



Our Programs and Achievements

2020 YEAR IN REVIEW
MYELOMA CANADA



**MYELOMA
CANADA**
MAKING MYELOMA MATTER

**15
YEARS**

MAKING MYELOMA MATTER

Myeloma Canada is the only national charitable organization created by, and for, Canadians impacted by multiple myeloma. The organization is driven to improve the lives of those affected by myeloma by empowering the community through awareness, education and advocacy programs, and supporting clinical research to find a cure. Since it was founded in 2005, Myeloma Canada has been making myeloma matter.

Our mission :

To improve the lives of Canadians impacted by myeloma through awareness-building, educational efforts, advocacy, fostering an empowered myeloma community and support of clinical research so that a cure may be found.

A Message from our Executive Director

We faced great challenges in 2020 and had to adapt (often and very quickly) to changing realities and scenarios. When the pandemic hit, we were right at the beginning of our 15th anniversary celebration. Our programs, events and activities for the year had already been planned and preparations were well underway. We had just launched the first leg of Myeloma S*cks, our bold awareness and donation campaign, as well as the annual Multiple Myeloma March, our flagship community and fundraising event. Like everyone else in the world, the pandemic took us by surprise.

We quickly rallied and put together webinars, moderated by experts, to address our community's concerns about the coronavirus and myeloma, created a COVID-19 InfoBulletin and section on our website. We implemented new strategies for sharing information and helped our support groups with technology.

Not only did we manage to accomplish all of our programming, such as publishing two new InfoGuides and the *Consensus Guideline Consortium on the Diagnosis of Multiple Myeloma and Related Disorders in Canada*, launching our new Myeloma Drug Access Navigator, and releasing our 1st-ever corporate video, but we were able to do even more, thanks to our community! We were particularly impressed by the way in which our Canadian myeloma community came together to make sure the Multiple Myeloma March would take place, and



the way they showed their support for the Myeloma Priority Setting Partnership (PSP) and other important research initiatives.

When I think of everything we've gone through, I'm immensely proud of all that's been achieved. We adapted and found ways to remain as responsive as possible, never losing sight of our community's well-being. Their support throughout the year enabled us to design and implement even better programs. Our ability to adapt together is truly a testament to what our community is capable of. Without their drive and confidence in us, we wouldn't have been able to accomplish a fraction of what we did together.

Our 15th anniversary has undoubtedly been celebrated in an exceptional way; alongside the pandemic, it provided us with the opportunity to generate new ideas, new perspectives, and new models. The year 2020 strengthened our conviction that together, we are committed to making myeloma matter, regardless of what life throws our way. We remain united, and that will never change.

A handwritten signature in black ink that reads "Martine Elias".

MARTINE ELIAS

OUR TEAM

MARTINE ELIAS

Executive Director

MICHELLE OANA

Director of Development
& Community Relations

MURIEL INGRASSIA, CPA, CMA

Manager of Operations

GABRIELE COLASURDO

Manager, Education
& Patient Services

JESSY RANGER

Manager, Public Affairs
& Communications
(Francophone Community)

MARCIE BARON

Manager, Communications
& Marketing

SHANEIKA HESLOP

Executive Assistant

PATRICIA CELESTIN

Development & Operations
Support Coordinator

Myeloma Canada BOARD OF DIRECTORS

JOHANNE MULLEN, MBA

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Partner, Deals Practice at
PricewaterhouseCoopers
Montreal, QC

ERIC LOW

Vice-Chair

Consultant
Eric Low Consulting
Edinburgh, UK

LORELEI DALRYMPLE

Treasurer

Team Lead, Servus Credit Union
Support Group Leader
Board Member, Canadian Myeloma
Research Group
Edmonton, AB

ANTOINETTE BOZAC

Secretary

Corporate Executive
General Counsel & Plan Trustee
Ontario Ministry of Education
Governor, Concordia University
Toronto, ON

ELLIS BASEVITZ, CPA, CA

Director

Co-founder and Senior Consultant
PSB Boisjoli
Montreal, QC

EMILY CROWE

Director

Senior Scientific Adviser
National Institute for Health
and Care Excellence (NICE)
London, UK

NANCY GRAY

Director

Past Executive Director, Financial
Affairs, McMaster University
Burlington, ON

TREVOR IVES

Director

CEO, Peter Ballantyne Group
of Companies
Aboriginal Business and
Corporate Development
Prince Albert, SK

MÉLANIE MARTEL

Director

Partner, DLA Piper (Canada) LLP
Board member, Société de
Transport de Laval
Montreal, QC

HIRA MIAN, MD

Director

Hematologist, Juravinski Cancer
Centre
Assistant Professor, McMaster
University
Hamilton, ON

BILL PAINE

Director

Senior Executive and board member of
many Canadian public companies and
charitable organizations
Vancouver, BC

DONNA REECE, MD

Director

Co-founder, Myeloma Canada
Research Network
Professor of Medicine,
University of Toronto
Princess Margaret Cancer Centre
Toronto, ON

ANTHONY REIMAN, MD

Director

Professor, Faculty of Medicine,
Assistant Dean of Research
Dalhousie Medicine New Brunswick
University of New Brunswick and
Atlantic Cancer Research Institute
Saint John, NB

ARLEIGH ROBERTSON

MCCURDY, MD

Director

Assistant Professor, Faculty of Medicine
University of Ottawa (Hematology and
Department of Medicine)
Lead, Multiple Myeloma Program
at The Ottawa Hospital
Clinician Investigator, Ottawa Hospital
Research Institute
Ottawa, ON

KEITH TAYLOR

Director

President, Partner consulting firm
specializing in police, justice,
governance and community issues
West Vancouver, BC

OUR PROGRAMS AND ACHIEVEMENTS

Education

DEVELOP, SUPPORT AND DISSEMINATE NECESSARY INFORMATION AND RESOURCES TO HELP OUR MYELOMA COMMUNITY MAKE INFORMED DECISIONS ABOUT THEIR HEALTHCARE.

Each year, Myeloma Canada hosts dozens of events, information sessions and webinars to keep in touch with the Canadian myeloma community. 2020 was a very different year. We were about to hold our third event of the year when COVID was declared a global pandemic. We rolled up our sleeves and organized an unprecedented number of webinars to ensure our community was kept informed about the latest research developments, myeloma treatment options, and reliable news on COVID-19. Unable to hold our annual National Conference, Myeloma Canada brought together members of the myeloma medical community from across the country to reassure and educate Canadian patients and caregivers in online webinars.

We are constantly striving to develop new tools with which to inform patients and their loved ones and help them better understand the challenges they face. In 2020, we created two InfoGuides and updated our support tools to promote shared decision-making and active participation in their healthcare.

OUR PROGRAMS AND ACHIEVEMENTS

Response to COVID-19

Enhanced communications and resources

48 InfoBulletins on COVID-19 and myeloma

- Website: Addition of a COVID-19 section, directly accessible from the Myeloma Canada home page, featuring frequent updates on pandemic news
- Introduced virtual meeting platform for staff and support group members
- Webinar series on COVID-19 and myeloma
- Increased dissemination of information

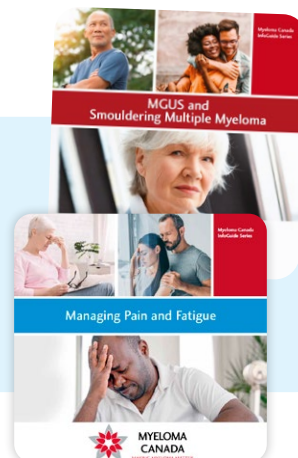
2 InfoSessions

- Granby (QC)
- Red Deer (AB)



2 InfoGuides

- Managing Pain & Fatigue
- MGUS and Smoldering Myeloma



34 webinars

8,200+ views

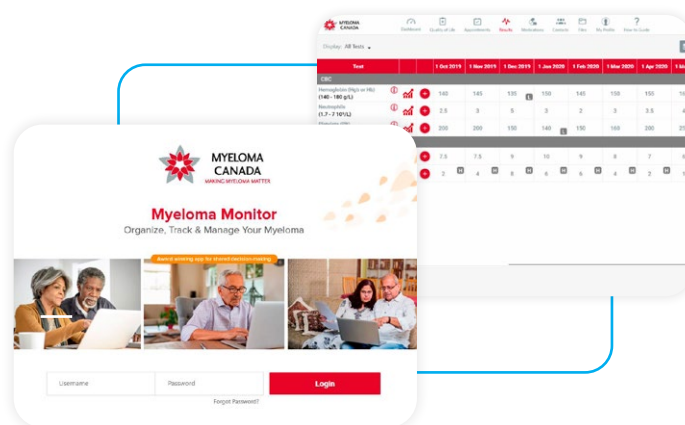


Myeloma Monitor Application

Recipient of Celgene's International ImpactHeme Award

Helping multiple myeloma patients organize, track and manage their disease.

- Released updated and improved version
- New online user guide
- Webinar on the application's features
- Among new features: section for organizing files, medication and supplements refill reminder options, emergency health card 'report', personalized home page dashboard, side effects section
- PC, MAC, iPad, iPhone and Android versions
- **422** downloads



My Life. My Myeloma Online Resource Centre

Recipient of Celgene's International ImpactHeme Award

Providing people living with myeloma the tools they need to actively participate in their healthcare journey.

- 6 new patient testimonial videos (3 English/3 French)
- Direct access to Myeloma Canada's Myeloma Drug Access Navigator
- **21,547** new users
- **24,750** pages viewed

OUR PROGRAMS AND ACHIEVEMENTS

Awareness

PROMOTE EARLY DIAGNOSIS FOR, AND INCREASE AWARENESS OF, MYELOMA AND THE WAYS IT AFFECTS THE LIVES OF PATIENTS AND THEIR FAMILIES.

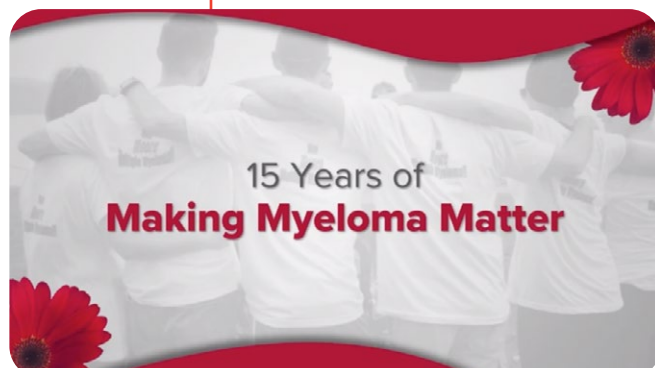
Our community members are, and will always be, our top priority. Despite the unprecedented circumstances of 2020, we used all possible means of communication to raise awareness for myeloma and increase the visibility of this little-known blood cancer.

Not only did 2020 mark the beginning of a new year and a new decade, but it was also Myeloma Canada's 15th anniversary. We knew that we'd have to mark this event in a bold and creative way, but nothing could have prepared us to what extent! Our efforts were not unnoticed...we generated more awareness and raised more funds for myeloma than ever before! We worked even harder for our Canadian myeloma community by continuously improving our website, increasing our social media presence, sharing reliable and up-to-date information through Myeloma Matters, our monthly e-newsletter, creating educational content, and participating virtually in numerous national and international events. We launched MYELOMA S*CKS/MYELOMA SOCKS, our very first integrated awareness and giving campaign, which succeeded in attracting a lot of attention. The campaign included a digital component, promotional items, and a direct mail program. Our community supported us in our many initiatives such as "Giving Tuesday" and by purchasing our branded face masks and socks; they answered our call by participating in numerous projects and shared their realities in the context of a pandemic.



Myeloma Canada's 15th anniversary highlights

- Revamped our Myeloma Canada logo and brand image, including many visual tools, and branded our five pillars
- Created a corporate "Case for Support" brochure and our 1st corporate video, "15 years of making myeloma matter"
- Launched the MYELOMA S*CKS and MYELOMA SOCKS awareness and fundraising campaign which included a direct mail piece, promotional items (2 styles of branded socks), digital and community-based promotions



1,555 face masks

875 logo socks

Branded Myeloma Canada items sold



4,146 followers

National Facebook page
(English and French)



996 followers



628 followers



559 followers

**24 Myeloma Matters
e-Newsletters**

(12 English/12 French)

- **20,000+ subscribers**



32 videos created

- **6 patient journey videos**
(3 English/3 French)
- **24 InfoVideos**
(12 English/12 French)
- **2 corporate videos**
(English and French)

Website

- Specific COVID-19 section created
- Updated our home page, Research, News & Events and Drug Access sections

▶ **157,753 unique visits**

▶ **200,878 page views**

24 virtual annual conferences and meetings, including:

- Accessing Cancer Clinical Trials and Real-World Evidence Methodologies Conference
- International Myeloma Working Group (IMWG) Annual Summit
- Quebec Cannabis Forum
- Myeloma Patient Europe—Community Advisory Board
- International Myeloma Foundation's Support Group Leader's Summit
- Myeloma Canada's Support Group Leaders' Summit
- Saskatchewan Myeloma Summit
- American Society of Hematology (ASH) Annual Meeting & Exposition
- Canadian Myeloma Research Group (CMRG) Inaugural Coverage of the 62nd ASH Annual Meeting & Exposition
- European Hematology Association (EHA) Annual Congress

All our publications are available free-of-charge for download or for order on myeloma.ca under "Resources". Videos and webinar recordings are posted on our YouTube channel.

OUR PROGRAMS AND ACHIEVEMENTS

Access & Advocacy

**ADVOCATE FOR ACCESS TO THE BEST TREATMENTS
AND SUPPORT SERVICES FOR MYELOMA PATIENTS.**

Although some of our initiatives were put on hold, 2020 was still as productive a year as was 2019 for patient advocacy.

We responded to the call by the federal government and participated in the public consultation on the Patented Medicine Prices Review Board (PMPRB) 2020 draft Guidelines, a hot topic from 2019. The delay in implementing recommendations that could jeopardize patient prognoses allowed us to once again, advocate for patients' rights in order to ensure that policies regulating drug access and clinical trials be maintained across the country. To further address this need, we launched our new Myeloma Drug Access Navigator and submitted numerous letters to provincial authorities calling for fair and safe access to treatments during the pandemic. We joined forces with many partners such as the Global Myeloma Action Network (GMAN); the Collective Oncology Network for Exchange, Cancer Care Innovation, Treatment Access and Education (CONNECTed); CanCertainty Coalition; l'Alliance des patients pour la santé, and the Quebec Cancer Coalition. We also created new partnerships with the Regroupement des organismes communautaires en oncologie, and Victimes de pesticides du Québec to address various issues including the recognition of occupational diseases, community and environmental influences, access to drugs and clinical trials, caregiving aid, and patient safety.

The work we do to keep our seat at the negotiating table is essential for improving the quality of life and survival rate of Canadians living with myeloma. The surveys we create, the submissions for drug access we present to government authorities, and the meetings we hold with elected officials and politicians across the country ensure that the voices of our community are heard, and that the healthcare system meets the needs of Canadians impacted by myeloma.

Access to treatment

Highlights

- The pCODR Expert Review Committee (pERC) recommended the reimbursement of daratumumab (Darzalex) prescribed in combination with lenalidomide (Revlimid) and dexamethasone (DRd) to patients with newly diagnosed multiple myeloma who are not eligible for an autologous stem cell transplant
- Health Canada approved daratumumab (Darzalex administered subcutaneously)
- CancerCare Manitoba and Manitoba Health added Revlimid to their list

Myeloma Drug Access Navigator

New!

- Simplifying the search for information on drugs in each Canadian province and territory
- Finding availability and coverage at a glance



3 community surveys

for submission to the pan-Canadian Oncology Drug Review (pCODR) for access to treatment, the Institut National d'Excellence en Santé et Services Sociaux (INESSS) and the Government of Ontario:

- Isatuximab (Sarclisa by injection)
- Daratumumab (Darzalex) administered subcutaneously
- Idecabtagene vicleucel (ide-cel, bb2121), Car T-cell immunotherapy

2 submissions to the Patented Medicine Prices Review Board (PMPRB) on draft Guidelines

one on behalf of Myeloma Canada, and the other on behalf of the CONECTed Patient Group (Collective Oncology Network for Exchange, CancerCare Innovation, Treatment Access and Education) with the help of Myeloma Canada's National Advocacy Committee.



OUR PROGRAMS AND ACHIEVEMENTS

Community Empowerment

**BUILD A PATIENT-DRIVEN, GRASSROOTS MYELOMA
COMMUNITY AND FACILITATE AN INTEGRATED NETWORK
OF MYELOMA STAKEHOLDERS.**

Even though the majority of our in-person events were postponed, we created many virtual programs to support our community members and enable them to stay in touch with one another. We did everything we could, as quickly as possible, so that our support groups could run their meetings online, and use Facebook and Zoom; we provided them with a host of tools for recruiting new members, and we developed creative strategies to keep our community informed and inspired.

The pandemic truly confirmed that the involvement of our members and volunteers - as support group leaders, event participants or organizers of their own fundraising activities - is unwavering. Together, we remain committed and strong to make more people aware of myeloma and to raise the funds we need to get one step closer to a cure. As an organization, we guide our members through all the important stages of their journey, and in turn, they support us so we can continue to work to improve their daily lives.

Issues of inequality were exposed publicly, and kept front and center, throughout 2020. Whether regarding the colour of one's skin, sexual orientation, gender, religion, nationality, ethnicity, political affiliations or ideologies, we communicated our condemnation of inequity to our members; we made a commitment to address issues of discrimination and disparities in Canadian healthcare. By working together, we are that much stronger.

Support Group Network

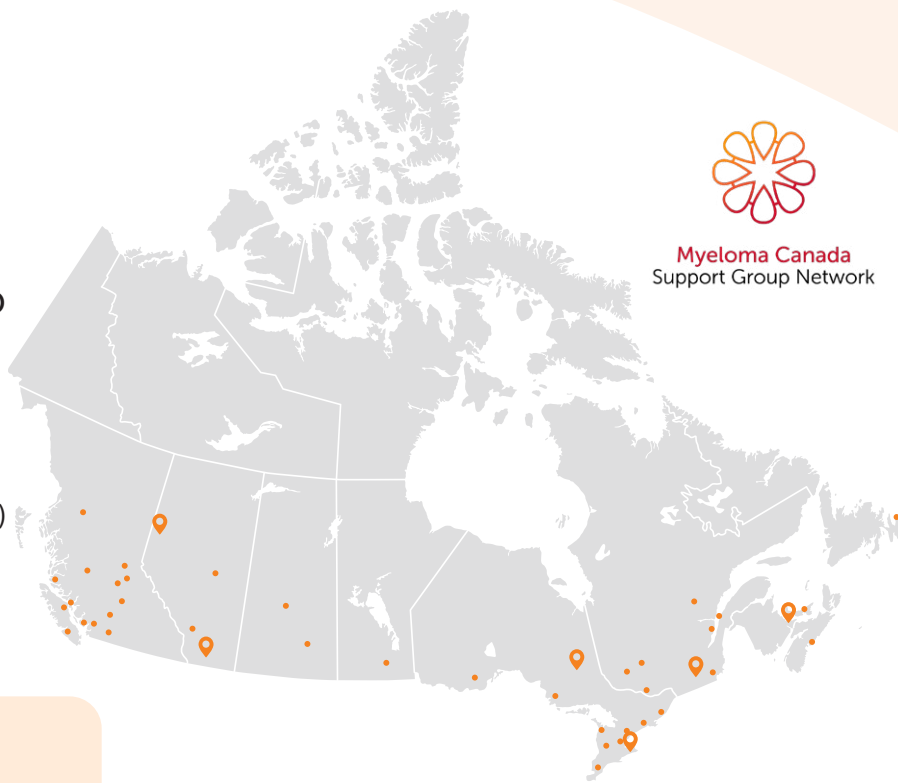
44 support groups

4 'Meet & Greet' events led to the creation of 6 new support groups:

- Grande Prairie (AB)
- Lethbridge (AB)
- Sudbury (ON)
- Niagara (ON)
- Lanaudière (QC)
- Moncton (NB)



Myeloma Canada
Support Group Network



793 members

in our Facebook online support groups
for patients and caregivers

Myeloma Canada's 13th annual (and 1st virtual) Support Group Leaders' Summit



65 participants

from all over Canada



MYELOMA CANADA'S
13TH ANNUAL SUPPORT
GROUP LEADERS'
SUMMIT

VIRTUAL MEETING
NOVEMBER 19, 2019
12:15 - 4:45 EDT



List of leaders 2020

Alberta

Martin Reed	Grande Prairie	North Western Alberta Myeloma Support Group
Tom Wolsey	Lethbridge	Lethbridge Myeloma Support Group
Deet Adam	Calgary	Southern Alberta Myeloma Patient Society (SAMPS) Support Group
Lorelei Dalrymple	Edmonton	Myeloma Alberta Support Society (MASS) Support Group

British Columbia

Linda Latham	Campbell River	North Island Multiple Myeloma Support Group
Allison Jennings and Susan McLean	Nanaimo	Nanaimo Multiple Myeloma Support Group
Barbara Morrison and Joe Veller	Maple Ridge	Fraser Valley Support Group
Warren Welling	Victoria	Vancouver Island Multiple Myeloma Support Group
Susan Schmaltz and Ron Surry	Kelowna	BC Southern Interior—Kelowna Chapter Support Group
Bob Trudeau and Bob Hamaguchi	Kamloops	BC Southern Interior—Kamloops Chapter Support Group
Ron Surry	Enderby	BC Southern Interior – Enderby Chapter Support Group
Eva Patten and Cyndi Logan	Prince George	Northern BC Multiple Myeloma Support Group
Kerry McKeen	Vancouver	Vancouver Myeloma Network Support Group
Kundan Uppal-Dubinsky and Bruce Marks	Surrey	Surrey & District Multiple Myeloma Support Group

Manitoba

Jackey LaBossiere	Winnipeg	Winnipeg Myeloma Support Group
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New Brunswick

Susan Collins	Saint John	Saint John Area Multiple Myeloma Support Group
Shawn Crossman	Moncton	Moncton Myeloma Support Group

Newfoundland and Labrador

David McConkey, Stephen Norman and Gary Cross	St. John's	Myeloma NL Support Group
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Nova Scotia

Julie Salsman and Trish MacDonald	Halifax	Nova Scotia Multiple Myeloma Support Group
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Ontario

Claudia Trost and Jeff Heyman	Kingston	Kingston Myeloma Support Group
Clive and Yvette Webb	Hamilton	Hamilton and District Multiple Myeloma Network Support Group
JoAnn Cartlidge	Windsor	Windsor and District Multiple Myeloma Support Group
Marion Bentley	Sault Ste Marie	Sault Ste. Marie Multiple Myeloma Support Group
Ev McDowell and Lisa Bowden	London	London and District Myeloma Support Group
Norma Linder and Juliette Royer	Halton-Peel	Halton-Peel Myeloma Support Group
David McMullen and Donald Hunter	Toronto	Toronto and District Multiple Myeloma Support Group
Brian and Liz Stockdale	Cobourg	Northumberland and District Multiple Myeloma Support Group
Iris Phillips	Picton	Picton Support Group
Robin Sully and Jean Shepherd	Ottawa	Ottawa-Gatineau Multiple Myeloma Community Network
Susan McDowell and Juliette Royer	Kitchener-Waterloo	Waterloo Region Myeloma Support Group
Denyse DeBernardi	North Bay	Myeloma Nipissing Support Group
Carly Mackevicius and Lise Mackevicius	Sudbury	Sudbury and District Myeloma Support Group
Linda Campbell	Niagara	Niagara Region Multiple Myeloma Support Network

Prince Edward Island

Bethany Reeves and Megan Gardiner	Charlottetown & Summerside	PEI Myeloma Support Group
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Quebec

Hervé Benoît, Danny Wade and Kristen Palynchuk	Montreal	Montreal Myeloma Support Group
Vénus Bélanger	Sherbrooke	Espoir Myélome Estrie Support Group
Manon Veilleux and Julie Martel	Quebec City	Myélome Québec Support Group
Danny Wade	Longueuil	Myélome Rive-Sud Support Group
Daniel Sarrazin and Chantal Tardif	Saint-Eustache	Laurentides Support Group
Benoît Brissette	Lanaudière	Myélome Lanaudière Support Group

Saskatchewan

Judi Worth and Marie Prokopiw	Saskatoon	Saskatoon Multiple Myeloma Support Group
Mona Neher and Sharon McIntosh	Regina	Saskatchewan Multiple Myeloma Support Group

Community events

Events organized by our community members are invaluable. Year after year, we marvel at our members' involvement and dedication to increase awareness and education for myeloma, and by their desire to always want to do more to support the cause. Their trust and support are what make them an inspiring community: passionate and determined individuals who contribute daily to promoting and improving the multiple myeloma landscape in Canada. We will never be able to thank them enough for their commitment.

\$61,050

**in donations raised through
community events and fundraising
campaigns**

Myeloma Canada's 12th Annual Multiple Myeloma March

- ▶ **\$596,590**
- ▶ **29 participating cities
+ 1 virtual March**
- ▶ **3,700 participants**
- ▶ **5,300 donations**
- ▶ **16,000km travelled
'together'**
- ▶ **1,047 pairs of March socks**
sold for a total of \$ 13,182

The Multiple Myeloma March, Myeloma Canada's flagship community and fundraising event, celebrated its 12th anniversary in 2020. Every year in the fall, the myeloma community gets together to take part in a 5km March to raise funds for better access to innovative treatments to improve the length and quality of life of those living myeloma. In 2020, given the restrictions and preventive measures surrounding COVID-19, and the need for social distancing, we added a new Personalized Distance Tracker and Challenge to help us stay healthy and active in the months leading up to the Multiple Myeloma March. We were absolutely amazed by the enthusiasm and creativity of our participants and March leaders! Not only were we impressed by their unparalleled passion to meet their personal challenges and objectives, but by their creative solutions for coming together. Whether physically together or apart, online or in person, our community members took whatever steps they could to make myeloma matter and raise funds to find a cure.



MULTIPLE MYELOMA MARCH



March leaders 2020

March	Leaders
Airdrie	Michelle Oana
Cobourg	Brian Stockdale
Halifax	Michael Senz and Julie Salsman
Hamilton	Nancy Gray
Kamloops	Bob Trudeau and Bob Hamaguchi
Kelowna	Susan Schmalz
Kingston	Rebecca Flint and Claudia Trost
Kitchener-Waterloo	Juliette Royer
Magog	Jessy Ranger and Vénus Bélanger
Melville	Lynn Hoffman
Mississauga	Anne Spencer
Moncton	Shawn Crossman
Montreal	Patricia Celestin
Newmarket	Kristy Ahola
Oshawa	Laurie Khaler
Ottawa	Frank Shepherd and Glenn Hussey
Prince George	Cyndi Logan
Regina	Joy Bhimji
St John's	Tina Soulier
Saskatoon	Marie Prokopiw and Judi Worth
Sault Ste Marie	Pamela Orchard and Judy Mills
Summerside	Megan Gardiner and Bethany Reeves
Thunder Bay	Leah Vanderwey
Vancouver Island	Allison Jennings and Susan McLean
Vancouver	Michelle Oana
Quebec City	Ann Lanouette
Windsor/Essex County	Erma Rount and Crystal Harvey
Winnipeg	Jackey LaBossiere



Myeloma Canada community awards 2020

Recognizing the exceptional leadership of our Canadian myeloma community.



Executive Director's Award

Manon Veilleux, Quebec City (QC)

For her active role within the Myeloma Canada Patient Advisory Council (PAC), as leader of the Quebec City Support Group, and for her involvement in the virtual edition of the 2020 Multiple Myeloma March.



Carolyn Henry Memorial TEAM Award

Julie Martel, Quebec City (QC)

For her commitment within the Coalition Priorité Cancer, making sure the patient voice is heard in the healthcare system, and for her significant contribution to Myeloma Canada's Awareness Day at the Quebec National Assembly at the end of 2019.



Nathalie Allard Memorial Award

Shawn Crossman, Moncton (NB)

For the second year in a row team #CrossmanStrong, led by Shawn, was the top fundraising team in Canada raising \$25,010 and surpassing last year's total of \$23,000.



Community Achievement Award

Micheline Garand, Montreal (QC)

For her participation for 10 consecutive years in the Multiple Myeloma March in Montreal, including 3 for which she was named top fundraiser.



Community Achievement Award

Patricia Prowse, Saskatoon (SK)

For forming a new team of 65 people for the Saskatoon Multiple Myeloma March, in honour of her dear friend Robbie. Thanks to the leadership and gusto of Patricia, they raised \$15,405 for the March, exceeding the city's overall goal through their team alone.



Newcomer of the Year Award

Bethany Reeves and Megan Gardiner (PEI)

For launching a new support group in PEI with satellite locations in both Summerside and Charlottetown, for organizing the very first Multiple Myeloma March in Summerside, for raising \$12,640, and for actively advocating for drug access to daratumumab in the province.



Notable Volunteer Award

Nancy Gray, Hamilton (ON)

For her dedication, perseverance and creativity in organizing the Hamilton Multiple Myeloma March in an extraordinary year. While following health measures and protocols, the event still managed to raise \$53,000.



Marion State Memorial Nursing Award

Wendy Bursey, Hamilton (ON)

For demonstrating excellence in nursing through her leadership, ability to work as a team, passion and commitment to advancing the care of myeloma patients.

Patient Advisory Council (PAC)

A message from the PAC Chair

In 2014, Myeloma Canada's Board of Directors created the Patient Advisory Council (PAC). The Council's primary objective was, and continues to be, to advise the Board of Directors on important issues for patients, caregivers, and support groups, by informing its members of the patient's perspective at the national and regional levels. The PAC also works closely with the Myeloma Canada professional team to support the organization's many activities.

In 2020, the PAC conducted a survey focusing on the long-term sustainability of support groups and succession planning, helped Myeloma Canada in its response to COVID-19 and its strategic planning, provided advice and comments on several documents and InfoGuides, and participated in, and supported, both the virtual Support Group Leaders' Summit and the Myeloma Canada Scientific Roundtable. The PAC also hosted a webinar to introduce ourselves to the Myeloma Canada community, while reiterating our support for them above and beyond the pandemic.

The PAC is committed to the well-being of the Canadian myeloma community. We will continue to provide an advisory function to the Board, and to participate in, and contribute to, Myeloma Canada programs and events.

We would also like to extend a special thank you to David McMullen for having assumed the position of interim Chair for 2020.

Glenn Hussey
Patient Advisory Council Chair



2021 PAC members:

- Glenn Hussey (Chair, Ontario)
- Susan McLean (Western Canada)
- Phil Harbridge (Western Canada)
- Rinat Avitzur (Ontario)
- Tanya Zigomanis (Ontario)
- Manon Veilleux (Quebec)
- David McConkey (Atlantic Canada)

OUR PROGRAMS AND ACHIEVEMENTS

Science & research

**FOSTER, SUPPORT, AND FUND MYELOMA-RELATED
RESEARCH THAT LEADS TO BETTER PATIENT OUTCOMES
AND LEADS TO A CURE.**

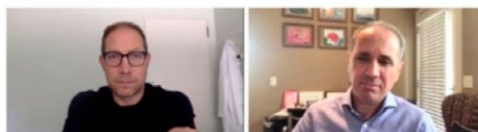
In 2020, Myeloma Canada invested in more research initiatives than ever before, thanks to the collective fundraising efforts of our community and organization, and the great generosity of our donors. A total of \$735,000 was invested in research, a new record for us! We reiterated our support for the Canadian Myeloma Research Group (CMRG), a national collaborative research organization; invested in Newfoundland and Labrador's participation in the CMRG National Myeloma Database project; supported research on risk stratification associated with myeloma and the future of precision medicine; contributed funds to researching factors that impact patient's quality of life and overall survival; and in allogeneic stem cell transplant research. We were delighted that myeloma researchers continued their work and went even further for the well-being of patients and for humanity. Supporting them is crucial for improving the quality of life of people affected by myeloma, and to get us closer to a cure.

Over the years, we've witnessed an increase in the number of new molecules for the treatment of myeloma, both approved and not yet approved in Canada, as well as in the number of treatment combinations being studied. In 2020, we made our very first submission to advocate for the first CAR T therapy for the Canadian market to be approved. Clinical research is in full swing and the results for myeloma are very promising. We have gone to great lengths to understand and learn what our members would like to see for future myeloma research by launching the second phase of the Myeloma Priority Setting Partnership (PSP), focused on identifying and understanding the research priorities of our community.

The challenges were significant, but the scientific community proved their commitment time and time again.

11th Annual (and 1st virtual) Myeloma Canada Scientific Roundtable

Annual meeting that serves as an incubator of ideas for the development of high-impact myeloma clinical trials in Canada.



 **150 participants**

Co-chairs: Dr Paola Neri (Calgary) and Dr Julie Stakiw (Saskatoon)



Myeloma Canada Research Network Consensus Guideline Consortium (MCRN-CGC)

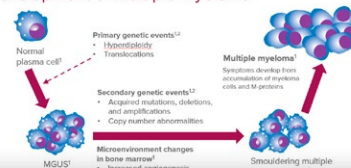
- Developed consensus recommendations on daily practice, existing guidelines and availability of evidence-based diagnostic tools for myeloma.
- First "Consensus Guidelines on the Diagnosis of Multiple Myeloma and Related Disorders: Recommendations of the Myeloma Canada Research Network Consensus Guideline Consortium" developed by 17 Canadian experts and published in *Clinical Lymphoma, Myeloma and Leukemia* journal

Accredited Myeloma Training Program Created in Collaboration with McGill University (QC)

- Identification of best practices in the diagnosis and management of myeloma
- **Scientific Planning Committee:** Dr Kevin Song (BC), Dr Richard LeBlanc (QC), Dr Rayan Kaedbey (QC), and Dr Darrell White (NE)
- Approved by the Faculty of Medicine's Office of Continued Professional Development at McGill University
- Allows for a Maintenance of Certification (MOC) from the Royal College of Physicians and Surgeons of Canada

Identifying Best Practices in the Diagnosis and Management of Myeloma

Development of Multiple Myeloma



Case Study: Aliyah



- ❖ 62-year-old accountant
- ❖ Complains of fatigue and weakness
- ❖ Recurrent urinary tract infections
- ❖ Initial workup shows:
 - Hemoglobin 9.8 g/dL
 - Skeletal survey (X-ray): No lesions
 - SPEP showed an IgG M-spike of 20 g/dL
 - Immunoglobulin quantification revealed an IgG of 25.14 g/L
 - Bone marrow aspiration: 14% **clonal** bone marrow plasma cells

Myeloma Priority Setting Partnership (PSP) – Phase 2

Patients, caregivers and healthcare professionals set the direction for future myeloma research and encourage funders to recognize priority research questions that remain unanswered. Review of the most popular questions from Phase 1 to determine the final Top 10 list of priority questions for future myeloma research.



581 participants (Phase 2)

Led by Dr Anthony Reiman (Medical oncologist and Canadian Cancer Society Research Chair)

Supervised by the James Lind Alliance

Approved by Horizon Health Network Research Ethics Board



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Our sincere thank you to our many partners and donors who helped support our cause in 2020. Your unwavering commitment in this time of uncertainty touches us deeply. Through your donations, we're able to pursue our mission and support clinical research that will lead to a cure.

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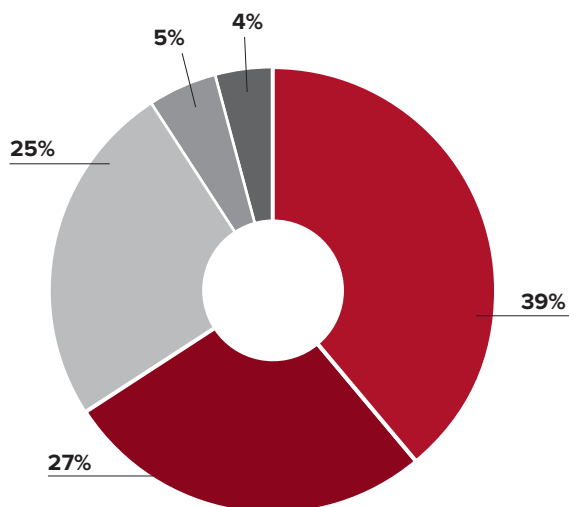
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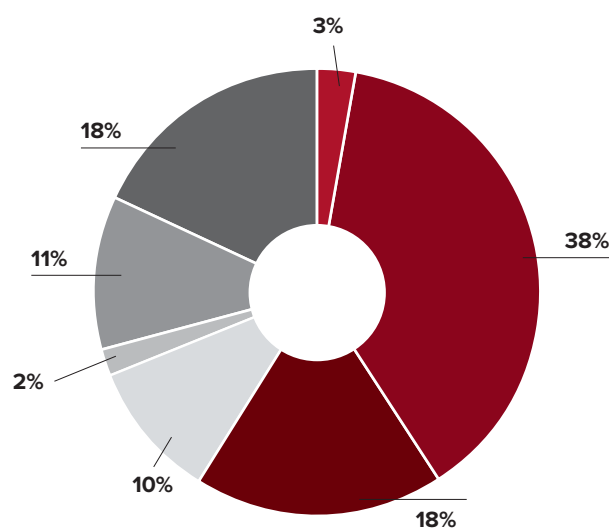
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- Corporate giving (pharmaceutical partners and other corporate sponsors)
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- Other contributions (online donations monthly donations, wills and more)
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