

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

AAMAC Announces \$45,000 MDS Grant

The Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC) is pleased to announce that it is funding a proposal to create Canadian Consensus Guidelines on the Treatment of myelodysplastic syndrome (MDS). In addition, this new two-year, \$45,000 grant will be named the Gord Sanford Memorial Grant in honour and in recognition of the extensive contributions made by our late President to Canadian patients.

The guidelines will focus on the diagnosis and management of MDS. They will be developed by Dr. Richard Wells, Co-Director, Myelodysplastic Syndromes Program at Sunnybrook Health Sciences Centre and the Chair of AAMAC's Medical and Scientific Advisory Committee, and an expert panel of 10 to 15 hematologists from across Canada.

"In the past few years there have been numerous major advances in MDS – including new pathological classification and prognostic systems, new approaches to supportive care, and new disease-modifying therapies," wrote Dr. Wells in his proposal. "It has been very difficult for practicing hematologists, oncologists and internists to keep pace with these developments and as a result practice patterns have become haphazard. To ensure delivery of proper, up-to-date care to Canadian MDS patients, it is essential to produce a strong, evidence-based practice guidelines."

Dr. Wells was part of a recent collaboration by Canadian hematologists

to create Canadian Consensus Guidelines on the management of iron to create Canadian

Consensus Guidelines for iron overload in MDS. Those guidelines were recently published after peer review in the journal *Leukemia Research*. It was during the development of the iron chelation guidelines that need for broader MDS guidelines was highlighted.

A consensus conference meeting will be held in May 2009 and following approval of recommendations by the panel, a manuscript will be drafted for submission to a peer-reviewed journal such as the *Canadian Medical Association Journal*.

AAMAC is pleased to support this effort which is designed to improve the lives of Canadians with MDS as reflected by the Board's unanimous support. The Board also agreed it was a most fitting tribute to Gord Sanford who worked tirelessly to improve the lives of other patients while fighting the disease himself.

Welcome New Board Members!

AAMAC is pleased to officially welcome Anna Chamrai to the Board. Anna has already made great contributions as our treasurer and we are grateful to have her continued involvement. We'd also like to extend a welcome to Andy May. Andy joined the Board this summer, about a year after his daughter received a successful bone marrow transplant for aplastic anemia. Both members are based in Ontario. Welcome Anna and Andy to the Board!



**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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Tribute to Liz Lemire

By Janice Cook

On July 7, day 11 post stem cell transplant, we were very saddened to hear of the passing of Liz Lemire of Calgary.

Since her 2002 diagnosis of aplastic anemia, Liz and her husband Mike have been very involved and great supporters of AAMAC. Until last August, Liz was co-coordinator of the Alberta Chapter, and was still a member of the Calgary support group, which she started in 2004.

Due to their many friends and contacts within the community, AAMAC has been the recipient of a number of fundraising efforts.

Among others, some of the projects they have helped bring about were the first AAMAC Patient Education Day, held in Edmonton in September 2006, and funding of a summer research project about MDS in 2007.

Liz was a wonderful, positive, fun, loving person, much admired by friends and cherished by family, and she will be missed and remembered forever.

Her memorial service was filled to overflowing, and the heartfelt tributes and stories had us alternately laughing and tearful. Her brother, Doug, who was her donor, gave a moving talk about the importance of stem cell donors, and OneMatch Stem Cell and Marrow Network cards and information was available for those interested to pick up.

Liz would have liked that, and it was another way she could leave her mark on the world and help others with the diagnosis of bone marrow failure.

Our sympathy and best wishes go to Mike, and her son Jamie, as well as all of her family and friends.

Alberta Chapter Update

By Janice Cook

AAMAC has again been included in the updated Calgary Early Intervention Resource Booklet used by Public Health Nurses and staff at Alberta Children's Hospital. We are listed under Parent Support Groups for medical illness and special needs. The listing updated our contact information and included our website. We are described as a valuable resource for parents of children with AA, MDS or PNH.

We have also been contacted by the wish co-ordinator for the northern Alberta Make-a-Wish Foundation. They want to spread awareness of their program and reach out to any families of children with AA, or MDS we know of who may benefit from it.

Because of our confidentiality rules, we can only make the information available to family, and leave it up to them to contact this program if they so desire. If you want their contact information, you can email me at cookjan@telus.net.

As long distance co-ordinator, my main role since moving out of province has been to call all people newly listed with our national office and find out if they need further information or contact. I have been able to put a few people in contact with others in their community in hopes of their finding support in this way. I have met with some of the former members of the Calgary support group informally and some of us still keep in touch.

Ontario Chapter Update

By Chris Meyer

Most of our chapter efforts this summer have been directed at

advocacy efforts related to access to medication (see the article about Revlimid as an example).

Looking ahead, there's still time to sign up for the Mark Patchell Memorial Golf Tournament in Owen Sound. Please contact the organizers listed on the events page if you would like to join us for a day on the greens while raising money for AAMAC.

I'm also looking forward to this year's Education Day and hope to see many patients and family members there in October. It promises to be very informative and will be a great opportunity to connect with other patients. Although no formal social event has been planned afterwards, there are many great local restaurants for those who wish to meet afterwards for dinner.

Revlimid Update

By Stan Chmelyk and Chris Meyer

A growing group of patients and family members have joined our efforts to advocate for access to Revlimid in Ontario. As of press time, we are awaiting a final decision from the Joint Oncology Drug Review (JODR) committee, which will make a recommendation to all the provinces (except Quebec), on whether or not to fund Revlimid through the provincial public formularies.

While the JODR recommendation could affect MDS patients across Canada, we have focused our efforts in Ontario where the JODR is currently housed and where a group of multiple myeloma patients also interested in access to Revlimid is working with us.

AAMAC has also started to work with a group of multiple myeloma patients in B.C. who are also concerned that if Revlimid is not funded for MDS patients, it does not bode well for them. (Health Canada is reviewing the medication for multiple myeloma.)

We are asking patients, family members and supporters in Ontario to

request a meeting with their local Member of Provincial Parliament (MPP) to discuss our concerns and share their stories. At that meeting, we request that they ask their MPP to write a letter to the Minister of Health and Long-term Care urging funding of Revlimid.

Template letters and a report back form are posted at www.aamac.ca. Just click on the word "advocate" on the home page. As well, we are now meeting by toll-free teleconference every week or two and interested patients, family and friends are welcome to join us. We will also post updates on our website including the teleconference information.

There is already some progress to report. On July 30, 2008 a meeting was held with Mona Sabharwal (Senior Manager, Drug Programs Management, Ontario Public Drug Programs) to discuss AAMAC's concerns about an initial JODR recommendation to not include Revlimid in the provincial formulary to treat MDS 5q- (which is what it was approved for by Health Canada).

The Chair of our Medical and Scientific Advisory Committee, Dr. Richard Wells, Board member Stan Chmelyk and two MDS patients currently using Revlimid were present representing MDS patient concerns. Mona Sabharwal and two colleagues (all pharmacists including Mona) represented Ontario's Ministry of Health and Long-term Care.

The meeting was very cordial and extended for a half hour beyond the one-hour that had been allotted for the meeting. Much of the discussion was quite technical and Dr. Wells was able to field those questions very well.

The two MDS patients gave a wonderful and very powerful account of their experience and the tremendous change in their quality of life as a result of Revlimid.

We learned that the JODR was still awaiting a submission from Celgene in reply to the initial JODR recommendation. The ministry had

waived the one-month deadline for Celgene's response, allowing the company more time.

We were also told that Helen Stevenson (Assistant Deputy Minister and Executive Officer, Ontario Public Drug Programs) who will make a decision for Ontario was looking at many different sources of information. The JODR recommendation is only one source she will use to make her decision. At this point the province has not said no and it has not said yes.

The meeting went very well and we came away feeling that our concerns had been heard. We will continue to advocate for patients regarding access to medication.

If you live in Ontario and have not already done so, please get involved. The more voices, the more likely we will be heard. It is also our hope that through this advocacy campaign we will build a network that can help us improve access to other currently approved medications such as Exjade and medications which are not yet available in Canada such as Decitabine.

Patients in other provinces are also welcome to adapt the templates should they wish to advocate for funding with their provincial government. We can also connect those in B.C. to the group already advocating in that province.

Many tools we have developed could also be used for other issues.

If you have any questions, please contact ontario@aamac.ca or phone Stan at (905) 457-0552.

Please note there was a problem with the ontario@aamac.ca e-mail address but this issue appears to have been resolved. If you did not receive an expected email from Chris please check your spam folder or email her at ontario@aamac.ca. Again, the materials and updates are also posted on our website.

AAMAC's Third Annual Patient Education Day

It's that time of year again! The 3rd Annual Patient Education Day will take place on Saturday October 4 and we are excited!

This eventful day at Toronto's Metro Hall will start off by commemorating AAMAC's 20th Anniversary with an introduction by AAMAC founder, Renee Levine. This will be followed by talks by healthcare professionals, such as Dr. Wells from Sunnybrook Dr. Dror from the Hospital for Sick Children, and Dr. Gupta from Princess Margaret Hospital.

There will be an open question and answer period, which is a great opportunity to have your questions addressed by medical experts.

The day will also include patients and families affected by bone marrow failure diseases sharing their stories. We hope that listening to another person's story will be insightful for members attending.

After lunch and the General Annual Meeting, the afternoon portion of the event this year will give you a choice between an adult focus and a pediatric focus. This is a great opportunity to meet with other patients and their families going through the same challenges.

We strongly encourage members to come to this free event. Travel sponsorships are also available on a first-come, first-serve basis to patients and families that live outside of the GTA. Please contact Chris Meyer for more information on the travel sponsorships and reimbursements at ontario@aamac.ca or (416) 994-6712.

A special thank-you to returning sponsors, Celgene and Novartis, for their continued support. A welcome and thank you as well to the Leukemia & Lymphoma Society of Canada for sponsoring us this year.

Thank you to Toronto City Councillor Gloria Lindsay Luby for helping us book Metro Hall for our event.

Special thanks to Caroline Laughlin, Silvia Marchesin and the late Gord Sanford for working hard on this event and putting together a wonderful program.

A detailed preliminary program and registration form appear on the next page. An up-to-date program is also available on our website.

We hope to see you in October!

Patient Education Day Logistics

Program

Join us on October 4th, 2008 at Metro Hall in Toronto for a full-day educational event. Please see the registration form and preliminary program on the next page. An up-to-date program is available on www.aamac.ca.

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.

Accommodations

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

* Holiday Inn On King, Downtown Toronto, one block away
370 King St. West
(416) 599-4000 or (800) 263-6364, www.hiok.com

* Marriott Residence Inn, Toronto Downtown/Entertainment District is one block away
255 Wellington Street West
(416) 581-1800 or (800) 331-3131, www.marriott.com

* Travelodge, Toronto Downtown West is about 1.5 km west
621 King St West at Bathurst Street
(416) 504-7441 or (800) 578-7878, www.travelodgetorontodowntown.com



**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

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, Ancaster</i>
GPS Health Navigational System	<i>Caroline Laughlin, Former AAMAC Director, and Margery Konan, Central East Community Care Access Centre, Scarborough</i>
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>

Educational Sponsors:



Break Sponsor:



Registration Form - Education Day

Saturday, October 4, 2008
8:00 a.m. – 4:00 p.m.

Metro Hall, 55 John Street, Toronto, Ontario



www.aamac.ca

Contact Information

Surname:	First name:
Title:	
Institution/Organization:	
Address:	City:
Province:	Postal code:
Telephone (Res.):	Telephone (Bus.):
Fax:	Email:

Profile (please check all applicable)

<input type="checkbox"/>	Patient, family member or friend <input type="checkbox"/> Aplastic Anemia <input type="checkbox"/> Myelodysplasia (MDS) <input type="checkbox"/> PNH
<input type="checkbox"/>	Representative of patient organization Name of organization: _____
<input type="checkbox"/>	Physician
<input type="checkbox"/>	Health professional
<input type="checkbox"/>	Industry representative

Breakfast, coffee breaks, and lunch will be provided.

There are a limited number of travel sponsorships available to a maximum of \$300 per person. If you require financial assistance to attend Education Day, please indicate this below. The purpose of the sponsorship is to assist patients and families from outside the Greater Toronto Area to attend. We will let you know as soon as possible if your sponsorship is approved. You will be required to bring receipts to Education Day for reimbursement at the event.

Travel Sponsorship

<input type="checkbox"/>	Yes, I require a travel sponsorship.
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There are no fees to register for the Education Day, however you must pre-register. The deadline for registration is **September 26, 2008**. Please submit registration forms to:

Janice Cook 2238 Bedford Place Abbotsford, BC V2T 4A5	E-mail: cookjan@telus.net Phone: (604) 504-7228
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For more information, contact:

Janice Cook, Registration Coordinator, (604) 504-7228, cookjan@telus.net, or
Caroline Laughlin, Education Day Co-chair, (416) 399-6639, wclaughlin@rogers.com

AA&MDSIF Patient and Family Conference Celebrates 25 Years

By Chris Meyer



Chris Meyer and Neil Horikoshi (Chair of AA&MDSIF) at the Foundation's 25th anniversary dinner

In July, I had the pleasure of attending the annual Aplastic Anemia & MDS International Foundation (AA&MDSIF) Patient and Family Conference in Washington, D.C. This five-day long event featured a nurse education day, an optional pre-conference orientation to the diseases and an optional advocacy day.

The main conference took place over two days and included special children's sessions. For adults, a wide variety of presentations were sophisticated, recognizing the high level of knowledge many patients develop over time.

More than 300 people registered this year, a record attendance that was fitting for the Foundation's 25th anniversary year.

Previously held each August, this year's conference was moved to July to allow patients to spend a day advocating on Capitol Hill for increased funds for bone marrow failure diseases.

If you have not attended an AA&MDSIF conference, I would strongly encourage you to in the future if you can. In addition to a roster of leading experts in bone marrow failure diseases, the conference provided a wonderful opportunity for patients and family

members to make friends and build their very own personal international support network.

A personal highlight for me was meeting Ruth and Neil Cuadra in person. They generously run www.marrowsforums.org, a free site where patients can talk electronically between conferences. Currently there are about 700 members and counting.

Although patients and family members share many common issues across borders, some issues are local and AAMAC now has a regional area specific to Canadians on the site.

As you can imagine, it would be difficult to convey five days of information in this newsletter. So I'd like to offer a couple of highlights that might be of particular interest to Canadian patients.

An interesting session called "Surfing for Your Health: The Internet and Bone Marrow Failure Diseases" showed patients how to use MedlinePlus and other National Library of Medicine (NLM) information sources. NLM does not accept advertising or link to pharmaceutical sites and has its content reviewed by medical experts, so the information is more neutral than many other sources. The session stressed considering the source of information when surfing the Internet since some sites are designed to sell products. An NLM drugs and supplements database allows patients to search by product or name. There is information from the NIH's Natural Center of Complimentary Health and Medicine and NLM operates www.clinicaltrials.gov which posts current information about open clinical trials. You can search by disease, medication and geographic locations including Canada.

Medical speakers included Dr. Gail Roboz, the Director of the Leukemia Program at the Weill Medical College of Cornell University and the New York Presbyterian Hospital in New York City, who discussed what we know about bone marrow failure diseases, who gets them and why.

She recommends that patients determine their International Prognostic Scoring System (IPSS) score with their doctor as it will help them determine a treatment course and discussed the challenge of diagnosing MDS. "In medical school they taught when you hear hoofs, look for a horse not a zebra," she said, highlighting the rareness of the disease. She added that persistent, unexplained abnormal blood counts that are trending in the wrong direction need an explanation.

Many of the sessions were videotaped and I understand that the Foundation may make some of this available at www.aamds.org in the future.

More than 140 patients and family members registered to meet with their representatives on Capital Hill. Specifically, they requested support of new funding for an initiative at the Centres for Disease Control (CDC) to set up a patient registry for surveillance and epidemiology (looking at the cause) of bone marrow failure diseases. The initiative was proposed by Congresswoman Doris Matsui. Her late husband had MDS.

As you may know, AAMAC itself has a long association with AA&MDSIF. In fact, we send some of its educational materials to new patients in Canada. I was pleased to present its Chair, Neil Horikoshi, with a donation in recognition of this support.

I hope many Canadians will attend next year's AA&MDSIF conference. Although a date and location have not yet been selected we will communicate that information in the newsletter when it is.



Albertans Lucie McGavin and her son James, also at the 25th anniversary dinner. Both photos courtesy of Alison Hines.

Racers Highlight AA & MDS in Canada

By Chris Meyer



BMG Motorsports car #38 was in both Ontario and Quebec recently raising awareness about bone marrow failure diseases.

BGB Motorsports was at Mosport in Ontario and at the Grand Prix de Trois-Rivieres in Quebec this summer helping to raise awareness for bone marrow failure diseases. Both the #83 and #38 BGB Porsches raced. The #83 car has extra special meaning as the Aplastic Anemia & MDS International Foundation celebrates the 25th anniversary of its founding in 1983.

The BGB Motorsports team's involvement is personal – Judi Wilkinson, the team's office manager, whose husband and son both work for BGB Motorsports, was diagnosed and treated for aplastic anemia five years ago. Knowing that thousands of people were watching the team's #83 car win at Daytona earlier in the season, Judi decided that if she could put the AA&MDSIF logo on the cars it would mean thousands of people learning about a disease too few have ever heard of.

Mark Your Calendars

Third Annual Mark Patchell Memorial Golf Tournament, Saturday, September 6, 2008, Scenic City Golf Club, Owen Sound, Ontario: \$100/person. Fees include 18 holes, power cart, dinner,

prizes, putting, closest to pin, and longest drive. Space limited to first 144 golfers. Contact Duane Bowman at (519) 986-1420 or patchellkids@aol.com. Proceeds go to AAMAC.

MDS Support Group Meeting, September 27, 2008, 10 a.m. noon, Hamilton, Ontario: This meeting, hosted by the Leukemia and Lymphoma Society, takes place at the Ancaster Christian Reformed Church (70 Garner Rd. East, in Ancaster). Contact Lea Greenwood at (416) 585-2873 or (866) 585-2873, or e-mail lea.greenwood@lls.org for more information.

Walk for PNH, Sunday, September 28, 2008, New York City, New York: Join PNH patients and families at the Third Annual Walk for PNH in Riverside Park. For details about the fundraiser visit the PNH Research and Support Foundation at www.pnhfoundation.org.

AAMAC's Third Annual Patient Education Day and Annual General Meeting, Saturday, October 4, 2008, Toronto, Ontario: Plan to attend this full-day educational event. It's a good learning opportunity as well as a chance to meet others dealing with bone marrow failure disease. Travel sponsorships are available on a first-come, first-served basis. A registration form and preliminary program is included in this newsletter. An up-to-date program is available on our website.

News of Note

AAMAC Letter Published in Globe & Mail Newspaper
The following letter to the editor by AAMAC Medical & Scientific Advisory Committee Chair Dr. Richard Wells was written in response to incorrect information about MDS which appeared in a tribute to the late Canadian fiddler Oliver Schroer.

"In your moving tribute to Oliver Schroer (Fiddler Was a Prolific

Composter And Performer With A Style All His Own – Obituaries, July 19), you repeat a common misperception concerning the bone marrow failure disease with which Mr. Schroer was diagnosed. This syndrome most emphatically does not "inevitably" lead to leukemia. Although some patients with myelodysplasia develop acute leukemia, about 70 per cent do not. In most cases, myelodysplastic syndrome is usually a chronic disorder that necessitates blood transfusions, not a harbinger of leukemia."

To read the tribute to Mr. Schroer visit the Globe and Mail website. You can also hear some of the 1,000 pieces Mr. Schroer composed during his lifetime at www.oliverschroer.com.

100 Questions & Answers About MDS

Our national office library has a new book called 100 Questions & Answers About MDS. Questions are organized in categories from symptoms and diagnosis to treatment and side effects. If you would like to borrow one of our three copies, please contact the office.

New Newsletter Editor!

I, Rolla Bahsous, am pleased to be your new Newsletter Editor. It has been a pleasure being on the Board for almost two years, and I am honoured to take on this exciting opportunity. I would like to thank Stan Chmelyk for being a great editor and I hope that I can follow his lead. I personally would like to thank Stan and Chris Meyer for being great mentors and guiding me in this new role. I look forward to upcoming issues!

I would also like to start to include patients' and members' personal milestones in the upcoming newsletters. If you have any happy news to share (i.e. a graduation, a new addition to the family, etc.) with members, please send it my way. You may contact me at rolla.aamac@gmail.com and I will try to include as many as I can.