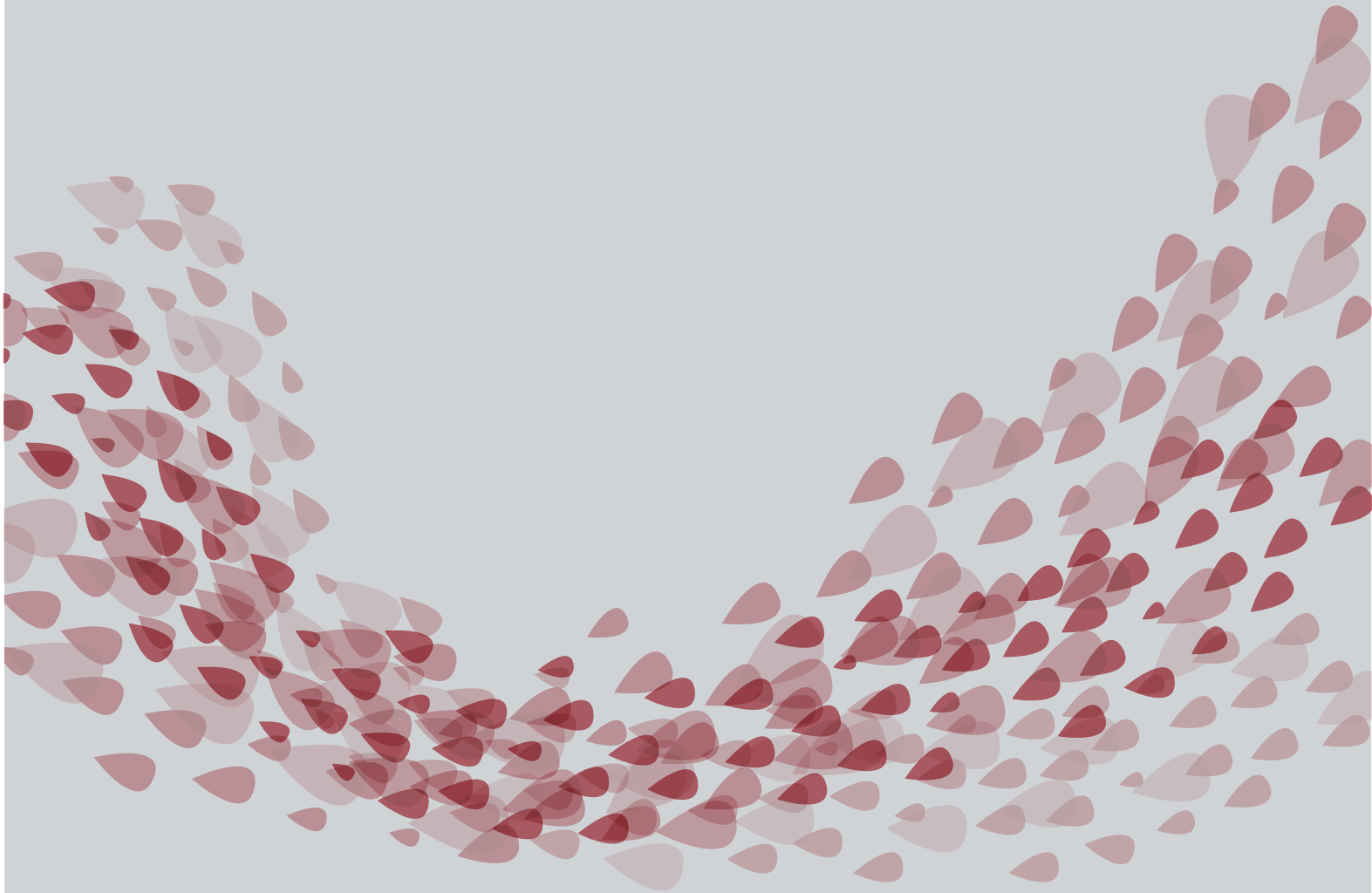


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A YEAR IN REVIEW

Myeloma Canada Milestones



MYELOMA
CANADA

MAKING MYELOMA MATTER

MYELOMA CANADA'S MISSION

To improve the lives of Canadians impacted by myeloma by accelerating access to better care through awareness, education, advocacy, community engagement and clinical research.

Myeloma Canada is a non-profit charitable organization created by, and for, people impacted by multiple myeloma, a relatively unknown cancer of the plasma cells. Exclusively devoted to the Canadian myeloma community, Myeloma Canada has been making myeloma matter since 2005.

As a patient-driven and patient-focused grassroots organization, Myeloma Canada drives collaborative efforts to unify the voice of the community to effectively shape the Canadian treatment landscape through a committed focus on the improvement of patient outcomes by:

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 promoting access to new drug trials in Canada

Empowering patients and caregivers through community engagement

The Myeloma Canada Research Network (MCRN), comprising Canada's leading researchers and clinicians from across the country, is the first and only platform that fuses national scientific research and advocacy. The MCRN develops and supports Canadian-designed clinical trials nationwide, publishes consensus statements on the management of the disease and collects data for its innovative national database, a key stepping stone in our search for a cure.

Myeloma Canada, in partnership with the Myeloma Canada Research Network, is dedicated to advancing the understanding, treatment and management of the disease and accelerating access to game-changing therapies for Canadians living with myeloma.

For more information about how Myeloma Canada is putting myeloma on the map, please visit myeloma.ca

MEET THE TEAM

MYELOMA CANADA



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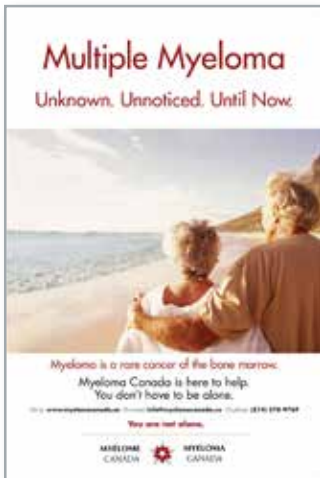


Molei Fu
Inhouse Monitor/Data
Manager
mfu@myeloma.ca

A MESSAGE FROM ALDO DEL COL CO-FOUNDER AND CHAIRMAN



Thanks to the unprecedented engagement of our community across the country, guided and supported by our passionate and caring team, Myeloma Canada continued to build on its exceptional accomplishments and introduce new programs to address the ever-changing landscape of challenges and opportunities.



Myeloma Canada was officially created on January 18, 2005, although much of the groundwork had already been laid the previous year. My original vision was to create a truly national organization with a focus on developing a sense of community where anyone impacted by myeloma did not have to feel alone. This was driven in no small part by my own feelings of fear, anxiety and aloneness when

I was diagnosed. Our first awareness piece was a poster that carried the message to the community: “*Myeloma Canada is here to help. You don't have to be alone.*” This philosophy has become engrained in the DNA of our organization and guides everything we do.

I am often invited to participate and speak at conferences and other events both here in Canada and internationally. Invariably, I am asked about how Myeloma Canada came to be regarded as one of the best patient organizations in Canada. The answer is simple: *Respect for the patient and a laser focus on delivering programs to help improve patient outcomes.* Although some organizations have a focus on advocacy, research or fundraising, Myeloma Canada delivers programs across all areas. A survey conducted by the Myeloma Canada Patient Advisory Council showed that our community

valued all four of our pillars (education, awareness, advocacy and research) more or less equally. This important feedback reassures us that we are aligned with the needs of our community.

This past year saw Myeloma Canada connect with more patients and caregivers than ever before, strengthening the ties that unite us, regardless of where we live. I am personally grateful to the grassroots efforts of countless volunteers across Canada for their dedication and to the thousands of donors who supported our mission. I invite you to read through the Year In Review and see how we made myeloma matter in 2017.

A MESSAGE FROM THE LEADERSHIP TEAM



Olivier Jérôme
Director of Operations

Building on the momentum of our successes of the previous year, 2017 was a banner year as it relates to fulfilling our mission. Every day across Canada, Myeloma Canada commits to improving the lives of Canadians impacted by myeloma by promoting access to better care. Thousands of patients, caregivers, friends, and families impacted by myeloma benefit from our programs across the country.

Founded on the pillars of our mission: awareness, education and support, access, and advocacy, as well as research and community engagement, our 2017 programming was rich in content.

Whether it is because of the quality of our educational material, the launch of our new website, the organization of 8 InfoSessions, the re-launch of our webinar series, the release of new InfoGuides or the updated edition of our Multiple Myeloma Patient Handbook, Myeloma Canada is recognized as an international leader.

To date, Myeloma Canada has invested over 3 million dollars in research. In collaboration with the MCRN, Myeloma Canada has been able to establish an internationally recognized cooperative research model bringing together scientists, clinicians, industry and patients to advance Canadian myeloma research.

Myeloma Canada's patient advocacy program saw a record number of submissions to government authorities in 2017 for access to innovative treatments. This year again, Myeloma Canada advocated for patients' rights to ensure transition between research innovation and equitable access to innovative treatments for all Canadian patients.

Community engagement also benefitted with the creation of five new support groups across the country and the participation of five new communities in the Multiple Myeloma March. Our community now has 29 support groups and 17 communities take part in our major annual fundraising event. This year, the Multiple Myeloma March raised over \$500,000 for our research and patient programs.

We thank you for your participation, devotion, commitment and for contributing, once again this year, to making myeloma matter.



Martine Elias, Director of Access, Advocacy and Community Relations

First, let me say how proud I am of our entire patient and caregiver community. When asked to step up and make your voices heard with your local government representatives, you did so in spades. This past fall, we sent over 600 personalized letters to members of

governments throughout the country to share our experiences with living with myeloma and why we cannot wait for new treatments to be listed on provincial formularies, despite being approved by Health Canada.

Again in 2017, we made many submissions to the various government bodies that decide if and how myeloma cancer drugs should be paid for in Canada, including several requests for reconsideration of drugs that had been rejected for funding. These submissions cannot be made without the input of many myeloma patients and their caregivers. Keeping our voices strong and loud is important so that people who control access to myeloma drugs understand what it is like to live with myeloma and can make informed decisions based on thorough knowledge of patients' needs. I thank all of you who have completed the surveys. For those who have not yet done so, we will have more for you to take part in during 2018!

This past year we assisted in establishing several new support groups, located in Quebec City, Sherbrooke, Thunder Bay and several satellite groups in British Columbia's South Interior. Myeloma Canada now works with 29 support groups located in all ten provinces. If anyone is interested in starting a new support group, please contact me. It is not difficult and Myeloma Canada is here to help. We now have a Support Group Leader Tool Kit that can be sent to anyone interested. Just send me an email and I will walk you through the easy steps it outlines for you.

Myeloma patients and their families have much to look forward to in 2018. Several new therapies approved in Canada in the past year will start to make their way through the provincial listing and reimbursement processes across the country that will ultimately provide access to these game-changing treatments. Nevertheless, we still face a challenge as these drugs go through the pricing negotiation process in the next few months.

Throughout 2017, I have had the opportunity to speak and meet with many wonderful people living with myeloma, and every one of those conversations, emails and meetings has had a deep impact on me. Every day, when I start my day, I think of every one of you, and it reaffirms why we do what we do at Myeloma Canada. For us, as a grassroots organization, myeloma patients come first—everything we do must have a positive impact on their lives. If it does not, it is not worth doing.

I wish everyone a fantastic 2018, with lots of love and laughter!



20 17

**RECOGNIZING
ACHIEVEMENTS**

Myeloma Canada Milestones

As we celebrated Canada's 150th birthday in 2017, Myeloma Canada also celebrated a year of proud accomplishments. This past year was an exceptional one for Myeloma Canada and the Canadian myeloma community, with many noteworthy milestones achieved.

It is incredible to witness what can be accomplished when we speak as a unified voice and work together to make myeloma matter. We would like to extend our sincere gratitude to the entire myeloma community for your continued support and for helping to put myeloma on the map.

With a renewed sense of passion, motivation and dedication for 2018 and beyond, the Myeloma Canada team is pleased to share with you Myeloma Canada Milestones: 2017 Year in Review.



EMPOWERMENT THROUGH EDUCATION

As the only national organization uniquely devoted to the Canadian myeloma community, Myeloma Canada leads the way in educating and empowering patients, caregivers and others impacted by myeloma from coast to coast.

INFOSESSIONS

Each year Myeloma Canada hosts InfoSessions for patients, their families and healthcare professionals, featuring guest speakers from the medical community in locations across Canada. InfoSessions are generally half-day forums designed to educate patients and caregivers on the many aspects of living with myeloma and its management. InfoSessions, many of which are held in smaller cities where there may be no local support group, also help bring the community together and enable patients to interact with the local healthcare team. Topics include understanding myeloma and its staging, treatment options, interpretation of blood tests, management of side effects, new myeloma therapies and updates on clinical trials and the Myeloma Canada Research Network.



Sherbrooke InfoSession



Kitchener-Waterloo InfoSession

In 2017 Myeloma Canada hosted 8 InfoSessions in the following communities:

- Vancouver, BC
- Saint John, NB
- Sherbrooke, QC
- Kitchener, ON
- Kelowna, BC
- St John's, NL
- Saskatoon, SK
- Thunder Bay, ON

DID YOU KNOW?

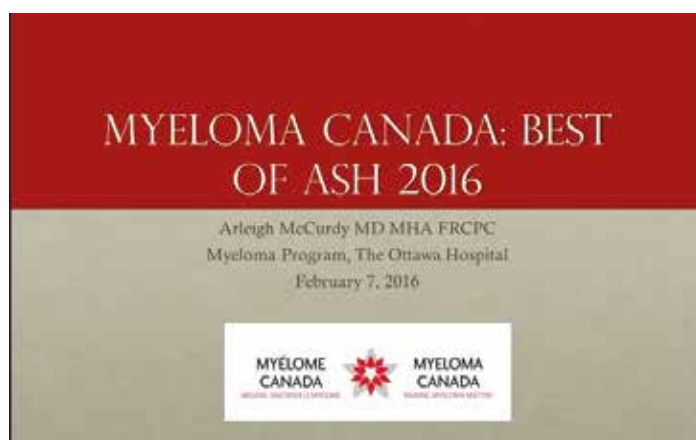
Over 2,000 patients and caregivers have attended a Myeloma Canada InfoSession since 2007.



EDUCATIONAL WEBINARS

As part of its educational program, and to further maximize patient outreach, in 2017 Myeloma Canada presented a series of informative webinars in both French and English. With each webinar covering a relevant and useful topic, these short sessions allow participants to login remotely and participate in a live session from the comfort of their homes.

These webinar sessions are also recorded and uploaded to Myeloma Canada's YouTube channel, making them available for viewing at any time.



2017 TOPICS

- The Best of ASH 2016 (French and English)
- Understanding the Drug Approval Process (French and English)
- Managing Side Effects (English)
- Myeloma and the Kidney (French)

**SUBSCRIBE TO OUR YOUTUBE CHANNEL
TO RECEIVE NOTIFICATIONS ON NEW RECORDINGS AND VIDEOS.**



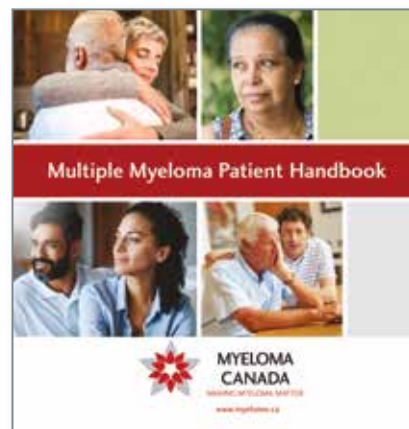
MYELOMA CANADA PATIENT HANDBOOK AND INFOGUIDES

Myeloma Canada offers several resource guides designed to advance the understanding, treatment and management of myeloma. Our educational materials are distributed through hospital libraries, myeloma clinics, support groups, information and awareness events, as well as directly to patients and caregivers. They include: *Multiple Myeloma Patient Handbook*, *Understanding Your Blood and Blood Tests InfoGuide*, *Myeloma Bone Disease InfoGuide* and *Myeloma and the Kidney InfoGuide*.

The updated Multiple Myeloma Patient Handbook is now available online and in print!

Myeloma Canada's Multiple Myeloma Patient Handbook is an educational publication that includes everything you need to know about myeloma and its treatment and management. Updates in the 2017 version include:

- Newly approved myeloma drugs
- Revised International Myeloma Working Group (IMWG) diagnosis criteria
- Updated advocacy section



DID YOU KNOW?

Each year, over 4,000 Handbooks and InfoGuides are printed and distributed across the country, and the average cost of a complete educational package to a newly diagnosed patient is \$35.

Download PDF copies of the Handbook or InfoGuides by visiting myeloma.ca and going to the “Resources” tab. To order a hard copy, email contact@myeloma.ca or telephone 1-888-798-5771.

NAVIGATING THE HEALTHCARE SYSTEM

A PEER-TO-PEER PROGRAM



Debbie Basevitz, a retired nurse and caregiver of a myeloma patient, volunteered to set up a peer-to-peer program for patients and caregivers designed to offer practical advice and help them better navigate the Canadian healthcare system.

Debbie gained first-hand experience of the system as a pediatric nurse in Montreal and a caregiver to her husband, who is living with multiple myeloma. Debbie can help guide you through the process and provide you with sound advice on how to navigate the system.

It has been a little over a year that I have had the privilege of working with 16 families from across Canada. My goal was to help these families navigate the healthcare system and provide individual support to them. In addition to the initial contact, I connected with each family three to four months later for a follow-up. It has been my pleasure to help myeloma patients and their families and I will continue to do so in the future.—Debbie Basevitz

To schedule a time to speak with Debbie:

Email her at debbiebasevitz@gmail.com.

She is available Monday to Friday, from 9:00 a.m. to 5:00 p.m., Eastern Time.

MYELOMA CANADA WEBSITE



The Myeloma Canada website is one of the most important components of its educational and awareness programs, as it is the most frequently used resource for up-to-date information on myeloma in Canada. In 2017, Myeloma Canada launched a brand-new website that optimized the information presented and increased viewership and engagement significantly.

The new website features everything you need to know about myeloma, as well as news on what’s happening in the Canadian myeloma community.

DID YOU KNOW?

On average, Myeloma Canada’s bilingual website receives over 10,000 visits per month.

TAKE A TOUR OF OUR NEW WEBSITE AT: MYELOMA.CA



UNKNOWN. UNNOTICED. UNTIL NOW.

Since its inception, Myeloma Canada has remained driven by the need to unify and strengthen the voice of the Canadian myeloma community. Over the past 13 years, Myeloma Canada has undertaken a number of initiatives to increase overall awareness to make myeloma matter.

FAMILY MEDICINE CONFERENCES

Myeloma Canada educates primary care physicians about myeloma and its early symptoms at the Pri-Med Canada conference in Toronto and the 2017 Annual Scientific Assembly in Regina.



Juliette Royer (left) and Norma Lindner (right)

As many patients and caregivers can attest to, getting an early diagnosis is key to improving patient outcomes and improving overall quality of life. As part of its Early Diagnosis Program, Myeloma Canada representatives, as well as patients living with myeloma, attended family medicine conferences to raise awareness among primary care physicians and increase their knowledge of myeloma and its early symptoms.

On May 10–13, Myeloma Canada was among the 200 exhibitors at the Pri-Med Canada (PMC) Conference in Toronto. The PMC is the largest annual continuing medical education conference in Canada, which thousands of family physicians, pharmacists, nurse practitioners, registered nurses and medical students attend in order to advance their knowledge of primary care.

Thank you to volunteers Patrick Taylor, David and Erika McMullen, Norma Lindner, Leslie Weatherby, Robert McCaw and Juliette Royer for representing Myeloma Canada and the Canadian myeloma community, putting myeloma on the map in primary care.

Myeloma Canada was also present at the 2017 Annual Scientific Assembly in Regina in September to also raise awareness among the family physicians attending that conference. Thank you to Mona Neher, Doug Page and Quentin Prudat for volunteering your time to help out with that important event!



Martine Elias, Director of Access, Advocacy and Community Relations at Myeloma Canada and Mona Neher, patient volunteer and support group leader in Regina

AWARENESS DAY ON PARLIAMENT HILL

On October 3, Myeloma Canada patient advocates from around the country gathered together on Parliament Hill in Ottawa to meet one-on-one with Members of Parliament to increase awareness about myeloma at the national level, as well as emphasize the need for funding vital research. Additionally, the meetings provided an opportunity to stress the importance of improving the Canadian regulatory drug review process and the affordability of new therapies, so that Canadians impacted by myeloma are able to access new, life-saving treatments in a timely manner.

Thank you to the patient advocates from across Canada for participating in this notable event putting myeloma on the map, as well as to our MPs for taking action to make myeloma matter. Patient advocates included David McConkey, David McMullen, Hervé Benoît, Frank Shepherd, Julie Gibbons, Julie Salsman, Keith Taylor, Lorelei Dalrymple, Michael Chibuk, Nancy Shamanna, Robin Sully, Ron Surry and Trish MacDonald.



Patient advocates Trish MacDonald from Nova Scotia, David McMullen from Ontario, Julie Salsman from Nova Scotia, Darren Fisher, MP for Dartmouth–Cole Harbour, and Patient Advocate Ron Surry from British Columbia



Patient advocate David McConkey from Newfoundland, James Maloney, MP for Etobicoke-Lakeshore, Martine Elias from Myeloma Canada, and Patient advocate Hervé Benoît from Quebec

AWARENESS DAY AT THE QUEBEC NATIONAL ASSEMBLY

On April 12, Myeloma Canada was pleased to join the organizers of the *Défi Cyclo-myélome*, along with several myeloma patients, as well as Dr Richard LeBlanc, Chairholder of the Myeloma Canada Research Chair at the Maisonneuve-Rosemont Hospital in Montreal, for an Awareness Day at the Quebec National Assembly in Quebec City. Over half a dozen MNAs from across the province were in attendance, as well as a representative from Quebec's health technology and medication assessment organization, the *Institut national d'excellence en santé et en services sociaux* (INESSS), to learn more about multiple myeloma and the importance of funding programs for advancing scientific research in the disease.

We would like to thank Maryse Bouchard and Francine Ducas for organizing this very successful event, as well as Dr LeBlanc and patient representatives Leonard Miller and Mélanie St-Jacques for their collaboration and for speaking to our provincial leaders on behalf of the myeloma community.



From left to right: Michelle Oana (Associate Director, Development and Communications, Myeloma Canada), Benoît Charrette (MNA for Deux-Montagnes), Sylvain Pagé (MNA for Labelle), Leonard Miller (participant, Défi Cyclo-myélome), Maryse Bouchard (co-founder, Défi Cyclo-myélome), Francine Ducas (co-founder, Défi Cyclo-myélome), Dr Richard LeBlanc (Chairholder of the Myeloma Canada Research Chair at Maisonneuve-Rosemont Hospital), Diane Lamarre (MNA for Taillon), Marie Montpetit (MNA for Crémazie), Sébastien Schneeberger (MNA for Drummond–Bois-Francis), Sylvie Bouchard (Director, Direction du médicament, INESSS), Mélanie St-Jacques (participant, Défi Cyclo-myélome), and Geoffrey Kelley (Minister responsible for Native Affairs)

Become a Myeloma Advocate!

Myeloma Canada is looking for patients and caregivers across the country who are willing to work with our organization to become myeloma advocates and share their stories about their journeys and experiences with the community at large.

If you are interested in learning more or how to get involved, please contact Martine Elias, Director of Access, Advocacy and Community Relations, at: melias@myeloma.ca



MYELOMA MATTERS NEWSLETTER

Every month, a national electronic newsletter, *Myeloma Matters*, is sent out to the Canadian myeloma community, providing the latest news about research, drug approvals, meetings, events, access and advocacy.

New in 2017 was the introduction of the “Spotlight on the Community” series that features personal stories from members of the community, including patients, caregivers and healthcare professionals.

The newsletters shown are:

- Spotlight on Karen Bjarnason, a 22-Year Surviving Patient from British Columbia**: "I have hope again!"
- A Day in the Life of Anthony Everett - A Myeloma Patient and Member of the Myeloma Canada Board of Directors, Representing British Columbia**
- THE PATIENT JOURNEY**: TERRY HEINE WOOD'S STORY - A 13 year survivor
- STEPS TO A CURE!**: CITIZEN-GARNEAU MYELOMA WALK
- Spotlight on Gilles Caron: Research is What Will Help Me Live Longer**

Share your story with us!

We are continually looking for patients, caregivers and members of the medical community who are willing to share their stories and experiences with the community, whether in a newsletter, on video, or as a patient advocate. For more information, get in touch with us at: contact@myeloma.ca

ARE YOU SUBSCRIBED TO MYELOMA MATTERS?

Stay on top of the latest news by having the *Myeloma Matters* newsletter delivered direct to your inbox. Visit myeloma.ca to subscribe by joining our community today!

MAKING WAVES IN THE MEDIA

Throughout 2017, Myeloma Canada left a significant footprint in various mass-media outlets nationwide, focusing an unprecedented level of attention on awareness of the disease in general, pressing issues in our healthcare system in respect to the drug approval process and the Multiple Myeloma March. Among the highlights were stories featured on CTV News, Global News, CBC's The National, Radio-Canada and Le Journal de Québec.

Powerful headlines included:

Canadians Living with Multiple Myeloma Need Access to Therapies Now

Canadian Cancer Patient Network Calls on Ministers of Health and Cancer Agencies to Lift the Veil of Secrecy on Committee That May Be Delaying or Restricting Access to New Cancer Drugs for Patients

Sisters Take Steps to Raise Awareness About Incurable Cancer



FOLLOW US ON SOCIAL MEDIA!



MYELOMA AWARENESS MONTH

March is known as International Myeloma Awareness Month, and Myeloma Canada made significant strides in putting myeloma on the map with the launch of the awareness campaign called "Myeloma is Not a Skin Cancer". By addressing head-on the common misconception that myeloma is related to melanoma, it was designed to increase general awareness about the symptoms of myeloma, in order to promote early diagnosis, as well as highlight the resources available through Myeloma Canada for newly diagnosed patients.

The social media and web campaign proved to be very successful, with over 20,000 visits to the Myeloma Canada website, and a total reach of 116,500 on social media.



MAKING MYELOMA MATTER

By unifying and strengthening the voice of the Canadian myeloma community, Myeloma Canada is committed to putting myeloma on the map.

PATIENT, CAREGIVER AND HEALTHCARE PROFESSIONAL SURVEYS

Although the prevalence of myeloma in Canada is increasing, myeloma remains a relatively unknown disease, which often results in delayed diagnosis and limited funding and reimbursement for new therapies. Myeloma Canada's role is to ensure the patient voice is heard. Sharing the patient perspective is key to influencing recommendations and reimbursement decisions for myeloma treatments by Health Technology Assessment (HTA) agencies such as the pan-Canadian Oncology Drug Review (pCODR) and *Institut national d'excellence en santé et en services sociaux* (INESSS), and provincial government drug plans. One of the ways Myeloma Canada meets this objective is by conducting patient, caregiver and healthcare professional surveys to better understand the patient journey and relay valuable information to decision makers. Myeloma Canada has also facilitated phone interviews for patients and caregivers to fully grasp their experiences and gather their valuable input.

Listening to patients is a vital part of pCODR's work. It recognizes that patients have a unique knowledge about what it is like to live with a specific disease or medical condition. What patients experience on treatment may not be reported in published literature; therefore, patient input can be important to share with payers and pCODR decision makers when evaluating a new drug or protocol for reimbursement.

Submissions made by Myeloma Canada in 2017:

- 3 patient and caregiver submissions made to pCODR
- 3 patient and caregiver submissions made to INESSS
- 2 clinician submissions made to pCODR
- 1 submission made to the Ontario Public Drug Program

DID YOU KNOW?

In 2017, Myeloma Canada received information via surveys from over 359 patients and caregivers and conducted close to 40 one-on-one interviews.

Respond to Myeloma Canada patient and caregiver surveys and do your part to make our voices heard. Join the Myeloma Canada mailing list to receive notices for participating.

Visit myeloma.ca to subscribe.

ADVOCATING FOR ACCESS

Awareness and advocacy go hand in hand. Many of the awareness programs that are in place are also intended to facilitate access to new therapies via health policy development and drug reimbursement. Holding an Awareness Day in various provincial legislatures and on Parliament Hill ensures health policy makers and public drug plan decision makers are educated about myeloma, so that they better understand the urgency of funding new myeloma drugs. Myeloma Canada also partners with patient groups, specifically in Alberta, Ontario, British Columbia and Quebec, in supporting province-specific advocacy efforts.



Myeloma Canada Advocacy Committee members Hervé Benoit, David McConkey and Lorelei Dalrymple pictured at the 2017 Awareness Day on Parliament Hill

PROVINCIAL DRUG FUNDING DECISIONS

Over the last two years, Health Canada approved four new drugs for the treatment of myeloma; this, however, is only the first step in the long process of securing their funding in provincial public drug programs. The pan-Canadian Oncology Drug Review (pCODR) undertakes rigorous, objective reviews of cancer drugs and provides funding recommendations to Canada's provinces and territories (excluding Quebec). The funders use this information as one element in their decision-making process to determine if a drug will be eligible for public reimbursement. The pCODR takes into account evidence from a number of sources, including patient groups, drug manufacturers, clinician-based tumour groups, and the pCODR Provincial Advisory Group.

2017 DRUG FUNDING ANNOUNCEMENTS

REVLIMID® (LENALIDOMIDE) IN FIRST LINE TREATMENT

As of March 24, 2017, the Ontario Public Drug Program agreed to fund Revlimid® (lenalidomide) as a first-line treatment for newly diagnosed myeloma patients who are not eligible for high-dose chemotherapy (also known as autologous stem cell transplant).

On April 1, 2017, British Columbia also approved provincial funding for Revlimid® as a first-line treatment for newly-diagnosed myeloma patients who are not eligible for high-dose chemotherapy (also known as autologous stem cell transplant).

Lastly, as of April 20, 2017, the Manitoba Drug Formulary began funding Revlimid® as an option for first-line treatment of patients with multiple myeloma who are not eligible for autologous stem cell transplant.

DARZALEX® (DARATUMUMAB)

As of April 17, 2017, Health Canada has approved Darzalex® (daratumumab), in combination with lenalidomide and dexamethasone, or bortezomib and dexamethasone, for the treatment of patients with multiple myeloma who have received at least one prior therapy. Due to the high unmet medical need for multiple myeloma patients, Darzalex® was granted a Priority Review status by Health Canada for this submission. Clinical trials have shown that Darzalex® combination therapy significantly improves progression-free survival (PFS) compared to standard of care regimens alone. As of December 31, 2017, daratumumab is not yet funded by any province.

KYPROLIS® (CARFILZOMIB)

On February 3, 2017, the pCODR Expert Review Committee (pERC) recommended reimbursement of Kyprolis® (carfilzomib) used in combination with dexamethasone for patients with relapsed multiple myeloma with a good performance status who have received one to three prior treatments, on the condition that its cost-effectiveness be improved to an acceptable level.

This means the pERC has concluded that Kyprolis® provides clinical benefits that Kyprolis®, but that provinces, through the pan-Canadian Pharmaceutical Alliance, should negotiate its price down to make it more cost-effective.

NINLARO® (IXAZOMIB)

On May 4, 2017, the pCODR Expert Review Committee (pERC) issued its initial recommendation for Ninlaro® (ixazomib) for multiple myeloma.

However, pERC did not recommend reimbursement of Ninlaro® (ixazomib) in combination with lenalidomide and dexamethasone for patients with multiple myeloma who have received at least one prior treatment and have high-risk cytogenetics, or who have received at least two prior therapies.

Although we are disappointed with this initial recommendation, Myeloma Canada is committed to working diligently with patient groups to continually ensure the patient voice is heard, as well as with drug manufacturers ensure that treatment options are available to Canadian patients.

KEY THIRD-PARTY PARTNERSHIPS

Myeloma Canada partners with other patient organizations and coalitions to drive change in the healthcare system toward a more favourable, patient-focused environment. We engage to ensure our voice is heard on issues such as national pharmacare, the pan-Canadian Pharmaceutical Alliance and strengthening the patient voice at the HTA level (pCODR and INESSS). This is done through either our own actions or working in association with other partner cancer groups.

Global Myeloma Action Network (GMAN)

Myeloma Canada is active internationally as a founding member of the Global Myeloma Action Network (GMAN). The Global Myeloma Action Network brings together advocacy leaders to mobilize the myeloma community to improve the lives of patients around the world.



Martine Elias, Director, Access, Advocacy and Community Relations and Aldo Del Col, Co-founder and Chairman of Myeloma Canada, at the 5th Annual GMAN Summit in June 2017

Recommendations on Proposed Amendments to the Patented Medicines Regulations

Health Canada holds various responsibilities influencing the landscape of our healthcare system, including drug safety, quality and effectiveness. In addition, it plays an important role with respect to drug pricing. As a patient organization, Myeloma Canada recognizes the regulations overseeing drug pricing need to be re-evaluated, especially given the changes in our ecosystem since their inception. Co-written by Myeloma Canada and endorsed by 16 other patient organizations, the



“Recommendations on Proposed Amendments to the Patented Medicines Regulations” document was submitted to Health Canada in order to drive change in the healthcare system towards a more patient-focused environment.

To read the full document, visit myeloma.ca, under “Resources – Advocacy in Canada”.

Become an iGive Member and Support Myeloma Canada!

You can now shop at your favourite stores online AND support Myeloma Canada at no extra cost! All you have to do is become an iGive member and start shopping!

iGive.com is a FREE service where online shopping helps supporters donate funds to a cause of their choice at no additional charge to the supporter or the cause!



Economic Club of Canada Luncheon

An informative luncheon was organized on May 13 by the Economic Club of Canada in Ottawa to discuss the importance of innovative medicines and therapies in treating cancer. Important questions were asked, discussion lines were opened and excellent insight was gained. With the patient voice at the center of the debate, all the panellists agreed that access to new and innovative medicines for treating cancer in Canada needs improvement, as well as on the necessity of finding better ways to work together as a community to streamline the process. Panellist Dr Darrell White, hematologist/oncologist and Chair of the Board of the Myeloma Canada Research Network (MCRN), pointed to Myeloma Canada and the MCRN as organizations that are successfully paving the way to improving patient care by providing access to innovative medicines through Canadian-designed clinical trials and unifying the voice of the Canadian myeloma community.

Thank you to Natasha Morano for organizing this worthwhile event, as well as to the expert panelists who led the armchair discussion, including myeloma representatives Lorelei Dalrymple, patient and Chair of the Myeloma Canada Patient Advisory Council and Dr Darrell White, MD, MSc, FRCPC, FACP, Professor and Senior Associate Dean, Faculty of Medicine, Dalhousie University, and hematologist at the QEII Health Sciences Centre in Halifax.



Panelists, from left to right: Bruce Williamson, Vice-President, Sales & Marketing, Janssen Inc.; Linda Eagen, Founder, Cancer Coaching, and President & CEO, Ottawa Regional Cancer Foundation; Lorelei Dalrymple, Chair, Myeloma Canada Patient Advisory Council; Dr Darrell White, Senior Associate Dean, Dalhousie University; and Pamela Fralick, President, Innovative Medicines Canada

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

CONNECTed
Collective Oncology Network for Exchange, Cancer Care Innovation, Treatment Access and Education



In 2015, the Save Your Skin Foundation invited a group of leaders in patient advocacy to discuss the need for a network focused on immuno-oncology and dedicated to ensuring access to these important therapies for cancer patients in Canada. Since then, CONNECTed has evolved into a coalition of patient advocates, dedicated to raising awareness of the needs of cancer patients through a unified voice. The group has been involved in addressing issues within the system, at the government level and in health technology assessments relating to immuno-oncology and other therapies.

Members of the CONNECTed coalition are:

- Myeloma Canada
- Save Your Skin Foundation
- Colorectal Cancer Canada
- Lung Cancer Canada
- Melanoma Network of Canada
- Lymphoma Canada

On October 18, CONNECTed issued a poignant and direct press release expressing its concern about the lack of transparency in the pan-Canadian review process that formalizes recommendations on the funding of cancer therapies in public drug plans.

Picked up nationally by reputable media outlets such as The Globe and Mail, CBC's The National, and many others, the message conveyed by the release, entitled "Canadian Cancer Patient Network Calls on Ministers of Health and Cancer Agencies to Lift the Veil of Secrecy on Committee That May Be Delaying or Restricting Access to New Cancer Drugs for Patients," was heard loud and clear across the country.

The CanCertainty Coalition



EQUAL AND FAIR CANCER TREATMENT FOR ALL

The CanCertainty Coalition is the united voice of 35 Canadian patient groups, including Myeloma Canada, joining together with oncologists and cancer care professionals to significantly improve the affordability and accessibility of take-home cancer treatments in Ontario and the Atlantic provinces.

The Coalition, along with oncologists, patients, caregivers and concerned citizens across those provinces, has been working to encourage the governments concerned to treat take-home and hospital-administered cancer treatments on an equal basis, regardless of the patient's private insurance status, age, or income. In April 2017, CanCertainty presented a health economist's budget impact analysis that indicated the funding gap could be closed in Nova Scotia with an additional \$1.8 million. In September 2017, the initial allocation of \$846,000 was committed, plus an additional \$2 million for each of two subsequent years.

Up until now, cancer patients in Nova Scotia have faced the highest out-of-pocket costs in Canada for take-home cancer medication, as well as significant administrative delays in starting their critical, life-saving treatments.

As a member of the Coalition, Myeloma Canada applauds the Nova Scotia government's decision to address the funding gap for take-home cancer medications by eliminating much of the financial hardship and related stress that patients in the province have experienced.

Have You Visited the Myeloma Canada Online Boutique?

Shop Myeloma Canada branded merchandise on our website and support the cause at the same time!

To see what we have in-store for you, visit

myeloma.ca under "Get Involved - Shop Myeloma Canada"



Myles the Teddy \$20



DRIVE ADVOCACY FOR TREATMENT ACCESS

Myeloma Advocacy Program (MAP)

WRITE YOUR MPP/MLA/MNA >

MYELOMA ADVOCACY PROGRAM (MAP)

New drug approvals by Health Canada do nothing for patients if they cannot access life-changing treatment. By working together, we become stronger, and by speaking as a unified voice for the Canadian myeloma community, we can make a difference. In order for governments to see us as a priority, we need to be vocal.

Launched in 2017, Myeloma Canada's MAP is a web-based platform and tool that enables the community to take part in common advocacy efforts focusing on drug access and reimbursement policies. Designed to mobilize members of the community, the interactive program facilitates sending direct and personalized letters to their local MPP/MLA/MNAs, urging them to take action. In two very successful campaigns during the spring and fall, 637 letters were sent to elected officials across the country. The many responses received from government representatives acknowledged the concerns expressed and indicated willingness to take the steps necessary to bring them forward.

To learn more about this program and share your voice, visit myelomacommunity.ca

MYELOMA CANADA

About Myeloma Canada | Download Patient Handbook | Advocate for Treatment Access

IT'S TIME TO GET THE APPROVED MYELOMA DRUGS FUNDED NOW!

PATIENTS CAN NO LONGER WAIT!

Cancer doesn't work around our schedules so myeloma patients shouldn't have to work around government's.

Multiple myeloma is a complex disease and is characterized by cycles of disease control and relapse and in most cases, treatment will eventually lose its effect. We are fortunate that several life-changing treatments have been approved by Health Canada in recent years. But even the best treatments are irrelevant if patients cannot access them. That is why, more than ever, we need to work together to make our voices heard in order to gain access to the new drugs that have proven to make a difference in managing this disease. Thousands of patients depend on it.

Over the past years, two myeloma drugs, **Revlimid (lenalidomide)** and **Darzalex (daratumumab)** received approvals by Health Canada and positive recommendations for funding by our Health Technology Assessment (HTA) government bodies. Yet neither of these advance treatments are subsidized by our provinces.

[Learn about the new treatments by clicking here.](#)

Medication approval does nothing for patients if they cannot access life-changing treatment. Things need to change and that starts with you.

By working together, we become stronger, and by speaking as a unified voice for the Canadian myeloma community, we can make a difference. In order for governments to see us as a priority, we need to be vocal. Help us get these treatments funded. Write your Local MPP/MLA/MNA and urge them to take action today!

WHY IS IT IMPORTANT TO TAKE ACTION?

- When someone is dealing with myeloma, it affects the entire family and loved ones. Fight for your mom, dad, grandpa, grandpa, brother, sister, daughter, son, and friends.
- Patients deserve the access to health and most invisible illnesses to manage their disease.
- Being able to properly manage a disease means a person is able to live a good quality of life and be productive in society.
- Governments react to voters. They need to hear myeloma patients can lead full, productive lives with access to these therapies.
- We need to work together to effect change!

BY WORKING TOGETHER, WE BECOME STRONGER

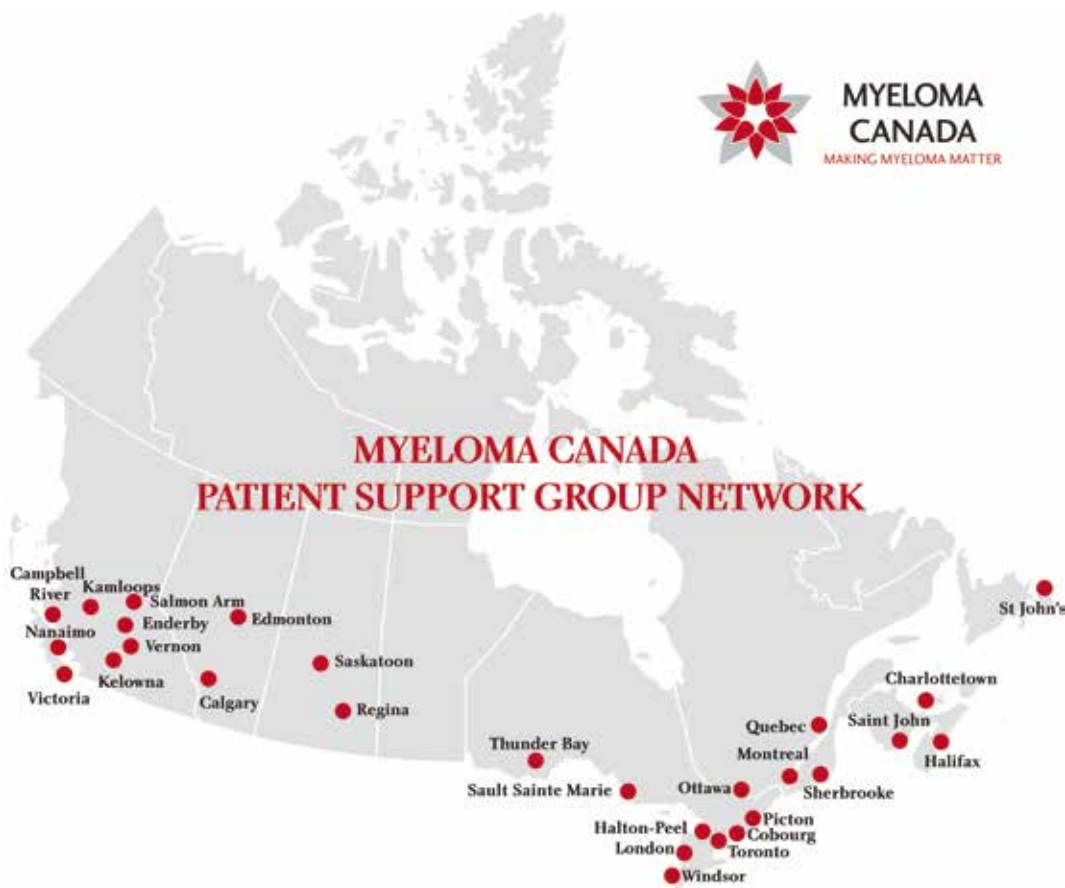
Working together as a community at the grassroots level can effectively shape the Canadian treatment landscape in order to accelerate access to better care.

MYELOMA CANADA PATIENT SUPPORT GROUP NETWORK

Focusing on grassroots patient outreach, Myeloma Canada works with 29 support groups across the country who meet and exchange regularly to learn more about the disease, how to self-advocate and support each other.

In 2017, five new support groups were created, providing patients and caregivers who live in smaller communities the opportunity to connect with other myeloma patients and share information and experiences.

To connect with a support group near you, visit myeloma.ca, under the “Find Support” tab.



If there is no support group in your area, but you would like information on how to start one, reach out to us at: contact@myeloma.ca

SUPPORT GROUP LEADER AND ADVOCACY SUMMIT



Iris Phillips, support group leader in Picton, Ontario



Robin Sully and Jean Shepherd, Co-leaders in Ottawa, Ontario

In order to empower and assist support group leaders in their vital work, Myeloma Canada hosts an annual Support Group Leaders Summit, where leaders from across the country are invited to learn and exchange, as well as discuss common issues, challenges and best practices.

Thirty-two support group leaders, as well as members of our Patient Advisory Council and Advocacy Committee from throughout Canada came together in Ottawa during the weekend of September 30 to network and share ideas and information. The Summit also provided an excellent opportunity to learn more about the latest research and clinical trials and how to leverage the available leader and patient advocate tools. Everyone walked away equipped with a wealth of information, tools and updates to share with their respective groups.

Special thanks to Martine Elias, Julie Salsman, Trish MacDonald, Linda Latham, Robin Sully, Jean Shepherd, Norma Lindner, Lorelei Dalrymple, Ron Surry, Michael Chibuk and Nancy Shamanna for their help in planning this meeting, as well as to Julie Salsman, Robin Sully, Norma Linder and Linda Latham for their hard work in delivering the Support Group Leader Tool Kit, which helps leaders in the important work they carry out in their local communities. Finally, a heartfelt thank you to guest speakers, Dr Reece, Dr Bourgeois-Daigneault, Naveen Bangia, Gail Christy and Bill Dempster for joining us presenting useful and poignant topics to our leaders.



OUR DEDICATED SUPPORT GROUP LEADERS FROM ACROSS THE COUNTRY

Campbell River, BC	North Island Multiple Myeloma Support Group	Linda Latham
Nanaimo, BC	Nanaimo Multiple Myeloma Support Group	Allison Jennings
Victoria, BC	Vancouver Island Multiple Myeloma Support Group	Ellen Mahoney & Larry Borterson
Kelowna, BC	BC Southern Interior – Kelowna Chapter	Susan Schmaltz & Ron Surry
Kamloops, BC	BC Southern Interior – Kamloops Chapter	Bob Trudeau & Bob Hamaguchi
Enderby, BC	BC Southern Interior – Enderby Chapter	Ron Surry
Vernon, BC	BC Southern Interior – Vernon Chapter	Marlene Godfrey
Salmon Arm, BC	BC Southern Interior – Salmon Arm Chapter	Linda Quintal
Calgary, AB	Southern Alberta Myeloma Patient Society	Michelle Zydgalo
Edmonton, AB	Myeloma Alberta Support Society	Bob Thiessen
Saskatoon, SK	Saskatoon Multiple Myeloma Support Group	Sonja Gabruch
Regina, SK	Saskatchewan Multiple Myeloma Support Group	Mona Neher
Windsor, ON	Windsor and District Multiple Myeloma Support Group	JoAnn Cartlidge
Thunder Bay, ON	Thunder Bay Myeloma Support Group	Rolland Manning
Sault Ste. Marie, ON	Sault Ste. Marie Multiple Myeloma Support Group	Marion Bentley & Maggie Ralph
London, ON	London and District Myeloma Support Group	Ev McDowell & Jeff Parton
Halton-Peel Area, ON	Halton-Peel Myeloma Support Group	Norma Linder & Juliette Royer
Toronto, ON	Toronto and District Multiple Myeloma Support Group	David McMullen & Donald Hunter
Cobourg, ON	Northumberland and District Multiple Myeloma Support Group	Leslie Weatherby
Picton, ON	Picton Support Group	Iris Phillips
Ottawa, ON	Myeloma Ottawa Gatineau Support Group	Robin Sully & Jean Shepherd
Montreal, QC	Montreal Myeloma Support Network	Hervé Benoit & Joanne Kerry
Sherbrooke, QC	Espoir Myélome Estrie Support Group	Vénus Bélanger
Quebec City, QC	Myélome Québec Support Group	Manon Veilleux
Saint John, NB	Saint John Area Multiple Myeloma Support Group	Susan Collins
Halifax, NS	Nova Scotia Multiple Myeloma Support Group	Julie Salsman & Trish MacDonald
Charlottetown, PE	Charlottetown Myeloma Support Group	Fran Freyer
St John's, NL	Myeloma NL	David McConkey & Stephen Norman

COMMUNITY EVENTS

This past year was a momentous one in terms of community events, fundraisers and activities. Hundreds of new and veteran volunteers stepped up to the plate once again in 2017 and donated their time and expertise to lend a hand in making myeloma matter in their communities. Throughout the year, there was certainly no shortage of grassroots local events across the country, which included four golf tournaments, two galas, five sporting events, two concerts and seventeen Multiple Myeloma Marches, to name but a few!

For a full overview of the 2017 community events and activities, visit the Spotlight on the Community section in this publication.



Photo taken at Gilda's Gala in Toronto on October 21

MYELOMA CANADA PATIENT ADVISORY COUNCIL (PAC)

Early in 2015, the Myeloma Canada Board of Directors approved the creation of the Patient Advisory Council (PAC). The primary purpose of the PAC is to provide the Board with valuable insights into the patient perspective on national and regional issues, as well as on other matters important to patients, caregivers and support groups.



The Myeloma Canada Patient Advisory Council. From left to right: Julie Salsman, Hervé Benoît, Lorelei Dalrymple, David McConkey, Keith Taylor and Julie Gibbons

A Letter from Lorelei Dalrymple, Chair of the PAC



Firstly, I have to start by thanking David McMullen and Ev McDowell for their invaluable contributions to the Patient Advisory Council (PAC) since its inception in 2015. David spearheaded our formation as Chair and Ev actively represented the Ontario region until their retirement from the PAC in 2016. We're grateful that both of these wonderful volunteers continue to be actively involved with Myeloma Canada and in the myeloma community.

The year 2017 saw continued development and increased collaboration for the PAC. We welcomed new members to our team: Keith Taylor for Western Canada, Julie Gibbons for Ontario and David McConkey for Atlantic Canada. The Myeloma Canada Board of Directors appointed me to the role of Chair, Julie Salsman took on the Vice-Chair role and Hervé Benoît continued on as the Quebec representative. In addition to being volunteers on the

PAC, we're also involved in a number of other Myeloma Canada and regional committees. Some of the activities we participated in were:

- Myeloma Canada committees – Early Detection, Support Group Leader (SGL) Toolkit, National Advocacy
- Economic Club of Canada – Lunch and Learn – Role of Innovative Medicines in the Fight Against Cancer
- Myeloma Canada 2018 Strategic Planning Session
- MCRN Scientific Roundtable
- SGL and Advocacy Summits and SGL Conference Calls
- Myeloma Awareness Day on Parliament Hill
- Myeloma Advocacy Program (MAP) 2.0

Our regional representatives reached out to the support groups in their areas to introduce themselves and obtain feedback on what's important to them and their communities, as well as to exchange on how the PAC and/or Myeloma Canada can assist them in achieving their goals. We also completed a comprehensive review of the new Myeloma Canada website and provided feedback, which resulted in several changes.

One of our biggest goals in 2017 was to look at our roles more strategically and align them with those of Myeloma Canada. This is to ensure the voice of the myeloma community is heard and we are working in concert, so that the programs being offered will meet the needs of patients, caregivers, family and friends living with myeloma. Through the collaborative efforts of the Myeloma Canada staff and PAC members, we are reviewing the services available and looking to capitalize on opportunities for PAC and SGL involvement in delivery to the national, regional and local myeloma communities.

I'm excited to see some of the ideas that originated in 2015 come to fruition, and even more excited to see how the PAC has evolved and where we can go in the coming years.

Warmest wishes to all,

Lorelei Dalrymple
Chair, PAC

PATIENT-DRIVEN. PATIENT-FOCUSED.

Collaboration with key academic and industry research partners is at the forefront of Myeloma Canada's research initiatives. Bringing more new treatment options to more patients in more centres across Canada will continue to drive Myeloma Canada's research mission in 2018.

HIGHLIGHTS FROM THE 2017 MYELOMA CANADA SCIENTIFIC ROUNDTABLE

On September 15 and 16, Myeloma Canada hosted the 8th annual Myeloma Canada Scientific Roundtable in Montreal. Co-chaired by Dr Jonathan Keats, head of the Multiple Myeloma Research Laboratory at TGen in Phoenix, Arizona and Dr Victor Zepeda, Assistant Professor and clinician scientist at the Tom Baker Cancer Centre in Calgary, the meeting brought together over 90 stakeholders, including Canada's top myeloma experts from coast to coast, scientists from the USA and Europe, our industry research partners and patient contributors. This year's international guest speakers included Dr Ashutosh Wechalekar from London, UK, Dr Peter Voorhees from Chapel Hill, North Carolina, Dr Dirk Hose from Heidelberg, Germany, Dr Jesús Berdeja from Nashville, Tennessee, and Dr Rafael Fonseca from Scottsdale, Arizona.

A wide range of current topics in myeloma research was discussed, including monoclonal gammopathy of undetermined significance (MGUS), smouldering myeloma, amyloidosis, minimal residual disease (MRD), CAR T-cell therapy and more.

The meeting is also an incubator for clinical trial ideas and supports our goal of developing high-impact, made-in-Canada clinical trials for patients across the country. The highly informative presentations sparked important discussions, the sharing of ideas and forward-thinking thought processes. All in all, the event invoked a positive sense of motivation and collaboration amongst all who attended.



2017 Myeloma Canada Scientific Roundtable

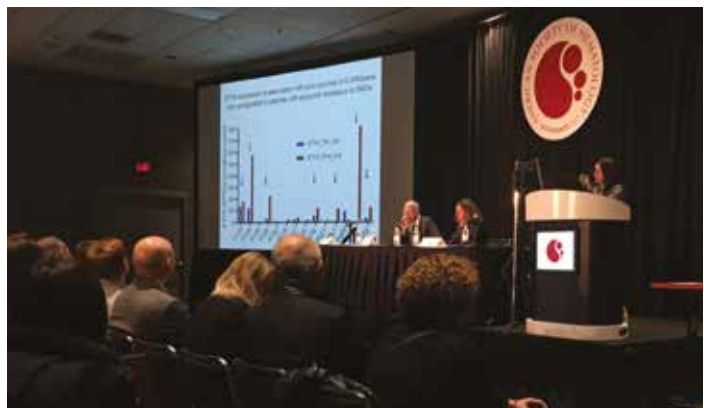
THE PATIENT VOICE HAS A SEAT AT THE MYELOMA CANADA SCIENTIFIC ROUNDTABLE

Thank you to patient representatives Lorelei Dalrymple, Julie Salsman, David McConkey, Hervé Benoît, Julie Gibbons, Keith Taylor, Sofia Tavoularis, Ellis Basevitz, Anthony Everett and Marsha McWhinnie for joining us at the Myeloma Canada Scientific Roundtable on September 15 and 16 in Montreal. Your presence at the event provided valuable input and perspective for our Canadian researchers and reminded them why patients belong at the forefront of clinical trial design.



Patient representatives, from left to right: Sofia Tavoularis, Marsha McWhinnie, Hervé Benoît, Lorelei Dalrymple, David McConkey, Julie Salsman, Keith Taylor and Julie Gibbons

59TH ASH ANNUAL MEETING & EXPOSITION: THE PREMIER EVENT IN MALIGNANT AND NON-MALIGNANT HEMATOLOGY



The American Society of Hematology (ASH) Annual Meeting, the world's most important gathering of hematologists, showcases thousands of scientific abstracts highlighting updates in the hottest topics in hematology. Over 25,000 hematology professionals from every subspecialty were present at this meeting, including many of our MCRN researchers who presented abstracts and posters. Kudos to our team for putting our world-class Canadian talent on the map!

Poster and oral presentations presented by MCRN researchers to the global community were as follows:

ORAL PRESENTATIONS

Deep and Durable Responses in Patients with Relapsed/Refractory Multiple Myeloma Treated with Monotherapy GSK2857916, an Antibody Drug Conjugate Against B-Cell Maturation Antigen (BCMA): Preliminary Results from Part 2 of Study BMA117159

Dr Suzanne Trudel
University of Toronto

Single Cell Resolution Profiling Defines the Innate and Adaptive Immune Repertoires Modulated By Daratumumab and IMiDs Treatment in Multiple Myeloma

Dr Paola Neri
University of Calgary

Transcriptional Plasticity Compensates for Ikaros and Aiolos Proteasomal Degradation and Mediates Resistance to IMiDs in Multiple Myeloma

Dr Paola Neri
University of Calgary



POSTER PRESENTATIONS

Selinexor in Combination with Weekly Low-Dose Bortezomib and Dexamethasone (SVd) Induces a High Response Rate with Durable Responses in Patients with Refractory Multiple Myeloma (MM)

Dr Nizar Bahlis

University of Calgary

Selinexor in Combination with Pomalidomide and Low-Dose Dexamethasone in a Relapsed/Refractory Multiple Myeloma Patient Population with Prior Proteasome Inhibitor and Lenalidomide Exposure

Dr Christine Chen

University of Toronto

Bortezomib Consolidation after Nonmyeloablative Allogeneic Transplant Is Safe and Leads to a High Incidence of Immunophenotypic Complete Response in High-Risk or Young Myeloma Patients

Dr Richard LeBlanc

Université de Montréal

Impact of Active Maintenance Treatment (MT) Compared to No MT on the Quality of Life of Patients with Multiple Myeloma Following First Autologous Stem Cell Transplant (ASCT)

Dr Jason Tay

University of Calgary

A Phase Ib/II Trial of Selinexor Combined with Lenalidomide and Low-Dose Dexamethasone in Patients with Relapsed/Refractory Multiple Myeloma

Dr Darrell White

Dalhousie University

Real-World Outcomes of Newly Diagnosed High-Risk Multiple Myeloma Patients Treated at Princess Margaret Cancer Centre: A Retrospective Chart Review

Dr Donna Reece

University of Toronto

Detection of Minimal Residual Disease in Autograft Is Prognostic of Survival Following Stem Cell Transplant in Multiple Myeloma

Dr Michael Chu

University of Alberta

Minimal Residual Disease (MRD) Assessed By Flow Cytometry in Patients with AL Amyloidosis Treated with Cyclophosphamide, Bortezomib and Dexamethasone (CyBorD)

Dr Victor Jimenez-Zepeda

University of Calgary

Bortezomib Maintenance for Patients with AL Amyloidosis: A Single Centre Experience

Dr Victor Jimenez-Zepeda

University of Calgary



AWARDS AND RECOGNITIONS

Marion State Memorial Myeloma Canada Nursing Award

Cathy Foster, primary care nurse in hematology at the Joseph Brant Hospital (JBH) Cancer Clinic in Burlington, Ontario, was this year's recipient of the Marion State Memorial Myeloma Canada Nursing Award. Cathy has dedicated 25 years to caring for hematology/oncology patients, mentoring nurses, coordinating with the pharmacy team and, most importantly, assisting oncologists and hematologists. She is the only primary hematology nurse employed at the JBH Cancer Clinic. Often described by her colleagues as doing the work of two nurses, Cathy is also known for paying particular attention to patient blood test results, and never hesitating to question what she sees as a critical concern. While always very professional during busy clinic times, she makes the effort to go above and beyond in advocating for treatment access for patients, who regard her as cheerful, vibrant and uplifting. Cathy accepted the award at the December 2 meeting of the Halton-Peel Area Myeloma Support Group.



Pictured above: Norma Lindner, Support Group Leader for the Halton Peel and Area Myeloma Support Group, Cathy Foster and Michelle Oana, Associate Director of Development and Communications at Myeloma Canada

Myeloma Canada created the Marion State Memorial Myeloma Canada Nursing Award in 2012 to recognize excellence in myeloma nursing care. The award is presented annually to a Canadian nurse who has demonstrated distinction and leadership in the care of multiple myeloma patients. Marion State graduated with a diploma in nursing from Toronto General Hospital in 1966 and later obtained a bachelor's degree in nursing from Ryerson University in Toronto. Diagnosed with multiple myeloma in 1996, Marion went on to found the Toronto and District Multiple Myeloma Support Group in 1997—the first myeloma patient group in Canada—providing a valuable example of support to other myeloma patients across the country. Until her passing in 2012, Marion continued to live a full and very productive life.

In addition to this award, Celgene donated \$5,000 to Myeloma Canada in tribute to Marion State.

Congratulations, Cathy, on your well-deserved recognition!

Myeloma Canada/Cancer Research Society Operating Grant



Myeloma Canada, in partnership with the Cancer Research Society, was pleased to announce that Dr Hong Chang, Cancer Clinical Research Unit (CCRU), Princess Margaret Cancer Centre and Affiliate Scientist, Toronto General Hospital Research Institute (TGHRI), was the recipient of the fourth jointly funded Myeloma Canada/Cancer Research Society Operating Grant for his project entitled "Role of MARCKS in multiple myeloma drug resistance." The 2016 jointly funded grant, focusing solely on myeloma research, was for \$120,000 over two years.

By analyzing protein from drug-sensitive and drug-resistant myeloma cells, Dr Chang and his team have discovered a novel protein called pMARCKS (phosphorylated myristoylated alanine-rich C-kinase substrate) that is highly expressed in drug-resistant myeloma cells. They propose to investigate the molecular mechanisms of pMARCKS and validate the protein as an important therapeutic target. To reach their goal they will establish a model to target pMARCKS with specific peptide inhibitors to overcome myeloma drug resistance. Their study will provide a potential new therapeutic strategy to improve the outcomes of patients with the disease.

Congratulations to Dr Chang and his team on moving us one step closer to finding a cure!



**MYELOMA
CANADA**
MAKING MYELOMA MATTER

THE MYELOMA CANADA RESEARCH NETWORK

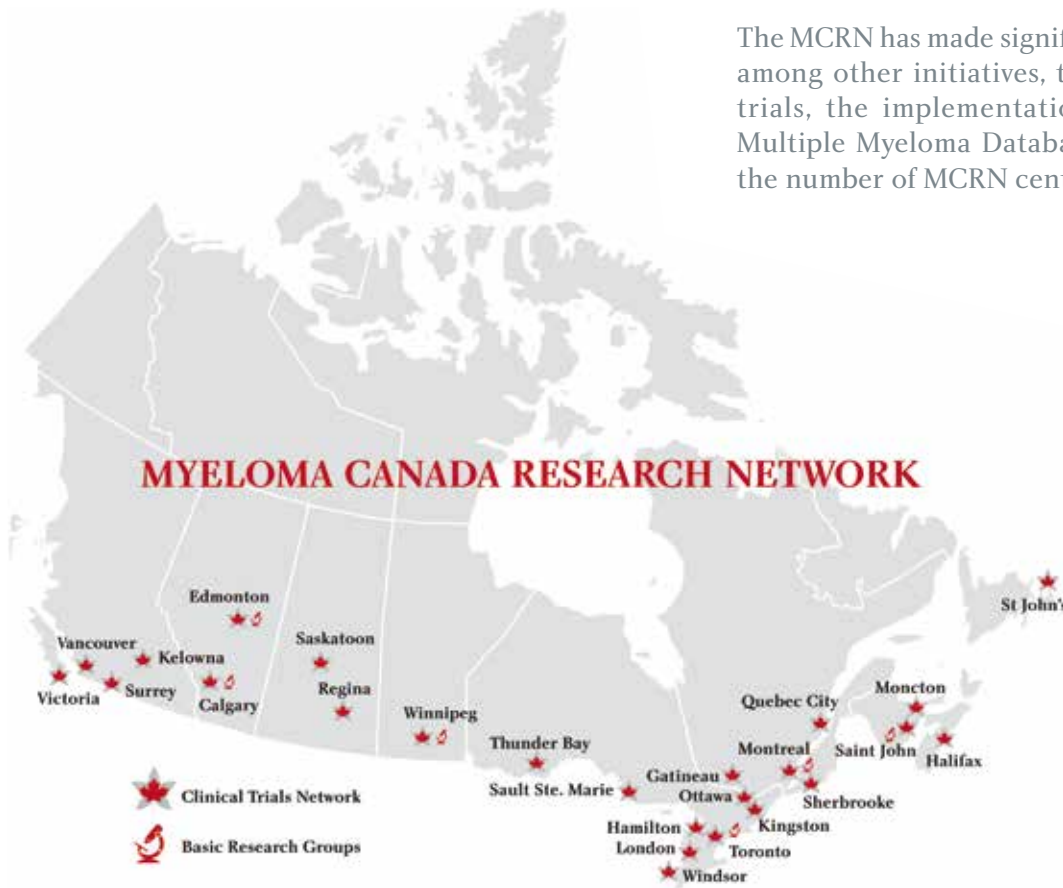
Redefining and Revolutionizing Research. Bringing More Clinical Trials to More Patients in More Centres Across Canada

The mission of the Myeloma Canada Research Network is to:

- Conduct innovative Phase I and II clinical and translational research in a collaborative manner to improve patient outcomes in multiple myeloma
- Publish evidence-based and peer-reviewed consensus statements on the diagnosis and treatment of myeloma
- Develop a nationwide myeloma patient database

One of the ways that Myeloma Canada, as a patient organization, fulfills its commitment to patient-focused clinical research can be seen in its collaboration with the Myeloma Canada Research Network (MCRN). The MCRN is a unique network made up of world-class Canadian myeloma researchers dedicated to bringing Canadian-designed clinical trials to patients across the country, while promoting the sharing of scientific data and clinical expertise amongst its members. The primary objective of the MCRN's work is to accelerate access to new therapies for Canadian patients, leading to improved overall outcomes.

The MCRN has made significant strides in 2017 through, among other initiatives, the activation of two clinical trials, the implementation of the MCRN Canadian Multiple Myeloma Database, and the rapid growth in the number of MCRN centres.



THE MYELOMA CANADA RESEARCH NETWORK (MCRN) IS A TRAILBLAZER IN THE CLINICAL RESEARCH LANDSCAPE THROUGH AN INNOVATIVE APPROACH TO CLINICAL TRIAL DESIGN

The unique aspect of an MCRN clinical trial is its 3-D approach to trial design. When a new trial concept is brought to the table for discussion, the reviewers examine and consider every element that could impact the success of the trial in the Canadian setting, not just the overall response rate to a drug or drugs.

3-D considerations for MCRN clinical trial designs:

Does this make sense for the patient?
During the design process, the patient voice is always included in the steering committee to ensure every decision that is made makes sense for the patient.

This includes, but is not limited to, the number of hospital visits, how the drug is administered, potential side effects and quality of life.

Does this make sense for our Canadian healthcare system?
Given our unique healthcare system, it is important to ensure that the regimen in the clinical trial setting makes sense in the real world. This includes consideration of drug and hospital costs, geography, provincial differences, as well as drug accessibility and potential future funding. Evaluating these elements at the clinical trial design stage has the potential to shape how and which drugs will be funded, and how they will be used in the real-world setting.

Does it work?
All things considered, we must never discount the importance of overall response rate and continue on our quest to find a cure.

By taking this multi-faceted approach to clinical research, the MCRN directly impacts how patients are being treated in Canada and, potentially, globally, and points the way to where we need to go in the future.

MCRN CLINICAL TRIALS AND THEIR UNIQUE FACETS

MCRN 001 – The BuMel Trial

When this trial protocol was being developed in 2012, most Canadian patients did not have access to lenalidomide (Revlimid®) maintenance treatment. Through this trial led by Dr Donna Reece in Toronto, the MCRN was not only able to offer newly-diagnosed patients lenalidomide maintenance following high-dose chemotherapy with autologous stem cell transplantation (ASCT), but also introduced a promising new tool for the management of myeloma—minimal residual disease or MRD. The trial also evaluated the efficacy of a modified conditioning regimen by adding busulfan to a lower dose of melphalan.

MCRN 002 – The STOMP Trial

Led by Dr Nizar Bahlis in Calgary and Dr Christine Chen in Toronto, the STOMP trial is playing a leading role in the clinical development of a promising new molecule, selinexor (KPT-330), a first-in-class selective inhibitor

of nuclear export (SINE™) compound developed by Karyopharm Therapeutics. This has given eligible patients across Canada early access to the innovative therapy.

MCRN 003 – The KCd Trial

Carfilzomib (Kyprolis®) is a new proteasome inhibitor that was approved by Health Canada in January 2016, but is not yet funded by any provincial drug plan. The KCd trial provides access to this new drug to eligible patients with the triplet combination of carfilzomib, cyclophosphamide and dexamethasone. Cyclophosphamide is believed to have immunomodulatory properties and may provide a more cost-effective alternative to other carfilzomib triplet combinations that have been studied.

The currently approved dosing schedule for carfilzomib is twice weekly. The trial, led by Dr Chris Venner from Edmonton, is evaluating a once-weekly dosing regimen that will be more convenient for the patient and also more cost-effective.

NEW RECRUITING TRIALS IN 2017

MCRN 004 – The LAURENTIANS Trial



Daratumumab (Darzalex®) is the first monoclonal antibody for the treatment of myeloma to be approved by Health Canada. Although daratumumab was approved by Health Canada on April 17, 2017, it is not yet covered by any of the provincial drug plans. For many patients in need, a clinical trial is one of the ways to access this treatment. Led by Dr Michael Sebag in Montreal, LAURENTIANS will not only provide access to daratumumab for eligible patients participating in the trial across the country, but it will also answer the question of how to optimize the use of expensive drug combinations through a cost-effective approach.

MCRN 005 – The BOSTON Trial

The **BOSTON** Trial - MCRN005

Karyopharm Therapeutics has turned to Canada to lead a global Phase III randomized clinical trial that will evaluate the efficacy and safety of selinexor (KPT-330), an oral selective inhibitor of nuclear export (SINE™) compound.

This pivotal trial is led by Dr Nizar Bahlis of the University of Calgary in Alberta. The study will compare the combination of selinexor, bortezomib (Velcade®) and dexamethasone (SvD) versus the combination of bortezomib and dexamethasone (Vd) in patients with relapsed or refractory myeloma who have had one to three prior lines of therapy.

BOSTON was designed based on data from the ongoing Phase II (MCRN 002) STOMP trial that has shown encouraging response data in the SvD combination arm, compared to historical response rates with the retreatment of a proteasome inhibitor (such as bortezomib) and dexamethasone alone.

DID YOU KNOW?

To date, 266 patients have been enrolled in an MCRN clinical trial.

DID YOU KNOW?

To date, Myeloma Canada has invested 3 million dollars in research.

THE MCRN CANADIAN MULTIPLE MYELOMA DATABASE TAKES A GIANT LEAP FORWARD

In 2016, The MCRN proudly launched the MCRN Canadian Multiple Myeloma Database—a first of its kind in Canada—to capture relevant data and optimize the care of Canadians across the country living with multiple myeloma, as well as to inform the design of Canadian-based clinical trials. The Database will identify different risk groups as well as gaps in myeloma outcomes. By accurately assessing where we stand now, we can chart the best course for future myeloma research in Canada. The Database, therefore, is a key component in our search for a cure for myeloma.

Throughout 2017, significant progress was made in terms of formalizing partnerships and agreements with participating centres and funnelling legacy data from local hospitals into the national Database. Right out of the gate, legacy data from nearly 6,000 patients was uploaded, and more is in progress. As of 2018, new prospective data will begin to be captured.

The Database, chaired by Dr Chris Venner, is a landmark achievement for the Canadian myeloma community. As the only myeloma database of its kind in the country, it will enable us to pose questions and draw conclusions that will help change practices and shape the treatment landscape for the future.



Dr Chris Venner, Chair of the MCRN Canadian Multiple Myeloma Database

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.

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Hematology Program
Cross Cancer Institute
Edmonton, AB

ACKNOWLEDGEMENTS

Myeloma Canada would like to acknowledge our industry supporters for their help in enabling us to deliver our programs to patients and caregivers across the country:

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MAKE MYELOMA MATTER

Every year, Myeloma Canada provides information to thousands of people with myeloma and their families and caregivers, and helps many more by providing programs and services such as the annual Myeloma Canada National Conference, Patient and Family InfoSessions, the *Myeloma Matters* newsletter and webinars.

That is why we need your help. We depend on support and generous donations from people like you to provide support to myeloma patients, their families and their caregivers. All donations are greatly appreciated and allow us to continue our vital work.



Ways 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.



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20 17

TOGETHER WE ARE
MAKING MYELOMA
MATTER

Spotlight on our Community



SPOTLIGHT ON OUR COMMUNITY

Myeloma Canada is proud to recognize the exceptional efforts put forth by the community in 2017. Your dedication towards advancing our cause has not gone unnoticed and has allowed Myeloma Canada to continue pursuing its mission of making myeloma matter. For this, we are very grateful. Two new MCRN clinical trials were activated; three new educational resource publications were created and published; over 600 letters from the community were delivered to government representatives as part of the Myeloma Canada Advocacy Program; awareness beyond the myeloma community was raised to new levels with national media coverage throughout the year; and the many outstanding events and engagement from coast to coast helped bring our community ever closer together.

Although there is still much more work left to do, as we look back on the past year, we are very proud of all that was achieved, thanks to your passion and dedication. It is with absolute certainty that we can say, together we are making myeloma matter!



2017 MULTIPLE MYELOMA MARCH



MULTIPLE MYELOMA MARCH

WALK THE WALK. MAKE MYELOMA MATTER.



The Multiple Myeloma March is the only annual large-scale fundraiser that exclusively supports the Canadian myeloma community. Each year, people across the country rally for a 5 km walk to increase awareness, raise funds for clinical research and advocacy efforts to accelerate access to game-changing therapies.

Last year marked the 9th edition of the annual Multiple Myeloma March campaign and we were filled with immense pride and gratitude to have witnessed just how far we have come as a community and how we, as Canadians, have rallied together from coast to coast to take action and advance our common goal of making myeloma matter.

This year in particular, we experienced incredible growth with 5 new communities coming on board, bringing us to a record 16 Multiple Myeloma Marches! It is heartwarming and humbling to be a part of this incredible community and see all that is being done regionally to ensure that our voices are heard nationally—loud and clear! In fact, thanks to all the patients and caregivers who

shared their stories, the March was featured over 115 times in the media this year alone. Furthermore, several government representatives heard our call and joined us as we walked the walk to make myeloma matter. We are also pleased to share that several new support groups were formed across the country, enabling many newly diagnosed patients to connect with Myeloma Canada as well as meet members in their local network.

This event has always been, and will always be, about bringing local communities together. We must not, however, discount the impact of every dollar raised. Since 2009, \$3 million has been invested in Canadian myeloma research, including funding for Canadian scientists through the Myeloma Canada Research Grant, and support for the establishment of the Myeloma Canada Research Network (MCRN) and the MCRN National Myeloma Database initiative. In addition, funding of \$640,000 has Myeloma Canada's advocacy programs has supported initiatives to accelerate access to new therapies and better care.

Thanks to you and your teams' generosity and hard work, we have collectively surpassed our fundraising goal of \$500,000, raising a total of \$502,390!

DID YOU KNOW?

Over 3,000 Canadians took part in the Multiple Myeloma March and walked the walk to make myeloma matter.

MULTIPLE MYELOMA MARCH LEADERS

It is important to recognize that, under the guidance of Myeloma Canada, the Multiple Myeloma Marches are organized by dedicated volunteers—vital Myeloma Canada Ambassadors in their respective communities—who are committed to raising awareness among and making myeloma matter to all Canadians. Their support is invaluable and we are grateful for their hard work and dedication.

Thank you to all the 2017 Multiple Myeloma March Leaders and Coordinators!

The 2017 March Leaders and Coordinators:

ENDERBY AND KELOWNA, BC

Ron Surry
Susan Schmaltz

PRINCE GEORGE, BC

Anthony Everett
Paulina Vegt
Cyndi Logan

VANCOUVER, BC

Sherrie Stockley
Danelle Laidlaw
Keith Taylor
Elizabeth Perrotta

KAMLOOPS, BC

Anna Evenrude
Bob Trudeau
Bob Hamaguchi

AIRDRIE, ALBERTA

Pamela Roberts

MELVILLE, SASKATCHEWAN

Lynn Hoffman
Stacey Krushel

WINNIPEG, MB

Kera Leask Prymak
Nori Leask

SAULT STE. MARIE, ON

Pamela Orchard
Judy Mills

KITCHENER, ON

Carlee England

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Rolland Manning

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MONTREAL, QC

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Véronique Bleau
Karine Bleau
Farah Petit-Frère

QUEBEC CITY, QC

Mélissa Landry
Ann Lanouette

HALIFAX, NS

Julie Salsman
Michael Senz
Barbra Beaver
Emily Nickerson
Monique Foran



TOP 2017 MULTIPLE MYELOMA MARCH FUNDRAISERS

It is with appreciation that Myeloma Canada is pleased to highlight the top 2017 Multiple Myeloma March fundraisers for their outstanding efforts:



TEAM COUGARS,
Airdrie

\$31,055



TEAM JULIE,
Quebec City

\$12,863



MARCHE
POUR NATHALIE ALLARD,
Montreal

\$22,295



WALK ON FOR SHAWN,
Kitchener

\$9,043



THE CAPTAIN'S CREW,
Airdrie

\$13,660



LIFE IS GOOD!,
Windsor-Essex County

\$8,635



TEAM MCKEEN,
Vancouver

\$13,145



LYNN'S TEAM,
Windsor-Essex County

\$8,580

SPOTLIGHT ON OUR COMMUNITY



WALK TALKIE,
Kamloops

\$8,205



VÉRONICA GILL,
Montreal

\$6,650



LA GANG DE JEAN,
Montreal

\$8,205



GUY TREMBLAY,
Quebec City

\$6,640



MICHELINE GARAND,
Montreal

\$7,945



OPEN SKY ORCHESTRA,
Winnipeg

\$6,035



EUGENE KOSTYRA,
Winnipeg

\$7,265



TEAM SUSAN,
Vancouver

\$6,000



Aldo Del Col, Co-founder and Chairman at Myeloma Canada, Kim Sullivan, Global News Montreal, Michelle Oana, Associate Director, Development and Communications at Myeloma Canada and Geoffrey Kelley, Minister responsible for Native Affairs

SPOTLIGHT ON PAMELA ROBERTS: AIRDRIE MULTIPLE MYELOMA MARCH LEADER AND CAPTAIN OF “THE COUGARS” TEAM

This event is near and dear to the heart of Pamela Roberts, March Leader in Airdrie, Alberta. Three of her family members have been affected by myeloma, including her brother Greg, who passed away in 2014 after several years of living with the disease.

Determined to make a difference in the lives of people impacted by myeloma, as well as honour her brother's memory, Pamela decided to get involved with the national March by initiating the Greg Roberts Memorial Walk and Run for Multiple Myeloma. Holding the event in Airdrie, Alberta is of special significance to Pamela, as it was the last place Greg lived before his passing.

“When my brother was diagnosed it was shocking. However, in retrospect, he had all the symptoms but had just never been tested for it. It's my hope that by raising awareness about multiple myeloma people will be able to get the help they need sooner, so that they will have a better quality of life during treatment.”

For the second year in a row, Pamela was also the captain of her team “The Cougars,” and was joined by her family and friends in raising funds for the Airdrie March, in memory of Greg. This year, however, they reached a new milestone. Not only were The Cougars the top fundraising team in Airdrie, but also the top fundraisers in all of Canada, raising a whopping \$31,055!

The team at Myeloma Canada would like to applaud Pamela and The Cougars for their dedication and involvement in our cause. Congratulations on achieving new heights this year and for helping make the 2017 March a memorable one.



Volunteer for a Multiple Myeloma March or initiate one in your community!
Get in touch with us at contact@myeloma.ca for details on how to get started.

2017 OTTAWA-GATINEAU MYELOMA WALK: STEPS TO A CURE!

Funding research into and raising awareness of myeloma are critical. On September 24, the Ottawa-Gatineau community took one step closer towards a cure for multiple myeloma at the Ottawa-Gatineau Myeloma Walk, Steps to a Cure! The Walk garnered over 300 participants for a 1 to 5 km walk at the Ron Kolbus Lakeside Centre in Ottawa and raised a record \$71,154 to support the work of Myeloma Canada and the Ottawa General Hospital.

Congratulations to the coordinators for all your hard work in promoting the Walk throughout the summer and for organizing such a successful event!



John Fraser, MPP for Ottawa South, at the ribbon cutting to kick off the 2017 Walk

The Steps to a Cure! coordinators for 2017 were:

David Rideout Robin Sully Gilles Caron
 Frank Shepherd Jean Shepherd Nicole Slunder

Congratulations to the top fundraisers for helping this community achieve a new milestone!



MYELOMA MATADORS
\$16,002



TEAM BUTTERFLY
\$4,480



GILLES CARON
\$10,450



DAVID RIDEOUT
\$3,230



RED HOT CHILI STEPPERS
\$5,091



THINK CURE
\$3,050

SPOTLIGHT ON OUR COMMUNITY

Our docs are walking the walk to make myeloma matter across the country! A big thank you goes out to these heroes for making a difference in the lives of those impacted by myeloma!



Dr Sindu Kanjeekal, Windsor/Essex County



Dr Jesse Shustik (right), Vancouver



Dr Andrea Kew, Ottawa



Dr Victor Zepeda-Jimenez, Airdrie



Dr Julie Côté, Quebec City



Dr Nicole Laferriere (left), Thunder Bay



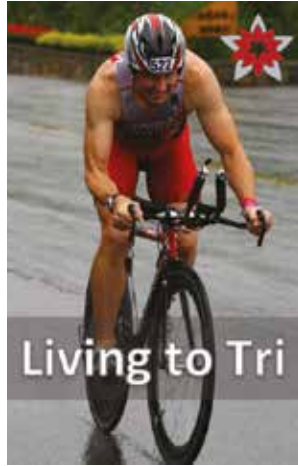
Dr Rami Kotb, Winnipeg

TAKING TO SPORTS FOR MYELOMA CANADA

LIVING TO TRI

“My father, Malcolm Stinson, was diagnosed with multiple myeloma in 2009, at the age of 49. During his stem cell transplant, he kept a positive attitude through physical activity, even bringing his bike with him to the Cross Cancer Institute in Edmonton. Within a year, he was back to competing as a triathlete, and by 2011 had traveled to Beijing for the World Triathlon Championships.

My dad has been active his whole life. He played ice and ball hockey for many years, with accomplishments such as being named to the Ball Hockey Hall of Fame as a “Top Point Leader.” He was also a coach for Team Canada at world ball hockey championships. Since I was 6, my father, along with my younger sister, Victoria, competed in BMX racing at everything from the provincial to world-class level. However, triathlon was his overriding passion. He competed at the Hawaii Ironman and was a 5-time competitor at the ITU World Triathlon Series. I am very proud of my father and all his achievements. He has been a superhero to me since I was a child (especially for his ability to bike down Groat Road exceeding the speed limit and passing cars).



In his professional life, my dad has created and manufactured products carried nationally by Home Depot and Rona, as well as a line of custom interior doors and wainscoting that are sold across western Canada. He now intends to give back to the myeloma community through raising awareness and supporting multiple myeloma research. He’ll do this by taking on a half-Ironman every day during the month of July!”

Triathlon changed Malcolm’s life and now he is using the sport to help and inspire everyone who is battling cancer.

Huge congratulations to Malcolm for completing 30 consecutive half-Ironman triathlons in 30 days with his Living to Tri initiative. Malcolm, a myeloma patient from Edmonton, set out to meet this incredible challenge in order to increase awareness and raise funds for myeloma. He wanted to “show people that not only can you live a full life with myeloma, you can live a great life.” Nearly \$10,000 was raised for the cause!



“My dad has been a superhero to me since I was a child.”

— Heather Stinson
(daughter of Malcolm Stinson, triathlete)



Malcolm Stinson with his two daughters Victoria (left) and Heather (right)

2ND EDITION OF THE PIERRE CORRIVEAU CLASSIC SOFTBALL TOURNAMENT



From August 4–6, the Corriveau family put on the second edition of the Pierre Corriveau Classic Softball Tournament benefiting Myeloma Canada. Sadly, Pierre succumbed to the disease on July 15, just three weeks before the event took place.

Nevertheless, Pierre's family honoured his wishes to move forward with the tournament, paying tribute to him as they played. We would like to extend a sincere thank you to the friends and family of Pierre Corriveau for your support in making myeloma matter. You have certainly honoured Pierre's memory in a very special way.

WALKING TO FIND A CURE FOR MULTIPLE MYELOMA

Determined to make a difference and provide support for research on the disease in Canada, Cécile Paquette Crouchman, along with her friends and family, held a fundraising walk on September 24 in Windsor, Ontario. Undeterred by the 40-degree weather, they managed to raise \$1,177 for Myeloma Canada. Thank you for your fortitude and unwavering resolve in increasing awareness and helping to advance vital research!

SWEAT FOR A CURE FAMILY BOOT CAMP



On August 5 this year, Windsor, Ontario was on fire at the Sweat for the Cure Family Boot Camp benefiting the Windsor-Essex County Multiple Myeloma March! Organized by the local March committee as a fun family event, the local YMCA decided to chip in and help out by donating their space and staff services for the afternoon in order to raise money for this worthy cause. We'd like to commend everyone who came out to sweat their hearts out for their great job

MARATHON TOURS IN PONT-ROUGE, IN HONOUR OF JULIE MARTEL



After one of their peers was diagnosed with multiple myeloma, the nurses in the perinatal department of the CIUSSS de la Capitale-Nationale (Portneuf region) decided to get together to help out a great cause.

Knowing that the money invested in research can really make a difference in the life of patients, they raised funds for Myeloma Canada by taking part in the Marathon Tours in Pont-Rouge on September 10. The team raised \$445!

Congratulations, and thank you for your involvement and support!

FORE! FUNDRAISING GOLF TOURNAMENTS AROUND THE COUNTRY

8TH ANNUAL SCRAMBLE FOR THE CURE

Congratulations for the 8th consecutive time to Gord Ross and his family for organizing an amazing golf tournament in Burlington, Ontario! Over 100 golfers, patients and caregivers from the Halton-Peel community were in attendance to support this annual event, which raised \$27,000 for Myeloma Canada! A special thank you to Natixis Global Asset Management for its very generous contribution and for helping to make the fundraiser possible once again this year.

During the tournament dinner, Myeloma Canada took the opportunity to celebrate Gord's contribution over the last eight years and present him with its Community Achievement Award for 2016. In addition to organizing the golf tournament with his family's help, Gord's commitment to supporting Myeloma Canada has included devoting his time to several local support groups in Ontario. We are pleased to announce the Scramble for the Cure tournament officially achieved a significant milestone in 2016, as it surpassed the \$150,000 fundraising mark!

Gord, your volunteerism and dedication to community is exemplary. We take our hats off to you!



Michelle Oana, Associate Director, Development and Communications, Myeloma Canada and Gord Ross, Event Founder and Coordinator



AECON CHARITY GOLF DAYS



On June 13 and September 12, Myeloma Canada was thrilled to be a part of the 16th Annual Aecon Infrastructure Charity Golf Day in Milton, Ontario and the 1st annual Charity Golf Day in Cochrane, Alberta. Myeloma Canada was extremely pleased to be selected as this year's beneficiary, in honour of an Aecon executive who is currently living with myeloma.

Both sold-out tournaments were beautiful events and a wonderful tribute to one of the company's own. Thank you to Aecon, organizers, sponsors and golfers for supporting Myeloma Canada by taking part in these fundraisers and for making myeloma matter. We're happy to announce that proceeds from both tournaments generated \$50,000 for Myeloma Canada!



LYNN ROUSSEAU MEMORIAL GOLF TOURNAMENT

Saturday, June 3 was the date of the 4th annual Lynn Rousseau Memorial Golf Tournament, in support of Lynn's Team, which takes part in Windsor's Multiple Myeloma March. The tournament raised significant funds for the cause once again this year, making it the top fundraiser in Windsor-Essex County—and one of the top fundraisers in Canada.

Congratulations to Dennis Rousseau and family for helping to raise over \$7,500! Your contribution has not gone unnoticed and is going a long way to help increase awareness of myeloma!



BREAKING BREAD FOR A CAUSE

THE WINDSOR-ESSEX COUNTY MULTIPLE MYELOMA MARCH FLAPJACK BREAKFAST

On May 28, a fun and delicious morning spent at Applebee's in Windsor raised funds for the 2017 Windsor-Essex County Multiple Myeloma March. With guests enjoying a flapjack breakfast, over \$625 was generated for the March!

Thank you to event organizers and March leaders Erma Rounq and Crystal Harvey for organizing this successful event for the second year in a row!



Crystal Harvey, Multiple Myeloma March Co-leader and Co-organizer of the Flapjack Breakfast event

CRESCO ADVISORY GROUP'S CORN MAZE – DUNK YOUR ADVISER

Financial advisers from Calgary's Cresco Advisory Group spent an enjoyable afternoon with 133 clients, friends and family at the Calgary Corn Maze to raise funds for Myeloma Canada. A dunk tank on-site was filled with cold water, providing the opportunity to “dunk your adviser.” Six advisers—good sports all—were dunked, to everyone's amusement. A whopping \$10,500 was collected thanks to Cresco Advisory Group matching the individual donations with a \$5,000 contribution!



A TIME TO CELEBRATE!

HAPPY 60TH BIRTHDAY TO TIM TIEGS!

Thank you for thinking of Myeloma Canada for your milestone birthday celebration! In lieu of gifts, Laurie and Tim Tiegs invited their guests to make a charitable contribution to Myeloma Canada in honour of a loved one living with myeloma. A sizeable \$350 was raised from the event!



2ND ANNUAL SAM'S MONTE CARLO CASINO NIGHT – A TRIBUTE TO RICHARD OANA



On behalf of the Oana family and the team at Myeloma Canada, we would like to sincerely thank all of the sponsors, donors, partners and guests for doing their part to make myeloma matter through the second annual Sam's Monte Carlo Casino Night – A Tribute to Richard Oana. The event was an astounding success and thanks to your generosity, we raised \$48,300 for Myeloma Canada this year!

We would like to thank our corporate sponsors for their very generous contributions to this event: NKF Devencore, Econo-Malls, Mercantile, Canderel, Groupe Montoni, TD Real Estate Group, TD Wealth, Spa Munari and Groupe Petra.

We would also like to highlight the contributions of our event partners, which played a significant role in making the evening a success: Auberge des Gallant, Cava Spiliadis, Beau's All Natural Brewing Company, Sugar Mama and Lise McAuley from CTV Montreal News.

TREVOR OLPERT CONCERT

The annual Trevor Olpert and the Open Sky Orchestra concerts on May 4 and 5 in Winnipeg were once again a success this year, raising over \$6,035 for the cause! Thank you to Trevor and his gang for their continued generosity and for putting on great shows, as well as to event coordinators Abbie Grieder and Heidi Foot for all their hard work in ensuring their success!



GILDA'S GALA

On October 21, 2017, Toronto's Judy Tavares organized a wonderful gala evening in memory of her mom, who passed away 25 years ago from myeloma. Described as a "25-year celebration of life," Gilda's Gala raised \$4,000 in support of Myeloma Canada. Thank you to Judy and everyone who took part in this fantastic event!



currently living with myeloma, so this tribute was one way for Linda to support her sibling's courageous journey and contribute to important research. Thank you to all the guests who donated, raising \$4,100 for the cause! Congratulations and thanks also to the happy couple for thinking of Myeloma Canada on their special day—I'chaim!

There are a number of ways you can make myeloma matter in your community. Host a bake sale. Host a gala. Run a 10 km race. Find the fundraising event that best suits you and go for it.

CONGRATULATIONS TO THE NEWLYWEDS!



On October 15, 2017, Linda Nash-Presidente from Toronto married the man of her dreams. As part of their celebration, in lieu of gifts, the newlyweds asked their guests to make a contribution to Myeloma Canada, a cause that is close to their hearts. Linda's sister is

Looking to plan an event? We can help!

Tell us about your fundraising ideas or ask us for more information. We will provide you with tools, resources, tips, and advice to help make your event a success!

Reach out to us at contact@myeloma.ca

RECOGNIZING OUTSTANDING LEADERSHIP IN THE COMMUNITY

CAROLYN HENRY MEMORIAL TEAM AWARD



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.

This year's award is presented to two women who, for many years and especially in 2017, have made significant strides in advocating for myeloma patients and for access to better care in Quebec. Myeloma Canada would like to applaud the efforts of Maryse Bouchard and Francine Ducas, founders of the "Défi Cyclo-myélome", for leading a very successful Awareness Day at the Quebec National Assembly that was attended by half a dozen MNAs from across the province, as well

as a representative from the Institut national d'excellence en santé et en services sociaux (INESSS). Congratulations for your well-deserved recognition and for advocating on behalf of myeloma patients across the province.

COMMUNITY ACHIEVEMENT AWARD



Determined to help make a difference and support Myeloma Canada in memory of her husband Ken, in 2010 Erma Rounq decided to roll up her sleeves and get involved by organizing the first Multiple Myeloma March in Windsor/Essex County. This year's event attracted 207 participants and raised \$41,000, pushing the seven-year fundraising total to \$215,000. Leading by example, Erma has been instrumental in bringing the community in Windsor/Essex County together and has greatly inspired community engagement from others. In fact, in 2017, the Windsor/Essex County myeloma community was held the highest number of events in Canada, and local participation continues to grow. We would like to congratulate Erma for her achievement in surpassing the \$200,000 milestone, as well as extend our thanks for her constant and enthusiastic involvement in the cause.

NOTABLE VOLUNTEER AWARD



Since she was inspired to help found a local support group after attending her first Myeloma Canada InfoSession for patients and caregivers in Halifax, Julie Salsman's volunteerism in her own community over the years has grown in scope to include the national community, and her engagement has been invaluable in advancing our cause. Her involvement in the many aspects of patient and caregiver support has been exemplary. Locally, she continues to act as a co-leader of the Nova Scotia Myeloma Support Group, as well as a co-leader of the annual Multiple Myeloma March in Halifax. At the national level, Julie serves as vice-chair of the Myeloma Patient Advisory Council and helps coordinate the Myeloma Canada Support Group Network. Launched in 2017, Julie was also instrumental in the development of the Support Group Leader Toolkit and is a member of the Myeloma Canada Advocacy Committee, playing a major role in Awareness Days across the country. Thank you, Julie, for stepping up to the plate and taking action to make myeloma matter.

NEWCOMER AWARD



In just a short amount of time, Rolland Manning, a caregiver from Thunder Bay, Ontario, has made a significant contribution to making myeloma matter in Northern Ontario. Organizing the first-ever Multiple Myeloma March in Thunder Bay, which raised a total of \$11,300, he has also spread awareness by making a splash in the local media 21 times and assisted in setting up the city's first-ever Myeloma Canada InfoSession. As if that weren't enough, Rolland initiated a new Support Group in Thunder Bay, allowing patients and caregivers from near and far to connect with a local network and find help. Thank you, Rolland for putting myeloma on the map in Thunder Bay.



JOIN OUR COMMUNITY



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