

*Education  
Support  
Research*

*Spring 2007*

Aplastic Anemia & Myelodysplasia Association of Canada

# NEWSLETTER

## *President's Message*

I would like to start off by thanking all of you who contributed to our direct mail campaign in the fall. You may not be aware of this, but AAMAC is entirely funded by the donations of members like yourself and by the fundraising efforts of volunteers. Thanks to your generosity over \$18,000 was raised. Thank you!

I am pleased to announce that Liz Lemire and Janice Cook, both of Calgary, will be co-coordinating the Alberta chapter. Both ladies have been long-time volunteers with the association. Janice will be doing double-duty as we welcome her to the national board of directors as well.

Spring will soon be upon us and our activities are gearing up. Please see the Mark Your Calendars section for events across the country. In particular, I invite you to join the Ontario Chapter at the Spring Swing event in April. Details can be found in the Ontario Chapter update, the Mark Your Calendar section, or on our website.

Thank you to board members Rolla Bahsous and Caroline Laughlin for representing AAMAC on the organizing committee of the *Childhood Marrow Failure and Myelodysplasia Meeting for Patients and Families* in Toronto. This gathering was led by Dr. Yigal Dror, one of the association's medical advisors.

It seems that more and more of our communication with members has to do with the drug options available to treat bone marrow failure diseases. These are exciting times as there is always something to update you about. Access to treatment options is of great concern to us. This newsletter will update you on the situation with respect to Exjade and Revlimid.

This issue of our newsletter is being circulated to over 300 Canadian hematologists as part of an ongoing awareness campaign. The package of information we have sent includes a poster, brochures, business cards and this newsletter. Please ask your doctor if they have received a package from the association and encourage them to put the poster up where patients can learn about the services that the association offers. If they have not received a package, please contact the national office and we would be pleased to send one out to them.

Regards,

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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## Update on Exjade

By *Silvia Marchesin*

Health Canada approved the first oral iron chelator in Canada: deferasirox (Exjade) in October 2006. Now the drug has moved into the Common Drug Review (CDR) process. This process is outlined on the CDR website, <http://www.cadth.ca/index.php/en/cdr/process>. On that site you can follow the progress of Exjade through the process. The end result is that an expert committee (called the Canadian Expert Drug Advisory Committee (CEDAC)) will recommend if Exjade should be covered by provincial drug plans.

The original idea behind the CDR was to have a nationwide body review drugs and make them available for provincial listing. However, even with the CDR, each province has its own approach to deciding which newly approved medicines should be covered under their drug benefit plan (for seniors and other individuals). So in fact, the CDR means an additional delay that patients face after Health Canada's approval of a drug.

In the case of Exjade, the expert committee recommendation is expected in late March 2007. Until this review is completed, we will not know whether Exjade will be recommended for broad use for all patients with iron overload due to transfusions or if there will be some restrictions.

There are two issues at stake here: to ensure that each province funds Exjade and to ensure that Exjade is available for all patients with iron overload due to transfusions.

AAMAC will be participating in discussions with other patient groups on how we can best advocate with both of these goals in mind. Of course we are committed to writing to the provincial health authorities on behalf of aplastic anemia, myelodysplasia, and PNH patients. We will keep you

posted on our website, [www.aamac.ca](http://www.aamac.ca) and in upcoming newsletters to let you know how you can help as well.

The last newsletter mentioned the Exjade Patient Support Program provided by Novartis Pharmaceuticals. "The EXJADE\* Patient Support Program offers assistance in obtaining reimbursement from public (government) and private (your insurance company) payers, as well as financial assistance if you cannot afford the full amount of your co-pay," according to the form itself.

Your doctor has to prescribe Exjade for you and fill in his part of the form. Then both the enrolment form and prescription need to be faxed to the program. After the enrolment form and the prescription have been faxed, patients should keep the original prescription. The patient will be contacted by the Exjade Patient Support Program to discuss reimbursement needs and start making arrangements for the prescription.

You can learn more about Exjade by visiting the Canadian Novartis website, [www.novartis.ca](http://www.novartis.ca), or by speaking with your doctor.

## Alberta Chapter Update

By *Liz Lemire*

I hope that everyone had a very good Christmas and is still following through with their New Year's resolutions! We are happy to announce that the Alberta Chapter Co-ordinator job has been filled by myself, Liz Lemire, and Janice Cook. We figured it would take two of us to fill Silvia Marchesin's shoes! We are sorry to see Silvia step down from this position but she hasn't gone far and is doing a great job as our National President. Both Janice and I have nothing but great things to say about Silvia and AAMAC for helping us understand and get us through when we were first diagnosed with aplastic anemia. So now we would like to aid

others who are being diagnosed or coping with AA, MDS, or PNH as best as we can.

The Calgary and area group is planning a spring support group meeting. It will take place on Sunday, April 15<sup>th</sup> at Janice Cook's house starting at 2 p.m. If you plan on attending please RSVP to Janice either by phone: 403-241-0053 or email: cookjan@telus.net. It is open to anyone affected by AA, MDS or PNH and any family members they'd like to bring along. It is a very casual day and the three or four meetings we have had so far seem to be enjoyed and appreciated by all attending.

The Edmonton and area group would like to announce that they are planning another Garage Sale on June 1 and 2. Silvia said that they had lots of fun last year, raised a lot of money - over \$1,000 -- and they want to do it again. Please contact Silvia at smarchesin@shaw.ca if you have any items you'd like to contribute to the garage sale or if you'd like to help out with the event. Remember, "One person's junk is another person's treasure!"

Silvia has mentioned that she had many volunteers over the past year help out at various events. In particular she would like to thank Michele King, Liz & Mike Lemire, Janice & Jim Cook and Kayla Cox.

## Ontario Chapter Update

By Chris Meyer

Spring is almost here and what better way to kick off the season than with Spring Swing!

Our third annual fundraising dinner will come alive with the fabulous big band sounds of *No Strings Attached*. It's a rare opportunity to see an 18-piece band and this group is always a big hit! We truly appreciate them donating their performance for the third year in a row. We are also extremely pleased

to welcome Enbridge Gas Distribution as our Evening Sponsor.

The evening is great value with a \$60 ticket including live music, a generous five-course Italian dinner, an open bar and the opportunity to bid on terrific silent auction items including artwork, entertainment packages, a natural gas barbecue, two VIA Rail tickets and beauty product baskets.

The sit down menu includes hors d'oeuvres and antipasto (prosciutto, melone, olives, grilled vegetables and bocconcini), Rigatoni Pomodoro, Gnocchi Smoked Salmon in Pink Sauce, Veal Marsala, Pollo Lemone, potatoes, vegetables, mixed salad and dessert crepes. There will be coffee, tea, espresso and cappuccino to choose from and pastries follow at 11 p.m.

There is still time to order tickets and I ask you to encourage family and friends to attend this event. Members of our volunteer committee work very hard to pull such a great night together and raise funds for AAMAC initiatives including support of research. Please come out and show your support or encourage others to attend on your behalf.

There is also still time to let me know if you would like to volunteer the evening of the event or know someone who would like to donate an item to the silent auction. We're still looking for silent auction items and have some tables available for business sponsors. I can be reached at 416-994-6712 or ontario@aamac.ca for more details.

I would like to thank Anita Huinink of Hamilton and her family for selling dozens of LifeBlood bracelets (and counting) while raising awareness about aplastic anemia! Anita has been ably assisted by her 8-year-old son Austin who was recently diagnosed with severe aplastic anemia. The family is also sharing Canadian Blood Services (CBS) brochures about the Unrelated Bone Marrow Donor Registry and encouraging people to join.

Volunteers and members participated in a conference at the Hospital for Sick Children in Toronto. Watch the summer newsletter for a report from Caroline Laughlin.

Volunteers have also been very busy at blood donor clinics. Thank you to Cheryl Cameron who paid tribute to her father's (John M. Cameron) memory by giving LifeBlood bracelets and brochures to donors at a blood donor clinic in Brampton on Boxing Day. It was wonderful to have someone volunteer at a clinic over the holidays and thank donors for their gift of life at a time when turnouts are traditionally low. This was Cheryl's first time thanking donors and she said it was a great experience, especially since several donors asked CBS for information about donating platelets after hearing about the needs of patients.

In February, Caroline Laughlin and I were pleased to hand out LifeBlood bracelets at an "In Honour" blood donor clinic in Etobicoke which was organized in memory of Mary Emily Giammarino who needed blood and platelets regularly after her diagnosis with MDS in 2006. Mary Emily's daughter Patricia showed her appreciation for the generosity of blood donors by handing out gift certificates to her beauty salon.

Thanking donors at clinics is one of the ways that AAMAC carries out its mandate to promote blood programs. The current issue of CBS' Central Ontario Region newsletter Bloodlines includes an article about our efforts. It highlights the importance of blood and platelet donors in Board member Stan Chmelyk's successful bone marrow transplant for MDS - Stan recently celebrated his "fifth birthday"! A link to the article appears on our website, [www.aamac.ca](http://www.aamac.ca), or you can contact me for a printed copy.

If you would like to get involved as a Chapter volunteer, please call me.

Our next support group meeting will be in Toronto on Saturday, May 5 from 3 to 5 p.m. We'll meet at Wellspring House on the grounds of

Sunnybrook Health Sciences Centre. Patients, their families and healthcare providers are invited to come out to this informal gathering and share experiences with MDS, aplastic anemia and PNH. Light refreshments and parking passes will be available. Please RSVP to me. I look forward to seeing many of you there!

We are also very pleased that volunteers Susan Bowers and Trevor and Patricia Thompson are organizing a support group meeting in Kingston on Thursday, May 10 at 7 p.m. Please RSVP to [ontario@aamac.ca](mailto:ontario@aamac.ca) or leave a message at our office for Susan. We hope that many of our members in eastern Ontario communities including Ottawa will be able to join us in Kingston.

## Atlantic Chapter Update

*By Gai Thomas*

In late November \$1,000 was donated to AAMAC by the Classic Chevy Club in memory of its late member Kenny Wentzell who died from MDS. The cheque was presented to Gai Thomas (Atlantic Chapter Acting Coordinator) on the shore of Halifax harbour by Maureen (Mo) Wentzell, Kenny's widow (see photo).



*Left to Right: Club President Jeff Kempton, Maureen Wentzell and Gai Thomas*

Our November meeting marks our first anniversary, and we held a small celebration with patients and friends before our regular meeting. At present we have 18 patient members, 29 family members (including six children) for a total of 47. We have

had some sad moments with the deaths of several members; however a number of previously seriously ill members are recovering from successful bone marrow transplants.

Our support group meetings are held on the last Tuesday of each month, September to June, at various times, in the VG Hospital Centennial Building 8A Conference Room.

Family events in 2007 will include a Sleigh Ride on March 3, an August Picnic and a Pre-Christmas Fun Day.

For further information and confirmation of meeting and event times please email [atlantic@aamac.ca](mailto:atlantic@aamac.ca) or call 902-455-2612.

## Aplastic Anemia Survivor Makes Donation

*By Gord Sanford*

For the last several years detectives Dave Ecklund and Pete Grande of the Toronto Police Services 42nd Division have held a fund raising golf tournament for AAMAC. This year Gord Sanford (AAMAC Director and past president) gratefully accepted a \$1,200-plus donation from these two officers. Seventeen years ago Dave had aplastic anemia and was the recipient of a successful bone marrow transplant at the Hospital for Sick Children in Toronto. Thanks Dave and Pete for your ongoing generous support!



*Left to Right: Dave Ecklund, Gord Sanford and Peter Grande*

## Nursing Grant Awarded

*By Reanne Booker*

The recipient of the 2006 Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) Nursing grant is Lucie Lacasse from the University of Ottawa. In addition to her varied nursing experience, Lucie has extensive experience as a Nurse Specialist in haemophilia and thrombosis care and was also the president of the Canadian Association of Nurses in Haemophilia care.

The Canadian Nurses Foundation (CNF) is a national non-profit charitable organization that was founded in 1962 by the Canadian Nurses Association. Through the support of nursing education and research, the association endeavours to promote health and quality care for Canadians. The CNF has more than 25 research partners throughout Canada and provides support to each province via scholarships for nurses at the baccalaureate, masters and doctoral levels.

AAMAC has supported a CNF nursing grant since 2000. The grant is awarded by the CNF to individuals pursuing graduate nursing studies who specialize in oncology/haematology or who have oncology/haematology as the focus of their research.

Do you have an idea for a fundraiser to raise money for AAMAC? We are always looking for fresh new ideas. Share your thoughts with us or become involved – call toll free 1-888-840-0039. Help share in the campaign to raise awareness of bone marrow failure diseases.

## Donate Online

Now you can donate online at [www.aamac.ca](http://www.aamac.ca).

Just click on the Donate Now button.

You can make a one-time donation or set up monthly donations. You can also dedicate a donation in memory of or in honour of someone.

If you'd prefer, there is also a donation form on the website that you can download and mail or fax in.

## Revlimid Update

By *Silvia Marchesin*

REVLIMID® (lenalidomide) is a relatively new treatment for myelodysplasia (MDS). In the United States it is approved by the Food and Drug Administration (FDA) for the treatment of a specific set of patients: those with "transfusion-dependent anemia due to Low- or Intermediate-1-risk myelodysplastic syndromes associated with a deletion 5q cytogenetic abnormality with or without additional cytogenetic abnormalities" ([www.revlimid.com](http://www.revlimid.com)).

For people with "deletion 5q" MDS who are receiving red blood cell transfusions for anemia, REVLIMID® may help eliminate or reduce the number of transfusions that are needed.

Recently the makers of Revlimid, Celgene Corporation, submitted an application to have the drug approved in Canada. Health Canada has agreed to an expedited review of this drug for the treatment of "deletion 5q" MDS. Expedited review means that Health Canada will review this drug within a shorter time than usual.

However, you do not have to wait to obtain Revlimid. Revlimid is currently available through Health Canada's Special Access Programme (SAP). So, please discuss this option with your doctor if you feel you might benefit from the drug. If Revlimid is an appropriate treatment for you, your doctor can obtain it via the SAP. Your doctor will have to complete the SAP form which is available from Health Canada's website at [http://www.hc-sc.gc.ca/dhp-mps/acces/drugs-drogues/index\\_e.html](http://www.hc-sc.gc.ca/dhp-mps/acces/drugs-drogues/index_e.html). Celgene Corporation is currently providing Revlimid compassionately through the SAP (that is, there is no cost to the patient).at [www.revlimid.com](http://www.revlimid.com) or by talking to your doctor.

## Ontario Drug Coverage Update

By *Chris Meyer*

On December 20, 2006 the Government of Ontario added 14 new drugs to the Ontario Drug Benefit (ODB) Program including Aranesp and Eprex for specific indications; however this extension does not include patients with MDS.

While not curative, Aranesp and Eprex (also called epo) stimulate the production of red blood cells in some patients with MDS and are now considered a standard of care for these patients by medical professionals.

According to Ontario's Ministry of Health and Long-Term Care, "Eprex and Aranesp are conditionally listed in the ODB Formulary and reimbursed for the treatment of chemotherapy-induced anemia in patients with cancer. Reimbursement of Eprex and Aranesp for the treatment of other indications, including myelodysplastic syndrome (MDS) will continue to be considered under the Individual Clinical Review mechanism." That mechanism is also known as Section 8. Not all patients who fail to qualify under Section 8 can afford the cost of treatment and it can place a significant financial burden on those who can.

With input from the Ontario members of AAMAC's Medical and Scientific Advisory Board, we will be writing the Ministry about the proven benefits of these drugs to many of our patients and urge the government to further extend access to Aranesp and Eprex. Making these drugs available to MDS patients through the ODB program would not only remove financial barriers to treatment, but provide faster access since the Section 8 process, if successful, can take four to six weeks from the decision to start treatment to drug access. We will keep you advised regarding our progress.

## Don't miss the 3<sup>rd</sup> Annual Spring Swing gala, April 14, 2007, Toronto.

Enjoy a five-course Italian dinner, live music by the 18-piece big band *No Strings Attached* and an opportunity to bid on fabulous silent auction items. Tickets are only \$60.

Contact Chris Meyer at [ontario@aamac.ca](mailto:ontario@aamac.ca) or 416-994-6712

## AAMAC Wishes to Establish Quebec Chapter

If you are interested in participating in a Quebec Chapter, please contact Silvia at [smarchesin@shaw.ca](mailto:smarchesin@shaw.ca) or 780-465-3414 to discuss this opportunity. The association needs bilingual speakers who are willing to lead the chapter, to speak with patients in Quebec and to participate in chapter activities like awareness and fundraising.

## Mark Your Calendars

**3<sup>rd</sup> Annual Fundraising Dinner, Dance & Silent Auction – April 14, 2007, Toronto:** Join us for our annual Spring Swing in Toronto on **April 14, 2007** at the Meridian Banquet Hall on Keele Street near Lawrence. This fabulous evening features live big band music by *No Strings Attached*, a generous Italian dinner and silent auction. Contact Chris Meyer at [ontario@aamac.ca](mailto:ontario@aamac.ca) or 416-994-6712 for details, to volunteer, to donate a silent auction item or to purchase a ticket. Visit [www.aamac.ca](http://www.aamac.ca) for event details.

**National Volunteer Week - April 15 to April 21:** A special week that pays tribute to the many volunteers across the country who unselfishly donate their time and energy in support of their communities and enriching the lives of others. AAMAC, like many other not-for-profit organizations, relies heavily on the efforts of volunteers. AAMAC takes this opportunity to recognize the contributions of its many volunteers and to offer them a most heartfelt THANK YOU!

**Alberta Chapter Support Group Meeting - April 15, 2007, Calgary:** Anyone affected by aplastic anemia, MDS or PNH and any family members are welcome to attend this spring support group meeting. It will take place on Sunday, April 15 starting at 2 p.m. If you plan on attending please RSVP to Janice either by phone: 403-241-0053 or email [cookjan@telus.net](mailto:cookjan@telus.net).

**1st Canadian Conference on Rare Disorders and Orphan Products Policy- April 23-24, 2007, Montreal:** The topic of discussions will be “Made-in-Canada” solutions to research, development and access to “orphan products” for rare diseases. For information updates visit: [www.raredisorders.ca](http://www.raredisorders.ca) or call: 1-877-302-7273.

**Ontario Chapter Support Group Meeting - May 5, 2007, Toronto:** Our next support group meeting will be in Toronto on Saturday, May 5 from 3 to 5 p.m. We'll meet at Wellspring House on the grounds of Sunnybrook Health Sciences Centre. Patients and family members are invited to come out to this informal gathering and meet others living with MDS, aplastic anemia or PNH. Light refreshments and parking passes will be available. Please RSVP to Chris Meyer at [ontario@aamac.ca](mailto:ontario@aamac.ca) or 416-994-6712.

**Great Human Race - May 5, 2007, Edmonton:** This year's event will be held on Saturday, May 5 at Churchill Square and is a 10-km run and five-km walk. Eighty percent of the pledges you raise will go to AAMAC. More information is available at the Great Human Race website: [www.greathumanrace.com](http://www.greathumanrace.com). Michele King is organizing the AAMAC group that will participate. You can contact her at [michele.king@shaw.ca](mailto:michele.king@shaw.ca) or 780-641-4130.

**Kingston Support Group Meeting – May 10, 2007, Kingston:** Volunteers Susan Bowers, Trevor and Patricia Thompson will be hosting a support group meeting in Kingston on Thursday, May 10 at 7:00 pm. Members from Ottawa and eastern Ontario communities are invited to attend. Please contact [ontario@aamac.ca](mailto:ontario@aamac.ca) or leave a message at our office for Susan if you need further information.

## News of Note

**Marrowforums Replaces AA-MDS-TALK Listserv**  
Since 1996 the AA-MDS-TALK listserv has allowed patients and family members around the world to discuss the issues they face and to support each other.

A listserv, or list server, is a small program that automatically sends messages to multiple e-mail addresses on a mailing list.

A new website named Marrowforums, at [www.marrowforums.org](http://www.marrowforums.org), serves the same purpose as the AA-MDS-TALK Listserv and will replace AA-MDS-TALK. The transition to the new site is now complete.

Vince Wessling and Ruth Cuadra, along with Ruth's husband, Neil Cuadra, run the new site. After treatment for both aplastic anemia and MDS, Ruth underwent a successful bone marrow transplant. With Vince's help, his wife Louise made a successful recovery from aplastic anemia.

To register for Marrowforums, visit [www.marrowforums.org/aamdstalk\\_welcome.html](http://www.marrowforums.org/aamdstalk_welcome.html) and follow the instructions provided. Registration and use of Marrowforums is free.

If you have any questions or need assistance, please contact Ruth at [ruthcuadra@marrowforums.org](mailto:ruthcuadra@marrowforums.org).

## Brecker Loses Battle with MDS

American jazz saxophonist Michael Brecker passed away in January following a two and a half year battle with MDS and then leukemia. During his career, he played with many musicians including Canadian Joni Mitchell. In 2002, Mr. Brecker, Herbie Hancock and Roy Hargrove released *Directions in Music*, a recording of a live concert at Toronto's Massey Hall, which celebrates the music of Miles Davis and John Coltrane. *Directions in Music* won a Grammy for Best Jazz Instrumental Album. After his diagnosis, Mr. Brecker and his family actively raised awareness about the importance of joining bone marrow donor registries.

### AAMAC Seeking Treasurer

If there is someone interested, or knows of someone who would like to fill the position of Treasurer, please contact Silvia Marchesin at 780-465-3414