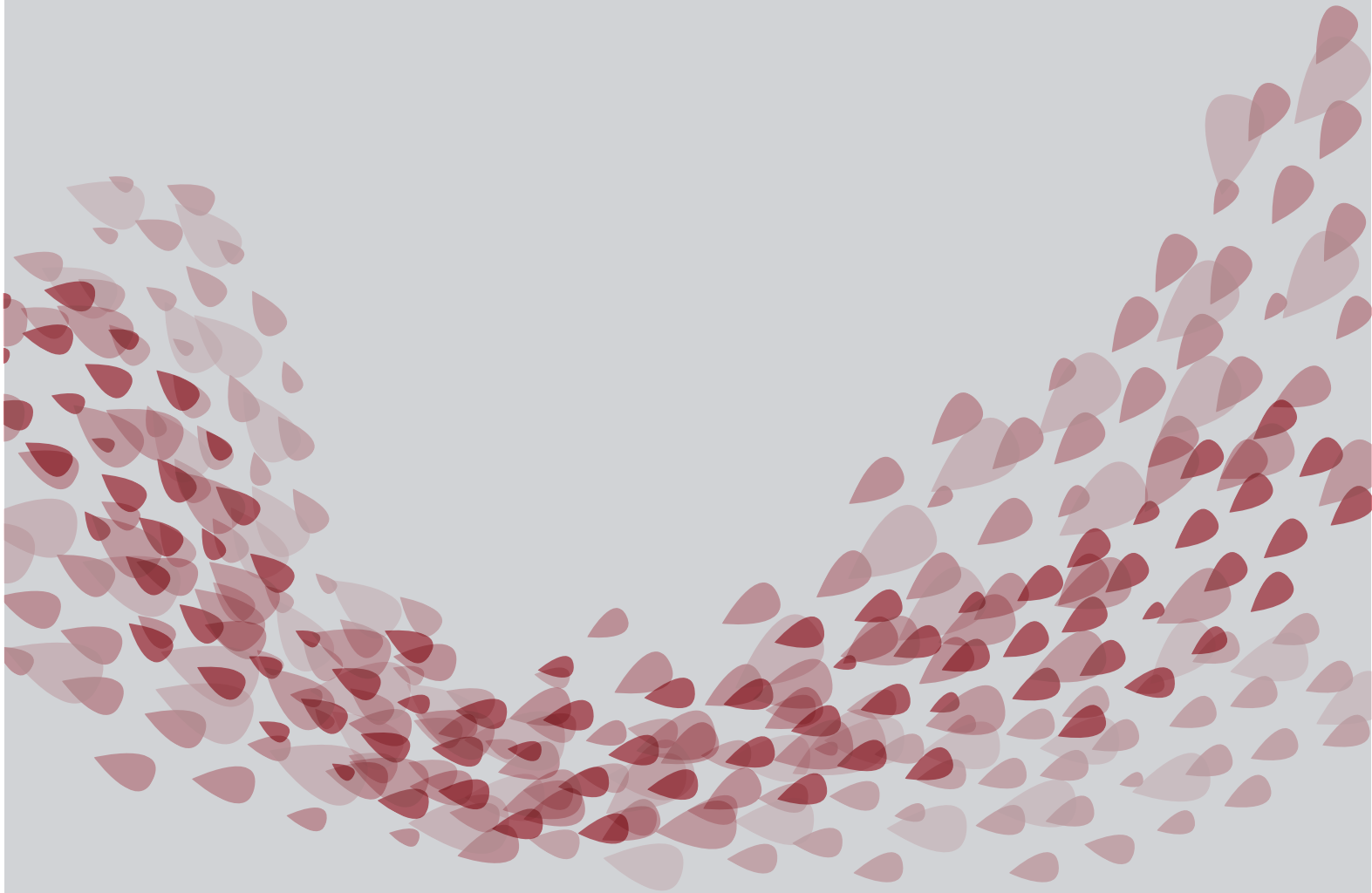


# 2017

ANNUAL REPORT



**MYELOMA  
CANADA**  
MAKING MYELOMA MATTER

---

## MYELOMA CANADA'S MISSION

To improve the lives of Canadians impacted by myeloma by accelerating access to better care through awareness, education, advocacy, community engagement and clinical research.

Myeloma Canada is a non-profit charitable organization created by, and for, people impacted by multiple myeloma, a relatively unknown cancer of the plasma cells. Exclusively devoted to the Canadian myeloma community, Myeloma Canada has been making myeloma matter since 2005.

As a patient-driven and patient-focused grassroots organization, Myeloma Canada drives collaborative efforts to unify the voice of the community to effectively shape the Canadian treatment landscape through a committed focus on the improvement of patient outcomes by:

**Providing educational resources** to patients, families and caregivers

---

**Increasing awareness** of the disease and its effects on the lives of patients and their families

---

**Facilitating access to new therapies**, treatment options and healthcare resources

---

**Advancing clinical research** and promoting access to new drug trials in Canada

---

**Empowering patients and caregivers** through community engagement

The Myeloma Canada Research Network (MCRN), comprising Canada's leading researchers and clinicians from across the country, is the first and only platform that fuses national scientific research and advocacy. The MCRN develops and supports Canadian-designed clinical trials nationwide, publishes consensus statements on the management of the disease and collects data for its innovative national database, a key stepping stone in our search for a cure.

Myeloma Canada, in partnership with the Myeloma Canada Research Network, is dedicated to advancing the understanding, treatment and management of the disease and accelerating access to game-changing therapies for Canadians living with myeloma.

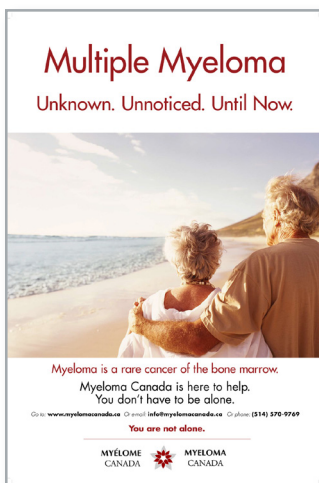
For more information about how Myeloma Canada is putting myeloma on the map, please visit [myeloma.ca](https://myeloma.ca)

---

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



Thanks to the unprecedented engagement of our community across the country, guided and supported by our passionate and caring team, Myeloma Canada continued to build on its exceptional accomplishments and introduce new programs to address the ever-changing landscape of challenges and opportunities.



Myeloma Canada was officially created on January 18, 2005, although much of the groundwork had already been laid the previous year. My original vision was to create a truly national organization with a focus on developing a sense of community where anyone impacted by myeloma did not have to feel alone. This

was driven in no small part by my own feelings of fear, anxiety and aloneness when I was diagnosed. Our first awareness piece was a poster that carried the message to the community: “Myeloma Canada is here to help. You don’t have to be alone.” This philosophy has become engrained in the DNA of our organization and guides everything we do.

I am often invited to participate and speak at conferences and other events both here in Canada and internationally. Invariably, I am asked about how Myeloma Canada came to be regarded as one of the best patient organizations in Canada. The answer is simple: *Respect for the patient and a laser focus on delivering programs to help improve patient outcomes.* Although some organizations have a focus on advocacy, research or fundraising, Myeloma Canada delivers programs across all areas. A survey conducted by the Myeloma Canada Patient Advisory Council showed that our community valued all four of our pillars (education, awareness, advocacy and research) more or less equally. This important feedback reassures us that we are aligned with the needs of our community.

This past year saw Myeloma Canada connect with more patients and caregivers than ever before, strengthening the ties that unite us, regardless of where we live. I am personally grateful to the grassroots efforts of countless volunteers across Canada for their dedication and to the thousands of donors who supported our mission. I invite you to read through the Year In Review and see how we made myeloma matter in 2017.

# 20 17

---

**RECOGNIZING  
ACHIEVEMENTS**

## Myeloma Canada Milestones

As we celebrated Canada's 150th birthday in 2017, Myeloma Canada also celebrated a year of proud accomplishments. This past year was an exceptional one for Myeloma Canada and the Canadian myeloma community, with many noteworthy milestones achieved.

It is incredible to witness what can be accomplished when we speak as a unified voice and work together to make myeloma matter. We would like to extend our sincere gratitude to the entire myeloma community for your continued support and for helping to put myeloma on the map.

With a renewed sense of passion, motivation and dedication for 2018 and beyond, the Myeloma Canada team is pleased to share with you Myeloma Canada Milestones: 2017 Annual Report.



---

## MYELOMA CANADA IN NUMBERS

\$488,254 was invested  
in science and research in

**2017**

**8**

InfoSessions  
and **6** Webinar were  
held across  
the country.

On average, Myeloma  
Canada's bilingual website  
receives over

**10,000 visits**  
per month

**\$342,792**

was invested in patient  
and education programs

Each year, over

**4,000 Handbooks  
and InfoGuides**

are printed and distributed across the  
country. The average cost of a complete  
educational package for a newly  
diagnosed patient is

**\$35**

**2**

new Myeloma Canada Research  
Network clinical trials were  
activated in Canada: MCRN 004  
– The LAURENTIANS Trial and  
MCRN 005 – The BOSTON Trial

---

**637** letters were sent to elected  
officials across the country by the  
Canadian myeloma community as  
part of Myeloma Canada's Advocacy  
Program (MAP)

---

There are

**29 support groups**

across the country, 5 of which were  
created in 2017

---

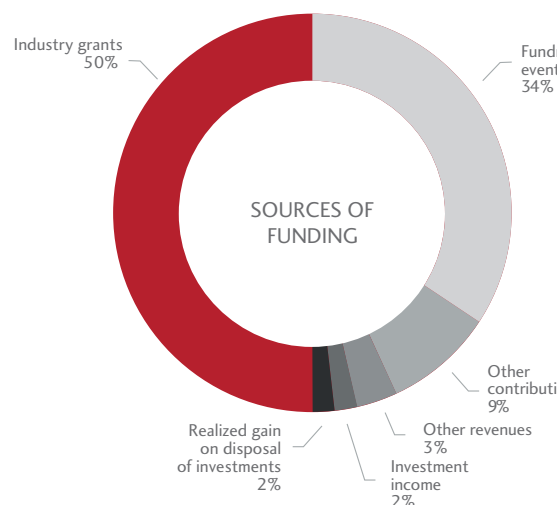
Listening to patients is a vital  
part of the Health Technology  
Assessment's (HTA) work and is  
an important part of the drug  
approval process. Myeloma  
Canada made **3** patient and  
caregiver submissions to  
pCODR, **3** patient and caregiver  
submissions to INESSS (Quebec),  
**2** clinician submissions to  
pCODR and 1 submission to the  
Ontario Public Drug Program

## 2017 AUDITED FINANCIAL STATEMENTS

### REVENUE

Industry grants	\$956,168
Fundraising events	\$655,525
Other contributions	\$176,979
Other revenues	\$53,659
Investment income	\$46,273
Realized gain on disposal of investments *	\$41,047

**TOTAL REVENUE** **\$1,929,651**

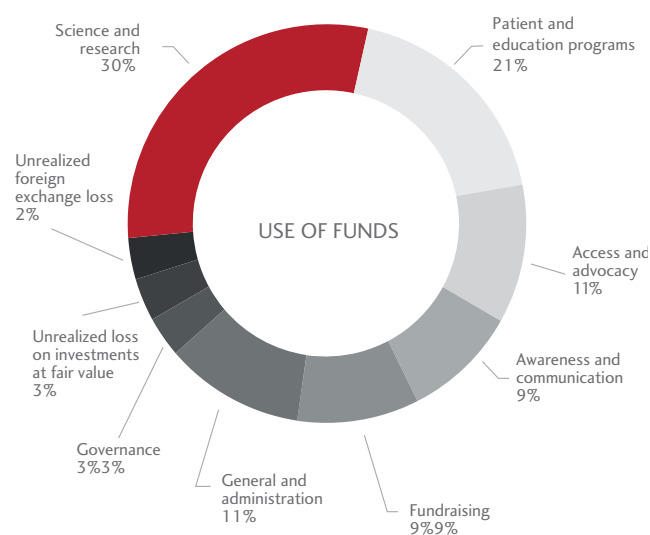


### EXPENDITURES

Science and research	\$488,254
Patient and education programs	\$342,792
Access and advocacy	\$183,956
Awareness and communication	\$145,518
Fundraising	\$164,597
General and administration	\$187,882
Governance	\$49,620
Unrealized loss on investments at fair value*	\$54,217
Unrealized foreign exchange loss*	\$30,011

**TOTAL EXPENDITURES** **\$1,646,847**

**Excess of revenue over expenditures for the year** **\$282,804**



\* Amounts reflecting Myeloma Canada's investment portfolio management. See the complete financial statement for details.

## MISSION

# ACCELERATING ACCESS TO BETTER CARE

“Prior to [the] first walk, I attended an InfoSession hosted by Myeloma Canada. For the first time I met other multiple myeloma patients. I learned so much from the guest speakers and Aldo Del Col. All the people I met that day had different symptoms but we all shared one thing in common; we were all affected by a disease that we all knew little about. This was the catalyst for me to take charge of my life and my myeloma. I needed to educate myself and be my own advocate.”

### **C. Hodge, Patient**

Ontario

---

“My wife and I have attended numerous Myeloma Canada National Conferences. These two-day conferences have provided me with a great opportunity to learn more about the disease, the new treatments and side effects management, and to meet fellow patients and some of the doctors who treat myeloma.”

### **V. Saunderson, Patient**

Manitoba

---

“We’re making great strides with the Myeloma Canada Research Network (MCRN). The MCRN has initiated clinical trials from Coast to Coast, enabling Canadians to gain access to clinical trials locally, thereby reducing their personal financial burden and hopefully offering them a treatment option that they would otherwise not be able to access for years. Kudos to our Canadian team for making waves in myeloma research on an international scale and proving that when we work together, big things can happen.”

### **Cindy Manchulenko, RN, BN, MSN**

**Clinical Trials Project Manager Clinical & Systems Transformation,**

**Board Member of the Myeloma Canada Research Network**

British Columbia

---



# JOIN OUR COMMUNITY

---



[myeloma.ca](http://myeloma.ca)

---

## CONTACT US

Tel : (514) 421-2242

Toll free : 1- 888-798-5771

Email : [contact@myeloma.ca](mailto:contact@myeloma.ca)