

A person wearing a bright red puffy jacket is seated in a black wheelchair, viewed from behind. Their arms are raised high in the air, reaching towards a vast, blue sky filled with wispy white clouds. They are standing in a field of tall, dry, golden-brown grass. In the distance, a range of mountains with patches of snow is visible under the bright sky. The overall mood is one of freedom, achievement, and hope.

Pushing Beyond Possible

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STRATEGIC PLAN
2017–2020



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**MESSAGE
FROM THE
CHAIR
AND THE
CEO**

We are pleased to present our new three-year strategic plan that will guide the work of Muscular Dystrophy Canada until 2020.

Entitled “**Pushing Beyond Possible,**” it builds upon the last plan and recognizes that we must work even harder as an organization, to ensure we are investing more money to support our critical mission work.

The title also reflects the incredible spirit of our clients*, the continued advancements being made by our research community, and the generous spirit of our donors.

The plan itself will focus on four key areas to fuel our work:

1. **Client-driven mission delivery** – delivering programs and services, research and advocacy that will have the greatest reach and impact on our clients and their families, researchers and clinicians.
2. **Donor-centered fund development** – enhancing annual campaigns, enhancing donor-directed programs and increasing the overall impact through mission investment.
3. **Integrated marketing and communications** – informing all areas of our work and connecting need and impact, in both official languages.
4. **Organizational Performance** – delivering excellences through all areas of our business.

*Client is defined as a person affected by a neuromuscular disorder.

Underpinning these areas, and critical to our success, is a focus on our most important asset—our people. Whether it is staff, Fire Fighters, volunteers, Healthcare providers or partners, the importance of our relationships is paramount. Therefore, we will ensure that we have empowered and inspired staff and volunteers who are even more engaged in the work of Muscular Dystrophy Canada in the years ahead.

We have set a path to evolve as an organization and transform how we work. The process that has resulted in this plan views many of the challenges we face through the lens of opportunity. We have a critical leadership role to play in the neuromuscular community; the life and work of our organization directly affects the quality of life of those we exist to serve and support.

We believe that if we keep this as the central focus of our work we can become the **trusted voice of the neuromuscular community; connecting money to mission.**

We would like to thank Board, staff, volunteers, clients, clinicians, researchers and donors who informed this plan through honest and thoughtful feedback. We hope you see yourselves reflected in the pages that follow.

We thank you for your continued support and we look forward to working with you—and making a positive impact on the lives of thousands of Canadians.



**BARBARA
STEAD-COYLE**
Chief Executive Officer



BUZZ GREEN
Chair of the
Board of Directors

*"We do things right and
we do the right things."*

EXECUTIVE SUMMARY

Our success will be defined through:

- our impact on the quality of life of those living with neuromuscular disorders
- our accountability to key donors and stakeholders
- our ever-increasing contribution to the research
- our people who are delivering excellence at all levels

"Start where you are. Use what you have. Do what you can."
— Arthur Ashe

These words serve as a guidepost for the development and execution of our new strategic plan. **"Pushing Beyond Possible: 2017-2020"** is informed by our organization's recent experiences and accomplishments; by sector best practices; and by the real and urgent needs of both those living with neuromuscular disorders, and those in a race against time to find a cure.

Every day across Canada, members of the Muscular Dystrophy Canada team interact with those who are living daily with the profound impacts of a neuromuscular disorder. At every step of the development of this strategic plan, we have asked ourselves, **"what more can we do?"**

Our answer is clear. **By 2020 Muscular Dystrophy Canada will increase its investment in mission, through more efficient fundraising practices and operations thus supporting more Canadians dealing with a neuromuscular disorder.**

The 50,000 plus Canadians living with neuromuscular disorders today have a greater life expectancy but not necessarily the expectation of a better quality of life. Emerging treatments hold great potential for improving quality of life but may be financially inaccessible to many. Promising new research and clinical trials are fast emerging and we must ensure Canadians are given access to these exciting breakthroughs—regardless of ability to pay. Critical to our success in pushing beyond possible is the need to re-align our team internally, anchor our decisions against outcomes, be innovative in our methods, engage new external stakeholders, and drive accountability at every step.

WHO WE ARE

VISION

To find a cure for neuromuscular disorders in our lifetime.

MISSION

To enhance the lives of those affected by neuromuscular disorders by continually working to provide ongoing support and resources while relentlessly searching for a cure through well-funded research.

VALUES

- Determination** We are resolute. No matter what the obstacle, we will not be deterred.
- Courage** We bravely move forward even when we are afraid or unsure of where the road will lead.
- Passion** Our enthusiasm and our appetite to learn, grow and make a difference is insatiable.
- Caring** We have genuine human concern for others. Never contrived and without a hint of pity or sympathy.

HOW WE LIVE OUR MISSION

We advocate for positive change, ensuring neuromuscular disorders are a priority for research investment and that clients have access to appropriate healthcare regardless of where they live.

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We connect with clients and their families to fill critical gaps and ensure individuals are empowered to live life on their own terms.

•

We engage and educate our stakeholders about the needs of the neuromuscular community.

•

We celebrate and thank our donors who are instrumental to moving us closer to realizing our shared vision.

UNDERSTANDING OUR ENVIRONMENT

The slowest now
Will later be fast
As the present now
Will later be past
The order is rapidly fading
And the first one
now will later be last
Cause the times
they are a-changing."
- Bob Dylan

Today's operating environment for Muscular Dystrophy Canada bears little resemblance to that of 1954, the year of its inception. Beyond change itself, the pace of change demands that our planning be not just adaptive, but anticipatory.

- **The world now relies on technology** to power systems, assimilate and deliver information, automate processes, and fuel a new way of running a business and interacting with the broader environment.
- **Donors and volunteers have more choice.** More than 86,000 charities in Canada raise money for causes that resonate with Canadians. And beyond traditional charitable causes, international humanitarian disasters and local crises reach donors in real time and spur instant philanthropy. Urgency is all around us.
- **Canadians have less money for charitable giving** and are re-shaping their philanthropy. Giving to a "good cause" is being replaced with the desire to put philanthropic dollars into action to do very specific good things.
- **Donors demand greater transparency and accountability** of charities against a backdrop of increasing suspicion that some charities aren't using donations efficiently to deliver on their missions.
- Due to advances in research, **people with neuromuscular disorders are living longer.** This means that we, as an organization, are faced with adapting to ever-changing client needs.
- **Clinical trials and emerging drugs are coming to market,** offering great promise for clients. These treatments will come with a significant cost, and we will need to understand the impact on our clients and families as well as the health system as a whole.
- **Partnerships are more important than ever,** allowing like-minded organizations to leverage opportunities, reduce redundancies and build a stronger united front on advocacy issues.

INCREASING MISSION IMPACT

"Every company faces a critical point when it must change dramatically to rise to the next level of performance. If the company fails to see and seize that moment, it will start to decline. The key is courage!"

— Andrew S. Gove,
Chairman of Intel

OUR GUIDELINES FOR CHANGE

We must:

- ✓ Accelerate our ability to adapt to the **changing needs and demographics of our clients.**
- ✓ Increase our **investment in research**; this will be achieved through revenue growth and administrative efficiencies, not through reducing services.
- ✓ **Target our mission-delivery efforts pro-actively**, in focus areas where our client market will accrue the greatest benefit. We will take our cues from our clients, families, healthcare professionals and researchers in this regard.
- ✓ Increase our investment in **research, programs and services, and patient advocacy** across the country.
- ✓ **Commit fully to the HUB model** as a core program, providing critical patient navigation supports to our clients; we must make it a central component of our operations and our fundraising. (HUB is a holistic approach to meeting the needs of clients—whether it be advocacy or systems navigation)
- ✓ **Invest in and strengthen** our partnerships such as healthcare providers, researchers, other funders and community groups.

OUR MISSION GOAL

We invest in the research, deliver holistic programs and services with the broadest reach and based in evidence, and advocate for changes in public policy that will maximize outcomes for our clients now and in the future.



What Success Looks Like

By 2020 our organization will have a strong and robust pipeline of research that will have a greater impact on those with neuromuscular disorders. Our model for programs and services will leverage systems navigation for maximum efficiency, and we will have emerged as a much stronger and more effective advocate in the arena of related public policy.

GROWING PHILANTHROPY

"In good times and bad,
we know that people
give because you meet
needs, not because you
have needs."
— Kay Sprinkel Grace

OUR GUIDELINES FOR CHANGE

We must:

- ✓ Focus on **revenue growth that ensures effectiveness and sustainability**. If done correctly we will expand our mission footprint—particularly in the areas of research investment.
- ✓ Increase **net revenue** available for mission, measuring ROI and carefully managing cost per dollar raised.
- ✓ Build **relationships** with donors, volunteers and our partners in the community to ensure success.
- ✓ **Streamline our systems**, making better use of technology and integrating industry best practices in fundraising.
- ✓ **Evaluate and adjust** every revenue stream to ensure proper ROI and benchmark against industry standards.
- ✓ Base decision-making on **analysis of data and market conditions**.
- ✓ Allocate our resources and attention to those **activities that hold the greatest promise** for growth.
- ✓ Ensure that **need and impact are connected** through meaningful storytelling.

OUR PHILANTHROPIC GOAL

We will implement a well-balanced fund development plan that is rooted in best practice and minimizes costs. We will increase donor and volunteer engagement through greater transparency, enhanced support and appropriate recognition.



What Success Looks Like

Our organization has a well-diversified, stable and sustainable fundraising program characterized by transparency and donor-centered thinking. With an expanded base of supporters nationwide, our annual cost-per-dollar-raised is low and our internal resources and attention are focused in areas of greatest fundraising priority. Our donors and volunteers are increasingly loyal to our cause and have confidence that we are utilizing their gifts wisely and for the greatest benefit for those impacted by neuromuscular disorders.

EXPANDING OUR REACH

"Donors don't give to institutions. They invest in ideas and people in whom they believe."
— G.T. Smith,
President of Davis
& Elkins College

OUR GUIDELINES FOR CHANGE

We must:

- ✓ Ensure marketing investments and activities **directly support increasing awareness of our organization's identity, purpose and value proposition.**
- ✓ Communicate a **greater understanding of neuromuscular disorders and their impact on the lives of Canadians.**
- ✓ **Unify national branded messaging**, appreciating that each region's uniqueness implies the need for some geographic customization.
- ✓ **Differentiate ourselves in a crowded market of charities**, ensuring our message reaches our targeted audiences.
- ✓ **Reflect our spirit of transparency and accountability**, reinforcing our position as a trusted charity-of-choice for Canadians.
- ✓ Root branding in our traditionally strong public associations with **Fire Fighters, volunteers, clients, families and the healthcare community.**
- ✓ Leverage technology and deliver messages **via the most effective means possible.**

OUR MARKETING GOAL

We will increase the level of public understanding of neuromuscular disorders, and of the implications for those affected in Canada. Our organization will be more widely acknowledged as a trusted, donor-centered Canadian charity working hard to improve the quality of life of those affected, and as an important contributor to finding a cure.



What Success Looks Like

Our organization's brand position is well-articulated and more broadly understood in both English and French. Our key stakeholders are more committed to us because they understand that, with their support, we are impacting more Canadians. There is a clear correlation between our improved communications capacity and increased revenue for our organization.



**EVOLVING
OUR
ORGANIZATION**

"Change will not come if we wait for some other person or some other time. We are the ones we've been waiting for. We are the change that we seek."
— Barack Obama

OUR GUIDELINES FOR CHANGE

We must:

- ✓ Adhere to Canada Revenue Agency (CRA) guidelines.
- ✓ Root decision-making in best practice and based on data.
- ✓ Maintain the mission of the organization, focusing on research, programs and services and advocacy.
- ✓ Deploy technology that is appropriate and user friendly, allowing for dissemination of information nationwide.

OUR OPERATIONAL GOAL

We will evolve our operations and infrastructure in order to realize greater efficiency, and to devote an ever-increasing proportion of our annual budget directly to our mission.



What Success Looks Like

We will be a high-performance organization that fosters a culture of continuous improvement across all functions and departments.

TRANSFORMING HOW WE WORK

"Nothing creates accountability and alignment more surely than a clear statement of the results you want to achieve."

*– Change the Culture,
Change the Game
Partners in Leadership*

OUR GUIDELINES FOR CHANGE

We must:

- ✓ Transform how we operate as an organization, re-defining how we work as both individuals and as a team; and how we achieve results.
- ✓ Strengthen our ability to monitor and manage performance.
- ✓ Clarify strategy and tactics, ensuring accountability, a smarter deployment of resources, and better communications.
- ✓ Share a common understanding of what we are working to accomplish, with well-defined and clearly aligned targets.
- ✓ Clarify and improve accountability and expectations, helping our team members be more successful in their roles.
- ✓ Structure the organization, aligning staff to the strategic priorities.
- ✓ Introduce a performance management system based on coaching and mentoring for success.
- ✓ Support a culture of openness, collaboration, individual accountability and trust.

OUR PEOPLE GOAL

Our people are connected to each other and are focused on excellence in service to our donors, clients, volunteers and partners.



What Success Looks Like

All members of our organization will understand our strategic direction, and their role in helping realize it. Staff will have clarity of purpose, sufficient support and resources and operate in a highly collaborative environment in which they know their scope of both authority and responsibility; where they are encouraged to innovate; and where they understand their performance benchmarks and organizational expectations.

APPENDIX A: HISTORY OF MUSCULAR DYSTROPHY CANADA

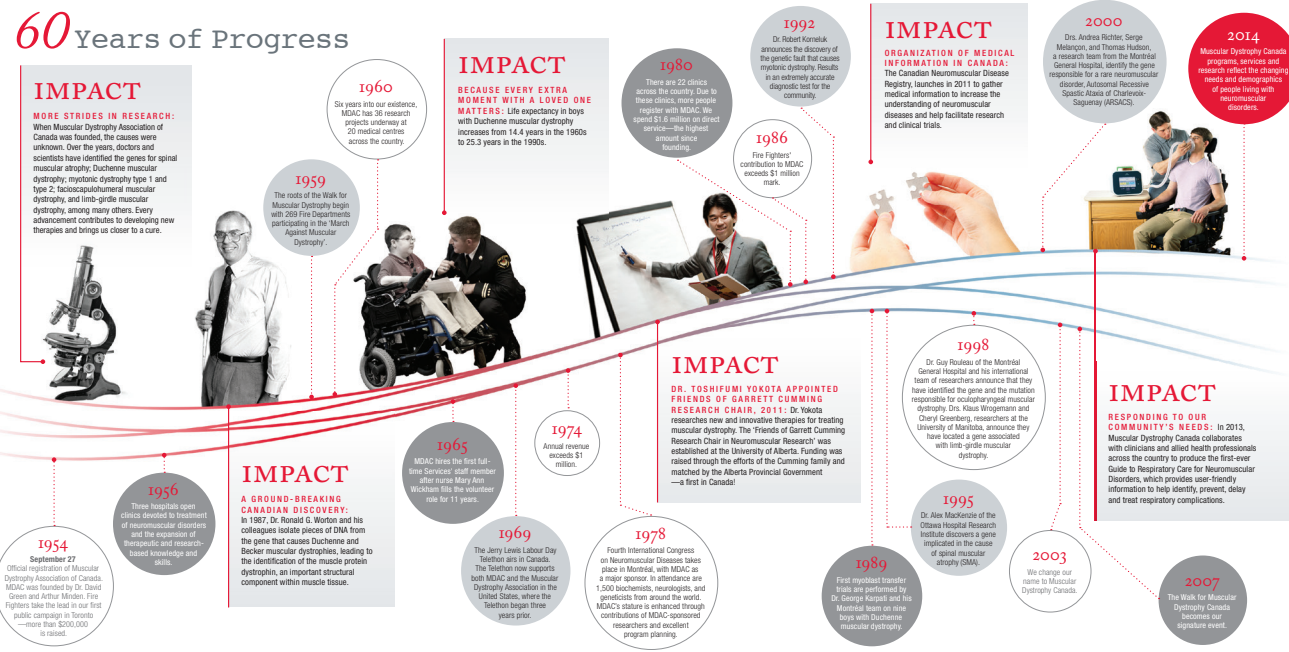
In 1954, a small group of parents with boys affected by muscular dystrophy came together to form the Muscular Dystrophy Association of Canada (later renamed Muscular Dystrophy Canada), to further research into the causes of neuromuscular disorders. Dr. David Green, co-founder of Muscular Dystrophy Association of Canada, had to face the challenge of introducing the Association into a market many felt was already overrun with charities. However, a few years later, in 1958, the Muscular Dystrophy Association of Canada would be proudly recognized as one of Canada's top 10 health organizations with a membership between 10,000-15,000 and new chapters opening up across the country every year.

Arthur Minden was co-founder with his friend, Dr. Green. He was also the first National President, holding that position for ten years, and was Chairman of the Board until his passing in 1966. During his time as President, Minden worked to involve the Fire Fighters in raising funds for muscular dystrophy. Fire Fighters came into the picture early on, initiating fundraising activities in 1954 that raised \$200,000 to fund the first six research projects. Fire departments have continued to be our strongest source of fundraising support.

Over the years, as our research efforts multiplied, we expanded our services to include education, referrals, equipment, advocacy, and ongoing peer support for those afflicted by neuromuscular disorders.

In 2000, Muscular Dystrophy Canada partnered with the ALS Society of Canada and the Canadian Institutes of Health Research in the Neuromuscular Research Partnership (NRP). This cooperative research-funding model has allowed us to more effectively use our research dollars to support a broader range of projects studying the causes, cures and treatments of muscular dystrophy and other neuromuscular disorders.

We thank all of
our committed
partners and
volunteers who
have helped us
along the way.



APPENDIX B: ABOUT MUSCULAR DYSTROPHY/ NEUROMUSCULAR DISORDERS

Muscular Dystrophy Canada supports people affected by muscular dystrophy and related muscle diseases. Together, these conditions are referred to as “neuromuscular disorders”.

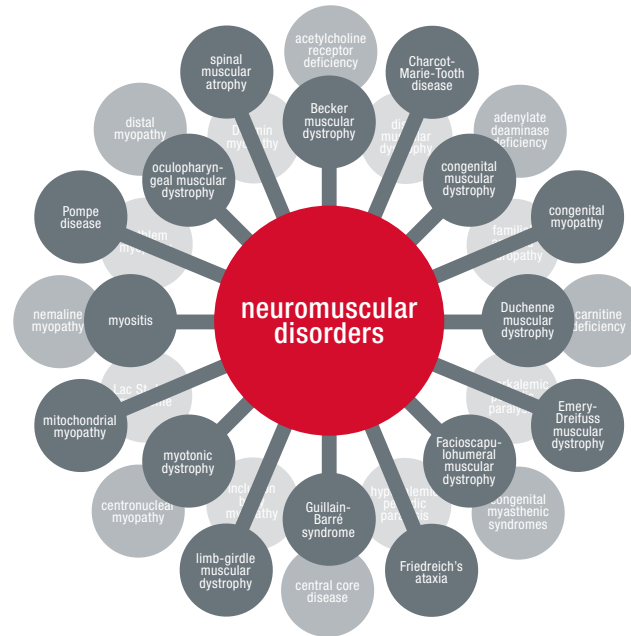
Neuromuscular disorders are a group of diseases that weaken the body’s muscles. The causes, symptoms, age of onset, severity and progression vary depending on the exact diagnosis and the individual.

Anyone can be affected. Contrary to popular belief, muscular dystrophy is not exclusively a childhood disorder. While some types of muscular dystrophy are first evident in infancy or early childhood, other types may not appear until later in life.

Most neuromuscular disorders are caused by genetic mutations. These mutations can be passed on from generation to generation, through a parent’s DNA, or they can occur in a single individual due to a spontaneous mutation.

The severity and progression will vary depending on the exact diagnosis and the individual. Most neuromuscular disorders are progressive, causing the muscles to gradually weaken over time. People diagnosed with a neuromuscular disorder may lose the ability to do things that are often taken for granted, like brushing your own teeth, feeding yourself, or climbing stairs. Some people will lose the ability to walk or even breathe on their own.

There is no cure. Medical interventions have increased the life span and improved the quality of life for many people living with neuromuscular disorders. These interventions focus on treating or delaying symptoms, enhancing physical mobility and social interactions, and preventing heart and lung complications.



Muscular Dystrophy Canada supports people affected by over 150 different types of neuromuscular disorders. This diagram shows just a fraction of the neuromuscular disorders covered by Muscular Dystrophy Canada. Disorders in dark grey bubbles are more prevalent than those in light grey. All neuromuscular disorders are considered to be rare or “orphan” diseases.