A YEAR IN REVIEW

2018

Myeloma Canada

Milestones

MYELOMA CANADA
MAKING MYELOMA MATTER

Myeloma Canada‘s Mission

To improve the lives of Canadians impacted by myeloma through awareness-building, educational activities, advocacy, support of clinical research and fostering an empowered myeloma community.

Because Myeloma Matters

Our Vision: A world where myeloma is no longer a debilitating or fatal disease.

Created by, and for, Canadians impacted by multiple myeloma, Myeloma Canada has been driving collaborative efforts to unify the voice of the myeloma community to effectively shape the Canadian treatment landscape - and make myeloma matter - since 2005.

Myeloma Canada’s goals include:

- **Providing educational resources** to patients, families and caregivers
- **Increasing awareness** of the disease and its effects on the lives of patients and their families
- **Facilitating access** to new therapies, treatment options and healthcare resources
- **Advancing clinical research** and promote access to new drug trials in Canada
- **Empowering patients and caregivers** through community engagement

THE TEAM



MARTINE ELIAS
Executive Director



OLIVIER JÉRÔME
Director of Operations



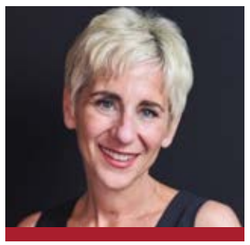
SHANEIKA HESLOP
Senior Administrative Assistant



MICHELLE OANA
Associate Director of Development and Community Relations



GABRIELE COLASURDO
Manager of Education and Patient Services



MARCIE BARON
Manager, Communications & Marketing



JESSY RANGER
Communications Coordinator



ANGELINA MAVRODIEVA
Administrative Assistant, Accounting

MYELOMA CANADA BOARD OF DIRECTORS



HARRIS POULIS
Chairman
Lawyer
General Counsel and Director of Legal Affairs
McGill University Health Centre
Montreal, QC



ALDO DEL COL, MBA, RPH
Co-founder and Special Advisor
Myeloma Canada
Montreal, QC



JOHANNE MULLEN, MBA
Vice-Chair
Partner, Infrastructure and Project Finance Leader
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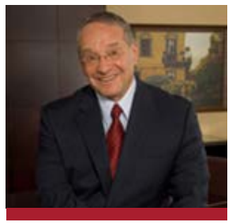

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ANTHONY EVERETT
Director
Chief Executive Officer
Tourism Vancouver Island
Nanaimo, BC



DONNA REECE, MD
Director
Co-founder
Myeloma Canada Research Network
Professor of Medicine, University of Toronto/ Princess Margaret Cancer Centre
Toronto, ON

A MESSAGE FROM ALDO DEL COL, CO-FOUNDER



It is with mixed emotions that I pen this message. As you may know, after many years of being at the helm of Myeloma Canada, I decided to step down as Chairman of the Board. I would like to take this opportunity to thank Harris Poulis, who assumed the role of Chairman in the spring, for his leadership in continuing to advance our vision, mission and values.

I am extending a heartfelt thank you to our incredible volunteers, supporters and medical community who, along with our dedicated staff, contributed to making 2018 another banner year for Myeloma Canada. You are the foundation upon which we have built this organization and the reason why we are making great progress in advancing our mission: to improve the lives of Canadians impacted by myeloma through awareness building, education, advocacy, support of clinical research and fostering an empowered myeloma community.

I'm proud to share some of our 2018 milestones:

1. **Community Engagement:** We launched and held 3 Meet & Greet sessions; increased our network to 33 support groups across Canada; created 3 'virtual' Facebook groups to enable patients and their loved ones to connect regardless of where they are in the country; welcomed a record 50+ attendees to our Support Group Leader Summit; and our annual Multiple Myeloma March had a banner year with 23 marches in 9 provinces across the country.

2. **Education:** We created and released a host of new educational materials including a new Clinical Trials InfoGuide, 9 webinars and a unique, personalized, online Clinical Trial Finder tool. We also held 8 InfoSessions across the country – more than ever before!

3. **Awareness:** We collaborated in developing an Early Diagnosis Survey; produced 7 videos; published an early diagnosis brochure to promote the timely diagnosis of myeloma; attended and spoke at 2 conferences focused on early awareness outreach to healthcare professionals; revamped our website to make it more personal and user-friendly, and increased our social media presence.

4. **Advocacy:** We represented the patient community at meetings regarding the National Pharmacare strategy; met with government officials in Quebec influencing research policy to support Myeloma Canada Research Network and other investigator-initiated trials; participated at government awareness days in Quebec, Ontario and British Columbia; took part in 12 advocacy campaigns as part of our Myeloma Advocacy Program, and chaired a national network of cancer patient groups.

5. **Research:** We, in collaboration with doctors from the Myeloma Canada Research Network, initiated the drafting of a Diagnosis Guidelines consensus document to be published in 2019; and our Myeloma Canada Scientific Roundtable boasted over 90 attendees, including patients, pharmaceutical companies, scientists and clinicians.

Our small but determined organization has made immense strides over the past year, and we plan to achieve even more in 2019. It has been a great honour and privilege to have met and collaborated with so many of you. Your tireless and relentless passion in supporting our cause continues to humble and overwhelm me.

Thank you again for your commitment, drive and dedication to Myeloma Canada, and to making myeloma matter.





ALDO DEL COL AWARDED GOVERNOR GENERAL'S MERITORIOUS SERVICE MEDAL

On November 5, 2018, in recognition of his pioneering efforts and dedicated service to the Canadian myeloma community, Aldo Del Col received the Meritorious Service Medal from Her Excellency the Right Honourable Julie Payette at Rideau Hall in Ottawa. This prestigious award, created by Her Majesty, Queen Elizabeth II in 1984, recognizes Aldo's outstanding level of service to the community in establishing a national organization for all Canadians directly or indirectly impacted by multiple myeloma.

In 2002, Aldo was diagnosed with myeloma. This was at a time when there was not much information on the disease, when treatment options were limited, and when resources for Canadians were nearly non existent. Aldo identified a need for an integrated national grassroots organization to support others impacted by this devastating disease. He wanted to create a community that would encourage hope and a positive outlook for the future for others touched by myeloma.

Aldo also co-founded the Myeloma Canada Research Network (MCRN) – the first and only national academic research group bringing together Canada's leading myeloma clinicians from coast-to-coast. The MCRN drives Canadian research focused on optimizing patient outcomes through collaboration and sharing of expertise, across 20 centres in Canada.

Above and beyond his work with Myeloma Canada and the MCRN, Aldo is involved with several other organizations and committees. He is a member of the Canadian Cancer Trials Group (CCTG) Hematology Executive Committee and the CCTG Molecular Tumour Board. This past spring, he was presented with an Award of Appreciation in recognition of his outstanding dedication to the Canadian Cancer Trials Group. Internationally, Aldo serves on the Board of Directors of the International Myeloma Foundation and is an active contributor to the Global Myeloma Action Network and member of the International Myeloma Society. He was recently named Member Emeritus of the Ontario College of Pharmacists in recognition of his work as a community pharmacist. Aldo also continues his volunteer work for Hope and Cope at the Jewish General Hospital in Montreal.

A MESSAGE FROM MARTINE ELIAS, EXECUTIVE DIRECTOR



WOW is the only word that comes to my mind when looking back at everything we've accomplished in 2018 to make myeloma matter! We delivered excellence on impactful programs because of the contributions of each member of this amazing community, our dedicated staff, our volunteers and because of the support of our partners.

As I took on the role of Executive Director this past June, I knew we had already made a big impact through the vision and action of our Co-founder Aldo Del Col, but so much more was to come.

This year, we launched many new and innovative programs. The 3 that come to mind are the Personal Clinical Trial Finder, 3 virtual support groups and our collaboration with the Myeloma Canada Research Network on the development of the first Canadian Myeloma Diagnosis Guidelines. You can learn more about these, and other exciting programs we launched, within this year's Year in Review.

I have had the pleasure to work with many patient organizations in my career and I can honestly say that Myeloma Canada distinguishes itself from the best of them in many ways. Our outreach and grassroots approach within our community is by far the best of any cancer group I know. Our educational programs are of high-quality, our advocacy initiatives and ability to take part in discussions that shape the health care system are unprecedented, and our support of research is unique. While I know how good we are, what makes me even more proud is when I hear it from other leaders in the patient-care community, from government officials and partners who recognize our impact, especially given how much we accomplish with such a small team. There is nothing better than being recognized as leaders for our cause.

I invite all of you to toot the Myeloma Canada horn! Because we're all doing this together!



Myeloma Canada

Our Programs and Achievements

2018 has been a banner year in the history of our organization. We celebrated the 10th anniversary of our signature event, the Multiple Myeloma March, and after 13 years, Aldo Del Col stepped down from his position as Chair on the Board of Directors. Myeloma Canada was created in 2005, emerging from Aldo's desire to establish a national organization created by, and for, Canadians impacted by myeloma. It was his empathy and his understanding of our community's need that successfully positioned Myeloma Canada as an advocacy leader for patients' rights. Today, Myeloma Canada stands out as a «single platform « for patients' needs while remaining focused on improving patient quality of life. The success of Myeloma Canada is unique because we listen to our community. Our patients are at the heart of everything we do.

As a special advisor to the Board of Directors, Aldo is still very active within our organization and involved in several projects. Thanks to his involvement and that of the new executive members, Myeloma Canada is now mobilizing the community more than ever and carrying a strong and united voice across the country. We are aware of the challenges patients face with our healthcare system and understand the important roles patients and caregivers play in improving the structure of healthcare. We are ready to grow, to take Myeloma Canada to new heights and to work even harder to ensure that our community members are heard and involved in their care.

Education

DEVELOP, SUPPORT and DISSEMINATE information and resources to help the myeloma community make informed decisions.

INFOSESSIONS AND EDUCATIONAL EVENTS

Each year in municipalities across the country, Myeloma Canada holds InfoSessions where guest speakers from the medical community cover various topics of interest for patients, their loved ones and healthcare professionals. Topics include treatment options, blood tests, side-effect management, and research development. Myeloma Canada also organizes many other educational events (webinars, Meet & Greets, etc.) that allow participants to learn more about the many aspects of myeloma.



Juliette (Jules) Royer at the Meet & Greet in Kitchener

In 2018, Myeloma Canada organized:

- **8 InfoSessions:** Oshawa, Moncton, Gatineau, Sudbury, Prince George, Whitehorse, Rimouski, Montreal
- **3 Meet & Greet** events for municipalities wishing to create a support group and learn more about the myeloma community: Surrey, Kitchener, Winnipeg
- **5 French and English webinars** on treatment plans, nutrition, clinical trials, and the latest research developments shared at the ASH (American Society of Hematology) and EHA (European Hematology Association) annual conferences
- More than **30 new educational videos** on clinical trials, patient journeys and research have been added to our **YouTube** channel (Myeloma Canada). You may view these, along with all webinars, webcasts and presentations that took place at various conferences throughout the year

EDUCATIONAL MATERIAL

Every year, Myeloma Canada strives to develop new educational tools for patients and their loved ones that promote a better understanding of the different aspects of the disease. Our educational material is made available in hospital libraries, myeloma clinics and support groups, and at educational and awareness events, or directly to patients and caregivers.

New InfoGuide: Clinical Trials as a Treatment Option

This newest of our InfoGuides aims to clarify and explain the clinical trial process. In addition to answering the most frequently asked questions, the information provided can help patients determine if a clinical trial is a good treatment option for them.



All of our educational material is available in both, PDF and hard copy formats. For PDF versions, please visit **myeloma.ca**, click on the "Educational Publications" section of the "Resources" tab.

- To order a hard copy of any of our guides, e-mail us at **contact@myeloma.ca** or call us toll-free at **1-888-798-5771**.

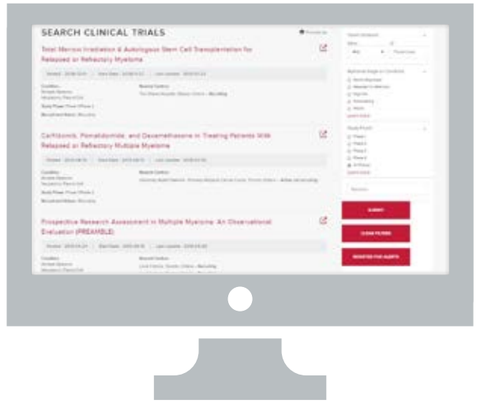
WEBSITE

The Myeloma Canada website is an important source of information for the Canadian myeloma community. Our team is continuously improving and further developing our website content. Toward the end of 2018, Myeloma Canada undertook the project of enhancing the user experience, making our site more personalized, intuitive and easy to use.

Myeloma Canada Personalized Clinical Trial Search Tool

For patients, scrolling through the list of clinical trials available in Canada and identifying those for which they are eligible can be very overwhelming. To simplify the process, Myeloma Canada launched a Personal Clinical Trial Finder search tool on our website. This user-friendly tool allows you to refine your search and display results based on:

- a geographical radius or travel distance
- a myeloma stage or condition
- a trial phase
- keywords



Myeloma Canada's Personal Clinical Trial Finder also features an alert for new trials that have not yet started the recruitment process. Access the tool by visiting **www.myeloma.ca/findtrials.**

Personalized Navigation

The type, stage, and symptoms of myeloma can vary from person-to-person and change over time. With this in mind, and aware of the many challenges that patients face, Myeloma Canada now offers a personalized navigation tool on our website that pares down information, making it more relevant to each person's situation and experience. The "I am…" search filter is now available on our homepage at **myeloma.ca**.

"Clinical Trials" Section

In 2018, Myeloma Canada invested a great deal of effort into increasing clinical trial awareness in Canada, as well as answering many questions and breaking down myths about clinical trials. In addition to our new InfoGuide on clinical trials, the launch of a clinical trial search tool, and a series of educational videos, the "Clinical Trials" section of our website was revamped to clarify and keep users updated on the most relevant information. For more, visit **myeloma.ca**.



Multiple Myeloma March

In 2018, to mark the 10th Anniversary of the Multiple Myeloma March, Myeloma Canada introduced a new web platform for a more user-friendly experience. This platform allowed us to improve the content hosted on each March's page, provided participants with an opportunity to maximize their fundraising efforts, and take advantage of our personalized tools. We've taken this new platform even further for 2019. Visit **myelomamarch.ca** to learn more.



MYELOMA CANADA NATIONAL CONFERENCE

This unique, patient-focused two-day conference is a tremendous opportunity to learn about the most recent developments in research, treatments and myeloma management. Nearly **200 patients and caregivers from across the country** joined us in May for the **13th Myeloma Canada National Conference** in Vancouver, British Columbia. Participants attended lectures and workshops given by leading Canadian and international experts on topics such as side-effect management, nutrition, and tips for caregivers.

Awareness

PROMOTE early diagnosis, INCREASE awareness of myeloma and the ways in which it affects the lives of patients and their families.

MYELOMA AWARENESS MONTH

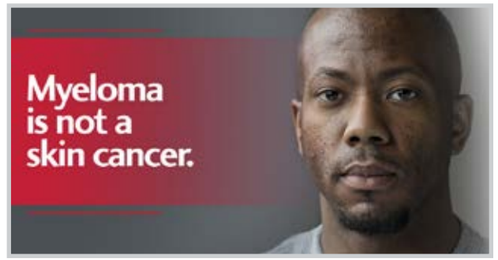
Together, Myeloma Canada and the international myeloma community have made tremendous progress in raising awareness of the disease. The quality of life of patients living with myeloma has improved considerably. **Over the past 15 years, the life expectancy of a myeloma patient has more than doubled as a result of innovative research, education, increased awareness, access to new treatments, and deeper community involvement.** The therapeutic landscape is constantly evolving and this positive momentum is a direct result of the tireless dedication of myeloma community members around the world. In March 2018, during Myeloma Awareness Month, Myeloma Canada launched a public awareness campaign.

Myeloma is Not a Skin Cancer

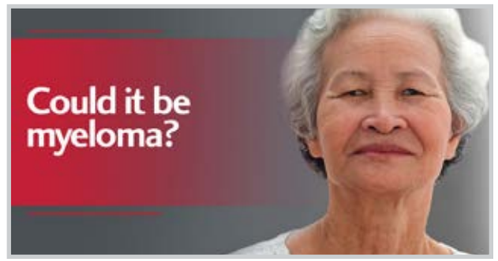
This general awareness campaign for myeloma was shared on social media and through email blasts. Too often, the first signs of myeloma are unnoticed by medical staff. It is by raising awareness within our community and the general population that we can make progress on early diagnosis.

Patient Journey Videos

People often feel emotionally overwhelmed when receiving a myeloma diagnosis. No one better understands this than another person living with myeloma. Myeloma Canada has created a series of short videos featuring patients describing their journeys. These videos, available on our YouTube channel and our website, are a great way to connect with others impacted by myeloma through the stories they share.









AWARENESS DAYS

Throughout the year, Myeloma Canada worked at promoting access to effective treatments and raising awareness for the importance of investing in research and clinical trials, across the country. Together with members of our community, we actively participated in Awareness Days to educate provincial and federal political leaders on the challenges faced by the Canadian myeloma community. In 2018, Myeloma Canada had the opportunity to meet with political representatives from **3 provinces**.

Quebec

APRIL

In April, a multiple myeloma Awareness Day at the National Assembly of Quebec was organized by Francine Ducas and Maryse Bouchard (Co-founders of the *Défi cyclo-myélome* challenge), and by the Maisonneuve-Rosemont Hospital, represented by Dr Richard LeBlanc (Chairholder of the Myeloma Canada Chair in Multiple Myeloma Research at the Université de Montréal). Representatives from Myeloma Canada also attended, along with patient representatives Danny Wade and Mélanie St Jacques from Quebec. The group had the opportunity to discuss and interact with members from all political parties.



The group with Martine Elias, and Members of the Parti Québécois Diane Lamarre (Taillon) and Dave Turcotte (Saint-Jean).

OCTOBER



Aldo Del Col, Co-founder of Myeloma Canada, Sharon Aloian, MPP John Fraser for Ottawa South, Martine Elias and Steve Beattie.

Ontario

In October, Myeloma Canada's voice was heard in Queen's Park during the Ontario Legislative Assembly. Martine Elias, Executive Director of Myeloma Canada, our Co-founder Aldo Del Col, and a delegation of patients met with members of Parliament and senior government officials. The group spoke with influential decision makers at both, the provincial and federal levels, to raise awareness about myeloma and patient advocacy.

British Columbia

NOVEMBER

In November, Myeloma Canada received tremendous support from BC MPs on Awareness Day. Patients from across the province, Martine Elias and Michelle Oana (Myeloma Canada's Associate Director of Development and Community Relations), met with **22 MPs** to raise awareness for myeloma and express the urgent need to add new drugs to the provincial listings. The group was invited to attend the Caucus Question Period, where Myeloma Canada was presented formally by Norm Letnick, Kelowna-Lake Country MP and Official Healthcare Critic for the opposition. Sonia Furstenau, MP for Cowichan Valley, also shared her personal story and connection to myeloma. The following week, Sonia spoke at the Legislative Assembly on the important work being done by Myeloma Canada, the importance of improving treatment access and raising awareness for myeloma. The video of Ms Furstenau's speech is available on our **YouTube** channel.



Ronald Surry, Robert Hamaguchi, Warren Welling, Allison Jennings, Tina and Jim Argue with Martine Elias and Michelle Oana.

MEETING WITH HEALTH PROFESSIONALS

Martine Elias participated in several events this year to raise awareness of myeloma within the medical community, as well as to recognize the amazing work being done for those affected by the disease.

2018 Family Medicine Forum

Early diagnosis is a priority for the myeloma community. Healthcare professionals need to be aware of the early signs and symptoms of myeloma so patients can be referred to specialists, such as hematologists, for a more in-depth assessment as quickly as possible. Early detection is crucial, as it could significantly impact quality of life and prognosis. A group of patient volunteers from the Greater Toronto Area worked with Martine Elias to share information about myeloma screening with thousands of general practitioners who attended the College of Physicians of Canada's Family Medicine Forum in Toronto.



Ev McDowell, and David and Erika McMullen.

Oncology Drug Navigators of Ontario (ODANO)



Alan Birch, nurse navigator at North York General Hospital and ODANO conference organizer, with Martine Elias.

Nurses play an essential role in the lives of patients. In recognition of the incredible work done by these devoted professionals, and to thank them for all that they do on a daily basis for our patients, Martine Elias had the honour of delivering the opening remark at the annual *Oncology Drug Navigators of Ontario* (ODANO) conference in Toronto.

Did you know?

Throughout the year, Myeloma Canada sends out surveys to learn more about the community's concerns. This year, researchers from the University of New Brunswick and Queen's University in Belfast (Northern Ireland) developed a short survey to identify the issues surrounding the diagnosis of multiple myeloma in Canada and create tools that can improve the diagnostic process for Canadian patients.

Awareness

30th Annual CANO/ACIO Conference

At the end of October, the annual Canadian Association of Nurses in Oncology (CANO) conference was held in Charlottetown, Prince Edward Island. Myeloma Canada was there to promote the various programs we offer to patients and their caregivers.

> "Attending the CANO reminded me of all the work done every day by oncology nurses for patients. I had the privilege to meet Nanette Cox-Kennett from Edmonton. A few years ago, Nanette was the first recipient of the Marion State Memorial Myeloma Canada Nursing Award."
>
> — Martine Elias



Time and time again, our incredible community has rallied together to drive initiatives that are not only highly valued, but of extreme importance. We extend a special thank you to:

- **Rolland Manning** and the Thunder Bay Myeloma Advocacy Group for being creative and putting myeloma on the map by facilitating a booth at the Health and Wellness Expo in Thunder Bay, Ontario.
- **The BC, Okanagan & Thompson region** support groups held a two-day information session in Kelowna, British-Columbia.

MYELOMA HEADLINES



The Myeloma Canada newsletter, Myeloma Matters, is sent out electronically each month to our community members. It includes the latest news on research, access to treatments, clinical trials, patient advocacy, Myeloma Canada, our community, activities and events.

In 2018, the Myeloma Canada newsletter not only allowed us to share good news, but also to engage with the community. Every month, nearly **18,000** people read our newsletter from coast-to-coast. **This proves that the bonds that unite us are real and that our community's enthusiasm drives general interest. In 2018, the "Spotlight" section, highlighting stories and experiences of the members of our community, was once again the most popular headline.**

We are always looking for patients, caregivers and healthcare professionals who are willing to share their stories and experiences. For more information, email us at **contact@myeloma.ca**.

MEDIA

In 2018, we had significant media coverage. Whether it was to raise awareness about the disease, to answer questions about the drug approval process within our healthcare system, or to profile the Multiple Myeloma March, Myeloma Canada was everywhere!

Our 2018 media exposure included:

- Video broadcast by Sonia Furstenau, MP for Cowichan Valley, British Columbia, who spoke at the Legislative Assembly to share her experience with myeloma and the important work being done by Myeloma Canada to improve access to treatment and to raise awareness for the disease;
- The publication of an article in The Globe and Mail on new treatments that increase survival rates for myeloma patients; and
- Headlines in Quebec and Ontario on The Governor General's Meritorious Service Medal being awarded to Aldo Del Col.





Follow us on social media!

Access & Advocacy

ADVOCATE for access to the best treatments and support services for myeloma patients.

TREATMENT ACCESS

Throughout 2018, several important discussions took place regarding access to myeloma treatments for Canadians. Myeloma Canada's involvement in these discussions was crucial for our community. Having a seat at the table and the opportunity to influence decision makers on major patient issues is essential. Our efforts have led to many meetings and collaborations with those involved in oncology treatment access.

Drug Pricing:

A consultation on the proposed Patented Medicine Prices Review Board (PMPRB)[1] regulation amendments was held in 2018. Our Executive Director, Martine Elias and Louise Binder, Policy Advisor at the Save Your Skin Foundation, co-signed the response to the proposed amendments which was endorsed by **17 patient organizations**. Patient organizations provided **8 tangible solutions**, including performance-based compensation measures, risk-sharing agreements and treatment compliance programs.

National Drug Insurance Plan:

The House of Commons Standing Committee on Healthcare recommended that Canada develop a National Pharmacare Plan to expand the current drug coverage under public and private plans, and to include drugs prescribed outside of hospitals. Martine Elias, along with political leaders from various patient support groups across Canada, and the Advisory Council on the Implementation of National Pharmacare, took part in the initial consultation, held in Toronto in July. Many myeloma patients were invited to participate in other Canadian cities. The discussions have begun, and everything suggests that it will be a constructive process.

Myeloma Advocacy Program (MAP)



There are many issues surrounding myeloma and it is important that our community be heard. We must educate decision makers on challenges faced by patients and caregivers. To do so, Myeloma Canada has developed an interactive platform, the Myeloma Advocacy Program (MAP), which allows our community members to get involved and raise awareness for our cause. Whether it is to ask for a more streamlined drug access process, or to make requests in the context of provincial or federal elections, MAP's automated system makes it easy to send out personalized letters to the appropriate MPs.

In 2018, thanks to MAP, patients from Ontario and Quebec were able to unite their voices by fueling the debate on the challenges faced by our community. Regardless of the role these MPs play in governments, they need to be made aware of our concerns.

Over 1,000 Letters Sent

The campaigns for access to Kyprolis and Darzalex were a huge success! 2018 saw the approval of Kyrpolis in almost every province of the country, as well as Darzalex in Quebec and Alberta.

We thank everyone who helped make these campaigns happen.

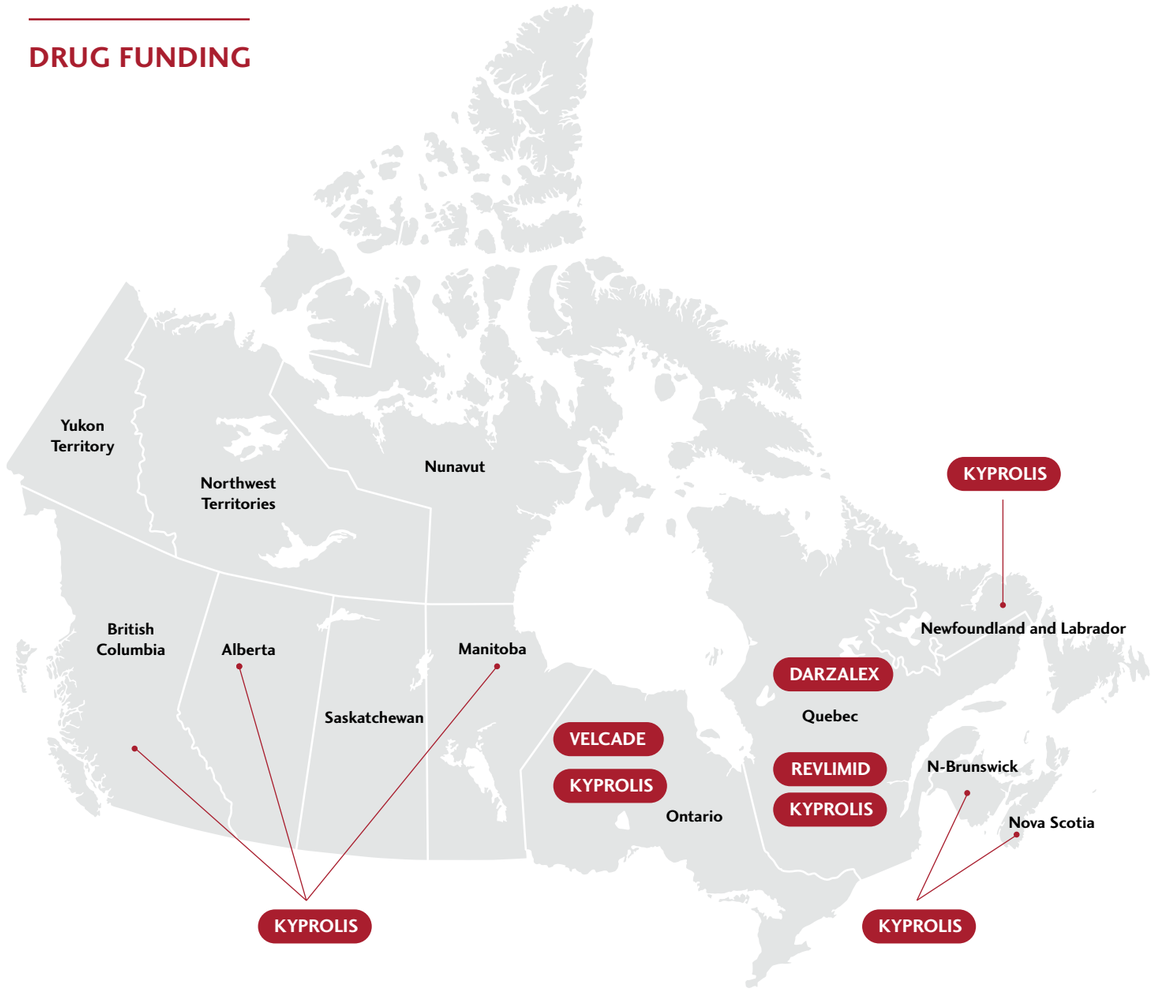
[1] *The PMPRB's role is to protect and inform Canadians by ensuring that the prices of patented medicines sold in Canada are not excessive and by reporting on pharmaceutical trends.*

Patient and Caregiver Surveys

Governments make decisions about myeloma drugs and it is important that the views of those affected by the disease are heard. Their contributions are extremely important and, while there is no guarantee, could help improve access to new myeloma drugs and combined treatments for Canadian patients.

In 2018, Myeloma Canada developed **5 drug-based surveys** for patients and caregivers. Of the 5 surveys, 3 were submitted to the **pan-Canadian Oncology Drug Review (pCODR)** and **2** to the **National Institute of Excellence in Health and Social Services (INESSS)**[2].

DRUG FUNDING



[2] *The pCPA is the national body responsible for provincial funding recommendations of oncology drugs approved by Health Canada. INESSS shares the same responsibility in Quebec.*

Access & Advocacy

DARZALEX (daratumumab)

In April 2018, Darzalex was in the final stages of review and approval before becoming accessible and covered through public drug plans. During this stage, drug price was negotiated between the pan-Canadian Pharmaceutical Alliance (pCPA) and the drug manufacturer.

The negotiations led by the pCPA and the drug manufacturer (Janssen) ended on **December 11, 2018**. It is now up to the provinces and cancer agencies to define the drug listing agreement, which would cover treatment costs for patients who need it.

Quebec was the first province to reimburse Darzalex in December of 2018.

KYPROLIS (carfilzomib)

In 2018, **8** provinces approved the use of Kyprolis in combination with Revlimid (lenalidomide) and dexamethasone or with dexamethasone alone for myeloma patients who received one or more previous treatments.

- Manitoba: March
- British Columbia: April
- Ontario: April
- Quebec: July
- Newfoundland and Labrador: July
- Alberta: October
- New Brunswick: December
- Nova Scotia: December

We hope that Prince Edward Island will follow suit in 2019 so that Kyprolis will officially be accessible countrywide!

REVLIMID (lenalidomide)

Quebec :

In June, Revlimid was added to the list of approved drugs in Quebec for first-line treatment of myeloma patients not eligible for transplant.

VELCADE (bortezomib)

Ontario :

Since June 1, 2018, Velcade (bortezomib), is now approved and covered in Ontario for the re-treatment of relapsed/refractory myeloma, with or without dexamethasone.This excellent news is the direct result of the hard work and perseverance of the Ontario Patient Advocacy Committee. **Members of this volunteer committee include Nina Rapoport, Norma Linder, Ev McDowell, Leslie Weatherby, Robin Sully, David McMullen, Sofia Tavoularis, Jan Wleugel, Steve Homewood, Bob McCaw, Cindy Leder, and Julie Gibbons.** The committee is led by Martine Elias.

For more information on new myeloma treatments available in Canada, visit the “Drug Approval Process” section of our website at **myeloma.ca**.

HELP ADVANCE Canadian myeloma research by making a donation today.

By making a donation to Myeloma Canada, you are helping advance clinical trial research and supporting accelerated access to better care.

Visit myeloma.ca to make your donation.

PARTNERSHIPS

Myeloma Canada partners with other patient organizations to contribute toward helping to improve the healthcare system and provide patients with an environment that better responds to their needs. Myeloma patients face many challenges; whether it be discussions about the national drug plan, the evaluation of healthcare technologies or drug pricing, patients and their loved ones must be heard.

Collective Oncology Network for Exchange, Cancer Care Innovation, Treatment Access and Education (CONECTed)

CONECTed RCONECTé

In 2018, Martine Elias was named president of the CONECTed group. Since 2015, CONECTed has been acting as a coalition for patient advocacy by raising awareness of the needs of cancer patients. Over the years, the group has been working on issues related to the healthcare system, government, immuno-oncology technology and other therapies. This collaboration led the way for 2 major achievements in 2018:

Whitepaper

13 patient organizations, including Myeloma Canada, have signed and endorsed a whitepaper entitled "Improving Access to Innovative Therapies in Canada". The paper addresses the gaps within the healthcare system that jeopardize access to innovative anti-cancer drugs and explains why it is crucial to introduce new means of accelerating access to promising new cancer treatments.

Recommendations on Proposed Amendments to the Patented Medicines Regulations

Myeloma Canada, Save Your Skin Foundation, and 28 Canadian patient associations came together to ask the Health Ministry and Health Canada to suspend the drug pricing review. The currently proposed drug pricing reforms under the Patented Medicine Prices Review Board (PMPRB) could be detrimental to patients requiring innovative therapies. Additionally, the reform may have a serious negative impact on investments that facilitate access to clinical trials. 8 tangible solutions have been proposed, including performance-based compensation measures, risk-sharing agreements or treatment compliance loyalty programs. Health Canada and the pharmaceutical industry need to work together and explore new solutions without compromising drug accessibility or safe-use.

Myeloma Canada is very much involved with:

La Coalition CanCertitude

The CanCertainty Coalition is the united voice behind 35 Canadian patient groups, including Myeloma Canada. Working with oncologists and healthcare professionals, the coalition aims to improve the accessibility and affordability of take-home cancer treatments in Ontario and Atlantic Canada.

The Global Myeloma Action Network (GMAN)

Myeloma Canada is one of the founding members of the GMAN. The GMAN brings together international advocacy leaders for patient rights in order to mobilize the myeloma community and improve the lives of patients worldwide.

Community Empowerment

BUILD a patient-driven, grassroots myeloma community and facilitate an integrated network of myeloma stakeholders.

SUPPORT GROUPS

Myeloma Canada works with a network of support groups in each province. Some meet in person while others meet online, or by teleconference. These groups may offer emotional support, help in coping with the diagnosis as well as share important information about disease management and available resources. They also provide an opportunity to meet with other patients, caregivers or close relatives.

In 2018, **7 new support groups** were created:

- **Quebec City, Quebec**
- **Kitchener-Waterloo, Ontario**
- **North Bay, Ontario**
- **Prince George, British Columbia**
- **Vancouver, British Columbia**
- **Surrey, British Columbia**
- **Winnipeg, Manitoba**

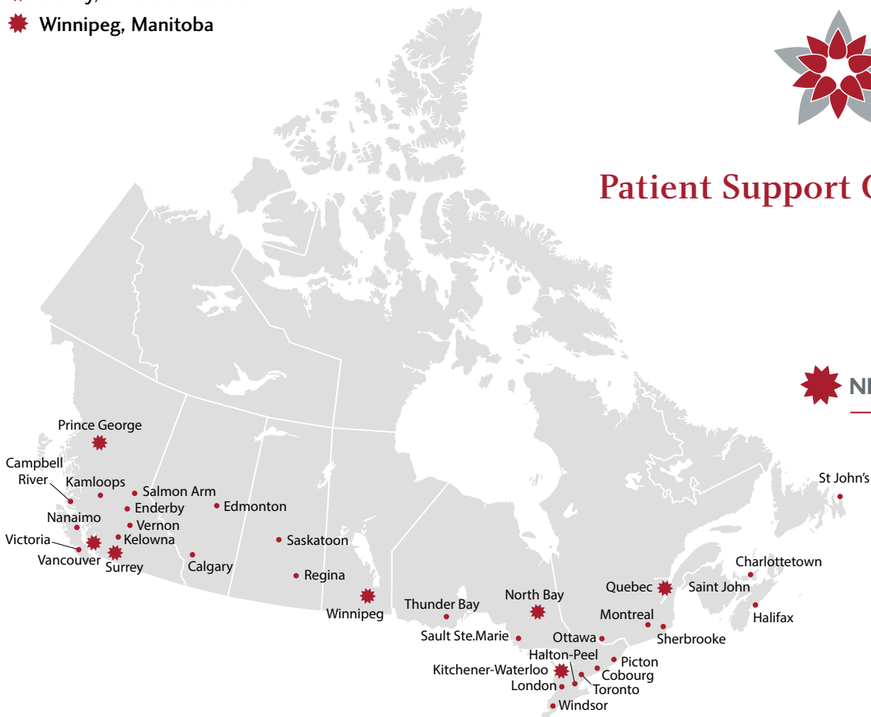
To meet the needs of our community, Myeloma Canada has also created **3 virtual support groups**.

- **Virtual support group for young patients and caregivers**
- **Virtual support group for caregivers**
- **Virtual support group for patients and caregivers of all ages**

These private groups provide a safe environment to connect and interact with others who face similar challenges. The virtual support groups - accessible only through Facebook - help eliminate geographic and language barriers, thanks to Facebook's auto-translate feature. These are closed groups, meaning that any information exchanged is kept private to the group and is not available to the general public; all group members must register to have access to shared content.

MYELOMA CANADA
MAKING MYELOMA MATTER

Patient Support Group Network



MYELOMA CANADA SUPPORT GROUP LEADER'S SUMMIT



During the weekend of November 2 to 4, 2018, a record number of group leaders from across the country attended the Myeloma Canada Support Group Leader's Summit. This annual networking event is an opportunity for participants to exchange knowledge and gain access to effective tools to share with their respective support groups. Their work is crucial and Myeloma Canada is committed to motivating our leaders with an inspirational event every year.



Vénus Bélanger, Hervé Benoît, Julie Martel, Danny Wade and Lorelei Dalrymple.

Community Empowerment

OUR LEADERS

British-Columbia		
Linda Latham	Campbell River	North Island Multiple Myeloma Support Group
Allison Jennings	Nanaimo	Nanaimo Multiple Myeloma Support Group
Warren Welling	Victoria	Vancouver Island Multiple Myeloma Support Group
Susan Schmaltz and Ron Surry	Kelowna	Myeloma Support Group for the BC Southern Interior – Kelowna Chapter
Bob Trudeau and Bob Hamaguchi	Kamloops	Kamloops Multiple Myeloma Support Group
Ron Surry	Enderby	Myeloma Support Group for the BC Southern Interior – Enderby Chapter
Marlene Godfrey	Vernon	Myeloma Support Group for the BC Southern Interior – Vernon Chapter
Linda Quintal	Salmon Arm	Myeloma Support Group for the BC Southern Interior – Salmon Arm Chapter
Eva Patten and Cyndi Logan	Prince George	Northern BC Multiple Myeloma Support Group
Linda Loverock and Kerry McKeen	Vancouver	Vancouver Myeloma Network
Kundan Uppal-Dubinsky and Sherrie Stockley	Surrey	Surrey & District Multiple Myeloma Support Group
Manitoba		
Jackey Labossière	Winnipeg	Winnipeg Myeloma Support Group
Alberta		
Michelle Zydgalo	Calgary	Southern Alberta Myeloma Patient Society (SAMPS)
Bob Thiessen	Edmonton	Myeloma Alberta Support Society (MASS)
Saskatchewan		
Judi Worth and Marie Prokopiw	Saskatoon	Saskatoon Multiple Myeloma Support Group
Mona Neher and Sharon McIntosh	Regina	Saskatchewan Multiple Myeloma Support Group, Regina
Ontario		
JoAnn Cartlidge	Windsor	Windsor & District Multiple Myeloma Support Group
Marion Bentley and Maggie Ralph	Sault Ste. Marie	Multiple Myeloma Sault Ste. Marie Support Group
Ev McDowell and Jeff Parton	London	London and District Myeloma Support Group
Norma Linder and Juliette Royer	Halton-Peel	Halton-Peel Myeloma Support Group
David McMullen and Donald Hunter	Toronto	Toronto & District Multiple Myeloma Support Group
Leslie Weatherby and Brian Stockdale	Cobourg	Northumberland and District Multiple Myeloma Support Group
Iris Phillips	Picton	Picton Support Group
Robin Sully and Jean Shepherd	Ottawa	The Ottawa-Gatineau Multiple Myeloma Community Network
Susan McDowell and Juliette Royer	Kitchener-Waterloo	The Waterloo Region Myeloma Support Group
Denyse DeBernardi	North Bay	Nipissing Multiple Myeloma Support Group
Quebec		
Hervé Benoît and Danny Wade	Montreal	Montreal Myeloma Support Network
Vénus Bélanger	Sherbrooke	Espoir Myélome Estrie Support Group
Manon Veilleux and Julie Martel	Ville de Quebec	Myeloma Quebec Support Group
New Brunswick		
Susan Collins	Saint John	Saint John Area Multiple Myeloma Support Group
Nova Scotia		
Julie Salsman and Trish MacDonald	Halifax	Nova Scotia Support Group
Prince Edward Island		
Fran Feher	Charlottetown	Charlottetown Myeloma Support Group
Newfoundland and Labrador		
David McConkey and Stephen Norman	St John's	Myeloma NL

COMMUNITY EVENTS

In 2018, the Canadian myeloma community was engaged more than ever in supporting our cause. Communities from across the country came together with a renewed commitment. Because of their support, and the support of **thousands of volunteers, nearly $705,000** was raised through community events!

Thanks to the **19 events** and **24 Multiple Myeloma Marches**, we have once again made it possible to fund educational, awareness, and patient advocacy programs, and have contributed to the advancement of myeloma research in Canada.











For a list of all community events and activities that took place in 2018, please see the "Spotlight on the Community" section on page 17.

Community Empowerment

PATIENT ADVISORY COUNCIL (PAC)

Since 2014, the primary mandate of the Patient Advisory Council (PAC) has been to share the patients' perspective at both, the regional and national levels, and to guide the Myeloma Canada Board of Directors in making decisions about important issues faced by patients, caregivers and support groups.

The PAC helps to plan several Myeloma Canada events, such as the National Conference, the Myeloma Canada Scientific Roundtable, our Support Group Leader's Summit, Patient Advocacy Summit, and Awareness Days.

In addition, the PAC contributes to the creation of informative tools and educational resources for our community.



2018 PAC members:

LORELEI DALRYMPLE
President, Alberta

JULIE SALSMAN
Vice President, Nova Scotia

DAVID MCCONKEY
Representative for Atlantic Region

KEITH TAYLOR
Representative for Western Canada

HERVÉ BENOIT
Representative for Quebec

JULIE GIBBONS
Representative for Ontario

A word from the PAC President



LORELEI DALRYMPLE
President

Greetings and best wishes for 2019 from the Patient Advisory Council!

2018 was a very busy year for us. Over the past year, in addition to our roles of ensuring the specific concerns, needs, and/or suggestions from all regions of Canada were heard and appropriate action was taken, we have been involved in a tremendous number of activities, such as:

- Myeloma Canada strategic planning for 2019, 2020 & 2021
- Myeloma Canada committees for Early Detection, the Support Group Leader Summit and National Advocacy
- International Myeloma Foundation (IMF) Support Group Leader Summit
- Several, "Town Hall" meetings regarding National Pharmacare
- Myeloma Canada's Scientific Roundtable and the National Conference
- Various InfoSessions and Meet & Greets
- Review of various publication materials
- Testing for a prototype of the "Myeloma Manager"
- Discussions towards drafting a framework for Patient Engagement in Research with the Myeloma Canada Research Network (MCRN)
- Partners in Research course

Also, in November 2018, Julie Gibbons, our regional representative from Ontario, retired from her position. We would like to thank Julie for all of her amazing contributions during her term with the PAC. Her departure has created an opening in the PAC, and with the Board's endorsement, we sent out a call for interest to fill the Ontario position. Due to the increasing number of support groups in Ontario and British Columbia, the Board approved increasing the number of representatives for Ontario and the Western Canada regions to 2 each; these additional positions were also included in the call for interest. The process to fill these positions was initiated in 2018, and we would like to thank the many wonderful people who responded.

We look forward to continuing to serve the Canadian myeloma community in 2019 and welcome any and all feedback. Please feel free to contact any PAC member by email. Please visit **myeloma.ca**, "About Myeloma Canada", click on "Who We Are" and select "Myeloma Canada Patient Advisory Council" for a list of our email addresses.



Research

FOSTER, SUPPORT and FUND myeloma-related research that leads to better patient outcomes.

2018 was a defining year for the myeloma community – especially in terms of research. Since myeloma patients are now living longer, new drugs are required to fight drug resistance.

Among the most significant progress made is a gene therapy known as Chimeric Antigen Receptor (CAR) T-cell therapy (commonly known as CAR-T). This is promising for myeloma patients who no longer respond to multiple prior treatments. Several clinical trials are underway in various countries, including Canada. The Canadian Agency for Drugs and Technologies in Health (CADTH) has provided details on how its CAR-T review was conducted and Myeloma Canada commented on the suggested process.

CLINICAL TRIALS

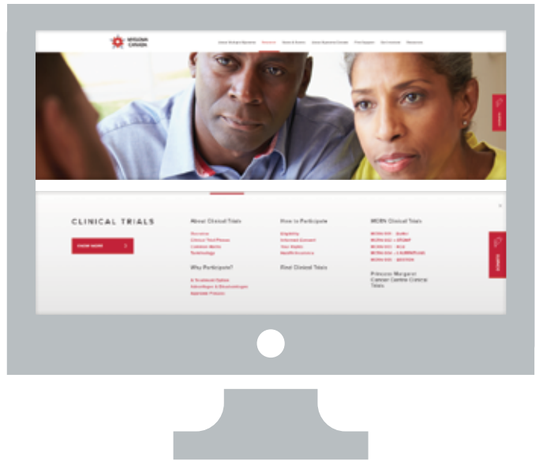
To increase public awareness, and to celebrate International Clinical Trials Day in May 2018, Myeloma Canada launched our Clinical Trial Module along with a series of educational videos, a new InfoGuide, and a Personal Clinical Trial Finder search tool. The information available on our website under "Clinical Trials" was also updated.

Clinical trials are an essential part of innovation and allow researchers to collect information about the dosing, efficacy and safety of a drug. Clinical trials are designed for each phase of the disease and provide access to drugs or treatment combinations that are not otherwise available to patients, or not covered by provincial drug plans.



Did you know?

On April 27, 2018, Myeloma Canada took part in the first-ever Consortium for the development of myeloma treatment standards. This meeting was held by the Myeloma Canada Research Network (MCRN) and was a significant milestone achieved for standardizing the diagnosis and treatment of myeloma in Canada. Researchers and hematologists across the country came together to develop and publish the first guidelines for diagnosing myeloma in Canada.



MYELOMA CANADA RESEARCH NETWORK
MAKING MYELOMA MATTER

In Canada, researchers figure prominently in the development of innovative and very promising clinical trials. In 2018, Myeloma Canada proudly supported the Myeloma Canada Research Network (MCRN) in the amount of **$480 000**. The MRCN is the first and only national organization bringing together Canada's leading cancer institutions and researchers to collaborate on advancing myeloma research. The MCRN platform facilitates advancement of research in myeloma by providing infrastructure and expertise in three core areas:

1. **Clinical trial development and management**
2. **Real-world evidence generation and research through the MCRN National Myeloma Database**
3. **Support of basic and translational research through its national Myeloma Bio Bank initiative**

MCRN also develops national treatment and consensus guidelines to improve patient care and outcomes.

Incorporating patient input in research design is a priority for MCRN and Myeloma Canada supports MCRN's patient-centric approach to research.

This past year the MCRN conducted several clinical trials that benefitted patients across the country.

The LAURENTIANS Trial MCRN 004

RRMC 004 › The LAURENTIANS Trial

Led by Dr Michael Sebag at the McGill University Health Centre in Montreal, this open-label trial includes 120 patients across Canada, divided into 2 study groups. One group will receive Darzalex (daratumumab), Cytoxan (cyclophosphamide), dexamethasone and Pomalyst (pomalidomide) while the other group will receive the same treatment regimen, except for Pomalyst which will be added only when the patient's disease progresses.

RRMC 005 › The BOSTON Trial

The BOSTON Trial - MCRN005

Karyopharm Therapeutics, manufacturers of selinexor, an oral Selective Inhibitor of Nuclear Export (SINE ™) compound, reached out to Canada to conduct a phase III global randomized clinical trial (NCT03110562) to assess the efficacy and safety of selinexor (KPT-330). Dr Nizar Bahlis of the Arnie Charbonneau Cancer Institute affiliated to the University of Calgary in Alberta, is the lead researcher. This trial will compare the combination of selinexor, bortezomib (Velcade) and dexamethasone (SVd) to the combination of bortezomib and dexamethasone (Vd) in patients with relapsed or refractory myeloma who have had 1-3 prior treatments.

RRMC 007 › BCMA

The *Multi-centre study of GSK2857916 in combination with pomalidomide and dexamethasone* includes a monoclonal antibody combined with a drug designed to act directly on myeloma cells (BCMA) and is administered intravenously in combination with 2 orally administered drugs. It began its recruitment process in 2018. Dr Suzanne Trudel from the Princess Margaret Cancer Centre is leading the study.

Did you know?

Karyopharm Therapeutics, the maker of selinexor, invited Aldo Del Col, our Co-founder, to speak to their employees and share his journey and experience with myeloma. In his speech, Aldo presented a strong case for how new drugs allow myeloma patients to live longer and more productive lives, and how innovative approaches are crucial when facing relapses caused by myeloma cells no longer responding to treatment.

Other Promising Clinical Trials

Stem cell transplant using cord blood (Montreal)



Dr Jean Roy, from the Maisonneuve-Rosemont Hospital, and Dr Guy Sauvageau's team from the Université de Montréal, currently oversee the *ECT-001 (UM171) Expanded Cord Blood Transplant to Treat High-Risk Multiple Myeloma*. The newly discovered molecule can increase, by 30 to 50 times, the number of stem cells contained in cord blood through an in vitro process. This is a major scientific breakthrough for stem cell transplants using donor cells (allogeneic transplant). Ten patients are currently participating in this study across the province of Quebec. The expertise of the researchers at the Maisonneuve-Rosemont Hospital - an important partner in the creation of the Myeloma Canada Chair on Multiple Myeloma Research at the Université de Montréal - is once again being showcased worldwide.

- To try Myeloma Canada's Personal Clinical Trial Finder search tool, visit **myeloma.ca/findtrials**
- To view educational videos on clinical trials, visit our YouTube channel (**Myeloma Canada**)

MYELOMA CANADA SCIENTIFIC ROUNDTABLE

The country's leading hematologists, myeloma researchers, and many international experts met in Montreal on September 28-29, 2018 for the 9th Myeloma Canada Scientific Roundtable. This go-to scientific event covered a large selection of topics, including the latest innovations in CAR-T cell therapy research, monoclonal antibody vaccines, clinical trial results, optimal doses for medicinal cannabis, as well as information on the latest developments for new therapies for myeloma patients. Once again, the event was a huge success. Thank you to all of our valued stakeholders for their participation.







Dr. Angela Dispenzieri

IMPORTANT ANNUAL MEETINGS

2018 Annual Meeting of the American Society of Hematology (ASH)



Aldo Del Col, Co-founder of Myeloma Canada, Greg Friberg MD, Vice President and Therapeutic Area Head, Hematology / Oncology Global Development, Amgen and Martine Elias, Executive Director of Myeloma Canada.

More than 25,000 hematologists attended the annual ASH meeting December 1-4, 2018 in San Diego, California. Myeloma Canada attended and profited from the more than 5,000 scientific abstracts presented, many of which were from Canadian experts. Presentations on the latest progress in myeloma research included:

- **The MAIA Trial:** The combination of Darzalex (daratumumab), Revlimid (lenalidomide) and dexamethasone (DRd) compared to Revlimid and dexamethasone (Rd) in newly diagnosed myeloma patients not eligible for a transplant;
- **Bi-specific T-cell engagers (BiTE):** A phase I study on increasing the dose of AMG 420 in patients with recurrent or refractory myeloma;
- **The GRIFFIN Trial:** The combination of Darzalex (daratumumab), Velcade (bortezomib), Revlimid (lenalidomide) and dexamethasone (DVRd) compared to Velcade, Revlimid and dexamethasone (VRd) in newly diagnosed patients eligible for an autologous stem cell transplant;
- Ongoing research on Chimeric Antigen Receptor T cells (CAR-T) transfer treatments;
- **The FORTE trial:** Induction therapy using Kyprolis (carfilzomib), Revlimid (lenalidomide) and dexamethasone (KRd) followed by an autologous stem cell transplant (ASCT) and KRd consolidation KRd (KRd-ASCT-KRd group) compared to 12 cycles of KRd (KRd12) or a Kyprolis, cyclophosphamide and dexamethasone (KCd) induction therapy followed by a ASCT and KCd consolidation (KRC-ASCT-KCd group) in newly diagnosed patients;
- **The STORM Trial:** Strong long-lasting responses to oral treatment with selinexor and low-dose dexamethasone in patients with penta-refractory myeloma.

The European Hematology Association (EHA) Conference

Attended by nearly 10,000 international hematologists, the 23rd Annual European Hematology Congress was held in Stockholm from June 14 to 17. Focusing on cutting-edge clinical practice, the Congress provided participants with a unique opportunity to update their knowledge and learn about the latest developments in hematology research. Dr Donna Reece of Toronto's Princess Margaret Hospital (PMH) and Chief Medical Officer for the Myeloma Canada Research Network, was interviewed on the use of CAR-T cell therapy in patients with recurrent or refractory multiple myeloma.

The International Myeloma Working Group (IMWG) Congress

The IMWG is made up of nearly 200 myeloma researchers from around the world, including Canadians Dr Suzanne Trudel (Toronto), Dr Chaim Shustik (Montreal), and Dr Nizar Bahlis (Calgary). The IMWG work on a wide range of research projects focused on clinical trials that address the needs of patients and the physicians who treat them, with the objective of long-term remission and improved quality of life for patients.

The 9th IMWG Congress was held June 11-13 in Stockholm, Sweden. Amongst topics covered were value-based pricing as a means for drug access, use of minimal residual disease (MRD) as a clinical decision-making tool, as well as CAR-T cell immunotherapy and BCMA clinical trial data and results.



Global Myeloma Action Network Summit

In 2013, the International Myeloma Foundation led the creation of the Global Myeloma Alliance, which then became the Global Myeloma Action Network (GMAN) in 2014. The goal of this network is to unite myeloma patient organizations from various countries in Europe, the Americas and Asia Pacific, and to combine advocacy efforts for the benefit of myeloma patients around the world. GMAN's goal is to bring these groups together to share best practices, explore common concerns, and increase public awareness for multiple myeloma.

As part of the 2018 Summit, Martine Elias, our Executive Director, was invited to present the content and benefits of a new concept: a training program on advocacy that would allow patient groups to acquire specific skills in this area.

Also at the Summit, Myeloma Canada was awarded the Susie Durie Novis Educational Grant Award for our Myeloma Advocacy Program (MAP). MAP represents a unique way of communicating and empowering the community to advocate and voice their concerns on important topics such as drug access. The award was created to assist member organizations of the International Myeloma Foundation's Global Myeloma Action Network to raise awareness and promote education and treatment access.

Research

AWARDS AND DISTINCTIONS

The Canadian Cancer Trials Group (CCTG) Recognition Award for Significant Contributions

On April 28, 2018, during its annual meeting, the Canadian Cancer Trials Group (CCTG) awarded our Co-founder, Aldo Del Col, the Recognition Award for his significant contributions and ongoing work to ensure that myeloma patients are heard and are able to participate in clinical trials and decision-making as it relates to their treatment.

Marion State Memorial Myeloma Canada Nursing Award

On December 8, 2018 Myeloma Canada was in Toronto to honour the work of Ellen Church, a clinical nurse specializing in myeloma at the Princess Margaret Cancer Center. Ellen was presented with the Marion State Memorial Myeloma Canada Nursing Award. This award recognizes Canadian nurses who demonstrate excellence in nursing through their leadership, teamwork, passion and commitment to myeloma patient care.



How You Can HELP?

DONATE

You can make your donation online at **www.myeloma.ca**, over the phone by calling toll-free at **1-888-798-5771**, or by mailing a **cheque** payable to Myeloma Canada to:

Myeloma Canada
1255 TransCanada Highway, Suite 160
Dorval, QC H9P 2V4

FUNDRAISE

There are other ways you can support Myeloma Canada, such as taking part in the annual Multiple Myeloma March held in cities across Canada, or by fundraising for Myeloma Canada in your local community. When so much about myeloma is beyond the control of the people that it affects and those who care for them, fundraising can be a rewarding and fun way of doing something positive for yourself and for others affected by myeloma.

Contact the fundraising team toll-free at **1-888-798-5771** for more information, or visit **www.myeloma.ca**.

Myeloma Canada

Spotlight on Our Community

Over the years, the notion of community and the principle of community involvement have become embedded in our organizational culture and they are an integral part of Myeloma Canada's DNA. Our community is what keeps us alive. Thanks to our community members, we have grown and are now recognized as a reference point for patient organizations around the world. We are grateful for everything they do, for their time, their energy, their ideas, and of course, for their drive to make a difference. Together, we have climbed many mountains and our role has always been to keep pace with our community and to evolve together.

In the pages that follow, we wish to highlight their remarkable and priceless contributions. Mostly, we wish to share how proud we are to have them by our side.



10 years
MULTIPLE MYELOMA MARCH



Multiple Myeloma March

10 YEARS ALREADY

The Multiple Myeloma March began 10 years ago. Maryse Bouchard, a myeloma patient, and her friend, Sylvie-Chantale Duquette, convinced our Co-founder, Aldo Del Col, to join them in their adventure. Despite a short planning window, over 100 people took part in the March and over $30,000 was raised. Today, the March is a major annual event, with thousands of volunteers, partners, and participants. It has helped us reach an unprecedented level of awareness and build relationships from coast-to-coast.

The 2018 Multiple Myeloma March:

- **23** communities
- **1** virtual March
- **$585,000**
- **3,500** participants
- **200** teams
- **5,662** donations
- **+ 129 :** radio, TV, print or online media hits across the country

The Multiple Myeloma March has 35 leaders. These individuals are key to our success!

Marches	Leaders
PRINCE GEORGE, BC	Cyndi Logan
VANCOUVER ISLAND, BC	Allison Jennings and Susan McLean
MELVILLE, SK	Lynn Hoffman
SAULT SAINTE MARIE, ON	Pamela Orchard and Judy Mills
KITCHENER-WATERLOO, ON	Carlee England
KAMLOOPS, BC	Bob Trudeau, Bob Hamaguchi, and Anna Evenrude
ST JOHN'S, NL	David McConkey and Stephen Norman
AIRDRIE, AB	Pamela Roberts
KELOWNA, BC	Ron Surry and Susan Schmalz
WINNIPEG, MB	Kim Krahn
HAMILTON, ON	Laura Briard and Nancy Gray
QUEBEC CITY, QC	Ann Lanouette
ENDERBY, BC	Ron Surry
THUNDER BAY, ON	Rolland Manning
OSHAWA, ON	Steve Beattie
MISSISSAUGA, ON	Norma Lindner, David McMullen and Anne Spencer
OTTAWA-GATINEAU, ON	Dave Rideout, Robin Sully, and Gilles Caron
SAINT JOHN, NB	Ken and Bernice Allaby
HALIFAX, NS	Michael Senz and Julie Salsman
MONTREAL, QC	Patricia Empsall
WINDSOR-ESSEX COUNTY, ON	Erma Roung and Crystal Harvey
SASKATOON, SK	Andrea Zwarich
VANCOUVER, BC	Michelle Oana

Thanks to the dedication and energy of all of our participants, volunteers and donors, we surpassed our goal for 2018! This success was a fantastic way to celebrate the 10th anniversary of our signature event that aims to increase awareness, raise funds for clinical research and to support patient advocacy.















Multiple Myeloma March
10 YEARS ALREADY

Did you know?

In 2018, we launched an innovative and user-friendly web platform for the Multiple Myeloma March along with a unique participant recognition campaign. The red Gerber Daisy, emblem of Myeloma Canada, was highlighted in the "Full Bloom" campaign. A symbol of our flourishing community, the Full Bloom campaign was created to thank 2018 Multiple Myeloma March participants for their support. This campaign presented a way for them to create their own Gerbera garden and to share their story on social media, using the hashtag **#MyMyelomaGarden**.



Jane Slowikowski and her very own Myeloma Garden.

TOP FUNDRAISERS

Myeloma Canada is thrilled to announce the top fundraisers for the 2018 Multiple Myeloma March:



$24,495

GREG ROBERTS RUNNERS
Airdrie, AB



$24,300

ROLLOVER MYELOMA
Vancouver, BC



$21,388

WALK ON WITH SHAWN
Kitchener-Waterloo, ON



$14,977

MYELOMA MATADORS (STEPS TO A CURE!)
Ottawa, ON



$11,235

LYNN'S TEAM
Windsor-Essex County, ON



$10,090

GILLES CARON
(STEPS TO A CURE!)
Ottawa, ON



$9,135

MICHELINE GARAND
Montreal, QC



$8,660

MYELOMANIACS
Saint John, NB



$8,641

TEAM BALBOA
Oshawa, ON



$8,530

LIFE IS GOOD
Windsor-Essex County, ON

SPOTLIGHT ON SHAWN PHILPOTT, MEMBER OF THE *WALK ON WITH SHAWN* TEAM

In 2017, Shawn was 56. His hips were bothering him. The pain intensified, spread to his back and revealed fractures and lesions in his vertebrae and ribs. After many tests, the diagnosis finally pointed to multiple myeloma. He had never heard about myeloma before. Immediately following diagnosis, he was admitted to the Princess Margaret Hospital (PMH) for a round of radiation. In September 2017, he started chemotherapy treatment at Humber River Hospital. It was then that he learnt about the Multiple Myeloma March in his girlfriend Barb's hometown of Kitchener-Waterloo. At the time, walking 5 km was not an option for him, but his wonderful future sisters-in-law stepped up and formed the "Walk on for Shawn" team. They, along with their husbands, became the top local fundraisers at this annual walk.





In October 2017, Shawn received a procedure called vertebroplasty, after which he was actually able bend over and touch his toes again. **"It was at this point in my treatment (pre-transplant) that Barb and I decided to get married and make it official, with our 5 wonderful children in tow, aged 14 to 21. At that point we had been together for 8 years."**

Multiple Myeloma March
10 YEARS ALREADY

On February 11, 2018, after 4 rounds of CyBorD, Shawn was ready for an autologous stem cell transplant. He then learned that he would be an outpatient for the transplant, and would have to make daily trips to the PMH—no matter how "crappy" he felt. **"The 14th floor nurses were wonderful. With a few minor bumps along the way, I was officially discharged from treatment on March 28. I rang the 'courage bell' that I had watched so many others before me ring. I remember the applause, smiles and a few tears by all in attendance."**

One year after the diagnosis, Shawn was determined to participate in the second annual Multiple Myeloma March in Kitchener-Waterloo with his family. Today, he is back at work full-time, returning to the activities he loves and learning to take it easy. It is a new normal. His monthly visits to the HRH are a part of it, but so are his projects. Shawn is now looking forward to taking that honeymoon with Barb and their 5 kids.



Spotlight on Our Community

COMMUNITY EVENTS

Community events are crucial for our organization, and our community was very active in 2018. A key contributor to our outreach and education initiatives was organizing some **20 events** across the country. Through these efforts, nearly **$187,000** was raised to help advance research and improve the quality of life of people affected by myeloma.

To all of our invaluable supporters who helped to make myeloma matter this year, we say "thank you".



$13,175

Allan Kovacik and his friends Rob Fleming, Toni Gendron and Mark Kotris of Calgary, Alberta for taking part in the *Cueballs for Cancer* challenge by shaving their heads and raising money to help advance myeloma research.



$21,738

Judy McHenry, her family and friends celebrated the life of Rick McHenry with a golf tournament organized in his memory at Saint-Raphael Golf Club in Montreal, Quebec.



$10,000

Dennis Rousseau and his devoted family surpassed, once again, their goal at the 5th Lynn Rousseau Memorial Golf Tournament in Windsor, Ontario.



$5,000

Trevor Olfer's for his 7th annual concert with the Open Sky Orchestra in support of Myeloma Canada and the Multiple Myeloma March in Winnipeg, Manitoba. We also wish to thank the 40 orchestra members for their valuable contributions, and Heidy Foot, a long-time volunteer. To date, nearly $50,000 has been raised through these concerts.



$4,400

Jennifer Radjenovich for organizing the 2nd annual *Mangia for Myeloma* event in honour of her father Guido Vettorello, a myeloma patient. All proceeds were donated to the Multiple Myeloma March in Windsor-Essex County, Ontario.

Spotlight on Our Community

Whether it be in honour or in memory of someone, or simply to support our cause, a community-created event is always a great idea. These events illustrate what our community is all about and mean so much to us.















Thank you to:

- **Linda Allard** who spent her lunch hours at Acier AGF in Longueuil, Quebec, wrapping Christmas presents for employees in exchange for donations to Myeloma Canada, and to the **AGF Foundation** who doubled the amount Linda rose.
- **Tom Alteen** for organizing the Drum Circle Fundraiser in St John's, Newfoundland, and to the 26 participants who took part in this initiative.
- Thank you to **Nathan Murdoch**, a young philanthropist, who, for his 12th birthday, asked for donations to Myeloma Canada in memory of his mother's close friend instead of gifts.
- The participants and the **McGregor Columbian Club** for their involvement in the Friday Fried Fish Evening in support of the Multiple Myeloma March in Windsor-Essex County, Ontario.
- **The Thunder Bay Myeloma Patient Advocacy Group** for organizing a silent auction and musical event, as well as a garage sale, for the Thunder Bay Multiple Myeloma March.
- **Noémi Labelle**, who took part in the Boston Marathon in honour of her mother, a myeloma patient, and for donating all funds raised to Myeloma Canada.
- **Carlee** and **Allie England**, Multiple Myeloma March leaders in Kitchener-Waterloo, Ontario, who organized a garage sale to launch their fundraising campaign.
- **Larry Borgerson**, the late leader of the Multiple Myeloma Support Group in Victoria, British Columbia, for his bold initiative with Thrifty Foods. Residents can now support Myeloma Canada while shopping at Thrifty Foods.

The community surrounding our offices in Dorval, Quebec, also supported us this year in our outreach and education initiatives. We are very appreciative of their support.



$48,500

Thank you to the Oana family for the 3rd Annual Sam's Monte Carlo Casino Night, in Saint-Marthe-de-Rigaud, Quebec, in honour of Richard Oana and in support of Myeloma Canada. We also wish to thank all the participants, sponsors, and volunteers who contributed to the success of this memorable evening.



$18,000

Thanks to the many participants, volunteers and sponsors of the inaugural edition of the Myeloma Canada Charity Golf Classic that took place at the Summerlea Golf Club in Montreal, Quebec.

COMMUNITY AWARDS

Recognizing the extraordinary leadership of the people around us is one of our fundamental commitments. Each year, we hand out awards to some of our community members across Canada who go above and beyond, highlighting their passion and support for our cause. Here are the 2018 award recipients:



Executive Director's Leadership Award:

TRISH MACDONALD

Martine Elias, Myeloma Canada's Executive Director, would like to acknowledge Trish's extraordinary work and **spirited engagement in advocating for access to new medications in her province, Nova Scotia**. We applaud her initiative in raising awareness about multiple myeloma in the community and with provincial government leaders, while encouraging others to do the same.

Spotlight on Our Community

Carolyn Henry Memorial TEAM Award:

RONALD SURRY, ROBERT HAMAGUCHI, WARREN WELLING, ALLISON JENNINGS, TINA & JIM ARGUE

The exceptional leadership and fervent engagement of this group in pioneering advocacy efforts in British Columbia have been exemplary over the last year. **They led a very successful Awareness Day at the BC Provincial Legislature, where 22 MLA's heard about the importance of listing new drugs on provincial formularies as quickly as possible**. As a result of the Awareness Day, MLA Sonia Furstenau, member for Cowichan Valley shared her own family experience with myeloma by making a statement at the BC Legislative Assembly (available on Myeloma Canada's YouTube channel).

*The Excellence in Advocacy Medal (TEAM) Award was created in 2009 to recognize outstanding achievements by patient advocates and their supporters who lead successful campaigns to fight for equitable access to myeloma treatments. In 2012, the award was renamed the **Carolyn Henry Memorial TEAM Award** in recognition of Carolyn's pioneering advocacy efforts.*





Community Achievement Award:

ALLAN KOVACIK

Congratulations to Allan on his achievement in raising **$13,175** through his fundraising campaign "Cueballs for Cancer". **Allan decided to shave his head bald with three close friends**. Feeling very fortunate for the care and treatment he received from the world-class team at the Tom Baker Cancer Centre, Allan wanted to raise funds for Myeloma Canada to further its research. We applaud his creative initiative in raising awareness in the community and funds for research and important patient programs.

Spotlight on Our Community



Notable Volunteer Award:

DAVID MCMULLEN

David's engagement is outstanding. In addition to his role as co-leader of the **Toronto & District Multiple Myeloma Support Group**, he is actively involved with both, the **Halton-Peel and London Support Groups**. In 2018, David was instrumental in planning and executing **3 Multiple Myeloma Marches in Ontario**: Mississauga, Hamilton and Oshawa. David also volunteered alongside Myeloma Canada at the **2018 Family Medicine Forum** as part of the Early Diagnosis Program, took part in the **Awareness Day at Queen's Park**, and added to the patient voice at this year's **Myeloma Canada Scientific Roundtable** as a patient representative. We applaud David's passionate commitment to our cause.



Nathalie Allard Memorial Award:

PAMELA ROBERTS

Congratulations to Pamela for her achievement in raising close to **$25,000** through her fundraising campaign for the **2018 Greg Roberts Memorial Walk/Run** (Airdrie Multiple Myeloma March). For the 2nd year, Pamela was the top fundraiser across the country.

The award is presented to Pamela in memory of **Nathalie Allard** who, for several years, dedicated her time to raising substantial funds for Myeloma Canada through her Montreal Multiple Myeloma March campaign. Through this award, we honour Nathalie's significant impact and those who follow in her footsteps.



Newcomer Award:

BERNICE AND KEN ALLABY

Bernice and Ken were quick to make myeloma matter in New Brunswick. **The first-ever Multiple Myeloma March in Saint John was a resounding success** and the results were beyond expectation. As a result of their hard work, the event raised **$13,719** for the cause, brought together close to 200 participants and was featured in the local media 8 times. As engaged leaders, they also managed to raise awareness beyond the myeloma community by including the fire department and a celebrity, emcee, and more.

Our Partners & Donors

We would like to take this opportunity to extend a heartfelt thank you to our many partners and donors for their generosity in 2018. We are extremely grateful for your commitment, your belief in our organization and the work we do. All of your donations go toward advancing our mission of improving the lives of Canadians impacted by myeloma through awareness-building, educational efforts, advocacy, support of clinical research, and fostering an empowered myeloma community.

In Numbers

$650,778
IN INDIVIDUAL AND PLANNED GIVING

$1,000 to $1,999

- André Desjardins
- Anita Woolridge
- Anthony Gaston
- Carole Duguay
- Colin Macpherson
- Craig Kirker
- David McMullen
- David Rideout
- Deanna Markle
- Denis Giasson
- Dennis Swanson
- Don Norman
- Donald Mulrain
- Donatella Guilbault
- Giancarlo Pellegrino
- Hans Wolf
- Herv Rector
- Jason Kaptyn
- Jean Shepherd
- Joe Zadzora
- Jordan Bonner
- Joseph Balinsky
- Kathleen Singer
- Kevin Tod
- Laura Briggs
- Louis Gagnon
- Lucas Erdman
- Mark Lachance
- Michael McGregor
- Michel Larouche
- Molly Demelo
- Peter Schlitt
- Philip Brown
- Robert Fitzpatrick
- Roberto Buffone
- Robin Sully
- Rosaire Gaudreault
- Ryan Wires
- Sally Kunz
- Sharon Briard
- Shawn Learn
- Solange Demers
- Susan Krahn
- Trevor Olfert

$2,000 or more

- Andy McJannett
- Anthony Gaston
- Ellis Basevitz
- Gavriel State
- Glen Kirkpatrick
- Isa King
- Jacqui Benton
- Kitty Cho
- Linda Torrance
- Margaret Stanfield
- Mingjie Xie
- Robbie Fleming
- Sharon Perkins
- Tanya Causgrove
- William Roberts

A total of $78,037
IN CORPORATE DONATIONS

$3,000 to $5,999

- Canderel Management Inc.
- Lariviere et Massicotte Pharmaciennes Inc.
- Leonard T Assaly Family Foundation
- Mercantile
- Potvin Allard CPA Inc.
- R.H.W. Property Group Inc.
- Vancouver Foundation

$6000 or more

- Devencore Ltd
- International Pipeline Conference Foundation

$19,837 received in unsolicited donations during the many events (silent auctions, draws, merchandise sales, 50/50 draws and food sales)

Legacy Giving

Bequests or planned giving is an important and easy way to ensure that your legacy and quest for improving the lives of patients and caregivers affected by myeloma will continue. With this in mind, we would like to pay special tribute to two individuals who generously included Myeloma Canada in their estate planning and wills.

- **LOUIS KING**
- **CHRISTINE MATTSON**

TO ALL OF YOU WHO HAVE CONTRIBUTED - IN ANY WAY - TO MYELOMA CANADA, WE THANK YOU FOR CHOOSING TO SUPPORT PATIENTS AND CAREGIVERS AFFECTED BY MYELOMA. WITHOUT YOUR CHARITABLE SUPPORT, WE WOULD NOT BE ABLE TO ACHIEVE OUR GOALS.

THANK YOU FOR HELPING US MAKE MYELOMA MATTER.

*Please feel free to contact us for information on how to include Myeloma Canada in your estate planning.

Join our COMMUNITY

myeloma.ca

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Toll free: 1-888-798-5771
Email: contact@myeloma.ca

MYELOMA CANADA
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