

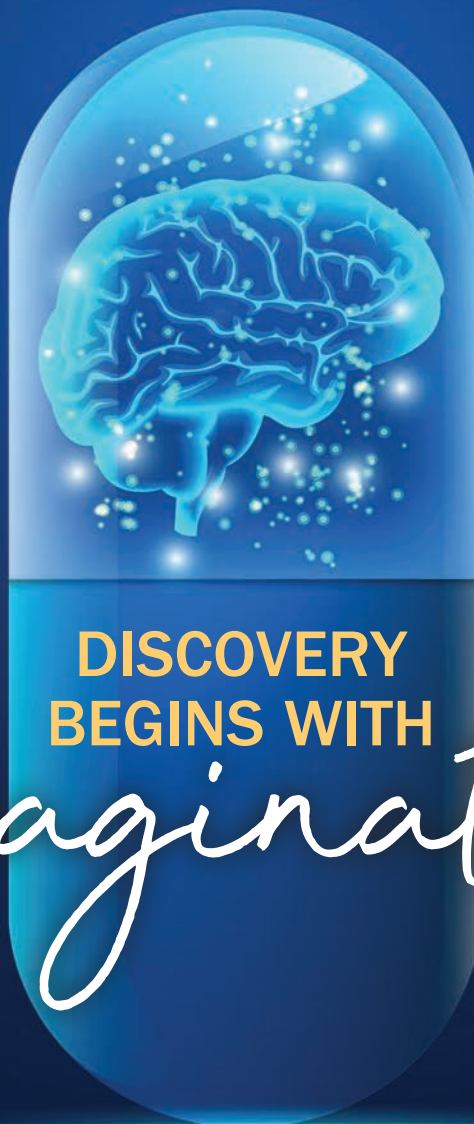


DYSTONIA  
MEDICAL  
RESEARCH  
FOUNDATION

# Dystonia Dialogue

NEWSLETTER OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

Winter 2021 | Volume 44 • No.3



DISCOVERY  
BEGINS WITH

*Imagination*

4

New Dystonia Drug  
Candidates Discovered

7

DMRF Co-Founder  
Appointed to Order  
of British Columbia

20

Family Healing in  
Living with Dystonia

# Inside this Issue

**4 New Dystonia Drug Candidates Discovered**  
Major Advances toward New Treatments

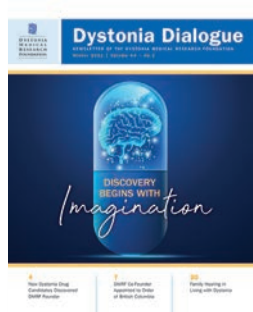
**12 Highlights from Virtual Dystonia Zoo Day**  
Thousands Unite to Raise Awareness & Research Funds

**16 Not Born Yesterday**  
Dystonia & Aging

**20 Family Healing in Living with Dystonia**  
Insights from DMRF Vice President of Support Dr. Karen Ross

**22 Personal Profile**  
Meet Kitteren 'Kit' Jester

## On the Cover:



Dystonia investigators around the world are expanding the boundaries of what is known about dystonia and implications for novel treatments. On page 4 read about the latest exciting discoveries in new potential drug candidates.

*The Dystonia Dialogue is supported by an educational grant from Revance Therapeutics.*

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.

### Staff

Janet L. Hieshetter  
*Executive Director*  
Veronica Diaz  
*Manager of Community Engagement*  
Jeane Em DuBose  
*Science & Technology Manager*  
Debbie Durrer  
*Director of Development*  
Jessica Feeley  
*Director of Communications & Education*  
Jennifer McNabola  
*Director of Finance*  
Martha Murphy  
*Information Coordinator & Brain Bank Liaison*  
Emma Pinto  
*Associate Director of Development & Database Management*

### Chief Scientific Advisor

Jan Teller, MA, PhD

### Dystonia Dialogue Editorial Board

Barbara Kessler, *Chair*  
Ed Cwalinski  
Paul Kavanaugh  
Dee Linde  
Allison London  
Anneliese Ornelis  
Diane Rudolph  
Paula Schneider

### Dystonia Medical Research Foundation

One East Wacker Drive  
Suite 1730  
Chicago, Illinois 60601-1980  
**Phone** 312 755 0198  
800 377 DYST (3978)  
**Web** [dystonia-foundation.org](http://dystonia-foundation.org)

Printed in the USA. © Dystonia Medical Research Foundation

### Dystonia Medical Research Foundation Board of Directors

Samuel Belzberg  
*(1928-2018) Co-Founder*  
Frances Belzberg  
*Honorary Chairperson & Co-Founder*  
Mahlon R. DeLong, MD  
*Scientific Director Emeritus, Lifetime Honorary Director*  
Stanley Fahn, MD  
*Lifetime Honorary Director*  
Art Kessler, *President*  
Richard A. Lewis, MD  
*Vice President of Science*  
Barbara Kessler  
*Vice President of Awareness & Education*  
Karen K. Ross, PhD  
*Vice President of Support*  
Carole Rawson  
*Vice President of Public Policy*  
Ronald Hersh  
*Vice President of Development*  
Mark Rudolph, *Treasurer*  
Sandra Weil, *Network Liaison*  
Jon Davis, *Director*  
John Downey, *Director*  
Donna Driscoll, *Director*  
Marilynne Herbert, *Director*  
Erwin Jackson, PhD, *Director*  
Stefanie Jackson, *Director*  
Brian Keane, *Director*  
Dennis Kessler, *Director*  
Rosalie Lewis, *Director*  
Allison London, *Director*  
Liz Rawson, *Director*  
Diane Rudolph, *Director*  
Paula Schneider, *Director*  
Pamela Sloate, JD, *Director*  
Joel S. Perlmutter, MD  
*Scientific Director, ex officio*  
Billy McLaughlin  
*Awareness Ambassador, ex officio*  
Janet Hieshetter  
*Executive Director, ex officio*

# Foundation Update



Art Kessler  
*President*

Some of us may remember learning about the scientific method in school, which generally goes like this: Knowledge is acquired by building evidence. The first step is to ask a question, then conduct research to investigate. State a hypothesis and test it. Make observations and analyze results. Make a conclusion and share the findings. The process repeats, and repeats again. Science is the cycle of building on ideas and using the knowledge gained to learn even more.

Science requires imagination as much as it does reasoning. It takes imagination to pose a meaningful question, envision a plan to arrive at an answer, and solve problems through research. It takes creativity and perseverance to see the process through. It takes clarity to objectively assess evidence.



Janet L. Hieshetter  
*Executive Director*

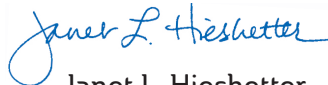
Imagination is what led Fran and Sam Belzberg to establish the DMRF—they imagined a future without dystonia. They imagined a full life for their daughter beyond dystonia. We are pleased to acknowledge that Fran was recently appointed to the Order of British Columbia, a tremendous honor to recognize individuals who turned vision into action to benefit society. She was honored in part for her transformation of dystonia research and resources for affected families by founding the DMRF. See page 7 to read more about the appointment and page 9 for remarks from Fran in light of DMRF's 45th anniversary.

The DMRF is committed to supporting scientific investigations that generate discoveries while building a research environment in which discovery is possible. On page 4 you can read about the latest exciting discoveries in new potential drug candidates. Earlier this year, DMRF hosted a webinar to update the community on the Dystonia Coalition, a remarkable testament to the growth and vibrancy of the dystonia field. (A recording is available for viewing at [dystonia-foundation.org/dystonia-coalition/](https://dystonia-foundation.org/dystonia-coalition/)). None of this would be possible without the establishment of the DMRF and a commitment to a rigorous scientific process.

While the science is constantly evolving, DMRF remains available to individuals and families impacted by all types of dystonia for information and support. Thank you for being a part of the DMRF family. It is a privilege for the DMRF leadership to be of service to the dystonia community.



Art Kessler  
President



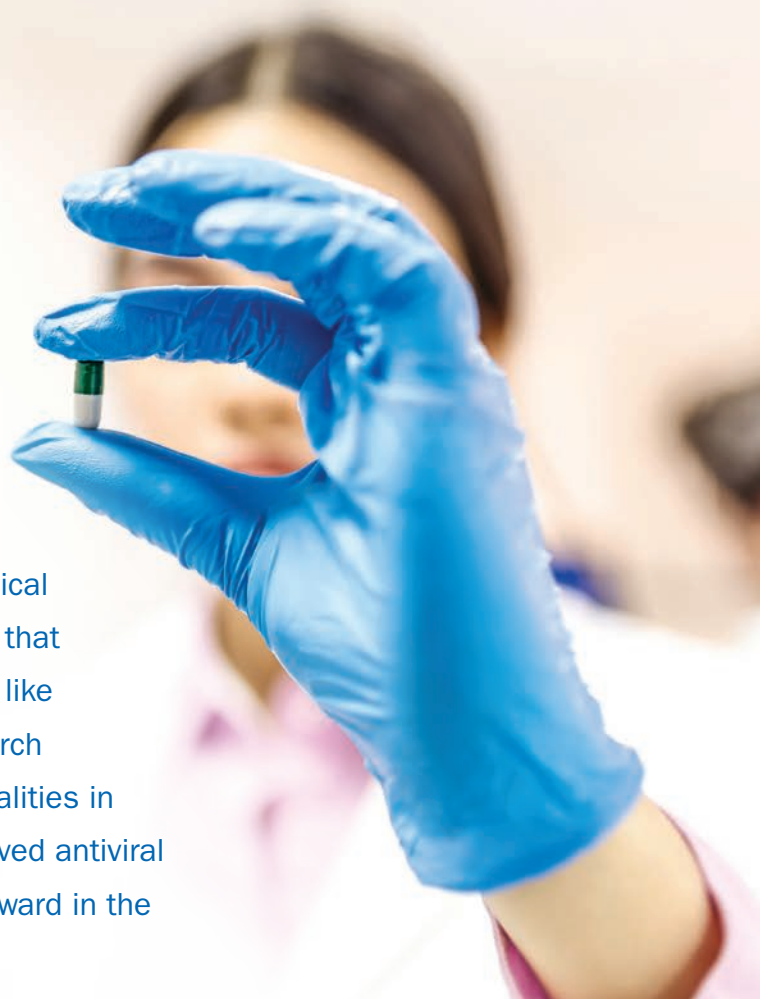
Janet L. Hieshetter  
Executive Director

***Give at Your Own Pace—Become a Monthly Donor***

*Visit: [dystonia-foundation.org/donate](https://dystonia-foundation.org/donate) or see enclosed business reply envelope.*

# New Dystonia Drug Candidates Discovered

Several research teams reported major advances in the development of new drugs to treat movement disorders including dystonia. In one of these preclinical studies, investigators identified several compounds that retain the beneficial effects of anticholinergic drugs like Artane while eliminating side effects. Another research group successfully corrected dystonic brain abnormalities in mice with a Food & Drug Administration (FDA)-approved antiviral drug. These studies represent remarkable leaps forward in the effort to develop novel dystonia treatments.



**P. Jeffrey Conn, PhD and colleagues have worked for years in pursuit of dystonia-specific drugs.**

## Next Generation Anticholinergics

A research team from Vanderbilt University School of Medicine led by past DMRF Medical & Scientific Advisory Council (MSAC) member Dr. P. Jeffrey Conn and colleagues Drs. Aaron Bender and Jerri Rook discovered and extensively characterized new compounds that reduce parkinsonism and dystonia in mice by targeting specific cholinergic receptors.

Many drugs work by acting on receptors, which are cellular proteins that receive information from outside the cell. Drugs binding to receptors may either activate or inhibit them, and this affects various cellular processes. Sometimes a drug acts to prevent other molecules, like neurotransmitters, from binding to that receptor.

Anticholinergic drugs, such as trihexyphenidyl (Artane), can be effective at controlling dystonia symptoms but are not a viable treatment for many patients because the side effects, including memory difficulties, sedation, or even hallucinations, can be unbearable. These unwanted effects occur because existing anticholinergic drugs act on many receptors in the

brain, not only the receptors associated with dystonia symptoms one would want to target. If the drugs acted more precisely, and targeted only the receptors associated with dystonia, this would eliminate the side effects.

The Vanderbilt research team first identified such specific receptors and then synthesized novel compounds that specifically reduced dystonic symptoms in dystonia mouse models. Three of these compounds have been thoroughly tested and characterized, making them prime candidates for further drug development and clinical testing.



In a subsequent paper, the team described a discovery of another highly selective preclinical drug candidate for the treatment of dystonia and other movement disorders.

These discoveries represent many years of research and are major advances in the exploration of more potent and specific anticholinergic drugs that reduce motor symptoms in dystonia and other movement disorders.

“Most dystonia patients are familiar with often terrible side effects of anticholinergics. Finding drug candidates that target specific cholinergic receptor subtypes without affecting others has been a true Holy Grail for pharmacologists. After many years of hard work, the Vanderbilt team led by Dr. Jeff Conn, finally delivered. We can only hope that these drug candidates will ultimately be as effective in the clinic as they are in the lab,” said Dr. Teller.

Current MSAC member, Dr. Ellen Hess of Emory University School of Medicine and Dr. Mark Moehle, a past recipient of the DMRF’s prestigious Mahlon DeLong Young Investigator Award, currently at the University of Florida, Gainesville, also participated in these studies.

*“The dystonia community, patients and researchers, have been waiting for these kinds of studies for years. And it took years to get to this point! Enormous research and organizational efforts were required to achieve these scientific feats.”*

*~ Dr. Jan Teller, DMRF  
Chief Scientific Advisor*



**Nicole Calakos, MD, PhD and her team identified a promising new drug for dystonia that is already FDA-approved.**

### **Antiviral Drug Corrects Dystonic Brain Abnormalities**

A team of researchers from Duke University led by past DMRF grant recipient and current member of the MSAC Dr. Nicole Calakos discovered that an existing FDA-approved drug corrects dystonia-specific brain changes in a mouse model of DYT1 dystonia.

DYT1 dystonia is a genetic dystonia that typically begins in childhood and progresses to generalized symptoms. Screening a library of drugs by using an assay they developed, the researchers found that the HIV antiviral drug ritonavir was among 18 compounds shown to have a specific and robust effect. Ritonavir belongs to a class of drugs called protease inhibitors and is used in combination with other drugs to treat HIV/AIDS (human immunodeficiency virus/acquired immunodeficiency syndrome). Ritonavir corrected abnormal TorsinA migration in the dystonic mouse neurons. Critically, ritonavir corrected the striatal cholinergic physiology disrupted in dystonia through a unique mechanism that is different from the mechanism that slows HIV infection. In the dystonia models, ritonavir acts on pathways related to cell stress response, in which TorsinA appears to play a critical role.

The results of this study provide strong preclinical support to further explore ritonavir and other analogous protease inhibitors for dystonia.

Dr. Teller said, “The Duke team led by Dr. Nicole Calakos achieved something quite astonishing. Many groups try to ‘repurpose’ existing drugs, to see if already approved and safe medications can be used for different indications. This can be a very chaotic process. The Duke team used a beautiful, systematic approach. They not only identified a promising drug for dystonia but, equally importantly, showed that its beneficial effects are inherently linked to a biological process compromised in DYT1 and other dystonias.”

Also from Calakos Lab, earlier this year DMRF grant recipient Dr. Ashley Helseth led a study with important implications for dystonia. The study characterized the influence of a specific cellular pathway engaged in cell stress response on dopamine signaling in part of the basal ganglia. This linked the pathway to processes in the brain related to learning and movement, suggesting it may be a potential target for novel treatments.

*Continued on page 6*

Continued from page 5

### Moving Forward

Drug discovery and development efforts are a critical part of DMRF's multi-faceted science strategy. The Vanderbilt and Duke investigators mentioned above were supported in part by funding from the of Defense (DOD) Peer Reviewed Medical Research Program, which began offering funding to dystonia investigators in 2010 at the urging of the Dystonia Advocacy Network led by DMRF. To date, the DOD has awarded more than \$23 million to dystonia researchers. This is in addition to the \$45 million in dystonia research supported by the National Institutes of Health.

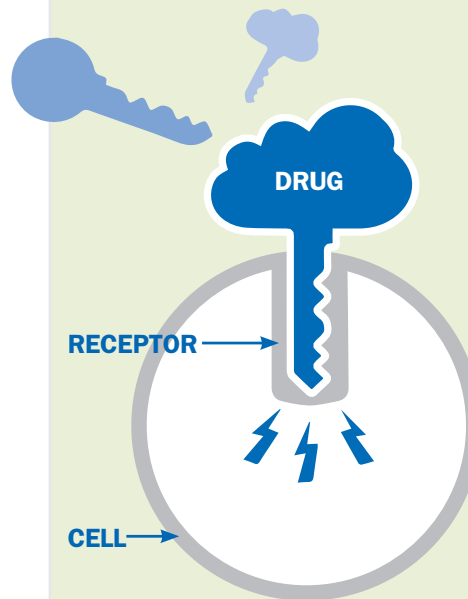
"Congratulations to everyone involved in these spectacular research achievements," said DMRF President Art Kessler. "We look forward to future updates with hope and enthusiasm."

"It is powerful to see our legislative advocacy efforts in support of federal research funding lead directly to groundbreaking scientific discovery," said Carole Rawson, Chair of the Dystonia Advocacy Network and DMRF's Vice President of Public Policy. "I want to thank our volunteer advocates who work every year to keep dystonia in the DOD Peer Reviewed Medical Research Program. This could not have happened without you."

Individuals and families affected by dystonia can play a critical role in accelerating new scientific discoveries by advocating for increased federal funding for dystonia researchers through the DOD Peer Reviewed Medical Research Program and the National Institutes of Health.

To learn more about joining the Dystonia Advocacy Network visit: [dystonia-foundation.org/get-involved/advocacy](http://dystonia-foundation.org/get-involved/advocacy)

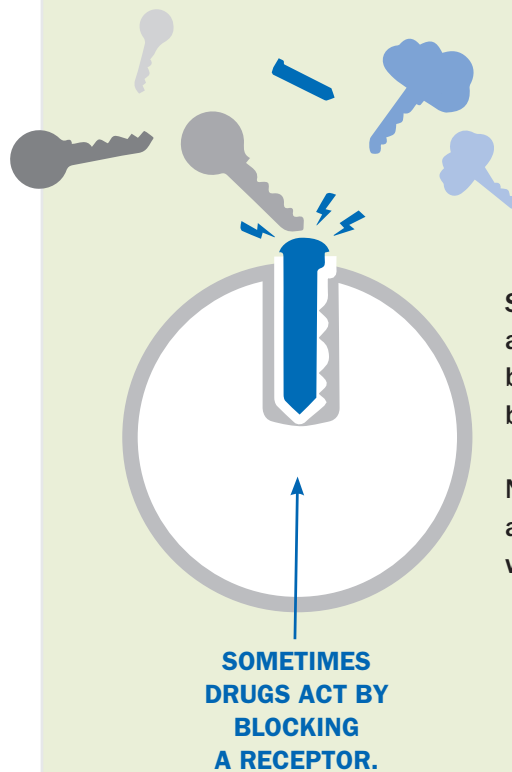
## DRUGS & RECEPTORS: HOW DRUGS WORK



Drugs most often work by acting on receptors in the brain and body. Receptors are protein molecules in cells that can receive information from outside the cell.

Receptors are like locks that are activated by a matching key.

A drug activates the receptor by binding to it. The activated receptor then sends signals to the cell in response to the drug.



Sometimes a drug fits into a receptor but only acts to block other molecules from binding to that receptor.

Neurotransmitters, hormones, and other molecules also work by binding to receptors.

# DMRF Co-Founder Frances Belzberg Appointed to the Order of British Columbia

Frances Belzberg, who in 1976 co-founded the DMRF with her late husband Samuel Belzberg, was one of 16 individuals appointed to the Order of British Columbia, the Province's highest recognition. More than 250 individuals were nominated this year. In 1996, Ms. Belzberg was appointed to the Order of Canada, the nation's second highest honor of merit.

In his testimony in support of the appointment, dystonia expert Dr. Anthony Lang explained that "[the] establishment of the DMRF essentially revolutionized the field" and that "Frances has been an active driver and supporter of the work of the foundation." Dr. Lang is Director of the Morton & Gloria Shulman Movement Disorders Clinic and Lily Safra Chair in Movement Disorders at the Toronto Western Hospital, and Officer of the Order of Canada.

Forty-five years later, Ms. Belzberg remains actively involved with DMRF and DMRF-Canada. President of DMRF Art Kessler remarked, "On behalf of the DMRF Board of Directors, we congratulate Fran on this achievement and thank her for her tireless efforts on behalf of the dystonia community. I have personally and profoundly benefitted from her vision for what DMRF has become and, like so many others who have been helped, am indebted to her decades of investment and dedication."

In addition to being recognized for founding the DMRF, Ms. Belzberg was honored for efforts to advance research and awareness for HIV/AIDS and for partnering with the Government of Canada on an initiative to inspire civic engagement among young people.

Ms. Belzberg was interviewed on CBC Radio about her recent achievement. A recording is available at: [dystonia-foundation.org/frances-belzberg-order-bc](https://dystonia-foundation.org/frances-belzberg-order-bc)



**Frances Belzberg was honored for her transformation of dystonia research and patient resources.**

## *\$5Cure4Dystonia Surpasses \$100K Raised for Research*



Dystonia awareness all-stars Mike Delise and Jason Dunn of Warren, Michigan continue their tireless efforts to promote dystonia awareness through \$5Cure4Dystonia. Launched in 2017, the effort has cumulatively raised more than \$100,000 in support of DMRF's research efforts to find a cure.

Jason developed dystonia around age five, and is a longtime childhood friend of Mike's children. Meeting Jason inspired Mike to become a devoted dystonia advocate. Jason has undergone four brain surgeries and countless medications, injections, and medical consultations. While dystonia has taken his ability to speak and walk easily, Jason is a powerful and popular advocate in the dystonia community. He has appeared on national television broadcasts, including *National Geographic's Extraordinary Humans*, numerous local news media, and gained an expansive social media following.

Jason and Mike have also advocated for dystonia on Capitol Hill in Washington, DC and at state and local levels. This year, Mike purchased billboard space featuring Jason's image to promote awareness and encourage people to visit [5dollarcure.com](https://5dollarcure.com) during Dystonia Awareness Month. The campaign was once again covered by reporter Deena Centofanti of Fox2Detroit. Michigan Governor Gretchen Whitmer issued a proclamation recognizing Dystonia Awareness Month in September.

# Why is the DMRF Important to You?



2021 marks 45 years since the DMRF was founded. Since 1976, the Foundation has

worked tirelessly, every day, on behalf of every affected individual and family. And we won't stop until there is a cure.

Whether you are new to DMRF or have been a member for decades, thank you. Over and over again, we are inspired by how the dystonia community steps up to support the DMRF and each other. Together we have pushed the dystonia field forward and welcomed major milestones, not only in research but also support and education programs. We are grateful for your support.

During our anniversary year, DMRF is collecting testimonials from the community to highlight what we have accomplished together. Submissions remain welcome. Visit [dystonia-foundation.org/why-important/](https://dystonia-foundation.org/why-important/) to share your remarks. Testimonials will be shared on the DMRF website and in future communications.



We connected with the DMRF in 1978, shortly after our son Art was diagnosed with generalized dystonia. We were looking for answers—we wanted to know what dystonia was, what treatments were available, and what research was being done. The DMRF provided all the answers as well as introducing us to others with the same goals. It provided us a way to contribute and be involved in reaching them. It has been very rewarding to see how the DMRF has grown over the decades and the advancements that have taken place. The DMRF has had a profound positive impact on our family.



~ *Dennis & Barb Kessler, DMRF Board of Directors*

*Dennis is DMRF Past President and Vice President of Development. Barb Kessler is Vice President of Awareness & Education and Chair of the Editorial Board*



DMRF brings together people who feel alone. I have met some of my best friends through the DMRF and hope to continue to meet new members and treat them like DMRF does, like a family member. Words can't express enough how much I feel or how much gratitude I have.



~ *Amy Yurchision, DMRF Supporter*







Just before going away to University our eldest daughter Cheri began to have difficulty with her handwriting, and her right leg began to kick her left leg. I took her to our GP. Not finding anything physically wrong with her, he said, it's the 1960s, she's a teenager—I'm going to send her to a psychiatrist. Maybe he can find out what's troubling her.



The psychiatrist, not finding anything wrong emotionally with Cheri, sent her back to the GP, and this dance continued for almost five years. Cheri married and moved to Los Angeles, where her symptoms became more pronounced. She connected with local doctors who went through the same exercise as they did in Vancouver. She went from the GP, to the psychiatrist, and back to the GP, who decided finally to send her to a neurologist, Dr. John Menkes. After spending much time with Cheri, Dr. Menkes decided that she had a unique condition called *dystonia musculorum deformans*. Only he had no idea how to treat it.

Once my husband had a label on it, he sprang into action. We collected Cheri and Dr. Menkes and went to the National Institutes of Health. We saw a doctor who used the word 'dystonia.' He had three patients that he identified with this peculiar condition. We went home. My husband and Dr. Menkes collected four or five neurologists and, around our kitchen table with bimonthly meetings, started discussing and researching dystonia and how to go about attacking it. Eventually we felt confident enough to open our office and create the Dystonia Medical Research Foundation. Dr. Menkes became our first Scientific Director. We have grown now into what is an international organization. It's easy to say the rest is history—45 years of history. But it's not easy to say that we have not yet found a cure.

I am grateful that we have found treatments and have been able to diagnose the condition quicker and alleviate some of the emotional strain that dystonia has on the individual. We are diligently finding new investigators. We also have to work diligently to find the funds to fund the new investigators. I am looking forward to the day that we can close the door and say goodbye to the Dystonia Medical Research Foundation.

~ Frances Belzberg, DMRF Co-Founder & Honorary Chair



The DMRF is turning 45 this year and so am I. What a wonderful time to be a part of such an important organization. When I was first diagnosed, the DMRF gave me hope. The information and support they gave me and my family was imperative to navigating this diagnosis of dystonia. I'm 27 years in on this journey and the DMRF has been there the entire time. Being a Support Leader and involved with the Pittsburgh Zoo Walk and becoming a legislative advocate for the DMRF has given me a sense of purpose. Playing an active role in my dystonia has made a positive difference in the way I handle my dystonia. Thank you to the DMRF. 45 is going to be our best year yet.



~ MaryRae Nee, DMRF Support Leader



Congratulations, DMRF, on 45 years. I have been with you every step of the way. Helping people, raising money for research—you do it all. We will find a cure. Lovely people, great organization.



~ Joey Farber, DMRF Support Leader



# Taking Charge of Your Care

## ✓ **Make Yourself a Priority.**

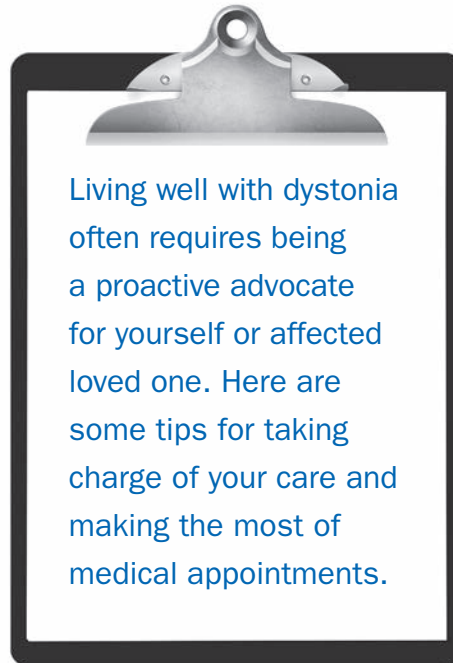
Even under the best of circumstances, dystonia is a life-changing disorder that requires management over time. Treatment can be time-consuming and inconvenient. When life gets busy or stressful, it can be tempting to ‘just deal with’ pain, medication side effects, or changes in how you feel. It may be easy to rationalize or ignore new or changing symptoms, delaying evaluation and care. Furthermore, the Covid-19 pandemic dramatically disrupted treatment for many in the dystonia community, including delaying botulinum neurotoxin injections and deep brain stimulation procedures in unavoidable ways. Listen to your body and reach out to your medical team when you need help. Remember that mental health is healthcare too.

## ✓ **Be Prepared.**

Read up on dystonia and treatments, or ask a loved one to help you. The more informed you are, the more meaningful questions you will be able to ask. Prepare a list of questions for your doctor or nurse prior to each appointment. It can be difficult to remember each question when a lot of information is being exchanged during an office visit. If possible, ask a loved one to attend appointments with you to take notes or help retain information.

## ✓ **Establish Rapport.**

It is important to establish a positive relationship with your physician and healthcare team. Consider your medical team as partners in your healthcare. Clear communication is key. Your doctor will have questions for you and you will have questions for them too. Medical appointments may feel intimidating or uncomfortable at times. You may feel understandably concerned, anxious, or in pain. Do your best to listen carefully and express your questions and concerns.



## ✓ **Focus Your Questions.**

Ask in advance how much time you can expect to have with your doctor during an appointment. Your doctor wants to address your questions and concerns but may have time restraints due to many patients who require their time and attention. Take time to write or audio record your questions in advance and take them with you. Start with your most urgent questions and concerns. If you are left with unanswered questions following an appointment with your doctor, follow up with a nurse or the admin staff to get the information you need.

## ✓ **Know Your Medical History.**

You will often be asked to recount your medical history, which may be lengthy. Have the essentials in a concise written format and bring it with you to appointments. Information to include may be: illnesses, traumas, and injuries, history of medication use and allergic reactions, family and medical history including cases of dystonia or other movement disorders in family members, allergies, and other medical conditions.

## ✓ **Take Advantage of Patient Portals.**

Many medical offices are using online patient portals. A patient portal is a secure website that provides you with access to your health information and medical records on the Internet. Accessing your personal medical records through a patient portal can help you be more actively involved in your care. Patient portals can help reduce phone tag with your doctor and sometimes even save a trip to the doctor's office. Most patient portals allow you to securely view and print portions of your medical record including recent doctor visits, discharge summaries, medications, and lab results. Other features may include completing intake forms, exchanging private email messages with your healthcare team, requesting prescription refills, scheduling appointments, making payments, and more.

### ☒ **Investigate Telehealth.**

Movement disorder clinics are increasingly using video conferencing, smartphone apps, and additional telehealth technology to care for and interact with patients. You may have the option to conduct appointments from the comfort of your home. Secure video conferencing can save you time, energy, and expense from traveling to your doctor's office.

### ☒ **Build Your Own Record.**

You are the center of your care team. It is helpful to have copies of your imaging scans, and test results at your fingertips when you need them. Your doctors may refer back to parts of your medical record or you may need them to seek a second opinion. As part of your personal record, consider keeping a health journal that includes regular observations about your symptoms and pain, documents the dates and duration of treatments, your response to treatments, and other information relevant to your dystonia and general health.

Maintain a record of your medications. Keep detailed records of supportive therapies and complementary/integrative therapies, including vitamins, supplements, and herbs.

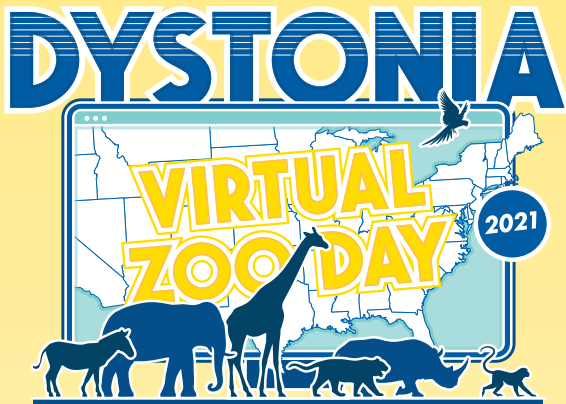
### ☒ **Remember You Have Choices.**

You have the right to appropriate treatment, and to make choices about your healthcare providers, medical institution, and course of treatment. Contact the DMRF if you need assistance locating movement disorder specialists for evaluation and treatment, or a second opinion. If you are having difficulty with your health insurance provider covering the treatments your doctor recommends, DMRF may be able to offer resources.

*Many thanks to members of the DMRF's private peer support Facebook groups for contributing to this content. For information about online and local DMRF support groups, visit: [dystonia-foundation.org/support](https://dystonia-foundation.org/support)*

## CONVERSATION STARTERS TO ASK YOUR DOCTOR

- ☐ What is my diagnosis?
- ☐ Is my dystonia isolated (primary) or acquired (secondary)?
- ☐ Does the dystonia appear to be associated with another neurological or metabolic disorder?
- ☐ Should I consult a genetic counselor? If so, what can I expect to learn?
- ☐ What are my treatment choices? Which do you recommend for me and why?
- ☐ What are the expected benefits from treatment?
- ☐ What are the risks and possible side effects of treatment? How can the side effects be managed?
- ☐ What can be done to address [insert specific symptom or problem]?
- ☐ How long will this course of treatment last? How often must it be repeated or re-evaluated?
- ☐ What are the brand and generic names of the drugs I will be taking?
- ☐ How will I know if the treatment is working?
- ☐ What are the symptoms or problems I should report right away?
- ☐ What are the chances my dystonia will worsen?
- ☐ What supportive therapies might be helpful? Is physical therapy, occupational therapy, or speech/voice therapy recommended?
- ☐ What new treatments are under investigation? Am I a candidate for a clinical study?
- ☐ What is the best time way to contact you if I have questions?
- ☐ Is there someone on call in your office if I have a problem after hours or on weekends?



## Raises Dystonia Awareness & Research Funds



DMRF hosted the second Virtual Dystonia Zoo Day on Saturday, September 25, 2021. National Sponsors were Allergan, an AbbVie Company; Merz Therapeutics; Ipsen; and Revance. The event raised over \$265,000 in support of the DMRF mission. All team donations were eligible to be matched by a generous anonymous donor, resulting in an additional \$100,000. The National Organizing Committee included DMRF Board Members, local event planners, and supporters: Kristin Cinglie, Jacquelyn Coello, Ed Cwalinski, Beth Farber, Karen Flanagan, Caleb Metherell, Shanna Schmitt, Paula Schneider, Pam Sloate, Brian Smuda, and Julia Wall.

In advance of the event, an Olympic-style Dystonia Zoo Day torch traveled virtually across the country, landing in a new city each day, throughout the month of September. The torch ultimately reached DMRF President Art Kessler and Executive Director Janet Hieshetter for the opening ceremony. Sessions included zoo keeper chats with Toledo Zoo & Aquarium and Como Park Zoo, appearances by puppet Lolly Lardpop performed by Leslie Carrara-Rudolph, inspiring stories from DMRF Board Member Jon Davis, DMRF supporter Kim Robinson, DMRF supporter Stacey Steinmetz and her son Daniel moderated by Julia Wall of Henry Ford Health System, an exercise demonstration with physical therapists Drs. Chelsea Richardson and Lincoln Beal of re+active therapy & wellness studio, and an adapted dance party led by Interpretations Dance Academy Dance Team.

DMRF supporter Kitteren 'Kit' Jester championed a chalk art challenge. (See page 22 for an interview with Kit). Participants submitted photos of their chalk art to be entered into a random drawing for dystonia awareness merchandise and prizes. The winners were Kaden Mendez of Team Omy and Heather Field Ruggiero.

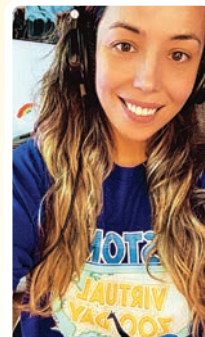
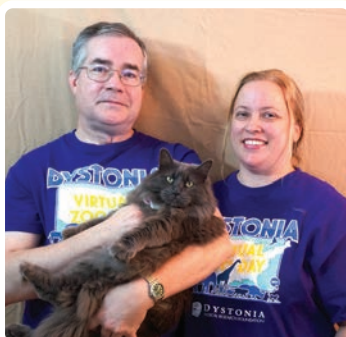
Throughout the day, Virtual Dystonia Zoo Day participants posted photos and video on social media using the hashtag #LetsZOOthis.

Many teams brought a great deal of creativity to their fundraising efforts. For example, National Organizing Committee member and guest speaker Julia Wall's grandchildren Peyton Gorham and Kerrigan Gorham had a lemonade stand to support the Henry Ford Healers. ACES Walking Challenge Club in Connecticut honored Tim Insogna with a walk in a local park. Musician Calvin Thomas performed a virtual concert in support of Team Wolfpuppi.

During the closing ceremony, Art Kessler and Janet Hieshetter extended their gratitude to everyone who contributed to the program. "It's been a wonderful day," said Art. "Thank you to all of our participants and donors—we couldn't do everything we do at the DMRF without your support."



*"Last year we were really excited to unite the entire community at the same time, on the same day, to raise awareness and work together towards a cure," said DMRF President Art Kessler during the opening remarks for Virtual Dystonia Zoo Day. "This year we are back, bigger and better than ever. All 50 states are represented, plus 8 countries."*





# People on the Move

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



In honor of DMRF Board Member **Allison London**, members of her family raced for a cure. Her husband **Dan London**, sister **Jen Goldman**, and cousin **Susan Greene** ran 13.1 miles as team 'It's All Relative' in the New Yorker Half Marathon on September 25. Dan finished first for his age group, Susan sixth for hers, and seventh for Jen. The team raised over \$60,000.



**Tracey Deyoung** and **Victoria Katz** organized the Dystonia Warrior Ride to benefit DMRF on September 25. Tracey is diagnosed with cervical dystonia, and Victoria has a loved one affected by generalized dystonia. The motorcycle ride invited participants to help promote awareness at multiple stops in north Illinois and southern Wisconsin.



June is Dystonia Awareness Month in New Jersey thanks to the teamwork of dedicated volunteers. DMRF Support Leaders and awareness all-stars **Janice and Len Nachbar** promote awareness and lead the Central Jersey Dystonia & Action Group and Dystonia Support & Action Group of Greater Philadelphia in memory of their daughter **Joanna Manusov** who tragically died this year. Support group members **Marguerite and Gary Weiss** obtained a Dystonia Awareness Proclamation from Ocean County. Janice and Len received a proclamation from Freehold Township. Banners hung on the columns at the entrance to Freehold Township Town Hall all month. In September, **Vinnie Medugno and The Chiclettes** invited the Nachbars to speak about dystonia at their show at PNC Bank Arts Center and dedicated the song "In Dreams" to Joanna's memory.

DMRF Support Leader **Sheila Killham** organized Hope on a Leash: Dogs4Dystonia Dog Walk in Marion, Iowa on August 28. The hybrid virtual and live outdoor activities included raffles, demonstrations, and costume contests.





Longtime DMRF supporter **Linda Davis** and friend **Niel Marturiello** organized the “Fight for a Cure—Dystonia Awareness” basket raffle to benefit DMRF on September 18. The event took place at VFW Post 2937 in Medford, New York. As part of the festivities, Linda recognized DMRF member **Lauren Bianco** for her awareness efforts. The event raised \$10,000. **Assemblyman Joe DeStefano**, **Senator Alexis Weik**, and Brookhaven **Councilman Neil Foley** honored Linda for her efforts on behalf of the dystonia community and each presented her with Dystonia Awareness Proclamations.



**Sheri Grube** of Burnsville, Minnesota has worked as a part-time visual artist and “full-time dystonia awareness advocate” since 2005, after being forced to retire early for health reasons and developing dystonia. She is partnering with DMRF to support research toward a dystonia cure through sales of her work. A portfolio of Sheri’s paintings is available at: [artsherigrube.com](http://artsherigrube.com)



**Kit Smith** of Costa Mesa, California is on a mountain conquering mission to raise dystonia awareness. He is three climbs away from reaching his goal to summit all 15 mountain peaks in California with an elevation of at least 14,000 feet. Kit was diagnosed with cervical dystonia five years ago. He is partnering with DMRF to raise funds in support of urgently needed research. Learn more and support Kit’s campaign at: [dystonia-foundation.org/kit-smith](http://dystonia-foundation.org/kit-smith)

### ***THANK YOU Social Media Fundraisers***

Thank you to everyone who generously collects donations to benefit DMRF on social media. Media platforms like Facebook and Instagram provide DMRF with little information about these fundraisers, and we wish to acknowledge all of our supporters.

To collect donations for DMRF through Facebook’s fundraiser tools, go to: [facebook.com/fundraisers](https://facebook.com/fundraisers) to get started.

Learn how to use Instagram donation stickers at: [help.instagram.com](https://help.instagram.com)

Please notify DMRF of your social media fundraiser. Tag or DM us on Facebook or Instagram (@dystoniamrf), or send a message via: [dystonia-foundation.org/contact](http://dystonia-foundation.org/contact)

# Not Born Yesterday: Dystonia & Aging

---

Whether someone has lived with dystonia for months or decades, the disorder often requires adjustments across many areas of daily life. The advantages of experience and aging can help ease certain aspects of the dystonia journey, while evolving realities may create new challenges.

Being aware of the natural aging process and how it may impact dystonia symptoms can help ensure optimal treatment outcomes and quality of life. If you are an adult over the age of 55 living with dystonia, you may wish to have a conversation with your movement disorder specialist about how the following issues may impact your individual treatment.

## Changes in Response to Medications

As people age they may become less responsive to drugs or more likely to experience side effects. Changes in the body's physiology may reduce the benefits of some drugs but create a potential for benefit in another, even if that drug has been tried before. For example, an individual who could not tolerate a drug at an average dose in their 40s may experience a benefit from the same drug a decade later at a fraction of the dose. Some individuals find that after trying many prescription medications, adequate relief with the least side effects can be achieved through over-the-counter analgesics and practices to support overall wellness such as regular relaxation practices and gentle exercise.

## Bone & Joint Conditions

Although bones and joints are not directly targeted by dystonia, the disorder may accelerate the onset of certain orthopedic or bone-related conditions. At the same time, the development of expected orthopedic conditions such as osteoporosis (a loss of bone mass resulting in fragile bones) and arthritis (inflammation of the joints—namely the cartilage and protective cushion structures of the joints) may aggravate dystonia symptoms. Both osteoporosis and arthritis can cause pain and restrict movement. Controlling the dystonia as much as possible may help delay the onset of these conditions, and addressing the bone and joint conditions will help avoid aggravating the dystonia.

## Long-term Effects on Bones, Joints & Muscles

Dystonia may cause long-term effects in bones, joints, and muscles. Individuals with cervical dystonia may be at risk for chronic arthritis of the neck with compression of the spinal

cord, inflammation or dislocation of discs in the upper spine, pain from pinched nerves, and chronic neck pain with secondary head pain and headache. Truncal dystonia symptoms (affecting the torso) may create inflammation or dislocation of discs in the spine and pain from pinched nerves. Arthritis of the spine may also be present. Individuals with dystonia in the legs may develop hip pain and arthritis. Severe dystonia in the legs may cause joint fusion in the ankle and/or muscle contracture. Focal hand dystonia may cause shoulder pain and arthritis in the shoulder, wrist, elbow, hand, and fingers.

Dystonia may cause painful muscle inflammation caused by excessive muscle contractions. This condition is called myofascial pain syndrome. The effects of degenerative bone and joint conditions and myofascial pain syndrome may be prevented and treated through medications, non-drug approaches to pain such as gentle massage and/or meditation, physical therapy to preserve range of motion and strengthen weakened muscles, and occupational therapy to address everyday challenges at home, in the workplace, and general mobility.

## Mobility & Balance

A number of factors associated with natural aging—including conditions such as osteoporosis and arthritis mentioned above—can affect a person's mobility and balance. One of the most serious dangers that these factors create is risk of injury due to trips and falls. Developing lower body strength and engaging in exercises focused on balance and smooth movement can help prevent falls. The potential side effects of certain medications may also contribute to mobility and balance problems.

The same factors that increase the risk of falling may also diminish a person's ability to recuperate as quickly from falls or other injuries. You may need to give yourself added time to recover from demanding activities such as traveling or rigorous household projects. Taking care of your joints and maintaining physical flexibility may help your body withstand



*"[Deep brain stimulation] is my answer to aging with dystonia. As I have aged, the medicine I take to control my symptoms has become less effective. To be able to continue to walk and decrease other symptoms, I had DBS surgery because it is the most current effective therapeutic treatment for [DYT1] dystonia. As I continue to age, DBS programmers will continue to manipulate the settings of my neurostimulator to search for the magical combination of voltage, pulse width, and amplitude to my brain in an attempt to help it send the correct messages for correct movement patterns. Even as I age, I still pray that one day there will be a gene therapy that will be effective, and I can have this hardware removed from my head, neck and chest, as well as stop dealing with the side effects of this medicine. I still want to walk, run, bike, hike, and swim with abandon. As an aging person with a chronic movement disorder that is still not fully understood, I plan to donate my brain to the dystonia brain bank for research upon my death."*

- Anonymous DMRF Member

these stresses. Small changes to your home may make the environment safer by addressing poor lighting or tripping hazards.

### **Fatigue & Rest**

Adequate sleep is an important component of good health and daily coping. Sleep challenges are common among individuals with dystonia. As people age, sleep patterns change, and it may become more even difficult to sleep soundly. You may need to spend more time in bed to acquire the same amount of sleep. It may become more challenging to stay physically comfortable in bed. Relaxation practices like self-hypnosis, breathing techniques, and meditation can help the body achieve rest and rejuvenation if you have trouble sleeping.

### **Physical Fitness**

Gentle exercise and maintaining physical fitness is important at every age to improve strength, balance, flexibility, and endurance. Each of these can help the body withstand the impact of dystonia. Exercise also helps promote a healthy emotional outlook, which has a profound effect on quality of life. Consider speaking with your doctor about the exercise options that are right for you. Consultation with a physical therapist or fitness trainer can provide direction regarding suitable types of exercise, an appropriate routine, and activities to modify or avoid. Consider cardiovascular exercise, strengthening techniques, flexibility exercises, water exercise, and inclusive fitness instruction classes and programs that prioritize accessibility for all body types and abilities.

### **Emotional Health**

Living with dystonia often involves constant problem-solving and overcoming challenges. Alternating feelings of empowerment and frustration are common. Because dystonia can be exhausting both physically and emotionally, some individuals feel worn out by years of coping with a chronic illness. Changes in employment, activities, living arrangements, finances, and relationships may lead to feelings of sadness, regret, denial, and frustration. Depression and anxiety are common among individuals with dystonia of all ages. It is normal to react to loss. Negative feelings that persist for more than two weeks may signify a need for professional support. Left untreated, mood disorders and anxiety can have serious health consequences. Treatment is available and may involve counseling, medications, and/or self-help practices.

### **Tips for Maintaining Emotional Health**

- If you feel overwhelmed by sadness, anger, fatigue, or worry, reach out for help. Consider speaking to your doctor about being evaluated for depression and anxiety.
- Remain as socially active as possible. Accept invitations from friends and family, and cultivate new friendships with people of all ages.

*Continued on page 18*

*"I'm 69 years old and have had cervical dystonia for 46 years. Dystonia has become a part of my life, but I don't consider that a negative. I have accepted it and acknowledge that it can create some limitations. I forgive myself for not being able to do as much as I used to do and realize that I tire more easily. I am grateful that my dystonia did not spread to other areas of my body and that my botulinum toxin treatments provide me with enough relief to lead a somewhat normal life. I think that those of us with dystonia need to remember to be 'kind' to ourselves. Having dystonia has also made me cognizant of the fact that almost everyone is dealing with something in their lives. We don't get to pick and choose what life hands us, so we make the best of the hand that we're dealt and keep a positive attitude as much as possible."*

~ Martha Murphy, DMRF Support Leader, Information Coordinator, & Brain Bank Liaison

*Continued from page 17*

- Find activities that are meaningful to you, particularly those that connect you to a greater community.
- Revisit activities that you enjoyed in the past.
- Develop and explore your spirituality.
- Physical exercise may help you feel better emotionally.
- Cultivate your curiosity and intellect. Learn about subjects that interest you.
- Participate in a dystonia support group, locally and/or online. Support groups provide the opportunity to simultaneously give and get support.

### **Vision**

Normal age-related vision changes typically begin around age 40. Individuals may begin to notice slight changes in vision that tend to progress over time. Blepharospasm (dystonia of the eyelid muscles) is a focal dystonia that can affect eyesight directly by causing excessive blinking or involuntary, and typically begins late in life. Additional forms of dystonia may also affect vision. Involuntary postures of the neck may make it challenging to face forward while walking or doing other tasks. Tremors and movements may make it difficult to insert contact lenses or wear glasses. Executive or progressive lenses may be more practical than traditional bifocal lenses. You may need to help inform your eye doctor about dystonia and how this affects your vision needs.

### **Multiple Healthcare Providers**

If you are consulting multiple doctors for various conditions, it is vital to keep each physician's office informed about the services and prescriptions provided by the others. Keeping all of your doctors informed of your total care will reduce the risk of undergoing procedures or receiving medications in combinations that are ineffective or unsafe.

### **Living Well with Dystonia**

Being aware of the natural effects of aging may help you anticipate ways to better manage dystonia and maintain and improve the quality of your life. The experience and wisdom accumulated by dealing with dystonia over time is an invaluable asset to your wellbeing.

*Special thanks to Neal Hermanowicz, MD, FAAN for reviewing this content.*

### **ADDITIONAL RESOURCES**

- **Dystonia & Exercise:** [dystonia-foundation.org/benefits-of-exercise](https://dystonia-foundation.org/benefits-of-exercise)
- **Sleep & Movement Disorders:** [dystonia-foundation.org/sleep](https://dystonia-foundation.org/sleep)
- **Emotional & Mental Health:** [dystonia-foundation.org/living-dystonia/mental-health](https://dystonia-foundation.org/living-dystonia/mental-health)

# Act Now to Give Later

*Registering as a Brain Donor is a Priceless Gift to Dystonia Research*



Registering 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 in advance to donate your brain.

## Why are Pathological Studies Important?

- Certain kinds of studies can only be done with postmortem tissue samples.
- So few pathological studies have been done in dystonia that some of the findings are contradictory and need to be clarified.
- Pathological studies are especially relevant for genetic and acquired dystonias in which the cause is known.
- Pathological studies and genetic studies provide opportunities to looking for commonalities among dystonia types.

## Discoveries Made Possible by Brain Donors:

- Studies examining the brains of volunteers with cervical dystonia found subtle changes in the cerebellum, supporting growing evidence that this brain area is highly relevant to dystonia.
- Pathological studies have found subtle brain changes in individuals with laryngeal dystonia/spasmodic dysphonia which are in need of validation and further study.
- The surprising discovery that the dystonia-causing protein TorsinA has a role in calcium physiology was made by findings in rodent brains and confirmed in human brain thanks to the availability of donated tissue samples.
- By examining tissue samples from individuals with rapid-onset dystonia-parkinsonism (RDP), investigators were able to identify RDP-associated pathology in several areas of the brain that would disrupt the maintenance of normal motor control. Treatment for RDP is challenging and these findings may help develop future therapies.

## Q&A

### *Can anyone register a brain donor?*

Registered donors can have any type of dystonia and must live within the contiguous United States. Certain circumstance will disqualify individuals from being donors, for example specific infectious health conditions.

### *Can family members register as brain donors?*

Yes. Biological relatives of dystonia-affected individuals may register even if they do not exhibit symptoms of dystonia. 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 24 hours a day is 800-272-4622 (800-BRAIN-BANK). 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?*

Yes. Brain donors must test negative for Covid-19 within 72 hours before time of death or within a couple of hours post-mortem through rapid testing. The brain bank needs to know if the donor ever tested positive for Covid-19. If the donor was vaccinated, they request the dates, doses, and type of vaccine received.

## How Do I Get Started?

1. Begin the registration process online at [dystonia-foundation.org/brain-donor/](https://dystonia-foundation.org/brain-donor/) or contact us at [brainbank@dystonia-foundation.org](mailto: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 and make them aware of the notification process.

*The DMRF works in partnership with the Harvard Brain Tissue Resource Center (HBTRC) at McLean Hospital in Belmont, Massachusetts.*

# Family Healing in Living with Dystonia

By Karen K. Ross, PhD,  
DMRF Vice President of Support

Our family felt like the rug was pulled out from under us when my son was first diagnosed with dystonia. Each family member was affected in profound ways, and we experienced the entire range of emotions. Shock, denial, and helplessness were just the beginning. Later we felt guilt, resentment, and even anger. At the time, we were told there were no cures and no treatments, and it was hard to even find a doctor that knew about dystonia.

I like to think of a family as a woven tapestry with each person making up a unique color and thread of the whole piece. When a family member is diagnosed with a chronic disorder such as dystonia, it may feel as if the tapestry is unraveling, never to be woven back together in the same pattern. Some families do come unraveled, but others go on to weave a whole new tapestry, brighter and stronger than before.

## Dystonia Affects the Entire Family

The stress of dealing with dystonia on a day-to-day basis can change the way each member reacts and relates to one another. Communication may break down. Where once there was openness and honesty, it may now be more difficult to express concerns and feelings.

I once spoke to a dystonia support group where a man brought up his feelings of loneliness and sadness because his adult children never asked him how he was doing or referred to his dystonia. In another instance a woman

spoke of her feelings of fear and loss and then said, “My husband wants me to be more positive and not so emotional, but I just can’t. I wish he could understand how I feel.”

Most people tend to think that it is only the ‘patient’ whose needs and feelings change but siblings, parents, spouses, grandparents, and friends are also dramatically affected. They too live with the emotions of grief, fear, sadness, loss, resentment, and anger.

Each member of a family has their own reality, their own view of the world, and their own set of feelings. Feelings are not right or wrong. While it is important to verbalize feelings, it is just as important to validate someone else’s feelings. The woman whose husband wants her to be more positive could say, “I realize that you have feelings that are different from mine, but I still need you to listen to what I am feeling.” By stating this to her husband, she is validating what he feels and is helping him to understand that she has a right to her feelings as well.



## *“The stress of dealing with dystonia on a day-to-day basis can change the way family members react and relate to one another.”*

### **Empathy is Essential**

One of the most healing and meaningful things family members can do for one another is to develop a position of empathy for one another. Empathy is being able to put yourself in another’s shoes for a moment. It’s not the same as pity or even compassion but rather it is the core of understanding. Each and every one of us has the desire and the need to be understood. For instance, a child might verbalize empathy to a parent by saying, “Mom, I remember how depressed I was when I broke my foot and couldn’t get around like I used to, so I can understand how it must be hard for you to not do all the things we’re used to doing.”

Or one spouse to another: “It must be difficult for you to deal with all the difficulties at work and then come home to the difficulties here.” These are the kinds of statements that lead to more positive connections.

### **Communicating Clearly through the Ups and Downs**

Over the years, the DMRF has repeatedly heard from dystonia-affected people that the support of family makes it possible for them to handle the ups and downs of living with the disorder. I recall one person stated it this way: “It’s important for family members to understand that there are good days and bad days—and sometimes good hours and bad hours—and that patience and understanding and love are the most important contributions they can make.”

It’s not always easy to verbalize feelings or to have empathy for other family members, but good communication skills and openness can create an environment that is both nurturing and healing for the whole family.

Here are a few communication suggestions:

- It’s helpful to start statements with ‘I’ instead of ‘you.’ For example, “I would like you to help me with a few chores this afternoon.” I need, I want, I feel, I like—these are direct statements that communicate what is going on with you.

- If you are the person who has dystonia, let family members know how they can be of assistance instead of letting them guess.
- It is helpful to have family meetings where members can discuss new situations, responsibilities, and talk about concerns or conflicts.
- Listening is as important as talking. Really listen to what a family member is saying. Give them your full attention and validate what they have said by paraphrasing or saying you understand. For example: “I understand it’s important for you to spend more time with me in the evenings, and I will try to make this possible.”
- The emotional health of children in a family is affected by the emotional relationship between their parents. Parents need to communicate and work on their relationship. It is important to seek professional counseling if you feel like you need help with your relationship.

The persistent intrusion of an illness or disorder affects all aspects of family life. Empathy, good communication skills, an attitude of acceptance, and flexibility will help to foster a resilient family. The challenges of adversity can nurture growth and compassion in each of us if we let it.

*Karen K. Ross, PhD is chair of the DMRF Support Committee, author of Holding the Hope: A Parent’s Guide to Living with Dystonia, and creator of meditation programs for dystonia-affected individuals and caregivers. She is a clinical psychologist and marriage and family therapist retired from private practice in Los Angeles.*

### **FIND SUPPORT**

DMRF support groups and online forums provide information and encouragement to individuals with all types of dystonia as well as family members. Visit: [dystonia-foundation.org/support](https://dystonia-foundation.org/support)

## PERSONAL PROFILE

# Kitteren ‘Kit’ Jester

24-year-old Kitteren (Kit) Jester recently obtained an undergraduate degree in psychology with additional studies in neurologic health and the whole-person care approach. Recently, he has given more attention to the arts in medicine and child life work. He is also currently doing research in psychiatry. After several years of commuting from Georgia to Minnesota for dystonia treatment, he now resides in Rochester, Minnesota.

### How did your dystonia symptoms begin and how were you diagnosed?

I was 17 when I noticed my feet were twisting, and it was more difficult to move. At school, it was hard to walk down the hallway, and my handwriting was starting to deteriorate. There was also some tremor. I’d take notes and couldn’t read them afterwards. On top of that, I had to stop driving. Something was going on, but there was some diagnostic fumbling at our local medical institution. Almost everything was being chalked up purely to a psychiatric disruption, and nobody wanted to help my case. It was my physical therapist who first recognized what was happening, and only one of the doctors I saw in the first investigational period mentioned dystonia more directly. About a month before this, however, was the first time I’d ever heard the word ‘dystonia.’ My mom and I were looking at videos on YouTube, when a video of a boy with generalized dystonia popped up. He and his mom were sharing his story for their local news. He had trouble walking and eventually lying down and sitting at the table. Ultimately, he underwent deep brain stimulation (DBS) surgery, which helped him immensely. It was an interesting story with a good ending, but we still didn’t know what was happening with me. My condition was nowhere near that point, and we didn’t have much insight. I remember looking at my mom and saying something like, “Well, thank goodness I don’t have that.”



**Kit led a chalk art challenge as part of this year’s Virtual Dystonia Zoo Day after discovering a new passion for creating chalk art in his driveway to encourage people.**

Funny how things end up, I guess. We then found the DMRF site. I then had enough basic awareness to recognize the term when it came up again later.

After a more thorough evaluation at a prominent movement disorders center months later, generalized dystonia finally became my primary diagnosis. It was difficult but also validating. By the next year’s Thanksgiving, my dystonia had progressed a lot, now involving muscles in my feet, legs, trunk, neck, and some on my face. Of the medications that helped, their side effects aren’t great. Everything was tight and uncomfortable, especially in the evening. I couldn’t sit at our table during dinner with family. I had to lean against a stepladder as my ‘chair,’ set my plate higher up on a box to reach it and use weighted silverware. I was later upset because I didn’t think I

would end up in that similar predicament like the other boy in the video. Within the next year was a hospitalization that turned very frightening because of my dystonia, and it prompted much more serious consideration of DBS. So, I had DBS a little less than two years after my dystonia diagnosis. I feel fortunate because I know the process can be much longer for some people. I also am aware that not everybody has support or access to the treatments that I’ve had. I think that’s important to acknowledge. Post-DBS, I’d subjectively estimate close to a 65-ish percent improvement in dystonia symptoms in general, but a lot of basic things are still hard. I

get botulinum toxin injections every 3–4 months. I also incorporate a lot of approaches from physical and occupational therapy as well as mindfulness activities. Then I always try to add color and fun when things are challenging or scary. That helps give me courage.

### Tell us about your chalk art.

I began drawing with chalk in May 2020. I knew I couldn't do much to help with the pandemic but wanted to do something. Everything was slow and lonely, and people were hurting. I was too, especially being trapped over 1,000 miles from my friends and support network at school. I'd wake up and it didn't feel like real life. At the same time, I wanted to express my gratitude for folks walking to work at the hospital down the street. I drew a simple cartoon of a dragon breathing fire on the virus and helping the people standing on top of the hospital buildings with swords and shields. Nothing realistic. I wrote, "Thank you for everything you're doing. Stay strong and brave, and awesome." I wanted to be encouraging but didn't intend to keep drawing. But then I did, again and again. I have only improved since. It is hard for a few reasons, but a big one is that it's difficult for me to bend my knees. I plank for minutes at a time and often crawl around, because getting up and down is tough. One helpful thing is that sidewalk chalk is thicker than a pencil or paintbrush and easier to hold. DBS helped my tremor but didn't fix everything. Chalk's also pretty forgiving if mistakes happen.

The response that I've gotten has been incredible. I connect with healthcare workers, neighbors, other community members, and sometimes patients or family members that can escape for a walk. I'll listen to their stories and I get to share some of mine. I can bring awareness to dystonia because it directly impacts many practical aspects in my creative process. Also, I don't think there's been a single time I've been outside—and just thinking about it makes me happy—I don't think there's been single time I've been outside when somebody hasn't said something kind to me, and I don't think I'll ever be used to that, in the best way. Every so often, I'll



find an anonymous gift on my front stoop or a note. Other people will smile or take pictures. Some tell me they share photos with their friends and family and colleagues in different states and other countries. People keep giving me chalk, to the point I don't need any more right now. I've found a way to make friends with everyone through a hard time in history. Everybody says to keep it up. For a little driveway operation, knowing

people are taking light from it is cool. It's even made news a couple times, which is awesome because more people are encouraged and so am I. The reach is beyond Rochester, obviously, and I'm even talking to you [DMRF]. It's amazing.

### Any advice for others with dystonia?

I could give lots of advice here but won't since there are many different things you can say. Everyone has something that they can find joy in. Dystonia can't take everything away. My last formal drawing class was 10 years ago. I've had dystonia now for seven. I didn't realize I could make art like this until a year ago. There is a picture I did last year of a tree, and I wrote a special message in the branches: "If we watch our heroes grow brighter, wiser, stronger, and braver every year, let us remember a new year begins every day." If you think about it, every day begins a new adventure, a new chance to be better than yesterday. Someone walked by as I was drawing and asked who were the heroes I was talking about? I had to think for a second, but speaking generally and probably more truthfully, I believe they're all the people we know who're doing the best they can—those are the heroes. People with dystonia are really strong, figuratively but also literally. There is so much that's remarkably beautiful and complicated about the organ living inside your skull. A lot of parts must work together, and anything impacting how that happens can have interesting yet potentially unfortunate consequences. If you're super hard on yourself, like I am—it may be difficult to do this—give yourself some grace when you're struggling. Keep doing the best you can. That's what I would say.



## Dystonia Dialogue

Dystonia Medical Research Foundation  
One East Wacker Drive • Suite 1730  
Chicago, Illinois 60601-1980

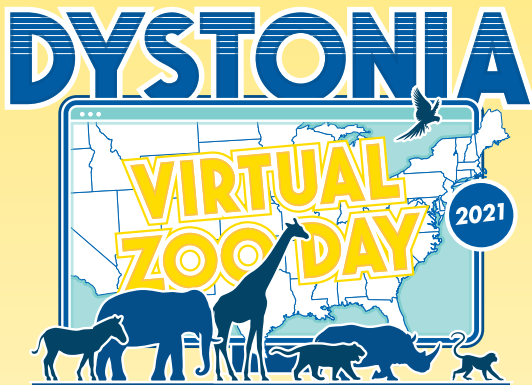
PHONE 312 755 0198 • 800 377 DYST (3978)

WEB <https://dystonia-foundation.org>



Non-profit  
Organization  
U.S. Postage  
**PAID**  
Random Lake, WI  
Permit No. 399

### MORE SCENES FROM VIRTUAL DYSTONIA ZOO DAY INSIDE!



**THANK  
YOU!**

**You are essential to the DMRF mission to find a cure.  
DONATE TODAY at [dystonia-foundation.org/donate](https://dystonia-foundation.org/donate)**