

# Breaking Down Barriers Together over the decades

## IMPACT

### MORE STRIDES IN RESEARCH:

When Muscular Dystrophy Association of Canada (MDAC) was founded, the causes were unknown. Over the years, doctors and scientists have identified the genes for spinal muscular atrophy; Duchenne muscular dystrophy; myotonic dystrophy type 1 and type 2; facioscapulohumeral muscular dystrophy, and limb-girdle muscular dystrophy, among many others. Every advancement contributes to developing new therapies and brings us closer cures.



**1959**

The roots of the Walk for Muscular Dystrophy begin with 269 Fire Departments participating in the 'March Against Muscular Dystrophy'.

**1960**

Six years into our existence, MDAC has 36 research projects underway at 20 medical centres across the country.



## IMPACT

### BECAUSE EVERY EXTRA MOMENT WITH A LOVED ONE MATTERS:

Life expectancy in boys with Duchenne muscular dystrophy increases from 14.4 years in the 1960s to 25.3 years in the 1990s.



## IMPACT

### DR TOSHIFUMI YOKOTA APPOINTED FRIENDS OF GARRETT CUMMING RESEARCH CHAIR,

2011: Dr Yokota researches new and innovative therapies for treating muscular dystrophy. The 'Friends of Garrett Cumming Research Chair in Neuromuscular Research' was established at the University of Alberta. Funding was raised through the efforts of the Cumming family and matched by the Alberta Provincial Government—a first in Canada!

**1992**

Dr Robert Korneluk announces the discovery of the genetic change that causes myotonic dystrophy. Results in an extremely accurate diagnostic test for the community.

**1980**

There are 22 clinics across the country. Due to these clinics, more people register with MDAC. We spend \$1.6 million on direct service—the highest amount since founding.

**1986**

Fire Fighters' contribution to MDAC exceeds \$1 million mark.

## IMPACT

### A GROUND-BREAKING CANADIAN DISCOVERY:

In 1987, Dr Ronald G. Worton and his colleagues isolate pieces of DNA from the gene that causes Duchenne and Becker muscular dystrophies, leading to the identification of the muscle protein dystrophin, an important structural component within muscle tissue.

**1956**

Three hospitals open clinics devoted to treatment of neuromuscular disorders and the expansion of therapeutic and research-based knowledge and skills.

**1954**

September 27  
Official registration of Muscular Dystrophy Association of Canada. MDAC was founded by Dr David Green and Arthur Minden. Fire Fighters take the lead in our first public campaign in Toronto—more than \$200,000 is raised.

## IMPACT

**ORGANIZATION OF MEDICAL INFORMATION IN CANADA:** The Canadian Neuromuscular Disease Registry, launches in 2011 to gather medical information to increase the understanding of neuromuscular diseases and help facilitate research and clinical trials.

**2000**

Drs. Andrea Richter, Serge Melançon, and Thomas Hudson, a research team from the Montréal General Hospital, identify the gene responsible for a rare neuromuscular disorder, Autosomal Recessive Spastic Ataxia of Charlevoix-Saguenay (ARSACS).

**2019**

Diversified research funding to include translational grants.

**2023**

MDC funds 17 research projects as well as launches multiple research initiatives that will inform Advocacy.

Together with CNDR and NMD4C, we launched a FSHD patient registry.

Walk4MD is rebranded to Walk & Roll for Muscular Dystrophy Canada and has expanded to include more than 30 virtual and in-person events.

**2024**

100% of provinces and territories in Canada practice newborn screening for spinal muscular atrophy (SMA).

**WALK&ROLL** for  
Muscular Dystrophy Canada

**100%**  
of Canada  
now screening  
newborns  
for SMA

**1998**

Dr Guy Rouleau of the Montréal General Hospital and his international team of researchers announce that they have identified the gene and the mutation responsible for oculopharyngeal muscular dystrophy. Drs. Klaus Wrogemann and Cheryl Greenberg, researchers at the University of Manitoba, announce they have located a gene associated with limb-girdle muscular dystrophy.

**2003**

We change our name to Muscular Dystrophy Canada.

## IMPACT

### RESPONDING TO OUR COMMUNITY'S NEEDS:

In 2013, Muscular Dystrophy Canada collaborates with clinicians and allied health professionals across the country to produce the first-ever Guide to Respiratory Care for Neuromuscular Disorders, which provides user-friendly information to help identify, prevent, delay and treat respiratory complications.

**2022**

MDC together with researchers from Ottawa are awarded funds to study the burden of inherited neuromuscular disorders from the Canadian Institutes of Health Research.

**2020**

3 disease-modifying therapies approved for SMA.

MDC launched the first-ever Canadian study on costs related to living with NMDs.

Added fellowship program to fund early career research and clinicians training to specialize in neuromuscular disorders.

MDC launches a multi-year, multi-phase endeavour in collaboration with Novartis Pharmaceuticals Canada Inc. to have spinal muscular atrophy added to newborn screening tests across the country, so that families can access life-changing treatments immediately.

The Neuromuscular Disease Network for Canada (NMD4C) is created to bring together the country's leading clinical, scientific, technical, and patient expertise to improve care, research, and collaboration in neuromuscular disease. NMD4C builds on existing national initiatives such as the Canadian Neuromuscular Disease Registry (CNDR), the Canadian Pediatric Neuromuscular Group (CPNG), and the former neuromuscular network CAN-NMD.