

# WHERE YOUR MONEY GOES

YEAR IN REVIEW 2021-2022

## Research

- Invested \$1.3 million to fund: nine new clinical and translational science research projects through our **Neuromuscular Disorder Research Grant Competition**; five fellowships (see next bullet); and, other projects so talented and dedicated Canadian researchers can develop new methods for disease diagnosis, uncover novel insight into disease pathogenesis, and develop new treatment options.
- Partnered with the Neuromuscular Disease Network for Canada (NMD4C) and the Canadian Society of Clinical Neurophysiologists, to fund three **national clinical fellowships** in neuromuscular medicine and electromyography, and two **national post-doctoral fellowships** in neuromuscular research ensuring top-ranked researchers receive funding and early-career scientists can conduct studies focused on NMD research.
- MDC partnered on multiple national and international team research studies, namely the **BIND study** with researchers and health economists in Ottawa and Calgary to study the indirect socio-economic cost of living with inherited NMDs; and, the GrowDMD study with teams from Canada, Germany and Italy to study patient experiences and systems to optimize care for transition to adulthood.

## Advocacy

- Spearheaded an **Advocacy Advisory Committee** by bringing together 19 stakeholders from the neuromuscular community to help us work towards inclusive policies that reflect and respect Canada's diversity, value the neuromuscular experience and are accessibility-focused.
- Thanks to a partnership with **Novartis Canada** and our unwavering supporters, our advocacy efforts resulted in Alberta, Saskatchewan, Manitoba, Yukon, and Nunavut joining Ontario in screening newborns for spinal muscular atrophy (SMA); Quebec, New Brunswick, Nova Scotia and Prince Edward Island are in the planning stages.
- Funded a first-of-its-kind project to evaluate the cost-effectiveness of newborn screening for SMA in Canada, including early treatment. The innovative national project, led by a team at the **Children's Hospital of Eastern Ontario**, will provide vital evidence for policy and decision-makers.
- Partnered with **Independent Living Canada** to equitably consult with individuals, organizations and stakeholders across disabilities to help inform the development of Canada's first Disability Inclusion Action Plan.

# Programs & Services

- **420 individuals** affected by neuromuscular disorders registered with MDC, an increase of 5% over the previous year; there was a 61% increase in assistive devices and equipment provided to Canadians; and, we increased the funds directed towards mission activities by 54% to ensure programs and support services were available for everyone who needed them.
- Launched the AccessAbility Program, sponsored by the **Canada Post Community Foundation**, to shift the classroom setting for students and educators by incorporating information and resources on disabilities, accessibility, inclusion and equity, and develop a digital storybook through which students can share their personal neuromuscular stories.
- Signed a **Statement of Intent** with Muscular Dystrophy UK, Muscular Dystrophy Australia and Muscular Dystrophy Foundation of South Africa to help break down barriers for individuals living with neuromuscular disorders, worldwide.

## Philanthropy

- **Events continue to be hosted virtually** with much success thanks to our committed event participants, donors, sponsors and volunteers.
- **Funds raised increased by 20%** helping us rebuild toward pre-pandemic fundraising revenue totals and ensured the needs of the NMD community continued to be met.
- **Fire Fighters** started rebuilding community Fill The Boot campaigns to increase funds raised, and are well on their way to pre-pandemic fundraising levels. MDC is hugely grateful for the dedication and commitment of Canadian Fire Fighters.



## HOW IT HAPPENED

Put simply, Muscular Dystrophy Canada has amazing supporters, volunteers, donors, sponsors, partners, Fire Fighters, staff and board members. The passion that these people have for breaking down barriers for the neuromuscular community is unparalleled, and we count ourselves very lucky to be on this mission, together, with them.

### In 2021-2022, we:

- **Teamed up** with NMD4C, and the Canadian Society of Clinical Neurophysiologists to offer fellowships and research grants for the most-promising studies, and ensure incredible advances continued to take place.
- **Collaborated with** local, provincial and federal governments, industry partners, healthcare and Canadians affected to identify inefficiencies, inconsistencies and gaps in policies and programs so that sustainable solutions and meaningful positive change for the neuromuscular disorder community could be created.
- **Partnered with** like-minded organizations, government and healthcare professionals to coordinate expertise and develop shared infrastructure to lower administrative costs, increase our mission expenditures and positively impact the lives of more Canadians affected by neuromuscular disorders.
- **Worked with** Fire Fighters, volunteers and supporters to find new ways to raise funds and lower administrative costs, to have the greatest impact possible on the neuromuscular community.