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Venture Philanthropy:
A Case Study of Three Nonprofit Organizations

Jessica Potts

A Practicum Paper
Submitted in Partial Fulfillment of the Requirements for the

Master of Public Administration

Kennesaw State University
December 2011

Department of Political Science and International Affairs

Master of Public Administration Program

College of Humanities & Social Sciences

Kennesaw State University

Kennesaw, Georgia

Certificate of Approval

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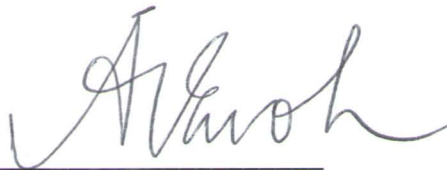
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Venture Philanthropy:

A Case Study of Three Nonprofit Organizations

Executive Summary

Beginning in the 1990s, a new kind of philanthropy emerged that was formulated on the premise of merging philanthropy with investing. The concept of turning philanthropy into social investing was coined venture philanthropy and has received substantial attention since its inception. Generally speaking, if the business model of the organization shows promise, investors will narrow their focus to that organization for multiple years rather than committing to one-year grants (Community Health Ventures for the Morino Institute 2010). In view of this, investors will engage in long term relationships and partner with the organization to support capital needs.

The Cystic Fibrosis Foundation, Juvenile Diabetes Research Foundation, and Michael J. Fox Foundation for Parkinson's Research are three disease-focused foundations that practice venture philanthropy in order to proactively identify and fill key gaps in public funding. Each nonprofit has a different focus, but each has a mission that is focused on providing efficient, effective, and transparent services, such as drug development, to a patient population that requires assistance. Each of these nonprofits was founded by individuals affected by the disease they support and has experienced both success and challenges during its lifespan. Conducting an analysis of these foundations gives a concentrated snapshot of the benefits and shortcomings of venture philanthropy as a nonprofit business model.

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Venture Philanthropy:

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Introduction

Beginning in the 1990s, a new kind of philanthropy emerged that was formulated on the premise of merging philanthropy with investing. This new development was, in part, a result of the 1991 democratic campaign that called on Americans to make greater and more consistent contributions, or social investments, that would lead to greater social impact. The concept of turning philanthropy into social investing was coined venture philanthropy and has received substantial attention since its inception. Generally speaking, if the business model of the organization shows promise, investors will narrow their focus to that organization for multiple years rather than committing to one-year grants (Community Health Ventures for the Morino Institute 2010). Investors engage in long term relationships and partner with the organization to support capital needs. In the following analysis, an exploratory case study of three nonprofit organizations that follow the venture philanthropy model is deployed to investigate the organization's best practices to determine whether or not the organization's missions are being realized. The organizations explored are: Cystic Fibrosis Foundation (CFF), Juvenile Diabetes Research Foundation (JDRF), and Michael J. Fox Foundation for Parkinson's Research (MJFF). The results of this case study are straightforward: for this very small focus group of nonprofit organizations, venture philanthropy has proven to be an effective model by which to operate.

Literature Review

Venture philanthropists, according to Peter Frumkin, transfer wisdom across sectors. Their approach and language has penetrated the private and community foundation world, the small giving circles and clubs that help guide new donors, and the territory of corporate philanthropy. To date, venture philanthropy has been tried in environments such as early childhood health, environmental protection, public health, and education. Although venture philanthropy is still relatively small in comparison to the billions of dollars donated per year across the country, its influence is growing with increased media attention, and more significantly, with the recent development of some of the nation's largest nonprofit organizations adopting its language and practices.

As Frumkin (2003) describes, venture philanthropy can be viewed as a three-legged stool, each representing a solution to a problem in traditional philanthropy practice. These three legs are: capitalization, engagement, and performance measurement. Frumkin suggests that scholars consider each of these "legs" separately to see how they support effective giving. In terms of engagement, venture philanthropy has focused on changing the relationship between the funder and recipient. Many disease foundations, for example, subscribe to venture philanthropy due to frustration with the slow pace of the traditional medical system (Chang 2010). Venture philanthropists believe the "work" begins once a financial commitment has been made. Often, venture philanthropies are collaborative, results-oriented, and mission-driven. Cultivating long-term relationships with investors can provide nonprofits with useful connections which could ultimately result in diversifying funds by connecting high net-worth investors in the organization's donor pool with a venture capitalist on the organization's Board of Directors (Community Health Ventures for the Morino Institute 2011). Another advantage of an engaged

relationship is investor satisfaction. Cultivating and engaging relationships with investors has very little to do with nonprofit performance. The experience that an investor has with the nonprofit is most important because, in venture philanthropy, the investor is a long-term supporter who is kept up to date with programs and financials needs of the organization. As Rebecca Wyhot (2004) states, “the nature of the nonprofit venture philanthropy relationship is involved, passionate, supportive, financially invested, proactive, accessible, and more committed than other funders.” Nonprofit organizations that follow the venture philanthropy model, particularly healthcare organizations, have been founded by patients and families to provide a service for a population that has been left without support or service by the government.

According to Frumkin (2003), venture philanthropists distinguish their work by the way they assess results. Venture philanthropists are particularly concerned with performance measurement and have made it the focal point of their approach to giving. The calculation of social return on investment is very much an application of a cost-benefit analysis that has been a key tool in the private sector for decades. The ability to calculate social return on investment has given venture philanthropy a language that appeals to younger investors. Similarly to the first leg of venture philanthropy, performance measurement is not without challenge. The challenge venture philanthropy faces is the reality of performance measurement in the nonprofit setting. It is very difficult to measure the benefits of philanthropic practice particularly when, in many cases, it has little relevance when applied to measurement. For example, the income streams of nonprofits can be estimated, but parts of nonprofit programs, for example, advocacy efforts, counseling, and arts performances, are difficult to monetarily quantify. The challenge facing venture philanthropy as the concept matures will be translating “making a difference” into monetary terms for those investors who demand a tangible return on social investment.

Venture philanthropy has developed a different approach to funding, one that builds on venture capital and offers longer term support and larger amounts of unrestricted financial support. This model emphasizes long-term funding designed to help organizations develop and grow. In her thesis, Joanne Chang (2010) investigates disease focused foundations (DFFs) in relation to venture philanthropy. Many DFFs, including the three nonprofits explored in this paper, serve a niche population which often experiences difficulty making medical advancements in today's medical environment. Such DFFs seek to create functioning markets where they perceive market-failure. In the case of many DFFs, market-failure occurs in the transition from the laboratory to clinical trials. The DFFs de-risk drug candidates in the drug discovery pipeline chain as the majority of drug development companies, pharmaceutical companies, and medical device companies tend not to engage and invest in the small markets that DFFs serve. DFFs provide capital during the drug development life cycle at the point where it is usually most scarce. DFFs proactively identify and fill gaps in public funding by funding high-risk, high-reward projects with a sound scientific basis (Odling-Smee 2007).

Methodology and Limitations

The following analysis outlines the core structure of the Cystic Fibrosis Foundation (CFF), Juvenile Diabetes Research Foundation (JDRF), and Michael J. Fox Foundation for Parkinson's Research (MJFF).

For each nonprofit organization, an analysis of strengths, weaknesses, opportunities, and threats (SWOT analysis) of an organization was used to determine if venture philanthropy could be considered a best practice to serve its respective population and mission effectively, efficiently, and with transparency. The limitation of conducting a SWOT analysis is that it is exploratory in nature and cannot be used as a measure to determine if venture philanthropy is an

appropriate model for all nonprofit organizations. For example, the organizations reviewed within this paper are healthcare nonprofit organizations which serve niche populations in the United States. The three SWOT analyses of these very specific organizations in one territory could not supply enough evidence in support of or opposition to venture philanthropy as a foundation model across all markets.

Findings

The Cystic Fibrosis Foundation, Juvenile Diabetes Research Foundation, and Michael J. Fox Foundation for Parkinson's Research are disease foundations that practice venture philanthropy in order to proactively identify and fill key gaps in public funding. Each nonprofit has a different focus, but each has a mission that is focused on providing efficient, effective, and transparent services, such as drug development, to a patient population that requires assistance. Each of these nonprofits was founded by individuals affected by the disease they support and has experienced both success and challenges during its lifespan. Conducting an analysis of these foundations gives a concentrated snapshot of the benefits and shortcomings of venture philanthropy as a nonprofit business model.

The Cystic Fibrosis Foundation

Founded in 1955, the mission of the Cystic Fibrosis Foundation (CFF) is to support the development of new drugs to fight the disease, improve the quality of life for those with cystic fibrosis (CF), and ultimately to find a cure (Cystic Fibrosis Foundation 2011). The Foundation funds and accredits more than one hundred and fifteen care centers, ninety adult care centers, fifty affiliate programs and eighty chapters and branch offices nation wide. The Cystic Fibrosis

Foundation is one of the most efficient organizations of its kind as a recipient of a 4-Star rating for sound fiscal management from Charity Navigator, and the accreditation by the Better Business Bureau's Wise Giving Alliance.

The Cystic Fibrosis Foundation asserts that until cystic fibrosis is cured, the Foundation will serve as the following six things: scientific pioneers, fund-raisers, advocates, investors, caregivers, and family. As scientific pioneers CFF partially funds the research and development of drug therapies necessary for CF patients. The Foundation has broadened its de-risking activities by investing more capital into therapies that are in Phase II and Phase III trials (Cystic Fibrosis Foundation 2011). The Cystic Fibrosis Foundation created a therapeutic drug pipeline that maps CFF supported drug therapies from the laboratory research stage to the end of the lifecycle where it is made available to patients (see Appendix A). The Foundation uses a point system to judge the progress of the pipeline from a bottom-up approach in conjunction with a top-down life expectancy measure. The Cystic Fibrosis Foundation takes many "shots of goal" to diversify its portfolio and to fill the gaps left open in care and drug development (Cystic Fibrosis Foundation 2009). Only 30,000 individuals in the United States are affected by cystic fibrosis; therefore, it is extremely important that the Foundation acts as an advocate for those with the disease. CFF dedicates a portion of its efforts educating the general public about the disease and attempting to gain legislative support. Additionally, the Foundation funds care centers, clinics, and pharmacies to help control the effects of the disease, but those control efforts are only fully realized with the support of family.

The Foundation's strategic plan is characterized as a plan that addresses the questions "where we want to go" and "how we're going to get there." CFF's five-year objectives represent the "where we want to go" aspect of the strategic plan which has four phases: developing new

medical treatments for people with cystic fibrosis; delivering high-quality, compassionate patient and family-centered care through the Care Center Network; helping patients and their families find new ways to improve their self-management skills; and expanding access to quality cystic fibrosis care.

The second aspect of the Cystic Fibrosis Foundation's strategic plan is characterized as the "how we're going to get there" phase. The Foundation says it will accomplish its objectives by working toward the following four goals: continuing to explore and develop new ways to fund the mission; continuing to nourish and maintain the "people pipeline," continuing to evaluate and improve the effectiveness of communications, taking full advantage of new means and strategies for reaching various audiences; and enhancing organizational structure so that all departments optimally align with the Foundation's science and medical program. Each of the four goals has specific sub-goals, which further demonstrate how the Foundation is going to reach its objectives listed in the first phase.

In order to explore and fund its mission, the Foundation is working to continue to grow its major fundraisers, such as its highest grossing, grassroots walk-a-thon, Great Strides, and other special events. The Foundation is also actively working to establish Corporate Leadership Council to help garner increased commitment from the corporate community. This particular sub-goal is one that has been fully adopted by the chapters and affiliates.

The Cystic Fibrosis Foundation has numerous strengths. From an overall perspective, structure is a major strength. As illustrated with its strategic plan, the concept of having a national office that disperses information to the chapters and affiliates is an efficient method of management. The national office is responsible for action plans, major decisions, human resources, and governance while the chapters are responsible for enacting those functions.

The Cystic Fibrosis Foundation prides itself on accountability. As noted previously, the Foundation has met the standards of the Better Business Bureau's Charity Accountability whose standards include how charities govern their organization, the ways it spends money, the truthfulness of its representations, and its willingness to disclose basic information to the public. Additionally, the Foundation has an A- rating from the American Institute of Philanthropy whose standards include the percentage spent on charitable purpose and the cost to raise \$100. One of the Foundation's selling points to donors is a statement based on efficiency. The Foundation says that for every dollar it receives, ninety cents of it goes to its mission.

Progress and drug development are two major strengths of the Foundation. When an organization represents a small population of people, it is paramount that its efforts continue to move forward. Today, there are currently thirty drugs working through the pipeline which is more than double what was available just ten years ago. The tangible progress that the Foundation can illustrate is what inspires donors with no connection to the disease to keep working towards the mission.

Like many nonprofit organizations, the Cystic Fibrosis Foundation has weaknesses that sometimes negatively affect the organization's ability to support its mission. In the case of CFF, high-risk projects in the past ten years have, in some cases, led to disappointing results that have cost the organization investors and accountability ratings. The Cystic Fibrosis Foundation protects its intellectual property, meaning the research it has funded towards drug development, and sometimes exercises its right to pursue relationships with pharmaceutical or development companies that may offer better odds of the drug to coming to fruition. In two cases last year, the Cystic Fibrosis Foundation had incidents with two pharmaceutical companies that had insufficient capital to finish its projects and thus the Foundation partnered with a different

clinical development company to increase the odds of the venture succeeding. These kinds of business decisions sometimes lead to decreased support by investors, particularly inexperienced investors. Unfortunately, some business maneuvers made by CFF led to its Charity Navigator Rating to be decreased from a 4-Star to a 3-Star rating in 2011 (Charity Navigator 2011). Similarly to the vast majority of nonprofit organizations, the Cystic Fibrosis Foundation does experience staff and volunteer burn out which leads to decreased fundraising which directly funds the Foundation's research and development arms. Being an orphan disease, a disease that affects less than 200,000 people in the United States, is both a weakness and opportunity for the Cystic Fibrosis Foundation (Rare Diseases Act of 2002). The disease inherently serves as a weakness for the C.F. Foundation because the pharmaceutical industry has little financial incentive for the private sector to make and market new medications to treat or prevent the cystic fibrosis; therefore, the burden of funding medical research and drug therapies is left solely to the Foundation and its investors which can create a very delicate situation.

Health organizations, like the Cystic Fibrosis Foundation, have the great opportunity to save lives. The Cystic Fibrosis Foundation in particular has the distinct opportunity to find a cure for the disease, a concept that was validated on October 19, 2011 when the Cystic Fibrosis Foundation's partnership with Vertex Pharmaceuticals resulted in the application to the United States Food and Drug Association (FDA) approval for KALEYDECO. If approved, KALEYDECO will be the first drug on the market that targets the underlying cause of cystic fibrosis (Vertex Pharmaceuticals Incorporated 2011).

The greatest threat to the Cystic Fibrosis Foundation is keeping the pharmaceutical companies, medical equipment companies, and researchers engaged in developing new therapies and equipment for cystic fibrosis patients. The state of the economy coupled with the

opportunity for greater profits with other forms of medical research often leads the companies to back out of their obligations with the CFF. In terms of drug development, the most critical piece of the CF Foundation's business model, typically, pharmaceutical companies abandon the project between Stages 2 and 3, the point in which they take over funding. While the Cystic Fibrosis Foundation has rights to the intellectual property gained in the partnership, the threat is losing time and donor support over market failures.

Juvenile Diabetes Research Foundation

The Juvenile Diabetes Research Foundation (JDRF) is the leading organization researching the cure for Type 1 Diabetes (T1D). It sets the global agenda for diabetes research, and is the largest charitable funder and advocate of diabetes science worldwide. The mission of JDRF is to find a cure for diabetes and its complications through the support of research. Type 1 Diabetes is an autoimmune disease that strikes children and adults suddenly, and can be fatal. Until a cure is found, people with T1D have to test their blood sugar and give themselves insulin injections multiple times or use a pump—each day, every day of their lives. Despite the intensive care, insulin is not a cure for diabetes, nor does it prevent its potential complications, which may include kidney failure, blindness, heart disease, stroke, and amputations (Juvenile Diabetes Research Foundation 2010a).

Since its inception in 1970 by parents of children with T1D, JDRF has awarded more than \$1.5 billion to diabetes research, including \$107 million last year (Juvenile Diabetes Research Foundation 2009). More than 80 percent of JDRF's expenditures directly support research and research-related education. JDRF has made a substantial impact on the landscape of Type 1 diabetes research by funding the basic research necessary to develop drug therapies and translate scientific findings to finding a cure. The Juvenile Diabetes Research Foundation

plays a unique role in developing and setting the landscape for Type 1 diabetes research by partnering with academia, pharmaceutical and biotechnology companies, venture capitalists, government entities, and other foundations to fund a cure for Type 1 diabetes (Juvenile Diabetes Research Foundation 2009).

The research goals of JDRF are to stop Type 1 diabetes or slow its progression in people who are newly diagnosed, reverse Type 1 diabetes, and prevent or reverse its complications, in those who have lived with the disease for years, to prevent Type 1 diabetes in people at risk and in future generations, and to improve treatment of Type 1 diabetes and provide better tools to achieve tight glucose control for people at all stages of the disease. JDRF targets its research funding efforts into two areas: cure and control. Funding for the cure includes immune therapies and beta cell therapies while control research funding encompasses glucose control and complications therapies. Last year, JDRF invested \$32 million to immune therapies, \$35 million to beta cell therapies, \$23 million to glucose control, \$17 million to complications therapies bringing the JDRF's investment to the mission to \$107 million dollars (Juvenile Diabetes Research Foundation 2009).

JDRF is the leader in setting the agenda for Type 1 diabetes research worldwide, and is the world's largest charitable funder and advocate of Type 1 diabetes research. JDRF uses its research leadership to bring about collaborations between top researchers in diverse fields to focus their energies on finding cures for T1D and its complications. JDRF's influence allows the foundation to ensure that the best researchers are searching for the cure.

Juvenile Diabetes Research Foundation excels in large part due to the exceptional organization of the Foundation. JDRF has six strategic therapeutic objectives against which each project is measured. With an average of \$2 million invested by the Foundation per project, it is

necessary that JDRF have some system of accountability to ensure that the mission is being fulfilled. One of the most impressive strengths of JDRF is the Industry Discovery and Development Partnerships (IDDP) initiative. IDDP seeks to create partnerships with biotech and pharmaceutical companies focusing on the discovery, development, and commercialization of therapeutics and devices for Type 1 diabetes (Juvenile Diabetes Research Foundation Industry and Discovery Development & Partnerships 2010b). At its inception, IDDP reached out to its partners for support, but over time, industry leaders interested in JDRF's mission have approached the organization rather than JDRF initiating the first contact. The IDDP therapeutic pipeline outlines the progress this initiative has made since 1970 mapping drug development from the laboratory to availability to patients (see Appendix B).

The Juvenile Diabetes Research Foundation has an incredibly large network of investors and stakeholders that fuel the mission. While this network of people is a major advantage, having such a network serves as a challenge as nonprofits of this caliber often struggle with inexperienced investors, micromanagement of staff, researchers, investors, and committees, and combating the image of being a controlling foundation. For example, JDRF has an in-house research department that works with external advisors to identify and recommend funding opportunities. This department manages relationships on behalf of the Foundation which has the potential to pose challenges when selecting, or not selecting, projects to fund. The Juvenile Diabetes Research Foundation has done due diligence concerning this challenge by having an advisory group of venture capitalists, biotech professionals, Board of Directors staff, and Foundation staff that analyze its project selections.

The Juvenile Diabetes Research Foundation performs gap analysis sessions to categorize problems in funding and science. These sessions identify both opportunities and threats in the

Foundation's future. JDRF identifies opportunities for future investments during gap analysis sessions that have the potential to lead to new, ground breaking developments to serve its mission. A unique opportunity JDRF has is government funding. There are 18.8 million people in the United States diagnosed with diabetes and another estimated 7 million undiagnosed which takes Type 1 diabetes out of the orphan disease classification (Juvenile Diabetes Research Foundation 2010a). T1D is an epidemic in the United States, and for that reason, JDRF has the opportunity to capitalize on the country's support of finding a cure for a disease that affects a large percentage of Americans. Similarly to the C.F. Foundation, JDRF is threatened by high-risk investments that have the potential to yield disappointing results to investors and patients. As with other disease foundations, it is necessary to invest in high-risk projects to increase the probability of new drug therapies to complete the lifecycle and make available to the patient population.

The Michael J. Fox Foundation for Parkinson's Research

The mission of the Michael J. Fox Foundation for Parkinson's Research (MJFF) is to find a cure for Parkinson's disease (PD) through an aggressively funded research agenda and to ensure the development of improved therapies for those living with Parkinson's today. The foundation has a strong network of human resources that keep the organization moving forward such as the Board of Directors, Founder's Council, Leadership Council, Patient Council, Scientific Advisors, and finally, the Foundation staff.

The Michael J. Fox Foundation Board of Directors is comprised of leaders in science, business, fundraising, and entertainment. According to the Foundation's website, the Board's expertise helps forge the path for Parkinson's research, assess the Foundation impact, and guide

the pursuit of improved Parkinson's treatments, and ultimately, a cure. Formed in 2008, the Foundation's Founders' Council was created to recognize individuals who have made significant and transformative contributions to the Foundation's efforts. These individuals may have served on the Board at the time of their contribution or may have served as advisors to the Foundation. The members of the Founder's Council continue to serve the Foundation on an as-needed basis often providing advice in their areas of expertise. The Leadership Council of the MJFF serves as an advisory Board to the Foundation that provides financial support and strategic insight on how to effectively and efficiently move towards a cure. In 2008, MJFF created the Patient Council that is a formal channel for the Foundation to solicit input from Parkinson's disease (PD) patients and the broader Parkinson's community. The Council advises the Foundation on programmatic fronts including: strategies to best convey patient priorities to the research community and its funders; content and emphasis for patient education and outreach relevant to MJFF's mission to find a cure; patient roles in developing novel ways to conduct research; and mechanisms for impact assessment.

One of the most unique aspects of MJFF's network of human resources is the network of Scientific Advisors. The Foundation's Scientific Advisory Board is a group of leading Parkinson's researchers from both academia and industry, clinicians who work with Parkinson's patients, and experts from related fields. These members come from all over the world to attend grant review assessments, workshops, and other relevant meetings to help determine which research programs will get the Foundation closer to improving Parkinson's treatments and curing the disease (Michael J. Fox Foundation for Parkinson's Research 2010).

The Michael J. Fox Foundation for Parkinson's Research has one clear measure of success: delivering patients better treatments and, ultimately, a cure for Parkinson's disease.

MJFF has developed a targeted approach to research funding that helps identify and prioritize the patient-relevant science that will allow the Foundation to reach its goal. The following chart exemplifies the MFJJ approach:



In the first stage of the approach, charting the course, the Foundation approaches leading specialists from around the globe to help maintain a comprehensive view of the field and determine the research areas that hold the most promise for improving diagnosis and treatment of Parkinson’s disease. In 2006, MJFF convened over 350 top researchers from academic and industry labs all over the world for meetings to set strategy and future direction (Michael J. Fox Foundation for Parkinson’s Research 2010). These meetings lead directly to funding initiatives, new collaborations and other action steps that will move the field forward faster. The second stage of the MJFF approach is the selection process. In this process, the Foundation's scientific staff and expert advisors review proposals from researchers around the world. The staff and

scientists are searching for ideas that are most readily translatable into new treatments, the teams that can execute those ideas, thoughtful and realistic work plans, and outcomes that can take them closer to the MJFF goal: delivering better treatments and, ultimately, a cure for PD. In the third stage, the research process, MJFF eliminates red tape to get funding to scientists as quickly as possible. MJFF funds projects quickly—in most cases, within two months. Scientific staff and advisors stay closely involved as research teams carry out their projects. MJFF establishes milestones and evaluates outcomes and progress. One of the ways MJFF conceptualizes and quantifies success is its Drug Development Pipeline, a common measure characteristic of health foundations, which maps the progress of funded drug therapies through the drug lifecycle (see Appendix C). Additionally, MJFF troubleshoots problems if they arise, and work with the team to set future directions. MJFF's interactive approach is its take on venture philanthropy. In comparison to other organizations, MJFF does not have an established record of moving as many drug therapies through the lifecycle of the pipeline, but the Foundation does use venture philanthropy as a measure of accountability.

The Michael J. Fox Foundation for Parkinson's Research excels in capitalizing on results. When MJFF learns of promising findings, whether or not they resulted from research funded by the Foundation, it works quickly to identify and partner with researchers equipped to further develop those discoveries in pursuit of the ultimate goal (Michael J. Fox Foundation for Parkinson's Research 2008). MJFF is unique in the sense that it capitalizes on research funded both by its own researchers and by others. Since its inception in 2000, the Foundation has funded more than \$264 million in Parkinson's research, either directly or through partnerships (Michael J. Fox Foundation for Parkinson's Research 2010).

Like the Cystic Fibrosis Foundation and Juvenile Diabetes Research Foundation, the Michael J. Fox Foundation for Parkinson's Research understands that science is risky by nature. The Foundation addresses the fact that not all research leads to positive outcomes but asserts that even negative outcomes are useful for informing the next steps. One weakness that could be noted of MJFF is that it does not have an endowment fund and relies entirely on fundraising and cultivating relationships to fund science and research. Without an endowment or government assistance, MJFF runs the high risk of losing vital financial support at the onset of disappointing results despite their position on research outcomes.

The Michael J. Fox Foundation for Parkinson's Research has the opportunity to continue to make great progress in PD research and care by continuing to cultivate relationships with industry heavy weights to fund research projects in cooperation with the Foundation. As an added opportunity for investors, the Foundation uniquely does not require that a company make a 1:1 match with MJFF to invest in a project which serves as a major incentive (Michael J. Fox Foundation for Parkinson's Research 2010).

The Michael J. Fox Foundation for Parkinson's Research is threatened by two things: its position on endowment funds and company matches. Having these funds in reserve provides a safety net for the organization—in short, should MJFF be affected by the economy or a damaged relationship with a key donor, the safety net of an endowment fund or company match would allow for research to continue and stride toward the ultimate goal of finding a cure for PD.

Conclusions

The results of this case study are straightforward: for this very small focus group of nonprofit organizations, venture philanthropy has proven to be an effective model by which to

operate. Venture philanthropy is an innovative way for organizations, particularly disease-focused organizations, to streamline funds directly into serving their missions. Venture philanthropy has proven to be particularly beneficial to organizations that serve an orphan disease, or less than 200,000 individuals, in the United States.

A common challenge that the Cystic Fibrosis Foundation, Juvenile Diabetes Research Foundation, and Michael J. Fox Foundation for Parkinson's Research share is the difficulty to see drug therapies through the lifecycle of development. For pharmaceutical and medical companies, the risk and expense of developing a drug therapy or medical device is not enough for the companies to invest in seeing the project from development to market availability. Venture philanthropy allows for organizations to invest in the development of drug therapies and/or devices at the most risky points of development where projects run the most risk of having market-failure. A recommendation for nonprofits that invest in drug development would be to consider intellectual property when making business decisions. For example, the Cystic Fibrosis Foundation sold the intellectual property to a promising drug coming through the pipeline and was able to use the proceeds of that transaction to fund KALEYDECO, the drug therapy earlier mentioned as the first oral medication for cystic fibrosis that targets the cause of the disease. Garnering funds for such large investments as drug development requires extensive fundraising, cultivating high net worth donors, and maximizing capital by all means possible.

Each of the three foundations analyzed uphold the four core principles of public administration: effectiveness, efficiency, economy, and equity. In terms of effectiveness, each organization develops standards by which success is measured—for each of the organizations, a therapeutic drug pipeline serves as a quantifiable measure of success. Each organization can clearly demonstrate that through the funding provided for its projects, there have been results.

Both the Cystic Fibrosis Foundation and Juvenile Diabetes Research Foundation have drugs therapies that have completed the entire cycle from laboratory research to the patient market which is a clear measure of effective philanthropy. Venture philanthropy, as a practice, is extremely efficient and each of the foundations analyzed discuss at length the efficiency of the organization, particularly in reference to funding. Each organization has no less than a 3-Star rating on Charity Navigator, a trusted source in evaluating the efficiency of nonprofit organizations. The Cystic Fibrosis Foundation, for example, prides itself on its tagline of “ninety cents of every dollar raised” going to fuel the mission of the organization.

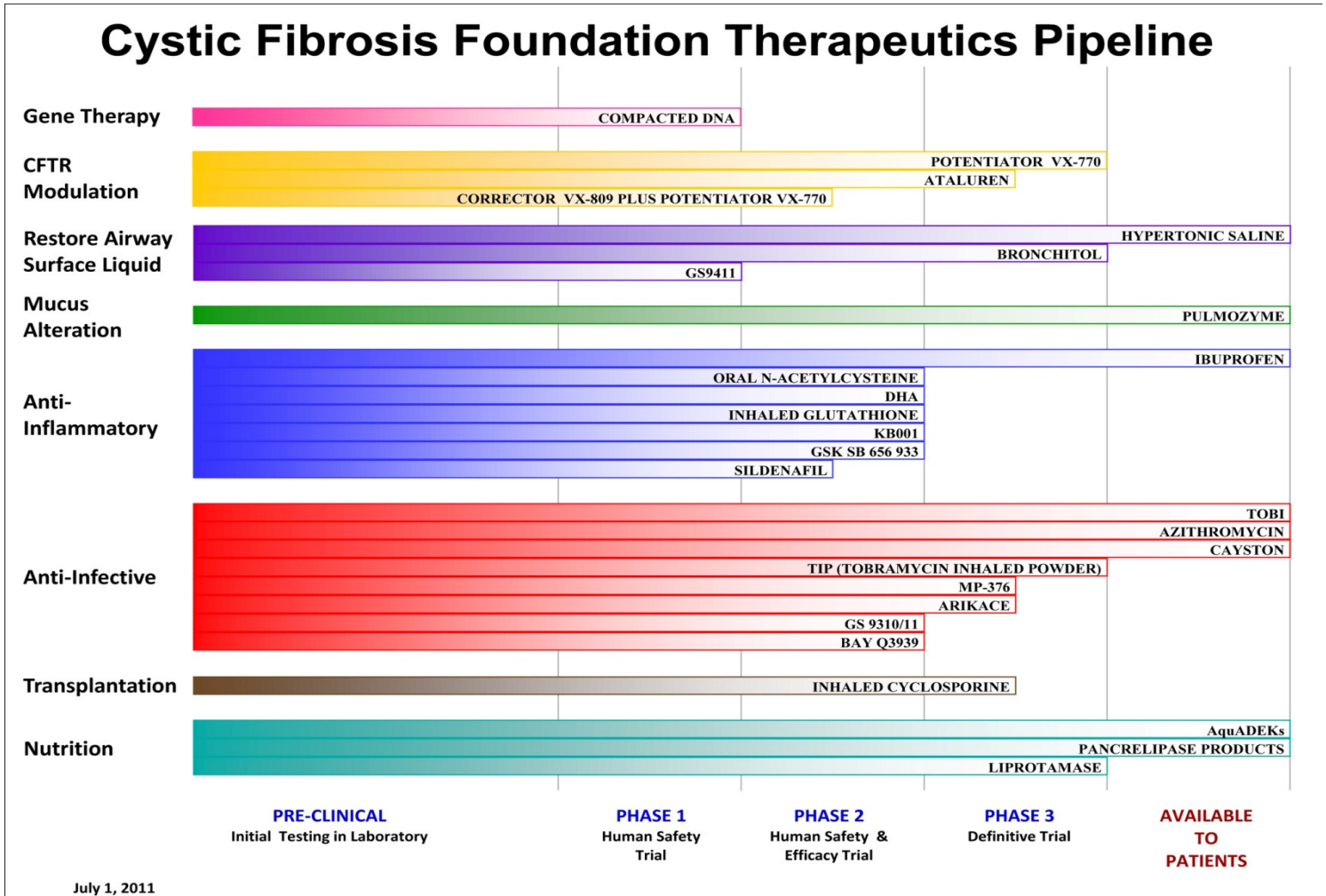
In terms of accountability and transparency, the Cystic Fibrosis Foundation, Juvenile Diabetes Research Foundation, and Michael J. Fox Foundation for Parkinson’s Research have developed superior measures for ensuring that both principles are acknowledged and upheld. Each foundation has a Board of Directors and various committees whose responsibilities are to assist in governing the organization. The Juvenile Diabetes Research Foundation has several medical and research committees for assessing projects in the therapeutic pipeline and making decisions based on science that determine the amount of funding the project will receive. Additionally, each organization has an internal and external audit for compliance and tax purposes in addition to having a 501(c)3 tax exempt status with the federal government.

As venture philanthropy matures, it is probable that it will further gain the support of sophisticated donors. It is undeniable that organizations across the United States, beyond the three organizations analyzed in the preceding analysis, have accomplished ambitious milestones with the direction of this model. The Michel J. Fox Foundation for Parkinson’s Research is an excellent example of young and successful venture philanthropy. Since its inception in 2000, the Foundation has initiated six programs that serve six different goals for the Foundation’s

mission—from evaluating targets to initiating a drug discovery program, the Foundation provides the capital to aggressively fill the gaps in public funding and support. Ultimately, the most important principle of nonprofit organizations is public service. Venture philanthropies are designed to serve percentages of the population that fall victim to bureaucracy and the red tape of large pharmaceutical companies.



















Appendices

Appendix A



Source: Cystic Fibrosis Foundation

Appendix B

	Discovery Research	Preclinical Research	Phase 1	Phase 2	Phase 3	To Patients	
Cure	 LCT living cell technologies™	DIABECELL® Encapsulated Cell Replacement Therapy					
	 XOMA	XOMA 5:3 Anti-IL 1β					
	 MACROGENICS	MGA031 Anti-CD3					
	 TOLERX immune resolve.	TRX-4 Anti-CD3*					
	 OSIRIS pharmaceutical, inc.	Prochymal Allogeneic MSCs					
	 NOVARTIS	Diabetes Drug Discovery					
	 Johnson & Johnson PHARMACEUTICAL RESEARCH & DEVELOPMENT	Diabetes Drug Discovery					
	 biogen idec	Beta Cell Regeneration Pathways					
	 HOUSEY	Beta Cell Regenerating Agents					
	 DeveloGen	Beta Cell Survival Agents					
	 Pfizer	Beta Cell Regeneration Drugs					
	 sanofi aventis	Diabetes Drug Discovery					
	 Lilly	Regenerative Medicine Collaboration					
	 NGM	Beta Cell Biologics					
	 AXAM	Autoimmune Drug Discovery					
	Treat	 Genentech IN BUSINESS FOR LIFE	Ranibizumab for Diabetic Macular Edema				
 Artificial Pancreas Project		Continuous Glucose Sensor Trials					
 SINOMED		SB-509 for Diabetic Neuropathy					
 AMYLIN		Metreleptin for Type 1 Diabetes					
 BD		Pramlintide/Insulin Co-formulation Development					
 Animas		Microneedle Technology					
 SmartCells, Inc.		Insulin Infusion Products					
Prevent	 Animas	1st Generation Artificial Pancreas					
	 SmartCells, Inc.	Glucose Regulated Insulin**					
	 SELECTA	Nanoparticle Vaccine Delivery					

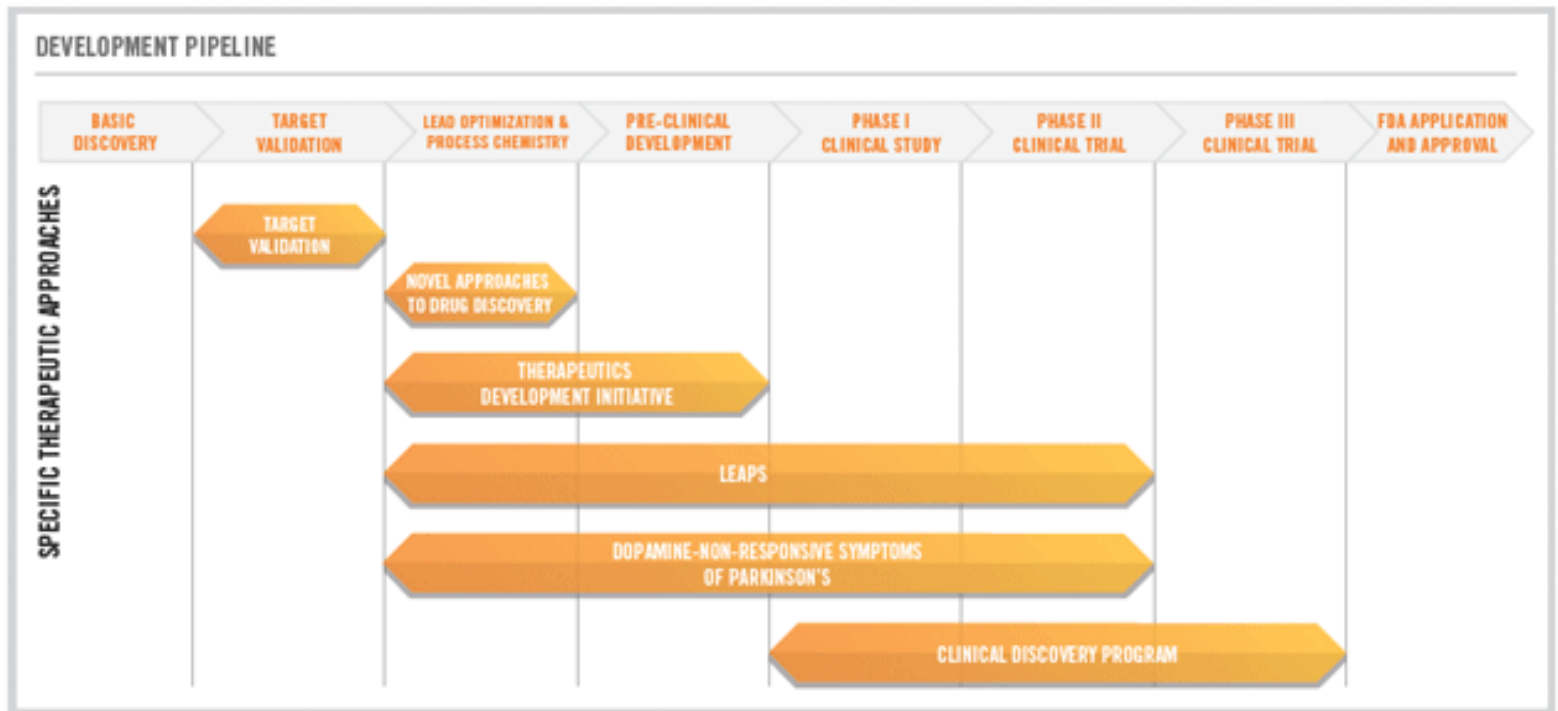
*GSK, Tolorex's licensing partner, continuing clinical development

**SmartCells acquired by Merck & Co; program continuing

Source: Juvenile Diabetes Research Foundation

Specific Therapeutic Approaches

These strategic funding initiatives motivate researchers and industry leaders to focus their efforts on Parkinson's-related projects.



Source: Michael J. Fox Foundation for Parkinson's Research

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