



Our Programs and Achievements

2021 YEAR IN REVIEW
MYELOMA CANADA



**MYELOMA
CANADA**
MAKING MYELOMA MATTER

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

When I look back at 2021, it's with a mix of emotions ranging from awe, frustration and anger to tremendous gratitude, hope and optimism. It's been a seesaw of clarity and confusion, of highs and lows and in-betweens. We made it through the second year of living in a world-wide pandemic, of Delta and Omicron variants, double vaccinations and booster shots, loosening and re-introduction of restrictions on in-person gatherings, fluctuating opening and closing of borders, the introduction of vaccine passports, all the while adapting to our new norm of Covid-19 testing, physical distancing, masking up, etc.

Our world has become smaller yet ironically, more accessible through technologies like Zoom. Fundamental human rights issues regarding equity, inclusivity, diversity, and advocacy came out of the shadows and shared centre stage with the pandemic. Never have communities come together to achieve so much.

It's never been more essential to establish and maintain positive, supportive relationships, reach out and not be afraid to ask or accept help from your healthcare provider, family, friend or other support network(s). The increasing demands on our time and energy, coupled with the continued stress of living within a pandemic can play havoc on all of us.

The power to persevere, to self-advocate for the most appropriate treatments and the best care is how we can achieve the best life for the myeloma community. The more we talk about myeloma, educate our fellow Canadians, the more people will come to understand the disease, recognize the myriad of symptoms that are too often brushed under the guise of something



innocuous or benign. The more awareness that's created for myeloma, the quicker people will be diagnosed and treated.

We did face some challenges with regards to new treatment funding and availability in Canada; the first Health Canada approved CAR T-cell immunotherapy for myeloma was not recommended for reimbursement by the provinces, and the pricing negotiations between manufacturers and the government agency for therapies such as daratumumab (Darzalex) in the sub-cutaneous formulation, and the newest CD38 monoclonal antibody, isatuxumab (Sarclisa), are not yet complete. But the good news is, the technology exists, and we foresee 2022 as being a very busy year for drug advocacy.

Regardless of the few bumps in the road we faced along the way, your dedication to making myeloma matter as a community is the reason why 2021 was an exceptional year for Myeloma Canada. We soared to new heights and exceeded even our own expectations in our programming, research investments and fundraising as a direct result of you, your passion, commitment, and support.

If I may ride the tailcoat of our 2021 theme, you proved to yourselves – and the entire Canadian myeloma community – that YOU most certainly have the POWER to improve the lives of thousands living with this disease.

A handwritten signature in dark ink, reading "Martine Elías".

MARTINE ELIAS

OUR TEAM

MARTINE ELIAS

Executive Director

MICHELLE OANA

Director of Development
& Community Relations

GABRIELE COLASURDO

Director, Science & Research

JESSY RANGER

Director, Patient Programs,
Health Policy & Advocacy

MARCIE BARON

Director, Corporate,
Communications & Marketing

MURIEL INGRASSIA, CPA, CMA

Manager of Operations

HELEN MAHSHIE

Regional Manager, Community
Engagement & Development
(Ontario)

SHANEIKA HESLOP

Senior Administrative Assistant

PATRICIA CELESTIN

Development & Digital
Support Coordinator

CONNOR MELLEGRS

Governance, Policy &
Administration Officer

AIDAN ROBERTSON

Health Policy & Advocacy Assistant

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National Institute for Health
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CEO, Peter Ballantyne Group
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Aboriginal Business and
Corporate Development
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Board member, Société de
Transport de Laval
Montreal, QC

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Director

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Centre
Assistant Professor, McMaster
University
Hamilton, ON

WILLIAM PAINE

Director

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

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Research Network
Professor of Medicine,
University of Toronto
Princess Margaret Cancer Centre
Toronto, ON

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

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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 stay connected with the Canadian myeloma community. 2021 continued to be a challenging year; we didn't let the cloud of COVID-19 get the better of us, once again, we adapted our programs to the realities of the pandemic and even worked on new projects for 2022. Since we were still unable to meet in-person for educational events, we provided new online InfoVideos and InfoWebinars throughout the year, developed new factual InfoSheets, and created more educational InfoGuides to support patients and their caregivers throughout their journey. For example, when the generic versions of Revlimid (lenalidomide) were approved for use in Canada, we promptly developed an InfoSheet on generics, and disseminated the information and its implications to the community. Our online platforms also made sure to capture all relevant information regarding the ever-evolving COVID-19 pandemic and was updated ongoingly, and as quickly as the news became available.

We are constantly striving to develop new tools with which to inform patients and their loved ones to help them better understand the challenges they face, and 2021 was no exception. We ensure that our community has the tools they need to better understand and manage their lives with myeloma, regardless of where they may be in their journey.

Response to COVID-19

Enhanced communications tools & messaging

Integration of InfoBulletins on COVID-19 and myeloma to our Myeloma Matters Newsletter

- Updated the COVID-19 website section, directly accessible from the Myeloma Canada home page, featuring pandemic news
- Webinar licensing enhancements for virtual meeting platform for staff and support group members
- Webinar series on COVID-19 and myeloma
- Increased dissemination of information

2 InfoSheets

- Generic Drugs in Canada
- Amyloid Light Chain (AL) Amyloidosis

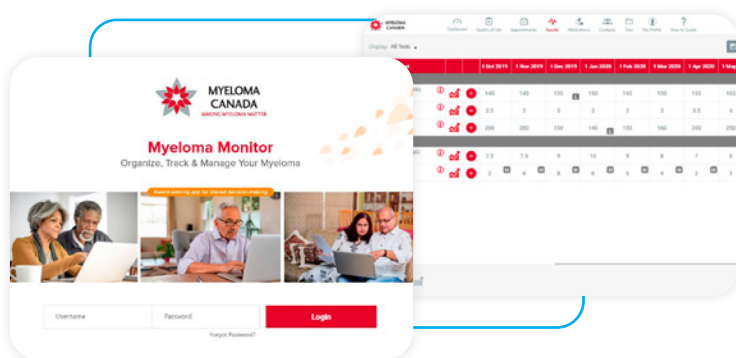


Myeloma Monitor Application

Recipient of Celgene's International ImpactHeme Award

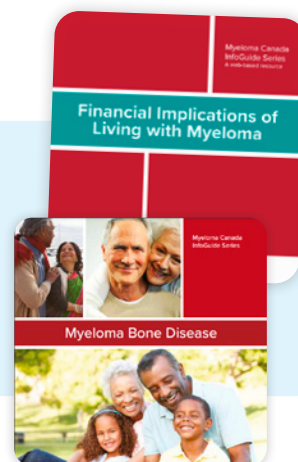
Helping multiple myeloma patients organize, track and manage their disease.

- **375** downloads



2 InfoGuides

- Financial Implications of Living with Myeloma
- Myeloma Bone Disease - updated



16 InfoWebinars

3,000+ views



10 InfoVideos

1,700+ views
5 EN | 5 FR



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.

- New Financial Implications of Living with Myeloma
- Direct access to Myeloma Canada's Myeloma Drug Access Navigator
- **1,478** users
- **1,814** sessions

OUR PROGRAMS AND ACHIEVEMENTS

Awareness

PROMOTE EARLY DIAGNOSIS FOR, AND INCREASE AWARENESS OF, MYELOMA AND THE WAYS IT AFFECTS THE LIVES OF THOSE LIVING WITH THE DISEASE, AND THEIR LOVED ONES.

We are convinced that each person has the individual power to make a difference, to grow the conversation, to help improve lives, and to keep the needle moving forward so that a cure may be found. In 2021, we launched a new awareness campaign, **YOU have the POWER**, highlighting the impact one person can have on the collective, and to appeal to our community to help drive our mission forward. The campaign included a digital component, promotional items, and a direct mail program. The community supported us every step of the way.

In 2021, we at Myeloma Canada worked harder for our community by continuously improving our website, increasing our social media presence, sharing reliable and up-to-date information through the Myeloma Matters Newsletter, creating educational content, and participating virtually in numerous national and international events.

Through different partnerships, we participated in several national awareness campaigns that focused on diagnosis and treatment delays due to the pandemic, and encouraged Canadians not to ignore or put off their health and cancer care because of this. With the help from our community, we used our power to make sure myeloma matters – wherever and how ever - we could. Together, we increased awareness and education, advocated on a personal and/or government level, supported one another, and of course, fundraised to help further our mutual cause and mission.



**MYELOMA
CANADA**

MAKING MYELOMA MATTER

INCLUSIVITY RESEARCH PROJECT

- Research agency hired to review literature, conduct a market assessment and build a list for potential outreach
- Interviews with healthcare professionals & patients were conducted to identify the gaps within, and needs of the community

MINI CAMPAIGNS

Created partnerships to raise awareness about the realities of cancer patients in a pandemic world

New Normal, Same Cancer

Blood Health, Media Planet

Blood Cancer Awareness Month

YOU HAVE THE POWER CAMPAIGN

Fully integrated outreach program and awareness campaign: direct mail, social media, digital platforms

DOUBLE YOUR IMPACT

Spring and fall fundraising campaign

The direct mail program raised **\$99,104**





4,365 followers

National Facebook page
(English and French)



996 followers



628 followers



559 followers

▶ **129,506 unique visits**

▶ **163,120 page views**

14 conferences & meetings

- Canadian Myeloma Research Priority Setting Workshop
- CARE CCG-QC 2021
- Living Well with Myeloma: How to Optimize and Protect your Immune System: A Nutrition Approach
- Waiting Room Revolution and Myeloma Canada presents: A sit down interview with Dr. Hira Mian
- Optimizing Precision Medicines - A Pillar of Health System Resiliency
- CARE at ASCO/EHA - Hematology Sessions
- International Myeloma Working Group Summit
- Workplace Mindfulness, Wellness, and Productivity
- Graft-versus-Host-Disease consultancy meeting with Novartis
- Consultation for Patients on the Deliberative Appraisal Process at CADTH
- CARE Education Winter Hematology Update
- Living Well with Myeloma: Resilience
- Hot Topics in Multiple Myeloma
- International Myeloma Foundation Patient & Family Webinar - From Vaccine to Variants: The Latest COVID-19 Safety Guidelines

24 Myeloma Matters e-Newsletters

(12 English/12 French)

- 20,000+ subscribers



COVID-19 INFOBULLETINS

Integrated into our monthly Myeloma Matters e-newsletter
Seperate bulletin on vaccination advocacy efforts

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 PEOPLE LIVING WITH MYELOMA.

In 2021, we had the opportunity to speak out on important issues by being invited to take part in several public consultations organized by Health Canada regarding a brand-new strategy for funding rare disease treatments, as well as changes to the regulatory framework for clinical trials in Canada. Through different partnerships with the Coalition Priorité Cancer and the Patient Advisory Committee of CATALIS Quebec, we were able to advocate for modifications to the current regulatory framework that limits access to clinical trials in Quebec, and influence clinical research priorities in the province. These discussions involved members of various organizations like ours, along with health professionals, researchers, and members of government bodies. It was a great opportunity to raise awareness for the issues our community are facing.

With the arrival of generic versions of lenalidomide and negative funding recommendations for certain treatments – such as the case for CAR T-cell immunotherapy and other cancer drugs – we vow to continue doing all we can to advocate on behalf of the myeloma community. Throughout the year, we saw many manufacturers go full speed ahead with requests to enter the market with new drugs or treatment combinations for multiple myeloma. By sharing your stories with us, you enabled us to continue our mission and helped us build strong submissions for drug access.

With regards to the COVID-19 pandemic situation, Myeloma Canada joined forces with support groups and many of our partners to ensure that cancer and immunocompromised individuals were granted accelerated access to COVID-19 vaccinations. We participated in consultations with the World Health Organization (WHO) and Canada's National Advisory Committee on Immunization (NACI), to whom we provided feedback and submitted a brief on process and framework modernization.

The work we do to keep our seat at the negotiating table is crucial; it ensures that the voices of our myeloma community members are heard, and that the healthcare system responds to your needs.

Highlights

- Succeeded in getting support for accelerated access to COVID-19 vaccines for myeloma patients in no less than 5 Canadian provinces
- Created a national advocacy campaign to make healthcare a priority during the federal election (in partnership with CONECTed and several Canadian patient organizations)
- Isatuximab (Sarclisa, for injection) with pomalidomide (Pomalyst) and dexamethasone was officially recommended for reimbursement (although not yet funded)
- New generic versions of lenalidomide capsules – commonly known as Revlimid - were approved
- Myeloma Awareness Day and Myeloma Awareness Month - proclaimed in 4 Canadian provinces
- Developed the “Declaration of Personal Health Data Rights in Canada” with a patient and caregiver-led Data Working Group, at the Patients Redefining the Future of Healthcare in Canada Summit



5 community surveys and reports

Submitted to the pan-Canadian Oncology Drug Review (pCODR), and the Institut National d'Excellence en Santé et Services Sociaux (INESSS) for access to new treatments:

- Selinexor (Xpovio) in combination with bortezomib (Velcade) and dexamethasone
- Isatuximab (Sarclisa) in combination with carfilzomib (Kyprolis) and dexamethasone
- Isatuximab with pomalidomide (Pomalyst) and dexamethasone before final recommendation
- Optimal pharmacotherapy for transplant-ineligible myeloma patients
- Idecabtagen vicleucel (ABECMA CAR-T)

3 submissions

- To pan-Canadian Pharmaceutical Alliance (pCPA) regarding the delay in price negotiation on use of isatuximab (Sarclisa) in combination with carfilzomib (Kyprolis) and dexamethasone
- To the Patented Medicine Prices Review Board (PMPRB) regarding Guideline Monitoring & Evaluation Plan (GMEP) in 2021
- To Health Canada's Public Consultations on the Clinical Trials Regulatory Modernization Initiative

Self-advocacy program

New!

- Virtual Care Planner
- Virtual Care Guide

National strategy for high-cost drugs for rare diseases

- Participation in public consultations
- Worked with our advocacy committee to file recommendations on behalf of Myeloma Canada
- Collaborated with partners such as CONECTed to file group recommendations



OUR PROGRAMS AND ACHIEVEMENTS

Community Empowerment

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

We continued to provide our support groups and community with technology and provided different tools to help them manage their virtual meetings and keep them informed and inspired. They proved to us once again how creative and resilient they were by constantly adapting to the safety regulations and guideline changes. Resilience, flexibility and agility were at the forefront of 2021. Among the many lessons we have learned, there is the ability to adapt and grow amidst an ever-changing environment. While the pandemic put our lives in an odd ‘constant state of flux’, together we found new ways to connect, to support one another and to ensure our spirit, drive and energy to make myeloma matter never faltered.

The Multiple Myeloma March achieved new records in terms of funding and creativity. The community fundraising came back and gave us a little taste of what our “new normal” would look like. While our Support Group Network was continuing its development, we launched a new Peer Support Program and a Conference for cancer advocates, creating new ways for the community to connect.

Without our wonderful volunteers and community members, Myeloma Canada would never be able to accomplish all that we do. Without their strength and conviction, we would not be the organization we are today. Their time and energy helped us pull through this pandemic.

OUR PROGRAMS AND ACHIEVEMENTS

Support Group Network

44 support groups

- + New virtual Francophone support group
- + New support group in Newmarket

3 MEET & GREETs

- 📍 North Bay, ON
- 📍 Newmarket, ON
- 📍 Lethbridge, AB



793 members

in our online Facebook support groups for patients and caregivers



NEW! HEALTH EMATTERS PROGRAM & CONFERENCE FOR ONLINE CANCER ADVOCATES



Myeloma Canada's 14th annual (and 2nd virtual) Support Group Leaders' Summit



65 participants

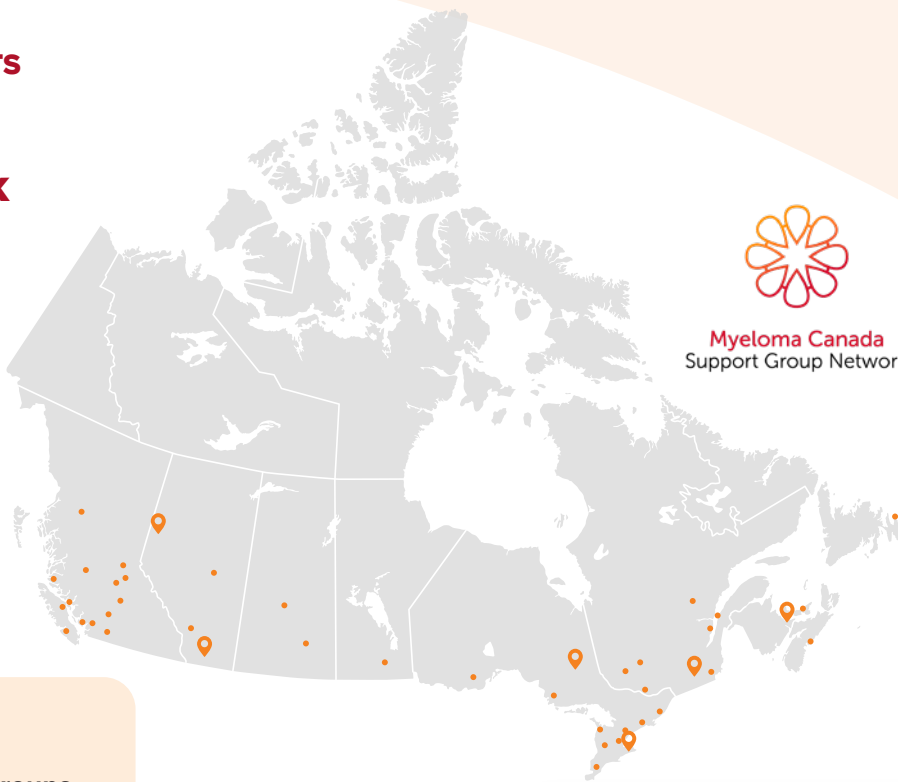
from all over Canada

NEW! MYELOMA PEER SUPPORT PROGRAM

In conjunction with Wellspring and the Fondation québécoise du cancer (to develop the French program)



Myeloma Canada
Support Group Network



2021 Support Group Leaders

Alberta

Martin Reed	Grande Prairie	North Western Alberta Myeloma Support Group
Brian Treadwell	Lethbridge	Lethbridge Myeloma Support Group
Bev Dunn	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
Susan McLean	Nanaimo	Nanaimo Multiple Myeloma Support Group
Barbara Morrison	Maple Ridge	Fraser Valley Support Group
Warren Welling	Victoria	Vancouver Island Multiple Myeloma Support Group
Susan Schmalz and Erwin Malzer	Kelowna	BC Southern Interior—Kelowna Chapter Support Group
Bob Trudeau	Kamloops	BC Southern Interior—Kamloops Chapter Support Group
Ron Surry	Enderby	BC Southern Interior – Enderby Chapter Support Group
Jenn Collins and Cyndi Logan	Prince George	Northern BC Multiple Myeloma Support Group
Kerry McKeen and Helene Lalonde	Vancouver	Vancouver Myeloma Network Support Group
Bruce Marks	Surrey	Surrey & District Multiple Myeloma Support Group

Manitoba

Jackey LaBosiere	Winnipeg	Winnipeg Myeloma Support Group
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New Brunswick

Carol Egan	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
Juliette Royer	Halton-Peel	Halton-Peel Myeloma Support Group
David McMullen and Donald Hunter	Toronto	Toronto and District Multiple Myeloma Support Group
Robert Moreton and Lynda Aiken	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	Kitchener-Waterloo	Waterloo Region Myeloma Support Group
Linda VanderSchaaf	North Bay	Myeloma Nipissing Support Group
Lise Mackevicius	Sudbury	Sudbury and District Myeloma Support Group
Linda Campbell	Niagara	Niagara Region Multiple Myeloma Support Network
Tanya Zigomanis	Newmarket	York Region Myeloma Support Group

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
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 their desire to always want to do more to support the cause. Their trust and support are what make them an inspiring community: enthusiastic 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.

\$133,836

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

Myeloma Canada's 13th Annual Multiple Myeloma March

- ▶ **\$700,000**
- ▶ **32 participating cities
+ 1 virtual March**
- ▶ **3,700 participants**
- ▶ **6,281 donations**
- ▶ **11,000 km travelled
'together'**
- ▶ **285 pairs of March socks**
sold for a total of \$4,468

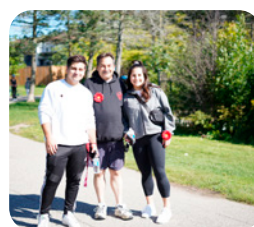
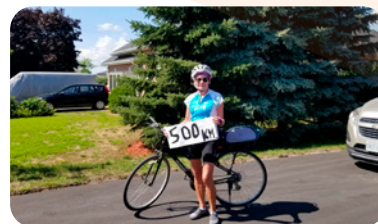
The Multiple Myeloma March, Myeloma Canada's flagship community and fundraising event, celebrated its 13th anniversary in 2021. Every year in the fall, the myeloma community gets together to take part in a 5km March to raise funds for better access to innovative treatments to improve the length and quality of life of those living myeloma. In 2021, the Multiple Myeloma March took place either in-person or virtually. It was your March, your way! For those who chose to participate virtually, many community members were creative in helping us raise essential funds for myeloma research. We were incredibly fortunate and thankful to have such a united and supportive community who made it possible again in 2021.



MULTIPLE MYELOMA MARCH

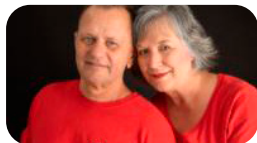
2021 Multiple Myeloma March leaders

City	Leaders
Airdrie	Michelle Oana
Cobourg	Rebecca Flint
Halifax	Michael Senz and Julie Salsman
Hamilton-Niagara	Nancy Gray and Victoria Falla
Kamloops	Bob Trudeau
Kelowna	Susan Schmalz
Kingston	Jeff Heyman and Claudia Trost
Kitchener-Waterloo	Louise Moriarity
Eastern Townships	Jessy Ranger and Vénus Bélanger
Mississauga	Orianna Scali
Moncton	Shawn Crossman
Montreal	Patricia Celestin and Patricia Empsall
Newmarket	Kristy Ahola
Oshawa	Laurie Khaler
Ottawa	Frank Shepherd and Glenn Hussey
Prince George	Cyndi Logan
Quebec City	Jérôme Goulet
Regina	Sharon McIntosh and Mona Neher
Sacré-Coeur	Sarah and Marilyse Bouchard
Saint John	Carol Egan
St John's	Tina Soulier
Saskatoon	Marie Prokopiw and Judi Worth
Sault Ste Marie	Marion Bentley
Summerside	Megan Gardiner and Bethany Reeves
Thunder Bay	Michelle Oana
Vancouver Island	Susan McLean
Vancouver	Michelle Oana
Windsor/Essex County	Erma Rount and Crystal Harvey
Winnipeg	Maria Marinelli



2021 Myeloma Canada community awards

Recognizing the exceptional leadership of our Canadian myeloma community.



Executive Director's Leadership Award

Erin Belzile – North Bay, ON

Erin is a strong advocate for better access to procedures and healthcare for those living in remote communities, featuring in a Patient Family and Caregiver Council (PFCC) video on a patient's perspective of the challenges within the healthcare system, which was for presentation to the Ontario Health Team (OHT). Erin also participated in a Myeloma Canada panel discussion on the issues and challenges for patients living in remote areas. Erin created a team and started her own virtual walk, raising \$14,700 for her first year and sharing their story several times in local media. Erin decided to fill the volunteer Group Leader position in the Nipissing Support Group.



Carolyn Henry Memorial TEAM Award

Alyssa Dickey - Patient advocacy - Etobicoke, ON

In 2021, Alyssa launched her blog, Myeloma in the Middle to raise awareness for myeloma and create an online community for younger folks living with the disease. Alyssa joined the Steering Committee for Health eMatters, Myeloma Canada's exciting new program and conference for online Canadian cancer advocates. She also works as a Peer Support volunteer for Myeloma Canada's Peer Support Program, giving younger Canadian adults with myeloma somewhere to turn to.

Phil Harbridge - Health policy advocacy - Surrey, BC

Phil is a valued member of Myeloma Canada's Patient Advisory Council (PAC) for Western Canada (and its Vice Chair). He was instrumental in advocating and accelerating 2nd dose vaccinations for myeloma patients in BC. Phil took it upon himself to connect with BC's Liberal Party Health Critic, went to the media and publicly highlighted the disparities in healthcare. With a committee of volunteers, he successfully obtained the first-ever proclamation for a Myeloma Awareness Day in BC on March 1, 2021!



NEW! 2021 Myeloma Canada Support Group Lifetime Achievement Award

JoAnn Cartlidge – Windsor, ON

For the past 20 years, JoAnn has been a beacon of light for the Windsor myeloma community. Over a decade has gone by since JoAnn's husband's passing, yet she remains as committed as ever to continue leading the group in his memory. JoAnn is a true pioneer, philanthropist and inspiration to the entire Canadian myeloma community.

Donald Hunter – Toronto, ON

Donald's exceptional contribution to the Ontario myeloma community dates years before Myeloma Canada even came into existence. In 1997, Donald was a caregiver to his now late wife Marion. It was then that he became involved on the Steering Committee of the 1st myeloma support group in Canada, the Toronto & District Multiple Myeloma Support Group. Over 20 years ago, Donald assumed the position of Treasurer and Meeting Venue Liaison and he has remained in the role ever since!



Marion State Memorial Nursing Award

Nurses of the Multiple Myeloma Clinical Research Team at l'Hôpital Maisonneuve-Rosemont, Montreal (QC)

For the first time, an exceptional team was honoured instead of one individual: Nathalie Lachapelle, Marie-Pier Lecours-Cyr, Myriam Hébert, Anne-Marie Châtelain and Édith Cartier. The five women have shown remarkable leadership in how they've adjusted their practices in the face of so many changes; they have had to re-organize their work, adapt new approaches for new realities, conduct follow-ups under unusual circumstances, regularly modify treatment plans and still make sure that patients and their families are - and feel - supported.

OUR PROGRAMS AND ACHIEVEMENTS



Notable Volunteer Award

Bruce Marks – Surrey, BC

For his role as Support Group Leader for the Surrey Myeloma Support Group in BC, but also as a Peer Support volunteer for Myeloma Canada's Peer Support Program. Bruce, along with volunteers, worked tirelessly to obtain the first-ever proclamation for a Myeloma Awareness Day in BC on March 1, 2021!

Tanya Zigomanis – Newmarket, ON

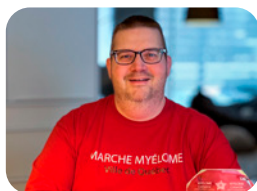
Despite Covid-19 restrictions, Tanya managed to launch the York Region and Area Myeloma Support Group. She is an active member of the Myeloma Canada Patient Advisory Council (PAC) and co-founded the International Facebook group called MM Survivors. Although Tanya hasn't been able to attend the Marches, she raised \$10,650 in 2021 alone!



Nathalie Allard Memorial Award

Team Shannon's Plasma Cell Mates – Team Captain, Brad Adams – Hamilton, ON

As team captain to "Team Shannon's Plasma Cell Mates", Brad's relentless energy and drive to raise awareness and funds for myeloma, and Myeloma Canada's 2021 Multiple Myeloma March in Hamilton, Ontario, was beyond inspiring. Brad and his teammates raised an incredible \$19,285.78, \$11,304 of which he raised alone.



Community Achievement Award

Jérôme Goulet - Quebec City, QC

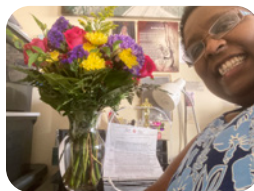
In 2020, Jérôme raised an incredible \$10,255 in his first year participating to the March. He took the role of March Leader for the 2021 Multiple Myeloma March in Quebec City, in addition to being the March's spokesperson for the second year in a row. The Quebec March was a tremendous success and brought in a record \$42,887, \$12,611 of which was raised by his team.



NEW! Myeloma Canada Support Group Leader Distinction Award

Beverly (Bev) Dunn – Calgary, AB

Since joining the myeloma community, Bev dove in head-first and became an involved member of the Southern Alberta Myeloma Patient Society (SAMPS) in Calgary, and became Vice-President of the Leadership Committee, and then President in 2021. Bev helped organize virtual meetings, educational conferences and mobilize volunteers for fundraising initiatives and committee roles. Bev was part of an amazing committee who managed to apply and obtain the first-ever proclamation for Myeloma Awareness Month in Alberta in 2021!



Juliette (Jules) Royer – Waterloo, ON

When diagnosed she found support in the Halton-Peel and Area Myeloma Support Group and soon joined as a group co-leader. Jules helped co-found the Waterloo Region Myeloma Support Group and served as co-leader for both support groups for many years. In 2021, after the passing of Norma Lindner, founder of the Halton-Peel and Area Support Group, Jules stepped in as Group Leader. Over the years, Jules has been involved in countless Myeloma Canada initiatives including the Myeloma Action Day at Queen's Park, the Multiple Myeloma Marches, the Peer Support Program and the first phase of our research project on identifying the needs and gaps of marginalized and under-represented populations living with myeloma.



Newcomer of the Year Award

Pierre Laforest – Dieppe, NB

Pierre quickly mobilized his friends and loved ones and launched "UNI Défi Everest Challenge", a new awareness and fundraising initiative in New Brunswick. In just a few months, Pierre managed to bring together more than 145 participants and raise an incredible \$82,711 for myeloma research!

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, while providing the patient perspective on national and regional issues. The PAC also works closely with the Myeloma Canada professional team to provide patient-focussed advice and feedback on the organization's many activities.

Highlights of PAC initiatives and activities in 2021 include:

- **Creating and submitting of reports to the Board of Directors for each Board meeting that summarized recent and planned activities of the PAC. These reports also included comments and recommendations on matters important to patients, caregivers, and Support Groups;**
- **Reviewing and updating of the PAC terms of Reference;**
- **Holding a Blue Sky Meeting to focus on the PAC role and activities. The top 5 initiatives were: continue organizing Support Group Leader Summits; expansion of Myeloma Awareness Day; increased support to Support Group Leaders; increased support around Covid-19; and increased focus on education and social perspectives for patients and caregivers;**
- **Building relationships with Support Group Leaders in each region of Canada, regularly meeting through conference and Zoom calls;**
- **Providing suggestions for Myeloma Canada's response to COVID-19, offering advice for myeloma patients and their families;**

- **Advocating for third doses of COVID vaccines for immunocompromised patients, and for a shortened timeline between doses (as per manufacturer's recommended guidelines);**
- **Providing advice and feedback on various documents including:**
 - the Declaration of Personal Health Data Rights in Canada;
 - the Guidelines to Establish Proclamations, the templates and the sample Proclamations for Myeloma Awareness Month;
 - the Myeloma Canada Advocacy Handbook.
- **Helping in planning, and presenting an update on the PAC, at the Support Group Leaders Virtual Summit;**
- **Holding an orientation session for the two new PAC representatives from Ontario;**
- **Participating, as observers, in the Myeloma Education sessions entitled "Identifying Best Practices in the Diagnosis and Management of Myeloma";**
- **Most PAC members participated in other Myeloma Canada initiatives and committees, and had leadership roles in the Multiple Myeloma Marches;**
- **Continually improving some PAC internal practices, to enhance our effectiveness.**

The PAC is committed to the well-being of the Canadian myeloma community. We will continue to focus on embedding the patient perspective in all Myeloma Canada activities.

Glenn Hussey

Patient Advisory Council Chair



2021 PAC members:

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

OUR PROGRAMS AND ACHIEVEMENTS

Science and research

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

Myeloma research is rapidly advancing. The past two years have been exciting ones for myeloma innovation in Canada, and thanks to your generous investments, Myeloma Canada continues to be a catalyst to it all. Your contributions have enabled us to invest over 1.2 million dollars over two years in many important research initiatives, all right here in Canada!

In 2021, along with continued investments in the Myeloma Research Priority Setting Partnership (PSP) and other exciting research projects, Myeloma Canada, once again, allocated significant research dollars to the Canadian Myeloma Research Group (CMRG), a not-for-profit research organization that has common goals with Myeloma Canada. In 2021, Myeloma Canada contributed a total of \$300,000 to CMRG's research activities including made-in-Canada clinical trials and the National Myeloma Database platform.

Furthermore, supporting myeloma research initiatives that are focused on improving quality of life, and helping to find a cure remains our top priority. Collaboration, investment, and determination are at the forefront of change. Myeloma Canada supported research projects in the development of redefining risk stratification and genetic profiling, understanding the disparities that people living with myeloma face and why certain immunotherapies are ineffective for myeloma, and supporting our international leaders in allogeneic stem cell transplant research.

Amongst our proudest accomplishments, was the publishing of the results of the Myeloma Research Priority Setting Partnership (PSP) initiative in the peer-reviewed British Journal of Haematology in November 2021. The paper, which documents the process and Top 10 priority questions for future multiple myeloma research, is publicly available for use on an international scale. A first of its kind globally, the PSP was a 4-phase project initiated in the fall of 2019. The goal of the project was to determine the top 10 unanswered myeloma research questions defined by you, our community, under the James Lind Alliance Priority Setting Partnership process. Our objective in supporting this important initiative was to guide Myeloma Canada's future research investments toward projects that are meaningful to our community. We're excited and proud to put these research questions into action on your behalf!

OUR PROGRAMS AND ACHIEVEMENTS

12th Annual Myeloma Canada Scientific Roundtable

Postponed to May 13-14, 2022 due to Covid-19

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 Kevin Song & Dr Keith Stewart



Myeloma Canada Impact Report

Our research investment principles are anchored in the core values that support the priorities identified by our myeloma community.

- Supporting the transformation of research into Real World Evidence (RWE)
- Redefining Risk Stratification and Genetic Profiling: the future of precision medicine
- Supporting contributing factors that impact quality of life and overall survival in myeloma
- Investing in unlocking mechanisms of drug resistance
- Supporting our international leaders in allogeneic stem cell transplant research
- Conducting the first Myeloma Priority Setting Partnership (PSP) to identify the top myeloma research priorities

Projects in which we invested in 2021 identified and addressed knowledge gaps in the diagnosis, treatment and science of myeloma and related plasma cell disorders, with the goal of improving quality of life and ultimately, finding a cure.



LIGNES DIRECTRICES DU GMPQ
Diagnostic et traitement du myélome multiple

GMPQ
Groupe des maladies plasmocytaires du Québec



Myeloma Canada Research Network Consensus Guideline Consortium

- Funded and managed by Myeloma Canada, the consortium develops consensus recommendations on daily practice, existing guidelines and availability of evidence-based diagnostic tools for myeloma.
- Second manuscript “Management of Myeloma Manifestations and Complications: The Cornerstone of Supportive Care: Recommendation of the Canadian Myeloma Research Group (formerly Myeloma Canada Research Network) Consensus Guideline Consortium” was published
- Third manuscript writing and discussion started on the treatment of transplant-ineligible myeloma patients

OUR PROGRAMS AND ACHIEVEMENTS

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 (NS)
- 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

6 virtual events completed

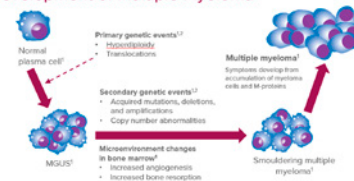
(Module 1 - 3; EN/FR)

300+ total healthcare provided registrations

Identifying Best Practices in the Diagnosis and Management of Myeloma

Module 1
Diagnosis of Multiple 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 Research Priority Setting Partnership (PSP)

Patients, caregivers and healthcare professionals set the direction for future myeloma research investments and encourage funders to recognize priority research questions that remain unanswered. Responses to final survey vetted for online workshop and full manuscript completed and shared via:

- Canadian Cancer Research Conference - Poster presentation
- NB Health Research Foundation Conference - Poster presentation
- NB Department of Health - Presentation
- Abstract published in supplemental issue of Blood Journal
- Correspondence article published in British Journal of Haematology

- BC SPOR SUPPORT Unit Conference - Abstract submitted

Supervised by the James Lind Alliance

Approved by Horizon Health Network Research Ethics Board

BJHaem
BRITISH JOURNAL OF HAEMATOLOGY

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The future of myeloma research in Canada: a James Lind Alliance priority setting partnership

Samantha Fowler, Lauren McLaughlin, Sarah Bridges, Marc Robichaud, Kevin Song, Lorelei Dalrymple, Robin Sully, Sharon Nelson, Suzanne

First published: 05 November 2021 | <https://doi.org/10.1111/bjh.18111>

Sections

Multiple myeloma, often referred to as myeloma, is an incurable cancer of the plasma cells which accumulate in the bone marrow and produce monoclonal protein resulting in hypercalcaemia, renal insufficiency, anaemia and bone deterioration.¹ To complicate matters further, both the disease and its treatment can impair organ function, sometimes in similar ways, contributing to significant disease burden, which can impair the quality of life for those living with myeloma.²

This is problematic given the growing incidence of the disease: between 1990 and 2016, the global incidence of myeloma increased by 126%.³ Simultaneously, research into treatment options for myeloma has led to people living longer.⁴ However, since there is currently no



OUR DONORS

We are grateful to our many partners and donors who helped support our cause in 2021. 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.

Individual donations

\$1,001 to \$2,000

- Dave Anderson
- Marje Barter-Cook
- Ellis Basevitz
- Wade Bennett
- Jean-Paul Boudreau
- Remi Bourlon
- Roberto Buffone
- Richard Carpenter
- Anthony Cella
- Nadia Cella
- Philippe D'Amour
- Joe De Simone
- Melanie Dubois
- Elizabeth Etue
- Mark Giralt
- Briana Greer
- Kenneth Huntley
- Trevor Ives
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- Yvette Stewart
- Pascal St-Germain
- Lennora Vanderwey
- Karen Wall
- Hans Wolf

\$2,001 to \$5,000

- William Anderson
- Mary Barbara Beaton
- Venus Belanger
- Francine Boucher
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- Pierre Carrier
- Marc D'Amour
- Donald and Mary Erickson
- Gisèle Fournier
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- Janene Sarabura
- Mark and Diana Sawers
- Christine Sidhom
- Sheldon Silverman
- Robin Sully
- Lorraine Tamburrino
- Mingjie Xie

\$5,001 to \$10,000

- Ross Carpenter
- Bradley Mederski
- Mario Saucier
- Dennis Sousa
- Patricia Prowse

\$25,000 and more

- Dominic Jean and Maria Del Col, in memory of Aldo Del Col

\$170,000 and more

- Michael Delesalle

Corporate donations

\$1,001 to \$4,000

- Dorothy Gibson Foundation
- Potvin Allard CPA Inc.
- Southern Alberta Myeloma Patient Society

\$4,001 to \$7,000

- Brookfield Partners Foundation
- Larivière et Massicotte Pharmaciennes Inc
- Pharmacie Michel Assaraf
- TD Metro Community Relations
- UNI C. Financière

\$7,001 and more

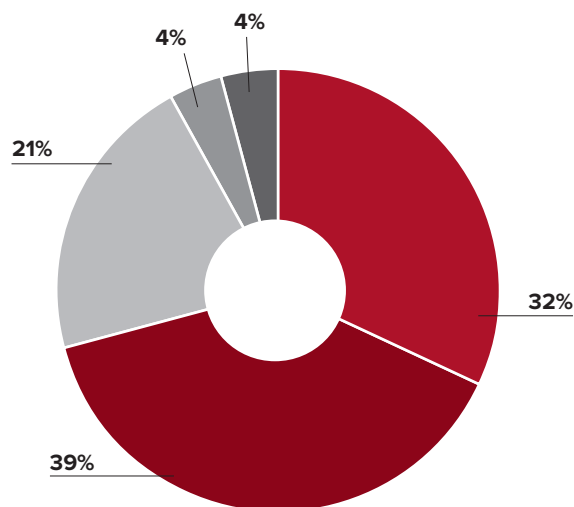
- Krabben Family Foundation
- L.A. Leasing
- Linda Torrance CGOUV Foundation

THANK YOU very much for your trust
and for helping us make myeloma matter.

2021 REVENUES: \$2,25M

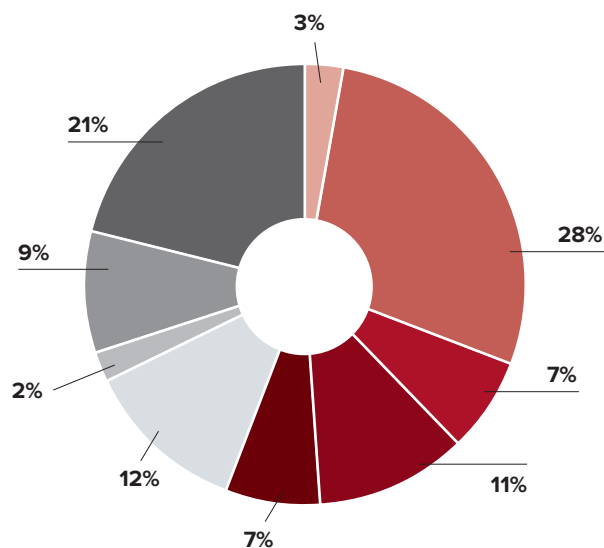
Where does the money come from?

- Corporate giving (pharmaceutical partners and other corporate sponsors)
- Fundraising events (Multiple Myeloma Marches and community events)
- Other contributions (online donations monthly donations, wills and more)
- Other revenue
- Investment income



Where does the money go?

- Governance
- Science and research
- Knowledge transfer
- Patient and education programs
- Community empowerment
- General and administration
- Access and advocacy
- Fundraising
- Awareness and communication



Sign up for our **NEWSLETTER** and join our **COMMUNITY** today!

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**MYELOMA
CANADA**

MAKING MYELOMA MATTER