

YOUR Power. | **Your footprint** **Your IMPACT.** | **on Canadian** **myeloma research**

Myeloma Canada Impact Report
2020-2021



**MYELOMA
CANADA**
MAKING MYELOMA MATTER

www.myeloma.ca



USING YOUR POWER FOR RESEARCH

Myeloma research is advancing, and fast. The past two years have been exciting ones for myeloma innovation in Canada, and thanks to your generous investments, Myeloma Canada continues to be a catalyst to it all.

Your contributions have enabled us to invest over 1.2 million dollars in many important research initiatives, all right here in Canada! Your power is making its mark on an international scale and turning heads of the global research community.

The **PROGRESS** is real. **LIVES** are improving.
The **CURE** is getting closer.



BUILDING HOPE THROUGH RESEARCH

MYELOMA CANADA RESEARCH PRINCIPLES

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.

Myeloma Canada is committed to supporting prioritized, clinically relevant research projects that correspond to, and further, our mission. Projects in which we invest identify and address knowledge gaps in the diagnosis, treatment and science of myeloma and related plasma cell disorders, with the goal of improving quality of life and ultimately, finding a cure.

As a grassroots organization, our research investment principles are anchored in the core values that support the priorities identified by our myeloma community. As such, they must satisfy one or more of the following principles:

1. have a direct impact on **improving quality of life and/or survival**,
2. have a direct impact on **increasing access to new therapies**, new treatment combinations, or improved treatment administration,
3. contribute to **health systems improvements** for people with myeloma, or a related plasma cell disorder.

While some projects may be conducted regionally, the research impact must benefit the national, or international, myeloma community.

Myeloma Canada has been making myeloma matter since it was founded in 2005. To learn more, visit myeloma.ca.



HIGHLIGHTS: 2020-2021

MYELOMA CANADA RESEARCH INVESTMENTS

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 2020 and 2021, Myeloma Canada contributed a total of \$600,000 (\$300,000 given in each year) 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, visit their website at www.cmrg.ca

50
researchers

30
centres

From their beginnings in 2016, the CMRG has grown into a global leader in myeloma research, with over 50 researchers across 30 centres in Canada.



“Thanks to your generosity through Myeloma Canada, the CMRG is helping to bring cutting edge laboratory discoveries into clinical trials quickly and efficiently for Canadian myeloma patients. Our team of myeloma experts develop and oversee clinical trials from inception to completion. Since our founding, over 390 patients have received myeloma treatment through one of our clinical trials. Our portfolio of clinical trials continues to grow each year.”

– Dr Darrel White

Supporting the transformation of research into Real World Evidence (RWE)

***The CMRG has one
of the largest and most
comprehensive multiple
myeloma databases
in the world.***

Real time patient data is collected on an ongoing basis from multiple centres across the country.

Until recently, the province of Newfoundland & Labrador had not been able to participate locally in the CMRG National Myeloma Database due to funding constraints. Myeloma Canada is thrilled to have invested in the Healthcare Foundation of St John's and directly support the initiation of the local database research program in Newfoundland. Under the direction of Dr Debra Bergstrom, these investments will benefit Newfoundlanders and all Canadians living with myeloma.



Redefining Risk Stratification and Genetic Profiling: the future of precision medicine

We know that progression and relapse are the biggest hurdles facing high-risk myeloma patients. Comprehensive genetic profiling will help experts understand the role dysregulated enzymes (APOBECs) play in enabling myeloma to evade treatment.

Your generous investment has enabled Dr Florian Kuchenbauer, Dr Arefeh Rouhi and their team at BC Cancer in Vancouver ignite progress to break down myeloma, piece-by-piece.

Your donation is helping to support the development of disease models that study potential drugs for high-risk multiple myeloma. These samples will lay the groundwork for genetic sequencing, a better understanding of the makeup of myeloma, and for identifying effective drug combinations.

This is the first and important step in personalized, precision medicine that will hopefully lay the groundwork for a cure.



“Right now, we are isolating myeloma cells from frozen whole bone marrow samples and optimizing the culture conditions to preserve them.”

– Dr Florian Kuchenbauer

Supporting contributing factors that impact quality of life and overall survival in myeloma

Unfortunately, quality of life and overall survival is not the same for all Canadians impacted by myeloma. The important question is why? What are the factors that seem to contribute negatively to this and how can we work to improve them?

Dr Hira Mian and her research team at the Juravinski Cancer Centre in Hamilton, Ontario are working toward understanding the realities and disparities that people living with myeloma face.

Dr Mian's study, "Symptom burden in transplant ineligible patients with newly diagnosed multiple myeloma: a population-based cohort study" analyzes 15 years' worth of data from tens of thousands of Ontario database entries, taking many factors into consideration including quality of life, i.e., pain, fatigue, depression, nausea, etc. – the same as those trackable in Myeloma Canada's Myeloma Monitor application.

The study also looks at overall survival and compares variables such as age, sex, geography, socio-economic status, treatments, and more.

Given the large set of data available from the entire province, Dr Mian and her team are working on another patient-centric study, *"The impact of socio-economic factors on outcomes in newly diagnosed patients in Ontario: a population-based cohort study"*. This study will unveil highly meaningful information for all Canadians living with myeloma and highlight areas of disparities which can be targeted for future intervention.

The outcome of these two important studies may enable us to improve overall quality of life and survival rates by identifying strengths, gaps, weaknesses, and opportunities in our healthcare system, future research, and programs.

quality of life
treatments
future

patient-centric optimal care survival



“Thanks to your generous support through Myeloma Canada, these studies have allowed us to observe important factors that impact quality of life and overall survival. We are working to better understand how these variables lead to disparities in healthcare and the healthcare system and will also help us identify gaps that need to be addressed to ensure optimal care for all people living with myeloma.”

– Dr Hira Mian

Investing in unlocking mechanisms of drug resistance

Understanding why certain immunotherapies don't work in myeloma but work very well in other cancers is a key component in our quest for a cure. Unlocking this mystery is the fundamental first step in being able to tailor and design effective, non-resistant immunotherapies that could benefit anyone living with myeloma.

Dr Michele Ardolino and Dr Arleigh McCurdy from the Ottawa Hospital Research Institute in Ottawa, Ontario, along with their colleagues, may have unlocked the first clue to understanding why myeloma is so resistant. In a recent study, Drs Ardolino and McCurdy discovered that a specific kind of immune cell with high anti-cancer capacity, called 'Natural Killer cells' (or NK cells), are suppressed by myeloma cells in a quite unusual way. In fact, when an NK cell encounters a myeloma cell, the cancer cells donate part of their surface to the NK cell, potentially suppressing its anti-cancer activity.

immune
fundamental
Research
anti-cancer
Natural Killer cells



“Thanks to investments from Myeloma Canada, a translational study was conducted and showed that the phenomenon observed in laboratory animals was also true in humans with myeloma. We’re excited keep studying this phenomenon, which we believe may hold great promises in unlocking new cancer immunotherapies for myeloma. These discoveries would be a giant leap forward to understanding the mechanisms of immunotherapy drug resistance and propel additional research studies in this area.”

– Dr Arleigh McCurdy and Dr Michele Ardolino



Supporting our international leaders in allogeneic stem cell transplant research

Of all available treatments for multiple myeloma, the only one that has demonstrated a “curative-intent” to-date is the allogeneic transplantation of hematopoietic stem cells, sometimes also known as a ‘third-party’ or ‘allo’ transplant. Historically, significant toxicities and negative experiences were associated with this treatment, so allogeneic transplantation was never considered as a standard treatment.

Over the past 20 years, the Department of Hematology and Oncology at Hôpital Maisonneuve-Rosemont in Montreal, Quebec has been gaining much international recognition. Under the leadership of Dr Richard LeBlanc and Dr Jean Roy, significant expertise has been developed in allogeneic transplants for the treatment of hematological cancers, and more specifically, myeloma.

Today, thanks to ongoing research, overall results of allogeneic transplants have markedly improved. This is largely due to a combination of better donor selection, better supportive therapies, and more effective antibiotics.

Myeloma Canada is excited for the future of this ongoing important research and is proud to have once again contributed to the Myeloma Canada Research Chair in Multiple Myeloma at the Maisonneuve Rosemont Hospital to support this unique work.

expertise
leadership
allogeneic transplants

closer to a cure
tremendous progress
ongoing efforts



*“Over the last two decades, **tremendous progress** has been made to better understand this disease and develop better treatments. This progress didn’t happen by chance; **it is the result of the ongoing efforts of the entire international multiple myeloma research community.** There is however much more work to be done toward finding a cure for most multiple myeloma patients. Philanthropic giving is essential so that we have the means to participate in this collective effort. Thank you to all the donors who are enabling researchers get **closer to a cure.**”*

– Dr Richard LeBlanc

Conducting the first Myeloma Priority Setting Partnership (PSP) to identify the top myeloma research priorities

A first of its kind globally, the Myeloma Research Priority Setting Partnership (PSP) was a 4-phase project initiated in the fall of 2019.

The goal of the project was to determine the top 10 unanswered myeloma research questions defined by you, our community, under the James Lind Alliance (JLA) Priority Setting Partnership process. Our objective in supporting this important initiative was to guide Myeloma Canada's future research investments toward projects that are meaningful to our community.

The Myeloma PSP is an important and ground-breaking initiative led by a Pan-Canadian Steering Group of Canadians living with myeloma, caregivers, healthcare professionals, Myeloma Canada representatives, and supported by researchers at the Maritime SPOR SUPPORT Unit (MSSU). The project was spearheaded by Dr Tony Reiman and funded by Myeloma Canada.

We surveyed our Myeloma Canada community and received over 3,000 research questions. Through a very specific JLA process of community surveys, analyses, and a consensus-building workshop, questions were vetted and narrowed down to the Top 10 unanswered myeloma research questions.

We're thrilled to announce that the results of the myeloma PSP were formally published in the peer-reviewed British Journal of Haematology in November 2021. The paper, which documents the process and Top 10 priority questions for future multiple myeloma research, is publicly available for use on an international scale.



meaningful
community
future research



“After having completed this fulsome and formal process and on the heels of the launch of Myeloma Canada’s new research strategy, we’re excited and proud to put these research questions into action on your behalf! Thank you to everyone who participated and to all of our generous donors who will help realize your research priorities!”

– Martine Elias, Executive Director, Myeloma Canada



YOU have the POWER to keep critical myeloma research moving forward.

The proof is right here, in every research initiative we're proud to sponsor **because of you.** The power of your dollar counts and is helping to improve the lives of all Canadians impacted by myeloma.

Together, let's make myeloma matter and help find a cure for the thousands of Canadians living with this complex disease. We are very grateful for your continued support.

Thank you
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 Myeloma Canada – National Page

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