

RARE – RESEARCH, ADVOCACY, RESILIENCE & EMPATHY
UNLOCKING STRENGTH AND CAPACITY IN THE RARE DISEASE
COMMUNITY

By

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ABSTRACT

Nonprofit organizations vary in size and capacity. They often start with a small group of passionate people brought together with a common focus. Often their mission has a direct impact on the individual member or their communities and loved ones. Today there are over 7,000 identified rare diseases and rare disease advocacy organizations representing patients and families that singularly are small in numbers. In the aggregate, however they represent one-in-ten individuals worldwide. This paper presents a case study of one rare disease advocacy organization from the perspective of an organizational consultant who is also a parent and advocate in the rare disease community. Building upon the case study, the paper includes a review of existing research and literature and interviews with other leaders in the nonprofit and rare disease advocacy community. The capstone examines leadership and other components of nonprofit organizations, including the role of the consultant, that help bring about transformative change and innovation within this sector.

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This capstone is dedicated to my oldest son, Joshua William Friedman.

"Because I knew you... I have been changed for Good"
(Stephen Schwartzman, *Wicked*)



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CHAPTER 1

INTRODUCTION

Nonprofit organizations vary in size and capacity. They often start with a small group of passionate people brought together with a common goal. As of 2012, there were over 1.5 million registered nonprofit organizations in the United States (Roeger, p.5). Approximately three quarters of these organizations had operating budgets of less than \$500,000 per year, many of them much smaller (2012, p.149). Many small nonprofit organizations, often characterized as “grassroots,” share a similar profile in that they are led by members with a high level of passion and energy towards a singular mission. Often times the mission has a direct impact on the individual or their communities and loved ones.

Rare disease organizations are especially challenged as their small numbers draw on much more finite resources and the gravity and urgency of their mission have life and death implications. In many cases they are represented by “kitchen-table” groups formed by parents of patients or even patients themselves and represent those impacted diseases that have been diagnosed less than 200,000 times (Dunkle, 2014, p.19). Over 7,000 rare diseases have been identified, some with patient populations in single digits and many with less than one thousand identified patients. Collectively, they represent more than 300 million people across the world. 50% of those diagnosed are children (Global Genes Alliance, 2015). These organizations demonstrate extreme passion and resiliency. To be truly effective, they must collaborate with other umbrella organizations such as the National Organization

for Rare Diseases (NORD), Global Genes, their governments, and universities such as the University of Pennsylvania's Orphan Disease Center, research centers, pharmaceutical companies, and each other. Despite these extreme challenges, many have grown to become model organizations that meet the increasing heavy load of their patient communities. As research and drug therapies have advanced, so have the needs of their constituents.

There has been little written with a specific focus on rare disease advocacy organizations. Similar to other nonprofit organizations, their focus on mission and outcomes rather than financial returns call for unique attributes in their leadership, members and operations. This capstone offers a case study of a recent consulting engagement that took place with a rare disease organization.

In addition to the case study, the capstone asks what separates the nonprofit sector from for-profit enterprises and explores the unique challenges and perspectives in the rare disease community. It also explores the role of the consultant and organizational development practitioner when working with nonprofit organizations and includes a survey with leaders of other small nonprofit organizations, including past and present Board members, Board Presidents and Executive Directors of several rare disease and grass-root organizations who discuss the trajectory of their organizations and how they may have been positively or negatively impacted when working with consultants. These are presented over the next four chapters that are described below.

The DCO Case Study

The case study recounts a recent consulting engagement with a small rare disease advocacy group. It includes my own history as a parent and advocate for a child with Dyskeratosis Congenita (DC), a rare biological telomere disorder. It shares the story of the consulting engagement with DC Outreach, Inc. (DCO) that I completed with classmate Bob Biglin and our advisor, Dr. Charline Russo as part of the University of Pennsylvania's Master's of Science in Organizational Dynamics - Organizational Consulting and Executive Coaching cohort program. The objective of this engagement was to help DCO's leaders develop a strategic plan that was grounded on the past successes of the organization and leverage their strengths to help them identify a common vision that would build their organizational capacity and effectively lead their growing patient and caregiver community into the future.

DCO was formed in 2006 by a small group of patients and parents with the following mission:

Our Mission is to provide information and support services to families worldwide affected by Dyskeratosis Congenita and Telomere Biology Disorders to encourage the medical community's research in finding causes and effective treatments, and to facilitate improved diagnosis by educating medical providers. (Dyskeratosis Congenita Outreach, Inc.).

This engagement had special meaning, as my oldest son Josh was lost to DC five years ago after battling this disease for over seventeen years. When Josh was diagnosed with DC in 2002, he was one of less than 400 individuals in the world to ever have been diagnosed with this disease. Since Josh's

diagnoses, DC has been diagnosed in over 1,000 additional individuals.

Although DC is considered an extremely rare “orphan disease,” it is believed that it goes undiagnosed more often than not. The DC and biological telomere disorder (BTD) community believe that diagnoses will continue to grow as doctors become more educated and aware in identifying these underlying conditions as they encounter them when treating their symptoms (Olson, 2016). We found DCO to be an organization that has punched well above its weight as their past accomplishments have moved mountains, yet they are faced with much more to do with limited and tired resources.

The Literature Review

Building from the experiences of the DCO case study, the literature review includes a blend of peer-reviewed articles, books and on-line sources that explore prevalent factors towards building the organizational capacity and effectiveness of non-profit organizations. Building from the experiences and learning of the DCO case study, the literature review focuses these observations to the following areas:

- *Rare disease advocacy organizations* – a brief retrospect on the emergence of rare disease patient advocacy organizations and what factors separate these organizations from other nonprofits. The history of the National Organization for Rare Disorders, a leading advocacy group representing thousands of rare disease organizations since the passing of the Orphan Drug Act in 1983 is presented to help frame the

unique challenges encountered by rare disease advocacy organizations.

- *The nonprofit/consultant relationship* – An examination of what methodologies and applications are most effective when working with nonprofit organizations as a consultant and how these relationships have helped lead these organizations to grow in effectiveness, innovation and capacity. Penelope Cagney's book *Nonprofit Consulting Essentials* provides insight in regard to the consultant's journey with nonprofits, and an analysis of the appreciative inquiry utilized with the DCO engagement is further examined.
- *Leadership and innovation in nonprofit organizations* – qualities and challenges that distinguish the nonprofit sector from for-profit enterprises. This section includes articles, research and insights from Peter Drucker and Frances Hesselbein that help set the foundation of the unique attributes found in the nonprofit sector. It also examines research in regard to approaches in building organizational capacity and innovation with such organizations as the Association of Retarded Citizens (ARC) and studies with leaders from other small nonprofit organizations.

Research Methodology, Assumptions, Data and Analysis

In addition to my own experiences with DCO, Chapter four includes insights from leaders of other nonprofit organizations, including those from the rare disease community. Those included in the interview process were some of

the most innovative and passionate people I've ever met. Each of the interviews offered fascinating perspectives of the inspirational journeys that each of the represented grass-root organizations encountered as they continue to grow and help others cope, advance research and overcome obstacles that are encountered at the most personal level.

Summary & Conclusions

Chapter five provides a summation of observations and findings discovered in the case study, the literature review and the survey of other nonprofit leaders. The chapter presents questions and research opportunities to consider that were not within the scope of this study, but would be valuable to pursue. The chapter concludes with my own reflections and thoughts in regard to the capstone experience and how this experience has influenced me as a parent, advocate, coach and consultant now and in the future.

CHAPTER 2

THE DCO CASE STUDY

The summer of 2016 was a rewarding time as my Penn OCEC Cohort V classmate Bob Biglin and I partnered under the supervision and guidance of Dr. Charline Russo to help an organization that has worked with few resources and a large mission. Dyskeratosis Congenita Outreach, Inc. is a 501c(3) advocacy and support group that serves patients and caregivers of Dyskeratosis Congenita (DC), a rare disease diagnosed in less than one in every one million people in the world. A recent article in Penn Today described DC as follows:

DC, is a rare, inherited disease for which there are limited treatment options and no cure. Typically diagnosed in childhood, the disorder causes stem cells to fail, leading to significant problems including bone marrow failure, lung fibrosis, dyskeratosis of the skin and intestinal atrophy and inflammation. Patients are also at heightened risk of several types of cancer. A common underlying feature of the disease is the presence of shortened telomeres. Telomeres are the structures that protect, or “cap,” the ends of chromosomes, but they tend to shorten with cell division and age, and can thus lose their protective functions. Many DC patients have a mutation in the DKC1 gene, which codes for a component of the enzyme called telomerase that helps maintain telomere length. Because telomerase is most essential in tissues that divide frequently, notably, epithelial tissues such as the skin, gut and lungs, this is where defects crop up in these individuals. (Baillie, 2016).

This engagement had special meaning, as my oldest son Josh was lost to DC five years ago after battling this disease for over seventeen years. When Josh was diagnosed with DC in 2002, there were less than 400 others ever diagnosed with this rare telomere disorder. Since then, DC has been diagnosed in over 1,000 other individuals. The DC and biological telomere disorder community believe that diagnoses will continue to grow as doctors become more

educated and aware in identifying DC manifestations in other conditions as they encounter them when treating their symptoms (Olson, 2016).

In 2006 a small group of patients and caregivers affected by DC formed DC Outreach, Inc. with the following mission:

Our Mission is to provide information and support services to families worldwide affected by Dyskeratosis Congenita and Telomere Biology Disorders to encourage the medical community's research in finding causes and effective treatments, and to facilitate improved diagnosis by educating medical providers. (<https://www.dcoutreach.org>).

My relationship with DC & DCO

I am a parent of a child lost to DC. Today those words are difficult to say and accept. They sadden and anger me. They are part of my identity and serve to inspire how I choose to move forward.

Through the first fifteen years of Josh's life, my wife Pattie and I had never met anyone, with the exception of doctors, who had any affiliation with this extremely rare condition. Josh was our first-born. As new parents, we felt confused and alone as we began understanding his condition and realizing his severe feeding issues, lack of growth, microcephaly and cognitive delays, and his phantom fevers in the middle of the night we were experiencing were not normal or healthy. It took eight years before a definitive diagnoses was reached. DC is so rare, and there are so few data points, we found ourselves at the forefront of the unknown. We resisted looking too far into the future and committed ourselves to living our lives with Josh in the moment. We rarely thought of Josh

as sick or disabled. To us he has always been and still is an integral part of our family.

Josh's first three years of life included severe feeding issues, a failure to gain weight and grow, and an understanding that he would need help throughout his life. At the age of three Josh weighed only seven-teen pounds, had difficulty walking and talking and was constantly tired and sick. At this time, we spent four months at the Seashore House at the Children's Hospital of Philadelphia (CHOP). After surviving some significant medical scares and setbacks, we were still without a diagnosis. We brought Josh home the week before the Christmas of 1997. He was stronger, walking and talking, and we could see that he would have a chance to live a viable and impactful life. We still did not have a diagnosis; however, we knew his immune system was compromised and began a life of treatments and doctor visits between school and activities.

When Josh was eight, Dr. Katherine Sullivan ("Dr. Kate" as we came to know her), an immunologist at CHOP, began to narrow down what she thought may be Josh's underlying condition. Dr. Sullivan along with the top geneticists at CHOP tested for multiple immunological disorders, syndromes and rare conditions. Ultimately, through collaboration with Dr. Indergeet Dokal, a DC specialist from Hammersmith Hospital in England, we were able to pinpoint Dyskeratosis Congenita as Josh's underlying diagnosis.

When we learned of Josh's diagnosis, we traveled to Hammersmith and met Dr. Dokal. He was a resource to us through Josh's life and remains a friend to the DC community and our family. Having a diagnosis did not bring much

relief nor did it lessen the fear we were experiencing as a family. We were still alone and Josh was only the 365th DC patient identified with DC that Dr. Dokal was aware of as he maintained a registry of DC patients from around the world. There were no support groups, massively attended walks or bike rides, broadcasts telethons, or Ice Bucket Challenges to spread awareness, raise money or provide connectivity for the few hundred people in the world diagnosed with this rare and little understood disease.

What we did find was local support from our friends, family and the special needs community in Voorhees, New Jersey and later in West Chester, Pennsylvania, where we now live. For fifteen years we managed Josh's care along with raising our younger children Noah and Katie. We were all affected as DC was part of our "normal" lives. At this time, Josh's care was manageable and with the exception of a few setbacks, his health was relatively stable. Our focus was more on family, friends and wellness rather than the science or advocacy that comes with a rare disease. This all changed during the winter of 2010.

One of the main complications for patients with DC is bone marrow failure. Josh's bone marrow was tested and monitored each year and for the first fifteen years of his life, it remained relatively healthy and stable. In early 2010 his annual bone marrow test revealed a decline in red-cell production and we began to see the first cracks in what had once been a manageable disease.

In addition to being a member of his drama club and a year-round participant and camper at Bournelyf Special Camp, Josh also played Challenger League baseball. The Challenger League included teams with children and

young adults with various physical and cognitive challenges along with “buddies” that helped them learn and perform the fundamentals of baseball. As a parent, the league offered a great social connection with the special needs community. It also offered weekly games that were incredibly slow to watch. One of the Challenger League rules is that each player has an at-bat in each inning. Thankfully the games were only three innings. The last player each inning would clear the bases with a home run. Every game ended in a tie. During a game early in the 2010 season, Josh was the cleanup hitter. When he hit his home run he struggled to get around the bases. When we hugged in the dugout I could see he was exhausted and he asked if I could pull him out of the game. I knew that we were heading towards a bad place.



A few weeks later Josh had another appointment with his hematologist who was quickly learning about DC. He had never heard of, none-the-less treated anyone, with this rare condition before Josh. After several more tests, we

were told that Josh's condition would only get worse and that the remainder of his life would be measured in months, not years.

As a parent of a child with a chronic illness, I would often find myself up late at night searching online for new information about DC. Shortly after realizing that things were not going to get better for Josh, I found a web-site called DC Outreach, a small support group for those dealing with DC. By now, it had been eight years since we had a name for Josh's disease. I quickly saw that there was a patient community, albeit small, for others coping with this disease. DCO's logo was "You are not alone". I briefly shared Josh's story on the site and within a day I heard back from DCO's President, Nancy Cornelius. I learned that Nancy lived with her family in New York. Nancy was diagnosed with DC while in her forties and she had a son, Charlie who was also diagnosed with DC. At this time Charlie was a student and member of the diving team at Villanova University. I also learned of another family who lived in New York, and whose father Seth, was originally from Lower Merion, Pennsylvania, and had a one-year-old daughter just diagnosed with DC. The next day I spoke with Seth and we realized that we grew up within a few miles from each other and albeit 10-years apart, we went to the same high school (Seth was at Lower Merion during the Kobe Bryant years, about ten years after I graduated). A few weeks later, Josh and I had lunch at Villanova with Charlie. Suddenly we weren't feeling so alone.

We had found a community and soon expanded our network to doctors and others who were some of the few in the world that understood this disease.

Through DCO, we also learned that we did not need to go back to London for care. Dr. Monica Bessler, a colleague of Dr. Dokal's at Hammersmith Hospital had recently come to practice and chair the Hematology department at CHOP. Dr. Bessler along with her Resident colleague Dr. Tim Olsen, who succeeded Dr. Bessler after her retirement and was a contributor to the DCO engagement as well as this study, were the very best people we could have met to support us through the final chapter of Josh's life. They were both extremely knowledgeable, caring and compassionate. They were with us through Josh's final months and days until his last breath. Sadly, Josh's health continued to deteriorate. We knew with Dr. Bessler, Dr. Olson and Dr. Sullivan at CHOP we had access to the best possible care in the world for Josh. At the age of seventeen, on November 18, 2011, Josh passed away. DCO had become a lifeline for us as we confronted this disease, grieved our loss and gained the support and knowledge offered from this tight-knit community.

Three years after losing Josh, I began working at the University of Pennsylvania. Part of what drew me to Penn was continuing the Organizational Dynamics (OD) program. I had started in 2001, but stopped after taking three courses as Josh's medical needs took precedent. Working at Penn offered me the unique experience to become closer with the doctors and researchers that I had gotten to know over the years that helped Josh. It also provided an opportunity to reengage in the OD program. I rejoined the program with a greater focus than I had when I started it. I wanted to help others who were dealing with similar challenges that I had as a parent and professional managing

an acute medical condition and facing the loss of a child. The Organizational Consulting and Executive Coaching cohort program offered by the OD curriculum was the ideal place to pursue this mission.

From parent and advocate to consultant

Two years after losing Josh and shortly after beginning my work at Penn, I became a DCO board member. DCO's monthly Board calls were always awkward for me. The Board meets monthly on the second Sunday night at 9PM. This time is difficult, but has worked best for its members as they are calling in from each of the US time zones and sometimes from the other side of the world. This was a large part of why I eventually left DCO's board. Sunday night is typically when my wife and I unwind together on our couch, so disrupting this to relive our DC experience became a hindrance toward coping with the loss of Josh. I also felt many of the topics that consumed these calls, often late into the evening, were things that could be better resolved with other DCO members and were not reliant on my input. The following e-mail to DCO's Board President and Treasurer was difficult to write, but expressed my thoughts at this time.

On Sat, Mar 12, 2016 at 3:01 PM, Microsoft Office User <bwf819@yahoo.com> wrote:

Robin, Lisa - This morning I was on a training ride for the MDBR and as often happens, I found myself lost in my thoughts. I want to share with you as we've gotten to know each other a bit over the years. I apologize for the long note, but you've both been helpful to me over the last couple of years and I'd like to share this with you.

I admire both of you for your resilience and determination as you fight through DC and endlessly work to help others as well as yourselves. Your energy and perseverance are truly inspirational.

I now find myself four + years since Josh passed away. My son Noah is now older than Josh was when he passed and will be entering Millersville University this fall. My daughter Katie is 15 and truly an exceptional student, dancer and young lady. Pattie and I continue to grieve but now find ourselves thinking more about Josh's life and less about what we went through managing a terminal disease. It's been a difficult road getting to where we are and I'm beginning to understand more now that it's time to focus more on what's in front of us and ahead of us while continuing to honor Josh's memory.

Over the last ten months, I've been engaged in a degreed executive coaching and Masters program at Penn. When I accepted a position at the University, I took a large cut in pay, but was motivated to do so as I've always felt a strong closeness to CHOP and Penn, I also wanted to help other grieving parents or those with children with chronic illnesses who have professional careers as I've experienced all of that myself and I found Penn offered me an opportunity to pursue that goal. Now that I'm about half way through the program, I realize that I do enjoy coaching and I think I'll be pretty good at it, but I need to figure out how to transition this into a career and also realize that it's much broader than the initial goal that motivated me to start.

I joined the DC Outreach Board last year following for a few reasons. One was I had reached out to Dr. Bessler and Dr. Olson who had treated Josh and was with us as he took his last breath to ask how I could help other DC families at Penn, she suggested I become involved again with DC Outreach. I also was grateful for the support DC Outreach and in particular Nancy Cornelius who were with us as Josh's health began to deteriorate and we began to understand that his condition was not going to get better. Lastly, I felt obligated as Josh's Dad to honor his memory and help others.

The challenge I've had and continue to have is that I'm stretched pretty thin. I started a new position within Penn this past January, I'm also still active with the board for Josh's camp, which is right down the street from where we live and includes families that we've become very close to throughout Josh's life. It's also helpful to us that Pattie, Noah and Katie are all involved with the camp throughout the year. Another challenge that has become more apparent is that it's becoming more emotionally draining for me to actively participate in DC Outreach. I feel that I contribute a lot with my board experiences and resources at Penn, but calling in on Sunday nights and other nights is a disruptive and difficult reminder to me as well as Pattie and our kids as we continue to move forward as a family. I stopped calling into the family calls which are wonderful, after Josh passed away, as it was too difficult to listen to others going through what we had and I did not feel I could offer much hope, especially as

difficult as the last 18 months of Josh's life was. Whereas this was once a way to help me cope with grieving, it's become more of a hindrance in moving through the grieving process. That's in large part why I've limited my participation to the monthly calls. I don't feel I've been as good a board member as I should be and right now, I don't think I can, it's hard for me to say that, but it's how I feel.

I'd like to remain a friend and resource to DC Outreach. I'm glad to continue to help as an advisor or maintaining relationships with Penn, but I don't think it's productive for me to continue on the Board.

I will call into tomorrow night's meeting as I have a few items on the agenda. I don't want to make a big deal about this on the call, and I'd like to get your thoughts on how and if I can best contribute without being a full-fledged board member before doing anything "official".

I appreciate your friendship and hope that you can understand how difficult this decision is for me, but I think it's one I need to make.

Best,

Bruce

After leaving the DCO Board, I wanted to maintain my connection with the organization. The OCEC cohort has been a transformational experience for me as I realized I would want to eventually transition my career from that of a finance professional to a coach and consultant. As part of the Cohort program, we were required to complete a consulting field experience. I could not think of a more rewarding experience than working with DCO. At this time I approached my classmate, Bob Biglin, with this idea and after we thought through an initial approach, we presented this plan to our advisor, Dr. Charline Russo.

As a parent of a child lost to DC and who found help and support from DCO during the most difficult time of our lives, and as a former board member of DCO, I struggled with defining my role as a consultant. I had known the Board members via phone and Internet, and even a few in-person contacts over the

past seven years. When Bob and I introduced our proposal to the Board members, I knew I needed to make the shift from DC parent and advocate to consultant. I was concerned my emotions would get in the way, and would result in the transference of my own experience with DC and rare diseases. I knew I needed to be objective and open myself up to the truths and experiences of other people. Getting out of one's own way is not an uncommon area of development for coaches and consultants, yet my concern was amplified as DC has had such a profound impact on my life and my immediate and extended family.

Developing a new relationship with DCO's Board

Over the past several years, DC has been diagnosed more frequently and the patient pool continues to expand. Consequently, DCO's Board finds itself working with a small budget and often searching for expertise and resources that are needed outside of the DC families that they serve. The Board consists of a small group of DC patients and caregivers, many physically and financially exhausted from the implications of managing a chronic illness. Until recently, only those directly impacted by the disease were board members. The disease has devastating implications to each patient's health and the well being of the patient and their caregivers. The current board members all shared a feeling of "burn-out" and felt they had so much to do with very little energy to continue to advocate and carry out their mission.

Through Board calls and other interactions with DCO's Board, transitioning my role as a board member to a consultant would be difficult for DCO's Board members and me. As Bob and I introduced the consulting

engagement to the Board during their August monthly Board Call, there was awkward silence. I realized about halfway through our meeting that we did not do a very good job setting the table and jumped right into the content and approach of the consulting engagement. This was in large part my own doing as I initiated the discussion, but forgot to introduce Bob to the other board members. This was the result of my own anxious energy and I realized we had lost our audience. I stopped in the middle of our presentation and acknowledged that I had not set up our discussion appropriately. We then took the time to introduce ourselves and asked each member what their thoughts and concerns may be as we outlined the proposal. This followed with a much more robust discussion and we left the Board meeting with the promise they would get back to us in the next several days with a decision in regard to proceeding with the engagement.

At this moment I realized, that although I knew I needed to manage myself carefully through the engagement and avoid assumptions based on my own experiences, I also needed to step back and breathe. I needed to be very deliberate in my interactions with DCO and balance the experiences that I was bringing to this engagement, with objectivity and professionalism. After the call, Bob and I spoke. I shared my feelings with Bob and we both recognized even more clearly how much we needed each other to effectively move forward with DCO.

Although maintaining a professional distance during the engagement with DCO presented a challenge to be managed, it was also an asset in truly understanding and helping the organization. As described in Edgar Schein's

Humble Consulting, I had entered the DCO engagement already with a “Level Two Relationship”, that is a more personal, more trusting and open relationship with DCO board members than typically experienced from an outsider’s point of view (2016, p. 15). Schein describes humble consulting as a consulting relationship that presumes the consultant is committed to being helpful, bringing a great deal of honest curiosity, and having a caring attitude. Even though I had an extensive relationship with DCO in the past, working with them as a consultant was new and it was important that Bob and I engaged in what Schein describes as the “personalization process”. We needed to get to know DCO and understand their true challenges by demonstrating genuine curiosity, caring and a commitment to helping. This process proved valuable in establishing a relationship-building process that would be used throughout the engagement and would lead to interactions that the client would find immediately helpful (2016, p. 13). I needed to recalibrate and re-personalize my relationship with DCO.

Building this relationship and establishing an awareness of how my relationship with DCO was influencing this new engagement was an important step in helping DCO understand their capacity for change and growth. As our work progressed, I was able to find a middle ground and balance what had become a very personal and close relationship with some of DCO’s board members over the years. The new context of our relationship enabled me to avoid becoming what Schein refers to as “content-seduced” and better manage myself to focus on the various processes that were occurring between DCO’s Board members, Bob and me (2016, p. 20).

This balance was first challenged when Bob and I first arrived at DCO's Camp Sunshine Retreat, where we were to present DCO's vision and strategic plan to their Board, families and medical advisors. When we arrived at Camp Sunshine, we were invited to have dinner with the camp families. We agreed that it would be rude not to interact with the families and we enjoyed meeting them and learning more personal stories of their coping with DC. This was a critical part of the personalization process.

The next day, after Bob and I presented the DCO vision and plan to its members, we were invited to be included in a camp picture with families, doctors and others at Camp Sunshine. I decided that I was not comfortable doing this. I felt that the camp and its pictures were to provide hope and encouragement for those coping with DC, and not a place to memorialize those who had been lost. I was stuck in-between the role of a consultant who maintained objectivity with our client and the role of a grieving parent amongst those who were currently survivors of DC. My relationship with DCO has changed since losing Josh and even more so now as I'm looked upon as a consultant. I was concerned that joining in with the families who were celebrating their time together at Camp Sunshine would create more confusion in regard to these roles. I believe stepping away at this time was appropriate.



Determining an approach

Understanding DCO's history and being familiar with other rare disease organizations was helpful in evaluating what we believed would be the most effective approach in structuring our engagement. One option was to follow a conventional problem-based approach in which we would survey the board for their objectives, evaluate their present state, develop a gap analysis, and then help them identify a plan to move forward. From our initial discussions with the Board, it became clear that there were much deeper challenges to be addressed if they were to successfully develop and execute a strategy focused on expanding their capabilities and outreach. Our initial evaluation of the Board and the organization's readiness to engage in a more comprehensive strategy development exercise revealed the following:

- *Board Fatigue:* Like many patient advocacy organizations, DCO had been built on the energy and commitment of a core group of patients and their families. None of the current Board members had professional experience as a non-profit leader and most had limited or no professional managerial

experience. Commitment, a passion for their mission, and a high degree of tenacity had fueled their growth and success. After years of supporting patients and families, while also managing the emotional and physical challenges of dealing with the disease themselves, many of the Board members were exhausted and becoming dispirited at the new challenges they were facing. A growing need for their services, lack of funding and challenges in raising funds, and lack of success in recruiting more active engagement amongst the organization's membership were all areas that would require vision and energy.

- *Absence of a coherent vision of the future for DCO:* Through our conversations with the Board collectively and individually, it became clear that a vision for the future of the organization was lacking. While some individual members had general thoughts about the organization's potential future, most were focused on serving the present needs of their members. Consequently, collective thought had not been given to the future. Through discussions, we learned that Board members were so consumed with delivering services to current and new members – everything from assembling, packaging and posting informational welcome packets, to managing the website and social media presence, and hosting a monthly family teleconference – it was apparent that there was no time or energy to plan for the future.
- *Lack of confidence in their skills as organizational leaders:* The absence of formal non-profit managerial skills, training and experience, combined

with pressures of meeting current needs of members, left the organization lacking confidence in its own ability to envision a thriving future. It was critical that they had the opportunity to step-back, assess their current state and understand the existing internal and external influences that would enable them to lead the organization on a journey to achieving that vision.

□ *Lack of a conscious appreciation for what they had already accomplished:*

During our initial discussions, we were surprised to observe that there did not seem to be a conscious awareness of the magnitude of what the organization had accomplished since it had been founded. As third parties looking in, we were surprised and impressed to see what a group of committed patients and families had accomplished with minimal non-profit training or experience, and relatively small amounts of funding. Since its formation in 2008, DCO has formally registered as a 501 c(3) non-profit; established a global patient directory; recruited a medical advisory board comprised of internationally accomplished researchers in the field of genetic orphan diseases; grown the organization's membership to over 400 members from five countries; held a biennial camp for DC families; and published a 400+ page medical diagnostic and clinician guidelines manual. While everyone we spoke with acknowledged these accomplishments, we did not believe that they fully comprehended the magnitude and importance of their success. Our initial take-away was "if they can do this as a layman's Board with no formal non-profit training,

imagine what would be possible if they were able to develop their skills in leading a mission based organization!”

From these initial observations - Board fatigue, a lack of a future vision, low self-confidence, low appreciation of previous accomplishments – we developed a set of priorities that we thought were critical to the success of this project:

- Emphasize the accomplishments of the organization to help build their self-confidence.
- Devise and accompany the Board on a journey of discovery, helping them to understand how they can leverage the strengths they currently have, while building new capability with additional training and support.
- Help them step back from the day-to-day firefighting, which consumed so much of their time and energy, to create the perspective to envision the possibilities for the future of DC Outreach.
- Work with the Board to help them prioritize which activities should be continued, which should be stopped, and to consider who they can enlist help from in the broader organization to share the workload.

Bob and I were influenced by what authors Sarah Lewis, Jonathan Passmore and Stefan Cantore present in their book, *Appreciative Inquiry for Change Management* (2011) as the “SOAR” model. SOAR is an acronym for Strengths, Opportunities, Aspirations and Results (2011, p. 189). The strategic planning process needed to be inclusive and as consultants, we needed to facilitate a process that was owned by DCO’s leaders and members. We

decided to incorporate David Cooperrider's Appreciative Inquiry (AI) model which is described on Case Western's Appreciative Inquiry Commons website as:

The cooperative search for the best in people, their organizations, and the world around them. It involves systematic discovery of what gives a system "life" when it is most effective and capable in economic, ecological, and human terms. AI involves the art and practice of asking questions that strengthen the system's capacity to heighten positive potential. It mobilizes inquiry through crafting an "unconditional positive question" often involving hundreds or sometimes thousands of people.
<https://appreciateiveinquiry.case.edu/intro/definition.cfm>).

With those priorities in mind, we felt that an approach informed by appreciative inquiry would provide the appropriate framework for creating momentum and energy for the organization and its leadership, through a strengths-based focus. We planned to employ an inquiry-based methodology to focus on strengths and opportunities and help DCO's Board move beyond perceived weaknesses and threats (Stavros, Cooperrider, & Kelly, 2003, p.6).

Appreciative Inquiry and DCO consultation

Based on our initial discussions with the DCO Board, our assessment of the current state of the organization, and the Board's objectives regarding a future strategy, we developed an engagement design built on the principles of Appreciative Inquiry. Although we were not able to convene a more traditional multi-day Appreciative Inquiry workshop, we were able to use those same concepts and constructs, while working within the time, geographic, and logistical constraints we faced. The engagement consisted of four major phases:

1. *Stakeholders and Questions*: We introduced our engagement process to the Board during a board meeting. This discussion included an overview of the

Appreciative Inquiry approach, a list of proposed questions for interviews and a rough timeline for the engagement (Appendix A).

2. *Interviews & surveys*: These included thirty individuals who represented patients, families, board members, doctors, researchers, leadership from partner organizations, and the pharmaceutical industry. We also conducted a prioritization exercise with the Board to agree on a set of questions that we would use for the interviews and surveys to be conducted with these stakeholders. Based on discussion with DCO's Board, we derived the following sets of questions for three different sets of stakeholders:

DCO Board members, patients and caregivers – this group included eight current and prior members of DCO's Board and eleven other DCO patients and caregivers from the United States, Canada, New Zealand and Sweden.

- a. What are you most proud of that DCO has accomplished?
- b. When DCO is at its best, what are the core factors or strengths that give the organization life?
- c. In your ideal world, what does DCO look like five years from now?
- d. From your vision of DCO in five years, what do you see as the most important attributes & skills for its Board members?
- e. Partnerships have proven to be very important to DCO. What existing partnerships should be strengthened and what new partnerships should be pursued to support the five-year vision?

DCO Doctors – this group included all six members of DCO’s Medical Advisory Board and two other doctors who have treated DC patients.

- a. What would you consider to be the most important areas for DCO to be engaged with in the medical and research communities in the next five years?
- b. What non-DC conditions should DCO consider when exploring possible partnerships?
- c. If DCO was able to sponsor research, what areas of research do you believe would be most important?

DCO Partner Organizations – this group included the leadership of five rare disease organizations and support groups that included Penn’s Orphan Disease Center, Global Genes, Camp Sunshine, Smart Patients and Repeat Diagnostics. In addition to the DCO partner organizations, we also interviewed a highly respected CEO of an orphan disease pharmaceutical company.

- a. As a partner with DCO, what core competencies and strengths do you feel DCO contribute and can build upon?
- b. How does DCO best compliment your organization and how could they best expand their influence with you in the coming years?
- c. What attributes do other rare disease advocacy groups demonstrate that have been valuable in growing a successful partnership with your organization. How can DCO increase their effectiveness in these areas?

- d. Are there other organizations that you have worked with that you believe would be a good partner for DCO? Who are they and would you be open to facilitating an introduction?
- 3. *Synthesis and reporting:* Using the data acquired during the interviews, we assessed and synthesized the feedback, developing key themes for each major constituency, and then developed recommendations to share with the Board and present to the DCO community who would be present at one of their biennial camp sessions at Camp Sunshine in Casco, Maine. The camp session would also provide the venue for us to facilitate a conversation amongst the community to help refine our broad strategy recommendations into a more specific action plan. The key themes for each constituency are listed in the body of the presentation made at Camp Sunshine (Appendix B).
- 4. *Create a detailed action plan:* The final step of the engagement was to incorporate everything we had learned through all of our interactions with the DCO community, and create an action plan for the organization to use. We primarily focused on creating a roadmap of specific activities and milestones that the Board could follow to kick-start their efforts. The detailed action plan was delivered to the Board (Appendix C). Along with a detailed action plan we also provided the Board with a draft of a “Call to Action” memo for their constituents as well as a draft job description for an Executive Director.

Throughout these interviews and surveys we found alignment in what DCO members and others had identified as their most profound accomplishments. Almost every DCO family and medical community member

interviewed identified the publication of DC's Clinical Guidelines as their biggest accomplishment. They also spoke about the ongoing support DCO provides through monthly parent and patient calls with members of their own medical advisory committee and others to help families fighting DC. Camp Sunshine and the simple fact that they've accomplished so much with so little were recurrent themes that members of the DCO community reflected upon in their responses.

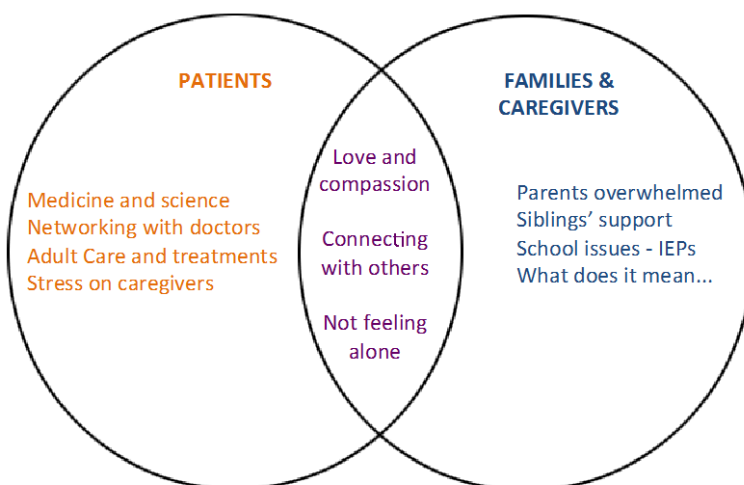
DCO members described the organization's biggest strengths. Strengths included tremendous commitment from a dedicated and responsive medical advisory board. They also expressed that DCO was at its best when members pulled together to help a family under difficult circumstances, and their ability to work together with a common focus and goal. These strengths were demonstrated during their participation at medical conferences and building strategic partnerships to advance their mission. DCO's board and its members were aligned in recognizing the valuable work they've done on behalf of their families.

Our interviews and data collection outlined a common vision and aspirations that included casting a broader net in identifying patients with DC and those with other telomere biological disorders. It also identified opportunities to build impactful relationships with the pharma community as well as taking a more active role in influencing research towards treatments and ultimately a cure for DC. These aspirations were broken down into four categories as presented below:

<p>Engagement with DC Community</p> <ul style="list-style-type: none"> • Regional chapters: raise awareness, expand networking, and broaden fund-raising reach • Focused support programs: tailored to needs of Patients, Parents, Caretakers, and Family members • Broader base of skills from within and outside of DC Community: legal, financial, social media, emotional wellness, development • Coordinated engagement with international DC organizations 	<p>Strategy-focused Board and dedicated Functional Committees</p> <ul style="list-style-type: none"> • Part-time Executive Director: runs routine Operations • Board focused on Strategy and Development • Board meets at least annually in-person; when possible, concurrent with conferences • Committees established to lead specific initiatives: Communication, Nomination Development, Wellness
<p>Research and Advocacy</p> <ul style="list-style-type: none"> • Focus on a cure • Medical Advisory Board leading mapping and prioritization of DC Research • Easier access to Telomere testing • Increased DCO presence at conferences and symposia • Actively engaged with 8 primary care centers in the US: raising awareness amongst clinicians for early diagnosis • Established at least two partnerships with Pharma 	<p>Robust, Sustainable Fundraising</p> <ul style="list-style-type: none"> • Regional Chapters: events and fund drives, provide funding base • Monetary support from Pharmaceutical partnerships • Active pursuit of Grant funding • Larger member base: expands potential network for fundraising

Members also identified differences and alignments between those who are adult patients with DC and those who are caregivers, mostly parents that are managing and living this illness through their children.

Unique and Common Needs



While identifying how DCO would build upon its history of accomplishing so much with so little, their community also realized that the organization needed to grow to meet these aspirations. Member engagement, expanding their network to individuals with valuable skills and commitment that were not as directly impacted with the disease, and focused fundraising were all aspirations that needed to be acted upon to build on their success. The vision included moving from a patient-driven group to an effective professional advocacy organization and it was agreed that a seasoned Executive Director who could work with a board focused on DCO's strategy and a committee structure as outlined below would be a critical factor towards moving forward.

Committee	Primary Responsibilities
Executive	Sets organizational strategy; sets priorities, established objective
Development and Communication	Leads fundraising strategy and execution Cultivates relationships, expands DC network for funding Leads and coordinates all communication activity
Wellness and Advocacy	Provides guidance to patients and families on navigating: medical resources, insurance, legal, personal financial, etc. Education resources (IEPs, School support entitlements) Family counseling
Medical	Advisory Board; Conferences; Pharma Partnerships; Clinical Guidelines, Protocol
Nomination	Sourcing and screening candidates for Board and Committees

Although ambitious, the plan presented generated energy and a sense of achievability from the Board and DCO members when presented at the Camp. DCO's Vice President, Rachel Godfrey, stood up after we presented their vision and proclaimed that she felt "DCO was so close to meeting these challenges, we just need those in this room to help!"

As we developed these thoughts and ideas into an articulate presentation, we began discussing what we thought would be needed for DCO to successfully move forward. We shared a concern that the current board members did not have the capacity or experience to organize these ideas into an actionable plan. We decided we needed to be prescriptive in outlining the tactical steps that the board would review, prioritize and execute upon. We also provided DCO with a draft job description for an Executive Director as well as a "Call to Action" to help them expand upon their member's engagement. This went beyond the initial scope of our engagement, but we agreed this would be critical to help DCO move forward. We discussed this plan with DCO and they were grateful for the

roadmap we provided. DCO's President, Robin Huiras expressed this as she shared the following with us in an e-mail (October 10, 2016):

Hi Bob & Bruce,
 Thanks so much for this.
 I was thinking today about the qualities that someone would need to have to run the group (there's so many). And it's so very nice to have you and Bruce thinking about this for me. It's just so kind of you and I thank so for your time and energies helping DCO. You both have given us a vision to work toward. It's not something I knew was missing, But now that it's there, the path forward makes so much more sense. Your work and ideas are so appreciated.
 Take care,
 Robin

Next steps with DCO – coaching a new President

Shortly after we returned from Camp Sunshine, DCO's president, Robin called me to let me know she would be stepping down from DCO's board at the end of the year. I was not surprised by Robin's news, as I could see she was physically and emotionally struggling from the disease while at the camp. Robin also told me that Katie, someone who had been a less-active board member whose son received a bone marrow transplant two years ago would be stepping into the role of Board President. I had interacted with Katie a few times over the past several years and had met her for the first time at Camp Sunshine. Katie seemed to have a lot of energy and passion towards helping others with DC. At camp, Katie and I had a conversation about her desire to be more active with DCO. She was struggling to understand how she could contribute. I shared with her some of my thoughts regarding the vision and what would be required to make it happen. At this time I realized that Bob and I had to help DCO's Board members and families find their story. It's a story many of them already know,

but we provided a framing to tell it and make it an effective tool in building resources and energy to make it happen.

After receiving the call from Robin and reflecting on my interaction with Katie, I realized there was still much I could do to help Katie in her new role and contribute towards her ability to successfully lead DCO towards their vision. The next weekend, I reached out to Dr. Russo and shared my thoughts about where we were in our engagement and how I could continue to be of help to DCO. I realized that I could not return to DCO's board, as the reasons I left still remain. I also realized that I could continue to help in a more focused and targeted way. I asked Dr. Russo for her thoughts if I moved my relationship from a consultant to DCO to a coach for their new President, Katie. As we discussed this idea, we agreed this would be a natural extension of our consulting engagement. When I approached Katie with this proposal she was very excited and energized to move forward. We agreed to begin formalizing this arrangement and as I write this capstone, we are excited to move forward with this engagement. This will serve as the coaching field experience in completing my MSOD by June 2017.

As I write this capstone, Katie and I are three months into our coaching engagement. This has provided an opportunity to help Katie see herself as a leader and define a vision that will enable DCO to continue to build on its previous successes. This is an especially challenging time for rare disease advocacy as our country's new President and his administration are targeting significant budget cuts towards federal research, namely the National Institute of Health (NIH). The role of DCO's leader is even more challenging as it will require

even greater collaboration with other rare disease organizations, the pharmaceutical industry and other research centers. Also, as DCO has recently transitioned this role to Katie, it will be important that they are able to move forward in their research, fundraising and advocacy initiatives with great urgency, while keeping DCO's patients and caregivers front and center. Katie is taking on this role at an especially challenging time and I have been learning with her as a coach and advocate.

Following our engagement with DCO, I spoke with other Executive Directors of nonprofits, friends, colleagues and just about anyone who would listen to our adventures over the summer. I realized that the DCO story is not an unusual one. There are thousands of other rare disease and other grassroots organizations that struggle with thin resources and ever-growing needs. As I near the end of Penn's Master's Program in Organizational Dynamics, I've realized that the nonprofit community is an area that provides enormous opportunities to utilize many of the skills I've learned throughout my career as well as life experiences and my ongoing education. This has created an exciting vision that I am currently developing and that this capstone explores further.

CHAPTER 3

LITERATURE REVIEW

Working with DCO during the summer of 2016 along with my personal experiences in the rare disease community has inspired me to go further in understanding and researching the influence of leadership and the role of the consultant in building organizational capacity and achieving outcomes in small non-profit organizations with a particular focus on rare disease advocacy. Building from the experiences and learning of the DCO case study, this literature review applies these observations to the following areas:

- *Rare disease advocacy organizations* –what factors separate these organizations from other nonprofits.
- *The nonprofit/consultant relationship* –what methodologies and applications are most effective when working with nonprofit organizations as a consultant and how these relationships have helped lead these organizations to grow in effectiveness, innovation and capacity.
- *Leadership and innovation in nonprofit organizations* – qualities and challenges that distinguish the nonprofit sector from for-profit enterprises.

Each of these topics are analyzed with the DCO case study in mind and the case study serves as a data point in comparing and contrasting the theories and arguments presented.

Rare disease advocacy organizations

Rare disease advocacy organizations, such as DCO share the commitment and passion that can lead to innovation and increased capacity. These organizations also have unique challenges when compared to larger organizations in the nonprofit sector. As demonstrated in the DCO case, Boards and volunteers of rare disease advocacy organization often consist of patients and caregivers that are stretched in many ways. One reality that amplifies these challenges is that the members of rare disease advocacy organizations are literally fighting for their lives. This leads not only to commitment, but also urgency. This is often exacerbated as by definition, these groups often lack size, scale and a forward looking perspective that would enable greater capacity for strategic leadership and vision. They are truly living their lives and managing their organizations on a day-to-day and moment-to-moment basis.

Featured in the medical journal *Science*, Dr. David Fajgenbaum, who's inspirational and incredible journey as doctor, researcher and rare disease patient is described in greater detail in the next chapter of this capstone, describes his work in fighting Castleman's Disease. Dr. Fajgenbaum is the founder and leader of the Castelman Disease Collaborative Network, whose mission is to prioritize and coordinate research into this disease. Dr. Fajgenbaum describes his passion as "intensely personal" (Thomas, 2017, p. 7).

Dr. Fajgenbaum's friend Josh Sommer describes Fajgenbaum as the "quarterback" for Castleman's disease and maintains that "every rare disease needs... someone to marshal the team, harness the resources, and lay out a game plan... People have to put their faith in this person" (Couzin-Frankel, 2016, p. 214). Fajgenbaum's journey exemplifies just how limited resources are for rare disease organizations as they address problems that are extremely complex and are literally life-or-death.

As rare advocacy organizations struggled with limited resources and a patient base too small to be attractive to those in the for-profit sector to take notice, transformational change was needed to bring these groups together to garner attention towards a collective mission. The history of National Organization for Rare Disorders (NORD) and the Orphan Disease Act offer other rare disease advocacy groups and those who look to partner with them as consultants, insight into what makes these organizations special and unique.

NORD is a nonprofit (501(c)(3)) organization dedicated to patient advocacy and individuals with rare diseases and the organizations that serve them. NORD's mission is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services (<https://rarediseases.org/about/what-we-do/history-leadership>). Founded in 1983 through its advocacy of the Orphan Drug Act of 1983, NORD is the leading rare disease umbrella organization in the United States. Their motto of "Alone we are rare. Together we are strong," serves to frame their mission and vision of:

- A national awareness and recognition of the challenges endured by people living with rare diseases;
- A culture of innovation that supports basic and translational research to create diagnostic tests and therapies for all rare diseases;
- Access for all patients to the diagnostics and therapies that will extend and improve their lives;
- A regulatory environment that encourages development and timely approval of safe effective diagnostics and treatments.

In 2014, the Journal of Orphan Drugs: Research and Reviews, published *A 30-year retrospective: National Organization for Rare Disorders, the Orphan Drug Act and the role of rare disease patient advocacy groups* by Mary Dunkley. The retrospective recounts the origin of a formalized rare disease community that was driven by a few-high profile individuals. Two of these individuals were Marjorie Guthrie, the widow of legendary folk singer Woody Guthrie, who died from the rare Huntington's Disease, and actor Jack Klugman (2014, p. 20).

Actor Jack Klugman, who starred in the popular television drama *Quincy, MA* was influenced by his brother, Maurice Klugman who was a producer on the show, and suffered from a rare form of cancer. In 1981, Maurice created a story depicting a young man suffering from Tourette's Syndrome and the orphan drug problem. When the episode aired, it sparked a firestorm of interest, particularly from individuals and families affected by rare diseases. In describing the episode, the Washington Post Wongblog depicts the following in an article paying tribute to Jack Klugman when he died in 2012:

In a fit of pique, Jack Klugman hit upon a novel idea. He and his brother wrote a second *Quincy* episode, this one revolving around an orphan drug bill that was being held up by a heartless (fictitious) senator. In a pivotal scene, Quincy confronts the senator in his office and demands that he look out the window. Peering down, the senator sees a huge crowd gathered with signs that read “We Want the Orphan Disease Act” and the Senator relents. To shoot the scene, the show’s producers hired 500 extras who really did suffer from rare diseases.... Hatch (Senator Hatch, a real-life congressman who was blocking the bill) too relented. Thanks to Klugman, the Waxman-Hatch Orphan Drug Act became law in 1983. It has been a remarkable success. The FDA has approved more than 300 orphan drugs, with 1,100 more under development (in 2012).

By definition, each rare disease advocacy organization is an underrepresented group with critical needs and hopes. Collectively, they represent over 7,000 diseases and 300 million people. Umbrella organizations like NORD have brought influence and power with numbers. They facilitate innovation to rare disease communities, including influence with legislation and pharmaceutical companies as well as the globalization of resources.

The nonprofit/professional relationship

Recognizing and understanding the unique strengths and challenges presented to nonprofit organizations informs the practitioner in how to best help mission-based organizations. Penelope Cagney examines the unique relationships that consultants and practitioners experience when working in the nonprofit sector in her 2010 book *Nonprofit Consulting Essentials*. Cagney writes, “Nonprofits have a range of consulting needs that differ from those of their for-profit counterparts... They must work with consultants who know how to work with them – who can use nonprofit strengths to advantage and shore-up their weaknesses, who respect their uniqueness and are aware of how they differ from business – consultants who know when it is appropriate to apply for-profit

thinking but also when it is best to develop their own (2010, p. 1).” Cagney refers to much of what Peter Drucker has observed in regard to the unique strengths of nonprofit organizations, she quotes Drucker, “The Girl Scouts, the Red Cross, the pastoral churches – our nonprofit organizations – are becoming America’s management leaders. In two areas, strategy and effectiveness of the board, they are practicing what most American businesses only preach. And in the most crucial area – the motivation and productivity of the knowledge workers – they are truly pioneers, working out the policies and practices that business will have to learn tomorrow” (2010, p. 2).

The DCO case demonstrated that unlocking the inherent passion and strengths that are found in the nonprofit culture presents a unique challenge to the consultant. Cagney describes the “... boundless passion found in nonprofits is a great asset but can also be a handicap. In the extreme it can seem to defy reason... As a result it is possible for board and staff to view with suspicion anyone who doesn’t share their commitment” (2010, p. 13). Prior to taking on the role of a consultant with DCO, I was a member of this community and remain an advocate as someone who had been directly impacted by this terrible disease. Although my history with the group and passion towards its mission were not something I ever felt I had to prove, I understood that my role as a consultant would be much different than the role of a parent. Part of the challenge throughout the engagement was to manage myself effectively, listen without prejudice while still maintaining high levels of empathy and unconditional positive regard. In *Flawless Consulting*, Peter Block stresses the power of authenticity in

the consulting relationship as he writes “... Acting authentically is the most powerful thing you can do at every stage of the process” (2011, p. 44). Carl Rogers stresses the power of empathy in *On Becoming a Person* as he writes “...if I can form a helping relationship to myself – if I can be sensitively aware of and accept my own feelings- then the likelihood is great that I can form a helping relationship toward another” (1995, p. 51). Sorting through my own experiences and feelings in regard to DC and DCO was an important step in effectively working with DCO. Cagney’s book addresses the unique relationship of the consultant with nonprofit organizations.

Cagney’s philosophy often references the humble consulting relationship as described by Edgar Schein (2016). Schein emphasizes that to truly understand organizations where problems are complex and ambiguous, which is especially true in organizations that are measuring outcomes based on their impact toward mission rather than primarily on dollars and cents, there must be a degree of “personalization” that the consultant offers and experiences to truly help an organization (2016, p. 7). In describing *personalization*, Schein describes a “Level 2” relationship that goes beyond a transactional relationship between the consultant and client, but also avoids the trappings of a more intimate relationship that may go beyond what is truly effective in understanding and helping an organization. Schein describes the Level 2 relationship as the consultant not opening the door to anything personal, but rather, creating a climate where the client will be able to become trusting to a degree where they may reveal what is really happening within an organization. He characterizes the

consulting relationship as one that includes a level of personalization, which he describes as the “fundamental process by which we move from being strangers to becoming acquainted, getting friendly, being teammates, getting connected, and in various ways developing the higher level of trust and openness that I am calling the Level Two relationship” (Schein, 2016, p. 111).

Schein’s approach resonates in regard to the dynamics described by Cagney as they both encourage the consultant to avoid becoming “content seduced” (2016, p. 20). Rather, the helping consultant enables the organization to build its own capacity. Cagney and Schein focus on the consulting process rather than simply the outcome. This was particularly relevant in the DCO case, as their needs went beyond problem solving, but rather, they had a more complex need of building organizational capacity.

“The Future of Organization Development in the Nonprofit Sector” provides a study that seeks to inform organizational development practitioners in regard to how they can most positively impact nonprofit organizations (Wirtenburg, 2007). The article outlines the findings of a survey of 235 nonprofit executives as well as a dozen corporate leaders seeking their input in regard to how organization development practitioners could most effectively (2007, p. 180):

- Align the organizational development field more closely with the substantive challenges facing the nonprofit sector;
- Add value by leveraging the strengths organizational development can offer nonprofit organizations;
- Blend theory with practice; and

- Create a significant and positive impact on civil society by infusing values and process expertise that are the building blocks of the interdisciplinary field of organizational development.

The survey revealed that the nonprofit organization leaders identified development and management of emerging leadership as the most neglected critical activity in their organizations. Respondent's specifically mentioned limited resources, especially funding their organization's small size, as responsible for the difficulties in developing leadership capacity. The responses also indicated that nonprofit organizations must continually change to sustain and achieve their mission. One respondent wrote, "Determining (and) communicating vision, observing others in the system as they attempt to translate vision into action, coaching for action, educating to overcome resistance, identifying the important dissatisfactions, (providing) reasons for change, and providing ongoing communication about those dissatisfactions" were all components in driving sustainable changes to meet nonprofit missions" (2007, p. 185-186).

The themes of leadership, innovation and transformation, vision and collaboration are common throughout the literature focused on helping nonprofit organizations. Although none of these attributes or outcomes are unique to nonprofits or rare disease advocacy organizations, this sector is challenged at a higher degree than many of their nonprofit counterparts. Not only by size and skill levels within the organization, but as was demonstrated in our work with DCO, just talking about the disease was difficult for those directly impacted by DC. Demonstrating empathy and positive regard proved to be of even greater

emphasis when working with a rare disease advocacy organization. This was particularly challenging while maintaining a professional and consultative relationship between the organization and the consultant. When planning the DCO engagement, Dr. Russo, Bob Biglin and I recognized this as a particular challenge and agreed that focusing an engagement on vision and Board efficacy would be a useful strategy in avoiding the overwhelming and morbid realities that rare disease organizations must overcome.

Analyzing the effectiveness of employing an Appreciative Inquiry approach

The DCO engagement centered on building a strategic plan that would enable DCO to grow its internal capacity and further deliver on its mission. As we evaluated approaches in working with DCO, Bob Biglin and I both had developed a foundational philosophy based on a humanistic approach to consulting. During our initial conversations with DCO's board, we understood that the Board was very much caught in the moment in meeting the needs of their constituents. They lacked the capacity and objectivity to take a step back and evaluate their strengths, what they had accomplished, and what challenges they would encounter in continuing to move DCO's mission forward.

From our initial discussions with the Board, it became clear that there were much deeper challenges to be addressed if they were to successfully develop and execute a strategy focused on expanding their capabilities and outreach. From these initial observations which included observing board fatigue, a lack of a future vision, low self-confidence, low appreciation of previous accomplishments. We felt that an approach informed by Appreciative Inquiry

would provide a productive framework for creating momentum for the organization and its leadership, through a strengths-based focus. This approach has been the subject of evaluation and analysis since Cooperrider introduced the world to his Appreciative Inquiry model.

When is Appreciative Inquiry Transformational? A Meta-Case Analysis (Bushe, 2005) and *Comparing Appreciative Inquiry to Action Research: OD Practitioner Perspectives* (Egan, 2005), are two articles that provide a strong foundation to understand when and how AI has been successful as well as its limitations.

When Is Appreciative Inquiry Transformational? A Meta-Case Analysis presents a series of case studies that evaluate whether an AI intervention has resulted in transformational change. In determining if each case was “transformational,” the analysis considered whether each case included the following two key outcomes (2005, pp. 163-164):

1. Did the AI intervention result in new knowledge or as more typical traditional OD and change management on new ways of doing things? Did it create one or more new lenses (images, models, theories) for looking at old issues?
2. Did a “generative metaphor” emerge out of this initiative? A “generative metaphor” is defined in this article, as “sayings or phrases that are in themselves provocative and can create new possibilities for action that are not previously considered.”

The twenty cases examined focused on specific initiatives within departments or subsidiaries of large companies. It found that 35% of the

examined cases using an AI approach resulted in what the authors defined as “transformational” change.

Comparing Appreciative Inquiry to Action Research: OD Practitioner

Perspectives examines the assumptions, approaches and implications of AI and AR for organizational development (OD) from the perspective of OD practitioners. The study includes interviews with OD practitioners to explore the strengths and weaknesses of AI compared to those of AR (Egan, p.29). The authors provide qualitative data that highlight the strengths and weaknesses of AI and AR approaches and summarize key items as follows (2005, p. 41):

AI Strengths	AR Strengths	AI Weaknesses	AR Weaknesses
Refines understanding about organizational capacity	Empowers employees and stakeholder to actualize change	Difficult interpersonal situations may be overlooked	Process may not thoroughly empower participants in the process to examine the breadth of organizational capacity
Helps to override previously difficult events	The process can be transferred to the client for independent use	Dissatisfied organization members may withdraw from the process	A clear exploration of available opportunities could be overshadowed by negative perceptions or feelings
Empowers employees to connect interpersonally	It is iterative or repeating allowing for continuous improvement	Employees may become frustrated with managers and executives unwilling to discuss important challenges being faced by the organization	AR keeps the organization moving from one unsolved problem to another.

Each of these studies stand on their own; however, they are intertwined and impactful in regard to considering the effectiveness of an AI approach as compared to the more traditional organizational development approaches such as action research.

Busche's meta-case analysis seeks to determine if AI leads to "transformational" change. It does not explore in great depth why this may or may not be the case. Busche does not denigrate AI as ineffective when a transformational change is not achieved, and recognizes that each individual case and the nature of the problem itself may be more or less determinates of what is actually transformational (2005, p. 177-178). Whether the AI process facilitates improved organizational learning and performance reaches the standard of "transformational" is not clear in this analysis. It also is not clear whether a 35% rate of achieving transformational change compares positively or negatively to alternative approaches. It is worth questioning and following up with the 35% of the case studies that did achieve a form of transformational or significant change. It would also be worth exploring whether these results were sustained any better or worse than a similar set of cases using alternative organizational development approaches.

Schein's *Humble Consulting* model demonstrates an emphasis on equipping the organization with the ability to generate a series of more modest yet impactful *adaptive moves* rather than bold and obvious *transformational* outcomes. Schein writes, "If the problem turns out to be complex... the client and helper should engage in a dialogue to figure out a feasible *adaptive move*, knowing that this may not solve the problem but will provide some comfort and will reveal new information on the basis of which to figure out the next adaptive move." He continues, "My clients and I will discover that the first real help is my enabling them to see the true complexity and messiness of the problem situation

and help them to abandon the quick fixes and/or knee-jerk reactions. Beyond that, the real help will be to evolve the right adaptive moves to deal with the realities of the situation that I help them to identify” (Schein, 2016, pp. 23-24). Schein’s approach is relevant in generating more sustainable outcomes and enabling the organization to grow by building its own capacities. These are critical factors to the success of building a strong and agile nonprofit organization.

In the case of our DCO case study, it is too soon to determine if a transformational change within DCO has occurred as a result to our AI intervention. Although we implemented an AI approach with DCO, we also consciously deviated from a pure AI approach as we felt we needed to be more prescriptive than not in providing an action plan to the organization rather than facilitating them through the development of their own plan. This was a function of both time and an assessment of the current organization’s strengths and competencies. The overall result of the DCO engagement was to provide an action plan that focused on organizational structure and milestones to enable DCO to achieve transformational changes in its future, but not necessarily to achieve this change through the intervention. It would be interesting to understand what and if incremental changes from the AI or alternative interventions examined in Busche’s analysis occurred prior to the transformational changes that he’s quantified in his study.

Whereas Busche’s meta-case focuses on AI outcomes, Egan’s comparison between AI and AR focuses on the strengths and weaknesses of

alternative processes. Egan introduces the idea of whether AI could effectively be included with AR or other problem solving approaches. Egan offers two perspectives from practitioners he interviewed for his study (2005, p. 44):

“We need to embrace the philosophy behind AI, not just use part of it” and,
 “It is important that the strength of AI be tapped, but it is also recognized that in some cases it is a consulting approach that can be used in conjunction with other approaches.”

Egan studies the benefits and limitations of the AI approach as compared to other approaches. He is not focused on the outcomes of these interventions as Bushe explores. Egan demonstrates that the process is just as critical in facilitating the capacity and growth of the organization to optimize and exceed its current state, as is the outcome of the specific engagement.

Problem solving and challenges facing the organization were not ignored as the DCO engagement evolved. However, they were not the main focus towards providing consultation and help. Consistent with the AI process, we worked with the Board and other DCO stakeholders to gather data and articulate their vision. Our approach was influenced by the philosophy offered by Edgar Schein in his book *Helping*, as Schein writes, “At the beginning of any helping relationship, and throughout its life, what is crucial is not the content of the client’s problem or the helper’s expertise, but the communication process that will enable both to figure out what is actually needed” (2011, p. 66). Egan’s analysis comparing AI and AR examines this process between alternative techniques whereas, as our case study demonstrates, a predominant philosophy and process may exist, but there is judgment and deviation exerted through its

application. No one size fits all, rather it is incumbent on the consultant or organizational development practitioner to understand what approach or approaches are most appropriate and tailor a blending of these philosophies to best serve the client. This is achieved through the *personalization* process that Schein describes in *Humble Consulting* (2016).

Examining whether AI translates into transformational or incremental changes in an organization may not be practical within the scope of this capstone. However, measuring where DCO's Board was in regard to its vision and capacity before and after our intervention may be an indicator of the potential learning and transformations they've enabled by building their capacity. Implementing an AI approach with appropriate variations appeared to be an effective way of helping DCO gain energy and momentum from their historic successes as well as outline a collective vision towards their future.

Leadership and Innovation in nonprofit organizations

Comparing nonprofits with for-profits offers interesting insight in its application to the DCO case study. Through the strategic planning process, DCO's board and constituents collectively articulated a vision that would expand its capacity and ability to deliver its mission to a wider patient population. Through this process it became apparent that to move this vision forward, DCO would have to reengineer its board structure and attract others from within and outside of the immediate DC community with committed passion and relevant skill sets to focus on specific areas of patient advocacy and support. Another critical element to DCO's vision was the need to recruit, fund and develop the

Executive Director position to transform DCO from a patient group to a professional advocacy organization. Like other nonprofit organizations, DCO would have to balance its passion and mission with the governance, skills, and leadership attributes that are more commonly found in the for-profit enterprise sector.

In 1989 the *Harvard Business Review* published Peter Drucker's *What Business Can Learn from Nonprofits*. Drucker's popularity and HBR's wide reach removed some of the stigma associated with nonprofit organizations as they've often been perceived as inferior to their for-profit counterparts in terms of business sophistication and organizational capacity. Others have followed Drucker's article with more in-depth empirical research and case studies specifically focused on nonprofit leadership and efficacy.

In Drucker's 1989 article, he examines how nonprofit organizations have become more prominent and illustrates a number of advantages nonprofits have leveraged that for-profit enterprises wish they could emulate. He points out that for nonprofits, money is a tool rather than an outcome as it is with for-profit enterprises. He also illustrates how successful nonprofit organizations' focus on mission rather than financial outcomes are more difficult to measure, but also have created levels of sophistication in nonprofits that would be beneficial to for-profit entities. Drucker writes, "Starting with the mission and its requirements may be the first lesson business can learn from successful nonprofits. It focuses the organization on action. It defines the specific strategies needed to attain crucial goals. It creates a disciplined organization. It alone can present the most

common degenerate disease of an organization... splintering their already limited resources on things that are “interesting” or look “profitable” rather than concentrating on a very small number of productive efforts (1989, p. 3).”

Drucker’s focus on the role of a nonprofit board and their CEO or Executive Director is relevant to recommendations in the DCO case study. As a CEO from a rare-disease pharmaceutical company emphasized in an interview that was part of DCO’s strategic planning process explained, “An effective Executive Director will transform the grass-root patient-driven group to a professional advocacy organization.” Drucker points out the dynamics of the relationship between non-profit CEOs and their Board counterparts as he writes, “Nonprofit organization CEOs complain that their board “meddles.” The directors, in turn, complain that the management “usurps” the board’s function. This has forced an increasing number of nonprofit organizations to realize that neither the board nor CEO is “the boss.” They are colleagues, working for the same goal but each having a different task. And they have learned that it is the CEO’s responsibility to define the tasks of each, the board’s and his or her own” (1989, p. 4). This was a point of emphasis throughout the DCO case study as on-boarding an Executive Director who reports to and works independently from the Board will be a critical success factor in building DCO’s capacity and resources.

Another area that Drucker addresses is community engagement and training. He emphasizes the importance of a clear mission and providing members and volunteers with the training and resources to enable them to effectively engage and add value to the organization. Drucker understands that

volunteers and employees, who may have sacrificed some of the drawings from the for-profit sector, do so as they often find self-fulfillment and value by working for a mission important to them and that will often help others. As Victor Frankl writes in his teaching of existentialism and finding meaning, “curing the soul by leading it to find meaning in life” (1963, p.7) is often the motivation of those that choose to engage with nonprofit, mission-based organizations. Drucker characterizes this as moving from a force of nonprofit volunteers to one of unpaid professionals. He writes, “What the nonprofit contribute to the volunteer is as important as what the volunteer contributes to the nonprofit” (1989, p. 6). Drucker emphasizes that volunteer professionals are not satisfied with just being helpers, but they thirst for much more and desire. Many nonprofit volunteers are knowledge workers in their own profession and they wish to be the same in their contribution to society. How nonprofits are able to leverage these dedicated and compassionate resources into innovation and transformational change that drives growing organizational capacity in the nonprofit sector is the subject of research and analysis that had followed Peter Drucker’s article.

Inspired by Peter Drucker’s work, Frances Hesselbien, a Girl Scout Troop leader in York, Pennsylvania implemented Drucker’s philosophies with her local troop. Her success in doing so caught the attention of the Girl Scouts of the USA organization, and she became its CEO in 1965 where she grew the Girl Scouts to a membership of over 2.25 million members and 780,000 employees until she was recruited by Drucker to run his Leader to Leader Institute in 1976.

Hesselbein, now 102 years old continues to lead this organization, now named to

Frances Hesselbein Leadership Institute, where she remains their CEO (Leahey, 2011). In her video *Frances Heisselbein on Her Journey with Peter Drucker*, Hesselbein shares her first interaction with Drucker in 1968 as she recalls him addressing her Girl Scout organization by saying, “You do not see yourselves “life-size”; you do not appreciate the significance of the work you do. Society pretends to care for its children and it does not. For a little while you give a girl a chance to be a girl in a society that forces her to grow up too soon.”

Hesselbein’s and Drucker’s relationship continued to grow and Hesselbein recalls an interview with Drucker in the New York Times where Drucker says that the Girl Scouts are the best managed organization in the country. The interviewer interjects, “you mean in the nonprofit sector” and Drucker corrects him clarifying that they are “simply the best in any sector, anywhere” (Hesselbein, 2011). Hesselbein’s Leadership Institute’s homepage describes its mission as to “strengthen and inspire the leadership of the social sector and their partners in business and government by connecting the public, private and social sectors with curated resources and relationships to serve, evolve and lead together. By fostering in 1) the passion to serve; 2) the discipline to listen; 3) the courage to question; and 4) the spirit to include, we work to create an open, responsive, global social sector.” (http://www.hesselbeininstitute.org/about_us, accessed February 9, 2017).

Drucker’s philosophies and Hesselbein’s application of these demonstrate many of the qualities and challenges that were experienced during the DCO engagement. DCO’s needed to take a step back and acknowledge the

tremendous work they had produced and celebrate these successes. Building organizational capacity by seeking specific skills that are fueled with passion from finding meaning from their mission will help them find those from inside and outside their immediate community contribute their skills to the organization. Researchers have gone further to examine the specific nonprofit sector attributes and leadership qualities that are most effective in this sector.

Australian Management professors, James Sarros, Brian Cooper and Joseph C. Santora in their 2010 *Leadership & Organizational Development Journal* article *Leadership vision, Organizational Culture, and Support for Innovation in Not-for-profit and For-profit Organizations* took Drucker's ideas a step further. They examined and compared the relationship of nonprofit organizations' social consciousness with the competitive motives found in for-profit enterprises. They compared each sector's ability to leverage these different motives to build upon leadership, vision, innovation and organizational strength.

Their study found that for nonprofits, a socially responsible cultural orientation mediates the relationship between leadership vision and organizational support for innovation. Alternatively, in for-profit companies, a competitive cultural orientation mediates this relationship. Their research includes interviews with nearly 1,500 Australian managers. The study found that socially responsible cultures enhance the impact of visionary leaders on innovation for nonprofit organizations, while competitive cultures have the same impact on for-profit enterprises (2010, p. 301). This research is important in regard to building strategies for building innovative and sustainable organizations

in the non-profit sector (2010, p. 291). Sorrow et al., write;

The capacity of leaders to define a vision for their organization is one thing, but to have that vision accepted and acted upon as anticipated both individually and organizationally is quite another proposition. Additionally, on the basis of these findings, the formulation and then implementation of vision is a considerably different proposition in for-profit versus nonprofit organizations. We propose that nonprofits are more likely to benefit from leader vision that encourages “buy in” to a set of principles that have social as well as economical implications and which run counter to the commercial imperatives of private enterprises. The study illustrates that organizational cultures play a major role in determining the impact of leadership vision on organizational leadership (2010, p. 301).

This was demonstrated in DCO’s strategic planning process, as their constituency looked to the Board to chart the course for DCO’s priorities and leadership’s abilities to build upon research, collaboration and patient support and wellness. The process also demonstrated that although the Board and members of DCO understood and acted on a common mission, they did not have the ability in regard to their perspective or capacity to step away and create a story they could share within and outside of their constituency. DCO had not yet fully utilized the strengths of their mission and vision to drive further innovation or impact to serve their growing constituency. The strategic planning process helped create awareness within DCO that a vision was needed and leadership at the Board would need to transition focus to help articulate and drive vision while a future Executive Director would be needed to implement that vision and lead the tactical operations of their organization.

Sarros’ work was informed by the 2004 *Nonprofit Management and Leadership* journal study, *Transformational Leadership, Organizational Culture, and Innovativeness in Nonprofit Organizations* written by Kristina Jaskyte from

the University of Georgia's School of Social Work. Jaskyte's exploratory study of leadership organizational culture and organizational innovativeness in nonprofits sampled 250 employees of the Alabama branch of the Association of Retarded Citizens (ARC), an organization that represents over 140,000 individuals with developmental disabilities (Jaskyte, 2004). Although this survey is limited to one organization, the ARC is similar to many rare disease advocacy groups, including DCO. Many DCO patients are impacted with mild to severe cognitive disabilities and many of the same characteristics of the ARC population are shared with the physical and cognitive impacts of rare diseases.

Jaskyte defines *innovation* as the ability of organizations to implement an idea, service, process, procedure, system, structure or product new to prevailing organizational practices (2004, pp. 158-159). Jaskyte's research examines the correlations between the ARC's capacity to be innovative with characteristics implicit with what is defined as *transformational leadership*. Jaskyte defines transformational leadership as a set of practices employed for developing relationships between leaders and employees. She defines organizational culture as the set of shared values that help organizational members understand organizational functioning and thus guide their thinking and behavior. These themes are central to the DCO case study as the success of implementation of DCO's strategy and shared vision is determined to be influenced in large part by its ability to transform its board and leadership role to one less centralized that will build capacity and drive innovation across its mission. These concepts are innovative to DCO as it has not worked within a shared governance model in the

past and will need to garner the resources of its members, partners and their contacts to continue to grow in meeting the expanding needs of their constituency.

Similar to Sarros, Jaskyte's study demonstrated that leadership practices that include "inspiring a shared vision," "enabling others to act," "encouraging the heart" and "modeling the way" were positively correlated with cultural consensus. However, the study also surmised that a strong cultural consensus characterized by stability and team orientation actually had a negative correlation with organizational effectiveness and innovation (2004, p. 162). The idea that innovation and effectiveness is enhanced by a degree of conflict is important as DCO's Board transitions many of its decision-making and implementation processes to more regionalized committees and Board sub-committees focused on specific areas impactful to their mission.

Although the data suggests that building a strong collective vision that is lead by DCO's board is counter to increasing their capacity, these factors are much more complex. What Jaskyte's analysis does support is that leaders must enable and empower others within the organization to create vision and contribute towards innovation in their own areas, rather than take a top-down approach in creating tasks and imploring action. Creating a sub-committee and regional branches of DCO will be catalysts in building DCO's member and non-member engagement as well as expand their capacity. For this approach to be successful, DCO's board must move from one that leads with a top-down or task-oriented approach to one that enables innovation at the sub-committee and local

levels. As Jaskyte cites in a 2001 article, *A Strong Cultures and Innovation: Oxymoron or Opportunity*, by authors Flynn and Chatman, “While some authors see strong culture impeding creativity, others argue that when the right values are widely shared, a culture will activate creativity and innovation” (2004, p. 163).

Moving from a small group of doers that provide a single voice to DCO’s constituents to a model that facilitates shared leadership across the organization will be transformational to DCO. It is a key success factor in their ability to grow their capacity and continue to deliver to its constituents with efficacy. Peter Drucker writes that organizations characterized by deeply embedded leadership practices and organizational values risk success because they can stop questioning the need to change and respond to the external environment. With growth and success, DCO finds itself in a place where their “reality has changed, but the theory of the business (or mission) has not changed with it” (1994. p. 98). Drucker’s works are relevant as DCO is no longer focused on a small patient group or limited research. They are becoming a much more impactful organization as demonstrated with their ability to influence research, increase clinical access, develop a prestigious medical advisory board and publish clinical guidelines which have been transformational to its members. They’ve gotten much larger in their accomplishments and to continue this trajectory they must move from a small-centralized cadre of leaders to a leadership model that is disbursed throughout their organization.

Conclusions from a review of the literature

Understanding the dynamics, strengths and challenges inherent in nonprofit organizations, and rare disease advocacy groups particularly, is an important element of equipping a consultant with the correct framing of how to best help these organizations. As described by Peter Drucker and demonstrated with case studies and surveys, nonprofit organizations bring the strength of compassion and mission that for-profit enterprises are envious to emulate. Familiarizing oneself with the brief history of rare disease advocacy also provides the consultant with a greater perspective of what unique characteristics and challenges their constituencies face and how they respond. The literature documents how leveraging leadership that is fueled with a mission and vision is a powerful tool for rare disease boards and executives to influence innovation and both transformational and adaptive changes for these to meet the challenges they face with limited resources. Applying an Appreciative Inquiry philosophy with appropriate critical analysis and some level of prescriptive acts to supplement for areas where DCO may have lacked skill or capacity appeared to be an appropriate approach in helping DCO enable its Board and members to create a vision and plan that will help them build capacity and resources to support the research and wellness that impact their members.

The AI literature demonstrates that applying this approach to an organizational development consultation was transformational for the DCO Board. This approach helped them recognize their strengths, accomplishments and opportunities.

CHAPTER 4



RESEARCH METHODOLOGIES, ASSUMPTIONS, DATA AND ANALYSIS

Research methodologies and assumptions

The mission of rare disease advocacy organizations is often life-or-death for its members as they focus on helping and supporting those who are very sick. As a parent, advocate, former board member and now as consultant to a rare disease organization, I have seen the passion and emotion inherent within a “kitchen-table” organization both propel and limit the capacity and effectiveness of an organization. Based on my experiences, I thought most, if not all, rare disease organizations ran on a shoestring budget and each struggled to fund and execute their missions. I assumed what was not present in skills and experience was compensated for in drive and determination. I also believed a strong Board and paid professional Executive Director were must haves for organizations to meet the needs of their constituents and influence research and resources towards those they advocate. Through the stories of others, I’ve found some of these assumptions, to various degrees to be true, while others were not the case.

Over the past three years, in large part through participation with the University of Pennsylvania’s Orphan Disease Center’s Million Dollar Bike Ride and Rare Disease Symposium, I’ve met other leaders in the rare disease advocacy community. Those included in this interview process were some of the most innovative and passionate people I’ve ever met. In addition to those in the rare disease community, I had the opportunity to interview the Executive Director

of a special needs camp that serves many from the rare disease community. Each of those I've interviewed shared insights, ideas and experiences. I am honored to be able to include the following individuals amongst those who participated in this journey:

<p>Kyle Bryant – an athlete, speaker and the spokesperson for the Friedreich's Ataxia Research Alliance (FARA).</p>  <p>(FARA, 2017)</p>	
<p>Kristin Smedley – a mother and advocate for two sons afflicted with CRB1-LCA, a rare disease diagnosed in less than 300 people in the United States. Kristin is a tenacious advocate, a popular speaker and well recognized in the rare disease community.</p>  <p>(CRB1.org, 2017)</p>	
<p>Dr. David Fajgenbaum – a patient, advocate, physician and faculty member at the University of Pennsylvania. Dr. Fajgenbaum learned that he suffered from Castleman Disease, a rare</p>	

inflammatory disorder that causes hyper-activation of the immune system.



(CDCN, 2017)



Anne Catlin – Executive Director of Bournelyf Special Camp. Bournelyf Special Camp is a summer educational and recreational day camp in West Chester, PA, for youth with intellectual disabilities and related disabilities.

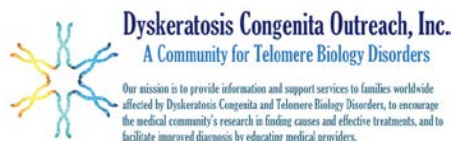


(campbournelyf, 2017)



(Annie with her baby in first row)

Robin Huiras & Lisa Helms-Guba – DCO's past President and current Treasurer. Both Robin and Lisa are DC patients and have shared their knowledge and experiences with others within and outside of the DC community. They are both a testament to courage, love and empowerment.



(dcoutreach, 2017)



Each person interviewed was asked the same series of questions, their answers and responses were open-ended and invited further probing and inquiry during each interview. Below is a list of the questions asked, what the underlying purpose was for each question and my own assumptions, right and wrong, that were present during these interviews.

- *Describe your journey from when your organization was first formed to where they stand now.*

This question was designed to understand the story of their organization. It included their involvement as founders or later members. Understanding where the organization started and their trajectory forward was valuable in seeing what resources were essential in building a successful advocacy organization.

My own assumption was that rare disease organizations typically began with very limited resources and little sophistication in regard to experiences and skills essential to effectively implement their missions.

- *What do you consider its most impactful successes/greatest accomplishments?*

This question was asked to understand what types of accomplishments leaders felt were most valuable.

I assumed that leaders would focus on patient support and research.

- *What contributed to these successes? What 2-3 things were most critical?*

This question was asked with a focus on what skills sets were essential in regard to creating transformation or innovation in a nonprofit.

I assumed that leaders would identify financial and high profile achievements that were geared towards curing or bringing wide-scale attention to their mission.

- *What challenges lie ahead for your organization?*

This question intended to learn of the areas of focus for vision and capacity building for each organization represented.

I assumed a wide variety of vision as each organization was at a different point in their evolution.

- *What would you consider as transformational to your organization? This can include things that have already happened as well as what may lie ahead.*

This question searched to understand what leaders viewed as *transformational* and how they viewed smaller, adaptive, steps on the way.

I assumed each leader would have a different definition of what was truly transformative to their organization.

- *Has your organization at any time used a consultant? If so, what were the most and least effective aspects of the consulting engagement?*

This question was designed to understand the effective or detrimental aspects of engaging with a consultant and why rare disease or grass-root organizations were different than more traditional organizations for consultants. It was also intended to gain perspective on why an appreciative approach and humble consulting methodology would or would not be most appropriate for these organizations.

I assumed that not all organizations had used consultants, but those that had would have experienced successes with a collaborative and personalized approach between the consultant and the leadership of the organization.

Similar to the appreciative inquiry approach employed during DCO engagement, these questions are designed to celebrate the accomplishments, identify opportunities and articulate a vision for each of the subject matter experts interviewed.

Data

Each of those interviewed had a unique and courageous story to tell. They share attributes of strength, passion, courage and leadership. Although each of their stories are different and their respective organizations are at various places in their journey, their focus on service and their desire to make a lasting impact that will improve and extend the lives of their constituents brings them together. An aggregation of the data from these interviews is presented in Appendix D, below is a brief presentation regarding each journey, from patient or caregiver to advocate to nonprofit leader.

Kyle Bryant – Friedreich's Ataxia Research Alliance (FARA)

Ten years ago, at the age of 25, Kyle was diagnosed with Friedreich's ataxia. Friedreich's ataxia (FA) is a debilitating, life-shortening, degenerative neuro-muscular disorder. About one in 50,000 people in the United States have Friedreich's ataxia. Kyle was a strong athlete who excelled in baseball and enjoyed outdoor activities. Shortly after receiving his diagnosis in 2007 he and his family felt that fundraising was a way they could feel a sense of empowerment as they were faced with Kyle's new diagnosis. Kyle soon developed an interest in a recumbent bike and within a year ventured to ride across the country with his father. Kyle's mom followed in the family car and his first ride garnered local and national attention. Kyle is an incredible speaker and inspiration to others within and outside of the rare disease community.

In 2009, Kyle joined the FARA Board and is currently the Director of rideAtaxia and a Director on the FARA Board. FARA's Board was strong from its inception as its founders included the retired CEO of Outback Steakhouse, a retired US Congressman and professionals in the communications, financial and legal fields. These skills have been valuable in setting their mission and focus as they continue to grow. Kyle emphasizes the Boards ongoing capacity as being built one relationship at a time. Setting realistic expectations and a constant focus on mission and values has helped steer FARA to its current level

of efficacy and they are positioned well to influence further research and provide support to their constituents.

Kristin Smedley – Curing Retinal Blindness



Kristin is the mother of two boys affected with a mutation of the CRB1 gene. A condition diagnosed in less than 300 patients in the United States and fewer than 1,000 patients globally. Her involvement started when she learned about a clinical trial that a larger “umbrella” disease of which CRB1 is related. When learning of this trial, she knew her children and others with the CRB1 mutation needed to be included and through “stalking” and persistence, she successfully advocated with fundraising and leveraging the local and national media. Kristin is known to be a consistent force at rare disease and optometry conferences. She is a professional speaker and exudes great energy in her work to create awareness for the CRB1 condition and advocating for a high standard of life for those impacted with blindness.

Dr. David Fajgenbaum – Castleman Disease Collaborative Network



As a medical student at the University of Pennsylvania’s Perlman School of Medicine David was faced with a sudden and life-threatening episode that included his organs shutting down and the real prospect that he would not survive what

was then an unknown condition. Three other times he's had near-death experiences from the rare immunological disorder, Castleman Disease. In addition to being a patient advocate, David is also a physician and faculty member at the Perlman School of Medicine. David also completed his MBA at Penn's Wharton School and was the quarterback at Georgetown University when an undergraduate student. In 2012 David partnered with the Castleman Awareness and Research Network, which had been founded in 2007 and merged this existing organization focused on patient support and wellness with his newly founded Castleman Disease Collaboration Network (CDCN), which would dedicate its mission towards research. David's experiences in science, business and the nonprofit organization he started at Georgetown to help students cope with grief (David lost his mother while an undergraduate student) served to implement a plan of collaboration and outreach that has set a model for the prioritization of research efforts throughout the world. David has dedicated his life and has offered himself as the personal clinical subject which has advanced treatment and research in this rare disease. He's an excellent speaker and has recently been featured in the New York Times, the medical journal Science and other local and national news outlets.

Anne Catlin – Bournelyf Special Camp



Annie & her older brother Joey at a Bournelyf event

Anne has been the Executive Director of Bournelyf Special Camp for the past ten years. Bournelyf's mission of promoting independence, support and friendship serves 150 campers and their families each year. Camper's range in age from seven to several campers in their thirties and forties. Anne, a special education teacher and mother of two, has been a volunteer, counselor and staff member at Bournelyf since her older brother Joey started as a camper more than twenty years ago. Bournelyf is a special organization to me as my son Josh attended the camp during the last four years of his life. Since Josh's death I have served on Bournelyf's Board of Directors and our family has volunteered during the summer camp session as well as other events throughout the year. Although not focused on rare disease advocacy, Bournelyf serves as an excellent example of a grass-root organization that has grown in capacity and impact since it's inception thirty-five years ago. Campers and families have found support and identity with others struggling with Downs Syndrome, autism and other cognitive challenges. Anne has been pivotal in their growth as she is a highly networked and knowledgeable Executive Director who has effectively

relied on a strong Board to steer and promote the camp's mission as it has evolved with a changing special needs environment.

Robin Huiras and Lisa Helms-Guba – Dyskeratosis Congenita Outreach, Inc.



*Robin (left), Lisa (right)
with Dr. Sharon Savage*

Robin Huiras and Lisa Helms-Guba are both DC patients and strong advocates to the DC community. Robin had been DCO's President since 2012 through 2016. She is a mother of two and a journalist living in Minneapolis, Minnesota. Robin has brought her reporting and communication skills to DCO as she founded their newsletter and ensures they speak with a common voice. Lisa has been DCO's Treasurer since 2011. She is a retired nurse in the US Air Force and mother of a teenager in Annapolis Maryland. Lisa brings a strong medical and scientific background to DCO and is a tireless advocate with an appreciation of strong governance and training. Working together with DCO's other Board members, they have transformed DCO from a small patient support group to an advocacy organization that has assembled a top-notch medical advisory board, published a 400-page clinical guideline book that is an extremely valuable resource to patients and doctors, influenced research with clinical application for DC and other biological telomere disorders and fostered a warm and powerful patient community that is focused on outreach and support. They

recognize DCO has come a long way and have set a foundation for the organization to continue to provide resources and support for its growing base of members. Both Robin and Lisa are fearless and relentless as they manage their own health challenges every day along with other family members impacted by DC. In addition to being valuable friends and supporters through Josh's hardest days, they have been incredibly generous in their time and insight towards their contributions in this capstone.

As I interviewed each person, I was in awe of his or her individual story. Each person shared openly and each agreed that his or her story should not be masked with anonymity. Each provided generous insight, emotion and feeling as they discussed their passion and commitment towards their individual and collective mission. What follows is a summary of the data collected by each individual for each question asked. This compilation of data is followed by an analysis that presents common themes and unique ideas as they relate to the topics of:

- Building board capacity;
- moments or changes that were transformational or adaptive to their organization;
- collaboration; and
- their experiences working with consultants.

I was truly blessed with a rock-star line-up of advocates and leaders and I'm honored to share their thoughts and visions.

Analysis

Through inquiry and subsequent discussion, each nonprofit leader shared their own story and their vision towards the future. Although each story was unique and perspectives differed, there were common themes that ran across each of the nonprofit organization experiences. Topics addressed within the interviews included building board capacity and staying focused on mission, the role of the patient or caregiver, the importance of collaboration and how each organization has worked to fund and influence research.

- *Building Board Capacity*

Building board capacity and recruiting the support of others was a common theme with each leader interviewed. This was addressed as a factor of success and accomplishment as well as a critical challenge to meet the future needs of the organization. In the case of FARA, Kyle Bryant described a very detailed and deliberate process of Board recruitment. As Kyle described, board meetings include a “white-board” session which focuses organizational gaps in skills what personal connections could help recruit volunteers to help meet these needs. The FARA board is well established and financially healthy and well connected as members include a congressman, a retired CEO of a highly visible corporation and several other high-profile individuals. Their nomination committee plays a key role in helping ensure they have access to those with the skills necessary to meet the ever-changing needs of their constituents.

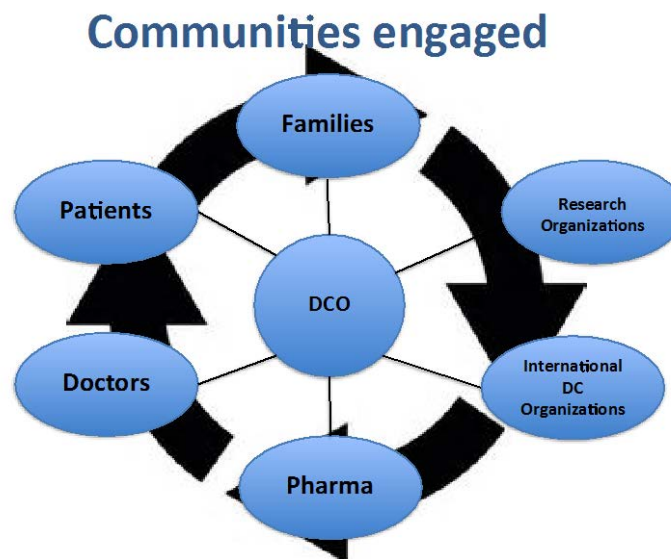
Anne Catlin, Executive Director of Bournelyf Special Camp (BSC) describes the evolution and maturation of BSC as largely dependent on a strong board that started with a small group of parents and church members (the camp is located on the grounds of a church) and has expanded to include others with no affiliation with the church or camp. These other individuals include a lawyer, CPA and an Executive Director of another local nonprofit organization. Bringing in others from outside the camp community has had a tangible impact on fundraising, addressing deferred maintenance needs of the camp and implementing a solid and sustainable financial strategy. It has also enabled Anne to focus more on developing her staff and implementing impactful programs for the campers both during the camp season and during events held each month, throughout the year.

Dr. Fajgenbaum from CDCN has supplemented his Board's scientific focus with volunteers from the University of Pennsylvania's Wharton School of Business. This has been a critical resource as CDCN has taken a business execution approach towards administering a model that drives collaboration amongst researchers and reaches broadly to gain access to the global scientific community.

In the case of DCO and CRB1, both organizations have achieved a great deal with limited resources. Much of this has been accomplished on the back of a few active caregivers and in the case of DCO, patients. Leaders from both organizations expressed that active board members were reaching "burn-out" and as Kristin Smedley put it, they are reaching the "five-year drop-off". As

demonstrated in the DCO case study, the DCO Board realizes that to continue to meet the needs of a growing patient database, it is critical that the Board implement a strategic plan that engages others from within and outside the DCO community. By dispersing governance they will have a greater ability to speed up execution and accomplish more. This aligns with the research of Sarrow and Jaskyte, which examine transformational leadership, and nonprofit management and leadership effectiveness as presented in the literature review.

The strength of a strong board which could provide leadership in driving and accelerating a rare disease organization's capacity and influence to its patients, partner organizations and other collaborators was presented in the DCO case study as a "fly-wheel effect" where momentum comes from the center leadership of the organization and is provided to those working towards its mission. This was illustrated as follows:



- *“Transformational Change” and “Adaptive Moves”*

Two of the rare disease advocacy leaders interviewed acknowledged that speed and urgency had a unique emphasized importance to those researching and managing rare diseases, but they also recognized that a path to curing a disease as Dr. Fajgenbaum described, is a “journey with many steps”. Dr. Fajgenbaum also felt that “it is critical for rare disease organizations to think beyond advocacy to scientific impact.”

Kyle Bryant felt it was important that not everything was measured to the standard of a “cure” as there is so much to be done to improve and extend the lives of rare disease patients. Each leader interviewed pointed to incremental steps, moments or transformative goals towards advancing the quality of life for their patients, families and caregivers. Generating awareness, whether by means of publishing clinical guidelines as is the case with DCO and CDCN or what Kyle Bryant refers to as “targeted awareness that brings a measurable change” was cited as transformational. The rare disease organizations value the work and results that are tangible, rather than simply creating exposure without meaningful outcomes. Kristin Smedley spoke of a recent US House Resolution recognizing “National Rare Eye Disease Day” that was written in braille as a transformational moment as its press coverage brought about a great level of dialogue to promote the capabilities of those impacted by blindness.

Schein's *Humble Consulting* model demonstrates an emphasis on equipping the organization with the ability to generate a series of more modest yet impactful *adaptive moves* rather than bold and obvious *transformational* outcomes. Schein writes, "If the problem turns out to be complex... the client and helper should engage in a dialogue to figure out a feasible *adaptive move*, knowing that this may not solve the problem but will provide some comfort and will reveal new information on the basis of which to figure out the next adaptive move" (Schein, 2016, pp. 23-24). Schein's words ring true as those interviewed shared a perspective that there are many impactful and important steps towards improving the quality of lives for those with rare diseases or other challenges that often fall short of a "cure."

- *Collaboration*

Collaboration was another prevalent theme towards building capacity and driving outcomes. Kristin Smedley, Robin Huiras and Lisa Helms-Guba spoke at length about their organization's alliances with NORD, the Genetic Alliance as well as with other rare disease advocacy organizations. As many rare disease patients may feel alone, organizations often feel lost while advocating for a disease that has so few patients. Rare disease organizations, symposiums and networking are all ways that leaders have described as ways of coming together and sharing collective views and resources.

Another area of focus for collaboration is within the medical community. This was discussed at length with Kyle Bryant and especially by Dr. Fajgenbaum, who is a part of the medical and research community. Both Kyle and Dr.

Fajgenbaum stressed how maintaining the visibility and presence of the rare disease patient is a critical factor in driving researchers, who are often perceived to be territorial and non-collaborative. In regard to Castleman Disease, Dr. Fajgenbaum shares that “getting all doctors to share samples is especially difficult. Good samples are hard to find; disaggregated research at research institutions and hospital labs slow things down. Aggregating this knowledge would definitely speed things up, unfortunately, not all researchers are interested in doing this.” Dr. Fajgenbaum created a collaborative research model that has been shared throughout the rare disease community. As both Dr. Fajgenbaum and Kyle Bryant emphasize, keeping the patient at the center of research is what will facilitate efficient and effective research outcomes. That feeling was also shared by Robin Huiras as she described DCO’s success in recruiting and maintaining an extremely knowledgeable and collaborative medical advisory board, one of their most significant accomplishments as described by both Robin and Lisa Helms-Guba.

- *Nonprofits working with consultants*

Of the five organizations with leaders interviewed, three of them have utilized outside consultants. FARA has used both a fundraising and two PR consultants, Bournelyf has used a grant writer and strategic planning consultant and DCO had recently engaged Bob Biglin and me as described in the case study.

Kyle Bryant shared FARA’s experience with consultants as mixed. When working with a fundraising consultant, they provided FARA with good ideas and

direction that made a difference to their fund raising efforts. On the two occasions of working with PR consultants, Kyle shared that neither went well as in both cases the consultant did not understand the values or culture of FARA nor did they understand why rare disease organizations are different. Kyle appreciated the personalization process implemented by the fund raising consultant. He also feels that consultants need to be visionary and tactical, saying “you can’t have one, you need both.”

Anne Catlin’s experience with an outside consultant was positive as the consultant had a history of working closely with the board and Executive Director as a grant writer for a number of years before leading them through a strategic planning process. Again, a high level of personalization had existed before jumping into the engagement. Similar to Kyle, Anne felt that it was important that the consultant be a bit prescriptive in terms of outlining a tactical plan after leading the Board and camp families to a strategic vision. She also felt being a good listener and working with data and filtering out emotions were valuable attributes brought by a third party consultant. The skills, perspective, and organization brought in by a consultant were all valuable elements that Anne noted when describing her organization’s positive experience.

Many of the elements described by Kyle and Anne were also evident during the DCO case study. Robin Huiras, DCO’s President at the time described the engagement as “very helpful” and valued the collection of synthesized outside information that was gathered and honest feedback that was incorporated into goals and outcomes. Robin also noted that the Board was

already aware of their problems and the Appreciative Inquiry approach used in the engagement was “spot-on” feeling an Action Research approach would not have been nearly as visionary or productive.

Conclusions

The stories and perspectives shared by Kyle Bryant, Kristin Smedley, Dr. David Fajgenbaum, Anne Catlin, Robin Huiras and Lisa Helms-Guba demonstrate that rare disease advocacy and small nonprofit organizations come in many different sizes and have a varied set of resources and priorities. The single most impactful value each of these organizations and their leaders share is the importance of keeping the patient (or camper) first and in the forefront of their mission and accomplishments. This is an important success factor as it has been shown to drive collaboration and urgency, both critical elements in facilitating research and outcomes for those struggling with diseases or conditions that compromise their quality life and in many cases survival. Each organization has also demonstrated and valued the benefit of a strong and diverse board. In the case of FARA and CDCN, their Boards already include active and passionate individuals with an abundance of access to others who can help their organizations. In the case of DCO and CRB1, they are in the earlier stages of building this capacity, but have a clear vision and plan in regard to how to build upon their previous successes and engage others who can ensure the growth and sustainability of their mission and organization. In the case of Bournelyf, their Board and community engagement has facilitated significant growth and financial stability over the past five years and they are now positioned

to begin building endowments and address long-term challenges that will secure the future of the camp for future generations.

Passion, drive, urgency, resilience, commitment, creativity and tenacity are all attributes found in each of those interviewed. As rare disease patients and caregivers face unique stressful challenges, it has been demonstrated that employing a visionary and strength-based approach towards working with them as a consultant or subject matter expert is an effective way of working towards positive outcomes when faced with very life-and-death medical and wellness issues.

CHAPTER 5

CONCLUSIONS AND AREAS OF FURTHER DISCOVERY

Being a part of the rare disease community as a caregiver, bereaved parent, advocate, consultant and now as an executive coach has been the most tragic and rewarding part of my life over the past twenty-two years. As parents and caregivers, my wife and I lived through an incredible life that our son gave to our family, friends and community. We came to understand our own resilience and frustration as we looked for an explanation for why our son was not growing or thriving. When we found that answer with a diagnosis of a rare disorder, we were determined to enable Josh to continue to live a happy and productive life and avoided projecting what the future may hold for him as much as we could. When Josh's health began to deteriorate, we found ourselves working with more urgency to connect with the few doctors and families that understood our circumstance. We found a small and passionate community that was there to help us and ensure we were exploring every option and receiving the best care available for our son. After losing Josh to this devastating disease, I found joining a Board that was working to advocate provided some healing and an opportunity to tribute Josh, but eventually that became an impediment to coping and living. At this time, I realized I could be much more effective in the DC and rare disease community as a consultant and coach who could provide perspective and counsel to help build and sustain a rare disease organization. This capstone has provided a path to the next steps in this journey, one that has

been inspired by my son and those that I've met at Penn and within the orphan disease community.

The DCO case study examined my own personal journey and how a small rare disease advocacy organization has been able to assemble an exceptional medical advisory board and tirelessly work to support a growing number of families who were often at the very beginning of a rare disease diagnosis and journey. It also illustrated an organization that relied on very few people, each either sick from the disease or relentlessly caring for a loved one that was impacted with DC. Our consulting engagement with DCO exemplified a focus on the positive and created a future vision to serve a community that is in great fear and often despair in regard to the sorrow they encounter every day. We found this approach to be effective as it enabled DCO's leaders to develop a plan that would require the help of others and build a board with the capacity to move towards their vision of influencing more research and growing its resources to support a growing number of patients and families.

The review of existing literature helped develop an understanding of what separates rare disease advocacy organizations from other small nonprofit organizations. Looking back at the history of the Rare Disease Act of 1983 and how a few high-profile advocates were able to draw attention to this population helped outline the unique challenges experienced when working towards bringing attention to diseases that singularly are small in patient numbers, but collectively represent one-in-ten individuals in the world's population. The review examined what makes the nonprofit sector special as compared to the for-profit enterprise

sector. Examining the work of Peter Drucker and his influence upon Frances Hesselbein as well as subsequent research into effective elements of leadership and innovation in the nonprofit sector provided a template to further understand successful ingredients of building capacity for nonprofit organizations. Lastly, examining the consultant's role in working with nonprofit organizations was outlined in a review of the works of Penelope Cagney and Edgar Schein. Schein's philosophy of developing a helping relationship with a strong level of personalization and partnering proved to be critical in providing effective consultation to rare disease advocacy organizations as was demonstrated in the DCO case study as well as in interviews with leaders of other nonprofit organizations that were included in this capstone. This was further expanded upon when examining the effectiveness of an Appreciative Inquiry approach as compared to more traditional Action-Research techniques in consulting.

The final section of this capstone offered insights, opinions and incredible stories from leaders of five small nonprofit organizations, four of them from the rare disease community and the fifth from a camp that services many from this same community. The importance of building organizational capacity and acquiring people with relevant skill sets to help these "kitchen-table" organizations are needed to supplement the efforts of a patient-centric board resonated with each interview. The importance of collaboration within the medical community and working to influence the science and research that was being done was another theme that was shared amongst multiple people of those interviewed. There is a common understanding that urgency and the need

to move forward quickly are paramount and unique to rare disease organizations as speed is truly a life-or-death issue. Most of all, each organization's leader shared the importance of having the patient and caregiver at the center of everything that was done. There is a high level of self-advocacy within the rare disease community and for others to help, whether as a consultant, paid employee or volunteer, compassion and personalization of the patient's struggle is an essential ingredient to effectively help these organizations grow and thrive.

The capstone study explores a broad array of issues and complexities in regard to nonprofit organizations and specifically those in the rare disease community. Since Peter Drucker's 1989 Harvard Business Review article, *What Businesses Can Learn From Nonprofits*, there has been a great deal more written and researched about the subject. Unfortunately, there has not been a mass of research in regard to rare disease advocacy organizations. The DCO case study serves as one example of work done with this community, but it is only one example. Future focus on these organizations would be valuable in helping leaders and practitioners in this community understand what processes and techniques are most effective. In regard to examining what constitutes *transformational* or *innovative* change within nonprofit organizations, further definition of what truly is transformational or innovative and the cause and effect of incremental steps in these cases would be relevant to the rare disease community. As the DCO case took place less than a year ago, it is too soon to access what changes were made and the results of these changes since the consulting engagement ended. As I have remained involved with DCO and I am

currently working as a coach to their new President, I do believe they will follow through on a number of the recommended steps towards meeting the vision they've outlined.

As someone who aspires to be a professional coach and consultant, and as a member of the rare disease community, I feel very privileged to have participated in this Capstone experience. The work and theories applied during the DCO experience and the insights gained from other research and literature, as well as the tremendous individuals I interviewed and learned from, have positioned me to continue to grow and help others not only in the rare disease community, but also in all sectors and professions. This has been a very personal journey for me. Coaching and consulting is centered on relationships and compassion. I look forward to continuing this journey as I give back to this community as a coach and consultant.

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APPENDIX A

DCO ENGAGEMENT PROPOSAL

CONSULTING ENGAGEMENT BRIEFING DOCUMENT: JULY 27, 2016

DYSKERATOSIS CONGENITA OUTREACH, INC.

USING APPRECIATIVE INQUIRY FOR SUSTAINABLE CHANGE

APPRECIATIVE INQUIRY (AI) IS A VISION-BASED APPROACH OF OPEN DIALOGUE THAT IS DESIGNED TO HELP ORGANIZATIONS AND THEIR PARTNERS CREATE A SHARED VISION FOR THE FUTURE.

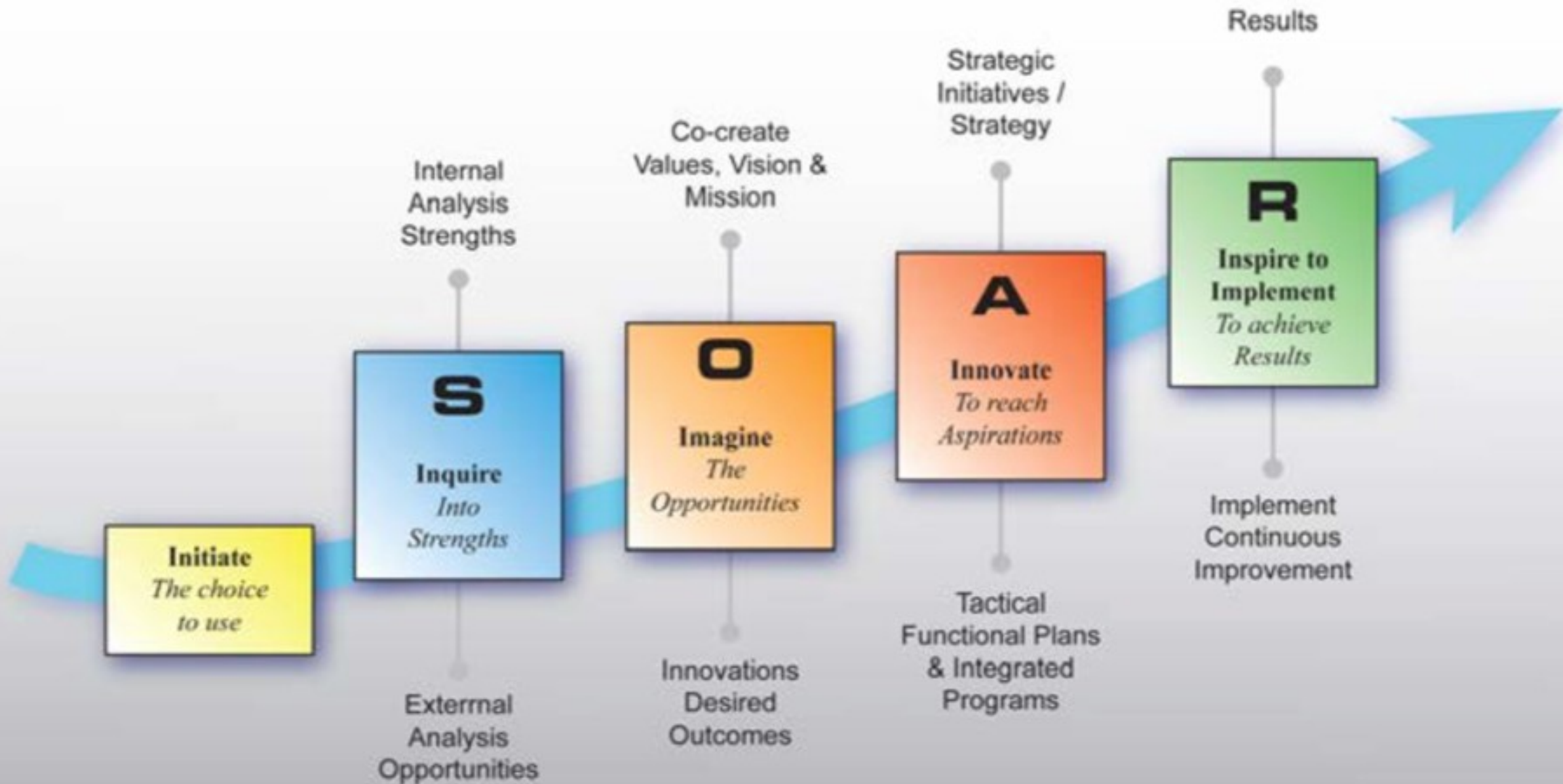
- ▶ It is highly participative, building stronger relationships in the organization and with partners.
- ▶ It is future focused.
- ▶ It fosters optimism and hope.
- ▶ It draws on the resources, and resourcefulness of the organization.
- ▶ It focuses on the positive to crowd out the negative.
- ▶ It builds organizational capacity beyond existing boundaries.

Appreciative Inquiry is about the co-evolutionary search for the best in people, their organizations, and the relevant world around them. In its broadest focus, it involves systematic discovery of what gives “life” to a living system when it is most alive, most effective, and most constructively capable in economic, ecological, and human terms.

- David Cooperrider

AI CHANGE STRATEGIES USE THE SOAR FRAMEWORK

SOAR Framework



Strengths, Opportunities, Aspirations, Results

POSITIVE QUESTIONS AND DIALOGUE ARE AT THE HEART OF AI DRIVEN CHANGE

PROPOSED QUESTIONS FOR DCO CONVERSATIONS

- ▶ What are you most proud of that DCO has accomplished?
- ▶ What is your most positive memory of time working with DCO?
- ▶ When DCO is working at its best, how would you describe that?
What happens, who's involved, what are the results?
- ▶ In your ideal world, what does DCO look like in five years?
- ▶ Can you describe DCO's biggest strengths?
- ▶ What are the capabilities of the organization that you want to strengthen the most?
- ▶ Who are partners that have the greatest impact on DCO's success?
- ▶ What partnerships could be developed to enhance DCO success?
- ▶ When DCO is at its best, what are the core factors or strengths that give life to DCO?
- ▶ What stakeholders have benefited the most from DCO?
- ▶ What stakeholders could DCO reach out to and expand their impact?
- ▶ What are the most valuable attributes contributed by DCO's Board Members?
- ▶ What additional attributes or skills would you like others to bring to the Board?

DCO CONSULTING ENGAGEMENT SCOPE & TIMELINE (1 OF 2)

Wednesday, July 27th 9PM ET – Introduction Call with Board President, Treasurer and Secretary

- ▶ Background and history of DC Outreach, Inc.
- ▶ Identify Stakeholders, Resources and Needs
- ▶ Outline timeline and objectives of engagement
- ▶ Outline data gathering process and timeline
- ▶ Design questions for those interviewed
- ▶ Format and participation for interviews
- ▶ Identify other data resources

Sunday, August 7th, 9PM ET – DCO Board Meeting

- ▶ Introduce engagement

▶ **Monday, July 25 – Friday, September 2**

- ▶ Interviews with Key Stakeholders & possible resources; include:
- ▶ Board Members
- ▶ DCO Families – include international (Pacific)
- ▶ Medical Advisors
- ▶ Pharma (Vin Milano)
- ▶ Penn's Orphan Disease Center (Dr. Wilson, Samantha Charleston, Monique Molloy)
- ▶ Other

DCO CONSULTING ENGAGEMENT SCOPE & TIMELINE (2 OF 2)

Sunday, September 4th – DCO Board Meeting

- ▶ Update Board

Saturday, September 17 – Sunday, September 18 – Camp Sunshine

- ▶ Share data with stakeholders
- ▶ Develop and Design future state of DC Outreach
- ▶ Build commitment and participation towards the future
- ▶ Develop actionable objectives and establish ownership and milestones

Sunday , October 2nd, 9PM ET – Board Meeting

- ▶ Share draft of strategic plan and agree on next steps

APPENDIX B

CAMP SUNSHINE PRESENTATION

DC Outreach

*Celebrating the Past
Envisioning the Future*

Camp Sunshine
Casco, Maine
September 17, 2016

Introductions

Bob Biglin

- Corporate executive with 30 years of multi-national experience
- Business consultant and coach
- Masters of Organizational Dynamics - 2017
- Board Member: Philadelphia Ronald McDonald house
- Two middle school-age children

**Bruce Friedman**

- Executive with over 25 years of experience in industry and higher education
- Masters of Organizational Dynamics - 2017
- Business consultant and coach
- Parent of three, including a child lost to DC

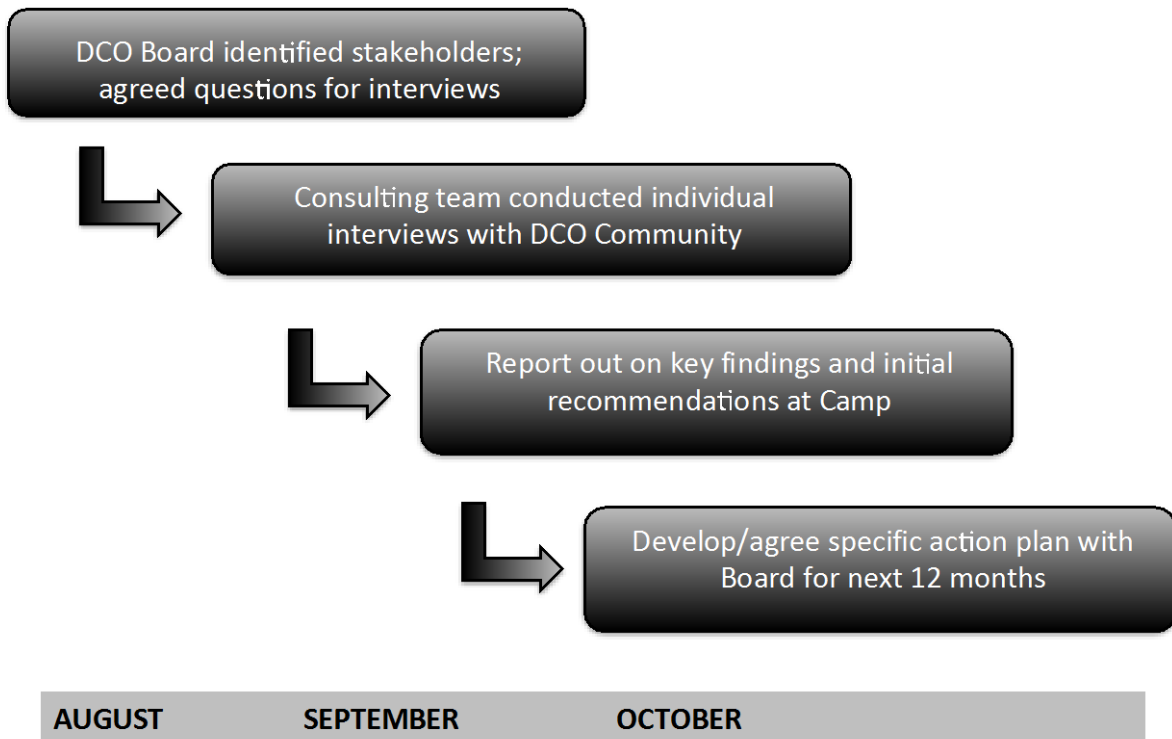


Objective

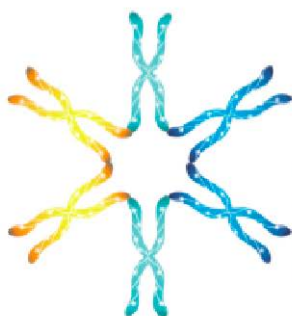
Build upon strengths and accomplishments of DCO and position its Board and families to move the organization forward as it delivers DCO's mission.

- **Strengths : Internal analysis**
- **Opportunities : Develop a shared vision**
- **Aspirations : Identify strategic initiatives and strategies**
- **Results : Inspire YOU to implement and achieve results**

Process



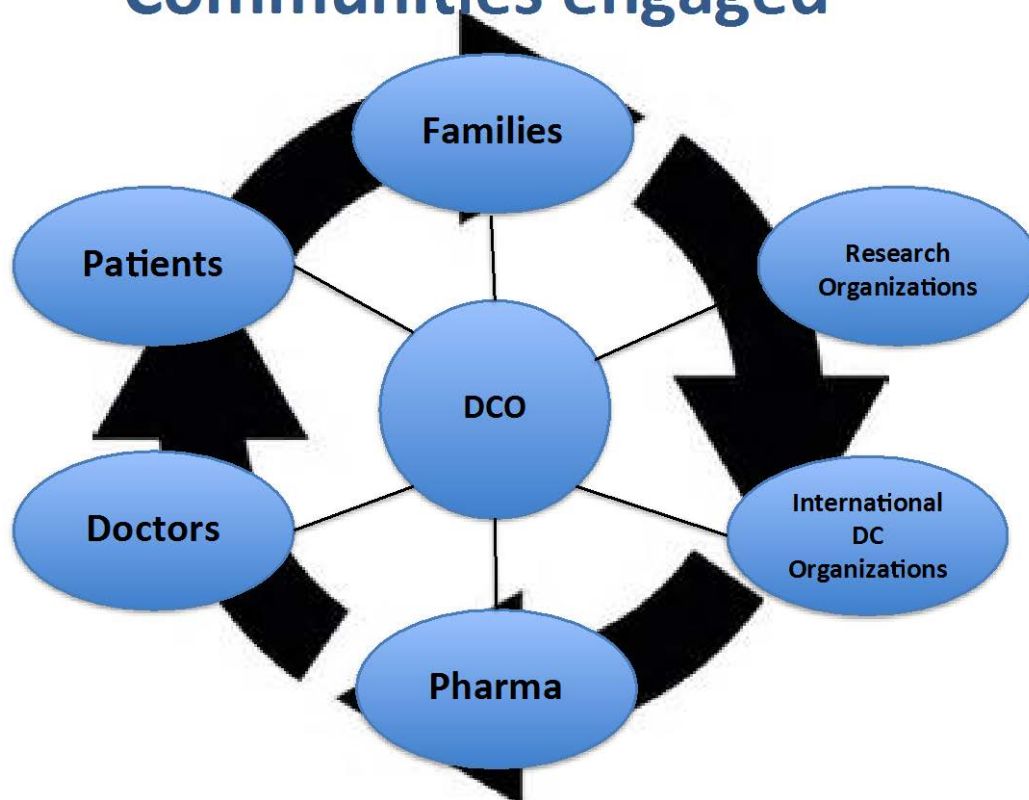
DCO's Mission



Dyskeratosis Congenita Outreach, Inc. **A Community for Telomere Biology Disorders**

Our mission is to provide information and support services to families worldwide affected by Dyskeratosis Congenita and Telomere Biology Disorders, to encourage the medical community's research in finding causes and effective treatments, and to facilitate improved diagnosis by educating medical providers.

Communities engaged



DCO Board & Family Questions

1. *What are you most proud of that DCO has accomplished?*
2. *When DCO is at its best, what are the core factors or strengths that give the organization life?*
3. *In your ideal world, what does DCO look like five years from now?*
4. *From your vision of DCO in five years, what do you see as the most important attributes & skills for its Board members?*
5. *Partnerships have proven to be very important to DCO. What existing partnerships should be strengthened and what new partnerships should be pursued to support the five year vision?*

What are you most proud of that DCO has accomplished?

- CAMP – “Crown Jewel” of DCO
- Clinical Guidelines – they’re awesome!
- Patient Registry – CENA/Genetic Alliance grant
- Establishing a Board and unbelievably dedicated and responsive medical advisory board. ASH Conference has been huge!
- Monthly phone sessions/chats – connecting families to resources
- Raising funds for research – MDBR!

When DCO is at its best, what are the core factors or strengths that give the organization life?

- Playing a part in a favorable or more informed outcome for a DC family
- When the Board communicates well – Consistent and like-minded messaging – Facebook, Constant Contact, newsletter, etc.
- Pulling together doctors and researchers with a singular focus of helping others with DC (ASH Conference)
- Each member feels vested with other members & families
- Coordinating camp – collaborative TEAM effort!

In your ideal world, what does DCO look like five years from now?

- Reach more families – cast a wider net with other telomere related disorders (Pulmonary Fibrosis, Immunological, GI, etc.)
- Part-time Executive Director – move from a Board-run advocacy group to a professionally run organization
- Global collaboration with local focus
- Spread the load – have other patients, families and people without direct DC connection contributing towards mission
- Get together more frequently
- DCO becomes a member supported organization – annual giving
- Bigger impact on research – focused on cure and treatment

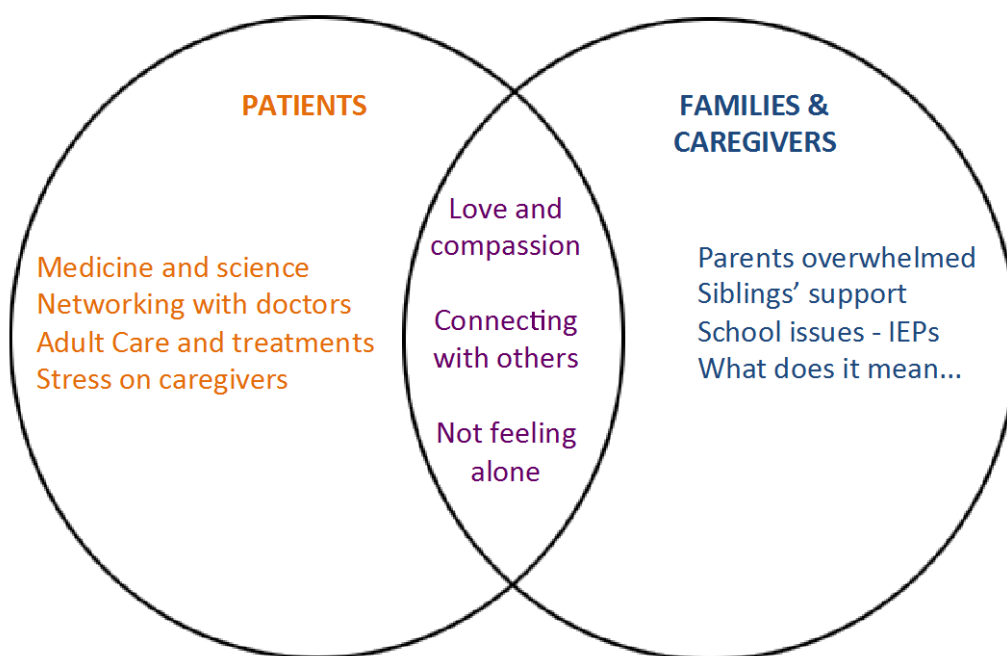
From your vision of DCO in five years, what do you see as the most important attributes & skills for its Board members?

- Passion, commitment, collaboration
- Ability to see the larger picture – strategic
- Effective communicators, social media, PR
- New ideas, freshness
- Fundraising – development
- Business acumen – non profit governance, finance, treasury, legal, board training
- Networking – engaging more people with genuine commitment to mission

What existing partnerships should be strengthened and what new partnerships should be pursued to support the five year vision?

- Camp Sunshine, Be-the-Match, CENA/Genetic Alliance, Aplastic Anemia, Global Genes– all well developed
- NORD, Penn ODC, International DC organizations (Australia, UK, Canada)
- Expand network of doctors – more focus on adult patients
- Develop more centers of care (i.e., U of Minnesota; Texas Children's Children's Hospital of Philadelphia, Boston Children's, Cincinnati, etc)
- Partner across disciplines – Pulmonologists, Genetic counselors, immunology, GI
- Partner with other rare disease organizations – Penn's Orphan Disease Center

Unique and Common Needs



What else...

- Capitalize on level of accomplishments to date and use this to energize efforts going forward...
- Financial stability - Needs a lot of people being committed, commitment includes money. As group, DCO is growing but funds are not.
- Strategic plan to generate new ideas and inspire others.
- Post minutes from meetings – more accessibility for others

Doctor & Researcher questions

- What would you consider to be the most important areas for DCO to be engaged with in the medical and research communities in the next five years?
- What non-DC conditions should DCO consider when exploring possible partnerships?
- If DCO was able to sponsor research, what areas of research do you believe would be most important?

Doctor/Researcher priorities for DCO engagement within the medical community in the next five years?

- Diagnosis & Treatment – many patients not diagnosed
- Awareness – Continued outreach in other disciplines (Pulmonary, Immunology, Gastro)
- Research towards cure and therapies
- Telomere testing – availability in US without insurance issues
- Clinical studies
- Develop and expand treatment centers – comprehensive care for DC patients

Thoughts from Pharma...

- Industry MUST partner with advocacy groups
 - Sponsorship & support - partnerships need to be about patient, not product
 - Rare disease orgs and doctors direct pharma to their patients to support clinical trials
- Marketing – how does DCO tell its story?
- Learning from other rare disease organizations - Need an Executive Director – make DCO someone's job.
- “Passionate capitalism” – take care of patients, business will be fine

Thoughts from current DCO Partners

“DCO is a team player...They are passionate, relentless in their commitment, intelligent and strategic...”

“Though they (DCO) are small, they are committed to making a difference... They could expand their influence if they had more funding to expand staff...”

“DCO has been exceptional in engaging their members. They could teach a lot of other small organizations how to do that well...”

What we heard: Common Themes across the community

- Clinical guidelines highly valued
- Camp!!
- Engagement with families (Facebook, etc.)
- Engagement across medical community
- A place to go for community
- Need structured and consistent fundraising
- DC Outreach is punching well above its weight!

Challenges

- It's not easy talking about DC
- Patients and families are stretched and need help
- Broader engagement with families
- Funding: building a stronger financial base
- Specific skill sets to support mission: legal, financial, social media, emotional wellness
- More awareness of DC at initial diagnosis
- Establishing formal partnerships with pharma industry
- Promoting better linkages across DC research and care centers

Your Vision of DC Outreach in 2021

Engagement with DC Community

- Regional chapters: raise awareness, expand networking, and broaden fund-raising reach
- Focused support programs: tailored to needs of Patients, Parents, Caretakers, and Family members
- Broader base of skills from within and outside of DC Community: legal, financial, social media, emotional wellness, development
- Coordinated engagement with international DC organizations

Strategy-focused Board and dedicated Functional Committees

- Part-time Executive Director: runs routine Operations
- Board focused on Strategy and Development
- Board meets at least annually in-person; when possible, concurrent with conferences
- Committees established to lead specific initiatives: Communication, Nomination Development, Wellness

Your Vision of DC Outreach in 2021

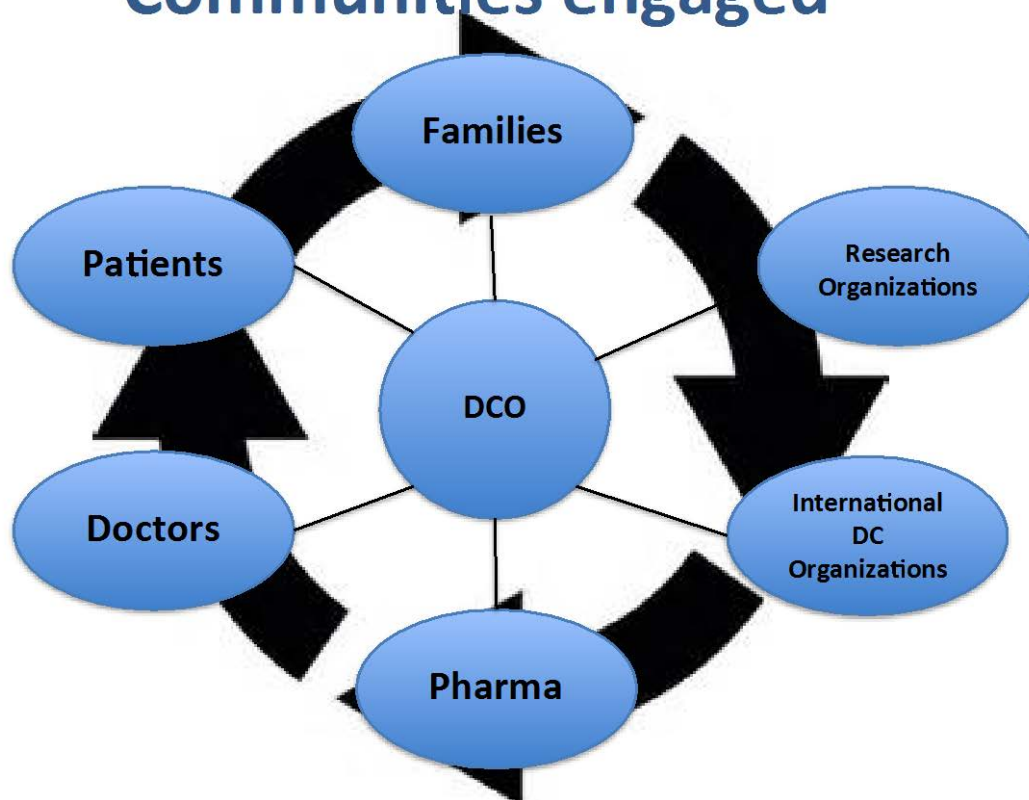
Research and Advocacy

- Focus on a cure
- Medical Advisory Board leading mapping and prioritization of DC Research
- Easier access to Telomere testing
- Increased DCO presence at conferences and symposia
- Actively engaged with 8 primary care centers in the US: raising awareness amongst clinicians for early diagnosis
- Established at least two partnerships with Pharma

Robust, Sustainable Fundraising

- Regional Chapters: events and fund drives, provide funding base
- Monetary support from Pharmaceutical partnerships
- Active pursuit of Grant funding
- Larger member base: expands potential network for fundraising

Communities engaged



Board Structure and Governance in 2021

Committee	Primary Responsibilities
Executive	Sets organizational strategy; sets priorities, established objective
Development and Communication	Leads fundraising strategy and execution Cultivates relationships, expands DC network for funding Leads and coordinates all communication activity
Wellness and Advocacy	Provides guidance to patients and families on navigating: medical resources, insurance, legal, personal financial, etc. Education resources (IEPs, School support entitlements) Family counseling
Medical	Advisory Board; Conferences; Pharma Partnerships; Clinical Guidelines, Protocol
Nomination	Sourcing and screening candidates for Board and Committees

Committees (other than Executive Committee) comprised of:

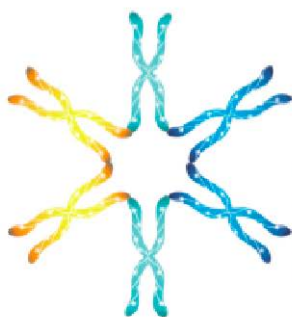
- Executive Director
- At least one Board member
- Members of DC Community
- Others with commitment, interest, or expertise

Roadmap: next 12 months

- Prioritize current operations and sustain critical functions
- Establish Regional Chapters
- Establish Committees, solicit volunteers
- Develop role description for part-time Executive Director
- Search for funding to support position (grants, sponsorships, etc.)

How you can help DCO...

- Your passion, commitment, skills, and energy can have a large impact on DC Outreach
- Reach out into your own communities
- Volunteer to support or lead a local chapter, or a functional Committee
- Help with Development efforts: foundations, grants, families, friends



Dyskeratosis Congenita Outreach, Inc.








A Community for Telomere Biology Disorders



Our mission is to provide information and support services to families worldwide affected by Dyskeratosis Congenita and Telomere Biology Disorders, to encourage the medical community's research in finding causes and effective treatments, and to facilitate improved diagnosis by educating medical providers.

APPENDIX C

DCO ACTION PLAN

Key Activities	Target Milestone	Prioritize operations, sustain critical functions	Establish Regional Chapters	Establish Committees Solicit Volunteers	Fundraising & Development	Hire Part-time Executive Director
Send Call to Action email to DCO Community	October 2016	●	●	●	●	
Survey to DCO Community to prioritize most critical activities to sustain, and frequency of activities	October 2016	●				
Launch Fundraising campaign to raise funds for part-time Executive Director	Nov 2016– Feb 2017				●	
Review geographic concentrations of DCO members and identify potential Chapter regions.	November 2016		●			
Develop Summary Description of Regional Chapter and Chapter leads	December 2016		●			
Transition Board Presidency from Robin to Katie	January 2017	●				
Email DCO community, targeting members by region, soliciting volunteers to start and lead Regional Chapters.	January 2017		●			

Develop Job Description for Executive Director	January 2017					
Explore sources for Exec Dir candidates with partner groups (NORD, Global Genes, etc.)	January 2017					
Exec Director candidate search and interviews	February – May 2017					
Hold kickoff conference call with Regional Chapter leads	March 2017					
Key Activities	Target Milestone	Prioritize operations, sustain critical functions	Establish Regional Chapters	Establish Committees Solicit Volunteers	Fundraising & Development	Hire Part-time Executive Director
Hire and onboard part-time Executive Director	May 2017					
Develop scope of responsibilities and key skills for each DCO Committee: Communication, Development, Wellness & Advocacy, Medical, Nominating	July 2016					
Enlist Regional Chapter Leaders to communicate goals and needs of Committees to their respective chapters, seeking volunteers and support.	August 2016					

Establish Committee charters	August 2016					
Launch DCO functional committees	September 2016					

APPENDIX D

AGGRETATION OF INTERVIEW DATA

Data – The following is an aggregation of data from interviews conducted between February 1 – 15, 2017

	Interview A	Interview 2	Interview 3
What do you consider the most impactful successes/greatest accomplishments?	<ul style="list-style-type: none"> • Not one or two things • Founding Board & President. Relationships built one at a time. • Relationships with neighbors, friends, co-workers, etc. • Allow patient to have the choice to be involved. 	<ul style="list-style-type: none"> • Went from a disorder nobody heard of or thought about to one of the first that ophthalmologists now think about • In 2016 local congressman submitted a resolution on Rare Disease Day in braille – very significant; Generated a lot of press; watershed moment. 	<ul style="list-style-type: none"> • Initially the disease was thought about and treated like cancer; Understood more with other physicians that it is an immune disorder, not a cancer. Reframed treatment & research. • Recent development of a diagnostic model for the disease, online now, soon to be published in a leading hematology journal. • Until recently, most clinical data came from David. Discovered pathway that personalized treatment.
What contributed to these successes?	<ul style="list-style-type: none"> • Creating a patient community • Integrity – Each meeting starts with their core values • Mission, Vision, Strategic Plan used as a guide • Bringing others to Board & organization with relevant skill sets. • What are gaps; who do they need; identify personal connections – done on a white board 	<ul style="list-style-type: none"> • Does not like the term “awareness” but does believe in moving awareness into action • Effective collaboration. Very visible in rare disease community; speaks at symposiums and is seen & heard. 	<ul style="list-style-type: none"> • Global community of researchers and physicians connected; trust & know the global community • Huge involvement of patients. Patients involved with the whole process • Execution – developed a plan with many steps; Not focused on “cure”, but many steps along the way. Break down and execute like a business plan. • 2 main sources of volunteer: <ul style="list-style-type: none"> ○ Patient Communities ○ Penn Community (Wharton & Med. Students)
What challenges lie ahead for your organization?	<ul style="list-style-type: none"> • Managing expectations • Not judging everything in regards to if it’s a “cure”; not healthy thinking. Recognize value of incremental steps. • Time is a barrier. Urgency a core value. Speeding business deals & science process is life-or-death. • Funding/money is a problem that can be figured out. 	<ul style="list-style-type: none"> • Growing too fast, volunteer dropping (5-year drop-off). • Need professional help in certain areas. • Open a Center of Excellence for patient care. 	<ul style="list-style-type: none"> • Getting all doctors to share samples. Good samples are hard to find; disaggregated research at research institutions, hospital labs. Need to gain access and coordinate and accelerate research. Researchers are not always interested in doing this.

	Interview 1	Interview 2	Interview 3
What would you consider transformational to your organization?	<ul style="list-style-type: none"> • Targeted awareness; something measurable that brings change. • No such thing as a “general public”. 	<ul style="list-style-type: none"> • House resolution in braille • Difficult as blindness is not life-threatening, but has large impact on quality of life • Kristin strives to keep blindness in fore-front <ul style="list-style-type: none"> ○ TED talk in March ○ Writing a book ○ Comcast commercial • Resources & job losses are issues • Likes to go to medical stds.to have them involved in rare disease groups early; see patient perspective 	<ul style="list-style-type: none"> • Bringing together patients and physicians • Business plan – “International Research Agenda” • Publishing Diagnostic Criteria • Biggest problem in rare disease orgs is redundancy and fracturing; too many foundations for the same disease; need to collaborate and have less organizations for the same disease. Critical to take action, speed results. • Think beyond advocacy to scientific impact; push Drs. Don’t wait.
Has your organization at any time used a consultant? If so, what were the most and least effective aspects of the consulting engagement?	<ul style="list-style-type: none"> • Worked with fund raising consultant w/ good results. Had good ideas and direction that made a difference. • Twice worked with 2 different PR consultants. Neither went well. <ul style="list-style-type: none"> ○ Did not understand values or culture ○ Did not understand why rare disease groups are different “because they’re rare” • Effective consultants need to be visionary & tactical. Can’t have just one, need both. 	<ul style="list-style-type: none"> • Have not used a consultant <p>Collaboration is key – rare disease orgs demonstrate this at high level</p> <p>Work together to “Halt the train of sorrow”</p>	<p>Has utilized Wharton students as consultants. Volunteers are like consultants. Rare diseases are often neglected, don’t get the attention they need. Family and patients with disease are more often the people in the organization Bigger sense of urgency – most meaningful work, constants/volunteers are working directly with patients</p>

	Interview 4	Interview 5	Interview 6
What do you consider the most impactful successes/greatest accomplishments?	<ul style="list-style-type: none"> Financial stability – Now able to address deferred maintenance, introduce new programs and establish endowments Alumni trips – nice trips, Emergence of other leaders within camp staff Strategic plan now being implemented and ready for a refresh 	<ul style="list-style-type: none"> DCO awarding a grant through Million Dollar Bike Ride Clinical Guidelines – collaboration and something that had not existed. 	<ul style="list-style-type: none"> Lisa started on the Board five years ago; she sees the Board now as much more professional and accountable. Focus on governance and compliance (documentation, tax, insurance, etc.) Clinical Guidelines were a turning point Mail list has grown from 100 to 900 Dr. Agarwal & Dr. Savage – developing the Telomere consortium
What contributed to these successes?	<ul style="list-style-type: none"> Alumni families – they see that they are provided with quality trips and quality care. Buy in from parents & staff Emphasis on quality, sees it now more as a parent Moving from shoe-string budget to better appearance of quality, safety <ul style="list-style-type: none"> Replacing vehicles/vans Updating obstacle course 	<ul style="list-style-type: none"> Clinical Guidelines – a lot of patience and confidence. Very slow moving and Robin's not very patient. MDBR/Grant – Be able to ask for help. Being "in need" is not a weakness, others are looking for ways to help. Perseverance. Belief in self. Humble confidence. Ability to convince others they are doing the right things to help. 	<ul style="list-style-type: none"> Representing the patient is important. Doctors are more willing to collaborate, as patients are involved. Following a period of internal conflict, there was an urgency to firm up the Board or it would not survive. Important each member has a role
What challenges lie ahead for your organization?	<ul style="list-style-type: none"> Funding is always a challenge Dependent on church grounds Meeting needs of what parents want Shifting population from Downs Syndrome to broader spectrum of disabilities, mostly autism 	<ul style="list-style-type: none"> Spreading awareness. Growing the group and engaging more families. Group needs to find a way to get people excited more than every 2 years (Camp). Amplifying outcomes. Put things in the face of members, show them it's a cause worth supporting Keep people engaged regardless of where they are in the DC process 	<ul style="list-style-type: none"> Sustainability – concerned about burn-out Non-board members need to help out more <ul style="list-style-type: none"> New board member from Camp Sunshine will be a great asset
What would you consider transformational to your organization?	<ul style="list-style-type: none"> Camp having its own space More frequency of events, particularly for alumni Help alumni as adults; concerned about those who age out 	<ul style="list-style-type: none"> Hiring a paid Executive Director to move our mission forward. Funding and influencing a significant grant for DC research 	<ul style="list-style-type: none"> Involvement of more people, shared vision Not a lot of spare time, current board is maxed –out

	<u>Interview 4</u>	<u>Interview 5</u>	<u>Interview 6</u>
Has your organization at any time used a consultant? If so, what were the most and least effective aspects of the consulting engagement?	<ul style="list-style-type: none"> • What makes NPO different: <ul style="list-style-type: none"> ○ Needs more leading; brings in perspective and skills ○ Camp is not everyone's first job, secondary • Strong understanding of NPO needs • Good listener and patient – filter and not easily swayed • Organize thoughts and ideas • Needs focus on succession planning; prescriptive with some things 	<ul style="list-style-type: none"> • Worked with Penn students to develop strategic plan (subject of this capstone's case study) • Very helpful, synthesized outside information; were able to get honest feedback and turn into outcomes and goals. • Concrete ideas; verbalized many things they already know. • AI approach was “spot on” • Board was already aware of their problems; would not have been productive to focus on them. • Group is young and leadership needed inspiration. 	<ul style="list-style-type: none"> • Medical Advisory Board – technical consultants • NORAD is a great resource

