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MAKING CONNECTIONS:
Investigators Explore Origins of Dystonia in the Brain

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On the Cover:
Investigators around the world are working to understand the brain structures and pathways involved in dystonia. A pathway is a sequence of interconnecting neurons. Nerve signals travel along these pathways, sparking every function in the brain and nervous system. There are 100 billion neurons—with 100 trillion connections—in the human brain. Solutions to dystonia are waiting in this vast neurological space, and DMRF is committed to finding them. Read about the latest DMRF-funded research projects on pages 14–15.

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

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

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

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Unless someone is personally affected by dystonia, it is difficult to appreciate the impact—and after-shocks—of the diagnosis on the lives of patients and those around them. Individuals and families must learn to embrace life’s unpredictability, make informed treatment choices, and carefully navigate the margin between living fully and honoring limitations. Daily living requires adapting to a ‘new normal.’

The DMRF family is now adjusting to the new normal without our Chairman and friend Sam Belzberg, who passed away earlier this year. The loss is felt throughout the dystonia community. We deeply appreciate the outpouring of sympathy to the Belzberg family. See page 4 to read about Sam’s immeasurable impact on dystonia research and the legacy of hope he leaves behind. We also lost a champion of family support, Harriett Farber, who transformed the lives of countless families. See page 4 to learn more about her wonderful work.

Grief and hope are the subjects of a timely article in this issue of the Dystonia Dialogue that shines light on the emotional aspects of a dystonia diagnosis. Vice President of Support Karen K. Ross, PhD discusses the feelings of loss associated with dystonia and tips for moving through grief in a healthy way. Attending to emotional and mental health is as important to living well as medically addressing the physical symptoms of dystonia, and DMRF has made it a recent priority to elevate this often overlooked issue.

The Board of Directors and leadership of the DMRF are all personally affected by dystonia. The daily work to fulfill the DMRF mission is grounded in the promise that the Foundation will do everything in its power to find a cure. Working every day toward a cure requires the vigilance and flexibility to pursue the clues that research provides and to stimulate a constant flow of new ideas. In this newsletter, you will read about our latest research projects. DMRF is partnering with outstanding investigators to continue studying the origins of dystonia in the brain and the implications for new treatment strategies. You will also find an update on our Clinical Fellowship Training Program which is helping to train young movement disorder specialists to treat dystonia and engage in dystonia research.

If you received this issue of the Dystonia Dialogue in the mail, it is because you are among the DMRF’s generous financial contributors. Thank you for your support. Your gifts make it possible for the Foundation to continue working to better the lives of everyone impacted by dystonia.
Remembering Our Chairman: Sam Belzberg

“Sam’s impact on dystonia research and those affected by it was immeasurable. He literally kick-started the field of dystonia research. Through his determination to unravel this mystery, he inspired countless others to tackle it. Like so many of us, Sam never accepted defeat to dystonia. Our dystonia family lost a great crusader, but his legacy will live on and we won’t let him down.”

~ Art Kessler, DMRF President

The DMRF Board of Directors and leadership were heartbroken to learn that Chairman and Co-Founder Samuel Belzberg died in March following a massive stroke. He passed away surrounded by family. Sam is survived by his wife of 68 years, Frances; his children, Cheri, Marc, Wendy and Lisa; 16 grandchildren and 12 great-grandchildren.

Sam was a Canadian businessman and philanthropist whose career included extensive international experience in finance and real estate. He and Fran founded the DMRF in 1976, shortly after their daughter Cheri was diagnosed. Sam was the ultimate dystonia advocate and champion, relentless in his drive to find a cure and to provide services for families, like his, whose lives were upended by the disorder. Sam remained closely involved in the DMRF’s activities until the end of his life.

It is difficult to overstate the influence he has had on elevating and transforming the field of dystonia research and the proliferation of programs in service to patients and families.

Sam’s vision and leadership illuminated a more hopeful path forward for every family touched by dystonia. His legacy lives on in the work of the Foundation and the countless families who continue to be helped.

In Memoriam: Harriett Farber

The DMRF family lost a dedicated family advocate in March. Longtime DMRF supporter and volunteer Harriett Farber passed away after prolonged illness. Harriett spent countless hours, over decades, offering encouragement to dystonia-affected families and fundraising for research toward a cure. The DMRF community is better for all of her efforts, and the countless families she helped are stronger because of her compassionate support.

Harriett’s late daughter Shari Farber-Tritt was affected by severe generalized dystonia since childhood. Harriett is survived by her husband Joel Farber, daughter Beth Farber, and son-in-law Steve Laser.

“Harriett was a pioneer in the dystonia community, providing support and education for families even before the national organization was born. Her passion for helping others was unmatched, and her death leaves a void in our community.”

~ Janet Hieshetter, DMRF Executive Director
September is Dystonia Awareness Month

You can promote dystonia awareness by joining Dystonia Moves Me, the DMRF’s annual awareness campaign. Dystonia Moves Me empowers volunteers to promote dystonia awareness locally and in social media.

There are several ways to take action for dystonia awareness:

- **Show your support by showing up.** DMRF events and educational meetings are happening throughout the country. Check for events in your area at dystonia-foundation.org/events. If you’re unable to attend an event, consider making a donation to support awareness efforts: dystonia-foundation.org/donate

- **Talk about it.** Read up on dystonia so you are prepared to inform family and friends. DMRF has a free downloadable fact sheet of talking points to help start the conversation available at dystonia-foundation.org/dystonia-moves-me

- **Make an awareness moment.** Keep wallet-sized information cards and stickers on hand to promote dystonia among the people you see on a daily basis. You can order here: dystonia-foundation.org/cards-stickers

- **Share what you know.** Throughout September, look for facts about dystonia posted daily from DMRF on Facebook and Twitter. Share on social.

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

*Let us know how you are promoting dystonia awareness by sharing your photos/videos:*

- Upload to www.dystonia-foundation.org/DMM_2018
- Email to awareness@dystonia-foundation.org
- Tag us on Facebook, Instagram, or Twitter (#dystoniamovesme)

**THANK YOU FOR YOUR SUPPORT!**
Clinical Fellowships Support Young Movement Disorder Specialists

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

As part of a commitment to nurturing the next generation of dystonia specialists, the DMRF offers one-year clinical fellowships to support the training of exceptionally qualified physicians in preparation for a clinical and/or research career in movement disorders with emphasis on dystonia. The fellowships are intended for second year movement disorder fellows.

**Congratulations to our 2018 DMRF Clinical Fellow and mentor:**
Noreen Bukhari-Parlakturk, MD, PhD
Duke University
Mentor: Nicole Calakos, MD, PhD
Project: Development of Plasticity Rectifying Approaches for Therapy of Task-Specific Dystonia Using Noninvasive Neuromodulation: Dr. Bukhari-Parlakturk’s project explores using transcranial magnetic stimulation (TMS) in patients with focal hand dystonia to reduce dystonic movements.

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 news stories about dystonia.

*The Clinical Fellowship Training Program is made possible by grants from Merz Pharmaceuticals and The Allergan Foundation.*

Scholarship for Young Investigators Honors Beloved Physician

Joan Miller, MD was a primary care physician in Seattle who developed cervical and limb dystonia following a spinal cord injury. A new DMRF award has been named in her memory. The Joan Miller Young Investigator Scholarship Award supports up-and-coming dystonia researchers by providing travel stipends to attend DMRF workshops and meetings. “She was an outstanding doctor,” says Peter Briglia, Dr. Miller’s husband of 42 years. “Patient care was the reason she went into medicine. She cherished the relationships she had with her patients.” Dr. Miller passed away in 2016.

Despite being a physician, Dr. Miller struggled for years before she was referred to a movement disorder specialist and her dystonia symptoms were correctly diagnosed. “I felt this [award] was a good way to do something positive and honor my wife. And to help more clinicians learn about dystonia,” explains Peter. “It’s crucial that patients are listened to, and listened to carefully.”

Attending scientific meetings is essential for young clinicians and researchers to establish careers in dystonia because meetings provide opportunities to present their work to an expert audience and to build relationships with leaders in the field. DMRF meetings take place throughout the country and abroad, and there are few avenues for young investigators to obtain travel funding. The Joan Miller Young Investigator Scholarship Award fulfills an important role in nurturing early career movement disorder specialists.

Dr. Miller received a BA in Chemistry from the University of Pennsylvania, and graduated from the University of Pennsylvania’s School of Veterinary Medicine. She ultimately attended the University of Washington’s School of Medicine, graduating in 1990. She earned numerous academic and professional awards, most notably being selected as one of Seattle Magazine’s Best Doctors in 2002.

**FIND THE DMRF ON sharecare.com/group/dystonia-medical-research-foundation**
Sharecare is a health and wellness social media platform. Create your profile and connect with the DMRF today.
Not Just Any Body: Living Well with Dystonia

Dystonia is a movement disorder that impacts the physical body, and it can also affect emotional and psychological health. Living well with dystonia includes treating the physical symptoms, protecting emotional and psychological well-being, and accommodating your unique treatment needs as an individual.

There is no single strategy for living well with dystonia that works for everyone. The following suggestions have been compiled from individuals with dystonia, support leaders, and healthcare professionals.

**Seek Out Expert Healthcare Providers.** It often takes a team of experienced professionals to diagnose and treat dystonia. This may include a movement disorder neurologist, physical therapist, psychiatrist, psychotherapist/counselor, and others.

**Actively Participate in Your Treatment.** Learn about dystonia. Make informed choices about your care with the input of your medical team.

**Develop a Multi-Layered Support System.** Seek out supportive family and friends, local dystonia support groups, online support groups, community events, and self-help resources. Enlist the help of a psychotherapist or counselor to help navigate concerns and vulnerabilities.

**Listen to Your Body.** Respect and honor your individual need for sleep, rest, nutrition, exercise, relaxation, and time/scheduling.

**Cautiously Explore Complementary Therapies.** Talk to your doctor about non-traditional therapies that interest you. Different complementary approaches may work for different people, but keep in mind that numerous practitioners and outfits falsely claim to have a unique ability to treat dystonia.

**Take Care of Your Relationships.** Resist the temptation to isolate from other people. If family or love relationships are strained, consider enlisting the help of a therapist to bring you closer to those you care about.

**Remain as Active and Social as Possible.** It may be physically and/or mentally demanding to go certain places or complete specific tasks. Plan ahead, pace yourself, and rest when needed.

**Embrace Awkward Social Situations.** Your symptoms may flare at extremely inopportune times. Strangers may occasionally misinterpret your body language. Be forgiving with yourself in these moments.

**Do Things You Enjoy.** It can be easy to let pleasurable activities and fun fall by the way side. Create space in your routine for activities and experiences that invigorate you and keep you going.

**Treat Depression & Anxiety.** Depression and anxiety can dramatically impact quality of life and the severity of motor symptoms. Consider being evaluated for depression and/or anxiety and, if symptoms are present, seek treatment.

**Be Mindful of Stress.** Regular stress reduction and relaxation practices can have a positive impact on symptoms and overall well-being.

**Contact the DMRF for Assistance.** We can be reached at dystonia@dystonia-foundation.org or 800-377-3978. Look for the DMRF on Facebook and Twitter.

Special thanks to Steven Frucht, MD and Pichet Termsarsab, MD for reviewing the content of this article.

Originally published in the Summer 2015 Dystonia Dialogue, this fact sheet is now available for free download at dystonia-foundation.org/print
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 next fiscal year. Thanks to these efforts, dystonia was confirmed as a condition eligible for study by the Department of Defense for fiscal year 2019.

The latest dystonia investigators to be awarded grants through the Peer-Reviewed Medical Research Program are past DMRF grant recipient Rekha Patel, PhD from University of South Carolina; DMRF Medical & Scientific Advisory Council Member Thomas U. Schwartz, PhD from Massachusetts Institute of Technology; and Fumiaki Yokoi, PhD from the University of Florida. Summaries of the projects are available at dystonia-foundation.org

As part of activities on Capitol Hill, Senator Susan Collins of Maine was presented with the DAN’s Distinguished Public Service Award for her support of the dystonia community.

The DMRF was proud to announce this year’s Douglas Kramer Young Advocate Award recipients: Rachael Mathews of Louisiana, Melissa Rentfrow of Maryland, and Sophia Taylor of Washington. The DMRF looks forward to working with these outstanding advocates on legislative and policy matters throughout the year.

The Douglas Kramer Young Advocate Award recognizes exceptional volunteers who are giving voice to dystonia through advocacy. The award was created by the late Florence Kramer who passed away earlier this year. She was a longtime generous supporter of DMRF and named the award in memory of her son.
ADVOCACY VICTORIES
Here are just a few of the DAN’s accomplishments:

Congressional Briefing on Dystonia
The first-ever Congressional Briefing on dystonia was held to improve dystonia awareness among US Representatives, Senators, and staffers.

Protected Access to Deep Brain Stimulation
The DAN prevented regulation proposed by the Centers for Medicare & Medicaid Services to limit deep brain stimulation access to volunteers enrolled in clinical studies. This would have prevented countless patients from having access to potentially life-changing treatment.

DOD Began to Support Dystonia Research
DAN advocates convinced legislators to add dystonia to the list of conditions eligible for study through the Department of Defense Peer-Reviewed Medical Research Program in the 2010 Defense Appropriations Bill. Advocates have successfully kept dystonia in the program every year since, resulting in millions of dollars in additional funding awarded to dystonia investigators.

Increased Funding for NIH
Each year dystonia advocates encourage Congress to increase funding for the National Institutes of Health (NIH) and support expansion of the dystonia research portfolio. This sustained outreach has helped funding for dystonia research at NIH reach $14 million annually.

Safeguards for New Biologic Therapies
Dystonia advocates successfully urged legislators to establish an approval process for follow-on biologic products at the Food & Drug Administration with significant patient safety provisions. Botulinum neurotoxin is a biologic and a mainstay of treatment for many with dystonia.

Protected Access to New Botulinum Toxin
At the urging of DAN advocates, the Centers for Medicare and Medicaid Services issued a temporary unique billing code for a newly approved botulinum neurotoxin type A product. This prevented a bureaucratic delay from denying patients access to treatment.

Strong Message to Congress
Members of Congress regularly hear from the dystonia community through annual appointments on Capitol Hill, visits in district offices, and ongoing correspondence from DAN advocates on issues relevant to the community.
Hiking for Healing

61-year-old Avis Brodess is back in Austin, Texas after hiking 683-miles along the Israel National Trail (Shvil Yisra’el). The rugged two-month camping trek required careful preparation: supplies to bring, sites to view along the way, and creative ways to recharge the battery-powered electrodes in her brain that suppress symptoms of dystonia.

“I must have been delirious thinking I could walk across Israel. But I did it!” says Avis. “Sometimes you have to dream big when it feels like your world is collapsing.”

Avis is diagnosed with cervical dystonia. “As a trained athlete, knowing what my body could and could not do was something I took for granted for many years. Losing all control and enduring chronic pain was something I had never experienced.” The symptoms began in her 30s and became completely disabling: “Before my first DBS [deep brain stimulation] surgery I was so symptomatic and in such pain I never left home and barely left my bedroom.” 2017 was an especially difficult year. She endured five surgeries, three of which were brain surgeries to address complications with the deep brain stimulation system. “Suffering, pain, helplessness, despair, diminished dignity, and loss-of-self left me numb and paralyzed for months,” she says. “I was mourning the loss of Avis: Avis the athlete, the gregarious, energetic, strong, happy person.”

Before dystonia, Avis had a groundbreaking career in finance and a busy family life. She was a top ranked junior tennis player, an avid women’s rugby player, and cycled all over the world. In 2008, she underwent deep brain stimulation. The multi-step neurosurgical procedure involved implanting electrodes in her brain and a battery-powered stimulator in her chest wall. The stimulator must be charged by a remote control device every few days to keep it functional. If the hardware powers down, the dystonia returns in full force. Deep brain stimulation “gave me my life back,” says Avis. “I’m ecstatic where I am today.”

As soon as Avis was cleared medically, she was intent on doing something transformative, radical. She chose a hiking group led by a couple whose son was one of 72 Israeli military personnel killed in a helicopter crash in 1997. The hike began as a pilgrimage for families affected by the crash to heal from their loss. Since that time, the excursion has grown to include people from all walks of life, participating for various reasons. Avis was part of a core group of 30 hikers. Additional hikers joined and departed along sections of the trail, at times maxing out at about 200.
Avis’ journey culminated with an emotional evening when she was invited to speak to the group about her experience with dystonia and why she chose to make the trip. “Every emotion I felt over the past several years of helplessness and despair came flooding out. One by one everyone came up to hug me. I was in a safe place. They gave me the opportunity to let go.”

In her time with the hiking group, Avis came to realize that her reasons for making the journey were not so unusual: “Nobody sets out on a two-month hike just to hike. Whether it be divorce, the loss of a spouse, loss of a child, marital problems, illness, depression—everyone out there is trying to come to a place of peace. Whatever struggles I came to The Shvil with, I know my strength, courage, and circle of support have increased dramatically. The friendships I made will forever be an inspiration.”

**Giving it a ‘Tri’**

Jennifer Middlebrook of Kissimmee, Florida arrived at the starting line of last year’s Ironman 70.3 Augusta triathlon against incredible odds. Her training prepared her to swim, bike, and run the grueling duration of the race, but without daily medication she can barely take a step. Whatever struggles I came to The Shvil with, I know my strength, courage, and circle of support have increased dramatically. The friendships I made will forever be an inspiration.”

Jennifer Middlebrook fell in love with triathlons. admitted to the hospital for an aggressive orthopedic surgery that required severing the bones in both legs. By chance, a pediatric neurologist stopped by her room to chat with her orthopedic doctor. The pediatric neurologist examined Jennifer, and the surgery was canceled. She was ultimately diagnosed with dopa-responsive dystonia—a neurological, not orthopedic, disorder. A low dose of oral levodopa, a drug commonly used to treat Parkinson’s disease, proved to be the treatment necessary to make the symptoms all but disappear.

“On a normal day, I take one pill and can go 24 hours with no symptoms. If I go past the 24 hour mark I get horrible clawing and Charlie horses in my legs and feet. So bad that I am in tears until the meds kick in,” Jennifer explains. “It is definitely my miracle drug, and I will always appreciate to the depths of my heart that doctor who took the time to see me in the hospital that day.”

Jennifer was in her 40s when she began a structured running program to lose weight and improve her health. She ran her first 5K race in 2013. She completed her first triathlon in 2014. “After I completed my first tri, I was hooked,” she says. “My husband thought I was crazy.” Jennifer gradually conquered increasingly ambitious races, all the while carefully maintaining the delicate balance of self-care that kept the dystonia controlled. This involved scheduling her training around her medication schedule and prioritizing sleep and nutrition. “Some of these races were very difficult because of my dystonia,” she says. “Until I learned how to correctly regulate my meds, I would start feeling symptoms around mile 9 or 10 and would have to finish the last 5K of the race in terrible pain.”

In 2017, Jennifer completed the Ironman 70.3 which consists of a 1.2-mile swim, a 56-mile bike ride, and a 13.1-mile run. “The Augusta Ironman 70.3 is the longest that I could ever hope for my legs to be able to finish. It was an incredible and exciting day,” says Jennifer.

Already in 2018, Jennifer has completed six races, including a 56-mile bike ride. She is registered for several additional triathlons, three 5Ks, a half marathon, and she will revisit the Augusta 70.3 Ironman in a relay with her husband. The child who could not walk grew into a powerful athlete who cherishes every step she takes: “I love being able to say that I am a triathlete! It is a badge of honor that I wear with pride. I am not fast, but so far I have finished every race.”
What’s New in Botulinum

Botulinum neurotoxin injections are one of the most common treatments for dystonia. This therapy has been in use for 30+ years, and continues to evolve through research.

Several botulinum neurotoxin products are approved by the US Food & Drug Administration for use in cervical dystonia and blepharospasm. Physicians are free to use botulinum neurotoxin “off label” for additional dystonias.

How Does it Work?

Botulinum neurotoxin is injected into muscle. It blocks signals from the nerves that make the muscle contract. When the signals are blocked, the muscle relaxes. The injections are repeated every four to six months.

Is it Safe?

Yes. Botulinum neurotoxin injections have decades of research and clinical experience to show they are a safe and effective medical therapy. Potential temporary side effects include muscle weakness and difficulty swallowing, depending on the site of the injections.

4 Brands of Botulinum Neurotoxin are Available in the USA

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<thead>
<tr>
<th>Brand Name</th>
<th>Medical Name</th>
<th>Manufacturer</th>
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<tr>
<td>Botox®</td>
<td>OnabotulinumtoxinA</td>
<td>Allergan, Inc.</td>
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<tr>
<td>Dysport®</td>
<td>AbobotulinumtoxinA</td>
<td>Ipsen, Ltd.</td>
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<tr>
<td>Myobloc®</td>
<td>RimabotulinumtoxinB</td>
<td>US WorldMeds</td>
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<tr>
<td>Xeomin®</td>
<td>IncobotulinumtoxinA</td>
<td>Merz Pharmaceuticals</td>
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Each botulinum toxin product is a unique drug with distinct biological qualities. They are not interchangeable.

Coping Tip

The phase in the botulinum neurotoxin treatment cycle when symptoms begin to return before the next injection appointment is a critical time. As symptoms and/or pain increase, individuals may be more likely to:

- Push themselves to do tasks or activities that make symptoms worse.
- Find it more challenging to manage stress.
- Rely on unhealthy coping mechanisms.

If you are struggling at points in your botulinum neurotoxin therapy cycle, share your concerns with your doctor.
Developing new botulinum neurotoxin products. Revance is studying a new botulinum neurotoxin product called daxibotulinumtoxinA for treating cervical dystonia. This product may offer a longer benefit from injections than other products, which means fewer appointments each year.

Decreasing side effects. These efforts include studying the chemical reaction of botulinum neurotoxin in body. This helps ensure the botulinum neurotoxin is targeted to act only where it is needed.

Decreasing injection pain. Investigators are experimenting with how botulinum neurotoxin solution is reconstituted to reduce acidity and lessen muscle pain. Studies have also explored the use of nitrous oxide and topical pain relievers during injections to help make patients—especially children—more comfortable during injections.

Muscle targeting. Electromyography (EMG) has long been used to help clinicians inject botulinum neurotoxin by identifying overactive muscles. Ultrasound is also now be used to guide the injections for improved accuracy.

Cost savings. Most botulinum neurotoxin products are stored as powders that have a shelf life of several years. The powder must be reconstituted with saline before it becomes injectable. After reconstitution, the shelf life is reduced to 8-24 hours. Some studies, however, suggest longer shelf life. The ability to safely store reconstituted botulinum neurotoxin solution—without any loss of potency—may have a considerable impact on the cost of therapy by reducing waste.

Optimizing injection results with additional therapies. Individuals with blepharospasm who were unable to open their eyes, and who did not respond to botulinum neurotoxin injections, did respond favorably to injections after an eyelid-lifting surgical procedure. This was demonstrated in a small clinical study.

More flexible treatment schedules. Botulinum neurotoxin injections are typically repeated on a strict schedule of 12–16 weeks. Many people experience a gradual return of symptoms before the next injections. Clinical researchers are carefully exploring injecting select patients on an alternative schedule, for example every 6 weeks, with promising preliminary results.

Many thanks to DMRF Clinical Fellow Avram Fraint, MD for reviewing the content of this article.
Researchers study the brain pathways associated with dystonia to pinpoint problem areas in the networks. Once the problem areas are identified, they can strategize ways to correct the imbalances. Brain structures implicated in dystonia include the basal ganglia, cerebellum, thalamus, midbrain, and cortex. Research is beginning to suggest that different brain structures may play important roles in different types of dystonia.

**What’s Different about the Dystonia Brain?**

As researchers continue to study the structures and pathways at play in dystonia, there seem to be several fundamental brain functions that are out of tune. These discoveries may ultimately help clarify the structures and pathways involved:

**The brain has a lead foot.**

Driving a vehicle smoothly requires careful balance of controlled acceleration and deceleration. Similarly, in order for a person to move in a controlled way, certain functions of the brain must be activated while other areas are suppressed. In dystonia, the brain loses the ability to apply the brakes to the functions that must be suppressed for normal movement to happen. This leads to chaotic signals from the brain to the muscles, resulting in too much muscle activation, the signature feature of dystonia.

**The brain misunderstands signals from the body.**

The nervous system must interpret information from the senses in order to coordinate and perform movement. Individuals with dystonia—as well as non-symptomatic gene mutation carriers—have subtle sensory problems that prevent the sensory and motor systems from cooperating properly in order to move the body in a controlled way.

**The brain is an over-achieving, stubborn learner.**

In dystonia, movements that the brain has learned over time—blinking, writing, walking, etc.—may become abnormal. Movements that were once mastered get “re-learned” incorrectly. And the brain cannot easily un-learn the abnormal movements or postures once they are imprinted. This may explain why the benefits of deep brain stimulation therapy for dystonia are delayed—it takes time for the brain to reset these movement habits.

Dystonia is a disorder of the brain and nervous system. The problem appears to lie in the network of pathways between specific brain structures. Nerve signals travel along these pathways carrying the instructions necessary for the brain to function and body to move. When the pathways malfunction, and areas of the brain responsible for movement cannot communicate properly, movement disorders such as dystonia can occur.
What New Research is Happening?

Investigators around the world are working to understand dystonia. DMRF is currently funding several grants focused on brain networks and pathways.

**Striatal Neuron Activity Patterns in Dystonia**

*Ellen Hess, PhD, Emory University*

The root causes of dystonia are not clearly understood but abnormal signaling in the striatum, part of the basal ganglia, is thought to be involved. It is now possible to record the firing patterns of dozens of neurons simultaneously in the striatum of awake dystonic mice to reveal the abnormal ‘neural code’ associated with dystonia. Technology known as in vivo microscopy is used to visualize the firing patterns of neurons within the striatum of mice with dystonia. The mice movements will also be recorded after they have been treated with drugs that alleviate the dystonia. By comparing the different firing patterns with and without dystonia, these experiments will reveal the neural code associated with dystonia for the first time. In the short term, these experiments provide important information that could be useful to guide stimulation parameters for deep brain stimulation in dystonia patients. In the long-term, understanding the neural code of dystonia will facilitate the development of novel therapeutics that target the abnormal neural code.

**What Treatments are Being Explored to Target Brain Pathways?**

- Deep brain stimulation
- Non-invasive neuromodulation techniques such as repetitive transcranial magnetic stimulation (rTMS) and transcranial direct current stimulation (tDCS)
- Brain rehabilitation/re-training

**Integrative Network and its Proprioceptive Modulation to Probe Physiology and Therapy of Cervical Dystonia**

*Aasef Shaikh, MD, PhD, Case Western Reserve University*

Cervical dystonia, affecting the neck muscles, is the most common form of dystonia. It is believed that cervical dystonia is caused by abnormal activity in the basal ganglia, a part of the brain that coordinates movement. However, new studies are suggesting that impairments to the cerebellum, the part of the brain that control coordination, and sense of body position (proprioception) can cause dystonia as well. Dr. Shaikh hypothesizes that these three brain functions—cerebellum, basal ganglia, and proprioception—work together as a ‘unifying network’ to influence the control of head movements. This study focuses on proprioception and the effect that vibration to the neck muscles may have on reducing proprioceptive impairment to help treat dystonia. The investigators measure the effects of neck vibration on the head movements of patients with cervical dystonia using a high-resolution magnetic field position tracking system. They will also measure the effects of neck vibration on the activity of the basal ganglia. The goal of this project is to define non-invasive, painless, and cost-effective therapies based on a novel, unifying network model detailing the biological mechanisms of cervical dystonia. Dr. Shaikh is a past DMRF Clinical Fellow.

**Three-Dimensional Network Architecture of Dystonia**

*An Vo, PhD, The Feinstein Institute for Medical Research*

Brain imaging techniques have advanced the understanding of network abnormalities in dystonia. It remains unknown, however, whether dystonia-related brain networks can be identified with resting state functional MRI (magnetic resonance imaging). MRI produces detailed, three-dimensional images of the brain. It is also unclear whether such brain networks correlate to underlying anatomical connections. Dr. Vo hypothesizes that dystonia is characterized by distinct functional and structural networks in the resting state. To test this hypothesis, she and her team are examining resting state functional MRI and diffusion MRI data in patients with dystonia. This work will advance the understanding of brain network architecture in dystonia. The new information should help identify areas within the brain network to target treatment and strategies to individually customize treatment.
**People on the Move**

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

TalentLaunch is a network of independently operated staffing and recruitment companies. At its headquarters grand opening celebration, TalentLaunch honored the family of employee Kevin Knaack with a surprise raffle to support the DMRF. Items for the raffle were donated by the Cleveland Cavaliers. TalentLaunch matched the money raised at the event and submitted a $2,000 donation to DMRF on behalf of the Knaack Family.

Co-Leaders of the Minnesota Dystonia Support Group, Brad and Shanna Schmitt, were invited by University of Minnesota Physical Therapy PhD student Rebekah Summers to speak to a group of future physical therapists about dystonia.

Supporters braved the rain to attend the 3rd Twin Cities Dystonia Zoo Walk organized by Shanna and Brad Schmitt, Billy McLaughlin, and members of the Minnesota Dystonia Support Group. Speakers included dystonia researcher Robert Raike, PhD. Governor Mark Dayton issued a proclamation recognizing June 16 as Dystonia Awareness Day in acknowledgement of the event.

A Dystonia Patient Conference took place in partnership with Cedars-Sinai Medical Center in Los Angeles. Speakers included Elliot Hogg, MD; Michele Tagliati, MD; and Echo Tan, MD.

A Dystonia Patient Symposium took place in partnership with Northwestern Medicine in Chicago. Speakers included Danny Bega, MD, MSCI; Cynthia L. Comella, MD; Niccolo E. Mencacci, MD, PhD; Joanna Blackburn, MD; Avram Fraint, MD; and DMRF Chief Scientific Officer Jan Teller, MA, PhD.

Amanda Sleeper organized the Nashua, New Hampshire Dystance4Dystonia Walk on June 2 to raise dystonia awareness and funds for research toward a cure.

Leader of the Dystonia Support & Advocacy Group of San Diego County Martha Murphy and member Bette George promoted awareness by distributing DMRF materials and fielding questions at the East County Health Fair.

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Social Giving
DMRF Supporters Use Facebook Fundraisers to Collect Donations

Ed and Donna Gewirtz have supported DMRF by inviting their contacts to give online and attend events.

DMRF is grateful to everyone who is using Facebook’s fundraiser tools to collect donations to support our mission. If you are raising donations via Facebook—or would like to begin doing so—please send us a message on Facebook. Facebook does not notify DMRF of these fundraisers, and we wish to acknowledge the generosity of all our supporters.

Longtime DMRF supporter Ed Gewirtz raised $1,700 in a matter of days by creating a Facebook fundraiser to celebrate his 70th birthday. He has lived with spasmodic dysphonia and segmental dystonia for 40+ years. “Choosing the DMRF as my charity of choice for my birthday fundraiser was a no brainer,” said Ed. “Money for research grants awarded by the Foundation along with its dedication to raise public awareness make me truly hopeful that finding a cure for all forms of dystonia one day is possible.” Among the many DMRF campaigns they have supported, the Gewirtz family are dedicated supporters of the annual Dystonia Bronx Zoo Walk.

Many thanks to the following Facebook fundraisers:

• Saundra Bernstein
• Teresa Catlin
• Lynne Garrow
• Mesha Kilbourne
• Marjorie O’Rourke
• Beth Paolero
• John Michael Cahall
• Jon Davis
• Ed Gewirtz
• Nathan Monroe
• Ashleigh Paige
• Kayla Pounds

Is someone missing from this list? Please let us know at dystonia@dystonia-foundation.org or 312-755-0198.

What is the Global Dystonia Registry?

The Global Dystonia Registry (GDR) is a confidential database of information voluntarily provided by individuals with dystonia. The goal of the GDR is to support future dystonia studies, including clinical and research trials. Although dystonia has many different manifestations, most experts believe all dystonias share a common mechanism that causes the disorder. Collecting information from different patient populations will help identify the common features they share. To date, 5,200 individuals have participated in this critical research initiative.

To learn more and/or register, go to: globaldystoniaregistry.org

The GDR compliments the scope of research for the Dystonia Coalition. The Dystonia Coalition is part of the Rare Diseases Clinical Research Network (RDCRN), an initiative of the Office of Rare Diseases Research (ORDR), NCATS. This consortium is funded by the NCATS.

Genetic Researchers Need Your Help

Finding genes associated with dystonia may be the key to understanding how to better treat or cure the disorder. A collaborative team from Mount Sinai Beth Israel in New York is conducting a study aimed at finding these genes.

If there are two or more living individuals in your family with any form of dystonia you may be eligible to volunteer for this important study.

Participants will be asked to complete a short questionnaire and medical record release form, sign study consents, and give a blood sample. Your information will be kept strictly confidential.

For more information please contact:
Deborah Raymond, MS, CGC
Genetic Counselor
Mount Sinai Beth Israel
P: 212-844-8713
E: deborah.raymond@mountsinai.org
One of the most powerful benefits of DMRF Zoo Walks and events is the sense of community formed when families gather around a common cause. In addition to raising dystonia awareness and funds for medical research toward a cure, these events provide a space for individuals and families to meet and bond.

DMRF members go above and beyond to support one another, often traveling great distances to attend events out of state. These are just a few examples of the extraordinary ways in which our members make the DMRF not just an organization, but a family.

“Supporting and organizing events to bring awareness to dystonia is a passion close to my heart. I want to bring awareness and acceptance to our home state in honor of my little hero—and everyone affected by dystonia. The amazing individuals my family has met along the way have truly turned into our Dystonia Family.”

—Sunshine Fox, DMRF Support Leader. Sunshine’s eight-year-old son Aidan has generalized dystonia. She, Chelsi Christman, and Sarah Ernstberger were so impressed by the Hunt for a Cure event they attended in Chicago that they organized the Indy Hunt for a Cure in their home state. The Chicago Hunt for a Cure was organized by the Farber family.

June Tritley, who organizes the St Louis Zoo Walk, and Shayla Anthony, who is a member of the Western Pennsylvania Dystonia Support Group, supported fellow mom Melissa Phelps who organizes the Cincinnati Zoo Walk.

Kayla Pounds and her supporters are loyal participants at Zoo Walks in Cincinnati and Cleveland.

Register for DMRF events at dystonia-foundation.org/events
Rosemary Young, who hosts the Detroit Zoo Walk, has supported multiple events including the Cincinnati Zoo Walk. She and family are pictured with Karen Flanagan, whose original Cleveland Zoo Walk has been replicated across the country. Karen has supported the Detroit Zoo Walk as well as St Louis and others.

“It’s important for me to support these Zoo Walks because it’s a great way to raise much-needed money for dystonia research. And it’s a great way for the people who are zoo visitors to find out about dystonia and know we exist!”

— In addition to being one of DMRF’s most loyal Twitter followers, Eric Jansen of Florida has supported numerous DMRF events including the Cleveland and Pittsburgh Zoo Walks.

Join us for a day at the zoo in support of the DMRF.

- Portland – August 19
- St. Louis – August 26
- Cincinnati – September 8
- Providence – September 8
- NYC/Bronx - September 16
- Cleveland – September 22
- Pittsburgh – September 23
- Fresno – September 29
- Philadelphia – September 30
- San Diego - November 3
- Phoenix - November 17

And Don’t Miss...

- Dystonia Awareness Month – September
- Dogs for Dystonia Walk (IA) – August 25
- Albuquerque (NM) Educational Meeting – September 9
- Stomp Out Dystonia (WI) – September 22
- Indy Hunt for a Cure – September 30
- Phoenix Educational Meeting - October 13
- Cleveland Educational Meeting - October 14
- Northwest Educational Meeting (WA) - October 20
- Boston Educational Meeting - October 28
- Chicago Basket Bash – October 28
- Dallas Educational Meeting - November 4
- TCS New York City Marathon – November 4
- Putnam, CT Dystance4Dystonia Walk – TBA
- St. Louis Educational Meeting – TBA
“One of the greatest challenges of living with dystonia is coming to terms with loss and grief. We usually associate grief with the death of a loved one, but grief can occur with any major loss in one’s life,” explains Karen K. Ross, PhD, clinical psychologist and DMRF Vice President of Support.

Individuals with dystonia experience the loss of the person they once were and the dream of the person they thought they were going to be. They may grieve the loss of a career, loss of financial security, loss of independence, and loss of identity.

“When you talk about grief, you can’t just talk about the person affected by dystonia,” says Dr. Ross, “because that grief is going on throughout the whole family. Spouses are affected. Siblings may feel a great deal of sadness and not know how to express it. Parents are grieving the loss of their dreams and fantasies about how their child will grow up, who they will be. Grandparents and other family members will also be deeply affected.”

Grief is a highly individual process. Everyone grieves a little differently. Adults and children grieve differently. Grief has no predictable timetable. There is no specific amount of time a person is “supposed” to grieve a loss.

Many people need help to work though grief. Dr. Ross elaborates: “Often when people are grieving they are also in shock. A trained mental health professional can help a person deal with loss and their inner feelings so they can move through the grief in a healthy way. I would also emphasize that your dystonia doctor cannot be your mental health support professional. Your neurologist is not a therapist and does not have the time or resources to help you in that way. But your doctor can be an excellent referral source.”

Working through grief is a process of learning to live with loss. The benefits of attending to grief are both emotional and physical, and can have a dramatic impact on improving overall quality of life.

**Common Emotional Reactions to Dystonia**

The following are common emotional reactions to dystonia. Individuals may experience a few or all of these. Some feelings may be more intense than others. It is common for individuals who are grieving to cycle back and forth through emotions over time. The information below is adapted from the book *On Grief and Grieving: Finding the Meaning of Grief through the Five Stages of Loss* by Elisabeth Kübler-Ross, MD and David Kessler.

**DENIAL.** Denial is often an initial reaction to loss. Something shocking has occurred. The world becomes overwhelming. Individuals may feel numb. They may wonder how they can go on, if they can go on—even why they should go on. Denial helps pace feelings of grief. It is the mind’s way of letting in only as much as a person can handle. As individuals recognize the reality of a loss, denial fades. Feelings that were denied and suppressed may surface.

**ANGER.** Anger is a necessary part of the healing process for many people. Anger may seem endless. People usually know more about suppressing anger than feeling it. Anger can extend to friends, doctors, family, themselves, but also to their faith or belief system. They feel cheated and abandoned. Anger can be an anchor, giving temporary structure to the nothingness of loss. The anger becomes something to hold onto. Anger feels better than feeling nothing.
BARGAINING/GUILT. The wish that life would go back to the way it was. After a loss, individuals may be consumed with hypothetical scenarios: “If I promise to be a better person, maybe I will wake up and realize this was all a bad dream.” Individuals become consumed by what could have been: “If only I was diagnosed sooner…” or “What if the diagnosis is all wrong…” Guilt is common. Individuals blame themselves for what they believe they could have done differently to change the outcome. Bargaining is an attempt to avoid feeling the pain of loss.

DEPRESSION. As grief progresses, individuals often feel empty. The depression of grieving may feel as though it will last forever. People feel sad and alone. Depression after a loss is normal. However, individuals with dystonia may be vulnerable to serious depressive disorders. If feelings of depression become persistent or overwhelming, professional help is critically important.

“I stuffed my grief. I was afraid of getting sucked into an abyss if I got sad. My days were spent trying to hang on and take care of myself. I didn’t think I could manage self-care if I allowed myself to get pulled under by sadness. I could have used some grief education at the time of diagnosis.”

~ Elizabeth Schultz, DMRF Supporter

At that point I realized, well, I had a new life. It’s not what I anticipated, but it’s what I have. So I started finding different ways of doing things. I learned what I had to do to have a better quality of life. I don’t think we ever stop grieving, whether we lose somebody or lose ourselves. I still hate dystonia. I still get angry and sometimes depressed. But it’s ok. Learning new life skills doesn’t make you less of a person.

~ Gina Rosendall-Saucedo, Founder & Leader of Mid-Michigan Dystonia Support Group
Tips for Coping

• Grief is a normal response to a dystonia diagnosis.

• It is essential to share your feelings with loved ones, a mental health therapist, and/or qualified faith-based counselor.

• Recognize that family members may be grieving.

• Build a network of supportive people and resources: family, friends, peer support groups, and online groups.

• Seek out expert medical care to make sure you are informed of all dystonia treatment options.

• Take good care of yourself: exercise, eat well, prioritize sleep/rest, and manage stress.

• Make time for creativity and pleasure. Do things that you enjoy and that are meaningful to you.

Time to Ask for Help

It may be time to talk to a mental health professional if:

• You don’t feel like yourself.

• You feel overwhelmed by sadness, anger, worry, or hopelessness.

• You can’t do the things you like to do.

• Friends and family have expressed concern about you.

• You feel like you need help.

To locate a mental health professional, ask your doctor, health insurance provider, or a professional organization such as the American Psychological Association (apa.org) or American Psychiatric Association (psychiatry.org). Or ask for recommendations from family and friends.

Acknowledgments

Karen K. Ross, PhD is a clinical psychologist and marriage and family therapist formerly in private practice in California. Dr. Ross began working with the DMRF in the very early years of the organization, soon after her son was diagnosed. She is the author of Holding the Hope: A Parent’s Guide to Living with Dystonia.

Acceptance

Acceptance is recognizing that a new reality is the permanent reality. A person may not like the new reality, but they make peace with it. They adjust and adapt. Finding acceptance may just mean having more good days than bad days. Individuals make new connections, new meaningful relationships, new discoveries about themselves. Instead of denying their feelings, they listen to their needs. There are moments of joy, gratitude, and peace.

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Dystonia has this cruel side to it where it attacks you with what you love to do the most. I had dedicated my life to my music, and it was all slipping away.

Once I had a diagnosis, it was important for me to get connected to other people who have the same thing. The relief of knowing what it was didn’t last long, when you find out how hard it can be to treat and that so far nobody has cured it. A sense of hopelessness sets in. My symptoms continued to get worse, and I had to completely quit playing. That’s a pretty big loss. It’s especially cruel for musicians because typically if a musician gets a little down, if they get depressed, you know what they like to do? They like to play their music! It makes them feel better. To lose that is to lose something very profound. Even though I walk down the street and you’d never know I have dystonia, it impacted my life dramatically—like it does a lot of people.

Once you get through that initial period of being shocked or discouraged you can focus on ways to adapt. My story has been all about adaptation and thinking about what are the things that I can still do. Dystonia was one of the worst things that ever happened to me, but it didn’t stop me from doing what I love. I don’t know how to make that happen for anyone else, but if it can happen for me it can happen for any one.

—Billy McLaughlin, Musician, DMRF Awareness Ambassador
Oromandibular dystonia may also be referred to as cranial dystonia.

Oromandibular dystonia symptoms usually begin later in life, between the ages of 40 and 70 years.

Musicians who play wind instruments may develop embouchure dystonia involving lips, jaw, and tongue.

Symptoms of oromandibular dystonia include:
- Grimacing, lip pursing, and other involuntary movements in the face and lips
- Inability to close the mouth
- Jaw clenches shut
- Teeth grinding
- Bottom jaw to shift toward one side or to the back
- Jaw pain
- Involuntary tongue movements

Oromandibular dystonia can occur sporadically or be caused by exposure to certain drugs, physical trauma, brain injury, or additional secondary factors.

Oromandibular dystonia frequently occurs with blepharospasm, a focal dystonia of the eyelids and brow. Oromandibular dystonia can also occur along with cervical dystonia or generalized dystonia.

Oromandibular dystonia is often worsened by emotional stress, talking, or chewing. Paradoxically, in some people, activities like speaking and chewing reduce symptoms.

Movement symptoms are often partially relieved by additional sensory tricks such as gently touching the lips or chin, chewing gum, biting on a toothpick, wearing an orthodontic device or mouth guard, or placing a finger near an eye or underneath the chin.

Oromandibular dystonia can cause profound disability due to impaired eating, swallowing, and speaking. Depression and social isolation are common and, if unaddressed, can be debilitating.

Treatments may include oral medications, botulinum neurotoxin injections, and/or deep brain stimulation. Complementary therapies may include speech therapy, swallowing therapy, nutritional counseling, and mental health evaluation and counseling.

Researchers around the world are investigating the causes of oromandibular dystonia and exploring new treatment strategies.

COPING TIPS
Members of the DMRF’s Oromandibular, Blepharospasm & Cranial Dystonia Support Forum on Facebook were asked to name their top coping mechanisms. Below is a sampling of the responses. Join the group at https://www.facebook.com/groups/OMDBleph/
- Talking
- Chewing gum
- Sleeping
- Singing
- Humming
- Botulinum neurotoxin injections
- Managing stress
- Meditation
- Exercise
- Communicating with other people with dystonia
- Seeing my mental health therapist as needed
- Focusing on a hobby
Contribute to Research by Registering as a Brain Donor

You can make an important contribution to dystonia research by registering in advance as a brain donor.

The DMRF works in partnership with the Harvard Brain Tissue Resource Center at McLean Hospital to maintain a private collection of brain tissue from individuals with all forms of dystonia. 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.