

Mission Matters

April 1, 2015 - March 31, 2016



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Muscular Dystrophy Canada. Mission Matters April 1, 2015 - March 31, 2016

Muscular Dystrophy Canada's mission is **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.**

This report provides a summary of our services activities - highlighting the work undertaken by our caring staff and volunteers working in our offices across the country between April 1, 2015 and March 31, 2016.

It is because of generous donors and the fundraising efforts of determined volunteers that we are able to offer these **exceptional services free of charge.**



WHO DOES MUSCULAR DYSTROPHY CANADA SERVE?

Muscular Dystrophy Canada provides support to people of **all ages and backgrounds** who are affected by **164 different types of neuromuscular disorders.**

The complete [list](#) is posted online.

We also support family members, friends, employers, educators and health care professionals with information, resources and community programming.

You are invited to join our Canada-wide community

Connect with people and stay informed

Sign up today

www.muscle.ca/we-can-help



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Financial Assistance

Muscular Dystrophy Canada enables people with neuromuscular disorders to lead independent and healthy lives by helping them obtain assistive devices.

Many people with neuromuscular disorders rely on assistive devices to aid in activities of daily living. The high cost of these devices can be a significant financial burden for individuals and families, especially if public or private health coverage is limited or unavailable.

Muscular Dystrophy Canada's longstanding and respected equipment funding program helps alleviate undue financial pressures by contributing towards:

- Mobility aids - power and manual wheelchairs, walkers and scooters
- Seating and position aids - specialty cushions, power tilt and lift chairs
- Orthopaedic devices - leg braces, AFOs and orthopaedic splinting
- Access equipment - stair glides, porch lifts and ramps
- Hospital beds and pressure-relief mattresses
- Breathing aids - ventilators and respiratory devices

This year, our direct investment of \$1,055,000.00 helped 497 Canadians to purchase 659 medically-prescribed assistive devices with a retail value of \$3,612,000.00.

QUESTION: How can I access the Equipment Funding Program?

ANSWER: The program is open to all residents of Canada who have a neuromuscular disorder and meet the program's eligibility criteria. To find out more, call us at 1.866.687.2538 to speak with member of our Services team. Or visit us online at www.muscle.ca/we-can-help to download the [Application Form](#).



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Financial Assistance Impact – Western Canada

Thank you so much for approving and funding my request for a mobility scooter. As my form of muscular dystrophy progressed, I came to accept my health decline as a "new normal" for me. I found myself staying home, turning down my children when they wanted to go on excursions, and generally withdrawing from my life. An opportunity arose for me to volunteer with March of Dimes. Problem was, their meetings were in Toronto. (I live in Calgary.) I attended one meeting and requested a wheelchair at the Toronto end. It took over one and half hours for someone to come and wheel me to baggage claim. In fact, I missed my accessible taxi - just because of the long assistance wait at the Toronto airport.

By the time my second Toronto meeting occurred, I had received my lightweight mobility scooter. What a miracle! No longer dependent on airport staff, I completely regained my independence and trip went off without a hitch! Believe me; your funding of the scooter has made a real difference in my life. Can you believe I will actually be able to go Christmas shopping with my kids and won't have to wait for them on the mall bench?!

I am extremely grateful to Muscular Dystrophy Canada, particularly the staff members who made it all happen for me. Also, to Canada Safeway which continues to support Canadians with muscular dystrophy. You are helping people live richer, fuller, more meaningful lives. Please accept my gratitude for the mobility scooter; and, thank you for the meaningful work you continue to do!

Person Affected by a Neuromuscular Disorder from BC.



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Support

Our passionate Services team provides support to the community in many ways. They:

- Attend **pediatric and adult neuromuscular clinics** to support patients and work collaboratively with **health care providers**
- Raise awareness about best practices and ways to prevent and treat respiratory complications
- Offer opportunities for people affected by neuromuscular disorders to **build a community of support** through events like Family Retreats and Bridges to the Future Youth Transitions Program, social and recreational events, and activities such as the Walk for Muscular Dystrophy 
- Answered **10,515 phone calls and e-mails** during the last year, providing support and information to people affected with neuromuscular disorders, family members, caregivers and healthcare professionals
- Provide individuals with support and tools to help them to advocate and navigate the complex health and social services systems. With this personalized assistance, our clients have succeeded in:
 - Achieving better health outcomes and preventing unnecessary secondary health complications
 - Obtaining relevant current information to make better informed decisions
 - Accessing primary health care, including respiratory care services, therapies and equipment
 - Advocating for services to meet personal care needs; and recruiting professionally trained, qualified attendant care
 - Ensuring children are appropriately supported in schools
 - Securing and maintaining appropriate housing and home care services
 - Accessing respite services for parents and caregivers



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Support Impact – Ontario/Nunavut

System Navigation Testimony Ontario/Nunavut

Meet the Ginnasio Family,

The Ginnasio family is a hard working lovely family. Michael Ginnasio is a four year old boy who was born with a very rare disorder, merosin-deficient congenital muscular dystrophy. He is a bright, intelligent and kind hearted child. Like many families affected by neuromuscular disorders, the Ginnasio family reached out to Muscular Dystrophy Canada frustrated, exhausted and overwhelmed.

Sandra, Michael's mother shares *"We find that we are constantly fighting for insurance coverage, or for appointment times that best suit our schedules, for appointments that aren't four months down the road, for goals in school and therapy that make sense. We feel as if we have to fight for everything and it is truly not fair"*.

The system navigation support is more than a referral or sharing resources. It is working directly, in partnership, with people affected by neuromuscular disorders to assist in accessing supports, to access the right service or support at the right time. It alleviates the burden for the individual and or their family. We have heard from our pediatric and adult populations, it is exhausting accessing services and supports due to wait long times, complicated application processes, lack of awareness related to neuromuscular disorders etc. Muscular Dystrophy Canada has staff that have solid skills in health care, community systems etc., formal relationships with service providers to address wait times concerns, and years of experience dealing with application processes etc. We know there is a need and the Ontario/Nunavut Region is best positioned to take a key role in providing assistance with navigating and accessing services and supports throughout any point of time, whether it be at the time of diagnosis, when needs change etc.

”

Stacey Lintern, Executive Director Ontario and Nunavut.

Sandra, Michael's mother also shares *"We are asking for assistance to make our lives LESS stressful"*.

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Examples of Muscular Dystrophy Canada system navigation supports provided to the Ginnasio family included:

- Worked with Michael's school to address concerns
- Worked with the family to access funding resources
- Worked with the family to connect with other families
- Worked with the family to enhance awareness and share information with allied health care providers



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Advocacy

Muscular Dystrophy Canada is passionate about influencing positive change!

We work together with other like-minded organizations and use our collective voices to identify issues and influence positive changes at the local, provincial and federal levels to influence systemic changes to health care and social services across Canada.

In 2015/2016, we contributed to 32 partnerships and collaborations focused on issues concerning tens of thousands of constituents.

Advocacy Impact

Western Canada

In Manitoba, Muscular Dystrophy Canada took the lead in establishing the Physical Disabilities Coalition of Manitoba (PDCM). Their Mission is “A united voice of organizations that support adults with physical disabilities in Manitoba” and their objective is to “Advocate for inclusive, meaningful, and affordable community-based services for adults with physical disabilities.”

Their goals include:

- Identifying gaps & barriers experienced by adults with physical disabilities
- Including organizations across Manitoba representing adults with physical disabilities
- Influencing policies and practices affecting adults with physical disabilities
- Creating awareness of both formal and informal services and supports

The organizations currently in the Coalition are: ALS Society of Manitoba, Cerebral Palsy Association of Manitoba, Manitoba League of Persons with Disabilities, MS Society of Canada, Muscular Dystrophy Canada, Parkinson Canada, Physiotherapy Association of Manitoba, Massage Therapy Association of Manitoba, Community Respite Services and Occupational Therapists Association of Manitoba.

Currently the PDCM has been working on getting health services (Physical Therapy, Occupational Therapy and Massage Therapy) covered for those who have physical disabilities, chronic debilitating diseases and/or life limiting diseases.

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Ontario/Nunavut

The Ontario region continues to have a concerted focus on partnerships and collaborations with like minded organizations that influence positive change, have the broadest reach with greatest impact, address barriers and recommend and implement creative innovative sustainable solutions. For example, Muscular Dystrophy Canada is working in partnership with the government, 5 service providers and legal consultants to address concerns related to access to primary care in hospital and community settings for people who are living with chronic and progressive disorders. The scope of this partnership includes children and adult populations. Muscular Dystrophy Canada has played various key roles in this partnership that have included: a lead in bringing key stakeholders together, providing evidence data to highlight concerns, sharing best practices to investigate sustainable solutions. To date outcomes have been positive. That have included: changes in health care delivery in Ontario, review and revisions of service caps and revisions of policy. This work translates to better services/supports for our community.

Atlantic

Across the country, employment rates for working age persons with a disability (15 to 64) are significantly lower than those without a disability and they are faced with serious disadvantages in the area of education and training. Regardless of the disability type or the province you live in, there are many common challenges and obstacles to overcome to reach ones full potential when living with disability. There is an identified need to create a dialogue around future planning and career goals with youth with disabilities and particularly those with complex needs. Much work is needed to dispel the myth that persons with disabilities are not employable and to challenge the mindset of youth with disabilities themselves and their caregivers/family.

Muscular Dystrophy Canada has taken steps to address this issue and has taken a leadership role with a partnership with the New Brunswick Disability Executives Network. This past year we raised the importance of this issue with the four Atlantic provincial governments. We have been successful in securing funds from three Atlantic Provinces to host Youth in Action Atlantic, a summit on life transitions and personal leadership for youth with a disability in Atlantic Canada. Youth in Action Atlantic will be a cross disability summit for youth living with a disability. The summit website is www.yia-aj.ca



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The conference has multiple goals. These will include:

- Creating a dialogue among youth with disabilities
- Empowering and inspiring youth to reach their full potential
- Supporting youth in achieving transition to post secondary education
- The development of employment goals

Key agenda highlights will be career exploration, post-secondary education supports and options, independent living, creating healthy relationships and transition to work planning.

Quebec

Muscular Dystrophy Canada is not the only organization to be challenged in these times of reorganization of the healthcare system and rationalization of expenditures.

The old saying, “strength in numbers”, expresses the need for Muscular Dystrophy Canada to unite with other organizations that share the same concerns in order to reach common goals and gain a better understanding of the current issues we all face. To this end, Muscular Dystrophy Canada has joined with the Quebec Division of the Multiple Sclerosis Society of Canada, the Quebec Federation of Alzheimer Societies, Parkinson Quebec and the Quebec ALS Society. In Quebec alone, our organizations represent 25,000 people with Parkinson’s disease, 6000 with amyotrophic lateral sclerosis, 125,000 with Alzheimer’s disease, 15,000 with muscular dystrophy and 20,000 with multiple sclerosis.

On October 29, 2015, these organizations were at the National Assembly to discuss the common needs of the 191,000 people they serve. They emphasized the need for injecting more resources in the health system and the importance of housing resources that meet the needs of adults with decreasing autonomy, access to care and medicines, as well as support for relatives.

Each of these strategic partnerships demonstrates the excitement and passion that exist to make our world more inclusive for those affected by neuromuscular disorders. Stay tuned for more!

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Information and Education

We are determined to raise awareness about neuromuscular disorders and provide individuals and their families, allied health professionals, employers, educators and community partners with information and educational opportunities. In 2015/16, we:

- Conducted 79 presentations focused on raising awareness about neuromuscular disorders and disabilities reaching over 1,934 participants
- Distributed 3,231 information packages
- Continued to circulate publications in English and French to support people affected by neuromuscular disorders by providing timely and relevant information

Education Impact – Atlantic

Information and Education-Atlantic Family Retreat

The 2015 Atlantic Family Retreat was a profound success in meeting our goals of building lasting connections, providing education and peer support opportunities for families and children impacted by neuromuscular disorders. New connections were created among families from all four Atlantic provinces; a first in our experience in hosting these events. Thanks to the generous support of Lawton's Home HealthCare, the exclusive funding partner for the retreat, Muscular Dystrophy Canada was able to continue hosting this important event and increase participation from prior years to include families with adults living with neuromuscular disorders. The 2015 Family Retreat was filled to capacity with roughly 120 individuals comprised of 25 families, Muscular Dystrophy Canada staff, Lawton's Home HealthCare Staff, educational presenters from Neuromuscular Clinics from across Atlantic Canada, local Fire Fighters and volunteers. As with every event we do, a strong emphasis was placed on education and learning. Sessions included topics such as Family Dynamics when dealing with disability, Real Life Rehab, Youth leadership and Adapted Recreation.



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About Our Passionate Community Networks and Chapters

Community Volunteer Chapters and Networks are the grassroots component of our organization made up of 28 local groups from coast to coast, who come together to support each other, create awareness and raise funds to support our mission. This year, across the country:

- 1,902 people attended 127 networking events
- 515 people attended 16 Educational Forums
- 3,711 points of contact were made with clients
- 220 requests for financial assistance were granted through Community Services Funds



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Questions?

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A Special Thank You to Our Donors

For more than 60 years, you have been helping us provide help, hope and possibilities to people living with neuromuscular disorders. From golf tournaments to raffles, to Fire Fighter rooftop campouts and boot drives, to individual, corporate and foundation partners, you have all invested in helping people live longer and better. Your contributions empower people to advocate for themselves and their family members, help them access the health care and other services they need, buy life-saving and life-enhancing mobility and accessibility devices, and enable us to invest in leading research.

We honour and appreciate the passion and commitment of our dedicated supporters.

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