

# Aplastic Anemia & Myelodysplasia Association of Canada

# NEWSLETTER

## *President's Message*

At the outset may I say how honoured I am to have been elected as AAMAC's President once again. I served in this position from 2004 until April 2006 when I had to step down due to serious health issues that I was dealing with at that time. With the excellent medical care at **Princess Margaret Hospital** and the continuing support I have from my family and friends I look forward to being able to fulfill my duties as President for the coming year.

On behalf of the Board of Directors and all our patients and supporters, I would like to extend a very sincere thank you to our **Past President Silvia Marchesin** for her outstanding contribution to the association during her term. Silvia has always put more than 100% into the job, doing much more than just the role of President. Thanks Silvia, your hard work is most appreciated by all. In addition may I extend our congratulations to Silvia and her husband Robert on the safe arrival of their baby daughter, Heather. We wish them every happiness with their new addition to the family.

We have a very talented executive and I look forward to another very productive year. I am pleased to announce that we have a new Treasurer, **Anna Chamrai**, who volunteered to join us with very impressive academic credentials. Welcome Anna.

Over 100 patients, friends and health professionals from across Canada attended our **Education Day** in September where we were updated on bone marrow failure disorders treatments by an impressive group of medical specialists. Everyone gained valuable knowledge and the presentations are now available on our website for those unable to attend. We held our **AGM** during the day, electing a new executive and reviewing our activities for the year. The organizing committee should take a bow for an excellent day, especially **Caroline Laughlin** who led the committee.

In October Caroline and I attended the **National & International Pharmaceutical Strategies Conference** comparing funding for drugs in Canada vs other countries. We expect some positive follow up from this conference. Funding for drugs for rare disorders is a major concern for our patients and we seize every opportunity to advance this further.

On Nov 2, **Chris Meyer** and I attended the **Toronto Myelodysplastic Syndromes Symposium** sponsored by the Dept of Medicine at the University of Toronto. It was well attended with medical professionals from the US and Canada. Although this symposium was primarily for haematologists and health professionals we learned more about the different treatments currently being used here and in the US. Chris will provide you with some of the highlights further on in this newsletter

Our annual fundraising letter was mailed recently and we hope to get another good response as in the past. Only through the continuing help of our supporters are we able to carry on meeting our objectives and assisting patients and their families with these rare bone marrow failure diseases. In this newsletter you will see a flyer for our 4<sup>th</sup> annual **Spring Gala on April 5, 2008**. This was a very successful event last year. The tickets are sold essentially at cost and we depend on the silent auction to be the real fund raiser. So if you have some items to donate to the auction we would be delighted to receive them anytime. The sooner the better in order to help the organizing committee.

In closing I would like to thank all our supporters and volunteers and wish everyone a happy and safe holiday season and the very best for the New Year.

Sincerely  
Gord Sanford  
President



**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 the Unrelated Bone Marrow Donor Registry; and raises funds for medical research.

#### **BOARD OF DIRECTORS 2007**

Rolla Bahsous  
Cindy Bell  
Reanne Booker  
Joyce Burnett, Secretary  
Stan Chmelyk, Newsletter Editor  
Janice Cook  
Silvia Marchesin  
Robert MacDonald  
Chris Meyer  
Gord Sanford, President  
Trevor Thompson  
Pam Wishart

#### **MEDICAL AND SCIENTIFIC ADVISORY COMMITTEE**

Dr. S. Couban  
Dr. Y. Dror  
Dr. A. Eaves  
Dr. V. Gupta  
Dr. L. Larratt  
Dr. K. Schultz  
Dr. R. Wells, Chair

#### **CHAPTER CO-ORDINATORS**

Cindy Bell, BC  
Liz Lemire/Janice Cook, Alberta  
Chris Meyer, Ontario  
Robert MacDonald, Atlantic

#### **OTHER**

Anna Chamrai, Treasurer

The Aplastic Anemia & Myelodysplasia Association of Canada Newsletter is published 3-4 times a year. The contents are not intended to provide medical advice, which should be obtained from a qualified health professional. No part of this publication may be used or reprinted without written permission. For submissions, inquiries or comments, please contact us at:

Aplastic Anemia and Myelodysplasia  
Association of Canada  
11181 Yonge Street, Suite 321  
Richmond Hill Ontario L4S 1L2  
(905) 780-0698 or 1 (888) 840-0039  
info@aamac.ca www.aamac.ca  
Charitable Registration Number:  
87557 2265 RR0001

## **BC Chapter Update**

*By Cindy Bell*

Well, the wet winter weather is certainly here now, but we do get to see the sun once in a while, which is always a treat!

We had a very worthwhile meeting on October 13, at Canadian Blood Services on Oak Street. Melanie Hyde, who is a Cytogenetics Technologist at Vancouver Hospital, spoke about "The Other End of the Bone Marrow Biopsy Needle". Melanie used a Power point presentation to explain the very technical aspects of the laboratory work that she does, and she did so with humour, and in words that everyone could understand.

On another note, I have decided to step down as the BC Chapter Coordinator effective December 31, 2007. I have been active in this position for 15 years now, and really feel that I need to take a break. It has been an amazing learning experience for me, and I am very grateful for that. I want to acknowledge the support that my parents, Anne and Gordon Bell, have given to me over these past 15 years. They have been at every meeting that I have held, and always provided all the refreshments. My Mom has always taken the minutes of the meetings, and my Dad has always put up all the directional signs. I don't know if I would have stayed in this position quite as long without their invaluable support. So, I especially want to thank them for their faithfulness over all these years. I am hopeful that someone in BC will be willing to take on this very important and worthwhile position in the near future.

I want to wish everyone a happy and joyous Christmas season this year, and a very healthy and exciting new year!

## **Alberta Chapter Update**

*By Janice Cook*

The Calgary support group spent a busy Thursday handing out lifeblood bracelets and Life Savers to our "Lifesavers" at a blood and platelet donor clinic in mid October. Thanks to Marshall and Pat Hansen and Bev Palko for assisting me at this event. Donors seem really happy to meet people that they may have helped and are very receptive to hearing about AAMAC and bone marrow failure disease. We met the presently most active donor in Calgary (over 200 donations) and he had never heard of AA or MDS or PNH.

The following Sunday, Marshall and Pat hosted a lovely lunch social in their home and we spent our time discussing medications and other treatments, dealing with fatigue and other problems associated with living with a chronic disease, sharing information that we have learned about our illnesses and just getting to know each other better. There are already two offers to host a similar meeting in the spring.

The Alberta Chapter is actively looking for someone to come forward and volunteer to become chapter coordinator or possibly to share the job. I am moving to BC later this fall and Liz is presently out of action due to illness. I think that the most important job is for someone to be there to accept calls or emails from newly diagnosed patients or their families to put them in touch with the office so they can be added to our newsletter mailing list, and get that all important package of pertinent information that Lois in our national office sends out to them. For many, this is a lifeline when first dealing with a scary, confusing diagnosis and it's important to have someone to respond to a call or an email. Please contact me if you have any questions about this: (403) 241-0053.

## Ontario Chapter Update

*By Chris Meyer*

Family and friends of the late Mark Patchell, including his wife Carole, son Spencer and daughter Leah, gathered again in Owen Sound in August for the second annual Mark Patchell Memorial Golf Tournament.

Organizers could not have asked for a more beautiful summer day to play 18 holes of golf. The event was a big success thanks to the hard work of organizers Duane Bowman, Nicole Lewis, Bob and Mary Clark, Rori Sim, Brianne Sim and Elaine Phillip. In addition to raising awareness about aplastic anemia and the association, the event raised \$945 to help AAMAC carry out its mandate! In addition to the organizers, I would like to thank Carole Patchell and her children for their generosity. Originally the organizers planned to split the funds raised between AAMAC and the Patchell family. However Carole asked that all the funds be donated to the association! Next year's tournament will take place the second Saturday after the long weekend in September. Watch our newsletter and website for more details.

Thank you to the Anemia Institute for including AAMAC materials at its Toronto City Hall Anemia Event on August 21, 2007. The event included a screening clinic to highlight anemia to the general public.

Thank you to Angela Li and Jen Rintoul for handing out LifeBlood bracelets the following day at Toronto Police Services headquarters where an August blood donor clinic was organized to show support for five-year-old Karlee May. Karlee, whose parents are both Toronto police officers, underwent a bone marrow transplant for aplastic anemia this past summer. This was the second such clinic which AAMAC attended.

Many Ontario members benefited from our annual Patient Education Day in Toronto and about 20 patients,

family members and friends attended a Chapter social gathering afterwards at Wayne Gretzky's Restaurant. On behalf of everyone who attended the patient day, I would like to extend a huge thank you to all of our speakers, including the patients who shared their stories, and the many local volunteers who made the day possible!

Special thanks also to Trevor and Patricia Thompson for hosting a support group meeting in Kingston during the Association's awareness week in October.

### Get Ready for Spring Swing 2008

Many Ontario volunteers are now gearing up for our Chapter's largest fundraising event of the year – Spring Swing featuring the live big band sounds of No Strings Attached and a silent auction with a great range of items! I'm also extremely pleased to report that Enbridge Gas Distribution returns as this year's Spring Swing presenting sponsor. Please reserve your ticket now and encourage family, friends and coworkers to attend.

Tickets include hors d'oeuvres, antipasto (prosciutto melone, olives, grilled vegetables and bocconcini), pasta (rigatoni pomodoro, small agnellotti parma), entrée (veal marsala and pollo limone, potatoes, vegetables, salad), dessert (crepes berries), standard bar and coffee/tea/espresso/cappuccino followed by a sweet table at 10:30 with pastries and cheese and crackers.

We've also started accepting silent auction items and will continue to do so until March 15. Please call me at (416) 994-6712 to reserve your spot, volunteer or request a corporate sponsorship package. Contact Stan Chmelyk regarding auction items at (905) 457-0552 or [schmelyk@sympatico.ca](mailto:schmelyk@sympatico.ca).

A copy of the event poster is included in the newsletter for Ontario members and I encourage you to post your copy in your local hospital, transfusion clinic or public area to help promote the event.

Finally, have you ever wondered what happens to blood after it's donated and before it is transfused into the patient? Please check the events section for details about our tour of Canadian Blood Services Toronto blood centre in April. Special thanks to Regional Director Renee Naiman for hosting this event. Space is limited so please contact me to reserve your place today.

## Atlantic Chapter Update

*By David McFarlane*

This quarter was a busy one. It all started with our meeting in June when we gathered at the Victoria General (VG) Hospital's lab. Dr. Rob Liwski developed a wonderful presentation incorporating bone marrow samples from some of our members (with their consent). The evening was incredibly informative and we all look forward to having a follow-up presentation sometime later this year.

We did not hold our regular meetings in July or August, but we did have our annual picnic on August 12 at Oakfield Park. The day was beautiful and even though the lake had been closed for the summer, it was re-opened the day before our picnic. We had a great turnout and everyone had a wonderful time. We hope that all of our future events turn out to be as enjoyable.



*Left to Right: Robert MacDonald, Jennifer Garvey, Dolores d'Entremont, Gai Thomas and David McFarlane*

All patients who have undergone a bone marrow transplant in Halifax are invited to a dinner each year. This is a wonderful opportunity to share stories and experiences. A large number of our patient members in the Atlantic Chapter fall into this category. I am told that this year's dinner was a hit, but I was not able to attend as I was representing the Atlantic Chapter at this year's Education Day. I'm glad that I chose to attend the Education Day, but I hope that next year I will be able to plan to attend both events.

October included AAMAC's awareness week. This year we set up a display at Canadian Blood Services and our members took turns visiting the CBS's collection clinic. We thanked donors for their generous contributions and handed out Life Savers to show them what their gift means to us.

Our next big events will include another visit to the VG Hospital's lab and our winter social. If you would like to get more information about the Atlantic Chapter's upcoming events please e-mail us at [atlantic@aamac.ca](mailto:atlantic@aamac.ca) or phone Robert at (902) 443-1615.

## Healthcare Providers Hear From MDS Experts

*By Chris Meyer*

Gord Sanford and I were pleased to represent AAMAC with a display at the day-long Toronto Myelodysplastic Syndromes Symposium 2007: Challenges and Opportunities on November 2.

About 70 healthcare professionals attended this event which was organized by Dr. Richard Wells and Dr. Rena Buckstein in collaboration with the University of Toronto's Office of Continuing Education and Professional Development (Division of Hematology Oncology, Department of Medicine), Sunnybrook Health Sciences Centre and Princess Margaret Hospital.

Leading international speakers included Dr. John Bennett, from the University of Rochester (who was part of the team which developed the early French-British-American or FAB classification system for MDS and the World Health Organization classification currently in use), Dr. Janice Gabrilove from Mount Sinai School of Medicine, Stephen Nimer from Memorial Sloan-Kettering Cancer Centre, all based in New York State, and Dr. Mikkael Sekeres from the Cleveland Clinic Lerner College of Medicine in Ohio. Local expert speakers included Drs. Wells and Buckstein from the Odette Cancer Centre at Sunnybrook and Drs. Jeffrey Lipton and Karen Yee from Princess Margaret.

Highly technical presentations covered the Epidemiology of MDS; Cytogenetics, Biologic and Clinical Markers for Refining the Prognostic Classification; Supportive Care and the Use of Hematopoietic Growth Factors; a look ahead at Imids and Novel Approaches to Treating MDS; Hypomethylating Agents in the Management of MDS; Chelating Therapy in MDS; Advances in Stem Cell Transplantation for MDS; Strategies to Improve Funding in MDS; and an overview of the Sunnybrook MDS Program.

Dr. Buckstein shared the findings of a single-centre study that Sunnybrook conducted to better estimate the number of patients with MDS at any one time (prevalence). She discussed the possibility of using unexplained anemia in the elderly as a surrogate marker for undiagnosed MDS. She also discussed the importance of increasing diagnosis, preferably by finding less invasive methods, and predicted that the healthcare burden of MDS will increase significantly in years to come.

Dr. Bennett discussed refinements to MDS classifications as more information is known, including the World Health Organization classification system which is expected to be revised in 2008.

In his discussion about hypomethylating agents, Dr. Nimer noted that supportive care is no longer a reasonable option for most MDS patients. "It's almost becoming unconscionable to tell a patient with MDS you'll be treated with supportive care," he said. (Currently there are no hypomethylating drugs approved in Canada although some patients have been able to access such drugs through clinical trials. We hope that application to Health Canada for Decitabine approval may be pursued by the manufacturer in the near future.)

Looking at advances in stem cell transplants, Dr. Lipton discussed the advantages and disadvantages of lower intensity stem cell transplants for patients up to and sometimes over the age of 70, investigations into auto-grafts which involve using some of the patients own bone marrow for transplant and using multiple units of cord blood to provide enough cells to transplant an adult. He also noted that some centres are using pre-transplant therapy involving de-methylating agents. He encouraged other doctors to have suitable MDS patients evaluated for a bone marrow transplant early and not wait too long to consider this option.

During his presentation on drug funding, Daniel Rego from Plasmid Biocommunications encouraged physicians to file requests for drugs with their respective provinces to illustrate the demand for the products and suggested ways that physicians, patient groups like AAMAC and industry could work to encourage governments to cover the cost of new treatment options.

Dr. Wells gave an update on the MDS program at Sunnybrook noting that it welcomed 100 new patients in 2006 with referrals and consultations from as far away as Newfoundland, Prince Edward Island, Quebec and Alberta. Currently 18 patients are enrolled in a decitabine clinical trial while another 17 are taking lenalidomide (Revlimid), available through Health Canada's Special Access Programme. The Centre has begun a registry and

database of patients with 200 people already included. Dr. Wells hopes to create web-based data entry that would allow for greater collaboration among Canadian doctors with a decentralized database and registry. The centre has also started an MDS tissue bank with 120 deposits so far. He encouraged interested healthcare providers with an interest in MDS to contact the centre about collaborating.

The day ended with an interesting series of patient case studies and the opportunity for audience members to “vote” for their recommended course of treatment using touch pad technology.

It was wonderful to see so many hematologists, nurses, pharmacists, researchers and other healthcare professionals interested in learning more about MDS. This type of educational programming is critical to ensuring that patients receive the best possible care. Another event is already being planned for next year.

## AAMAC Funding Pediatric Research Through the C<sup>17</sup> Research Network

By *Kathy Brodeur-Robb, Executive Director, C<sup>17</sup> Research Network*

The C<sup>17</sup> Research Network is a Canada-wide group of pediatric hematology and oncology researchers working in the 17 pediatric cancer centres across Canada. These researchers all work with the Children's Oncology Group (COG), an international research group of more than 240 hospitals that conduct clinical trials for children with cancer.

COG is currently conducting a study called “*The Treatment of Down Syndrome (DS) Children with Acute Myeloid Leukemia (AML) and Myelodysplastic Syndrome (MDS) Under the Age of 4 Years.*” The study is approved in Canada and is currently open in nine of the pediatric hematology/oncology centres in Canada.

Research has shown that children with DS have a higher risk of developing myelodysplasia or leukemia than children who do not have DS. On the other hand, children with DS who develop AML/MDS respond better to chemotherapy than children with AML/MDS who do not have DS.

The main goal of the study is to see if it is possible to reduce the amount of chemotherapy in DS children with AML or MDS, to decrease the possible drug side effects (particularly to the heart), while still maintaining as high a survival rate as previous studies. Another goal is to study the unique biological features of AML/MDS in these children to identify why they have an extremely high overall survival rate, and to try to identify what is different about the small number of patients who do not have as good a response.

About 205 children are expected to take part in this study worldwide.

## Patient Education Day

By *Rolla Babsous*

More than one hundred patients, family members, AAMAC board members, doctors and healthcare professionals from all across Canada gathered at Metro Hall in Toronto on September 29 to share inspirational stories, experiences, and medical information. This was AAMAC's largest patient education day to date. With attendees from across Canada, the three bone marrow failure diseases of aplastic anemia, myelodysplasia and PNH, were well represented by attendees from five provinces.

After registration, breakfast, and a warm welcome, Samar Chaker gave an inspirational patient story about her struggles and success with aplastic anemia. Dr. Robert Klaassen followed with a discussion on the treatments of aplastic anemia in children. Dr. Yigal Dror then gave a talk on childhood MDS symptoms and treatments.

Following a break, Joan Weir shared her patient experience. Dr. Vikas Gupta outlined treatment of aplastic anemia while Dr. Richard Wells went over treatment options for MDS.

During the lunch break, attendees were given the chance to attend AAMAC's Annual General Meeting, where the Board was introduced and re-elected.

Following the wonderful lunch, Dr. John Doyle explored scenarios in finding possible donors for bone marrow transplantation. Afterwards, board member Stan Chmelyk shared his journey as a bone marrow transplant recipient, and bone marrow transplant nurse and board member Reanne Booker discussed both the emotional and physical path to recovery involved in bone marrow transplantation.



*Dr. Doyle of the Hospital for Sick Children, pictured with Samar Chaker, a patient speaker, at our Education Day.*

Colleen Savage then gave a thought-provoking talk about the politics involved in access to drugs for patients with these illnesses and similar diseases.

It is important to mention that attendees had opportunities to ask healthcare professionals questions in panel Q&As following each presentation. They were also encouraged to fill out a feedback

survey, in which we received an overwhelmingly positive response.

We thank the wonderful speakers who shared their amazing patient stories, including Samar Chaker, Joan Weir, and Stan Chmelyk. We also wish to thank our sponsors for supporting this wonderful event: Novartis and Celgene, as well as Toronto Councillor Gloria Lindsay-Luby for the generous use of Metro Hall.

A big thank-you goes out to volunteers who worked hard to make this day a great success: Bill Laughlin, Carole Sanford, Jennette Rintoul, Victoria Fleming, Angela Li, Yirong Song, Lois Henderson and, from Harbord Collegiate's Key Club, Sara Kanagasabai, Melissa Tom-Kun and Bridget Nhu Dang. Thank you also goes out to the members of AAMAC's Board of Directors, for their commitment and hard work on this enlightening event

We look forward to next year's Patient Education Day. Please keep an eye on the website and newsletter for further information.

## Bone Marrow Survivor Offers Hope To Patients

By Stan Chmelyk



*The following remarks were delivered by AAMAC Board member Stan Chmelyk to attendees at our Patient Education Day in September*

In August of 2001 I was working as manager of research for a chemical company (I am a chemical engineer by

training). I was 45 years old at the time, my career was going well and we had just purchased a new house and moved to Brampton, Ontario from Toronto. I was physically active and strong and did not feel ill in any significant way.

I had been roughhousing with my youngest son, and he had punched me in the shoulder, which resulted in a large bruise which encircled my right arm. My mother had bruised easily so I dismissed the injury as simply a tendency to bruise that I had inherited from her. The bruise persisted and my wife insisted I see a doctor. I protested, but I sensed her real concern that something was very wrong and agreed to go.

My new family doctor took a blood sample and advised me that if I did not hear from him that everything was OK. Within a couple of days the doctor called me at my work; his voice filled with tension, and said he was referring me to an oncologist. I had to look up the word oncologist to determine that it referred to a specialist dealing with cancer. I could sense that something was very wrong.

Later that week I met with the oncologist and he informed me that my platelets (blood cells responsible for controlling bleeding) were extremely low (they measured 1, when the normal range is 150 – 400). As well, my neutrophils (the white blood cells that combat certain types of infection) were listed as not detectable.

I was at grave risk of having a spontaneous bleed which the doctors would be unable to control and could lead to death. A minor injury, cut or a fall, could be fatal. I was told not to use a straight razor, to brush my teeth only with a sponge brush and to refrain from strenuous activities. I was also put on prophylactic antibiotics to guard against infections. In the case of a fever, I literally had hours to get to emergency so they could administer intravenous antibiotics. During the visit with the oncologist he extracted a sample of marrow for testing from my hip using a long needle. This procedure is not nearly as painful or

ominous as it sounds – I have had worse experiences at the dentist.

Within a week, I had my diagnosis confirmed; it was myelodysplasia, also called myelodysplastic syndrome (MDS). This is a rare, very dangerous and incurable bone marrow failure disease. They started giving me transfusions of platelets twice weekly to try and get my counts up. Unfortunately my immune system began rejecting the infused platelets almost immediately and within an hour or two of the infusion the levels would drop right back down where they began. They continued giving me the transfusions as there was nothing further they could do to prevent the possibility of a serious bleed. During the course of my treatment I received about 30 to 35 platelet transfusions and 4 or 5 units of whole blood. I cannot express how thankful I am to the Canadian Blood Services and their donors for the blood products I received.

It was in the week or two after my diagnosis that I went into a complete panic. I was a vibrant middle aged man that went to see the doctor about some bruising and was given what amounted to a death sentence. From what I could determine from the internet (despite a caution from my doctor not to put too much stock in the information online), I had perhaps six months to a year to live. I would go nights without sleep and scaring myself completely with each new website I found on the internet. This is as close to madness as I ever want to get.

We had just moved to Brampton and did not have any friends – my family was on the west coast and my wife's family was on the east coast. We did not have a large network of support from which to draw upon. I was not aware (nor was my doctor) of the existence of the Aplastic Anemia and Myelodysplasia Association of Canada. I could certainly have made use of their support and the reliable information they could provide. What little information I could find online was very discouraging in prognosis. My wife and family, although

extremely concerned about me, did not know what to say to make me feel better. They were just as much victims as I was.

The oncologist could see that I was having problems dealing with the news and he gave some advice that helped me tremendously. He said to me, 'You have what you have – there is nothing you can do to change that. Accept it and go forward.' At this point I realized that I had to change my state of mind both for my well being as well as for those around me.

Within three weeks of diagnosis, and with my poor response to the platelet transfusions, the oncologist informed me that he was referring me to another specialist at the Princess Margaret Hospital (PMH) who would talk to me about a bone marrow transplant (BMT). As the oncologist put it, 'If you had leukemia I could help you, I am sorry.' Imagine, wishing that you actually had leukemia. As it turned out, I was in the latter stages of MDS and I was likely in transition to a very dangerous form of leukemia called acute myelogenous leukemia (AML). By the time of my eventual transplant I likely had AML.

The specialist at the PMH agreed that I had to have the BMT and indicated that there was a fair bit of urgency in having it done. He was suggesting that it be done before Christmas (it was then the end of August).

Unfortunately the PMH was short of nurses and only about one half the beds were available so the quickest they could schedule the procedure was in February. I could sense they did not want to wait this long and they gave me the option of several other hospitals and we chose the Ottawa General Hospital.

In the later part of November 2001 (three months after my diagnosis) my wife and I packed up the car and we drove to Ottawa for what was to be a six-week stay. We left behind our 8 year old daughter with our adult son with the support of my mother who had flown out from BC. We had made arrangements to fly my brother from

northern British Columbia to Ottawa. Blood testing had shown that he was a close enough match to me to be considered a bone marrow donor. During our time in Ottawa we stayed at the "Rotel," a hotel run and subsidized by the Rotary Club.

BMTs at the Ottawa General are done a little differently than was common practice at other institutions. The clinic was run on an out-patient basis whereby one would go for a daily check-up and blood test, be given their prescribed drugs and then released. It was only when they became very ill that the patients were admitted to hospital. My wife and I were in Ottawa for a period of six weeks and I actually was admitted to the hospital for three of those weeks.

I am not sure I could tell you what I was doing during Christmas a couple of years ago, but I can tell you exactly where I was and what I was doing during the Christmas of 2001. I received the stem cells they had separated from my brother's blood on Nov 27 (my rebirthday). It is common to actually harvest the stem cells from the blood of a donor and infuse them into the patient. This is as opposed to taking actual bone marrow from the donor and infusing it into the patient. This whole period in Ottawa is kind of a blur to me and I recall various isolated snippets. I was hospitalized about a week after receiving the stem cells. I was discharged to an out-patient basis right around Christmas and then New Year's Eve we were released and allowed to travel back home to Brampton.

I had follow-up visits to the PMH initially about three times weekly and they tapered off as my condition improved. It took about a year for me to recover most of my strength and after about two years I was off medications. It is now six years post transplant and I have clinic visits to the PMH once a year. My blood results are perfectly normal and I lead a relatively normal life.

Looking back would I go through it again? Yes, without hesitation – how often does one get a death sentence

commuted? I am so happy to have been given a second chance. Certainly my life has changed and there are some restrictions on what I am capable of, however the lenses on the glasses of life have changed for me. I have a much greater appreciation of what really matters in life. I am closer to my family and more aware of the beauty of the world around me. I appreciate each day, one day at a time.

How did I cope throughout this journey? I had the support of a loving and resourceful wife without whom I would not be here. I also had support from family, friends and coworkers. I received the very best of care from some very talented health care professionals. I have absolutely nothing but good to say about the care I received from the doctors and nurses treating me. I am so lucky I live in a country that has a public health care system that treats patients as individuals and not statistics. Given the risky nature of the BMT procedure (I was given a 30% chance of surviving), I am not sure whether a private insurance firm would have financed the transplant. A sense of humour is important. It may not improve your health but it relieves tension and makes life a lot easier on the caregivers supporting you. Lastly never give up hope. I am proof positive that even with a very grim prognosis there is reason to be positive.

## AAMDSIF Conference in Las Vegas

*By Janice Cook*

I was privileged to have the opportunity to attend the Aplastic Anemia and MDS International Foundation annual Patient and Family Conference in Las Vegas, August 15 to 17. It was full of up-to-date information on bone marrow failure diseases, including research and treatments, given by an impressive panel of experts in their fields. There were 275 registrants, the largest ever.

Dr. Neal Young, from the National

Heart, Lung and Blood Institute gave an overview of Bone Marrow Failure Diseases, and spoke about their shared mechanisms or pathophysiology that may respond to similar treatments. Then he discussed genetics and gene mutation as a major focus of research in AA in the last few years. Some genetic risk factors have now been identified, along with PNH clones, and the future discoveries over the next decade should help decide on the right treatment for different diseases.

Dr Ron Paquette, from the University of California, spoke about the future of research and scientific highlights in the past year focusing on drug approvals and disapprovals. We were given a partial list of 10 new MDS drugs and treatments currently in U.S. clinical trials. Campath and Sirolimus for AA, decitabine (Dacogen) and azacytidine (Vidaza) for MDS and eculizumab (Soliris) for PNH were all highlighted as being advances in therapy. We were told about the recent controversy about ESAs (Erythropoiesis-stimulating agents.) In May, they were associated with increased risks of death due to clotting events in cancer patients and increased resistance to chemotherapy or radiation, so it was proposed that coverage for ESA treatment in MDS should end. In July, there was public outcry over this, as it is not clear if there is increased risk in MDS. Ongoing studies of G-CSF, Exjade, Dacogen, and Soliris, are taking place.

Dr. Steven Gore, from the Sidney Kimmel Cancer Center of Johns Hopkins, spoke about MDS and iron overload. He feels it is more useful to

classify MDS as a chronic leukemia, and discussed diagnosis by the IPSS (International Prognostic Scoring System). He also feels that MDS is common and under-reported, and that each patient should be evaluated for the potential for an allogeneic stem cell transplant, either myeloablative or non-myeloablative, which is the only curative therapy for MDS. He discussed five drugs and their various pros and cons. Regardless of the therapy chosen he stressed the need for communication with your doctor to devise a treatment plan for a complicated disease.

Dr. Jaroslaw Maciejewski's (Cleveland Clinic, Taussig Cancer Center) topic was PNH. His presentation centered on describing the latest in research and treatment options, including, steroids, anticoagulants, immunosuppressant therapy, and of course eculizumab. He is also interested in epidemiology and the first epidemiological studies for bone marrow failure disease that are recently underway.

Dr David Margolis, from the Children's Hospital of Wisconsin talked about pediatric issues, including short and long term outcomes of matched sibling bone marrow transplantation (BMT), intensive immune suppression, and alternative donor transplants. He also raised questions that are being asked more these days such as: 'Should I have a baby to save my baby?' and 'Should we cryopreserve cord blood for future use?'

Dr Joachim Deeg (Fred Hutchinson Cancer Research Center and University of Washington School of

Medicine) spoke about BMTs. He discussed the more than 30 years of follow-up data now available and different conditioning regimens including newer ones designed to reduce toxicity. He also discussed Graft Versus Host Disease (GVHD) and survival rates after transplant.

There were also question and answer sessions with the panelists and roundtable discussions focusing on individual disease or topics. There was an introduction to MARROWFORUMS ([www.marrowforums.org](http://www.marrowforums.org)) which has been set up by a long-time AAMDSIF board member to function as a support and information network for patients and their families. An interesting luncheon session featured a mom and daughter who hiked across America to celebrate the daughter's recovery from AA and raise awareness and funds ([www.ourhike.com](http://www.ourhike.com)). I found them truly inspiring.

The last session of the conference was by Paul Donoghue, PhD. It was called A Message of Hope. His talk was about living with an invisible chronic illness, and communicating with others in a way that is helpful. He is the author of "Sick and Tired of Feeling Sick and Tired," and "Are You Really Listening?"

I thank AAMAC for the opportunity to attend this conference. It was a wonderful learning opportunity and I truly enjoyed the chance to meet those I connected with including Canadians. I know that some of us will keep in touch.

# The Angel Pendant

## FUNDRAISER

"How wonderful it is that nobody need wait a single moment before starting to improve the whole world."

Anne Frank

for more information, visit: [www.theangelpendant.com](http://www.theangelpendant.com), but please note: AAMAC will only receive proceeds from orders placed through us

### The Angel Pendant Story

In 2001, Stan W. Tait, renowned Canadian jewellery designer, was asked to create an Angel Pendant as a gift for a friend suffering from cancer. Deeply touched by his client's love and support for her friend, he began making Angel Pendants for people in his own life dealing with difficult times. Realizing the enormous potential we all have to make a difference in the lives of those we love, Mr. Tait resolved to donate a portion of the proceeds from the sale of each Angel Pendant to worthy causes such as ours.

### Don't We All Need an Angel in our Life?

What better way to show you care than with a symbolic angel to "watch over" your loved ones all year 'round. These lovely pendants and pins make the perfect gift for those you care about and are concerned for. The unique, eye-catching angel design is a natural conversation starter at holiday events and functions.

### Aplastic Anemia and Myelodysplasia

#### Assn of Canada Angel Pendant Fundraiser

We are very pleased to have the Angel Pendant as an ongoing item that can be purchased from our national office.



Actual Size 1" high by 5.8" wide

When you purchase a sterling silver lapel pin or pendant (18" or 20" chain included) for \$60, **almost 50% is donated to AAMAC.**

When you purchase a 14k gold lapel pin or pendant (chain not included) for \$155, **43% is donated to AAMAC.**

*f*

Mr  Mrs  Ms  Miss \_\_\_\_\_  
first name last name

Address: \_\_\_\_\_ City: \_\_\_\_\_ Prov: \_\_\_\_\_ Postal Code: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Quantity	Item	Total
_____	Angel Pendants - sterling silver with 18" chain @ \$60 each	\$ _____
_____	Angel Pendants - sterling silver with 20" chain @ \$60 each	\$ _____
_____	Angel Pendants - 14k gold <i>without chain</i> @ \$155 each	\$ _____
_____	Angel Lapel Pins - sterling silver @ \$60 each	\$ _____
_____	Angel Lapel Pins - 14k gold @ \$155 each	\$ _____
<b>Total (no charge for shipping and handling):</b>		\$ _____

Cheque payable to "AAMAC" enclosed  Visa  MasterCard Name on card:  as above or: \_\_\_\_\_

Card #: \_\_\_\_\_ Expiry: \_\_\_\_\_ / \_\_\_\_\_ Signature: \_\_\_\_\_

mail to: AAMAC, 11181 Yonge Street, Suite 321, Richmond Hill ON L4S 1L2, or

fax to: 905-780-1648, or

call: 1-888-840-0039 or 905-780-0698 to charge by phone

## Mark Your Calendars

**Spring Swing 2008, Saturday, April 5, 2008, Toronto, Ontario:** Reserve your ticket now for our fourth annual Spring Swing dinner, dance and silent auction, once again featuring the big band No Strings Attached! Tickets sold out in 2007 so don't be disappointed. Dinner, drinks and live music are included again for the low price of \$60 per person! We've also started accepting silent auction items and will continue to do so until March 15. Please call Chris Meyer at (416) 994-6712 to reserve your spot or volunteer. Contact Stan Chmelyk regarding auction items at (905) 457-0552 or schmelyk@sympatico.ca.

**Toronto Blood Centre Tour, Tuesday, April 22, 2008, 6 p.m., Toronto, Ontario:** Join us for a behind the scenes tour of Canadian Blood Services' blood centre in Toronto (close to Sick Kids, Princess Margaret Hospital and the College Park subway stop) and see the interesting journey that each blood donation takes. Members will gather for coffee and light sandwiches at 67 College Street before walking to see the various labs where blood is divided into components, such as red blood cells and platelets, tested and made ready for delivery. Regional Director Renee Naiman will answer questions. Spaces are limited so contact Chris Meyer at ontario@aamac.ca or (416) 994-6712 to reserve your spot today.

**Canadian Transplant Games August 5 to 10, 2008, Windsor, Ontario:** The 2008 Canadian Transplant Games, hosted by the Canadian Transplant Association, will be in Windsor, Ontario, from August 5 to 10, 2008. More than 300 organ and tissue transplant recipients from ages 5 to 76, including bone marrow transplant recipients, are expected. Sports include track and field, swimming, tennis, table tennis, squash, badminton, golf, volleyball, lawn bowling and bowling. For details visit [www.ctawindsor.org](http://www.ctawindsor.org).

## News of Note

**Newsletter Now Available Online**  
Starting with the Spring 2007 edition, we are posting newsletters on our website at [www.aamac.ca](http://www.aamac.ca). The newsletter will be in Adobe PDF format and will be available for viewing on a read-only basis.

**Join Our Newsletter Mailing List**  
Did you pick up this newsletter at an event or clinic? If our quarterly newsletter is not being mailed to your home already, join our mailing list. It's free and easy. Just contact the office at the mailing address, email address or phone numbers listed on page 2. Already on our list? Please don't forget to let us know if you move.

**Missed Our Patient Education Day?**  
Presentation slides are now posted at [www.aamac.ca](http://www.aamac.ca). Special thanks to our speakers for making their presentations available.

**Congratulations Dr. Messner!**  
Dr. Hans Messner was honoured September 17, 2007 with a Lifetime Achievement Award for outstanding contributions to Canada's blood system at a national ceremony in Ottawa. The eighth annual "Honouring our Lifeblood" event was hosted by Canadian Blood Services (CBS) at the Canada Aviation Museum and honours Canadians who improve and save lives through their support of the blood system.

Many AAMAC patients in Ontario know Dr. Messner as the Director of the Bone Marrow Transplant Program at Princess Margaret Hospital in Toronto. AAMAC extends its congratulations to Dr. Messner!

Blood donors, bone marrow donors and volunteers were also recognized at the event for their important contributions to the blood system and patients.

AAMAC President Gord Sanford, who is also a CBS Director, and AAMAC Director Pam Wishart, who

represents AAMAC as a member of CBS's National Liaison Committee attended the ceremony.

Canadian Blood Services is a national, not-for-profit charitable organization that manages the blood supply in all provinces and territories except Quebec and oversees the country's unrelated bone marrow donor registry.

**Driving Home Need for Blood**  
Drivers in Ontario can raise awareness about the need for blood with a "Give Blood" license plate. Call the Ministry of Transportation at 1 (800) 288-6758 or visit [www.mto.gov.on.ca](http://www.mto.gov.on.ca) for information. Across the country, Canadians can also buy inexpensive license plate holders for their vehicles from [www.blood.ca](http://www.blood.ca).

### It's a girl!!!



*Silvia Marchesin with daughter Heather*

The AAMAC Board would like to extend congratulations to Silvia and her husband, Robert, on the arrival of their daughter Heather.

### Christmas Shopping?

The sterling silver and gold angel pendants and pins that we are selling as a fundraiser make a perfect Christmas gift. Please have your order in by December 7 to ensure arrival before Christmas.