



DYSTONIA  
MEDICAL  
RESEARCH  
FOUNDATION

# Dystonia Dialogue

NEWSLETTER OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

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## Knowledge is Power



**7**

What Friends and Family  
Should Know About Dystonia

**10**

Navigating Common  
Oral Medications Used  
for Dystonia

**15**

New Mental Health  
Survey Report

# Inside this Issue

## 4 Observing Alleviating Maneuvers in Cervical Dystonia

A study from the DMRF Journal.

## 7 What Friends and Family Should Know about Dystonia

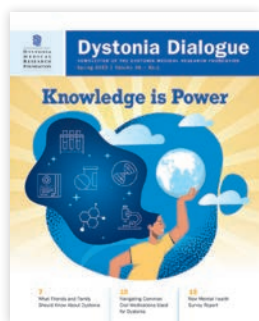
DMRF community leaders share insights on life with dystonia.

## 10 Navigating Common Oral Medications Used for Dystonia

Dystonia patients perform a balancing act between medication benefits and side effects.

## 18 Personal Profile

Meet Linda Davis



### On the Cover:

Learning as much as possible about dystonia is empowering. In this issue, DMRF presents research on alleviating maneuvers for cervical dystonia (p.4), insight on common oral medications (p.10), and shared experiences from others living with dystonia.

*The Dystonia Dialogue is supported by Ipsen Biopharmaceuticals.*

### WHAT IS DYSTONIA?

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

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

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

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

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# Foundation Update



Mark Rudolph  
*President*

The DMRF is dedicated to providing you with information and support to help you successfully manage dystonia while researchers continue their important work to unravel the mysteries of this disorder.

We recognize the importance of your having accurate, up-to-date information about the disorder so those living with dystonia can make the best treatment decisions. **Knowledge is Power**, and learning as much as you can about dystonia is empowering. The foundation is committed to assisting your efforts to: be aware of treatment options; have the opportunity to talk with others who have a similar treatment plan; learn new coping strategies; and to stay abreast of advancements in research.



Janet L. Hieshetter  
*Executive Director*

For example, the DMRF has a website that is rich with information designed to keep you in-the-know. Also, our network of support groups and on-line forums are managed by selfless leaders who work tirelessly to provide learning opportunities and to quickly dispel any inaccuracies. Last year, close to 120 support meetings were held. Each of these meetings presented an opportunity to learn and connect with others. Please contact the DMRF to learn more about how you can avail yourself of the support program.

In this issue, you will find information on oral medications, a summary of the mental health survey released last fall, and other information designed to help you stay informed. If you are not receiving the E-news, please let us know. We would be happy to arrange for you to receive the information this monthly newsletter includes.

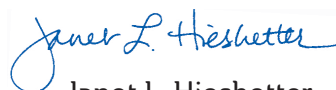
This year, the DMRF will again host webinars on topics many of you have suggested. Support leaders will organize meetings locally (many will be available virtually) to help increase your understanding of key aspects of dystonia. The DMRF will work with the other members of the Dystonia Advocacy Network to again develop an advocacy program to help our elected representatives be aware of what dystonia is, how it changes lives, and what they can do to support the dystonia community.

The DMRF looks forward to being able to present the Samuel Belzberg 6th International Dystonia Symposium, a global meeting to increase the power of dystonia researchers by learning from one another and helping to identify potential new areas for exploration. We plan to provide a lay summary of this exciting meeting to help you learn more about the areas of research that show promise.

We are all in this together, helping each other so we can direct our collective power toward closing the doors of the DMRF forever because there is no longer a need. Thank you for your support of the DMRF and for joining us in this fight.



Mark Rudolph  
President



Janet L. Hieshetter  
Executive Director



From the DMRF Journal

# Observing the Diversity of Alleviating Maneuvers in Cervical Dystonia

Dystonia, the third most common movement disorder, is characterized by involuntary muscle contractions that produce abnormal postures of varying severity, intensity, and duration. Alleviating maneuvers (AMs), often referred to as “sensory tricks”, have been defined as “voluntary actions that specifically correct the abnormal posture or alleviate the dystonic movements” (Albanese et al., 2013). For this study, the researchers extensively reviewed the existing clinical literature to select 15 commonly described AMs and then included any others described during patient interviews. These AMs were then divided into five groups based on their similarities. (See accompanying chart.) This study used a detailed patient interview to explore any patterns between different clinical features of cervical dystonia (CD) and the benefit of five different categories of AMs.

Study participants were selected if they had adult-onset focal CD and were excluded if they had cognitive impairment, movement disorders other than CD, other neurological conditions, and any prior neurosurgeries, including deep brain stimulation. All participants were undergoing treatment with botulinum neurotoxin injections. To avoid treatment influencing the data, data was collected from each patient 3+ months after their most recent injections.

This resulted in 100 participants, 71 of whom were female, with an average age of 62 years old, and an average time since symptom onset (disease duration) of 14 years. Of these 100 participants, 47 experienced head tremors, and 27 experienced tremors in a non-dystonic body area. In addition to basic patient demographics, the severity of their CD was assessed, and they were asked to describe their experience with AMs, the frequency with which they use them, and to rate their symptom “alleviating power” on a visual 10-point scale.

## Frequency and therapeutic effect of the different categories of AMs

First and foremost, 75% of study participants reported using at least one AM, with the most commonly used being the passive category, reported by 58%. 62% of the study

**Alleviating maneuvers (AMs), often referred to as “sensory tricks”, have been defined as “voluntary actions that specifically correct the abnormal posture or alleviate the dystonic movements.”**

*Albanese et al., 2013*

participants reported using more than one category and almost all (34/37) of the patients that reported using two or more categories use the passive AMs. Interestingly, the amount of symptom relief reported for these different categories of AMs was comparable, with the averages falling between 6 and 7 on a 10-point scale, 10 being the most effective. The only exception was the most commonly used category, the passive, which had a significantly greater alleviating impact than the least common group, the pure sensory.

## Patterns between patient demographics and the success of different types of AMs

Correlation analyses are used to show whether there are associations between two features in a research study. Here the different features are the frequency of use and amount of symptom relief of the different AM categories and the patient demographics. The researchers found that the frequency of use of pure sensory AMs positively correlated with age, meaning the older participants used this category more frequently. They also found that patients who experience more severe CD symptoms or associated disability use the passive AM category more, and those with greater CD severity reported more symptom relief from this method. Furthermore, patients with greater dystonia-related disability, severity, and frequency of CD-related pain more commonly used a combination of the passive and active non-oppositional AMs than just passive alone. These findings suggest that not only do AMs continue to work for those with greater CD severity, disability, or pain, but many patients benefit from using a diverse set of AMs.

# 5 TYPES OF ALLEVIATING MANEUVERS FOR CERVICAL DYSTONIA

## PURE SENSORY

The sensory effect that results from wearing a variety of head or neckware.

Examples: Wearing a scarf or neck collar, glasses, a hat, or a helmet.



## COMPLEX MOTOR

Complex motor movements that are not directly related to the CD, such as walking, talking, yawning, chewing, or closing the eyes.



## SENSORIMOTOR: PASSIVE

Intentional positioning that relaxes the muscles supporting the upright position of the cervical spine that are often engaged by CD.

Examples: Resting the back of your head on your hand, the car headrest, a pillow, the couch, or laying on a side.



## SENSORIMOTOR: ACTIVE + NON-OPPOSITIONAL

Gently touching parts of your face (chin, nose, or cheek), neck, or the back of your head with your hands



## SENSORIMOTOR: ACTIVE + OPPOSITIONAL

Using your hands to push against your chin, forehead, cheek, neck, or upper back, or pushing your head against vertical surfaces (ie: car headrest)



Interestingly, the active oppositional AMs were less effective and used less often by those with longer disease duration. The higher frequency of use and greater effect of active oppositional AMs earlier in the disease progression can be explained by a few possibilities. Early on in disease progression (1) the milder strength or severity of dystonic postures can make them easier to overcome by an applied, counteracting force; (2) patients may be more likely to instinctively counteract their dystonic postures using force; (3) perhaps due to the first two explanations, patients may be unaware that comparable relief can be attained through light touch (active non-oppositional), and that upon learning of these more easily applied AMs they discontinue the with the active oppositional AMs.

Notably, participants who used more than one type of AM used them with similar frequency and therapeutic effect.

### Why are passive AMs so effective?

At first glance, passive AMs alleviate symptoms by a simple change in posture and possible added benefit from the sensory input provided by an object being used. However, the success and frequency of use of this method across the study participants also suggest that this method may temporarily correct one of the suggested causes of dystonia: an error in the proprioceptive feedback loop, the feedback loop that describes one of the communication systems between the body and the brain that is negatively impacted by dystonia.

Proprioceptors are specialized cells or neurons that communicate sensory information about movement, action, and your location in space from your body to your brain. The brain uses this information to deliver movement-related instructions back to the muscles. The cells that deliver these instructions from the brain back to the muscles, triggering muscle contractions, are another type of specialized neuron

*Continued on page 6*



Continued from page 5

called motor neurons. Together these cells make up a communication loop between the body and the brain and are responsible for maintaining stable body posture and coordinated movement as we navigate through varied environments. For example, allowing us to walk without having to actively think about each step.

In patients with CD, the information being sent from the muscles in the neck to the brain is misinterpreted. Botulinum neurotoxin, a primary treatment for CD, works by blocking the motor neurons that initiate a muscle contraction, blocking both the muscle contraction and the resulting information being sent to the brain that is then misinterpreted in CD patients. Reducing the information being sent to the brain decreases the wrong signals getting sent back to the muscles producing dystonia. It is thought that the passive AMs work through a similar mechanism. Repositioning the neck passively removes the need for muscle contraction (to support the head) reducing the signals being misinterpreted at the level of the brain in this feedback loop—functionally turning the volume down on the ongoing signals being sent between the muscles and the brain and back.

*Study by Drs. Laura Avanzino, Francesca Di Biasio, Gaia Bonassi, Elisa Pelosin, Nicholas Cothros, Roberta Marchese, and Davide Martino.*

*Study brief originally published in the journal, Dystonia, May 17, 2022. Summary by Kylie McPherson, PhD.*

## STUDY OFFERS ADVICE FOR KEY FINDINGS

### *1. There are five categories of alleviating maneuvers (AMs) that produce the same degree of symptom relief for the cervical dystonia (CD) patients that use them.*

Of the five types, one provides pure sensory input (ie: wearing a hat or scarf) and another is complex motor movement (ie: walking or talking). The other three are a combination of sensory and motor (termed “sensorimotor”), the first being sensorimotor passive (ie: natural positions that allow your dystonic muscles to rest like laying on a pillow), then sensorimotor active non- oppositional (ie: gently touching parts of your face, neck, upper back), and sensorimotor active oppositional (ie: pushing on your chin, forehead, etc.).

**Advice:** There are many AMs that work for CD patients, so explore these different possibilities and find what individual methods or types of AMs help best manage your symptoms.

### *2. The majority of patients find symptom relief from more than one category of alleviating maneuvers (AMs).*

**Advice:** It is worth trying a variety of different AMs, even if you have found success with one category already, to increase the number of tools at your disposal. For example, if you currently exclusively use passive AMs (ie: laying down with a pillow), try active non-oppositional AMs (ie: light touch to your face, neck, or back) that would be more feasible in other situations like while driving.

### *3. Active oppositional AMs (ie: using your hands to apply force to your chin or head) are used less often and provide decreased symptom relief in patients with longer disease duration.*

**Advice:** If you use active oppositional AMs, consider trying active non-oppositional AMs to determine if there are less-taxing methods that produce the same relief for you.

### *4. Patients who experience more severe CD symptoms or associated disability use the passive AM category more and report more symptom relief from this method.*

**Advice:** If you have been reluctant to try sensory tricks because your symptoms are severe or have progressed recently, this could actually be an indication that you will receive greater symptom relief from passive AMs (ie: laying down).

# What Friends and Family Should Know About Dystonia

*DMRF community leaders share insights on life with dystonia.*



The DMRF has heard from many in the dystonia community that they wished their inner circle of family and friends knew more about the disorder and its effects. To develop dystonia resources for friends and family, the DMRF constantly seeks input from dystonia patients and primary caregivers for their perspective and guidance.

Living well with dystonia requires multiple layers of support from people with varying degrees of dystonia knowledge. Medical teams and immediate caregivers are the primary tier with first-hand experience and the deepest knowledge about dystonia. Friends and family living outside the household make up an important second tier of support.

In an informal survey, the DMRF asked Dystonia Support Group Leaders:

- What are three things you would like your friends and family to know about dystonia?
- What do you think they misunderstand the most about dystonia?

Their responses fell into three key areas of information for friends and family: (1) Basic facts about dystonia; (2) What it's like to live with dystonia, and (3) Ways that friends and family can be supportive.

## **(1) Basic Facts About Dystonia**

Friends and family should first learn the basic facts about dystonia as a movement disorder, including what it is and is not.

"Dystonia is a real condition, an actual brain disorder. When I was newly diagnosed, some did not feel dystonia was an authentic condition," one support leader shared.

*Continued on page 8*

Support leaders recommend relating dystonia to other movement disorders friends and family may be more familiar with, such as essential tremor and Parkinson's disease. However, DMRF resources should be used to clarify the various types of dystonia and that it is a condition on its own and does not necessarily lead to other movement disorders.

Educating friends and family about dystonia as a chronic condition will be another priority for DMRF resource content. "Dystonia is not a temporary condition and is not something you can control on your own," another support leader added.

## **(2) What It's Like to Live With Dystonia**

Friends and family likely won't have first-hand experience living with dystonia, but they should be aware of some of its challenges. While treatments, like botulinum neurotoxin, deep brain stimulation (DBS), oral medications, and other therapies, are available, there is no quick fix. Dystonia can be physically painful, often accompanied by anxiety and/or depression, which also may require treatment.

Even without physical pain, living with dystonia can be extremely stressful, since it requires managing people's expectations and confusion about the condition. "Some days are better than others. The severity of symptoms may vary and not be consistent," a support leader said.

Individuals with dystonia typically choose a combination of treatments, which are ever evolving and require constant attention throughout their lifetime. Friends and family need to know that managing symptoms and maintaining treatment can be all consuming for those living with dystonia.

"I have many physicians I go to for symptoms of dystonia, such as DBS management, mental health, physical or occupational therapy. My calendar consists mostly of medical appointments," a support leader said.

## **(3) How Friends and Family Can Help**

Gaining a better understanding of dystonia is the first step in being able to help a friend or family member with dystonia. Some DMRF Support Group Leaders also offered practical ways friends and family can help.

People with dystonia may not be able to participate in as many activities as they once did or participate in the same way, but they still want to be involved. Friends and family shouldn't be offended when invitations are turned down; they should continue to invite, adjust the activity, and make accommodations for their friend with dystonia whenever possible.

"I would like friends and family to know that I still want to be included. Sometimes it's hard to focus on what is being said because I am moving or worrying about what I look like. A comfortable place to sit can be so wonderful," a support leader said.

People with dystonia may be self-conscious about how they look and what others think of them. They can't control or predict the movement of their bodies, but this has no correlation with intelligence. They are fully aware of how others respond, react, and treat them.

"I think people can discount sufferer's intelligence or awareness because they are moving with dystonia," a support leader said.

Most people with dystonia are open to questions and thoughtful discussions about their condition, but friends and family should not attempt to treat or cure dystonia. Recommending a chiropractor, herbalist, or restrictive diet is not helpful.

DMRF Support Group Leaders agree friends and family can help most by being good friends. They can get more educated about dystonia, check in with their friend who has dystonia regularly, and offer practical assistance rather than advice.

## **THE DMRF WOULD LIKE YOUR INPUT.**

What would you like friends and family to know about dystonia? Email us: [awareness@dystonia-foundation.org](mailto:awareness@dystonia-foundation.org)



# Izzy Derkos Offers a Caregiver's Perspective on Dystonia

To get a caregiver's perspective on life with dystonia, DMRF spoke with Izzy Derkos, whose wife, Karen, has been living with cervical dystonia for more than 40 years. "I don't consider myself a caregiver. Karen is my wife. We're in a relationship, and this terrible thing happened," Izzy said. "We just celebrated our 60th anniversary, and I value each day so much more because of her."

He said the first symptoms of dystonia came on suddenly when he and his wife were walking in the snow. "She began having trouble swallowing and breathing. I was really worried," he said. Other incidents of uncontrolled movements in her head and neck soon followed. "To see her go through that and know there's something horribly wrong, you want to figure it out. That was the start of the journey."

It was the early 70s. Very little was known about dystonia, and the search for answers was long and hard. At the time, they also had three young children ages 10, 11 and 12. "I felt helpless, like I couldn't provide anything. All I could do was encourage her to have hope for a better day, have faith. But it was very difficult to watch Karen go through this."

Like so many with dystonia in those early days, Karen made hundreds of phone calls and met with numerous doctors all over the country. "A number of doctors told her it was all in her head," Izzy said.

She eventually found a neurologist who diagnosed her with dystonia and helped connect them with another doctor in San Francisco who was doing experimental treatment using botulinum neurotoxin (BNT) for cervical dystonia. Izzy went to all of her sessions when



Izzy and Karen Derkos

he could to watch her get the injections, and still accompanies her on most of her sessions 34 years later.

"It's painful for me to watch it. She's so tough." Izzy stands in awe of his wife's strength, tenacity, and ability to work through her suffering without losing hope. Because of damage to her spinal column from years of dystonic movements, she had surgery in 2018 to fuse two vertebrae together. The surgery had to be done because of the damage dystonia was causing, Izzy said, but its effectiveness in terms of pain relief has been minimal. Her pain remains constant now, especially in her lower back area, and her BNT regiment is about 50% effective, he says.

Izzy offers a few tips for living with dystonia that he's learned from Karen:

## **Be disciplined about a daily routine.**

He says his wife gets up before him to exercise on the treadmill every day even when she may not feel up to it.

## **Have a passion for something you enjoy.**

Karen is a glass artist. Izzy says her time working with her hands and being creative in the studio takes her mind to another place where dystonia is not the focus.

**Share your feelings.** Izzy and Karen use a number system. Severity of symptoms, pain levels, and emotional capacity can vary daily and throughout the day. Izzy asks Karen what her number is on a scale of 1 to 10, 10 being the worst. This keeps it simple for Karen because she doesn't have to go into detail. And, Izzy can gauge how he can help even if it's by giving her some space.

Izzy doesn't expect friends and family to understand the details of caring for a loved one with dystonia, but he's eager to share his story and what he's learned if it will help others in the dystonia community. He even credits dystonia for his improved positive outlook on life.

"There's no way I can ever feel bad about anything that happens to me because I see all that she goes through and deals with every day. She just finds a way."

# Navigating Common Oral Medications Used for Dystonia

*Dystonia patients perform a balancing act between medication benefits and side effects.*



While no magic pill for dystonia exists, oral medications are one piece of the treatment puzzle to help manage the disease. Oral meds can provide relief from some dystonia symptoms, but they're imperfect. Dystonia patients and their doctors need to find the right balance between benefit and potential side effects for any treatment option.

Oral medications used to treat dystonia vary greatly for each individual and should be managed with your doctor. While other medications may be prescribed to address symptoms unique to individuals, this article focuses on the more common oral medications used to treat dystonia.

About 70% of dystonia patients take some type of medication either injectable or oral. Of patients taking medications, more than half either use oral medications alone or in combination with botulinum neurotoxin (BNT).

"All the drugs we use for dystonia are off label. There is no oral medication approved by the Food and Drug Administration specifically for use with dystonia," said Dr. Cynthia Comella, a movement disorder neurologist at Rush Medical Center, Chicago.

The most common oral medications used to treat dystonia fall into five categories: anticholinergics, benzodiazapines,

baclofen, dopaminergic agents, and tetrabenazine. (See accompanying article.) All oral medications prescribed for dystonia are systemic, meaning they affect the entire body. Side effects are common and need to be managed under a doctor's supervision.

## Relying On Experience

Patients should ask their doctors which medications seem to work best for their dystonia types, as well as possible side effects and how often they occur. "Patients need to be aware of side effects. If they occur, they should contact their physician so the medications can be altered," Comella said.

Unfortunately, there has not been a lot of research conducted on oral medications for dystonia, so little scientific data exists to point physicians to one medication over another. With no clear data, physicians and their patients rely on the experience of others with the medication. Physicians recommend what's worked with other patients who have similar dystonia types, and dystonia patients rely on their own experience by giving the drug a test run.

Neurologists typically start patients on small doses of medication and ramp the dosage up slowly to find the right balance between benefit and potential side effects. Introduction of an oral medication typically takes about three months, depending on the medication. "With dystonia you don't get an instant benefit. You want to give it some time to see whether it's beneficial and to see if there are adverse effects at that dose," Comella said.

## Understanding Side Effects

Side effects and their severity vary by medication and individual, but nausea is common with many oral meds taken for dystonia. Anticholinergics can affect the memory, urinary retention and cause dry mouth. “I hear things like, ‘I can’t think. I can’t remember things. I feel sedated,’” Comella said.

Benzodiazepines, which are typically used as antianxiety agents, are most frequently used by botulinum neurotoxin (BNT) patients who take the medications during the wearing off period before their next BNT injection. Common side effects include drowsiness, light-headedness, confusion and dizziness.

Baclofen can be effective particularly in children with dystonia because their brains can tolerate the side effects better, Comella says. Interestingly, children take higher doses of baclofen and reduce dosage or eliminate the drug as they age. Common side effects are sedation and nausea.

Some patients with specific types of dystonia respond very well to dopaminergic agents, which increase the neurotransmitter dopamine. While dopa-responsive dystonia is rare, Comella says it is worth exploring especially with newly diagnosed patients. “It responds almost in a curative fashion to low doses of carbidopa levodopa. You don’t want to miss it, particularly in children,” she said. Short term side effects are minimal.

Dopamine depleters, tetrabenazine being the oldest and most commonly used for dystonia, reduces the activity of dopamine. The main side effects are depression, sedation and possible drug-induced parkinsonism. Several newer modifications, deutetabenazine and valbenazine, have demonstrated less severe side effects but remain largely untested for dystonia.

## Evaluating Medications

Communicating with your doctor is critical when evaluating medication effectiveness, side effects, dosage and even termination. Just as you ramp up oral medication dosages under the supervision of a physician, dystonia patients need to ease off the medications with incrementally smaller doses as well.

“You don’t want to start something, get a brain used to it and take it away cold turkey,” Comella said.

*Continued on page 12*

## CATEGORIES OF MEDICATIONS COMMONLY USED TO TREAT DYSTONIA

### • Anticholinergics

Anticholinergic drugs include Artane® (trihexyphenidyl), Cogentin® (benztropine), and Parsitan® (ethopropazine). These medications act by blocking a neurotransmitter chemical called acetylcholine, which plays an important role in muscle activation.

### • Benzodiazepines

Benzodiazepines include Valium® (diazepam), Klonopin (clonazepam), and Ativan® (lorazepam). These drugs act on the neurotransmitter chemical GABA-A among other neurotransmitter systems.

### • Baclofen

Baclofen (Lioresal®) stimulates the body’s ability to process a neurotransmitter called GABA-B. Baclofen can be taken orally, or the medication can be continuously fed into the nervous system by a surgically implanted device, often called a baclofen pump.

### • Dopaminergic Agents

Some patients with specific types of dystonia respond to drugs that increase the neurotransmitter dopamine. The one used for dopa responsive dystonia is levodopa. Drugs that block or deplete dopamine are generally discouraged from use in treating dystonia because of the risk of tardive syndromes, which may worsen movement symptoms.

### • Tetrabenazine

Tetrabenazine (Xenazine®) is a drug that depletes dopamine. It can be effective but has many side effects. Deutetabenazine and valbenazine are also dopamine depleters but have not been studied well for dystonia.

She also recommends patients talk with their pharmacists about possible interactions with other drugs they may be taking, such as anticoagulants, antiarrhythmics or antihypertensives.

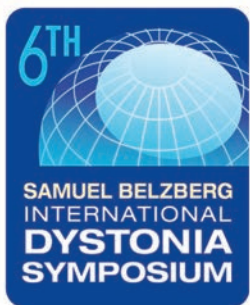
Herbal medications are not recommended for treating dystonia, and patients need to inform their doctors of anything they're taking in that realm as well. "People think if it's an herb, it's natural, it's safe," Comella said. "Not true. You just don't know what you're taking when you take an herbal medication, and they all have pharmacological activity."

Managing oral medications for dystonia is a process that requires open communication and trust between doctor and patient. Doctors may even need to help patients "clean house" by getting rid of medications that aren't effective and are burdening them with side effects.

"Managing patient expectations is one of the most important things a doctor needs to do, educating them about what to expect and when to call us," Comella said. "We don't dictate treatments; we discuss treatments because every patient's situation can be different. If you don't focus on the patient, you're missing the boat."

## STRATEGIES FOR MANAGING ORAL MEDICATION

- ▶ **Bring a list of all prescription medications to your doctor.** Before beginning oral medications for dystonia, bring a list of all current medications to your doctor to check for potential drug combination interactions and initiate open, honest communication about compliance.
- ▶ **Talk to your doctor about side effects before starting medications for dystonia.** Understand the common and more extreme side effects for oral medications, so you know what to expect and when to call your doctor should they occur.
- ▶ **Ramp up dosages slowly under your doctor's supervision.** It may take two to three months to increase dosage to achieve the right balance of benefit and side effects. Ramping up the amount slowly allows the body to get used to the medication, reducing the potential for more severe side effects.
- ▶ **Call your doctor if you're experiencing unusual or extreme side effects.** Side effects are common with all medications taken for dystonia. However, call your doctor immediately with any questions, concerns, or if you're experiencing something you've never had before.
- ▶ **Do not abruptly quit oral medications taken for dystonia.** If you decide the medication isn't right for you, call your doctor to help you ease off the medication with incrementally smaller doses.
- ▶ **Reevaluate oral medications periodically.** Sometimes the combination of oral medications taken for dystonia and other health problems can become unmanageable both in terms of side effects and daily maintenance. It may be time to "clean house" and reevaluate which medications are helpful and which ones are not.
- ▶ **Communicate with your doctor about any herbal medications.** Tell your doctor about any herbal remedies you take regularly because they have pharmacological effects as well. Just because it's "natural" doesn't necessarily mean it's good for you.



# International Symposium Brings Together Top Dystonia Investigators

The Samuel Belzberg 6th International Dystonia Symposium will be held this June. DMRF science leaders share their expectations for the symposium and how the dystonia community benefits.

More than 500 of the world's top dystonia research investigators are expected to meet June 1-3 in Dublin, Ireland, for the Samuel Belzberg 6th International Dystonia Symposium (IDS6), organized and co-hosted by DMRF and Dystonia Europe. The symposium, held only when enough new and emerging science has amassed, last met in Barcelona, Spain, more than 10 years ago.

We spoke with DMRF science leaders to find out their expectations of the upcoming international symposium and its impact on the dystonia patient community. Richard Lewis, MD, is DMRF Vice President of Science and has three sons with dystonia. Joel Perlmutter, MD, Elliot H. Stein Family Professor of Neurology at Washington University and DMRF Scientific Director, is a renowned researcher and physician who treats dystonia patients. Jan Teller, PhD, MA, has been coordinating various facets of dystonia research for DMRF for more than 15 years and is the DMRF's Chief Science Advisor.

## Bringing Together Disparate Ideas

Since the first international meeting more than 45 years ago, interest in dystonia science and research has exploded geographically and across disciplines. "We used to know very little about dystonia, but now, there are so many different facets and approaches to dystonia," Teller said. "We have genetics, neurophysiology,

cell biology, molecular biology, venturing into very sophisticated clinical science. Also imaging and even artificial intelligence approaches. It's a complete package for dystonia now."

DMRF science leaders are excited at the prospect of bringing so many researchers together from around the world in one location to focus on dystonia. "The greatest advantage is to bring those people together, so they can cross fertilize and enhance each of their research activities," Perlmutter said.

Topics on the agenda include the definition and classification of dystonia; the relationship between dystonia, tremor, Parkinson's disease, and ataxia; dystonia in pediatrics; non-motor features of dystonia; dystonia genetics; and much more. The schedule and major themes are selected, but the real work will be the conversations in the hallways and the scientific posters on emerging, new, novel data, Teller noted.

## Advancing Dystonia Research

DMRF scientists agree it is hard to predict which areas of dystonia research will have the biggest impact for clinical application in the future. But, the collaboration that occurs at the symposium is essential for advancing the science, understanding and treatment of dystonia. The biggest challenge now, says Teller, is how to

integrate all the new science that has emerged from such diverse areas of interest.

"How do we communicate new discoveries in one area that might influence another? How can geneticists bend towards neurophysiology or imaging, for example. It's actually very beautiful to watch this happening, especially with very bright clinicians," he said.

The symposium also helps engage young, up-and-coming investigators, encouraging their career in dystonia research. "We've noticed when a young investigator is in the room with more seasoned investigators, there's enrichment and excitement going on," Lewis said.

Any research that emerges from the symposium is years away from clinical application, but meeting of the greatest minds in dystonia is where it all begins. Symposium findings also help guide the DMRF's support for areas of dystonia research that need the most attention or have the most promise for dystonia patients.

"I think the most important outcome of the symposium will be the one we have no clue we're going to find... the unexpected," Perlmutter said. The DMRF plans to develop a lay summary of this exciting and important meeting to be available later in 2023.



# 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!



**Rani Vargas** was celebrated by the New York Islanders as a local hero during their hockey game on Friday, January 27. Rani has DYT1 dystonia and was nominated by her employer to be recognized as a local hero. Rani's sister, Toni Fitzgerald, works at the Center for Neurosciences at the Feinstein Institutes for Medical Research in Manhasset, NY. Toni, a long-time friend of DMRF for her work with dystonia research trials, was present during the ceremony honoring her sister.

DMRF Support Leaders met virtually on January 24th to learn of the activities planned for the year, to exchange ideas for meetings, and give and receive support from one another. They also had the opportunity to meet with DMRF President **Mark Rudolph**. The gatherings are scheduled throughout the year to support the work of DMRF's dedicated leaders.



**Mike Delise**, co-founder of the \$5Cure4Dystonia, was a guest on the Mitch Albom radio show on WJR in Detroit in December. Mike gave a nice overview of dystonia and spoke about the need for dystonia research. Mike and **Jason Dunn**, have raised more than \$100,000 since founding the \$5Cure4Dystonia campaign.



The Colorado Dystonia Support group met at the end of October. Group leader **Paul Kavanaugh** reported that it was wonderful to be meeting in person and that they had a productive meeting.



**Daniel S.** celebrated his one-year anniversary of his DBS by organizing a fund raiser for the DMRF. Daniel and his family and friends wanted to thank the DMRF and all who supported him through his surgery with a fund raiser. One of Daniel's favorite restaurants offered to donate a percentage of the sales to the DMRF.

# DMRF Mental Health Survey to Help Guide Future Programming

*Here's what we learned about your dystonia and mental health concerns from an informal survey conducted last fall.*

Mental health has long been critical to the overall health of dystonia patients, and the DMRF is taking steps to find out more about where it can best provide support in this area. Early last year, the DMRF established its Mental Health Programming Committee to bring mental health issues to the forefront and provide programming catered specifically for the dystonia patient community.

To better direct their efforts, the committee developed an informal web-based survey on mental health and dystonia, which was open to the DMRF patient community for five weeks in October and November last year. The survey allowed adults affected by dystonia to share their thoughts and opinions on mental health, while allowing the DMRF to evaluate the community's interest in further programming and resources regarding mental health.

"We were pleased with the number of responses," said Karen Ross, PhD, Vice President of Mental Health Programming for the DMRF. "We know it's not fully representative of the entire dystonia community, but it provides a snapshot that will help guide our programming."

## High Interest in Mental Health Issues

Response was outstanding—more than 800 individuals responded to the informal 21-question survey. The outpouring of responses confirmed the high demand for mental health programming.

The survey was limited to those over the age of 18 with a dystonia diagnosis. Survey participants were asked questions relating to types of mental health support they currently receive or are interested in receiving and barriers to care. They were also asked to rank mental health and dystonia topics from a list of options provided by DMRF as well as open-ended feedback on additional topics for consideration. Here's a sampling of what we learned.

More than 70% of survey respondents said they were interested in receiving some level of mental health support.

Key interests included, but were not limited to:

- Learning how to handle grief that comes with a dystonia diagnosis
- Handling the emotions associated with isolation, loneliness, and loss of identity
- Finding strategies to deal with the chronic pain
- Developing the ability to cope with dystonia
- Having a neutral third party to discuss problems, especially one that understands chronic illness

About half of survey respondents receive some sort of mental health care, including community-based services, online mental health support, care provided by mental health professional, in-person/virtual talk therapy, and/or in-person/virtual support groups.

**Cost was ranked as the biggest barrier to care** with 34% of respondents ranking it as their top concern. The ability to find a provider that aligns with the patients' needs was the second most important barrier to care: 21% struggle with this issue. An inability to access support—from barriers like lack of appointment availability, transportation issues, and internet access—was the third most popular response at 17%. Also mentioned were privacy concerns, stigma around seeking mental health services, and not knowing where to start.

## Topics of Interest

The DMRF provided a list of potential topics on mental health and dystonia, and asked respondents to rank their interest. This is a sampling of options provided by the DMRF that received more than 150 positive responses.

- Is there a relationship between dystonia and mental health conditions?
- How do I know if I need professional help for my mental health?
- How can I find mental health professionals or services?
- How can I afford mental health services?
- How do mental health medications and dystonia medications interact?

*Continued on page 16*

*Continued from page 15*

- How do I talk to my doctors, movement specialists, or other allied health worker about mental health concerns?
- How do others successfully address depression and/or anxiety?

Most revealing, however, were the thoughtful, personal answers DMRF received from respondents to the survey's open-ended questions on additional topics to consider and areas of concern about the relationship between mental health, dystonia, and the DMRF's efforts to tackle the critical area.

A sampling of **additional topics that were suggested:**

- TMS (trans-cranial magnetic stimulation) and its level of effectiveness and relationship to non-motor symptoms of dystonia.
- Information about mental health medications that may cause dystonia; alternative mental health treatments that don't require medication, as many SSRIs (selective serotonin reuptake inhibitor) cannot be used by dystonia patients.
- How to find a mental health provider who is knowledgeable about dystonia and can assist with the grief that comes from life-altering circumstances.
- Shared stories of success from dystonia patients who have developed effective coping strategies.
- How DBS affects mood change; how DBS relates to mental health.
- List of self-help resources.
- Help on how to address medical professionals who are not concerned with mental health.
- Therapy with a focus on chronic pain.
- Addressing social anxiety and avoidance associated with dystonia.

A sampling of **personal responses about mental health and dystonia:**

"Although my neurologist is very approachable, dealing with my mental health issues does not feel promoted, as that is another area of specialty. We also have limited time for our appointments, which include botulinum neurotoxin injections and updating her on how well current treatment is working."

"It is important for physicians to treat the whole person, not just the physical person. Some movement disorder clinics have a social worker; people associate a social

worker with helping patients find services related to transportation, insurance issues, etc. Therefore, it is important for patients to understand the difference between a social worker and a mental health specialist and for them to know who and how to contact a mental health specialist."

"Some days I manage well. Others are a struggle. Chronic pain and fatigue, worsening balance, fear of losing more independence. Support groups are a big help. You discover you are not alone and that many have far worse struggles than you."

### **Where Do We Go From Here?**

DMRF's Mental Health Programming Committee will meet this spring to discuss the results of its survey and narrow down which mental health pain points DMRF may be able to address.

"We're aware this survey is not representative of the entire dystonia community, and there are some mental health issues DMRF can't really assist, like cost of mental health care or transportation. But, maybe we can offer a mental health resource list or organize a webinar to address specific dystonia mental health questions? We'll see what we come up with after we meet with everyone and get their unique perspectives," Ross said.

The DMRF is also hosting a scientific workshop in March to discuss non-motor symptoms of dystonia. The two-day virtual meeting will bring researchers together to discuss available evidence and urgent research questions on non-motor symptoms in adult-onset dystonia with the goal to identify potential collaborative projects that are worth pursuing.

### ***Dystonia Information for Mental Health Providers***

DMRF has developed resource packets to help you inform mental health providers about dystonia with the goal to improve care. The packet is available for you to download and bring to your appointments or send to your providers. Information includes an introduction for mental health professionals, dystonia fact sheets, non-motor aspects of dystonia, and dystonia and social anxiety information. **Resources for Mental Health Professionals** can be found at [dystonia-foundation.org](https://dystonia-foundation.org) under the *Living With Dystonia* tab.



# DMRF Salutes Mark Hallett For His Contributions to the Dystonia Community

Mark Hallett, M.D., a pioneer in dystonia research and long-time friend of the DMRF, has announced his retirement from the National Institute of Health where he served as chief of the Medical Neurology Branch at the National Institute of Neurological Disorders and Stroke (NINDS).

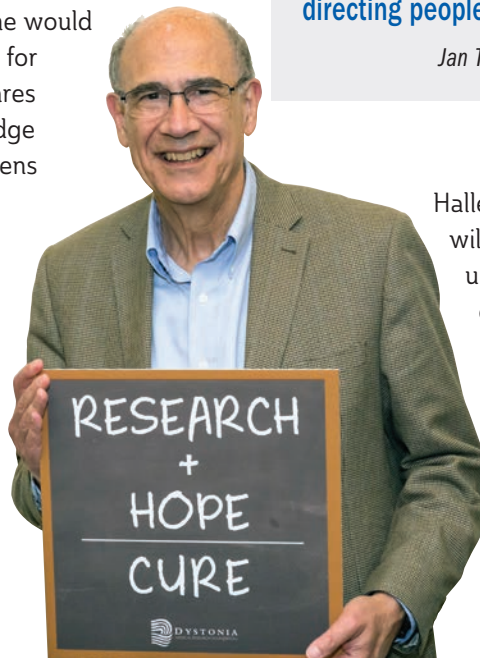
His breadth of knowledge is vast and list of accomplishments long, but Hallett is well known to the DMRF community for his humility and generous spirit. “He always had time for you,” said Jan Teller, DMRF Chief Science Advisor. “He was an extremely busy person, but he would always respond to questions or requests for his input. He’s so reliable and always shares his knowledge. Mark never sees knowledge as a competition, which sometimes happens in the scientific community.”

Before coming to NINDS in 1984, Hallett served as a Harvard University William C. Moseley Jr. traveling fellow at the Institute of Psychiatry in London, was chief of the Clinical Neurophysiology Laboratory at Brigham and Women’s Hospital in Boston, and rose to associate professor of neurology at Harvard Medical School.

At NINDS, Hallett’s research centered on the principles of normal human voluntary movement, understanding the motor system and movement disorders including dystonia, parkinsonism and myoclonus, and the use of transcranial magnetic stimulation (TMS) and botulinum toxin to treat movement disorders. His laboratory has studied motor learning, brain reorganization in various disorders, the effects of fatigue on corticospinal excitability, the ability for fine finger control and, more recently, volition (decision-making) and its disorders, including tic and functional movement disorders.

## Impact on Dystonia Community

“Mark has exceptionally broad knowledge of neurology, dystonia, on every topic,” Teller said. “As a physician, he was the ultimate authority in making diagnoses of dystonia or directing people to other neurologists or institutions.”



**“As a physician, Mark was the ultimate authority in making diagnoses of dystonia or directing people to other neurologists or institutions.”**

*Jan Teller, DMRF Chief Science Advisor*

Hallett’s impact on the dystonia community will continue for years to come. He contributed to the definition and classification of dystonia, which has been critical to dystonia research, diagnosis, and treatment. He also helped define certain areas and standards for myoclonus dystonia and trained more than 150 fellows at the NIH. Many of whom have become leaders in neurology and neuroscience.

Hallett participated in and often led many DMRF scientific meetings over the years. “When Mark was present, we knew that at discussion time there would be no silence. He always has questions, which is a sign of a very scientific mind,” Teller said. “He’s always full of enthusiasm, ideas, energy. He’s just one of my favorite people.”

At 79, Hallett says he plans to relax and travel in his retirement. But, in true Hallett fashion, he will continue in an emeritus position at NIH and plans to publish many manuscripts. He’ll also continue to serve on the DMRF Medical and Scientific Advisory Counsel.

“I’m going to retire...but not much,” Hallett said when he spoke at the NINDS scientific symposium held recently in his honor.

# Personal Profile

# Linda Davis

Linda Davis has been a crusader for dystonia awareness since being diagnosed with cervical dystonia in 2009.

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

I was first diagnosed with cervical dystonia in November of 2009. They haven't changed my diagnosis officially, but I have dystonia in different body parts as well. I have it in my feet, legs and face, so I would call it multi focal.

We first noticed something was wrong in 2008 at my mom's 75th birthday party. I saw in the pictures from mom's party that in every photograph I was looking off to the side. People viewing the photos asked, "Why are you always looking off to the side in these pictures?" At the time, I didn't know why, but I knew something was wrong. When I tried to go to sleep, my head kept turning into the pillow, and it wouldn't stop. It's very hard to go to sleep when you think you're going to suffocate yourself because your head won't stop turning into the pillow.

It took me nearly a year to admit something was really wrong and make that first doctor appointment. I finally went to my primary care who said I should see a neurologist. I was one of the lucky ones. When I went to see the neurologist, he diagnosed me within 15 minutes.

Then they sent me to a multitude of tests...CT scans, MRIs, blood work...all to rule out everything else before they could say with certainty that I had dystonia. Why? Because there's no diagnostic test for dystonia. People don't know that. Most people are really surprised when they learn there's no diagnostic test.

## How did you get involved in dystonia fundraising and awareness events?

I have my own screen printing business, Balsam Printing. Through that, I've met so many people in the community and



Davis at her Fight for a Cure Dystonia fundraiser in 2021

have been involved in so many organizations ever since my son was in second grade. [Linda has been married for 32 years, and her son is now 27.] I started working on the board for the Medford Chamber of Commerce and served as president as well.

My first dystonia fundraiser was put on by the Medford Chamber of Commerce at the end of our concert series during the last week of August in 2018. The other board members spearheaded by Erinkelly Connell were so supportive and suggested kicking off Dystonia Awareness Month at our last concert. I am so grateful for the support of all our local elected officials in helping me raise awareness beginning back in 2015 with then Assemblyman Dean Murray who is now senator.

Unfortunately, I had to step down as president from the chamber. It was affecting my health. I was getting worse. There was so much stress involved. I stayed active with the chamber, but just wasn't on the board anymore.

Then, I got a little involved with \$5Cure4Dystonia created by Mike Delise and Jason Dunn. They're in Michigan and asked me to help spread awareness in New York. At that point you looked at me and couldn't really see that I had anything wrong. I'd wear the dystonia t-shirts everywhere. I don't know if it's a New York thing or what, but not one person came up to me in New York and asked me about dystonia.

In 2021, I reached out to the senator in our area to get a proclamation for Dystonia Awareness Month in September. They wanted an event or fundraiser to promote, but I didn't have anything at the time. So I went to my friend from the chamber board, Niel Marturiello, and we decided to do a basket auction. He said, "Pick a date, let's do this! You take



## Linda's Tips for Living with Dystonia

- **Never give up.**
- **Have a support system.** Mine is my husband, son, mom and my friends. I have great friends.
- **Humor.** Try and find humor in every situation. It keeps my sanity.
- **Join the support forums, but be careful.**  
On-line support forums can offer a lot of good advice and tools for living with dystonia, but not all forums are created equal. DMRF support forums are closely monitored, so that no inaccurate information is shared. Other forums are a little less careful and may present misinformation about treatments or even a cure for dystonia.
- **Connect with DMRF.** I'm so grateful for the support they provide. They've helped point me to specialists, but most of all they've given me information on dystonia I can't get anywhere else.

## How are you doing now, and why do you continue to fundraise for dystonia?

I consider myself lucky because my neurologist diagnosed me right away, and I was able to start treatment in January, 2010, with botulinum neurotoxin injections.

I've been doing the injections for 13 years. For the past 3 years, I've tried a few different botulinum neurotoxin variants because I've built some tolerance to the treatment. I'm also on medications for the dystonia and essential tremors. I'm on so many medications, some days I feel like I'm a walking zombie. I have to be able to work, so they keep me functioning.

Fight for a Cure Dystonia has become my slogan really. That's why we come out and raise funds and awareness... for others with dystonia symptoms much worse than mine. I'm on a few dystonia support boards, and you see people like me. Then you see these kids and babies with generalized dystonia. It breaks my heart. Something has got to be done for them. I don't do this for me. I do it for those that are so much more severe, babies, those with generalized dystonia, wheelchair bound, house bound.

care of the baskets, and I'll do everything else." And, he did. We raised \$10,000! We had all the elected officials there, chamber board members, everyone. It was a great night.

We decided to do it again in 2022 and raised another \$10,000. The only problem is I had a really hard time physically after this fundraiser. As soon as it was done, I crashed. I guess from the stress and emotions from the day, it took a toll on my body. I've since settled down a bit, but I've definitely progressed from where I was before the fundraiser.

I couldn't even imagine. I have a small taste of it. But when comparing to them, it's like having a hang nail versus an amputation. Am I minimizing my own symptoms? Maybe.

People ask me all the time how I can be so happy and always have a smile on my face. I'm like, what's the alternative, crying? When I'm at home in my house I'll scream, cry, yell, have temper tantrums because I'm frustrated. But, I don't take that outside with me.



*Join with others around the country to advocate for the dystonia community. You can make a significant difference through your efforts. To learn more, contact [dystonia\\_advocacy@dystonia-foundation.org](mailto:dystonia_advocacy@dystonia-foundation.org)*

## Dystonia Dialogue

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The DMRF earned the highest ratings from  
**Guidestar (platinum)** and **Charity Navigator (four-star)**.

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