



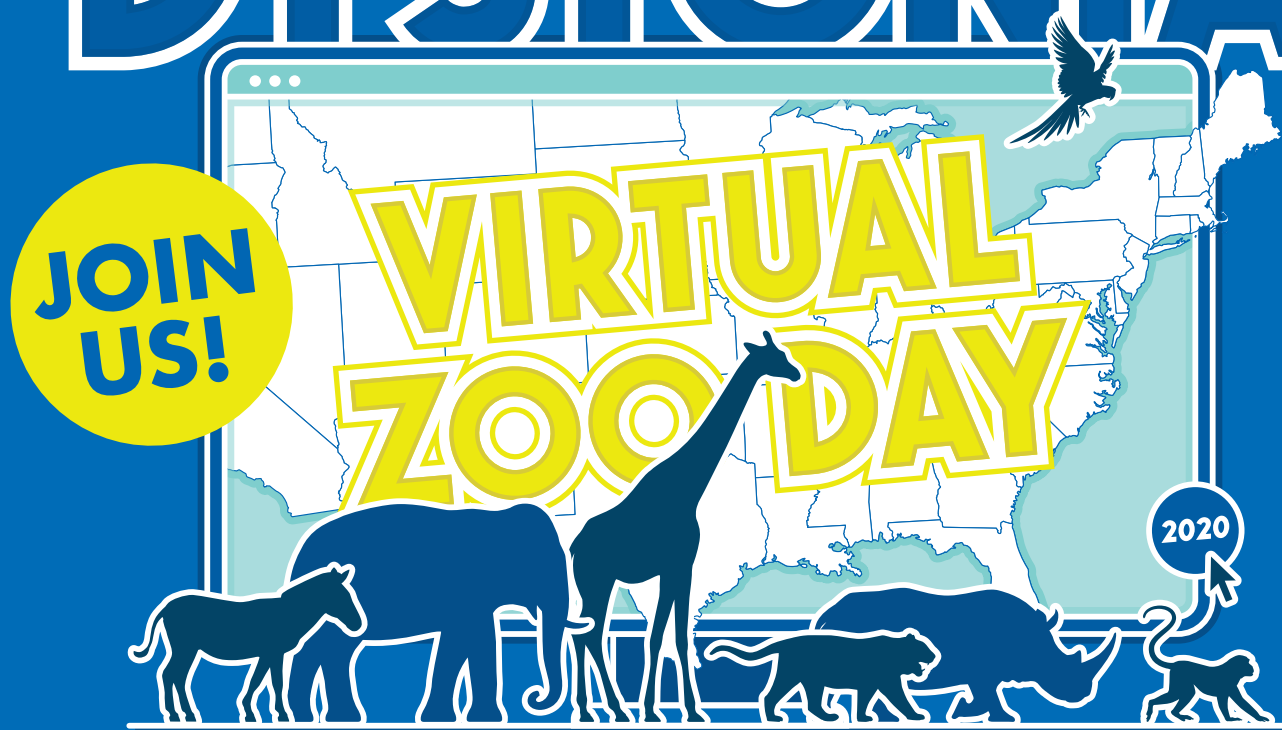
DYSTONIA
MEDICAL
RESEARCH
FOUNDATION

Dystonia Dialogue

NEWSLETTER OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

Summer 2020 | Volume 43 • No. 2

DYSTONIA



SEPTEMBER 12, 2020

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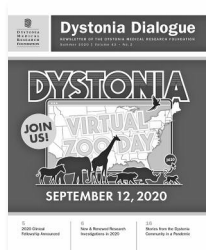
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On the Cover:



The dystonia community is uniting for an exciting national day of action to boost dystonia awareness and raise funds for medical research toward a cure. Individuals with all types of dystonia, as well as family members and friends, are invited to take part in the DMRF's first-ever Virtual Dystonia Zoo

Day. Join us for a live-streamed event on Saturday, September 12, 2020 and add your voice to this fun and important effort.

Learn more on pages 12–13.

What is Dystonia?

Dystonia is a disorder that affects the nervous system. Abnormal signals from the brain cause 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



Art Kessler
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Janet L. Hieshetter
Executive Director

The health and safety of the dystonia community has always been at the heart of the DMRF mission, and 2020 has only reinforced this priority. It has been an unusual and challenging year. The leadership of the DMRF has thought long and hard about how to manage our programs during the Covid-19 pandemic while avoiding unnecessary risk. We are rising to the challenge, never losing sight of our absolute commitment to all of you who depend upon and support our work.

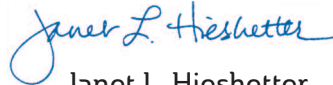
Many people in society are now experiencing what individuals and families affected by dystonia deal with on a regular basis: the uncertainty of grappling with a serious illness, the care with which we select sources of information, the disappointment of missing gatherings due to health concerns, financial worries, and the strain of adapting to a new normal. The pandemic has taken a hard toll on many in the dystonia community; we are grateful so many of you have reached out to DMRF for assistance in the past months. We are in awe of your perseverance and creativity in coping.

DMRF remains here for you. We made the hard decisions to cancel in-person events and local support group meetings, but our outreach has not diminished. We have adapted. The Dystonia Advocacy Network's Advocacy Day on Capitol Hill in March was transformed into a virtual event, ironically allowing almost triple the number of people to participate compared to a typical in-person event. Our support groups are meeting via video conference to help keep local communities connected. Instead of our popular Dystonia Zoo Walks, we are organizing the first-ever Virtual Dystonia Zoo Day to benefit the DMRF on September 12, 2020. We have curated resources to help you attend to self-care needs: physical, emotional, and mental. More information about each of these efforts and more can be found in this newsletter.

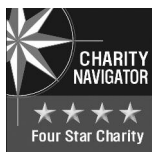
The work does not stop. The DMRF's commitment to you does not stop. The push for a cure does not stop. Dystonia researchers remain active and engaged. It is more important than ever to nurture relationships and connect socially, even from a physical or geographic distance. No one should have to face dystonia alone, and DMRF is committed to making sure no one does. Thank you for continuing to support our work.



Art Kessler
President



Janet L. Hieshetter
Executive Director



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

DMRF and Physicians Partner to Strengthen Patient Education Resources

The newly formed Clinical Educational Resources Committee (CERC) was assembled to formally invite clinicians to provide feedback and guidance on DMRF's educational materials. The committee is chaired by past DMRF Clinical Fellow Harini Sarva, MD, movement disorder specialist at New York-Presbyterian Hospital and Assistant Professor of Clinical Neurology, Weill Cornell Medical College. The committee convened in June to comprehensively review and discuss DMRF's catalog of brochures and fact sheets. DMRF educational materials are consistently medically reviewed, and this committee is an added step to ensure the quality of publications by asking physicians for their feedback on how to ensure resources are both accurate and effective.

In addition to serving as chair of the CERC, Dr. Sarva has volunteered her time and expertise to numerous DMRF programs, including educational resources and community events. She recently provided some remarks on her role as a movement disorder specialist and commitment to patients.

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

HS: I really enjoy relying on the history and exam, and the diversity of conditions. With continuing research into genetics and treatments, the knowledge of many movement disorders is expanding. Also I think the role of technology in evaluating patients with movement disorders is exciting.

DD: How has your role as a clinician changed in light of the Covid-19 pandemic?

HS: The increasing role of telemedicine has changed the landscape for mostly the better. It is difficult to replicate the



Dr. Harini Sarva is Chair of the DMRF Clinical Educational Resources Committee.

Clinical Educational Resources Committee

- Harini Sarva, MD (Chair), Weill Cornell Medicine
- Christopher Groth, MD, University of Iowa
- Abhimanyu Mahajan, MD, MHS, Rush University
- Lindsey Neimand, MD, Caremount Medical

All members of the CERC are past DMRF Clinical Fellows. Learn more about DMRF's Clinical Fellowship Training Program at dystonia-foundation.org/research/fellow-training/

entire neurological exam, however. It has enabled me to obtain a different view of my patients.

DD: How do you approach helping your dystonia patients learn about their diagnosis? Especially since dystonia is not widely known.

HS: I try to conceptualize the pathophysiology as simply as I can. Sometimes I will use visual aids and I also provide them with informational materials from the DMRF.

DD: In addition to your profession as a movement disorder specialist, you have partnered with DMRF on educational meetings, attended

Dystonia Zoo Walks, and reviewed educational resources. Why go those extra miles on behalf of dystonia patients and families?

HS: Because dystonia is more common than we think, and it is important for people to obtain the correct diagnosis to prevent or reduce unnecessary testing and incorrect treatments. I think early diagnosis and appropriate counseling are reassuring and empowering for patients and their families.

DD: What has support from DMRF meant to you and your career?

HS: It's been tremendous. I've learned so much from the DMRF's support and collaboration. I will always be grateful for the wonderful support from the DMRF from my days as a fellow to now.

Dr. Sarva partnered with DMRF on a webinar "Telemedicine & Dystonia," which was broadcast in May and is available for viewing at dystonia-foundation.org/treatment. Movement disorder clinics are increasingly using video conferencing, smartphone apps, and other technology to help care for and interact with patients.

DMRF Clinical Fellowships Train Young Movement Disorder Specialists

Evaluation by a movement disorder specialist can have a dramatic impact on quickening dystonia diagnosis time, increasing treatment options, and maximizing benefit from treatment. Many individuals with dystonia must travel significant distance and endure long waits for appointment openings to access a physician with the necessary qualifications to diagnose and treat dystonia. In response to the urgent need for additional clinical experts, the DMRF supports one-year clinical fellowships to train second-year fellow physicians in the diagnosis and treatment of movement disorders with special competence in dystonia. A fellow is a physician who has completed their residency and elects to complete further training in a specialty. DMRF clinical fellowships focus on training in both the clinical evaluation and care of patients with dystonia and clinical research on dystonia. The training is patient-oriented and includes hands-on experience in clinics as well as participation in professional meetings and workshops.

CONGRATULATIONS TO OUR 2020 DMRF CLINICAL FELLOW AND MENTORS:

Margi Patel, MD

Emory University School of Medicine

Mentors: Stewart Factor, DO &
Svjetlana Miocinovic, MD, PhD

Research Project: Evaluating quantitative response and temporal profile of improvement of dystonia across multiple body regions to bilateral deep brain stimulation in isolated non-acquired dystonia patients

DMRF is proud to acknowledge that Dr. Miocinovic is a past Clinical Fellow.

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

Financial Assistance Programs Available for Botulinum Neurotoxin Therapy

Pharmaceutical companies offer assistance programs to help patients who qualify afford botulinum neurotoxin therapy. The DMRF recently held a series of webinars describing these programs. Information is also available on the manufacturers' websites.

Botox® Savings Program – Allergan

The Botox® Savings Program helps eligible patients receive money back on out-of-pocket costs not covered by insurance. For information, visit botoxsavingsprogram.com or call 800-442-6869.

Ipsen CARES Program (Dysport®)


Ipsen CARES Program helps patients get access to Dysport® therapy. Several types of assistance are available for eligible patients including benefit certification, prior-authorization assistance, co-pay assistance, assistance for non- or under-insured patients, and specialty pharmacy coordination. For more information, visit ipsencares.com or call 866-435-5677.

Myobloc® Co-Pay & Patient Assistance Programs - Supernus

The Myobloc® Co-Pay Program provides eligible patients with out-of-pocket expenses for Myobloc®. Myobloc® is available at no charge to patients approved for the Patient Assistance Program. For information, visit myobloc.com or call 888-461-2255, Option 3.

Xeomin® Assistance Programs – Merz

The Xeomin® Patient Co-payment Program offers eligible patients assistance for their actual out-of-pocket costs for treatment with Xeomin®. The Patient Assistance Program provides Xeomin® at no cost to eligible patients experiencing financial hardship and without third party drug coverage. For more information, visit xeomin.com/patient-resources or call 888-493-6646.



DMRF Research Grants Fund Diverse Investigations into Dystonia Origins

Dystonia is a movement disorder characterized by excessive muscle contractions that cause abnormal movements and postures. Dystonia is not caused by pathology in a specific brain structure, but by dysfunctional circuits of communication between multiple brain areas responsible for coordinating and controlling body movement.

Despite substantial progress made in understanding various aspects of dystonia, there is a need for greater understanding of the basic mechanisms of dystonia and implementing existing knowledge into clinical practice. To accelerate development of novel approaches and transformative research, the DMRF supports studies that will fundamentally change our understanding of brain dysfunction in dystonia as well as innovative clinical studies that capitalize on current progress in the field. Three such new grants were awarded in 2020.

Continuing grants from 2019 reflect studies to explore dystonia brain circuits and networks. These awards are part of an ongoing effort to push the envelope of what is known about dystonia by funding innovative research projects with a focus on incentivizing collaborative, cross-disciplinary investigations. Two projects in the current grant cycle were renewed for second year funding.

Genetic Modifiers of Penetrance in DYT1 Dystonia

David Arkadir, MD, PhD

Hadassah Medical Center and Hebrew University of Jerusalem

Some types of dystonia are hereditary, for example, DYT1 dystonia caused by mutation in the TOR1A gene. It is not clear, however, why individuals with the same genetic

mutation can develop different severities of symptoms. On the extremes, one individual may experience severe dystonia that starts in childhood and leads to significant motor disability while another individual may be totally asymptomatic and not even aware of having the genetic mutation. The research team believes that other genes, yet to be discovered, determine whether an individual carrying a potentially dystonia-causing genetic mutation will develop this movement disorder or not. They propose to find this gene(s) by comparing the genomes of individuals who have mutation in the TOR1A gene, with or without apparent dystonia symptoms. The goal is to find genes that protect some individuals from developing dystonia, even in the presence of the mutated gene.

Unraveling Hierarchical Network Loops in Isolated Dystonia (2nd year)

Xin Jin, PhD

Salk Institute for Biological Studies

Supported in collaboration with Cure Dystonia Now and Benign Essential Blepharospasm Research Foundation

The intricate networks in the human brain responsible for controlling body movement are comprised of many millions of neurons across dozens of brain areas. Dr. Jin and his team are working to understand the network activity that underlies dystonia symptoms, and to possibly prevent symptoms from

developing. This grant is focusing on blepharospasm, a focal dystonia of the eyelid and brow muscles, as a model to understand dystonia networks more broadly.

The Role of Cholinergic Neurons in Isolated Focal Cervical Dystonia

Scott Norris, MD

Washington University School of Medicine

Cervical dystonia produces excessive involuntary muscle contractions in the neck. These muscle contractions result in uncomfortable, awkward, and sometimes painful positions of the head, neck, and shoulders. This research project focuses on improving understanding of the brain's role in cervical dystonia, specifically directed toward improved treatment. The investigators will use state-of-the-art brain imaging techniques, positron emission tomography (PET) and magnetic resonance imaging (MRI), to observe the working brain. PET allows researchers to observe chemical messengers (neurotransmitters) in the brain, in this case acetylcholine. MRI allows researchers to observe how one region of the brain communicates with other brain regions. Combining PET and MRI techniques provides a powerful opportunity to determine how altered chemical messenger levels may influence the way brain regions communicate in cervical dystonia by comparing brain activity of patients with cervical dystonia and control volunteers without cervical dystonia. Acetylcholine is a neurotransmitter of interest because some dystonia patients improve when taking medications that alter levels of acetylcholine. The researchers suspect that brain regions that use acetylcholine are damaged in patients with cervical dystonia and therefore the communication between brain regions that rely on acetylcholine is disrupted. If they find that acetylcholine affects how brain regions communicate in cervical dystonia, future research can attempt to correct the communication problem with new medication or brain stimulation therapies.

These awards are part of an ongoing effort to push the envelope of what is known about dystonia by funding innovative research projects with a focus on incentivizing collaborative, cross-disciplinary investigations.

Cholinergic Interneuron Dysfunction in a Phenotypic Mouse Model of Dystonia

Mariangela Scarduzio, PhD

University of Alabama at Birmingham

Dystonia is challenging to adequately treat, particularly because the underlying brain circuitry problem is not well understood. Studies indicate that a specific population of brain cells, namely striatal cholinergic interneurons, is dysfunctional in both dystonia animal models and in dystonia patients. Accordingly, dystonia is effectively treated with drugs that reduce striatal cholinergic interneuron

function, suggesting that enhanced cholinergic function may play a key role in dystonia. Utilizing a genetic animal model of dystonia that exhibits dystonia triggered by caffeine (transgenic paroxysmal nonkinesigenic dyskinesia (PNKD) mutant mice), the researchers have obtained preliminary data showing striatal cholinergic interneuron dysfunction similar to that observed in non-manifesting dystonia models. In this proposal, they will attempt to correlate dysfunction of striatal cholinergic interneurons with dystonic symptoms in dystonia-manifesting PNKD mice. They expect the experiments to answer crucial questions necessary for linking disease causing mutations to abnormal movements.

Interregional Brain Connectivity in a Mouse Model of Cerebellar-Induced Dystonia (2nd year)

Roy Sillitoe, PhD

Baylor College of Medicine

Supported in collaboration with Cure Dystonia Now

This project uses a unique genetic mouse model of dystonia and diffusor tensor imaging, a type of magnetic resonance imaging (MRI), to define how specific brain network changes lead to dystonia symptoms. This work also seeks to better understand developmental aspects of dystonia, namely why and how dystonia progresses over time. Dr. Sillitoe and team are ultimately seeking to define the functional brain network of dystonia as a way to better target therapies such as oral medications and deep brain stimulation.

New Grant Explores Patient Response to Alcohol in Myoclonus-Dystonia

The Myoclonus-Dystonia Research Program is a partnership between the DMRF and the Brown Family Foundation focused on advancing knowledge of this inherited movement disorder. Myoclonus-dystonia (M-D) is a movement disorder characterized by a combination of rapid, brief muscle contractions (myoclonus) and/or sustained twisting and repetitive movements that result in abnormal postures (dystonia). Non-movement features may include obsessive compulsive disorder, depression, anxiety, alcohol abuse, and panic attacks.

The latest call for M-D research proposals focused on getting to the bottom of an aspect of the disorder that may have significant implications for designing new treatments: patient response to alcohol. One of the noticeable characteristics of M-D is that consuming alcohol often results in a dramatic reduction in myoclonus symptoms and may also reduce dystonia symptoms. However, the negative health effects of excessive or prolonged alcohol consumption prevent it from being a viable therapeutic option. One study suggested that over 40% of individuals with M-D meet criteria for alcohol dependence.

M-D is not the only type of dystonia that responds to alcohol. A survey of nearly 1,300 individuals with dystonia by the Dystonia Coalition found that nearly 30% percent reported reduction of dystonia symptoms with alcohol. The survey included participants with focal, segmental, and generalized dystonia.

These findings raise the possibility for new therapies that mimic the benefits of alcohol without the unhealthy risks. The following study examines the utility of an alternative type of alcohol as a treatment approach.

Octanol Effect on Symptoms and Network Dysfunction in Myoclonus Dystonia: An Intoxication-Free Therapy?

Cecile Gallea, PhD, Salpêtrière Hospital, Paris

Myoclonus-dystonia (M-D) is a movement disorder caused by mutations in the SGCE/DYT11 gene. The neurological

basis of this disorder remains elusive, but evidence points towards a network dysfunction involving the cerebellum, the striatum, and the cortical motor areas. The myoclonus in M-D often improves after consuming ethylic alcohol (EthA). While other treatment options have frequently been ineffective or poorly-tolerated, the addictive and neurodegenerative consequences of chronic alcohol consumption prevent its use as a sustainable treatment option. Octanoic alcohol (OctA) may represent a beneficial alternative to EthA: it alleviates motor symptoms in patients with essential tremor in a way similar to EthA but without causing intoxication or other adverse effects. However, the mechanism of action of OctA and the neural circuits it affects are currently unknown. This collaborative project will use a translational and multi-modal approach. In an M-D mouse model, the researchers will investigate the efficacy of OctA to reduce dystonia and repetitive, myoclonic-like, jerking movements in mice that have improved after administration of EthA. In M-D patients, the research team will test whether OctA reduces myoclonus severity as well as non-motor symptoms such as anxiety. Lastly, they will isolate the OctA-responsive network using functional MRI (magnetic resonance imaging) in M-D patients and electrophysiological recordings in the M-D mouse model. The project will provide preliminary data to explore new non-invasive therapeutic options. These preliminary data will be the starting point of a bigger collaborative work to unify efforts to deepen understanding of the mechanisms underlying M-D symptoms and pathophysiology.

People on the Move

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

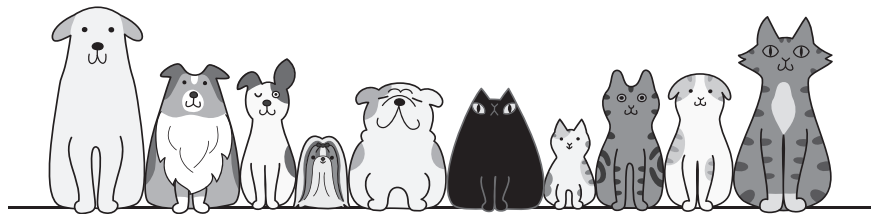
Julie Greene of Minnesota nominated DMRF to be recognized during cable shopping channel HSN's Customer Appreciation Month in April. HSN Cares selected DMRF from hundreds of entries to receive \$1,000 as part of the HSN Cares annual \$1,000 A Day Giveaway campaign.



Instead of gifts, nine-year-old birthday girl **Kelley Facine** asked friends and family to make donations to **5dollarcure.com** in honor of her cousin and dystonia

awareness all-star **Jason Dunn**. She raised \$560! Earlier in the year Kelley's dad **Nathan Facine** set up a Super Bowl squares fundraiser in support of the campaign. All donations to **#5dollarcure4dystonia** support medical research.

Dogs for Dystonia Raise Awareness & Research Funds



Dogs for Dystonia is an annual campaign to raise awareness while celebrating the special bond between people and their dogs. Each February, dog lovers unite in a Virtual Dog Walk to raise visibility of dystonia and the urgent need for research toward a cure.

The following dogs and owners each raised more than \$500!

- Virginia Bryan and Snoopy
- Dee Linde and Violet
- Terri Chapman and Sydney
- Maddie Paolero and JJ
- Emily McNaughton and Molly
- Eric Greenberg and Coolidge & McKinley
- Nick-E Mershon and Roxie

The DMRF wishes to thank all the generous people and pooches—and a couple of cats—who participated in this important and fun campaign.

IN MEMORIAM

The DMRF community sadly lost several special members in recent months:

- **Stewart Babb**, past president and member of the South Carolina Dystonia Support Group
- **Anne Brett**, founding member of a live Internet chat for individuals with laryngeal dystonia/spasmodic dysphonia
- **Jeff Harris**, co-moderator of the Online Dystonia Bulletin Board and past member of the *Dystonia Dialogue* Editorial Board
- **Novyce King**, past leader and member of the South Carolina Dystonia Support Group

DMRF is grateful for the hours and energy each of these support leaders invested in helping others in the dystonia community. We extend our deepest sympathies to their families.

Dystonia Advocates Pivot to Virtual Action to Educate Congress

The Dystonia Advocacy Network's (DAN) Advocacy Day planned for March 24–25, 2020 in Washington, DC was cancelled due to the Covid-19 outbreak, but the virus did not prevent the dystonia community from reaching out to Congress and giving voice to the needs of affected individuals and families. Hundreds of people reached out to their US Senators and US Representatives to push the DAN legislative agenda—far exceeding the number of advocates typically able to attend Dystonia Advocacy on Capitol Hill. DAN unites around issues of common concern to the entire dystonia patient community. Below are the current legislative priorities at the core of the DAN's ongoing outreach and advocacy efforts.



Dystonia Advocacy Network

DMRF is proud to provide staff support for the DAN.

Benign Essential Blepharospasm
Research Foundation (BEBRF)

Dystonia Medical Research
Foundation (DMRF)

National Spasmodic
Dysphonia Association (NSDA)

National Spasmodic
Torticollis Association (NSTA)

Medical Research

Funding for the National Institutes of Health (NIH).

The bulk of federally-supported dystonia research is conducted through NIH. Each year, DAN advocates call on Congress to provide NIH with meaningful funding increases so that the dystonia research portfolio continues to expand, advance our understanding of the disorder, and further efforts to identify improved treatment options and possible cures. DAN advocates asked for the NIH to be funded with at least \$44.7 billion in FY 2021, a \$3 billion funding increase. NIH coordinates with proportional increases for the various Institutes and Centers, particularly the National Institute of Neurological Disorders & Stroke. Investment in NIH research has led to improvements in our scientific understanding of dystonia. A meaningful funding increase will ensure current efforts continue.

Participation in Department of Defense (DOD) Research Activities.

Unlike NIH, which funds medical research proposals in any area of study, the DOD's Congressionally-Directed, Peer-Reviewed Medical Research Program (PRMRP) only funds research into conditions that are specifically recognized by lawmakers. Traumatic brain injury (TBI) and other traumatic injuries can be catalysts for the onset of dystonia. As military personnel remain deployed, dystonia is becoming increasingly prevalent among veterans. More research is needed to understand the mechanism between combat injuries and dystonia. DAN advocates asked that dystonia continues to be recognized as a condition eligible for study through the DOD Peer-Reviewed Medical Research Program (PRMRP) for FY 2021. Important research efforts through the PRMRP are working to improve the lives of individuals, including veterans and active duty military personnel, affected by dystonia.

Funding for the Centers for Disease Control and Prevention (CDC).

DAN is advocating funding of CDC at \$8.3 billion in FY 2021. The National Center for Injury Prevention and Control supports research into traumatic brain injury (TBI) that is associated with dystonia. Advocates also support providing \$5 million in

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.

Learn how to get involved at dystonia-foundation.org/dystonia-moves-me. Follow DMRF on Facebook, Twitter, and Instagram for the latest information and updates.

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

dedicated, line-item funding for a "Chronic Disease Education and Awareness Program" at CDC, as outlined in the FY 2020 House Labor, Health and Human Services, Education, and Related Agencies (LHHS) Appropriations Bill, to support public health campaigns in specific areas.

Patient Care

Affordable Care Act Reform.

DAN advocates educated legislators about the needs of patients who may be affected by changes to the Affordable Care Act including:

- Prohibiting insurer discrimination against pre-existing conditions
- Allowing young adults to stay on their parents' health insurance until age 26
- Establishing out-of-pocket maximums for covered services
- Prohibiting annual and lifetime caps on insurance coverage

These protections have made it possible for individuals with chronic health conditions to obtain insurance coverage and protect them from outrageous medical bills.

Patient Access

Supporting the Americans with Disabilities Act (ADA) of 1990.

It is critical that Congress protect elements of the ADA that require businesses to become and remain ADA compliant instead of placing the undue burden onto individuals with disabilities.

How You Can Help

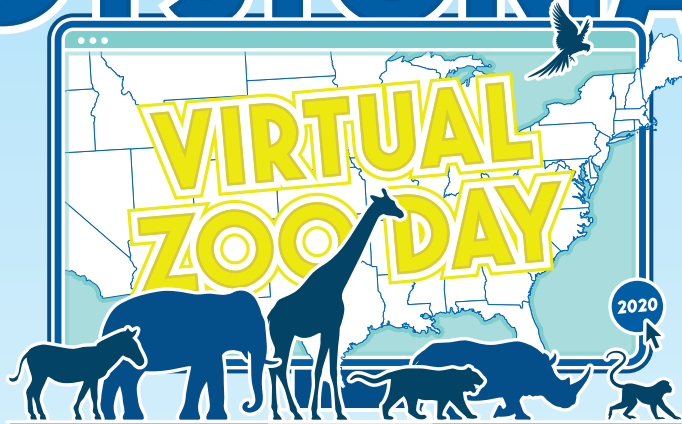
By becoming a dystonia advocate, you can have a powerful effect on the laws and policies that affect your life and the lives of others in the dystonia community. To get started:

- Sign up to receive DAN legislative alerts via email at: dystonia-advocacy.org/contact
- When you receive a DAN legislative alert, respond promptly by calling or sending an email to your legislators. The DAN makes it easy. Every legislative alert includes simple instructions to take action.

For more information on the DAN and becoming a dystonia advocate, visit dystonia-foundation.org/advocacy or contact the DMRF at dystonia@dystonia-foundation.org or 312-755-0198.

DYSTONIA

SATURDAY, SE



On a single day, DMRF sup
The dystonia community is
and raise funds for medica

LOCATION

This is an online event. The event website is:
dystonia-foundation.org/lets-zoo-this

PROGRAM FOR THE DAY

There will be a livestream program beginning at 11:00 am Central Time (USA). Sessions throughout the day will include a live zookeeper chat, Q&A with movement disorder experts, children's activities, and much more. Details at the event home page.

HOW TO PARTICIPATE

- 1 Visit dystonia-foundation.org/lets-zoo-this for complete event details.
- 2 Sign up to join us September 12, 2020.
- 3 Order your official Virtual Dystonia Zoo Day t-shirt.
- 4 Make a donation. **100% of all gifts will be matched!**
- 5 Invite family members and friends to participate.

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NEUROSCIENCES

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Porters across the country will be acting together, while staying apart.
Uniting for an exciting national day of action to boost dystonia awareness
and research toward a cure.

WHY PARTICIPATE?

You'll connect with others in the dystonia community and bring visibility to dystonia nationwide. Your support will ensure DMRF continues to offer programs and resources to individuals and families impacted by dystonia and advance urgently-needed medical research.

ROAR YOUR SUPPORT

Sign up to show support for the Virtual Dystonia Zoo Day on September 12. Goodies to make the day extra fun are included in Family and Party Packs.

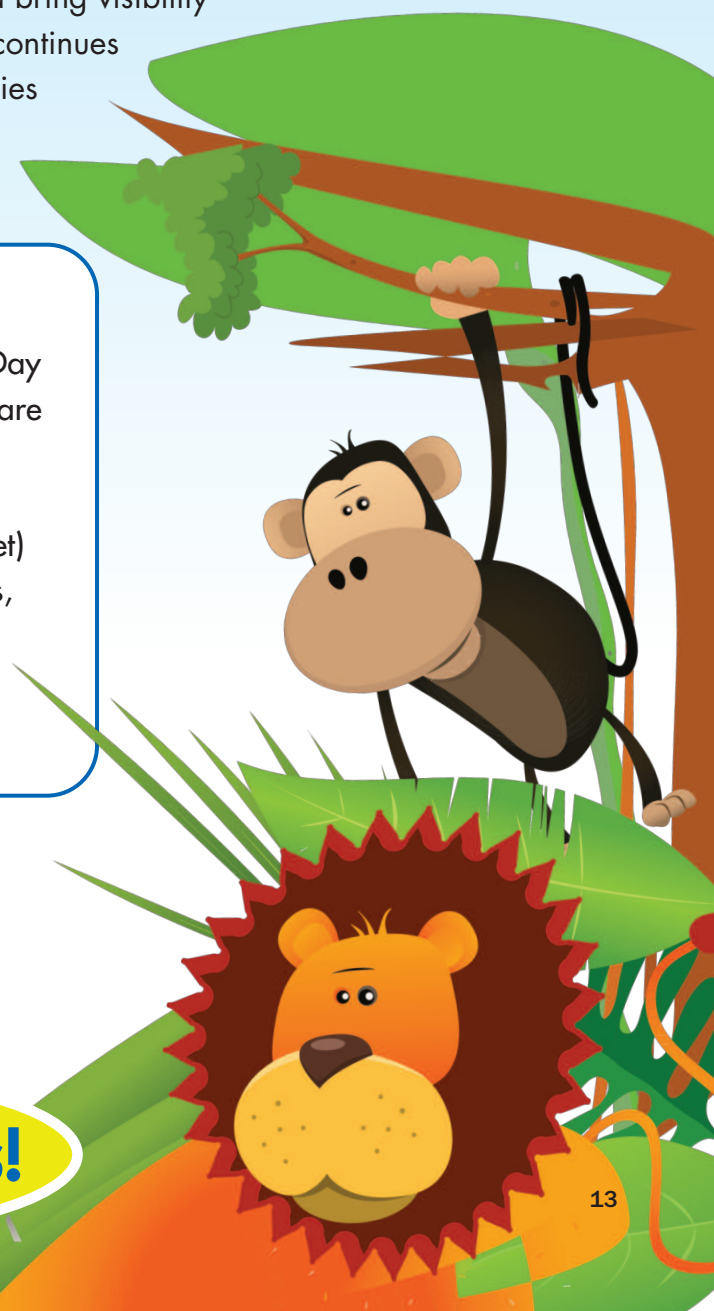
- Virtual Event Ticket - Free
- Virtual Dystonia Zoo Day T-shirt - \$10 (includes ticket)
- Family Pack - \$50 (includes 4 shirts, 4 animal masks, activity kit, and ticket)
- Party Pack - \$100 (includes 10 shirts, 10 animal masks, activity kit, and ticket)

PLACE YOUR ORDER AT:

dystonia-foundation.org/lets-zoo-this

Deadline for shirt orders in time to ship for event is August 27, 2020.

#LetsZOOthis!





Self-Care is Vital to Living Well with Dystonia

When is the last time you did something kind for yourself? Do you show yourself compassion as readily as you might to someone you care about? Self-care is the practice of taking an active role in protecting well-being and happiness, in particular during periods of stress. Self-care includes any deliberate activity to take care of your physical, mental, and emotional health.

The DMRF has assembled a number of tips and resources to help you take good care of yourself.

Listen to Your Body.

If your dystonia symptoms are changing, or treatment has been delayed, reach out to your doctor for guidance on how to stay as physically comfortable as possible. Adjusting medication dosing or prescriptions for topical medicines may be appropriate to address symptoms and/or pain.

Resources that can help:

Overview of Dystonia Treatments
dystonia-foundation.org/treatment

Stay in Touch with Medical Professionals.

If your primary care or movement disorder clinics do not offer office visits, look into whether you can communicate with your doctors via phone, email, or video conference.

Resources that can help:

“Dystonia & Telemedicine” with Harini Sarva, MD
dystonia-foundation.org/treatment

Understand Your Covid-19 Risk.

Talk to your doctor about your level of risk for Covid-19. Consult credible sources for current information and public health recommendations, such as the US Centers for Disease Control & Prevention (CDC), World Health Organization (WHO), and local public health agencies.

Resources that can help:

“Dystonia & Covid-19: Your Questions Answered” with Mark Hallett, MD & Robert Chen, MB BCh, MB BChir
dystonia-foundation.org/covid-19-webinar

Connect Socially.

Many local DMRF support groups are meeting by video conference instead of in-person due to public health precautions. There are also online groups to help connect you with others in the dystonia community.

Resources that can help:

Finding Support – DMRF Support Groups & Online Forums
dystonia-foundation.org/support

Pay Attention to Non-Motor Symptoms.

Dystonia is a neurological disorder that affects the physical body as well as emotional and mental health. Depression and anxiety are common. Many mental health providers are seeing patients in office as well as offering consultations by phone or video conference.

Resources that can help:

Emotional & Mental Health
dystonia-foundation.org/living-dystonia/mental-health

Make Stress Reduction Routine.

Regular practices to ease physical and emotional tension can profoundly benefit quality of life. Simple breathing and mindfulness exercises can be incorporated into your daily routine, even for just a few minutes at a time.

Resources that can help:

Mindfulness Meditation Exercises with Karen K. Ross, PhD
dystonia-foundation.org/mindfulness

Acknowledge Grief.

Stress can trigger strong and complex emotions. Especially during times of change or transition, take time to recognize your emotions and acknowledge feelings of loss, if present.

Resources that can help:

“At a Loss: Dystonia & Grief”

dystonia-foundation.org/living-dystonia/mental-health

Don't Snooze on Sleep.

Quality sleep is among the top self-care activities that can boost your coping and physical wellness. Individuals with dystonia frequently experience problems with sleep. Consult your doctor if you are concerned about sleep or not sleeping well 75% of the time.

Resources that can help:

“Sleep & Movement Disorders” with Danette C. Taylor, DO, MS, FACN

dystonia-foundation.org/dystonia-sleep

Embrace Exercise.

The benefits of exercise can be profound: strength, endurance, energy, stress reduction. Consider consulting a physical therapist to design an exercise regimen just for you. Many physical therapists are seeing patients in office as well as offering consultations by video conference.

Resources that can help:

Tips for Exercise

dystonia-foundation.org/benefits-of-exercise

Carefully Explore Integrative Therapies.

Talk to your doctor about non-traditional therapies that interest you. Beware of health fraud scams and practitioners who claim to have a special ability to treat dystonia without offering credible evidence.

Resources that can help:

“Naturally Curious: An Integrative Approach to Treating Dystonia” with Danny Bega, MD

dystonia-foundation.org/integrative-treatment

Reach Out to DMRF.

If you have questions or concerns and are not sure where to turn, start by contacting the DMRF at dystonia@dystonia-foundation.org or 800-377-3978. You can also connect with DMRF on Facebook, Twitter, and Instagram.



Study Examines Massage Therapy for Dystonia

Many individuals with dystonia seek out complementary and integrative therapies to help manage symptoms, including massage. However, the use of massage for dystonia is not well documented or studied. A recent case report, using objective rating scales, suggests that massage can temporarily reduce pain intensity, pain and spasm frequency, and dystonia symptoms in activities of daily living. Results pertaining to pain noted a significant decrease in frequency of nighttime sleep disruptions caused by pain. The study describes a single dystonia patient who underwent five massage treatments over six weeks. Techniques applied include Swedish massage, hydrotherapy, and myofascial release. The patient was also assigned exercises to complete at home. The study suggests that further research is needed to determine how effective massage therapy for dystonia may be and to determine efficient and safe treatments.

Lipnicki, M. Massage Therapy for Dystonia: a Case Report. Int J Ther Massage Bodywork. 2020 May; 13(2): 33–44.

During the Covid-19 pandemic, consult your doctor and public health officials for guidance on the safety of local massage services.



Stories from the Dystonia Community in a Pandemic

The Covid-19 outbreak has had a disproportionate impact on individuals with disabilities and chronic medical conditions, including those with dystonia. There has been widespread disruption of local public services, delays in treatment appointments, and changes to everyday routines.

The DMRF checked in with several members of the dystonia community to see how they were faring in these unusual times.

WAYNE

Wayne Branson resides in Auburn, Washington, not far from the first reported case of Covid-19 in the United States. "All of a sudden we're sitting in the middle of The Hot Zone," he recalled, after reports of infections began exploding in March. "It got my attention because I am a cancer survivor and also a dystonic person, and I'm on a pile of pills that can weaken my immune response." His neurologist was adamant that he stop reporting into work and provided documentation for his employer, an aircraft manufacturing company where he has worked for 13 years.

The day after Wayne took medical leave, he and 95% of the factory staff were laid off. Most of those employed at the company are individuals with disabilities.

Wayne was diagnosed with thyroid cancer in the late 1990s while pursuing a graduate degree in chemistry. He has been cancer-free since 1999, defying the prognosis that he would not survive six months. In 2008, he was diagnosed with dystonia, after decades of escalating symptoms. By 2016 it became generalized. "I was having trouble walking," he recalled, "I couldn't go up and down stairs. The cramping at night was incredible—my back would arch off the bed." A combination of oral medications and lifestyle adjustments have kept his symptoms and pain fairly controlled.



Wayne Branson has made extra efforts to stay connected to family and friends while sheltering in place.

"The cancer is gone, except for the fact that it changed my attitude about being alive," he shared. "Every day is new and fresh and it really helps me with the dystonia because there are good days and there are rough days."

Wayne is accustomed to self-isolating as a precaution during flu season, but he soon realized Covid-19 created a different situation entirely. Half his income disappeared. No more chatting up clerks in the grocery store or small talk with co-workers. Ventures outside the home are limited to quick trips for essentials. At the end of the work day, he used to stay an extra hour to break up large wooden pallets to fit more compactly in the company's recycling dumpster. The exercise helped him sleep at night. He stopped volunteering at a nearby aquarium run by a local college. "I'm missing all that interaction with the world. I had some savings. All of these things were vaporized. I'm like everybody else, waiting. And all I can do now is sit at home. There's nowhere to go."

Before the pandemic, Wayne rarely had dinner with his three housemates. Now they have dinner multiple times a week, sharing stories and telling jokes. “My online friends suddenly became even more important, and it’s really very different,” he said. He corresponds with friends and family members all over the world, including a cousin in the United Kingdom who is also affected by dystonia.

“I’m glad that I studied things like biochemistry as much as I did because it helps me understand what’s happening with the pandemic,” Wayne said. “I surround myself with positive things, things I enjoy—I really like to find out what are the latest things going on in quantum mechanics. I find YouTube videos of funny, campy, 1950s science fiction stuff. I look for opportunities to encourage other people, because when I encourage someone, I feel encouraged.”

Wayne has kept in touch with his physicians via phone and video conference. His neurologist insists on weekly check-ins via confidential email. One of the things they discussed is adjustments to his medications to address increasing symptoms he has been experiencing due to the added stress of sheltering in place. “I still have access to doctors even though I can’t go anywhere and they can’t see me in the clinic,” he explained. “Something that I really encourage people to do is reach out how you can. And don’t be afraid to talk to your medical team, especially if you are isolated.”

JANIS

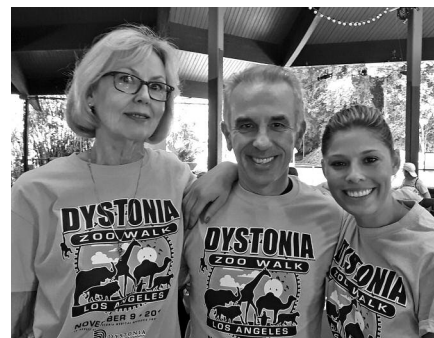
“At 71, I kind of appreciated that the world slowed down a little because, even though I live in a suburb of Los Angeles, kind of far out, people zip around and I feel like I’m always trying to keep up.” Janis Eiler is a former security and investigations professional who retired early several years ago due to cervical dystonia. She is a past Co-Leader of the Los Angeles Dystonia Support Group.

In May, her neurologist’s office informed her that her botulinum neurotoxin therapy appointment coming up in a few days was canceled. They could offer no estimate for when she might be rescheduled.

“The injections help me a lot,” she explained. “I don’t get real emotional, but I was like, really? I was really counting on this. I had no timeframe whatsoever and that’s hard for me, knowing that I would be declining.”

The delay in treatment immediately brought to mind her condition during an early clinical trial for botulinum neurotoxin. In retrospect, she realized she was given a placebo. This meant she was without treatment for weeks during the study. “I had flashbacks of the pain and headaches,” she said. “The headaches would be really terrible and the muscle pulling, my head would be pulled to one side. At best, I could walk around at work with a clipboard holding my chin up and at home I’d wear a soft collar.”

Even though Janis’ adult children live nearby, social distancing precautions complicate her access to their assistance. “So, the fear was I’m basically all alone. What do I do now?” she thought



Janis Eiler (L) is a co-organizer of the Los Angeles Dystonia Zoo Walk. Pictured with co-organizer Jacquelyn Coello (R) and Dr. Michele Tagliati.

Fortunately, Janis’ injections were rescheduled three weeks after she was due. But the procedure had changed. She had to be tested for the Covid-19 virus 72 hours in advance of the appointment. The testing was a strange experience: “They did the testing through a wall with these arms that look like a space suit with gloves. It was really funny because it came through at a certain height, and I’m about six feet tall, so I had to lean way down for them to do the throat swab and nasal thing. That was basically it. When I went on Monday for my [injections], I knew it would be a big deal and it was.”

On the day of her appointment, she checked in at the main entrance of the medical center. She had to wash her hands, wear a face mask, and answer a litany of questions. This earned her a sticker on her shirt to indicate she was allowed to proceed into the building. When she arrived at the clinic waiting room, she was the only patient there. The nurse who greeted her was covered head to toe in protective medical equipment. Even the manner in which her doctor administered the injections was different: “Normally he will rest a hand

Continued on page 18

Continued from page 17

on my shoulder and talk to me, and give me the shots, reassure me. But he was all gloved up and suited up—it was just like, here it comes! They kind of hurt.”

Before and since receiving her injections, Janis has been exploring various means to stay as comfortable as possible both physically and mentally while sheltering in place. She is meditating more, exploring gentle stretching exercises she can do from home, and uses aromatherapy to create a calming atmosphere. She adopted a second cat. “Having a pet is nice because they’re affectionate and they’re fun. They keep you running around, doing stuff,” she said.

Her favorite “low tech” wellness solutions are regular walks with her daughter and daily afternoon naps she never previously had time for. “Anxiety makes my condition way worse, makes my headaches way worse, and I tend to cycle downward when I start to think, what if this, and then what if this, and oh no... and that’s when I say, okay, you need to lay down and read a book and fall asleep. That really helps me break that anxiety cycle.”

KELSEY

2020 was going to be a big year for Kelsey. She planned to swim the San Francisco Bay from Alcatraz Island, train for a fall marathon, and travel with her husband. As a DMRF Douglas Kramer Young Advocate Award recipient, she and her mom were planning to travel from Texas to Washington, DC for Dystonia Advocacy Day. She also came to the sobering realization that her dystonia was worsening and she needed deep brain stimulation (DBS).

For four years, Kelsey has worked as a radiation therapist and computed tomography tech in a busy cancer center. She is on her feet all day, has close interaction with patients, and does a lot of heavy lifting. As the country began to shut down due to the pandemic, the cancer center got busier. Several staff members were quarantined due to Covid-19 exposure or sent home for the day with elevated temperatures. Due to personnel shortages, a skeleton crew works 14-hour days that begin at 5:30 am. Staff must often work alone in situations where they would normally work in pairs.

For most of her employment at the center, Kelsey was able to keep her dystonia private. The twitches in her arms and body are not frequent enough for most people to notice. The dystonia causes posturing in her foot, curvature in her spine, and mild symptoms in her hands. In February, several fingers began to noticeably contract inward, affecting her grip. When she shared her situation with supervisors, she was encouraged by the initial response. “They were very understanding at the beginning and then Covid-19 hit and, even though disability isn’t something you can become too busy for, I think my workplace just became too busy to worry about it,” she said. When she expressed concern to senior faculty that she needed assistance to deadlift and transition an immobile 300lb patient, the response was, “You’re resourceful. You’ll figure it out.” When she informed a supervisor that her neurologist recommended DBS and she would need to schedule time off for surgery, the supervisor expressed annoyance that Kelsey’s medical leave might cause a scheduling inconvenience. “I have absolute confidence that I can take care of my patients,” Kelsey

explained, “but I don’t have the confidence that I’m going to be safe or uninjured in the process.”

These days Kelsey comes home from work exhausted. “Sometimes I’ll go home and I’ll just feel defeated, and I think to myself, does everyone else feel this way? I think the best thing that I’ve done is, just have your bad moment, but don’t let your bad day become your bad life,” she said.

For years, fitness has been Kelsey’s outlet for fun, managing stress, and staying in shape. Her favorite activities are rigorous obstacle course races: running, jumping, climbing, swimming. Lately, weight training and other activities have been made more difficult due to the changes in her hands and grip. She and her husband have stayed active during the pandemic by exercising in a park near their home.

As grueling as the past several months have been for Kelsey physically, the emotional aspects have hit especially hard. “Dealing with the physical combined with the mental stress of feeling like people aren’t taking you seriously, or they think that you’re exaggerating, that is what can make people fall down that well of self-pity and depression,” she said.

She credits a supportive spouse and church community for helping her cope. Despite the declining ability in her hands, she finds comfort in playing music. She explained, “I still force myself to sit down at a piano and sing praise and worship and really just allow me a moment to get over myself.”

She expects to have her first surgery of the DBS process this fall. “DBS is my light at the end of the tunnel,” she said.

AIDAN & SUNSHINE

"We tease Aidan that he's had us in training for a pandemic for years," joked Sunshine Fox, whose 10-year-old son has dystonia. "We have always been very vigilant with hand-washing and sanitizing, extra precautions to keep him safe." Sunshine is a Co-Leader of the Central Indiana Dystonia Support Group.

Aidan is diagnosed with a rare neurometabolic disorder that includes dystonia and microcephaly. His mobility, speech, and development are affected. Dystonia affects the core muscles surrounding his diaphragm, reducing his ability to cough; this makes him susceptible to dangerous lung infections. "We constantly keep an eye on those lungs, so when this pandemic started and the virus was affecting the lungs, it was immediately like, oh my gosh, this could affect Aidan so terribly," said Sunshine.

To complicate matters further, as the virus outbreak escalated, Aidan was in the middle of the deep brain stimulation (DBS) process. The family was commuting from Whiteland, Indiana to a major movement disorder center in Cincinnati for Aidan's care. He had a first surgery in January, a second in February. Two weeks after the second surgery, the neurostimulators implanted in his body were turned on at very low settings, with the intention of returning to the clinic every month for adjustments. Before they could visit the clinic for another adjustment, everything shut down due to the pandemic.

Sunshine's husband Darrick began working from home. Aidan and his sisters Kendra (18) and Alissa (15) were home from school. Sunshine continued part-time work at a garden center. The



Sunshine and Darrick Fox and their three children have spent a lot more time together since the Covid shutdown.

family already employed in-home nurses five days a week and upped their hours to help care for Aidan.

At the height of the country's transition to sheltering in place and shutting down all but essential businesses in late March, Sunshine paused to wonder what Aidan must be thinking about it all. She made a post to her Facebook page that began: "All is right in Aidan's world." She explained: "He was totally unaware of what was going on outside his front door. He was focused on his family's home. His sisters are home all the time and Dad's home and his favorite nurses are here. He's getting spoiled because he doesn't feel good. I had a moment of stepping away from all my concern that people aren't taking this virus seriously, all the overwhelming chatter in my head, and I could see that this isn't so bad for Aidan. He was okay. He was safe."

As the weeks passed, the botulinum neurotoxin injections that had kept Aidan's dystonia fairly controlled began to wear off, causing the symptoms to intensify. His stimulator settings could not be adjusted to compensate,

because the clinic was not seeing patients due to the shutdown. "The month of April was absolutely miserable for Aidan," said Sunshine, "We knew it was going to be a rough go for a while. We just weren't prepared for a pandemic in the middle of it."

Aidan celebrated his 10th birthday on April 19. The family rallied during the tough weeks to help keep his spirits up and keep him as comfortable as possible. "We work really good as a team," Sunshine said. "Our girls are so fantastic and their life has been turned upside down by having Aidan as a brother, but they haven't let it make them bitter or upset. He just loves them to pieces and they love him."

Aidan was able to get back into the clinic for a DBS adjustment in May. He returned to physical therapy in June. Sunshine is grateful for these "baby steps" toward a more familiar routine: "He's ready to get some normalcy back into his life. It's been a long haul for him."

It is unclear what the lasting impact of the pandemic will be for the Fox family. Certain routine, even mundane, facets of life have become weightier. Every Wednesday, after physical therapy, Sunshine and Aidan used to go shopping. "It's those little moments of, am I ever going to feel comfortable taking him back to Target?" she wondered out loud. "Those mommy and Aidan moments that I kind of took for granted in the past. He doesn't quite understand, why are we not doing that anymore? It'll be a long time before I'm comfortable doing some of those little things that we used to do."

“I Felt My Old Self Come Back”

Resilience in Aftermath of Dystonia Diagnosis

“Some of the incredible things about human beings are the needs to persevere, re-evaluate, and somehow get up and face another day. We rebound out of necessity,” said Sandra Lopez, LMSW, a medical social worker in Michigan.

For 45 years she has worked with individuals with various chronic health conditions. She is an expert in helping people navigate the self-discovery process that almost inevitably unfolds after an unexpected diagnosis or disability.

Ms. Lopez has also lived this process firsthand. Although she was diagnosed with cervical dystonia 38 years ago, memories of those early, anxious days remain fresh in her mind.

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It started when her husband noticed her head drifting to the right while playing video games with their son. She didn't notice it was happening until he pointed it out.

She consulted her primary care physician, who diagnosed her with cervical dystonia. “Those first couple of weeks, I didn't eat, I was depressed. My neck was getting worse. All of the ‘what ifs’ came to mind,” she recalled. “What if I can't do my job? What if I can't be a wife, a mother? So much of that is fear. It's not necessarily reality because you're projecting things that could happen, and usually it's not quite as bad as we anticipate. But that immobilized me during the first month or so.”

Choreographing daily activities around the posture of her neck became exhausting. She could not hold her head straight without intense concentration and effort. “Having to prop my head up continually wore me out. Everything at that point was a challenge and a struggle.” She couldn't face forward while walking down the long hospital halls at work. She had to physically hold her head to eat. She steadied her head against the headboard of her four-year-old's bed when reading to him at night. Unable to continue knitting, which she loved, she found moments of distraction by needlepointing on her back and holding her work above her.

She dreaded any situation that might prompt someone to ask, *what's wrong with your neck?* “I never explained because it's such a rare condition, no one understood,” she said. She stopped socializing unless absolutely necessary.

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A watershed moment occurred when her mother-in-law shared a newspaper article about a cervical dystonia clinic opening in Detroit. After a six month wait for an appointment, the physician confirmed the diagnosis and recommended a low dose of clonazepam. Within a week, her symptoms dramatically decreased. “I could just feel my neck loosen up. It was almost like being reborn,” she said. “I felt my old self come back.” It took a long time for her to trust that the medication would continue to work. It has, all these years later, along with regular botulinum neurotoxin injections.

“When I paint such a negative picture of what went on during those 10 months, I want to still give people who are newly diagnosed hope,” said Ms. Lopez. “You are still the same person that you were. You may look a little bit different, you may have pain, but you are still the same person.”

Cognitive Behavioral Therapy (CBT) can be effective in helping individuals steer safely through stressful life situations. Ms. Lopez explained: “A thought is not always a reality. Cognitive Behavioral Therapy shows us how quickly anxious thoughts and feelings of impending doom can snowball and drive us further into depression. This progression of thoughts, feelings, and actions can be stopped and evaluated quickly. When you find yourself saying, *My dystonia will never get better, how can I work or be a normal functioning person, etc.*, ask yourself, is my fear based on current issues or anticipation? If it's not reality, I can think it through, stop the negative progression, and focus on this current moment.”

CBT is often used, either alone or in combination with other therapies, to treat mental health disorders such as depression and anxiety.

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Over the years, Ms. Lopez has organized support groups for people with various chronic illnesses in the Detroit area. She recalls a powerful exercise she once initiated in a meeting for individuals with autoimmune disorders, such as lupus and rheumatoid arthritis, noting its relevance to dystonia and daily activities.

“This is a real hands on, working class area,” she explained. “We have the Big Three [automobile manufacturers] here and there is this sense that your worth is somehow tied to what you can do physically, what you can produce.” She challenged the group to think about the qualities they valued in themselves separate from physical performance. Many were initially stumped. They had never considered it before.

“A lot of people surprisingly couldn’t acknowledge what their strengths were, what their positive qualities were, or what they liked about themselves.” Ms. Lopez gave a few examples: “Are you a good listener? Are you empathetic? If somebody needs help, will you offer your assistance? When you take stock of what you have to offer the people around you, that’s what you can pride yourself on. But it’s hard to do. So much of our self-worth is based on what we can accomplish physically.”

In cataloguing her own strengths, Ms. Lopez believes her experiences with dystonia made her a better social worker: “Dystonia was definitely a challenge that I would not have opted to go through, but it’s given me more insight and more tolerance. I had the sensitivity, but I didn’t have a full understanding and appreciation for how severely certain conditions, like dystonia, can negatively impact every facet of daily life.”

If you or a loved one receive care for dystonia at a major medical center or hospital, consider inquiring with patient services whether there are medical social workers available to help support you.



COPING TIPS

- Seek out expert medical advice. Explore treatment options until you find what works best for you.
- Stay informed about developments in dystonia research and new treatment opportunities.
- Take stock of positive qualities about yourself, especially those that are not associated with physical ability.
- Trust that you will adjust to new circumstances and challenges.
- Find ways to do activities you find enjoyable and relaxing.
- Find ways to give your mind a break from worries and complaints, even if for a few moments.
- Reach out for peer support through local dystonia support groups or online groups.
- Surround yourself with positive people and influences. Notice how negativity impacts you physically and emotionally.
- Celebrate your successes, including small everyday moments that bring satisfaction.
- Seek out professional help to protect mental health and address co-occurring depression and anxiety.
- Ask for help when you need it, and without guilt. This applies to spouses and caregivers, too.
- Remember dystonia does not define who you are.

DID YOU KNOW?

Quick Facts about Botulinum Neurotoxin Injections

Botulinum neurotoxin (BNT) injections are a common treatment for dystonia. This therapy is used to treat dystonia symptoms in a specific group of muscles, for example, the neck, face, or a limb. Despite the popularity of this treatment for dystonia, certain important aspects of the therapy may come as a surprise to new patients.

BNT is not a chemical drug.

BNT is a biological product, or biologic. Additional examples of biologics include vaccines, blood transfusion components, gene therapy, tissues, and many other medical products. BNT is derived from the bacterium *Clostridium botulinum*. Ironically this is the bacterium responsible for botulism, a disease associated with eating contaminated food. Complex manufacturing techniques transform by-products of the bacterium into a safe and effective therapy that is commonly used for a number of medical conditions.

There are multiple brands.

Multiple brands of BNT are available in the US, each with a distinct medical name. Each brand is created from a different strain of the *Clostridium botulinum* bacterium. They are not interchangeable. Some dystonia patients respond better to some brands of BNT than others.

- Botox® (OnabotulinumtoxinA)
- Dysport® (AbobotulinumtoxinA)
- Myobloc® (RimabotulinumtoxinB)
- Xeomin® (IncobotulinumtoxinA)

BNT interrupts communication between nerves and muscles.

BNT is injected directly into muscle to block the release of chemicals that activate muscle contractions. This reduces excessive dystonic muscle contractions, and the muscle relaxes. The effects may last for 10–16 weeks.

Most people need more than one injection per appointment.

BNT injections are not like a vaccine, which involve a single prick. Very large muscle groups treated with BNT will require multiple injection sites. Small muscle groups, such as the vocal cord muscles, may only require one prick of the needle.

BNT takes time to start working.

Most patients feel the effects of injections in 3–10 days. It may take 2–4 weeks to experience the full benefit of treatment.

Injections must be repeated.

BNT injections are an ongoing treatment that must be repeated every 3–4 months for most dystonia patients. Each session of injections provides an opportunity to adjust the dose and muscles injected, therefore customizing the treatment to the individual.

BNT may not provide 100% relief.

BNT may not completely eliminate dystonia symptoms and/or pain, but the improvement can be dramatic and profoundly improve quality of life. BNT therapy may be combined with oral medications and supportive therapies for maximum symptom relief.

Several factors influence treatment results.

BNT therapy must be customized to each patient's unique symptoms and needs. Multiple factors must be in sync for successful treatment. These include:

- Appropriate dosing
- The specific muscles involved in dystonia
- The specific sites in the muscles where BNT is injected
- The skill and technique of the doctor giving the injection
- Clear communication between doctor and patient, so both parties agree on the specific symptoms treated and what to expect from treatment

Dystonia Walk at the Bronx Zoo— Helping Out a Friend

By Adam Storino



Nine-year-old Adam Storino was given a school assignment to write about a memorable time he enjoyed helping someone. In his essay, he described his attendance at the DMRF's Bronx Dystonia Zoo Walk in September of last year. Adam's family attended the event in honor of Allison (Hersh) London, who led Team Ali's ZooGooders. Adam's mother Rachel Avidan shared his essay with DMRF.

Doctors may use guidance technology.

Because the precision of BNT therapy is important, some doctors will use tools to help locate targets in the muscles to inject. This can include electromyography (EMG) or ultrasound. Whether a doctor uses guidance can depend on their training and experience, and muscle groups injected.

It can take up to a year to get right.

Because of the many factors that determine the success of BNT injections, it may be necessary to be injected on two or three occasions before the best benefit is achieved.

The skill of the doctor giving the injections is critical.

It is important to locate an appropriately trained and experienced doctor. Travel to a major movement disorder clinic may be required to access a qualified specialist. DMRF offers a searchable directory of physicians: dystonia-foundation.org/find-a-doctor

Many thanks to past DMRF Clinical Fellow Abhimanyu Mahajan, MD, MHS of Rush University for reviewing the content of this article.

I have a family friend that has a disease called, "Dystonia," which is a disease that causes involuntary muscle contractions that cause repetitive or twisting movements. Dystonia may affect one or more parts of the body, and sometimes the entire body. This past summer at the Bronx Zoo I walked to help her cause. Even though I was there for her, I had a great time. My Grammy and me and my mom and my Aunt Sara, my cousins—Hannah, Max and Skylar—all came. We walked through the Bronx Zoo and we saw a peacock walking around the entire zoo! And the peacock started following us until we got to the Bear Exhibit.

After the Bears we went to Insects and Reptiles. I saw lady bugs, caterpillars, snakes, and Komodo Dragons. It was an adventurous moment because they were all super cool to see. Then we went on a Safari ride! While in the Safari we saw giraffes, zebras, rhinos, bob-cats, alligators, flamingos, lions and tigers and bears oh my!

After we saw all the animals we went to have lunch. We saw Allison Hersh who is the one with dystonia. We all ate together and they made us special chicken fingers and fries that were delicious. They are my favorite.

At the end, we took one more trip around the zoo. Saw some more animals and it was a day I will always remember. Even though I went with my mom to help a friend raise money, it was a really special day.

The Dystonia Walk at the Bronx Zoo was amazing to help a friend and also have fun with my family. We walked through the entire Bronx Zoo for 10 miles... and we even went around a bit again after the walk, so I must have walked 15–20 miles that day! But it was for such a great cause!

See page 12 to learn how you can participate in the first-ever Virtual Dystonia Zoo Day to benefit DMRF on September 12, 2020.

Dystonia Dialogue

Dystonia Medical Research Foundation

One East Wacker Drive • Suite 1730

Chicago, Illinois 60601-1980

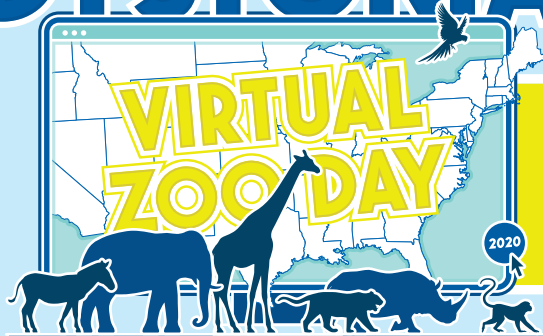
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DYSTONIA



**SATURDAY,
SEPTEMBER 12, 2020
11:00 AM CT**

"DMRF is bringing the fun and energy of our local Zoo Walks to a virtual stage, so people and families from all over the country can join together in the fight for a cure. The Virtual Dystonia Zoo Day is an opportunity for all of us—no matter how dystonia has impacted our lives—to get involved and contribute."

RONALD HERSH, VICE PRESIDENT OF DEVELOPMENT

Ronald and June Hersh honored daughter Allison London by supporting Ali's ZooGooders, the top-earning team at the 2019 Bronx Dystonia Zoo Walk

dystonia-foundation.org/lets-zoo-this

#LetsZOOthis!

