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## Creating a Medical Nonprofit

An Honors College Project Thesis

Presented to

The Department of Chemistry and Biochemistry

Abilene Christian University

In partial fulfillment
of the requirements for
Honors Scholar

by

Kelsie Roberts

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This Project Thesis, directed and approved by the candidate's committee, has been accepted by the Honors College of Abilene Christian University in partial fulfillment of the requirements for the distinction

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#### **ABSTRACT**

Research was conducted on creating a nonprofit and investigating nonprofit organizations which already exist. The focus was on creating a nonprofit dedicated to aiding individuals afflicted with a chronic disease or disorder, that are currently underserved and render a significant burden on individuals and families involved. I highlighted the differences between nonprofit and for-profit organizations, described potential individuals the organization would strive to benefit, and stated additional requirements for starting a nonprofit. I concluded that the best structure for the social purpose of improving the quality of life of a population of individuals with a chronic neurological disease—through social support, fundraisers, financial contributions, and research grants—was a nonprofit organization. The potential nonprofit would file for a Certificate of Formation with the Secretary of State of Texas and file federal papers to be a 501(c)(3) tax-exempt nonprofit for a chronic neurological disease.

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### **Goals and Purposes**

This thesis project was conducted to research how to create a nonprofit organization, specifically an organization devoted to a particular portion of the community who are underserved and afflicted with a chronic illness. Research was directed toward nonprofit organizations already benefiting the community, charitable benefits associated with using spare change, the potential community the organization would pledge to serve, the requirements of starting a nonprofit, potential responsibilities of the Board of Directors, and additional tasks necessary to run a nonprofit.

The ultimate goal of this pursuit is to take this initial research to potential members of the Board of Directors and collectively create a nonprofit organization dedicated to serving individuals afflicted with a chronic disease or disorder, which is both underfunded in research and entails a significant burden on the families involved. Secondly, in the pursuit of creating a socially responsible organization, one of the major purposes of conducting this project is to seek healing and provide a caring environment for individuals struggling through physical and emotional pain. Additionally, by researching chronic diseases and disorders, I hope to broaden my medical background as I pursue a degree in medicine.

## **Existing Nonprofit Organizations**

One way to create social change that benefits both social causes and the economy is the collection of loose change. However, people often have little desire to collect loose change found on the ground. Josh Sunburn from TIME also describes pennies as a burden on the economy when he explains that the seigniorage—the difference between the face value of a coin and the cost of producing it—of the penny is -1.4¢. In addition, it was determined that the US

government ultimately lost \$27 million in 2010 from producing the penny, and \$60 million in 2011 (Sanburn, 2013). Therefore, the production of the penny is not cost effective to the economy, creating additional financial burdens. However, although the penny has little to no value to the economy, incorporating something that the economy deems worthless and turning it into hope for individuals who are in a relatively hopeless state, could be worthwhile to a social cause.

Many organizations have already tapped into this very idea. The "Pennies for Patients" foundation seeks to help patients who have Leukemia and Lymphoma, by collecting pennies and other loose change with the help of school children, and donating it to *The Leukemia* & Lymphoma Society. Operating since 1994, the foundation has raised over \$150 million with the help of community elementary school, middle school and high school students across the country ("15 Billion-Penny Milestone," 2016). Additionally, the nonprofit organization Common Cents, which has been operating for over 17 years, has an event called the "Penny Harvest". This national educational program is dedicated to teaching children about their beneficial worth in society, while raising over half a million dollars through penny collections ("15 Billion-Penny Milestone," 2016). Habitat for Humanity, a nonprofit dedicated to providing reliable houses to families around the world, has acknowledged the idea of the value of the penny, establishing a "Parade of Pennies" fundraiser and receiving over ten thousand dollars in composite donations ("Our Mission, Vision, and Principles," 2017). Every winter the Salvation Army also rests its hope on the donation of loose change and other willing donations. Throughout the year, the Salvation Army hosts a "Red Kettle Campaign" within communities, collecting large sums of pennies to benefit a variety of individuals, including: veterans, the homeless, children, families, and the elderly ("Doing the Most Good," 2017). Pennies from Heaven, also known as Caleb's

Foundation, has a mission to help families who have a child diagnosed with a critically ill disease. Pennies and larger donations go towards helping families in this position to pay for rent, groceries, electric bills, medical bills, and transportation, necessities to carry on living. The fundraiser was started up in memory of a young two-year old, Caleb Joseph, who lost his life after doctors discovered a malignant tumor in his brain. *Pennies from Heaven* now strives to bring relief and support to families who are going through similar tragedies ("Pennies from Heaven," 2014). Overall, these nonprofit organizations collect spare change, along with other donations, to help fund their missions. Whether these missions are centered around medical care, housing, or job support, the collection of coins has already proven to benefit social causes.

Other nonprofit organizations finance their social mission through larger charitable donations, charity activities (bike marathons, 5K walks, etc.), loans, and membership fees. Many of these organizations can be found within one's own community, and perhaps go unnoticed as a nonprofit. For example, it was not until several years after I had my first paying job, as a basketball score-keeper at the neighborhood YMCA, that I realized that the YMCA is in fact a nonprofit organization. The organization's mission is centered around youth development, healthy living, and being socially responsible by giving back to the community ("Organizational Profile," 2017). Throughout my junior and senior year in college, I had the opportunity to volunteer for the nonprofit, Meals on Wheels, delivering food to elderly and socially handicapped individuals throughout the Abilene community ("About Meals on Wheels," 2017). Lastly, several housing changes throughout my college years led to piles of donations that my family would send to the nonprofit, Goodwill. This organization declares to provide career training programs for the youth, elderly, veterans, physically and mentally disabled, and individuals with criminal backgrounds, through monetary and material donations ("About Us,"

2017). In summary, it is easy to get involved or donate to a nonprofit within one's own community. Organizations such as YMCA, Meals on Wheels and Goodwill can be found throughout the country, providing volunteer opportunities and donation boxes for all community members to get involved within a social cause.

Other nonprofits are directly associated with medical diseases and disorders, providing a variety of services for the population of people diagnosed with their associated disease, including services such as: accurate publication of medical knowledge, financial aid for families or individuals affected, and direct medical care for patients. Additionally, these nonprofits can fund medical research pertaining to preventative care or treatment options for their associated illness. Examples of such nonprofits include well-known organizations such as the American Diabetes Association, the American Cancer Society, and the National Breast Cancer Foundation. However, there are numerous other nonprofit organizations dedicated to different illnesses and striving for diverse goals, which all seek to help their affected population overcome the challenges of a medical illness. Fight for Sight is a nonprofit organized in 1946, that is dedicated to promoting research associated with vision. In the past, they have raised funds for eye clinics, sought treatment for patients with retinitis pigmentosa—an inherited, degenerative disease of the eye which gradually affects vision, due to the destruction of photoreceptor cells of the retina and advocated for legislation to aid the blind ("History," 2017). There is also The Oral Cancer Foundation which is devoted "to reduce suffering and save lives through prevention, education, research, advocacy, and patient support activities" for patients with a variety of cancers that affect areas of the mouth and throat regions ("The Oral Cancer," 2017). In addition, there are many smaller nonprofit organizations that are dedicated to serving families affected by a medical illness. The Autism Spectrum Disorder Foundation is just one of many organizations dedicated

to serving families and individuals with autism, a mental disorder that can significantly handicap an individual's ability to communicate, form relationships, and conduct abstract thinking. The Autism Spectrum Disorder Foundation strives to provide credible information about the disorder, educate the public about autism, provide financial aid to families affected, and support community service organizations dedicated to social and intellectual growth of autistic individuals ("What is ASDF," 2017). Furthermore, this foundation partners with other nonprofits, such as The Bridge of Georgia and Parker Autism Foundation, in a collaborative effort to better the lives of individuals and families affected by autism. Additionally, the Multiple Myeloma Research Foundation seeks to research progressive treatment options for patients with Multiple Myeloma—a malignant cancer of plasma cells, which are immune cells that mature from B cells to produce antibodies that help fight infections in the body ("Welcome to Multiple," 2017). There are many other beneficial nonprofit organizations, such as Myasthenia Gravis Foundation of America, the Muscular Dystrophy Association, and the CureDuchenne organization, which all strive to better the lives of individuals affected with these chronic diseases.

While their designated goals and guiding principles might be different from each other, each of these medical nonprofit organizations serve a particular population of individuals affected by a chronic illness. They strive to help their community financially, emotionally, and physically, pursuing a social mission that benefits their designated community. Overall, these nonprofits provide a necessary contribution to these individuals that are struggling through physical and emotional pain. The potential nonprofit detailed in this thesis strives to do the same for a community of patients that are currently underserved within medical research and have little financial assistance from any existing nonprofits.

#### **Diseases and Disorders**

There are many diseases and disorders that are still lacking significant research funding and a primary nonprofit association. While many associations are dedicated to diseases such as breast cancer, diabetes, HIV/AIDS and other well-known illnesses, rarer disorders can often be underserved due to their lower frequency within the population. In this section I will describe a few of these under serviced disorders, which my nonprofit could choose to focus upon.

#### Acoustic Neuroma

Acoustic neuroma is a rare disorder which is characterized by a benign tumor on the eighth cranial nerve that affects a person's balance and hearing. The tumor is usually unilateral, meaning that it only occurs on one side of the brain, and the growth of the tumor is gradual. If it goes untreated, the tumor can push against the eighth cranial nerve causing neurological complications and eventually death. Major symptoms include one-sided hearing loss and balance disturbances. In most cases, the hearing loss is gradual, but in some cases the hearing loss is sudden or even fluctuates ("What is an Acoustic Neuroma," 2017). There can also be symptoms of ringing in the ear and dizziness is often reported. In addition, if the tumor grows large enough, it has the potential to affect the seventh cranial nerve, causing facial weakness and possibly paralysis of facial muscles ("Acoustic Neuroma," 2016). Furthermore, some tumors may press against the brainstem, affecting cerebrospinal fluid circulation causing a variety of other complications, including headaches, confusion, and impaired voluntary movements ("Acoustic Neuroma," 2016). Leading treatment options are surgical removal of the tumor and radiation exposure to the area. The reason for tumor growth on the eighth cranial nerve is currently unknown, and there are currently no risk factors associated to its cause, though prior exposure to radiation and prolonged exposure to loud noises have been previously investigated to cause

acoustic neuroma with inconclusive results ("Acoustic Neuroma," 2016). It affects greater percentages of women than men, is estimated to affect approximately 1 in 100,000 individuals, and usually occurs in people ages 30 to 60 years old, but in rare cases it can occur in children ("Acoustic Neuroma," 2016).

While some research is being conducted on potential drug treatments for acoustic neuroma and the effects of aspirin on the tumor growth ("Acoustic Neuroma," 2016), additional research into potential causes and therapies could be beneficial. The U.S. government and other private organizations help fund current research into potential drug treatments for acoustic neuroma, and there are a few organizations in place, such as the Acoustic Neuroma Association, Children's Tumor Foundation, and Vestibular Disorders Association that can help advocate for these patients. However, the Acoustic Neuroma Association is strictly an informative and socially supportive organization that seeks to provide educational information about the disorder and construct "national and local support networks for those affected by acoustic neuroma" ("Mission Statement," 2017). Additional financial support could be provided to families affected, covering medical cost not covered by the patient's healthcare provider, such as surgical procedures and hearing aids. Financial contributions could be funneled toward additional research into drug treatments and potential risk factors. Additionally, fundraisers and social activities could be constructed by the nonprofit particularly for individuals affected with acoustic neuroma. This could provide additional social support and financial aid to research projects pertaining to acoustic neuroma.

## Dejerine-Sottas

Dejerine-Sottas disease is an inherited neurological disorder which leads to a steady decline in mobility for individuals affected. It is considered a hereditary motor sensory

neuropathy and results in the thickening of peripheral nerves, due to the inheritance of an autosomal dominant trait ("Dejerine Sottas Disease," 2016). This thickening is the consequence of demyelination, the breakdown of a neuron's protective sheath, of peripheral nerves, which leads to symptoms of "pain, weakness, numbness, and a tingling, prickling or burning sensation in the legs" ("Dejerine Sottas Disease," 2016). Additionally, there can be atrophy of the patient's leg muscles and loss of reflexes within limbs affected. The onset of Dejerine-Sottas disease is usually sudden, occurring between the ages of 10 to 30 years old. The exact prevalence of Dejerine-Sottas is unknown, with an estimated incidence of less than one in a million people ("Charcot-Marie-Tooth," 2015). Unfortunately, there is no cure for the disorder and patients are simply treated for their symptoms and provided with supportive care. Surgeries are conducted to help stabilize joints and assistance is provided to patients and families with mobility restrictions ("Dejerine Sottas Disease," 2016).

The Center for Peripheral Neuropathy is dedicated to helping educate the public about various peripheral neuropathies, conduct clinical research to determine possible causes and cures of these disorders and provide some treatment to individuals affected ("Dejerine Sottas Disease," 2016). Other organizations such as the National Institute of Neurological Disorders and Stroke, Center for Peripheral Neuropathy, and Child Neurology Foundation also help fund research devoted to the cause, risk factors, cure, and treatment of Dejerine-Sottas disease, along with other neurological disorders. However, no organization is dedicated solely to Dejerine-Sottas disease, and the multitude of neurological diseases supported by the previously described organizations make it difficult to determine the financial support each particular disorder is actually receiving. Therefore, individuals with Dejerine-Sottas disease could benefit from an

organization dedicated to funding and or conducting research focused on their treatment and potential cure.

## **Social Enterprise versus Nonprofit**

In *Mission, Inc.*, Kevin Lynch and Julius Walls explain that some of the goals of a nonprofit should be to return value to the community and to uplift employees instead of simply extracting work from them. They highlight that these values are also central to a social enterprise. A social enterprise is defined by authors Kevin Lynch and Julius Walls in *Mission*, *Inc.*, as a business corporation that is founded and run on a social purpose for the common good of a community (Lynch & Walls, 2009). Essentially, the organization pledges to uphold a social mission that benefits the community in some aspect, and funnels business profits primarily into that mission.

To identify potential corporation structures for my organization, I compiled descriptive definitions of different legal entities, from information provided directly from *Mission, Inc.*(Lynch & Walls, 2009) and *Brief Description and Summary of Characteristics of Various Business Entities* (D. Totusek, personal communication, February 14, 2017):

**Nonprofit Corporations** are created "under state law for specified not-for-profit purposes" (D. Totusek, personal communication, February 14, 2017). Therefore, this type of corporation is not focused on creating a profit for owners or investors in the company; instead, the focus is on a detailed social purpose. The corporation "cannot issue shares and cannot distribute profits" (Bromberger with Lynch & Walls, 2009, p. 44) because there are no owners, but the organization can have a board of directors to oversee the corporation. Specifically, Texas requires a nonprofit organization to have a board of directors, with at least three board

members (D. Totusek, personal communication, February 14, 2017). Some organizations may have memberships, which are authoritative positions within the organization that have certain powers, such as the power to vote for board directors and grant particular sales, while other organizations function without members and are called self-perpetuating. However, there must at least be a president and secretary of the corporation. Although the Certificate of Formation is filled with the Secretary of State of the designated state, separate fillings must be conducted with the IRS to be recognized as a tax-exempt organization. If the nonprofit organization is granted 501(c)(3) status under the IRS Internal Revenue Code, then donations to the nonprofit can be tax-deductible and subtracted from the donor's personal taxable income. Additionally, an approved 501(c)(3) nonprofit does not have to pay sales tax, property taxes, and federal taxes, but are still subject to Social Security and Medicare taxes. A nonprofit is restricted to financing its mission and overhead through donations, membership fees, revenues from the corporation's sponsored activities, and loans (D. Totusek, personal communication, February 14, 2017). This corporation can claim debt and pay lenders with commercially reasonable interest and a nonprofit's debt can also be classified into different classes of debts, which each have different economic rights (Lynch & Walls, 2009). However, nonprofits may have to pay Unrelated Business Income Tax, which is a tax on any income that is not related to the nonprofit's mission in any significant way, other than to create income for the nonprofit. Examples include forms of publishing and advertising in which the nonprofit was making money from producing advertising for related organizations (Lynch & Walls, 2009).

For-profit social enterprises are corporations or companies that are founded on and pledge to serve a specified social purpose to its community. These organizations can take the form of any for-profit organization: C corporations, S corporations, a Limited Liability Company, etc. C corporations and S corporations are owned by one or more shareholders and formed under state law through the filling of a Certificate of Formation (D. Totusek, personal communication, February 14, 2017). Additionally, C corporations and S corporations are overseen by directors who are elected by the shareholders, who hold these directors accountable for the business's results. Finances for any for-profit corporation can come from shareholder lending, revenues acquired from the business, and capital from independent investors. C corporations, a type of for-profit corporation, must also have the minimum board positions of a president and secretary. C corporations file 1120 federal income tax return and pay between a 15% and 35% tax on profits. After this initial tax, C corporation shareholder's dividends are also taxed at "individual rates ranging from 10% to 39.6%" (D. Totusek, personal communication, February 14, 2017). S corporations are similar to C corporations, but differ in that all shareholders elect to report the corporation's income or losses on the shareholders' personal income taxes at allocated pro rates. These rates would range from 10% to 39.6%, but essentially dividends would only be taxed once (D. Totusek, personal communication, February 14, 2017). State franchise tax may also be owed to both a C corporation's or S corporation's state of operations. In recent years, Limited Liability Companies, which can be a hybrid of both a partnership and a corporation, have been a popular structure for social enterprises.

These organizations are owned by members who may manage the company or designate managers who would oversee the management of the company. Corporate bylaws and operating agreements would identify the responsibilities of members and managers (D. Totusek, personal communication, February 14, 2017). The company is formed through the filing of a Certificate of Formation with the Secretary of State of the company's state of operations. Members of the company ultimately have no personal liabilities for debts that the LLC acquires. A LLC can be financed with members' contributions, borrowed money, revenues produced from the business, and investors capital. Additionally, a LLC can be taxed in a variety of different ways, depending on the members' preferences. A "single member LLC can be taxed as a proprietorship, a C corporation, or an S corporation", whereas a "multi-member LLC can be taxed as a partnership, C corporation or S corporation" (D. Totusek, personal communication, February 14, 2017). LLCs may also be subject to state franchise tax. Benefit Corporations are for-profit business structures in which shareholders clearly designate a social or environmental purpose and judge performance of the company on that social mission as well as on the company's profits. These corporations must satisfy special state law requirements; however, they receive no special tax exemptions. A benefit corporation simply differs from C corporations and S corporations "in regard to purpose, accountability and transparency" (D. Totusek, personal communication, February 14, 2017). **B corporations** are a type of for-profit business designation which must be approved by a board of professionals, B Lab, and pass social and environmental screens (Lynch & Walls, 2009, p. 50). L3C corporations "allow for

the creation of a hybrid between a nonprofit organization and a for-profit corporation" and require that the company have a low for-profit percentage, with charity or educational goals as its main purpose (Lynch & Walls, 2009, p. 50).

For-profit social enterprises have a clear advantage over nonprofit enterprises in that these organizations are allowed more flexibility in raising capital. While a social enterprise can use invested capital, capital in which the investor is expecting to receive a financial return, nonprofits are limited to donated capital, capital that is not expected to have financial return (Lynch & Walls, 2009). However, having invested capital is only an advantage so long as the corporation has a continuous operation that generates revenue for the organization. If the organization does not have this generation of revenue, then overhead and other expenses will drain the invested capital of the company, both taking away monetary means from the organization's mission and destroying the advantage for being a for-profit company. For-profit pursuits also come with some disadvantages. The contributions to these businesses are not tax deductible, as are contributions to a 501(c)(3) nonprofit, and contributions by the for-profit businesses themselves are deductible only up to 10% of the entire net income of the business (Lynch & Walls, 2009). Another shortcoming is that the managers of a for-profit organization have a contractual obligation "to run the company in the best interest of the shareholder," which may be through maximizing financial returns (Lynch & Walls, 2009, p. 45). However, L3C and Benefit Corporations also take into consideration their socially defined purposes when evaluating shareholders' expectations for the corporation. Nonprofits, however, are only accountable to the community, through the board of directors that govern it, and are not subject to maximizing investments at the potential expense of their mission and employees.

There are other advantages for both nonprofits and social enterprises. Both entities share the opportunity to hire talented people who are passionate about serving the organization's cause. Additionally, stakeholders, investors, and bankers may admire an organization with a designated social purpose and want it to succeed, putting nonprofits and social enterprises in a good starting position with these individuals (Lynch & Walls, 2009).

Lynch and Walls argue for the necessity of social enterprises because nonprofits rely solely on public contributions instead of on revenue that could be funneled into the social mission from a socially responsible business. Additionally, they argue that "usually a combination of entities is required" (Bromberger with Lynch & Walls, 2009, p. 44) for a nonprofit to become large enough to change the world. Although I think they mistakenly equate the size of a business to the amount of change it can bring, Lynch and Walls do convincingly argue that a social mission can be advanced with additional resources that a for-profit partner can provide a nonprofit. The combining of a for-profit subsidiary with a nonprofit parent company could provide beneficial advantages to a social cause (Lynch & Walls, 2009). For example, the Columbus Zoo is a nonprofit corporation whose main mission is the conservation of wildlife, however, the corporation owns an 18-hole golf course, a waterpark, and is currently building a hotel. Although separate subsidiaries were not used in this case, this example illustrates how for-profit ventures can help finance the social mission of a nonprofit.

## **Nonprofit Board of Directors**

To be qualified as a nonprofit corporation, under state law and federal recognition, the organization cannot have owners, instead it will often be led by a board of directors (D. Totusek, personal communication, February 14, 2017). Under Texas law, a board of directors is required, as are bylaws that describe their terms of service and frequency of meetings (D. Crisp, personal

communication, February 14, 2017). Within the nonprofit organization, the board serves as the ultimate authority, with the general responsibilities of determining the mission, selecting, evaluating and compensating the organization's CEO, approving the strategic plan, setting policies for management, and reviewing and evaluating management performance. These responsibilities can be referred to as governance duties, however, members of the board will have additional obligations to the organization to aid in public relations and fundraising (D. Crisp, personal communication, February 14, 2017).

It is suggested that board members have qualities such as credibility and trustworthiness, and that their presence on the board adds value, whether through "industry expertise, technical knowledge," understanding of community dynamics, legal counsel or financial networking (D. Crisp, personal communication, February 14, 2017). Most importantly board members must be passionate about the cause and desire to make a positive contribution to an underserved population.

With all this in consideration, I have compiled a core group of potential board members to govern the nonprofit detailed in the Potential Structure and Mission of Nonprofit section:

Kathryn Pacheco is planning to study law with a concentration in entertainment and intellectual property law. She will graduate this year with a degree in business management from Texas A&M University. Her pursuits in the sports and entertainment industries could be beneficial in fundraising capital for the nonprofit, and possibly in recruiting high-profile clients to get involved in the nonprofit. Kathryn's future expertise in law and connections to other lawyers will also be crucial in forming the nonprofit and when seeking attorney advance on company pursuits. Kathryn hopes to end up in California, at UCLA's law school and to continue working around that area after

graduation. Her knowledge of the location would be a great asset for tapping into hubs of the west coast, to both gain financial support from businesses located there and to help support potential patients in that area.

Jordan Marshal will finish this year with a Bachelor of Science in Economics with a concentration in Finance and Real Estate from the University of Pennsylvania, and will start a consulting job in New York. His abilities in consulting will be paramount in developing relationships with banks, investors and other companies. Additionally, his interest in real estate and contracting could be useful in determining the nonprofit's premium location and further resources. With Jordan located on the East coast and having attended an Ivy League school, his background could open many doors for the organization.

Zach Moore is a third-year medical student at Marshal University, with a Bachelor's degree in Biology from Abilene Christian University, interested in pursuing a medical residency in neurology. Zach will be paramount to the social purpose of the nonprofit, as his medical skills will help the board understand the medical and social perspectives of the patients and families the nonprofit will be dedicated to serving. He will also be able to contribute a physician's perspective to the discussion and could have access to hospitals and medical professionals closely aligned with the goals of the nonprofit.

Rebecca Stark graduates with a Biochemistry degree from Abilene Christian University this spring and enters the Texas Tech University Health Science Center School of Pharmacy in the fall of 2017, pursuing a dual degree of a doctorate in pharmacy and an MBA in Health Organizational Management. Rebecca has strong ties to A&M, Abilene

Christian University, and Texas Tech University and participates in significant cancer research for Texas Tech University. With her strong interest in hospital management and pharmaceuticals, Rebecca would be a great asset, contributing additional medical perspectives to the board.

Megan Kriger has a Bachelor of Science in Kinesiology and Nutrition from Abilene Christian University and is currently finishing her first year at Hardin Simmons University, pursuing a doctorate of physical therapy. As the potential nonprofit seeks to help patients with a neurological complication, a board member with extensive knowledge in therapeutic medicine would be beneficially to understanding the treatment of the disease. Megan is also a devout Catholic, which could provide additional support and mission opportunities to the organization. Megan also has a strong interest in healthy living and working with geriatric patients, adding diverse interests to the board.

Last, I will graduate this spring with a Biochemistry degree from Abilene Christian University, hoping to go on to medical school next year. With a strong interest in surgery, I could provide a different medical perspective for the social mission as well as other medical resources. As a four-year NCAA athlete and team captain, I could provide beneficial leadership skills, connect with athletic organizations and be crucial in coordinating the creation of the nonprofit.

This board would consist of a small group of members, with varying perspectives, experiences, and expertise. Since each member is familiar with at least one other member, positive relationships are already in place and a collectively determined social purpose can be kept within a small group. While the potential members of the board are all relatively young, the

start-up of the nonprofit would potentially occur after each member has gained their graduate degrees or settled into their profession, to allow each to gain expertise in their fields and financial stability. Each of these members contributes valuable strengths to the board and their expertise would be paramount in both the start-up of a nonprofit and its regulation. Additional board members could also be considered after the creation of the nonprofit, with majority agreement from pre-existing board members.

Choosing an executive director, who would oversee the management of the organization, would be one of the first responsibilities of the board of directors. Monthly board meetings would be required to start up the business, and then at least two official meetings would be conducted annually to discuss progress and strategies presented to the board, with executive power to act between meetings.

## Potential Structure and Mission of Nonprofit

In consideration of the interests presented by members of the Board of Directors and initial investigations into a few neurological diseases, I suggest that the nonprofit center its mission around a rare neurological disease, such as acoustic neuroma, which has a prevalence of at least 1 case in 100,000 people, and which has minimal social support and minimal financial grants for research into its prevention and cure. The nonprofit would have the opportunity to help over three thousand individuals and families affected by this disease in the United States.

The Osteogenesis Imperfecta Foundation is "the only voluntary national health organization" dedicated to improving the quality of life of individuals with Osteogenesis Imperfecta ("Mission," 2015). Started by parents with children affected by this disease, the organization proclaims a dedication to "research, education, awareness, and mutual support" ("Mission," 2015). Today it conducts fundraisers, has local support groups, sponsors a national

convention, provides information about the disease, and organizes funding for research into gene therapy.

Similar to the Osteogenesis Imperfecta Foundation, I would like my nonprofit to improve the quality of life of its patient population, specifically through social support groups, organized fundraisers (such as 5K runs and bike marathons), financial contributions to help pay for the care of patients, and research into therapy and a potential cure for the neurological disease. In addition, the organization would strive to be a leading informant of the latest research pertaining to the disease and provide accurate descriptions pertaining to the aspects of the illness. The sponsorship of a national convention for the neurological disease would also be an excellent fundraising and informative activity for the nonprofit to pursue.

The organization will also require a defined structure. This will be the foundation on which the organization will be built. Structure can affect how the organization is governed, how it communicates, how the organization is taxed, and the level of the support it can expect to get from the community, the government, banks, and other possible supporting organizations (Lynch & Walls, 2009). The structure of the organization will therefore be paramount to effective communication and management of the organization.

The organization would file to be a nonprofit with 501(c)(3) status under the IRS Internal Revenue Code because the organization's focus is on patient relief through financial contributions and emotional and educational support. While fundraising and donated capital can create monetary contributions to the nonprofit, invested capital and the generation of revenue through for-profit ventures would serve no additional purpose to the mission of the organization, other than the creation of money. Therefore, a nonprofit organization better fits the specified mission. Donations to the organization would be tax-deductible for donors, and there would be

no obligation for management to maximize financial returns for shareholders, allowing the organization to be focused on the designated social purpose.

Additionally, the organization would file for a Certificate of Formation with the Secretary of State of Texas, since all potential members of the Board of Directors have significant ties to Texas. Texas would be the home base of the organization, but the organization would reach out to individuals affected from all areas of the country, with fundraisers close to areas with a high percentage of individuals the organization pledges to serve. Lastly, if the board of directors felt that invested capital and the generation of continuous revenue—through the selling of a product or by providing a service—would be beneficial to the social mission, specified by the guiding principles and bylaws of the potential organization, then an L3C corporation would be a preferred structure for the social enterprise, and the board would have to choose a state for its base of operations that recognizes L3C corporations.

## Further Steps to Make a Nonprofit or Social Enterprise

Before beginning to operate a nonprofit or social enterprise, a set of written guiding principles should be established with collaboration from the board members, in order for all members of the board of directors and management executives to be on the same page. These principles are more thorough than a mission statement and should be short and simple, stating overarching principles that provide some structure and guidance to management, without handicapping them (Lynch & Walls, 2009). After the directors have agreed upon these bylaws, the bylaws should also be widely publicized for customer and employee benefit.

Some examples of potential guiding principles for the nonprofit include:

 Serve the organization with integrity and professionalism, having a passion for serving others

- 2. Pursue an improvement in the quality of life of individuals afflicted with the neurological disease
- 3. Take into consideration the needs of the families and individuals we pledge to serve
- 4. Provide accurate information and financial support to individuals diagnosed with the neurological disease

A business plan will also help articulate to employees, investors, and banks what the organization seeks to produce and accomplish. According to *Mission, Inc.* a typical business plan will include the following sections (Lynch & Walls, 2009, p. 55-59):

- 1. Executive Summary: a mini-business plan
- 2. Background
- 3. Products
- 4. Operations
- 5. Market
- 6. Strategy
- 7. Management
- 8. Financial Information
- 9. Summary: concluding statements

As the organization begins to take form, or even before the organization is created, becoming an expert in the organization's particular field will be beneficial for understanding the market the organization is entering and the people the mission seeks to serve. *Mission, Inc.* suggests that leaders of the organization should go to conferences and trade shows, get involved

in blogs related to the organization, and read industry publications relevant to one's social mission (Lynch & Walls, 2009).

Additionally, a "thorough, multipurpose understanding of money" (Lynch & Walls, 2009, p. 23) is recommended for board members and management. To function properly, both management and board members must be able to comprehend income statements, balance sheets, and concepts such as assets, liabilities, and equity (Lynch & Walls, 2009). Originally, the management of finances is something that I was hoping to shuffle off responsibility for, but the more I read up on the matter, the more I am convinced that a Master in Business Administration would be worth pursuing. Not only would it be an additional asset to the board, it would be crucial for understanding important business documents.

Mission, Inc. also states that nonprofit corporations and social enterprises "need both mission and margin" to be successful (Lynch & Walls, 2009, p. 30). One is not more important than the other, because without margin (money) there can be no mission and without mission the corporation has failed the purpose of its creation (Lynch & Walls, 2009). With this understanding, it is paramount that a dedication to a neurological disease not be overshadowed by the collection of monetary and material donations for the organization, but also that the collection of donations not be taken for granted.

Lastly, *Mission, Inc.* emphasizes that the biggest battle that a social enterprise or nonprofit must face is the fight for the right people managing the business. The organization will want people who will not only extremely support the organization, but who are passionate about the cause, and possibly connected to the social purpose with experience. When the board of directors is officially created with guiding principles, the first major goal would be to find a willing and knowledgeable executive director who has experience with the neurological disease

the organization would pledge to serve, and who is passionate about the treatment of individuals with this disease. Additional steps, including the creation of a business plan, determining financial management, and employee hiring will all follow this initial phase.

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