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Genetic Counseling & Dystonia

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On the Cover:
From “Octymoron” by Josh Anderson, an illustrator and draftsman who developed cervical dystonia in 2000. The illustration is a play on words between octopuses and oxymoron, relating to the animal’s solitary nature contradicted by an exercise in repetition. This work is part of a series called Microcosms.

See page 14 for an interview with Josh and additional examples of his work.
Dear Friends,

Jonas Salk, the famous medical researcher who developed the first effective polio vaccine, famously said: “The reward for work well done is the opportunity to do more.”

The work of the DMRF is more important than ever, because there is more than ever to do. Curing dystonia is an ambitious goal, but we know we can get there.

Research continues to provide important advancements that inspire ongoing studies and new directions to pursue. This issue of the Dystonia Dialogue includes brief updates on page 10 describing remarkable new findings on the role of the cerebellum in dystonia and the development of a brilliant new model that clarifies the complex neurological causes for blepharospasm, a debilitating focal dystonia of the eyelid and brow muscles. Furthermore, see page 12 for summaries of the exciting new research projects the DMRF is funding this year, thanks to your support.

When government leaders shape healthcare-related policies, it is critical that the interests and needs of the dystonia community be included in the debate. As a member and administrative center for the Dystonia Advocacy Network, the DMRF continues to keep a vigilant watch on emerging policy and take action when needed. Nearly 100 advocates convened on Capitol Hill for Dystonia Advocacy Day, March 20–21.

Individuals with dystonia continue to report difficulty finding physicians trained in movement disorders. Or they may wait months before an appointment opening. The DMRF is responding to the urgent need for additional movement disorder specialists by offering clinical fellowships to train outstanding physicians. See page 8 to read about this program.

Every day we hear from individuals and families in need of information, guidance, and support. Our support group leaders and online group moderators provide an open hand to the newly diagnosed, those who may be struggling, and those eager to participate in awareness, fundraising for research, and supporting others.

Your support of the DMRF allows us to do more. Your generous contributions bring us closer to the day when a cure is found and our work is complete. Until that time, we will not stop pursuing every opportunity to advance research, promote awareness, and provide support resources to affected individuals and families.

Thank you for being a part of the DMRF.

Sincerely,

Art Kessler
President

Janet L. Hieshetter
Executive Director
UNSTOPPABLE!

Ben Beach Runs 50th Boston Marathon despite Dystonia

On April 17 Ben Beach of Bethesda, Maryland, crossed the finish line at the Boston Marathon for the 50th consecutive year. That is not a typo: fifty as in 5–0. Ben retains the record for the most consecutive Boston Marathon races. He has competed 15 times since developing focal leg dystonia, which challenges his gait.

“The race turned out better than I could have imagined. I am relieved!” said Ben following the race. “I had a lot of opportunities to tell people about dystonia, so that was very satisfying.” In this and previous years, Ben’s story has been covered extensively in major news outlets including The Washington Post and Associated Press, advancing dystonia awareness nationally and internationally. Ben’s accomplishment was recognized by Runners World as one of “The Best Moments of the 2017 Boston Marathon.”

Ben developed dystonia in his left leg in 2002. It took four years of doctor visits before he was diagnosed, and he then began treatment at the National Institutes of Health (NIH). Treatment with quarterly therapeutic botulinum neurotoxin injections has preserved his ability to walk and run, albeit with a limp.

“Ben’s accomplishment is remarkable for any human being, let alone someone with the added challenge of dystonia,” says Janet Hieshetter, DMRF Executive Director. “He is truly an inspiration to all of us at the DMRF and in the dystonia community.”

“When dystonia entered my life 15 years ago, I assumed my running career was over,” says Ben. “I’m grateful to the people at NIH and everyone else who’s helped me keep going. I’ve also learned how adaptable the human body is.”

DMRF supporter Ben Beach developed focal leg dystonia 15 years ago.
Go, Ben, Go!

In advance of the Boston Marathon, runners who support the DMRF through the Dystance4Dystonia program sent Ben their well wishes and encouragement. Here are a few examples of their messages.

“On behalf of the DMRF Board of Directors and leadership, you have our utmost admiration and respect for conquering 50 Boston Marathons. The fortitude this requires is astounding. As someone who has tried to live beyond the limitations dystonia imposes and to always be grateful for what I have, I personally offer my most sincere appreciation for what it must have taken for you to arrive at this moment. Cheers and congratulations! Have a great race.”
~Art Kessler, President, DMRF

“Ben, wishing you all the best running the Boston Marathon! Always remember your mind is stronger than you think and you are running for all the people that never will have the opportunity to do this race! We are all rooting for you!”
~Carrie Siu Butt, Dystance4Dystonia Runner and DMRF Supporter

“I am inspired by learning how patients who carry the burden of living with dystonia every day face the challenges caused by the disease. Ben, I am blown away by your story! You took on dystonia head on and did not let it stop you from achieving an unbelievable milestone! As someone who has finished ‘just’ two marathons, I take my hat off. I also commend you for using your story to help bring greater public awareness to dystonia. This disease changes lives, but clearly has not defined yours. I will share your story with my patents and colleagues—and fellow runners.”
~Pedro Gonzalez-Alegre, MD, Associate Professor, Department of Neurology, Division of Movement Disorders, University of Pennsylvania

“Ben—you have everyone in the dystonia community rooting for you and cheering you on. Thank you for demonstrating that dystonia does not define or decide what is possible for us. All of us must chart our own path, find our own way, and you are among our most inspiring trailblazers. Thank you and enjoy the run as best you can.”
~Tim Landis, Dystance4Dystonia Runner and DMRF Supporter

Contribute to Research by Registering as a Brain Donor

The DMRF works in partnership with the Harvard Brain Tissue Resource Center (HBTRC) at McLean Hospital in Belmont, Massachusetts to assist people interested in supporting research by 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 encourage and facilitate brain donation. Donated tissue is available to researchers for dystonia-related studies.

For more information on brain donation or to begin the registration process, visit dystonia-foundation.org/brain or contact the DMRF at 800-377-3978 or brainbank@dystonia-foundation.org.
You can help promote dystonia awareness and reach the undiagnosed by joining *Dystonia Moves Me*, the DMRF’s annual awareness campaign. Dystonia Moves Me gives volunteers tools to promote dystonia awareness locally and in social media.

Awareness efforts in 2017 will focus on reaching individuals who may be living with dystonia symptoms but not yet diagnosed. The DMRF is calling on volunteers to ask their neighborhood healthcare offices and businesses to provide dystonia awareness materials in their waiting rooms during Dystonia Awareness Month (September). The DMRF has created special displays that make it easy to outfit a waiting room with information about dystonia.

Volunteers are encouraged to identify healthcare practices where individuals may be seeking help for undiagnosed dystonia symptoms. In addition to movement disorder neurologists, volunteers are encouraged to work with local general neurologists, child neurologists, physical therapists, occupational therapists, chiropractors, ophthalmologists, speech pathologists, and dentists. In addition to helping identify new dystonia patients, this effort simultaneously helps healthcare professionals in fields outside of movement disorders become aware of dystonia and DMRF resources for patients.

Every volunteer who participates in the campaign and sends the DMRF a photo or video of their awareness efforts will be entered into a random drawing for a $100 American Express gift card.

To get started, order your free Dystonia Moves Me Volunteer Kit online at dystonia-foundation.org/DMM-kit or call 800-377-3978. The instructions make it easy for you to invite up to five local healthcare practices to request a Waiting Room Kit for their office. The DMRF will ship the awareness material displays directly to the healthcare offices.

Throughout Dystonia Awareness month, stay informed about activities and highlights from the Dystonia Moves Me campaign by connecting on Facebook, Twitter, Instagram, and Sharecare.

Many thanks to the 2017 Dystonia Moves Me Committee for guiding plans for this year’s campaign: Monica Alley, Erin Marshall, Jason Ornelis, Annie Ritsch, and Brad Schmitt.
On March 21–22, 2017, the Dystonia Advocacy Network (DAN) hosted Advocacy Day in Washington, DC to speak on behalf of individuals with dystonia and encourage Members of Congress to support the DAN’s legislative priorities.

Advocates requested that dystonia continue to be a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program and that the National Institutes of Health are provided ample funding for the 2018 Fiscal Year. The DAN also sought to preserve basic patient protections from the Affordable Care Act. These protections include prohibiting discrimination against pre-existing conditions, establishing out-of-pocket maximums for covered services, and Medicaid funding.

As part of activities on Capitol Hill, the DMRF was proud to welcome this year’s Douglas Kramer Young Advocate Award recipients: Anneliese Ornelis, Shasta Partee, June Tritley, and Scott Wood. The DMRF looks forward to working with these outstanding advocates on legislative and policy matters throughout the year. The annual Douglas Kramer Young Advocate Award recognizes exceptional volunteers who are giving voice to dystonia through advocacy.

After meeting with DAN advocates, a number of Congressional offices asked for additional stories of how dystonia affects people’s lives. These stories help Members of Congress understand the urgency and importance of our legislative agenda. The DMRF will collect these stories and use them to help support our advocacy efforts.

To share your story, visit dystonia-foundation.org/DAN_stories.
DMRF Clinical Fellowships Help Train Dystonia Experts

“Dystonia can be such a debilitating disease. Everyday activities such as going to the store, driving a car, working a job, going out with friends can be so difficult for people with this condition. So, as a neurologist, to be able to improve a patient’s quality of life is very motivating,” says Elliot Hogg, MD, movement disorder specialist and researcher at Cedars-Sinai Medical Center in Los Angeles. Dr. Hogg is one of 27 elite neurologists to participate in the DMRF’s clinical fellowship training program since it began in 2010.

There is an urgent need for training additional movement disorder experts in dystonia through clinical fellowships. Evaluation by a movement disorder neurologist can make a significant difference in terms of the treatment options available to dystonia patients and benefit from treatment.

As part of a commitment to nurturing the next generation of dystonia specialists, the DMRF sponsors one-year $75,000 clinical fellowships to train second-year fellow physicians in the diagnosis and treatment of movement disorders with special competence in dystonia.

Dr. Hogg has spent the last year training with Michele Tagliati, MD, Director of the Cedars-Sinai Movement Disorder Program and pioneer in the use of deep brain stimulation therapy for dystonia and other movement disorders. In addition to caring for patients, Dr. Hogg has been engaged in critical dystonia research. Most recently, he and colleagues have been looking at long-term outcomes of dystonia patients treated with deep brain stimulation, a treatment that involves implanted medical devices. “DBS is a powerful tool for the treatment of dystonia, but it also becomes part of a dystonia patient’s life for years or decades,” Dr. Hogg explains. “While other studies have demonstrated that DBS offers significant benefits in the short term, there are few long-term studies. Our research shows that even 10 years after surgery, quality of life remains high in patients who received this life-changing treatment, and this may help inform other patients who are considering DBS.” Data from this work was presented at the 1st Pan American Parkinson’s Disease and Movement Disorder Congress in Miami and the 21st International Congress of Parkinson’s Disease and Movement Disorders in Vancouver.

Past DMRF clinical fellows have earned positions in movement disorder programs at prestigious institutions and are filling gaps in communities previously without movement disorder experts. Clinical fellows remain engaged with the DMRF as reviewers for DMRF educational materials, speakers at support group meetings, participants at dystonia awareness events, and medical experts for local news stories.

“Movement disorders is a unique field of medicine and an area where few physicians receive training,” explains
Researchers Clarify Complex Neurological Causes for Blepharospasm

Drs. David Peterson and Terrence Sejnowski at University of California San Diego have developed a model to explain the origins of blepharospasm, focal dystonia of the eyelid and brow muscles resulting in involuntary blinking and eye closure.

Many researchers believe dystonia occurs due to an underlying vulnerability in the brain combined with an external trigger, but the mechanism is not understood. Blepharospasm patients, for example, have abnormalities in brain circuits associated with blinking, and symptom onset is frequently preceded by complaints of dry eye, light sensitivity, and other eye symptoms. By combining concepts from neuroscience, engineering, and mathematics, Drs. Peterson and Sejnowski have created a novel framework that may explain the complex combination of conditions in the nervous system that leads to blepharospasm symptoms. This model can be tested using available animal models and may ultimately provide a guide to prevent or reverse the disorder.


Investigators Uncover New Mechanism—and Potentially Novel Surgical Target—for Dystonia

Dystonia is caused not by a single malfunctioning brain structure but because of many complications in the brain networks that connect areas of the brain that control movement. Investigators at Baylor College of Medicine published a study examining the interactions of several such brain areas, the inferior olive and the cerebellum, in dystonia. Using genetically modified mice, they blocked neurons in the inferior olive from signaling to the cerebellum. The mice developed a dystonic movement disorder with twisting limb movements and tremor, demonstrating that dysfunction in signaling between these brain structures is a mechanism that may cause dystonia. Remarkably, the investigators were able to reverse the movement disorder symptoms with drugs, and—most notably—with deep brain stimulation to the cerebellum. Researchers have been increasingly interested in clarifying the role of the cerebellum in dystonia and what this might mean for novel therapies. The most common target for deep brain stimulation in human dystonia patients is the subthalamic nucleus, part of the basal ganglia, but this study intriguingly points to the cerebellar nuclei as potential surgical targets.

New Model Explores Role of Cerebellum in DYT1 Dystonia

The basal ganglia and cerebellum are brain structures that regulate motor movement and motor learning. A balance between these two systems allows for smooth, coordinated movement. Dystonia can occur in humans when either system is disrupted or damaged. Researchers have been increasingly interested in clarifying the role of the cerebellum in dystonia. A team led by past DMRF Medical & Scientific Advisory Council Member Dr. Kamran Khodakhah at Albert Einstein College of Medicine have demonstrated in mouse models that the cerebellum is the main site of dysfunction in DYT1 dystonia. DYT1 dystonia occurs when a protein in the brain called TorsinA becomes mutated and fails to function normally. Dr. Khodakhah’s team created a new mouse model to explore the effects of TorsinA in dystonia. Reducing the amount of TorsinA in the cerebellum of these mice induced dystonia symptoms. Intriguingly, reducing the amount of TorsinA in the basal ganglia of these mice did not produce dystonia symptoms. When these experiments were conducted in juvenile mice, the animals showed no symptoms, suggesting the young mice were able to compensate for the TorsinA loss.

The investigators found the loss of TorsinA function caused the cerebellum to generate faulty output signals. They propose the downstream effect of these faulty signals from the cerebellum could ultimately disrupt basal ganglia function. Future studies in this mouse model could help clarify the precise changes in the cerebellum induced by failure of TorsinA and point toward new treatment strategies for DYT1 and other inherited dystonias.


TorsinA & LAP1 Proteins are Required for Nuclear Migration

One of the known causes of dystonia is the malfunction of a protein called TorsinA. TorsinA is found in human neurons and other cell types and appears to have a role in multiple cell processes. A team led by DMRF grant recipient Dr. G. W. Gant Luxton at University of Minnesota have added a new role to TorsinA’s expanding repertoire. Experimenting in cell models, he and his team have demonstrated that TorsinA and its activator protein, LAP1, regulate protein complexes that facilitate nuclear migration. Relocating the nucleus of a cell is required for many processes including fertilization, muscle development, and neuronal growth. These experiments used fibroblasts (cells that make up connective tissue), not neurons, so it is unclear at this time how relevant the discoveries may be to dystonia. However, other investigators have discovered fibroblast abnormalities in human dystonia patients, and future experiments with this model may offer a new perspective from which to ultimately clarify TorsinA function.

The study was highlighted by Cell Biology journal with a special introduction by Drs. Daniel Starr and Lesilee Rose, a former DMRF grant recipient whose work has contributed important TorsinA findings.

Test Taking Tips

Genetic Counselors Inform Patients & Families about Testing for Dystonia

“Every family has its own relationship with dystonia,” says Deborah Raymond, MS, CGC, Genetic Counselor at Mount Sinai Beth Israel. “Genetic counseling is an opportunity for families to learn about dystonia, how it’s inherited, and discuss options for testing—including how testing might or might not benefit the family.”

The genetics of dystonia are complex. A lot has changed in the 20+ years that Raymond has worked in movement disorders: multiple dystonia genes have been discovered, new testing technologies are available, companies have begun offering direct-to-consumer testing without requiring a physician’s prescription, and the potential for confusion among patients and families is greater than ever.

Decisions, Decisions

A genetic counselor can help dystonia patients and their family members determine whether they are candidates for genetic testing, whether they wish to be tested, and what method of testing might be appropriate. A genetic counselor also helps families understand results from testing.

A gene is a segment of genetic material responsible for a specific life function. A genome is the complete genetic make-up of a living thing. The technologies available for diagnostic genetic testing allow for single-gene testing, testing for mutations in multiple genes at once, and targeting sections of a patient’s genome to identify faulty genes.

“Testing is obviously evolving a lot, and there are a number of genes that we usually focus on first when we see a dystonia patient,” explains Raymond. Examples of dystonia-causing genes include DYT1/TOR1A, DYT6/THAP1, DYT11/SGCE, and many others.

Recommendations for genetic testing depend on a number of factors: the clinician’s findings from the neurological exam, patient history, family history, and sometimes ethnicity. “All these factors can play into the most likely gene that is involved and where testing should start,” says Raymond. “For example, if somebody has childhood onset dystonia and has Ashkenazi Jewish background, there’s more than a 90% chance that it’s DYT1 dystonia, especially if symptoms started in a leg. Now, there is some newly available testing that can be helpful in cases where the person has a constellation of symptoms that includes dystonia, but you can’t quite fit them into any of the known classifications. In that situation it may be appropriate to use a type of testing where we can look at many genes at once.”

Continued on page 20
Basic & Clinical Aspects of Dystonia

DMRF Funds Research Projects Focused on Treatment

Decades of investing in dystonia research have produced a vibrant field brimming with new opportunities for medical discoveries to improve lives.

The DMRF Medical & Scientific Advisory Council is made up of distinguished clinicians and scientists whose expertise guides the Foundation’s science programs and research funding. The DMRF’s science plan is reviewed annually to inform the topics and scheduling for research funding cycles.

The DMRF issued a request for research proposals inviting projects on any aspect of basic research on dystonia or clinical work directed at developing new and improved treatments. The Foundation is proud to fund the following outstanding projects on basic and clinical aspects of dystonia.

Neuroanatomical Substrates for Disrupted Eif2alpha Signaling in Dystonia
Nicole Calakos, MD, PhD
Duke University
Observations in multiple forms of dystonia—including DYT1, DYT6, and cervical dystonia—have implicated a cellular pathway in the brain called eIF2-alpha as a central source of dysfunction. This study proposes to identify the brain regions, cell types, and developmental periods in which the pathway’s activation is disrupted in DYT1+ mouse models and to test whether boosting the pathway’s activity will reduce negative effects of the DYT1 mutation. This knowledge will advance understanding of the cellular mechanism of dystonia and inform experiments to determine whether targeting the eIF2-alpha pathway is a beneficial treatment strategy.

Tremor, Oscillations, Synaptic Plasticity, and DBS for Dystonia
William Hutchison, PhD
Toronto Western Hospital (Canada)
Deep brain stimulation (DBS) can be an effective treatment for severe dystonia, but the mechanisms underlying DBS treatment are not well understood. This study seeks to better understand how and why DBS works by investigating cell activity in neurosurgical target sites in the brain. The goal is to gain insight into the mechanisms of tremor and dystonia, and possibly translate this knowledge to develop new targets for drug treatment.

Determining the Role of Torsin in Nuclear Pore Complex Assembly
Patrick Lusk, PhD
Yale University
DYT1 dystonia is caused by a genetic abnormality that leads to the expression of defective TorsinA protein in cells throughout the body. Researchers hypothesize that abnormal TorsinA disrupts the transport of specific molecules in and out of the cell nucleus. Data from the proposed study are expected to substantially advance understanding of Torsin function and dysfunction, and to facilitate the development of more effective treatment strategies.
Synaptic Plasticity in a Mouse Model of Paroxysmal Dystonia
Alexandra Nelson, MD, PhD
University of California, San Francisco
This study uses a new mouse model of dystonia, based on a genetic form of the human disorder called paroxysmal kinesigenic dyskinesias, to examine how dystonia alters communication between neurons. Researchers hope this study will form the foundation for a larger research program aimed at understanding the fundamental cellular and circuit changes that cause dystonia so that new and more effective drugs or brain stimulation approaches can be developed.

Investigation of Striato-Pallidal Connections in a Mouse Model of DYT1 Dystonia
Giuseppe Sciamanna, PhD
University of Rome tor Vergata (Italy)
An area of the brain called the external globus pallidus (GPe), which is part of the basal ganglia, is strongly implicated in the development of DYT1 dystonia. GPe receives input from an area of the brain called the striatum, and projects to the other components of the basal ganglia. This project will investigate how the interaction among the components of the basal ganglia may be altered in dystonia, and could represent a crucial step toward understanding the cellular basis of dystonic symptoms.

Dystonia-associated Endoplasmic Reticulum Defects and the (De)regulation of Neurotransmission
Patrik Verstreken, PhD
VIB Leuven (Belgium)
This research group recently discovered that Torsin genes regulate cellular lipid metabolism in mice, humans, and fruit flies. Their hypothesis is that abnormal lipid biology is the origin of DYT1 dystonia. The plan is to investigate how abnormal Torsin lipid biology affects neurons and test whether manipulation of lipid enzymes can correct neuronal defects caused by Torsin dysfunction. These experiments are vital to verify that lipid metabolism is indeed a key target for DYT1 dystonia, and determine whether lipid biology is important for dystonia research.

For more in-depth research project summaries, visit dystonia-foundation.org/funded_projects

Glossary

Neurons are cells in the brain and spinal cord. Neurons communicate with each other by transmitting signals along brain pathways (also called brain circuits or networks).

The nucleus of a cell contains the cell’s genetic material and controls the cell’s functions.

Lipids are fat molecules and have important roles in the structure and function of living cells, including neurons.

TorsinA is a protein found in neurons that causes dystonia when it fails to function normally. The DYT1/TOR1 gene encodes TorsinA.

Several genes can cause early onset generalized dystonia, including DYT1/TOR1 and DYT6/THAP1.

Cervical dystonia causes extreme muscle spasms and pain in the neck, causing involuntary movements and awkward head positions.

Paroxysmal kinesigenic dyskinesias (PKD) is a movement disorder causing episodes of irregular jerking or shaking movements triggered by sudden motion such as standing up quickly or being startled. PKD can be caused by mutations in the DYT10/PRRT2 gene.

Basal ganglia are clusters of neurons deep in the brain that are involved in normal voluntary movement.

Striatum is an area of the brain that sends sensory information to structures in the basal ganglia for processing.
Josh Anderson recalls being enthralled, at a very young age, by drawing. “It started with a three-dimensional cube my mom drew,” he explains, “and then she erased a few lines and turned it into a block. I was like, how did you do that? I was amazed. So, I took that block and added water and fish and made an aquarium. This was at age 4 or 5.”

His father once added racing track marks behind a vehicle Josh drew, and it was as if the drawing came alive. “It was magic. It’s like I found my calling in that moment.”

Josh is an illustrator and draftsman who remains fascinated by the transformative power of ink on a page: “Some of the things that inspire me are germs and organisms, psychology, the human struggle, monsters, animals, and then I incorporate humor into that. I draw the relationship between these things and the human condition. Empathy plays a huge role in my work. I want to let people know they aren’t alone.”

There is a wit and intensity to Josh’s illustrations that reflect his resilience. Art and humor have been critical to his narrow escape from dark times. He says, “I had a very dysfunctional family growing up and a lot of loss issues, and a lot of substance abuse issues. I’m in recovery and I have really come out the other side of that. Art allows me to fill in the blanks of my life, to connect the dots. It helps me understand how I could have behaved differently in the past and apply it to my future.”

Josh’s introduction to dystonia began in 2000 as a passenger in a car wreck that propelled him head first into the windshield. “Luckily I didn’t break my face, so my dashing charisma remained intact,” he jokes, “but the position of my head is how I hit that windshield—back and to the left. My neck froze.” Months later, an episode that felt like a panic attack left him momentarily unable to turn his head. His unexplained symptoms went into overdrive after an important relationship ended: “It broke my little heart. Sadly, it broke my neck too. I had full-on symptoms. I went into a nine month black out on drugs and alcohol. I was in hell: limping around, unconscious, contorted, trying to solve this mystery going on with my body.”

In 2004, Josh was diagnosed with spasmodic torticollis, also known as cervical dystonia. Cervical dystonia causes extreme muscle spasms and pain in the neck, causing involuntary movements and awkward head positions. “I was like, wow, there is a name for this! But I was almost in denial, like this can’t be neurological, I’ll get over this.” Ironically, the initial reward for seeking treatment for substance abuse was a worsening of the dystonia. “Even after I sobered up, it actually felt—maybe because I was conscious—it got worse. It was very dark for four or five years. I was twisted and contorted. I was in emotional, physical, spiritual, mental anguish. That’s why I love people with dystonia, because they understand this.”

For Josh, the process of reclaiming his life from dystonia echoes his recovery from drugs and alcohol. “How did I get here?” he says, “it’s almost like the moment of clarity for the alcoholic—one day you wake up and you’re different. My old life was drugs, alcohol, basements, punk rock shows, and partying. My new life is all about recovery, addressing dystonia, staying sober, being a good person, and loving people. And all the work that comes with therapy and meetings and talking and communication and art—and
of course the botulinum toxin injections and medicine help you get to that point of recovery. It’s almost more difficult to maintain recovery than getting to recovery.”

Over the years, Josh found a combination of medical treatments and wellness therapies that works for him. He has limited mobility in his neck and terrible pain when he turns his head, but the symptoms are infinitely more controlled. “I really think that every time you laugh you take away a spasm from dystonia. It loses its power with acceptance. I throw the word acceptance around a lot, but if anyone knows how hard it is to accept this thing, it’s me. I really want to stress to people that there is light at the end of the tunnel.”

Learning to accept dystonia has given Josh a new perspective on what he has gained through his experiences: “Somehow I have gotten to the place where I’m grateful for dystonia. I’m grateful for the medical field that addresses the physical part, and I’m grateful for the resources I have to address it emotionally and spiritually, and a process to learn from it. I’m grateful for my wife. Unconditional love and patience, that’s helped me a lot.”

Earlier this year, Josh donated his piece “Dystonia” to the DMRF to use for awareness purposes. It was adapted into a social media meme to increase visibility of dystonia and the DMRF. Proceeds from a limited edition t-shirt will support the DMRF mission. Shirts are available for pre-order for $15 until August 31 at dystonia-foundation.org/josh_anderson_shirt

Josh Anderson lives and works in Santa Fe, New Mexico. Find him on Facebook and Instagram at @joshandersonartist

If you are struggling with drugs or alcohol, consider speaking with a doctor or mental health professional about available treatment options.
People on the Move

The DMRF is grateful for the grassroots volunteers across the country working to improve dystonia awareness and raise funds for medical research. Every volunteer makes a difference!

Thanks to Sandra and Robert Nathans of New Jersey, the Westminster Choir of 1st Presbyterian Church at Caldwell donated the Easter Vigil collection to the DMRF. The Nathans’ daughter, Lydia Nathans is a choir alum. Sandra and Robert are advisors for the annual Westminster Choir Tour. Lydia and brother Jack have generalized dystonia and the family are longtime DMRF supporters.

The DMRF thanks members of the Central California Dystonia Support Group and leaders Luanne Pinedo Madden, David Madden, and Holly Machado for hosting the first Dystonia Zoo Walk of the year in April at Fresno-Chaffee Zoo. Many thanks as well to Melvin Helm, MD and Harrol Hutchison, MD for sharing insights into diagnosing and treating dystonia. Participants were joined by Parker, mascot of the Fresno Grizzlies Baseball Team.

The Minnesota Dystonia Educational Symposium in April organized by the Minnesota Dystonia Support Group was a huge success with over 70 people attending. Guest speakers included movement disorder experts Jerrold Vitek, MD, PhD and Lauren Schrock, MD, and DMRF Chief Scientific Officer Jan Teller, MA, PhD.

Fatta Nahab, MD spoke to the Dystonia Support & Advocacy Group of San Diego County on the evaluation and management of dystonia. Founder and leader of the support group, Martha Murphy, was featured in the Spring 2017 issue of the Dystonia Dialogue to commemorate the group’s 30th anniversary.

The DMRF thanks to Megan Wirts, Mike Logan, Nardos Osterhart, David Dyer, and Stu McAllister for a Comedy Fundraiser for Dystonia at Dr. Grin’s in Grand Rapids, Michigan. The benefit supported the DMRF via the $5DollarCure4Dystonia campaign ($5dollarcure.com). See page 22 for an interview with Megan Wirts.

The Living Well with Dystonia Patient Symposium was held May 7 in New York City. Featured speakers included movement disorder specialist Susan Bressman, MD, Joan Miravite, NP, Richard Sabel, OTR, MA, MPH, GCFP, and DMRF Chief Scientific Officer Jan Teller, MA, PhD. Many thanks to DMRF Board Member Pamela Sloate for her invaluable role in organizing the meeting. Select presentations from the program are available for viewing on the DMRF YouTube channel: youtube.com/FacesofDystonia.

Jace’s Twisted Ride with Dystonia was a Poker Run and awareness event organized by Cory and Nicole Hall in honor of their son Jace, who has dystonia. Thanks as well to Jace’s grandmother Christine Adkison for her role in preparations for the event.

Friends and family of late Manhattan attorney Marshall Isaacs gathered for a special event to celebrate his life and promote dystonia awareness. Stacey Prince organized “Dystonia Moves Me: In Memory of Marshall Isaacs” to honor her friend with dystonia by supporting the DMRF.
Stand Up for a Dystonia Cure

The DMRF has joined forces with Pumped Up SUP and Earth River SUP (Stand Up Paddleboards) in announcing a new campaign to raise awareness of dystonia and help raise funds to find a cure. Everyone who supports Stand Up for a Dystonia Cure will be entered into a drawing to win a package featuring an Earth River SUP 11-0 Skylake Inflatable Paddleboard Package including a paddle, pump, backpack, t-shirt, and hat. This campaign will run through August 24, 2017. To make a donation and be entered into the drawing, visit: dystonia-foundation.org/SUP.

In addition, Pumped Up SUP has partnered with DMRF to donate a portion of proceeds from sales of Earth River SUP Paddleboards from now through August 24, 2017. Customers will receive a $100 discount and Pumped Up SUP will donate $100 to DMRF on any Earth River Sup paddle board purchased via this promotion. To save $100 on a paddleboard and support the DMRF, visit: pumpedupsup.com/collections/earth-river-sup. You must use coupon code DMRF100 at checkout for the discount and donation to be applied.

On June 17, hundreds gathered for 2nd Twin Cities Dystonia Zoo Walk organized by Shanna and Brad Schmitt, Billy McLaughlin, and members of the Minnesota Dystonia Support Group. Speakers included St. Paul Mayor Mayor Chris Coleman and dystonia researcher Joshua Aman, PhD.

In June, Sue Baron and family held the Southern New England Dystonia Zoo Walk at Southwick’s Zoo in Mendon, Massachusetts. Mandi Guilfoyle spoke about her experiences with dystonia and deep brain stimulation, emphasizing the importance of continued dystonia research.

The Township Committee of Freehold Township, New Jersey issued a proclamation designating June as Dystonia Awareness Month. This is the 18th year that the Township has issued a Dystonia Awareness Proclamation in partnership with DMRF support leaders Janice and Len Nachbar and their daughter Joanna Manusov.
Puppy Love

*Dogs for Dystonia Raises Awareness & Celebrates Humanity’s Best Friend*

Perhaps only small children can match the outrageous, shameless joy of a dog that is happy to see you. Dogs are unrivaled in their loyalty, zest for life, and uncanny ability to transform even the most stoic human into a baby-talking, belly-rubbing softy. Dogs make us feel good.

Dogs have a special place in the dystonia community. They are beloved pets, trained assistants, trusted confidants, and skillful wingmen in social situations. Dogs for Dystonia is an annual campaign to raise awareness while celebrating the special bond between people and their dogs. Each February, dog lovers unite in a Virtual Dog Walk to raise visibility of dystonia and the urgent need for research toward a cure.

Among the participants in this year’s Virtual Walk was Reno, a black Labrador and Golden Retriever mix belonging to 23-year-old DMRF supporter Maddie Paolero of Rhode Island. Maddie was diagnosed with dystonia in kindergarten. She uses a wheelchair for mobility, and has difficulty talking and writing.

Maddie and her parents, Beth and Tony Paolero, first considered applying for an assistance dog while attending a DMRF symposium and befriending DMRF Support Leader Jenelle Dorner who was attending with her dog. The Paoleros ultimately worked with Canine Companions for Independence. Some of the tasks Reno is trained to do include retrieving items Maddie needs or drops, carrying items, tugging things, opening and closing drawers and doors, and barking when Maddie needs to get someone’s attention. Reno is now 12 years old—a senior in dog years—so he is retiring.

“He started to have arthritis in his hips,” Maddie explains, “so he has slowed down, and I don’t lean on him to transfer from my chair, but that’s ok. Lately he’s been going to church and a few places that we know are easy for him, but mostly he helps me at home now. He spends a lot of time enjoying the back yard and his orthopedic bed. Our house and van are perfect for him because we have ramps for me.”

Beth captures the profound ways in which Reno has impacted her daughter’s life and outlook: “Tony and I have seen how much Reno has done for Maddie these past 10 years. His skills help Maddie be more independent, but he has helped her connect with people and be more confident in public. Instead of that girl in the wheelchair, she is that girl with the really cool dog.”

Reno was scheduled to travel to New York this summer for public access recertification, but after the Paoleros spoke with his trainer about the requirements, they made a joint decision to retire Reno from public service. Canine Companions for Independence will re-home retired service dogs if needed, but Reno will remain with his family. “Reno is part of me,” says Maddie. “He helps me do things and cheers me up. Now he needs me to drive my power chair at a slower speed, and that’s no problem because he’s always been there for me.”

To learn about all the dogs that participated in this year’s Virtual Dog Walk, visit: dystonia-foundation.org/virtualwalk
Six Things My Dog Taught Me

Lisa Troub was diagnosed with rapid-onset dystonia-parkinsonism in 2013. She and her dachshund Blueberry participated in this year’s Virtual Dog Walk. The following is adapted from her blog “Little Writings” to explain how Blueberry is more than a pet.

I adopted Blueberry from the Arizona Humane Society. Ever since, Blue has been my shadow. Here are some of the things he has taught me:

1. Take your time walking.
Blue is a wonderful walker, and really enjoys his walks. Sometimes he wants to run. But he checks in by looking back at me to see how I am. He is a wanderer and an explorer. I do have to tell him to slow down if I am not feeling too good or I cannot keep up with him. He knows when I am not up to par, and we walk at our own pace. But when I feel good, we breathlessly run. The pace does not matter, the key is that I am walking.

2. Nap as much as needed.
Odds are that Blue will be napping if he is not eating or playing. He passes out in some of the strangest positions, and occasionally snores. I am fatigued very often, especially living in the desert, but it is something I need to manage. It is often better that I rest than continue with errands and to-do lists because I will feel worse. And I need to not feel guilty about how much I napped and how I should be spending my time because that is wasted energy. Besides, Blue loves to cuddle.

3. Be open to new adventures.
Blue loves hopping into the passenger seat for a trip, to the dog store, the park, to visit my parents, anywhere. He is my co-pilot. He really does not care where we go because it is all about the ride.

Before I leave my home, I always assess where I am going, what I will be doing, if I will be alone or with others, and how I am feeling. And if something is not jiving, then I will stay home, creating my own adventure with my husband and Blue. Living in the moment is wonderful, but I have to listen to my body and respond accordingly. Also, for my morale, it helps if I start each day positively for whatever adventures may come.

4. Touch is the best form of comfort.
Belly rubs, back scratches, and head rubs are my dog’s favorite things. He nudges hands and arms if he is not being petted. He is an only child so he receives all the love, and he cannot get enough.

It is bliss being hugged by my husband. Most of the time I feel better when he holds my hand, hugs, and/or kisses me. Sometimes all it takes to get centered is a familiar touch; equally gratifying is seeing how I comfort my husband and Blue.

5. Be confident in my skin.
Dachshunds are nicknamed hot dogs and wiener dogs. Some people will stare, point, and holler at the sight of Blueberry in excitement. It does not bother him; he loves people. The stride in his walk exemplifies his confidence.

Sometimes I feel uncomfortable when people stare at my unbalanced walk. Yet, I am gaining more confidence and have a pep in my step. It is not always easy, but Blueberry helps me along.

6. Listening is enough.
He knows. He knows when I am happy, disappointed, stressed, relieved, upset. Blue will look at me as though he understands. And sometimes that is all anyone needs: to be heard.

Check out Lisa’s Dogs for Dystonia blog entry, “Blue to the Rescue” at dogsfordystonia.blogspot.com
Issues to Consider Before Testing

Part of the genetic counselor’s role is to help patients and families think through all the implications of testing, some of which may not be obvious. For example:

- **Genetic testing may influence treatment options.** Research suggests that patients who are positive for certain dystonia genes, including DYT1/TOR1 and the newly discovered DYT28/KMT2B, seem to respond especially well to deep brain stimulation surgery.

- **There are different rules for testing adults and children.** “A lot of thought has been given to testing as it applies to children,” says Raymond. “If a child has symptoms, the genetic information could be helpful medically. However, there is consensus that it’s not recommended for parents to have an asymptomatic child tested, because that child should be able to make that choice for themselves when they are of age.”

- **Genetic testing can be a psychologically and emotionally sensitive issue.** Genetic counselors are not licensed clinical psychologists, but they are trained in counseling. Raymond explains: “People have their own values and contexts and relationships that influence how they see the risk. For example, there can be anxieties or feelings of guilt. All these aspects are important to discuss and think about before testing and sometimes after.”

- **There are laws that protect against genetic discrimination by health insurance providers, but these laws are not absolute and do not apply to disability or life insurance.** Issues of insurance and privacy are complex and can have far-reaching consequences that are important to anticipate as much as possible.

- **Genetic testing may not provide all the answers.** Raymond explains: “There are certain people for whom finding a dystonia gene with the testing available is unlikely, so genetic counseling may be more about clarifying what testing will tell us, what it won’t tell us, and exploring the inheritance pattern in the family for clues to help explain the risk. But if you have questions, by all means, it’s appropriate to have counseling.”

Direct-to-Consumer Genetic Testing

Up until recently, genetic testing has been available only through physicians and genetic counselors. Direct-to-consumer genetic testing is advertised directly to patients by private companies. Patients provide their genetic information via a saliva sample directly to the company without necessarily involving a doctor or insurance provider in the process.

Multiple medical and scientific organizations and regulating bodies have expressed concerns about taking genetic testing out of a healthcare setting. Some of these concerns involve patient education, marketing, lack of regulation, and privacy.

“Direct-to-consumer testing is definitely an option that is available in some states, but for all of the reasons that we are discussing, the concern is that people aren’t really able to anticipate all the aspects when they send in their spit sample because they don’t get counseling before the testing,” Raymond explains. “Anybody who is considering direct-to-consumer testing should speak with a genetic counselor, or their physician, before they make the decision to test so they can think through the complexities ahead of time.”

Working with a Genetic Counselor

If you have questions about the genetics of dystonia, consider talking to your doctor about seeing a genetic counselor, ideally one with a background that includes neurological disorders. Genetic counselors can be identified by referrals from your doctor, through your health insurance provider, or professional genetic counseling organizations such as the National Society of Genetic Counselors.

Deborah Raymond, MS, CGC, is a certified genetic counselor and clinical researcher in the Mirken Department of Neurology Center for Movement Disorders at Mount Sinai Beth Israel Medical Center where she counsels patients and families about genetic movement disorders and options for genetic testing, and is a senior coordinator of research studies aimed at understanding the genetic causes of dystonia and Parkinson’s disease.

This article is the first of a two-part series. Look for an update on the genetics of dystonia in the next Dystonia Dialogue.
Common Misconceptions about Dystonia Genetics

• There is one genetic test for dystonia. This is not accurate. There are several types of genetic testing available for dystonia, and several dystonia genes that can be detected.

• If you are negative for the DYT1 gene, your dystonia is not genetic. This is not necessarily true. There are multiple genes for dystonia. A dystonia patient can test negative for all known genes, and the dystonia may still be genetic—the gene has not yet been discovered.

• If you have a dystonia gene, you are guaranteed to get dystonia. This is not true. Most people who inherit a dystonia gene never develop symptoms. However, their biological children may be at risk of inheriting the gene and developing symptoms.

Types of Testing

Single Gene Sequencing
Dystonia can be caused by a single faulty gene. Testing can be focused to look at one specific gene.

Genetic Panels
Testing can look for multiple dystonia-causing genes at once.

Whole Exome Sequencing
Testing can look for changes in the ~20,000 genes involved in the body’s functions and identify those genes that may be contributing to dystonia symptoms. However, this type of testing cannot pick up all types of mutations and may generate findings that are inconclusive.

Whole Genome Sequencing
Testing can look for changes in the entire genetic code including parts that do not contain genes but may be important for gene function. This method is used primarily for research purposes and does not yet have a clear clinical application for dystonia.

Dystonia 101

Dystonia can be a confusing disorder to understand. Here are the basics:

• Dystonia is a neurological disorder. It affects the brain’s ability to control voluntary muscle movement.

• Dystonia does not affect vital organs such as the heart.

• There are many forms of dystonia. It can affect a single body area or multiple muscle groups.

• Dystonia may occur with other movement symptoms such as tremor, myoclonus, or parkinsonism.

• Inherited dystonias are those with a known genetic origin, for example mutations in the DYT-designated genes such as DYT1, DYT5, or DYT11.

• Dystonia may result from birth injury, drug exposure, brain injury, infection, and other secondary causes.

• Treatment options include oral medications, botulinum neurotoxin injections, deep brain stimulation, and less invasive methods such as physical or occupational therapy.

• Individuals with dystonia may experience depression and anxiety disorders, including social phobia.

• Stress does not cause dystonia, but symptoms may worsen in stressful situations.

For more information, visit dystonia-foundation.org

Stay in Touch!
Sign up for the DMRF’s monthly e-newsletter dystonia-foundation.org/email
PERSONAL PROFILE
Megan Wirts

Megan Wirts of Grant, Michigan is a former respiratory therapist who began experiencing dystonia symptoms in 2012. After several misdiagnoses, she was diagnosed with generalized dystonia in 2015. Earlier this year she helped organize and performed in a Dystonia Comedy Fundraiser in support of the DMRF. She authors a column entitled “Megan Again” in Near North Now, a local online news source.

How did your symptoms start and how were you diagnosed?
It started on the right side of my face. I don’t think it started in the typical way, so the doctors didn’t know what was going on with me. I was experiencing facial spasms, head tremors, and spasms in my right arm and hand. I also was having spasms in my legs and back, but I didn’t realize they were all connected until later. I was initially misdiagnosed, and between 2012 and 2015 I had two brain surgeries. After my second surgery in 2015, my face continued to spasm, along with my entire body. I was also dizzy and off balance all the time. I had lots of pain in my face, neck, and shoulders. I had no idea what was happening to me. When it was clear I wasn’t getting better, my surgeon said—he was profusely apologetic—he said, you have dystonia. So, I went home and looked up dystonia online and it was obvious that was what I have. There was no denying it. Nobody wants to hear you have an incurable disorder, but it was a relief to have an answer. I was sad about it, but also happy because I was convinced that I was dying of something else before I was properly diagnosed. I thought finally I can move on with my life. Eventually I found a good neurologist who takes good care of me, but it was a struggle to find a doctor. The whole thing was frustrating and scary and heartbreaking.

How has dystonia impacted your life?
Dystonia has definitely changed my life quite a bit. The biggest things I had to deal with were leaving my career and not being able to drive any more. I loved my job and not being able to do it any longer was a difficult adjustment. Not only was the loss of income and the sacrifices that had to be made hard, but not having that social outlet was also hard for me. I felt like I lost so much of my independence and relationships with people. Where I live, you have to drive to get anywhere. I miss just getting in the car and taking my kids to the beach or the zoo—we used to do so much. I also just want to go to the grocery store by myself, you know? And I can’t do that. When you are unable to drive or leave your house, you become quite isolated. I didn’t realize how much I needed to be around people until I wasn’t. Any chance I have to get out, I try. I have to push through the pain in order to live my life. So, I do. I just have to pick and choose what I want to do because I know afterwards I’m going to need rest for a day or two or five, depending on what I did. I’ve learned to listen to my body when it’s telling me it’s had enough. When I overdo it I’m miserable. I was very active before. It was hard to slow down, slow myself way down.

Talk about your stand-up.
I get to tell funny stories about my life and tell people about dystonia in a humorous way, not a sad way. It’s fun and I can spread awareness. It’s also one of the scariest things I’ve ever done, but I love to perform and I feel more like myself when I’m on stage. When I talk about dystonia in my comedy, I
don’t want dystonia to necessarily be the joke; I don’t want to be the joke. I want people think about the way they treat people with disabilities. One of my bits is about how everywhere I go I am an inspiration and I have no idea why I am so inspiring. Maybe not every person with a disability feels like they are an inspiration, maybe they just want to be treated like a regular human being. Maybe I just want to get tampons at the grocery store and not be told by a total stranger that I am brave for doing it. Experiencing my life as a person with a disability has been a huge change for me. The way people react to me now is funny to me. I don’t mind when people tell me that I am inspiring when I am doing comedy and when I’m writing because I feel like those are things that people could be inspired by. It’s a stereotype that people with disabilities are meant to be an inspiration for able bodied people. We aren’t. We are just trying to live our lives. I try to explain to people that I’m not that brave or special. I’m a regular woman, wife, and mother who happens to have dystonia. Being able to educate people while making them laugh is something I like to do. When I used to work in a hospital and worked with kids who were disabled, I’m sure I said and did some of the same things that people say and do to me now. So, I know that when people are telling me you’re so brave or everything happens for a reason and things like that—I know they are coming from a good place. I don’t get angry about it, I use it as an opportunity to educate and I am able to do it through my comedy as well.

Is there anything about dystonia you wish you had been told when you were diagnosed?

That it is going to be ok. You don’t have to be sad about it all the time. You can be happy, you can still live your life. It’s going to be different and a huge adjustment. I didn’t realize how different my life was going to be, but I am learning to adapt. It sounds cheesy, but I would also say to never give up and never stop being yourself. This is going to be hard, but you can do hard things. And it’s not a straight line, either. Accepting that I have dystonia was not a straight line. It was this rollercoaster zig zag: One day I’m ok with it and accept that this is how my life is, and the next day I feel like it’s awful and I want my life back the way it was! Then the next day I tell myself this isn’t so bad, I can get through this. It’s this constant struggle, and something I’m probably always going to struggle with. I will get through it though. It’s also important to have a good support system and people that care about you and want to help you live your best life. Don’t be afraid to ask for help. It’s not weakness. It’s a sign of strength to know that you need help—whether you need a ride to the grocery store or you need to talk with a therapist. You need help and you shouldn’t be ashamed of it. I have a great husband and I have amazing friends and family. I’ve been really lucky in that respect. I don’t know if I would be in such a good place if I didn’t have them.

How have you seen your family and friends adjust to dystonia?

I accepted dystonia much sooner than my friends and family did. When I told them that I was not going to get better some of them thought that meant I was giving up on my life. I had to explain to them that’s not what I meant. I’m not giving up, I’m just accepting it. I think that was hard for my family and friends, to realize that dystonia doesn’t have a cure—yet. Maybe it will someday, I still have hope. I’m getting the best medications and therapies I can get right now, and this is how my life is. It was hard for them to not want to push me to keep trying experimental things that made me uncomfortable or made me feel worse, especially when none of it worked. I didn’t want to any more, I just wanted to relax and live my life as best as I can.

My husband, I’m sure he did not think, 15 years ago when we got married, that he was going to be married to a woman with a disability. That was not on the horizon. He’s had to come to terms with things and accept things too. I could not have asked for a better husband. He is awesome. He loves me so much. And he never complains about having to do more housework and work more hours and do all the driving. He’s had to pick up a lot of slack, and that makes me feel guilty. But he tries to make me not feel guilty. He says you know what, this is our life now and it’s ok, this is how it is. Our children didn’t seem to have any issues adjusting to this life. I’m still just their mom who loves them. I have some very close friends also, and that helps me feel less alone. They accept me for who I am and how I am and they don’t try to change it, so it’s good.
## Dystonia Zoo Walks

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<td>St. Louis</td>
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## And Don’t Miss...

- Dystonia Awareness Month – September
- Dystonia Patient Forum (Lansing, MI) – September 8
- Cards Against Dystonia Poker Night (Shakopee, MN) – September 9
- Toss4Dystonia (Buffalo, NY) – September 16
- Dogs for Dystonia Walk (Marion, IA) – October 7
- Chicago Basket Bash – October 29

*For a complete list of events as dates are confirmed, visit dystonia-foundation.org/events*