

# BUILDING AN IDEAL WORLD FOR IMPROVING PATIENT OUTCOMES IN ONCOLOGY

## Myeloma Canada's experience

MYÉLOME  
CANADA



MYELOMA  
CANADA



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## WHO WE ARE

Myeloma Canada is a registered non-profit organization created by, and for people living with multiple myeloma. As the only national organization exclusively devoted to the Canadian myeloma community, we have been making myeloma matter since 2005.

Aldo Del Col,  
Co-founder & Chairman

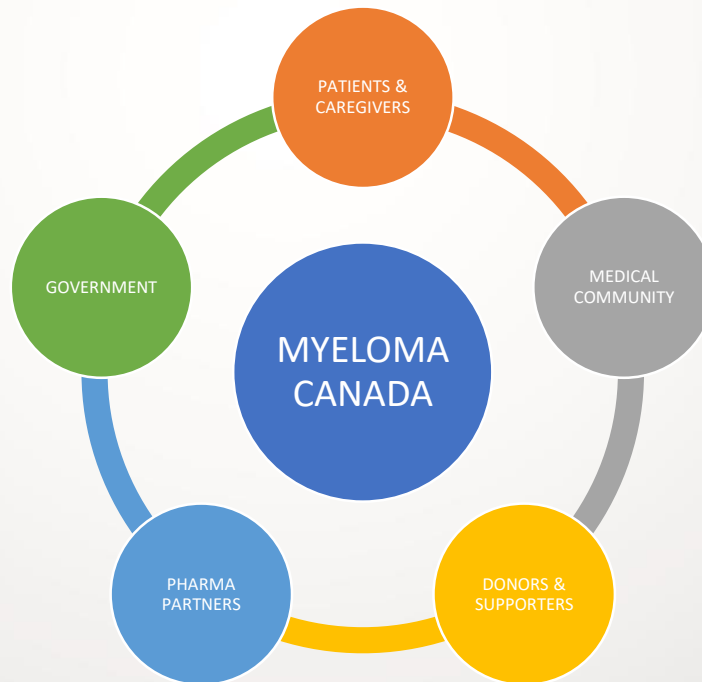


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## WHAT WE DO

### Our commitment

By making myeloma matter and unifying and strengthening the voice of the Canadian myeloma community, Myeloma Canada is putting myeloma on the map and helping improve patient outcomes.

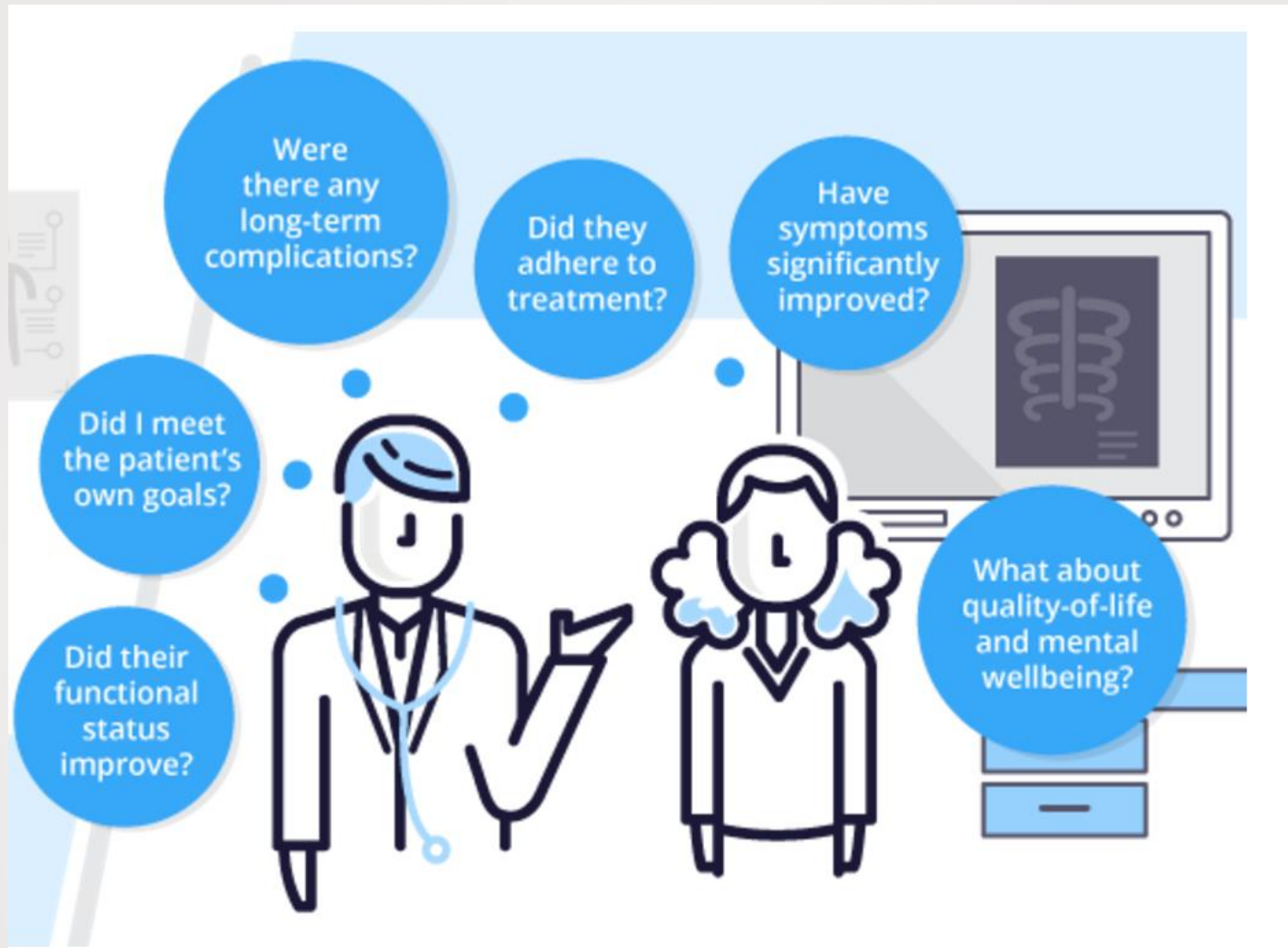


# Why patient evidence is important?

- There may only be limited evidence about the real impact of treatment on the daily lives of patients, their caregivers and the public.
- The best way to ensure that the real impact is understood is for the patients themselves (and their caregivers) to provide evidence.
- It is this unique insight that patients and patient groups can most usefully contribute to the reimbursement decision making process.
- Patients and their caregivers understand and can describe the true benefits delivered by a treatment and the real extent of the unwanted effects.



# Why patient outcomes matter to patients?



**“Patient-reported outcomes as the next frontier in quality measurement” Dr Francis Wong MD**



# Patients shaping the research agenda



# THE MCRN MISSION

As a patient organization, Myeloma Canada promotes its commitment to patient-focused clinical research in collaboration with the Myeloma Canada Research Network (MCRN).

**The mission of the Myeloma Canada Research Network is to**

- Conduct innovative Phase I and II clinical and translational research in a collaborative manner to improve patient outcomes in multiple myeloma
- Publish evidence-based and peer reviewed consensus statements on the diagnosis and treatment of myeloma
- Develop a nationwide myeloma patient database





# The MCRN is comprised of 24 centres in 9 provinces across Canada



**Bringing more clinical trials, to more patients,  
in more centres across Canada**





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# HOW DOES THE MCRN BENEFIT PATIENTS?

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- Increasing access to more trials, in more centres across Canada
- Access to new molecules or treatment combinations not yet approved by Health Canada, or not yet reimbursed
- Ensuring the patient voice is heard through patient representation on the Clinical Trial Steering Committee and the Protocol Review Committee
- Providing real-world evidence to help guide clinical decision-making, ultimately improving patient outcomes
- Promoting coast-to-coast collaboration, allowing researchers quick access to shared findings and data allowing for improved diagnosis and optimal treatment management
- Hosting clinical research in Canada may accelerate new treatment approvals



# Myeloma Canada Research Network Clinical Trials

## MCRN 001 Trial - Completed

- **Title:** A Phase II Study of Busulfan & Melphalan as Conditioning Regimen for ASCT in Patients Who Received Bortezomib Based Induction for Newly Diagnosed Multiple Myeloma Followed by Lenalidomide Maintenance Until Progression.

## MCRN 003 Trial - Recruiting

- **Title:** A single arm phase II study of high-dose weekly Kyprolis plus cyclophosphamide and dexamethasone in the treatment of relapsed multiple myeloma 1-3 prior therapies.

## MCRN 004 Trial – Recruitment to start in summer 2017

- **Title:** A randomized phase II open label, study of Daratumumab with weekly low-dose oral Cyclophosphamide with or without pomalidomide in patients with relapsed and refractory multiple myeloma.



# MCRN National Database

- A first of its kind in Canada, the MCRN Canadian Multiple Myeloma Database will inform the design of Canadian-based clinical trials and help guide clinical decision-making.
- The Database will identify different risk groups as well as gaps in current myeloma treatment approaches. By accurately assessing where we are now, we can chart the best course for future myeloma research in Canada.
- The Database, therefore, is a key component of our search for a cure of myeloma.



Dr Chris Venner, Chair of the MCRN Canadian Multiple Myeloma Database, discusses the launch of this ground breaking initiative



# Why Engage in the Development of a National Database?

- ✓ Evaluate the outcomes of multiple myeloma patients in Canada
- ✓ Identify the variances in treatments plans versus patient outcomes across Canada
- ✓ Identify the strengths and weaknesses in the management of multiple myeloma in Canada
- ✓ Understand the regional needs to provide adequate care to multiple myeloma patients
- ✓ Support the development of centers of excellence in multiple myeloma research
- ✓ Understand the impact of novel therapeutic strategies for overall myeloma patient outcomes
- ✓ Inform future clinical trial activity of the MCRN and beyond for patients in Canada



# MCRN Database: How?

- Develop user friendly data entry platform
- Log patient information *retrospectively* to better support current translational programs
- Incorporate *prospective* data entry into clinical programs to facilitate a more accurate snapshot of the Canadian therapeutic landscape at a given point in time



# MCRN Database: Principles



- Must be simple
- Must be easy to enter data
- Must be secure
- Must be easy to export data based on clinically relevant queries
- Must be usable at multiple sites
- Must be merge-able
- Must be linked with local data management infrastructure with long term commitment to the program
- Governance and steering committee



# MCRN CANADIAN MULTIPLE MYELOMA DATABASE

“Because if we don’t know how we’re doing,  
then we don’t know where we are going.”

Dr Donna Reece,  
Co-founder and Chief Medical Officer, MCRN  
Professor of Medicine, University of Toronto  
Princess Margaret Cancer Centre



MYELOMA CANADA  
RESEARCH NETWORK

MAKING MYELOMA MATTER





# What types of research questions can be asked?

- **Canadian benchmarking for current standards of care**

- CyBorD-ASCT-Len maint
- CyBorD in transplant ineligible
- Outcomes and various regimens with Pom

- **Canadian experience with new agents being introduced**

- Dara
- KRd
- IRD

- **Descriptive/translational studies of unique patient groups**

- High risk CG
- Early relapse
- Long-term survivors (>10Y)



- **Access across the provinces**

- Patterns of use (continuous vs fixed cycles, re-use or not, mechanism of access (insurance vs formulary))

- **Outcomes of patients fitting upcoming criteria for use of soon-to-be funded regimens**

- Current outcomes of double exposed/double refractory
- 1-3 prior lines
- > 3 prior lines

- **Patients reported outcomes and QoL**

- Best assessed in prospective cohort



# Challenges

- Funding
- Payer involvement
- Industry involvement
- Integrity of data and research
- Database research query process

