

# Myeloma Canada Milestones

2012: A Year In Review



**MYELOMA  
CANADA**  
MAKING MYELOMA MATTER

## National Conference

Myeloma Canada's flagship event and the foundation of its education and awareness programs is the National Conference.

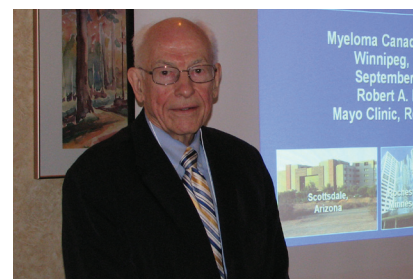
The eighth annual conference was held on September 29 in Winnipeg, Manitoba. There, more than 150 patients, caregivers, health care professionals and industry representatives benefited from presentations by leading national and international myeloma experts on topics such as treatment advances, novel therapies and clinical trials. Many of the presentations were recorded and are available on the Myeloma Canada website at [www.myeloma.ca](http://www.myeloma.ca).

The 2013 conference takes place in Ottawa on July 13.



Among the presenters at the National Conference, from left to right: Sharon Moncek\*, Aldo Del Col, Dr. Joseph Mikhael, Dr. Ade Olujuhngbe, Dr. Ludger Klewes, Susan Meisels and Cindy Manchulenko.

**\*IN MEMORIAM:** On February 6, 2013, Sharon Moncek lost her four-year battle with myeloma in Winnipeg, Manitoba. Following her diagnosis, Sharon became a strong advocate for myeloma patients in Manitoba as a key member of the Manitoba Myeloma advocacy team that successfully led a province-wide campaign to secure provincial funding for Revlimid®. In January 2012, Sharon and her team were awarded the TEAM Award in recognition of their advocacy efforts. This past fall, despite having just started new treatments, Sharon agreed to emcee the Myeloma Canada National Conference, where she shared her personal story with grace and wit. Sharon will be remembered for her generous and caring spirit and her determination to face challenges with a positive attitude.



Dr. Robert Kyle from the Mayo Clinic leads a session on MGUS and smouldering myeloma.



Dr. Anne Sherwood, Director of Scientific Affairs, The Binding Site



Dr. Joseph Mikhael of the Mayo Clinic presenting Myeloma 101.

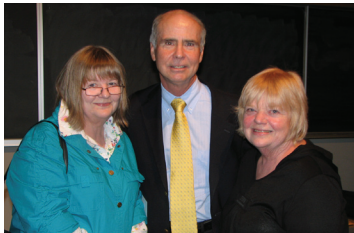
## Myeloma Canada InfoSessions

Myeloma Canada's well attended InfoSessions provide a valuable opportunity for participants to learn more about multiple myeloma from various collaborators while meeting others in their community who have been touched by this disease.

In 2012, Myeloma Canada conducted eight half-day InfoSessions across the country: in St. John's, NL; Halifax, NS; Montreal, QC; Toronto, ON; Windsor, ON; Sudbury, ON; Kelowna, BC and Vancouver, BC.



At the Windsor InfoSession, from left to right: Dr. Jeffery Zonder (Karmanos Cancer Institute, Detroit, MI), Dr. Caroline Hamm (Windsor Regional Cancer Centre), Erma Roung (Windsor Multiple Myeloma March Coordinator) and Aldo Del Col (Myeloma Canada)



At the Vancouver InfoSession: Donna Dickinson and Lillian Barton, co-leaders of the Vancouver Island Multiple Myeloma support group, join Dr. Ken Anderson of the Dana Farber Cancer Institute in Boston, MA.



At the Toronto InfoSession, from left to right: Dr. Meletios A. Dimopoulos (University of Athens School of Medicine), Anne Spencer (Mississauga Multiple Myeloma March Coordinator) and Aldo Del Col (Myeloma Canada)



At the Halifax InfoSession: On the left, Dr. Darrel White (Queen II Health Sciences Centre, Halifax, NS) and Dr. Keith Stewart (Dean for Research, Mayo Clinic, Scottsdale, AZ)



At the Sudbury InfoSession: Jill Lang Ward (Sault Ste. Marie Multiple Myeloma March Coordinator), Dr. Jason Tay (Ottawa General Hospital) and Aldo Del Col

## Myeloma Canada Patient Information Library

In 2012, Myeloma Canada introduced a new series of information booklets called InfoGuides to complement our existing publications. The series provides in-depth information on issues of interest to the myeloma community.

The following publications are available free of charge to patients, caregivers, hospitals and anyone with an interest in learning more about myeloma. They can also be downloaded from our website, [www.myeloma.ca](http://www.myeloma.ca), or ordered by email at [info@myeloma.ca](mailto:info@myeloma.ca).

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

Feedback from patients, caregivers, health care professionals and other cancer organizations on the publications has been extremely positive, with the Multiple Myeloma Patient Handbook in particular considered the best in its class. We owe the success of these publications in no small part to the invaluable input we receive from patients and caregivers.



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

## Multiple myeloma: Maintaining Momentum

One of our main goals and biggest challenges at Myeloma Canada is keeping the word out there and maintaining the momentum as we strive for increased awareness, research advancements and overall support for multiple myeloma. A big step in the right direction took place last December at the closing evening of the American Society of Hematology (ASH) meeting in Atlanta, Georgia.

There, Myeloma Canada welcomed more than 40 international journalists to “Maintaining Momentum”, an event that gave them an opportunity to meet and interview myeloma patients, who recounted their personal stories of living with myeloma.

At the event, reporters viewed video footage of several North American patients and caregivers. Through these moving personal tales, they learned more about myeloma and the important role new therapies are playing in providing many patients with an improved quality of life.

Several patients were in attendance to share their stories in person, including Linda Latham, a 17-year survivor of multiple myeloma from Vancouver Island, BC; Patricia Workman, a New York City patient who was a volunteer at Ground Zero after the September 11 attacks, and who believes this may have played a role in her diagnosis several years later; and 71-year-old American patient Don Wright, who has completed an astonishing 70 marathons spanning all 50 US states, all since his diagnosis with myeloma eight years ago.

## Patients matter

Myeloma Canada is grateful to all of the patients who shared their stories at the ASH meeting. We were reminded never to underestimate the huge impact that patients have in encouraging research, driving awareness and advocating for access to new treatments for multiple myeloma.



*Mike Kacsor, Linda Latham and Aldo Del Col at the multiple myeloma Maintaining Momentum event*

## Advocacy Summit

September 28 saw leaders from eight provinces across the country gather together in Winnipeg, Manitoba, for the third annual Myeloma Canada Advocacy Summit.

The 2012 summit's distinguished roster of speakers shared information and opened up discussions on a range of crucial and timely topics such as the drug approval process, the role of the patient voice in pCODR decision-making, changes in private drug insurance plans and more.

Speakers included Mr. Bryson Brown, patient representative on the pCODR Executive Review Committee (pERC), and Ms. Tara Besant from Great-West Life, representing the private insurance industry. Mr. William Dempster of 3Sixty Public Affairs facilitated the meeting and provided an update of the Canadian drug approval and funding landscape.

Opening the summit was Mr. Robert Shaffer, newly appointed co-chair of the pERC and Acting Executive Director of the Manitoba Health Provincial Drug Program.

## Carolyn Henry Memorial TEAM Award

The Excellence in Advocacy Medal (TEAM) Award was created in 2009 to recognize outstanding achievements by individuals who strive to make a difference by fighting for equitable access to myeloma treatments in their province. At the 2012 summit, the award was renamed the Carolyn Henry Memorial TEAM award, in memory and recognition of this outstanding advocate's pioneering efforts and dedication to improving the quality of life for fellow myeloma patients. Carolyn's daughters, Suzanne and Vanessa, attended the renaming ceremony.

Myeloma Canada named Carol Westberg of Calgary, Alberta, as the first recipient of the Carolyn Henry Memorial TEAM Award. A passionate advocate for the myeloma community, Ms. Westberg was awarded the honour for her championing of such causes as the need for a National Catastrophic Drug Coverage Program and funding for expensive life-saving drugs.

Sadly, on January 24, Carol Henry lost her eight-year battle with myeloma. She will be deeply missed, but through our memories of her and her dedication, her legacy will live on.

**The TEAM award is awarded annually in recognition of outstanding advocacy efforts**



*Presenting the Carolyn Henry Memorial TEAM Award to Carol Westberg are Alan Patt, Director of Government Relations and Market Access, Celgene, and Aldo Del Col, co-founder and Executive Director, Myeloma Canada*

## Myeloma Canada prepares first patient evidence submission to the pan-Canadian Oncology Drug Review (pCODR)

We're making our voice heard!

The pan-Canadian Oncology Drug Review (pCODR) is a national government-funded organization that evaluates cancer drugs and makes recommendations to the provinces and territories to guide their drug funding decisions.

Last October, Myeloma Canada participated in its first patient evidence submission to the pCODR in support of funding for bortezomib (Velcade®) as an induction therapy for newly diagnosed, transplant-eligible myeloma patients in Ontario. Ontario is the only province that continues to withhold funding for bortezomib as an induction therapy.

The response to the online survey was overwhelming, with 476 responses received, the strongest response seen to date by the pCODR! Despite the fact that the submission was for Ontario, almost half of the survey respondents were from other provinces. This demonstrates the commitment of Canada's myeloma community to help patients no matter where they live.

As it moves through the review process, you can check the status of the bortezomib issue on the pCODR website ([www.pCODR.ca](http://www.pCODR.ca)) under "Find a Review." The Clinical Guidance Report will be posted publicly on the pCODR website when the pERC Initial Recommendation is issued. It will include a detailed summary of the Myeloma Canada patient input provided to the pCODR at the start of the review.

## Thalomid® Approved for Funding in Ontario

The Ontario Public Drug Programs (OPDP) under their Exceptional Access Program (EAP) announced that Thalomid® (thalidomide) would be funded for the treatment of patients 65 years of age or older with previously untreated multiple myeloma AND who are unsuitable for stem cell transplantation. Funding is provided for a maximum of 12 cycles of six weeks each.

Ontario is the third province, after Quebec and British Columbia, to approve funding for Thalomid®.

## Myeloma Canada, Université de Montréal and Maisonneuve-Rosemont Hospital create Myeloma Canada research chair to improve patient outcomes

On September 12, 2012, Myeloma Canada, together with the Université de Montréal, Maisonneuve-Rosemont Hospital (MRH), Celgene and the MRH Foundation, announced the creation of the Myeloma Canada Chair in Multiple Myeloma Research.

The Chair's aim is to improve patient outcomes by advancing clinical and basic research and to create tools to ensure patients and the Canadian myeloma community are kept informed of and benefit from research advancements.

A unique feature of the Myeloma Canada Chair is the opportunity to take a lead role as a member of the Chair's Management Committee. This will ensure that the patient's voice is heard and the Chair maintain its focus on clinical and basic research to complement Myeloma Canada's core mission of improving outcomes for all myeloma patients throughout Canada.

The Myeloma Canada Chair in Multiple Myeloma Research will be led by Dr. Richard LeBlanc, Professor of Medicine at the Université de Montréal and a medical hematologist and oncologist at Maisonneuve-Rosemont Hospital. Dr. LeBlanc is recognized for his involvement in caring for patients with multiple myeloma and his work as Medical Director of the Immunology Laboratory at MRH. He is also a member of Myeloma Canada's Scientific Advisory Board and the Myeloma Canada Research Network.

In addition to clinical research, the Myeloma Canada Chair in Multiple Myeloma Research will support basic and translational research through the MRH myeloma tissue bank and immunotherapy research in cooperation with the Institute for Research in Immunology and Cancer (IRIC), a world-renowned research institution based at the Université de Montréal.



The Myeloma Canada Chair in Multiple Myeloma Research at the Université de Montréal was launched in the presence of (from left to right): Kevin Leshuk (Vice President and General Manager of Celgene Inc.), Dr. Manon Boily (Executive Director of Maisonneuve-Rosemont Hospital), Dr. Richard LeBlanc (Chair holder), John Lemieux (co-founder and President, Myeloma Canada), Dr. Guy Breton (Rector of Université de Montréal) and Dr. Hélène Boisjoly (Dean of the university's Faculty of Medicine)



From left to right: John Lemieux (co-founder and President, Myeloma Canada), Dr. Richard LeBlanc (Chair holder), Aldo Del Col (co-founder and Executive Director, Myeloma Canada)

## Myeloma Canada announces recipient of the 2012 research grant

Myeloma Canada's goal, as a patient-driven, patient-focused organization, is to improve outcomes for all Canadians living with myeloma through education, awareness, advocacy and research. As part of our continuing efforts to advance Canadian myeloma research, Myeloma Canada established the Myeloma Canada Research Grant in 2011. With guidance from Myeloma Canada's Scientific Advisory Board and the Myeloma Canada Research Network, selection criteria were established to guide the Peer Review Committee in their evaluation and selection process. The Peer Review Committee, composed of members of the Scientific Advisory Board, reviews and evaluates each application based on its merits in light of the established criteria. We are pleased to announce that the recipient of the 2012 Myeloma Canada Research Grant in the amount of \$50,000 is Dr. Paola Neri, Assistant Professor of Medicine at the University of Calgary.

The objective of Dr. Neri's research project, entitled miRNome-guided tool to predict sensitivity or resistance to lenalidomide in multiple myeloma patients, is to help identify which myeloma patients will respond to lenalidomide (Revlimid®) and which will not. With nearly a third of relapsed patients failing to respond to lenalidomide, Dr. Neri's research proposal intends to identify small genomic sequences (miRNAs) as biomarkers and modifiers of response to lenalidomide, thereby permitting an individualized therapy for multiple myeloma patients.

Congratulations to Dr. Neri on being this year's recipient of the Myeloma Canada Research Grant.

The Myeloma Canada Research Grant is made possible through generous donations to the annual Multiple Myeloma March.



Dr. Paola Neri, recipient of the 2012 Myeloma Canada Research Grant

## Making myeloma patients matter at the 54<sup>th</sup> annual meeting of the American Society of Hematology (ASH)

At the ASH annual meeting, held from December 8-11 in Atlanta, Georgia, experts from around the world presented the latest research findings that promise to advance the treatment of blood cancers including multiple myeloma. Myeloma Canada, in collaboration with the International Myeloma Foundation and the IMF Latin America, welcomed patients and journalists from around the world to a workshop on December 9. The goals were to put into perspective the latest treatments for myeloma presented at the meeting, raise awareness and share patient stories.

The myeloma specialists who spoke during the workshop included Dr. Brian G.M. Durie, International Myeloma Foundation; Dr. Paul G. Richardson, Dana-Farber Cancer Institute; Dr. Xavier Leleu, Hôpital Claude Huriez, France; and Dr. Robert Orlowski, University of Texas MD Anderson Cancer Center.

Patients also had the opportunity to share their stories with the doctors and journalists who were present. "These patient profiles are important because they clearly show the value of the newest treatments, some of which are available in Canada only in clinical trials," said Aldo Del Col, co-founder and Executive Director of Myeloma Canada. "We hope to encourage more drug approvals and earlier access to new treatments by showing first-hand how medical advances can help myeloma patients live longer, productive lives."

Mike Kacsor, a co-leader of the Toronto support group, was featured in a video shown during the workshop. He shared the story of his active life. Sixteen years after his myeloma diagnosis, Mike says, "I was about to be married when I learned I had multiple myeloma. I wasn't sure how my fiancée would react, but we did get married and we celebrated our 15<sup>th</sup> anniversary this year."



Susie Novis, International Myeloma Foundation, Paula Van Riper, Central New Jersey Myeloma Support Group, Aldo Del Col, Myeloma Canada, Christine Battistini, IMF Latin America



## Myeloma Canada announces creation of nursing award



*Emile and Jonathon State sharing Marion's story at the announcement of the Marion State Memorial Myeloma Canada Nursing Award*

In their role as front-line members of a hospital's health care team, oncology nurses are vital in delivering treatments and providing information, follow-up and general support to myeloma patients. Myeloma Canada believes it is important to acknowledge the role nurses play as integral members of the health care delivery team and recognize outstanding contributions to myeloma nursing.

The nursing award was named in recognition of Marion State, a nurse herself, for her extraordinary contribution to the Canadian myeloma community. Myeloma Canada announced the creation of the Marion State Memorial Myeloma Canada Nursing Award at last year's National Conference in Winnipeg in the presence of Marion's husband Emile and son Jonathon. The award will recognize excellence in myeloma nursing care and be presented annually to a Canadian nurse who has demonstrated leadership in either clinical practice, research or teaching.

## Myeloma Canada Scientific Roundtable

The third annual meeting of the Myeloma Canada Scientific Roundtable, held in Montreal on November 2 and 3, attracted 17 of Canada's key investigators and clinicians. The purpose of this forum is to update and exchange information on the basic and translational research being done in Canada and the US and provide the opportunity to discuss and plan future scientific and investigator-initiated clinical initiatives. Industry representatives were also invited to update the attendees on their company's myeloma program and pipeline. Special invited guests included Dr. Jonathan Keats from TGen in Phoenix, AZ; Dr. Ryan Brinkman from the Terry Fox Laboratory in Vancouver, BC; Dr. Muzaffar Qazilbash from the MD Anderson Cancer Center in Houston, TX; and Mr. Daniel Tessier from Genome Quebec in Montreal, QC.



*From left to right: Dr. Christine Chen (Princess Margaret Hospital, Toronto, ON), Dr. Heather Sutherland (Vancouver General Hospital, Vancouver, BC), Dr. James Witowsky (Senior Medical Science Liaison, Onyx Pharmaceuticals),*



*The Alberta team at the Scientific Roundtable. From left to right: Dr. Andrew Belch, Dr. Paola Neri and Dr. Nizar Bahlis*



*Dr. Richard LeBlanc (Maisonneuve-Rosemont Hospital, Montreal, QC) with Dr. Ade Olujuhunge (CancerCare Manitoba, Winnipeg, MB)*



*The third annual Myeloma Canada Scientific Roundtable was the most successful ever, with 25 participants including Canada's leading investigators, scientists and clinicians, medical representatives from industry partners and research organizations, and special guest speakers from the USA and Canada.*



## MULTIPLE MYELOMA MARCH

### Multiple Myeloma March Makes Great Strides in 2012

The Multiple Myeloma March campaign made great strides in 2012 by raising over half a million dollars, a 30 percent increase over last year.

### A story worth telling

In 2009, the first Multiple Myeloma March took place in Montreal with 300 marchers and raised \$34,000. In 2011, the March raised close to \$400,000 and involved six communities: Halifax, Montreal, Saskatoon, Sault Ste Marie, Windsor and Winnipeg. In 2012, the March grew to include 11 communities, attracting more than 2,500 participants.

Communities participating for the first time in 2012 included: Ottawa, Mississauga, St John's, NL and Quebec City. The credit for this growth truly goes out to the volunteers, donors, sponsors and marchers who are helping make myeloma matter for the entire Canadian myeloma community.

### Where the funds go

Funds raised during the campaign help further research in Canada, benefiting all Canadian myeloma patients. Among the research projects being funded are the Myeloma Canada Research Grant, the Myeloma Canada Research Network and the Myeloma Canada Research Chair at the Université de Montréal. The Marches also help drive awareness and advocacy efforts and allow Myeloma Canada to respond to an increasing demand for educational material and patient programs. Minimizing administration costs wherever possible, we ensure that funds are allocated to improving the lives of myeloma patients across Canada.

### Thank you to all the volunteers

It is also important to recognize that this achievement is made possible due to the efforts of dedicated March Coordinators and their organizing committees who tirelessly recruit volunteers, encourage individuals to participate and solicit funds and gifts from generous donors and sponsors.

Myeloma Canada wishes to thank the following March coordinators and their respective committees for having organized the 2012 Marches. Their tireless efforts contributed to the advancement of myeloma research in Canada and improvements in the lives of myeloma patients and their caregivers across Canada: Rhonda Birenbaum and Bill Cowley, Ottawa, ON; Laurie and Maude Carrier, Québec City, QC; Charlene and Erin Ferguson, Saskatoon, SK; Heidi Foot and Nori Leask, Winnipeg, MB; Robert Hillier, St John's, NL; Jill Lang Ward and Mike Caputo, Sault Ste Marie, ON; Erma Roung and Angel Ferguson, Windsor, ON; Julie Salsman, Halifax, NS; and Anne Spencer, Mississauga, ON.

**Mark your calendar for the 2013 Multiple Myeloma March: Sunday, September 22<sup>nd</sup>, 2013**

**To find out more about a March in your community and how you can get involved, email us at: [info@myeloma.ca](mailto:info@myeloma.ca)**



# Myeloma Canada: Making Myeloma Matter

## Making myeloma matter through fundraising

### The Movers and Shakers that are Making Myeloma Matter

Many individuals in the Myeloma Canada community kept busy last year organizing local fundraising events to help support Myeloma Canada's goals of education, access, awareness and research. Not only were the events successful in raising money and awareness, they were also lots of fun!

### Mine Over Matter Triathlon

*Organized by: James Parkin, Milton, ON*

James Parkin from MHBC Planning contacted Myeloma Canada to raise funds for the cause through his team's participation in the Mine Over Matter Off Road Triathlon In Milton, Ontario. The event took place on August 26<sup>th</sup> and was held at Kelso Quarry Park (old Milton Limestone Quarry). MHBC Planning took part in this event to raise funds on behalf of their co-worker Glen Harrison who has worked for the company for 27 years.

Glen was recovering from a year-long battle with multiple myeloma and looking forward to getting back to work in September. Raising money through the triathlon was one way for the MHBC Team to show their support for Glen and to raise money for research to help all myeloma patients. Glen was involved in the rehabilitation plans for the Milton Quarry so they felt it was a fitting venue for their fundraising. The MHBC Team had two participants in the full triathlon and three teams in the short course relay event. Dave Aston completed his first full triathlon and James Parkin moved up a spot to finish third in his age group. Our relay teams (Parkin, Bogaert and Philips/Sinclair) finished 2<sup>nd</sup>, 3<sup>rd</sup> and 4<sup>th</sup>.

The event raised a remarkable \$7,500 thanks to generous sponsors and donors.



\$7 500 was raised through the "Mine over Matter" triathlon for Myeloma Canada's education and research programs.

### Third Annual Scramble for the Cure

*Organized by: Gord Ross, Burlington, ON*

On June 18<sup>th</sup>, Gord Ross hosted the 3<sup>rd</sup> Annual Scramble For the Cure Golf Tournament in memory of his sister and father who passed away from multiple myeloma. With over 100 golfers participating in the tournament, over \$20,000 was raised. The event would not have been possible without the hard work and dedication of Gord, sponsors, donors and, of course, the keen golfers.



*Gord and Claire Ross*



*The fourth annual Scramble For the Cure will be held on June 17<sup>th</sup>.*

## In Memory of Dirk Gettle Fundraiser

Organized by: *Bev Hartnell, Regina, SK*

Last April Bev lost her soul mate, Dirk Gettle, to multiple myeloma, just 20 days shy of his 58<sup>th</sup> birthday. Dirk had been diagnosed with multiple myeloma in 2003 and had two successful stem cell transplants in Saskatoon, the first in 2003 and the second in 2008. Dirk was a special man who touched and enhanced the lives of so many people. It is said that when a warrior dies in battle, it is a victory. Dirk was a warrior and Bev wanted to honour him and help Myeloma Canada in its national fundraising campaign. Last October 13<sup>th</sup> Bev organized a supper and silent auction that was attended by 200 family and friends. The event was a huge success, raising \$11,500.

“Dirk was a truly amazing man, who I loved with all my heart and who will never be forgotten” - Bev Hartnell.



*Bev Hartnell and Dirk Gettle*

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## Trick-or-Donate

Organized by: *Brooke Petreny and Friends, Moosomin, SK*

It's always wonderful to see the younger generation plan fundraising activities. So when we received an email from 14 year old Brooke Petreny of Moosomin, Saskatchewan enquiring donation boxes so she could go door-to-door on Halloween and raise money for Myeloma Canada, we were more than willing to help! Brooke and her four best friends, Kelsey Firkola, Jenisse Bradley, Sara Crespo and Kylie Cousins got dressed up in Myeloma Canada t-shirts scarves and bracelets, split up into two groups and went door-to-door amongst trick-or-treaters to collect funds and raise awareness for myeloma. Brooke and her friends got coverage in two local newspapers and raised a total of \$3,000, a fantastic feat for their first fundraiser!



*From Left to Right: Sara Crespo, Kylie Cousins, Brooke Petreny, Kelsey Firkola and Jenisse Bradley.*

We also wish to thank Joanne Mellquist (West Vancouver, BC), Lynn Hoffman (Melville, SK), Sara Walsh (Summerville, PE), The Hull Family (Dutton, ON), Ron Trumper (Montreal, QC) and thousands of others who have volunteered, donated and participated in various Myeloma Canada activities. Thank you for making myeloma matter across Canada.

## 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 2004.

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 sixteen 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](http://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](mailto: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](http://www.myeloma.ca)