

Myeloma Canada Milestones

2013: A Year In Review



**MYELOMA
CANADA**
MAKING MYELOMA MATTER



It's with much satisfaction that I see 2013 come to a close at Myeloma Canada. We have many achievements to our credit, all in a context of profound change. On the research side, 2013 marked the launch of our MCRN 001 clinical trial, a phase II study aimed at newly diagnosed patients who are eligible for a stem cell transplant. The study is being conducted at 10 centres across the country.

We all know that access to new treatments is a driving force in our struggle to conquer multiple myeloma. During the year, putting its money where its mouth is, Myeloma Canada submitted two requests for review to pCODR (pan-Canadian Oncology Drug Review), in order to demonstrate the importance of two different drugs to treat myeloma. Both requests helped us obtain positive recommendations from pCODR.

To raise awareness of multiple myeloma, we began an advocacy campaign with elected officials, which included meeting members of the government and opposition parties in Quebec. In several Canadian cities, we also held InfoSessions on the disease and the treatments available. In addition, we continued our efforts to spread the word by distributing educational materials in various Canadian hospitals.

Our team also changed during 2013. Aldo Del Col, our co-founder who was Executive Director, chose to take up the new position of Chief Scientific Advisor. Our Executive Director is now Francine Gendron, who is supported by Lynne Beauchemin, Administrative Assistant, and Helen Steiman, Communications Coordinator. In addition, I took over from John Lemieux as President of the Board of Directors, as he needed to devote time and energy to his own recovery.

Many new initiatives are already on the drawing board for 2014. In particular, we're embarking on a cross-Canada tour to consult with our members on how to achieve our 2015-2018 strategic plan. We're holding our first Support Group Leaders Summit to support the work of the people responsible for some 20 support groups across the country. Many patients still face problems of access, while several new treatments are under development. In 2014, we intend to redouble our efforts to ensure that all Canadians have fair access to available treatments.

The strength of an organization depends on the people in it. As a result, the entire myeloma community can be proud of the accomplishments of our organization, Myeloma Canada, in 2013. To all those who participated in the March, who supported a patient, who got involved in advocacy, who responded to our online surveys on the use of different drugs, who organized a fundraising event, who gave your time, who devoted your career to research and who believe that together we'll conquer myeloma, I thank you.

A handwritten signature in black ink that reads "Denis Bilodeau". The signature is written in a cursive, flowing style.

Denis Bilodeau
President of the Board of Directors



It's with much optimism that I end the year 2013 as the Executive Director of Myeloma Canada. During the first eight months of my mandate, I was able to take stock of the major challenges we face, from the perspectives of research, access to treatments and developing our organization. In a variety of Canadian communities, I had the privilege of meeting people living with myeloma who have chosen to get involved to help other patients. I met patients who are well-informed and determined to act, people mobilized around a common goal to conquer myeloma. All of these meetings have been the driving force behind my integration into the Canadian myeloma community.

Myeloma Canada is undeniably a complex organization, in terms of the scope of its efforts and geographical diversity. Created by the master hand of Aldo Del Col, who was the Executive Director until April 2013, the organization built up a range of services worthy of a national entity.

I wish to thank Aldo for his accomplishments in the growth and evolution of Myeloma Canada, as well as the invaluable support he has provided since I took up the position. He is a brilliant advisor and a dedicated mentor.

I firmly believe that the growth of Myeloma Canada will continue, thanks to the contribution of all patients and their families, whom we devotedly represent, from coast to coast to coast. Myeloma Canada is a national organization founded by patients. To continue our work, we must fully understand the daily lives of these people. For this reason, in spring 2014 we're beginning a country-wide consultation of all our stakeholders. We're going to meet patients and families in a dozen Canadian cities, to take the pulse of their needs and learn how our key stakeholders envision the future of their national organization. The results will provide the basis of a three-year strategic plan, which the Board will draw up in the fall of 2014.

In 2014, Myeloma Canada will continue its vital work in our areas of interest, which are science and research, advocacy for access to care, as well as promoting and raising public awareness of our cause. We'll turn to the Canadian myeloma community to ensure that our strategic choices are in tune with their reality. Myeloma Canada wants to hear from the people to whom our mission is dedicated: patients and their families. Our challenge is to maintain and build on a range of innovative services tailored to them, always with a view to improving the lives of myeloma patients and their loved ones.

In closing, I want to thank each of you who, over the past months, have expressed your support for Myeloma Canada by giving your time and energy, sometimes putting aside your own condition to devote yourself to the common cause. Without your contribution, Myeloma Canada could not have accomplished all the feats you'll read about in this annual report. Many of you organized fundraising campaigns, motivated those around you to take part in the Multiple Myeloma March, invested your time in a support group, or spearheaded initiatives to promote our cause. Your participation in our online surveys helped us present well-documented evidence to inform the decision-makers on the importance of access to new treatments. You're all agents of change, and by harmonizing our efforts, we'll make great things happen and win the fight.

I'd also like to thank the members of the Board of Directors and the staff at Myeloma Canada. In a year of momentous change, you've enabled us to stay focussed on our highest goal: to conquer myeloma!

Enjoy the read!

A handwritten signature in black ink, which appears to read "Francine Gendron". The signature is fluid and cursive.

Francine Gendron
Executive Director

Myeloma Canada's ninth National Conference held in Ottawa

The National Conference, whose ninth edition was held in Ottawa this year, is undoubtedly Myeloma Canada's flagship event.

More than 160 patients, caregivers, health care professionals and pharmaceutical industry representatives took part in the event.



Once again this year, our speakers included leading researchers and experts in the treatment of multiple myeloma from Canada and the United States. They addressed a wide range of topics, including the basics of myeloma, different therapeutic approaches as well as myeloma-related bone disease and the interpretation of blood and lab tests.



Caregivers were able to attend a closed-door workshop to share and acquire essential tools to maintain their life balance. Greatly appreciated by participants, this workshop will most certainly be part of the Conference program in 2014.

The account by Monica Brunet, the caregiver and wife of Vincent, a myeloma patient, was without a doubt the most poignant moment of the day. She told us the moving story of the struggle experienced by her husband and father of their two young children.

She recounted that when Vincent realized he had exhausted all treatment options available in Canada, he chose not to give up. He turned to the United States to gain access to new treatments in clinical trials. After a number of trials, and with the support of American doctors touched by his determination, he managed to defy the disease and enjoy life with his family.

This account of persistence and courage gave the audience a message of hope: the important thing is to never give up and never accept "no" for an answer, but to continue searching for the best solution.



The National Conference was an opportunity for Myeloma Canada's President John Lemieux to highlight recent organizational changes. Aldo Del Col, Executive Director and co-founder of Myeloma Canada, chose to leave his position last April to dedicate himself to the organization's science and research portfolio. Mr. Del Col now occupies the position of Chief Scientific Advisor. John Lemieux offered an emotional tribute to the work accomplished by Aldo Del Col since the founding of Myeloma Canada and to the commitment and determination he has shown which have contributed to the organization's growth. Attendees did not spare their applause in appreciation.

Mr. Del Col made it clear that he was leaving his Executive Director position with a heavy heart, but that

his decision, made after careful consideration, would allow Myeloma Canada to experience new growth. Since the development of the scientific portfolio would require a considerable investment of time and energy on his part, he believed it more appropriate to give up the directorship, which is now occupied by Francine Gendron. During her speech, Ms. Gendron expressed her commitment to continue developing Myeloma Canada in the spirit of its founders John Lemieux and Aldo Del Col.



Myeloma Canada InfoSessions

Myeloma Canada held four InfoSessions in 2013: in Halifax, Saskatoon and Montreal. Patients in Montreal and Halifax had the privilege of attending a conference given by Dr. Xavier Leleu of Lille, France, on the topic of maintenance treatments. In Halifax, the InfoSession welcomed Dr. Sergio Giralt of New York, who gave a talk entitled “Myeloma in 20 Questions or More,” where participants were invited to ask all the questions on their minds.

The team of myeloma specialists in Saskatoon, consisting of Dr. Julie Stakiw, Dr. Mohamed Elemery, Dr. Rebecca MacKay and social worker Ms. Renee Stuckel, also took part in a Myeloma Canada InfoSession. The topics they discussed included Myeloma 101, the different treatment strategies available to patients who are either eligible or ineligible for a transplant, and the treatment options in the event of a relapse. Lastly, Mr. Aldo Col introduced the audience to the variety of services offered by Myeloma Canada.

In 2013, Myeloma Canada had the privilege of inviting internationally renowned doctors to various InfoSessions, thanks to our collaboration with our partners Celgene and Janssen. We thank them for their contribution.



Myeloma Canada Patient Information Library

In 2013, Myeloma Canada expanded its series of “InfoGuide” brochures with the publication of the French version of the InfoGuide entitled Understanding Your Blood and Blood Tests. The series provides in-depth information on topics of interest to the myeloma community.

The publications listed below are available at no charge to patients, caregivers, hospital staff and all those who wish to learn more about myeloma. You can download them from our Web site at www.myeloma.ca, or request printed copies by sending an email to info@myeloma.ca.

- Myeloma Canada Brochure
- Multiple Myeloma Patient Handbook
- Myeloma Bone Disease InfoGuide
- Understanding Your Blood and Blood Tests InfoGuide



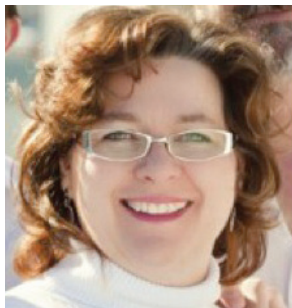
The Myeloma Canada Information Library includes the Multiple Myeloma Handbook, Understanding Your Blood and Blood Tests InfoGuide and Myeloma Bone Disease InfoGuide.

These publications continue to receive very high marks from readers, especially the Multiple Myeloma Patient Handbook, which has been praised as the best of its kind. We owe a great deal of this success to the invaluable contribution of patients and caregivers.

Patient Programs represented 20% of Myeloma Canada expenditures in 2013

\$ 20%

Marion State Nursing Award



Nanette Cox-Kennett

On December 5, 2013, Myeloma Canada had the pleasure of announcing the first winner of the Marion State Memorial Myeloma Canada Nursing Award.

With a great sense of pride, we handed out the very first Marion State award to Nanette Cox-Kennett. Nanette has more than 20 years of experience in oncology and has been working for the past five years as a clinical manager and nurse practitioner for the bone marrow transplant team and the hematology group at the Cross Cancer Institute in Edmonton, Alberta.

The Marion State Memorial Myeloma Canada Nursing Award recognizes the work of nurses who distinguish themselves by their leadership, passion and commitment to advancing the care of multiple myeloma patients through example and teamwork. Myeloma Canada created the award in honour of Marion State and her extraordinary contributions to the Canadian myeloma community.

Marion State received a diploma in nursing from Toronto General Hospital in 1966, followed by a Bachelor of Nursing from Ryerson University in Toronto. After being diagnosed herself with multiple myeloma in 1996, Marion founded a support group for multiple myeloma patients in the Greater Toronto Area in 1998. It was the first group of its kind in Canada. Marion continued to live an active life until her passing in 2012.

Awareness, Outreach and Fundraising represented 16% of Myeloma Canada expenditures in 2013

\$ 16%

Learning from the IMF's 14th Support Group Leaders Summit



Attending the IMF Support Group Leaders Summit, from left to right: Norma Lindner, Stephen Angelini, Francine Gendron, Aldo Del Col, Susie Novis, Dr. Brian Durie

Again this year, we attended the IMF's annual Support Group Leaders Summit held in Dallas, Texas from July 26 to 28.

Thanks to our collaboration with the IMF, we were able to invite two of our own leaders: Norma Lindner, from the Halton/Peel Region and Steve Angelini, co-leader of the Montreal Myeloma Support Network. The event gave us all the opportunity to hear from Dr. Brian Durie, among other speakers, on the progress of myeloma treatments and how ground-breaking research is leading to the possibility of finding a cure within the next few years.

The Summit offered our guests the opportunity to discuss their successes and challenges, and improve their understanding of their role as group leaders. It was not only a way to thank them for their outstanding gifts of time and hard work, but also an occasion to remind them how important their contribution is to our community, in facilitating support groups and raising public awareness of myeloma.

Lastly, the summit enabled us to communicate the value of informing patients and caregivers on the importance of staying well and maintaining healthy habits.

Following the success of the IMF Summit, we're very pleased to announce the launch of our very own Support Group Leaders Summit, with the first meeting taking place in September 2014.

Myeloma Canada brings daratumumab clinical trial to Canada

One of the most exciting recent breakthroughs in treatment strategies for myeloma is the development of anti-CD38 monoclonal antibodies (MoAbs). The relatively high expression of the cell surface antigen CD38 on all myeloma cells suggests that CD38 is a potential therapeutic antibody target for the treatment of myeloma. At least three CD38 MoAbs are currently in development, including SAR650984 (Sanofi), MOR202 (MorphoSys/Celgene) and daratumumab (Genmab/Janssen). Of these, daratumumab is at the most advanced stage.

In April 2013, daratumumab was granted “fast track” and “breakthrough therapy” designations from the FDA in the United States for the treatment of myeloma patients who have relapsed after other therapies and have no further treatment options. “Breakthrough therapy” designation is an FDA program intended to expedite the development and review of drugs to treat serious or life-threatening diseases.

Access to new and promising therapies is often the only option for patients who have tried all other available treatments. Last November, Myeloma Canada was given the disappointing news that the Phase II daratumumab trial would not be conducted in Canada. Within a week, Myeloma Canada arranged to meet with senior executives in the US and quickly succeeded in making this important clinical trial available to Canadian patients in seven centres across the country.

Through forums such as the annual Myeloma Canada Scientific Roundtable, the American Society of Hematology (ASH) and the European Hematology Association (EHA), Myeloma Canada continues to proactively engage the research and pharmaceutical communities to ensure that Canadian patients have access to new and promising therapies.

Carolyn Henry Memorial TEAM Award

On the occasion of our ninth National Conference, Myeloma Canada had the pleasure of presenting the Carolyn Henry Memorial TEAM Award to Ms. Ev McDowell and Mr. Jeff Parton, co-leaders of the support group in the region of London, Ontario.



John Lemieux, Aldo Del Col, Jeff Parton, Ev McDowell, Alan Patt, Francine Gendron

This award aims to underscore the outstanding work of these leaders to improve the quality of life of people living with multiple myeloma.

The Excellence in Advocacy Medal (TEAM) from Myeloma Canada was created in 2009 with the goal of honouring the exceptional achievements of individuals who seek to make a difference by promoting fair access to myeloma treatments in their province. At the 2012 Summit, the award was renamed the Carolyn Henry Memorial TEAM Award in honour of the efforts and dedication of this ardent defender of the myeloma community. Carolyn worked hard to improve the quality of life of myeloma patients. Unfortunately, she lost her twelve-year battle with myeloma in January 2012.

Access and Advocacy represented 11% of Myeloma Canada expenditures in 2013

\$ 11%

2013 Advocacy Summit: Defending the rights of our community

Myeloma Canada's fourth annual Advocacy Summit was held in Toronto on October 4, 2013.

Fifteen leaders and members of support groups from across the country attended the event. The Summit provided the ideal platform to discuss important matters such as drug approval processes, the role of the patient's voice in pCODR decision-making, changes in private drug insurance plans and more.

The fourth Summit began with an update on the situation of public funding for drugs in Canada. Participants then had the opportunity to hear Mr. Scott Gavura of CancerCare Ontario, who summarized the situation of public reimbursement of cancer drugs in Ontario, along with Mr. Jean-Michel Lavoie of Sun Life Financial, who provided an update on private insurance plans.

Myeloma Canada took the opportunity to report on our advocacy efforts in 2013 with various government bodies and private companies to promote access to new treatments for all Canadians. Among these efforts, we would like to point out the application filed with pCODR officials for public funding of bortezomib (Velcade®) in Ontario as an induction therapy before a stem cell transplant. We also petitioned in support of pan-Canadian reimbursement for lenalidomide (Revlimid®) as a maintenance therapy following a stem cell transplant

in patients recently diagnosed with the disease. In a happy coincidence, October 4 was the exact date when pCODR officials made their recommendation that public drug plans in Canada reimburse Revlimid® as a maintenance therapy. It was a great opportunity to celebrate this major victory for the Canadian myeloma community, and a tangible example of the importance of maintaining our advocacy efforts for access to drugs and treatments.

Later in the day, participants had the chance to find out more about the various drugs currently in development or likely to be submitted to Health Canada for approval in the coming months.



Ultimately, the Summit gave us the opportunity to exchange ideas and build a common understanding of issues that need specific action over the next year. Topics of discussion included the process to make pomalidomide (Pomalyst®) available to patients, the importance of creating more opportunities to raise awareness among stakeholders, the adoption of a Canadian framework for orphan drugs, and the probable merger of Canada's two drug review programs: pCODR and CADTH.

Myeloma Canada represents patient voice at Janssen's annual Global Leadership Meeting

Last November, Myeloma Canada was invited to participate in Janssen's annual Global Leadership Meeting of senior executives in New York. Aldo Del Col, co-founder and Chief Scientific Advisor, represented the patient voice on a panel consisting of experts in the areas of health technology assessment, pharmaceutical research and clinical medicine. Several issues were addressed by the panel, including the cost of innovative pharmaceutical research, the value of new therapies and the role of patients. In his closing remarks, Mr. Del Col appealed to corporate decision makers in the pharmaceutical industry to always ask themselves how their actions will impact patient lives and outcomes, and emphasized the importance of including the patient voice in the early stages of clinical trial development.



Aldo Del Col, co-founder and Chief Scientific Advisor, Myeloma Canada, in discussion with Dr. Regina Benjamin, 18th Surgeon General of the United States, at Janssen's annual Global Leadership Meeting

Myeloma Canada promotes made-in-Canada clinical trials

The Myeloma Canada Research Network (MCRN) is a national collaborative project that brings together Canada's leading researchers and clinicians to improve patient outcomes through cooperative research and shared expertise. Led and supported by Myeloma Canada, MCRN is the first and only initiative in Canada that seeks to create a truly national platform to foster scientific and clinical cooperation aimed at improving the lives of myeloma patients.

The goals of MCRN are to:

- Conduct innovative clinical and translational research in a collaborative manner to improve outcomes for patients living with myeloma.
- Write scientifically valid and peer-reviewed consensus opinions on the diagnosis and treatment of myeloma.

The first clinical trial, MCRN 001, was opened last spring and includes hospitals in Vancouver, Edmonton, Saskatoon, Toronto, Ottawa, London, Montreal, Saint John and Halifax, with Calgary conducting the genomics component of the trial. It is a Phase II trial with a target enrollment of 78 patients.

The trial is for newly-diagnosed, transplant-eligible patients. Following a bortezomib-based induction treatment, eligible patients undergo a two-drug conditioning regimen consisting of busulfan and melphalan (BuMel), a departure from the standard single-drug conditioning regimen using melphalan. This approach seeks to answer the question as to whether the two-drug approach is better than melphalan alone. Bone marrow samples collected from the patients are sent to the Calgary lab for genomics analysis.

One hundred days following the transplant, a minimal residual disease (MRD) analysis is done on the bone marrow

sample. MRD refers to the small number of myeloma cells that remain in the patient after treatment, and is the major cause of relapse. Now, however, very sensitive tests are available that can measure minute levels of myeloma cells in tissue samples, sometimes as low as one myeloma cell in a million normal cells.

The results of the MRD analysis following the BuMel conditioning regimen will provide the data required to compare against results of the standard melphalan conditioning regimen and will offer an early indication whether the two-drug approach is superior.

Patients will also be placed on lenalidomide maintenance, commencing one hundred days following the transplant.

The key to success in advancing myeloma research in Canada is collaboration. MCRN 001 is an outstanding example of how home-grown Canadian myeloma research can be done. Myeloma Canada is very grateful for the tireless dedication of the researchers and clinicians across Canada who participated in this study. We also acknowledge the important contribution of our industry partners, notably Otsuka and Celgene, whose financial support made the trial possible.

In addition, we extend a special thank you to myeloma patients and their families everywhere who, despite the challenges of living with the disease, support Myeloma Canada's efforts to advance Canadian myeloma research through their fundraising campaigns and donations.

Working together in collaboration, we can all make myeloma matter.

**Science and Research
represented 41% of Myeloma
Canada expenditures in 2013**

\$ 41%

Myeloma Canada Research Grant Improving patients' quality of life through research



Dr. Suzanne Trudel is this year's recipient of the annual Myeloma Canada Research Grant.

Earlier in 2013, Myeloma Canada announced the recipient of the Myeloma Canada Research Grant for \$50,000: Dr. Suzanne Trudel of the Princess Margaret Cancer Centre in Toronto.

The Myeloma Canada Research Grant, which is funded exclusively through private donations and funds raised in the Multiple Myeloma March, is awarded each year to a researcher specializing in multiple myeloma. The grant was created in 2011 to advance Canadian research in myeloma and help improve the lives of patients.

The funding is awarded to Canadian researchers whose work on myeloma best meets the criteria set by the Scientific Advisory Board at Myeloma Canada and focuses on the clinical outcomes of patients. The Peer Review Committee, comprising members of the Scientific Advisory Board, studies and evaluates each request based on the selection criteria.

Dr. Trudel's project involves identifying predictive markers for response and resistance mechanisms to MEK inhibitors used to treat tumours associated with myeloma.

Dr. Trudel is a member of the Division of Medical Oncology and Hematology at Princess Margaret Cancer Centre, University Health Network, and an Assistant Professor in the Department of Medicine, University of Toronto. She is also an associate researcher at the Ontario Institute for Cancer Research, as well as a member of the Institute of Medical Science and of the Medical Biophysics department in the Faculty of Medicine, University of Toronto.

Myeloma Canada partners with Cancer Research Society



**The Cancer
Research
Society**

In its continuing efforts to increase funding of peer-reviewed Canadian myeloma research, Myeloma Canada has entered into a

partnership agreement with the Cancer Research Society that will increase the value of the Myeloma Canada Research Grant from \$50,000 to \$120,000. The Cancer Research Society is a national not-for-profit organization whose sole mission is to fund cancer research exclusively and to offer seed money for the most promising original ideas, projects and researchers across Canada.

This joint program will support the most promising Canadian myeloma research through a national competition where the best proposal will be granted the award. A scientific committee, comprised of peers, will select the project to be funded.

The Myeloma Canada Research Grant is funded solely through individual donations and proceeds from the annual Multiple Myeloma March.

Myeloma Canada's Investment in Research in 2013

\$200,000 for Myeloma Canada Chair in Myeloma Research at Maisonneuve-Rosemont Hospital

\$50,000 for Myeloma Canada Research Grant

Myeloma Canada Scientific Roundtable



The fourth annual meeting of the Myeloma Canada Scientific Roundtable was held in Montreal on November 1 and 2, 2013. The purpose of this forum is to bring together myeloma researchers from the major treatment and research centres across Canada, so that they can update and exchange information on the basic and translational research being conducted in Canada, as well as discuss and plan new clinical initiatives.

Twenty-one researchers and clinicians attended the event. They represented thirteen myeloma treatment centres across Canada, each associated with a university conducting myeloma-related research. Medical and scientific representatives from eight research-based pharmaceutical companies updated the attendees on their company's myeloma program and pipeline. In addition, four internationally-renowned myeloma researchers participated as guest speakers.



The fourth annual Myeloma Canada Scientific Roundtable was the most successful ever, with more than 50 participants, including Canada's leading investigators, scientists, clinicians, medical representatives from the pharmaceutical industry and research organizations, along with special guest speakers from the Mayo Clinic and Dana-Farber Cancer Institute.

Highlights of the 2013 Myeloma Canada Scientific Roundtable

DAY 1 Science Day

The objective of "Science Day" was to provide an opportunity for researchers to present updates on their ongoing scientific work and to discuss clinical trial ideas. The topics of the presentations included:

- Developing a "Master Protocol" of genomics-guided therapy for myeloma (Dr Nizar Bahlis; Tom Baker Cancer Centre, Calgary)
- Review of data from the ongoing clinical trial of allogeneic stem cell transplants followed by bortezomib (Dr. Richard LeBlanc; Maisonneuve-Rosemont Hospital, Montreal)
- Update on myeloma genomics research (Dr. Jonathan Keats; TGen, Phoenix)
- Introduction to a comprehensive cellular immunotherapy project (Dr. Denis Claude Roy; Maisonneuve-Rosemont Hospital, Montreal)
- Reprogramming the immune microenvironment in myeloma (Dr. Marta Chesi; Mayo Clinic, Scottsdale)
- Mechanisms of bortezomib resistance (Dr. Rodger Tiedemann; Princess Margaret Cancer Centre, Toronto)
- Targeting CS1 receptors on myeloma cells with elotuzumab (Dr. André Veillette; Institute of Clinical Research, Montreal)
- Targeting the MYC gene in myeloma (Dr. Leif Bergsagel; Mayo Clinic, Scottsdale)
- Myeloma extramedullary disease (Dr. Constantine Mitsiades; Dana-Farber Cancer Institute, Boston)

DAY 2 Pharma Day

Medical and scientific representatives from Celgene, Janssen, Onyx, Amgen, Novartis, Otsuka, Takeda-Millennium and GlaxoSmithKline presented updates on their respective pipelines for myeloma drugs and discussed ideas for future MCRN clinical trials.

The patient perspective

Mr. David McMullen, Co-Chair of the Toronto and District Multiple Myeloma Support Group and Vice-Chair of the Halton-Peel and Area Myeloma Support Group, was an invited guest at the Scientific Roundtable. Here are his impressions and observations: "As a myeloma patient, I was immensely impressed by the high calibre of talent, dedication and passion of our myeloma researchers in Canada. We owe them huge appreciation and gratitude. Much credit is also due to Myeloma Canada for facilitating collaboration between Canadian myeloma researchers through the MCRN, for stimulating research and for maximizing the potential of Canada's myeloma research community. This work will greatly benefit all Canadian myeloma patients."



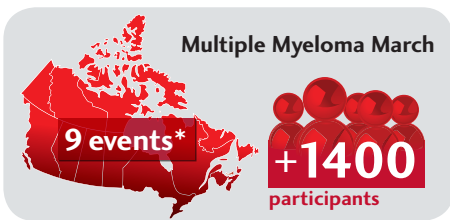


MULTIPLE MYELOMA MARCH

The Multiple Myeloma March, organized by Myeloma Canada, is an annual event that brings together patients, their families and friends to raise awareness among Canadians of this form of cancer, which remains relatively unknown and incurable.



Montreal



*St-John's cancelled – death of coordinator 3 weeks prior to the March

In 2013, we celebrated the fifth anniversary of the March. The event was created in Montreal in 2009 by Maryse Bouchard, a person living with multiple myeloma, along with

her family and her good friend, Sylvie-Chantale Duquette. The event made its way across Canada, involving 9 cities in 2013, and brought together more than 2,000 volunteers and participants. As real catalysts for change, these dedicated people raised funds to support the cause, contribute to the development of patient programs, and advance research to improve the quality of life of people living with multiple myeloma. Thanks to the funds raised, we have been able to finance the Myeloma Canada Research Chair at Montreal's Maisonneuve-Rosemont Hospital, along with the Myeloma Canada Research Grant and the genomics study associated with our first clinical trial, MCRN 001.



Mississauga



Sault Ste. Marie

We wish to thank the volunteer coordinators who enabled the Multiple Myeloma March to take place once again in 2013.

Participating cities	Coordinators
Halifax	Trish MacDonald and Julie Salsman
Melville	Lynn Hoffman
Mississauga	Anne Spencer
Montreal	Francine Ducas
Quebec City	Laurie and Maude Carrier
Saskatoon	Charlene Ferguson
Sault Ste. Marie	Jill Lang Ward
Windsor-Essex County	Erma Roung
Winnipeg	Heidy Foot, Nori Foot and Shelly Baker

We also extend our thanks to all volunteers and supporters who got involved in the fight against multiple myeloma in 2013.



Windsor

We especially salute the contribution of Mr. Bob Hillier, a man who was very active in the myeloma community and deeply involved in organizing the Multiple Myeloma March in St. John's, Newfoundland and Labrador. Unfortunately, Mr. Hillier lost his battle with multiple myeloma a few days before the March.



Quebec City

Thoughts from the Canadian myeloma community

All our efforts in research, education and advocacy are valuable only if they positively impact the people who matter most: myeloma patients, their families and caregivers. We're proud to share with you a few personal testimonials of how we're making myeloma matter to Canadians.

I attended the Advocacy Summit in Winnipeg, and on hearing the report from Myeloma Canada, was amazed at the work that this little organization has accomplished in only eight years. The projects that really impressed me were the Scientific Advisory Board, the research grants, the National Patient and Caregiver Conference, the patient survey, the InfoSessions held across the country, as well as the many educational publications now available.



Myeloma Canada has also found time to maintain close contact with Myeloma UK and the IMF, and to ensure that the organization is represented at major conferences.

Congratulations to the Board and all the staff at Myeloma Canada!

Linda Latham,
Multiple myeloma patient
North Island Support
Group Leader
Campbell River, BC



I am so grateful for the guidance and information that Myeloma Canada offered me. Multiple myeloma is such a complicated disease, and having an organization like this to help me understand it has been of vital importance.

I also appreciate all the patient advocacy work they do on our behalf to ensure that we have the best treatments available. I knew little about the availability of drugs for cancer patients until I got sick. Thankfully, Myeloma Canada was there for me.

Lorraine McCallum
of Peterborough, ON,
with her youngest child of
10 months, after her
diagnosis of
multiple myeloma.

When I look back over the past year of accomplishments at Myeloma Canada, I'm amazed at what can be achieved with drive, motivation and vision. Through the efforts of Aldo Del Col and his tiny staff, plus the volunteer board of directors, our myeloma patients have been energized, informed and mobilized into a powerful force.

Our clinical trial physicians and translational research scientists from across Canada benefited from the buzz and momentum gained from rubbing shoulders at our annual Myeloma Canada Scientific Roundtable meeting, held in Montreal last November, and again when we met at ASH in December in Atlanta. There's a tremendous sense of "we can do it" that comes from pooling the strengths of our nationwide team, resulting in several clinical trial programs, launched in 2013 to study novel new agents in relapsed patients and to improve our initial frontline therapy at the time of stem cell autotransplantation.



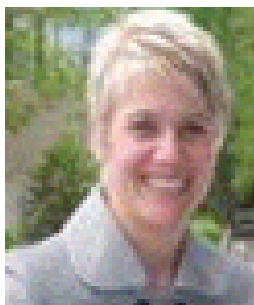
Myeloma Canada has been a remarkably inspiring organization for patients, doctors and scientists alike. I look forward to even bigger things in 2014.

Andrew R. Belch, MD, FRCPC
Cross Cancer Institute
Edmonton, AB



Myeloma Canada has helped greatly in making Canadians more aware that multiple myeloma is not melanoma or multiple sclerosis, but a separate disease, a cancer of the bone marrow. We appreciate Myeloma Canada's efforts in advocating at the national level to provide patients with better treatments.

Nancy Shamanna,
Multiple myeloma patient
Columnist for the Myeloma
Beacon
Calgary, AB



*Renee Stuckel, RSW
Dept. of Psychosocial Oncology
Provincial Malignant
Hematology/ Blood and
Marrow Transplant Program
Saskatoon Cancer Centre
Saskatoon, SK*

Myeloma Canada has been an invaluable organization for our patients and their families. The resource materials they provide have been comprehensive and easy to understand. In addition, the support groups have offered a much-needed opportunity to connect with other patients and caregivers who are going through a similar experience.

While I was looking for answers following my multiple myeloma diagnosis, I found in Myeloma Canada all the information and support I needed. One of the volunteers from the Montreal support group brought great comfort by listening to me and offering words of encouragement.



*Francine Ducas
Multiple myeloma patient
and volunteer
Montreal, QC*

For the past three years, I have been involved as a volunteer and would like to share with you the amount of effort and dedication displayed by Myeloma Canada in education and raising awareness, as well as furthering research to overcome this disease.

I'm very grateful to Myeloma Canada for their support, which gives me courage to continue on the path to healing.

Myeloma Canada matters! When I was diagnosed in November 2010, I had never heard of myeloma, and therefore had a major learning curve to achieve in order to stay healthy. Myeloma Canada continues to be a reliable and informative resource, along with a support to help me weather the storm.



*David McConkey,
Marathon runner, artist and
multiple myeloma patient
Change Islands and St. John's,
NL*

I'm impressed with the dedication and passion of the staff and volunteers at Myeloma Canada. I especially appreciate the focus on people living with myeloma, and on other aspects that make a difference, such as research and advocacy.

Moving forward with Myeloma Canada!



*Joseph Mikhael MD, MEd,
FRCPC, FACP
Consultant Hematologist,
Mayo Clinic Arizona
Associate Chair of
Education, Department of
Medicine
Program Director, Hematology-
Oncology Fellowship
Associate Professor, Mayo
College of Medicine
Mayo Clinic in Arizona*

As a physician dedicated to the care of patients with myeloma, it was so exciting for me to be involved in the Myeloma Canada National Conference in Ottawa. I saw a group of patients who, under the great direction of Myeloma Canada, had the opportunity to learn about this horrible disease, from the basics to the latest in research and clinical trials. I could see how it empowered them with education, knowledge and advocacy – critical elements required to overcome this disease.

The venue and schedule allowed for great breakout sessions and interaction with world experts in myeloma, along with the creation of a community that is very welcome in this field. I feel privileged to be a part of it.

Fundraising events drive awareness and research

Again this year, Myeloma Canada is building on the success of fundraising campaigns across Canada. The year 2013 was especially successful, allowing us conduct several campaigns whose proceeds have been allocated to further our goals of education, access to care, public awareness and research.



On March 2, 2013, more than 200 members and friends of the Ramagnano family gathered in Concord, Ontario, to pay tribute to Antonietta Ramagnano, who lost her fight against myeloma in 2011.

The event, which included a dinner and dance accompanied by a silent auction, raised close to \$20,000 in support of public awareness and myeloma research.

(From left to right) Michele Ramagnano, Antonio Ramagnano, Aldo Del Col, Patricia Ramagnano, Amanda Ferri, Nat Ferri and Frank Ramagnano

On June 17, Gord Ross organized the fourth annual golf tournament *Scramble for the Cure*, in honour of his sister Becky Ross and his father James Ross, who both died of multiple myeloma. More than 100 golfers participated, and the event raised a sum of \$29,384.



Gord and Claire Ross

When Jean-François Mongrain learned that his uncle André Scarpino suffered from multiple myeloma, he told himself that he had to do something. As a result, this avid sportsman convinced three friends to accompany him on a new challenge. From August 15 to 17, Jean-François and his teammates Mario



(From left to right) Mario Gélinas, Alexandre St-Jacques, Éric Forget and Jean-François Mongrain

Gélinas, Alexandre St-Jacques and Eric Forget took up the challenge to cycle 300 km. from Jean-François' city of residence, Mont-Saint-Hilaire, Quebec, to his hometown of La Tuque, where his uncle André also lives, to raise funds and awareness of multiple myeloma.

When they arrived at La Tuque, the group was warmly greeted by relatives and friends who wanted to congratulate them. The event ended with a fundraising dinner, which enabled the group to raise more than \$38,000.

We also wish to thank the thousands of other volunteers, donors and participants in the various activities held by Myeloma Canada to promote our cause across the country.

About Myeloma Canada

Myeloma Canada is a registered non-profit organization created by, and for, people living with multiple myeloma. As the only national organization exclusively devoted to the Canadian myeloma community, we have been making myeloma matter since 2005.

Myeloma Canada seeks to strengthen the voice of the Canadian myeloma community by working with leading myeloma researchers and clinicians, local support groups and other cancer organizations to improve the quality of life of myeloma patients, their caregivers and their families through education, awareness, advocacy and research.

Our mission is to:

- Provide educational resources to patients, families and caregivers
- Increase awareness of the disease and its effects on the lives of patients and their families
- Facilitate access to new therapies, treatment options and healthcare resources
- Advance clinical research and promote access to new drug trials in Canada

What is Multiple Myeloma?

Multiple myeloma, commonly referred to as myeloma, is an incurable cancer of the plasma cells. Plasma cells are found in the bone marrow and are part of the immune system that makes antibodies to help fight infections.

Because plasma cells are found in the blood, myeloma is referred to as a hematologic or blood cancer. The word “multiple” is often used because the malignant cells are not typically limited to one area of the body, but affect the bone marrow in multiple regions.

Although there is currently no cure for myeloma, the past decade has seen effective new treatments that have increased median overall survival from 3 – 5 years to over 7 years. Many patients now lead full lives for years after diagnosis.

What Causes Multiple Myeloma?

To date no specific causes for myeloma have been identified; however, a possible link has been suggested between exposure to chemicals, pollutants, radiation or other environmental factors and an increased risk of developing myeloma.

How Common Is It?

Multiple myeloma affects approximately 7,000 Canadians, with an estimated 2,300 new cases of the disease diagnosed in Canada in 2011. Myeloma most often affects individuals between the ages of 65 and 70, and is more common in men.

Characteristics of Multiple Myeloma

There are often no symptoms in the early stages of myeloma and in some cases it may be discovered accidentally during routine blood testing. When present, symptoms may be vague and similar to those of other conditions.

Malignant plasma cells grow and crowd out healthy cells in the bone marrow, impacting the body in a number of ways, including:

- Production of fewer red blood cells, which may result in anemia and fatigue
- Suppression of healthy white blood cell production, which can lead to recurrent infections
- Attacking and weakening of bones, which may lead to osteoporosis, pain and fractures
- Impairment of kidney and nerve functions

Myeloma is a complex disease and patients may experience all, some, or none of the described symptoms.

Seven Canadians are diagnosed with multiple myeloma every day. Although new treatments have helped some patients live longer, more productive lives, we still lose more than 1,300 Canadians to this incurable disease each year. With increasing research, the overall outlook for myeloma patients is steadily improving.

Finding Support

There are twenty one myeloma support groups in nine provinces across Canada. Myeloma Canada provides financial support to many of these groups so that they can continue to meet the needs of their local myeloma community. For information on local support groups, visit www.myeloma.ca and click on “find support”.

To reach Myeloma Canada:

Telephone: (514) 426-5885 or 1-888-798-5771
E-mail: info@myeloma.ca
Mailing Address: PO Box 326
Kirkland, QC
H9H 0A4

For more information about Myeloma Canada or to make a donation, please visit www.myeloma.ca