



Tyler's Hope for a Dystonia Cure

Executive Summary & Business Plan

Submitted by:

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Executive Summary

About our Organization

Tyler's Hope for a Dystonia Cure, Inc. is a non-profit 501(c) (3) organization committed to funding neurology research to prevent and cure DYT1 Dystonia while creating greater awareness of this disorder. Our US Tax I.D. Number is 20-3733312.

100% of our funding is made possible through the generosity of individual and corporate contributors.

We have developed a Medical Advisory Board consisting of leading clinicians and researchers in this field whose purpose is to provide the Board of Directors with recommendations as to the most effective use of the funds collected in pursuit of greater insights into the cause, potential treatments, and ultimate cures for Torsion Dystonia and its derivatives.

Based on these recommendations, we will disburse the funds as follows:

Annual Disbursement: 20% of the funds collected in the current year based on the Board's recommendation.

Capital Account: The remaining 80% of the funds collected will be held by a qualified third-party in escrow and invested in mutual funds, US government-backed issues and other securities deemed appropriate by the Board. While pursuing a reasonable rate of return for the Capital Account, our primary investment strategy will be to protect the principal amounts collected until the goal (below) has been achieved.

Once the balance in the Capital Account reaches \$5,000,000.00, the funds will be disbursed to the entity determined to have the greatest potential for impact in the research for a Dystonia cure.

We will continue our capital raising efforts and follow the stated disbursement formula until a cure has been found or until our Board determines that combining our efforts with other, similarly-focused entities is in the best interest of our quest.

Mission Statement

Tyler's Hope for a Dystonia Cure was created to passionately pursue solutions and a cure to the pain and limitations caused by DYT1 Dystonia.

We are inspired by the fearless energy, courage and love of life exemplified daily by our namesake.

Our Focus, Goals and Commitment

We believe that finding a cure for DYT1 Dystonia is only a fraction of time and funding. "Dystonia has a known location and known gene product in the human DNA sequence. It is not degenerative like Alzheimers and Parkinson's Disease and therefore, with investment of the proper resources a cure should be achieved" (Dr. Michael Okun)

Our vision of the most rapid path to a cure for DYT1 Dystonia begins with the establishment of a Dystonia Research Institute in the State of Florida. We envision this center to be the equivalent of a medical "Think Tank" with a singular focus as a Brain Repair Center.

We believe that a funded roundtable where the research leaders in Dystonia, Parkinsons and other basal ganglian disorders can gather to share results, hypothesis and targeted study results will generate new momentum to find better treatments and cures for these movement disorders.

We believe that a tremendous percentage of research time is lost each year as clinicians and researchers are forced to fulfill administrative and non-productive functions as a component of their daily responsibilities. In addition, individual research efforts can create blinders and natural paths with a singular focus.

By combining the creative capacities of our best and brightest researchers in an unencumbered environment, we believe that new ideas will be identified by the combining known or fractional facts. Next-generation advances will be developed from slightly altered or newly interpreted views, and the core spirits of the researchers will be invigorated through the gathering of brilliant minds focused on a single goal.

As a compliment, the funds collected by Tyler's Hope will be used to:

Generate interest and support of research in all direct and related fields;

Promote collaboration, communication and between research scientists, institutions, and other support organizations ;

Support and incentivize the leaders in this area by providing the economic fuel needed to sustain the research, momentum, and enthusiasm of the teams and individuals pursuing a cure.

To improve the quality of life for Dystonia patients through a greater understanding and alleviation of motion-limiting symptoms of this disorder.

Create a greater and growing public sense of awareness of Dystonia by enthusiastically sponsoring events, public speaking and visibility within the media and through positive, passionate word of mouth.

About Dystonia

Dystonia is a neurological movement disorder characterized by involuntary muscle contractions, which force certain parts of the body into abnormal, sometimes painful, movements or postures. Dystonia causes uncontrollable, painful spasms and can affect any part of the body including the arms and legs, trunk, neck, eyelids, face, or vocal cords.

If dystonia causes any type of impairment, it is because muscle contractions interfere with normal function. Features such as cognition, strength, and the senses, including vision and hearing are normal. While dystonia is not fatal, it is a chronic disorder and prognosis is difficult to predict.

It is the third most common movement disorder after Parkinson's disease and Tremor.

Dystonia does not discriminate - affecting all races and ethnic groups.

An estimated 500,000 Americans, often inaccurately diagnosed and receiving improper medical treatment, suffer with dystonia.

One third of all dystonia patients are children.

Dystonia affects more people than Muscular Dystrophy, Huntington's disease and Lou Gehrig's disease.

Treatment rarely brings about total remission, and there is no known cure.

A Brief History of Dystonia

Dystonia, like many other chronic neurological disorders, was recognized as a distinct entity only relatively recently. Even before the term "dystonia" was coined, people with the syndrome were being reported explicitly in the literature.

In 1911, Hermann Oppenheim, an esteemed Berlin neurologist who wrote a leading textbook of neurology, was impressed with the variation in muscle tone seen in a neurologic syndrome that he had encountered in several young boys. He coined the term "dystonia" to indicate that "muscle tone was hypotonic at one occasion and in tonic muscle spasm at another, usually, but exclusively, elicited upon volitional movements." The term was widely accepted and has been used by neurologists ever since, even though throughout time, the definition changes. In addition to alteration of muscle tone, Oppenheim also described twisted postures associated with the muscle spasms affecting limbs and trunk, bizarre walking with bending and twisting of the torso, rapid and sometimes rhythmic jerking movements, and progression of symptoms leading eventually to sustained fixed postural deformities.

In 1944, Ernst Herz, from analysis of cinematographic and electromyographic recordings, regarded slow sustained postures as the best definition for dystonia.

In 1962, Derek Denny-Brown expanded upon this definition and defined dystonia as a fixed or relatively fixed attitude. One problem with using only sustained postures for the definition of dystonia is that it allows all types of abnormal postures to be called dystonia, such as fixed postures that could develop from a stroke. Another problem is that these definitions do not take into account the other types of abnormal movements seen in the disorder.

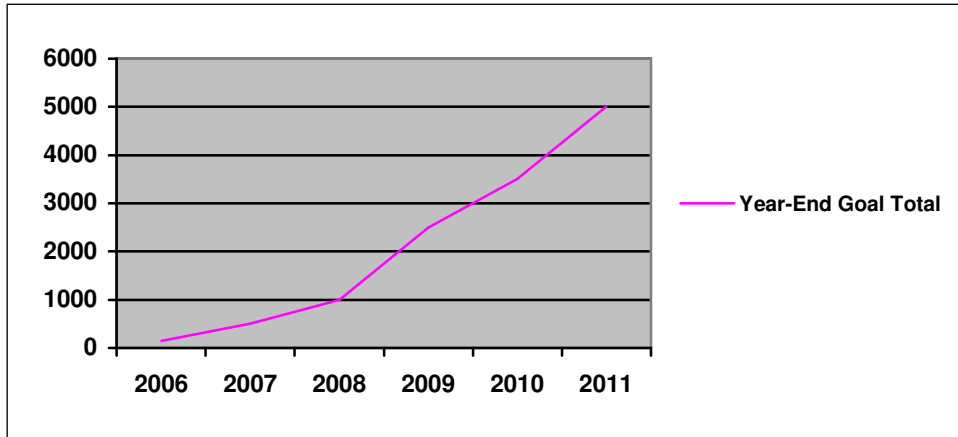
In February, 1984, a committee consisting of members of the Scientific Advisory Board of the Dystonia Medical Research Foundation met, deliberated, and developed the following definition: "dystonia is a syndrome of sustained muscle contractions, frequently causing twisting and repetitive movements, or abnormal postures." The committee consisted of Drs. André Barbeau, Donald B. Calne, Stanley Fahn, C. David Marsden, John H. Menkes, and G. Fred Wooten. This definition is still utilized.

This committee also proposed a classification scheme for all types of dystonia, recommending that there should be three classification schemes: by age at onset, by parts of body affected, and by etiology. With the advent of discovering different genetic types of dystonia, the etiologic classification was changed at the time of the 3rd International Dystonia Symposium in 1996. The main definition of dystonia will most likely remain the same, but the etiologic classification will change over time as new genetic forms are described.

Credits: Dystonia History taken from Dystonia Medical Research Foundation website

Financial Goals

After less than one year and only one fund raising, we have collected over \$140,000.00.



Our Goal: 5 million in 5 years

“We believe that finding a cure for DYT1 Dystonia is only a function of time and funding”

Dr. Michael Okun



Key Medical Advisors



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Michael S. Okun, MD, Co-Director of the Movement Disorders Center, neurologist and movement disorders expert, received his B.A. in History from Florida State University, and his M.D. from the University of Florida where he graduated with Honors. Dr. Okun went on to complete an internship at the University of Florida and a residency in Neurology. He then completed two fellowships at Emory University, one in movement disorders and a second in microelectrode recording and surgical treatments for movement disorders. He was recruited back to the University of Florida in 2002 to create the University of Florida Movement Disorders Center. The Center, which he co-directs, has over 20 interdisciplinary researchers in all areas of Parkinson's disease and movement disorders. The center is unique in that it provides interdisciplinary care for patients, as well as important bench and translational research.

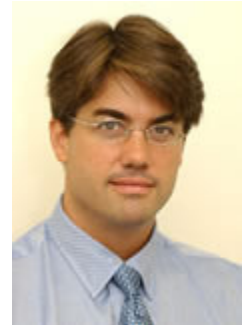
Dr. Okun is supported by grants from the National Institutes of Health and the Michael J. Fox Foundation for Parkinson's Disease Research. His main area of focus is on programmable brain implants for Parkinson's disease, tremor, dystonia, complex movement disorders, and behavioral disorders such as Obsessive Compulsive Disease. Dr. Okun, and the team at the University of Florida, also have two NIH projects exploring the cognitive, behavioral, and mood effects of brain stimulation.

Dr. Okun is also a faculty member in the Department of History at the University of Florida, and, in addition to founding and administrating the History of Medicine lecture series, he teaches an undergraduate/junior honors course on the History of Medicine. Additionally, he has recently published a book of prose and poetry about the medical school experience, Lessons from the Bedside.

Key Medical Advisors



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Dr. Foote is one of the few (if not the only) neurosurgeon in the world to do a movement disorders neurology fellowship (Emory) as well as a movement disorders neurosurgery fellowship (Grenoble, France). He is an engineer and a DBS surgeon and is interested in device development for Parkinson's disease and movement disorders.

Kelly Foote was born in Salt Lake City on May 17, 1966. He attended the University of Utah College of Engineering, from which he graduated cum laude in 1991. He graduated from the University of Utah College of Medicine in 1995. He performed a surgical internship at the University of Florida in 1996 and completed his neurosurgical residency in December, 2001. Dr. Foote completed his fellowship training in movement disorder surgery at the University of Grenoble and Emory University and joined the University of Florida neurosurgery faculty as an Assistant Professor in July, 2002.

Dr. Foote has received many honors and awards, including Phi Beta Kappa, Alpha Omega Alpha, the Congress of Neurological Surgeons' Resident Award, and the Chuck Shank Award (for excellence in neurosurgery). He has active research interests in computer assisted neurosurgery.

Special interests: Movement disorder surgery, stereotactic surgery, radiosurgery, brain tumors

Articles and Updates

Neurologist tapped to lead national Parkinson's group

By John Pastor

One of the directors of the University of Florida Movement Disorders Center has been named the medical director of the [National Parkinson Foundation](#).

[Michael Okun, M.D.](#), a neurologist in the UF College of Medicine, will represent the foundation in the medical and scientific communities and provide guidance regarding medical and scientific issues relating to Parkinson's disease, according to an announcement in February. The three-year appointment will not affect his position at UF.

"With the appointment of Dr. Okun, NPF has taken a huge step toward enhancing the amount and the level of service to the Parkinson community, including researchers and clinicians, as well as persons with Parkinson's disease and their care partners," said foundation Chairman Paul Orefice in a printed release.

"A crucial factor in our success against Parkinson's disease will be our ability to pool worldwide resources for research, clinical care and outreach," Okun said. "We want to take advantage of all of our opportunities for synergy, partnership and collaboration, particularly within the 40-plus international centers of excellence funded by NPF. We would like to aid the Parkinson community in coming together to develop better symptomatic treatments, improve diagnosis in rural areas, and deliver care to the underserved and to eradicate this disease through meaningful research."



Okun is co-director of UF's Movement Disorders Center along with [Kelly Foote, M.D.](#), an assistant professor of neurosurgery, and [Hubert Fernandez, M.D.](#), a neurologist and director of clinical trials for movement disorders. Together, they answer questions from Parkinson patients and family members on a Web-based "ask the expert" forum sponsored by the foundation.

"Dr. Okun is absolutely dedicated to finding new treatments and a cure for Parkinson's disease," said Dennis Steindler, Ph.D., executive director of UF's McKnight Brain Institute. "He's a great movement disorders clinician and he works with a great team. His work with the National Parkinson Foundation has been extremely positive for the Movement Disorders Center, the McKnight Brain Institute and the University of Florida."

Founded in 1957 and headquartered in Miami, the National Parkinson Foundation was created to serve those affected by Parkinson's disease and to support research aimed at curing the disease. "We at NPF know Dr. Okun well," said Nathan Slewett, NPF chairman emeritus. "We have funded Parkinson research that he is performing, and we have heard him speak on numerous occasions in various forums, always with great enthusiasm and a wealth of knowledge about the disease that we are all intent on eradicating."

Key Partners in our Pursuit of a Cure

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Key Movement Disorder Organizations

Michael J. Fox Foundation	http://www.michaeljfox.org
National Parkinson Foundation	http://www.parkinson.org
National Institutes of Health	http://www.nih.gov
Tyler's Hope for a Dystonia Cure.	http://www.tylershope.org
Huntington's Study Group	http://www.huntington-study-group.org
Movement Disorders Society	http://www.movementdisorders.org
International Essential Tremor Foundation	http://www.essentialtremor.org
Tremor ActionNetwork	http://www.tremoraction.org
Benign Essential Blepharospasm Research	http://www.blepharospasm.org
Myoclonus Research Foundation	http://www.myoclonus.com
RLS ResearchFoundation	http://www.rls.org
Society for PSP	http://www.psp.org
Care for Dystonia	http://www.care4dystonia.org

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