



DEFEAT
DUCHENNE
CANADA

STRATEGIC PLAN

2024-2028

VISION

A future without Duchenne.

MISSION

Defeat Duchenne Canada is the country's only national charity dedicated to ending Duchenne muscular dystrophy.

Our goal is to provide leadership in research, advocacy and support to ensure every Canadian affected by Duchenne muscular dystrophy can live long and active lives.

VALUES

Focused - Everything we do is to help every person affected by Duchenne.

Determined - We can make change happen.

Inclusive - Diversity makes us stronger.

Collaborative - We achieve more when we share knowledge.

Trustworthy - We tell the truth and keep our word.

STRATEGIC PRIORITIES

Our overarching goal is to enhance the quality of life and extend longevity for all Canadians impacted by Duchenne muscular dystrophy. Our five-year strategic plan is centered around forging strong partnerships with key stakeholders, including government agencies, healthcare providers, researchers, donors, corporate partners, and, most importantly, families.

Working collaboratively, we will make a positive impact by focusing our efforts on four strategic pillars; *Research, Advocacy, Education & Support and Community Engagement.*

4 STRATEGIC PILLARS



Research

Goal: Solidify Defeat Duchenne Canada’s position as an international leader in funding innovative research and improving outcomes of all Canadians diagnosed with Duchenne muscular dystrophy.

Advocacy

Goal: Secure robust federal and provincial support, enabling Defeat Duchenne Canada to drive significant advancements in research, treatment and care through legislation and regulatory initiatives.

Education & Support

Goal: Deliver comprehensive education and unwavering support to individuals living with Duchenne, their families, and healthcare professionals, with the ultimate aim of ensuring consistent and optimal standardized care.

Community Engagement

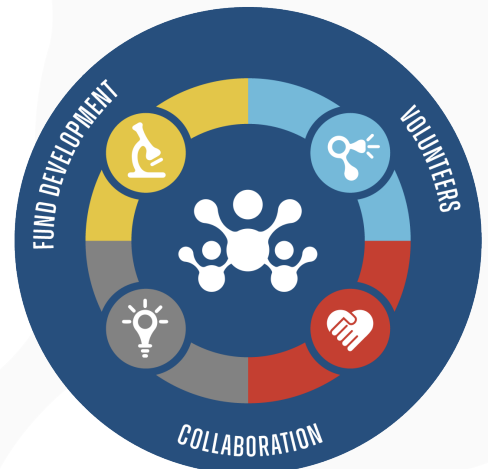
Goal: Cultivate a strong and inclusive “family of families” dedicated to raising both awareness and crucial funds for research, care and support.

ENABLING STRATEGIES

Fund Development - Without the generosity of our individual and corporate donors and collaborating partners, there would be no way for us to achieve our strategic objectives.

Volunteers - Dedicated volunteers make all the difference! By donating their time and talent, they enable us to make the impactful difference we strive to make, everyday!

Collaborators - As a small charity, focused on making a big impact, we rely on the support of key collaborators with common goals and values to strengthen our collective voice.



GOALS, OBJECTIVES, TACTICS AND SUCCESS MEASURES BY STRATEGIC PILLAR:



RESEARCH

Solidify Defeat Duchenne Canada’s position as an international leader in funding innovative research and improving outcomes of all Canadians diagnosed with Duchenne muscular dystrophy.

OBJECTIVES (what)	PROPOSED TACTICS (how)	SUCCESS 5 YEARS (at the end of this strategic plan)	SUCCESS 10 YEARS (at the end of the next strategic plan)
<p>Develop and launch a research strategy that will improve outcomes of all people diagnosed with Duchenne muscular dystrophy</p>	<ul style="list-style-type: none"> • Work with Research and Duchenne Family Advisory Committees to clearly define our approach to research • Investigate co-funding opportunities with similar organizations worldwide • Investigate creation of commercial funding model. Create policies to guide decision making and process. • Seek and find appropriate bench funding • Research fellowship/ infrastructure support for next generation of researchers/clinicians • Introduce an Innovation Fund to encourage risk-taking in research approaches that may result in breakthroughs • Support and provide input to enhance Canadian Neuromuscular Disease Registry (CNDR) 	<ul style="list-style-type: none"> • Research strategy to support the drug development pipeline and innovative therapies from discovery through approval to national access, implemented • Enhanced support for pre-clinical and academic research focused on root cause -restore or replace dystrophin and symptoms • Funding innovative projects designed to significantly change outcomes in Duchenne muscular dystrophy (DMD) • Funding next generation of scientists/clinicians to ensure sustainability and interest in Duchenne muscular dystrophy (DMD) 	<ul style="list-style-type: none"> • Variety of treatment options approved and accessed in Canada targeting replacement/restoration of dystrophin (gene therapy, CRISPR, exon skipping, etc.) • Variety of treatment options approved and accessed in Canada targeting symptoms of Duchenne (fibrosis, heart function, inflammation, etc.) • Strong international relationships with “like” patient advocacy organizations



RESEARCH

OBJECTIVES (what)	PROPOSED TACTICS (how)	SUCCESS 5 YEARS (at the end of this strategic plan)	SUCCESS 10 YEARS (at the end of the next strategic plan)
<p>Become an international leader in Duchenne research</p>	<ul style="list-style-type: none"> • Consult with patients, clinicians and researchers to invest in the development of novel treatments and clinical trials aimed to improve outcomes for all Duchenne Muscular Dystrophy patients • Lead quarterly pharmaceutical meetings • Gather and share quarterly updates from current funded researchers • Develop and deliver Research Webinars • Update, promote and maintain best in class Clinical Trial Finder Tool • Develop a research-focused communication strategy including strategic partnership communications (Neuromuscular Disease Network for Canada-NMD4C, Canadian Neuromuscular Disease Registry-CNDR, World Duchenne Organizations-WDO) • Host an annual research symposium for researchers, clinicians, and families 	<ul style="list-style-type: none"> • Forge strong relationships with all bio-pharmaceutical companies working on Duchenne Muscular Dystrophy • Families feel informed about the latest bio-pharmaceutical and clinical trial resources (Clinical Trial Finder Tool) • Regular reports sent to donors on research progress • Monthly updates provided by all industry and research consortium partners • Advancements made in Canadian government research funding 	<ul style="list-style-type: none"> • Earn national and international recognition from key players in the Duchenne muscular dystrophy community, as a leader in advocating for and funding pioneering transformative research and discoveries



ADVOCACY

Secure robust federal and provincial support, enabling Defeat Duchenne Canada to drive significant advancements in Duchenne research, care and treatment through legislative and regulatory initiatives.

OBJECTIVES (what)	PROPOSED TACTICS (how)	SUCCESS 5 YEARS (at the end of this strategic plan)	SUCCESS 10 YEARS (at the end of the next strategic plan)
<p>Establish National Advocacy Infrastructure to increase strength of our unified voice</p>	<ul style="list-style-type: none"> • Create a national Advocacy Network/Committee comprised of family advocates and a consortium of Canadian rare disease experts • Create a robust national network of well-trained and highly engaged Advocacy Ambassadors 	<ul style="list-style-type: none"> • Members of Advocacy Network/Committee are actively engaged in external committees with like-minded organizations to facilitate timely information sharing and allow for quick and nimble response to rapid changes in Rare Disease/ Duchenne Muscular Dystrophy landscape and legislative/procedural changes • Improved reimbursement process to ensure affordability of treatments for all Canadians • Rare disease drug strategy to include incentives to encourage more applications to Health • Defeat Duchenne Canada representation on CORD (Canadian Organization for Rare Disease) board of directors 	<ul style="list-style-type: none"> • Overall investment of \$10 million made into Duchenne research Consulting with patients, clinicians and researchers to invest in the development of novel treatments and clinical trials • Equitable access and affordability of treatments across Canada • Annual government funding commitment to Duchenne research (\$3 million/year) as part of collaborative research investment



ADVOCACY

OBJECTIVES (what)	PROPOSED TACTICS (how)	SUCCESS 5 YEARS (at the end of this strategic plan)	SUCCESS 10 YEARS (at the end of the next strategic plan)
Advance Advocacy Efforts and Access to Care	<ul style="list-style-type: none">• Conduct research about Provincial health care systems/benefits to develop impactful provincial advocacy strategies• Leverage Patient Standards of Care manuscript in advocacy efforts to push for the changes required to ensure acceptable Standards of Care are available to all Canadians, particularly those transitioning from youth to adulthood• Launch lobby/marketing campaign “Time is Muscle” to advocate for timely access to current medications• Lobby Federally and Provincially to improve stand	<ul style="list-style-type: none">• Pathways to timely access established• Standards of Care met or exceeded in minimum 5 provincial Centres of Excellence• Access to safe and effective treatments available in European Union/United States US	<ul style="list-style-type: none">• Standards of Care met or exceeded in every Canadian province/territory



EDUCATION & SUPPORT

Deliver comprehensive education and unwavering support to individuals living with Duchenne, their families, and medical professionals, with the ultimate aim of ensuring consistent and optimal standardized care.

OBJECTIVES (what)	PROPOSED TACTICS (how)	SUCCESS 5 YEARS (at the end of this strategic plan)	SUCCESS 10 YEARS (at the end of the next strategic plan)
<p>Evaluate, and grow programs, resources, services and develop new programs to ensure the needs of all families are met</p>	<ul style="list-style-type: none"> • Develop a toolkit for newly diagnosed • Create a Blog (contributors - staff, clinicians, researchers, family, etc.) to enhance information sharing and support • Investigate the potential for a 1:1 phone call support service (Health Care Professionals) • Develop a peer support program for families – parents teens/adults • Expand webinar series • Grow sponsorship revenue for education • Explore the opportunity to hold an Annual family and clinician conference • Explore traveling family workshops (3-4X year – different provinces) 	<ul style="list-style-type: none"> • Newly diagnosed families receive their toolkit and 1:1 phone call within 10 days of diagnosis (initiation of family journey) • Grow pharmaceutical and corporate sponsorships to \$400,000 to support mission delivery • Peer Support Program in place for families or teens • Hold at least one traveling family workshop annually 	<ul style="list-style-type: none"> • Grow industry and corporate sponsorships to \$600,000 to ensure strategic mission objectives can be fully executed • Peer support programs in place for caregivers, teens and adults with Duchenne Muscular Dystrophy • Hold 4 traveling family workshops annually across Canada



EDUCATION & SUPPORT

OBJECTIVES (what)	PROPOSED TACTICS (how)	SUCCESS 5 YEARS (at the end of this strategic plan)	SUCCESS 10 YEARS (at the end of the next strategic plan)
<p>Improve patient outcomes and drive positive change in healthcare</p>	<ul style="list-style-type: none"> • Create data sharing process with clinic leads/Canadian Neuromuscular Disease Registry- CNDR • Hold Healthcare Professionals Conference (in collaboration with key collaborators) • Work with all pediatric and adult neuromuscular care centres to achieve World Duchenne Organizations - WDO accreditation • Develop relationships with neuromuscular healthcare professionals across Canada (pediatric & adult) • Develop and nurture relationships with national/international Duchenne patient organizations • Serve as leaders in generating education and support initiatives for families and healthcare professionals • Play key role in developing Patient Standards of Care Manuscript (with partners- Neuromuscular Disease Network for Canada, Muscular Dystrophy Canada) 	<ul style="list-style-type: none"> • All clinics will have ample supply of Defeat Duchenne Canada marketing material on display/distributed • Process in place to track % of Duchenne Muscular Dystrophy patients referred to Defeat Duchenne Canada through clinics across Canada • Defeat Duchenne Canada lead educational materials for healthcare professionals being delivered in sites across Canada 	<ul style="list-style-type: none"> • All neuromuscular care centres are certified with World Duchenne Organization’s Accredited Duchenne Centres Program • 100% of patients attending clinics are referred to Defeat Duchenne Canada • 90% of patients contact Defeat Duchenne Canada • 80% of patients engage in Defeat Duchenne Canada’s education and/or support programs • Duchenne Muscular Dystrophy patients in all provinces able to access equitable and standards of care, as per Patient Standards of Care Manuscript (with focus on transitions from youth to adulthood)



COMMUNITY ENGAGEMENT

Cultivate a strong and inclusive “family of families” dedicated to raising both awareness and crucial funds for research, care and support.

OBJECTIVES (what)	PROPOSED TACTICS (how)	SUCCESS 5 YEARS (at the end of this strategic plan)	SUCCESS 10 YEARS (at the end of the next strategic plan)
<p>Strengthen the connection between Defeat Duchenne Canada and Duchenne families across Canada</p>	<ul style="list-style-type: none"> • Develop a national engagement plan • Create a family “Journey “Map. Serve as a connector to ensure families can access the information and services they need, whether it be through Defeat Duchenne Canada or other support organizations • Improve collection and reporting of stakeholder data • Create family engagement structure definitions and RE tracking process • Develop family communications plan • Increase stakeholder engagement with pediatric and adult neuromuscular care staff across Canada (annual clinician outreach, data update on staff changes, survey on resources needs, etc.) • Develop a national award program to appropriately acknowledge key contributors (volunteers, fundraisers, etc.) 	<ul style="list-style-type: none"> • Families guided and supported through engagement opportunities based on their individual needs and interests from first point of contact through multiple engagement points and opportunities • Family/stakeholder data is collected and used to guide interactions and deepen engagement 	<ul style="list-style-type: none"> • All families supported from diagnosis onward • Family/stakeholder data used to create customized engagement plans



COMMUNITY ENGAGEMENT

OBJECTIVES (what)	PROPOSED TACTICS (how)	SUCCESS 5 YEARS (at the end of this strategic plan)	SUCCESS 10 YEARS (at the end of the next strategic plan)
<p>Increase exposure and reach of Defeat Duchenne Canada through marketing initiatives to increase awareness of DMD, support more families, boost the brand and amplify trust</p>	<ul style="list-style-type: none"> • Create national annual awareness campaigns for Rare Disease Day, Duchenne Awareness Month, World Duchenne Awareness Day • Work with agency of choice on one digital marketing campaign per year • Amplify storytelling with new family submission process • Stakeholder survey on brand, tools, and website 	<ul style="list-style-type: none"> • Increased number of family members at each level of the engagement structure (i.e., Contact, Engaged and Ambassador) • Reach 50% of Canadian family units affected by Duchenne MD (400 Canadian Neuromuscular Disease Registry-CNDR) • Being a known voice for healthcare, families, government and industry (“go to organization”) • Increase e-newsletter subscription • Increase number of social media followers • Increase number of social media engagement • Increase number of website users 	<ul style="list-style-type: none"> • Reach 100% of Canadian family units affected by Duchenne muscular dystrophy (800 Canadian Neuromuscular Disease Registry-CNDR)



COMMUNITY ENGAGEMENT

OBJECTIVES (what)	PROPOSED TACTICS (how)	SUCCESS 5 YEARS (at the end of this strategic plan)	SUCCESS 10 YEARS (at the end of the next strategic plan)
Reach unprecedented heights in fundraising	<ul style="list-style-type: none">• Execute, evaluate and renew the National Philanthropy Plan• Continue to innovate and build our signature Walk to Defeat Duchenne event• Develop tools and pathways to promote and support family and community events• Work in collaboration with the Business Development Committee to grow corporate partnerships• Create strategies to enhance and grow Individual and monthly giving• Develop and execute plan to grow legacy and planned giving• Enhance direct mail fundraising campaigns• Develop and execute comprehensive Donor communications and stewardship plan/matrix• Form and work in partnership with Development Committee	<ul style="list-style-type: none">• Raise \$1.7M• Create new philanthropy plan through to 2027• Donor journey is developed and refined	<ul style="list-style-type: none">• Raise a combined 5 million dollars a year from all existing and new revenue sources



COMMUNITY ENGAGEMENT

OBJECTIVES (what)	PROPOSED TACTICS (how)	SUCCESS 5 YEARS (at the end of this strategic plan)	SUCCESS 10 YEARS (at the end of the next strategic plan)
Engage stakeholders across Canada by implementing a national Volunteer Program	<ul style="list-style-type: none"> Identify volunteer opportunities across all lines of business Lead the creation and management of a national volunteer program Lead the development, implementation and evaluation of a national engagement plan 	<ul style="list-style-type: none"> Culture of volunteerism ingrained across the organization and all program areas 18 active Advocacy volunteers 8-10 active Research committee volunteers with pipeline to consistently maintain engagement levels Community volunteers engaged as members of board committees Growth in the number of families engaged 	<ul style="list-style-type: none"> Active, trained volunteer advocates in every Province Volunteers working in partnership with staff in support of all mission-related activities

Commonly Used Acronyms:

DMD - Duchenne Muscular Dystrophy

DDC - Defeat Duchenne Canada

RFAC - Duchenne Canada’s Research Funding Advisory Committee

DFAC - Duchenne Canada’s Duchenne Family Advisory Committee

CNDR - Canadian Neuromuscular Disease Registry

NMD4C - Neuromuscular Disease Network for Canada

WDO - World Duchenne Organization