

2016

A YEAR IN REVIEW

Myeloma Canada Milestones



**MYELOMA
CANADA**

MAKING MYELOMA MATTER

Myeloma Canada is the only national organization uniquely devoted to the Canadian myeloma community. Founded in 2005 by two myeloma patients, Myeloma Canada is a **patient-driven, patient-focused, grassroots** organization, whose goals are to:

Provide educational resources and support to patients, families and caregivers

Increase awareness of the disease and its effects on the lives of patients and families

Promote clinical research and access to new drug trials in Canada

Facilitate access to new therapies, treatment options and health care resources

**OUR COMMITMENT :
MAKE MYELOMA MATTER**

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

MEET THE TEAM



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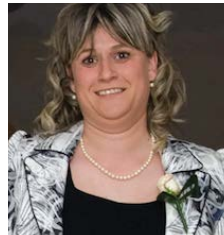
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A MESSAGE FROM ALDO DEL COL CO-FOUNDER AND CHAIRMAN

This past year has been a transformative one for Myeloma Canada. Led by a small, passionate and results-driven team with a renewed focus on grassroots, community-led initiatives, Myeloma Canada made significant advances in our shared cause of improving patient outcomes and making myeloma matter.

From our founding in 2005, we have focused on our four-fold mission of providing community-wide education, raising awareness among key decision makers and the public at large, advocating for universal, funded access to novel therapies and lastly, driving efforts to foster collaboration to help realize Canada's potential to become a world leader in myeloma research. With the collaboration and support of our many stakeholders, Myeloma Canada has come to serve as an international model for patient advocacy, community engagement and research.

The past year we realized several innovative and groundbreaking achievements, including:

- The creation of the Myeloma Canada Research Network (MCRN) as a distinct entity to better focus on advancing Canadian myeloma research. The MCRN now includes 24 centres in 9 provinces across Canada.
- The launch of the MCRN Canadian Multiple Myeloma Database in September attracted widespread interest from patients, researchers, health technology assessment bodies such as pCODR as well as the media.
- The Patient Advisory Council undertook the first national survey of patients and caregivers.
- The activation of clinical trial MCRN 003 in cooperation with the Canadian Cancer Trials Group. The MCRN's third clinical trial will evaluate the efficacy of weekly high-dose carfilzomib in combination with cyclophosphamide and dexamethasone.
- The Myeloma Awareness Day held at the Legislative Assembly of Alberta in Edmonton in November.
- Our national awareness and fundraising event, the Multiple Myeloma March, expanded westward, with new Marches in Calgary, Kelowna and Enderby, raising a record \$512,000.



Our ongoing programs continued to grow and improve, notably:

- Grassroots efforts helped the support group network grow to 24 cities with the creation of new groups in Kingston and Saint John.
- The National Conference, held in Montreal in May, attracted over 230 attendees from across Canada and many others via our live webcast. Additionally, regional InfoSessions were held in Windsor, Quebec City, Kingston and Winnipeg.
- The Scientific Roundtable brought together over 80 participants from Canada, the US and Europe, representing clinicians, researchers, patients and industry partners.
- Our community outreach doubled with the re-launch of our social media pages and online newsletters.
- The Support Group Leaders Summit held in Edmonton attracted a record 24 participants from across the country.
- Internationally, Myeloma Canada was invited to participate in the Global Myeloma Action Network meetings in Copenhagen and San Diego and a global Patient Advisory Board meeting in Zagreb.
- A record number of Canadian myeloma researchers were invited to present their work at the prestigious American Society of Hematology meeting held in San Diego in December.

We could not have successfully undertaken our many programs without the participation and support of our many stakeholders and partners – patients and caregivers, local support groups, doctors, nurses and other healthcare professionals, researchers, the pharmaceutical and biotechnology industries, international myeloma organizations, other Canadian patient and advocacy groups and federal and provincial regulators. Myeloma Canada, with your support, has come to play a leadership role in setting new standards for patient organizations.

The current research environment has never been as prolific and dynamic, providing patients with increased options for treatment, with the hope that in the not too distant future myeloma will be re-classified as a chronic rather than an ultimately fatal disease.

Despite our many achievements, however, many challenges remain in 2017 and beyond, not the least of which is public funding for innovative treatments that result in improved survival outcomes. A record four new myeloma treatments were approved by Health Canada in 2016, but none have thus far been approved for government funding.

Myeloma Canada will continue to work hard to make our collective voices heard to ensure you will hear more from us, and more often, about our programs for 2017. At this time, I wish to personally thank all our stakeholders and, in particular donors and volunteers, for their help in making 2016 the success that it has been.

We count on you to continue to demonstrate your passion and commitment to our shared cause of improving patient outcomes.

A MESSAGE FROM THE LEADERSHIP TEAM



Martine Elias
Director of Access, Advocacy
and Community Relations

Throughout 2016 we made a record number of submissions to the government bodies that decide if and how myeloma cancer drugs should be paid for in Canada. These submissions cannot be made without the input of many myeloma patients and their caregivers. Your input and comments collected through the numerous surveys we sent throughout the year are used to develop a comprehensive document that highlights patient and caregiver perspectives to the decision makers. I thank all of you who have completed the surveys. For those who have not, we will have more for you to participate in during 2017.

This past year we supported the establishment of three new support groups in Saint John, Kelowna and the Kingston area. Myeloma Canada now works with 24 support groups located in all ten provinces. I am confident we will see more support groups created in other areas across the country. There are notable cities where there are no support groups – such as Vancouver and Quebec City. If anyone is interested in starting a new support group, please contact me. It is not difficult and Myeloma Canada is here to help, especially as we now have a new Support Group Leaders Toolkit, developed by a wonderful group of support group leader volunteers.

Myeloma patients and their families have much to look forward to in 2017. Several new therapies approved during the last 12 months in Canada will start to make their way through the reimbursement and provincial listing processes across the country and will ultimately provide access to these game-changing treatments. Ensuring that patients have access to these drugs fuels my passion and gives me the drive to do what

I do. The upcoming year will be an exciting one, but will also require hard work from everyone in the community to ensure patient voices are heard.

I look forward to working with other cancer patient organisations and partners to engender changes in how the different governments in our country manage cancer health policies to make sure they are patient-focused, make sense for you and improve your health outcomes.



Olivier Jerome
Director of Operations

In the spirit of pursuing our mission and carrying out the strategic plan put forward by the Board of Directors and the Myeloma Canada staff, it was a great honour for me to join the team as the Director of Operations earlier this year. From the very beginning, I was not only drawn to Myeloma Canada's mission and vision, but also impressed by the breadth of patient programs and the strong scientific leadership of this patient organization.

2016 highlighted Myeloma Canada's renewed passion and commitment towards the myeloma community demonstrated by the impressive number of activities and programs achieved. Moreover, the high level of

engagement from all stakeholders in the myeloma community has ensured the success of our programs and sustainability for the future.

This commitment begins at the local level with patients, caregivers and families who come together in their communities to participate in the various initiatives such as InfoSessions, Support Groups, educational seminars and events, in order to raise awareness and drive change.

Engagement is also reflected in the increasing number of industry partners who, in addition to supporting our patient programs, contribute generously to scientific research and clinical trials through the MCRN.

Our superb team, the binding glue for all of our various stakeholders, is the driving force behind Myeloma Canada's programs, as well as the voice of the patients, caregivers, researchers, healthcare professionals and industry partners. Thank you all for your renewed support, generosity and dedication.

We look forward to working with you in 2017 in the pursuit of our common goal to make myeloma matter.

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RECOGNIZING
ACHIEVEMENTS

Myeloma Canada Milestones

Thanks to the committed team at Myeloma Canada along with the dedication and support from the myeloma community across the country, Myeloma Canada made momentous strides in 2016 by increasing awareness, empowering patients and their caregivers through education, facilitating access to new therapies and driving research, and serving as an international model for patient advocacy, grassroots community engagement and research.

Keeping in line with the four pillars of our mission - Education, Awareness, Access and Advocacy, and Research – we are proud to share with you Myeloma Canada's outstanding achievements throughout 2016.

EMPOWERMENT THROUGH EDUCATION

As the only national organization uniquely devoted to the Canadian myeloma community, Myeloma Canada continually works to educate and empower all patients, caregivers and healthcare professionals 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 cities across Canada. InfoSessions are generally half-day sessions that address many aspects of living with myeloma including treatment options, interpretation of blood tests, management of side effects, new myeloma therapies and MCRN updates. **Over the past 10 years, Myeloma Canada has organized 33 InfoSessions, from St John's, NL to Victoria, BC and cities in between.**

To further maximize and strengthen our community outreach, Myeloma Canada offered live webcasts for those who could not attend an InfoSession in person. The recorded InfoSessions are available on Myeloma Canada's YouTube Channel.

- ♥ In 2016, Myeloma Canada hosted four InfoSessions in Kingston, Winnipeg, Windsor and Quebec City.
- ♥ There are over 98 educational videos available on the Myeloma Canada YouTube channel.



KINGSTON INFOSESSION

From left to right: Dr. Hugh Langley, Primary Physician, South East Regional Cancer Program, Annette Hay, Hematologist, Canadian Cancer Trials Group, Leslie Weatherby, Co-bourg Support Group Leader, Dr John Matthews, Hematologist, Kingston General Hospital and Aldo Del Col, Co-founder and Chairman, Myeloma Canada

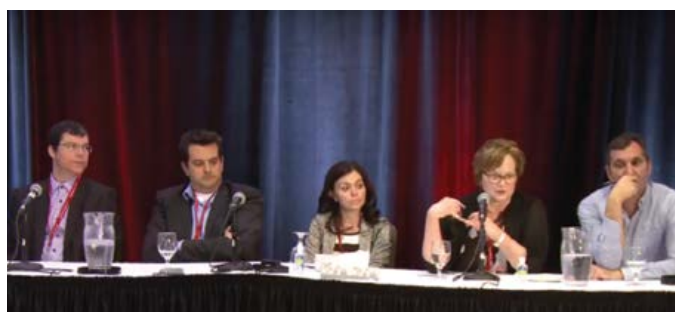


WINNIPEG INFOSESSION



THE 12th ANNUAL MYELOMA CANADA NATIONAL CONFERENCE

“There was clearly sincere applause after each speaker, and for the Conference as a whole. The atmosphere was positive throughout, and I believe attendees went home feeling better than when they came.”



From left to right: Dr Richard LeBlanc, Dominic Duquette, Dr Paola Neri, Dr Donna Reece, Dr Michael Sebag

It was a full house!

Myeloma Canada extends a heartfelt thank you to all the participants who joined us for the 12th Annual National Conference in Montreal, as well as those who participated via the live webcast. It was an overwhelming success with over 230 patients, caregivers and medical professionals in attendance. The Conference was an exceptional opportunity to bring together the myeloma community to share new and valuable information, exchange useful tips and knowledge, and connect with other patients, caregivers, support groups, the medical community, and of course, the Myeloma Canada team.

THIS YEAR'S FEATURED SPEAKERS INCLUDED:

Monique Papillon

Master of Ceremonies

Julie Côté, MD

Hematologist-oncologist, Centre hospitalier universitaire (CHU) de Québec, Quebec City

Lorelei Dalrymple

Western Canada Representative and Interim Chair, Myeloma Canada Patient Advisory Council, Edmonton

Aldo Del Col, RPh, BScPhm, MBA

Co-founder and Chairman, Myeloma Canada and Myeloma Canada Research Network, Montreal

Dominic Duquette, MScPhm

Pharmacist, Coordinator of Pharmaceutical Services and Care, CHU, Quebec City

Martine M. Elias, BSc, MSc

Director of Access, Advocacy & Community Relations, Myeloma Canada, Montreal

Martin Gyger, MD

Hematologist-Oncologist, Sir Mortimer B. Davis-Jewish General Hospital and Professor of Medicine, McGill University, Montreal

Richard LeBlanc, MD

Hematologist and Oncologist, Maisonneuve-Rosemont Hospital, Montreal

Suzanne Lentsch, MD, PhD

Associate Professor of Medicine and Director of Multiple Myeloma Service, Columbia University Medical Center, New York

Paola Neri, MD, Ph.D.

Clinical Associate Professor of Medicine and Attending Physician, Hematology, Southern Alberta Cancer Research Institute, University of Calgary, Calgary

Donna E. Reece, MD, FRCPC

Program Director, Multiple Myeloma and Related Diseases, Princess Margaret Hospital, Toronto

Denis-Claude Roy, MD, FRCPC

Director of the Centre de recherche Hôpital Maisonneuve-Rosemont and Centre of Excellence in Cellular Therapy, Hôpital Maisonneuve-Rosemont, Montreal

Michael Sebag, MD, Ph.D.

Hematologist, McGill University Health Centre, Montreal

Christopher Paul Venner, MD

Hematologist and Assistant Professor, Medical Oncology, Cross Cancer Institute, Edmonton

Teresa S. Miceli, RN, BSN, OCN

BMT RN Care Coordinator, Mayo Clinic, Rochester

We would also like to express our gratitude to the event sponsors, Celgene, Takeda, The Binding Site, Bristol-Myers Squibb, Janssen and Novartis. And lastly, a special thank you to all the dynamic speakers, dedicated volunteers and staff for making this event possible. To view the recorded sessions, visit the Myeloma Canada YouTube channel.



“I am a renal pathologist working in Montreal, and I have attended the last National Myeloma Canada Conference in Montreal. Following the event, I felt I had to tell you how deeply touched I was by it.

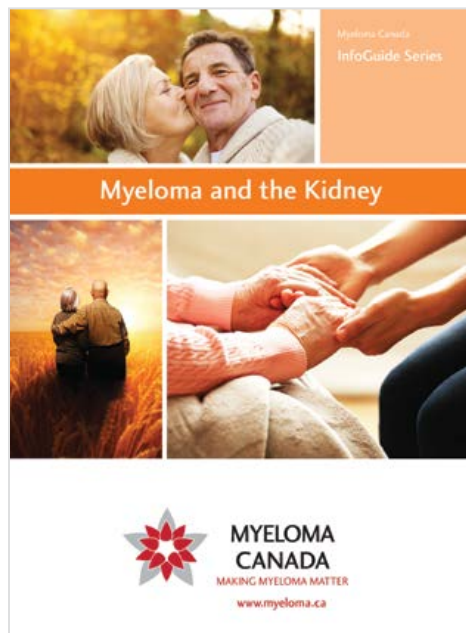
It was my first Myeloma Canada meeting, and I was profoundly impressed by the amplitude of it: I saw involved patients and dedicated health professionals working together to better understand and fight the disease. It was beautiful, and this is why I wanted to thank you and all your team for the work you accomplish.”

MYELOMA CANADA PATIENT HANDBOOK AND INFOGUIDES



Myeloma Canada offers several educational resource guides that are available online and in print. These include: the Multiple Myeloma Patient Handbook, Understanding Your Blood and Blood Test InfoGuide and the Bone Disease InfoGuide. New in 2016 was the Myeloma and the Kidney InfoGuide. Our educational material is distributed through hospital libraries, myeloma clinics, support groups, educational and awareness events as well as directly to patients and caregivers.

📍 Did you know each year over 10,000 Handbooks and InfoGuides are printed and distributed across the country to patients, caregivers and the medical community?



MYELOMA CANADA LAUNCHES A NAVIGATOR PROGRAM FOR PATIENTS AND THEIR FAMILIES

You spoke and Myeloma Canada listened! This past October, Myeloma Canada announced the launch of a new initiative that provides helpful advice to myeloma patients and their caregivers. This new program, which is available to all patients, whether newly-diagnosed or long-term survivors, is intended to help better navigate the health care system and other services.

Spearheading this important new service is Debbie Basevitz. As a peer-to-peer navigator for our Canadian myeloma community, Debbie provides guidance and insights in navigating the healthcare system to help patients identify resources available to them and how to get the care they need.

We could not have a better person for the role! Debbie is the wife and caregiver of a myeloma patient. Following her recent retirement from a fulfilling career as a pediatric nurse in Montreal, Debbie approached Myeloma Canada and volunteered to initiate a peer-to-peer navigator program, something she felt could be of great benefit to our community. In her professional and private life, she has been a fierce advocate for securing the best possible care and support for her husband, her family, and the infants she cared for. From first-hand experience, she has strong knowledge of healthcare system in Canada and will be able to provide valuable insights as to how to navigate the system.



Available Monday to Friday from 9:00am to 5:00pm Eastern Time, you can contact **Debbie** by email to arrange a mutually convenient time to begin your dialogue at debbiebasevitz@gmail.com

Our new peer-to-peer navigator program is another way Myeloma Canada is making myeloma matter.

SUPPORT GROUP LEADERS SUMMIT



Focusing on grassroots patient outreach, Myeloma Canada works with 24 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 order to empower and facilitate the support group leaders in their important work, Myeloma Canada hosts a national Support Group Leaders Summit each year, where leaders from across the country are invited to learn and exchange, discuss common issues, challenges and best practices. This year's summit was held in Edmonton, on November 4th and 5th. A highlight of the two-day meeting was the unveiling of the new Support Group Leaders Toolkit, which was enthusiastically received by everyone. Special thanks to Martine Elias, Julie Salsman, Robin Sully, Norma Lindner, Lorelei Dalrymple and Linda Latham for their hard work in creating this invaluable tool to help support group leaders in the important work they do in their local communities.

OUR DEDICATED SUPPORT GROUP LEADERS FROM COAST TO COAST

- | | |
|------------------|----------------------------------|
| St. John's, NF | David McConkey & Stephen Norman |
| Charlottetown | Fran Freyer |
| Halifax | Julie Salsman & Trish MacDonald |
| Saint John, NB | Susan Collins |
| Montreal | Joanne Kerry & Hervé Benoit |
| Ottawa | Robin Sully & Jean Shepherd |
| Kingston | Iris Philips |
| Cobourg | Leslie Weatherby |
| Halton-Peel | Norma Lindner |
| Toronto | David McMullen |
| London | Ev McDowell & Jeff Parton |
| Windsor | JoAnn Cartlidge |
| Sault Ste. Marie | Marion Bentley |
| Winnipeg | Tom Roche |
| Regina | Mona Nehar & Sharon Macintosh |
| Saskatoon | Judi Worth & Sonja Gabruch |
| Edmonton | Bob Thiessen & Lorelei Dalrymple |
| Calgary | Norma Gilbert & Phil Unland |
| Kelowna | Ron Surry & Germaine Nadon |
| Vernon | Marlene Godfrey |
| Salmon Arm | Linda Quintal |
| Victoria | Bob Calnan |
| Nanaimo | Dianne Martin & Allison Jennings |
| Campbell River | Linda Latham |

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 12 years, Myeloma Canada has undertaken several activities to increase overall awareness to make myeloma matter.

FAMILY MEDICINE FORUM

Representatives from Myeloma Canada and patients living with myeloma recently attended the Family Medicine Forum in Vancouver to raise awareness of myeloma with family doctors. As many patients can attest to, a timely diagnosis remains a significant challenge and in the majority of cases, patients are diagnosed at an advanced stage, after they suffer bone or kidney damage. Given that the presenting symptoms are often “vague” (e.g. fatigue, back pain) and most people who develop myeloma are in their mid-60’s or older, often times the appropriate follow-up or diagnostic tests are not done, thereby delaying the diagnosis. With over 2,000 family doctors in attendance at this year’s event, the Family Medicine Forum proved to be an excellent opportunity to highlight the symptoms to look out for and promote the importance of a timely diagnosis. Thank you to Lorelei Dalrymple, Ev McDowell, Martine Elias and Tony and Kara Malley, for assisting Myeloma Canada in bringing awareness to family physicians about the importance of early diagnosis.

CANADIAN ASSOCIATION OF ONCOLOGY NURSES (CANO)



Martine Elias and Aldo Del Col representing Myeloma Canada at CANO

Martine Elias, Director of Access, Advocacy and Community Relations, and Aldo Del Col, Co-founder and Chairman, represented Myeloma Canada at the Canadian Association of Oncology Nurses (CANO) annual conference held recently in Calgary. Oncology nurses play an integral role in patient care and are often the primary source of information. By highlighting the educational material that is available, as well as promoting the support groups across the country, nurses will be better able to help and support their patients in their times of need. With over 500 nurses in attendance this year, Martine and Aldo were kept busy raising awareness of Myeloma Canada’s patient services and distributing educational material. Building strong working relationship with nurses supports Myeloma Canada’s goal of reaching out to influential stakeholders to strengthen our coast-to-coast networks.

AWARENESS DAY

Each year, Myeloma Canada hosts an Awareness Day in provincial legislatures, to meet with elected officials and the Ministry of Health to increase awareness of the disease and share the challenges patients face living with myeloma, with the ultimate goal of advocating for provincial funding of new therapies. Since 2014, Myeloma Canada has organized Awareness Days in both Ontario and Quebec; this year's focus was on Alberta.

Thank you to both patient support groups in Alberta, the Southern Alberta Myeloma Patient Society (SAMPS) and the Myeloma Alberta Support Society (MASS) for representing and advocating for the myeloma community in Alberta, alongside Myeloma Canada. Together, we are making a difference!



From left to right: Dr Bob Turner, Edmonton MLA, Dr Jason Tay, Tom Baker Cancer Centre, Dr Irwin Sandhu, Cross Cancer Centre, Dr Chris Venner, Cross Cancer Centre, Debra Drever, Calgary MLA and Aldo Del Col, Co-founder and Chairman, Myeloma Canada



From left to right: Nicole Goehring, Edmonton-Castle Downs MLA, Aldo Del Col, Co-founder and Chairman, Myeloma Canada, Lorelei Dalrymple, Patient Advisory Council and Support Group Leader of the Myeloma Alberta Support Society, Jon Carson, Edmonton-Meadowlark MLA, and Michael Chibuk, Myeloma Alberta Support Society

MEDIA OUTREACH



Martine Elias, Director of Access, Advocacy and Community Relations

Throughout 2016, Myeloma Canada made a significant footprint in an array of mass media outlets. Through TV, radio, online newspapers, print and social media, the level of coverage and reach was unprecedented. Myeloma Canada directed a substantial amount of attention toward raising disease awareness, new Health Canada drug approvals, the Multiple Myeloma March, and the launch of the ground-breaking Myeloma Canada Research Network Canadian Multiple Myeloma Database. Media highlights included: CTV News, Global News, Best in Health Radio, The National, Radio Canada, RDI, Journal de Québec and CBC.

Myeloma Canada was featured over 90 times in the media in 2016.

Myeloma Canada also became very active on various social media platforms in 2016. The number of followers and subsequent community engagement increased dramatically in 2016, not to mention the dozens of local community pages that share and engage in Myeloma Canada's postings, allowing for increased awareness of Myeloma Canada and its valuable programs.

There are over 3,000 followers on Myeloma Canada's social media platforms.



MYELOMA CANADA WEBSITE

The Myeloma Canada Team has been working diligently over the last several months to prepare for the completely re-designed interactive website that will be launched in the first quarter of 2017.

The sleek new design is very user friendly, clean and responsive on mobile and tablet devices. Although many areas of the website will remain similar to current content, additional areas will be further developed and emphasized. These areas include:

- Fundraising and ways to get involved
- Community events, meetings and conferences
- Support Group pages
- Myeloma Canada Research Network microsite
- Multiple Myeloma March microsite
- Advocacy programs
- Social media links
- Online patient management portal




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 AND CAREGIVER SURVEYS

Although the prevalence of myeloma in Canada is increasing, it remains a relatively unknown disease, often resulting 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 influence recommendations and reimbursement decisions of myeloma treatments by Health Technology Assessment (HTA) agencies such as the pan-Canadian Oncology Drug Review (pCODR) and l'Institut national d'excellence en santé et en services sociaux (INESSS), and provincial payers. One of the ways Myeloma Canada meets this objective is by conducting patient and caregiver 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 the patient experience and gather their valuable input.

 In 2016, Myeloma Canada collected information via surveys from over 1,000 patients and caregivers and conducted close to 100 one on one interviews.

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. The Awareness Day in provincial legislatures is an example of ensuring health policy makers and payers are educated about myeloma, so that we are in a more favourable position to have drugs funded. Myeloma Canada also partners with patient advocacy groups, specifically in Alberta and Ontario by supporting province-specific advocacy efforts. Myeloma Canada is also active internationally, as a founding member of the Global Myeloma Action Network (GMAN). The GMAN brings together advocacy leaders in myeloma to mobilize the myeloma community to improve the lives of patients around the world.

Over the years, an unprecedented number of new treatments have become available to Canadian myeloma patients thanks to the advocacy efforts and collaboration of Myeloma Canada with its industry partners and advocacy groups across the country.

SUBMISSIONS TO THE PAN CANADIAN ONCOLOGY DRUG REVIEW (pCODR) AND TO INSTITUT NATIONAL D'EXCELLENCE EN SANTÉ ET EN SERVICES SOCIAUX (INESSS)

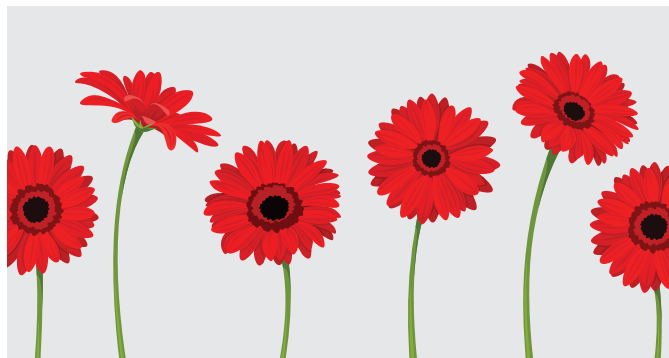
The pan-Canadian Oncology Drug Review (pCODR) undertakes rigorous, objective reviews of cancer drugs and provides funding recommendations to Canada's provinces and territories (excluding Quebec). The funders use this information as one element of their decision-making process to determine if a drug will be eligible for public reimbursement. 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.

Listening to patients is a vital part of pCODR's work. They recognize that patients have a unique knowledge about what it is like to live with a specific disease or medical condition. What patient experience may not be reported in published literature. Patient value can be important to share with payers and pCODRs decision makers.

In 2016 Myeloma Canada conducted two major surveys amongst patients and caregivers in Canada and in the US to evaluate disease impact on quality of life, patient needs, treatment expectations and impact of new therapies. These surveys serve to inform and populate Myeloma Canada's patient submission to the pCODR.

♥ In the last year Myeloma Canada produced 3 patient submissions to pCODR. They were for daratumumab (Darzalex), carfilzomib (Kyprolis) in combination with dexamethasone, and for ixazomib (Ninlaro) in combination with lenalidomide (Revlimid) and dexamethasone.

Early in 2016 pCODR initiated a new pilot initiative to increase opportunities for clinician input and feedback in the pCODR review process. This allows for clinician input to be incorporated into the pCODR process in a formal and meaningful way.



♥ Working with the members of the MCRN, Myeloma Canada coordinates this input process of behalf of clinicians.

L'Institut national d'excellence en santé et en services sociaux (INESSS) also invites patient organizations to submit input to their drug reviews.

♥ Myeloma Canada provided submissions for carfilzomib (Kyprolis) in combination with dexamethasone and Revlimid and for daratumumab (Darzalex).

HEALTH CANADA APPROVALS AND PROVINCIAL DRUG FUNDING DECISIONS

This past year, Health Canada approved four new drugs for the treatment of myeloma, more than have been approved over the past ten years. Health Canada approval, however, is only the first step in the long process of securing provincial funding for public drug programs.

Health Canada approvals

Kyprolis® (carfilzomib): January 15, 2016

Empliciti® (elotuzumab): June 21, 2016

Darzalex® (daratumumab): June 29, 2016

Ninlaro® (ixazomib): August 8, 2016

PROVINCIAL DRUG FUNDING ANNOUNCEMENTS

- In March 2016, **Pomalyst**® (pomalidomide) in combination with **dexamethasone** as third-line therapy and beyond for patients with multiple myeloma was approved for reimbursement on the Régie de l'assurance maladie du Québec (RAMQ)
- On October 18, 2016, Alberta Health Services announced that **Revlimid**® is funded as a first line treatment in patients with multiple myeloma who are not eligible for an autologous stem cell transplant. Criteria are as follows: Treatment should be in combination with dexamethasone for patients with *ECOG PS < 2 and until disease progression.
- As of October 26, 2016, The Saskatchewan Cancer Agency announced that **Revlimid**® is funded as a first line treatment for patients with multiple myeloma who are not eligible for an autologous stem cell transplant. Criteria are as follows: Treatment must be given in combination with dexamethasone for patients with an *ECOG performance status of less than or equal to 2 and continued until disease progression.
- On November 8, 2016, the Yukon drug plan announced that **Revlimid**® is funded as a first line treatment for patients with multiple myeloma who are not eligible for an autologous stem cell transplant. Criteria are as follows: Any newly diagnosed multiple myeloma patient as an option for first line treatment who are not eligible for an autologous stem-cell transplant. Treatment should be in combination with dexamethasone for patients with an ECOG performance status less than or equal to 2 and continued until disease progression.

- On December 1, 2016, Nova Scotia announced that **Revlimid**® is now funded as a first line treatment for patients with multiple myeloma who are not eligible for an autologous stem cell transplant. Criteria are as follows: Treatment should be in combination with dexamethasone for patients with ECOG performance status 0-2, and until disease progression

* **ECOG definition:** ECOG Performance Status. These scales and criteria are used by doctors and researchers to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient and determine the appropriate treatment.

We would like to thank the patient and caregiver community who participated in Myeloma Canada's advocacy efforts throughout the past year. By working together, we become stronger. By speaking as a unified voice for the Canadian myeloma community we have made a difference.



THIRD PARTY KEY PARTNERSHIPS

Myeloma Canada partners with other patient organizations and coalitions to drive change in the health care system toward a more favourable patient-focused healthcare environment. We engage and 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 by either intervening ourselves or by working in association with other cancer partner groups.

In 2016, we partnered with aligned cancer groups to create an immuno-oncology network for patient organizations. The patient network aims to become a leader and important resource in the fast-developing area of immuno-oncology. This includes promoting a greater understanding of immuno-oncology and its value among policymakers, regulatory and HTA agencies, healthcare professionals, patients and the general public.

Myeloma Canada also became an active member on the board of the Canadian Cancer Action Network (CCAN), another channel to influence and ensure the patient voice is heard.

Finally, although Health Canada approvals and provincial funding are crucial to gain access to new therapies, Myeloma Canada also helps shape the private insurance landscape by bringing awareness to the decision makers in the private sector and advocating for drug reimbursement.

In 2016, Myeloma Canada collaborated with other cancer organizations to ensure the Manulife DrugWatch program was modified to address cancer patients needs who are covered under a private drug plan.

EDUCATION ON ADVOCACY

On November 6, Support Group Leaders from coast to coast took part in Myeloma Canada's Annual Advocacy Summit. By engaging patient leaders across the country we are able to drive engagement and mobilize the local communities to take action and help improve the ecosystem patients live in every day. An important learning tool and common theme for the Advocacy Summit event was 'how to self-advocate'. Seminar topics included:

- Learning how to become a strong advocacy leader and engaging others in the Support Group
- A review of new and existing therapies
- Developing practical advocacy tactics and action plan driving to success
- Defining an advocacy issue and using tools to develop an action plan

Thank you to Julie Salsman, Norma Lindner, Robin Sully, Nancy Shamanna, Ron Surry, Lorelei Dalrymple and Linda Latham for assisting with the planning of both the Support Group Leaders and Advocacy Summits held on November 4-6 in Edmonton.

In 2016, 26 Support Group Leaders participated at the Advocacy Summit held in Edmonton.



Kathy Kovacs Burns, MSc., MHSA, PhD. Director Alberta Health Services, leading a seminar and practical workshop on how to self-advocate and engage others

PATIENT DRIVEN. PATIENT FOCUSED.

Research and collaboration with key academic and industry research partners are at the forefront of Myeloma Canada's research programs. Bringing more trials to more patients in more centres across Canada will continue to drive Myeloma Canada's mission in 2017.



MYELOMA CANADA SCIENTIFIC ROUNDTABLE

On September 16 and 17, Myeloma Canada hosted the 7th annual Myeloma Canada Scientific Roundtable in Montreal. Co-chaired by Dr Tony Reiman from Saint John and Dr Chris Venner from Edmonton, the meeting brought together over 80 stakeholders, including Canada's top myeloma experts from coast to coast, scientists from the USA and Europe, our industry research partners and patients. This year's guest speakers included Dr Ola Landgren from Memorial Sloan Kettering Cancer Center in New York; Dr Antonio Palumbo; Dr Marta Chesi and Dr Leif Bergsagel from the Mayo Clinic in Scottsdale; Dr Noemi Puig from University Hospital in Salamanca, Spain; Dr David Murray from the Mayo Clinic in Rochester; Dr Jonathan Keats from the Translational Genomics Research Institute in Scottsdale; and Dr Don Morris, this year's recipient of the Myeloma Canada/Cancer Research Society Research Grant, from the Tom Baker Cancer Centre in Calgary.

A wide range of current topics in myeloma research were discussed, including minimal residual disease (MRD), genomics, cell therapy, oncolytic viral therapy and individualization of myeloma therapy using risk stratification models.

Additionally, clinical trial ideas incorporating innovative immuno-oncology strategies were discussed resulting in three new MCRN clinical trials that will be further developed.

The meeting is 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 Scientific Roundtable was a huge success, with each year proving to be better than the last. The highly valuable presentations and topics sparked important discussions, the sharing of ideas and forward-thinking thought processes.



Dr Donna Reece from the Princess Margaret Cancer Centre in Toronto



Celgene's Patient Partner Meeting: Catalizing Excellence in Advocacy

MEMBERS OF THE MCRN INVITED TO PRESENT AT THE PRESTIGIOUS AMERICAN SOCIETY OF HEMATOLOGY (ASH) MEETING IN SAN DIEGO

Each year, Myeloma Canada is present at the world's premier event in hematology, the ASH Annual Meeting. Not only an opportunity to meet and exchange with key researchers, industry partners and patients, Myeloma Canada also hosts a meeting with of the MCRN to discuss the latest developments in myeloma research and to develop new clinical trial proposals.

Furthermore, at the upcoming ASH meeting in San Diego, a record number of MCRN investigators were invited to present updates on their research studies.

MCRN 001 – **Dr Donna Reece,** Princess Margaret Cancer Centre, Toronto.

Poster presentation “Myeloma Canada Research Network (MCRN)-001 ASCT study of Busulfan + Melphalan (BuMel) conditioning followed by lenalidomide maintenance: Updated results including serial Minimal Residual Disease (MRD) and involved Serum Hevylite™ Chain (HLC) ratio assessments”.

MCRN 002 – **Dr Nizar Bahlis,** Tom Baker Cancer Centre, Calgary.

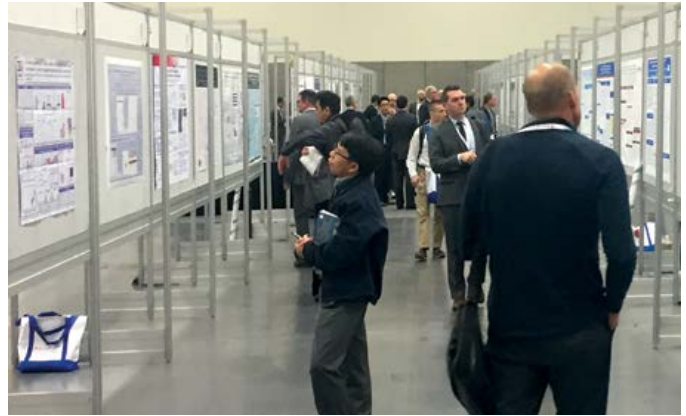
Oral presentation “Selinexor in combination with bortezomib and dexamethasone (SdB) demonstrates significant activity in patients with refractory multiple myeloma including proteasome-inhibitor refractory patients: Results of the Phase I STOMP Trial”.

MCRN 002 – **Dr Christine Chen,** Princess Margaret Cancer Centre, Toronto.

Poster presentation “Selinexor shows synergy in combination with pomalidomide and low-dose dexamethasone in patients with relapsed / refractory multiple myeloma”.



Myeloma session on the latest advances in immunotherapy



Poster presentations at ASH, including many authors and co-authors from the MCRN

Dr Richard LeBlanc,
Chair, Myeloma Canada Research Chair at
Maisonneuve-Rosemont Hospital, Montreal.

Poster presentation “Non-myeloablative allogeneic stem cell transplant followed by bortezomib in high-risk multiple myeloma patients”.

Dr Paola Neri,
Tom Baker Cancer Centre, Calgary.

Oral presentation “Cereblon splicing of Exon 10 mediates IMiDs resistance in multiple myeloma: Clinical validation in the CoMMpass trial”.

Dr Julie Côté,
CHUQ-Hôpital de l’Enfant-Jésus, Quebec City.

Poster presentation “Pattern of first relapse in multiple myeloma patients after a CyBorD induction regimen and autologous stem cell transplantation (ASCT): Impact of maintenance therapy in the real-world setting”.

Dr Anca Prica,
Princess Margaret Cancer Centre, Toronto.

Poster presentation “Cost analysis of stored autologous peripheral blood stem cells for a second autologous transplantation in multiple myeloma patients: A Markov model”.

Dr Victor Zepeda,
Tom Baker Cancer Centre, Calgary.

Poster presentation “Cyclophosphamide, Bortezomib and Dexamethasone (CyBorD) compared to Bortezomib, Thalidomide and Dexamethasone (VTD) as induction therapy for the treatment of transplant-eligible multiple myeloma.”

Dr Michael Chu,
CrossCancer Institute, Edmonton.

Poster presentation “Ex- vivo modelling of multiple myeloma provides basis for studying treatment combinations and immunotherapy”.

AWARDS AND RECOGNITIONS



Aldo Del Col, Co-founder and Chairman, Myeloma Canada, with Tiziana Vadacchino

Tiziana Vadacchino, Stem Cell Nurse Clinician from the Jewish General Hospital (JGH) in Montreal was this year’s recipient of the Myeloma Canada Marion State Memorial Nursing Award. Working at the JGH for more than 18 years and for 13 years as an oncology nurse, specializing in hematopoietic stem cell transplants, Tiziana has demonstrated excellence and leadership in oncology patient care that has not gone unrecognized. Tiziana accepted the award in person on November 19th at the “Quest for the Cure” event hosted by Celgene in Toronto.

In 2012, Myeloma Canada created the Marion State Memorial Myeloma Canada Nursing Award to recognize excellence in myeloma nursing care. The award is presented annually to a Canadian nurse who

Myeloma Canada, in partnership with the Cancer Research Society, announced Dr Don Morris, Associate Professor at University of Calgary and Director of the Tom Baker Cancer Centre Translational Laboratory, as the recipient of the third jointly-funded Myeloma Canada/Cancer Research Society Operating Grant for his project entitled “Next generation immune treatment strategies for multiple myeloma: immune modulators in conjunction with oncolytic viral therapy”. The value of the grant is \$120,000 over two years.

has demonstrated distinction and leadership in the care of multiple myeloma patients. Marion graduated with a diploma in nursing from Toronto General Hospital in 1966 and later a Bachelors of Nursing from Ryerson University in Toronto. Diagnosed with multiple myeloma in 1996, Marion went on to found the Toronto & District Multiple Myeloma Support Group in 1998, the first myeloma patient group in Canada, providing valuable support to other myeloma patients across the country. Marion lived a full productive life for 15 years until her passing in 2012.

In addition to the award, Celgene donated \$5,000 to Myeloma Canada as a tribute to Marion State.

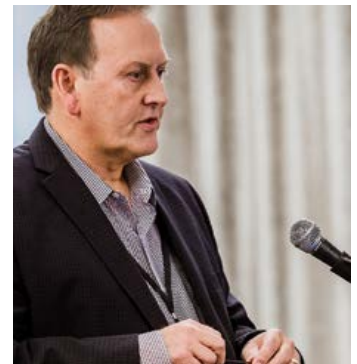


Marion State

Congratulations to Tiziana on her well-deserved recognition.

Funding for the research grant is made possible by the money raised through the Multiple Myeloma March held each September in cities across Canada.

Congratulations Dr Morris!



Dr Don Morris

THE MYELOMA CANADA RESEARCH NETWORK

One of the major ways that Myeloma Canada - as a patient organization-demonstrates its commitment to patient-focused clinical research can be seen by its collaboration with the MCRN. The MCRN is unique network consisting 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 MCRN's work is to gain access to new therapies in an accelerated manner for Canadian patients, leading to improved overall outcomes.

The mission of the Myeloma Canada Research Network is to:

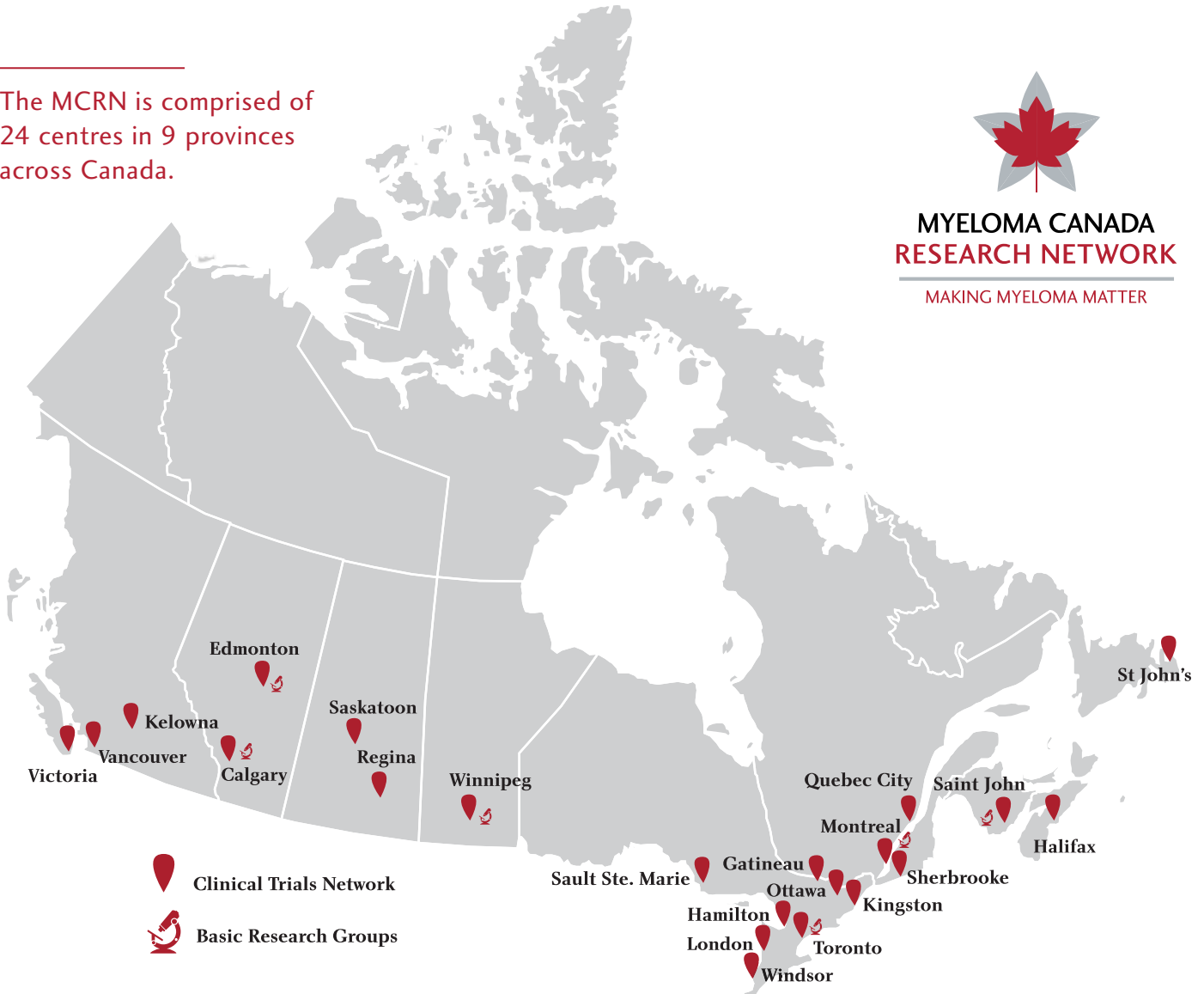
- Conduct innovative Phase I and II clinical and translational research in a collaborative manner to improve patient outcomes in multiple myeloma
- Publish evidence-based and peer-reviewed consensus statements on the diagnosis and treatment of myeloma
- Develop a nationwide myeloma patient database

The MCRN is comprised of 24 centres in 9 provinces across Canada.



MYELOMA CANADA RESEARCH NETWORK

MAKING MYELOMA MATTER



BRINGING MORE CLINICAL TRIALS, TO MORE PATIENTS IN MORE CENTRES ACROSS CANADA

The MCRN brings innovative Canadian-designed clinical trials to hundreds of patients in 24 centres in 9 provinces across Canada, in order to study the efficacy of new treatments that are not yet approved by Health Canada or new treatment combinations. Furthermore, focusing on high-impact Phase I and Phase II clinical trials, the collaboration amongst the centres allows the network of researchers to leverage expertise and share findings and knowledge amongst all of the members across the country, specifically in:

- Genomics
- Drug target evaluation
- Minimal residual disease
- Mechanisms of resistance
- Cell therapy
- Immunotherapy
- High-risk disease

The very first trial, MCRN 001, or the “BuMel” trial, led by Dr Donna Reece of the Princess Margaret Cancer Centre, opened in 2013 and was designed to evaluate different strategies to improve the outcome of newly-diagnosed myeloma patients undergoing high-dose chemotherapy (“autologous stem cell transplant” or “ASCT”). MCRN 001 included the following key strategies: incorporation of novel agents into the induction regimen, enhancement of the conditioning regimen, use of serial marrow minimal residual disease (MRD) analyses and serum heavy-light chain measurements to evaluate response and incorporation of maintenance therapy. In addition to the MCRN 001 trial, which has completed recruitment, the MCRN has two other trials that are currently open, and there are three additional MCRN trials in different stages of development across the country. The newer trials will focus on the promising area of immuno-oncology and evaluate new immune approaches in the treatment of myeloma.

The MCRN 002 (STOMP) trial led by Dr Nizar Bahlis (Calgary) and Dr Christine Chen (Toronto), evaluates a promising new molecule, selinexor or KPT-330, a first-in-class Selective Inhibitor of Nuclear Export (SINETM) compound being developed by Karyopharm Therapeutics in Boston. The trial combines selinexor, with dexamethasone and a “backbone” therapy: either

bortezomib, lenalidomide or pomalidomide in patients with relapsed or refractory myeloma.

MCRN 003 or the KCd trial (Kyprolis + Cyclophosphamide + dexamethasone) led by Dr Andrew Belch and Dr Christopher Venner (Edmonton), will evaluate the efficacy of a weekly high-dose regimen of carfilzomib (Kyprolis) in combination with cyclophosphamide and low-dose dexamethasone in the treatment of patients with relapsed myeloma after one to three therapies.

“If we don’t know how we’re doing, then we don’t know where we are going.”

Dr Donna Reece

On September 1, The MCRN proudly launched the MCRN Canadian Multiple Myeloma Database - a first of its kind in Canada - to capture relevant data and to optimize the care of Canadians living with multiple myeloma across our country as well as inform the design of Canadian-based clinical trials and how we can participate in international trials. The Database will identify different risk groups as well as gaps in myeloma outcomes. By accurately assessing where we are 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 of myeloma.

In a recent interview on Global TV, Dr Christopher Venner, Chair of the MCRN Canadian Multiple Myeloma Database, stated “the purpose is to provide a Canadian bent on all of the data that are out there. A lot of the things we generalize to try and estimate how well we expect patients to do is based on American data or European clinical trial data, that doesn’t always reflect how patients are living with this disease [in Canada]”.



Left: Dr Chris Venner, Chair of the Myeloma Canada Research Network Canadian Multiple Myeloma Database discussing the launch of this ground-breaking project.

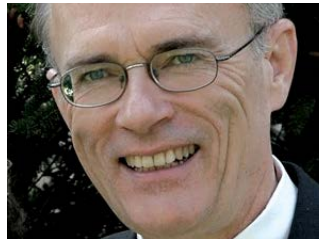
There are currently 12 centres across the country participating in the Database:

- Princess Margaret Cancer Centre, Toronto
- Cross Cancer Institute, Edmonton
- The Ottawa Hospital, Ottawa
- BC Cancer Agency, Vancouver
- McGill University, Montreal
- Tom Baker Cancer Centre, Calgary
- Maisonneuve-Rosemont Hospital Research Centre, Montreal
- Windsor Cancer Research Group, Windsor
- University of Saskatchewan, Saskatoon
- Dalhousie University, Saint John
- CancerCare Manitoba, Winnipeg
- London Regional Cancer Program, London

MYELOMA CANADA PATIENT ADVISORY COUNCIL

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 function as an advisory to the Board of Directors on matters important to patients, caregivers and support groups, providing the patient perspective on national and regional issues to the Board.

THE 2016 MEMBRES OF THE PAC ARE :



David McMullen
Chair



Lorelei Dalrymple
Western Canada Representative



Julie Salsman
Atlantic Canada Representative



Hervé Benoit
Quebec Representative



Ev McDowell
Ontario Representative

One of the major accomplishments of the PAC in 2016 was a national online survey conducted for myeloma patients and caregivers across Canada. The purpose was to gain insight from respondents on the programs and services currently offered by Myeloma Canada and provide suggestions for the future. We would like to thank the PAC for preparing this important survey, the Support Group Leaders for assisting with the distribution of the survey and the hundreds of patients and caregivers who responded with their valuable input.

The PAC also participated and assisted in the planning of several Myeloma Canada events including: the National Conference, Scientific Roundtable, Support Group Leader and Advocacy Summits, the Awareness Day, and the Family Medicine Forum. Most notably however, was the development of the Support Group Leader Toolkit, which has been enthusiastically received by Support Group Leaders across the country.

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Christopher Venner, MD
Director
Chair, MCRN Canadian
Multiple Myeloma Database
Clinical Lead-Malignant
Hematology Program
Cross Cancer Institute
Edmonton, AB

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TOGETHER WE ARE
MAKING MYELOMA
MATTER

Spotlight on our Community



SPOTLIGHT ON OUR COMMUNITY

Myeloma Canada is pleased to recognize the outstanding efforts put forth by the community over the past year. 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. Thanks to your continued support, significant milestones were reached this year alone, including the launch of the groundbreaking MCRN and the MCRN Canadian Multiple Myeloma Database. Awareness beyond the myeloma community was raised to new levels with myeloma covered over 100 times in the media. Advocacy efforts were intensified, laying the foundation for new treatments. And the many outstanding community events and engagement from coast to coast helped bring our small community even closer together.

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

2016 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, communities across the country rally for a 5 km walk to increase awareness, raise funds for research and to help support Myeloma Canada's numerous patient programs.

Thanks to your generous contributions from the Multiple Myeloma March, over 80% of funds raised contributed to the 1 million spent in clinical research alone. With a number of new therapies on the horizon for 2017 and beyond, our work is far from being done. More than ever, Myeloma Canada needs your help to ensure Canadian patients gain access to these game-changing therapies.

GRASSROOTS EFFORTS TO DRIVE CHANGE

Fostering a sense of "togetherness" and common purpose, the Multiple Myeloma March has a unique way of bringing people together to strengthen the voice of the Canadian myeloma community. Myeloma Canada and thousands of individuals from coast to coast have worked passionately together over the last 8 years towards the common goal of driving change and making myeloma matter, by helping patients and their families learn about the disease while raising awareness in the community.

In 2009, the first Multiple Myeloma March took pace in Montreal when a patient volunteer and her best friend set out on a mission to drive change along with 300 marchers and raised an impressive \$34,000. Since that time, the March has evolved into Myeloma Canada's signature fundraising event, gathering thousands of marchers in over 12 cities in 2016 alone.

Since its inception, the Multiple Myeloma March has been on the upswing, raising over 2.5 million dollars, and setting a record of \$512,363 in 2016, surpassing our ambitious fundraising goal of \$500,000.

It is important to recognize that under the guidance of Myeloma Canada, the Multiple Myeloma Marches are organized solely by dedicated volunteers in their respective communities, who are vital Myeloma Canada ambassadors in the community, committed to raising awareness and making myeloma matter for all Canadians. Their support is invaluable and we are grateful for their hard work and dedication, which has not gone unnoticed.

**Thank you to the
2016 Multiple Myeloma
March leaders
and coordinators!**

SPOTLIGHT ON OUR COMMUNITY

The 2016 March leaders:

ENDERBY AND KELOWNA, BC

Ron Surry
Germaine Nadon
Marlene Godfrey

CALGARY, AB

Pamela Roberts

MELVILLE, SK

Lynn Hoffman
Stacy Krushel

WINNIPEG, MB

Heidy Foot
Abbie Grieder

SAULT SAINTE-MARIE, ON

Pamela Orchard
Judy Mills

GREATER TORONTO AREA

Anne Spencer
Angela Spencer

OTTAWA-GATINEAU, ON

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

WINDSOR-ESSEX COUNTY, ON

Erma Rounq
Crystal Harvey

MONTREAL, QC

Nathalie Allard
Patricia Empsall

QUEBEC CITY, QC

Mélissa Landry

HALIFAX, NS

Julie Salsman
Michael Senz
Barbra Beaver
Emily Nickerson
Monique Foran



TOP MULTIPLE MYELOMA MARCH FUNDRAISERS IN 2016

It is thanks to our very generous donors from across that country that we have not only exceeded our fundraising goal of \$500,000, but achieved a 22% increase over 2015! Congratulations to all those who have successfully contributed to this important event!

It is with appreciation that Myeloma Canada is pleased to celebrate the top 2016 Multiple Myeloma March fundraisers for their outstanding fundraising efforts:



Team Greg Roberts Runners
Calgary
\$9,980



Team Nathalie Allard
Montreal
\$52,813



Team In Memory of Jeni Keene
Ottawa-Gatineau
\$9,790



Team Les Vainqueurs
Montreal
\$12,725



Gilles Caron
Ottawa-Gatineau
\$9,348



Team Gord & Gloria Lowry
Winnipeg
\$11,395



Team Be Happy and Be Lazy,
Greater Toronto Area
\$9,165

SPOTLIGHT ON OUR COMMUNITY



**Team
Maggie's Marchers
Winnipeg**
\$8,727



**Team
pour Nathalie Pépin
Montreal**
\$6,800



**Myeloma Matadors
Ottawa-Gatineau**
\$8,522



**Micheline Garand
Montreal**
\$6,310



**Lynn's Team
Windsor/ Essex County**
\$8,160



**Team Life is Good
Windsor/Essex County**
\$6,231



**Irene Podgorski
Ottawa-Gatineau**
\$6,815



**Team Pete's Posse
Montreal**
\$6,195

*"Giving is not just about making a donation.
It's about making a difference"*

– Kathy Calvin

**2016 MULTIPLE MYELOMA MARCH
KICK-OFF EVENT HIGHLIGHTS**

Throughout the year many March committees host kick-off events to raise awareness about the March and launch their campaign. From garage sales to concerts and everything in between, it's safe to say we certainly have a creative and outgoing community! Thank you to all of the volunteers and organizers who are passionately making our voice heard in the community.

Winnipeg

**THIRD ANNUAL BURGER AND
A BEVY FOR BRYAN'S PEEPS AND PAWS**



Congratulations to Joyce McGregor and family for organizing the 3rd Annual Burger and a Bevy for Bryan's Peeps and Paws benefiting the Winnipeg Multiple Myeloma March! The event was a huge success raising over \$2,200! Face painting, great laughs, delicious food & drink, and good friends. What a fantastic way to spend your Sunday, and for a great cause!

**TREVOR OLFERT &
THE OPEN SKY ORCHESTRA CONCERT**



Our heartfelt thanks go out to March Leader's Abbie Grieder and Heidy Foot, as well as Trevor Olfert, his family and the Open Sky Orchestra for their continued fundraising efforts and support raising approximately \$6,000 for 2016 Winnipeg Multiple Myeloma March! Thank you for making myeloma matter!

Calgary

OFFICE BOTTLE DRIVE

Congratulations to Pamela Roberts from Calgary for her very creative fundraising efforts! An office bottle drive landed her with \$455 dollars raised towards her March fundraising campaign. You don't need to do the math to know that this translates into an enormous amount of bottles!



"Since the Alberta economy has taken such a hit over the past 12 months, I knew I had to be creative in my fundraising efforts. I asked the company I work for, ARC Financial Corp., if I could donate the refunds from our empty water and pop bottles. They happily agreed and also become a local sponsor for Calgary's inaugural Multiple Myeloma March on September 25!"

– Pamela Roberts,
March Leader



Windsor/Essex County

LYNN ROUSSEAU MEMORIAL GOLF TOURNAMENT

On June 5th, Dennis Rousseau and family, held their third annual golf tournament, in memory of Lynn Rousseau. Benefiting the Windsor/Essex County Multiple Myeloma March, the tournament raised an impressive \$8,000 for the cause!

PANCAKE BREAKFAST

Yet another successful fundraiser for the Multiple Myeloma March! This time, the event took place in Windsor, Ontario. March Leaders Erma Rounq and Crystal Harvey hosted a pancake breakfast at Applebee's for a whopping 98 people, and raised over \$1,100 for the cause! Now that's a big stack of pancakes! Thank you to the organizers and Applebee's for the fundraising support, and for providing a 'short stack for a tall cause'.



Kelowna

GARAGE SALE

What better way to make a couple hundred bucks for the Multiple Myeloma March, then to host a community garage sale? Kelowna Multiple Myeloma March leaders Ron Surry and Germain Nadon, raised \$250 to kick off his March campaign!



Montreal

5TH ANNUAL ZUMBATHON

Congrats to Laura Smith from Montreal for organizing and completing the 5th annual Zumba-thon for her Multiple Myeloma March fundraising campaign! This year, Laura and her mom have raised over \$1000 from the event!

"My dad lost his battle with multiple myeloma in August 2014," says Laura Smith, a Multiple Myeloma March volunteer for the Montreal community. "Volunteering and participating in the Multiple Myeloma March became part of what we did as a family in order to support my dad and all those fighting this disease. By bringing greater awareness to this important cause, we will be able to raise more funds for research and hopefully, find a cure. Participating in the March is my special way of keeping my dad's memory alive."





Team Nathalie Allard 2016

SPOTLIGHT ON TEAM NATHALIE ALLARD

Meet Denis Potvin and Nathalie Allard from the Montreal Multiple Myeloma March's **Team Nathalie Allard**. Last year, the pair raised a team record high of \$36,000 for their March fundraising campaign. Yet Denis was not satisfied. In 2016, he was set on a mission to raise a minimum of \$50,000. Not only beating their personal record, we are pleased to announce Team Nathalie Allard reached a national fundraising record, raising a whopping **\$52,814!**

Nathalie has been living with the myeloma for almost 5 years and is one of the rare cases of being diagnosed at a very young age.

"I have received many treatments over the last years, and I am lucky to be receiving such great care from the staff at the Jewish General Hospital in Montreal. I am also blessed with an extraordinary husband, family and friends who help me give me the strength to keep fighting this battle, which is an everyday struggle"

Two years ago, Nathalie and her husband Denis decided to take part in the Multiple Myeloma March to support Myeloma Canada and Canadian myeloma research, in order to help patients and families living with the disease. In 2016, Nathalie rose to the occasion and volunteered to take on the role of the Multiple Myeloma March Leader in Montreal. "There is not much I can do about what I am living with," stated Nathalie "but at the very least, I can contribute what I can to the cause to help develop pathways to new treatments to ultimately help find a cure".

The team at Myeloma Canada would like to extend a heartfelt thank you Nathalie and Team Nathalie Allard for not only helping to achieve a fundraising record high in Montreal, but for also making this year's March a memorable one.



From left to right: Kim Sullivan from Global News Montreal, Patricia Empsall, March Coordinator, Nathalie Allard, March Leader and top fundraiser, and Michelle Oana, Associate Director of Development and Communications, Myeloma Canada

Congratulations your outstanding dedication and success!

2016 COMMUNITY EVENTS



RUNNING FOR A CAUSE

Trail Trek for Judy

A huge congratulations to Sara Montgomery, for having completed her 110 km Trail Trek over three days to raise funds for Myeloma Canada, in memory of her mom Judy. Sara raised an impressive \$8,000 for the cause, surpassing her original fundraising goal by \$3,000!

SARA'S STORY

In October 2015, my family lost my mother, Judy Montgomery, to multiple myeloma. Before her diagnosis in 2012, I had never heard of this disease. One of the first things I learned is that it is one of three main blood cancers (along with lymphoma and leukemia), and that the prevalence of myeloma is increasing. More and more of us are having this disease impact our lives like it has my family's.

Myeloma is treatable but a cure is still being searched for. Recent research has led to significant gains in the understanding and treatment of the disease, with new therapies helping patients live longer and with better quality of life. Myeloma Canada provides education and support, raises awareness, and improves access to clinical trials and new treatments.

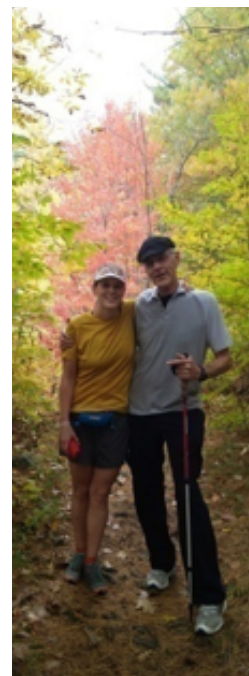
From October 16-18, I ran every trail loop in Ontario's Frontenac Provincial Park to raise awareness and funds for Myeloma Canada. My undertaking followed the guidelines of the Frontenac Challenge, an annual hiking initiative set up by the park which encourages people to cover all of the 11 remote and rugged back-country hiking trail loops. The Frontenac Challenge gives hikers two months to complete the route,

but it was my goal to run the challenge in three days. The final loop was completed with my father, Peter Montgomery.

I drew inspiration from my mother's incredible strength and courage as she faced the many challenges that came her way during her treatment. Her optimism and determination to live each day to its fullest will always be incredibly inspirational to me. This was my way of honouring my mother's memory, and to feel a connection to her as I went through this symbolic challenge. My mom formed a strong bond with the myeloma patients she met, and found comfort in their friendship. In all aspects of her life, she was a great believer in the power of community.



Sara Montgomery mid-way through her Trail Trek



Sara and her father, Peter Montgomery

The 5th Annual Fulton Campbell Half Marathon and Laura Lee Walsh 5k Run benefitting Myeloma Canada.



Mitchell & Sara Visser

Since 2011, Sara Visser has been organizing fundraising races in memory of her mother, Laura Lee Walsh, who was diagnosed in 2007 and lost her fight on February 2, 2009.

Sara organized her first multiple myeloma awareness run in 2011, with the Red's Corner Fun Run, a single fundraiser sponsored by local restaurant Red's Corner. Recalling the day as hectic, Sara was touched by the outpouring of support. This rewarding experience led her to become race director of the Fulton Campbell Memorial Half Marathon. In 2012, she renamed the event's 5k option the Laura Lee Walsh 5k Run and donated the funds raised to Myeloma Canada.

“The run is in honour of my mother,” says Sara. “She was generous, kind and loved by her students and the PEI community. It’s wonderful to have people participate in an event in her name that helps her cause.”

With the support of her husband, father and three siblings, Sara plans to continue paying tribute to her mother by raising awareness and funds for multiple myeloma research. “I hope that, over the next 10 years, I continue to hear positive news about medical advances in terms of multiple myeloma,” says Sara.

A beloved community member and teacher, Laura Lee Walsh’s memory lives on thanks to her family and to the numerous volunteers, supporters and participants of the run who are making myeloma matter on PEI.

It was a hot and sunny day! Over 100 participants took part in the Fulton Campbell Memorial Half Marathon and the Laura Lee Walsh 5k Run on June 27, 2016, which raised \$1,800 for Myeloma Canada.

SPORTING FOR MYELOMA CANADA

Ball Hockey 4 Multiple Myeloma

On July 9, 2016, Brandon Winsor organized his first ever fundraiser, Ball Hockey 4 Multiple Myeloma, for Myeloma Canada in honour of his mom, Christine. Rallying his friends and family in Harbour Grace, Newfoundland, Brandon raised \$1,500 for the cause.



“My mother, Christine Winsor, who is living with multiple myeloma, gave me the motivation to organize this event to help raise funds and increase awareness in Newfoundland. Thank you for supporting a great cause, and making myeloma matter!”

– Brandon Winsor

7th Annual Scramble for the Cure Golf Tournament

A beautiful sunny day spent with friends, family, colleagues and the myeloma community from the Halton Peel area, with lots of laughs and golf swings (both good and bad), followed by a delicious charity dinner with many amazing prizes. Thank you Gord Ross and family for once again organizing a spectacular golf tournament in Burlington, Ontario. This year's Scramble for the Cure tournament raised an impressive \$32,000!

“Scramble for the Cure was held originally in memory of my sister, Becky Ross, and my father, Jim Ross, who both left us too early after brave battles with multiple myeloma. The tournament has grown substantially throughout the first six years, and unfortunately so has the number of people now affected by myeloma. There are many people now playing and participating in one way or another on behalf of their loved ones whose lives have now been affected by myeloma. Collectively we'll ‘Drive Away Cancer’!”

– Gord Ross,
Event Founder & Coordinator



IT'S SHOW TIME!

Benefit Concert



Johanne Gaumond, a music teacher and performer for 26 years in the Outaouais region in Quebec, has organized many benefit concerts over the years for an array of causes. In 2016 Johanne decided to focus her efforts on myeloma, a cause near and dear to her. Passionate about advancing myeloma research and supporting her local community, Johanne's event raised a noteworthy \$5,000 for the cause. Merci Johanne!

Christmas Concert

Each year for the last seven years, Kevin and Brenda Hull from the small town of Dutton, Ontario, have hosted memorable charity concerts benefitting Myeloma Canada. This year's Christmas concert on December 10, featuring performances by their daughter Lindsay Hall and Eric Walker, raised a noteworthy \$800 for the cause. Congratulations to the Hull's for raising over \$12,000 for Myeloma Canada over the last seven years!



Myeloma Canada's Inaugural Casino Night in Partnership with the Oana Family

Sam's Premier Monte Carlo Casino Night, held on October 29, 2016, was a night to honour the memory of Richard Oana, a man of influence in the commercial real estate sector and previous member of the Myeloma Canada Board of Directors. The event raised a notable \$42,000 in its first year!

Many of Montreal's most influential commercial real estate leaders gathered at the event to pay tribute to one of their own. For Mr Jonathan Wener, Chairman and CEO of Canderel, supporting the cause was not only important, it also hit close to home:

"My elderly mother passed away from multiple myeloma. It was hard to see her suffer, but I was especially devastated to learn that Richard was diagnosed with the disease and that he died at such a young age. It was very difficult for my colleagues and me. Richard was a true friend, an associate who embodied the very definition of fairness, passion and professionalism. We miss him terribly, but we are pleased to participate in the evening and to honour his memory so that others don't have to suffer from this devastating disease."



From left to right, event organizers: Michael Brennan, Michelle Oana, Christiane Oana, Melanie Oana, Stathy Papachronis

"Great food, great company, and lots of laughs were had by all. All around great fun! Thank you for making this first event a memorable one and for making myeloma matter."

– P. Normandin

RECOGNIZING OUTSTANDING LEADERSHIP AND DEDICATION

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 led successful campaigns to fight for equitable access to myeloma treatments. In 2012, the award was re-named the Carolyn Henry Memorial TEAM Award in recognition of Carolyn's pioneering advocacy efforts. This year's award was presented to the Ontario Advocacy Committee, represented by Robin Sully, Jan Wleugle and the late Kirk Boyd for their outstanding efforts in helping to improve the lives of patients in Ontario.



Jan Wleugle et Robin Sully of the Ontario Advocacy Committee and Martine Elias, Myeloma Canada

Community Achievement Award

Myeloma Canada would like to outline the significant contribution Gord Ross has made to Myeloma Canada and the Canadian myeloma community over the past 7 years. Not only has Gord implicated himself to supporting Myeloma Canada and dedicating his time to several local support groups in Ontario over the years, he and his family have also organized 7 consecutive annual fundraising golf tournaments benefitting Myeloma Canada. We are pleased to announce the Scramble for the Cure Charity Classic golf tournament has officially achieved a significant milestone in 2016 surpassing the \$100,000 fundraising mark! Your volunteerism and dedication to the community is exemplary. We take our hats off to you!



Gord Ross and his wife Claire

Notable Volunteer Award

Following in the footsteps of her aunt Maggie, Heidi Foot, Multiple Myeloma March leader in Winnipeg, has demonstrated exceptional leadership in the Manitoba community by not only heading the exemplary Marches in Winnipeg since 2010, but by having built a strong community network for myeloma patients and caregivers in Manitoba. Leading by example, Heidi has largely inspired community engagement from others and the myeloma community in Winnipeg is fortunate to have such a motivated and dedicated volunteer in their corner. We would like to applaud Heidi's achievements over the years and would like to thank her for continued motivation and enthusiasm towards the cause.



Heidi Foot, Multiple Myeloma March Leader

Newcomer Award

In just a short amount of time, Ron Surry from Enderby, British Columbia, has made a significant impact on both the local and national myeloma communities. Building a support group network spanning the large geographical region of the Okanagan Valley covering Osoyoos to Revelstoke, Ron has travelled the region to build a strong support system for myeloma patients and caregivers in the BC Interior. As if that wasn't enough, Ron also led two Multiple Myeloma Marches this year in Enderby and Kelowna, as well as participating in both the Myeloma Canada and International Myeloma Foundation's Support Group Leaders Summits, as well as assisting with the planning of the Legislature Awareness Day in Alberta. Thank you Ron for achieving milestones and making a difference in British Columbia!



Ron Surry from Enderby, British Columbia,

JOIN OUR COMMUNITY



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