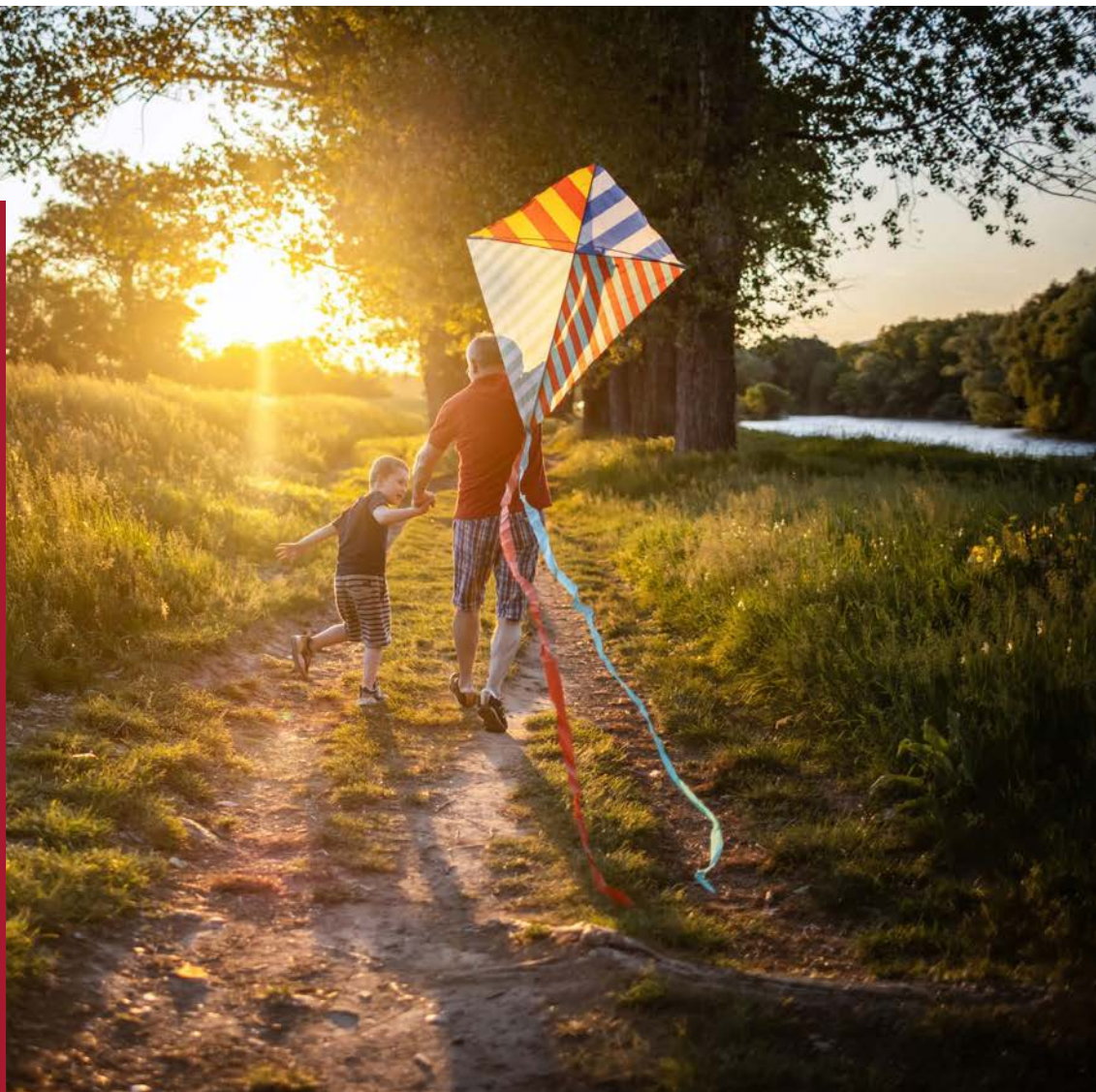


**Making Myeloma Matter:
Strategic Plan 2023–2027**

Building
tomorrow,
today



myeloma.ca



**MYELOMA
CANADA**
MAKING MYELOMA MATTER





Martine Elias
Executive Director

A word of thanks to our community

Myeloma Canada's Strategic Plan for 2023–2027 would not have been possible without the invaluable input and insights from the following: our remarkable Canadian myeloma community of people living with myeloma and those who care for them; our Patient Advisory Council (PAC); support group leaders and volunteers; myeloma clinicians; experts in health policy; our pharmaceutical partners; and of course, Myeloma Canada staff and our Board of Directors.

Thank you to everyone who shared their vision not only for Myeloma Canada, but also for myeloma in Canada. We could never do our work without you, your support, or your confidence in our organization.



What is myeloma?

Myeloma is the 2nd most common form of blood cancer, yet sadly, most people have never heard of it. Myeloma is associated with the abnormal behaviour and uncontrolled growth of a type of white blood cell—the *plasma cell*. Plasma cells are made in the bone marrow—the spongy tissue found inside bones—and are an important component of the body's immune system because they produce antibodies.

In myeloma, abnormal plasma cells (also known as *myeloma cells*) interfere with the production of normal healthy blood cells in the bone marrow and overproduce inactive clones of abnormal antibodies that can negatively affect different parts of the body such as the bones and kidneys.

The cause or causes of myeloma remain unknown, but there is increasing research that suggests possible associations between myeloma and a decline in immune function, genetic factors, and the environment.



Who we are

Myeloma Canada is the only national charitable organization created by, and for, Canadians impacted by multiple myeloma. We are driven to improve the lives of those affected by this disease by empowering our community through awareness, education, and advocacy programs, and by supporting clinical research to find a cure.

We are committed to making myeloma matter, and have been since our founding in 2005.

To learn more, please visit our website at myeloma.ca.

The number of Canadians diagnosed with myeloma is steadily increasing year after year. While there is not yet a cure, people with myeloma are living longer and better lives thanks to recent breakthroughs in research and treatment.

More needs to be done: we need to increase awareness of this disease; we need more funding and research to help improve the quality of life for Canadians living with myeloma; and ultimately, we need to find a cure.



Our promise

To improve the lives of and empower all Canadians affected by myeloma and accelerate access to the best care while supporting the pursuit of its cure and prevention.



At a glance

Building tomorrow, today

MYELOMA CANADA'S 2023–2027 STRATEGIC PLAN

Strategic goals

1 | No one left behind

2 | Mobilize and empower

3 | Invest in science and research

4 | Bring out the best in our people



Diversity, inclusivity, and equity

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.





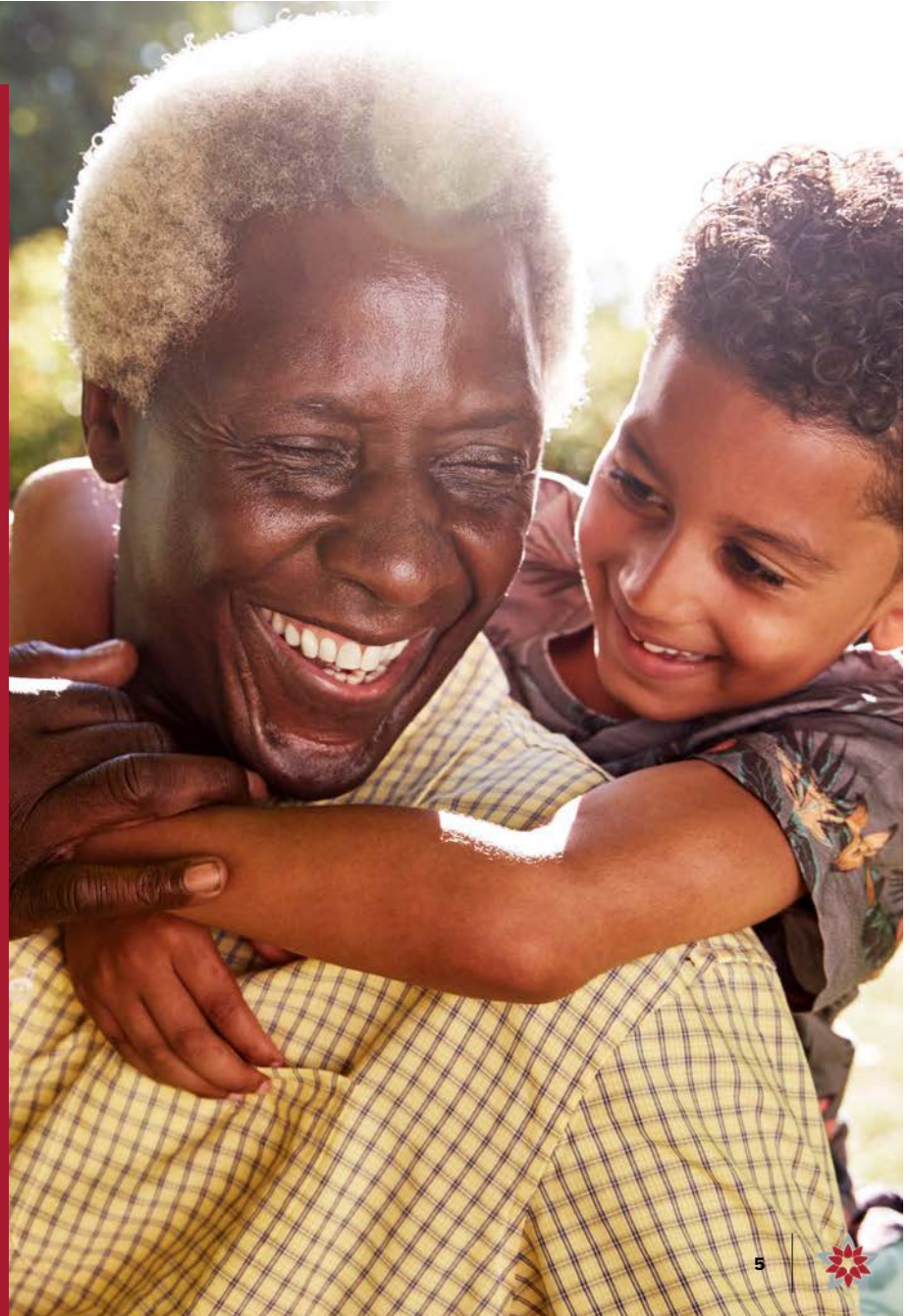
Our research priorities

As a grassroots organization, we are fully committed to improving the lives of all Canadians affected by myeloma. This commitment guides all that we do, including the decisions we make regarding our research investments.

The Myeloma Priority Setting Partnership (PSP)

The PSP was a unique project that surveyed the Canadian myeloma community to determine their top 10 priorities for future myeloma research. A pan-Canadian committee consisting of Canadians living with myeloma, caregivers, and healthcare professionals worked together through the established James Lind Alliance (JLA) process to vet over 3,000 questions before arriving at the final list. This exhaustive process included community surveys, analyses, and a consensus-building workshop.

The Myeloma PSP was supported by Myeloma Canada and representatives and researchers at the Maritime SPOR SUPPORT Unit (MSSU). The project was spearheaded by Dr Tony Reiman, medical oncologist at the Saint John Regional Hospital within the Horizon Health Network (New Brunswick) and Science Lead for the MSSU team (Saint John).



Working toward answering the prioritized top 10 myeloma research questions is of utmost importance to us and our community

1. How can we cure myeloma?
2. Are novel immunotherapies effective for the treatment of myeloma?
3. How can we improve the diagnosis (e.g., faster, less invasive) of myeloma, and what is the impact of earlier diagnosis on patient outcomes?
4. What are new treatments for myeloma patients that will improve life expectancy with fewer adverse side effects?
5. How can we personalize a patient's treatment based on their type of myeloma and genetic profile, and what is the impact of personalized medicine on treatment efficacy and disease outcomes?
6. How can we prevent bone deterioration and/or repair bones that have been damaged without negative side effects or surgery?
7. How can we safely reduce, cycle, or stop the use of medications to reduce the side effects of treatment and maintain control over myeloma?
8. How can we reduce or manage the short- and long-term effects of myeloma treatment?
9. What is the most effective way (i.e., drug combinations, sequence, frequency, and intensity) to treat refractory, relapsed, and drug-resistant myeloma?
10. Can we develop treatments specifically for high-risk or aggressive myeloma that will improve outcomes for these patients?



Our research principles

As a patient-founded, patient-driven organization, our research investment principles are anchored in the core values that support the priorities identified by our myeloma community.

Research funded by Myeloma Canada must satisfy one or more of the following principles:

- » Have a direct impact on improving quality of life and/or survival of those living with myeloma.
- » Have a direct impact on increasing access to new therapies, new treatment combinations, or improved treatment administration.
- » Contribute to improving health systems.



How we built this plan

Since it was founded in 2005 by Aldo Del Col and John Lemieux—both of whom had myeloma—community has always been the heart and soul of Myeloma Canada. It was only natural that we turned to our community for their vision of the future for Myeloma Canada, and for myeloma in Canada.

The million-dollar question

When imagining the future, we asked our PAC, support group leaders across Canada, and Myeloma Canada staff a single question:

If Myeloma Canada received a million dollars that fell from the sky, what program/initiatives would you like to see realized?

The 5-year vision

We posed a slightly different question to our stakeholders, clinicians, health policy makers, patient coalitions, pharmaceutical partners, and caregivers:

In five years, I would like Myeloma Canada to be a patient organization that does the following...

Putting it all together

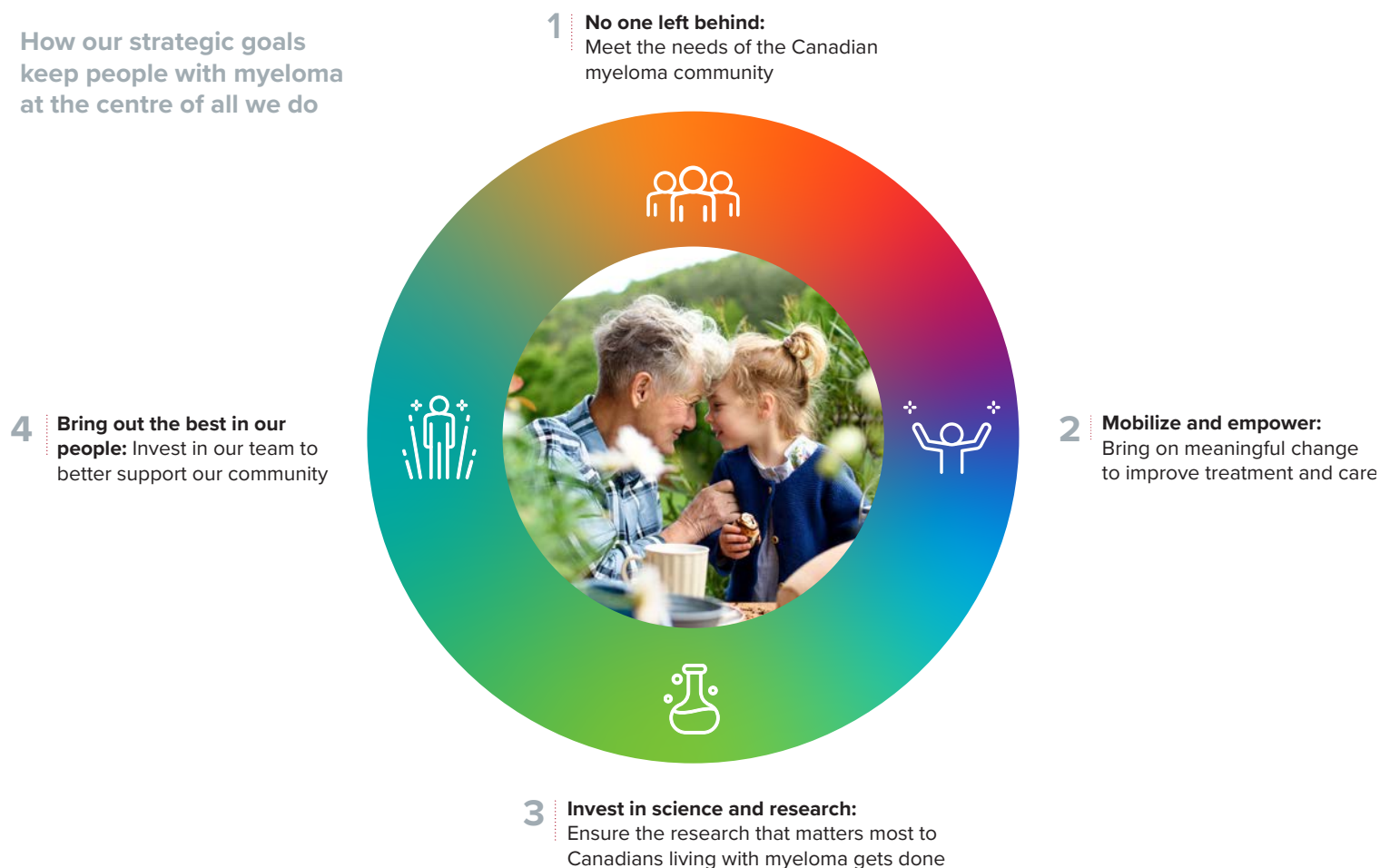
Myeloma Canada leadership and board members carefully read through the hundreds of responses we received. The answers were inspiring and challenging, but most of all, they confirmed the importance of Myeloma Canada's continued leadership and work on behalf of the broader myeloma community.

As we went through the feedback, key themes became apparent. These themes formed the basis of our four strategic goals outlined in this document; they will be the yardstick against which we will measure our current and future successes.



Our strategic goals: putting the person first

How our strategic goals
keep people with myeloma
at the centre of all we do





No one left behind

Meet the needs of the Canadian myeloma community



We are dedicated to meeting the needs of Canadians living with myeloma—and their families—by becoming their trusted resource. We will leave no stone unturned in our quest.

We will achieve this by:

- » expanding our reach and the scope of our resources to ensure that information on Myeloma Canada and myeloma is available in every Canadian hospital and cancer centre where myeloma is treated;
- » engaging with patients and their families to determine their ever-changing needs and act on their feedback to ensure that these are met through our programs and resources;
- » further developing and refining the ways we work with and support people living with myeloma to become advocates in their own treatment, care, and well-being.





How we'll know we've succeeded

- » Half of the Canadian myeloma community (people living with myeloma and their caregivers) will have been reached and will have engaged in at least one of our programs.
- » Two-thirds of those newly diagnosed with myeloma will have visited our website, signed up for our newsletter, received/downloaded our materials, or viewed our videos.
- » Our programs and services will have received excellent reviews, including high engagement scores.
- » Our programs will have had a positive impact and motivated people living with myeloma to learn more about, or be more involved in, their care.
- » We have improved our reach and impact within diverse, marginalized/under-represented, and remote populations to help them achieve better care and outcomes.
- » Patients and caregivers state their quality of life has been improved by being part of our community and our programs.





Mobilize and empower

**Bring on meaningful
change to improve
treatment and care**



We will work tirelessly to ensure accelerated access to new and existing treatments and advocate for the best care.

We will achieve this by:

- » defining best practice standards and optimal models for the delivery of treatment and care;
- » contributing to the scientific, clinical, and wider educational and developmental needs of healthcare professionals involved in myeloma patient care;
- » influencing policy design and the systems for assessing the value, benefits, and risks of new treatments;
- » proactively seeking partnerships with Canadian and international organizations to advance the care of people living with myeloma.





How we'll know we've succeeded

- » At least one of the following four provinces—British Columbia, Alberta, Ontario, Quebec—will have adopted one new best practice in improving the care of people living with myeloma;
- » Key healthcare professionals recognize Myeloma Canada as having meaningfully improved their knowledge and practice in caring for myeloma patients;
- » We have participated in at least two collaborative programs with other patient groups or organizations (local or international);
- » At least two innovative listing agreements (such as an evidence-based listing agreement or an outcome-based listing agreement based on real-world evidence) are in progress or in place.





Invest in science and research

Ensure the research that matters most to Canadians living with myeloma gets done



We will deliver on our research strategy to improve patient outcomes and overall well-being

We will achieve this by:

- » supporting the research priorities determined by our community of people living with myeloma, their caregivers, and healthcare providers;
- » providing funding to myeloma researchers* through a focused and innovative grants program, and by commissioning research projects that align with our research strategy;
- » supporting the work of the Canadian Myeloma Research Group (CMRG) as well as other research organizations that complement our objectives;
- » empowering and educating patients to become active participants in clinical trials, bio-banking, real-world-evidence research, and more.

*We will fund myeloma researchers living outside of Canada provided the research project takes place in Canada and will benefit the Canadian myeloma community.





How we'll know we've succeeded

- » Our financial support to the CMRG—and/or other research organizations—will have increased, advancing our common goals.
- » Myeloma Canada research investments will be generating research projects in line with our goals and strategy.
- » Myeloma Priority Setting Partnership (PSP) research project results will have been delivered.
- » A minimum of four innovative research grants will have been funded.
- » Canadians living with myeloma will have better knowledge about clinical research as measured by surveys and patient participation in clinical trials, where available.
- » Relevant research into equity for treatment and care for marginalized and under-represented or under-served communities and populations will have been integrated into our programs.





Bring out the best in our people

Invest in our team to better support our community



We will invest in our people, including our volunteers, to better support our diverse community and become a high-performing and sustainable organization.

We will achieve this by:

- » investing in the development of our dedicated team of staff and volunteers;
- » fostering the development of strong patient leaders and partners to advocate for the interests and rights of those living with myeloma;
- » complying with legal requirements—and following best practices in non-profit governance and management—with the objective of achieving Imagine Canada Level 2 accreditation;
- » raising sufficient funds to ensure we can deliver the programs our community needs.



STRATEGIC GOAL 4



Bring out the best in our people: Invest in our team to better support our community



How we'll know we've succeeded

- » Staff satisfaction, including engagement and empowerment, will have increased year-over-year and will be significantly above average.
- » Our team will be better at delivering our programs and supporting the diversity of our community.
- » Education and mentorship programs for all staff will have been implemented.
- » Our Patient Leader Network, made up of at least 20 well-trained advocates and patient ambassadors, will be working to influence governments and policy makers.
- » We will have achieved Imagine Canada Level 2 accreditation.
- » We will have received positive feedback from across our entire community and from our stakeholders. This will be evaluated through website analytics, social media reach, engagement, and qualitative and quantitative surveys.
- » Our organization will have a stated and demonstrated environmental, social, and corporate governance mindset.
- » We will have achieved our annual financial revenue targets while maintaining fiscally sound expenditures.



We are
committed
to achieving
our goals

Growing stronger to better serve our community

The measure of any successful organization is its ability to act on and implement change where necessary. We believe in the strength of our people; in continuous improvement; and in ensuring a responsible, flexible, and transparent organization that can adapt to the challenges it faces.

We are prepared to do what it takes—while being fiscally conscious—to ensure that Myeloma Canada achieves the goals outlined in our Strategic Plan.





**MYELOMA
CANADA**
MAKING MYELOMA MATTER



Myeloma Canada is the only national charitable organization created by, and for, Canadians impacted by multiple myeloma.
© 2022 Myeloma Canada. All rights reserved.
Charitable number 862533296R0001

For more information or to sign up for our monthly newsletter, join our community, or make a donation, please visit us at myeloma.ca