

A YEAR
in review

2019

Our Programs and Achievements
MYELOMA CANADA



**MYELOMA
CANADA**
MAKING MYELOMA MATTER

15
YEARS

MAKING MYELOMA MATTER

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

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

MESSAGE FROM THE EXECUTIVE DIRECTOR

For Myeloma Canada, 2019 was undoubtedly an important and busy year. It was also a year that saw many twists, turns and changes. We said goodbye to some colleagues and wished them the best of luck, and we were excited to welcome in new team members, who brought us new projects and fresh ideas. Most notably and sadly, our Co-founder, Aldo Del Col passed away in August, after a 17-year battle with myeloma. It's never easy to say goodbye, but sometimes life forces us to do so, and so we adapt.

We rolled up our sleeves to provide our community with vital tools and information they need to stay informed and empowered in their healthcare journey with myeloma. We launched the award-winning *Myeloma Monitor* interactive application and the *My Life. My Myeloma. Online Resource Centre*, published two InfoGuides - one of which is specifically for caregivers - and created two distinct research programs. In 2019, major health issues – including fair access to drugs – were discussed across the country. We had a strong presence, and were very productive on both, political and community fronts, ensuring the patient voice was heard and represented.

For an organization to be truly patient-focused, patients must be a part of the team and involved in the development of clinical trials, as well as in the creation of new patient-oriented programs, brochures or websites. We have done – and will continue to do - just that. We consulted with our community members every step of the way to make sure that our initiatives and programs met their needs.

These are just some of the initiatives we were able to invest in, thanks to a record-breaking year of fundraising campaigns and programs. We would have never been able to raise the funds we did in 2019 without the incredible dedication and efforts of our community. What was achieved is a pure testament to our wonderful

community, their belief in - and support of - our mission, and their desire to do whatever possible to advance myeloma research in Canada.

Although Aldo has left us, his impact and underlying presence within the organization are more than engrained in our culture and in our DNA. Aldo may have left the table, but before he did, he made sure to give us a permanent place that we now own, and where our voices will always be heard. That's why, year after year, our Myeloma Canada team, along with our community members, work tirelessly to improve the lives of those impacted by this incurable cancer. Our core values are, and will continue to be, those of a community-based organization that is patient-driven and patient-focused.

I want to thank you for your unwavering faith in, and great support of, Myeloma Canada. This organization brings together the most incredible community of people I have had the honour of meeting, and with whom I have had the privilege of working. None of what we do would be possible without you. Know that I am always here for you, to listen and discuss.

Regards,



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

OUR TEAM

Martine Elias

Executive Director

Michelle Oana

Director of Development
and Community Relations

Muriel Ingrassia

Manager of Operations

Gabriele Colasurdo

Manager of Education and Patient
Services

Jessy Ranger

Manager, Public Affairs
& Communications
(Francophone Community)

Marcie Baron

Manager, Communications
& Marketing

Shaneika Heslop

Senior Administrative Assistant

Patricia Célestin

Development and Operations
Support Coordinator

MYELOMA CANADA BOARD OF DIRECTORS

Johanne Mullen, MBA

Vice-Chair
Partner, Infrastructure and Project
Finance Leader
PricewaterhouseCoopers
Montreal, QC

Eric Low

Vice-Chair
Consultant
Eric Low Consulting
Edinburgh, (UK)

Ellis Basevitz, CPA, CA

Treasurer
Co-founder and Senior Consultant
PSB Boisjoli
Montreal, QC

Anthony Reiman, MD

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

Anthony Everett

Director
Chief Executive Officer
Tourism Vancouver Island
Nanaimo, BC

Donna Reece, MD

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

Antoinette Bozac

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

Emily Crowe, (PhD)

Director
Senior Scientific Adviser
NICE - National Institute for Health
and Care Excellence
London, UK

Lorelei Dalrymple

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

Mélanie Martel

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

Keith Taylor

President, Partner Consulting
firm specializing in police, justice,
governance and community issues
London, UK



Education

Develop, support and disseminate the necessary information and resources to help our myeloma community make informed decisions about their healthcare.

Each year, Myeloma Canada meets with myeloma community members and local experts from across the country to share information on the most recent progress in research and myeloma treatment options. We organize dozens of free local InfoSessions across Canada, host webinars and produce educational videos and materials. Our annual National Conference brings together our Canadian myeloma community for a unique opportunity to share and learn over a two-day period.

It's important to us that those living with myeloma - and their loved ones - are informed and equipped to better understand the challenges they face. As such, we strive to develop new tools that help educate and empower our community. In 2019, we published two InfoGuides and launched two award-winning, innovative resource tools that promote and improve shared decision-making, enabling those impacted by myeloma to actively participate in their healthcare journey: the My Life. My Myeloma Online Resource Centre, and the Myeloma Monitor application.


OUR PROGRAMS AND ACHIEVEMENTS

10 InfoSessions


- Abbotsford (BC)
- Charlottetown (PEI)
- Lanaudière (QC)
- Montreal (QC)
- Regina (SK)
- Saguenay-Lac-St-Jean (QC)
- Saint-Jérôme (QC)
- Sydney (NS)
- Thunder Bay (ON)
- Yellowknife (YT)



Myeloma Canada National Conference - Toronto (ON)

 220 participants

5 webinars

 more than 700 views

2 InfoGuides

- High-Dose Therapy and Autologous Stem Cell Transplantation
- Multiple Myeloma Caregiver Handbook

Myeloma Monitor application — Recipient of Celgene International's ImpactHeme Award

An award-winning interactive and personalized application designed to help multiple myeloma patients better organize, track and manage their disease.



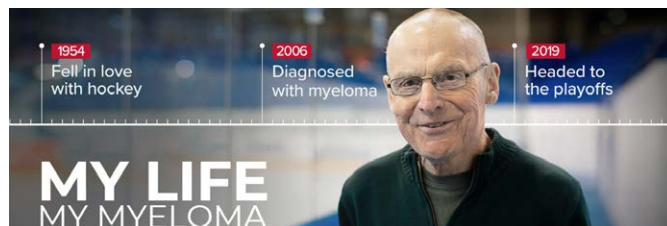
PC, MAC, iPad, iPhone and Android versions



150 downloads

My Life. My Myeloma. Online Resource Centre

- Recipient of Celgene International's ImpactHeme Award



A unique web platform giving those impacted by myeloma the tools they need to play an active role and share in their important healthcare decision-making. Tools include:

- 3 Patient Journey videos
- Decision-Making Guide
- Discussion Guide: My Healthcare
- Myeloma Monitor
- 32,000 new users
- 36,750 pages viewed

Awareness

Promote early diagnosis for, and increase awareness of, myeloma and the ways it affects the lives of patients and their families.

People living in Canada and whose lives have been impacted by myeloma are at the very heart of our outreach and awareness efforts. Through new programs, our website, social media platforms, the dissemination of reliable and up-to-date information in our monthly e-newsletter, the creation of educational videos, and our presence at various national and international events, we use whatever method and media that's appropriate to promote and bring awareness to this incurable cancer. Through their participation at events and in programs, our community members play an important role in helping to increase awareness for this relatively unknown disease. They not only provide a human face for myeloma, but bring to life the ways this cancer shapes their reality and affects their lives. By sharing their experiences, they help shed light on myeloma and raise awareness within their communities and across the nation.

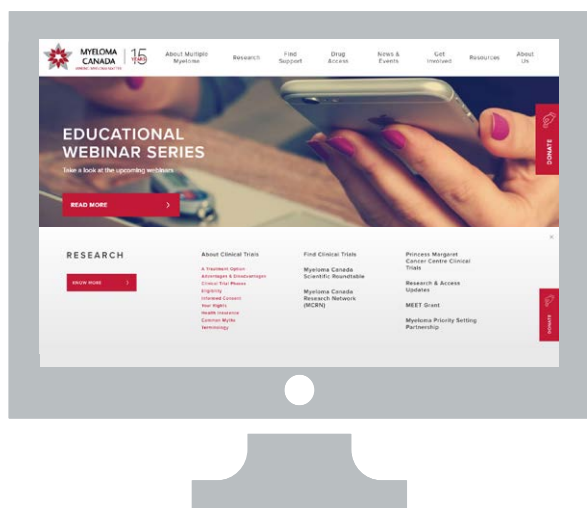
We must continue to bring awareness of this second most common form of blood cancer to the general public and to the medical community. It's essential so that we can educate, advocate and raise critical funds for programs that enable early diagnosis, better prognosis, more effective treatment options, improved quality of life, and ultimately a cure. The challenges faced by all those impacted by myeloma cannot be ignored.

OUR PROGRAMS AND ACHIEVEMENTS

Website

Revamped current “Research” section and others
Created new “Being a Caregiver” section

- ▶ 172,377 unique visits
- ▶ 217,560 page views



3,846 followers
National Facebook page
(English and French)



883 members



481 members



456 members

**24 Myeloma Matters
e-Newsletters (12 English/12
French)**

Over 20,000 subscribers



**37 videos created
(19 English/18 French)**

- 5 Patient Journey videos (3 English, 2 French)
- 24 InfoVideos (12 English, 12 French)
- 8 Educational Whiteboard videos (4 English, 4 French)

All of our support material (downloadable on myeloma.ca, or available in printed version by contacting us at contact@myeloma.ca), is available free of charge, as is access to our library of webinar recordings on our YouTube channel.

Conferences and meetings

- The 10th Annual Conférence pour vaincre le cancer, organized by Coalition Priorité Cancer
- Real World Evidence Methodology Conference
- Family Medicine Forum (FMF)



Access & Advocacy

Advocate for access to the best treatments and support services for myeloma patients.

Several important advocacy announcements were made in 2019.

In April, Myeloma Canada joined forces with the Canadian Organization for Rare Disorders (CORD), a Canadian alliance representing a network of rare diseases and medical conditions. Together, we said “no” to the new regulation surrounding drug prices proposed by the Patented Medicine Price Review Board (PMPRB) that would jeopardize the prognosis of patients by forcing companies to either stop or delay distributing their drugs in Canada. In June, the highly anticipated Canadian Strategy for Cancer Control (CSCC) was published, reporting on the most pressing challenges in oncology, including early diagnosis and support for those affected. A few months later, we joined forces with All.Can, an international, multi-stakeholder not-for-profit organization working to improve the efficiency of cancer care by focusing on what matters to patients. Together, we collected comments from more than 300 patients and proposed concrete solutions to a strategy that calls for better healthcare for Canadian cancer patients. Over the same period, the Canadian Cancer Society (CCS) published its statistical report which provided renewed hope for the future; in the last 20 years, the survival rate for patients with blood cancer has increased more than for any other type of cancer.

OUR PROGRAMS AND ACHIEVEMENTS

The advocacy work we do, with the help of our community, is essential to improving the quality and longevity of life for Canadians living with myeloma. When we create surveys, submit proposals to government authorities for drug access, or meet with members of Parliament and politicians across the country, we are advocating for the rights of all those impacted by this disease. That's why Myeloma Canada did not hesitate to comment on the proposed national pharmacare plan or to join the PMPRB Review Committee to ensure that patients' voices were heard. And, our Quebec myeloma community and our Ontario Advocacy Committee – all made up of volunteers - worked tirelessly to advocate for treatment access for patients in their provinces.

We continue to join forces with our national and international partners, such as the International Myeloma Foundation (IMF), Global Myeloma Action Network (GMAN), the Collective Oncology Network for Exchange, Cancer Care Innovation, Treatment Access and Education (CONECTed), the Canadian Cancer Action Network (CCAN), CanCertainty Coalition, and Quebec's Coalition Priorité Cancer. Together, we participate in various initiatives that allow us to have a seat at the table and ensure that the healthcare system is aware of the evolving needs of patients.

Highlights

- The Canadian Agency for Drugs and Technologies in Health (CADTH) recommends the funding of pomalidomide (Pomalyst) in combination with dexamethasone and bortezomib (Velcade).
- Health Canada approves the use of daratumumab (Darzalex) in combination with lenalidomide (Revlimid) and dexamethasone.
- New Brunswick approves the use of carfilzomib (Kyprolis) in combination with dexamethasone.
- Saskatchewan officially recognizes myeloma as an occupational disease for firemen.
- Nomination of David McMullen, a long-time member of the Myeloma Canada community, to the Canadian Agency for Drugs and Technology Health's (CADTH) Patient and Community Advisory Committee.

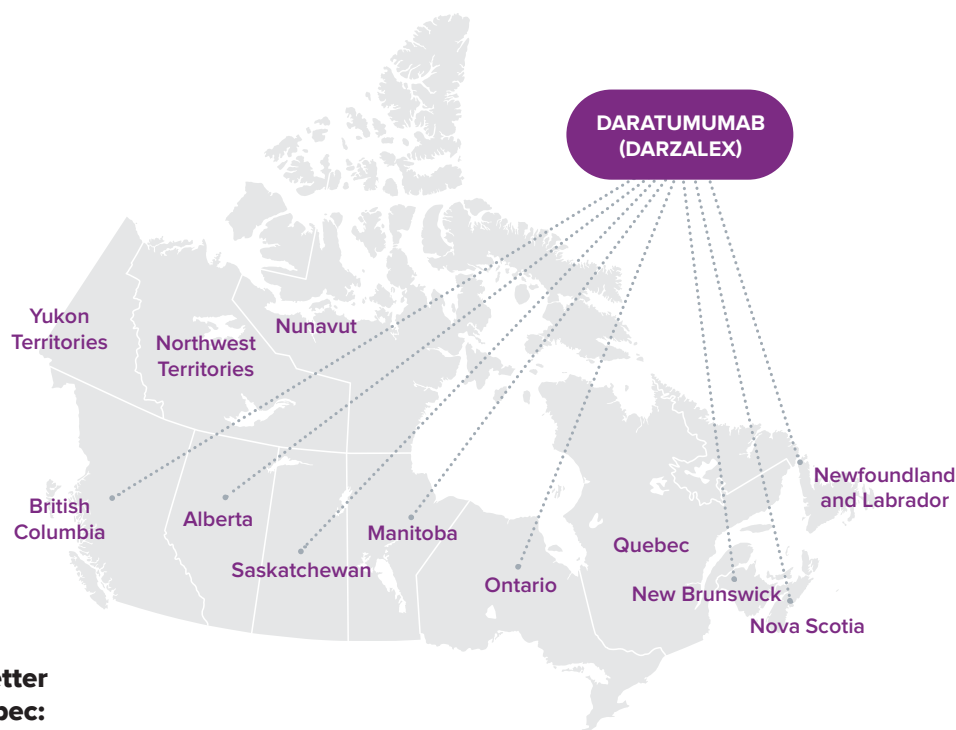
OUR PROGRAMS AND ACHIEVEMENTS

Access to treatments

8 provinces reimburse the use of daratumumab (Darzalex):

- Alberta
- Manitoba
- British Columbia
- Ontario
- Saskatchewan
- Newfoundland and Labrador
- New Brunswick
- Nova Scotia

Quebec was the first province to reimburse Darzalex in December of 2018.



3 key meetings to advocate for better access to clinical research in Quebec:

- Ministry of Health and Social Services
- Ministry of Economy and Innovation
- Quebec Research Fund—Health

2 Awareness Days at the Quebec National Assembly on the importance of:

- Personalized medicine in oncology - organized by Quebec's Coalition Priorité Cancer
- Clinical trials in myeloma patient care, (official meetings with members of Parliament, such as the Minister for Health and Social Services, 6 patients and caregivers)

2 surveys within our community to gather information for our proposals to the Institut national d'excellence en santé et services sociaux (INESSS) and the panCanadian Oncology Drug Review (pCODR) for treatment access to:

- Pomalidomide (Pomalyst) in combination with bortezomib (Velcade) and dexamethasone
- Daratumumab (Darzalex) as first-line treatment for patients not eligible for a stem cell transplant

2 Myeloma Advocacy Programs (MAP) during the election period:

- Alberta's provincial elections
- Pan-Canadian "Vote Health First" initiative with Save Your Skin Foundation, the Canadian Psoriasis Network and CONECTed, for the federal election



6 Annual conferences and meetings

- Canadian Association for Healthcare Reimbursement
- Canadian Agency for Drugs and Technologies in Health
- Multiple Myeloma Research Foundation Patient Summit
- Drug Pricing Summit
- All.Can
- GMAN (Global Myeloma Action Network)

Community Empowerment

Build a patient-driven, grassroots myeloma community and facilitate an integrated network of myeloma stakeholders.

Our community is the foundation upon which our organization is built and our members play an essential role in all that we do. Without them, we wouldn't be able to create and deliver the materials, programs and initiatives they need.

In 2019, we organized our first Voices of Myeloma Summit designed to inspire and empower patients, have them share their stories in an impactful way, and encourage them to use social media to become stronger myeloma advocates. We also worked with Leger, Canada's largest market research and analytics company, to create the "Myeloma Canada – Patient and Caregiver Survey" to better understand the needs of our community and determine if our efforts were aligned with our mission. 448 community members answered our survey, proving us with great insight on our current and future initiatives and programs.

Our commitment to our community is unwavering and initiatives like these allow us to reinforce the bonds that unite us.

As a patient-driven organization, it is our ethos to support our community members in any way we can, to be there for them throughout all the important stages of their journey, and to give them the recognition they deserve within our organization. Their involvement as volunteers, support group leaders, participants in our event and as fundraising events organizers is what drives us to give our best every day and makes us grow a little more each year.

OUR PROGRAMS AND ACHIEVEMENTS

Support Group Network

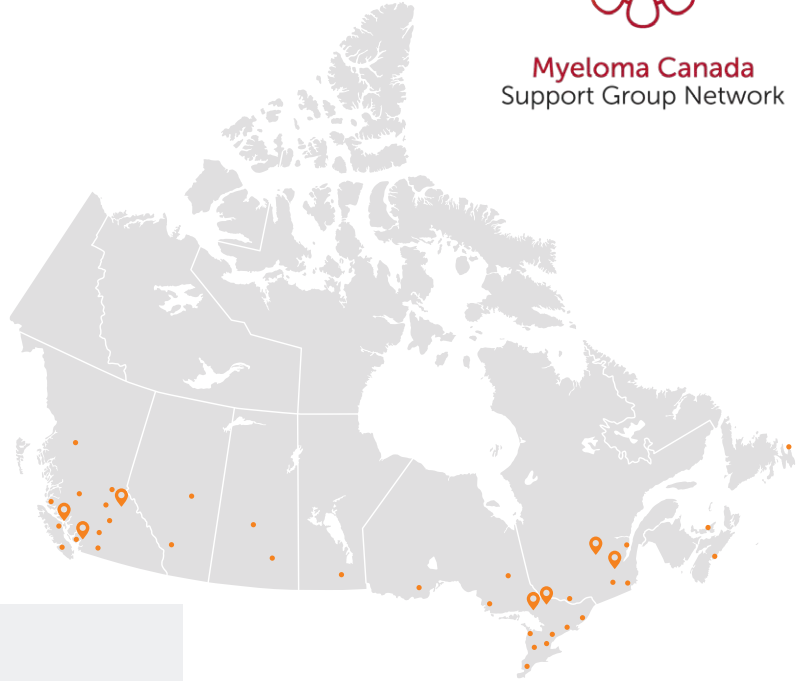


Myeloma Canada
Support Group Network

38 support groups

7 new support groups were created following our Meet & Greet events:

- Prince George (BC)
- Vancouver (BC)
- Laurentians (QC)
- Longueuil (QC)
- Hamilton (ON)
- Maple Ridge (BC)
- Kingston (ON)



534 members

in our 3 Facebook virtual support groups:
for Patients, for Caregivers, and for Young Patients
& Caregivers

Myeloma Canada's Support Group Leaders Summit



60 participants

from across the country

OUR PROGRAMS AND ACHIEVEMENTS

List of leaders

Alberta

Deet Adam	Calgary	Southern Alberta Myeloma Patient Society (SAMPS)
Lorelei Dalrymple	Edmonton	Myeloma Alberta Support Society (MASS)

British Columbia

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

Prince Edward Island

Bethany Reeves and Megan Gardiner	Charlottetown	Charlottetown Myeloma Support Group
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Manitoba

Jackey LaBossiere	Winnipeg	Winnipeg Myeloma Support Group
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New Brunswick

Susan Collins	Saint John	Saint John Area Multiple Myeloma Support Group
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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, Helen Prpa and Sharon Aloian	Hamilton	Hamilton and District Multiple Myeloma Network
JoAnn Cartlidge	Windsor	Windsor Myeloma Support Group
Marion Bentley	Sault Ste. Marie	Sault Ste. Marie Multiple Myeloma Support Group
Ev McDowell and Jeff Parton	London	London and District Myeloma Support Group
Norma Linder and Juliette Royer	Halton-Peel	Halton-Peel and Area Myeloma Support Group
David McMullen and Donald Hunter	Toronto	Toronto and District Multiple Myeloma Support Group
Brian and Liz Stockdale	Cobourg	Northumberland and District Multiple Myeloma Support Group
Iris Phillips	Picton	Picton Support Group
Robin Sully and Jean Shepherd	Ottawa	Ottawa-Gatineau Multiple Myeloma Community Network
Susan McDowell and Juliette Royer	Kitchener-Waterloo	Waterloo Region Myeloma Support Group
Denyse DeBernardi	North Bay	Nipissing Myeloma Support Group

Quebec

Hervé Benoît, Danny Wade and Courtney Rubin	Montreal	Montreal Myeloma Support Network
Vénus Bélanger	Sherbrooke	<i>Espoir Myélome Estrie</i> Support Group
Manon Veilleux and Julie Martel	Quebec City	<i>Myélome Québec</i> Support Group
Danny Wade and Jean-François Couture	Longueuil	<i>Myélome Rive-Sud</i> Support Group
Daniel Sarrazin and Chantal Tardif	Saint-Eustache	<i>Des Laurentides</i> 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

Newfoundland-Labrador

David McConkey, Stephen Norman and Gary Cross	Newfoundland	Myeloma Newfoundland Support Group
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OUR PROGRAMS AND ACHIEVEMENTS

Patient Advisory Council (PAC)

A word from the PAC President

In 2014, Myeloma Canada's Board of Directors created the Patient Advisory Council (PAC). The Board's primary objective was, and remains, to advise the Board of Directors on issues important to patients, caregivers, and support groups, as well as to make sure the patient voice is represented at both, national and regional levels. The PAC also works closely with the Myeloma Canada team to support its many activities. This year for example, we collaborated on the review of Myeloma Canada's Operational Plan, offered our advice on numerous documents, including advocacy initiatives and drug submissions, new educational publications, and participated in the development of the Myeloma Monitor app.

When our community or Myeloma Canada need us, PAC members always make ourselves available. Our support of the organization, and their event-planning, is not only welcome, but necessary. New members

joined the PAC in 2019 so that we could ensure better community representation across the country. We are, more than ever, here for you and to work hard to make sure your voices heard.

Thank you!



Lorelei Dalrymple
President, Myeloma Canada
Patient Advisory Council

PAC members:

- Lorelei Dalrymple, President
- David McConkey, Atlantic Canada
- Hervé Benoît, Quebec
- Deb McKnight, Ontario
- Glenn Hussey, Ontario
- Susan McLean, Western Canada
- Keith Taylor, Western Canada

Community events

The events organized by our community members are essential. Throughout the years, our community has been incredibly active and has proudly contributed to our outreach and education initiatives by organizing various fundraising events to support our cause. Our community members' passion, creativity, generosity and efforts are at the core of our mission and we cannot thank them enough for their support and all that they do.

Community events

\$ 152,434

**Myeloma Canada's Sam's
4th Annual Monte Carlo Casino
Night**

\$ 37,500

**Myeloma Canada's 2nd Charity
Golf Classic**

\$ 24,429



OUR PROGRAMS AND ACHIEVEMENTS

Multiple Myeloma March



MULTIPLE MYELOMA MARCH

In 2019, the Multiple Myeloma Walk, our signature fundraising and community event, celebrated its 11th anniversary. Every fall, myeloma communities from across the country take part in a 5km walk to raise important funds for research and access to innovative treatments that will improve life expectancy and quality of life, and help find a cure for those living with myeloma. Thanks to our experienced leaders and our dedicated community, we have once again reached new heights.



- ▶ \$670,000
- ▶ 28 participating cities + 1 virtual March
- ▶ 3,700 participants
- ▶ 430 volunteers
- ▶ 240 teams
- ▶ 7,216 donations



OUR PROGRAMS AND ACHIEVEMENTS



MULTIPLE MYELOMA MARCH

Top Fundraising Campaigns

\$ 22,310

**#CrossmanStrong
Moncton (NB)**

\$ 17,695

**Greg Roberts Runners
Airdrie (AB)**

\$ 17,620

**Myelomamaniacs
Newmarket (ON)**

\$ 17,459

**Tania's Tribe
Newmarket (ON)**

\$ 13,942

**Myeloma Matadors
Ottawa (ON)**



Multiple Myeloma March leaders

March	Leaders
Prince George	Cyndi Logan
Vancouver Island	Allison Jennings & Susan McLean
Melville	Lynn Hoffman
Sault Ste. Marie	Pamela Orchard & Judy Mills
Kitchener-Waterloo	Carlee England
Kamloops	Bob Trudeau, Bob Hamaguchi, Anna Evenrude
St John's	Tina Soulier
Airdrie	Pamela Roberts
Kelowna	Ron Surry & Susan Schmalz
Winnipeg	Kim Krahn & Jackey LaBossiere
Hamilton	Nancy Gray
Quebec City	Ann Lanouette
Thunder Bay	Lea Vanderwey
Oshawa	Jessy Ranger
Mississauga	Anne Spencer
Ottawa	Frank Shepherd & Glenn Hussey
Saint John	Lauren Cook & Nicole Barry
Halifax	Michael Senz & Julie Salsman
Montreal	Michelle Oana & Patricia Empsall
Windsor/Essex County	Erma ROUNG & Crystal Harvey
Saskatoon	Marie Prokopiw & Judi Worth
Cobourg	Brian Stockdale
Newmarket	Kristy Ahola
Vancouver	Michelle Oana
Kingston	Claudia Trost, Iris Phillips, Shaneika Heslop
Regina	Kathy Dorsett, Helen Grimm, Marcie Baron
Moncton	Shawn Crossman
Magog	Jessy Ranger & Vénus Bélanger

OUR PROGRAMS AND ACHIEVEMENTS

Community awards

Recognizing the exceptional leadership of our Canadian myeloma community members.



**Myeloma Canada
Executive Director Award**

Lorelei Dalrymple, Edmonton (AB)

For her exceptional work, unparalleled dedication and involvement in numerous Myeloma Canada activities.



**Myeloma Canada
Carolyn Henry Memorial
TEAM Award**

Jackey LaBossiere, Winnipeg (MB)

For her outreach efforts within the community and with the media, and for her help in organizing the Awareness Day at the Provincial Legislative Assembly.



**Myeloma Canada Nathalie
Allard Memorial Award**

Shawn Crossman, Moncton (NB)

For raising close to \$23,000 for the Moncton Multiple Myeloma March, making him the top fundraiser across the country.



**Myeloma Canada
Community Achievement
Award**

Vettorello Family, Windsor (ON)

For their volunteer involvement in the Windsor-Essex County Multiple Myeloma March both as committee members and participants, soliciting local sponsors and organizing fundraising events.



**Myeloma Canada
Newcomer of the Year
Award**

Kristy Ahola, Newmarket (ON)

For successfully organizing the first Multiple Myeloma March in Newmarket, which raised \$50,779 and included local political representatives and the media.



**Myeloma Canada Notable
Volunteer Award**

Vénus Bélanger, Sherbrooke (QC)

For her involvement as leader of the *Myélome Estrie* support group, as the organizer of the Magog Multiple Myeloma March, and for her participation in patient rights advocacy initiatives in Quebec.



**Myeloma Canada
Marion State Memorial
Nursing Award**

Farah McKenzie (BC)

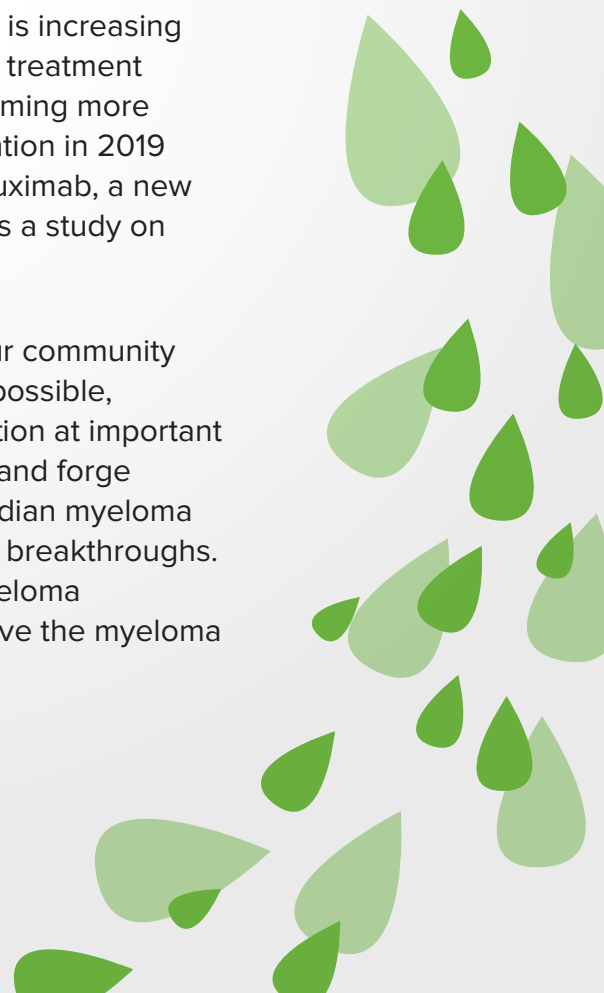
For her excellence in nursing through her leadership, teamwork, passion and commitment to advancing the care of myeloma patients.

Research & Science

Foster, support, and fund myeloma-related research that leads to better patient outcomes and leads to a cure.

One of the fundamental elements of Myeloma Canada's mission is to support research. This is crucial, not only for improving the quality of lives for those living with myeloma, but for finding a cure. 2019 saw great progress in clinical research and the results for myeloma are very promising. The number of new myeloma treatments approved (and not yet approved) in Canada, as well as the number of treatment combinations currently under review is increasing exponentially, with exciting results. Triple and even quadruple treatment protocols are the way of the future. CAR-T therapies are becoming more and more encouraging. Daratumumab was the center of attention in 2019 and is quickly becoming essential to myeloma treatment. Isatuximab, a new CD38 like daratumumab, has produced positive results, as has a study on venetoclax.

Understanding the research needs, wants and concerns of our community is crucial to us. We make every effort to involve them, where possible, through surveys, events and feedback. Through our participation at important international and national scientific events, we support, meet and forge important relationships with current and up-and-coming Canadian myeloma experts, and learn first-hand about current developments and breakthroughs. We are committed to doing what we can so that Canada's myeloma researchers can pursue their vital work and continue to improve the myeloma landscape.



OUR PROGRAMS AND ACHIEVEMENTS

10th Annual Myeloma Canada Scientific Roundtable



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

Co-chairs:

- Dr Richard LeBlanc, Maisonneuve-Rosemont Hospital
- Dr Arleigh McCurdy, The Ottawa Hospital

- ▶ 120 participants
- ▶ 60 myeloma experts and 14 clinical nurses



Myeloma Priority Setting Partnership (PSP)

The first program of its kind in Canada that uses patient input to identify and define the direction of future myeloma research and encourage funding agencies to recognize pressing patient issues that remain unanswered..

530 participants (Phase 1)

Led by Dr Antony Reiman (Medical oncologist and Canadian Cancer Society Research Chair holder). Supervised by the James Lind Alliance, approved by Horizon Health Network Research Ethics Board.

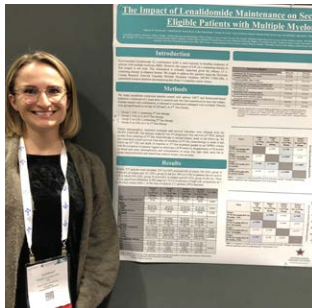
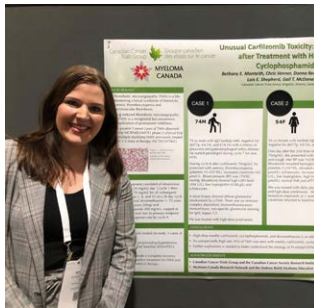
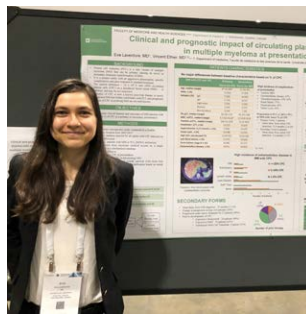
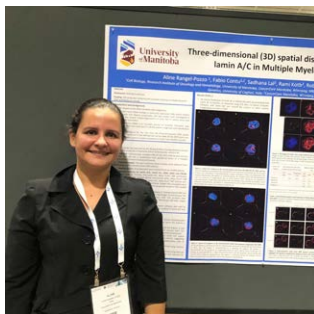


OUR PROGRAMS AND ACHIEVEMENTS

Dr Andrew R. Belch Myeloma Education and Enriched Training grant (MEET)

Enables qualified young researchers to attend international myeloma conferences.

4 recipients: Bethany Monteith Ames, Eva Laverdure, Aline Rangel Pozzo, Hannah Cherniawsky



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

- Led the development of consensus recommendations on daily practices, existing guidelines and the availability of evidence-based diagnostic tools for myeloma.
- 17 Canadian experts
- First Guidelines on the Diagnosis of Multiple Myeloma and Related Disorders
- Guidelines on Multiple Myeloma and Related Disorders diagnosis in Canada
- Accredited Training Program

11 Annual conferences and meetings

- Canadian Agency for Drugs and Technologies in Health (CADTH)
- Canadian Clinical Trials Group (CCTG)
- European Hematology Association (EHA) Annual Congress
- International Myeloma Workshop (IMW)
- Real World Evidence Methodology Conference
- Défi-cyclo myélome for the Myeloma Canada Chair in Multiple Myeloma Research at the Université de Montréal
- Multiple Myeloma Research Foundation (MMRF) Patient Summit
- American Society of Hematology (ASH) Annual Congress
- American Society of Clinical Oncology Annual Congress
- IMWG (International Myeloma Working Group)
- Myeloma Day at Princess Margaret Hospital



OUR DONORS

We would like to extend a heartfelt thank you to our many partners and donors for their support in 2019. We are grateful for your commitment to our cause. Your donations allow us to pursue our mission and support clinical research that will help find a cure.

THANK YOU
from the bottom of our hearts
for your trust and for making
myeloma matter.

Individual donations \$2,000 and more

- Kristy Ahola
- Tanya Causgrove
- Alan Kirkpatrick
- Paul Bolan
- William Anderson
- Jean-Marie Bourassa
- Robin Sully
- Mark Bishop
- Denis Potvin
- Sharon Perkins
- Margaret A. Stanfield
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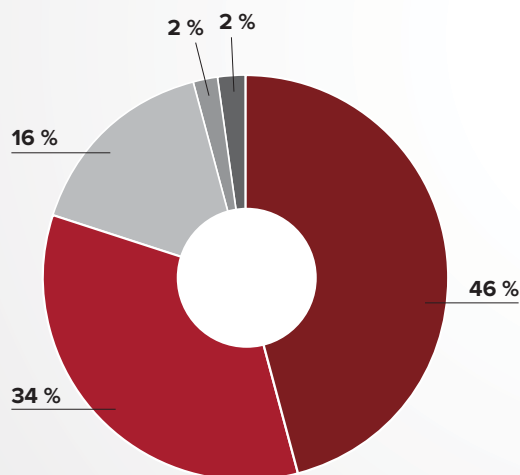
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2019 REVENUES: \$2.3 MILLION

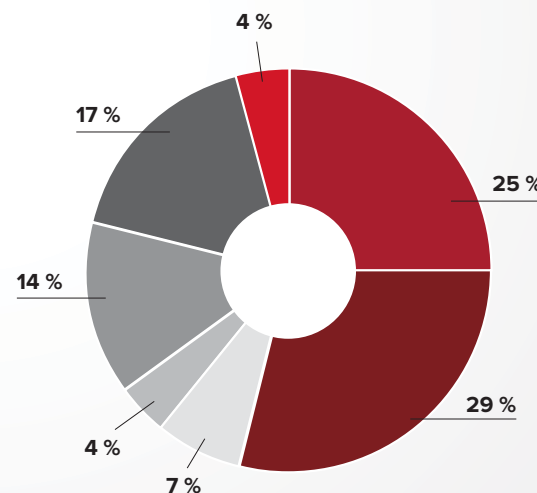
Where does the money come from?

- Corporate giving
(pharmaceutical partners & corporate sponsors)
- Fundraising events
(Marches & community events)
- Contributions
(Online donations, monthly donations, wills, etc.)
- Other revenue
- Investment income



Where does the money go?

- Governance
- Science and research
- Patient and education programs
- General and administration
- Access and advocacy
- Fundraising
- Awareness and communication



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15
YEARS