

Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

President's Message

Our annual patient education day in Vancouver, BC was a great success with almost 100 people attending – patients with aplastic anemia, myelodysplastic syndrome and PNH, family members, health care providers and representatives from event sponsors which included Celgene Inc., Alexion Pharma Canada and Genzyme Canada. If you were unable to join us, I would encourage you to check our website, www.aamac.ca, for videos of the wonderful roster of speakers we heard from.

As part of the event we also elected our 2011-2012 Board. I am pleased to let you know that the following individuals stood for re-election: Pam Wishart (BC), Janice Cook (BC), Reanne Booker (Alberta), Silvia Marchesin (Alberta), Anna Chamrai (Ontario), Stan Chmelyk (Ontario), Rolla Bahsous (Ontario), Robert MacDonald (Nova Scotia), and me (Ontario). Although he was unable to join us in Vancouver because his daughter returned to hospital for her second bone marrow transplant for aplastic anemia, Andy May (Ontario) was also re-elected to the Board. In addition, we welcomed Catherine Knoll to the Board for her first term. Catherine has coordinated AAMAC's patient support groups in Ottawa for a number of years and we are extremely pleased that she has joined us. To learn more about your Board, please see their bios in this newsletter. If you would be interested in volunteering on a Board committee, please let me know.

In addition to the Board, I am extremely pleased to announce that we have hired a part-time executive director who was able to attend Education Day. Cindy Anthony will be based in the Greater Toronto Area and joins our part-time administrative assistant Lois Henderson. For the past six years, Cindy has been Executive Director at Camp Quality which provides a week-long camping experience to children with cancer as well as year round support to Canadian children with cancer and their families. Cindy also has extensive experience with other charities and is an active community volunteer. She currently dedicates personal time at a Toronto-area hospice, providing support to clients and their families. We look forward to working with her and to better serving our patient community with her assistance. Welcome Cindy!

Planning is already underway for 2012 and we hope to hold our next patient education day in Montreal next fall. Please let us know if you would like to help us organize this event and stay tuned to the newsletter and our website for more details including the date. Also watch the next newsletter for an update from Pam Wishart who will be representing AAMAC at this December's American Hematology Association conference. While there she will also attend meetings including the 1st Global MDS Forum to share learnings with a number of patient groups from around the world.

I wish all our members a safe, happy and healthy holiday season and a Happy New Year!

Chris



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 OneMatch Stem Cell and Marrow Network; and raises funds for medical research.

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Patient Education Day 2011 in BC a Success!

By Janice Cook and Pam Wishart

Education Day 2011 was held on October 22 on a morning filled with "BC Sunshine." Although some of our participants arrived dripping wet, inside was warm and friendly, and a busy day of learning about bone marrow failure was about to begin.

Although unable to attend himself, Dr. Alan Eaves provided us with a terrific replacement in Dr. Philip Beer from the Terry Fox Lab. His humour and entertaining slides made it a pleasure to learn about blood, bone marrow and stem cells, and his particular focus on MDS research at a cellular level.

Next up was Dr. Tom Nevill, with the Leukemia/Bone Marrow Transplant Program of BC. He described the differences and similarities in MDS, AA and PNH. After a short break, Dr. Nevill was up again to tell us about the Marrow Failure Syndrome Clinic at Vancouver General Hospital. His slides showed the MDS prevalence in BC as 150 to 200 new cases per year from our population of 4.4 million – the reason the clinic was established in 2008. After hearing his first talk, we understood why people with bone marrow failure syndromes other than MDS have been included in the clinic to capture the MDS patients. The clinic's goals include providing new non-transplant treatment as it becomes available, participation in clinical research trials, a desire to establish a provincial data base, and the collection of tissue for a cell bank and laboratory slides.

Dr. Kirk Schultz, Director, Childhood Cancer and Blood Research, BC Children's Hospital in Vancouver, gave a presentation on Marrow Failure Syndromes in Children. Starting with descriptions of some of the inherited childhood anemias, he progressed to acquired anemias such as AA. We were asked to watch and listen closely as we would be given symptoms and then asked to determine which of the

anemias the patient had! He was an excellent teacher as we were all able to correctly diagnose the patients.

After lunch, we listened to Dr. Michael Barnett, from the Leukemia/BMT Program of BC, talk about Transfusion-Related Iron Overload, which affects so many people with bone marrow failure. After a patient shared their personal story, Dr. Barnett spoke about Transplantation as a Treatment for AA, PNH and MDS. As we had both post-transplant and pre-transplant patients in the audience, the information was helpful and interesting.

We were pleased to hear from Becky Luk, the Patient Transplantation Liaison specialist from the OneMatch Stem Cell and Marrow Network. She discussed the role and functions of OneMatch in serving Canadian and international patients in search of a stem cell donor match. The process from search to procurement of stem cells or cord blood units was introduced. The presentation looked at the trends of Canadian stem cell and cord blood use, as well as strategies employed to build a registry that will better serve patients' needs. An update on Canada's National Public Cord Blood Bank project was included.

Throughout the day we had some wonderful personal stories by patients. They shared some of their feelings and thoughts about the life they have lived since diagnosis and treatment, and provided insight and inspiration to all of us.

We were able to offer a question and answer panel with Dr. Barnett, Becky Luk and AAMAC Board member Reanne Booker, who works as a Nurse Practitioner with the BMT Program at the Tom Baker Centre in Calgary.

Our last presentation of the day was a treat. Bill Laughlin, an early member and longtime supporter of AAMAC, chose to join CORD's Arctic Quest in August 2011. Bill and his wife Caroline represent AAMAC at CORD, which is the Canadian Organization for Rare Disorders. Bill's

wonderful adventure took place to showcase and advocate for people across Canada who are affected by a rare disorder. He had wonderful pictures to show us as well as serious information about the need for Canada to have a policy on rare disorders and a national orphan drug policy. This, of course, would help all Canadians have access to life-saving drugs no matter where in Canada they live.



Bill Laughlin is joined by two of the Arctic Quest's guides at 66 degrees 33' N.

By the time our day was done, the BC sun was shining once again and we were sure that all who attended had learned something new. We hope that many new contacts between patients were made. We met new patients, nurses and doctors during the planning and organizing of this event, and hope that our goal of having all diagnosed BC patients hear about AAMAC support and education programs can be helped along by networking such as there was at Education Day. Thank you all for attending.

And thanks go to all our Education Day helpers: Darien Adley, Jim Cook, Cindy Van der Eijk, Eileen and Paul Sue, Iris Russell, Caroline Laughlin, Pat and John Egyed, Xiomara Godinez, Lisa Ross, Lois Henderson, Silvia Marchesin and Chris Meyer.

Thank you very much to our sponsors, Celgene, Alexion, and Genzyme for helping to make this event possible. As well as travel subsidies to help offset costs associated with attending, we also will have our hematologists' presentations posted on our website, www.aamac.ca, for members across Canada to see and hear. We thank our webmaster Paul Sue for posting those.

Ontario Chapter Update

By Stan Chmelyk

The Toronto support group meetings have been going well. We had our first meeting after the summer break (the meetings for July and August were cancelled for the summer) on September 10 with a fairly good turnout. Since the October meeting fell on the Thanksgiving holiday weekend, it was decided to cancel that meeting as it is important for patients to spend time with their family for this holiday. The November 12 meeting was chaired by AAMAC President, Chris Meyer, who was filling in for me as I had picked up a bug and didn't want to compromise the immunosuppressed patients. Chris had very large turnout for the November meeting and is suggesting we may think about using the cafeteria at the Canadian Blood Services building at 67 College St for the December 10 meeting as many of the patients at the November meeting are interested in hearing Dr. Hans Messner from the Princess Margaret Hospital give a talk on Stem Cell Transplantation at the December 10 meeting. We may be a bit cramped in the Board Room where the meetings are normally held and may need the extra space in the cafeteria.

An important note to patients is that Dr. Rena Buckstein from Sunnybrook Health Sciences Centre has agreed to give a presentation to the group on some of latest developments in bone marrow failure research presented at some of the major conferences she has attended. We are very fortunate to have the support of internationally recognized specialists such as Drs. Messner and Buckstein and I encourage patients to try to make it to the December and January meetings if they are able. We are making an effort to bring in expert speakers to as many of our meetings as possible. If you have any suggestions on topics that might be of interest to the group, please send me a note at stan_c@primus.ca.

Atlantic Chapter Update

By Robert MacDonald

The chapter held a social gathering on Sept 24. Seven members were present. Plans for the year and into next year were discussed. The Chapter plans a Christmas party on Dec 9.

Plans are in the works for a joint presentation with CBS on the One-Match program. The intent is to target the local universities to inform and encourage the students to consider becoming blood donors and to sign up for the stem cell and bone marrow donor registry. Particular emphasis will be directed to ethnic groups other than Caucasian since many are under-represented on the registry.

Five of our core support group members were present at the annual Bone Marrow Transplant Dinner held here in Halifax to honour those who received transplants since the establishment of the transplant clinic.

The Chapter was saddened by the death of two of our members since our last report. We offer sincere condolences to their families.

The Atlantic Chapter is for anyone interested in attending our gatherings or receiving group emails to gather information on the diseases or treatments available and especially to support each other. For information please contact the Chapter by calling (902) 443-1615 or emailing rob.jack@ns.sympatico.ca.

AAMAC Nursing Grant Awarded

By Reanne Booker

AAMAC is proud to support excellence in nursing and continues to fund a nursing scholarship awarded annually through the Canadian Nurses Foundation.

The Canadian Nurses Foundation is a national organization whose mandate is to provide financial support for Canadian Nurses involved in higher

education, research, home health-care and specialty certification.

Together with the Canadian Nurses Foundation, AAMAC has established a nursing scholarship, the Aplastic Anemia and Myelodysplasia Association of Canada Nursing Grant, for nurses pursuing advanced education with a focus on hematology and/or oncology. The 2011 recipient of the Grant is Tara McKeown.

Tara is a Registered Nurse at the Hospital for Sick Children in Toronto and works in the Haematology/Oncology in-patient unit. She is pursuing her Master's degree at the University of Toronto with a view to work as a Nurse Practitioner in pediatric oncology following the completion of her program. Tara's additional professional endeavours include membership on the Nursing Practice Council and the Hematology/Oncology Palliative Care Committee and participation as a speaker at the annual Chemotherapy Conference at the Hospital for Sick Children.

BC Cancer Foundation Funds AML Project

By Chris Meyer

Fellow volunteers including Pam Wishart, Cindy Van der Eijk and I recently attended a BC Cancer Foundation fundraiser courtesy of Celgene, one of the event sponsors.

The event raised \$1.5 million in support of the Personalized Medicine Project which will begin by focusing on Acute Myeloid Leukemia (AML) and a number of rare pediatric cancers.

“Genomics Applied to the Management of Acute Myeloid Leukemia (AML)” is led by Dr. Aly Karsan, Medical Director of the Cancer Genetics Laboratory at the BC Cancer Agency and Dr. Marco Marra, Director of the BC Cancer Agency's Genome Sciences Centre.

According to the Foundation's website, “AML is presently treated with stem cell transplantation or

chemotherapy. This AML project will increase the use of genomic data to improve the therapeutic stratification of patients, thereby leading to more personalized treatment and hopefully improved outcomes.”

Dr. Aly Karsan, project lead and head of Clinical Diagnostic Genomics at the BC Cancer Agency, says, “We are ecstatic to begin this project, which will identify all genetic markers and mutations associated with AML.” Dr. Karsan's research interests also include MDS. For more information about the Personalized Medicine Project, visit bccancerfoundation.com.

Life Beyond Limits: Rosemary's Story

Earlier this year, AAMAC joined a coalition called Life Beyond Limits and encouraged Canadian MDS patients to share their stories on the website www.mdslifebeyonlimits.org. Volunteer Rosemary Pauer did just that and for those who do not have internet access, we share her story below. Rosemary was also selected as the only Canadian to be photographed for a photography exhibit that will open in California this December to coincide with the American Hematology Society meetings.

By Rosemary Pauer

I am 75 years old and am glad to share my story about my MDS journey in the hope that it will help or encourage others, although it is not very interesting. I have been retired since 2001. Eight years ago I was diagnosed with high blood pressure and cholesterol and had yearly routine blood tests for the cholesterol. In 2008 I started to feel very tired, sometimes could hardly drag one foot after the other going upstairs, but I thought that it was just part of growing old, so didn't concern myself with it too much.

After a blood test in late 2008 my doctor called me sounding worried

and said my blood count was too low, and suggested a colonoscopy. That revealed nothing, so he made an appointment for me to see an oncologist who specialised in blood disorders, as he thought I had leukemia. I went through the whole disbelief, anger (I wrote a poem) and depression at that time. I skipped bargaining as I felt that there was something seriously wrong. I remember playing 83 games of Freecell in three days, as it was the only thing took my mind off the worry. Never telling anybody, I spent a miserable Christmas.

I saw the oncologist in January of 2009 and he told me I had myelodysplastic syndrome. I had him write it down as I had never heard of this weird disease. He told me there was no cure, but it could be treated with blood transfusions as necessary, and suggested I look it up online. I was too old for a bone marrow transplant, as here they generally do not do them for people over 65, unless they are in exceptionally good health. When I went online and looked up MDS, I saw the sentence “some doctors call this disease cancer” and immediately went offline as I was terrified. In March of 2009 I had a bone marrow biopsy and some time after my doctor called me in great excitement. Apparently I had some kind of abnormality in my DNA called 5q minus, and for that condition there was a medication available, called Revlimid. I was his very first patient with that abnormality. He is a senior medical oncologist at a very large hospital, but apparently the 5q minus variation of MDS is quite rare.

The next time I saw my oncologist my blood count was so low (71) that he arranged for me to have two units of blood the next day and he suggested I start taking Revlimid. I had, by then, plucked up courage and looked it up online, and the list of side effects intimidated me, so I wondered if I could do without. It was then that my

oncologist told me about the life expectancy of people with MDS, which came as rather a shock, so of course I agreed to take the Revlimid if I was approved. My doctor had to apply for permission for me to take it, as, being over 65, the Province (of Ontario) would pay for it, if I was approved.

By then I was back online to look things up and I found AAMAC, AAMDSIF (the Aplastic Anemia and MDS International Foundation) and the MDS Foundation, which have been really helpful. I always participate in the webinars for MDS patients, as I learn a lot and can ask questions too. I feel very fortunate to have the webinars which are a great help.

In October 2009, I needed two more units of blood, but the good news was that I had been approved to take Revlimid, so I started on it on October 16. Within a couple of weeks I started feeling better, had more energy, and a blood test showed my HGB count up to 91. The blood count went up at each visit to my doctor, until it reached 119 and I had all my old energy back. After nearly two years, the Revlimid is still working, although for the last year I have developed peripheral neuropathy in my feet and ankles. This is the only side effect I have experienced and fortunately it is not my hands. I realise that Revlimid can stop working, but I will deal with that when it happens, and at the last blood test, the hemoglobin, which fluctuates, was back up to 119. The platelets are low, and the white blood count down, but my oncologist is monitoring them regularly.

Another health issue did arise and in 2009 I was told that I have mitral valve prolapse (leaky heart valve) so a cardiologist keeps an eye on that now.

As to life with MDS responding to treatment, it's great. I can work on my garden, which I put in years ago before I realised that it was far too

complicated for an old person to manage, and I walk about two miles every day. Last year I walked in the 5k Scotiabank Toronto marathon with the AAMAC Marrow Movers team, and was so proud of the medal I received for finishing the course. I plan to go in it again this year and am already training myself with 5k walks.* I can even run upstairs!

For years I was a quilter, and before I got MDS, a friend said that the local Hospice needed comfort quilts for their clients, so I started sewing. Then she told me the local Wellspring Cancer Support Centre would be glad of quilts too, so I made some for them. If I hear of anyone with cancer, they get a quilt, and at the last count I have made and given away over 120 quilts. It gives me great satisfaction to know that I am giving comfort to people who really need it and I enjoy making the quilts. I even made a "journey" quilt for myself, with all that has happened to me during my MDS journey and I use this as a tablecloth when I have a little display for AAMAC at a local event.

What has helped me cope with MDS best is Wellspring, the local cancer support centre. My oncologist is the Medical Director of Wellspring and said it would be fine for me to go there, so I joined them in January 2010.

I have met many wonderful people and learned many helpful things to help cope with an incurable disease. I go regularly to meditation (helps calm the mind) and yoga, as well as a weekly Relaxation and Visualisation class, which gives us all kinds of techniques we can use when things get bad. The friends I meet there are very supportive, and we help each other, sharing the good and bad news, laughing and crying together and knowing that the others understand how you feel as they have been there themselves. I don't know how I would manage without Wellspring. Through

Wellspring, I have a great volunteer job. I go to the local Oncology Clinic, and talk to the patients getting chemo. I tell them about Wellspring, what programmes are available, and what a great place it is, full of fun and laughter and sharing and encourage them to come. I generally chat with them if they want to talk, and if I can calm someone's fears and let them know that there is life after a diagnosis and chemo, then I feel I have done something to help them on their journey.

I am back to my gardening, although I have to remember that I am 75, not 45, when I try to lift heavy rocks and paving stones! On holidays with my daughter we go hiking and exploring, and we have a great time. At Wellspring I have learned to value every day and not to worry about the future. I realise that Revlimid does not always work for ever, but I will deal with that when it happens, I am not going to borrow trouble and who knows, I might beat the average! I find an enormous amount of joy in life and welcome each day that I can get out of bed and say "well, I'm still here." The small things of life don't bother me any more, and although it might sound odd, I can honestly say that right now I am happier and enjoying life more than I did before my diagnosis, as I appreciate each day more and value the life and friends I have.

I have never felt that my age affected the way my oncologist has treated me. He always gives me his full attention and answers my many questions, and he makes me laugh. With my age, heart condition and high blood pressure, a bone marrow transplant is out of the question, but if I have needed a blood transfusion, I have been in for one the very next day. I see him every three months, and my doctor is as delighted as I am that Revlimid is working. He pats me on the shoulder and says "you're worth it." I feel that he really cares about me as a person, and nothing is too much

trouble for him. I am very fortunate to have him for my doctor and I know I am getting the very best care available.

If I could offer some advice to anyone starting out on the MDS journey, it is this:

- Find out all you can about your version of the disease. The sponsors of “Life Beyond Limits” have great websites, but be careful if you go other places on line. Participate in webinars when you can as they teach you so much.
- Write out your questions for your oncologist, and then write down the answers as you get them. If you don’t understand something, keep asking until you do.
- Find a support group, or make one with friends. You need people you can really talk to, who understand how you feel, and are supportive, so a cancer support group is ideal.
- Learn to be happy with what you can do, and if your body tells you to rest, listen to it and sit down for a break. You have a serious disease, so don’t try to do too much.
- If you have the energy, do something for other people. It helps them and makes you feel better too.
- Don’t sweat the small stuff, and enjoy the little pleasures life brings – a beautiful sunset, the garden after a snowfall, a purring cat, sun on your back.
- Don’t let your mind make up nightmare scenarios of “what might happen.” Ask yourself “has it happened?” and if the answer is “No” then it’s just your brain playing mind games. Calm down and enjoy your day.
- Say “this moment is all I have, and I am going to make it count.”

There is life beyond an MDS

diagnosis, and it can be great! Good luck with yours!

**As you’ll read in the next article, Rosemary completed the 5k walk again this year after submitting this story to Life Beyond Limits.*

Marrow Movers Update!

By Susan O’Halloran



Members of this year’s Marrow Movers team celebrate after crossing the finish line.

On a grey and cool morning, our Marrow Movers team finally got to meet each other face to face as we assembled to take part in the Scotiabank Toronto Waterfront Marathon Charity Challenge. Of course, our first challenge was finding each other, but for the most part that was mastered by the start of the event (this year, a very civilized noon start allowed us to get a good sleep and good breakfast under our belts!) As it was an all-female team this year, we managed to talk and walk –both at a good pace—and before we knew it, the 5K distance was completed. A few steep hills, lots of supportive cheers and calls of encouragement, and the finish line was upon us.

Our eight-person team at the 5K distance included Rosemary Pauer, Victoria Fleming, Krista Hale, Chris Meyer, Susan O’Halloran, and Oriana, Anna and Palma Loduca. Carole Sanford registered for the event but had to withdraw at the last minute – we missed her!

We’d like to send a special thanks to Maria Donahue and Kelsey Luit, who flew in from Winnipeg to run the half marathon (21K) distance for AAMAC.

We didn’t get a chance to meet them as their event started at 7 am.

As well as the funds we raised, it was a chance to meet some exceptional people with great spirit and commitment that made this day so special. I hope we can all do it again in 2012.

Get to Know Your Board

The following individuals have been elected to the 2011-2012 AAMAC Board of Directors.

As a teenager, **Rolla Bahsous** donated bone marrow for her younger sister Rana’s bone marrow transplant after Rana was diagnosed with MDS in 2000. Rolla joined the Board in 2006 and has been the Association’s newsletter editor since 2008. Rolla lives in the Greater Toronto Area where she currently works as an online freelance writer for several entertainment websites and as a Teaching Assistant in Communication and Cultural Studies at the University of Toronto. She is also pursuing her Masters in Drama at the University of Toronto. In 2011, Rolla published a book called *Keeping Daisies* which touches on her family’s experience with bone marrow failure. “I believe in our mission and cause,” says Rolla. “It’s organizations like AAMAC that helped my family in our time of need when my sister was ill.”

Reanne Booker joined the board in 2006 and currently serves as AAMAC’s nursing grant liaison. She is a Nurse Practitioner with the Surgical Oncology and Blood and Marrow Transplant Programs at the Tom Baker Cancer Centre in Calgary and holds a Master’s of Nursing (2007, University of Alberta) and a Bachelor of Science in Nursing (2001, University of Alberta). Reanne also volunteers with the Southern Alberta Myeloma Patient Society, the Southern Alberta Sexual Health Association (SASHA) and the Kids Cancer Care Foundation of Alberta. She believes

that AAMAC is a very important organization for patients and their families. "I am happy to be involved with such a wonderful organization and can see the direct positive impact AAMAC has on patients and families dealing with bone marrow failure disorders," Reanne says.

Anna Chamrai joined AAMAC in 2007 as Treasurer. She is responsible for day to day financials, monthly reconciliation, budget and year-end operations. Anna graduated in 2007 from the Schulich School of Business with an MBA. Anna also holds a CMA and has an MSc in Mathematics from the St. Petersburg State University in Russia. She is currently working for RBC.

Stan Chmelyk was diagnosed with MDS (RAEB) in August of 2001. He received a stem cell transplant in November of the same year with his brother as the donor. Ten years post-transplant, Stan remains free of MDS and enjoys normal blood counts. Stan joined AAMAC in 2004 and has held positions of newsletter editor, co-coordinator of the Ontario Chapter in Toronto, and served as President for two years. Stan was active in advocating for the public funding of drugs such as Revlimid, Vidaza, Exjade, Soliris and Cyclosporine. He currently chairs the monthly Toronto patient support group meetings. A chemical engineer by trade, Stan worked for 13 years in the research and development department for a plastics manufacturer prior to his illness. Fifty-five years young, Stan has three grown children and resides in Brampton, Ontario with his wife Patti. Stan refers to himself as "an example of hope for others that MDS can be beaten."

Janice Cook is currently in remission after being diagnosed with severe aplastic anemia in 2004. Janice joined the Board in 2007. She has served as the Alberta Chapter co-coordinator in Calgary and, after moving to Mission, British Columbia, became a co-coordinator of the Association's BC Chapter. A nurse by profession who currently works in a local hospital's emergency room,

Janice also represents the Association as a volunteer with the National Rare Blood Diseases Organization (NRBDO). "People feel so alone and frightened when diagnosed," says Janice. "Hearing from my support person for the first time was a life line for me and I want to help others feel that if I can. I know a lot of the questions they have since I had them myself. My background means that I can see things from their perspective as well as from a hospital's and a nurse's. I can try and explain things and teach them the questions to ask and help them to understand the information they have been given. I believe that knowledge empowers patients and can help them to cope with a stressful diagnosis." Janice appreciates the grassroots, volunteer nature of the Association and is proud to work with and learn from other volunteers who share an interest in giving back to others. In addition to her volunteer work, Janice is a busy grandma of five.

Since 2009, **Catherine Knoll** has chaired the Ottawa Support Group meeting. She was diagnosed with aplastic anemia in 2008. She has served on a number of other Boards including a preschool and two school councils, all in a financial capacity. She is the partner/owner of a consumer show management company and previously worked in the banking sector. She has an MBA and a Bachelor of Commerce. "I think the role of a support group is critical to allow patients to make connections with other patients and their families in order to share their experiences," says Catherine.

Robert MacDonald is a native "Bluenoser" who has lived in Halifax for the past 41 years. He was diagnosed with MDS in 2002 and it advanced to AML in 2003. Robert received a stem cell transplant in September 2003 – his twin sister was the donor – and he has been in remission since. He is a charter and founding member of the Atlantic Chapter of AAMAC which began in 2005 and he has served as Atlantic Chapter coordinator since 2007. "I was inspired by the late Gai Thomas

to become active on a local level to provide education and support to Atlantic Canadians diagnosed with these rare blood disorders," Robert says.

Silvia Marchesin joined the board in 1996 after having volunteered with the Alberta chapter since its inception in 1993. She was the Alberta Chapter coordinator for almost 10 years, President for a two-year term and Acting President for a period. Silvia has represented AAMAC on the Network of Rare Blood Disorders Organization (NRBDO) since it was founded in 2004 and also represents AAMAC at a local NRBDO group in Alberta. She was diagnosed with aplastic anemia in 1992 and subsequently with PNH in 1995. Silvia lives in Edmonton and holds a Bachelor of Science from the University of Alberta and has worked as a systems analyst and business analyst for a local college. Silvia supports a number of other organizations and is currently volunteering with her community league. She volunteers with AAMAC because she wants to make a difference. "I want people to have hope, to see you can survive, and to know that they are not alone in dealing with these life-altering diseases."

Andy May lives in Caledon, Ontario. He is a retired Toronto Police Officer whose four-year-old daughter Karlee was diagnosed with aplastic anemia in 2007. After she recovered from a bone marrow transplant, Andy joined the Board of Directors with AAMAC in 2008 as a way of "giving back" to patients and families after receiving support from this organization. Andy has served as Ontario Chapter coordinator and has been actively involved in fundraising. Unfortunately, his daughter Karlee has recently been diagnosed with bone marrow failure again associated with severe aplastic anemia and is currently undergoing a second transplant. Andy continues to advocate the message to support Canadian Blood Services and the OneMatch Stem Cell and Marrow Registry.

Chris Meyer began volunteering with the Association with her husband Rod Crocker after he was diagnosed with MDS in 2002. After his death in 2005 due to complications following a bone marrow transplant, Chris joined the Board of AAMAC and continued his work as Ontario Chapter coordinator. She has also served as newsletter editor and is currently the Association's President. Chris lives in Toronto and has a Bachelor of Applied Arts in Journalism from Ryerson University and is accredited by the International Association of Business Communicators. She has experience in the non-profit, healthcare and energy sectors, including a role promoting blood donation for the Canadian Red Cross years before her husband's MDS diagnosis. Over the course of his disease, Rod required more than 100 units of blood and blood products and an unrelated bone marrow donation, so Chris remains a strong supporter of Canadian Blood Services and the OneMatch Stem Cell and Marrow Registry.

Pam Wishart was diagnosed with MDS in early 2000 after several years of feeling more and more unfit despite exercising regularly. In 2003 she attended an Aplastic Anemia & MDS International Foundation (AAMDSIF) patient conference in San Francisco where she met one other Canadian, Sheila Rivest, who was on the Board of AAMAC at the time. Pam remembers the feeling of being with people who completely understood her disease and how important that was. Later that year, Pam was asked to join the AAMAC board and has been a Board member since. Currently serving as Secretary, she is also AAMAC's representative on the National Liaison Committee of the Canadian Blood Services and since moving from Montreal to Victoria recently has been the co-coordinator of the BC Chapter. Pam has a Bachelor of Science degree with a Specialization in Biochemistry from Concordia University.

If you are interested in being nominated to the Board in future, please contact Chris Meyer at

chris_meyer@sympatico.ca for more information.

News of Note

AA and MDS Awareness Week

December 1 to 7, 2011 marks Aplastic Anemia and MDS Awareness Week. Next year, the American awareness week moves to March 1 to 7 to coincide with the National Organization for Rare Disorders (NORD) and Canadian Organization of Rare Disorders (CORD) Rare Disease Day at the end of February.

Mark Your Calendars

The Fifth World Rare Disorder Day February 29, 2012 in Ottawa

The Canadian Organization of Rare Disorders (CORD) invites you and your friends to attend the Rare Disorder Dinner Gala. This is an opportunity for leaders and stakeholders in the field of rare disorders to help promote awareness, celebrate successes and raise funds for research in rare diseases. Attendees will include government representatives, researchers, industry partners and patient groups from across Canada.

On February 28, 2012 CORD invites you to speak with members of Parliament and Senators regarding the proposed new legislation related to an Orphan Drug Policy. A training session about advocating for this important legislation will precede your visit to the Hill. We encourage all those who are affected by aplastic anemia, myelodysplasia or PNH to come to Ottawa in late February to participate in this event.

For more information regarding both days please contact Caroline Laughlin at (416) 399-6639 or CORD at (416) 969-7431.

Monthly Toronto Support Group Meeting, Toronto, ON

Returning this winter is our regular Toronto support group meeting the second Saturday of each month from 2 to 4 p.m. at Canadian Blood Services, 67 College Street. On December 10, 2011 hear Dr. Hans Messner from Princess Margaret Hospital talk about stem cell transplantation. On January 14, 2012 we are pleased to have guest speaker Dr. Rena Buckstein, from Sunnybrook Health Sciences Centre join us.

Watch for more details about the meetings on February 11, March 10, April 14, May 12 and June 9.

Please call for information. Come out and meet other patients and families dealing with the same bone marrow failure disease as yours. Share stories, compare notes, learn how others are coping and see how they are responding to treatments. Share as much or as little as you are comfortable with in an informal setting. For more information or to RSVP please contact Stan Chmelyk by phone at (905) 457-9858 or email stan_c@primus.ca. We hope to see you there.

Monthly Ottawa Support Group Meetings, Ottawa, ON

The AAMAC Ottawa support group meets on the second Saturday of every month at the Ottawa General Hospital, 501 Smyth Road, Room 5100. Meetings are from 3 to 5 p.m. and are open to all patients, their families and supporters. For more information, please don't hesitate to contact Catherine Knoll at (613) 852-2092 or aamac.ottawa@gmail.com.

Monthly Halifax Support Group Meeting, Halifax, NS

Our next meeting will take place on January 14, 2012, in the Dickson Building, QE11, 1 to 3 pm. Kim Ingalls, technical specialist in Hematology, will give a presentation on red blood cells (hemoglobin) This topic will be very informative for people with rare blood disorders. Anyone interested is invited to attend! Please contact Robert at (902) 443-1615 or rob.jack@ns.sympatico.ca for more information.