

*Education
Support
Research*

Fall 2007

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

President's Message

During the summer, I was very fortunate to holiday in Newfoundland and Nova Scotia. During my travels, I was pleased to enjoy a lunch and a visit with the new Atlantic Chapter co-coordinators. As you may have read in a previous newsletter, they are: Robert MacDonald, David McFarlane and Linda Watt. I am very encouraged by the enthusiasm and commitment of these volunteers who have carried on the good work started by Gai Thomas. I am also pleased to report that Robert MacDonald will be sitting on the board of directors representing the Atlantic region of the country.

The association is very active again this fall. Specifically, I'd like to draw your attention to the Saturday, September 29 Education Day and Annual General Meeting. This is an excellent opportunity for patients, family members and healthcare professionals to learn more about bone marrow failure and to meet other patients and families. The preliminary program is included in this newsletter and will provide you with a good idea of the excellent topics and speakers that have been arranged by the program committee of Caroline Laughlin, Gord Sanford, Chris Meyer and myself. Please see our website for the final program.

I am pleased to inform you that we will be offering a limited number of travel sponsorships to financially assist those who might like to attend from outside the Greater Toronto Area. A registration form is included in this newsletter. Please register early!

The third week of October will bring our national Awareness Week. A number of chapters have activities planned for this week and are looking for volunteers. Please see the Mark Your Calendars section of this newsletter for details on these and other upcoming events.

I will be stepping down as president at the upcoming AGM as my term has come to an end. I would like to thank the board of directors, and all the volunteers I have worked over the years for their support and encouragement. I will still be serving the association as a director.

Silvia Marchesin
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.

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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

Alberta Chapter Update

By Liz Lemire

Well things have slowed right down for the summer after a busy spring of fundraising in both Calgary and Edmonton. The Garage Sale held up in Edmonton was a great success amounting to around \$1,350 being raised in the two-day event. Silvia Marchesin, with the help of family and friends – Clarence Rhodes, Dorina Marchesin, Karen and Amanda Boyko, Robert Boyko, Tammy Woolgar and Susan Kerr – reported that they had a great time chatting with the customers and raising awareness of AAMAC.

Down in Calgary the Calgary Old Time Hockey Players Association Annual Golf Tournament on June 4 brought in a grand total of \$2,110 from the sale of ‘mulligans’, ‘hole sponsorships’ and ‘hole-in-one’ contest. Janice Cook and Liz Lemire handed out LifeBlood bracelets to anyone who bought a mulligan and that was very well received by the golfers. We’d like to thank this association for their continued support. At another golf tournament this spring attended by Mike Lemire they passed a hat around and collected \$180 for the association. Thanks again to you Mike and your fellow golfers.

Cindy Dalziel who is the wife of Jason, a Calgary aplastic anemia patient, donated her 10% share of an online “Pampered Chef” party to AAMAC. She collected just under \$150 and also raised awareness of our association. A big thanks to Cindy for doing that and hopefully everyone is enjoying their new kitchen gadgets!! Jason received a bone marrow transplant this winter and is reportedly doing well. Jason and Cindy found out about the association through the information package mailed out from our national office and found it very helpful.

In late August one of our new Calgary Support group members, Lucie McGavin, and her son are traveling independently to the AAMDSIF conference in Las Vegas. Jim and Janice Cook will also be attending as Janice will be representing our board. I’m sure this will prove to be a great opportunity for these people and they will bring back with them lots of info that can be shared with us. Have fun and don’t leave too much money at the ‘tables’ or ‘slots’!!

The Calgary office of Canadian Blood Services has again allowed us to come down to their blood donor clinic to hold an “Appreciation Day” during the AA, MDS & PNH Awareness Week. The date is set for Thursday October 18 from 9 a.m to 1 pm. If you could come down and spend an hour or two handing out ‘Lifesavers’ and bracelets and thanking donors, please give Liz a call at (403) 275-4595. Canadian Blood Services’ address is 737-13th Ave. S.W. Calgary. Also to end off the Awareness Week, the Calgary and area support group is holding its fall meeting on Sunday October 21 at 2 pm at the home of Mike and Liz Lemire. Please RSVP to Liz at (403) 275-4595 or alberta@aamac.ca before the 21st. It will be a casual gathering of patients and any family members who would like to attend.

Enjoy the rest of your summer and I look forward to seeing you at either the Blood Donor Appreciation Day on October 18 or the October 21 Support Group meeting.

Ontario Chapter Update

By Chris Meyer

In addition to our efforts to encourage drug funding for bone marrow failure patients in Ontario (see article), local volunteers have been very active in other ways this summer.

Special thanks to Victoria and Gordon Fleming who organized a garage sale

in June for AAMAC. The couple chose AAMAC as the sale's beneficiary in memory of Victoria's father Valdemars Jankovskis, who had MDS. With sale items contributed by friends and colleagues, the garage sale raised \$320 and lots of awareness! Special thanks to youngsters Emily and Michaela Di Nunzio who sold 30 LifeBlood bracelets!

A big thank you also goes out to AAMAC Director Stan Chmelyk who continues to share his experience as a bone marrow and blood recipient with Ontario high school students. On June 7, Stan encouraged 17-year-old students at several Toronto area schools to give blood. Seventeen is the minimum age for a blood donor and this group is critical to reach as many lifelong donors start young. The presentations were well received and in a couple of schools the blood donation quota was exceeded.

In July, Stan and I were very pleased to set up an information booth at a Toronto Police Service 13 Division barbecue which raised \$10,500 towards aplastic anemia research at the Hospital for Sick Children. Almost 50 people also purchased AAMAC LifeBlood bracelets to raise awareness about aplastic anemia.

The event was organized to show support for five-year-old Karlee May who underwent a bone marrow transplant for aplastic anemia at the hospital earlier this summer.

Karlee's parents are both Toronto police officers who share AAMAC's interest in raising awareness about the importance of blood donation and joining the Unrelated Bone Marrow Donor Registry (UBMDR). Canadian Blood Services also set up a booth at the event and, on the day of the barbecue, the Caledon Citizen ran a front-page article about Karlee to promote local blood donor clinics in Peel Region.

Dr. Yigal Dror, the Director of the Marrow Failure and Myelodysplasia Program at the Hospital for Sick Children and member of AAMAC's Medical and Scientific Advisory

Committee, told those in attendance about the important work that the hospital is doing to help children with bone marrow failure diseases and explained what aplastic anemia is and how it is treated. Other speakers included Karlee's mother, Leah Gilfoy, who encouraged everyone in attendance to give blood and join the UBMDR. Also present were Karlee's sister Victoria and brother Tyler, who donated bone marrow for the transplant.

Thank you to AAMAC Director Rolla Bahsous and her sister Rena who gave LifeBlood bracelets to blood donors at a Canadian Blood Services clinic at the Hospital for Sick Children in support of Karlee the week after the barbecue. (Rolla donated bone marrow to her sister after Rana was diagnosed with MDS.) The clinic was also attended by members of Karlee's family and Toronto Police Chief Bill Blair. Another clinic in support of Karlee is planned at police headquarters in August.

I wish Karlee and her family the very best and thank the family for raising research funds and promoting Canadian Blood Services programs especially during this time.



Leah Gilfoy (centre) holds a giant card for her daughter Karlee (pictured on the card). The card was signed by well wishers including event organizers Ian (right) and Jodi (left) McArthur. Photo courtesy Lee Bagatin.

Congratulations to Christine Ichim, a researcher in leukemia and MDS in Dr. Well's lab at Sunnybrook Health

Sciences Centre who also helps AAMAC raise awareness about bone marrow failure diseases. She received the University of Toronto's Adel S. Sedra Distinguished Graduate Award for doctoral candidates in recognition of her achievements inside and outside university life. AAMAC was among those to nominate her for this award which comes with a research fellowship of up to \$25,000. For details, visit http://www.sunnybrook.ca/research/stories/topping_the_dream.

In other volunteer news, many of our 2007 Spring Swing volunteers gathered for a social evening in July, to celebrate the success of the fundraiser. We also started to look ahead to next year and tentatively set the date for our next Spring Swing as April 5, 2008. If you would like to be involved in the next event as a volunteer, donor or attendee, please see the event section on the back page for details. We will also share details in the newsletter and at www.aamac.ca.

Patients and Family Members Encouraged to Attend Education Day

Looking ahead, I hope to see many Ontario members, their families and healthcare providers at our annual Patient Education Day which returns to Toronto this year.

I encourage everyone with a connection to aplastic anemia, MDS or PNH to come out to learn the latest about the diseases from Canadian experts. You'll also meet others with bone marrow failure diseases and hear about their experiences. New this year is a session of particular interest to patients who have had or are considering a bone marrow transplant. After the formal program, everyone is welcome to gather socially at a nearby eatery.

This day-long event takes place September 29, 2007 and is well worth the trip to the city. Located at Metro Hall, it is conveniently located near the Spadina exit on the Gardiner Expressway in the city's picturesque theatre district. Underground parking

is available onsite and reasonably priced hotels are within a short distance. We welcome volunteers to assist with preparation and the day of the event.

Please also let me know if you would be interested in putting up a display at a local hospital or blood donor clinic to mark our annual awareness week this October.

Atlantic Chapter Update

By *Linda Watt*

Our chapter started the summer with a seminar presented by Dr. Robert Liwski, Hematopathologist here at the QEII Health Sciences Centre in Halifax. He delivered an excellent slide show of what the lab sees in diagnosing patients with MDS, AA and PNH. Included were cases of our members which made it that much more stimulating and personal. We hope to have Dr. Liwski speak again as everyone enjoyed his expertise and kindness. A potluck dinner followed the seminar – thanks to all who contributed – as usual it was delicious.

The highlight of July was a visit from Silvia Marchesin who took the time out of her vacation to the east to stop in and meet two of the coordinators (unfortunately I couldn't attend). Robert MacDonald, his wife Jackie, and David McFarlane met with Silvia and discussed questions that we had, having just recently taken over as coordinators of the Atlantic Chapter. We have planned a picnic for August 12 at Oakfield Park, so we are praying for good weather – lately it's been either hot and humid or torrential rains. All members and family are invited to attend in what will surely be a fun-filled afternoon.

We have finally designated an official board member of our chapter. Robert MacDonald has graciously volunteered to take on the responsibilities of the role for the next year. David

McFarlane and I will fill in when needed.

Upcoming events for the fall include starting up our monthly meetings after a summer hiatus, creating a new display in the Hematology Clinic area, and visiting Canadian Blood Services to distribute Lifesavers during Awareness Week.

Lastly we would like to wish Gai Thomas, our previous Chapter Coordinator, all the best in the next year as she returns to her roots in Australia. Be well Gai.

Supporting Patients in Southeastern Ontario

By *Susan Bowers*

The Southeastern Ontario support group met on a sunny evening in Kingston, Ontario this past May. As well as five “regulars,” two new visitors arrived from Ottawa! We discussed some issues that would help patients and advocates who are looking for support with these blood diseases.

There was interest in developing a list of suggested do's and don'ts that would be easily accessible on the AAMAC website. Obviously every patient's condition is different, but are there items everyone should avoid such as benzene, chemicals or pesticides to name a few? Are there foods or nutritional supplements people might find helpful?

Another suggestion was that patients with low blood counts should talk to their doctors about registering with an organization such as Medic Alert or American Medical ID, which also accepts Canadian patients. (Information is available at www.medicalert.ca and www.americanmedical-id.com.)

To be honest, we are grateful that our group is small – we hope it means fewer people with these diseases! However it also could mean that there are patients in the dark who are not

aware of the gathering. We encourage healthcare providers who know of new patients or patients seeking some support or help to contact AAMAC.

Our next meeting is Thursday, October 18 at 7 p.m. in Kingston. Please contact Trevor at rigitari@aol.com or Susan at susdragon@gmail.com if you are interested in getting together. Alternatively, you can leave a message for us at the national office, 1-888-840-0039.

Bone Marrow Recipient Meets Donor During National Blood Donor Week

By *Sarah Hayden, Canadian Blood Services*

Jennifer Rogers is one of 17 million Canadians whose lives have been touched, through blood donation, by people they have never met or had the opportunity to thank. For Jennifer, however, this changed on June 11 when she met her bone marrow donor and thanked a select group of blood donors at the Maid of the Mist in Niagara Falls, Ontario.

Jennifer was diagnosed with aplastic anemia in October 2005. She was fortunate that her physicians found a match from the Unrelated Bone Marrow Donor Registry, and in March, 2006, she received a life-saving bone marrow transplant. During her treatment, Jennifer also required several units of blood.

Jennifer's meeting with her donor, Linda Kraay, a resident of Lacombe, Alberta, took place at the beginning of National Blood Donor Week, June 11 to 16, 2007. Jennifer and Linda were joined by Niagara Falls mayor Ted Salci and event host, Hamilton native Rick Campanelli of Entertainment Tonight Canada.

“Canadians play a big part in ensuring there are blood products available to patients in need,” said Judy Compton, Regional Director for Canadian Blood

Services in Southern Ontario Region. “Because of the generosity of these donors, recipients like Jennifer are able to enjoy many of life’s most precious moments.”



Unrelated bone marrow transplant recipient Jennifer Rogers (centre) in Niagara Falls with donor Linda Kraay (right) and host Rick Campanelli (left).

Encouraging Drug Funding in Ontario

By Silvia Marchesin and Chris Meyer

In May, Dr. Richard Wells, Gord and Carole Sanford and Chris Meyer attended a press conference at Queen’s Park organized by the Anemia Institute for Research and Education (AIRE) to draw attention to the issue of provincial funding for Exjade.

Exjade is an oral drug used to treat patients with excess iron in their blood due to regular blood transfusions. The treatment of removing excess iron is called iron chelation. Without treatment, patients with iron overload are at risk for serious complications including organ failure.

The press conference was quickly organized in response to a recommendation by the Ontario Committee to Evaluate Drugs (CED). The CED recommended that the Ontario Drug Benefit Program provide very restricted reimbursement of Exjade which would have meant that bone marrow failure patients would have had no way to access it other than paying for it themselves or through a third-party insurance.

Speaking on behalf of AAMAC at the press conference was the Chair of our

Medical and Scientific Advisory Committee, Dr. Richard Wells. Other speakers included Durhane Wong-Reiger from AIRE, Riyad Elbard, President of the Thalassemia Foundation of Canada and Dotty Nicholas, President of the Sickle Cell Association of Ontario. All of the groups represented share an interest in ensuring that the provincial government reimburse Exjade which was approved by Health Canada last October. We are asking the Ontario Drug Benefit Program to reimburse Exjade for all patients who are dealing with iron overload due to transfusions regardless of the underlying condition.

Various AAMAC representatives including our President Silvia Marchesin have also sent letters urging coverage of Exjade to Ontario’s Minister of Health, the Honourable George Smitherman, and other decision-makers at the Ministry of Health. AAMAC’s Medical and Scientific Advisory Committee and a group of hematologists who treat MDS patients in Hamilton, London, Toronto and Ottawa have also written the government, urging coverage of the drug.

Thankfully, the CED will be re-reviewing the Exjade application. We are hopeful of a more positive outcome.

The other drug for iron chelation (deferoxamine/Desferal) is delivered by pump, often five days a week for 10-12 hours a day. While this drug works for many patients, it may not be appropriate for all. For example, some patients experience serious reactions to the drug and the difficulty of administering it can make compliance difficult for others, including children and teenagers.

We have requested a meeting with the Ministry to discuss our concerns and encourage broader funding. However, as of press time, we have yet to receive a response to our request.

We encourage Ontario members interested in ensuring that MDS, aplastic anemia and PNH patients have access to new drugs such as

Exjade to write to the Minister of Health about this issue. Please ensure a copy of the letter is sent to Chris or Silvia at the association office so that we can follow up on this with the government. Also, if you would like to be advised of any timely developments requiring action on this issue, please send your email address to Chris at ontario@aamac.ca.

Medical Grant Update

By Silvia Marchesin

As I reported in a previous newsletter, we were partnering with the Canadian Institutes of Health Research to offer a fellowship grant in the area of bone marrow failure. Unfortunately, we did not have any relevant applications and therefore, did not provide any research funding.

As a result, we have re-evaluated our research grant and chosen to offer operating grants instead. We will be partnering with the C17 Research Network to offer a pediatric bone marrow failure grant over two years. The AAMAC/C17 grant is for a total of \$45,000 over two years.

The Council of Canadian Pediatric Hematology/Oncology Program Directors (CCPHOD) established the C17 Research Network as they recognized “a need for nationwide collaborative research in hematologic and oncologic diseases of children, as well as in the use of stem cell transplantation for these and other disorders.” The network supports a multi-centre, multi-disciplinary approach within a broad scope of research in pediatric hematology, oncology, and hematopoietic stem cell research.

We would like to thank our Medical and Scientific Advisory Committee for their direction and advice in establishing this partnership and grant.

We are in the process of establishing a second grant, an adult-focused one, with another non-profit organization.

I hope to report on this in the next newsletter.

Lifeblood – A Bone Marrow Transplant

By Rolla Babsous



Bone marrow donor, Rolla Babsous on the left, sister Rana, the marrow recipient on the right.

On Thanksgiving night, I was offered a position on the Board of Directors of the Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC). That's a mouthful to say because it's a national association for complicated illnesses. These illnesses are rare bone marrow failure diseases. Aplastic anemia is a bone marrow disorder in which bone marrow fails to make blood cells. Myelodysplasia, also known as Myelodysplastic Syndrome (MDS), is similar to aplastic anemia as there is a lower production of blood cells, and those that are produced are unhealthy or immature. AAMAC also represents patients suffering from Paroxysmal Nocturnal Hemoglobinuria (PNH) that develops from mutated stem cells in bone marrow.

Associations like AAMAC are important because they deal with illnesses similar to blood cancers like leukemia, except these illnesses are not classified as cancers, so they do not receive sufficient funding for research and patient support.

AAMAC was established in 1987 and is now made up of patients, parents, medical advisors, and volunteers who know someone with these illnesses. AAMAC's first primary goal was to encourage formation of a national

bone marrow donor registry in Canada. Today, AAMAC offers patients and families support, and uses educational material to promote awareness about bone marrow illnesses and the serious need for bone marrow donors. Currently, AAMAC is heading the "LifeBlood" campaign, a fundraiser selling LifeBlood bracelets to raise funds for research. LifeBlood is a word for the blood that runs through us all – a blood that keeps us alive.

I accepted the position gladly.

Seven years ago, I wouldn't have known any of these illnesses even existed. But in late 2000, my ten-year-old sister, Rana, was diagnosed with MDS. Before that, Rana used to get sick easily and repeatedly took antibiotics. She also got very tired often, and bruised easily. After several tests and blood transfusions at The Hospital for Sick Children, the doctors told my parents the somewhat good news: it isn't leukemia, it's MDS. The only way to make her better is to destroy her entire immune system with rounds of chemotherapy and radiation, and then build it up again with a bone marrow transplant. If left untreated, the illness would progress and could potentially turn into leukemia. This didn't upset Rana very much until she was told that she would lose all her hair.

A week later, my entire family was tested to see if there was a bone marrow match. After more blood tests, doctors confirmed that I was the match. I have to admit, knowing that you are responsible for another person's health is an interesting experience, especially at only thirteen years old. On one hand, I was scared because I had no idea what was going to happen to me (especially because I was terrified of needles). On the other hand, I was worried that it might not work.

On December 14, 2000, Rana was taken to Sick Kids to begin her treatment and preparation with the chemo and radiation. She was then moved into isolation, where only my parents were allowed to see her. This

was done to keep all germs out since she had practically no immune system.

December 21, 2000, I remember was a Tuesday. I had to wake up at 5 am. It was still dark outside and very quiet. The roads were so clear that we got to Sick Kids within only ten minutes. My dad went to see Rana, and my mom came with me. By 9 am, I was lying on an operating table in a blue hospital gown. The nurses were extra friendly. The room smelled like antiseptic. The radio was on like this was a casual thing. I remember one nurse asked me what I wanted for Christmas, as a Backstreet Boys song played in the background. I breathed through an oxygen mask and told him I wanted Rana to get better, and of course, some Backstreet Boys tickets. He chuckled and switched on my oxygen mask. I inhaled "silly gas" and went to sleep.

When I woke up in a mobile bed, with an IV attached to my hand in a recovery room, I knew it was over. My mom told me that they were going to give Rana my bone marrow in a couple of hours. I was so groggy, but I distinctly heard a nurse tell my mother how lucky we were that there was a match in the family. There were several children on the same hospital floor who were still waiting for bone marrow donors.

Many people in need of bone marrow donors are still waiting and without them, they cannot be cured. Some people are lucky and have matches in their families. Others are not so lucky and are on waiting lists. I'm not a doctor but I speak from experience. Donating bone marrow isn't as painful or as hard as it first seemed. The marrow was harvested from my lower back through special syringes. Recovery time is really short. I was sore right after the procedure and I couldn't move much, but the next day I was up and about with some soreness in my back. It felt like I worked out too hard and pulled a muscle. The pain is nothing compared to what Rana was going through: countless needles, nausea, and weakness – not to mention the emotions a ten-year-old goes through

stuck in a hospital bed, with clumps of hair falling out on her pillow. A few days of some discomfort (a week tops) is definitely worth another person's life. I'm sure many people don't know about bone marrow donation because blood and organ donations are more popularly known. I didn't even hear about it until I had to.

After Rana's transplant, she had to take more pills than she could count. There was always a fear that her body would reject my bone marrow. She also endured several expected complications, including high fevers, temporary diabetes (from the anti-rejection medications), and shingles. She also couldn't be around too many people at once, for the fear of catching a germ. Luckily, her bone marrow started to make new healthy blood cells, and her blood counts increased. Seven years later, Rana is doing very well and one year away from graduating high school.

AAMAC and Sick Kids are one of the reasons Rana's transplant was successful. The amazing staff at The Hospital for Sick Kids together with AAMAC's support made the transplant possible and saved my sister's life. Both AAMAC and The Hospital for Sick Children need donations to continue to fund crucial research and support for patients affected by these diseases. For more information, please feel free to contact me by e-mail or visit www.aamac.ca or www.sickkids.ca.

I would also like to say that I am not just writing this article to promote AAMAC or Sick Kids. I just want to spread awareness of these illnesses, because it is something very important to me. My family was lucky to have a related match for Rana, but thousands of families are not as lucky. However, I am also not trying to convince readers to go out and register with the bone marrow donor registry, or donate blood. If you do consider that, just know that giving someone "LifeBlood" is one of the best feelings in the world. But if I could persuade just one person to follow up on this article, let alone learn something new

about bone marrow failure diseases, then I have achieved my goal.

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NRBDO Update

By Silvia Marchesin

As many of you will be aware, AAMAC has participated in the Network for Rare Blood Disorder Organizations (NRBDO) for about three years now. This network is a coalition of the following patient groups:

- Aplastic Anemia and Myelodysplasia Association of Canada
- Canadian Hereditary Angioedema Society
- Canadian Immunodeficiencies Patient Organization
- Canadian Neuropathy Association
- Canadian Porphyria Foundation
- Canadian Sickle Cell Society & Sickle Cell Association of Ontario
- Canadian Organization for Rare Disorders
- Thalassemia Foundation of Canada
- Canadian Hemophilia Society

Our last meeting was in Toronto at the end of April. Each group provided an update on relevant issues including: comprehensive care and government relations, governance and creation of local chapters, patient registries, and standards of care.

We also discussed access to new therapies including the recently approved oral iron chelator, Exjade. Along with AAMAC, the Thalassemia Foundation of Canada and Sickle Cell patient groups represent people who need regular red blood cell transfusions. As a result, iron overload is a serious concern for all of us. We agreed to support each other in encouraging the provincial governments to fund Exjade for all patients who need it.

This past year the Canadian Organization for Rare Blood Disorders has had several forums and a conference on an orphan drug policy. As all of the participants represent rare disorders, we want to stay involved so that we can have input into the development of an orphan drug policy. We also discussed the recent report on the National Pharmaceutical Strategy. This progress report can be found at: http://www.hc-sc.gc.ca/hcs-sss/pubs/pharma/2006-nps-snpp/index_e.html.

Dr. Bruce Ritchie updated us on the Blood Borne Pathogen Surveillance Project (BBPSP). Dr. Ritchie recently installed a robot which increases the number of samples that can be processed daily. You can read about this at: <http://www.expressnews.ualberta.ca/newsreleases.cfm?id=8214>. The BBPSP originally started collecting samples from haemophilic patients, but has now been expanded to include patients with bone marrow failures.

There was also an update on blood safety. In particular, the network discussed the proposed change to existing blood donor deferral criteria for men who have had sex with another male (MSM). See the "Blood Safety" article for a full description.

Finally, the future of the network was discussed. All participants have found the network to be immensely helpful in furthering common goals, in supporting each other, in building a better support community for our members. We want the network to continue, but we have no funding. So the challenge will be to secure funding for the continuation of the network. To focus our efforts in the next short-term, we are proposing another conference in late 2008 where we will see what advances have been made in Canadian regions with respect to our most critical issue, the development of comprehensive care clinics for rare blood disorders.

Blood Safety

By Silvia Marchesin

“Currently, Canadian Blood Services indefinitely defers any male from donating blood if he has had sex with another male, even once, since 1977 (MSM). The MSM deferral is part of our screening procedures that are designed to identify a variety of behaviours and circumstances known to increase risk to the safety of the blood supply “(from the Canadian Blood Services website, www.blood.ca).

In April 2007, Canadian Blood Services consulted with stakeholders and interest groups to gather their views and input on the above policy. As blood recipients, we need to ensure that the blood system is held to the highest standard. As a result, AAMAC wrote to support no change in the deferral policy.

The Canadian Hemophilia Society has developed a formal position on this entitled “Current Donor Deferral Criteria Are in the Best Interests of Blood Safety”. You can read the full document at: <http://www.hemophilia.ca/en/1.2.2.php>. The AAMAC Board of Directors unanimously voted to support this well-articulated position.

Finally, Director Pam Wishart who sits on Canadian Blood Services’ National Liaison Committee re-iterated our position during recent committee meetings.

We are pleased that the Canadian Blood Services’ Board of Directors has now reviewed the MSM deferral policy and decided not to change it.

She lost a daughter, but not hope

Michele Henry, Toronto Star Staff Reporter

Reprinted courtesy Torstar Syndication Services

In 1990, Phillipa Lue pleaded for bone marrow. Now she’s spreading the word about stem cells

When thousands of people donated blood and money in 1990 in a frantic effort to save the life of 6-year-old Elizabeth Lue, no one had ever heard of stem cells.

Today, they represent a hope for curing what killed her.

The little girl captured the heart of Canadians with her fight to stay alive. She suffered from aplastic anemia, a rare blood disorder, and died Aug. 7, 1990, after a four-month campaign to find her a bone marrow match.

Nearly two decades later, her mother, Phillipa Lue, and Dr. Joseph Wong, a community leader who spearheaded the effort to keep her alive, want to revive Elizabeth’s legacy. They plan to put \$250,000 gathered in her name into helping Canadian Blood Services make stem cells, extracted from umbilical cords, accessible to the general public.

The money, left over from the Elizabeth Lue Bone Marrow Foundation, sits in several Bank of Montreal accounts.

“When Elizabeth passed away we wanted to make sure her death was not in vain,” Lue says. “Time has shown us there are many others like her and no family should have to go through what we went through. The foundation and the work are in her memory.”

Elizabeth was diagnosed with the fatal illness in January 1990, and doctors predicted it would take 5,000 people to find her a bone marrow match. Only a transplant could save her from a disorder that stopped her bone marrow from making sufficient blood cells.

Canadians opened their hearts, wallets as thousands of donors had blood tested. The four-month campaign to save six-year-old Elizabeth Lue from a fatal blood disorder raised more than \$1 million in 1990.

More than 10,000 people gave blood but to no avail.

After Elizabeth died, some of the fund money was used to help others find bone marrow. Wong also gave some money to the Hospital for Sick Children to finance bone marrow research. But the bulk of the funds remained untouched.

Wong and Lue debated what to do with the \$250,000, until they learned about stem cells. The non-specific cells came into public consciousness at the turn of this century. Stem cells, which can develop into various types of tissue, such as blood, make finding a match less important than it is with bone marrow or blood.

For that reason, more and more transplants today are done with stem cells extracted from discarded umbilical cords, rather than cells taken from bone marrow.

When Wong and Lue heard that Canadian Blood Services recommended last month establishing a national cord blood registry, their minds were made up.

“The future is in cord blood and stem cells,” Wong says. “Science is at a stage of exciting developments.”

Wong and Lue are determined to use the fund money to educate the public about cord blood, stem cells and draw awareness to donating such tissue to the registry.

In 1990, there was considerable worry that stigma in the Chinese population about giving away bodily tissue would prevent possible matches from coming forward. And finding an exact match for Elizabeth was like searching for a needle in a haystack, Wong says.

Wong and Lue plan to use the money raised in Elizabeth's name to teach the public, especially those in minority populations, why it's important to donate cord blood after a birth to the registry once it's set up.

Dr. Armand Keating, stem cell expert and professor of medicine at U of T, says a registry could help people from communities that are underrepresented in blood and marrow banks. "Most samples are from western European extraction," he says. "Quite a few patients don't have access to tissue."

Canadian Blood Services is pushing to establish a national database of cord blood, and Nanaimo federal James Lunney tabled a private member's bill six weeks ago to allocate money for such a project.

That gives Lue hope. "A public registry could be used to help, to benefit everybody."

Girl's donor list saved this 34-year-old from New Jersey

She'd never heard of Elizabeth Lue.

Cammy Lee had no idea that the bone marrow donor who came forward to save her life had first tried to rescue the six-year-old girl. Lee found out about Elizabeth, who died in August 1990, more than two years later, long after her own bone marrow transplant.

Elizabeth's parents approached Lee to tell her their daughter's story.

Lee, now 34, was diagnosed with leukemia in 1986. After six years of chemotherapy, her cancer returned in 1992. She needed a bone marrow donor.

A registry co-ordinator at a hospital in New Jersey, where Lee lived with her parents, began scouring the globe for a match. After an exhaustive search, Lee found luck in Toronto.

The Canadian Red Cross, now called Canadian Blood Services, had more than 10,000 samples from Chinese donors on record from a campaign in 1990 to save Elizabeth.

Virginia Lau had come forward to help save Lue.

Lau, who is believed to be living in Beijing, didn't end up being a match for Lue, but two years later, she was found to have the same marrow type as Lee.

Today, Lee works for the Cammy Lee Leukemia Foundation, set up in 1992 by her family to find a local match. She recruits potential marrow and stem cell donors.

Education Day Logistics

Where is Metro Hall?

Metro Hall is conveniently located near the Spadina exit on the Gardiner Expressway in Toronto's picturesque theatre district. Underground parking is available onsite as well as one block away. If you take the subway, exit at the St. Andrew stop on the University line and walk west to Metro Hall.

Program

Registration and Breakfast will start at 8:00 am. The program will commence shortly after that. A preliminary program is included with this newsletter. The final program will be posted on our website, www.aamac.ca.

Accommodations

Reasonably priced hotels are within a short walk or drive of Metro Hall.

*** Holiday Inn On King, Downtown Toronto Hotel is one block away**

370 King St. West

Phone: (416) 599-4000 or 1-(800) 263-6364

www.hiok.com

*** Marriott Residence Inn, Toronto Downtown/Entertainment District is one block away**

255 Wellington Street West

Phone: (416) 581-1800 or 1-(800) 331-3131

www.marriott.com

*** Travelodge, Toronto Downtown West is about 1.5 km west**

621 King St West (at Bathurst Street)

Phone: (416) 504-7441 or 1 (800) 578-7878

www.travelodgetorontodowntown.com

Mark Your Calendars

Academic Half-Day in Hematology, Toronto, Ontario:

Saturday, September 15, 2007, 12 to 5 pm. Organized by Hematology Residents & Dr. Christine Cserti, University Health Network/University of Toronto, this program is designed for the learning needs of practicing physicians & physicians-in-training. The event is being held at the Courtyard by Marriot, 475 Yonge St. (at College), Alexander Room. Contact Margery at (416) 969-7457 or margery@optimizinghealth.org for further details.

September 29, 2007, Patient Education Day and Annual General Meeting, 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 registration form and preliminary program are included in this newsletter. The final program will be available at www.aamac.ca.

Social Gathering, Toronto, Ontario:

Saturday, September 29, 2007 at 5:30 p.m. Please join us after the Patient Education Day for an informal social gathering for patients, family, friends and healthcare providers at a nearby eatery (tentatively Wayne Gretzky's Restaurant on Blue Jays Way). Food and drinks not included. Final details will be posted on the website closer to the date and also shared with attendees at the Education Day. For more information, please call Chris at (416) 994-6712.

Blood Donor Appreciation Day, Calgary, Alberta:

Thursday, October 18, 2007 (9 a.m. to 1 pm). If you are interested in taking part in this event for either an hour of your time or for the whole time, please contact Liz Lemire at (403) 275-4595 or alberta@aamac.ca.

Southeastern Ontario Support Group Meeting, Kingston, Ontario:

Thursday, October 18 at 7 pm. To rsvp, please contact Trevor at rigitari@aol.com, Susan at susdragon@gmail.com or leave a message at the national office, 1 (888) 840-0039.

October, MDS Update Conference, Toronto, Ontario:

November 2, 2007. The conference will be held at Sutton Place Hotel in Toronto. This conference is for physicians who treat MDS patients. If you are a myelodysplasia patient, please encourage your physician to attend this important event being organized by AAMAC's Medical and Scientific Advisory Committee chair, Dr. Richard Wells, and by Dr. Rena Buckstein. Drs Wells and Buckstein are co-directors of the Crashley MDS Research Laboratory at the Odette Cancer Centre in Toronto.

Calgary and area AA, MDS, PNH support group meeting, Calgary, Alberta:

Sunday, October 21, 2007 at 2 pm. Support group meeting to be held at the home of Mike and Liz Lemire. RSVP to Liz at (403) 275-4595 or alberta@aamac.ca.

Spring Swing 2008, tentatively Saturday, April 5, 2008, Toronto, Ontario:

Reserve your ticket now for our fourth annual Spring Swing dinner, dance and silent auction. 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 silent auction items at (905) 457-0552 or schmelyk@sympatico.ca.

Sunnybrook and the Cancer Centre over many years. The Centre is home to the Crashley Myelodysplastic Syndrome Research Program.

Newsletter is now available online.

Starting with the Spring 2007 edition, we will be posting the newsletters on our website at www.aamac.ca. The newsletter will be in Adobe PDF format and will be available for viewing on a read-only basis.

Donate Online

Now 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 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.

French Brochures Now Available

AAMAC is pleased to announce that the new brochures are now available in French. Please contact the national office at 1-888-840-0039 to order your copies.

News of Note

Sunnybrook Renames Cancer Centre. The Toronto Sunnybrook Regional Cancer Centre has been renamed the Edmond Odette Cancer Centre in recognition of Mr. & Mrs. Edmond G. Odette who have made repeated and significant donations to