

2016

ANNUAL REPORT



**MYELOMA
CANADA**

MAKING MYELOMA MATTER

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

Provide educational resources and support to patients, families and caregivers

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

Promote clinical research and access to new drug trials in Canada

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

**OUR COMMITMENT :
MAKE MYELOMA MATTER**

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

A MESSAGE FROM ALDO DEL COL, CO-FOUNDER AND CHAIRMAN



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

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

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

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

Our ongoing programs continued to grow and improve, notably:

- Grassroots efforts helped the support group network grow to 24 cities with the creation of new groups in Kingston and Saint John.

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

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

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

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

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

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

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RECOGNIZING
ACHIEVEMENTS

Myeloma Canada Milestones

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

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

MYELOMA CANADA IN NUMBERS

230

patients and caregivers
attended the 2016
Myeloma Canada
National Conference

4

patient and
caregiver
InfoSessions
were held
across the
country

\$512,000

was raised at the 2016
Multiple Myeloma March, Myeloma
Canada's signature event

4

new myeloma
drugs were
approved by
Health Canada
in 2016

24

support groups across the
country meet and exchange
regularly to learn more
about the disease

16

MCRN sites are currently
participating in an active
MCRN clinical trial

10,000

Myeloma Canada Patient
Handbooks and InfoGuides
were printed and distributed
across the country

2016

is the year the Myeloma Canada
Research Network (MCRN) and
the MCRN Canadian Multiple
Myeloma Database were
officially created

24 CENTRES

from coast-to-coast are part of
the Myeloma Canada Research
Network (MCRN)

\$522,967

was invested in Canadian
myeloma research in 2016

3

is the number of patient submissions
Myeloma Canada made to the
panCanadian Oncology Drug Review
(pCODR) on behalf of myeloma
patients and caregivers in order to
advocate for drug reimbursement

\$2,476,158

was invested by Myeloma
Canada in Canadian myeloma
research since 2009

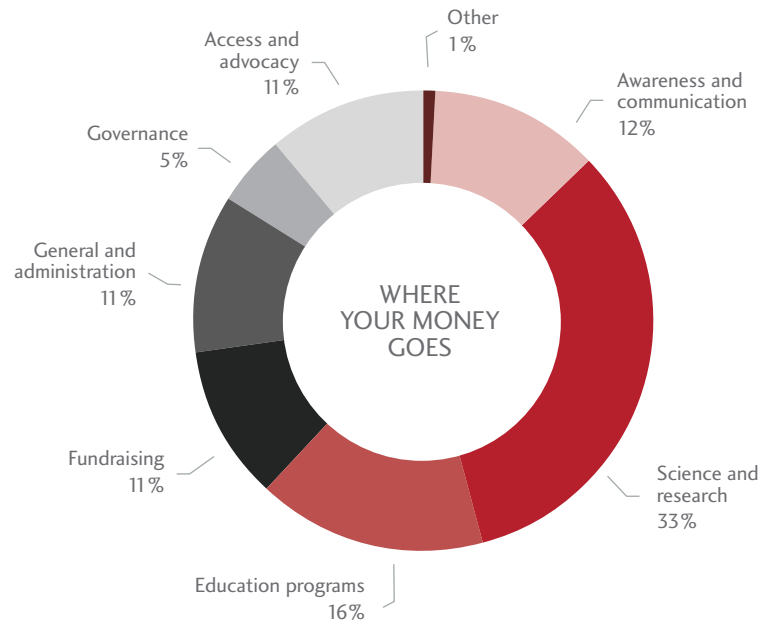
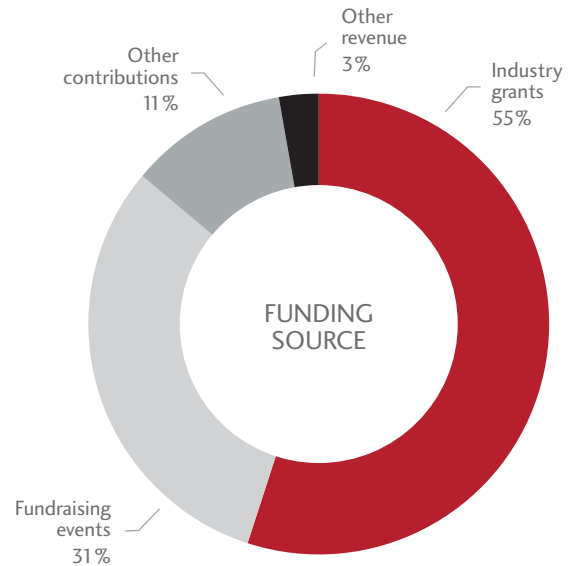


2016 AUDITED FINANCIAL STATEMENTS

REVENUE	
Industry grants	\$993,391
Fundraising events	\$560,346
Other contributions	\$199,301
Other revenue	\$6,885
Investment income	\$15,280
Realized loss on disposal of investments	(\$16,859)
Unrealized gain on investments at fair value	\$42,184
TOTAL REVENUE	\$1,800,528

EXPENDITURES	
Awareness and communication	\$194,772
Science and research	\$522,967
Patient and education programs	\$252,437
Fundraising	\$175,246
General and administration	\$166,873
Governance	\$71,588
Access and advocacy	\$182,620
Other	\$6,246
TOTAL EXPENSE	\$1,572,749

Excess of revenue over expenditures for the year **\$227,779**





PATIENT DRIVEN. PATIENT FOCUSED.

“In the early 2000’s, the average life expectancy for myeloma patients was 3-5 years. With the help of Myeloma Canada and the research done in many Canadian hospitals, as well as the research institutes around the world, most patients now live much longer.”

G. Caron, Patient,
Gatineau, Quebec

“In our search for knowledge and support we happened upon the Myeloma Canada National Conference in Ottawa. What better place to become informed and meet like-minded people than at a National Conference. Sessions educated us on the current status of the disease, on-going research and development of new drugs and treatments, testimonials from peers and HOPE.”

B. Wigle, Caregiver,
Halton-Peel, Ontario

“I hope to help bring awareness to myeloma through my board experience and have recently been honoured with a position on Myeloma Canada’s Board of Directors. Life is truly amazing; in a little under three years I have gone from never having heard the word myeloma to being a part of a wonderful organization dedicated to strengthening the voice of the Canadian myeloma community and improving the quality of life of myeloma patients, their caregivers and families.”

Anthony Everett, Patient and Member
of the Myeloma Canada Board of Directors,
Prince George, British Columbia



JOIN OUR COMMUNITY



myeloma.ca

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