

## Teaching Note

# DEFEAT DUCHENNE CANADA: SCALING UP A CHARITABLE ORGANIZATION<sup>1</sup>

*Robert Mackalski and Mary Dellar wrote this teaching note as an aid to instructors in the classroom use of the case Defeat Duchenne Canada: Scaling Up a Charitable Organization, No. W30129. This teaching note should not be used in any way that would prejudice the future use of the case.*

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## SYNOPSIS

Perry Esler, the chief executive officer of Defeat Duchenne Canada is eager to scale up the operations of his charitable organization, from its local origins in London, Ontario to a national and impactful venture. Esler and his team have to find the best way to develop awareness of Duchenne muscular dystrophy to secure much-needed funding for research and improve access to treatment for the rare disease. Despite facing multiple resource constraints, including a name and branding change from Jesse's Journey to Defeat Duchenne Canada, Esler and his team have to focus their efforts on generating the greatest impact.

## LEARNING OBJECTIVES

This case offers students insight on the issues of segmentation and branding for a charitable organization. After working through the case and assignment questions, students will be able to accomplish the following objectives:

- Appreciate the complex marketing challenges of a charitable organization that focuses on a rare disease.
- Evaluate brand identity and company name change for a charitable organization.
- Analyze and prioritize the stakeholder groups and segments of a charitable organization.
- Create a business strategy driven on a target audience to scale a resource-constrained organization.
- Develop appropriate messaging for a charitable organization.

## POSITION IN COURSE

This case is suitable for introductory courses in marketing, marketing strategy, services marketing, and brand management at the undergraduate or graduate levels. The case can also be used in courses that focus on marketing in relation to not-for-profit organizations and in similar executive-level courses.

<sup>1</sup> All case facts and case research that are referenced in this teaching note are supported by the sources and information contained in the associated case document (product No. W30129) unless otherwise specified.

## RELEVANT READINGS

- Anderson, Alan R., and Philip Kotler. “Segmentation, Targeting and Positioning.” *Strategic Marketing for Nonprofit Organizations*. (Upper Saddle River, NJ: Pearson, 2008), 137–57.
- Sargeant, Adrian, and John B. Ford. “The Power of Brands.” *Stanford Social Innovation Review* (Winter 2007): 41–47.
- Keller, Kevin Lane. *Strategic Brand Management*, 5th ed. (Upper Saddle River, NJ: Pearson, 2020).
- Rawal, Priyanka. “AIDA Marketing Communication Model: Stimulating a Purchase Decision in the Minds of the Consumers through a Linear Progression of Steps.” *International Journal of Multidisciplinary Research in Social & Management Sciences* 1, no. 1 (2013): 37–44.
- Lavidge, Robert J., and Gary A. Steiner. “A Model for Predictive Measures of Advertising Effectiveness.” *Journal of Marketing* 25 (October 1961): 59–62.
- Barry, Thomas E., and Daniel J. Howard. “A Review and Critique of the Hierarchy of Effects in Advertising.” *International Journal of Advertising* 9, no. 2 (1990): 121–35.
- Miller, Kivi Leroux. “Spread Your Message Further by Telling Stories.” In *The Nonprofit Marketing Guide*, 2nd ed. (Hoboken, NJ: John Wiley & Sons, 2021), 97–98.

## SUPPLEMENTAL MATERIALS

- DefeatDuchenne. “Defeat Duchenne Canada Introduction—John Davidson, Founder.” February 16, 2022. YouTube video, 1:58. <https://www.youtube.com/watch?v=1Swpb9EDDDs>.
- Creative Outpost. “Duchenne—‘World’s Strongest Boys.’” 2016. Vimeo video, 1:01. <https://vimeo.com/175580503>.
- DefeatDuchenne. “Defeat Duchenne Canada: 2022 Research Grant Update—Dr. Ronald Cohn.” June 7, 2022. YouTube video, 4:07. <https://www.youtube.com/watch?v=fyQQIxws8sA>.

## ASSIGNMENT QUESTIONS

1. What was the impact of John Davidson and Jesse’s Journey?
2. Evaluate the decision to change the name from Jesse’s Journey to Defeat Duchenne Canada.
3. What makes marketing Defeat Duchenne Canada so challenging?
4. Who are the stakeholders of Defeat Duchenne Canada? What do they receive from the organization? What do they contribute? What incentivizes each group?
5. As Esler prepares to scale Defeat Duchenne Canada, which stakeholder group should have the priority focus? Why?
6. Esler is considering different approaches to deploy a campaign to support the key priority group. Evaluate the options.
7. What makes great messaging for Defeat Duchenne Canada?

## TEACHING PLAN

The instructor can open the case discussion by asking students what deciding factors may have provoked them to support a specific charity, and how they showed their support (e.g., financially, by volunteering, in other ways). The instructor can expand the discussion further by asking if any of the organizations that students supported were related to a rare disease (see Exhibit 1).

The teaching plan below is recommended for a session of 75 minutes with the following specific time allotments:

Discussion Point	Time (in Minutes)
Impact of John Davidson and Jesse's Journey (Assignment Question 1)	5
Decision to change the name from Jesse's Journey to Defeat Duchenne Canada (Assignment Question 2)	10
What makes marketing so challenging (Assignment Question 3)	10
Stakeholders of Defeat Duchenne Canada (Assignment Question 4)	20
Which stakeholder group to focus on (Assignment Question 5)	10
Different approaches to support key group (Assignment Question 6)	15
Great messaging for Defeat Duchenne Canada (Assignment Question 7)	5

## ANALYSIS

### 1. What was the impact of John Davidson and Jesse's Journey?

Davidson's impact cannot be overstated. Had he not started his walk with his son Jesse, there might not be an organization tackling Duchenne muscular dystrophy in Canada; or if one had started up, that organization would not have organized the same way, with the same people, or in the same geographical area.

Davidson and his walks set the tone for the organization and established the Jesse's Journey brand. The instructor can help students understand this concept by using an iconic leader as the brand's representative (e.g., Elon Musk for Tesla, Richard Branson for Virgin, Steve Jobs for Apple). Davidson's experience led Jesse's Journey to fight Duchenne muscular dystrophy by using a different approach than US organizations such as CureDuchenne or Parent Project Muscular Dystrophy. Even after Jesse's Journey was rebranded as Defeat Duchenne Canada, the attributes and philosophies of the founder lived on.<sup>2</sup> The instructor can refer to the work of Harris and Ogbonna to explain how Davidson leaves a lasting strategic legacy.<sup>3</sup>

Davidson recognized a need. At the time, there was no support or research funding in Canada for Duchenne boys and their families. The early organization identified and developed means to fill this gap. Through the Jesse's Journey walks, Davidson united families affected by Duchenne, created initial awareness for the disease (especially in the local region and in various national communities), and raised CA\$15 million<sup>4</sup> for research projects around the world.

Through his walks and engagements with interested supporters, Davidson shared his passion and vision. He attracted a certain kind of volunteer and created an organization, systems, and structures to build a common history for Jesse's Journey. His efforts led to annual events such as the Walks to Defeat Duchenne, various fundraising efforts for research, and community building based on caring for affected children.

<sup>2</sup> Joanne Martin, Sim B. Sitkin, and Michael Boehm, *Founders and the Elusiveness of a Cultural Legacy* (New York, NY: Gage, 1985).

<sup>3</sup> Lloyd C. Harris and Emmanuel Ogbonna, "The Strategic Legacy of Company Founders," *Long Range Planning* 32, no.3 (1999): 333–43.

<sup>4</sup> All currency amounts are in CA\$ unless otherwise specified.

## 2. Evaluate the decision to change the name from Jesse's Journey to Defeat Duchenne Canada.

An organization may decide to undergo a name or branding change for several different reasons, including the following objectives:<sup>5</sup>

- Signal a shift in corporate strategy
- Distance itself from a scandal
- Rebrand following a merger or acquisition
- Divest a brand
- Rebrand following a leveraged buyout
- Rebrand following a sale of the organization's assets

In his book *Strategic Brand Management*, Keller explains that name changes can be complicated, time-consuming, and expensive, suggesting that they should only be considered for compelling marketing or financial reasons. A name change can require legal changes and virtual presence updates (e.g., new social media accounts, updated website, revised search engine optimization). It can also shed the positive brand equity (e.g., brand awareness, favourable brand image) that the organization may have built up over time.<sup>6</sup>

### Arguments against Changing the Company's Name

Compelling reasons against changing the Jesse's Journey name include almost 30 years of operation, hard-fought awareness within the Duchenne community, and goodwill developed among Duchenne researchers and health care workers. Jesse's Journey also had a strong base in the regional market where it operated, which likely spilled over into Toronto, Canada's largest and most dominant city. The Jesse's Journey name was also associated with the heartbreaking story of a father pushing his afflicted son across the country in a wheelchair. It seems likely that the founder would object to the removal of his son's name and legacy from the organization's brand.

### Arguments for Changing the Company's Name

The organization needed a new name for the strategic purpose of developing a national organization. Although the name Jesse's Journey had a strong regional presence, it lacked the scope of a national organization. The new name, Defeat Duchenne Canada, is effective in the use of the term "Defeat," which signals an intention to overcome, or find a cure for, Duchenne. The former name, Jesse's Journey, did not include the term "Duchenne," the actual name of the disease and remained more abstract, implying that the organization was fighting an unnamed disease that affected Jesse. Adding "Canada" to the name also helped signal that this is the national organization representing the official source and authority of the disease for Canada.

Even after a name change, there are ways to preserve some of the existing Jesse's Journey brand equity. The heritage of Davidson can be retained by maintaining the annual Jesse's Journey walk, finding ways to honour Jesse through events such as awards and recognition, and making effective use of Davidson in the name of the foundation.

The instructor can remind students that changing the organization's name was only possible with Davidson's approval. The discussion can shift to Davidson, Jesse's father, supporting the decision to rebrand the organization. To conclude the discussion of this assignment question, the instructor can show the class the YouTube video "Defeat Duchenne Canada Introduction—John Davidson, Founder" (see Supplemental Materials).

<sup>5</sup> Kevin Lane Keller, *Strategic Brand Management*, 5th ed. (Upper Saddle River, NJ: Pearson, 2020), 426.

<sup>6</sup> Keller, *Strategic Brand Management*.

### 3. What makes marketing Defeat Duchenne Canada so challenging?

Duchenne muscular dystrophy is officially designated as a rare disease.<sup>7</sup> The uncommon occurrence of the disease provides formidable marketing challenges.

There is very low awareness of the disease. As Ken Wilson points out, Duchenne lacks awareness among the general population (see case heading “The Jesse’s Journey Story”). By contrast, everyone has heard of, knows someone who has been affected by, or has been personally affected by more common diseases like cancer, heart disease, or diabetes. In addition, Davidson’s high-profile walks across Canada took place almost 30 years ago. Today’s parents of Duchenne children may have been children at the time or not yet born, further limiting the awareness that existed in the 1990s.

From a marketing point-of-view, awareness of the disease (and awareness of the severity of the disease) is an antecedent for awareness for the Defeat Duchenne Canada organization. The foundational importance of awareness can be shown in different marketing models (see Exhibit TN-1).

#### Smaller Network Effects for Messaging

The number of people suffering from the disease results in a relatively smaller base to drive social media, develop fundraising efforts, and cultivate corporate sponsorships. Based on Canada’s population of 38 million,<sup>8</sup> the number of people affected by the disease makes for a low percentage of awareness drivers at 800 families, even though the disease has high incidence of striking the family repeatedly because it is transmitted mainly by a gene from the mother. To make matters more challenging, Defeat Duchenne Canada is only in touch with a little more than 1 out of every 3 of the families currently affected by Duchenne.

#### Limited Contribution from Families

The economic impact of the disease robs the primary stakeholders’ financial abilities to contribute to the cause. This is because the disease is particularly cruel on their budget. The expenses can be a significant amount of money incurred over a long period of approximately 30 years, with increasing costs over time.

Some of the expenses that families affected by Duchenne incur include the following costs:

- Van or large vehicle purchase with specialized modifications
- Specialized schooling
- Wheelchairs, walkers, motorized individual vehicles
- Medications (both conventional and experimental)
- Therapies
- Surgical procedures

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<sup>7</sup> Duchenne affects one out of every 5,000 people, but Health Canada recognizes a rare disease as “having a rate of affliction of one out of 2,000 people, although not all countries agree on this figure (e.g., a rare disease in the United States affects less than 200,000 people, or six out of 10,000 people); “Drugs for Rare Diseases: A Review of National and International Health Technology Assessment Agencies and Public Payers’ Decision-Making Processes,” Canadian Agency for Drugs and Technologies in Health (CADTH), May 26, 2020, <https://www.cadth.ca/drugs-rare-diseases-review-national-and-international-health-technology-assessment-agencies-and>; “Rare Diseases at FDA,” United States Food and Drug Administration, accessed December 22, 2022, <https://www.fda.gov/patients/rare-diseases-fda>.

<sup>8</sup> “Canada’s Population Estimates, Third Quarter 2022,” Statistics Canada, December 21, 2022, <https://www150.statcan.gc.ca/n1/daily-quotidien/221221/dq221221f-eng.htm>.

- House renovations or purchase of more accommodating single floor home with
  - wheelchair ramps, accessibility
  - stair lifts or elevators
  - bathroom revisions
  - common living area revisions
  - specialized furniture
- Travel to major medical centres to receive appropriate diagnosis and regular treatments

The instructor can remind the class that almost half of Canadians live in rural or low population areas, where Duchenne diagnostics are not likely available. The extensive travel required may also affect the ability of parents to hold full-time employment.

Students must also recognize that the financial situation of families affected by Duchenne can become dire over time. In turn, this issue reduces Defeat Duchenne Canada's ability to fundraise or receive legacy donations (i.e., donations made in honour of the patient).

### Smaller Base and Fewer Resources Leading to Fewer Good News Stories

Fighting Duchenne does not generate many big wins in the form of discoveries or cures. The life expectancy of patients is increasing, but extending the life expectancy of an individual confined to wheelchair does not convey the same message that a potential cure would, such as a patient being able to walk after a clinical trial. For Defeat Duchenne Canada, this is a double-edged sword. The organization needs good stories to drive enthusiasm for donations and resources, but donations and resources are needed to get big wins.

Comparing the fight against breast cancer to the fight against Duchenne may not be on an even level (breast cancer affects one out of every eight women and one out of every 800 men, whereas Duchenne affects one out of every 5,000 boys.<sup>9</sup> However, breast cancer charities raise US\$6 billion each year, leading to advances in screening, treatments, and therapies.<sup>10</sup> As a result, the fight against breast cancer has successfully reduced fatal outcomes, with an army of survivors and thousands of powerful, uplifting stories—which has also resulted in many more donations.

### Large Number of Stakeholder Groups

Of the many stakeholder groups involved, each one has different needs, contributions, and incentives related to the disease. Therefore, Defeat Duchenne Canada must provide customized messaging and marketing strategies for the various groups.

#### **4. Who are the stakeholders of Defeat Duchenne Canada? What do they receive from the organization? What do they contribute? What incentivizes each group?**

Student responses to this assignment question may vary. However, students should recognize that at the very core of the organization is a community of stakeholder coming together. As students discuss the possible contribution of each stakeholder, the instructor can point out the importance of building a stakeholder support network. These stakeholders can continue to encourage others and even call upon non-current or less engaged supporters to support Defeat Duchenne Canada.

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<sup>9</sup> "Cancer at a Glance," Centers for Disease Control and Prevention, accessed July 28, 2022, <https://gis.cdc.gov/Cancer/USCS/#/AtAGlance>.

<sup>10</sup> "Cancer at a Glance," Centers for Disease Control and Prevention.

The instructor can ask students to rank the stakeholders in terms of their particular level of importance and their ability to serve as a potential brand ambassador. This is an important factor in Defeat Duchenne Canada's ability to continue to build on that support network over time. The instructor can also challenge students to identify a gap in the list of stakeholder groups (see Exhibit TN-2).

**5. As Esler prepares to scale Defeat Duchenne Canada, which stakeholder group should have the priority focus? Why?**

In the various options for student response to this assignment question, the best arguments will focus on families affected by Duchenne muscular dystrophy.

Duchenne Patient Families

The families of children with Duchenne, and the sufferers of Duchenne themselves, are the reason the organization exists. Without these families, there is no organization.

This is also the stakeholder group that has the most to gain from Defeat Duchenne Canada's efforts. As such, if relationships are properly cultivated, they will be the most committed to the organization's cause. The more value they see in the organization, the greater their engagement.

Duchenne muscular dystrophy is a niche disease that affects fewer people than more widespread diseases such as heart disease, cancer, or diabetes. As such, its aim is not to reach mass recognition in terms of support, but it is important for the organization to reach all the Duchenne families. Currently, only 312 of the 800 families affected with the disease are connected to Defeat Duchenne Canada. Therefore, the organization has a lot of work to do.

Given that Jesse's Journey has mainly a regional focus, the other 488 families affected by the disease are likely located in different regions of the country. In addition, approximately 37 boys born in Canada each year—of the 185,000 males born in Canada annually—will become affected by the disease.<sup>11</sup> By engaging these families, Defeat Duchenne Canada can achieve a national presence. By becoming known and relevant to the families, Defeat Duchenne Canada can create a *family of families*. Both existing groups of families affected by Duchenne and newly diagnosed families can help relatives, neighbours, colleagues, and friends become *aware*, *interested*, and *supportive* of the cause. Volunteerism, or maybe even a national corporate sponsorship, can precipitate from this point.

Some families may also provide a legacy donation. For example, families that have lost a son to Duchenne may eventually choose to provide a donation in the name of their son to help fund a cure for the next generation. However, focusing the scope of the organization only on families affected by the disease can limit scalability. Esler must consider that support from corporate, celebrity, public policy, and health representatives can also play an important role.

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<sup>11</sup> "Number of Births in Canada from 2000 to 2021, by Gender," Statista, accessed July 28, 2022, <https://www.statista.com/statistics/446025/births-in-canada-by-gender>.

**6. Esler is considering different approaches to deploy a campaign to support the key priority group. Evaluate the options.**

Several options for scaling up the organization are provided in the case for Esler to consider (see case heading “Looking Ahead”):

- Adding a celebrity supporter
- Finding a national corporate sponsor
- Launching a health care provider campaign
- Enhancing social media exposure
- Working with public policy-makers

Defeat Duchenne Canada has a CA\$1.1 million annual budget (see case Exhibit 2). The lion’s share (63 per cent) of the revenue is designated for research, driven by interest from the Jesse Davidson Foundation, which is required to be spent on research. The amount of CA\$560,000 is allocated to philanthropy, education, and advocacy. As Defeat Duchenne Canada strives to achieve a national presence, it can use the available annual budget to reach its goals.

Adding a Celebrity Supporter

This option may generate much discussion from students. A celebrity can add glamour, awareness, social networks (including other celebrities), financial support, special events, and media appeal. Example of celebrities who have made an impact on charities by associating their name and support include Hollywood actor Michael J. Fox (Foundation for Parkinson’s Research), English singer Ella Henderson (Teenage Cancer Trust), professional hockey player PK Subban (Montreal Children’s Hospital Foundation), Canadian singer Shawn Mendes (American Red Cross), Hollywood actor Matt Damon (Water.org), and professional wrestler John Cena (Make-A-Wish Foundation).<sup>12</sup> However, Defeat Duchenne Canada may lack the network or experience to secure a celebrity endorser.

Finding a National Corporate Sponsor

A national corporate sponsor is an appealing option for generating new financial sources and awareness. However, the competition for sponsorship dollars is fierce, and Defeat Duchenne Canada can offer only a limited amount of visibility to the sponsor, which makes this option a hard sell. With only modest regional success to date and an inexperienced and unproven network, Defeat Duchenne Canada may need a champion within a national organization who has a personal mission to fight Duchenne muscular dystrophy.

This point strengthens the argument of growing the organization’s community (as discussed in assignment question 5). Currently, the main fundraiser event of the organization, the annual Walk to Defeat Duchenne, raises approximately CA\$250,000 and involves the 312 member families. Doubling the number of families involved in the event from coast to coast could potentially double the donation amount to CA\$500,000 and create a widespread network of families.

In comparison, just one supportive national corporate sponsor could change the economics of the organization with one corporate donation of CA\$250,000, the equivalent of 312 families working together to raise funds. Students can suggest a potential corporate partner with national reach, some health or well-being mandate, and links to youth.

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<sup>12</sup> Dan Ketchum, “21 Celebrities Who Run Foundations or Charities,” GO Banking Rates, August 2, 2019, <https://www.gobankingrates.com/net-worth/celebrities/celebrities-run-foundations-charities>.



### Launching a Health Care Provider Campaign

Health care professionals such as doctors and nurse practitioners who interface with children are on the front lines of the fight against Duchenne. These professionals are an identifiable target audience with the largest impact on the affected families.

Students can be asked to consider a scenario where a physician diagnoses a child with Duchenne muscular dystrophy, a diagnosis that drastically changes the lives of the child and his family. Leaving the doctor's office with that diagnosis gives the family a sense of grief and hopelessness, but the health care professional can provide some relief by offering the family hope and direction (e.g., "Here's what you need to know. Read this information. Visit this web site. Attend this conference. Monitor the updates on these drugs that are in clinical trials."). The earlier Duchenne is diagnosed, the sooner treatments can begin. The families should be encouraged to become a part of the Defeat Duchenne Canada community.

In addition to physicians and nurse practitioners, physiotherapists can provide much needed expertise, direction, and advice for Duchenne patients and families. Patients may spend a lot of time in therapy, which allows physiotherapists to share best practices, findings, and resources and gain new expertise.

### Enhancing Social Media Exposure

The argument for increasing social media exposure can point to other successful organizations that used social media campaigns effectively in their fight against diseases, such as amyotrophic lateral sclerosis (ALS Ice Bucket Challenge) and prostate cancer (Movember). This option may be the most economical in terms of financial resources and Defeat Duchenne Canada has the required communication experience. In addition, social media efforts can benefit affected families by offering an immediate connection with other families of children with Duchenne. However, launching a major social media campaign can be a daunting task with the risk that an extremely popular (i.e., viral) idea and execution fails to materialize.

### Working with Public Policy-Makers

Capturing the imagination of policy-makers, which seemed to fall short in the case of Jesse's Journey, is important for advocacy at both the national and provincial levels. Unlike the United States, Canada does not have a national rare disease plan. As treatments and drugs become available, their costs are not subsidized, which results in extremely high expenses, becoming financially cost-prohibitive for many families who are already taxed with other Duchenne-related expenses. Some carefully targeted personal relationship building with key policy-makers could provide enormous benefit for the Defeat Duchenne Canada member families.

Health Canada is a department of the Canadian federal government that acts as the regulatory authority responsible for clinical trials in Canada. This is one key group to target. Lobbying can be effective in introducing clinical trials of a new treatment or speeding up approvals of promising new drugs. Provincial relations are also a key factor because pricing of approved drugs is set by the health department of each individual province. Without advocacy at the provincial level, the drug pricing level is likely to be high due to the rareness of the disease.

The impact with policy-makers can be substantial. In the United States, Parent Project Muscular Dystrophy fights for advocacy in various ways.<sup>13</sup> It has increased access and coverage through the United States Food and Drug Administration approvals of therapies. It has expanded newborn screening infrastructure. It has also successfully lobbied the Center for Disease Control and Prevention, National Institutes of Health, Food and Drug Administration, and other groups to glean US\$600 million specifically for Duchenne research.<sup>14</sup>

Policy-makers may also be encouraged to promote positive policies that will make news-worthy stories.

However, a vast amount of relationship building would be required to make these initiatives successful that would require significant time and travel expenses, especially with Canada's 10 provinces and three territories spread out across 5,000 kilometres of land. Government representatives also tend to have their own priorities and change with every election. The rareness of Duchenne muscular dystrophy may also mean that it becomes a lower priority for policy-makers. Although government decision-making is slow, and Esler would benefit from a quick win, a public policy-maker campaign can be important, particularly for the long-term impact of the organization.

To scale up Defeat Duchenne Canada, Esler must carefully navigate the needs of the five key stakeholder groups discussed above. A particularly challenging factor is that the emphasis will vary, and he will have to focus on one key audience over another at different times. For example, in expanding the annual Walk to Defeat Duchenne, Esler will have to focus on ensuring that there are enough patient families, and thus volunteers, to make the event successful. This may require an adequate amount of media attention and potentially getting corporate or other donor types interested and involved in the event.

One powerful way to conclude the discussion of this assignment question is to remind students that the families are the priority stakeholder group. The instructor can highlight this point by drawing a two-by-two matrix of impact versus effort (see Exhibit TN-3). Impact refers to direct or indirect impact on the priority stakeholder group (i.e., the families). Effort refers to the hard work required in terms of time and resources.

Finally, the instructor can point out that Esler will need both short-term and long-term strategies to achieve his goals of scaling up his organization, which leads into the last assignment question on the right messaging for Defeat Duchenne Canada.

## **6. What makes great messaging for Defeat Duchenne Canada?**

Given the rarity of Duchenne muscular dystrophy and the limited budget for a national organization, leveraging the organization's member families—and their awareness and incentives—would be a good starting point. For maximum effectiveness, this group should be mobilized to make the messaging compel action. People feel more encouraged to act when they feel that there is a connection.

As discussed earlier, the rarity of Duchenne means that most people do not know someone afflicted or impacted by the disease. Supporters need to feel what the impact from the disease feels like. Therefore, it is critical to create a connection between a potential donor, or other potential supporters, and ensure them that their action (i.e., funding, advocacy, volunteerism) will have a positive result and make a difference. This means that Defeat Duchenne Canada needs to be at the intersection of affected families and potential supporters.

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<sup>13</sup> "Stronger with Every Beat," Parent Project Muscular Dystrophy, accessed July 14, 2022, <https://www.parentprojectmd.org>.

<sup>14</sup> "Ongoing Initiatives," Parent Project Muscular Dystrophy, accessed July 14, 2022 <https://www.parentprojectmd.org/advocacy/ongoing-initiatives>.

A business leader, politician, or health care professional who is also a parent or guardian of a young child can be asked to relate to the emotions Davidson must have felt when pushing his young son in a wheelchair with a desperate tangible plea of support. This approach should be applied to all messaging, appealing directly to the values of key stakeholders. The fact that this disease affects young children can stir deep emotion in the hearts of donors, and fundraising campaigns are most effective when they trigger an emotional response.

For Defeat Duchenne Canada's marketing story to resonate, it should embody the following six aspects, as Kivi Leroux Miller details in her book *The Nonprofit Marketing Guide*:<sup>15</sup>

- *Be Brief.* Tell the story within two minutes (maximum 500 words).
- *Be straightforward.* Stay on task; tangential anecdotes are a reason to lose interest.
- *Be personal.* Duchenne has many stories (e.g., young hockey prodigy Deccan Gill) that will be relevant to any hockey parent or former player, but limit the number of people in the story and focus on the afflicted child.
- *Be authentic.* The story must be true, using the actual name, age, and characteristics of the affected child; hypothetical stories risk counterarguing by the target audience.
- *Include conflict or imperfections.* Unwelcome outcomes bring reality to stories and make the targets want to know the outcome; this disease is debilitating to affected families, and although difficult, those stories should be told.
- *Close with a message.* A clear goal is necessary for non-profit marketing to be successful; the listener or reader has to know exactly what is expected of them and what action they need to take.

## WHAT HAPPENED

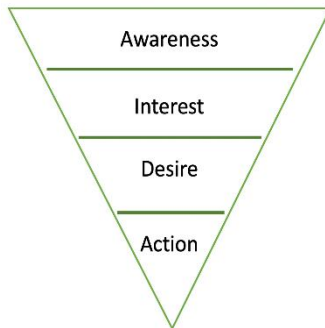
Defeat Duchenne Canada aggressively pursued building a national organization. Funding was directed to out-of-the-box high potential research projects, as depicted in the video “Defeat Duchenne Canada: 2022 Research Grant Update—Dr. Ronald Cohn” (see Supplemental Materials). The organization has also added member families through an aggressive digital strategy that used YouTube and search engine optimization. Defeat Duchenne Canada is giving a face to the fight against the disease by the organization's boys, through positive and optimistic messaging.

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<sup>15</sup> Kivi Leroux Miller, “Spread Your Message Further by Telling Stories,” in *The Nonprofit Marketing Guide*, 2nd ed. ( Hoboken, N J: John Wiley & Sons, 2021), 97–98.

## EXHIBIT TN-1: MARKETING MODELS

## AIDA Model



The **AIDA model**: Awareness → Interest → Desire → Action

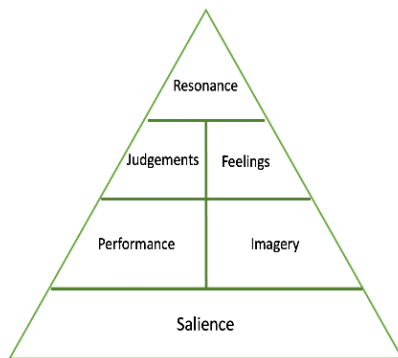
The AIDA model is a hierarchy of effects model in marketing. The model posits that consumers move through a series of sequential stages when making a purchase decision. The first necessary stage is that consumers are aware of an offering and know it is available.

There are different variations of the AIDA model, each presenting awareness as the first step in the process.

Awareness → Knowledge → Liking → Preference → Conviction → Purchase

Awareness → Interest → Conviction → Desire → Action

## Brand Resonance Model



The brand resonance model postulates that there are four sequential levels to build a brand that resonates (i.e., has meaningful relationships) with consumers. The first level is salience, which is a proxy for brand awareness. According to this Keller model, only until salience is built can higher order brand equity sources manifest.

Source: Created by the case author based on Priyanka Rawal, "AIDA Marketing Communication Model: Stimulating a Purchase Decision in the Minds of the Consumers through a Linear Progression of Steps," *International Journal of Multidisciplinary Research in Social & Management Sciences* 1, no. 1 (2013): 37–44; R.J. Lavidge and Steiner, G. A., "A Model for Predictive Measures of Advertising Effectiveness," *Journal of Marketing*, October 1961, 59–62; Thomas E. Barry and Daniel J. Howard, "A Review and Critique of the Hierarchy of Effects in Advertising," *International Journal of Advertising* 9, no. 2 (1990): 121–35; Kevin Lane Keller, *Strategic Brand Management*, 5th ed. (Upper Saddle River, NJ: Pearson, 2020), 78–94.

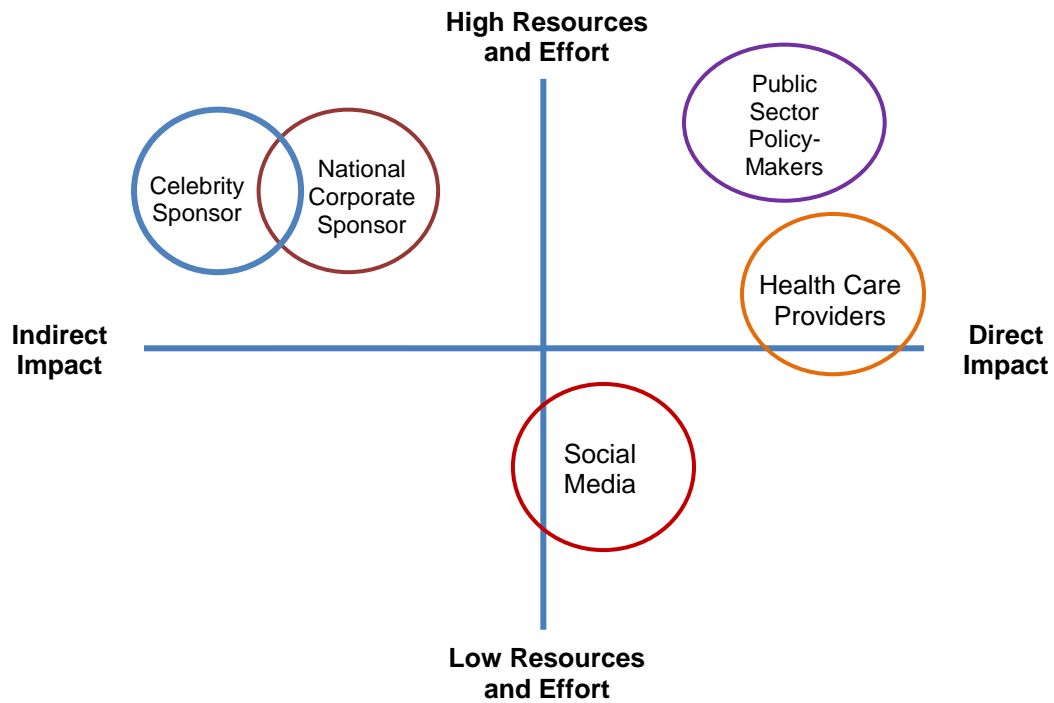
## EXHIBIT TN-2: DEFEAT DUCHENNE CANADA STAKEHOLDERS

Stakeholder	What They Receive	What They Contribute	Stakeholder's Incentive
<b>Duchenne Patient Families</b>	<ul style="list-style-type: none"> <li>• Credible, reliable education on Duchenne</li> <li>• Up-to-date information on treatments and available resources (e.g., physiotherapy)</li> <li>• Encouragement</li> <li>• Networking with other families</li> <li>• Advocacy for individual families (e.g., special van)</li> </ul>	<ul style="list-style-type: none"> <li>• Heart of the network</li> <li>• Family support—the reason the organization exists</li> <li>• Donations and fundraising</li> <li>• Advocating for their children or for a cure</li> <li>• Spreading the word to family, friends, colleagues</li> </ul>	<ul style="list-style-type: none"> <li>• Love</li> <li>• Better quality of life for impacted children</li> <li>• Ideally, a cure</li> <li>• Better quality of life for the family</li> </ul>
<b>Health Care Professionals (Neuro Pediatricians, Family Doctors, Nurses, Physiotherapists, Social Workers)</b>	<ul style="list-style-type: none"> <li>• Patient education materials (mailed, pamphlet displays, website)</li> <li>• A place to direct the families for self-education of the families and a place to start</li> <li>• Better educated families, more meaningful discussions; can participate more fully in decision-making</li> </ul>	<ul style="list-style-type: none"> <li>• Comprehensive integrated care for patient</li> </ul>	<ul style="list-style-type: none"> <li>• Providing better patient care</li> </ul>
<b>Researchers</b>	<ul style="list-style-type: none"> <li>• Funding to do research for cures, treatments, or diagnostics</li> <li>• Increases the researchers' profile in academics and community</li> <li>• Ability of researchers to hire students who may also be researchers or in the medical field</li> <li>• Candidates for trials</li> </ul>	<ul style="list-style-type: none"> <li>• Providing a better-informed medical profession to serve the needs of the children</li> </ul>	<ul style="list-style-type: none"> <li>• Developing cures</li> <li>• Having personal accomplishment in science</li> </ul>
<b>Pharmaceutical Companies</b>	<ul style="list-style-type: none"> <li>• Publicity, public relations, creating goodwill</li> <li>• Candidates for trials</li> </ul>	<ul style="list-style-type: none"> <li>• Giving money to organization for research</li> <li>• Compassionate giving programs</li> </ul>	<ul style="list-style-type: none"> <li>• Making money, with common diseases as the most desirable due to largest profit (e.g. cholesterol, diabetes)</li> <li>• Biological medicines preferred due to their high prices</li> </ul>
<b>Legacy Families</b>	<ul style="list-style-type: none"> <li>• Honour</li> <li>• Legacy</li> </ul>	<ul style="list-style-type: none"> <li>• Donations</li> <li>• If famous, allow the name to be associated to the organization</li> </ul>	<ul style="list-style-type: none"> <li>• Altruism</li> <li>• Posterity</li> </ul>
<b>Friends and Colleagues</b>	<ul style="list-style-type: none"> <li>• Education</li> <li>• Being part of an organization that is doing good</li> </ul>	<ul style="list-style-type: none"> <li>• Donations</li> <li>• Fundraising</li> <li>• Volunteering</li> <li>• Respite (breaks for parents)</li> </ul>	<ul style="list-style-type: none"> <li>• Love</li> <li>• Friendship</li> <li>• Altruism</li> </ul>

## EXHIBIT TN-2 (CONTINUED)

Stakeholder	What They Receive	What They Contribute	Stakeholder's Incentive
<b>Volunteers</b>	<ul style="list-style-type: none"> <li>• Education</li> <li>• Being part of an organization that is doing good</li> </ul>	<ul style="list-style-type: none"> <li>• Donations</li> <li>• Fundraising</li> <li>• Volunteering</li> <li>• Respite (breaks for parents)</li> </ul>	<ul style="list-style-type: none"> <li>• Love</li> <li>• Altruism</li> </ul>
<b>Public Sector Policy-Makers</b>	<ul style="list-style-type: none"> <li>• Awareness</li> <li>• Information</li> <li>• Motivation to help Duchenne families</li> </ul>	<ul style="list-style-type: none"> <li>• Influence public policy (e.g., laws for wheelchair ramps, elevators, wide enough bathroom stalls)</li> <li>• Government grants</li> <li>• Approving drugs and treatments more quickly</li> <li>• Subsidizing expensive experimental drugs</li> </ul>	<ul style="list-style-type: none"> <li>• Re-election</li> <li>• Altruism</li> </ul>
<b>Corporate Donors and Sponsors</b>	<ul style="list-style-type: none"> <li>• Publicity</li> <li>• Tax credits</li> <li>• Being a good member of the community</li> <li>• Business (e.g., buy our special shoes)</li> </ul>	<ul style="list-style-type: none"> <li>• Donations (money or equipment)</li> <li>• Favourable profile</li> </ul>	<ul style="list-style-type: none"> <li>• Sales</li> <li>• Altruism</li> </ul>
<b>Muscular Dystrophy and Duchenne Associations</b>	<ul style="list-style-type: none"> <li>• Partnering in research funding</li> <li>• Sharing best practices</li> </ul>	<ul style="list-style-type: none"> <li>• Partnering in research funding</li> <li>• Sharing best practices</li> </ul>	<ul style="list-style-type: none"> <li>• Altruism</li> <li>• Cures and treatments</li> </ul>

Source: Created by case authors based on company documents.

**EXHIBIT TN-3: IMPACT VERSUS EFFORT MATRIX: DEFEAT DUCHENNE CANADA  
CAMPAIGN OPTIONS**

Source: Created by the case authors based on Bjørn Andersen, Tom Fagerhaug, and Marti Beltz, *Root Cause Analysis and Improvement in the Healthcare Sector: A Step-by-Step Guide* (Milwaukee, WI: ASQ Quality Press, 2010), 19, 146–47.