



DYSTONIA
MEDICAL
RESEARCH
FOUNDATION

Dystonia Dialogue

NEWSLETTER OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

Winter 2022 | Volume 45 • No.3

ADVANCING DYSTONIA RESEARCH SINCE 1976



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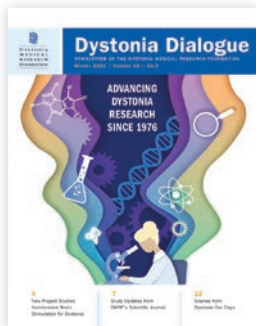
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Dystonia investigators around the world are expanding the boundaries of what is known about dystonia and implications for novel treatments. See page 4 to read about the latest research project supported by DMRF.

The Dystonia Dialogue is supported by Ipsen Biopharmaceuticals.

WHAT IS DYSTONIA?

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

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

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

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Foundation Update



Mark Rudolph
President

The DMRF believes the best service we can provide the dystonia community is to work every day toward better therapies and a cure. We will do the work necessary to reach our goal, no matter where in the world we must go for answers. The leadership of the DMRF is reminded every day that the truest measure of our research efforts is the impact on people's lives.

We are proud to announce an additional DMRF-funded research project, thanks to the support of the Cure Dystonia Now Fund. See page 4 to read about efforts to develop non-invasive therapeutic brain stimulation for focal dystonia by past DMRF research fellow Leighton Hinkley, PhD. Non-invasive neuromodulation is an exciting and fast-developing area of dystonia research with great potential for innovative treatment approaches.



Janet L. Hieshetter
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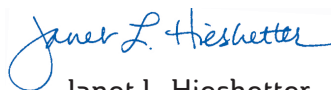
In the meantime, until additional therapies and a cure are available, the DMRF remains committed to providing support and information to individuals and families impacted by all types of dystonia. DMRF hosted a number of recent webinars, which are available for viewing on our YouTube channel, on topics including Dystonia & Physical Therapy, the Legacy of the DYT1/TOR1A Gene Discovery, and Registering as a Brain Donor.

It has been gratifying this year to help re-unite members of the dystonia community after the forced isolation of the pandemic. See page 12 for information on our return to in-person Dystonia Zoo Days and additional community events—as well as the 3rd Virtual Dystonia Zoo Day. On page 5 you can read about DMRF support groups hosting “Dystonia Strong” events to help individuals build their personal support networks. Many support groups continue to offer virtual meetings via video conferencing and/or hybrid meetings that provide the opportunity to participate in-person or virtually. If you haven't already, we encourage you to reach out to the nearest DMRF support group and/or online support forums. There is simply no substitute for connecting with others who understand life with dystonia.

The DMRF leadership never loses sight of how much we appreciate and depend on the support of our community. We welcome everyone who wishes to join us and be part of our efforts to make a difference. Thank you for being a part of the DMRF.



Mark Rudolph
President



Janet L. Hieshetter
Executive Director

SIGN UP FOR E-NEWS

DMRF offers a free monthly email update on news, activities, and events.

For the latest information from the DMRF community, sign up at: dystonia-foundation.org/email

DMRF-Funded Project Explores Non-Invasive Neuromodulation Therapy for Focal Dystonia

Earlier this year, DMRF issued a call for research proposals focused on non-invasive brain stimulation therapies to treat dystonia. The following project was supported through DMRF's Cure Dystonia Now Fund.

Personalized Functional Neuromodulation of Common Deficits in Focal Dystonias

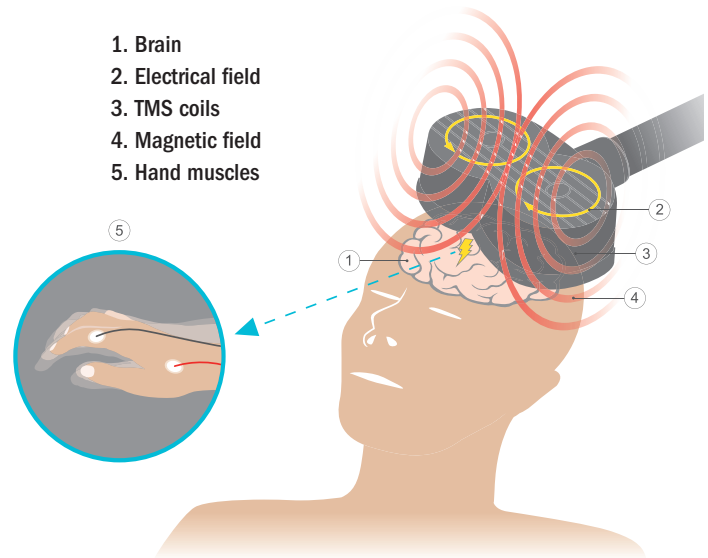
Leighton Hinkley, PhD

University of California, San Francisco

Non-invasive neuromodulation—where brain stimulation is delivered without surgery—is an exciting new method for treating movement disorders including focal dystonia. One particular technique, repetitive transcranial magnetic stimulation (rTMS), has provided clinical benefit for many neurological and psychiatric conditions and has been approved by the US Food & Drug Administration (FDA) to treat conditions such as major depressive disorder. While great effort has been made over the past two decades to develop rTMS as a treatment option for focal dystonia, studies have failed to deliver a consistent effective protocol to reduce the dystonia symptoms.

Although there are different ways to deliver rTMS, most studies using rTMS for dystonia stimulated the exact same region of the brain across all patients, assuming that this one location is the focus of the disorder. Focal dystonia can impact different structures of the body, for example, the vocal cords in laryngeal dystonia or the hand in task-specific focal hand dystonia. One reason why previous rTMS trials for dystonia have not had great success may be because the optimal rTMS stimulation target is not in the exact same location for each and every person.

In this study, investigators are adopting a personalized approach for identifying the correct place to stimulate using rTMS for focal dystonia. They hypothesize that the specific regions of the brain that act as dystonia “hotspots” for stimulation will vary across the frontal and parietal lobes of the brain in each patient, true to the nature of dystonia being different in every individual. To identify these specific hotspots, they take a next-generation approach using non-invasive neuroimaging including functional magnetic



Non-invasive neuromodulation like rTMS delivers stimulation to targets in the brain through the skin and skull.

resonance imaging (fMRI) and magnetoencephalography (MEG) to identify abnormally connected or abnormally active regions of the brain in patients. Resting-state fMRI maps are a powerful way to look at functional connections in the brain and differences in those connections. Guided by this brain imaging data, the investigators will generate personalized maps of optimal sites to stimulate with rTMS. Using these personalized maps as a guide, they will deliver a single session of rTMS to see if stimulating that patient-specific region has an effect on symptoms of laryngeal dystonia and task-specific focal hand dystonia as well as some of the cognitive and behavioral features seen in those movement disorders.

The goal of the project is to provide a framework and option for delivering neuromodulation in a better way than what is currently available. The investigators need to understand the best way to deliver neuromodulation for each patient before advancing to large scale treatment trials and ultimately the clinic. A more informed approach guided by neuroscience for the treatment of dystonia will ultimately help patients get the greatest benefit from neuromodulation.

Dystonia Strong Events Re-Unite Community



DMRF support groups across the country hosted Dystonia Strong-themed events to help the community re-connect after the social isolation of the Covid-19 pandemic. Dystonia support groups are invaluable sources of information, understanding, validation, and friendship. Support groups that participated include the Southeast Pennsylvania Support Group led by Raman Patel, the Fairfield, CA Support Group led by Carol Flynn, the North Carolina Support Group led by Crystal Edmonds, and the Metro Detroit Support Group led by Jules Watkins.

With input from the community, DMRF also launched a line of Dystonia Strong awareness merchandise including a baseball style shirt, yard flag, notecards, magnets, and more. For more information, visit: dystonia-foundation.org/strong



Thank you to Janice and Len Nachbar for successfully requesting a proclamation recognizing Dystonia Awareness Month in September from Mayor Laura Hoydick in their home city of Stratford, Connecticut. The Nachbars have tirelessly worked to increase dystonia awareness and support medical research toward a cure on behalf of their late daughter and beloved dystonia advocate Joanna Manusov. Joanna's dog Nicki was in attendance for the photo.

Create a Legacy of Caring

The DMRF Legacy Society was created to recognize those who have made a lifetime commitment to the mission against dystonia. There are a number of planned giving options to build a legacy through the DMRF, either by joining our Legacy Society or making a specific gift. You can make a commitment of support today that is fulfilled in the future.

Options include:

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

For more information, please contact Director of Development Debbie Durrer at ddurrer@dystonia-foundation.org or visit dystonia-foundation.org/legacy

Take Action to Give Dystonia a Voice: Join the Dystonia Advocacy Network

The Dystonia Advocacy Network (DAN) is a grassroots organization that brings individuals affected by dystonia together to speak out with a single, powerful voice on legislative and public policy issues that impact the dystonia community. The DAN mobilizes the dystonia community throughout the year to make a difference.



Dystonia
Advocacy Network

The DAN welcomes and represents individuals with all forms of dystonia and is led by the following dystonia organizations:

- Benign Essential Blepharospasm Research Foundation (BEBRF)
- Dystonia Medical Research Foundation (DMRF)
- Dysphonia International (formerly National Spasmodic Dysphonia Association)
- National Spasmodic Torticollis Association (NSTA)

Dystonia advocates develop relationships with their legislative leaders to help them understand the challenges of living with dystonia. The DAN continuously works to adopt and advance a legislative agenda that raises awareness of dystonia, educates policymakers about dystonia, addresses patient care issues, and moves research forward. Your voice is needed to help find the cure for dystonia.

The number of engaged dystonia advocates has more than doubled over the past two years, and we thank everyone who has stepped up to represent the dystonia community in this important way.

To learn more about becoming a legislative advocate, contact DMRF at advocacy@dystonia-foundation.org or call 800-377-3978. You can learn more about DAN's priorities by visiting: dystonia-foundation.org/advocacy

Advocacy Accomplishments

Here are just a few examples of how DAN advocates have made an impact.

- ▶ 1st Congressional Briefing on Dystonia
- ▶ Protected access to deep brain stimulation
- ▶ \$23M in dystonia research through Department of Defense Peer-Reviewed Medical Research Program
- ▶ Expanded dystonia research portfolio at National Institutes of Health to \$14M annually
- ▶ Safeguards for new biologic therapies
- ▶ Outlawed discrimination based on genetic information
- ▶ Protected access to new therapeutic botulinum neurotoxins
- ▶ Increased awareness in both houses of Congress, Centers for Medicare & Medicaid Services, Food & Drug Administration, and additional federal agencies

"My father had dystonia, I have dystonia, and my daughter has dystonia. It is my hope and prayer that we can wipe dystonia out for future generations.

With everyone's help, I believe we can."

*Carole Rawson, DMRF Vice President of Public Policy
Committee & Chair of Dystonia Advocacy Network*



From the DMRF Journal Deep Dive into Blepharospasm

Blepharospasm is a type of dystonia characterized by spasms of the muscles that control the eyelids. Blepharospasm can manifest as exaggerated blinking, eyelid fluttering, and difficulty opening the eyelid, which is controlled by a separate muscle than the one that closes the eyelid. In addition to the motor features, individuals with blepharospasm often report non-motor symptoms such as dry or gritty sensations in the eyes, light sensitivity (where light is not only unpleasant but can trigger spasms), depression, and anxiety. Roughly half of those with blepharospasm also experience a progression in their dystonia from the muscles that control their eyelids to other regions of the upper face, jaw, tongue, and neck, among other areas. Blepharospasm can cause disabling vision impairment.



AT A GLANCE

- **Investigators studied 10,000+ cases of blepharospasm.**
- **Common symptoms include increased blinking, soreness or pain, light sensitivity, and dry eyes.**
- **60% of individuals experienced some degree of symptom spread.**

Diagnosis is often delayed because the symptoms are not well recognized. The purpose of a study by the Dystonia Coalition led by past DMRF Clinical Fellow Laura Scorr, MD was to provide a comprehensive picture of blepharospasm's clinical features including presenting features, motor features, and non-motor features. The first part of the study involved a research review that summarized clinical features for 10,324 cases taken from 41 prior reports. The second part involved a summary of clinical features for 884 cases enrolled in a large multicenter cohort collected by Dystonia Coalition investigators, along with an analysis of the factors that contribute to the spread of dystonia beyond the eye region.

From the cases in the literature and the Dystonia Coalition, blepharospasm typically begins in the 50s and is more frequent in women. Many individuals presented with motor

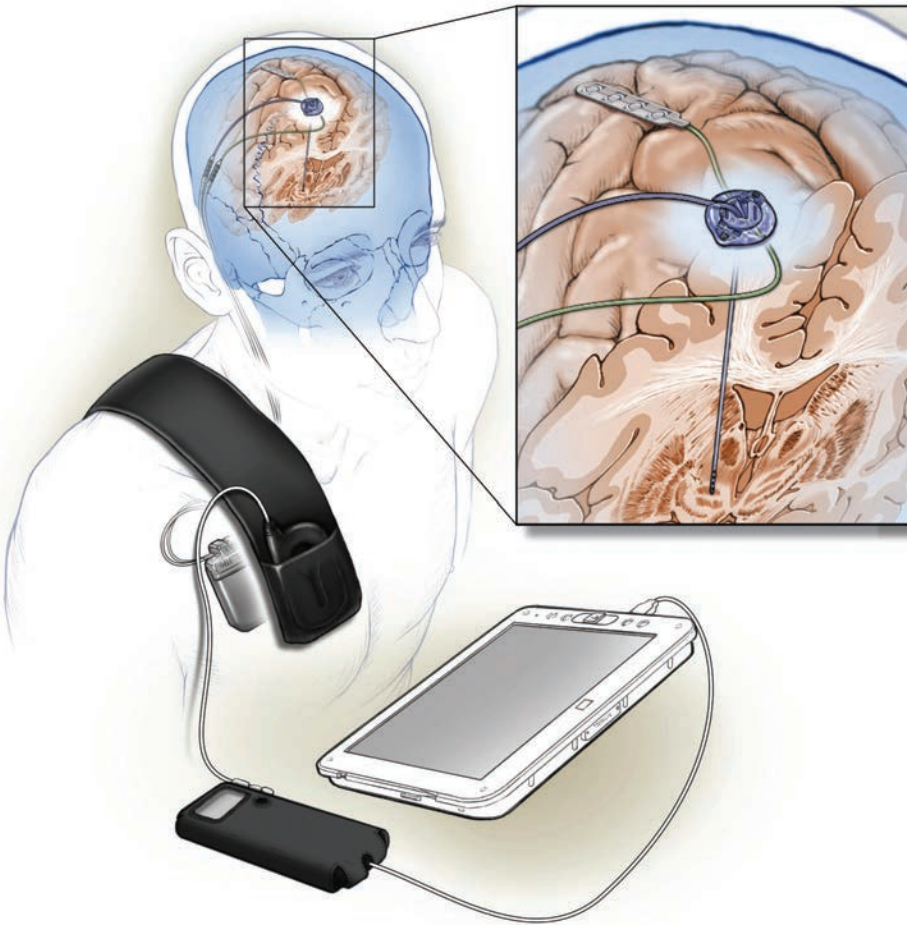
symptoms such as increased blinking (52%) or non-motor sensory features such as eye soreness or pain (39%), light sensitivity (36%), or dry eyes (11%). Around half of the 884 cases in the Dystonia Coalition group study reported lessened dystonia severity when using a sensory trick such as gently touching the eyes. Non-motor features were also common including anxiety disorders (34–40%) and depression (21–24%). Among cases presenting with blepharospasm in the Dystonia Coalition patients, 61% experienced spread of dystonia to other regions, most commonly the oromandibular region and neck. Features associated with spread included severity of blepharospasm, family history of dystonia, depression, and anxiety. This study provides a comprehensive summary of the

features of blepharospasm, along with novel insights that will help reduce misdiagnosis and better treat patients based on an understanding of the possibility of symptom progression.

*Scorr Laura M., Cho Hyun Joo, Kilic-Berkmen Gamze, McKay J. Lucas, Hallett Mark, Klein Christine, Baumer Tobias, Berman Brian D., Feuerstein Jeanne S., Perlmuter Joel S., Berardelli Alfredo, Ferrazzano Gina, Wagle-Shukla Aparna, Malaty Irene A., Jankovic Joseph, Bellows Steven T., Barbano Richard L., Vidailhet Marie, Roze Emmanuel, Bonnet Cecilia, Mahajan Abhimanyu, LeDoux Mark S., Fung Victor S.C., Chang Florence C.F., Defazio Giovanni, Ercoli Tomaso, Factor Stewart, Wojno Ted, Jinnah H. A. Clinical features and evolution of blepharospasm: a multicenter international cohort and systematic literature review. *Dystonia*. 2022; 1. doi:10.3389/dyst.2022.10359*

Dystonia, the DMRF's scientific journal, is available at: dystonia-foundation.org/journal

Case Study: “Smarter” Deep Brain Stimulation Increases Treatment Benefit



Electrodes capable of stimulating and sensing electrical activity are implanted in the brain and connected to a small computer under the scalp. Data from the computer can be read by an external device. Image courtesy of Starr Lab/Ken Probst.

Deep brain stimulation (DBS) is a well-established treatment option for dystonia that applies constant stimulation to targeted brain regions. Regular stimulation at high frequencies can reduce the brain activity that produces dystonia but also reduces signaling within the same region, potentially affecting other brain functions. This can lead to side effects such as involuntary erratic movements, slowed movement, and impaired

speech, depending on the area of the brain treated.

A DBS method where the stimulation intensity adapts to fluctuating symptom severity, referred to as adaptive DBS (aDBS), has been used in people with Parkinson's disease to customize stimulation parameters according to an individual patient's needs. Adaptive DBS is a possible method to better treat dystonia symptoms by decreasing

AT A GLANCE

- New DBS devices can adjust to individual brain activity.
- Adaptive DBS is beginning to be explored for dystonia.
- Adaptive DBS may improve response to DBS by reducing side effects and conserving energy.

the side effects that can occur with the constant high stimulation used with current DBS treatment. A study published last year in *Experimental Neurology* led by DMRF grant recipient Simon Little, MBBS, MRCP, PhD of University of California, San Francisco, investigated the application of adaptive DBS for dystonia treatment.

The central goals of the study were to:

1. Identify patterns of brain activity in the absence of DBS stimulation that were altered by conventional DBS stimulation,
2. Use those patterns to trigger adaptive DBS stimulation, and
3. Compare the therapeutic success between the two types of stimulation.

A single patient with cervical dystonia had a neurostimulator implanted with sensing electrodes on the surface of the brain and stimulating leads targeting the pallidum deep in the brain. In addition to delivering the therapeutic brain stimulation, these leads were able to sense the electric signals of

the brain activity which could then be analyzed by the investigators.

The researchers successfully identified a specific pattern in brain activity that was present before the brain stimulation was applied and suppressed by the addition of conventional DBS. When using this pattern to trigger DBS stimulation they found a small improvement in the objective cervical dystonia measurements and a larger improvement in the patient's self-assessment, which included a subjective rating of tremor, neck stiffness, and pain. Overall, they found that adaptive DBS reduced the total electric energy delivered via stimulation by 71%, despite having a higher possible maximum level of stimulation compared to conventional DBS.

The researchers concluded that adaptive DBS improved patient benefit, expanded therapeutic potential, and reduced the total electrical energy delivered. Future studies with larger numbers of study participants will be helpful to further confirm the therapeutic success.

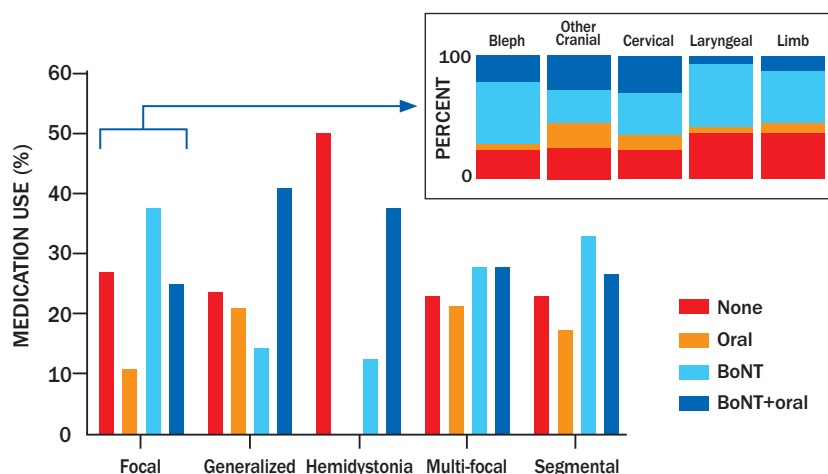
Johnson V, Wilt R, Gilron R, Anso J, Perrone R, Beudel M, Piña-Fuentes D, Saal J, Ostrem JL, Bledsoe I, Starr P, Little S. Embedded adaptive deep brain stimulation for cervical dystonia controlled by motor cortex theta oscillations. Experimental Neurology. 2021 Nov;345:113825.

Investigators Examine Medication Use Across Dystonia Types

Dystonia Coalition researchers set out to learn more about what medical therapies individuals with dystonia are using. They reviewed 2,100+ individuals across 37 movement disorder clinics in the United States, Canada, Europe, and Australia. The patients included individuals with focal, generalized, segmental, multi-focal, and hemi- dystonia.

They found 73% of individuals were using medications (oral or injected medications) and 27% using no dystonia medications. Furthermore, 61% of the total group used botulinum neurotoxin (BoNT) therapy alone or in combination with oral medications. Differences were found in medication use patterns by dystonia type, with the lowest oral medication use in focal dystonia and highest use in generalized dystonia.

The goal of this investigation was to better understand medication use in the dystonia community. This study provides an opportunity to explore possible strategies to customize dystonia treatment among the various dystonia types, always with the intention to improve results for patients.



Pirio Richardson S, Wegele AR, Skipper B, Deligtisch A, Jinnah HA; Dystonia Coalition Investigators. Dystonia treatment: Patterns of medication use in an international cohort. Neurology. 2017 Feb 7; 88(6):543-550.



Registering as Brain Donor is Priceless Gift to Dystonia Research

Registering in advance as a brain donor provides dystonia investigators with an essential resource for future research. There is an urgent need for brain tissue samples for pathological studies. You can help advance dystonia research by registering to donate your brain.

Questions & Answers

Can anyone register a brain donor?

Registered donors must live within the contiguous United States. Certain infectious health conditions may disqualify individuals from being donors.

Do you need family members to register?

Yes. Asymptomatic carriers of dystonia-causing genes are strongly encouraged to register.

What happens when the donor is near death or dies?

The brain bank needs to be immediately notified by the donor's next-of-kin or legal representative to authorize brain tissue recovery. The number to call when a donor is near death or newly deceased is 800-272-4622. The donor's tissue must arrive at the brain bank within 24 hours after death. Once brain recovery has been authorized, the brain bank staff makes contact with a qualified local pathologist to perform the recovery and arrange for transportation of the brain tissue. The family is not responsible for coordinating transport to the brain bank.

Must donors be tested for Covid-19?

No, that requirement has been lifted.

How Do I Get Started?

1. Let us know you are interested in learning more about registering as a brain donor by contacting the DMRF at brainbank@dystonia-foundation.org or 800-377-3978.
2. Inform your next-of-kin or legal representative that you are registering to donate your brain to dystonia research.

24 HOURS

The maximum window of time after death that a brain is viable for collection.

\$0 COST

There is no cost to the registered donor or family.

Making a Difference in Research: Registering as a Brain Donor Webinar



The DMRF works in partnership with the Harvard Brain Tissue Resource Center (HBTRC) at McLean Hospital in Belmont, Massachusetts to assist people interested in registering as brain donors.

Sabina Berretta, MD, Director of the HBTRC/NIH Neuro-BioBank; Martha Murphy, DMRF Brain Bank Liaison; and Janet Hieshetter, DMRF Executive Director recently had a conversation about contributing to dystonia research through brain donation. A recording is available at: dystonia-foundation.org/brain-bank-webinar



From the *DMRF Journal*

Investigators Create Pilot Tele-Yoga Program for Cervical Dystonia

Cervical dystonia (CD) is the most common type of adult-onset dystonia. It affects muscles that control the head and neck. Symptoms can include tremor and muscle spasms. Quality of life is influenced not only by the muscle symptoms but also by frequent pain, anxiety, depression, and sleep difficulties.

Botulinum neurotoxin is currently the main treatment to improve the motor symptoms and pain associated with CD, however, individuals often experience symptoms in between injections. There is great need to identify safe supplementary treatments that can provide additional relief.

Yoga is a system of lifestyle practices with roots in ancient India. Some aspects of yoga have become popular in mainstream fitness and wellness communities. Low-impact yoga exercises and breathing techniques have been shown to be beneficial for individuals with chronic neck pain and other movement disorders such as Parkinson disease, however, the value of yoga for CD symptoms has not been evaluated. To increase access to this intervention, investigators at Rutgers University led by DMRF Medical & Scientific Advisory Council Member Jean-François Daneault, PhD set out to test whether remote yoga or “tele-yoga” could have a positive impact on CD.

Fifteen CD patients with little to no previous yoga experience enrolled in a six-week program of twice-weekly live one-on-one yoga sessions with a certified instructor. Each session included 30 minutes of breathing exercises, yoga postures, and relaxation. The study measured the patients’ ability to adhere to the program, technological challenges, any adverse events, enjoyment, whether the participants continued the yoga practice after the first six weeks, CD symptoms, overall physical abilities, and quality of life features.

AT A GLANCE

- Investigators offered live yoga instruction to individuals with dystonia via video conference.
- Study participants rated the experience a 9 out of 10 for enjoyment.
- Yoga exercises may need to be modified for individuals with dystonia for optimal benefit.

Of the 14 participants that completed the full study, tele-yoga attendance was high with 168/180 sessions completed and 11 participants attending 100% of their sessions. All participants reported CD-related pain and/or additional pain (hip, lower back, and ankle) prior to starting the tele-yoga program. Seven participants reported temporary increases in pain from specific postures. Mild adverse events such as brief dizziness, headache, or CD symptom increase related to posture changes

did occur and ended after the session. The tele-yoga also produced five incidences of new soreness. These instances prompted the instructor to modify the yoga treatment for those individuals, which resolved all reported issues prior to the end of the study. This suggests that individuals should be prepared to communicate with instructors about possible exercise modifications to increase benefit and avoid discomfort.

Importantly, participants ranked their overall enjoyment of the yoga intervention at 9+ on a 0-10 scale. More specifically the breathing exercises were ranked 8, 9+ for the postures, and 8+ for the relaxation portion.

Participants experienced three significant benefits from the program: a reduction in CD-related stigma, reduction in CD severity (but not pain), and improved emotional wellbeing. Overall, this study finds tele-yoga to be feasible, safe, and beneficial for individuals with CD. The findings support further research on tele-yoga as an addition to an individual’s treatment program.

James-Palmer Aurora M., Daneault Jean-François. Tele-yoga for the management of cervical dystonia: A safety and feasibility trial. Dystonia. 2022; 1. doi:10.3389/dyst.2021.10015

Dystonia, the DMRF’s scientific journal, is available at: dystonia-foundation.org/journal

Dystonia Community Unites In-Person & Virtually

THANK YOU to the **DMRF** community for all you have done, and continue to do, to increase awareness of dystonia. In-person and virtual Dystonia Zoo Days and community events have cumulatively raised \$2.2 million in support of the **DMRF** mission since 2012. Your efforts help bring visibility to dystonia and generate the funding investigators need to continue working toward a cure.

DYSTONIA ZOO DAY NATIONAL SPONSORS



ELEPHANT SPONSORS

- Ali's ZooGooders
- Barrow Neurological Institute
- Flanagan Family
- M Health Fairview
- Medtronic
- Mount Sinai Hospital
- Revance
- Rudolph Family
- Wining-Peterson Family



The DMRF officially launched a series of Dystonia Zoo Days with a **Virtual Kick-Off Celebration** on August 18th. DMRF President Mark Rudolph and Executive Director Janet Hieshetter provided a preview of in-person and virtual Dystonia Zoo Day events.

On August 20th, the **5th Portland Dystonia Zoo Day** marked the first in-person event of the Dystonia Zoo Day season. DMRF Community Leadership Council member Dee Linde was presented with an award commemorating the event's fifth year. Tina Beattie and Erinn Stimson also served on the organizing committee. Guests included Drs. Seth Oliveria and Joanna O'Leary, MD from Providence Brain and Spine Institute.

The **2nd Toledo Dystonia Zoo Day** took place on August 27th thanks to the efforts of Kristin Cinglie. Dr. Mehmood Rashid from University of Toledo provided remarks. WTOL Channel 11 covered the event.

The **6th Pamela Sloate Bronx Dystonia Zoo Day** took place on September 10th. DMRF Board Member Liz Rawson presented Dr. Susan Bressman with the DMRF's Changing Lives through Science Award for her contributions to the discovery of the DYT1/TORIA dystonia-causing gene 25 years ago. Special guests included Lolly Lardpop performed by acclaimed puppeteer Leslie Carrara-Rudolph known for her Sesame Street characters.

The **Indy Hunt for a Cure for Dystonia** took place September 10th in Garfield Park, Indianapolis. The organizing committee included Sarah Ernstberger and Sunshine Fox.

Longtime DMRF supporter Linda Davis and Niel Marturiello organized the **"Fight for a Cure—Dystonia Awareness"** basket raffle to benefit DMRF on September 17th. Legislator Dominick Thorne presented Linda with a Certificate of Merit from Suffolk County Legislature for her dystonia awareness efforts. Dean Murray presented her with a Dystonia Awareness Proclamation on behalf of Senator Alexis Weik.

The **1st Boston Dystonia Zoo Day** took place on September 17th. Past President

to Raise Awareness & Funds for Research

DMRF Past President Art Kessler presented Drs. Xandra Breakefield and Laurie Ozelius with Changing Lives through Science Awards at the Boston Zoo Day.



DMRF Board Member Liz Rawson presented Dr. Susan Bressman with a Changing Lives through Science Award at the Bronx Zoo Day.



Art Kessler presented Drs. Xandra Breakefield and Laurie Ozelius with Changing Lives through Science Awards for their contributions to the discovery of the DYT1/TORIA dystonia-causing gene. The DMRF is grateful to event organizers Paula Schneider, who serves as DMRF's Vice President of Support, and Linda Cline and Mary Letson who lead the Greater Boston Dystonia Support Group.

Members of the Western, Pennsylvania Dystonia Support Group organized the **7th Pittsburgh Dystonia Zoo Day** on September 18th. Event organizers were Ed Cwalinski, MaryRae Nee, Tara Sorley, and Chris Mack. Ed and MaryRae lead the Western Pennsylvania Support Group. Chris Mack, Co-Host of The

Fan Morning Show on 93.7, led a brief program that featured remarks from Dr. Taylor Abel from UPMC Children's Hospital of Pittsburgh.

The Flanagan Family, who created the original Dystonia Zoo Day, hosted the **9th Cleveland Dystonia Zoo Day** on September 25th. Many thanks to event organizers DMRF Community Leadership Council Member Karen Flanagan and Kim Meeker. DMRF Medical & Scientific Advisory Council Member Dr. Aasef Shaikh of University Hospitals, Cleveland VA Medical Center, and Case Western Reserve University provided remarks.

The **2nd Los Angeles Dystonia Zoo Day** on October 1st was organized by Community Leadership Council member Jacquelyn Coello. DMRF President Mark

Rudolph led the program. Dr. Natalie Diaz of Pacific Neuroscience Institute provided remarks.

The **5th Twin Cities Dystonia Zoo Day** on October 2nd was organized by Shanna and Brad Schmitt, who also lead the Minnesota Dystonia Support Group. Shanna serves on the DMRF Community Leadership Council. DMRF Awareness Ambassador Billy McLaughlin provided remarks.

In honor of Tracey Deyoung, Better Halves and the Fat Bastards motorcycle group organized the **2nd Dystonia Warrior Ride** and dystonia awareness after party to benefit DMRF on September 24th.

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Scenes from DMRF Events

Thank you to our attendees, team leaders, speakers, and sponsors!



Dystonia & Mental Health: Where to Start

Mental health is a familiar topic of conversation among members of the Minnesota Dystonia Support Group led by spouses Brad and Shanna Schmitt. “It seems like virtually everyone deals with it to one degree or another,” said Brad, “which is understandable because you’re dealing with a chronic health condition that’s going to affect you for the rest of your life. That’s going to get you down from time to time.”



Support group co-leader Brad Schmitt hopes to help normalize conversations about seeking professional mental health services.

AT A GLANCE

- **Untreated mental health disorders reduce quality of life for individuals with dystonia.**
- **The Covid-19 pandemic has taken a toll on many people’s mental health.**
- **DMRF created a Mental Health Programming Committee to formalize efforts to address mental health needs.**

Mental health issues are common in the general public and even more common in the dystonia community. Some people struggle with depression and anxiety years before their dystonia diagnosis. Others develop mental health issues in reaction to dystonia and the challenges that come with it.

“Although it’s very common, people are kind of at a loss as to how to deal with it,” Brad continued.

A dystonia diagnosis is life changing. The disorder can cause varying degrees of disability and pain. Response to treatment can be inconsistent and may come with side effects. The impact of dystonia on a person’s life can affect relationships, work, finances, education, everyday

living activities, and sense of self. Each individual has emotional, mental, and spiritual needs that are unique to their history and circumstances. Movement disorder neurologists are increasingly recommending that addressing the emotional and mental aspects of dystonia are essential for helping patients feel and function as well as possible.

Demand for mental health services in the United States has been increasing over the last decade, especially among young people. The Covid-19 pandemic made the situation all the more urgent. In a recent study of 50,000 adults by public health experts at the University of Montana, the most significant obstacle to seeking professional mental health resources was affordability. “Lingering social stigmas and scarcity of services” were also noted obstacles to people getting help.

Brad was diagnosed with cervical dystonia 14 years ago, at age 38. Having an explanation for his symptoms provided only a brief feeling of relief. “What became very anxiety-producing, depression-producing, was the combination of not being able to work and having the disability insurance company wanting to claim there was nothing wrong with me.” Despite the opinions of multiple medical experts and successfully obtaining Social Security Disability Insurance benefits, the disability insurance he purchased through his employer suddenly stopped authorizing payments. The dispute escalated into an exhausting, demoralizing lawsuit.

“That’s when I decided I needed to do something,” he said. The intensity of frustration and helplessness he felt at the time was overwhelming.

Brad chose to see a clinical psychologist and saw her for about a year and a half. “It was beneficial,” he said. “Obviously, the mental health professional can’t directly address the things you are dealing with. They can’t fix your dystonia. If your spouse is

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unsupportive, they can't make them a more compassionate person. They certainly can't make the insurance company agree that you're disabled. But what they can do is offer you some methods for how to deal with that without wanting to harm yourself or someone else, or without resorting to self-medicating with alcohol or drugs as people can be prone to do when they get depressed or anxious." Among the tools Brad gained from his therapist were guided relaxation exercises and an adaptive yoga practice for combatting stress and supporting his overall wellbeing.

The lawsuit was resolved after two years. Brad credits this as a major contributor to reducing the worry he felt for his financial security and future. He is vigilant about following a treatment plan that has become key to maintaining a good quality of life. He is also quick to mention how essential the support of his spouse Shanna has been to arrive at the better place he's at today, both physically and mentally.

Brad acknowledges that it can be challenging for individuals with dystonia to find health professionals that are a good match for their needs, and this can include mental health professionals too. Communication has been crucial to getting the most he can out of his care. "Whether it's a physical treatment like botulinum neurotoxin injections or seeing a psychologist, having two-way communication between the patient and the professional is probably the most important thing to getting positive results," he said.

One of the first priorities of the DMRF's newly formed Mental Health Programming Committee was to help bridge

"People need to get away from thinking of mental health as somehow different from physical health."

the information gap between individuals with dystonia in need of mental health services and mental health providers. DMRF curated materials that individuals with dystonia can provide a mental health professional to provide background information and help begin conversation about the impact of dystonia on their lives.

By openly sharing his experiences with his support group members, Brad hopes to normalize conversations about seeking professional mental health services. "People need to get away from thinking of mental health as somehow different from physical health. If you have a physical ailment, you go and see a doctor about it. If you're having mental health issues—depression, anxiety, whatever it may be—there shouldn't be a stigma or any ill feeling about doing the same. It's all health."

Dystonia resources for mental health professionals are available at: dystonia-foundation.org/mental-health-pros

IF YOU ARE IN CRISIS:

- **Call** the National Suicide Prevention Lifeline at 800-273-8255/En español 888-628-9454
- **Chat** online at suicidepreventionlifeline.org
- **Dial 988.** This is a new three-digit dialing code that will route US callers to the National Suicide Prevention Lifeline.
- **Text** "HELLO" to 741741

MENTAL HEALTH SELF-CHECK: DO I NEED HELP?

Taking time to assess how you feel mentally can help identify whether you might need help.

If you are experiencing symptoms of depression or feelings of anxiety, notice how much these are affecting your daily life.



Do I have mild symptoms that have lasted LESS THAN TWO WEEKS?

- ☒ Feeling a little down
- ☒ Feeling down but still able to do daily activities: job, schoolwork, housework
- ☒ Some trouble sleeping
- ☒ Feeling down but still able to take care of yourself and others

If so, self-care and life enrichment activities can help:

- Exercising (including gentle exercise)
- Spending time outdoors, close to nature
- Socializing with other people (virtually or in-person)
- Getting enough sleep and rest
- Eating healthy and staying hydrated
- Communicating with a trusted friend or family member
- Practicing meditation, relaxation, and/or mindfulness (even for 5–10 minutes at a time)
- Connect with a DMRF support group or online forum.

Do I have significant symptoms that have lasted TWO WEEKS OR MORE?

- ☒ Difficulty sleeping
- ☒ Appetite changes that cause unintended weight changes
- ☒ Struggling to get out of bed in the morning because of mood
- ☒ Difficulty concentrating
- ☒ Loss of interest in things you usually find enjoyable
- ☒ Unable to perform daily activities and responsibilities
- ☒ Avoiding social situations and people who care about you
- ☒ Thoughts of death or harming yourself

If so, consider seeking professional help.

Here are some options to help you get started:

- Contact your primary care doctor
- Contact your dystonia doctor
- Contact mental health professionals provided by your insurance provider
- Ask family or friends for recommendations
- Contact organizations such as the Anxiety & Depression Association of America (adaa.org) or American Psychological Association (locator.apa.org). Some may identify professionals who specialize in chronic health conditions.
- Contact Mental Health Services at your local Department of Health
- Contact the Substance Abuse and Mental Health Services Administration (SAMHSA) hotline at 800-662-HELP (4357) or samhsa.gov

Source: National Institute of Mental Health (nimh.nih.gov/health/find-help)

Deep Brain Stimulation in Children: Questions for the Medical Team

Deep brain stimulation (DBS) is a surgically implanted medical device used to treat a variety of neurological disorders. The stimulation to the brain is adjusted by remote control.

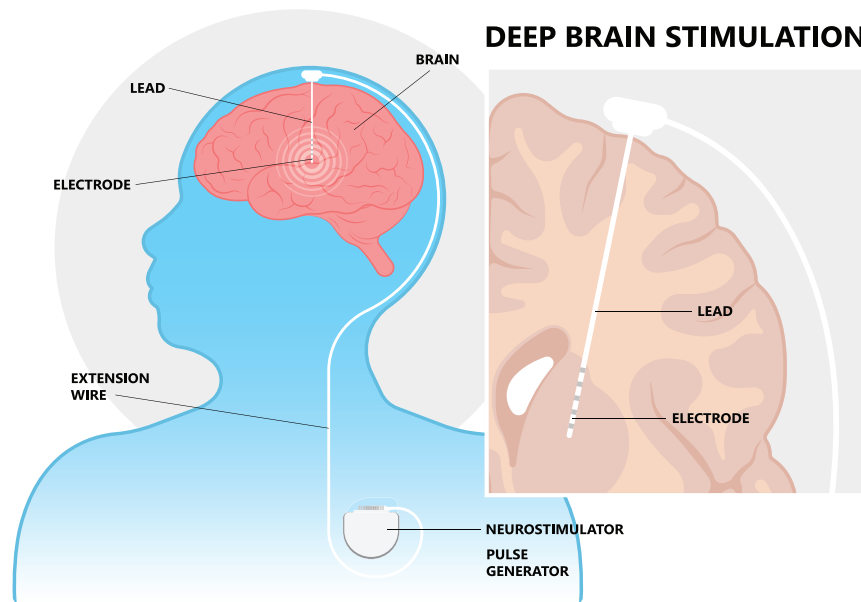
DBS may be an option for children with dystonia when it becomes clear that medical therapies are not successfully controlling symptoms.

Not all children with dystonia are candidates for DBS. It can be difficult to predict the amount of benefit to expect.

The following factors tend to influence outcomes from DBS in children:

- A short time between symptom onset and beginning DBS therapy tends to favor beneficial outcomes.
- Children with genetic dystonias, including DYT1/TOR1A, KMT2B, and DYT11/SCGE dystonia, tend to have favorable results from DBS.
- Children with dyskinetic cerebral palsy tend to have less response to DBS with only about 27% experiencing significant improvement in cases studied.
- Dystonic movements may respond more rapidly and better than fixed dystonic postures.
- Symptoms that tend to not improve with DBS include weakness, ataxia, and spasticity.

Contact DMRF to connect with families who have been through the DBS process: dystonia-foundation.org/contact



DEEP BRAIN STIMULATION

12 QUESTIONS FOR CHILD'S MEDICAL TEAM

If you are considering deep brain stimulation for your child, the following questions may be helpful in conversations with your child's medical team.

1. Is my child a good candidate for DBS? Why or why not?
2. What are the steps and timeline of the DBS process, from beginning to end (including work-up, surgeries, device programming, stimulator upgrades, etc.)?
3. What are the advantages, and disadvantages, of having DBS?
4. What benefits can we expect for my child?
5. Is there a chance their symptoms will get worse? If so, which symptoms?
6. To what degree will DBS help [insert symptom/issue: pain, walking difficulties, trouble using hands, difficulty with seating, sleep difficulties, speech/communication challenges, etc.]?
7. What are the risks: during surgery, after surgery, and long-term?
8. What is the experience of the medical center and surgical team with DBS for dystonia in children?
9. What are the most common complications your young DBS patients have, how often do they occur, and how are they resolved?
10. How will the stimulator programming and adjustments take place? How many appointments, over what period of time, should we expect?
11. Is there anything about DBS for my child I should know that we have not yet discussed?
12. Plus questions the child may have.

For an extended list of questions, visit: dystonia-foundation.org/dbs-children

Dystonia Coalition Engages Investigators Around the Globe

Update on Recent Projects & Programs

As part of DMRF's role as an administrative center for the Dystonia Coalition, the Foundation virtually hosted the Dystonia Coalition's 10th annual meeting earlier this year. The Dystonia Coalition is a groundbreaking collaboration of medical researchers and patient advocacy groups focused on accelerating clinical research in the field. Fifty-six research centers in North America, Europe, Asia, and Australia are participating. New investigators and institutions may join the effort at any time. The Dystonia Coalition began in 2009 with a \$6 million, five-year grant from the Office of Rare Diseases Research (ORDR) and the National Institute of Neurological Disorders & Stroke (NINDS). The Coalition is currently funded through 2024 by the ORDR in the National Center for Advancing Translational Sciences (NCATS) and the NINDS. The Program Director is Dr. H. A. Jinnah of Emory University School of Medicine. DMRF Scientific Director Dr. Joel S. Perlmutter of Washington University in St Louis is Co-Director.

In Dr. Jinnah's most recent update webinar on the Dystonia Coalition for patients and families facilitated by DMRF, he explained: "What do we need to establish new treatments. We need cooperation among experts and engagement from people who have dystonia, we need a good understanding of dystonia, we need good tools to measure new treatments and know if they work or not, and we need new approaches—new ideas for treatment and new experts to help study dystonia. The Dystonia Coalition is filling gaps in all these areas."

The Dystonia Coalition's open invitation to new investigators and broad collaborations have led to the collection of



10 ANNUAL MEETINGS

180

Scientific Papers
Published

56

Participating
Research Centers

4 CONTINENTS

Research Center Locations
NORTH AMERICA | EUROPE | ASIA | AUSTRALIA

unprecedented amounts of detailed clinical data, video recorded examinations, and DNA samples from thousands of individuals with dystonia across different projects. Additional accomplishments include developing and testing new rating scales for cervical dystonia, blepharospasm, and laryngeal dystonia. Dystonia Coalition investigators have published 180 research papers in the medical literature to share discoveries and advancements.

Goals

The Dystonia Coalition has focused its major projects on key unmet needs for translating scientific discoveries into potential new therapies.

Studies that address clinical trial readiness have been a priority. The Dystonia Coalition focuses initially on the isolated focal dystonias including cervical dystonia, laryngeal dystonia, blepharospasm and craniofacial dystonia, and limb dystonias. The four main studies each involve several academic centers that are actively enrolling patient volunteers:

Project 1: Natural History

*Project Leader: Joel S. Perlmutter, MD,
Washington University in St. Louis*

The goal of this study is to get a fuller understanding of the different forms of isolated dystonia and how they may change over time.

Project 2: Biobank

*Project Leader: Joel S. Perlmutter, MD,
Washington University in St. Louis*

The goal is to build a large collection of DNA and additional biosamples from patients with isolated focal dystonia for future studies.

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Project 3: Patient-Centered Outcomes Measures

*Project Leader: Sarah Pirio Richardson, MD,
University of New Mexico*

The aim is to create tools patients can use to track response to botulinum neurotoxin treatment.

Project 4: Objective Measures

*Project Leader: David Peterson, PhD,
University of California in San Diego and the Salk Institute*

The goal is to use advances in digital technology to develop objective diagnostic tools to measure the severity of dystonia.

Additional Programs

The Dystonia Coalition encourages the development of new studies and investigations relevant to dystonia through funding efforts that include:

- **Pilot Projects Program.** The goal of this program is to foster the most promising clinical and translational studies relevant to isolated dystonia. DMRF is currently co-supporting two Pilot Projects.
- **Career Development Award.** The primary goal of this program is to facilitate career development for junior investigators interested in clinical and translational research relating to dystonia.

Administration

Emory University serves as the Central Coordinating Center for the Dystonia Coalition's activities.

The DMRF supports the Dystonia Coalition by providing staff and organizational support for managing subcontracts for paying all recruiting sites for the various projects, the Pilot Projects Program, the Career Development Awards, and the annual meeting. The DMRF Executive Director serves on the Dystonia Coalition Executive Committee, and the Chief Scientific Advisor has served as a reviewer for the Career Development Awards and Pilot Projects Program. This unique model provides enormous savings for both research costs and time, enabling investigators to focus on clinical and scientific needs.

*For more information, about the Dystonia Coalition, visit:
dystonia-foundation.org/research/dystonia-coalition*

DMRF Clinical Fellows: Interview with Margi Patel, MD

In response to the urgent need for additional movement disorder specialists, the DMRF sponsors clinical fellowships to help train physicians in the diagnosis and treatment of movement disorders with special competence in dystonia. The fellowships focus on training in both the clinical evaluation and care of patients with dystonia and clinical research on dystonia.

Margi Patel, MD completed a clinical fellowship in movement disorders at Emory University mentored by Stewart Factor, DO and Svjetlana Miocinovic, MD, PhD. DMRF is proud to note that Dr. Miocinovic is also a past DMRF clinical fellow.

Dr. Patel recently updated DMRF on her practice and activities:

What are your favorite things about being a movement disorder specialist?

My absolute favorite thing about movement disorders is my patients. Neurological diseases can hit suddenly, or over some time, but either way they are devastating. They change the way of life, not just for those who suffer with them, but also for their loved ones. Out of all the neurological diseases, I feel that movement disorders are the toughest, for the patients, and for us as clinicians too. This is what piqued my interest in this subject. Often, the diagnosis of these disorders relies on clinical history and examination because there are not many diagnostic tools and studies that can help with these disorders. And some of them, like dystonia, are so rare, that it can often take several years between symptom onset and proper diagnosis, and thus management. The field of movement disorders is also constantly evolving with newer data and newer methods of treatment. I have interest in all and everything that is movement disorders, but I do have a special inclination towards dystonia.

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Did Covid-19 affect your clinical fellowship training and how your clinic cared for patients?

As it did most of the world, Covid-19 affected many aspects of my life and career. I was towards the end of my first year of the two-year fellowship program when the pandemic hit hard. And in a field where we deal with patients every day, and meet people every day, it did not bear well when the world shut down. As movement disorders specialists who are primarily based out of clinics, we had to continue to see our patients and at the same time help our fellow physicians in the hospital who were either getting sick themselves or burnt out working 24/7 caring for very sick patients in the hospitals. However, we were grateful for the quick implementation of telemedicine. It helped us to cling to patient care while avoiding more exposure to the pandemic. For those that could not have their care managed via telemedicine and had to come in-person to the clinics, I still remember donning the N-95 mask, the gown, the face shield, and talking through them with the fog on my glasses. So, although it affected my clinical fellowship to some extent, I was still thankful to my attending physicians and my fellowship institute to quickly start caring for the patients again and teach us as they would otherwise, if not more, while keeping a safe environment for all.

With movement disorders, it is extremely common to suffer from depression and anxiety. And the first question I would ask each one of my patients was “How is your mood? Can I help do something to make anything better for you?” The pandemic has been very rough on our profession but has also made us all more compassionate, more appreciative of things which we would have otherwise taken for granted.

Talk about your telehealth practice.

I was in a special situation for the past few months. I graduated from fellowship in July 2021, but my husband still had another year left before he finished his studies. Hence, I chose not to take up a permanent job as it was still not decided which city we would settle down in. Temporarily, I ended up working as a movement disorders specialist and a neurohospitalist, both in-person and as a tele-specialist for about a year and a half. Since then, my husband and I have moved to Texas. I have now joined Baylor University



Past Clinical Fellow Dr. Margi Patel sees telehealth as a beneficial option for many movement disorder patients.

Medical Center, Baylor Scott and White, in Dallas where I will be helping build a robust and comprehensive movement disorders program. When the pandemic hit, I became the telehealth mascot at my fellowship institution. I saw and recognized the value of telehealth during times like these, and continued to extend the knowledge, skill, and care via telemedicine for my patients even afterwards. Most of our patients have difficulty with access and transportation, and for them, telemedicine is a blessing. While I would want to see a patient in-person for initial evaluation, for a thorough examination and to formulate a suspected diagnosis, I do

think telehealth can be strategically utilized for follow-up care interspersed with in-person visits. It is a great resource to stay in close follow-up connections with my patients, and sometimes, if appropriate, to even discuss urgent issues face-to-face, giving an opportunity to do a quick examination over video.

What has the support of DMRF meant to you?

Being a part of DMRF, there has been boundless institutional and foundation support to me as a fellow and even beyond. Through the platform of being a DMRF fellow and given my clinical and research interests in dystonia and its treatment, I was able to design my second year of fellowship dedicated to addressing these goals. I had a significant exposure to all patients with movement disorders, but especially dystonia, under the guidance of several different movement disorders neurologists. With the constant support of DMRF, I had an opportunity to sustain professional growth alongside neurologists, neurosurgeons, psychiatrists, neuropsychologists, nurse practitioners, scientists, geneticists, research coordinators, and social workers, working together as a team.

Mentorship always plays a big role in any field, and more so in healthcare. Through DMRF, I have developed a lasting mentor relationship which continues to be with me even today. It is commendable that DMRF provides such great support to aspiring movement disorders physicians like myself, and for that, I will be forever grateful.

Learn more about telehealth for dystonia at: dystonia-foundation.org/treatment

Personal Profile Karen Kieltyka

Karen Kieltyka developed symptoms of dystonia as a child but was not diagnosed until well into adulthood. She started and co-leads the Dystonia Support Group of Greater Cleveland.

How did your symptoms begin and how were you diagnosed?

My dystonia journey is a long one. I was born with cerebral palsy however my case was always mild. By age 12 I noticed my tremors were getting worse. Once I finished school and went to work full time, I started with symptoms of cervical dystonia, but I didn't know what it was and no one else knew what it was either. At age 41 I took my son to see a pediatric neurologist because he was having different issues, but the doctor was more interested in diagnosing me. My son's neurologist asked me what I had, and I told him I was born with cerebral palsy. He asked, "Are you sure?" That threw me for a loop. He gave me the name of a movement disorder specialist. I went to see the neurologist and was diagnosed with generalized dystonia. So, I probably had it when I was 12 or maybe I was just born with the dystonia, I don't know. Typically, cerebral palsy doesn't get worse, and mine progressed throughout my life. It's been a long journey and I was evaluated for deep brain stimulation (DBS) in 1990 but was told no at the time. I was re-evaluated in 2012 and again was told no. I was re-evaluated again last year, and this time was told yes.



the tremor was so bad. I would say I've seen a 95% improvement in my left hand since then. I'm doing things I've never done before. The surgery went better than what I had hoped for and better than what the doctors hoped for. I'm very pleased. The doctors weren't sure it was going to work for me, but it did. A lot of things have improved, not just my hand. My neck is straight. My head doesn't shake. That was a bonus because they said they didn't expect that to happen. I had a second DBS in 2022 for the left side of my brain. Prior to that, I did feel

terribly unbalanced as one side of my body tremored and the other side did not. During that interim, I couldn't understand why I was so tired all the time.

Now that I've completed both surgeries, I'm able to have better quality of life. It's the little things that mean the most to me. I've always felt I had a creative side and am having a great time exploring different art mediums such as painting, print making, and other areas. I've always enjoyed writing and finally have started writing my first book. I was lucky. I have to thank the DMRF because you helped me with this journey in terms of providing information and everything.

You had DBS during the pandemic. Tell us about your experience.

I had DBS surgery last year in September. It was scary because if I would have caught Covid, I would have had to delay the surgery. I didn't want to do that because having surgery is anxiety-provoking and then to get DBS on top of that is scary. My neurologist called right after the pandemic started and told me I was a candidate. After the Covid restrictions for surgery were lifted they went ahead and scheduled me. Recovery took me about three months to feel back to normal. I have a severe tremor in both hands so they did the right side of my brain to control my left hand because I am left-handed. I knew I could go back and do the other side of my brain if I chose to. Prior to the surgery I wasn't able to sign my name, make coffee, or even do the cooking because

How did you connect with DMRF and what inspired you to become a support group leader?

My movement disorder neurologist told me about DMRF so I started researching a little more. When I became a support group leader I felt very alone in my journey. People didn't understand, and I felt like I wasn't getting a whole lot of support. So I was always a pretty determined person. The isolation of no one understanding is why I became a support group leader. I enjoy connecting with people who have dystonia and who can share their experience. I also like getting people connected and educating others about dystonia. It's such a value to the dystonia community to have a support group. Thank you to all support group leaders.

Personal Profile Tina Marr

Tina Marr developed symptoms of dystonia in her hand while working as a court reporter. She co-leads the Dystonia Support Group of Greater Cleveland.

How did your symptoms begin and how were you diagnosed?

I worked as a court reporter and had no idea that dystonia was occurring in my body until I began noticing that I wasn't as accurate in my job on my steno machine. This was in the spring of 2003. I was seeing many more errors in my stenography than usual. It was happening every day. I started seeing a pattern of the same types of errors. Any time the middle finger was involved, the keystrokes would not be there. I wondered if there was something wrong with my machine but that didn't seem to be the issue. I decided the next time I was on a job I would watch my hands because I never look at my hands. It was a shock to me. I saw my middle finger—all the rest of my fingers were doing their thing—raised an inch above the others while I'm writing. When I lowered it, it was rarely hitting the key. It was moving but permanently in an elevated position when I was on the machine, not at other times. That was the beginning of my journey. I assumed there was something wrong with my hand, I had no idea it was from my brain. A hand surgeon told me I had focal hand dystonia. He sent me to a movement disorder clinic. The neurologist explained exactly what I had. We tried medications and injections, but there wasn't anything they could do to allow me to return to my line of work. That's where I left it. That is the more emotional side of having this affliction is that you feel uncertain at that point about what to do. It cost me my job, which I loved dearly. I don't see a movement specialist now. I've just been keeping up with research and reading DMRF materials.

How did you connect with DMRF?

My neurologist was very kind. He shared journal articles with me that were pretty technical and then I wanted to read more. One of the articles was about writer's cramp [focal hand dystonia]. I was fascinated to learn from that article that one gentleman taught himself to write with the other hand to overcome it, and the dystonia then went to that hand. There is something about this disorder that I find very interesting. After I digested the articles, I went to the



internet to search about focal hand dystonia and found the DMRF that way.

What inspired you to become a support group leader?

I learned about DMRF in around 2007 or '08 and started making donations and began receiving the *Dystonia Dialogue* magazine. I became active in the Cleveland group because DMRF sent me a postcard about the new group forming. I thought that was awesome. I called Karen Kielytyka and asked

if I could attend the meeting. I was very eager to meet other people that had dystonia. The reason I was willing to become a co-leader was because Karen suggested at a meeting that having a co-leader would be helpful to her. I volunteered because I'm a giving person and I always try to support other people and it seemed natural to help her. I'm not a leader so it was going outside my comfort zone, but I did it to help her. I really respect her and admire her.

Why are support groups important?

Especially for people with dystonia, it helps them feel like they are not odd or peculiar. I think generally we feel like we're the only ones that have this weird thing happening. Nobody seems to know about it. Usually when I mention it to people they don't know what it is and it's surprising. I think support groups are an important resource because they help us connect with other people like us. We know we are not alone, and it gives us comfort. I feel it's very important for any person with dystonia to be open to the idea of seeing what a support group can do for them because they won't know unless they go. I would not have predicted that I would get as much out of it as I do. People owe it to themselves to give it a try. They might be pleasantly surprised.

REACH OUT

Connect with DMRF support groups and online forums at dystonia-foundation.org/support

Dystonia Dialogue

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Inside! Scenes from Dystonia Zoo Days and Community Events...

