



Our Programs and Achievements

2022 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. Myeloma Canada has been making myeloma matter since it was founded in 2005.

OUR PROMISE:

To improve the lives and empower all Canadians affected by myeloma, accelerate access to the best care, while supporting the pursuit of its cure and prevention. We do this by empowering the Canadian myeloma community through awareness, education and advocacy programs, and supporting science and research to find a cure.

OUR PLEDGE:

We pledge to cultivate and maintain an inclusive environment for our community and our organization. This includes respecting and addressing the diverse needs of all people— First Nations, Métis, and Inuit; under-represented and marginalized populations; the LGBTQIA2S+ community; cultural, racial, and ethnic minorities—in all that we do.



A message from our Executive Director

The year 2022 was exceptional for Myeloma Canada. Not only did we realize all the goals we had set for ourselves, but we surpassed our own expectations. Through the unfaltering dedication and support of our community and donors, we accomplished even more than we had anticipated.

Over the past few years, so much of our lives has been focused on the pandemic, staying safe and staying healthy. 2022 saw the removal of nearly all COVID-19 restrictions and the reopening of international borders in most countries, and the global rollout of COVID-19 vaccines continued.

With the loosening of restrictions, we were thrilled to safely reinstate in-person gatherings, keeping the Zoom virtual platform active so more of our community could join our conferences and events. We formed new strategic partnerships with other patient organizations and intensified our advocacy work fighting for equitable access to drug therapies, treatment and care. We held meetings with government officials, participated at influential national and international health conferences and meetings, growing our leadership position and reputation within the myeloma and patient organization worlds. Through these efforts, we played an important role in having new drug therapies approved and made accessible to our community.

We grew our support group network with new local and on-line support groups and a French Peer-to-Peer support program. We travelled across the country to spread myeloma awareness, education as well as maintain and increase our reach. We achieved unprecedented success with our Multiple Myeloma Awareness Month campaign, as well as our awareness and giving programs. We developed an impactful,

multi-tiered campaign that not only brought awareness to myeloma but advocated for all Canadians living with this disease to have the right to quality healthcare and services.

Together with our incredible volunteers, we created more awareness and raised record-breaking funds. We developed an exciting science and research strategy based entirely on our community's input, launched our grant program, and funded close to the same amount for Canadian myeloma research than in 2020 and 2021 combined!

We worked hard on developing our 5-year strategic directions plan that not only addresses our vision for Myeloma Canada but for myeloma in Canada, and developed our new Promise. We furthered and formalized our commitment to equity, diversity, and inclusion in our newly launched Pledge. As the only non-profit, national organization in Canada exclusively devoted to improving the lives of each and every Canadian impacted by myeloma, it is imperative that we reach – and create a welcoming and safe space – for all Canadians affected by this disease.

The successes we've realized across our 5 strategic pillars – education, awareness, advocacy, community empowerment, and science and research – have been possible because of our community's unwavering dedication to making myeloma matter.

It truly takes a village. And our village is our remarkable community. Thank you for helping to make 2022 a year like no other and setting the barre even higher for 2023.


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

SHANEIKA HESLOP

Senior Administrative Assistant

CONNOR MELLEGRS

Governance, Policy &
Administration Officer

JUSTIN MOORE

National Fundraising and
Development Lead

HELEN MAHSHIE

Regional Manager, Community
Engagement & Development
(Ontario)

PATRICIA CELESTIN

Development & Digital
Support Coordinator

KARINE GRAVEL

Project Manager, Education and
Patient Services

AIDAN ROBERTSON

Health Policy & Advocacy Assistant

SOPHIA MENDOZA

Event Coordinator

Myeloma Canada BOARD OF DIRECTORS

MÉLANIE MARTEL

Chair

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

WILLIAM PAINE

Co-Chair

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

LORELEI DALRYMPLE

Treasurer

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

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Secretary

CFO, Davis Legacy Group of Companies
Managing Director, Dynamis Consulting
Group
CFO, NorthCounty Tire Distributors
CFO, TYDAX Fitness
CFO, Complete Shipping Solutions
Owner, Herc's Nutrition St Albert
St Albert, AB

ELLIS BASEVITZ, CPA, CA

Director

Co-founder and Senior Consultant
PSB Boisjoli
Montreal, QC

JOYCE CHEHADE

Director

Senior Marketer Mood Disorders,
Lundbeck
Board member, Annie Parker Foundation
Montreal, QC

ADRIAN CRACIUN

Director

Director, Finance and Corporate
Controller, Ottawa International Airport
Authority
Ottawa, ON

LISA ELSER

Director

Gem Cutter and Gemologist, Custom
Cut Gems Co.
Port Moody, BC

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

HIRA MIAN, MD

Director

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

ANTHONY REIMAN, MD

Director

Medical oncologist
Canadian Cancer Society Research
Chair, University of New Brunswick
Professor, Department of Medicine,
Dalhousie University
Department of Oncology, Saint John
Regional Hospital
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

SANDOR SAJNOVICS

Director

Commissioner, Canada Energy
Regulator
Calgary, AB

JULIE STAKIW, MD

Director

Medical Director, Oncology & Clinical
Professor Hematological Oncology,
University of Saskatchewan
Saskatoon, SK

KEITH TAYLOR

Director

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

OUR PROGRAMS AND ACHIEVEMENTS

CORPORATE

SOME OF OUR ACCOMPLISHMENTS

Imagine Canada accreditation

- Work in progress to obtain Level 2 accreditation
- Complete overhaul of internal processes and policies

NEW!

Making Myeloma Matter: Building tomorrow, today

Strategic Plan (2023 - 2027) brochure launched



NEW!

Updated corporate messaging

- Promise
- EDI pledge

STRENGTHENING OUR NETWORK OF INVALUABLE PARTNERSHIPS

Myeloma Canada proudly partners with many national and international patient organizations and coalitions to advance the cause of cancer in Canada. Together we help effect positive change for a more patient-focused environment.

In 2022, our growing network included:

Provincial (QC)

- Alliance des patients pour la santé
- Catalis Recherche Québec
- Coalition Priorité Cancer
- Regroupement des Organismes Communautaires en Oncologie (ROCO)
- Victimes des pesticides du Québec

National

- All.Can Canada
- Canadian Agency for Drugs and Technologies in Health (CADTH)
- Canadian Association for Healthcare Reimbursement
- Canadian Myeloma Research Group (CMRG)
- Canadian Organization for Rare Disorders (CORD)
- Cancer Action Now
- Cancertainty
- CONECTed – Collective Oncology Network for Exchange, Cancer Care Innovation, Treatment Access and Education
- Innovative Medicine Canada
- Health eMatters
- Myeloma Alberta Support Society (MASS)
- PDCI
- Southern Alberta Myeloma Patient Society (SAMPS)

International

- Global Myeloma Action Network (GMAN)
- International Myeloma Foundation (IMF)
- Myeloma Patients Europe (MPE)
- Myeloma Patients Europe (MPE) Community Advisory Board
- Real World Evidence (RWE) 4 Decisions



OUR PROGRAMS AND ACHIEVEMENTS

Education

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

Having an informed and empowered community is a cornerstone of Myeloma Canada's promise. Every year, we host dozens of events, InfoSessions and webinars to keep our community up-to-date on the latest myeloma news and breakthroughs. We create InfoVideos and InfoWebinars based on our community's interests and questions, and develop new programs to support our community.

The pandemic brought with many insights in terms of how to deliver programs and information effectively and efficiently to our community. With restrictions from the COVID-19 pandemic lifted, and in response to our community's wishes, we cautiously re-instated in-person events, while maintaining the flexibility of a hybrid model. This enabled us to reach and provide information to even more Canadians impacted by myeloma than if we held in-person events alone. We also increased our online presence, sharing educational information on myeloma, as well as the pandemic, to a broader audience.

In 2022, we proudly held an incredible 11 InfoSessions across the country, launched exciting new tools like an online glossary on our website, developed new and updated existing InfoGuides, InfoSheets, and continued holding our highly successful InfoWebinars.

As important as it is to understand the disease, it's just as critical to understand the importance of taking care of yourself and practicing wellness as much as possible. As such, we launched a wellness section on our website that includes an array of nutritious and healthy recipes by Gill Compton, Certified Naturopathic Nutrition/Natural Chef, and past caregiver. Gill generously donated her time and expertise to develop healthy recipes to help strengthen the immune system.

And, as we do each year, we started to plan and develop new programs and content for 2023, all in an effort to ensure people living with myeloma and their carers feel supported, informed and empowered throughout all stages of their journey.

OUR PROGRAMS AND ACHIEVEMENTS

EDUCATION

Response to COVID-19

- Enhanced communications tools & messaging
- Regular updates to the COVID-19 website section on myeloma.ca and through our monthly e-newsletter, Myeloma Matters
- Improved webinar licensing for virtual meetings for staff and support group members
- InfoWebinars on COVID-19 and myeloma

2 InfoSheets

- Amyloid Light Chain (AL) Amyloidosis (Launched)

Updated!

- Could it be myeloma? (CRAB)



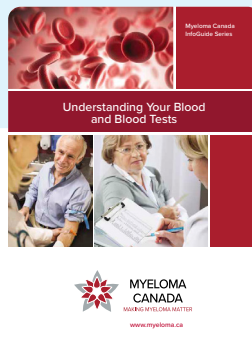
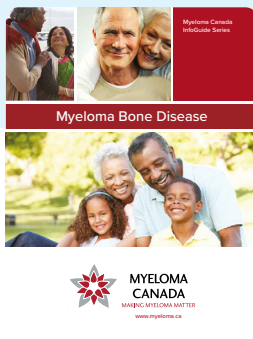
3 InfoGuides

NEW!

- Myeloma Immunotherapy InfoGuide

UPDATED!

- Myeloma Bone Disease
- Understanding Your Blood and Blood Tests (Launched)



8 InfoWebinars

Including **4** in **NEW** Digital literacy series

3,000+ views



NEW!

InfoVideos (1 EN | 1 FR)

Immunotherapy



67,700

total InfoVideo views for 2022

11 InfoSessions

Important events for anyone impacted by myeloma featuring guest speakers from the medical community who discuss how to best understand and manage life with myeloma.

- BC: Langley, Kelowna
- MB: Brandon
- NB: Moncton
- ON: Mississauga, Thunder Bay, Windsor
- QC: Laval, Lévis, St-Hyacinthe, Vaudreuil

Kelowna Patient & Caregiver Education Conference

Among presentations: understanding clinical trials, new research in myeloma, cannabis and its uses in symptom management, myeloma and the kidney.

OUR PROGRAMS AND ACHIEVEMENTS

EDUCATION

NEW! on myeloma.ca

- Online Glossary
- AL Amyloidosis section
- Wellness section featuring **8** new recipes

Chocolate Orange Avocado Mousse
DESSERT
- Gluten-free
- Dairy-free
- Vegan

Sesame Mango Chicken Salad
MEAL
- Gluten-free
- Dairy-free

Maple Pecan Energy Balls
SNACK
- Gluten-free
- Dairy-free
- Vegan

Warming Chickpea Salad
MEAL
- Gluten-free
- Dairy-free
- Vegan

Myeloma Monitor Application

Recipient of Celgene's International ImpactHeme Award

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

Myeloma Monitor
Organize, Track & Manage Your Myeloma

Username: _____ Password: _____ Login

PARTNERSHIP with IMD Health Global

Providing easily accessible, up-to-date digital health education to healthcare providers, patients and their families on the IMD platform.

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.

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.

Creating awareness for myeloma within the general population as well as our Canadian myeloma community is essential for early diagnosis, earlier access to treatments and care, and ultimately better outcomes and quality of living.

As such, we embarked on aggressive awareness initiatives and campaigns throughout 2022, using a variety of communications tactics, platforms and messages. We launched a new awareness campaign that brought to light the inequities in access to healthcare and vital drug therapies across the country. We launched our fully integrated bilingual “YOU MATTER. YOUR POSTAL CODE SHOULDN’T” (“You M4T T3R. Your POSTAL CODE Shouldn’t”) campaign in March for Myeloma Awareness Month and promoted the theme through awareness and giving programs over direct mail, social media and digital platforms. We also added a new and highly successful Proclamation component: to have the month of March officially proclaimed Multiple Myeloma Awareness Month across Canada. This was met with record-breaking community participation resulting in tremendous successes throughout the country.

Along with addressing inequities in drug access, we continued to move forward to further our own Equity, Diversity and Inclusivity (EDI) commitment. We worked with independent consultants to define and start incorporating the principles of EDI into all our communications and messaging. We proudly developed and unveiled our official EDI pledge: *To cultivate and maintain an inclusive environment for our community and our organization. This includes respecting and addressing the diverse needs of all people— First Nations, Métis, and Inuit; under-represented and marginalized populations; the LGBTQIA2S+ community; cultural, racial, and ethnic minorities—in all that we do.*

We are committed to grow awareness for myeloma – and Myeloma Canada – as far and wide as possible, as well as provide our highly diverse community with the tools they need to stay informed and empowered. We evaluated our digital platforms, and started to work on creating a new, more responsive website which will be launching in 2023.

We increased social media activity, strategic Google ad campaigns, improvements to our Myeloma Matters e-newsletter, sharing and promoting new educational content, and virtual participation in numerous national and international events and conferences.

2022 was a transformative year on many accounts for myeloma and Myeloma Canada. With the help from our community, we used our voice to make sure myeloma matters – no matter who you are, or where you live. 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.

OUR PROGRAMS AND ACHIEVEMENTS

AWARENESS

INCLUSIVITY RESEARCH PROJECT

Advancing our EDI commitment

- Launched our corporate EDI Pledge
- Started incorporating EDI into all messaging
- 1st sensitivity training for staff and support group leaders

MYELOMA AWARENESS & GIVING CAMPAIGNS

record breaking **\$101,216** raised
Spring and Fall giving programs combined



“You M4T T3R. Your POSTAL CODE Shouldn’t”

Spring campaign (Myeloma Awareness Month)

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



“DOUBLE YOUR IMPACT: Join the fight for life for every Canadian with myeloma.”

Fall campaign (Giving Tuesday)



NEW!

Myeloma Awareness Month Proclamations and recognitions

10 provinces/territories officially proclaimed March as MAM

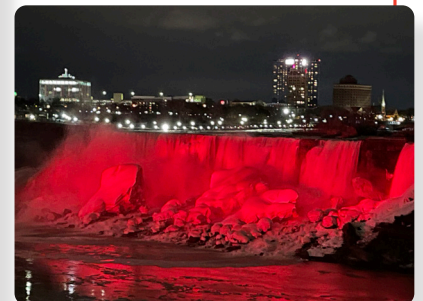
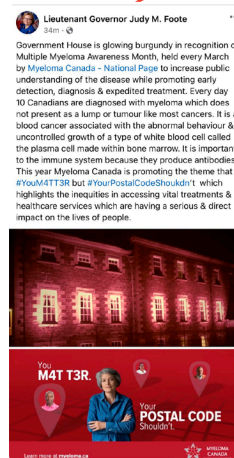
Alberta, British Columbia, Manitoba, New Brunswick, Newfoundland and Labrador, Nova Scotia, Prince Edward Island, Saskatchewan, Northwest Territories, and the Yukon.

9 cities/municipalities officially proclaimed Myeloma Awareness Days

North Bay, Cornwall, Toronto (ON); Halifax (NS); Vancouver, Prince George, Kelowna, Richmond (BC); St. Johns (NL).

8 monuments/buildings lit in honour of MAM

Niagara Falls, City of Hamilton sign, City of Mississauga Clocktower, City of London sign (ON); Calgary Tower, Edmonton High Level Bridge (AB); City of Winnipeg sign (MB); Newfoundland and Labrador Government House.



OUR PROGRAMS AND ACHIEVEMENTS

AWARENESS

Social media



4,661 followers
National Facebook page
(English and French)



1,228 followers



850 followers



1,004 followers

myeloma.ca

- ▶ **194,608** unique visits
- ▶ **221,624** page views

12 Myeloma Matters e-Newsletters

(12 English/12 French)

- **25,900+** subscribers
- COVID-19 information integrated into our monthly Myeloma Matters e-newsletter
- Separate bulletin on vaccination advocacy efforts



MINI CAMPAIGNS



Alliance of 30 health care organizations came together to urge governments across the country to make cancer a priority as we re-build our healthcare systems in the wake of COVID-19.

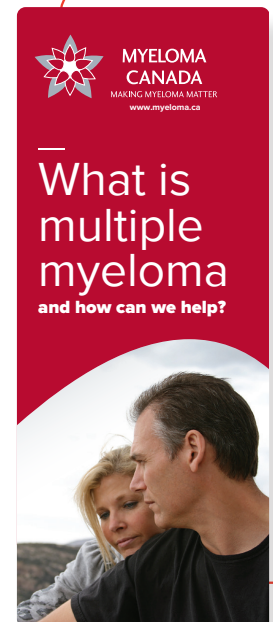
15 conferences & meetings
(National and International)

Google ad campaign

New campaigns and optimized ad accounts support major events and programs

UPDATED! MINI CORPORATE BROCHURE

Complete redesign and update



NEW! Web redesign

Started redesign for improved user experience

OUR PROGRAMS AND ACHIEVEMENTS

Access & Advocacy

ADVOCATE FOR ACCESS TO THE BEST TREATMENTS AND SUPPORT SERVICES FOR PEOPLE LIVING WITH MYELOMA.

Myeloma Canada believes strongly in advancing health equity, the foundational principle that no matter who you are or where you live in our great country, everyone should have the same access to the same treatments, drug therapies and care. As such, this was our theme for Myeloma Awareness Month and our Spring awareness and giving campaigns. We're proud to say that we made incredible strides throughout 2022 in advancing these issues, and continue to do so.

2022 was a banner year for Myeloma Canada's advocacy initiatives and successes. We increased our strength, reach, voice and visibility by entering into 7 new collaborative partnerships with other patient and/or health-oriented organizations to fight for improvements in our healthcare systems. We held Legislative Action Days in the Maritimes and are proud to announce that daratumumab is now accessible in both Prince Edward Island and the Northwest Territories! We moderated focus groups, made important drug submissions to regulatory agencies, and actively contributed to ongoing consultations and negotiations regarding equitable drug access.

We also created the Myeloma Canada Advocacy Handbook that explains advocacy, its importance and the many ways you can advocate for yourself to ensure your voice and needs are respected and heard.

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. By sharing your stories with us, we're able to build strong submissions for drug access and move closer to achieving equity in access to healthcare and treatments for all Canadians impacted by myeloma.

Highlights

- **CADTH recommended the reimbursement of two important treatments**, with conditions on usage:
 - **Daratumumab** (Darzalex) SC in combination with bortezomib, cyclophosphamide, and dexamethasone, for the treatment of adult patients with newly diagnosed light chain (AL) amyloidosis.
 - **Isatuximab** (Sarclisa) in combination with carfilzomib and dexamethasone for the treatment of patients with multiple myeloma who have received at least one prior therapy.
- **Our advocacy efforts were a success and now every Canadian province and territory has added daratumumab sub-q to their formulary... including PEI!**
- **Myeloma Canada's Executive Director, in collaboration with CONECTed, led the patient voice in shaping final recommendations to the PMPRB for improvements in drug access strategies.** The results were extremely positive, with new cancer drugs and clinical trials being better secured for availability for our community.
- **Partnered with All.Can Canada** on the report, 'Optimizing Diagnosis in Canadian Cancer Care'.
- **Partnered with Healthling.ca and 30 other organizations**, and signed their letter published in the National Post urging our health representatives to see caregivers as an essential part of care.
- **Collaborated on PDCI's Biopharmaceutical Ecosystem Index: Where does Canada Rank on its Attractiveness for New Medicine Launch.** As a member of the independent Editorial Advisory Board (composed of biopharmaceutical experts and experts on pharmaceutical policy and patient access issues), we contributed to identify, prioritize, and weigh a set of indicators that global decision-makers view as important influencers on where and when new medicines should come to market.
- **As part of the organizing committee, participated in the Coalition Priorité Cancer au Québec's General Assembly**, and contributed to the preparation of the final report submitted to members of the Government of Quebec.
- Continuing to work on **provincial reimbursement issues** regarding lenalidomide (generic version of Revlimid) for all provinces.

7 collaborative partnerships

- 1. Victimes des Pesticides du Québec/Occupational risks factors**
 - Pesticide consultations in Quebec with the Pest Management Regulatory Agency (PMRA).
 - Follow-up on the tabling of Bill 59, which aims to modernize the health and safety regime.
 - Advocating that myeloma be added to the list of recognized occupational diseases associated with pesticides.
- 2. Coalition Cancer Quebec**
 - Part of the organizing committee for the «États généraux» on cancer in Quebec with participation of the Health and Social Services Minister and Opposition critics.
 - Generics issue: Bill 92 introducing a ban against financial assistance to patients through a new Section 80.2 of the Act respecting prescription drug insurance.
 - Follow-up on the circulaires issue for access to clinical trials.
 - Myeloma Canada's Director, Patient Programs, Health Policy & Advocacy appointed to the Board of Directors.
- 3. Regroupement des Organismes Communitaires en Oncologie**
 - Patient and Caregiver Advisory Committee - National committee of community organizations in oncology of Quebec.
- 4. Catalis Quebec**
 - Member of the Patients Organization Committee in charge of bringing clinical trials information to Quebec patients in French.
 - Member of Clinical Trials Quebec's Personalized Support Service pilot project.
- 5. Canadian Association for Healthcare Reimbursement**
 - Panelist.
- 6. CADTH Provisional Funding Algorithm**
 - Stakeholder-input on proposed scope in Multiple Myeloma.
- 7. Innovative Medicine Canada**
 - Member of the annual meeting organizing committee.
 - Conducted interviews with the Health Minister and health critics for the opposition party.

OUR PROGRAMS AND ACHIEVEMENTS

ADVOCACY

Legislative actions in the Atlantic region

- **12** meetings held on drug access issues in Atlantic Canada
- Daratumumab added to the PEI and NT formularies



7 submissions

1. Maribavir: For the treatment of adults with post-transplant cytomegalovirus (CMV) infection/disease who are refractory and/or resistant to one or more prior antiviral therapies
2. CADTH Provisional Funding Algorithm Stakeholder Input on Proposed Scope in Multiple Myeloma
3. Xpovio (Selinexor) with bortezomib (Velcade) and dexamethasone for the treatment of relapse/refractory multiple myeloma
4. CADTH Reimbursement Review Feedback on Selinexor Draft Recommendation
5. Ciltacabtagene autoleucel (cilta-cel) CAR-T cell immunotherapy, Carvykti, for the treatment of relapse/refractory multiple myeloma
6. CADTH's Consultation on Real-World Evidence Reporting Guidance
7. Proposed updates to PMPRB Guidelines

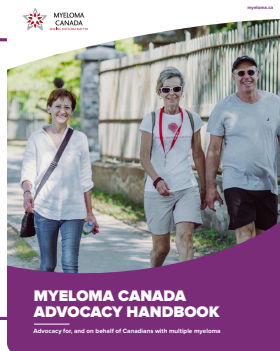
2 focus groups moderated

- Selinexor (XPOVIO)
- Blenrep (belantamab mafodotin-blmf)

Self-advocacy

NEW!

Self-advocacy Handbook and workshop (Launched)



OUR PROGRAMS AND ACHIEVEMENTS

Community Empowerment

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

The pandemic brought with many lessons, one of which was the ability to pivot and think outside-the-box in reaching and staying connected to our diverse and geographically dispersed community. Instead of feeling isolated from one another, we used technology to bring us closer together. While we were able to reinstate in-person gatherings, we also kept the Zoom virtual platform active and held hybrid conferences and events. We held not one, but two (2) Support Group Leaders' Summits and two (2) Health eMatters conferences for online cancer advocates!

Our events had further reach than if they had been in-person alone. Community members who may not have otherwise been able to attend (due to health or finances) were able to participate from the comfort and security of their own homes...we even had community members participating from their cancer centre or hospital while receiving treatment. And, those who were able and ready to gather in person, did. It was a win-win situation with record-breaking involvement.

The heart and success of Myeloma Canada is our community of volunteers. Not only do they hold their own creative and exciting fundraisers, but they spearhead local participation within our vital annual national fundraising events. The 14th annual Multiple Myeloma March was another stellar success, with record-breaking participation of 35 communities, not including the many virtual Marches that also took place.

Our newly minted annual fundraiser, the Myeloma Canada Ride: Bike to Beat Myeloma started conservatively with one ride each in Ontario, Alberta and British Columbia. The Ride exceeded our expectations and goals! Due to popular demand, we'll be growing the event to 7 Rides in 2023.

Without the strength and conviction of our wonderful volunteers and community members, Myeloma Canada would never be able to accomplish all that we do. Their time and energy helped us pull through the pandemic and provided us with ability to embark on new and exciting programs to bring our local and national community closer. Our volunteers are the heart and soul of our organization and without them, we would not be who we are today.

OUR PROGRAMS AND ACHIEVEMENTS

COMMUNITY EMPOWERMENT

Myeloma Canada Support Group Network

48 local support groups

5 new local groups

- Cornwall, ON
- Laurentians, QC
- Red Deer, AB
- Chaudières-Appalaches, QC
- Sudbury, ON

5 virtual support groups

NEW! Myeloma and AL Amyloidosis Support Group



1,274 members

In our online Facebook support groups

2 peer-to-peer support programs

- English program with Wellspring
- **NEW!** French program with the Fondation québécoise du cancer

8 Meet & Greets

For areas that don't yet have a local support group, these are often the springboard from which a support group will be formed. Meet and exchange with others living with or caring for someone with myeloma. Learn the latest developments in myeloma research and symptom management from local experts.

- Cornwall, ON (Virtual)
- Laurentians, QC
- Newmarket, ON
- Niagara, ON
- Red Deer, AB
- Saint John, NB
- Sudbury, ON
- Victoria, BC

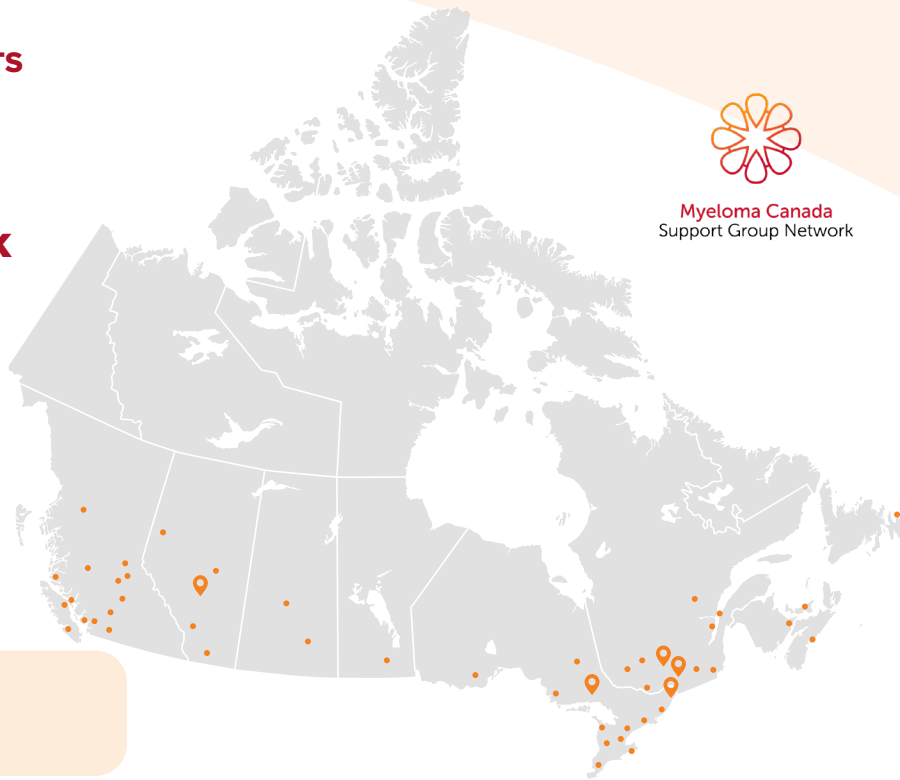


15th and 16th annual Support Group Leaders' Summit

- 2 hybrid Summits: Spring and Fall
- More than 75 leaders (in-person or virtual) participated at each event
- **18 new leaders!**



Myeloma Canada
Support Group Network



Health Matters

Program & annual conference for online cancer advocates

- **2** hybrid conferences held: Spring and Fall
- Total of **90** participants from **7** provinces and **2** states, including **14** patient organizations
- **22** different cancers represented



RESPONSE TO COVID-19

- **NEW!** Introduction of hybrid meetings
- On-going training & support for support group leaders on new technologies for support groups: Facebook support groups accounts
- Zoom - continued use of licenses to host virtual meetings

OUR PROGRAMS AND ACHIEVEMENTS

COMMUNITY EMPOWERMENT



Myeloma Canada
Support Group Network

2022 Support Group Leaders

Alberta

Katy Boll	Red Deer	Central Alberta Myeloma & Amyloidosis Support Group
Lorelei Dalrymple & Hans Wolf	Edmonton	Myeloma Alberta Support Society (MASS) Support Group
Bev Dunn & Elliot Laukacik	Calgary	Southern Alberta Myeloma Patient Society (SAMPS) Support Group
Hetti Huls	Grande Prairie	North Western Alberta Myeloma Support Group
Bayo & Yinka Oladele	Calgary	Oladele Foundation – African Cancer Support Group
Brian Treadwell	Lethbridge	Lethbridge Myeloma Support Group

British Columbia

Helene Lalonde & Yolande Paine	Vancouver	Vancouver Myeloma Network Support Group
Linda Latham & Valerie Evans	Campbell River	North Island Multiple Myeloma Support Group
Cyndi Logan & Jenn Collins	Prince George	Northern BC Multiple Myeloma Support Group
Bruce Marks & Kundan Uppal-Dubinsky	Surrey	Surrey & District Multiple Myeloma Support Group
Janice Martens & Sylvia Jagpal	Fraser Valley	Fraser Valley Support Group
Susan McLean & Elizabeth Kalbfleisch	Nanaimo	Nanaimo Multiple Myeloma Support Group
Maureen Murray & Brian McQuhae	Victoria	Vancouver Island Multiple Myeloma Support Group
Susan Schmalz & Erwin Malzer	Kelowna	BC Southern Interior – Kelowna Chapter Support Group
Bob Trudeau	Kamloops	Kamloops Chapter Support Group

Manitoba

Jackey LaBossiere	Winnipeg	Winnipeg Myeloma Support Group
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New Brunswick

Ginette Landry, Sally Crate, Judy Kaine, Bernice Allaby, Paula Cameron	Saint John	Saint John Area Multiple Myeloma Support Group
Shawn Crossman & Heather Kennedy	Moncton	Moncton Myeloma Support Group

Newfoundland and Labrador

Gary Cross, Brent Smith, Stephen Norman	St. John's	Myeloma NL Support Group
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Nova Scotia

Julie Salsman & Barbara Beaver	Halifax	Nova Scotia Multiple Myeloma Support Group
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Ontario

Erin Belzile	North Bay	Myeloma Nipissing Support Group
Marion Bentley, Maggie Ralph, Diane Brown	Sault Ste Marie	Sault Ste Marie Multiple Myeloma Support Group
Tania Bertrand	Brampton	Brampton-Etobicoke Myeloma Support Group
JoAnn Cartlidge	Windsor	Windsor & District Multiple Myeloma Support Group
Jane Greggio & Glenda Hillier	Niagara	Niagara Region Multiple Myeloma Support Network
Roy & Debbie James	Owen Sound	Grey-Bruce Myeloma Support Group
Della Krieger, Nicole Wittke, Bernd Wittke, Lise Mackevicius	Sudbury	Sudbury & District Myeloma Support Group
Ev McDowell & Lisa Bowden	London	London & District Myeloma Support Group
Susan McDowell	Kitchener-Waterloo	Waterloo Region Myeloma Support Group
David McMullen, Donald Hunter, Bob McCaw, Jan Wleugel, Munira Premji, Patrick Taylor, Rinat Avitzur, Jocelyn Kervin	Toronto	Toronto & District Multiple Myeloma Support Group
Iris Phillips	Picton	Picton Support Group
Jules Royer	Halton-Peel	Halton-Peel Myeloma Support Group
Robin Sully & Jean Shepherd	Ottawa	Ottawa-Gatineau Multiple Myeloma Community Network
Mary Ann Tuomi	Thunder Bay	Thunder Bay Myeloma Support Group
Claudia Trost & Jeff Heyman	Kingston	Kingston Myeloma Support Group
Linda VanderSchaaf & Mary Brinks	Cornwall	Cornwall Area Myeloma Support Group
Clive & Yvette Webb, Jennifer Enright & Martyn Olenick	Hamilton	Hamilton & District Multiple Myeloma Network Support Group
Tanya Zigomanis	Newmarket	York Region Myeloma Support Group

OUR PROGRAMS AND ACHIEVEMENTS

COMMUNITY EMPOWERMENT

2022 Support Group Leaders

Prince Edward Island

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

Vénus Bélanger	Sherbrooke	Espoir Myélome Estrie Support Group
Véronica Gill	Saint-Jérôme	Laurentians Myeloma Support Group
Sylvie Levesque	Chaudière-Appalaches	Myélome Chaudière-Appalaches
Julie Martel & Emmanuel Mercier	Québec	Myélome Québec
Emmanuel Mercier	Saguenay	Myélome Saguenay
Kristen Palynchuk	Montreal	Montreal Myeloma Support Group
Danny Wade & Lyzane Bissonnette	Longueuil	Myélome Rive-Sud Support Group

Saskatchewan

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

Community events

Our amazing, engaged community never ceases to inspire us! Their commitment and passion to increase awareness and raise funds for our cause is invaluable and second-to-none. We are forever being overwhelmed by their support, trust and determination. Their enthusiasm and contribution to promoting and improving the lives of all Canadians with myeloma lays the foundation for our mutual success. Thank you is simply not enough!

\$174,398 raised

9 community fundraisers

\$393,541

General donations and corporate campaigns



New!

1st annual Myeloma Canada Ride: Bike to Beat Myeloma



THE MYELOMA CANADA RIDE
MYELOMARIDE.CA

▶ **\$194,462** raised

▶ **3 Canadian communities:**
Red Deer (AB), Niagara Region (ON), and Richmond BC

▶ **336** participants

▶ **1,764** donations

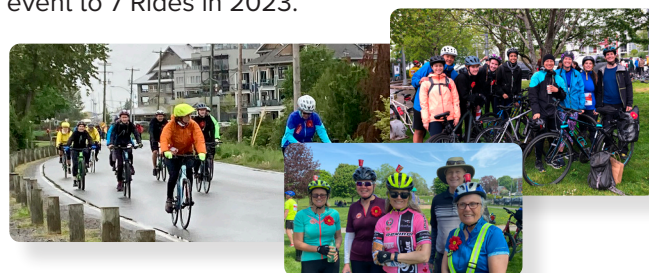
Myeloma Canada excitedly launched our newest annual national fundraising event: The Myeloma Canada Ride: Bike to Beat Myeloma in the spring of 2022.

Each of the 3 Rides featured 2 routes:

- a shorter and more leisurely 30 - 40 km route, or
- a longer and more challenging 70 - 90 km option.

Funds raised through The Myeloma Canada Ride will support scientific advancements and impactful research initiatives that enable Canadians with myeloma to live longer and better lives, and to help find a cure.

Surpassing our anticipated participation and fundraising goals and due to popular demand, we'll be growing the event to 7 Rides in 2023.



OUR PROGRAMS AND ACHIEVEMENTS

COMMUNITY EMPOWERMENT

2022 Multiple Myeloma March Leaders



MULTIPLE MYELOMA MARCH

www.myelomamarch.ca

City	Leaders
Airdrie	Trish Murray
Cobourg	Rebecca Flint
Halifax	Michael Senz & Julie Salsman
Hamilton-Niagara	Nancy Gray
Kamloops	Bob Trudeau
Kelowna	Susan Schmalz
Kingston	Jeff Heyman & Claudia Trost
Kitchener-Waterloo	Louise Moriarity
Cornwall	Mary Brink
Eastern Townships	Julie Nadeau
Mississauga	Helen Mahshie
Moncton	Shawn Crossman
Montreal	Patricia Celestin & Patricia Empsall
Newmarket	Kristy Ahola
Oshawa	Laurie Khaler
Ottawa	Frank Shepherd & Glenn Hussey
Prince George	Jenn Collins
Quebec City	Jérôme Goulet
Quesnel	Cyndi Logan
Regina	Mona Neher & Patricia Celestin
Rive-Sud	Danny Wade & Lyzane Bissonnette
Sacré-Coeur	Sarah & Marilyse Bouchard
Saint John	Michelle Oana
St John's	Tina Soulier
Saskatoon	Marie Prokopiw & Judi Worth
Sault Ste Marie	Patricia Celestin
Sudbury	Della Krieger
Summerside	Megan Gardiner & Bethany Reeves
Thunder Bay	Michelle Oana
Vancouver	Michelle Oana
Vancouver Island	Susan McLean
White Rock	Phil Harbridge
Windsor/Essex County	Jenny Radjenovic
Winnipeg	Maria Marinelli

Myeloma Canada's 14th annual Multiple Myeloma March

Myeloma Canada's flagship community and fundraising event, the Multiple Myeloma March, celebrated its 14th anniversary in 2022 and surpassed all our expectations! For the past 14 years, communities across Canada hold a 5k march/walk in the fall to raise essential funds and awareness for myeloma, myeloma research and improving the quality and length of life of Canadians living with the disease.

For a second year running, it was "Your March, your way" with a record-breaking 35 communities participating either in-person, virtually, or a combination of the two. Our community is truly incredible. Their creativity, energy, devotion and support of each other, and of Myeloma Canada is tremendous. **It's thanks to our generous supporters and selfless volunteers that together, we continue to make myeloma matter every day.**



OUR PROGRAMS AND ACHIEVEMENTS

COMMUNITY EMPOWERMENT



- ▶ **\$698,702.65** raised
- ▶ **Record-breaking participation**
- ▶ **35** local communities
- ▶ **1,418** participants
- ▶ **5,831** donations



2022 Myeloma Canada community awards

Recognizing the exceptional leadership of our Canadian myeloma community.



The Excellence in Advocacy Medal (TEAM) Award

Megan and Dwight Gardiner – Summerside, PEI

Megan and Dwight are extensively involved in the PEI myeloma community, the PEI Myeloma Support Group and the Summerside Multiple Myeloma March. Throughout 2022, both Megan and Dwight were extremely active in important myeloma advocacy initiatives. They not only participated, but succeeded, in having the province of PEI proclaim March as “Multiple Myeloma Awareness Month” and “Amyloidosis Awareness Month” for the very first time. At our Atlantic Legislative Action Days, both Megan and Dwight graciously shared their stories with invited provincial MPs. They actively participated in four (4) vital official meetings with PEI government officials that resulted in daratumumab finally being added to the provincial drug reimbursement list! To say that this was an enormous success and a tremendous step forward for the PEI myeloma community is an understatement!



Notable Volunteer Award

Danny Wade – South Shore, Quebec

Danny is a spirited co-leader for the South Shore Myeloma Support Group and moderator of his community’s Facebook support group. In 2022, Danny and his co-leader, Lyzane Bissonnette, kickstarted a new Multiple Myeloma March in Ste Julie, raising close to \$20,000 in their first year! Danny also spearheaded a branded hoodie campaign and partnered with a local retirement home for their Christmas market which raised over \$4,000 for our cause. Danny has been a dynamic participant at Myeloma Canada Support Group Leaders’ Summits, attended the Myeloma Canada Scientific Roundtable, the Health eMatters conference, and inspired attendees at Myeloma Canada’s Vaudreuil InfoSession with his story. Last but not least, once again Danny showed his huge heart by organizing and delivering signed cards to in-hospital myeloma patients over the holidays.

OUR PROGRAMS AND ACHIEVEMENTS

COMMUNITY EMPOWERMENT



Community Achievement Award

Steven Bell – Winnipeg, MB

In 2022, Steven took part in his 4th Winnipeg Multiple Myeloma March, although the first year was in spirit as he was undergoing treatment. Over the last 4 years, Steven's team, UnbreakaBEL, raised an outstanding \$44,405, and \$7,281 in 2022 alone! As if that weren't enough, in December 2022 Steven and his friends at Norak Crossfit organized a hybrid yoga fundraiser at the gym with proceeds benefitting Myeloma Canada. 'Move for Myeloma' was a huge success, raising a whopping \$9,471 thanks to Steven's terrific promotion of the event. Steven's outreach was incredible: he courageously shared his story digitally on social media and connected with his large network to support our cause. Steven's story was also highlighted in the Spotlight section of our December 2022 issue of Myeloma Matters.



Support Group Leader Distinction Award

Jackey LaBossiere – Winnipeg, MB

As leader of the Winnipeg Myeloma Support Group and throughout the pandemic, Jackey didn't skip a beat in holding regular meetings and uplifting the spirits and morale of her group members. Jackey's influence goes well beyond her Support Group Leader role. Through her energy and passion, Jackey assisted the 2022 March leader in planning an amazing virtual walk for their community. Jackey's great ideas on increasing participation helped make the event an ultra-success! Furthermore, Jackey's determination and grit resulted in Manitoba officially proclaiming March as Myeloma Awareness Month for the 4th time, and in getting the Winnipeg sign lit red in recognition of this important awareness initiative. Last but not least, Jackey generously shared her story, positivity and enthusiasm for getting involved and giving back with attendees at Myeloma Canada's InfoSession in Brandon.



Myeloma Canada Newcomer Award

Della Krieger, Bernd & Nicole Wittke, Lise Mackevicius, Erin Belzile - ON

In just one year, this group has come together to form the Northeastern Ontario Myeloma Support Group, host a Meet & Greet event, and several support group meetings. They also organized a new 2022 Multiple Myeloma March in Sudbury, with more than 75 participants, raising over \$13,985 in their first year. Della, Bernd, Nicole, Lise and Erin also organized an amazing virtual Myeloma Canada Ride that raised \$18,452! This dynamic group was responsible for obtaining an official proclamation for the city of North Bay for Myeloma Awareness Month 2022, garnered a huge amount of media attention in all of Northeastern Ontario, and much more!



Nathalie Allard Memorial Award

Jérôme Goulet – Quebec City, QC

In 2021, Jérôme was awarded the Myeloma Canada Community Achievement Award. In 2022, his contribution to our myeloma community was, once again, truly remarkable. Jérôme's relentless energy and drive in raising awareness and funds for myeloma and Myeloma Canada's Multiple Myeloma March is why Team L'armée de Jésus was the 2022 top fundraising team in all of Canada, raising an incredible \$31,379! Jérôme's passion, spirit and commitment are truly an inspiration!

OUR PROGRAMS AND ACHIEVEMENTS

COMMUNITY EMPOWERMENT



Executive Director's Leadership Award

David McMullen - Toronto, ON

David's extraordinary work and spirited engagement in empowering the Canadian myeloma community has been exemplary since 2012! David has been a passionate support group leader and engaged committee member in over half a dozen support groups in the GTA for more than a decade! He is also a Peer volunteer in our Peer-to-Peer Support program. David has been instrumental in planning, executing and attending countless Multiple Myeloma Marches throughout Ontario and is an extraordinary community advocate and member. David has attended the Myeloma Canada Scientific Roundtable since 2013, and in 2014, was the first Chair of the new Myeloma Canada Patient Advisory Council (PAC). David earned the tremendous honour of being one of 12 members of the Patient and Community Advisory Committee of the Canadian Agency for Drugs and Technologies in Health (CADTH) and is also a patient representative in the Canadian Cancer Trials Group (CCTG). In 2018, David received Myeloma Canada's Notable Volunteer Award and in 2022, Ontario's distinguished June Callwood Outstanding Achievement Award for Voluntarism. David's compassion and respect for all, especially his wife and caregiver Erika, is beyond measure.



Support Group Lifetime Achievement Award

Ev McDowell - London, ON

Ev's exceptional contribution to the Ontario myeloma community dates years before Myeloma Canada came into existence. As founder of the London and District Myeloma Support Group, Ev became involved in the Steering Committee of one of the 1st myeloma support groups in Canada!

For over 20 years, Ev has been, and continues to be, an active and invaluable member of the support group committee. Ev is cherished within the support group and the larger Canadian myeloma community. Over the years, her positive energy has been an inspiration to hundreds of Canadians impacted by myeloma, whether through her participation in Myeloma Canada conferences, summits, and local events or through her support group.



Marion State Memorial Nursing Award

Anna Giulione - Calgary, AB

Anna is the Clinical Research Nurse (Multiple Myeloma) at the Tom Baker Cancer Centre in Calgary, AB. Her specialty is the care of research participants for Hematology-Oncology clinical research studies for newly diagnosed and relapsed or refractory multiple myeloma. Anna has high clinical standards of care, amazing empathy and is dedicated to her patients. She is an engaged advocate and fundraiser for myeloma patients, research, and the myeloma community. Anna is an active member of the Southern Alberta Myeloma Patient Society (SAMPS) board of directors, and is Nurse Liaison between SAMPS members, patients, and myeloma physicians at the Tom Baker Cancer Centre. Anna is also greatly valued by Myeloma Canada, providing spirited and informative webinars and presentations for our community.

OUR PROGRAMS AND ACHIEVEMENTS

COMMUNITY EMPOWERMENT

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-focused advice and feedback on the organization's many activities.

Highlights of PAC's 2022 initiatives and activities 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;
- PAC Vice Chair, Phil Harbridge, represented the group at the Board retreat in May;
- Building relationships with Support Group Leaders in each region of Canada, regularly meeting through conference and Zoom calls;
- Continuing to provide support for myeloma patients and their families within the context of a continued COVID-19 environment;
- Providing advice and feedback on various documents including revisions to the Myeloma Patient Handbook, and the new Myeloma Immunotherapy InfoGuide;

- Participating in two very successful Support Group Leader Summits in Vancouver and Halifax, and providing an overview of PAC's current activities and future plans;
- Attending two Myeloma Canada Scientific Roundtables focusing on new myeloma drugs, treatments and research;
- Attending the Health eMatters Conference (Phil Harbridge) for cancer advocates to network, learn, and hone their skillsets to become better at raising awareness on issues mattering most to them;
- Welcoming Shawn Crossman, the new PAC representative from Atlantic Canada;
- Establishing a working group to provide input to the Myeloma Canada website redesign project;
- Having representation at a national Family Doctors Conference in Toronto to help better educate General Practitioners about multiple myeloma;
- Most PAC members participated in other Myeloma Canada initiatives and committees, and had leadership roles in Multiple Myeloma Marches across the country;
- Continually improving PAC's 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



2022 PAC members:

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

OUR PROGRAMS AND ACHIEVEMENTS

Science and research

**SUPPORT MYELOMA SCIENCE AND FUND MYELOMA RESEARCH
THAT LEADS TO BETTER PATIENT OUTCOMES AND A CURE.**

Building hope through research: Supporting important Canadian myeloma science and research initiatives.

Myeloma science and research is rapidly advancing and along with it, Myeloma Canada's role in supporting innovative Canadian initiatives. Thanks to the tremendous generosity of our donors, Myeloma Canada continues to be a valued and respected catalyst to it all. In 2022 alone, Myeloma Canada proudly invested over \$1.244 million dollars in important Canadian myeloma research and scientific advancements to improve diagnosis, enhance quality of life and support the quest for a cure. This investment is approximately the same as what we invested in 2020 and 2021 combined!

As a grassroots organization, we are committed to invest in projects that matter to our community. Our investment principles are anchored in the core values and priorities our myeloma community identified in the Myeloma Priority Setting Partnership (PSP). A first of its kind globally, the PSP was a ground-breaking collaborative project between the Horizon Health Network, the Maritime SPOR SUPPORT UNIT (MSSU), and Myeloma Canada. Initiated in the fall of 2019, the goal of the project was to determine the top 10 unanswered myeloma research questions defined by our community, under the James Lind Alliance Priority Setting Partnership process. (For more information on the Myeloma PSP, visit myeloma.ca.)

Our science and research investment strategy supports projects that have a direct impact on

- improving patient and caregiver quality of life
- preventing or delaying disease progression
- increasing overall survival, and
- improving health delivery systems.

Together we can do more. Fueling innovative trials through the Canadian Myeloma Research Group: Myeloma Canada continues to be a strong supporter of the Canadian Myeloma Research Group (CMRG), a not for profit research organization that has common goals with Myeloma Canada. In 2022, Myeloma Canada contributed \$300,000 to CMRG's research activities including made-in-Canada clinical trials and the National Myeloma Database platform. To find out more about the CMRG and the wonderful work they do, please visit their website at www.cmrg.ca.

OUR PROGRAMS AND ACHIEVEMENTS

SCIENCE AND RESEARCH

Myeloma Canada was also a financial supporter of the CMRG's work on a Real-World Evidence (RWE) study undertaken by the CMRG in collaboration with the Canadian Agency for Drugs and Technologies in Health (CADTH). The study is part of CADTH's ground-breaking project, "Optimal Pharmacotherapy for Transplant-Ineligible Multiple Myeloma".

We continued to support our international leaders in allogeneic stem cell transplant research at the Myeloma Canada Research Chair in Multiple Myeloma at the Hôpital Maisonneuve-Rosemont (QC), ongoing research programs under the leadership of Dr Arleigh McCurdy at the Ottawa Hospital Research Institute (ON), and a study examining efficacy versus effectiveness in multiple myeloma management by Dr Hira Mian and her research team at the Juravinski Cancer Centre (ON).

In 2022, Myeloma Canada awarded two (2) research grants to advance Canadian myeloma science and research through The Aldo Del Col Research Grant. Six (6) additional grants were awarded through The Dr Andrew R Belch Myeloma Education and Enriched Training (MEET) Grant. We held two (2) Myeloma Canada Scientific Roundtable meetings (hybrid) and continued to lead the development of Canadian-based myeloma consensus guidelines for the standardized diagnosis and care of myeloma within the medical community. We also established a partnership with Queen's University Continuing Professional Development to create an important education program for primary care providers on the identification and referral of patients suspected of having myeloma, to be launched in 2023.

Breakthroughs in myeloma research, drug therapies and treatment are advancing at unparalleled speeds. People with myeloma are enjoying their loved ones longer, quality of life is improving, and the overall landscape is more hopeful than ever. We are forever grateful for our supporters and generous donors in enabling us to assume an active role in these exciting times.

12th and 13th annual Myeloma Canada Scientific Roundtable

Myeloma Canada was the first, and remains the only, Canadian organization to bring together top myeloma experts (doctors, researchers, clinicians, and nurses) from the major myeloma treatment and research centres across Canada, with international myeloma specialists, industry partners, and patient representatives, on an annual basis to:

- discuss the state of clinical trials in Canada and develop high-impact made-in-Canada clinical trials for patients across the country;
- exchange highlights of recent myeloma research and treatment development work;
- review new myeloma therapies in the research pipeline;
- facilitate planning and collaboration of future Canadian myeloma research.



 **240+** participants

In-person and virtual attendees

- **2 hybrid events**
- **Spring co-chairs:** Dr Kevin Song (Vancouver, BC) & Dr Keith Stewart (Toronto, ON)
- **Fall co-chairs:** Dr Nizar Bahlis (Calgary, AB) & Dr Annette Hay (Kingston, ON)

OUR PROGRAMS AND ACHIEVEMENTS

SCIENCE AND RESEARCH

Canadian Myeloma 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. Collaborative project between the Horizon Health Network, the Maritime SPOR SUPPORT UNIT (MSSU), and Myeloma Canada.

Abstract submitted by BC SPOR SUPPORT Unit Conference

Supervised by the James Lind Alliance

Approved by Horizon Health Network Research Ethics Board

1 journal article

British Journal of Haematology

The future of myeloma research in Canada and beyond: Results of a James Lind Alliance priority setting partnership.



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 deterioration¹. 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.¹

This is problematic given the growing incidence of the disease; between 1996 and 2016, the global incidence of myeloma increased by 126%.¹ Simultaneously, research into treatment options for myeloma has led to people living longer.¹ However, since there is currently no cure for myeloma, future research is needed to advance the diagnosis, treatment and management of myeloma and improve the quality of life of those living with this disease.

3 published abstracts

Clinical Lymphoma, Myeloma and Leukemia

Moving from research priorities to clinical research: Implementing the results of a priority setting partnership on multiple myeloma.

HemaSphere -*The agenda for future multiple myeloma research according to patients, caregivers, and clinicians.*

Blood - *Patient, caregiver, and healthcare provider priorities for future multiple myeloma research: Results of a James Lind Alliance priority setting partnership.*

1 oral presentation

March 10, 2022 - BC SPOR SUPPORT Unit Putting People First Virtual Conference

Collaboration across the nation: Lessons learned from a pan-Canadian priority setting partnership on multiple myeloma

2 poster presentations



August 26, 2022 - International Myeloma Society Annual Meeting, Los Angeles, USA

Moving from research priorities to clinical research: Implementing the results of a priority setting partnership on multiple myeloma

November 13, 2021 - Virtual Canadian Cancer Research Conference

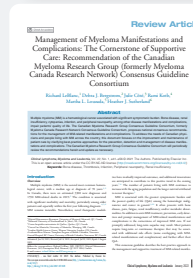
The future of myeloma research in Canada: The results of a James Lind Alliance priority setting partnership.

Canadian Evidence-based Myeloma Consensus Guidelines

Led and managed by Myeloma Canada, the consortium develops consensus recommendations on daily practice, existing guidelines and availability of evidence-based diagnostic tools for myeloma.



1. Consensus Guidelines on the Diagnosis of Multiple Myeloma and Related Disorders – July 2020



2. Canadian Consensus Recommendations for the Management of Myeloma-Related Manifestations and Complications: The Cornerstone of Supportive Care – January 2022

3. First Line Treatment of Newly Diagnosed Transplant Ineligible Multiple Myeloma—Developed in 2022; published Q1 2023.

OUR PROGRAMS AND ACHIEVEMENTS

SCIENCE AND RESEARCH

New!

Myeloma Canada Grant Competition

Supporting research projects that have the greatest potential for yielding important advances and outcomes for our Canadian myeloma community.



The Aldo Del Col Research Grant was created to honour the legacy and memory of our co-founder Aldo Del Col. This grant funds patient-prioritized Canadian research projects on one or more research priorities identified through the Myeloma PSP.



The Dr Andrew R Belch Myeloma Education and Enriched Training (MEET) Grant was created in 2019 to foster the development and participation of qualified young Canadian myeloma investigators at national and international medical/scientific meetings or conferences.

2 Aldo Del Col Research Grants awarded

1. Dr Alissa Visram

Ottawa Hospital Research Institute, Ottawa, ON
Can BCMA trogocytosis compromise the anti-tumour activity of CAR-NK cells?

2. Margaret McNeely, PhD

Cross Cancer Institute, Edmonton, AB
A novel eHealth application to support exercise prehabilitation prior to stem cell transplantation in individuals with multiple myeloma.

6 Dr Belch MEET Grants awarded

1. Dr Jean-Sébastien Claveau

Hematologist and Multiple Myeloma, Fellow, Mayo Clinic, Rochester, MN
Bortezomib maintenance after upfront allogeneic transplantation in myeloma patients: less chronic GVHD and immunosuppression but still no impact on survival.

2. Samantha Fowler

Clinical Research Manager, Maritime SPOR SUPPORT Unit Horizon Health Network, Saint John, NB
Moving from research priorities to clinical research: Implementing the results of a Priority Setting Partnership on multiple myeloma.

3. Dr Guido Lancman

Princess Margaret Cancer Centre, Toronto, ON
Infections and Severe Hypogammaglobulinemia in Multiple Myeloma Patients Treated with Anti-BCMA Bispecific Antibodies

4. Afsaneh Panahi

PhD Candidate, Terry Fox Laboratory – BC Cancer, Vancouver, BC
Identification of Misclassified Multiple Myeloma Patient Risk Subgroups with a Novel Biological Disease Stratifier.

5. Dr Holly Lee

Hematologist and Research Fellow, University of Calgary, Calgary, AB
Point Mutations in BCMA Extracellular Domain Mediate Resistance to BCMA Targeting Immune Therapies.

6. Dr Alissa Visram

Hematologist, The Ottawa Hospital, Ottawa, ON
The Impact of Marginalization on Treatment Receipt and Overall Survival in Newly Diagnosed Multiple Myeloma Patients in Ontario: A Population-based Cohort Study.

New partnerships

- **Groupe des maladies plasmocytaires du Québec GMPQ**
Working on guidelines for the treatment of relapsed/refractory myeloma.
- **Queen's University Continuing Professional Development**
Creating a program for primary care providers on the identification and referral of patients suspected of having myeloma. (Launching in 2023)



2022 Impact Report

Your 2022 footprint on Canadian myeloma research and scientific advancements

- In development; launched Q2 2023

OUR PROGRAMS AND ACHIEVEMENTS

OUR DONORS

We are grateful to our many partners and donors who helped support our cause in 2022. Your unwavering commitment is unparalleled and touches us deeply. Through your generous donations, we are able to pursue our promise and pledge to the Canadian myeloma community.

Individual donations

\$1,000 to \$1,999

- William Appleby
- Gregory Balkwill
- Alexandra Bell
- Debra Bergstrom
- Ryan Bissonnette
- Marilia Bothamley
- Anne Bowers
- Roberto Buffone
- Elizabeth Campbell
- Ida Cardinali
- Frank Chislette
- Joshua Clausen
- Christophe Côté
- Randy Cox
- Wendy Craig
- Donald Davis
- Dale Delesalle
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- Radhika Dixit
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- Lucas Erdman
- Fran Fendelet
- Brian Forster
- Claude Fortin
- Beth Gentleman
- Terry Gilbert
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- Andrew & Nancy Gray
- Laura Hawkins
- Tony & Sandra Higdon, family & friends
- Ken Huntley
- Cathy Imrie
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- Brian Roche
- Jervis Rodrigues
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- Steven Simoneau
- Cameron Smith
- Don Snider
- Louise Sofka
- Blair & Yvette Stewart
- Guy Tremblay
- William Wall
- Bernie & Jeanette Webber
- Nicole Wittke
- Eleanore Zacharias
- Anonymous
- Anonymous
- Anonymous
- Anonymous
- Anonymous

\$2,000 to \$4,999

- Ellis Basevitz
- Claude Benton
- Charles Buchalter
- Jennie Cox
- Gisèle Fournier
- Robert Goodall
- Xian Hung
- Wayne Johnson
- Karen L'Heureux
- Doris Losier
- Jennifer McNeill
- Paul Monson
- John Nicholson
- Martine Normandin
- Donald Oborowsky
- Catherine Pinco
- Jessica Portelance
- Avron Ritch
- Matthew Sarmatiuk
- Margaret A. Stanfield
- Robin Sully
- Hans Wolf
- Anonymous
- Anonymous
- Anonymous

\$5,000 to \$9,999

- Vénus Belanger
- Jacques Dussault
- Megan Gardiner
- Suzu Legg
- Susan Meeds
- Nathan Stephens
- Thomas Vokey
- Anonymous

\$10,000 and more

- Maria Del Col
- Elaine Letourneau

Corporate donations

\$1,000 to \$3,999

- Aberdeen Glen Golf Course
- AJA Assurances Inc
- Anako Foundation
- Arbutus Properties
- Batchbank Corp.
- Brattys LLP
- Cambridge Toyota
- Cardi Construction Ltd.
- Carrelages de Montréal Ltée
- CDA Landscaping
- Crowfoot Dodge Chrysler Inc.
- Dr Henri LeBlanc cp Inc
- Extend Pharmacy
- Frovich & Associates
- Juel Fund - Nicola Wealth Private Giving Foundation
- LTE Service Solutions
- Newfoundland Chocolate Company
- Platinum Atlantic Realty
- Proludik
- Russell Technical Services
- SCC Marketing Reps Inc.
- Wespro Drywall Inc.
- Whitehorse Liquidity Partners Inc.
- Anonymous
- Anonymous

\$4,000 to \$6,999

- AC Waste Services Inc.
- Costco Wholesale Canada Ltd
- E.R Squibb & Sons LLC
- Industrielle Alliance
- Insulpro Insulation Inc
- Krabben Family Foundation
- Larrivière & Massicotte
- Pharmacie Michel Assaraf
- Southern Alberta Myeloma Patient Society
- TD
- Vancouver Foundation

More than \$7,000

- GFL Environmental Inc.
- Leonard T Assaly Family Foundation
- Listel Hospitality Group (Bearfoot Bistro)
- McDowell Family Foundation

THANK YOU

for your trust and support, and for joining us in making myeloma matter.

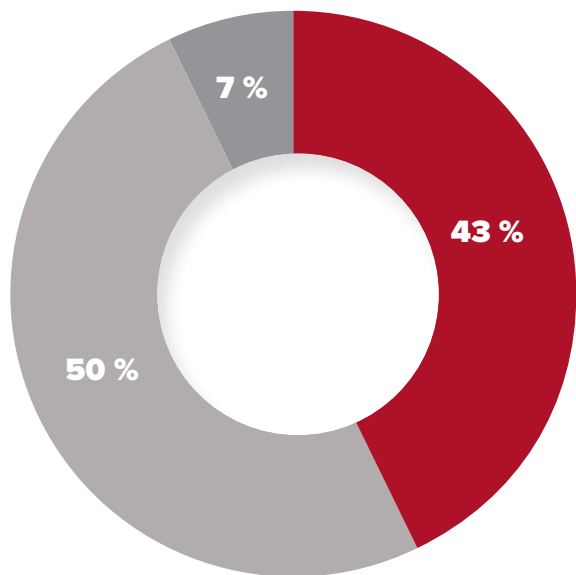
OUR PROGRAMS AND ACHIEVEMENTS

FINANCES

2022 REVENUES: \$4,219,519

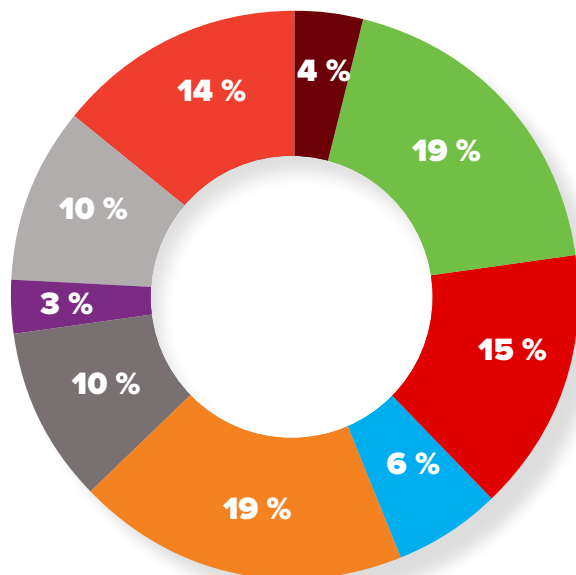
Where does the money come from?

- Corporate giving (pharmaceutical partners and other corporate sponsors)
- Fundraising events (Multiple Myeloma March, Myeloma Canada Ride, and community events)
- Other contributions (online donations, monthly donations, wills and more)



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



**On behalf of the Canadian
myeloma community,
we are grateful for you and
your continued support in
making myeloma matter.**

**For more information, to sign
up for our newsletter, join our
community or make a donation,
please visit:**

myeloma.ca

or contact us at:

contact@myeloma.ca

Tel: 514 421-2242

Toll-free: 1-888-798-5771

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