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DEFEAT DUCHENNE CANADA: SCALING UP A CHARITABLE ORGANIZATION

Robert Mackalski, Mary Dellar, and Marc Ducusin wrote this case solely to provide material for class discussion. The authors do not intend to illustrate either effective or ineffective handling of a managerial situation. The authors may have disguised certain names and other identifying information to protect confidentiality.

So much is owed to John Davidson. Without him, there would be no money for the cure; there wouldn't be a community of support. We've come from zero to promise. We will find a cure for this savage disease.

Perry Esler, chief executive officer, Defeat Duchenne Canada

Perry Esler knew his organization was at a crossroads. As the chief executive officer of Defeat Duchenne Canada, Esler led the charge to broaden the charitable initiative beyond its home base of London, Ontario, Canada.[1] His goal was to reach a national audience. Originally founded in 1995 as Jesse's Journey, the organization underwent extensive rebranding in February 2022. The rebranding efforts were intended to widen fundraising efforts for Duchenne muscular dystrophy efforts to find a cure, expand community support, and advocate to key stakeholder groups. Duchenne was a rare but fatal condition that affected one in 5,000 boys, with no known cure. It was the most aggressive form of muscular dystrophy. Duchenne required mobility aids, home accessibility modification, expensive medication, physiotherapy treatment, and surgical procedures to combat the disease's debilitating effects. Medical research and funding were vital to bring the world closer to finding a cure, and advocacy was instrumental in ensuring patient access to treatment.

Esler and his team knew they wanted to do more for the Duchenne community outside London. They had to advocate for families across the country, whose lives had been changed forever by this devastating condition. The organization wanted to scale up operations to best develop awareness of the disease and secure much-needed research funding and treatment access. However, with limited resources at their disposal, where should the team's efforts be focused to generate the greatest impact? Which stakeholders merited the most attention? Ultimately, how should the organization scale up operations? With a new brand, Defeat Duchenne Canada had a wider platform for its powerful message and life-changing mission. Although the relative rarity of Duchenne tended to belie its severity, the organization's fight against this devastating condition was renewed with a wider-reaching vision.

[1] With a population of 425,000, London was roughly located between Toronto and Chicago; "Census Profile, 2021 Census of Population, City of London," Statistics Canada, accessed July 22, 2022, https://www12.statcan.gc.ca/census-recensement/2021/dp-pd/prof/details/page.cfm?Lang=E&SearchText=london.

THE JESSE'S JOURNEY STORY

"This is the story of a father who wanted to do something for his son," Esler said of the genesis behind the organization. The idea was born in 1995, when John Davidson pushed his 15-year-old son Jesse's wheelchair 3,300 kilometres across Ontario from April to September to raise funds and awareness for Jesse's condition. Their journey raised CA$1 million.[2] By the end, people were lining the sides of the road to cheer on the father-and-son team. In 1998, to generate buzz outside the London, Ontario area, Davidson embarked on a solo 268-day trek of 8,272 kilometres that earned the Guinness World Record for the fastest crossing of Canada on foot.[3] The feat raised over $2 million and launched the Jesse Davidson Foundation.

The act of walking across the province, and later the country, had special symbolic meaning to anyone affected by Duchenne: a progressive muscle-wasting disease that started at the bottom of the feet and moved up the ankles toward the heart and lungs. People diagnosed with Duchenne typically needed a wheelchair when they reached their teenage years and often lost the use of their arms several years later. The rare condition afflicted specifically children and adolescents (see Exhibit 1). It almost exclusively affected boys, although mothers tended to be carriers and the genetic mutation could afflict multiple children in a family. Some patients developed the disease as a result of a spontaneous mutation of the dystrophin gene that occurred randomly for unknown reasons.[4] At the time of the Davidsons' walk across Ontario, life expectancy for people afflicted with Duchenne was in the late 20s, although many boys did not live past their teens. In 2009, Jesse Davidson himself managed to reach the maximum longevity expectations of that time, surviving until age 29.

The Davidson family's inspiring story resonated emotionally by putting human faces to the name of a little-known disease. The success and exposure of the two walks gave the organization tangibility and an impetus that it would not otherwise have had. Yet, its work was still mainly known within the Ontario region. Ken Wilson, the organization's board director and chair of the marketing advisory committee, observed the limited public awareness of the Jesse's Journey brand and of Duchenne itself. As the father of a boy with Duchenne, Wilson became involved with the organization after seeking resources for his family:

> When you are dealing with a rare disease, you start out dealing with an awareness issue. Everyone has heard of and been impacted (directly or indirectly) with cancer. But Duchenne muscular dystrophy? Not a chance. We had also never heard of Jesse's Journey; perhaps we would have if we lived where Jesse's Journey took place. After our son's diagnosis, when we were looking for information on Duchenne muscular dystrophy, there were no pamphlets at the local hospital about Jesse's Journey; its website was not showing up in Internet search results. I literally joined another organization's board of directors as a volunteer for a few years to help in any way I could. Eventually I did come across Jesse's Journey, but I asked, "Who is Jesse and what journey is he on?" I recognized that for it to be a true resource for families dealing with this horrible disease, that the organization had to have a name that was a quick get.

Defeat Duchenne Canada was thus born to rebrand the organization with a national voice, focus, and presence. The new name emphasized action, building on the language employed by actual families who saw first-hand their boys' strength in battling the disease. The tagline, "Fight for Our Boys," reinforced this proactive attitude, uniting listeners with a rallying cry that stressed inner fortitude and resilience as much as any physical strength. Crucially, the rebrand had to respect the story and legacy of Jesse Davidson and

[2] All currency amounts are in CA$ unless otherwise specified.
[3] "Awards and Honours," The Right Road with John Davidson, accessed July 20, 2022, http://www.therightroad.ca/awards.htm.
[4] "Rare Disease Database: Duchenne Muscular Dystrophy," Nord, accessed July 22, 2022, https://rarediseases.org/rare-diseases/duchenne-muscular-dystrophy.

pay homage to the organization's roots. The tribute to Jesse remained visible through the Jesse Davidson Foundation and events like the annual Walk to Defeat Duchenne. Most significantly, the rebranding from Jesse's Journey to Defeat Duchenne Canada preserved the spirit of the Davidsons' story while expanding the narrative from one family to a whole community, from a single journey to a nationwide fight.

A MISSION OF HOPE

When the organization was called Jesse's Journey, its focus was simply on raising money for research. With the rebrand of Defeat Duchenne Canada, the ultimate aim was to find a cure. The strategic plan to achieve this goal consisted of four interrelated pillars: 1) research funding, 2) advocacy, 3) education, and 4) resource development.

Through these four main types of offerings, the organization aimed to become the go-to resource for all things related to Duchenne. In addition to raising funds, Defeat Duchenne Canada's activities, such as its annual Walk to Defeat Duchenne, were also important ways of generating awareness and shining a light on the community of families affected by the disease. The organization further advocated for access to treatment in Canada. "We're a patient advocacy organization," Esler emphasized. "If we want to be the best at what can do for this community, fundraising and philanthropy [are] how we will meet that and how we will be able to do more."

Defeat Duchenne Canada thus stood apart from other organizations, such as Muscular Dystrophy Canada (MDC), which concerned muscular dystrophy generally and had different priorities. Esler did not view MDC as a competitor, and Defeat Duchenne Canada did not receive any funds from MDC. However, the two organizations had partnered for funding research in the past.

As noted on the Defeat Duchenne Canada website, the Canadian Neuromuscular Disease Registry reported that around 800 boys and young men in Canada were living with Duchenne.[5] Defeat Duchenne Canada was the nation's only registered charity devoted specifically to their needs. The organization's national database included 349 families currently affected by the disease. Among those families, 312 had sons living with Duchenne and in the other 37 families, children had died from the disease.

Behind these statistics were the families of newly diagnosed boys who came to the organization with hope. Their experiences attested to the disease's devastating effects and the urgent need for research. Wilson spoke candidly of the "utter shock" that he and his family felt when their son was diagnosed:

> We had never heard of the disease, and as our pediatrician was telling us about it, our vision for our son's future came crashing down. Once the shock wore off, we channelled the sorrow we were experiencing and "leaned in" and started researching all of the medical advances happening, and there were several promising ones. Medical research equates to one word for us—*hope*. We hope our son has the chance for a better life than the current trajectory. We hope that he is able to realize some of his own dreams. We hope that he outlives us. Hope is all we have, and we will do everything possible to try to translate hope to a cure—or at least a better life.

Boys diagnosed with Duchenne began their lives like any other neighbourhood kid—brimming with energy, dreams, and their own unique interests. Some excelled at sports or music, while others were budding scholars or class clowns. Some were even prodigies in their own fields. For example, one young hockey prodigy, Deccan Gill, was a member of the Defeat Duchenne Canada community. Deccan was diagnosed

[5] "About Duchenne," Defeat Duchenne Canada, accessed December 22, 2022, https://defeatduchenne.ca/about-duchenne.

with Duchenne at age three and garnered national attention for his athleticism and spirit.[6] With assistance and treatment, boys like Deccan could graduate from school and earn a university degree.

Although scientists had yet to find a cure for Duchenne, steroids were commonly used to counter the disease's muscle-degenerating effects. These treatments, however, had serious side-effects, often causing weight gain and sometimes stunting or limiting growth, depending on the complexity of the disease and the individual mutation. As a result of the disease and its treatment, boys with Duchenne were often physically smaller than their peers. The additional psychological and behavioural side-effects prompted some parents to opt out of treatment.

Available treatments were not perfect, but they had advanced significantly over the previous decade, as more pharmaceutical companies started clinical trials in Canada and around the world. Canada faced the additional complexity of pending approval to some medications that been already approved in the United States and United Kingdom. Pricing structures also impacted access to treatment for families affected by Duchenne.

Describing the financial toll of Duchenne on a family, Esler said that the costs increased "as the child begins to mature, and you start thinking about a new home or retrofitting the home you're in. Maybe it's the $80,000 van you have to purchase, [or] the wheelchair goes from a basic wheelchair to a motorized, to a stand-up. . . . It's those living expenses as the boys become young men and age into the process."

Clinical visits also imposed challenges. Some patients had to travel across the country for clinical trials outside the family's home town. Despite the cumulative difficulties and costs incurred by the disease trajectory, Defeat Duchenne Canada ultimately offered a life-affirming message of determination and hope on the horizon.

The main events held by the organization aligned with its four pillars. Representing the first pillar, the annual research grant announcement in June unveiled the organization's plans to direct investments and donations toward the most innovative and promising research. This event gave the donors, volunteers, and family a chance to learn about the research being funded. The recipients and amounts were approved by the research advisory committee and family advisory committee. Since 1995, approximately $16 million had been used to fund 56 different projects worldwide.

Under the remaining three pillars—education, advocacy, and resource development—the organization hosted a special event called Family Forum. The annual event was held in person before the outbreak of the COVID-19 pandemic in March 2020, and then virtually after restrictions on public gathering were mandated. This event helped families learn from researchers and doctors about the latest research, care developments, and resources. The Family Forum further also offered families with Duchenne a sense of support, which they had not previously been accustomed to receiving.

The largest fundraising and awareness event was the annual Walk to Defeat Duchenne, which united families, stakeholders, and their networks to created teams for participation in the walk and fundraising through peer-to-peer connections. Walk to Defeat Duchenne started as a London area event and was expanded to several communities across the nation. The event raised approximately $250,000 each year. Since its start in the 1990s, the Walk to Defeat Duchenne saw participants travel to Ontario to walk with John Davidson himself.

[6] Merella Fernandez and Ben Cousins, "Five-Year-Old Leafs Fan Impresses His Idols and Fans Alike with Hockey Trick Shots," CTV News, May 31, 2021, https://www.ctvnews.ca/lifestyle/five-year-old-leafs-fan-impresses-his-idols-and-fans-alike-with-hockey-trick-shots-1.5450791.

During the pandemic, the event went virtual and participants across the country were encouraged to walk safely anywhere in their local community. By 2022, the event had grown to approximately 400 participants nationwide, with groups coast-to-coast walking in their own communities.

Overall, Defeat Duchenne Canada generated an average of $1.1 million in annual revenues, comprising donations and earned interest by the Jesse Davidson Foundation. In recent years, more than half of total annual revenues was interest earned by the Jesse Davidson Foundation. That money was required to support research, which meant that the bulk of earned revenue went to research. Specifically, approximately 66 per cent of the average annual $1.1 million revenue went to research, 6 per cent to advocacy, 10 per cent to education, and the remainder was divided among resource development, philanthropy, special projects, and administration.

Within the previous few years, the organization's advocacy work had forged important relationships with some pharmaceutical companies; however, it had yet to partner with any major corporations. Current sponsorships included a local pizza franchise in London, but little effort had been dedicated to securing a major national corporate sponsor. Attention from a national corporation could potentially benefit the organization, but it would require dedicating limited available time and resources, which would detract from other efforts. Nonetheless, the organization's efforts had borne encouraging results to date.

Thanks to research conducted over the years, the life expectancy of people with Duchenne had risen. Rochelle ten Haaf, the organization's national director of marketing and stakeholder engagement, noted that early diagnosis and better care had allowed young men with the disease to survive into their 30s—sometimes up to their early 40s. She referred to one researcher, the president of the SickKids Foundation, who hoped to change the language describing the disease from "life-shortening" to "life-threatening." She also expressed the potential of early treatment to prolong life and make Duchenne more manageable. These advances fuelled optimism, according to ten Haaf, "We believe medical advances will one day even render the condition preventable. And while day-to-day progress may be slow, we know that we can win in the long run."

THE GLOBAL FIGHT AGAINST DUCHENNE

Defeat Duchenne Canada was not alone in the worldwide fight against the disease. Many of its counterpart organizations around the world were similarly initiated by the families of boys and young men with Duchenne. The US initiative CureDuchenne was founded by two parents, Paul and Debra Miller, and was focused on research. It had raised more than US$50 million.[7] The organization also generated funding through venture philanthropy through its fundraising arm called CureDuchenne Ventures. Since 2014, this venture had garnered over US$2.3 billion from pharmaceutical, biotechnology, and venture capital companies.[8]

Another US organization called Parent Project Muscular Dystrophy was focused on advocacy. It worked closely with clinics to impact federal policy, demand optimal care and coverage for families, and ensure access to therapies approved by the United States Food and Drug Administration (FDA).[9] Parent Project Muscular Dystrophy had a string of advocacy successes that included health care reforms for affordable access, insurance benefit cap removals, coverage for pre-existing conditions, newborn baby screening infrastructure, and access and coverage to FDA-approved treatments. Some of its annual revenue (over US$5 million in 2020) also went toward research funding.[10]

[7] "Founder's Message," CureDuchenne, accessed July 28, 2022, https://www.cureduchenne.org/about/founders-message/.
[8] "Ventures," CureDuchenne, accessed July 22, 2022, https://www.cureduchenne.org/ventures/.
[9] "Ongoing Initiatives," Parent Project Muscular Dystrophy, accessed July 28, 2022, https://www.parentprojectmd.org/advocacy/ongoing-initiatives.
[10] "Ongoing Initiatives," Parent Project Muscular Dystrophy.

Duchenne UK and Duchenne Australia had broader scopes and operated with a similar model to that of Defeat Duchenne Canada. These organizations spread their resources across education, philanthropy, advocacy for the Duchenne community, and research toward a cure. Duchenne UK was founded by two mothers, Emily Reuben and Alex Johnson, who had combined their separate organizations.[11] Its revenues were divided between research, education, fundraising, and management, similar to the four pillars of Defeat Duchenne Canada's efforts. Duchenne Australia's three founders were likewise parents of sons with Duchenne. Their organization also emphasized four pillars: care and support, awareness and education, research and data, and advocacy and collaboration.[12]

These organizations and several others were members of the World Duchenne Organization, an umbrella organization that disseminated information about different initiatives and activities in the global fight, including conferences and fundraising projects.[13] This worldwide community of advocates spoke to a need for increased resources and greater awareness about the rare form of muscular dystrophy known as Duchenne.

CHALLENGES

The relative rarity of Duchenne led to low levels of awareness in the community, which made it challenging to create a national campaign across Canada. Esler and his team saw the narrative and messaging components as key factors, but they wondered, "How do we make the story impactful, so it matters to the average person on the street?"

The US organization CureDuchenne was able to reach a vast audience thanks to support from high-profile celebrities such as the popular musician Justin Bieber. However, Defeat Duchenne Canada lacked a famous figurehead or celebrity spokesperson to draw public attention to its message and efforts. The organization relied on word-of-mouth promotion as the most relevant driver for publicity. Most stakeholders tended to learn about the organization from friends, but this method failed to connect affected families to resources they required from the start of the disease.

As ten Haaf noted, Defeat Duchenne Canada needed to reach patients and their families from the outset of the disease trajectory. The organization could then advocate for them and serve their needs from the beginning. From a marketing perspective, she confirmed that the organization had established a "connection with health care stakeholders across our country. We've done a decent job at connecting with new families through our education and fundraising initiatives, but certainly we need to do more to get to them at the point of diagnosis. . . . We need our health care professionals to have our backs, to say that we're there to support the family upon diagnosis for all their emotional, psychosocial needs, [and for] education about the disease and managing it for the future."

For example, pediatric neurologists were in a particularly good position to inform patients about Defeat Duchenne Canada as a valuable resource. Stronger relationships with the health care system overall would help validate and promote the organization's work, ensuring that its message would reach the target audience at the optimal time to make a difference.

Other considerations were necessary for a national campaign. The organization's fundraising efforts had been fruitful, but donation fatigue was an ongoing issue without outcomes from research funding being clearly demonstrated.

[11] "Our Team," DuchenneUK, accessed July 22, 2022, https://www.duchenneuk.org/our-team-and-trustees.
[12] "Our Approach," DuchenneUK, accessed July 22, 2022, https://www.duchenneaustralia.org/our-approach.
[13] "Welcome To WDO," World Duchenne Organization, accessed July 22, 2022, https://www.worldduchenne.org.

Esler acknowledged that they still had a long way to go, while reiterating a firm sense of purpose and communal solidarity. "We're not yet raising nearly enough money to do all the things we want to do to help as many Duchenne families as we can," he remarked. "We're not going to get there [by] raising $900,000 a year."

LOOKING AHEAD

Defeat Duchenne Canada had come a long way from Jesse's Journey. What began as a father and son's trek across Ontario to the nation's capital had grown into a multi-million-dollar organization raising awareness throughout Canada, funding crucial research, and uniting a community of families to advocate for their access to treatment and resources.

With so much at stake in the fight, the rebranded initiative had to weigh the impact versus the effort of its choices. How might its resources best be used to generate the maximum impact? How should the various types of stakeholders be prioritized and mobilized? What was the best way to scale up operations for Defeat Duchenne Canada?

A celebrity supporter could help heighten awareness, whereas national sponsors could increase funding. Improved outreach to the Canadian health care system could facilitate access for families to information and resources, but so might a campaign to government policy-makers. A social media campaign could also prove effective. Any of these efforts would strain the organization's limited resources, which made it critical to prioritize efforts.

Esler and his team had to determine the best approach for the new brand. Their goal was to defeat a debilitating condition that affected patients from boyhood to adulthood. However, their work was a marathon, rather than a sprint.

EXHIBIT 1: COMPARATIVE INCIDENCES OF SELECTIVE DISEASES AFFECTING CHILDREN AND ADOLESCENTS IN CANADA

Child or Adolescent Disease	Incidence per 10,000 People	Condition
Autism	100	Heterogeneous neurodevelopmental conditions, characterized by early-onset difficulties in social communication and unusually restricted, repetitive behaviour and interests, that tends to affect males more than females
Cancer (Child or Adolescent)	35	Large number of diseases characterized by the development of abnormal cells that divide uncontrollably and have the ability to infiltrate and destroy normal body tissue
Celiac Disease	70.9	Immune reaction to eating gluten, a protein found mostly in grains, with intestinal damage that often causes diarrhea, fatigue, weight loss, bloating and anemia, and that can lead to serious complications
Cystic Fibrosis	3 (Caucasian) 8 (non-Caucasian)	Inherited disorder that causes severe damage to the lungs, digestive system, and other organs in the body
Diabetes (Type 1)	19.5	Chronic condition in which the pancreas produces little or no insulin (also known as juvenile diabetes)
Diabetes (Type 2)	12.5	Long-term (chronic) condition resulting in too much sugar circulating in the bloodstream, with high blood sugar levels potentially causing circulatory, nervous, and immune system disorders
Duchenne Muscular Dystrophy	20 (Boys) 0 (Girls)	Rapidly progressive, x-linked, lethal neuromuscular disorder, present from birth, which occurs almost exclusively in males
Inflammatory Bowel (Crohn's Disease plus Ulcerative Colitis)	77	Chronic inflammation of the digestive track usually characterized by diarrhea, rectal bleeding, abdominal pain, fatigue, and weight loss
Multiple Sclerosis	100	Potentially disabling disease of the brain and spinal cord (central nervous system)

Source: Created by the case authors based on Meng-Chuan Lai, Michael V. Lombardo, and Simon Baron-Cohen, "Autism," *The Lancet* 383, no. 9920 (2014): 896–910, https://doi.org/10.1016/S0140-6736(13)61539-1; Elizabeth Ward, Carol DeSantis, Anthony Robbins, Betsy Kohler, and Ahmedin Jemal, "Childhood and Adolescent Cancer Statistics, 2014," *CA: A Cancer Journal for Clinicians* 64, no. 2 (2014): 83–103; "Cancer," Mayo Clinic, accessed July 22, 2022, https://www.mayoclinic.org/diseases-conditions/cancer/symptoms-causes/syc-20370588; Alberto Rubio-Tapia, Alberto, Jonas F. Ludvigsson, Tricia L. Brantner, Joseph A. Murray, and James E. Everhart," The Prevalence of Celiac Disease in the United States," *Official Journal of the American College of Gastroenterology* 107, no. 10 (2012): 1538–44; "Celiac Disease," Mayo Clinic, accessed July 22, 2022, https://www.mayoclinic.org/diseases-conditions/celiac-disease/symptoms-causes/syc-20352220; Michael R. Kosorok, Wen-Hsiang Wei, and Philip M. Farrell, "The Incidence of Cystic Fibrosis," *Statistics in Medicine* 15, no. 5 (1996): 449–62; "Cystic Fibrosis," Mayo Clinic, accessed July 22, 2022, https://www.mayoclinic.org/diseases-conditions/cystic-fibrosis/symptoms-causes/syc-20353700; "Type-2 Diabetes," Mayo Clinic, accessed June 25, 2022, https://www.mayoclinic.org/diseases-conditions/type-2-diabetes/symptoms-causes/syc-20351193; Steve Ryder, Regina M. Leadley, Nigel Thomas Armstrong, and Marie Westwood, "The Burden, Epidemiology, Costs and Treatment for Duchenne Muscular Dystrophy: An Evidence Review," *Orphanet Journal of Rare Diseases* 12, no. 1 (2017): 1–21; Stuart J. Moat, Donald M. Bradley, Rachel Salmon, Angus Clarke, and Louise Hartley, "Newborn Bloodspot Screening for Duchenne Muscular Dystrophy: 21 Years' Experience in Wales (UK)," *European Journal of Human Genetics* 21, no. 10 (2013): 1049–53; Yizhou Ye, Sudhakar Manne, William R. Treem, and Dimitri Bennett, "Prevalence of Inflammatory Bowel Disease in Pediatric and Adult Populations: Recent Estimates from Large National Databases in the United States, 2007–16," *Inflammatory Bowel Diseases* 26, no. 4 (2020): 619–25; "Inflammatory Bowel Disease (IBD)," Mayo Clinic, accessed July 28, 2022, https://www.mayoclinic.org/diseases-conditions/inflammatory-bowel-disease/symptoms-causes/syc-20353315; "Multiple Sclerosis (MS)," Mayo Clinic, accessed July 28, 2022, https://www.mayoclinic.org/diseases-conditions/multiple-sclerosis/symptoms-causes/syc-20350269.