Dystonia Moves Me
Campaign Unites Community for Awareness

Mahlon DeLong Earns Lasker-DeBakey Clinical Medical Research Award

2014 Research Funding Announcements
Throughout September, dystonia-affected individuals and families used their stories to increase public awareness through the DMRF’s Dystonia Moves Me campaign. The challenge was to educate 30 new people about dystonia during the 30 days of September.

The DMRF was flooded with images and stories from volunteers detailing their dystonia awareness adventures. Tricia Bono of Connecticut, whose teenage daughter Sullivan has dystonia, partnered with her employer East River Energy to emblazon one of their fuel trucks with the Dystonia Moves Me emblem. The truck was unveiled in a ceremony that included representation from the Governor’s office and local press. (See page 14 for more with Sullivan Bono.)

Dystonia advocate and Lions fan Jason Dunn of Michigan took a moment to educate kicker Nate Freeze about dystonia during a pre-season practice. Dee Linde and Valentino Ramirez Lopez informed the server (in Spanish, no less) at Dee’s birthday dinner celebration at a restaurant in Oregon. Other volunteers educated their neighbors, hair stylists, store clerks, bowling league buddies, choir members, family members, and more.

Public figures including Congresswoman Jan Schakowsky, Georgia Governor Nathan Deal, guitar great Tommy Emmanuel, WGN anchor Mark Suppelsa, and MasterChef cast member Jaimee Vitolo lent their support. (See page 22 for an interview with Jaimee Vitolo.) Major League Baseball and the Chicago Cubs partnered with the DMRF to host “Dystonia Day at Wrigley Field” and promoted dystonia awareness via social media.

Figures are still being calculated to estimate the number of people reached by the campaign. Over 500 Dystonia Moves Me kits were requested, and each volunteer who requested a kit aimed to reach at least 30 people, which easily adds up to tens of thousands.

To view the stories featured during Dystonia Awareness Month, go to: www.dystonia-foundation.org/dystoniamovesme. If you are interested in participating in the campaign next year, let us know at awareness@dystonia-foundation.org
Inside This Issue

2 Dystonia Moves Me
Volunteers Make Awareness Personal

6 Mahlon DeLong Earns Lasker-DeBakey
Clinical Medical Research Award
Scientific Director is Recognized with Highly Prestigious
Prize for Research

7 Sam Belzberg Honored for Philanthropy
DMRF Co-Founder is Named Weizmann Leading Man

8 2014 Research Funding Announcements
DMRF-Funded Investigators Around the World are
Working Toward a Cure

19 Let’s Zoo This
One Family’s Dystance4Dystonia Walk Inspires
Events Across the Country

What is Dystonia?
Dystonia is a disorder that affects the nervous system. Improper
signaling from the brain causes muscles to contract and twist involuntarily.
Dystonia can affect a single body area or multiple muscle groups. There
are several forms of dystonia, and dozens of diseases and conditions
include dystonia as a significant symptom. For more information visit:
http://www.dystonia-foundation.org

On the Cover:
Dystonia-affected individuals and families used their
stories to increase public awareness through the DMRF’s
Dystonia Moves Me campaign. Volunteers helped put a
face to the word "dystonia" by sharing how the disorder
impacts their lives and the lives of their loved ones. The
challenge was to educate 30 new people about dystonia
during the 30 days of Dystonia Awareness Month in
September. The DMRF was flooded with images and stories from
volunteers detailing their dystonia awareness adventures. Read more on page 2.

For more examples of how the dystonia community commemorated Dystonia
Awareness Month, see page 12 for “People on the Move.”

Partial support of the Dystonia Dialogue is provided by educational grants from Allergan, Inc.
and Merz Pharmaceuticals.
Foundation Update

Dear Friends,

We repeat this often because it drives everything we do: The DMRF believes the best service we can provide the dystonia community is to work every day toward better therapies and a cure. We will do the work necessary to reach our goal, no matter where in the world we must go for answers. The leadership of the DMRF is reminded every day that the real measure of our research efforts is the impact on people’s lives. In the meantime until a cure is available, we remain committed to providing support and information to individuals and families impacted by all forms of dystonia. We are not going anywhere until our mission is met.

Since 1976 the DMRF has been a catalyst in the field, inspiring advancements through smart collaborations. The Foundation has funded over 500 investigator-initiated projects. We evolved from investing in a small number of clinical and research centers to partnering with scientists all over the world. Science activities include contracting with researchers on specific work, engaging the biotech industry, hosting scientific workshops, providing opportunities for the next generation of experts, and serving as an administrative center for the Dystonia Coalition, a groundbreaking research collaboration supported through the National Institutes of Health.

We are proud to have played an essential role in elevating the field of dystonia to the forefront of movement disorders and to have supported the most significant scientific advancements. The DMRF’s efforts have led to the discovery of dystonia genes, testing new treatments, uncovering the roles of specific proteins and molecules in the brain, new resources for researchers to accelerate progress, and identifying new drug targets.

The science is showing us that a cure is possible, and that our progress is limited only by the imaginations of the brightest minds in movement disorders and funding to invest. The DMRF is leaving no stone unturned, in any corner of the world, that may accelerate our efforts to provide relief for individuals and families living with dystonia. Thank you for continuing to make this work possible through your generous support and the confidence you have in the DMRF.

P.S. from Art Kessler: I need to acknowledge two special anniversaries. This year marks the 20th anniversary of Dr. Mahlon DeLong serving as Scientific Director and the 10th anniversary of Janet Hieshetter joining the DMRF as Executive Director. The expertise, insight, and leadership they have provided the Foundation are truly extraordinary. The DMRF would not be the strong organization it is today without their tireless work and compassionate dedication. On behalf of the Board of Directors, Medical & Scientific Advisory Council, staff, and community, I am appreciative of every minute they have invested in making life better for individuals impacted by dystonia and helping the DMRF pursue its mission for a cure.
DMRF Supporter Nominated for Eagle Rare Life Award

The DMRF is proud to announce that member Melissa Phelps has been nominated for an Eagle Rare Life award for her efforts to support families with dystonia. If she receives enough online votes, the DMRF may be eligible for a $50,000 donation.

Voting runs through January 6, 2015 and individuals can vote every 24 hours. Please help Melissa by voting online as often as you can and encouraging family and friends to do the same: http://eaglerarelife.com/content/melissa-phelps

Read about Melissa’s latest efforts to support the DMRF on page 12.

Review of Dystonia Models Highlights DMRF-Funded Studies

The DMRF provided partial support for studies critically reviewed in a comprehensive article on genetic animal models of dystonia. The paper was recently published in Progress in Neurobiology by Franziska Richter, DVM, PhD and Angelika Richter, MD of the Department of Veterinary Medicine, University of Leipzig, Germany.

Animal models allow researchers to conduct studies on dystonia mechanisms and test treatments before going to clinical trials. Many models of dystonia are currently available: rodents, zebrafish, roundworms, and others. Rodent models are especially critical for pathophysiological studies and for preclinical drug testing. Available models replicate certain features of human dystonia and are essential for developing urgently needed treatments. The review provides a critical assessment of progress in this area, describing many studies that were supported by the DMRF.

Citation: Genetic animal models of dystonia: Common features and diversities. Richter F; Richter A. Prog Neurobiol. 2014 Jul 15.

Mahlon DeLong Earns Lasker-DeBakey Clinical Medical Research Award

The DMRF congratulates Mahlon DeLong, MD on being named the 2014 Lasker-DeBakey Clinical Medical Research Award recipient. Dr. DeLong shares this award with Alim Louis Benabid, MD, PhD of Université Joseph Fourier in Grenoble, France for their roles in developing deep brain stimulation of the subthalamic nucleus. Dr. DeLong, William Timmie Professor of Neurology at Emory University School of Medicine, has served as Scientific Director of the DMRF since 1994. Earlier this year Dr. DeLong received the 2014 Breakthrough Award in Life Sciences.

DMRF President Art Kessler remarked, “Dr. DeLong is a remarkable investigator, clinician, and man—it’s wonderful to see him recognized with an honor as prestigious as the Lasker Award. Treatment for dystonia would not be what it is today without his contributions to the research. The DMRF is deeply grateful to Dr. DeLong for his ongoing leadership and guidance with our science program.”

The Lasker Awards recognize the contributions of scientists, clinicians, and public servants who have made major advances in the understanding, treatment, or prevention of human disease.

Recipients are selected by a distinguished international jury.
Sam Belzberg Honored for Philanthropy

DMRF Co-Founder and Chairman of the Board, Sam Belzberg will be honored by Weizmann Canada at a national gala on November 16. Weizmann Canada is celebrating its 50th anniversary by recognizing outstanding Canadian men who exemplify philanthropy, success, and the desire to make a difference.

Sam Belzberg is a highly successful real estate developer, noted philanthropist, and financier. He and wife Fran founded the DMRF in 1976 shortly after their daughter was diagnosed. For nearly 40 years Sam has remained steadfastly dedicated to the Foundation and the dystonia community.

“Sam’s vision and leadership transformed the opportunities available for individuals and families impacted by dystonia, and this is just one of his charitable pursuits,” explains DMRF President Art Kessler. “His respect for science and compassionate concern for other people are evident in so many of his impressive accomplishments. Sam is committed to making the world a better place and has taken every opportunity to do so. The DMRF congratulates him on being named a Weizmann Leading Man.”

In addition to his trailblazing work with dystonia, Sam founded Action Canada in 2001 which is an institution that partners with the Government of Canada to endow 20 fellowships a year for individuals who are interested in making a positive difference in Canada. His many awards include the Order of Canada in 1988 from the Governor General. In 1989 Simon Fraser University officially opened the Samuel and Frances Belzberg Library. In 1992 he received the Governor General of Canada Award, and in 2001 was promoted to Officer of the Order of Canada. The Order of BC was bestowed upon him in 2009. The Yeshiva University presented Sam with an Honorary Doctorate in 2010, and, in 2012, he was awarded the Queen Elizabeth II Diamond Jubilee 60th anniversary commemorative medal.

DAN Continues Push for DOD Dystonia Research Funding

Dystonia Advocacy Network (DAN) volunteers in key districts made summer visits to their Members of Congress to continue urging legislators to support the inclusion of dystonia in the Department of Defense (DOD) Congressionally-Directed Medical Research Program. Don and Paula Gates, Kayla Scire (representative for Senator Ed Markey), Diane Zaia, and Bruce Austin were one such group that met in Boston. Dystonia advocates are waiting for budget announcements for FY2015 to learn whether dystonia will continue to be included in the DOD Medical Research Program for another year.
2014 Research Projects

The DMRF regularly invites scientists from all over the world to apply for funding to support research on dystonia. The Foundation also negotiates research contracts to work on a specific project and address a knowledge gap in the field. This would not be possible without the continuous support of DMRF members and years of investment in basic science.

The DMRF is proud to share this year’s outstanding research investigations, some of which are continuing from previous years. Congratulations to this year’s award recipients, and infinite thanks to our supporters for making this research funding possible.

STANLEY FAHN AWARDS
The Stanley Fahn Award is presented to young investigators who conduct groundbreaking dystonia research with a focus on improved treatments. The DMRF established this award in honor of Stanley Fahn, MD who has made visionary and lasting contributions to the field of dystonia.

“Regulatory RNA Networks in Inherited Dystonia” – 3rd year
Pedro Gonzalez-Alegre, MD, University of Pennsylvania
Now in the third year, this project is advancing our understanding of the dystonia mechanism by closely examining neurons for the consequences of dystonia-causing mutations in the DYT1 and DYT6 genes. TorsinA, the protein associated with the DYT1 gene for early onset dystonia, is believed to have a role in monitoring other proteins in cells. THAP1, the protein associated with the DYT6 gene for early and late onset primary dystonias, is believed to influence how torsinA functions. One of the aims of Dr. Gonzalez-Alegre’s work is to characterize the precise disruptions in neurons linked to both mutated torsinA and THAP1.

“D2 Dopamine Receptor Signaling Alteration in a Mouse Model of DYT1 Dystonia: A Novel Rescue Approach” – 3rd year
Antonio Pisani, MD, PhD, Fondazione Santa Lucia, University of Rome
Dr. Pisani previously identified a link between a dystonia-causing gene mutation and changes in specific receptor proteins in the brain. His latest work further explores the effects of this mutation on neurotransmitters in the brain. Using electrophysiological techniques, he and his team have managed to pinpoint and characterize specific brain activity changes in rodent models of DYT1 dystonia.

RESEARCH GRANTS & CONTRACTS
Research grants are available in support of hypothesis-driven research at the genetic, molecular, cellular, systems, or behavioral levels that may lead to a better understanding of the pathophysiology or to new therapies for any or all forms of dystonia. Contracts provide the opportunity to direct research through the identification of specific, milestone-driven projects conducted by identified investigators and closely monitored by the DMRF’s Chief Scientific Officer.

“Development of Novel Reagents to Augment Cholinergic Signaling in Dystonia”
Randy Blakely, PhD, Craig Lindsley, PhD, J. Scott Daniels, PhD, Vanderbilt University Medical Center
Medications that impact the nervous system by reducing signals carried by the neurotransmitter acetylcholine have proven helpful in the treatment of dystonia. A team of researchers led by Dr. Randy Blakely is testing a group of molecules that could potentially be developed into drugs that reduce dystonia symptoms by affecting acetylcholine but with fewer side effects than existing drugs of this kind.

“A New Gene and a Novel Pathway Leading to Myoclonus-Dystonia”
Dennis Bulman, PhD, Children’s Hospital of Eastern Ontario Research Institute
This project builds upon Dr. Bulman’s discovery of a novel gene mutation that causes myoclonus-dystonia.
Since nothing is yet known about the function of this gene, which his called lncRNA, the study aims to clarify its role in regulating other genes including SGCE, the major gene associated with myoclonus-dystonia. The DMRF is collaborating with the Brown Family Foundation to support this project.

“Interactions of M4 and D1/Gαolf Signaling in Striatum: Implications for Treatment of Primary Dystonia”
Jeffrey Conn, PhD, Vanderbilt University Medical Center, Jürgen Wess, PhD, National Institutes of Health, Denis Hervé, PhD, French Institute of Health and Medical Research (INSERM)
Recent genetic studies reveal that mutations in the GNAL gene cause primary torsion dystonia. The protein that GNAL encodes, called Gαolf, is present in an area of the brain known to be involved in normal movement and motor control called the striatum. Gαolf is specifically involved in communication between neurons and carrying messages transmitted by the neurotransmitter dopamine. Furthermore, the neurotransmitter acetylcholine acts on specific neurotransmitter receptors to suppress Gαolf. A team of researchers led by Dr. Jeffrey Conn is examining how drugs that act on these receptors might restore the balance of dopamine and acetylcholine in the brain, and possibly provide a novel treatment approach.

“The Mechanism of Developmental Dysfunction in DYT6 Dystonia”
William Dauer, MD, University of Michigan
Dr. Dauer’s goal is to identify transcriptional targets of the THAP1 gene which when mutated has been found to cause DYT6 primary torsion dystonia. The biological pathways impacted by THAP1 will also be investigated to identify which key pathways may be disrupted by dystonia-causing mutations. The study explores the role of developmental changes that may play a role in initiating dystonia.

“Whole Exome Sequencing in Families with Myoclonus-Dystonia Syndrome without SGCE Mutations from Turkey and Germany”
Thomas Gasser, MD, University of Tübingen, Germany
This work aims to genetically analyze various families affected by myoclonus-dystonia in search of new genes associated with the disorder. These studies involve a collaboration among clinical research groups in Germany and Turkey as well as a genetics company based in Germany. The DMRF is collaborating with the Brown Family Foundation to support this project.

“Encoding of Interhemispheric Interactions in Mirror Dystonia: A Window to the Physiology of Dystonia” – 2nd year
Asha Kishore, MD, Sree Chitra Tirunal Institute for Medical Sciences and Technology, India
Dr. Kishore and team are using a technique called transcranial magnetic stimulation (TMS) to examine the phenomenon of “mirror dystonia” and gain a better understanding of the changes in brain activity associated with dystonia movements. Mirror dystonia occurs when, for example, an individual with writer’s cramp in his/her dominant hand attempts to write with the opposite hand, and yet dystonia symptoms persist in the resting hand.

“Structural Characterization of Torsin1A with its Interactors at the Nuclear Envelope” – 2nd year
Thomas Schwartz, PhD, Massachusetts Institute of Technology
Dr. Schwartz’s project seeks to learn more about the function of the dystonia protein torsinA by defining its three-dimensional structure. Within the atomic structure lie the clues to fully understand its function and the ability to influence this function by developing specific drugs.

“Cellular Screening Assay of RNAi in Dopaminergic Neurons Using Induced Pluripotent Stem Cells”
Chang-Hyun Song, DVM, PhD, Daegu Haany University, Republic of Korea
This project is part of the DMRF’s ongoing effort to identify new drug targets. A previous research contract with BioFocus funded by the DMRF led to the identification of a number of proteins and genes that potentially can rescue cells from defects caused by the DYT1 mutation. Dr. Song is attempting to create an assay to help select the most promising targets for drug discovery efforts.

Continued on page 10
Continued from page 9

**RESEARCH FELLOWSHIPS**

“Identification of Genetic Causes of Dystonia in a Homogeneous Population” – 2nd year  
Kristoffer Haugarvoll, PhD, Haukeland University Hospital, Norway  
Dr. Haugarvoll and team are investigating the relationship between cervical dystonia and essential tremor by studying families impacted by both. This study may also shed new light on the phenomenon of reduced penetrance whereby only a percentage of people who inherit most known dystonia-causing mutations ever develop symptoms.

“Targeted and Genome Wide Analyses of Factors that Modify TorsinAΔE” – 2nd year  
Lucia Zacchi, PhD, Fundacion Instituto Leloir, Argentina  
One approach for developing new dystonia therapies is to identify cellular processes or genetic factors that selectively affect the protein torsinA which is known to be abnormal in individuals with specific dystonias. Dr. Zacchi’s work will identify new genetic factors that affect normal and abnormal torsinA that could eventually lead to therapies designed to reduce the effects of abnormal torsinA while enhancing the effects of normal torsinA.

**CLINICAL TRAINING FELLOWSHIPS**

The DMRF is fostering the next generation of dystonia leaders by offering one-year fellowships to train neurologists in preparation for a clinical career in movement disorders with special focus on diagnosing and treating dystonia. Congratulations to this year’s fellows and their mentors:

Erin Deegan, MD  
Beth Israel Medical Center, New York  
Mentor: Rachel Saunders-Pullman, MD, MPH

Svetlana Miocinovic, MD, PhD  
University of California, San Francisco  
Mentor: Phil Starr, MD

Pichet Termsarasab, MD  
Mount Sinai School of Medicine, New York  
Mentor: Steven Frucht, MD

---

**Scientific Workshops as Engines for Progress**

As part of the ongoing effort to fund the best science in the most meaningful and efficient manner, the DMRF performed a thorough assessment of research programs last year. After recommendations from the Science Committee, the Board of Directors approved a new format for accepting research proposals designed to focus on the most promising and exciting topics in the field.

The DMRF will continue to host scientific workshops on the most pressing dystonia research issues, and one of the outcomes from each workshop will be a request for relevant research proposals. Requests for applications are posted on the DMRF website as released, along with information on guidelines and deadlines.

This new approach to identifying and supporting key research projects began in 2014 with a workshop on receptor neuropharmacology. Experts from around the world convened to discuss the development of medications that may one day benefit those living with dystonia.

The DMRF has a long history of bringing experts together from around the world to assess a specific aspect of dystonia research, discuss, brainstorm, and develop a strategy to advance understanding in that area. Important, often unexpected, new directions and collaborations result from every meeting.

The DMRF remains receptive to all new investigator-initiated ideas and approaches, which are accepted throughout the year.

For more information about DMRF science activities, visit www.dystonia-foundation.org/research.

Stay in Touch!  
Sign up for the DMRF’s monthly e-newsletter for the latest updates and announcements: www.dystonia-foundation.org/email
I work as a nurse practitioner in developmental-behavioral pediatrics. I am 28 years old and was diagnosed with generalized torsion dystonia at the age of 11. My dystonia spread rapidly, and by age 14 it affected the majority of muscles in my body. I had difficulty walking and completing many activities of daily living. Through the persistence of my parents, we searched to find a treatment to allow me to live my life to the fullest. At age 14, I had a baclofen pump implanted to deliver medications directly into my spinal column. The pump worked well; it enabled me to live life as a typical teenager. But, being a typical teenager, I often tested the limits of my pump. I swam competitively which caused my intrathecal catheter to break, requiring me to undergo various surgeries.

As I was completing my high school years, my dream was to attend college in Washington, DC (six hours away from my parents). During my freshman year, I had to take a semester leave as a result of another surgery to replace a broken intrathecal catheter, but I came back and completed my undergraduate degree in four years and graduated with honors. Also, the summer before my senior year in college, after much research, I elected to have deep brain stimulation surgery which involved implanting electrodes into my brain powered by a stimulator in my chest. Again, I responded well to this new treatment for dystonia. After completing my undergraduate work in nursing, I was accepted into a dual Masters degree program at Case Western Reserve: Masters of Science in Nursing and Masters in Bio-Ethics. I completed the dual program with honors in two years. My goal was to choose a profession where I can be an advocate for the patient.

As I look back over my life, and especially since being diagnosed with dystonia, my parents were my best advocates. They continually sought the latest and best treatments available and allowed me to live my dreams, not keeping me in a protected bubble. Throughout my journey with dystonia, perseverance has been an overriding theme. My parents continued to search for answers despite multiple misdiagnoses and dead ends. I was determined to not be defined by my dystonia and to fight to achieve my goals throughout each stage of my life.

As a medical professional, perseverance is an important attribute for both the individual diagnosed with dystonia and his/her support system. The patients and families who are likely to have the best outcomes become active participants in healthcare delivery, set realistic, measurable short and long-term goals, and advocate for different therapeutic options and research.

Since my diagnosis with dystonia, the DMRF provided my family with a source of support and a community we could go to with questions related to health insurance, research, and finding information. While I attended college in Washington DC, the DMRF and I teamed up on multiple occasions to lobby Capitol Hill on issues that were of importance to me and to the greater dystonia community. During that time, the DMRF provided me and my family with resources and references to meet with patient assistance organizations that ultimately helped me afford my treatments. The DMRF remains a tremendous source of support through continued advocacy, research, and providing families the opportunity to connect with and learn from one another.
Old and new friends took to the greens along the Mississippi River on August 11 to raise visibility of dystonia and funds for research toward a cure at the 6th Annual Minnesota Dystonia Golf Classic at a new course outside Minneapolis. Many thanks to longtime member Wayne Erickson for his efforts to organize the tournament, awards ceremony, dinner, and silent auction and congratulations on another extremely successful event. Guitarist, composter, and DMRF Board Member Billy McLaughlin performed at the evening reception.

A group of supporters led by Ben Humphrey, son of DMRF Board Member Donna Driscoll, hosted a no limit Texas Holdem Poker Tournament in Columbus, Minnesota on August 30. The event raised awareness and funds in support of research.

The Margolis family and supporters ran in honor of Eric Margolis at the Run the Goose 7K in Gloucester, Massachusetts over Labor Day weekend.

The Chicago Cubs joined with the DMRF to host Dystonia Day at Wrigley Field on September 23 to raise awareness of dystonia and funds for research.

The 2nd Annual Toss4Dystonia Cornhole Tournament took place September 20 in Rochester, New York. Jim and Cassie Metherell hosted the event in honor of their son Caleb who has dystonia. Over 80 teams and hundreds of spectators gathered in Frontier Field for this very original event in support of research toward a cure and greater awareness. Many thanks to Allergan for their sponsorship.

Melissa Phelps organized the 2nd Dystance4Dystonia Cincinnati Zoo Walk that took place on September 13 in honor of her daughters, Olivia and Madison. Over 700 people attended, breaking the record for most attendees at a DMRF zoo walk. Congratulations to Melissa and her supporters for this astounding accomplishment! Melissa also spearheaded efforts to include a football-themed "Kick Out Dystonia" parade float on Homecoming Weekend, which won first prize.

Greg and Alicia Troy hosted a Barn Dance fundraiser in Gilroy, California that included a silent auction, refreshments, and dancing.

This Labor Day, DMRF Board Member and longtime patient advocate Paula Schneider ran the 37th Annual Stratton Faxon New Haven Road Race with friends and family. Having struggled for many years with severe symptoms of dystonia, the opportunity to run for all those who cannot was especially meaningful for her.

Bob Mayer ran the Central Florida American Mud Race in September to raise funds for dystonia research in honor of his wife Laura who is affected by cervical dystonia and myoclonus.

The DMRF is deeply grateful for our grassroots supporters who work year round to promote dystonia awareness and fundraise for medical research. Volunteers were especially active during Dystonia Awareness Month in September, creating a groundswell of awareness across the country. In addition to the events and activities included below, volunteers secured articles in local news media, obtained awareness proclamations from local governments, and used social media to raise visibility of dystonia and enlist the support of public figures.
Many thanks to Karen Flanagan, her mother Jane Ann Flanagan, and aunt Gale Flanagan for hosting the 3rd Dystance4Dystonia Cleveland Zoo Walk on September 27. Learn more about the Flanagans on page 19.

Angie and Louis Amato and daughter Sydney raised funds toward the Dystance4Dystonia Cincinnati Zoo Walk by hosting a bake sale and enlisting the support of Walmart. They also recruited a team of 50 people to participate in the walk.

Miyoshi McMurry of Arizona partnered with healthcare providers and local businesses to host a “Dystonia Moves Me” awareness event on September 7. Her children David and Naomi made presentations at school.

Lynn Williams of Nevada challenged area restaurants and casinos including Winnemucca Inn and Winners to add dystonia awareness messages to their business marquis signs in a high traffic area during Dystonia Awareness Month. She also made presentations to community groups and secured articles in local news outlets.

The DMRF wishes to acknowledge the generous gifts received in memory of the following:

<table>
<thead>
<tr>
<th>Name</th>
<th>Person Represented</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laurel Anne Bradley</td>
<td>Donald Mears</td>
</tr>
<tr>
<td>Dewayne Cagle</td>
<td>Susan Owens</td>
</tr>
<tr>
<td>Edward Fleisher</td>
<td>Nettie Pancik</td>
</tr>
<tr>
<td>Michael Greenberg</td>
<td>Dennis Peavey</td>
</tr>
<tr>
<td>Edward Hahne</td>
<td>Ermegildo “Gene”</td>
</tr>
<tr>
<td>William H. Jackson, Jr.</td>
<td>Pomponio</td>
</tr>
<tr>
<td>Cookie Kaplan</td>
<td>Martha Restarsi</td>
</tr>
<tr>
<td>Rita Kaye</td>
<td>Cynthia Sanders</td>
</tr>
<tr>
<td>David Mattson</td>
<td>Matthew Simmons</td>
</tr>
<tr>
<td>Rudy McCann</td>
<td>Gerry Weinberg</td>
</tr>
</tbody>
</table>

The DMRF thanks Allergan, Merz, and US WorldMeds for their lead sponsorship of the 2014 Dystance4Dystonia Zoo Walks held in Cincinnati, Cleveland, Detroit, and Pittsburgh.

Sally Gill ran the Prairie State Marathon on October 11 in Independence Grove, Illinois in honor of friend Tom Seaman who has lived with dystonia for 13 years.

The Western Pennsylvania Dystonia Support Group hosted the first-ever Dystance4Dystonia Pittsburgh Zoo Walk on September 21, attracting over 400 attendees—tremendous for a first-time event. Many thanks to organizers Ed Cwalinski, Mary Rae Nee, and Shayla Anthony for bringing together the local dystonia community and raising urgently-needed funds for medical research.

The DMRF partnered with the Yale School of Medicine to present Advances in Dystonia, an educational meeting to provide accurate information on what dystonia is and how it can be treated on September 6 in Orange, Connecticut. DMRF Board Member Paula Schneider was integral to organizing the event. Speakers included Yale faculty Duarte G. Machado MD, Bahman Jabbari MD, Jason L. Gerrard MD, PhD, DMRF members Tricia and Sullivan Bono, and DMRF Executive Director Janet Hieshetter.

Martha Murphy and members of the Dystonia Support & Advocacy Group of San Diego County Mary Friedel, Diane Collins, and Jan Harrell partnered with a local business to collect donations and distribute educational materials. Also during awareness month, group members secured a number of media interviews and hosted a booth at Summer Healthcare Saturday health fair for the fourth year in a row.
CANDID KIDS Young People with Dystonia

13-Year-Old Awareness Volunteer Talks Dystonia with Hillary Clinton

Thirteen-year-old Sullivan Bono is one of hundreds of people across the country who joined the Dystonia Moves Me campaign. The campaign challenged volunteers to educate 30 people about dystonia during the 30 days of September. The very first person Sullivan reached was none other than Hillary Clinton, former United States Secretary of State, US Senator, and First Lady. Sullivan met Ms. Clinton at a book signing in Connecticut.

“It was an honor to meet her,” says Sullivan. “She was one of the very few people I have talked to who knew what dystonia was. She was a Senator, so she knows a lot, but I was shocked she knew.”

Ms. Clinton spent more time chatting with Sullivan than anyone else at the book signing. Sullivan added, “She gave me a high five when I told her I was an A student.”

Sullivan and her mother Tricia Bono have been working hard to promote dystonia awareness. They convinced the company Tricia works for, East River Energy, to place the “Dystonia Moves Me” logo on one of their fuel trucks. They distributed flyers at the New Haven Road Race, and have appeared on local TV and in newspapers.

“When you ask people if they have heard of dystonia, you hear some interesting things,” says Tricia. “Someone we met said it was a tropical island, and another person said it was something from Harry Potter!”

Sullivan explains why awareness is important to her: “I hope that by people understanding dystonia, they can better understand me and others with disabilities. And that they will donate to research for a cure. I want to spread awareness so that other people don’t go through what I had to go through.”
In order to fulfill the charitable project required for 13-year-old Jacob Stone to complete his Bar Mitzvah, he chose to support the DMRF by collecting donations and hosting a charity kick ball tournament. He did this in honor of his grandfather David Grossman who suddenly developed severe cervical dystonia five years ago.

“I wanted to choose something that touched my life,” explains Jacob when asked how he decided to support the DMRF. “Without medical research there wouldn’t be any help for people like my Grandpa who need it the most. I want dystonia to become a curable disease like polio.”

Jacob’s grandfather has had multiple surgeries and two stimulators placed in his brain to help control his symptoms. Although he still has some trouble with balance and his voice, he is doing much better since his most recent surgery.

Over 30 people, plus family members, gathered on August 17 to learn about dystonia, play kick ball, and support the DMRF. Jacob raised over $1,000. “It feels great,” he says. “My grandfather is very proud of me.”

“I went to the game and it was fun,” says Mr. Grossman. “Jacob is a pretty mature young man. We are certainly very proud of him. I’m proud of all my grandchildren.”

While Jacob is passionate about supporting research, he also wants to help improve dystonia awareness: “I wish people knew what it was like to have dystonia, so they wouldn’t stare as much. Just because you have dystonia that doesn’t mean you’re not an equal person in society. People won’t even look at homeless people, but they will stare at my Grandpa.”

The DMRF is extremely grateful to Jacob, his parents Amy and Jeff Stone, and grandparents David and Diane Grossman for their generous support.
One Size Does Not Fit All
Doctors Must Tailor Treatment for Dystonia

Like the sharp dresser who is skeptical of any garment that promises “One Size Fits All,” individuals diagnosed with dystonia should expect their treatment to be custom-fit just for them. Doctors and patients must work together to discover the combination of therapies that works best in each case. There are numerous treatment options, not all of which are appropriate for everyone. A therapy that benefits one patient may not necessarily work as well for another. Individuals may have additional medical conditions that influence treatment. As dystonia research continues to progress, treatment options will continue to expand.

The purpose of treatment is to improve quality of life with minimum side effects. This primarily involves lessening the physical symptoms of dystonia: the muscle spasms, involuntary movements, and abnormal postures. Treatment may also involve treating the secondary effects of dystonia: pain, changes in daily living, impact on mood and emotional health, and overall wellness.

This article provides an overview of available dystonia treatments and important considerations when seeking treatment for dystonia.

Working with the Right Medical Team
Generally speaking, the specialist with the expertise to diagnose and treat dystonia is a neurologist with training in movement disorders. Not all neurologists are movement disorder specialists. A movement disorder specialist is most likely to be informed of the latest research in dystonia and new developments in treatment. Otolaryngologists, speech pathologists, neuro-ophthalmologists, ophthalmologists, or other physicians with special training or experience may also treat focal dystonias that fall under their specialties.

The first step in seeking the best treatment for dystonia is to work with a movement disorder specialist to confirm diagnosis and create a treatment plan. Particularly if the dystonia is attributed to a specific cause—such as brain injury, exposure to certain medications, or another neurological or metabolic disorder—treatment must involve addressing these underlying issues. In many cases, treating dystonia is a multidisciplinary effort quarterbacked by a movement disorder neurologist but potentially involving additional healthcare professionals with specialized training.

Oral Medications
There are many oral medications that have been shown to improve dystonia. No single drug works for every individual, and several trials of medications may be necessary to determine which are most appropriate. Patients are typically started on low doses of medication that are gradually increased until the benefit is fully realized and/or side effects warrant a lower dose.

There are several categories of medications frequently used in the treatment of dystonia. These categories include:
- Anticholinergics: Artane (trihexyphenidyl), Cogentin (benztropine), or Parsitan (ethopropazine).
- Benzodiazepines: Valium (diazepam), Klonopin (clonazepam), and Ativan (lorazepam).
- Baclofen (Lioresal) can be taken orally and administered by a surgically implanted device that delivers the medication directly into the spinal column.
- Dopaminergic agents/dopamine-depleting agents: Sinemet (levodopa), Parlodel (bromocriptine), Clozaril (clozapine), Xenazine (tetrabenazine), or Serpalan (reserpine).

Therapeutic Botulinum Neurotoxin
Botulinum neurotoxin injections are the first line treatment for many focal dystonias including cervical dystonia/spasmodic torticollis, blepharospasm, spasmodic dysphonia/laryngeal dystonia, oromandibular dystonia,
and focal limb dystonia. The injections are given into the muscles, often with electromyography (EMG) guidance, and must be repeated every three to six months. Depending on the muscles injected, unwanted weakness can occur as a side effect of treatment and is usually temporary. Adjusting dose and injection sites can minimize side effects.

Although a medication with the word “toxin” in the name may seem unsettling, botulinum neurotoxin injections have decades of research and clinical experience demonstrating that they are a safe and effective medical therapy. Two types of botulinum neurotoxin are available for therapeutic purposes in the United States: type A and type B. There are four brands approved by the Food & Drug Administration for use in the United States: Botox (type A), Dysport (type A), Myobloc (type B), and Xeomin (type A).

**Deep Brain Stimulation**

Deep brain stimulation (DBS) is a surgical procedure used to treat a variety of neurological diseases, including dystonia and other movement disorders. A pulse generator—essentially a brain pacemaker—delivers electrical stimulation to the areas of the brain associated with dystonia. The stimulation is adjusted to achieve the best settings for each individual patient.

DBS is not appropriate for all individuals with dystonia, and not all patients who undergo the procedure will experience the same results. Ultimately, DBS may be considered if medications and other treatments have failed, and if the symptoms negatively affect quality of life to the extent that the surgical risks are justified. It may be appropriate to discuss DBS with the treating movement neurologist early in the course of treatment, before possible contractures and other skeletal deformities develop, because these secondary effects of dystonia limit the degree to which movement symptoms improve.

**Pallidotomy & Thalamotomy**

Not all that long ago, surgically creating permanent lesions in the brain was essentially the only available treatment for severe cases of generalized dystonia.

Since the development of deep brain stimulation (DBS), lesioning brain surgeries such as pallidotomy and thalamotomy are done less frequently. However, these approaches are not obsolete and may be options for some patients, especially given the vast advancements in brain imaging and targeting areas of the brain with greater precision.

**Peripheral Surgeries**

Before the development of botulinum neurotoxin injections, surgical techniques were developed to treat specific focal dystonias by targeting nerves and/or muscles. Peripheral surgical techniques were developed for blepharospasm, cervical dystonia, and spasmodic dysphonia/laryngeal dystonia. Because of the availability of botulinum neurotoxin and the emerging use of deep brain stimulation to treat focal dystonias such as cervical dystonia, peripheral surgeries are done less frequently but may be options for particular patients when recommended and performed by the appropriate medical and surgical team.

**Physical Therapy**

Physical therapy and its role in treating certain dystonias is a topic of increasing interest and investigation among movement disorder specialists because of the potential to improve function and quality of life. Advances in physical therapy combined with improved understanding of the nervous system are resulting in a greater range of options for dystonia patients. Physical therapy for dystonia is often combined with other medical treatments such as oral medications, botulinum neurotoxin injections, deep brain stimulation, and others. Physical therapy can help reduce dystonia symptoms and limit some of the long-term effects of dystonia on joints, bones, and muscles.

Continued on page 18
Occupational therapy can address issues such as mobility and energy conservation, and identify improvements to the home environment or adaptive equipment and technology to make life better.

**Complementary Techniques**

It is common for individuals with dystonia to seek out non-traditional therapies, generally in the form of natural products or mind and body techniques. Natural products may include vitamins or supplements; mind and body techniques represent a wide spectrum of approaches including acupuncture, stress reduction, massage, and ancient/folk therapeutic practices. These therapies are generally not well-studied and the data are mostly anecdotal. It is essential for patients to inform their doctor(s) about all non-traditional therapies they are considering. Different complementary approaches may work for different people, but in some cases these approaches are not safe or credible. It is also essential that patients seek trustworthy sources of information about dystonia and treatment, and to insist that healthcare practitioners provide evidence that supports the recommended treatment strategy.

**Overall Wellness**

A treatment plan for dystonia should attempt to reduce the dystonia symptoms while also attending to the unique needs of the individual as a whole person. Although dystonia is a movement disorder that impacts the physical body, it can also have an impact on emotional and psychological well-being. Not only can the onset of symptoms, disability, and pain be stressful, but there may be increased risk for depression and anxiety associated with some forms of dystonia. Evaluations for depression and anxiety can identify additional options to help improve quality of life. Likewise, addressing secondary effects of dystonia such as fatigue, pain, speech impairment, or swallowing difficulties may require special effort but result in improved general well-being.

**Future of Dystonia Treatment**

Improved treatments are a major focus of the DMRF’s research efforts, including partnering with drug discovery companies to discover new targets for medications, uncovering new treatment approaches, and funding investigators who are working to make existing treatments more effective.

Researchers around the world are working on:
- Making existing medications better tolerated with fewer side effects.
- Making therapies such as botulinum neurotoxins and deep brain stimulation work more effectively and for more people.
- Determining whether targeting slightly different areas of the brain in deep brain stimulation may benefit specific clusters of patients.
- Non-invasive brain stimulation therapies that do not require surgery.
- Rehabilitation techniques to retrain brain and body to move with fewer symptoms.
- Discovering or developing medications designed specifically to treat dystonia.
- Discovering or developing therapies that specifically target genetic dystonias.
- Looking at existing medications and treatments approved for other disorders that may be relevant to dystonia.

Meanwhile, advances in medical and research technology may reveal new treatment opportunities and unexpected discoveries can happen any time through basic research. Treatment for dystonia will continue to improve as the research progresses.

**Resources**

If you need assistance locating movement disorder centers in your region, or information on dystonia treatments, contact the DMRF at dystonia@dystonia-foundation.org or 800-377-3978.

Many thanks to Umer Akbar, MD for reviewing the content of this article. Dr. Akbar recently completed a DMRF Clinical Fellowship. He is Assistant Professor of Neurology at Alpert Medical School of Brown University and movement disorder specialist at Rhode Island Hospital.

The Dystonia Coalition provides dystonia treatment guidelines for doctors and medical professionals: [http://rarediseasesnetwork.epi.usf.edu/dystonia/](http://rarediseasesnetwork.epi.usf.edu/dystonia/)
Let’s Zoo This
One Family’s Dystance4Dystonia Zoo Walk Inspires Events Across the Country

“I never heard of dystonia until I was diagnosed with it in my left hand nineteen years ago,” explains Karen Flanagan. “Over the years my symptoms continued to develop, severely affecting my mobility and speech. Today, dystonia affects my whole body.”

Karen was ultimately diagnosed with rapid-onset dystonia parkinsonism, a rare movement disorder that is characterized by abrupt onset of dystonia with parkinsonian movements. Symptoms frequently affect the face, limbs, and speech. Individuals may experience anxiety, depression, and seizures. The age of onset ranges from four to 55 years.

Karen explains, “This affects every moment of my daily life, preventing me from living my life the way I thought I would. I have involuntary muscle movements along with the Parkinson’s symptoms often referred to as ‘freezing.’ I am unable to move when this occurs.”

Several years ago Karen decided she wanted to take action to support the DMRF and raise awareness. She enlisted the help of her mother Jane Ann Flanagan and aunt Gale Flanagan. Gale explains, “While brainstorming one evening, we recalled attending many successful fundraising events at the zoo. It was unanimous that this would be the perfect venue for a dystonia event.”

The first-ever Dystance4Dystonia Zoo Walk took place in Cleveland in 2012.

The Flanagans set out to bring awareness to their Ohio community, but little did they know that their event would be replicated across the country. Dystance4Dystonia Zoo Walks have become one of the DMRF’s most successful community programs. In 2014 alone, volunteers in Detroit, Cincinnati, and Pittsburgh followed the Flanagan’s model and promoted dystonia awareness and raised funds for research by partnering with local zoos. Zoos and botanical gardens are natural venues for fundraising events; they are generally centrally located, wheelchair-accessible, and built to accommodate crowds. The event is not a competition, which provides an alternative to charity 5K races.

Attendees are provided a fun day at the zoo in support of urgently-needed dystonia research.

On September 27, Karen and supporters held the 3rd Annual Dystance4Dystonia Cleveland Zoo Walk which attracted hundreds of people. Over the years, the family has raised a significant amount of funds in support of the DMRF’s work.

“We believe in the mission of the DMRF,” says Karen. “Awareness is so important. It allows others in the community to know we are out here and they don’t have to go through this alone. Supporting the needs of affected individuals and their families is essential and, most importantly, continued research is needed for treatments and discovering a cure.”

Gale echoes Karen’s passion: “It saddens me that the majority of the public is unaware of dystonia. When meeting someone with dystonia for the first time, people create their own assumptions which are usually incorrect. My hope is that the public learns that it is ok to ask questions. These individuals remain bright, witty, amazing people following the diagnosis—just look at my niece!”

Around the country, DMRF supporters like the Flanagans are organizing creative events in support of dystonia research toward a cure. These events attract individuals and families directly impacted by dystonia, and invite the public to help make a difference while having fun.

If you are interested in hosting a zoo walk or other fundraising event in support of the DMRF, please contact us at 312-755-0198 dystonia@dystonia-foundation.org.
The Wild, Wild Web of Medical Information

Choosing Online Sources Carefully

Dystonia is complex, and it can take some time to become knowledgeable about the disorder, treatment options, and ongoing research. Many people look to the internet as a primary source of information about dystonia and additional medical topics. The internet offers a wealth of information. Some of it is accurate and some of it is not. In some cases, information is wrong or even potentially hazardous.

Tammy Zarr, a member of the DMRF’s Cervical Dystonia Support Forum on Facebook shares how she vets sources online: “Big red flags to me are anything that touts a supposed ‘cure’ or ‘cause’ using unsubstantiated, non-peer-reviewed pseudoscience.”

Member of the 20/30 Dystonia Group online Sharon Parrett explains, “I try to find the backup science to go with the claim that is being made. Stay away from any site that offers a quick cure. I also check out the authors of articles to make sure they are credible and science based—and not just someone posting on the internet.”

When searching online, individuals must choose their sources carefully. A team of researchers recently published a study in *The Journal of the American Osteopathic Association* demonstrating that nine out of 10 pages on a popular website often consulted for medical information contain serious inaccuracies and/or lack credible sources to back up the content provided.

A professional-looking website does not always mean the information is accurate. A website may claim to have expertise on a particular subject but offer no evidence to demonstrate that expertise.

When assessing a website or social media page that offers information on dystonia, consider:

- Who is the author of the information? To whom does the website belong? *If this is not clear, the content may be suspect.*

ARTICLE AT A GLANCE

- There is a great deal of incorrect information about dystonia on the internet.
- Individuals must choose sources carefully when searching for medical information online.
- A professional-looking website does not always mean the content is accurate.
- Multiple source of information are needed to build a sound knowledge of dystonia.

- What makes the website/organization an authority on dystonia? *The credentials of those involved in providing the content should be clear and relevant.*

- Does the website have a bias? *Notice if a website is trying to persuade you to subscribe to a specific way of thinking or to purchase something. This may influence how information is presented.*

- Is the site updated regularly? *Information on dystonia changes rapidly, and information may quickly become out of date.*
Peer-Reviewed Research vs. Personal Testimonials

Research projects funded by the DMRF are peer-reviewed, meaning that an investigator who applies for funding must submit a proposal describing the work they plan to do and how they plan to do it. Members of the Medical & Scientific Advisory Council assess whether the proposals present sufficient grounds to justify their request for funding. Likewise, articles that are published in medical journals are peer-reviewed, meaning that the information is subject to analysis and criticism from other researchers before being shared with the public.

Compare this, for example, to a website that describes a new treatment using video testimonials. Online videos are not substitutes for methods and data subjected to review by research professionals and made public in medical journals. Anyone can post a video online, and there is no process to verify important details such as whether the patients in the videos are properly diagnosed, the credentials and experience of the practitioner administering the treatment, how the treatment was applied, and the circumstances under which the video was filmed and edited.

• Is the information well written?
  Credible resources should be easy to read and well-presented.

If a credible website or organization provides links to other sites and organizations, each of those sources must be assessed on their own merit. Just because a credible website links to another site does not guarantee the second website is a trustworthy source of information.

The DMRF encourages individuals to seek out multiple sources of information to build their knowledge of dystonia. Sound sources for information may include your doctor and medical team, professional organizations, websites, webinars, print and online publications, patient conferences, and support groups. If you have questions about medical information you find online, contact your doctor’s office. The DMRF website offers a wealth of information about dystonia and DMRF resources at www.dystonia-foundation.org.
How did your dystonia begin and how were you diagnosed?  
I’ve been soft spoken and have had restless legs and hand cramps for as long as I can remember—like early teenage years. It wasn’t until I was 23 that I realized I should not be feeling the way I do, and I needed an answer about my worsening symptoms. My joints always ached, my legs kicked all night, and it started to feel impossible to speak. I had my primary care physician refer me to a neurologist, and it may have been the best decision of my life. During my first visit, my neurologist right away had a feeling that I had dystonia. I had a few MRIs done, and then he sent me to a movement specialist. She walked in, took one look at me, and said you have dystonia. It was incredible that she knew right away, but she said my neck position gave it away. This was about a month ago, and I just had my first visit to an ear-nose-and-throat specialist. After a few tests, he confirmed I have spasmodic dysphonia.

How does dystonia affect you today?  
It mostly affects the left side of my body. I have spasms in all my extremities, my neck, and my face. Spasmodic dysphonia makes my voice break and sound breathy. I really have to strain for people to hear me. I can’t wait to get all of this under control and see what it’s like to not feel tense all the time. Hopefully no more breaking dishes or stabbing myself in the eye with my toothbrush.

Many congratulations on your MasterChef experience. How did the excitement and stress of that opportunity impact you physically?  
Thank you! It made my dystonia symptoms so much worse, but it was totally worth it! It made me much more aware of my condition. I had no idea I had dystonia while we were filming. All I knew was that I had some sort of neurological disorder. I kept notes of symptoms, and how the stress from the show affected them. A few months later I went back to the doctors and finally got my diagnosis.

Does dystonia interfere in the kitchen?  
Working in a kitchen makes my dystonia better. Baking pastries all day keeps me relaxed and being occupied helps me not focus on the pain. Kneading dough and working out my hands is like physical therapy too! There are a few things I can’t do, like very detailed decorating, but that’s okay.

What medical therapies have helped you the most?  
We are working on my treatment plan now. I tried a medication, but unfortunately it made me feel much worse. I also get my first botulinum toxin injections for my voice in two weeks! I’m very excited.

What has helped you cope?  
I really just try to stay positive. Just because I’m in pain and have dystonia doesn’t mean I can’t live a happy life. Doing the things I love and being with my family help me feel more at ease.

What would you like the public to understand about dystonia?  
I’m still learning about dystonia. I had never heard of it until a few months ago. I want people to be aware that this disorder is real and affects so many people. More awareness will hopefully bring more research and better treatments.

What has been the reaction to your public announcement that you are affected by dystonia?  
It has been amazing. I wasn’t sure what to expect, but everyone has been so supportive. I can’t believe how thankful people have been that I made a public announcement. I’m bringing so much awareness to dystonia! I’m helping people’s lives. I am on a mission now!
How did your symptoms begin and how were you diagnosed?
In 2004 I was back in radio, and that’s when I met dystonia. My work environment was pretty stressful—dysfunctional is probably a better word to describe it. I started feeling my neck pull to the left. I noticed myself getting irritable, feeling tired, having pain in my neck and getting headaches. I went to my primary care provider three times before he said ok something is up, and he sent me to a neurologist. By that time he could see I couldn’t keep my head straight. I was so lucky to have hit on a neurologist who knew exactly what dystonia was. No sooner had I sat in the chair in her office, she said you have dystonia. She said she could tell by the way I was walking and by the way my head is pulling. Obviously I was taken aback.

What medical treatments have helped you?
As the stress in my life continued to pile up, my head kept getting worse. I would be sitting in a meeting, in pain, and my head would be flipping and flopping. I’d have to get up and tell the group to finish without me. I couldn’t think straight. I couldn’t focus. None of the oral medications worked. I went through three or four different neurologists for botulinum toxin injections. I ended up having to quit my job. I was alone. I felt incompetent. I could not make good decisions. I started isolating and taking lots of pain medication. Ultimately I was invited to join a clinical trial for deep brain stimulation [DBS], which I jumped at. So on October 8, 2010 I had DBS in San Francisco. I didn’t know what was going to happen but I was ready to do anything to help myself get better. After the DBS, the honeymoon period was great for about a month. Ironically, before the programming set it, I got addicted to pain pills and I was drinking a lot. I lost my brother to pancreatic cancer, then my father six months later. I decided to go to rehab to get off the pain meds in 2011, and it worked really well for me. I have not used pain meds since.

What helps you cope?
After 10 years of dealing with this, I feel like I’m coming out the other side—finally. Many people say they can’t tell anything is wrong with me now. My family and friends are supportive. I have an interest in life again. I feel really good after I swim and do physical therapy exercises in water. I get in the pool five times a week. I stretch, meditate, and swim with a mask and snorkel so I can really stretch and move my head and body. When I float on my back my dystonia just absolutely goes away. Water is my happy place.

Talk about your involvement with local dystonia support groups.
Support groups are very important. We listen to each other. We’re very compassionate with each other. It’s really nice to know you’re not alone. Dystonia is a very confusing disorder. The public doesn’t understand. Your family doesn’t understand—especially how it affects you not just physically but mentally. Dystonia really messes with your head. You start losing your sense of well being, value, and what you contribute to society. You begin to doubt yourself: can you really work, can you perform, can you be a normal person?

Any guidance for people who are struggling?
What can I say to people other than hang in there. You have to live it. You have to own it. It’s not going to go away. Just do the best you can every day and know there are others out there who care and want to support you. It takes time. It takes patience. There is a lot of emotional and physical pain involved in this. Do the best you can because if you work at it you can come through it and have a quality of life again.
UPCOMING EVENTS
Join us at the following DMRF events:

November 16, 2014
Washington, DC Support Group
Dystonia Conference
Silver Spring, MD

November 18, 2014
Dystonia Educational Meeting
Philadelphia, PA

December 19, 2014
11th Annual Help Find a Cure 4 Dystonia Benefit
Hazleton, PA

April 14–15, 2015
Dystonia Advocacy Day
Washington, DC

See www.dystonia-foundation.org for additional events as dates are confirmed.