

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

President's Message

It's spring time and this is a busy time of the year for AAMAC. A wonderful tribute was just held in Calgary, Alberta to honour the memory of Liz Lemire. Thank you to Liz's family for directing the funds raised to help other patients. Please see the article in this issue for details about this tremendous tribute which was AAMAC's largest fundraising event of the year. As we go to print, volunteers in Ontario are focused on another event – the annual Spring Swing, dinner, dance and silent auction held in Toronto at the Meridian Banquet Hall on May 15. We always get many compliments from our guests about the great time they have had and we have seen tremendous growth in this event over the years. With a gourmet Italian dinner an 18-piece swing jazz band, open bar and great deals at the silent auction, there is no better time to be had in Toronto for \$70 per ticket. Like events across the country, this event is organized and run completely by an absolutely wonderful group of volunteers. We are always looking for volunteer help – if you would be interested in getting involved, please contact us at 1 (888) 840-0039 or info@aamac.ca.

We are also well into the preparations for our annual Patient Education Day, taking place in Ottawa on October 16, 2010. As usual, we will have an excellent slate of speakers to present the latest information on the treatment of AA, MDS and PNH. There is no charge to attend and I encourage you to mark your calendars now. We will be posting detailed information on our website and in upcoming newsletters as the event draws near.

I am pleased to say that we now have had three patient support group meetings in the Toronto region and will continue to hold our meetings on the second Saturday of each month. Volunteer Caroline Laughlin is now attending clinics at the Hospital for Sick Children and Sunnybrook Health Sciences Centre to reach out to patients and make them aware of AAMAC, and the support and information that we are able to offer. This year our goal is to establish similar support groups in Winnipeg and in Montreal.

We recently received some exciting news. Vidaza, manufactured by Celgene and used in the treatment of intermediate and high risk MDS patients, has been approved by the Alberta government for inclusion on the province's public formulary. Patients who meet certain criteria will now be able to access the drug in Alberta at no cost. AAMAC continues its advocacy efforts in Ontario to have the drug approved and patient/specialist meetings with the Ontario Ministry are scheduled for later this month. We also continue to advocate in other areas. As this issue goes to print, we have learned just today, May 21, 2010, that Vidaza has been approved for funding in Ontario!

I would like to close by acknowledging Canadian National Volunteer Week held April 18 to 24. With the exception of one paid part-time administrative assistant, our organization is run strictly by (indeed exists) through the tremendous efforts of many dedicated volunteers. I cannot express in word the gratitude and admiration I have for these people who give so freely of their time. I am truly humbled and honored to work with such wonderful individuals whose sole goal is to deliver hope to patients and families suffering from bone marrow failure diseases, AA, MDS and PNH.

Sincerely,
Stan Chmelyk,
President, AAMAC



**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.

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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 treating patients associated with bone marrow failure, however those that have been affected by these illnesses often feel alone and overwhelmed by the sudden impact the diseases 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 who are struggling with these issues.

The Alberta Chapter would like to organize support groups throughout the province with the help of interested individuals in the various communities. If you are interested in getting involved in this sort of group please contact me at alberta@aamac.ca or call or office and we will help you organize your group in your area.

We are in the process of organizing a support and education session with Canadian Blood Services. The date has not been finalized but watch the AAMAC website or the Canada Forum at www.marrowforums.org for more details.

Ontario Chapter Update

By Andy May

We have held three patient support group meetings at the Sunnybrook Wellspring Centre in Toronto. These meetings are an opportunity for patients to share stories and

information with others undergoing similar challenges to those they are experiencing. It is one more step in the continuum of care beyond the clinic setting. The group has settled on a regular meeting schedule of the second Saturday of each month. Wellspring is undergoing an expansion and the construction would not allow us to conduct our meetings on a regular basis. Canadian Blood Services has most graciously offered the use of its board room at its office at 67 College Street in Toronto to conduct our meetings on a continuous basis. Our next meeting on Saturday, June 12 from 3:00 to 5:00 pm will be held at this location. The location could not be more ideal as it a very short walk to the subway system as well as Princess Margaret Hospital and there is parking across the street, at very reasonable rates (\$5.00 per day on Saturdays). I hope that we will have the same excellent response that Bob Ross has been able to achieve with the support group in Ottawa.

I have written before about the amazing effects of volunteers and the impact on this organization. Although we are extremely fortunate to have an employee as an administrative assistant working in our national AAMAC office, this organization is completely volunteer driven, from our president right to the last person doing "your thing, big or small" to assist.

As you read this article, Spring Swing 2010 is behind us. I was reflecting just prior to the event and wanted to comment and commend the dedicated volunteers who make this event a success. Planning starts shortly after the gala dinner, dance and silent auction from the previous year. Tasks are assigned and looked after heading into the current year's event. The dedication by our volunteers is incredible. Without singling anyone out I would like to thank each and every one of you who assisted with this enormous event. Its success is because of people like you.

AAMAC Ontario has volunteers organizing and attending support groups for our patients, families and friends in the Ottawa and Toronto

areas. I believe this is the most important mandate of AAMAC, for all your efforts in support: Thank You.

If you would like to volunteer for an event or support group or just to help us out by doing “your thing, big or small” you can contact us at our national office at (905) 780-0698 or toll-free at 1 (888) 840-0039 or info@aamac.ca

In closing, a quick reminder as we enter the summer season if you're able please give blood.

BC Chapter Update

By Janice Cook and Pam Wishart

The BC Chapter held a meeting on Sunday, April 25. Although the turnout was low, the meeting was deemed a success. Dr. Mark Scott gave an excellent presentation on the work being done to hide red blood cell antigens so that the body doesn't recognize them as foreign and mount an attack. Red blood cells are amazing – they travel miles through the body at high speed, have to squeeze through very narrow openings and be able to supply oxygen and pick up carbon dioxide as needed. The research he talked about involved coating the cells with a polymer which covers antigens yet still allows the cells to perform all their other functions. To date the majority of the work has been done using mice and seems to work well; however, it remains to be seen if it will work as well in humans.

This work is of interest to the military for whom a safe supply of blood which does not have to be matched to the recipient could save lives during a war. A side benefit is that it is also of particular interest to the few of us who have developed antibodies to red cell antigens, making finding a match extremely difficult and costly.

After the presentation, we discussed the possibility of having an Education Day in Vancouver in the fall of 2011. We commented on the difficulty of updating the Chapter list; Janice

updated the list two years ago and Pam either emailed or mailed information about the meeting to every member on the Chapter list or BC addresses on AAMAC's newsletter mailing list (approximately 90 people). We received a total of 12 replies and several letters were returned “addressee unknown” or “moved.”

The members present were interested in informal local meetings for coffee and tea and we will see what we can do to set this up.

BC members please contact us at info@aamac.ca or by mail care of the office to let us know your current address, telephone number, email address and interests.

Atlantic Chapter Update

By Robert MacDonald

Since the last newsletter, the Atlantic Chapter met on two occasions, Saturday, February 27 and Saturday, April 24. The February meeting was a social gathering with lunch at the Atlantica Hotel. Plans were formulated for an education presentation and luncheon. Six members were present and a good discussion ensued. Gwen Barry offered to make a new contact/membership list using our Education Day registrations.

The Lunch and Learn presentation took place again at the Atlantica Hotel on Saturday, April 24 with guest speaker, Mary Lou Robertson, social worker and medical resource specialist at the Queen Elizabeth II Health Sciences Centre. She deals with patients from oncology, hematology and anti-coagulation services. Her talk was very informative and well-received by the members. She covered such topics as the rational policies and process of acquiring drugs not yet included on the drug formulary. She explained her role in assisting patients to access and find funding for prescribed drugs. She also explained her role as an advocate, educator and consultant in obtaining drugs for those

in need. We were pleased to have 14 people in attendance. Lunch and a short business meeting followed. Our sincere thank you to AAMAC for providing the funding for this day.

On April 16 and 17 the Canadian Organization of Rare Diseases (CORD) sponsored a conference here in Halifax on how drugs gain the approval of the provinces and some tips on how to advocate for drug coverage. Of the 20 people registered, five were from our chapter.

This month the chapter welcomed back Gai Thomas after her vacation to her native land, Australia. Also a big thank you to Gwen for a fantastic job of doing up the contact booklet.

Future plans are to have another mini Lunch and Learn the last Saturday in June and a family summer barbecue. For information on the Atlantic Chapter you may contact Robert at (902) 443-1615 or email rob.jack@ns.sympatico.ca

What Can I Do?

By Debbie Ouimet and Sylvie-Chantale Duquette

Have you ever felt like your life is suddenly frozen in time and you can't seem to move on? I started to feel that way when Audrey, my beautiful daughter, was diagnosed with aplastic anemia when she was five years old.

Our family got lucky. Audrey received excellent medical care and got better. We just got on with our lives and last year out of the blue on a winter night... We rushed to the Montreal Children's Hospital and this time the diagnosis was devastating: PNH, an incurable disease. Finding out that Audrey was possibly the youngest patient at 13 years old with this disease created even more worry.

Who can I talk to, who has lived through this ... This time around I decided to act and not wait on the sideline. The Power of One is so underestimated, I realized ... As patients and caregivers we also have a

role to play in our wellbeing. We must unite and care for one another. Money for support and research can only come from building awareness and touching everyone on your path, not knowing the impact it may have.

At Audrey's school, secondary 4 and 5 students have to do a personal project: fundraising, community work, etc. Through a friend who knew an amazing young lady attending the same school as Audrey I was able to initiate with her a simple yet effective fundraising activity including a week of awareness. What a joy to see the interest and care shown by young people for Audrey's condition. We sold 500 calendars telling Audrey's story, 100 at school and 400 with the help of family and friends.

We would love for other stories to be told across the country in the years to come. As a family, we will do whatever we can to change the outlook of this dreadful disease. We cannot stop and no one should! That is why we want to start a Montreal Chapter where we can feel empowered through other stories of patients and their loved ones.

Liz Lemire Memorial Fundraiser

By Silvia Marchesin

Liz Lemire was a co-coordinator of the Alberta Chapter who passed away almost two years ago. Her family, in particular her son Jamie and husband Mike, wanted to have one special event as a memorial for Liz and as a fundraiser for AAMAC.

I was very touched to be asked to speak at this event on April 30 in Calgary. I was representing AAMAC, the beneficiary of the fundraiser. But I was also there to let people know about the support that Liz gave to Albertans dealing with bone marrow failure disease, to educate people a bit about aplastic anemia, and to announce the creation of the Liz Lemire Memorial Scholarship Fund. This nursing scholarship will be offered every year, in perpetuity, to an

Alberta nurse who is studying in the area of hematology/oncology. As the first scholarship will be awarded later this year, we will write more about this in a later newsletter.

The other speaker at the event was a man who has successfully battled leukemia, first having a bone marrow transplant, and then a stem cell transplant. His story was very inspiring and he reminded everyone of the constant need for blood products.

The event was touted as a social and fundraiser and indeed it was both of those things.

There were over 300 people present, over 100 silent auction items, and six live auction items. People had a good chance to mingle while looking at the items, or enjoying the piano music. There was also a table with photos of Liz for people to peruse through.

Mike has a long history with the local hockey community and was able to get some interesting hockey paraphernalia including a signed Oilers' Wayne Gretzky game jersey. There were other equally interesting items in the live auction including a weekend at an Invermere condo, a "ride along" on the Calgary City Police's Hawks

Helicopter (something that you can't buy), and two round trip tickets anywhere WestJet flies.

The rest of Liz's family, Joan & John Rouse, and Bob, Jan & Stuart Clare, worked hard at the welcome table, and at the tables set up for the winning bids to be processed. Their fingers were flying on the calculators.

The generosity of the Lemire family's friends is quite remarkable. Through the combination of auction items, small raffles and individual donations, they raised over \$50,000 for the association.

Apart from being a well-organized event, and very enjoyable evening, it was a real tribute to Liz.

To the Lemire family: Thank you for your loyalty to this grassroots organization. AAMAC's commitment to you is that we will use the funds generated to support and educate patients and their families, and to fund research into bone marrow failure

Photo below: Event Organizers: front: John Rouse, middle: Mike Lemire, Jan Clare, Jamie Lemire, Joan Rouse, back: Bob Clare, Stuart Clare



Vidaza and Exjade progress in Alberta

Vidaza on Alberta Formulary:

As of May 1, 2010 Alberta Health Services has listed Vidaza (generic name azacitidine) under the Outpatient Cancer Drug Benefit Program. The Alberta Health Services provides cancer drugs specified in the Outpatient Cancer Drug Benefit Program, at no charge, to eligible residents for the treatment of cancer.

The listing for azacitidine is for the treatment of patients with MDS with IPSS high-intermediate and high-risk scores or AML with up to 30% blasts and myelodysplastic features. Prescribing of the medication is limited to written authorization by certain physicians only.

You can get all the details at: <http://www.cancerboard.ab.ca/NR/rdonlyres/D3381BED-88A2-49C2-9E5E-D0FA8B356A24/0/MasterOutpatientdrugprogrambenefitlist.pdf>

A link to this information will also be posted on the AAMAC website under the “What’s New” section of the home page.

Alberta is the first province to put Vidaza on the formulary for funding. This does not mean it isn’t available in other parts of the country, just that there is some special access or authorization process that must be gone through to get the medication there.

Exjade access expanded in Alberta:

Alberta Blue Cross has updated its coverage for the new iron chelator Exjade.

Effective April 1, 2010 the criteria outlining when Exjade would be funded has been expanded. Full details can be found at: https://www.ab.bluecross.ca/dbl/pdfs/ahwdbl_april_list.pdf

A link to this information will also be posted on the AAMAC website under

the What’s New section of the home page.

From the Alberta Blue Cross website, the benefit is described as: “For patients who require iron chelation therapy but in whom deferoxamine is contraindicated. Information is required regarding the contraindication to use of deferoxamine. Contraindications may include one or more of the following: known or suspected sensitivity to deferoxamine, recurrent injection or infusion-site reactions associated with deferoxamine administration (e.g., cellulitis), inability to obtain or maintain vascular access, concomitant bleeding disorders, or risk of bleeding due to anticoagulation.”

A physician still has to apply using the Special Authorization process.

Aplastic Anemia Patient Promotes Bone Marrow Donation in Chinese Community

By *Chris Meyer*

Long-time AAMAC volunteer and aplastic anemia patient Yvonne (Yirong) Song was among those raising awareness about the need for stem cell donors in the Chinese community.

Yvonne shared her story at the “327 National Chinese Stem Cell Drive” at First Markham Place in Markham, Ontario on March 27 (hence the reference to 327).

“My two brothers are not my match, so I may need to find a donor from the stem cell registry someday,” Yvonne said, explaining the reason for her involvement. She is currently waiting to see if a recent ATG treatment will increase her blood counts.

The stem cell drive also took place at the Splendid China Mall in Scarborough, Ontario, the Chinese Gospel Church in Toronto and Aberdeen Centre in Richmond, BC.

The national event was organized by the OtherHalf – Chinese Stem Cell Initiative and Canadian Blood Services’ OneMatch Stem Cell and Marrow Network. The mission of the OtherHalf is to help increase the number of registrants of Chinese origin in the stem cell registry worldwide. Also supporting the stem cell drive was Dr. John Doyle Section Head, Section of Blood & Marrow Transplant at The Hospital for Sick Children in Toronto.

Everyone between the ages of 17 and 50 was encouraged to register as a potential donor by providing an oral tissue sample with cotton swab sticks.

The result of the joint effort was an incredible 4,025 new registrants in one day!

According to the organizations, less than 30 per cent of patients in need of a stem cell transplant will find a compatible stem cell donor from a sibling and as a result most must rely on the generosity of an unrelated donor. Among these patients are individuals with aplastic anemia, myelodysplastic syndrome and PNH.

The event news release indicated that the majority (82%) of registrants within Canada’s stem cell network are Caucasians. Unfortunately, Chinese represent only 2% of the Canadian registry and about 4% of the global stem cell database. “That is why Caucasian patients have about an 80% chance of finding an unrelated stem cell donor for transplants and Chinese patients have only a 10% chance of finding one,” it read. “With the likelihood of finding a match far greater within one’s own ethnic group, more Chinese Canadians are needed to register as a stem cell donor with Canadian Blood Services’ stem cell program, OneMatch Stem Cell and Marrow Network.”

It is estimated that there are currently at least 20 patients of Chinese origin in Canada urgently waiting for an unrelated stem cell or bone marrow donor.

The OtherHalf – Chinese Stem Cell

Initiative was started by a group of concerned Chinese Canadians who would like to help increase the number of registrants of Chinese origin in the stem cell registry. In collaboration with OneMatch, a member of the global stem cell network, it organizes stem cell drives and awareness campaigns targeting the Chinese community about stem cell donation.

For more information, visit www.chinesestemcell.ca or www.onematch.ca.

Birthday Wishes

By Silvia Marchesin



Vivienne is shown here between her parents Thanh and Anh Nguyen.

When Vivienne Nguyen turned nine years old, she didn't ask for a new bike. In fact, she didn't ask for anything.

Instead of birthday presents, she wanted people to make a donation to AAMAC. A friend of the family had recently passed away from leukemia after a six year battle with aplastic anemia. Vivienne heard about AAMAC from that family and decided that she wanted to support the organization to help other people.

I met up with Vivienne at the Liz Lemire Memorial Fundaiser in Calgary in April and she and her parents were kind enough to agree to have this story printed. Of course her parents are proud of their daughter's sense of community. They told me that Vivienne is getting prepared to cut her long hair for cancer patients, so that they might have real hair wigs.

To those of you who worry about the next generation ... let me show you Vivienne! She has shown leadership, compassion and generosity. Vivienne, you're an inspiration!

News of Note

Attention parents and patients at the Hospital for Sick Children and Sunnybrook: AAMAC volunteer Caroline Laughlin will be at the Marrow Failure Clinic at the Hospital for Sick Children in Toronto regularly. She will be at HSC on May 31st and June 7th. Do stop by and chat with her on the 8th floor's new clinic waiting room and get your free AAMAC bracelet. Caroline will also be at the Sunnybrook Health Sciences Centre MDS clinic at the Odette Cancer Centre held by Dr. Richard Wells. She will be there on May 28th and June 11. Drop by to learn more about AAMAC and how we can help you and your family. Caroline is looking forward to talking to patients and their families at these clinics.

Special Announcement

In the last issue of this newsletter we printed an article entitled "Progress in Comprehensive Care for Rare Blood Disorders Conference." It described the November 2009 conference which was hosted by the NRBDO, a coalition of rare blood disorder organizations working together to further common goals. We are pleased to inform you that this article has also been printed in the March 2010 issue of Hemophilia Today, the Canadian Hemophilia Society's newsletter, and in the Canadian Hematology Society's newsletter.

If you would like to read the article, you can visit the AAMAC website, www.aamac.ca and click on the "Newsletters" link to see past issues.

Marrowforums Canadian Content:

Marrowforums is an online forum which enables people to share stories and exchange information. Many patients and caregivers find a great deal of support from this online community. The discussions are

organized into forums and threads, with each thread covering a specific topic. This makes it easy to find information, ask questions, and read what others have posted.

There is a Canadian section of Marrowforums which is moderated by AAMAC's Alberta chapter coordinator, Doug Mylie. Go to the Regional Discussions section of the forum site where you will find a section for Canada. You will need to register to participate in the discussion but can use a pseudonym for privacy.

Visit Marrowforums now at www.marrowforums.org.

Mark Your Calendars

Join the Marrow Movers in

September 2010: Join patients, family and friends in Toronto on Sunday, September 26, 2010 for the Toronto Waterfront Marathon and five-kilometre walk as we raise funds for AAMAC. Last year walkers of all ages came together for several enjoyable hours walking along the waterfront to City Hall. This year's event is confirmed. For details about the marathon route visit www.torontowaterfrontmarathon.com. AAMAC's page will be up in the near future.

To join the Marrow Movers watch for details at www.aamac.ca and in our next newsletter or email marrowmovers@gmail.com.

Education Day, October 16, 2010 at

the Ottawa Marriott Hotel: More information will follow in our next newsletter and on our website. If you are interested in attending please contact Bob Ross by email at aamac.ottawa@gmail.com or call (613) 882-2416. You can also contact the AAMAC office info@aamac.ca.

World Blood Donor Day, June 14,

2010: This is a day to celebrate and thank those who donate their blood without any reward, except the knowledge that they have helped to save lives!

Regular Monthly Toronto Support Group Meeting: We now have a regular Toronto support group meeting the second Saturday of each month from 3 to 5 p.m. at Canadian Blood Services, 67 College Street.

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 schmelyk@sympatico.ca. We hope to see you there. Please feel free to spread the word.

How Drugs Are Approved and Funded in Canada: What Every Patient Should Know: The Canadian Organization for Rare Disorders (CORD) is hosting two-day interactive training seminars titled "How Drugs Are Approved and Funded in Canada: What Every Patient Should Know." These educational seminars are specifically designed for patients and laypeople who want to better understand the processes related to drug research, development, approval, and availability through provincial drug plans. Trainings sessions are being held across Canada. The next sessions are:

June 11 - 12, 2010, Days Inn, Montreal, QC: This session will be held in French. Pour vous inscrire ou pour plus d'information concernant l'atelier de formation sur « Comment les médicaments sont approuvés et remboursés au Canada : ce que tout patient devrait savoir » qui se tiendra à Montréal en français les 11 et 12 juin, s.v.p. contacter Gail Ouellette gail.ouellette@mail.mcgill.ca or (819) 543-0550.

September 17 - 18, 2010, Verity Club, Toronto, ON: Please visit <http://www.raredisorders.ca/newsEvents.html> for more details

AA&MDSIF Patient & Family Conference, July 10 - 13, 2010 in the Washington, DC area: These conferences will bring hundreds of patients and their families together with a selection of the world's most accomplished medical experts in bone marrow failure diseases and their treatment. Registration is now open. See the AA&MDSIF website for details at www.aamds.org.

One-Day AA&MDSIF Conference for Patients and Families, June 19, 2010, Seattle, WA: This free event is a collaborative effort between the Fred Hutchinson Cancer Research Center (FHCRC) and the Aplastic Anemia & MDS International Foundation (AA&MDSIF). Visit www.aamds.org for details.

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

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Earl J. Banford
John R. Barton
Alexander Bowen
Joe Burleigh
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Danny Carrick
Alexandre Castonguay*
Vern Coles
Talsa Coon
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*Multiple Leaves