



Backgrounder for Quebec Election Campaign - 2018

Multiple Myeloma: Our Disease

Multiple myeloma, commonly referred to as myeloma, is a cancer of the plasma cells found in the bone marrow. A plasma cell is a type of immune cell that produces antibodies to fight infection. The cause or causes of myeloma remain unknown.

Every day, 8 Canadians are diagnosed with myeloma, with an average age of diagnosis in the mid-sixties. Based on the 2017 incidence rate of myeloma provided by the Canadian Cancer Society and the annual population growth projected by Statistics Canada about 290,000 Canadians alive today are expected to develop myeloma at some point in their lives. In 2017, over 680 Quebec residents were newly diagnosed with myeloma. Despite a growing prevalence, myeloma remains relatively unknown.

Although there is yet no cure, as a result of newly available drugs the disease is becoming more treatable, with many patients being able to lead full lives for many years after diagnosis. However, increased research and access to emerging treatments remains essential to improve the outlook for myeloma patients.

Myeloma Canada: Our Patient Organization

Myeloma Canada is a non-profit, charitable organization created by, and for people impacted by multiple myeloma. Exclusively devoted to the Canadian myeloma community, the organisation has been making myeloma matter since 2005. With the head office based out of Montreal, Myeloma Canada maintains a constant finger on the pulse in Quebec government affairs and makes sure to be well-informed on any developments related to health matters.

As a patient-driven, patient-focused grassroots organization, Myeloma Canada is dedicated to accelerating access to more effective therapies for Canadians living with myeloma. Myeloma Canada drives collaborative efforts to unify the voice of the community to effectively shape the Canadian treatment landscape with a committed focus on the improvement of patient outcomes.

Empowerment of patients and caregivers through educational programs advances the understanding, treatment and management of the disease. Moreover, early awareness programs promote timely diagnosis.

Since the creation of the Myeloma Canada Research Network (MCRN) in 2016, the those impacted by myeloma are benefiting from a unique platform that brings fuses clinical research and patient advocacy. In Addition to developing and supporting Canadian-designed clinical trials nationwide, the MCRN collects data for its first and only national database, a key tool in developing new treatments and an important stepping stone in our search for a cure.

Myeloma Canada ensures the patient voice is heard by actively engaging the community to take action at all levels, from clinical trial design to patient care. For more information about how Myeloma Canada is putting myeloma on the map please visit myeloma.ca.

Our Urgent Concerns:

1. Quebec patients need timely and affordable access to effective myeloma treatments. Without these treatments, patients will die. In particular, Quebec patients need immediate access to re-treatment with lenalidomide, as well as treatment with daratumumab and ixazomib. Most treatments that are proven to be effective through clinical research, have been approved by Health Canada and have been recommended for funding. However, in most cases they are still not available for patients living in Quebec.
2. Additional investments in research are needed to improve treatments and ultimately find a cure.

Our Immediate Requests to the Quebec Government:

1. Accelerate and improve accessibility to effective myeloma treatments

- The number of Quebec patients impacted by myeloma is continually increasing and several new, and potentially life-changing treatments are becoming available. These treatments need to be accessible and affordable for patients in Quebec as well as for their public payer and private insurers.
- Many of these new treatments have proven to be effective in treating myeloma. Patients need Health Canada, the pan-Canadian evaluators and the *Institut national d'excellence en santé et en services sociaux* (INESSS) to speed up the review process and approve funding in order to make them available for patients.
- Each level of the drug review process can be improved for the accessibility and affordability of new myeloma therapies by:
 - Considering patient values when determining if a drug price is affordable. Patients need to be involved in all aspects of developing any new pharmacare strategies and programs.
 - Increasing timely access by rationalizing, clarifying and bolstering the capacity of governments involved in the access process to avoid duplication, delays and unnecessary resources to review potentially life-saving therapies and by reviewing earlier data in an accelerated fashion.

2. Invest in myeloma research

- Invest more provincial funding in health research and clinical networks.
- Leverage investments and research tools that are supported by clinics and patients in Quebec. By way of example, researchers can tap into the MCRN database. This unique national database captures “real world” evidence, the data that is most sought after by decision makers and policy makers. The data captured also informs the design of Canadian-designed clinical trials and can help clinicians identify risk groups and gaps in current treatments.

3. Approve public funding for re-treatment with lenalidomide, and for treatment with daratumumab and ixazomib.