Infantile Scoliosis Early Treatment Process

United States
Heather Haytt-M...

Project Summary

Concise Summary: Help us pitch this solution! Provide an explanation within 3-4 short sentences.

The innovation of the Infantile Scoliosis Outreach Program’s Early Treatment (ET) Process is one that phenomenally enhances the quality of life for infants with infantile scoliosis without the invasion of traditionally prescribed, costly and dangerous surgery. Too often this surgery is proven to be insignificant in the reversal of curve progression and does not attend to the desperation and anxiety families feel when imagining the future lives of their children. Children ages birth to 2 are provided with an alternative solution in the form of ET Plaster of Paris Jackets (POP) that...
accelerate the body’s natural ability to self-resolve. By aiding and training the spine to grow straight, a permanent path towards healthy living is
forged that prevents the use of repeated surgeries that are often accompanied by extreme risk and high financial burdens. This innovation is a
form of healthcare affordability that lowers medical supply costs, requires only one night’s stay in a hospital each treatment and limits
complications and “salvage” surgeries.

Traditional responses employ the “wait and watch” method that utilizes observation and a brace that does nothing to contribute to curve
correction. In addition, the brace is a mere stalling mechanism that is worn until spinal curves deteriorate into a state that may jeopardize internal
organs. One such condition, Thoracic Insufficiency Syndrome (TIS), causes permanent deformities and chronic conditions that render the chest
 cavity unable to expand and contract for normal lung function and growth. The eventual progression of severe infantile scoliosis compromises
heart and lung functions and leads to dependence on ventilators, severe deformity and shortened life span. The ET innovation is one that allows
children and families to forego complicated medical interactions and doctors and patients to move forward with solutions that not only promote
natural healing, but peace of mind, as well.

The early treatment process (ET) of infantile scoliosis is a disruptive approach that negates the “wait and watch” method and empowers
children and families to move forward with solutions that not only promote natural healing, but peace of mind, as well. The ET innovation is
one that eliminates repeated surgeries, lowers medical supply costs and improves the medical community’s ability to treat infants and
children in a more cost effective and natural manner.

Innovation

Define the innovation

The innovation of the Infantile Scoliosis Outreach Program’s Early Treatment (ET) Process is one that phenomenally enhances the quality of life for
infants with infantile scoliosis without the invasion of traditionally prescribed, costly and dangerous surgery. Too often this surgery is proven to be
insignificant in the reversal of curve progression and does not attend to the desperation and anxiety families feel when imagining the future lives of
their children. Children ages birth to 2 are provided with an alternative solution in the form of ET Plaster of Paris Jackets (POP) that accelerate the
body’s natural ability to self-resolve. By aiding and training the spine to grow straight, a permanent path towards healthy living is forged that prevents
the use of repeated surgeries that are often accompanied by extreme risk and high financial burdens. This innovation is a form of healthcare
affordability that lowers medical supply costs, requires only one night’s stay in a hospital each treatment and limits complications and "salvage"
surgeries.

Traditional responses employ the “wait and watch” method that utilizes observation and a brace that does nothing to contribute to curve correction.
In addition, the brace is a mere stalling mechanism that is worn until spinal curves deteriorate into a state that may jeopardize internal organs. One
such condition, Thoracic Insufficiency Syndrome (TIS), causes permanent deformities and chronic conditions that render the chest cavity unable to
expand and contract for normal lung function and growth. The eventual progression of severe infantile scoliosis compromises heart and lung
functions and leads to dependence on ventilators, severe deformity and shortened life span. The ET innovation is one that allows children and
families to forego complicated medical interactions and doctors and patients to move forward with solutions that not only promote natural healing, but
peace of mind, as well.

Context for Disruption:

The context for disruption is rooted in the age old philosophy surrounding the basis for understanding infantile scoliosis and its affects on the body.
As with any effective disruption, the Early Treatment Process begins with providing not only an alternative solution, but presenting an alternative
view point of the problem to the public. Since Hippocrates, orthopedic surgeons have been taught that infantile scoliosis worsens with growth. As the
body grows, so does the condition. However, the ET Process is an approach that negates this mentality and recognizes the body’s ability to self
resolve. This disruptive approach will change the entire paradigm of thought and activity related to progressive infantile scoliosis. In fact, the only
reason infantile scoliosis continues to damage lives is because it is allowed to. For years, the orthopedic community has spent thousands of hours and
millions of dollars attempting to thwart and force infantile scoliosis through invasive surgery and other extreme medical responses to this
condition. The orthopedic community had yet to be presented with such a simple and inexpensive solution that would eventually eradicate the long
term effects of such a complicated condition. However, the ET Process will enhance the medical community’s ability to treat infants and children in a
more cost effective and natural manner.
As in the model referenced by Dr. Clay Christensen regarding nurse practitioners and walk-in clinics, the ET Process provides an alternatively simple, life saving mechanism to the public in a much more inclusive, accessible and preferred fashion. Already, in cities across the country and around the globe, well over 200 families have chosen to employ the ET Process for their infants, with an additional one hundred families currently on a waiting list. Finally, a listserv with nearly 150 families have expressed the unfortunate scenario of missing the window for treatment while still an infant.

**Delivery Model**

The Infantile Scoliosis Outreach Program (ISOP) is fortunate in that its target population of physicians and parents are also its most proactive partners. In order for this innovative approach to become a mainstream form of treatment, pediatric physicians and orthopedic surgeons must buy into its preventative philosophy and practice. Through grassroots communication the surgeons are being reached. The first mechanism for communication utilized by thousands of visitors each month is the ISOP website (www.infantilescoliosis.org) that includes a CAST (Casting as an Alternative for Scoliosis Treatment) Support Group, personal stories, links to medical journals, information for current treatments for infantile scoliosis and successful reports on the Early Treatment Process. In addition, physicians are targeted to participate in Early Treatment educational seminars facilitated by leading medical personnel and researchers. These seminars provide targeted physicians with the principles of Early Treatment and instructions on how to apply this new, nonsurgical method to young patients. Fortunately, many of the physicians already reached have joined the ranks of Early Treatment Process believers and contribute to several outreach activities that include case studies, surveys and tutorials to be published in medical journals regarding the effectiveness of this proven treatment.

Another target population is parents of children with infantile scoliosis. Outreach strategies include the ISOP website, as well as parent initiated seminars. Educational information provided to parents motivates the masses to demand this alternative solution when doctors insist on prescribing premature surgeries. A well educated population of parents is a cornerstone strategy that effectively promotes equality in communication and decision making for alternative solutions with physicians.

**Key Operational Partnerships**

ISOP has initiated three integral partnerships to this point. The first is with a few Shriners Hospitals in different cities across the country who have adopted this innovative approach for young patients with infantile scoliosis. Shriners Centers of Excellence have provided free training to doctors. As a result, ISOP has branched out to additional centers for care, such as: Children’s Hospitals of Rochester, NY; Sydney, Australia; and Denver, CO. The second major partner of ISOP is Cerebral Palsy (CP) of Colorado. Since its inception 60 years ago, CP of Colorado has stretched its arms around thousands of families experiencing challenges due to multiple barriers and disabilities. Last year, Cerebral Palsy of Colorado provided services to over 15,000 Coloradans. The Statewide Services arm of this organization is a leader in empowering and enhancing communication for parents and families regarding healthcare initiatives and information dissemination. Finally, Doctor Min Mehta, FRCS, MD of the Royal National Orthopedic Hospital in Stanmore & London (retired), the pioneer of the Early Treatment Process, has followed nearly 150 infants for years using this non-surgical process and reveals that spines remain straight after treatment. Dr. Mehta is a published author and is currently assisting ISOP in training U.S. physicians. Through these partnerships, ISOP is in great need of launching itself into the mainstream frame of mind for all parents.

**Impact**

**Financial Model**

ISOP is supported by CP of Colorado, which serves as ISOP’s fiscal agent. CP is a 60 year old nonprofit organization that implements GAAP and provides financial statements on an accrual basis.

**What is your annual operating budget?**

$115,000

**What are your current sources of revenue? (please list any sources that are foundation grants)**

Current revenue sources include both financial and in-kind donations. To date, ISOP has depended on the giving nature of parents and families, who have witnessed first hand their children overcome what was expected to be a life long barrier to freedom and happiness. In addition, special events conducted by parents have raised $45,000 with additional events on the planning board. Corporate sponsorships have been pursued that include contact with organizations such as Medtronic and Johnson & Johnson for funding operational expenses for upcoming ET programs. Finally, several orthopedic surgeons who have accepted the Early Treatment method as truth have effectively utilized facilities and their own time to conduct Early Treatment educational seminars to further validate this approach among their colleagues in the medical community.

**Effectiveness**

Over 300 orthopedic surgeons and physicians have been introduced to Early Treatment Process at the 2006 Scoliosis Research Society Meeting in Monterey, CA. In addition, orthopedic surgeons in Shriners Hospitals nationwide have conducted trainings for their colleagues within the Shriners Network and elsewhere. However, the number of orthopedic surgeons and physicians reached thus far is not even a mere scratch on the number of of practicing orthopedic surgeons throughout the country and around the globe. Though progress has been made, time is of essence regading making sure that desperate families have access to trained orthopedic surgeons.

As for additional outreach, the number of website hits and parent phone calls has increased exponentially in each of the past five years. In 2001, ISOP recorded 7,200 inquiries into the program via its website and telephone calls. Already in 2007, 9,000 families have initiated contact with the program. This sets a pace for over 21,000 by year’s end. These numbers are a testament to the swollen demand that this alternative solution has created. The effectiveness of parent outreach has created a demand for three Early Treatment Process seminars to occur in 2007 in Rochester, NY; Chicago, IL; and Sydney, Australia. The existence of demand in Sydney, Australia will eventually appeal to a broader, more global collection of physicians who will set the pace for promoting this solution as the future’s conventional method. Due to parent demand, even before the seminar has begun, 40 infants are awaiting treatment by trained physicians.

**Which element of the program proved itself most effective?**

As for short term effectiveness, the initial class of trained orthopedic surgeons has proven to be a valuable resource for saving infants and children with infantile scoliosis. This much appreciated resource has proven to be integral in order to permanently eradicate progressive infantile scoliosis. However, the most effective, long-term element of success has been the contribution of parents and families. These primary stakeholders have been instrumental in information gathering and dissemination, presenting personal testimonials and advocating on behalf the ET strategy. Through effective communication and information sharing, parents become more confident and zealous when approaching the medical community with alternatives for their children. Many families currently travel significant distances to both attend and help facilitate Early Treatment educational seminars. In turn, these same families return to the Internet and their home communities to further share information with
local providers and parents.

**Number of clients in the last year?**

ET Process Seminars held in recent years have been able to aid at least 185 children in growing straight, permanently. In addition, 270 parents proactively participate in the CAST support group; 50 orthopedic surgeons and technologists have been trained; over 1,800 website hits are recorded each month; and 360 phone calls per year are received inquiring about the program. These last numbers reflect an average of 60 people per day entertaining curiosities surrounding alternative treatments for infantile scoliosis.

**What is the potential demand?**

The potential demand for this alternative solution is both exciting and disheartening. Excitement exists knowing that a more effective and accessible solution is available to thousands of families. However, the demand remains disheartening, due the inability to accurately place a numerical estimation on the number of infants in need of this innovative treatment. The truth remains that thousands of the infants are never officially diagnosed with infantile scoliosis until later in childhood. Current estimates acknowledge that as many as one child in every grade school throughout the United States and around the world was never properly diagnosed with infantile scoliosis at a younger age. However, there is hope that, with greater information being provided to both current and expectant parents, greater awareness and knowledge surrounding the issue will increase the number of properly diagnosed children. In addition, it is only natural to assume that a high number of underserved children exist within the realms of government provided medical insurance and free county health clinics.

**Scaling up Strategy**

ISOP’s strategy entails a greater focus on increased trainings for orthopedic surgeons, as well as, diversifying and multiplying the number of parents and families aware of this solution. As for orthopedic surgeons, focus will be placed on the pediatric community and their ability to properly diagnose infantile scoliosis at a much younger age than traditionally conducted. A simple exam should be performed at every Well-Baby check-up so children can immediately be referred to an orthopedic doctor, who practices this innovative solution with infantile scoliosis.

In addition, ISOP understands that a majority of parents involved with its strategies are present because they are the ones who proactively seek the information. This is evident by low numbers of low income and minority families who may not have access to the Internet and distant educational seminars. Currently, zero African-American and Hispanic/Latino families have taken advantage of information sharing events. ISOP is aware that infantile scoliosis does not discriminate and that outreach efforts must include people of all backgrounds. ISOP intends to implement a more diverse outreach strategy, that will include posters and outreach packets available to families in health departments, clinics and other venues where a more diverse population of people will be reached.

Finally, ISOP intends to work with the American Academy of Pediatrics to ensure proper and timely diagnosis.

Though we are proud of early successes, compared to its potential success, ISOP is still very much at the start-up stage in its mission. All efforts and progress must be dedicated to spreading its solution to an entire world of people in a matter of minutes.

**Stage of the initiative:**

0

**Expansion plan:**

The most important area for expansion is in ISOP’s ability to market itself. In order to better education orthopedic surgeons and mobilize parents, a comprehensive marketing plan must be devised. From this plan, a more effective strategy of outreach can be implemented.

In addition, many older youth have unfortunately missed out on the ET Process as infants. The unfortunate consequence of missing out on early treatment is that limited resources are available regarding solutions and healthy living. Beyond physical development, emotional and social development of youth living with an undetected form of infantile scoliosis is integral to life and expansion of information. This Juvenile Scoliosis Outreach Program (JSOP) will entail greater information regarding the Vepr and Halo Treatment, which is an older child form of treatment. Currently, information regarding these forms of treatment can be found on the ISOP website, but families in need of services have few places to go for care. The JSOP initiative will respond to families unable to receive ET treatment.

Eventually, a free standing facility dedicated to the provision of the Early Treatment Process and related resources will be constructed and will provide opportunities for greater research and numbers of people to be served.

**Origin of the Initiative**

ISOP was established in 2003 in Denver, Colorado, by the mother of a child with infantile scoliosis. She was seeking information and alternatives about gentle, non-invasive modes of treatment for the disorder. Prior to ISOP’s official formation, the founding mother started the website, infantilescoliosis.com to disseminate information and create a virtual community for infantile scoliosis patients. From its inception, this website began to increase awareness of infantile scoliosis and provide up-to-date educational material to numerous inquiring families around the globe. Though the founding mother is an example of a parent who missed out on the ET Process, she is devoted to making sure that parents like her do not have to suffer through similar endeavors.

**Sustainability**

**What are your two main challenges to finance the growth of your initiative?**

The biggest challenge for growth in relation to finances is the ability to conduct educational seminars. These seminars are not only costly in obtaining space and materials for large audiences, but often time sensitive. This means that educational seminars are often held due to parent demand, who need this information with little time to lose. Costs include getting parents to these seminars from significant distances in order to help them make healthy decisions in a timely manner. In addition, creating a forum for orthopedic surgeons to become trained on this treatment method often comes with higher price tag.

The second challenge for growth related to finances is in outreach. Once a more effective marketing plan is designed, it is assumed that greater sources of funding will be needed to carry out the desired plans. As already witnessed, the global demand for information is increasing and this small, grassroots organization must be able to keep up.

One thing to always remember is that infantile scoliosis has a small window of time in which the ET process can be effective. This in turn creates a sense of urgency and desparation among families.
How did you hear about this contest and what is your main incentive to participate?

As a researcher, the Robert Wood Johnson and Changemakers websites are common sites to visit. Imagine a place where thousands of individuals meet to discuss alternative strategies and solutions for greater progress towards healthy and happy living!

The Story

Do you have an annual financial statement?
Yes.

Do you currently have an annual financial statement that tracks profit/loss?
Yes.

Please describe the amount (and/or type) of funding you need to implement your initiative, at year 1 and at year 5.

Year one endeavors will catapult ISOP into greater effectiveness among orthopedic surgeons and their availability to parents in need. Funding will be used for Research Support assistance, an ETP Planning Coordinator, creation of a marketing plan and stipends for parents to travel to ISOP facilitated events and educational seminars. By year five, funding will be utilized to enhance and implement the marketing plan, provide honorariums for trained orthopedic surgeons as well as provide follow-up consultation with surgeons and parents.

Source URL: https://www.changemakers.com/disruptive/entries/infantile-scoliosis-early-treatment-process#comment-0