

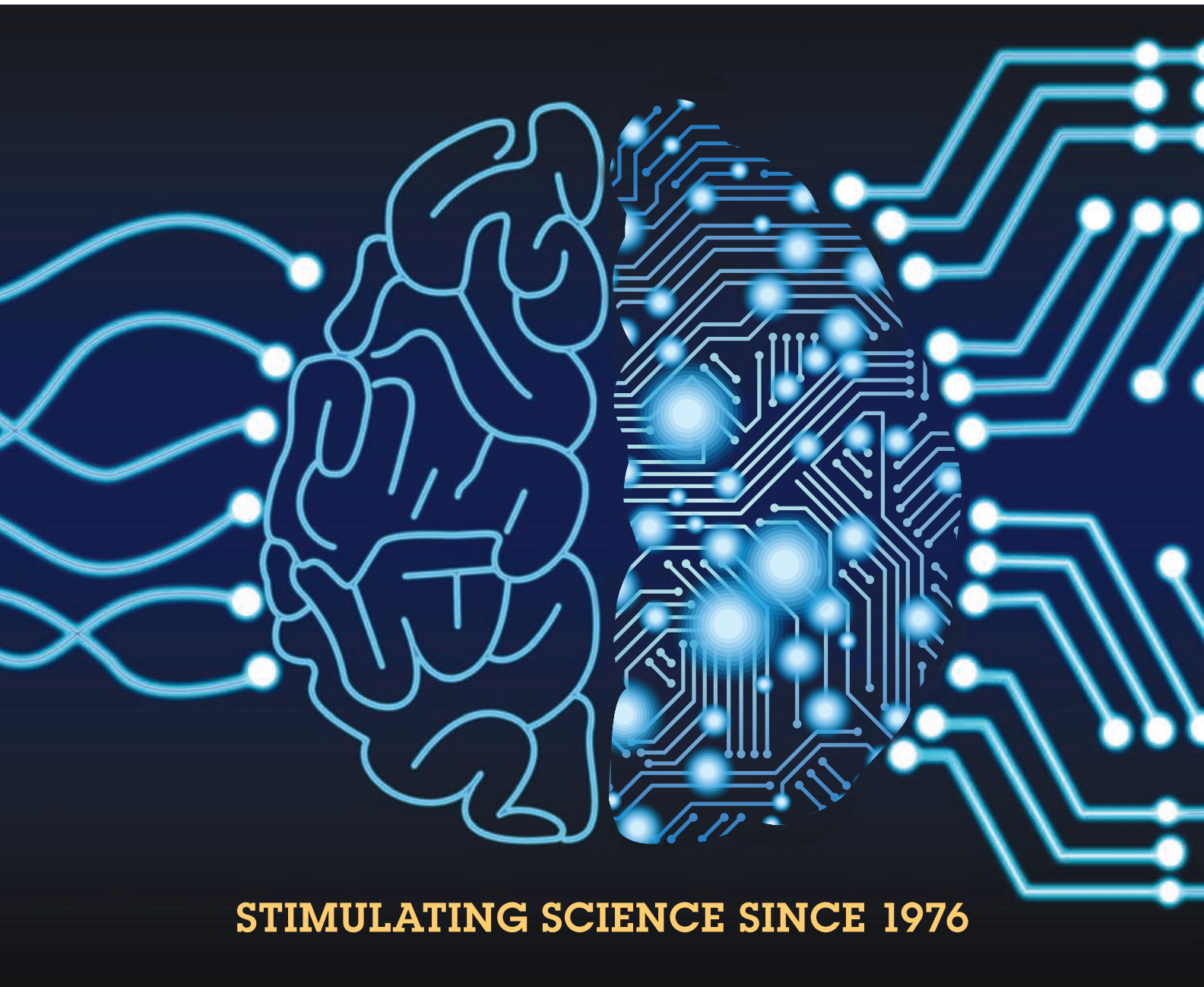


DYSTONIA  
MEDICAL  
RESEARCH  
FOUNDATION

# Dystonia Dialogue

NEWSLETTER OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

Spring 2020 | Volume 43 • No.1



**STIMULATING SCIENCE SINCE 1976**

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## What is Dystonia?

Dystonia is a disorder that affects the nervous system. Abnormal signaling from the brain causes muscles to contract excessively. This results in involuntary body movements and postures. Dystonia can affect a single body area or multiple muscle groups. There are numerous types of dystonia, and dozens of diseases and conditions may include dystonia as a symptom. For more information visit: [www.dystonia-foundation.org](http://www.dystonia-foundation.org)

## On the Cover:



DMRF science efforts ignite discovery while growing the dystonia field. Investigators funded by DMRF have produced an abundance of discoveries. Like pieces of a puzzle, these discoveries are fitting together to generate a detailed understanding of dystonia. The emerging picture is one of a complex brain disorder whose mysteries raise fundamental questions about how the nervous system produces and controls body movement.

See page 5 to read about DMRF's latest research fellowship awards to engage young investigators, and page 8 for an interview with Chief Scientific Advisor Jan Teller, MA, PhD.

The *Dystonia Dialogue* is the magazine of the Dystonia Medical Research Foundation (DMRF). It is published three times a year to provide information to individuals affected by dystonia, family members, and supporters of the DMRF.

The Dystonia Medical Research Foundation (DMRF) is a non-profit, 501c(3) organization founded in 1976. The mission is to advance research for more effective treatments and a cure, to promote awareness and education, and to support the well being of affected individuals and families.

The *Dystonia Dialogue* reports on developments in dystonia research and treatments but does not endorse or recommend any of the therapies discussed. Individuals are urged to consult a physician with questions and concerns about their symptoms and care.

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# Foundation Update



Art Kessler  
President

The Dystonia Medical Research Foundation (DMRF) is looking forward to a full and productive year in 2020, thanks to the generosity of supporters like you. 20/20 is the measure of clear vision. We approach the coming year with focus, clarity, and imagination. Our long-term vision is a world without dystonia. Every action the DMRF takes brings us closer to that day.

We will continue funding critical research grant and fellowship awards, representing outstanding new studies by leaders in the field and brilliant young scientists. See page 5 for our latest research fellowship award announcements. We are also addressing the need for additional movement disorder specialists by training young physicians through our clinical fellowship awards, to be announced this summer.



Janet L. Hieshetter  
Executive Director

DMRF is leading a global effort to address the most urgent research priorities and plot next directions at the Samuel Belzberg 6th International Dystonia Symposium (SBIDS6), June 4–6, in Dublin, Ireland. Hundreds of experts from around the world will attend. Nearly nine years have passed since the 5th International Dystonia Symposium in Barcelona, Spain. Since that time, understanding of dystonia has increased significantly. The symposium, designed specifically for clinicians and researchers, will provide an overview of important scientific advances in the field and stimulate discussion within and across disciplines. SBIDS6 is a joint effort of DMRF and European partners.

In the meantime, advocates are gathering on Capitol Hill March 24–25 for Dystonia Advocacy Day, organized by the Dystonia Advocacy Network, with staff support from DMRF. The event includes legislative training and meetings with Members of Congress to educate them about dystonia and the needs of the dystonia community. See page 12 for more information.

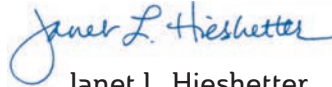
We will continue bringing you the latest information on dystonia from leading experts at educational meetings across the country. Stay tuned for dates and locations to be announced soon. There will be additional opportunities to connect with others in the dystonia community, including 12 family-friendly Dystonia Zoo Walks plus additional awareness events. More than 100 support group meetings will be held in the coming year, providing the invaluable opportunity for peer support.

What does a future without dystonia look like? We won't stop until we find out.

Thank you for your support. Your donations and participation make it possible for the Foundation to continue working toward a cure for every person and family affected by dystonia.



Art Kessler  
President



Janet L. Hieshetter  
Executive Director



**DMRF earned the highest ratings from Charity Navigator and Guidestar. Give with confidence, knowing your contributions are used effectively and responsibly.**



**Cheri Tannenbaum is the daughter of DMRF Founders Samuel and Frances Belzberg.**

# DMRF Founding Member Shares Philosophy for Living Well

Cheri Tannenbaum has long pushed back against society's tendency to applaud individuals with disabilities as inherently inspirational. She finds the "inspiration pedestal" strange and isolating.

"How would you like to be unable to speak intelligibly?

How would you enjoy having an awkward gait that makes you prone to falling and causes people to stare as you shuffle by? Living with dystonia is not something I would have chosen for myself," Cheri explained. "To tell the truth, what I really long for is normalcy. Wherever I go, people are always telling me that I am an inspiration. This makes me feel like a total fraud, because to my mind I'm just doing what I have to do to drag myself out of bed every morning and face another day."

Cheri, daughter of DMRF Founders Samuel and Frances Belzberg, has published a memoir, *Woman of Few Words: My Creative Journey with Dystonia*. She is sharing her philosophy on how to be a functioning, fulfilled individual despite daunting challenges.

"If others are inspired by me, I consider it an honor," she said. "I do hope this book heartens all those who have been tested by God through a disability. I fervently believe that, with faith, courage, and fortitude, you can live a fulfilling life full of happiness, blessings, and contentment."

Cheri was born and raised in Canada. She spent her teen years during the 1960s as a fun-loving, free spirit. While attending college in the United States, she began experiencing unexplained, debilitating symptoms. She became unable to speak or walk normally. After two years, she was diagnosed with dystonia. Soon after her diagnosis, in 1976, her parents founded the DMRF.

Cheri pursued a career in education, married, and has three children. When dystonia made it too difficult to continue teaching, she established *Designs By Cheri* and built a successful career as a jewelry and garment designer. She lives in Efrat, Israel with her husband of 45 years, Harvey.

DMRF is grateful to Cheri for sharing her profound story to increase awareness of dystonia and offer validation and understanding to others in the dystonia community. *Woman of Few Words: My Creative Journey with Dystonia* is available for purchase through Amazon and Gefen Publishing ([www.gefenpublishing.com](http://www.gefenpublishing.com)).



## CREATE A LEGACY OF CARING

While the DMRF cannot operate without the generous cash donations received every day, there are some gifts for which we are happy to patiently wait. You can make a commitment of support today that is fulfilled in the future. The DMRF Legacy Society was created to recognize those who have made a lifetime commitment to the mission to cure dystonia.

There are a number of planned giving options to build a legacy through the DMRF, either by joining our Legacy Society or making a specific gift. Planned giving options can include:

- ☒ Wills & Bequests
- ☒ Life Income Gifts:  
Charitable Trusts &  
Gift Annuities
- ☒ Qualified Retirement Plans
- ☒ Real Estate

For more information, please contact Director of Development Debbie Durrer at [ddurrer@dystonia-foundation.org](mailto:ddurrer@dystonia-foundation.org) or visit [www.dystonia-foundation.org/legacy](http://www.dystonia-foundation.org/legacy)



# Research Fellowship Awards Explore Dystonia Causes & Mechanisms

The DMRF announced the latest research fellowship awards to advance progress toward improved dystonia treatment options and ultimately a cure. The two-year awards are designed to help postdoctoral scientists establish careers in basic research focusing on dystonia.

Despite substantial progress made in understanding various aspects of dystonia, much remains to be learned about the causes and basic disease mechanisms. To accelerate development of novel approaches and translational research, the DMRF is supporting postdoctoral fellows who undertake studies to fundamentally change our understanding of the brain dysfunction and molecular mechanisms underlying dystonia.

Awardees are as follows:

## **BARBARA OLIVER MEMORIAL DYSTONIA RESEARCH AWARD**

### **Developmental Regulation of eIF2alpha Pathway Activity and its Significance for DYT1 Dystonia**

*Ashley Helseth, MD, PhD, Duke University (USA)*

*Mentor: Nicole Calakos, MD, PhD*

Existing dystonia treatments suppress symptoms without correcting the disease process. This project proposes to advance understanding of dystonia mechanisms and explore specific cellular pathways to target for treatment. Observations in multiple types of dystonia have implicated a specific cellular pathway in the brain as a central source of dysfunction. This pathway is involved in responding to cellular stressors and mediating plasticity responses in the brain. Dr. Helseth proposes to identify the brain regions, cell types, and developmental periods in which the pathway's activation is disrupted in dystonia mouse models and to test whether targeting the pathway through genetic manipulations will modulate the negative effects. This knowledge will advance understanding of the cellular mechanism of dystonia and provide key proof-of-principle experiments to determine whether targeting the pathway for treatment is beneficial.

## **DAVID M. RUDOLPH DYSTONIA RESEARCH FUND AWARD**

### **Impact of Microglia on Abnormal Synaptic Plasticity and Development of Dystonia in Transgenic DYT1 Mouse Models**

*Lisa Rauschenberger, MD, PhD,*

*University Hospital of Würzburg (Germany)*

*Mentor: Chi Wang Ip, MD, PhD*

Dystonia represents a group of movement disorders with diverse symptoms and numerous causative genes identified. Environmental factors such as peripheral trauma have been suggested as a possible trigger for dystonia in genetically predisposed individuals. A mutation in the DYT1/TOR1A gene is responsible for early onset torsion dystonia, among the most well-studied dystonia types. The pathophysiology of dystonia is largely unclear, but maladaptive synaptic plasticity is suspected to be one of the driving factors. This means movements that the brain has learned—blinking, writing, walking—get “re-learned” incorrectly, resulting in dystonia. The brain cannot easily un-learn the abnormal movements or postures once they are imprinted.

Dr. Rauschenberger hypothesizes that a disruption in how the nervous system integrates motor and sensory information causes maladaptive plasticity, which is in part supported by microglia, a group of highly-specialized cells. The researchers aim to analyze the pathophysiological concepts behind early onset torsion dystonia by creating and analyzing transgenic dystonia mouse models. The models will be highly valuable in future research, paving the way for treatment studies. Analyzing the role of microglia in dystonia is the first experiment of its kind and may lead to breakthrough insights into the origins of the disorder.

# Winning Dystonia Awareness Video Confronts Public Misunderstanding

Brian Smuda is tired of strangers hitting him up for drugs. “If I was in a wheelchair, nobody would be asking me for coke, Molly, crack, ecstasy, acid, or how drunk I am,” he said.

Despite a dramatically successful result from deep brain stimulation (DBS) to treat severe tardive dyskinesias (TD), Brian still finds that people sometimes wildly misread his body language, mistaking him for someone under the influence.

He knows he is not alone in feeling misunderstood. “You have to keep trucking because the people that are judging you are unaware, they don’t know your situation. They may comment and have their lurking eyes, but if you can somehow interact with them, you can educate them.”

In 2012, Brian began experiencing symptoms of TD, uncontrollable movements triggered by a medication prescribed for Tourette syndrome, which he has had since childhood. A slow creep of symptoms over six years escalated into constant, excruciating muscle contractions all over his body, relentlessly keeping him in constant movement. Brian stopped leaving his house. He slept only when too utterly exhausted to stay awake. Just five months after DBS in 2018, the uncontrollable movements had all but disappeared. Today, he runs his own business and returned to an active life: traveling, biking, skiing, kayaking, and anything else he wants to do.

He has become passionate about promoting greater public respect for the experiences of people with all types of disabilities. He also pushes for greater awareness of tardive dyskinesias and dystonia. “Those of us with this condition are handi-capable. Our bodies may not perform at top notch or appear ‘normal’—which is a word I despise—but those of us with these conditions would love to be as active and as ‘able’ as the majority of society,” he said. “We are all human and can’t let any label, ability or disability, religion or race, level of wealth, or age, divide you from me, or one human from another.”



**Brian Smuda is using his story to improve societal awareness of medication-induced movement disorders.**

Brian won DMRF’s “How I Explain Dystonia” awareness video contest last fall by submitting a video that explains his strategy for dealing with questions from strangers, including those mistakenly trying to score. Brian carries a stack of wallet cards he created to hand out as an awareness tool. The cards provide a brief description of TD, information about DBS, and plainly state, *I do not drink or do drugs. This is me.* He explained, “It’s almost like a get-out-of-jail-free card. They look at it. They read it. They’re like, whoa, that’s you? They understand more.”

Brian documents his experiences through online videos and his blog, *The Haircut Book*. To view the video he submitted to the DMRF’s awareness video contest, visit: <https://youtu.be/nO23lBcHe4k>

*DMRF offers free wallet-sized information cards as well as brochures and fact sheets. To order, visit [www.dystonia-foundation.org/brochures](http://www.dystonia-foundation.org/brochures)*

# People on the Move

The DMRF is grateful for the grassroots volunteers across the country working to improve dystonia awareness and fundraise in their communities. Every volunteer makes a difference!



In honor of his 50th birthday, **Lance Howitt** collected donations to support medical research that focuses on deep brain stimulation (DBS) for the treatment

of dystonia. DBS has been life-changing for his wife **Julie** and son **Isaac**. His campaign supported DMRF-USA and DMRF-Canada.



**David Firer** ran the Massapequa Turkey Trot, his very first 5K race, in November to raise dystonia awareness and research funds in honor of his grandfather **Joe Firer**. David was joined by his parents, **Julia and Michael Firer**, who also completed the race. The family hoped to raise \$750, and brought in \$2,600!

The Code Family hosted a multi-family tag sale in October to benefit the DMRF in honor of loved one **David Rudolph**. The original charity tag sale was held in 2004, spearheaded by David's then 13-year-old cousin Ethan as a community service project to raise funds for research and public awareness. The tag sale to benefit DMRF has continued many years since. Special thanks to the tag sale team: **Susan and Howard Code, Emily Code, Ethan and Kristin Code**, and **Grace Coward**.



**Dylan Sharp** and classmates at Oak Hill High School in West Virginia dedicated their Make a Difference school assignment to raising dystonia awareness and funds for research.

Their event, a raffle and bake sale, was covered by the local news. Dylan was diagnosed with dystonia at age nine. He and his mom **Wanda McCune** are devoted dystonia advocates.

## Educational Meetings Provide Access to Local Experts & Resources

The DMRF organized a series of educational meetings throughout the fall in cities across the country, supported by an educational grant from Allergan. Each half-day program featured a presentation from a movement disorder specialist, patient testimonial, and information about DMRF resources and programs with an emphasis on how individuals and families can join DMRF efforts to find a cure. Many thanks to all those who attended and our guest speakers.

**Location**  
Denver, CO  
Cincinnati, OH  
Providence, RI  
Detroit, MI  
Atlanta, GA  
Omaha, NE  
Orlando, FL

**Medical Speaker**  
Brian Berman, MD  
Abhi Mahajan, MD  
Umer Akbar, MD  
Neepa Patel, MD & Ellen Air, MD  
Laura Scorr, MD  
Diego Torres-Russotto, MD  
Ramon Rodriguez, MD

**Patient Speaker**  
Ray Skibitsky  
Marsha Brune  
Vivian Coutinho  
Kim Robinson  
Debbie Wilkinson  
Eric Tipler  
Kay Cooksey

*To be notified of upcoming educational meetings taking place near you, join DMRF's email list. Sign up at [www.dystonia-foundation.org/email](http://www.dystonia-foundation.org/email)*



# RESEARCH BITS

## Quick Questions with Dr. Jan Teller

The DMRF leads a global research effort, grounded in the belief that the best service the Foundation can provide the dystonia community is to work every day toward improved therapies and a cure. Jan Teller, MA, PhD, DMRF's Chief Scientific Advisor since 2006, recently commented on a handful of areas in which DMRF-funded investigators have made critical discoveries and progress.

**DD: How would you summarize DMRF's contributions to dystonia research over 40+ years?**

**JT:** Almost half a century ago, DMRF spearheaded dystonia research as we know it today. DMRF initiated, supported, stimulated, and catalyzed essential scientific and medical efforts that created the modern dystonia field and gradually engaged critical institutions and participants in the process. Passion and unwavering commitment on the part of the Board of Directors have driven the Foundation over the years to stay the course.

**DD: How have DMRF's efforts clarified how dystonia affects the brain?**

**JT:** Work by DMRF Scientific Director Emeritus Dr. Mahlon DeLong was groundbreaking and clearly pointed to the brain circuit abnormalities in dystonia. The basal ganglia, structures deep in the brain, have since been a focus of dystonia research for decades now. Scores of DMRF-funded investigators have collectively helped further clarify the underlying neurology of the dystonia brain. What is emerging is a very complex picture of dystonia as a disorder involving brain pathways where interactions among specific neurons impact movement. Central to

these problems are neurotransmitters, chemicals that direct body movement. These neurotransmitters are produced and influenced by processes at the microscopic cell level.

**DD: How did the DYT1/TOR1A gene discovery mark an important new era in dystonia research? Why are genetic studies important?**

**JT:** One of the major goals of modern medicine is to identify molecular causes of diseases. Genes are the windows into these molecular causes. Once gained, this knowledge helps in designing therapeutic strategies based on biological mechanisms. This is in contrast to current therapies, which suppress symptoms without correcting the underlying problem. Identifying the DYT1/TOR1A mutation as the cause of early onset isolated dystonia played such a role. It showed that this form of dystonia is firmly linked to a gene defect and cellular consequences of it. This discovery opened a new chapter in dystonia research and prompted more, ultimately also successful, studies in dystonia genetics. DMRF-funded investigators have since identified numerous genes including DYT6/THAP1, DYT25/GNAL, DYT16/PRKRA, and others.

**DD: Many investigations funded by DMRF have applied cutting edge techniques or technologies to learn about dystonia, often at critical times. How does the evolution of technology impact dystonia research progress?**

**JT:** Technology drives medical and scientific progress. New tools extend our capability to explore biological mechanisms of disease. Undoubtedly, numerous new technologies, often enhanced by novel computational methods, tremendously help in basic and clinical dystonia research. Especially, modern engineering and material science dramatically improve medical diagnosis and treatment that is available to neurosurgeons and neurologists in the treatment of dystonia. Neuroimaging and deep brain stimulation come to mind as examples—the technologies are rapidly changing.

**DD: What are we learning now that investigators are finding commonalities among different dystonia-causing genes?**

**JT:** Clinically speaking, we have multiple forms of dystonia with different causes and different symptoms, yet, we categorize them together as 'dystonias' because they all originate in the brain



and affect movement control in a very specific way. Even though we discover more and more causative genes for various dystonias, we believe that some basic mechanisms, from molecular and cellular to those involving brain structures and networks, are responsible for dystonia in general. We believe that understanding one form of a well-defined dystonia will help us understand other forms because of their ultimate functional overlap.

**DD:** Because science can be unpredictable, how important is it for DMRF research efforts to leave room to respond to new or unexpected opportunities?

**JT:** It is impossible to predict the future of dystonia research in the long run. We know that we have to continue what we started and push for more where knowledge gaps are evident. However, there is always something unknown or unpredictable that might be discovered serendipitously. There might be someone, somewhere, thinking differently, having an original, revolutionary idea or making an unexpected breakthrough observation. DMRF has always been ready for this, making quick assessments and seizing such opportunities because they may disappear and never come back. Our programs are deliberately open and customized to support bold ideas and unconventional, risky projects. Although always measured, these efforts are aimed at one goal: full understanding of dystonia to better treat, and possibly cure, all who suffer from it.

## Mom Honors Son & Promotes Awareness at TCS NYC Marathon



**Stephanie Sorgie supported DMRF in honor of six-year-old Johnny.**

"It is so, so hard to accept the fact I cannot make Johnny's cerebral palsy go away, or that it cannot be cured right now. It is who Johnny is, but no one wants to see their child struggle. Anything I can do to help this cause, I will."

Stephanie Sorgie honored her six-year-old son Johnny by representing Team DMRF at the 2019 TCS New York City

Marathon. Due to the brain injury associated with athetoid cerebral palsy, Johnny experiences persistent dystonia. "Johnny is so full of life," said Stephanie. "He loves people and is very social, bursting with personality, ambition, and determination."

Since 2013, Team DMRF at the TCS New York City Marathon has raised over \$170,000 in support of the mission to find a cure. Team members have included family and friends of individuals with dystonia, as well as runners affected by dystonia themselves.

"I will never forget this day, this run, and its meaning. It was a privilege," said Stephanie. "I am grateful the DMRF exists and allowed me to bring awareness to this community."

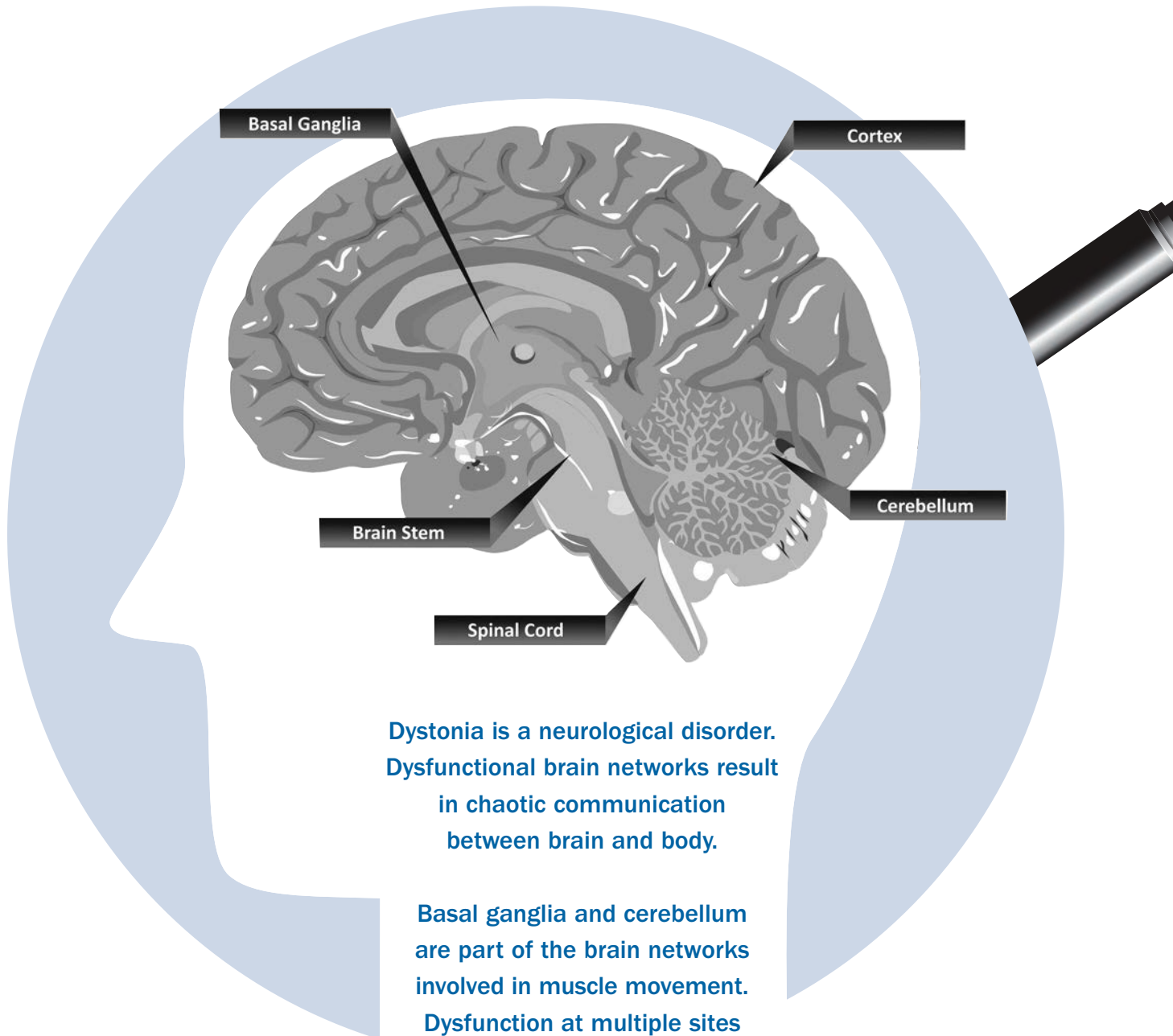
*Interested in running for DMRF? If you would like to fundraise at a local race, please send an email to [dystonia@dystonia-foundation.org](mailto:dystonia@dystonia-foundation.org) or call 800-377-3978. By lending your support, spirit, and legs to this cause, you will help the DMRF make strides toward better therapies and a cure.*

Athetoid cerebral palsy, also known as dyskinetic cerebral palsy, is a movement disorder that occurs in infancy, caused by damage to the developing brain. This type of cerebral palsy is characterized by abnormal, involuntary movements, which can often include dystonia.

# BODY OF EVIDENCE: Where Does Dystonia

Dystonia is often described in relation to the part of the body affected by symptoms. For example, cervical dystonia affects muscles along the cervical spine in the neck. Blepharospasm causes excessive, involuntary blinking and closure of the eyes. But what's going on deep inside the body to cause these symptoms?

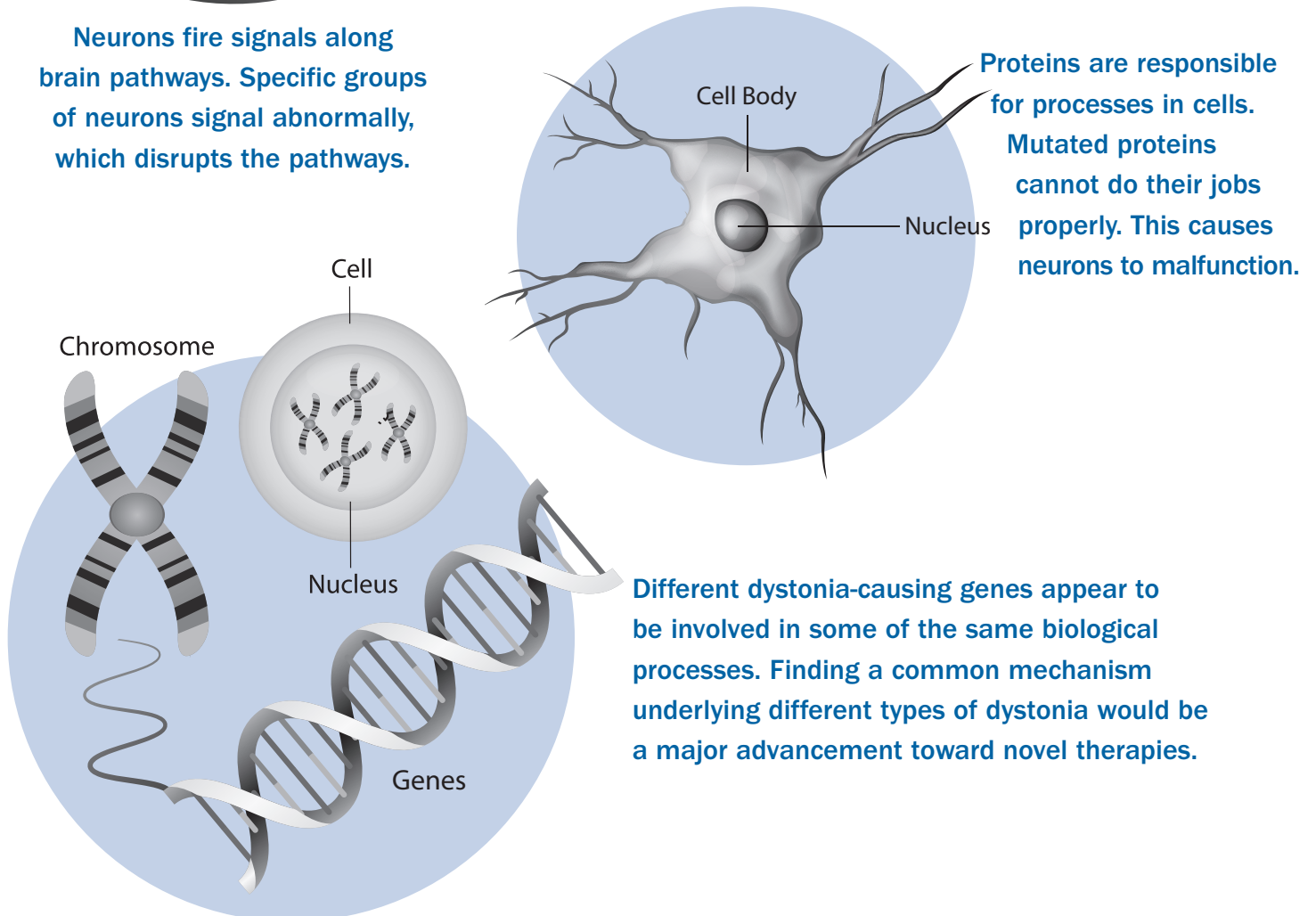
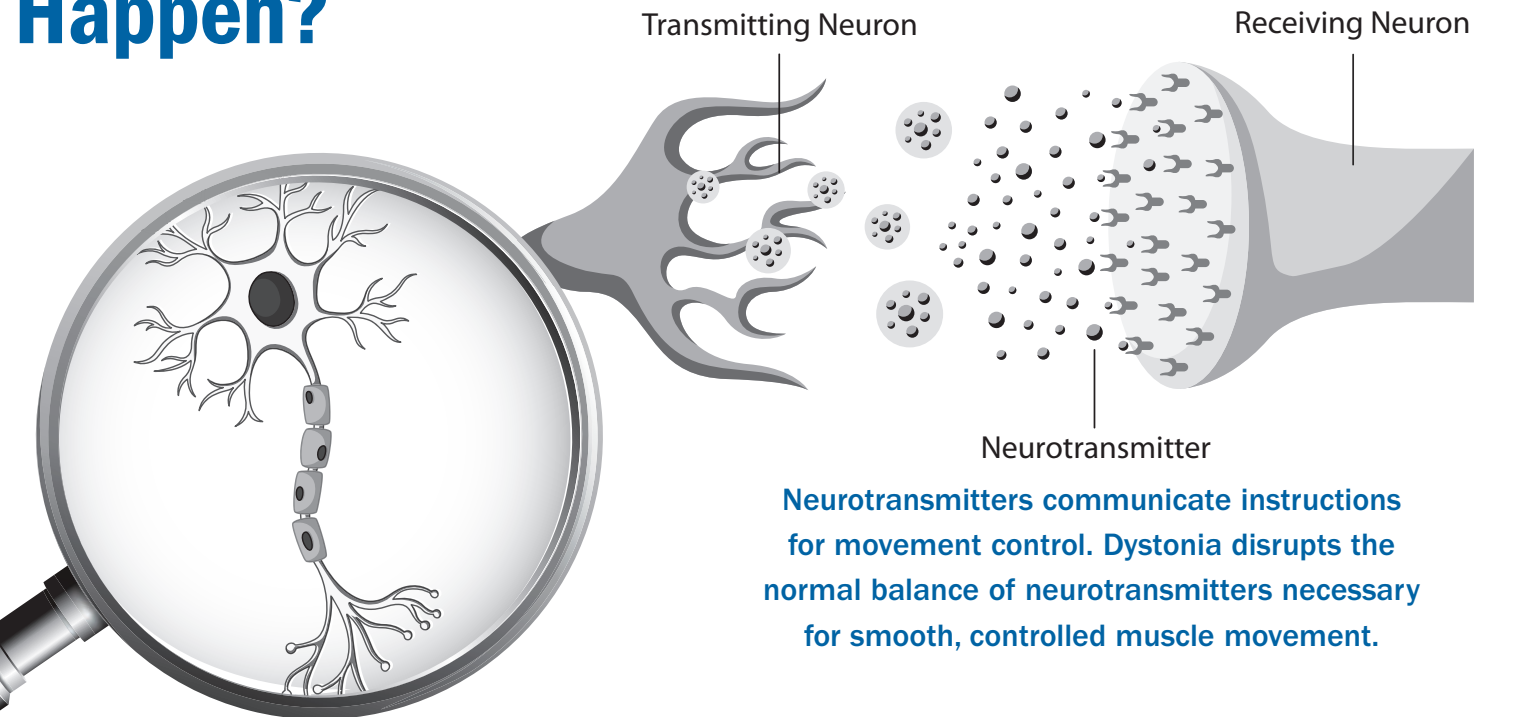
Here are a few examples of what investigators have identified as dystonia problem points.



Dystonia is a neurological disorder. Dysfunctional brain networks result in chaotic communication between brain and body.

Basal ganglia and cerebellum are part of the brain networks involved in muscle movement. Dysfunction at multiple sites along the networks can cause movement problems.

# Happen?



# Dystonia Advocates Head to Washington for Annual Hill Day

Dystonia advocates from across the country will receive legislative training and attend meetings in Congressional offices as part of Dystonia Advocacy Day, March 24–25, 2020 in Washington, DC. Dystonia Advocacy Day is organized by the Dystonia Advocacy Network (DAN), a grassroots organization that brings people together to speak out with a unified, powerful voice on legislative and public policy issues relevant to dystonia.



## Dystonia Advocacy Network

DMRF is proud to provide  
staff support for the DAN.

Benign Essential Blepharospasm  
Research Foundation (BEBRF)

Dystonia Medical Research  
Foundation (DMRF)

National Spasmodic  
Dysphonia Association (NSDA)

National Spasmodic  
Torticollis Association (NSTA)

The DAN continuously works to develop and advance a legislative agenda that raises awareness, educates policymakers, addresses patient care issues, and moves research forward. Dystonia Advocacy Day is held each spring on Capitol Hill. DMRF is proud to provide staff support for the DAN.

DMRF also supports the Douglas Kramer Young Advocate Awards, designed to engage young people in dystonia advocacy. Each year, recipients attend Dystonia Advocacy Day.

DAN advocates work year round to develop relationships with legislative leaders and enlist their help to address the challenges faced by those living with dystonia and their families.

### How You Can Help

By becoming a dystonia advocate, you can have a powerful effect on the laws and policies that affect your life and the lives of others in the dystonia community.

To get started:

- Visit [www.dystonia-advocacy.org/agenda](http://www.dystonia-advocacy.org/agenda) to get familiar with the most urgent issues facing the dystonia community.
- Sign up to receive DAN legislative alerts via email at: [www.dystonia-advocacy.org/contact](http://www.dystonia-advocacy.org/contact)
- When you receive a DAN legislative alert, respond promptly by calling or sending an email to your legislators. The DAN makes it easy. Every legislative alert includes simple instructions to take action.

*For more information on the DAN and becoming a dystonia advocate,  
visit [www.dystonia-foundation.org/advocacy](http://www.dystonia-foundation.org/advocacy) or contact the  
DMRF at [dystonia@dystonia-foundation.org](mailto:dystonia@dystonia-foundation.org) or 312-755-0198.*





## How Does Advocacy Impact Dystonia Research?

# \$17M

**Awarded to dystonia investigators by DOD**

# \$15M

**Annual amount of dystonia research funded at NIH**

# 100+

**Number of meetings dystonia advocates will have with Members of Congress this year**



Legislative advocacy can be a powerful catalyst to stimulate medical research. DAN advocates first convinced Congress to include dystonia on the list of diseases eligible for study through the Department of Defense's (DOD) Peer-Reviewed Medical Research Program in the FY 2010 Defense Appropriations Bill. DAN volunteer advocates have successfully kept dystonia in the research program every year since, resulting in \$17 million awarded to dystonia investigators. This is in addition to the approximately \$15 million awarded annually to dystonia investigators through the National Institutes of Health (NIH).

Numerous dystonia investigators previously funded by DMRP have successfully applied for NIH and DOD funding.

Interviews with dystonia investigators are available for viewing at [www.dystonia-foundation.org/get-involved/advocacy-network/](http://www.dystonia-foundation.org/get-involved/advocacy-network/)



**Volunteers gather on Capitol Hill every year to educate legislators about dystonia.**





# Naturally Curious

## *An Integrative Approach to Treating Dystonia*

“Even when we treat symptoms in dystonia, people are still sometimes left with bothersome symptoms, and they're also dealing with more than just the physical symptoms that we can see,” explained Danny Bega, MD, neurologist and movement disorders specialist at Northwestern Medicine in Chicago.



“A lot of patients with dystonia are dealing with non-physical, non-motor symptoms, whether it's anxiety or sleep problems or pain. They're trying fix all of their problems, not just the one problem, which makes sense.”



Living well with dystonia often requires a combination of treatment approaches. Available medical therapies such as oral medications, botulinum neurotoxin injections, and surgical interventions may be more effective for some people than others. In a study of 400 individuals with adult onset dystonia, researchers at University of Tennessee Health Science Center in Memphis found that 53% of patients reported using non-mainstream therapies, 90% reported receiving standard medical therapy, and 48% used both. Conversations about treatment options—both medical and non-mainstream—are constant at dystonia support group meetings and in online forums.

Integrative medicine is a blend of modern medical practices with non-mainstream approaches, often referred to as complementary or alternative therapies. These complementary therapies can include natural products (such as vitamins, herbs, and supplements), mind-body techniques (for example, tai chi, yoga, and relaxation practices), and alternative systems (for example, traditional Chinese or Indian medicine).

Dr. Bega often finds himself in conversation with patients about complementary therapies, which are among his research interests. “We don't want people to think of these modalities as alternatives to Western conventional medicine, but rather something that should be used along with conventional medicine,” he explained. “Systems that should be integrated together, combined, and considered as a whole.”

Sarah Roers is among those who use a combination of therapeutic approaches. She was diagnosed with cervical dystonia about a year and a half ago. “Acupuncture, chiropractor, massage, tens unit, yoga, and especially Pilates help me with my CD. I also get botulinum neurotoxin injections every three months,” she said. “I think it is especially important to find really good practitioners in each field.”

### Promises vs. Evidence

It can be a challenge for patients to find credible, accurate information on complementary therapies. The marketplace is full of largely unregulated products and services, available commercially and often promoted by slick advertising. How does a consumer tell the difference between a potentially safe and beneficial complementary therapy and a product or service that is being hyped irresponsibly? Or even fraudulently.

Jennifer Johnson was diagnosed with generalized dystonia in 2013. “I think that myself and those with dystonia are at very high risk of fraud and scams because dystonia often leaves us in pain and feeling hopeless about our treatment options,” she said. “We often have frustration with traditional medicine helping us, and therefore are vulnerable to scams and fraud that promise some help or relief.”

“Most of the things that are advertised, that sound too good to be true, are too good to be true,” said Dr. Bega, “and there’s a reason that doctors aren’t prescribing these things to all of their patients. It’s not because we want to withhold, it’s because these headlines are not accurate or they are overblown.”

He continued, “Decisions about treatment should be evidence-based, because there’s a lot of room for headlines to be misleading, for placebo results showing that something works, not because it actually works, but because there’s expectation of benefit. On the other hand, just because something doesn’t have evidence, that doesn’t necessarily mean it doesn’t work. It may not have been studied.”

Part of the growing interest in an integrative approach to medicine—not just in movement disorders but across disciplines—is to study complementary therapies with the same rigor that is applied to standard medical therapies, so physicians and patients have credible information by which to make treatment decisions.

A man with cervical dystonia who Dr. Bega was treating with botulinum neurotoxin reported that the injections helped quite a bit, but repeatedly mentioned that acupuncture was making the biggest difference for him. Dr. Bega shared that unfortunately there was a lack of good studies on acupuncture in dystonia. “When I’m specifically recommending an integrative strategy,” Dr. Bega explained, “I’m looking for the actual evidence, just like I would with any other recommendation I make. So, I thought, why don’t we do a study?” Dr. Bega led a study in a small group of cervical dystonia patients comparing results from acupuncture in conjunction with botulinum neurotoxin injections and botulinum neurotoxin alone. Every participant reported improvement from the added acupuncture, including reduced pain. Many continued seeking acupuncture after the study ended. However, the rating scale measurements Dr. Bega used to assess severity of dystonic movements and postures remained the same. “We didn’t see a meaningful difference objectively,” he said. “It didn’t answer all of our questions, but it suggests that it may be worth studying acupuncture in bigger groups, in larger detail, to see if it actually can help with pain because the patients I’ve seen have said it does. I still can’t prove that it works. I can say that in those 10 people it was safe and well tolerated and they enjoyed it.”

*Continued on page 16*

## Tips for Talking with Your Doctor

- Be open with your doctor about complementary therapies you are using or are interested in using.
- Tell your doctor about the specific symptom or issue you are seeking to address with complementary therapy.
- Tell your doctor how you learned about the product, service, or practice. If you learned about a potential therapy from an article, advertisement, or website, share the information with your doctor.
- Ask your doctor if the approach you are interested in poses any safety concerns.
- Ask your doctor if the approach you are interested in may interfere with existing treatments.

The National Center for Complementary & Integrative Health (NCCIH) is the federal government’s lead agency for scientific research on the diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine. Find information, including available data on various complementary therapies and tips on how to be an informed consumer, at [www.nccih.nih.gov](http://www.nccih.nih.gov)

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### Importance of Communication

Communication between patients and physicians is critical to crafting an individual treatment plan, especially when it comes to implementing complementary therapies. Physicians depend on candid feedback from patients regarding response to treatment and whether there are persisting symptoms that need to be addressed.

Dr. Bega stressed the importance of rapport among doctors and patients: “It says something about your relationship with your physician if you’re afraid to tell your physician about things that you have questions about or that you’re interested in. Maybe you need to think about the comfort of that relationship and whether that’s the right physician for you. Patients should and need to be bringing these things up. Number one, because there might be an interaction that your physician needs to know about.” This is especially the case for vitamins, supplements, and herbs (including CBD and other medical cannabis products) which can cause adverse effects or interfere with medications. Mind-body techniques are generally among the safest complementary therapies, especially those with a meditative focus, but there may be individuals for whom certain practices or exercise are not recommended.

By training, movement disorder specialists are experts in the medical therapies that are proven safe and beneficial in dystonia: oral medications, botulinum neurotoxins, and deep brain stimulation. As physicians, their priority is the health and safety of patients, and this may mean carefully considering additional options commensurate with their knowledge and comfort. Dr. Bega summarized: “Hopefully you find a physician who’s willing to work with you and guide you into where you might find safe ways to learn more about these integrated practices, realizing that not everything that’s natural is safe, so it is important to discuss these things with your doctor and to be very cautious about miracle cures and headlines.”

*Presentations by Danny Bega, MD on integrative therapies and medical cannabis are available for viewing at [www.dystonia-foundation.org/complementary-therapy/](http://www.dystonia-foundation.org/complementary-therapy/)*



### RED FLAGS

The US Food & Drug Administration (FDA) defines health fraud as the deceptive sale or advertising of products that claim to be effective against medical conditions or otherwise beneficial to health, but which have not been proven safe and effective for those purposes.

Be aware of these indications of potential fraud or false claims:

- Claims that a product is a quick, effective cure-all, or diagnostic tool, for a wide variety of ailments.
- Suggestions that a product, service, or technique can treat or cure diseases.
- Promotions using words such as ‘scientific breakthrough,’ ‘miraculous cure,’ ‘secret ingredient,’ and ‘ancient remedy.’
- Impressive-sounding terms that are meaningless nonsense, e.g. ‘cellular hyperstimulation point’ or ‘deficient interneurological synthesis.’
- Dramatic, unsubstantiated testimonials by consumers claiming amazing results.
- Limited availability and advance payment required.
- Promises of no-risk, money-back guarantees.
- Claims that the product is natural or non-toxic. This does not always mean safe.
- Claims that the medical community is not aware of a therapy, or is withholding a therapy from patients.

Professional-looking websites or apps are not always legit. Avoid websites or apps that fail to list a company’s name, physical location, phone number, or other contact information.

**For additional information from the FDA about protecting against health fraud, visit [www.fda.gov/ForConsumers/](http://www.fda.gov/ForConsumers/)**



# Dystonia & Sleep

Good sleep is among the top self-care activities that can boost your coping and physical wellness.



- Individuals with dystonia frequently experience insomnia and problems with sleep.
- Insomnia may occur prior to developing dystonia, or as a result of dystonia.
- Some sources suggest more than 60% of individuals with dystonia have fatigue or daytime sleepiness.
- Sleep problems may not automatically improve even if dystonia symptoms are well controlled.
- Fatigue and poor sleep quality are associated with the development or worsening of anxiety and depression.
- Sleep problems may require specific treatment. It can take time to find the combination of approaches that works best.
- Treatment for sleep difficulty may include learning new sleep habits, such building a routine around sleep, and getting in touch with your individual sleep cycles.
- Consuming alcohol, tobacco, caffeine, and certain medications (for example, to treat emphysema or COPD) may interfere with sleep.
- The presence of additional disorders, such as restless leg syndrome and sleep apnea, may prevent quality sleep.
- Caregivers are also at risk for problems with sleep.
- Sleeping well 75% of the time is within healthy range.

*Adapted from the webinar "Sleep & Movement Disorders" with Danette C. Taylor, DO, MS, FACN, presented by Dystonia Medical Research Foundation and available for viewing at [www.youtube.com/FacesofDystonia](http://www.youtube.com/FacesofDystonia)*

## Registering as a Brain Donor is Priceless Investment in Future Research



Registering in advance as a brain donor is a way to contribute to the field of dystonia research that benefits researchers working today and in the future.

The DMRF works in partnership with the Harvard Brain Tissue Resource Center (HBTRC) at McLean Hospital in Belmont, Massachusetts to assist people interested in registering as brain donors. The HBTRC maintains a private collection of brain tissue from individuals with all forms of dystonia. The DMRF also serves as the administrative center for the Dystonia Brain Collective, a partnership among several dystonia patient groups to facilitate brain donation for research purposes. Donated tissue is available to investigators for dystonia-related studies.

For more information or to begin the registration process, visit [www.dystonia-foundation.org/brain](http://www.dystonia-foundation.org/brain) or contact the DMRF at 800-377-3978 or [brainbank@dystonia-foundation.org](mailto:brainbank@dystonia-foundation.org).

### About Brain Donation

- Brain tissue samples are a rare and valuable resource for dystonia investigators.
- Certain types of research studies can only be done with post-mortem brain tissue samples. Brain donors are essential to future scientific progress.
- Brain donation does not alter the appearance of the donor or interfere with memorial services or remembrance practices.
- There is no cost to the donor or family.
- Brain donation does not violate the tenets of most religious or spiritual organizations.
- Donor information remains confidential. However donors must inform next of kin that they are registered to donate their brain.
- Donated brain tissue must arrive at the HBTRC within 24 hours of death. HBTRC staff are available 24 hours a day.
- Individuals can withdraw from the program at any time.
- By combining brain donation with financial support, you multiply your contribution to the progress of dystonia research.



## PERSONAL PROFILE

# Meet Hunter Webster

Hunter Webster resides in Virginia and is a senior vice president with a major hotel management company. He is a longtime supporter of DMRF and Co-Leader of the Greater Washington, DC Dystonia Support Group.

### How does dystonia affect you and how were you diagnosed?

I have oromandibular dystonia and writer's cramp in my right hand. In 2007, about a week after a tonsillectomy, I began to experience challenges with talking. My tongue will spasm and kind of curl, it pulls, to the left and when the tongue spasms it makes it more difficult to enunciate. The other issue was that writing was becoming very difficult. It was more challenging to hold the pen, and the fine motor skills of writing letters was becoming increasingly difficult. I couldn't figure out what the heck was going on. I went to a neurologist who said, I think you have dystonia but it's not my area of expertise. He recommended a movement disorder specialist. The movement disorder specialist was right to the point: You have dystonia, here's what the issue is, here's what's going on. That whole process took about a year. Once I had a diagnosis, I had the natural questions: how do you get rid of it? How do you deal with it? What's treatment like?

Once I learned that there's no cure, you go through a process: denial, depression, then acceptance. Each phase takes time to navigate. The denial piece is, I just can't believe there is not a cure. I can't believe this is it. You get angry. Your body is rebelling against you, and you don't know why. You're not happy, you have an attitude. That was the denial phase for me. Then you hit depression because you realize that this is what you have, you realize that you have a disability that is extremely visible, meaning that when I'm talking I can't hide it. Michael J. Fox said, when he contracted Parkinson's and dystonia, he said your vanity has to go out the window. You have to realize that people are looking at you, especially if they don't know you, they may be thinking what is wrong with you, what's up with your mouth? You go through this stage of why me, thinking your life is over, thinking about all the things you hoped to do. I've always been very career-

oriented and I've got a fairly senior job at my company, and now you think all the things I wanted to do professionally are not going to happen. It's difficult. At the same time, you know there are folks who have it way worse than I do. Then you get to the point where you accept where you are in life. You figure out how to live with it. That's where I am today.

### How have you coped?

I have what I have. I'm not going to let it dominate me or dictate who I am. Case in point, writing with my right hand became too difficult. Instead of getting Botox® shots all over my arm and trying to find a different position to hold the pen and all that, I taught myself to write left-handed. It took about four months to get there, but it was my way of figuring out what's next because I can't write anymore. Let me get my daughter's ABC books and begin practicing. That was my approach: is there another way to get there. You learn to listen to your body and you find ways to compensate.

One of the things that took a long time was getting Botox® shots in my tongue. Oromandibular dystonia is extremely tough to treat because when you give Botox® in the tongue, it's a highly sensitive area. There's a lot of calibration and time and effort that needs to happen before you can find the right amount—whether it's injections or whatever treatment that works best for you. I'm never going to be perfect. Never going to talk the way I was able to talk before. I talk for a living. I give talks to groups and large crowds all the time. So, how do I get to a point where I can talk, be understood, and this won't impact my ability to communicate. I've gotten to that point. I got involved early with the DC support group. I was at that early stage of denial, when you want to find answers to everything. I connected with the support group and it has been extremely helpful. When any kind of ailment happens to you, you initially think why me? I'm the only one

in the whole world going through this mess. And then you find that there are people just like you and people who are struggling and trying to get answers and there's a community there. There's satisfaction also in being able to help someone else who's trying to figure out what is going on.

Stress plays a major role in how dystonic you are that day. Sometimes it's stress at work, I'm traveling, I'm in and out of airports, and it's difficult. Eating foods is probably the next challenge because that chewing motion is impacted. I'm learning what foods are more difficult for me than others. I've had to learn how my body reacts to dystonia and what makes dystonia worse so I can avoid doing those things. I exercise every day. Working out is a good way for me to clear my head. I have my books that I read, things that quiet my mind because work keeps my mind running 88 million miles an hour. Finding the things that balance you: work out, watch TV, read, go for a run, knit, crochet, whatever relaxes you and quiets your mind. Those things really help you get through the day managing dystonia.

The hardest thing for me, personally, was working through that depression period. I thought, well, my career is over. No one's going to look at me the same way. Thank God for my family. They've been wonderful. My wife has been so supportive. I couldn't have gotten to this point without her. I've learned that you cannot go through something like this alone. You have to be willing to accept people, whether it's a support group or someone there to help you. Even at work, I had colleagues who helped me. One of the things that helped me deal with it is that I don't hide it. If I meet someone new or if I am talking to a group for the first time, I'll say hey guys I'm fighting through a disorder that causes challenges for me to enunciate sometimes so if there is anything I'm saying and it doesn't come out clearly, just ask me to repeat it. Every time I've done that it's worked out great, but it's a leap of faith because you're sharing something intensely personal and it's a sign of being vulnerable. I had to allow myself to do that and accept that it's okay to get help.

### Any advice for others with dystonia?

Your doctor has to be part of your team. You have to feel good and comfortable with whatever medical professional is there to support you. And if you don't feel good about them, find another one. We are the ones who are fighting and living with this ailment every day. Not the doctor. Care providers are part of your team. Your team is your family, your friends, your colleagues at work. Who's on your team? If you don't feel good about the people on your team then change your team because your team impacts the severity of your dystonia on a daily basis. You must surround yourself with influences that positively impact your dystonia, not negatively impact it.

### ADULT ONSET FOCAL DYSTONIA

Dystonia that begins in adulthood usually affects a specific part of the body. It typically occurs without additional neurological symptoms. The areas of the body most commonly affected are the neck, face, limbs, or larynx (voice box).

**Oromandibular dystonia**, sometimes called cranial dystonia, is characterized by forceful muscle contractions of the lower face, jaw, and/or tongue. The muscle contractions cause involuntary movements that interfere with opening and closing the mouth and may affect chewing and speech.

Dystonia that affects the face and lip muscles of musicians who play wind instruments is **embouchure dystonia**.

**Hand dystonia** is a focal dystonia characterized by excessive, involuntary muscle contractions in the fingers, hand, and/or forearm. Symptoms may occur only during a specific activity requiring use of the hand, such as playing an instrument or typing.

**Writer's cramp** is a dystonia that presents when a person is writing.

## Dystonia Dialogue

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