

Aplastic Anemia & Myelodysplasia Association of Canada NEWSLETTER

Tribute to AAMAC President Gord Sanford

It is with great sadness that we let members know about the passing of our President Gord Sanford on May 14, 2008. The following is a tribute to Gord written by long-time Association volunteer Caroline Laughlin and read by Bill Laughlin on behalf of the Association at Gord's memorial service in Richmond Hill, Ontario.

When Gord was diagnosed with myelodysplasia, he contacted the Aplastic Anemia and Myelodysplasia Association of Canada – AAMAC for short. He was at his wit's end as doctors had told him that nothing could be done and he must simply put his life in order. He asked if the association could give him any information about possible treatments and hospitals where they were available. AAMAC does offer support and current information on this disease and we were able to guide him to hospitals and treatments that would at least give him some options. He sought out doctors here at Princess Margaret Hospital and started treatment very soon afterwards with new hope and optimism for the future.

He came to AAMAC support group meetings, listened and learned from others going through the same difficulties. He shared his experiences and offered support to others. He talked to patients, near and far, and soon became a member of our Board. It wasn't very long before he became its President, all the while taking treatment himself.

Gord has been responsible for many changes and much growth in our organization. He spearheaded the first of our successful silent auction fundraisers. He even postponed very intense chemotherapy so that he could attend and host the event in 2006.

He encouraged the Board to establish a permanent office which is now just up the road. He supported the creation of local chapters, and his only regret was that he was not well enough to attend the launch of the Atlantic Chapter in the fall of 2005. He was amazing at just picking up the phone to talk to anyone who could advise us about getting more access to new therapies, regardless of whether it was doctors, bureaucrats or drug company representatives.

An opportunity came to apply for the stakeholder position on the Board of Canadian Blood Services and he has served in that capacity ever since. We have had two Education Day patient conferences across the country and are working on our third in October. Gord was always at the ready on the planning committees. Another advocacy group wanted AAMAC to join them in sessions to learn how to seek government approval and support for new drug therapies. Who was the first to talk to them and encourage us to learn from them? Gord. In fact his next meeting was already on the calendar for next week. Just two weeks ago he had set up a meeting with a prominent pharmaceutical company to ascertain how we could work together to be better advocates for patients who are not well enough to be advocates for themselves.

He represented AAMAC in the Network of Rare Blood Disorder Organizations and attended many of their conferences where he contributed to all the discussions. He helped organize a conference for rare diseases and attended many of the meetings both in person and on conference calls with the Canadian Organization for Rare Disorders (CORD). (continued on the next page)



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.

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Tribute Continued...

He represented AAMAC at the Aplastic Anemia & MDS International Foundation conferences. There he learned more about the diseases and available treatments and brought his new-found knowledge back to our patients.

His spirit and his hard work have influenced all of the operations of AAMAC and made us much more effective at trying to help those who contact us.

On a personal note, we will remember Gord particularly in connection with the silent auction/dinner/dance fundraisers I referred to earlier. We have now held four of these annual events and each has been more successful than its predecessors.

Just as important as the financial success of these endeavours has been the opportunity they have provided for us to see Gord delighted in a happy social context, surrounded by his very supportive, hard-working family and his army of faithful friends. He was obviously able to draw renewed strength from them and he certainly provided all of us with a great example of cheerful dedication and steadfast resolve. We owe him much and we will miss him greatly.

Alberta Chapter Update

By Janice Cook

As yet no one has come forward to take over as chapter coordinator. As there is so little to report from Alberta this time I'd like to take the opportunity to tell everyone about a special young lady from High Prairie, Alberta.

Kayla (Cox) Killoran was 22 and her little boy Konnor had just turned two when she was diagnosed with severe aplastic anemia in the spring of 2006. She was treated in Edmonton with immunosuppression treatment. Kayla

attended our patient education day in September of that year, and then found out that winter that she had no bone marrow match. Although she is in partial remission, she worries about what the future will hold for her as a young mother.

She and her husband Josh and Konnor moved to High Prairie, Alberta last spring. She has now taken on the challenge of raising awareness there about bone marrow failure disease, the need for blood donors and most especially the need for more people to sign up for OneMatch (the Stem Cell and Bone Marrow Network of Canadian Blood Services).

She has raised about \$200 in AAMAC LifeBlood bracelet sales and has spoken to a number of community groups including the Royal Purple, the newspaper and the local Health Council at a Community Information Day. Now she is teaming up with them and a group has been organized to get the word out in the town's high schools as well as the Tri-Native Council in the area. They also hope to speak on local radio.

Although her community is too small to make a blood donor clinic possible, she has recruited at least two new donors, and has been told by OneMatch that donations in the area are up drastically since she started. Kayla says that she is doing this for Konnor, but her efforts show the kind of incentive and drive that may end up helping many others. I'm proud to know you Kayla.

Ontario Chapter Update

By Chris Meyer and Stan Chmelyk

A strong group of active volunteers in Ontario have been extremely busy this Spring. See Rolla's article about our 20th anniversary celebration at this year's annual Spring Swing.

In April I had the pleasure of meeting MDS patients at a new support group in Hamilton, Ontario organized by Dr. Brian Leber of McMaster Health Sciences Centre and the Leukemia &

Lymphoma Society of Canada. More than a dozen patients and family members attended to discuss advocating for new medications for MDS. The meeting is held quarterly and hosted by two local nurses, Karen Running and Tammy De Gelder from the Juravinski Cancer Centre.

AAMAC members with MDS and their families are welcome to attend these meetings.

In May, AAMAC held its spring support group meeting at the Toronto Blood Centre. The Canadian Blood Services' Renee Naiman provided sandwiches and took about a dozen members on an information-filled tour of the centre. We started in the original board room of what was the Victoria Hospital for Sick Children and heard about the history of the site.

The centre is basically a new building within the exterior of the old building. Next, we saw blood donations arriving from clinics held that day in an area from Hamilton to Bellville and north to Owen Sound and south of Sudbury.

Donations are divided into red blood cells, platelets and other blood components while laboratories carry out extensive testing for diseases including HIV and West Nile disease at the same time. A new process now allows platelets to be processed more quickly and the centre does pre-pooling of platelet donations at the centre to allow for bacterial testing.

We also learned about the centre's rare blood bank – one of only three such banks in Canada. Rare units are frozen for up to 10 years until they're needed. The "blood bank," where blood is stored before it is delivered to hospitals, was the last stop on the tour. Thank you to Renee for providing this insightful tour and for answering our many questions about the process.

Finally, I would like to thank those who expressed an interest in participating in the Scotiabank Toronto Waterfront Marathon. Unfortunately there were not enough participants for us to take part as an

official charity this year however we may look at doing this in the future.

Atlantic Chapter Update

By *Linda Watt*

I think summer is more anticipated than ever this year from the west coast to the east coast. I now refuse to wear my big, puffy winter coat – let the warm weather begin!

At our last monthly meeting we have had guest speakers. The first were two social workers from the QEII Health Sciences Centre here in Halifax who surprised us all with what they can offer through resources, funds and information on drug coverage – which is a complicated issue that varies province to province. We will definitely benefit from their services when approached by members in need.

The second speaker was Jo-anne Edwards, a nurse practitioner with the Bone Marrow Transplant (BMT) team at the Hematology Clinic of the QEII Health Sciences Centre. It was a very informal question and answer session where we could have gone on for hours. Jo-anne was able to demystify the process of selecting donors, the decision-making on using bone marrow or peripheral stem cells, which chemotherapies to use, along with many other questions that we've always wanted to ask.

It was very interesting and I have to commend our health care professionals for their availability, willingness, eagerness and support of our group. I hope everyone across Canada is as fortunate as we are.

At our next meeting we hope to discuss the possibilities of sending a member(s) to upcoming events such as the AAMDSIF 2008 family and patient conference in Virginia and the AAMAC education day in Toronto. As we anticipate the warm weather and spending more time outdoors, we are looking forward to once again having a BBQ or picnic over the summer. This is a great chance for

members and their family and friends to get together and enjoy life!

I would like to inform everyone that we have changed the time and location of our monthly meetings. Thanks to one of our members, Gwen Barry, we have a cheerful meeting room associated with the Victoria Order of Nurses (VON) services at the Halifax Shopping Centre. We usually meet the last Wednesday of the month between 3 and 5 p.m., but call or e-mail Robert to confirm at atlantic@aamac.ca or (902) 443-1615.

Have a great summer everyone!

AAMAC Spring Swing 2008

By *Rolla Babsons*

The annual Spring Swing was a great success this year! Over 300 people, dressed in suits and gowns, gathered at Meridian Banquet Hall on Saturday April 5, 2008 for great food, great music and a great silent auction!

This year marks AAMAC's 20th Anniversary, so Spring Swing was a great way to celebrate. Tickets were completely sold out this year!

Almost 160 silent auction items, including cosmetic baskets, chocolate baskets, jewellery, books, theatre tickets and boat cruises were generously donated. Thanks as well to some of our corporate donors, Westjet, Via Rail and Microsoft. The results of this year's silent auction surpassed last year's with a grand total of over \$14,000 raised from the silent auction alone.

Special thanks to our evening's presenting sponsor, Enbridge Gas Distribution, to our platinum sponsor Celgene and to sponsor Novartis.

A very special thanks to all of the fellow volunteers who made this evening possible: Cheryl Cameron, Anna Chamrai, Mandy Chmelyk, Stan Chmelyk, David Ecklund, Gordon Fleming, Victoria Fleming, Lois Henderson, Lori Korkola, Caroline Laughlin, Bill Laughlin, Angela Li,

Irene McEvoy, Dawn McGinnis, Andy May, Chris Meyer, Jenette Rintoul, John Rintoul, Adrienne Sanford, Carole Sanford, David Sanford, Kathie Sanford, Kevin Sanford, Laura Sanford, Yirong Song, John Wilson, Linda Wilson and the members of the Harbord Collegiate Key Club. Thank you for setting the hall up, gathering silent auction items, and taking payments for the items. And of course, the event would not have been such a success without the hard work of Gord Sanford who co-founded this annual fundraiser.

A special thank you to the fabulous 19-piece band No Strings Attached for wonderful live music, and to Santos at Meridian Banquet Hall for dinner.

And finally, thank you to all of our guests for joining us in this wonderful fundraising celebration and to those who could not attend but made a donation instead! Happy 20th Anniversary AAMAC!

20th Anniversary Speeches

The following speeches were delivered at Spring Swing by Association founder Renee Levine and long-time AAMAC volunteer Bill Laughlin at Spring Swing to mark the Association's 20th anniversary.

Renee Levine's Remarks

A long time ago, before the days of cell phones, Google and e-mail, our son Michael was diagnosed with aplastic anemia. (In fact, we actually borrowed someone's answering machine while we were at the hospital – wow that makes me feel like a dinosaur! But the truth of the matter is that it was just over twenty years ago.) Information was scarce. The odd book that was kicking around was outdated and frankly did not contain particularly optimistic prognoses for aplastic anemia patients.

We were lucky and thanks to wonderful circumstances and wonderful medical care, Michael had a successful bone marrow transplant.

I'm pleased to say that he is married with two kids now!

Coming home from the hospital was a very isolating experience and boy have things changed over the years!

One day, while we were at home avoiding contact with the human world, I came across a minute filler ad in Parent magazine. I think it was probably the first and only time I've ever read that magazine. Out popped an ad for the Aplastic Anemia Foundation of America. I could not believe my eyes – somebody had actually heard of this disease and it was in a mainstream magazine. It was then that I decided that patients, parents and the medical community should have access to current information and network with others in the same situation.

We needed to fundraise to help find better treatments for those who were not as fortunate.

Naively, I approached the Hospital for Sick Children about my vision of establishing a Canadian organization for Aplastic Anemia. I just could not fathom raising money for research and sending it across the border, losing money on exchange along the way.

The Sick Kids Foundation was incredible – they gifted me with a designer who created a logo, paid for our letterhead and a brochure, but most importantly, they gifted me with Dr. Freedman!! That poor man was an unwitting volunteer and he was a driving force.

Together we crafted a brochure that Sick Kids sent out to all their aplastic anemia patients from the previous five years and Dr. Freedman sent his letter of endorsement with it. Princess Margaret followed suit. By the way, the American organization supplied me with numerous brochures and all the support in the world to start a Canadian organization. (By the way, 20 years later, they still supply brochures.)

People started to call and we held several meetings in living rooms and

around kitchen tables. Mostly these meetings were a chance to vent and share experiences. Sick Kids once again came to the fore. They provided us with meeting rooms and we began to hold meetings there. Our core group grew. But we needed a focus. We were all coming from different places – parents (some with successful outcomes, others not), adults, family members etc. We found a common goal – lobbying the Canadian government to establish a national bone marrow registry. Our little organization has made a difference. Many activities, meetings, fund raising campaigns, silent auctions, blood donor clinics later....

We have obviously come such a long way from those days and I will leave it to Bill to speak about the present. There have been so many people including friends, family and in some cases complete strangers, who have done so much to advance the cause.

There are hospitals, doctors and volunteers across the country that have lent their support to the Aplastic Anemia and Myelodysplasia Association. I just can't begin to name names although there are some very special people in this room who have done so much. I am gratified because there are names on the Board of Directors who I don't know – the torch has been passed. I am so proud to be looking at this sea of people who are celebrating with us tonight.

I would like to ask you to raise your glasses to toast 20 years of hard work, thousands of research dollars and making a difference in people's lives.

Bill Laughlin's Remarks

Honoured guests, ladies and gentlemen, my name is Bill Laughlin. My wife, Caroline and I have been associated with this organization since shortly after its formation and I am honoured to speak to you briefly tonight.

This was to have been the speech of our president, Gord Sanford, but Gord has spent the last several days having intensive chemotherapy in the

hospital so I will try to tell you what I think he would want to say.

First of all I would like to thank Renee Levine for speaking to you tonight and describing a little about the founding of our organization. We cannot exaggerate the great debt that we owe to you. Thanks for your vision, your determination and your remarkable perseverance.

As Renee explained, one of the major goals of this organization was to lobby for the creation of the Canadian unrelated bone marrow registry and to support the Canadian Red Cross in providing blood transfusions and services to our patients.

The bone marrow registry did come into existence not long after the birth of this organization. Of course it was only useful if it had many registered donors, so our organization immediately undertook to attend blood donor clinics and actively recruiting potential marrow donors to be tested and join the registry.

Much has changed. The registry has grown successfully and become connected to a world-wide group of such registries. Its name recently changed to OneMatch and it is a precious resource for bone marrow failure patients. Many of our patients are alive today thanks to a bone marrow transplant.

All blood related services are managed by the Canadian Blood Services and our president Gord Sanford sits on the Board of Directors of that organization, so our connection remains. We also have strong representation with a number of other organizations who lobby the federal government on behalf of patients. Some of these are the Canadian Organization of Rare Disorders, the Network of Rare Blood Disorder Organizations and the Institute for Optimizing Health Outcomes.

Another goal of our organization has been raising funds to support research to understand basic nature of the bone marrow failure diseases and to develop more effective means of treatment and

hopefully to cure them or to prevent them.

Our early efforts at fund raising were very difficult because few people had ever heard of these diseases, but perseverance has been rewarded. I believe we have now raised over a million dollars in our 20 years of existence. We have supported research efforts at many hospitals including the Hospital for Sick Children, Princess Margaret Hospital and Sunnybrook Health Sciences Centre, here in Toronto, and Vancouver Cancer Hospital and Edmonton General Continuing Care Centre in the west.

We have supported specialized development work with bone marrow transplant nurses. We are currently supporting research projects at pediatric hematology centres in Canada.

Our funds come from our many individual supporters like yourselves as well as from corporate sponsors like Enbridge and the pharmaceutical companies Celgene and Novartis who are supporting us tonight as generous sponsors.

It gives me great pleasure to announce tonight that it has just been confirmed that AAMAC will be the recipient of the Elizabeth Lorraine Hill Charitable Trust Fund. The fund is being held in trust and will be transferred to us upon the death of Mrs. Hill. It is expected that the value of the bequest will be about \$500,000. Exciting news!

Our other great goal is to support patients and their families when they are struggling with aplastic anemia, myelodysplasia or PNH. We do this by trying to provide patients and their families with accurate information about the diseases and the resources available to help them. We arrange for them to talk to other patients who are willing to share their experiences and provide encouragement.

Small support group meetings are held regularly so that patients may meet and share information with each other. Education day conferences with medical presenters are held. Our third

such conference will take place here in Toronto on October 4th and will undoubtedly have several hundred attendees.

We would be remiss if we did not recognize the Aplastic Anemia MDS Foundation of America, now called the Aplastic Anemia & MDS International Foundation. Initial contact with this organization was made by Renee. Caroline Laughlin was the first member of our group to attend its annual conference in 1993. After the American Foundation became international, Caroline and Sheila Rivest served on its Board as Canadian representatives. The American foundation has generously provided us with printed medical information to distribute to our patients.

We started as the Aplastic Anemia Family association of Ontario. Now we are the Aplastic Anemia & Myelodysplasia Association of Canada. We also advocate for patients with PNH, a rare disorder with similarities to aplastic anemia. We have chapters in British Columbia, Alberta, Ontario and the Maritimes.

Tonight we honour those who founded AAMAC and those who continue to carry on their vision.

Join Our Advocacy Efforts in Ontario

By Chris Meyer

As announced in the last newsletter, AAMAC formed a small committee to advocate for patients, particularly around access to medications.

AAMAC has been working with groups including the Anemia Institute to advocate for public funding of a relatively new oral chelation medication in Ontario for some time without success as yet.

Most recently we began working with a group of multiple myeloma patients in Ontario who share an interest in public funding for Revlimid with some MDS patients. This medication is the only medication currently approved by

Health Canada specifically for MDS. (The approval is specifically for patients with a 5q- chromosome abnormality.)

The multiple myeloma patients we are working with have already successfully advocated for funding of another medication, so we hope to learn a great deal by working with them on a common concern. In May, we attended an informative meeting funded by Celgene to learn about advocacy and how medications are approved and funded in Canada. Much of the information shared was not only useful for advocating for medication but many other things from research funding to improved patient care and even personal situations at home.

Following the meeting, attendees expressed great interest in working together and getting others to join in our efforts.

If you live in Ontario and have a connection to a person with MDS, you can help. Just contact Chris at ontario@aamac.ca or call Stan at (905) 457-0552.

Plans may include meetings with Members of Provincial Parliament to share our concerns. More information including upcoming meetings will be posted at www.aamac.ca under the Ontario Chapter page.

As you know, MDS is an uncommon disease so the more voices, the better our chances of being heard. Since people with aplastic anemia and PNH can develop MDS, I would also encourage other patients to advocate for access to medications now in case they should ever need them in future.

We hope that making our voices heard will help ensure that if Health Canada decides that a medication is safe and effective and a medical specialist wants to treat a patient with that medication, the patient will be able to access it even if they don't have the ability to pay for it themselves.



Tree of Life

The Tree of Life was created and donated by David McTavish. The Tree of Life is a way of recognizing those who have been affected by aplastic anemia, myelodysplasia or PNH. You may make a tax-deductible donation of \$150 to have a special person's name inscribed on the tree. This beautiful carved tree is on display at our Annual General Meeting and other meetings in the Toronto area, whenever possible. The rest of the time it hangs on the wall at the national office. If you are interested in honouring your loved one(s) through the Tree of Life, please call our office at (905) 780-0698 or 1 (888) 840-0039, or visit our website at www.aamac.ca.

In Memory Of

Giovanni Arcuri
Earl J. Banford
John R. Barton
Joe Burleigh
John Maxwell Cameron*
Danny Carrick
Alexandre Castonguay*
Vern Coles
Talsa Coon
Rodney W. Crocker
Barbara Jean Cronyn
Barbara Culbert
Keith Curry*
Constantine Deplares
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Stephanie Dawn Temple
Paul Ullrich
Kenny Wentzell
Stanley Foch Willis
Nicole Wilson

In Honour Of

Cindy Bell
Paul Coad
Pietro Di Ilio
Barbara Doiron
Dr. Melvin Freedman
Bill Gryba
Rumi Guzder
Bill Hunt
Caroline Laughlin*
William Laughlin*
Liz Lemire*
Renee Levine
Lori Lockwood
Silvia Marchesin
Don McIntyre
Beatrice and David Murphy
Heather Parsons
Kris Plotzke
Carrie Plotzke-Cleghorn
Gord Sanford
Bernice Teasdale
Trevor Thompson

*Multiple Leaves



**Education Day, October 4, 2008
Preliminary Program**

8:00 a.m. – 4:00 p.m.

Metro Hall, 55 John Street, Toronto, Ontario

Morning

Registration & Breakfast Buffet

Welcome	
AAMAC's 20th Anniversary	<i>Renee Levine, AAMAC Founder</i>
Factory Closures, Defective Goods, and Lack of Skilled Workers: Problems for the Bone Marrow and the Global Economy	<i>Dr. Richard Wells, Director, Crashley Myelodysplastic Syndrome Laboratory, Sunnybrook Research Institute, Toronto</i>
Personal Experience with MDS	<i>Dave Barclay, Hamilton</i>
Blood Safety/ Blood Research	
Personal Experience with Aplastic Anemia	<i>Andy May, Caledon</i>
Bone Marrow Transplantation	<i>Dr. Hans Messner, Princess Margaret Hospital, Toronto</i>

Lunch & Annual General Meeting

Afternoon - Adult Focus

The Incidence and Prevalence of MDS	<i>Dr. Rena Buckstein, Co-Director of MDS Research Program, Odette Cancer Centre, Sunnybrook Health Sciences Centre, Toronto</i>
Treatment Options for Aplastic Anemia and PNH	<i>Dr. Vikas Gupta, Staff Physician, Leukemia / Blood and Marrow Transplant Program, Princess Margaret Hospital, Toronto</i>
Advocating for Treatment	<i>Ryan Clarke, President, Advocacy Solutions, Mississauga</i>

Afternoon - Pediatric Focus

Recent Advances in Pediatric Aplastic Anemia	<i>Dr. Evan Shereck, Clinical Assistant Professor, Division of Pediatric Hematology/Oncology/BMT, BC Children's Hospital, Vancouver</i>
Myelodysplastic Syndrome (MDS): What is it and How Does it Impact on Quality of Life?	<i>Dr. Robert Klaassen, Assistant Professor, Department of Pediatrics, Division of Hematology/Oncology, Children's Hospital of Eastern Ontario, Ottawa</i>
Inherited Marrow Failure Syndromes	<i>Dr. Yigal Dror, Director, Marrow Failure and Myelodysplasia Program, The Hospital for Sick Children, Toronto</i>

Mark Your Calendars

Aplastic Anemia & MDS International Foundation 2008 Patient & Family Conference, Sunday, July 27 to Tuesday, July 29, 2008, Arlington, Virginia

Hundreds of patients and their families will be attending from across the U.S. and other countries to hear from leading medical experts about the latest in research and treatment of aplastic anemia and myelodysplasia. For information visit www.aamds.org/aplastic/events/patient_and_family_c/2008conference.php or call 1 (800) 747-2820.

Canadian Transplant Games August 5 to 10, 2008, Windsor, Ontario

The 2008 Canadian Transplant Games are hosted by the Canadian Transplant Association. More than 300 organ and tissue transplant recipients from ages five 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.

Third Annual Mark Patchell Memorial Golf Tournament, Saturday, September 6, 2008, Scenic City Golf Club

Fee of \$100 per person includes 18 holes, power cart, dinner, prizes, putting contest, closest to pin and longest drive. Space is limited to the first 144 golfers. Contact Duane Bowman at (519) 986-1420 or email him at patchellkids@aol.com. Proceeds go to AAMAC.

Patient Education Day and Annual General Meeting, Saturday, October 4, 2008, Metro Hall Toronto, Ontario

Plan to attend this full-day, not to be missed educational event specifically for our patients. It's a great learning opportunity as well as a chance to meet others dealing with aplastic anemia, MDS or PNH. A preliminary program is included in this newsletter. Once again, we have an excellent slate

of speakers that you're sure to learn a lot from.

The final program and a registration form will be available on our website, www.aamac.ca, in July. Both will also be included in the next newsletter. There is no cost to attend, however, you must pre-register.

News of Note

New Patient Booklet About Unrelated Transplants Available

The OneMatch Stem Cell and Marrow Network Guide for Patients booklet is now available. It provides general information to patients and their families about the OneMatch unrelated matching program. Some copies are available at the AAMAC office or at www.onematch.ca under the patient section.

Canadians Urged to Join Bone Marrow Registry

Asian Canadians were recently encouraged to join OneMatch at a media conference in Scarborough, Ontario in May.

Madellina Lau, whose daughter Carolyn has leukemia and needs a match, was joined by Phillipa Lue, whose daughter died in 1990 while awaiting a bone marrow transplant for aplastic anemia.

Patients are more likely to find a donor in their own ethnic community so it is important to have as many Canadians from diverse ethnic communities as possible join. To sign up for the registry or for more information, visit www.OneMatch.ca or call toll free 1-888-2DONATE (1-888-236-6283).

Third Canadian MDS Center of Excellence Named

Congratulations to Princess Margaret Hospital (PMH) in Toronto which was recently designated as a Center of Excellence by the U.S.-based Myelodysplastic Syndromes Foundation.

PMH is a comprehensive cancer treatment and research centre in Toronto, Ontario.

The others to have received this designation are the Hospital for Sick Children and the Odette Cancer Centre at Sunnybrook Health Sciences Centre, also in Toronto.

To be recognized as a Center of Excellence, an institution must have an established university (or equivalent) program; recognized morphologic expertise in MDS; available cytogenetics (chromosome evaluation) and/or molecular genetics; documentation of peer-reviewed publications in the field and the ability; intention to register patients in the MDS International Registry Database; and ongoing research including Institutional Review Board-approved clinical trials.

First National Blood Donor Week

The week of June 9, 2008 marked the first National Blood Donor Week recognized by the Government of Canada. The week, culminating June 14 on World Blood Donor Day, was an opportunity to thank volunteer donors for their gift. This year's theme, "Many Happy Returns," was chosen to highlight the importance of committed, lifelong donors, and the many opportunities to save lives through blood donation each year.

Canadian Blood Services encouraged donors to give during the summer when recruiting blood donors is traditionally more challenging. From June to August this year, it estimates that patients will require the donations from 219,000 donors.

Donate Online

You can donate online at www.aamac.ca. Just click on the Donate Now button. You can make a one-time donation or set up monthly donations. You can also dedicate a donation in memory of or in honour of someone. If you'd prefer, there is also a donation form on the website that you can download and mail or fax in.