The Internet’s Black Box: What Parents of Children with Duchenne or Becker Muscular Dystrophy are Finding Online

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Jacqueline Marianna Morello Leonard

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Abstract

The Internet’s Black Box: What Parents of Children with Duchenne or Becker Muscular Dystrophy are Finding Online

A thesis presented to the Graduate Program in Genetic Counseling

Graduate School of Arts and Sciences
Brandeis University
Waltham, Massachusetts

By Jacqueline Marianna Morello Leonard

The Internet and use of social media is an important means of communication and an unique source for information gathering in today’s modern society. More than ever, parents and caregivers turn to online sources to get information about their children’s health. Approximately 83% of parents undergoing a genetic evaluation searched the internet for information. However, there is minimal research that examines parental or caregiver internet use in rare disease populations. In our study, we surveyed parents who have a child affected with Duchenne Muscular Dystrophy (DMD) or Becker Muscular Dystrophy (BMD). We employed a mostly quantitative survey with some qualitative components, and recruited online and in person. We found that all parents searched online for information primarily before diagnosis (25.3%), or immediately after (70.9%). Around half of parents were not given internet resources at diagnosis (51.3%), and most of this group reported that this would have been helpful for them (87.5%). More parents reported experiencing barriers such as being unsure on which resources to trust if they were not provided with internet resources at diagnosis. Participants reported the highest rated scores for satisfaction with readability, amount of information and quality of information for Parent Project MD. Majority of respondents felt that searching online was overwhelming (77.3%) and themes for why included
amount of information, the emotion tied with the prognosis, and because of outdated information and misinformation. Most participants reported that information found online changed medical management (60.5%) for their child. Overall, we believe this work provides further clarity into the online experience of parents in a rare disease population, and highlights and reinforces the need for providing internet resources at diagnosis. We think this work provides the foundation for future development of best practice guidelines for websites.

**Keywords:** Internet, Social Media, Genetic Counseling, Internet Referrals, Internet Usage, Duchenne Muscular Dystrophy, Becker Muscular Dystrophy, Web Searching, Searching Online, Websites
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List of Abbreviations

AONs: Anti-sense Oligonucleotides
**DMD**: Duchenne Muscular Dystrophy
**DMD**: Dystrophin Gene
**BMD**: Becker Muscular Dystrophy
I: Introduction and Background

1.1 Duchenne Muscular Dystrophy

Duchenne Muscular Dystrophy is a X-linked recessive genetic disease that is characterized by a progressive muscle weakness with a shortened life span due to cardiac and/or respiratory complications. It affects 1 in approximately every 3,600 to 4,700 males in North America (Bushby et al., 2010; Dooley, Gordon, Dodds, & MacSween, 2010). Duchenne’s Muscular Dystrophy, or DMD, is classified as a primary dystrophinopathy. This is a classification of muscle disease that is caused by pathogenic variants, usually large deletions, in the DMD gene at Xp21.2 (Bushby et al., 2010; Darras, Miller, & Urion, 2014). Most patients have an almost complete loss of expression of the DMD gene product, dystrophin (Hoffman et al., 1987). Classically, symptom onset is between two to five years of age. Boys present with developmental delay in motor functions including; frequent falls, delays sitting and standing, and progressive muscle weakness causing a waddling gait (Bushby et al., 2010; Darras et al., 2014; Essen et al., 1997). This condition is significantly and rapidly progressive, and most boys lose ambulation by 13 years of age. Life expectancy is shortened due to respiratory complications or cardiac failure by late in their second decade or early in their third (Bushby et al., 2010).

For many years, the natural history of those with DMD remained relatively consistent, owing to a lack of major breakthroughs in treatment or cures for DMD. Recently, many advances and studies of the DMD community found success at treating the symptoms of the muscle weakness vs curing DMD and this began to effect both the quality and quantity of life of the DMD patient, effectively changing the natural history. Earlier studies of DMD that recruited patients
from 1961-1982 found that patients lost ambulation at an average of 9.5 years of age, and on average passed away at around 17 years of age (Essen et al., 1997). Today, ambulation is lost at upwards of 11-13 years of age (Bushby et al., 2010). Without intervention, the mean age of death was around 19 years of age, but with modern multidisciplinary care that includes mechanical assistance with ventilation, drug treatment with steroids, early afterload reduction such as angiotensin-converting enzyme inhibitors for cardiac management, and management of spine deformities, the average age of death moved into the third or fourth decade of life (Bushby et al., 2010; Duboc et al., 2007; Falzarano, Scotton, Passarelli, & Ferlini, 2015). Becker Muscular Dystrophy (BMD) is known as the less-severe form of DMD, typically due to non-truncating mutations in the DMD gene (Bello et al., 2016). Patients affected with BMD experience a much more heterogeneous presentation than DMD, and is generally much milder (Bello et al., 2016). Ambulation in this population is lost after 16 years of age and can vary, in comparison to DMD where ambulation is lost by 13 years of age (Bello et al., 2016).

Treatment with corticosteroids have been used since the late 1980s, and represent one of the major avenues of therapy for use in DMD and BMD patients (Falzarano et al., 2015). A steroid known as EMFLAZA™, or deflazacort, just received FDA approval for DMD in February 2017, approved for boys ages five and older. Cohort analysis determined that long-term treatment with steroids causes slower progression of the disease, two extra years of walking and the prolonging of meaningful functional abilities following consistent treatment (Henricson et al., 2013; Pane et al., 2014). Recent advancements in genetic therapies and new drugs are also giving new hope to children affected by DMD and their families. One of the most significant advances in recent years is a molecular approach that offers the potential to restore some dystrophin activity to muscles through anti-sense oligonucleotide molecules (AONs) that cause single or double exon skipping.
that may help to up to 83% of DMD patients (Aartsma-Rus et al., 2009; Fairclough, Wood, & Davies, 2013; Hoffman et al., 2011). Published this past year, the exon skipping drug Exondys 51 was found to lead to a significantly slower rate of decline in ambulation over three years when compared to historical controls (Mendell et al., 2016). In September of 2016, Exondys 51 was FDA approved, and developed for DMD patients amenable to exon 51 skipping. This first exon skipping drug is estimated to be applicable to approximately 13% of DMD patients (Mendell et al., 2016).

Another molecular therapy currently in clinical trial involves premature stop codon read-through, which may apply to 10-15% of DMD patients (Fairclough et al., 2013). This therapy involves a drug known as Ataluren. Ataluren, or PTC124, is a small molecule that is able to make ribosomes less sensitive to premature stop codons, allowing for the read through of the stop codon and creation of longer protein similar to the non-mutated endogenous product (Bushby et al., 2014). While not currently approved for use in the United States and only approved in Europe, recent clinical trial data, while not statistically significant, is promising. Data currently shows decreases in progression, increases in time walking, and increased North Star Ambulatory Assessments as compared to placebo (Bushby et al., 2016; Quinlivan et al., 2016) Though these therapies would not cure DMD entirely, it is theorized that it significantly slows progression with ambulation loss around 13-16 years of age or later and a lifespan into their 80s, though preliminary data is inconclusive as to this treatment’s efficacy (Fairclough et al., 2013, Voit et al., 2014). Finally, early studies using the CRISPR/cas9 gene editing system in patient cells and in mouse models is currently seeing success in restoring some dystrophin expression that results in some functional muscle improvement (Nelson et al., 2016; Tabebordbar et al., 2016). Overall, the DMD research community represents a rapid field of investigation, with many clinical trials currently in progress
that could by the next decade, lead to significant improvements in the lives of those affected by DMD. (Robinson-Hamm & Gersbach, 2016).

1.2 Health Care in the Internet Age

As physician’s have less time to spend with patients and as they’re unlikely to see many cases of a rare disease, it can be difficult for them to keep up with all the current research. As such, in the case of a rare genetic disorders such as DMD, patients are more frequently turning to sources other than their health care providers to gain more information about their child’s disease and its natural history. Social media and the internet are an increasingly important tool for use in health care as patients and family members seek health information and support. For many, the internet is a vast and extensive knowledge network that is easily accessible. The scientific and medical literature propose that consumers access the Internet for health information in one of three ways: searching directly for health information based on specific queries, participating in support groups, and consulting with health professionals (Cline & Haynes, 2001). Data from the Pew Research Center suggests that 72% of individuals have at one time searched for health information, primarily beginning their search at a search engine such as Google (Pew Internet Project, 2013). In particular, this organization found that 53% of adults living with one or more chronic conditions, including genetic conditions, look online for health information (Pew Internet Project, 2013). When examined across the United States, it’s estimated that the number of Web users seeking health-based information has increased from 54 million in 1998, to 117 million in 2005 and is now estimated to exceed 140 million (Amante, Hogan, Pagoto, English, & Lapane, 2015; Madden & Fox, 2006; Wald, Dube, & Anthony, 2007). However, it is important to note that these numbers are likely underestimates, as these stats do not account for bias as more households and individuals
own personal computers and smartphones today, which leads to easier access online (Amante et al., 2015).

The rapid growth of the internet provides a unique possibility for people seeking supportive communication (Wright & Bell, 2003). The popularity of social networking sites such as Facebook allow for the increasing use of social networking sites in health care through the creation of disease-specific pages and groups that support individuals affected by medical conditions (Koteyko, Hunt, & Gunter, 2015). Recent studies show that modern social networking sites and online social support can be effective in providing patients and families a place for crucial support and a community like them (Chretien & Kind, 2013; Mohd Roffeei, Abdullah, & Basar, 2015; Schumacher et al., 2014). Multiple groups report that these online support systems can empower patients and/or their parents and families through reinforcement of previously given provider information on medical management and health information, and through the action of sharing their experiences, feelings and strategies for how they have coped with the genetic condition they are faced with (Baas et al., 2015; Greene, 2015; Koteyko et al., 2015; Merolli, Gray, Martin-Sanchez, & Lopez-Campos, 2015). When a family is coping with a rare genetic condition we know this can create unique family experiences, mental challenges, and negative psychosocial implications (Cantwell, Muldoon, & Gallagher, 2014; Krabbenborg et al., 2016). This results in a population that is uniquely suited to online support groups given their unique experiences, and studies show that patient empowerment through social support and information has the power to decrease stress and result in better physical health (Cantwell et al., 2014).

Multiple demographic factors are found to vary with health information technology use. These are age, sex, ethnicity, education level and marital status (Amante et al., 2015). For health in specific, the demographics most likely to go online for health information are individuals
between the ages of 30-49, and those 65 and older, non-Hispanic whites, women, those with higher health literacy, college graduates, and those that use the Internet regularly already (Cutilli, 2010; Jensen, King, Davis, & Guntzviller, 2010; Pew Internet Project, 2013). Overall, this is a significant proportion of the population that are looking to the internet to find information regarding their health or the health of loved ones. However, health literacy is reported as a major barrier to gathering and understanding reliable medical and health information online (Gutierrez, Kindratt, Pagels, Foster, & Gimpel, 2014). An individual’s health literacy level will affect their ability to interpret the health information they are finding online, and therefore will likely affect how they feel and what they understand about that information. Most health information found online is on average at a grade 12 level for readability, emphasizing that health information online can often be difficult to understand (McInnes & Haglund, 2011). As the average individual in the United States reads at the grade 8 level, this creates a discrepancy that may frustrate, overwhelm, and alienate patients and their families (Gutierrez et al., 2014, McInnes & Haglund, 2011).

1.3 Internet Use and Genetic Counseling

There are many studies in the literature that examine internet use and health care from a broad perspective. There is a limited amount of research studies in the genetic counseling community specifically that examine what websites patients and families are finding online and what which have been helpful. As such, patient Internet use from a genetic counseling perspective is a “black box” of information not yet fully examined.

When faced with a chronic health problem and a genetic diagnosis, previous studies have shown that parents will seek out information to help them adjust to an uncertain future, fulfill a perceived responsibility of becoming an “expert” in their child’s condition, and to help them cope with this new diagnosis (Hummelinck & Pollock, 2006; Schaffer, Kuczynski, & Skinner, 2008;
Skinner & Schaffer, 2005). A landmark study completed in 2009 examined whether parents of a child referred for genetic services sought information online prior to an appointment. They found in this study that 69% of parents of these children searched the Internet for information, while an additional 14% of respondents had someone close to them search the information online for them, for a total of 83% of families receiving information from online sources prior to the genetics visit (Roche & Skinner, 2009). This number is estimated to be higher than estimates reported for other pediatric specialties (Wainstein, Sterling-Levis, Baker, Taitz, & Brydon, 2006). The parents who searched online for information reported that they sought information online regarding what to expect from their clinic visit, how best to prepare questions for their physician, examples of questions to ask, and to learn basic information on genetic terminology and concepts (Roche & Skinner, 2009). Having a diagnostic term in hand was extremely beneficial, and parents reported primarily using that term to begin their search (Roche & Skinner, 2009). Parents reported that once they found a site they trusted, they were unlikely to continue searching for new ones (Roche & Skinner, 2009). Parents reported convenience, anonymity, privacy and the ability to find previously un-obtained information as the main advantages of searching online (Roche & Skinner, 2009). These parents also reported that they felt that online sources were more up-to-date than printed sources provided in clinic (Roche & Skinner, 2009). Parents reported that one of the major difficulties of going online for information was the amount of information, and that this could become overwhelming (Roche & Skinner, 2009). Overall, those with lower incomes and less education were less likely to have ever used the Internet to search for health information, possibly reflecting the role of health literacy and online sources (Roche & Skinner, 2009). Of import, some parents expressed a need for guidance in assessing website reliability (Roche & Skinner, 2009). In conclusion, the authors proposed that genetic centers should begin to consider collaborative studies
to evaluate examples of information patients are accessing in an effort to judge educational effectiveness, which we aim to help provide (Roche & Skinner, 2009).

Regarding support group use and genetic disease, a major landmark paper in this area examined the use of internet support groups and the impacts they had for parents of children affected by Cornelia de Lange Syndrome (Cacioppo, Conway, Mehta, Krantz, & Noon, 2016). This study found that 82% of participants (142/170) visited an online support group on Facebook or through a discussion forum to find emotional support (71.7%) or health and management information regarding their child’s diagnosis (63.9%). Common motivators for seeking out support and/or information were wanting to connect to other parents, lack of prior knowledge about the diagnosis, lack of emotional support in their personal life, lack of information regarding management, feeling as though they had received inadequate information from their providers, or wanting to help others in the support group (Cacioppo et al., 2016). Most individuals participating reported finding online support groups to be helpful for medical information and emotional support (63.9%) (Cacioppo et al., 2016). Of note, Cacioppo et al. found that internet support group participation had a concrete effect on aspects of the child’s care. This effect was most profound on day-to-day management, diet, therapeutic interventions, and health care providers (Cacioppo et al., 2016).

One major argument made in a recent article from 2015 entitled “It’s Time for the Genetic Counseling Profession to Embrace Social Media”, stated that considering a genetic counselors role as an educator, a major role for genetic counselors in today’s online society could be providing patients with reliable online references, resources and communities to reduce the risk of misinformation (Gallagher, McCuaig, Benoit, & Davies, 2016). This is reflected by the need expressed by parents in Roche & Skinner to have help and guidance from their providers in
searching online for information. However, for most diseases we lack a lot of the data behind which sources are reliable, and which are the most helpful for our patients. It’s regarded that a major concern in the evolving relationship between health care and the Internet is the risk of disseminating poor quality information (Gallagher et al., 2016). Due to the ease of creating user generated content, content can be created that contains misinformation. Depending on that user’s audience, this misinformation can spread and create disastrous consequences for health. One broad, and publicized example of this in recent years is the anti-vaccination movement. The Internet played a major role in the dissemination and sensationalizing of what was ultimately unreliable and misinformed information (Kata, 2010). When examined, 52% of individuals believe “all” or “almost all” information they find online to be credible, which can easily lead to misconceptions based on misleading information (Rainie & Fox, 2000). Due to the Internet’s nature, the online environment can sometimes be labelled “a modern day Pandora’s Box”, as inaccurate and deceptive information can be wildly available (Mayer & Till, 1996). As such, caution needs to be taken when evaluating the reliability of certain information online. This reinforces the need presented in the article by Roche et al. and Gallagher et al., that there may be a significant role for genetic counselors to play in the dissemination of accurate and reliable information online.

There is currently a gap in literature assessing website reliability so that genetic counselors can best provide patients with most accurate and reliable sources. As one study by Hamm et al. in 2013 states, the descriptive and qualitative data that currently exists examines fairly broad topics, but there is a current lack of studies focusing on how effective internet use is for specific populations (Hamm et al., 2013). We believe it would be beneficial to the genetic counseling community to complete a study that examines the DMD and BMD parent population as population
representative of a rare disease where extensive research is being completed and the current information is changing rapidly. DMD is particularly interesting as the natural history of the condition has changed drastically over the course of the past decade. This change may affect what parents could be finding online if websites are not up to date. Our knowledge of the prognosis of DMD is changing with new treatments and advances. Internet resources can be slow to update and can often include out-of-date information. Therefore, examining the DMD and BMD population may provide unique insights into the importance of understanding the online web searching experience of a rare disease population. We plan to do this by examining the exploration of websites that patients and their families are finding; what was found to be helpful, what was overwhelming, why they searched online, and how the information online affected their lives and their child’s lives. By examining this patient niche we believe this work can guide providers to ensure we are sending patients and their families to the appropriate sites that reinforce said the information learned in clinic, reduce misinformation, and keep families safe from unreliable sources. The social media journey and experience of parents is a phenomenon not yet extensively explored, and this work aims to provide an increased understanding of the role of patient and family Internet use in genetic health care.
II: Methodology

2.1 IRB Approval
The Institutional Research Boards of Boston Children’s Hospital and Brandeis University reviewed and approved this research. Due to the anonymous nature of our survey, both IRB’s decided the study was exempt for approval.

2.2 Participants
Our main study population was parents and/or primary caregivers of children with Duchenne Muscular Dystrophy (DMD) or Becker Muscular Dystrophy (BMD). We focused on parents and/or primary caregivers of those children that were given a diagnosis within the past ten years. Parents of children diagnosed outside that time range were excluded. This was to compile a patient population during a time where the Internet was a reliable and present source of information for parents to access. We also required parents and/or caregivers to have used the Internet in the past ten years to search for information about DMD. To ensure that within the study we only obtain information from those that are relevant, we included several questions at the onset of the survey that acted as exclusionary conditions (Appendix 3). This ensured that those parents and/or caregivers that answered most the questions met our inclusion criteria.

We recruited individuals through the DuchenneConnect online mailing list. They distributed our recruitment brochure (Appendix 2) to 1837 eligible individuals. Those that signed up for this mailing list have identified themselves as being open to research participation. We also recruited individuals through in person recruitment in the Neuromuscular Clinic at Boston
Children’s Hospital. By recruiting participants both online and in person through clinic, we hoped that this would reduce recruitment bias in our sample population. Our recruitment notice included a link to our survey, and encouraged participants to contact myself or Elicia Estrella, MS, LCGC directly by email if they had any questions or concerns.

2.3 Procedures
Data collection took place through a quantitative survey with additional open ended questions in place to allow for our participants to elaborate on their answers to certain questions (Appendix 3). This allowed us to complete statistical analysis for quantitative questions, and theme analysis following our qualitative queries. Our survey was partially modified from the survey used in Cacciopo et al., 2016. Furthermore, the survey from Cacciopo et al., 2016 used a focus group prior to their launching of the survey, and some of their questions were modified for our purposes.

Data collection was completed anonymously to protect participant privacy. The survey was hosted on the Brandeis server of qualtrics.com. Our survey was separated into the following sections: Inclusion Criteria, Internet Use, Internet Support Groups, and Psychosocial Considerations (Appendix 3). This allowed us to ask questions to our participants on a wide range of topics regarding their online and web searching experience looking for information on Duchenne Muscular Dystrophy. Demographic information was included at the end of the survey. We gave the option for participants to skip any question other than major inclusion criterion. Some survey question choices were randomized to prevent participant bias of clicking top choices.

2.4 Data Management & Analysis
Anonymous data collected was downloaded from qualtrics and held on an encrypted laptop. Data was analyzed through two methods: statistical analysis and analysis for themes. For closed-ended quantitative questions, we used the statistical software SPSS Statistics to examine for statistically
significant values (p<0.05). We applied thematic analysis by examining the qualitative open-ended questions for unifying themes and major areas of focus.
III: Results

3.1 Internet Survey Participants

We had 80 total respondents to our survey: 77 who have a child diagnosed with DMD, and 3 who have a child diagnosed with Becker Muscular Dystrophy (BMD). On average, it has been 5.36 years (standard deviation = 2.8) since their child’s diagnosis. Individuals heard about the diagnosis in person (50/80 or 63.3%) or over the phone (25/80 or 31.6%). Participants mostly rated their experience at diagnosis as extremely negative (37/80 or 46.3%) or slightly negative (18/80 or 22.5%). All 80 participants reported that they had used the internet to search for information regarding DMD/BMD before or after their child’s diagnosis. They searched either before the diagnosis (20/80 or 25.3%) or immediately after (56/80 or 70.9%). Please see Table 6.1 in the Appendix for further demographic information.

3.2 Respondent Experiences with Searching Online for Information Post-Diagnosis

Overall, 51.3% of participants (41/76) did not receive internet resources from their health care provider(s) at diagnosis. Most of the 36.3% who did receive resources (29/76) reported that this was a helpful starting point to begin their search (27/29 or 93.1%). For the 41 participants that did not, the majority reported that having recommended online material would have been helpful (42/46 or 87.5%). Parents reported multiple factors that influenced their decision to search online for information, which are found in Figure 1 below.
In total, participants reported visiting 27 different websites that provide information regarding Duchenne or Becker Muscular Dystrophy. The full list can be found in Appendix 3 within this survey questions. The five most visited websites were Parent Project MD (71/80), MDA.org (70/80), Duchenne Connect (67/80), CureDuchenne.org (61/80) and WebMD (38/80). Participants rated each website according to their satisfaction with the amount of information provided, with the quality of the information on the website, and with the readability of said information. The differences in satisfaction between the bottom 5 websites (WebMd, Mayoclinic.org, Wikipedia, CDC.org, with the worst rated being Medscape.com) and the top 5 websites (top website was Parent Project MD, followed by Duchenne Connect, Charley’s Fund, CureDuchenne.org and MDA.org) is statistically significant (p<0.01). The ratings for the top 5 and the bottom 5 rated websites are found in Figures 3.2 and 3.3.
Figure 3.2: The top 5 best DMD/BMD related websites as rated by participants. 80 total respondents. By average, the top-rated website was Parent Project MD with an overall satisfaction score of 4.59, followed by Duchenne Connect (4.35), Charley’s Fund (4.22), CureDuchenne.org (4.2), and MDA.org (3.95).

Figure 3.3: The bottom 5 worst DMD/BMD related websites as rated by participants. 80 total respondents. By average, the worst rated website was Medscape.com with an overall satisfaction score of 3.28, followed by CDC.gov (3.34), Wikipedia (3.36), Mayoclinic.org (3.46) and WebMD (3.50).
Participants rated their experience online regarding their search for medical information primarily as extremely useful (29/72 or 39.2%), very useful (27/72 or 36.5%) or somewhat useful (15/72 or 20.3%). Themes for why included finding community (“I was able to connect with others and find a place to get treatment”; “helped me cope and learn about others fighting”), helped to find additional resources and information for management at their own time and pace (“they always seem to be updated frequently which is nice to have the most accurate information”), that it provided a place to turn to after a terrible diagnosis (“it gave me options for better care after a terrible diagnosis experience”), that they felt a more personal connection to the information online (“many of the above websites give the info as one who has experience the life of Duchenne themselves”) and that the information could be overwhelming (“Initial searches...provided way too many choices. I needed direction on which sites to search for.”; “There is so much to understand, and it takes time and research”).

Most respondents (32/53, or 60.4%) reported that their child or their family participated in clinical studies related to DMD/BMD that they learned about through online sources. Participants were statistically more likely to participate in a clinical study they heard about online if they felt that their experience searching online for information was extremely useful, or, if they searched online for new information once per week or once per month (p<0.05).

A majority reported that they felt the information they found online was overwhelming (58/75 or 77.3%). Themes for why included difficulty in assessing what best applied to their child (“it’s hard to determine what best applies to me”; “because nothing is cut and dry, every child is different”; “it’s a treasure hunt for useful information”), the amount of information (“the information can be a lot to take in when you process the end results for your child”; “I didn’t know what to look for and there was so much information”), that the prognosis is scary (“no one wants...
to read these things about their own child, it’s heartbreaking”; “I read to help myself understand, but with understanding comes great fear and sadness”), that there can be many differing opinions (“there are so many different opinions for DMD... I often question if I am making the right choice”; “too many potential developments and clinical trials and yet, none of them actually materializing”), and finding out-of-date or inaccurate information (“hard to distinguish what was timely and accurate, a lot of misinformation”; “There is a lot of outdated information online”). Feeling overwhelmed was not influenced by factors such as time since diagnosis, education or income level, or experience at diagnosis. Female participants were statistically more likely to feel overwhelmed by information online than male participants (p<0.05) (Table 3.1).

Table 3.1: Frequency Table of Participant Gender against whether they found the information online overwhelming or not. There was a statistically significant difference in between the male and female participant groups (p<0.05)

<table>
<thead>
<tr>
<th>Did you ever feel as though the information you found was overwhelming?</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your gender?</td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>5</td>
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</tbody>
</table>

Major barrier’s felt by participants searching online included feeling as though there’s too much information out there (21/40 or 52.5%), being unsure of which resources to trust (18/40 or 45%), confusion on which websites were the most informative (15/40 or 37.5%) and confusion on which websites to access (13/40 or 32.5%). While not statistically significant, more participants reported experiencing barriers to their online search if they were not provided internet resources at diagnosis.
Table 3.2: Participant barriers experienced if they were provided resources at diagnosis against if they were not. A trend was noted that more participants who were not provided resources, reported experiencing more barriers than those who had been given resources.

Most respondents did not feel that they have encountered misinformation online (42/76 or 55.3%). For the 34/76 respondents (44.7%) who reported encountering misinformation, themes included supplements and diet, “a quick fix”, or natural treatments (“people saying they could cure DMD with nutrition and supplements”) and out-dated information (“mobility and life expectancy was based on old information”; “stats that are a little outdated”). Some participants stressed the importance of being cautious and the difficulty in determining what is true and false online. One stated “You must be cautious about the sites you choose to read. Because parents are desperately seeking ways to save our sons some sites will offer solutions that are not legitimate but many people will buy in because we have no other hope”. A majority discovered that information was misinformation because it contradicted information they trusted (20/39 or 51.3%) or they asked for clarification from a health provider (14/39 or 35.9%).

Most participants rated themselves as somewhat likely to trust information they read online about DMD/BMD (45/76 or 59.2%). Likeliness to trust information was not affected by gender, income or education level. Participants who reported not encountering misinformation online were statistically more likely to trust information they read online about DMD/BMD (p<0.05) than those
that had found misinformation. Similarly, most participants rated themselves as neutral (14/76 or 18.4%) or somewhat comfortable (31/76 or 40.8%) in using information found online in making health decisions for their children. Participants of higher education levels were statistically less likely to be comfortable using information found online in making health decisions (p<0.01).

Overall, themes for what participants found searching online included hope, good support, information websites, management information, clinical trials, and a few “go-to” resources, giving them a “good sense of the research going on”. Many participants stated that searching online provided them “valid proof that [they] can hold out hope”, and they found “that they are not alone in fighting this disease”. While many acknowledged the initial part of their search was overwhelming, they highlighted how they eventually were pointed in the right direction, and eventually found what they felt to be accurate information. One parent stated, “In the beginning, we found an abundance of terrifying, dismal, unhelpful information. Since then, we’ve connected with DuchenneConnect, PPMD, Cure Duchenne, etc, which has completely changed our outlook on the information available online”. Another, “Knowing the experience of other parents who have children with Duchenne is priceless. ... I’m able to find the information I am looking for from what I consider reputable sources and I am better equipped to manage my son’s care”.

3.3 Respondent Experiences with Internet Support Groups Post-Diagnosis

Overall, 53/76 participants (69.7%) reported that that they visited an Internet-based support group to find support or information about their child’s diagnosis. Main reasons why included wanting to connect with other parents (48/53 or 90.6%), and wanting to contribute to DMD/BMD research (27/53 or 50.9%). Participants who lived further away from their child’s clinic are statistically more likely to use Internet Support Groups (p<0.05).
3.4 The Psychosocial and Medical Impact of Searching Online

When asked to rate the emotional impact of their experiences searching online, the majority rated the experience as mixed (39/75 or 52%), followed by positive (35/75 or 46.7%). No respondents rated the impact as negative. Many participants reported that aspects of their lives changed because of information they gained from online sources. The top 5 changes made were medical management for their child (46/76 or 60.5%), their perception of their child with DMD/BMD (42/76 or 55.3%), their family dynamic (26/76 or 34.2%), their family finances (22.4%), or their family location or housing (16/76 or 21.1%). When medical management was examined further, we found many changes made to their child’s medical care included, see below in Figure 3.4.

Figure 3.4: Aspects of the participant’s child's care that changed because of information gained from their experience searching online. 76 total respondents.
IV: Discussion

The emergence of the global Internet has led to its use as a unique and powerful tool in the search for information, including health information. It has a profound and unique impact on the amount and types of information that parents with a child with a genetic condition can obtain. In our study, we found that all individuals who participated used the internet as a resource. We found that this had concrete effects both positive and negative on their lives and the lives of their children who are affected by DMD/BMD.

4.1 Providing Resources at the Time of Diagnosis

The participants in our study were mostly parents and mothers, which are two characteristic demographics known to be associated with higher rates of internet use (Amante et al., 2015; Madden & Fox, 2006; Roche & Skinner, 2009). Additionally, our participants were mostly white, a majority with a higher household income than the United States average, and of high education level with a majority having at least a college or an advanced degree. These demographics, are also associated with higher rates of Internet use, especially with a genetic disease in a family (Amante et al., 2015; Rice, 2006; Roche & Skinner, 2009; Taylor, Alman, & Manchester, 2001). Based on our demographic information, we can assume a high rate of health literacy amongst our patient group (Gutierrez et al., 2014). An example of this phenomenon is reflected by how our participants with a higher education level were statistically less likely to trust the information they would read online in making healthcare decisions. Interestingly we still found that the feelings of being overwhelmed by the information online were still very prominent in this group despite the
high health literacy in this group (Gutierrez et al., 2014). Our data suggests that while feeling overwhelmed was not impacted by income, education, or ethnicity, it was by gender, with female respondents statistically more likely to feel overwhelmed than males. This indicates that feeling overwhelmed is not strictly linked with an estimation of health literacy. From a provider perspective, this may reflect the importance of providing referrals and resources to all patients that come through our doors.

A majority noted their experience at diagnosis to be either extremely negative (46.3%), or slightly negative (22.5%). This data reflects the literature examining parental experiences, which find approximately 60%-70% reporting negative experiences following a diagnosis of a genetic condition (Ashtiani, Makela, Carrion, & Austin, 2014; Waxler, Cherniske, Dieter, Herd, & Pober, 2013). While research suggests the value parents place in having a diagnosis and a name for what their child is experiencing, the disclosure itself is understandably a very negative experience (Makela, Birch, Friedman, & Marra, 2009). While the breaking of bad news for a significant condition such as Duchenne Muscular Dystrophy is something that is never likely to be a positive experience, there is a role for genetic counselors and health care providers in doing what we can to help parents through the experience.

The theme of hope was one that we found throughout our study. In asking what respondents were hoping to find, and what they did find in their online searches, many participants highlighted the need for hope not only in their diagnostic odyssey but also throughout their child’s lifetime. Previous literature on this topic highlights the importance of parents receiving a message that includes hope during the diagnosis disclosure, but we are the first study to highlight this as a factor influencing the search for information following a diagnosis as well (Ashtiani et al., 2014; Waxler et al., 2013).
In examining support group usage, we found that as families lived further away from their child’s main neurologic clinic, they were statistically more likely to use Internet Support Groups. This stresses the importance of acknowledging how parents may turn to easy-to-access resources such as online sources when in person resources may be harder to access. We found that primary motivations for accessing support groups include wanting to connect with other parents (90.6%), and wanting to contribute to research (50.9%). Other studies have implicated the search for information and advice from other parents as additional motivators (Cacioppo et al., 2016). This further highlights the importance of providing good quality and accurate internet resources to parents, especially to those whose access to providers may be impeded.

One striking piece of data was over half of respondents had not received internet resources or links from their health care providers following diagnosis, and yet most reported that it would have been helpful to have been provided resources. When asked why searching online for information was overwhelming, a major theme was the amount of information available and the difficulty of sorting through to find the information most applicable to themselves and their child. When we probed regarding barriers experienced searching online for information, many respondents felt that the major barriers they had experienced centered around knowing which were the best websites with the most up to date and accurate information. Parents also noted the large amount of information out there (52.5%), being unsure on which resources to trust (45%), confusion on which websites were the most informative (37.5%), and confusion on which websites to access (32.5%). When each barrier was examined further, more people who said that they were not given resources at diagnosis reported experiencing each of these barriers when compared to people who were given resources at diagnosis (Table 3.2). When most participants report they are not given any internet resources at diagnosis, and are subsequently reporting having difficulty
identifying appropriate and accurate information about their child’s condition, health providers are missing a key contact point for helping their patient acquire online information and ultimately helping them adjust and accept their child’s diagnosis. By identifying this need, we can now stress the importance of providing internet resources to families at the time of diagnosis.

4.2 Participant Estimations of Website Reliability

Prior studies in the literature note that parents of children with a genetic disorder are in particular need of reliable knowledge, due to the rarity of the condition (Baas et al., 2015). This was supported by our study which showed the top motivators for searching online; additional information about the condition, and a lack of prior knowledge about the diagnosis. In Roche, et al., 2009, parents of children undergoing genetic evaluation expressed a need for further guidance in assessing website reliability. In addition, our thematic data suggests that it took time for participants to find the best websites for them. For instance, one participant stated that part of why they felt the information online to be overwhelming was because “I didn’t know what to look for and there was so much information”. In addition, another stated that “initial searches yielded way too much information. I needed specific direction”. This highlights the need to provide that direction in this population. In this study, by asking participants to rank websites on their satisfaction with their readability, quality of information and amount of information, we have a concrete list of the highest rated websites by parents and caregivers of children affected by DMD or BMD. We believe this list will be useful in providing resources to families. However, of note is the potential differences between what providers may rate as the best websites, versus what parents have rated. Websites that providers may trust more, such as GeneReviews, Genetics Home Reference, PubMed, or OMIM, were much lower ranked than family and support oriented websites such as Duchenne Connect. This highlights the need for further research to examine how genetic
counselors or clinician’s may rate websites and what they look for in websites. For the best website ratings, it may be important not only to get the parent and family perspective, but also the perspective of health care providers. If we can average family and provider ratings that would direct us to the most accurate ratings and best websites to refer our patients.

Examination of our data against what comes up on the first page of Google leads to interesting conclusions. For instance, the top 8 websites that appear when you search ‘Duchenne Muscular Dystrophy’ into Google are in order: MDA.org, Parent Project MD, Wikipedia, MedlinePlus, RareDiseases.info, Genetics Home Reference, WebMed, and CureDuchenne.org. Despite appearing very early in the search, our study showed that Genetics Home Reference only had 1 visit, and similarly RareDiseases.info was visited by only 9 respondents. The others show some of the top-rated websites (MDA, PPMD and CureDuchenne), and the worst-rated (Wikipedia, MedlinePlus, and WebMD). Interestingly, our other 2 top rated websites, Charley’s Fund and DuchenneConnect, do not appear until page 4 and page 5 respectively. This emphasises the extent to which parents and caregivers are thoroughly searching for information online and stresses the need for GC and providers to help guide patients and families to the accurate informational sites.

4.3 The Need for Websites to Keep Up-to-Date

The Duchenne and Becker Muscular Dystrophy population is a particularly interesting one as with the many clinical trials and recent treatment advances, it represents a genetic disease in which the previous understanding of its natural history is rapidly being replaced. With the advent of molecular therapies such as the Exondys 51, and increased symptom treatment individuals are living 10 to 20 years longer as compared to the life expectancy from the 1980s and 1990s (Bushby et al., 2010, 2016; Essen et al., 1997; Falzarano et al., 2015; Passamano et al., 2012). As such, we
hypothesized that individuals could encounter this out-of-date information online which could contribute to misunderstandings about the current DMD landscape. This hypothesis proved correct as participants when explaining why they felt overwhelmed reported that out-of-date information and statistics contributed. As such, we believe this highlights the need for websites to stay up-to-date on the most current information. While the ever-changing landscape for a disease such as DMD may prove difficult to keep up with at times, we found in our study that finding out of date information contributes to a participant’s feeling overwhelmed.

4.4 Misinformation Online

Misinformation is prevalent online, and as such we expected many participants to have encountered it in online. While the prevalence of this misinformation is a significant concern for many, it is proposed that genetic health providers should view their patient’s internet experience as an opportunity to extend their reach outside their clinic (Roche & Skinner, 2009). As such, a discussion and inquiry into parents’ Internet searching could be a very important part of the genetic counseling session. This could validate the parents’ search, yet also correct misinformation and reinforce accurate information. This would help identify what kinds of information the family is accessing, and help identify barriers the family may face in understanding the information they are finding and help point them in the right direction (Roche & Skinner, 2009). In this thesis we highlight the potential importance of providing resources at diagnosis; there may also be import in keeping a list of websites that can be provided in sessions following diagnosis as well to help reinforce accurate information.

Most encouraging was that many respondents reported that they go to their providers for clarification on information online (35.9%). However, health literacy does come into play, as respondents with lower education levels were statistically more likely to be comfortable using
information found online in making healthcare decisions. This highlights the need in clinic to continue to be aware of the needs of lower health literacy families, to help make them aware of what is online.

4.5 Overall Practice Implications – Importance of Providing Resources at Diagnosis

Our study highlights the importance that the online search plays in parents and caregivers gaining information about a genetic disorder. Similar to other studies, we found common motivators for searching online such as seeking out community, finding out information about management or the diagnosis itself (Cacioppo et al., 2016). We also found similar concrete effects of internet use: seeing changes on day-to-day management, therapeutic interventions and healthcare providers (Cacioppo et al., 2016). Unique to our study is noting the extent to which parents are finding and enrolling in clinical trials that they have found through online means. This is an important consideration as clinical trials are a major source of research. Ensuring parents have appropriate access to find these trials is very important, and as providers we need to acknowledge the importance of online sources in matching up families with trials in the area. Our research helps to highlight the utility of medical information learned through the online searching experience, as most of our participants saw a change to their lives or the healthcare of their children through information learned, and overall felt that the experience was extremely (39.2%) or very (36.5%) useful. While the literature often focuses on the positive aspects of the online experience, we also aimed to examine some of the negatives as well, such as encountering misinformation, feeling that the information can be heartbreaking, and feeling overwhelmed.

A main goal of our study was to examine the parental and caregiver experience online to better tailor resources at diagnosis. We believe our data clearly emphasizes the need for patients to be provided with online resources at diagnosis. Genetic counselors or other providers should
identify a list of parents- or caregiver-rated websites, and highlight the importance that these sanctioned websites stay up to date and accurate. We highlight the importance of staying aware of a family’s health literacy, to best direct them to the most appropriate resources. There may also be a role for genetic counselors in best directing families to resources where they can find out more about clinical trials, given the extent to which the participants in our study enrolled in clinical trials they found online. With this, we also propose the use of open communication and discussion during a session, to best understand what the family has read and searched, and emphasize or correct information as we see relevant.

However, we also must be realistic surrounding what can be best done at the time of diagnosis. The literature provides evidence of how diagnosis can be a very negative and overwhelming time (Ashtiani et al., 2014; Makela et al., 2009). This can be made even more overwhelming due to the amount of information provided, the family’s often lack of genetic knowledge, and denial regarding diagnosis, which can contribute to misunderstandings (Klitzman, 2010). This is highlighted in our data, as the main factor influencing the online search was to find additional medical information not provided by providers. This may be reflecting the denial regarding the diagnosis, and may reflect how the literature notes difficulty in remembering information provided at diagnosis (Klitzman, 2010). As healthcare providers, it can sometimes not be in our patient’s best interest to force some of these discussions at diagnosis itself. This may depend on the patient themselves and what they’re needs are in that moment. Rather than ensuring one discusses misinformation for instance, resources such as pamphlets could be developed at clinics that list the top-rated websites, and include information about what to be cautious of online. That would ensure that the parent or caregiver receives information about online resources at
4.6 Study Limitations

There are several limitations to this study. Firstly, there may be bias in our parental ratings of websites, as Parent Project MD and DuchenneConnect were major sources of survey distribution. In our participant population, we aimed to decrease ascertainment bias by recruiting online and in person, however most respondents were still recruited online. As well, it is possible that the finding that all our participants searched online for information is a function of selection bias – that families who did not search online were less likely to participate in our study. Additionally, our study demographics showed mostly Caucasian individuals, mothers, with extensive education, which led to a less representative sample.

4.7 Future Directions

We believe that many future studies could result from our work. The influence of the online experience in healthcare has previously not been well understood or studied. Our results constitute the most in depth research into the parental online experience following a genetic diagnosis. While the data may not be generalizable across all rare genetic disease populations, this is valuable insight into a unique population. Future work could continue this research in a more heterogeneous population of patients with rare diseases. Additionally, we could expand this examination to survey genetic counselors and other health care providers, to compare and contrast their feelings about website accuracy, to compile a provider-rated list of websites and examine their thoughts regarding internet referrals. We hope that this work can be expanded further to aid in the development of National Society of Genetic Counselor (NSGC) best practice guidelines for recommending websites to patients. We feel that such guidelines would better direct parents and caregivers to the
most accurate information online, help reduce misinformation, and aid patients and their families in processing their given diagnosis.
V: Conclusions

Prior to this project, there was a gap in the genetic counseling literature assaying website reliability and the full online experience of parents and caregivers from a rare disease population. Our study provides crucial insight into the online and web searching experience of parents and caregivers of children with a diagnosis of Duchenne or Becker Muscular Dystrophy. This allows for greater insight into what parents and caregivers are searching for and their online experience once they leave a provider’s office. Our study shows that online sources are a valuable and useful resource for these families. The information found on many of the websites results in concrete changes to the family’s life and to their lives of their child affected. Our findings emphasize the need for Internet referrals and resources provided to families following a diagnosis to; reduce overwhelming feelings when they go online, reduce misinformation, and direct them to the online sources with the most accurate information. This is reflected by previous studies that propose the need for genetic counselors to provide patients with reliable online references, resources, and communities (Gallagher et al., 2016). Overall, we believe this work has significant relevancy regarding referral provision at diagnosis. With future studies building upon our work, we believe this study is a foundation for the future development of NSGC best practice guidelines for rare disease websites.
VI: References


VII: Appendix

Appendix 1: Demographic Information from Participants

<table>
<thead>
<tr>
<th>Demographic Information</th>
<th>Total number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child with DMD or BMD?</strong></td>
<td>80</td>
</tr>
<tr>
<td>DMD</td>
<td>77 (96.3)</td>
</tr>
<tr>
<td>BMD</td>
<td>3 (3.7)</td>
</tr>
<tr>
<td><strong>Average age of participant’s child</strong></td>
<td>80</td>
</tr>
<tr>
<td></td>
<td>8.5 years (+/- 3.5)</td>
</tr>
<tr>
<td><strong>Time since Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>0–2 years since diagnosis</td>
<td>28 (35)</td>
</tr>
<tr>
<td>3-5 years since diagnosis</td>
<td>20 (25)</td>
</tr>
<tr>
<td>6 - 9 years since diagnosis</td>
<td>32 (40)</td>
</tr>
<tr>
<td><strong>Participants Gender</strong></td>
<td>76</td>
</tr>
<tr>
<td>Female</td>
<td>63 (82.9)</td>
</tr>
<tr>
<td>Male</td>
<td>12 (15.8)</td>
</tr>
<tr>
<td>Prefer Not to Say</td>
<td>1 (1.3)</td>
</tr>
<tr>
<td><strong>Participants Age</strong></td>
<td>74</td>
</tr>
<tr>
<td></td>
<td>40.2 years (+/- 7.4)</td>
</tr>
<tr>
<td><strong>Relationship to child with DMD/BMD</strong></td>
<td>74</td>
</tr>
<tr>
<td>Mother</td>
<td>60 (81.1)</td>
</tr>
<tr>
<td>Father</td>
<td>9 (12.1)</td>
</tr>
<tr>
<td>Grandmother</td>
<td>1 (1.4)</td>
</tr>
<tr>
<td>Adoptive Mother</td>
<td>3 (4.1)</td>
</tr>
<tr>
<td>Adoptive Father</td>
<td>1 (1.4)</td>
</tr>
<tr>
<td><strong>Participant's Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>62 (83.8)</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>4 (5.3)</td>
</tr>
<tr>
<td>South Asian</td>
<td>3 (4.1)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (4.1)</td>
</tr>
<tr>
<td>East Asian</td>
<td>1 (1.3)</td>
</tr>
</tbody>
</table>
### Participant's Education Level

<table>
<thead>
<tr>
<th>Level</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advanced Degree</td>
<td>20 (27)</td>
</tr>
<tr>
<td>College Degree</td>
<td>33 (44.6)</td>
</tr>
<tr>
<td>Some College</td>
<td>14 (18.9)</td>
</tr>
<tr>
<td>Trade School</td>
<td>1 (1.4)</td>
</tr>
<tr>
<td>High School</td>
<td>6 (8.1)</td>
</tr>
</tbody>
</table>

### Participant's Income Level

<table>
<thead>
<tr>
<th>Income Level</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>$0-$29,999</td>
<td>8 (11.3)</td>
</tr>
<tr>
<td>$30,000 - $59,999</td>
<td>15 (21.1)</td>
</tr>
<tr>
<td>$60,000 - $89,999</td>
<td>16 (22.5)</td>
</tr>
<tr>
<td>$90,000+</td>
<td>32 (45.1)</td>
</tr>
</tbody>
</table>

### How many affected children?

<table>
<thead>
<tr>
<th>Number</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>69 (86.3)</td>
</tr>
<tr>
<td>Two</td>
<td>10 (12.5)</td>
</tr>
<tr>
<td>Three</td>
<td>1 (1.3)</td>
</tr>
</tbody>
</table>

### At what age was your child diagnosed?

<table>
<thead>
<tr>
<th>Age</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-2 years</td>
<td>18 (22.5)</td>
</tr>
<tr>
<td>3-5 years</td>
<td>33 (41.2)</td>
</tr>
<tr>
<td>6 - 8 years</td>
<td>24 (30)</td>
</tr>
<tr>
<td>9 - 12 years</td>
<td>4 (5)</td>
</tr>
<tr>
<td>13 + years</td>
<td>1 (1.3)</td>
</tr>
</tbody>
</table>

### Where you found to be a carrier of a mutation in Dystrophin?

<table>
<thead>
<tr>
<th>Response</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>36 (48.7)</td>
</tr>
<tr>
<td>No</td>
<td>30 (40.5)</td>
</tr>
<tr>
<td>I don't remember</td>
<td>8 (10.8)</td>
</tr>
</tbody>
</table>

### What is the gender of your child with DMD/BMD?

<table>
<thead>
<tr>
<th>Gender</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>75 (98.7)</td>
</tr>
<tr>
<td>Female</td>
<td>1 (1.3)</td>
</tr>
</tbody>
</table>

Table 7.1: Demographic information collected from participants.
Appendix 2: Recruitment Notice

Purpose of the study: This study is part of a Master’s Thesis project and will explore the online activity and web searching experience of parents of children with Duchenne Muscular Dystrophy or Becker Muscular Dystrophy.

Who can participate? Parents of children with Duchenne Muscular Dystrophy or Becker Muscular Dystrophy.

Where is the study being conducted? The study is a combined effort of Brandeis University and Boston Children’s Hospital.

What do I have to do if I’m in the study and what is the time commitment? You will need to fill out a survey to explore your online activity and web searching experience. The survey takes less than 20 minutes to complete, it is anonymous, and both parents in a family welcome to participate.

The information gained from this survey will provide insight into what parents are finding online and how useful is the information. We aim to use our study results to help direct parents to high quality websites, reduce misinformation, and tailor referrals for additional help if needed by families.

What will I receive from participating? Your time and participation is very much appreciated! In thanks, if you participate you have the chance to win one of three $50 amazon gift cards.

If you feel that participating in this survey has brought up any feelings or issues you would like to discuss with a genetic counselor, please contact Elicia Estrella, MS, CGC, LGC to schedule an appointment 617-919-4552

This research is being conducted by: Elicia Estrella MS, CGC, LGC and Jackie Leonard, MSc. Please feel free to contact us at elicia.estrella@childrens.harvard.edu or jleonard@brandeis.edu if you have any questions or concerns.

Appendix 3: Survey Questions

The Internet's Black Box: What Parents of Children with Duchenne or Becker Muscular Dystrophy are Finding Online

**Purpose of the study:** As part of a master’s thesis project, this research will explore the online activity and web searching experience of parents of children with Duchenne Muscular Dystrophy or Becker Muscular Dystrophy.

**Who can participate?** Parents of children with Duchenne Muscular Dystrophy or Becker Muscular Dystrophy. Both parents in a family are welcome to participate.

**What do I have to do if I’m in the study and what is the time commitment?** You will need to fill out an online survey to explore your online activity and web searching experience. The survey takes less than 20 minutes to complete, it is anonymous, and both parents in a family are welcome to participate.

The information gained from this survey will provide insight into what parents are finding online and how useful is the information. We aim to use our study results to help direct parents to high quality websites, to reduce misinformation, and to tailor referrals for additional help if needed by families.

Keep in mind that survey responses are anonymous and participation is voluntary. You may choose to skip questions or stop participation at any time. No personal or identifying information will be collected or stored as part of this study.

**What will I receive from participating?** Your time and participation is very much appreciated!

In thanks, if you participate you have the chance to win one of three $50 amazon gift cards. If you choose to enter the gift card raffle, you will be asked to provide your email so we can contact you. This email address will not be linked to or stored with your survey responses.

This research is being conducted by: Elicia Estrella MS, CGC and Jacqueline Leonard, MSc.

Please feel free to contact Jacqueline at jmmleonard@brandeis.edu if you have any questions or concerns.

If you feel that participating in this survey has brought up any feelings or issues you would like to discuss with a genetic counselor, please contact Elicia Estrella, MS, CGC, LGC to schedule an appointment 617-919-4552.

The Institutional Review Boards (IRB) at Boston Children's Hospital and Brandeis University have reviewed and approved this study. The IRB evaluates human research studies like these to ensure that research subjects’ rights and welfare are protected. If you have questions about your rights or if you have a complaint, you can call the IRB Office at 617-355-7052.

By clicking "Next" you agree to participate in this survey.
1. Do you have a child/children affected by Duchenne Muscular Dystrophy (DMD) or Becker Muscular Dystrophy (BMD)?
   - DMD (1)
   - BMD (2)
   - Neither (3)

   If Neither Is Selected, Then Skip To End of Survey

2. How many affected children do you have?
   - One (1)
   - Two (2)
   - Other (3) ____________________

3. At what age was your child diagnosed with DMD/BMD?
   - 0 - 2 years (1)
   - 3 - 5 years (2)
   - 6 - 8 years (3)
   - 9 - 12 years (4)
   - 13 + years (5)

4. How many years has it been since your child's diagnosis?
   - 0 (1)
   - 1 (2)
   - 2 (3)
   - 3 (4)
   - 4 (5)
   - 5 (6)
   - 6 (7)
   - 7 (8)
   - 8 (9)
   - 9 (10)
   - 10 (11)
   - 11 + (12)

   If 11 + Is Selected, Then Skip To End of Survey

5. How old is your child now? ____________________

6. How did you hear about your child's diagnosis of DMD/BMD?
   - In person (1)
   - Over the phone (2)
   - Other (please specify) (3) ____________________
7. Overall, how would you rate your experience at diagnosis?
   - Extremely positive (1)
   - Slightly positive (2)
   - Neither positive nor negative (4)
   - Slightly negative (5)
   - Extremely negative (7)

8. Please select which of the following is true about genetic testing for your child.
   - A mutation was found in the Dystrophin gene (1)
   - My child has not had genetic testing (2)
   - My child has had genetic testing, but no mutation was identified (3)
   - I don't know (4)

**Section 1: Internet Use**

9. How much time (in hours) do you spend in total on the Internet on a typical day?
   - 0 - 1 hours (1)
   - 2 - 3 hours (2)
   - 4 - 5 hours (3)
   - 6 - 7 hours (4)
   - 8+ hours (5)

10. Please rate your comfort level using the Internet.
    - Extremely comfortable (1)
    - Somewhat comfortable (2)
    - Neither comfortable nor uncomfortable (3)
    - Somewhat uncomfortable (4)
    - Extremely uncomfortable (5)

11. Have you ever used the Internet to search for information about DMD/BMD, after your child's diagnosis?
    - Yes (1) (Continue)
    - No (2) (Skip to #16)

12. Which of the following influenced your decision to look for information on DMD/BMD following your child's diagnosis (Please select all that apply)
    - Lack of prior knowledge about the diagnosis (1)
    - Inadequate information from healthcare providers (2)
    - Incorrect information from healthcare providers (3)
    - Lack of information regarding management for BMD/DMD (4)
    - Wanting a second opinion about the diagnosis (5)
    - Wanting to search for additional medical information not provided by providers (6)
    - Other (please specify) (7) ____________________
13. After your child's diagnosis, were you provided with any internet resources by your health care provider(s)?
   - Yes (1)
   - No (2)
   - I don't remember (3)
   Condition: Yes Is Selected. Skip To: 14. If yes, was this a helpful starting point to begin your search?
   Condition: No Is Selected. Skip To: 15. If no, do you think it would have been helpful to have had recommended online material?
   Condition: I don't remember Is Selected. Skip To: #20. After 14 or 15 answered, skip to #20.

14. If yes, was this a helpful starting point to begin your search?
   - Yes (1)
   - No (2)
   - Other (please specify) (4) ____________________

15. If no, do you think it would have been helpful to have had recommended online material?
   - Yes (1)
   - No (2)
   - Other (please specify) (3) ____________________

Only show if no was selected in #11. After this set of questions (16 – 19), skip to end of survey

16. What was the reason that you have not searched the Internet for information about DMD/BMD? (Please select all that apply)
   - No access to Internet at home (1)
   - Not interested in looking (2)
   - I am happy with the information provided by my child's health care team and at appointments (3)
   - Other (please specify) (4) ____________________

17. After your child's diagnosis, were you provided with any internet resources by your health care provider(s)?
   - Yes (1)
   - No (2)
   - I don't remember (4)
   Condition: Yes Is Selected. Skip To: 18. If yes, was this a helpful starting point to begin your search?
   Condition: No Is Selected. Skip To: 19. If no, do you think it would have been helpful to have had recommended online material?

18. If yes, was this a helpful starting point to begin your search?
   - Yes (1)
   - No (2)
   - Other (please specify) (3) ____________________

19. If no, do you think it would have been helpful to have had recommended online material?
   - Yes (1)
   - No (2)
   - Other (please specify) (3) ____________________
20. How long after your child was diagnosed with DMD/BMD did you seek information online?
- Immediately (1)
- 1 - 3 weeks (2)
- 1 - 3 months (3)
- 4 - 7 months (4)
- 8 - 12 months (5)
- More than 1 year (6)
- I had begun seeking information online before my child was diagnosed (7)

21. What factors motivated you to click on certain websites other than others?
- Their website name (1)
- Their brief description (2)
- Recommendations from other parents (3)
- Recommendations from health providers (4)
- Other (please specify) (5) ____________________

22. Which of the following websites or blogs have you found or visited during your online search? Please select all that apply.
- MDA.org (1)
- Medline-Plus (2)
- Wikipedia (3)
- Parent Project MD (4)
- DuchenneConnect (5)
- CureDuchenne.org (6)
- Genetics Home Reference (7)
- GeneReviews (8)
- WebMD (9)
- RareDisease.info (10)
- National Organization of Rare Diseases (11)
- Suneel's Light (12)
- Medscape.com (13)
- Mayoclinic.org (14)
- DuchenneUK (15)
- OMIM (16)
- Healthline.com (17)
- CDC.gov (18)
- DMDfund.org (19)
- Muscular Dystrophy UK (20)
- Team Joseph (21)
- MuscularDystrophynews.com (22)
- Charley's Fund (23)
- Other (please specify) (24) ____________________
- Blogs (please specify) (25) ____________________
- Newspaper (please specify) (26) ____________________
23. On a scale from 1 to 5 (where 1 = very dissatisfied and 5 = very satisfied) please rate your satisfaction with the amount of information provided about DMD/BMD from each website you examined.

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<th>Website</th>
<th>1 = Very Dissatisfied (1)</th>
<th>2 = Somewhat Dissatisfied (2)</th>
<th>3 = Neither Dissatisfied or Satisfied (3)</th>
<th>4 = Somewhat Satisfied (4)</th>
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24. On a scale from 1 to 5 (where 1 = very dissatisfied and 5 = very satisfied) please rate your satisfaction with the quality of information provided about DMD/BMD from each website you examined.

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25. On a scale from 1 to 5 (where 1 = very dissatisfied and 5 = very satisfied) please rate your satisfaction with the readability of each website, and how easy it was to understand the information on each website you examined.

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26. On a scale of 1 to 5 (1 = not at all useful to 5 = extremely useful), how useful was your experience online in terms of finding medical information?
   ○ 1 = Not at all useful (1)
   ○ 2 = Slightly useful (2)
   ○ 3 = Moderately useful (3)
   ○ 4 = Very useful (4)
   ○ 5 = Extremely useful (5)

27. Please explain why you chose your answer to the above question. __________________________

28. Did you ever feel as though the information you found was overwhelming?
   ○ Yes (1)
   ○ No (2)

29. If YES: Please explain why you chose your answer to the above question.
   __________________________

30. Did you ever feel that you came across misinformation online?
   ○ Yes (1)
   ○ No (2)

31. If YES: please explain what type of misinformation you encountered, and where. __________________________

32. How did you discover that the information you found was misinformation?
   ☐ A fellow parent informed me (1)
   ☐ I asked a healthcare provider for clarification (2)
   ☐ I asked for a fellow parent's opinion (3)
   ☐ It contradicted information I trusted (4)
   ☐ Other (please specify) (5) __________________________

33. Have you ever taken action against misinformation online?
   ○ Yes (1)
   ○ No (2)

34. Why or why not? __________________________
35. Overall, what were you hoping to find through searching online? ________________

36. Overall, what have you found from searching online? ________________

37. How likely are you to trust information you read online about DMD/BMD?
   - Extremely unlikely (1)
   - Somewhat unlikely (2)
   - Neither likely nor unlikely (3)
   - Somewhat likely (4)
   - Extremely likely (5)

38. Please rate how comfortable you are in using information found online in making health decisions for your child.
   - Very comfortable (1)
   - Somewhat comfortable (2)
   - Neutral (3)
   - Somewhat uncomfortable (4)
   - Very uncomfortable (5)

39. What are some barriers you’ve experienced while searching online for information on DMD/BMD? (Please select all that apply.)
   - Lack of reliable Internet access (1)
   - Confusion on which websites to access (2)
   - Confusion on which websites are the most informative (3)
   - Feeling as though there's too much information out there (4)
   - Being unsure on which resources to trust (5)
   - I have not felt as though I've experienced barriers searching online (6)
   - Other (please specify) (7) ____________________

40. How often do you search for new information regarding DMD/BMD?
   - Once per week (1)
   - Once per month (2)
   - Once per every 3 - 6 months (3)
   - Once per year (4)
   - Have not looked for new information in the past year (5)

41. On a scale from 1 to 5 (where 1 = not helpful at all and 5 = very helpful), please rate how helpful online sources are in keeping up to date with the latest news regarding DMD/BMD.
   - 1 = not helpful at all (1)
   - 2 = rarely helpful (2)
   - 3 = neither unhelpful or helpful (3)
   - 4 = moderately helpful (4)
   - 5 = very helpful (5)
42. Did you search for information online about the Exondys drug approval?
   - Yes (1)
   - No (2)

Section 2: Internet Support Groups

43. Have you ever visited an Internet-based support group to find support or information about your child's diagnosis?
   - Yes (1)
   - No (2)

Display This Question:
   If Have you ever visited an Internet-based support group to find support or information about your child's diagnosis?: No Is Selected

44. What are some reasons that you have not visited an Internet support group related to DMD/BMD? (Please select all that apply.)
   - No access to Internet at home (1)
   - Not interested in Internet-based support groups (2)
   - Did not need emotional support (3)
   - Did not need any medical information (4)
   - Concern about privacy and/or confidentiality on the Internet (5)
   - Other (please specify) (6) ____________________

Display This Question:
   If Have you ever visited an Internet-based support group to find support or information about your child's diagnosis?: Yes Is Selected

45. Which of the following influenced your decision to look for DMD/BMD support groups on the Internet? Please select all that apply. ("Support" may include emotional, educational, or medical support.)
   - Lack of emotional support (1)
   - Wanting to connect with another parent who has a child with DMD/BMD (2)
   - Wanting to help others in the support group (3)
   - Wanting to contribute to DMD/BMD research (4)
   - Other (please specify) (5) ____________________
46. How long after you child was diagnosed with DMD/BMD did you seek support online?
- Immediately (1)
- 1 - 3 weeks (2)
- 1 - 3 months (3)
- 4 - 7 months (4)
- 8 - 12 months (5)
- More than 1 year (6)
- I had begun seeking support online before my child was diagnosed (7)

47. When describing your participation in Internet Support Groups for DMD/BMD, would you describe yourself as a spectator (observing posts and threads), an active participant (posing your own questions, answers, thoughts, or feelings), or both?
- Spectator (1)
- Active Participant (2)
- Both (3)

48. How often do you check your Internet Support Group(s), on average?
- More than once per day (1)
- Once per day (2)
- Once per week (3)
- Once every two weeks (4)
- Once per month (5)
- Less than once per month (6)

49. Please select the location of the Internet Support Groups that you have used to find support for your child's DMD/BMD diagnosis, if any. (Please select all that apply.)
- Facebook (1)
- Twitter (2)
- Discussion Boards run by an organization (3)
- Blogs (4)
- Video-sharing sites (for example: YouTube) (5)
- Other (please specify) (6) ____________________
50. On a scale of 1 to 5 (where 1 = very dissatisfied and 5 = very satisfied), please rate your satisfaction with each of the types of Internet Support Groups you have visited.

<table>
<thead>
<tr>
<th></th>
<th>1 = Very Dissatisfied (1)</th>
<th>2 = Somewhat Dissatisfied (2)</th>
<th>3 = Neutral (3)</th>
<th>4 = Somewhat Satisfied (4)</th>
<th>5 = Very Satisfied (5)</th>
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<tbody>
<tr>
<td>Facebook (x1)</td>
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<td>Discussion Boards run by an organization (x3)</td>
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<td>Blogs (x4)</td>
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<td>Video-sharing sites (for example: YouTube) (x5)</td>
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</table>

51. On a scale of 1 to 5 (where 1 = not helpful at all and 5 = extremely helpful), please rate how helpful your experience with Internet Support Groups has been in terms of finding support.

<table>
<thead>
<tr>
<th></th>
<th>1 = Not helpful at all (1)</th>
<th>2 = Rarely helpful (2)</th>
<th>3 = Moderately helpful (3)</th>
<th>4 = Very helpful (4)</th>
<th>5 = Extremely helpful (5)</th>
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</table>
52. Have you found Internet Support Groups or Informational websites to be the most useful tool in learning more about current research studies or clinical trials for patients with DMD/BMD and/or their families?

- Internet Support Groups (1)
- Informational Websites (2)
- Both equally (3)
- I prefer non-internet based sources (4)

53. Have you, your child, or your family participated in a study related to DMD/BMD that you learned about through online sources?

- Yes (1)
- No (2)

Section 3: Psychosocial Considerations

54. Which of the following have changed as a result of information gained from online sources? (Please select all that apply.)

- Family location/housing (1)
- Parent's jobs (2)
- Family finances (3)
- Family dynamic (openness, communication, etc) (4)
- Medical management (5)
- Your perception of your child with DMD/BMD (6)
- Your behaviour towards your other children, if any (7)
- Your behaviour towards your extended family (8)
- No change (9)
- Other (please specify) (10) ____________________

55. Which of the following aspects of your child's care has changed as a result of information gained from your experience searching online? (Please select all that apply.)

- Health insurance (1)
- Life insurance (2)
- Long term care or disability insurance (3)
- Mediation (4)
- Diet (5)
- Healthcare providers (physician, specialists, etc) (6)
- School system (7)
- Therapy Interventions (occupational therapy, physical therapy, etc) (8)
- Enrollment in clinical trials (9)
- Day-to-day management (10)
- No change (11)
- Other (please specify) (12) ____________________
56. Overall, would you consider the emotional impact of your experience searching online for information to be: Positive, Negative, or Mixed?
○ Positive (1)
○ Negative (2)
○ Mixed (3)
○ No impact (4)

Section 4: Demographics

57. What is your gender?
○ Male (1)
○ Female (2)
○ Prefer not to say (3)

58. What is the gender of your child with DMD/BMD?
○ Male (1)
○ Female (2)

59. What is your relationship to your child with DMD/BMD?
○ Mother (1)
○ Father (2)
○ Grandmother (3)
○ Grandfather (4)
○ Adoptive Mother (5)
○ Adoptive Father (6)
○ Legal Guardian (7)
○ Other (please specify) (8) __________________________________

60. What is your age? ____________________

61. Were you found to be a carrier for a mutation in Dystrophin?
○ Yes (1)
○ No (2)
○ I don't remember (3)

62. Which of the following describes your ethnicity?
○ Hispanic or Latino (1)
○ Non-Hispanic White (2)
○ Black (3)
○ Native American (4)
○ South Asian (5)
○ East Asian (6)
○ Other (please specify) (7) ____________________
63. Which of the following describes your highest level of education?

- Some high school (1)
- High School/GED (2)
- Trade School (3)
- Some College (4)
- College Degree (5)
- Advanced Degree (Masters, PhD) (6)

64. Please provide an estimate of your household income.

- $0-29,999 (1)
- $30,000 - 59,999 (2)
- $60,000 - 89,999 (3)
- $90,000 + (4)

65. How far do you have to drive (in hours) to get to your closest DMD/BMD clinic?

- 0 - 1 hour (1)
- 2 - 4 hours (2)
- 5 - 7 hours (3)
- 8 - 10 hours (4)
- 11 + hours (5)