. To order your free copy, please call the office or email info@aamac.ca.