



## What is Dystonia?

Dystonia is a neurological disorder that causes intense, involuntary muscle contractions. These muscle spasms make it difficult for patients to move their bodies freely and control their body movements.

Dystonia affects men, women, and children of all ages and backgrounds. Conservative estimates suggest dystonia affects no fewer than 250,000 people in the USA and potentially millions worldwide.

## WHAT WE DO

For 40+ years, the DMRF has been of service to the dystonia community by:

- Providing global leadership on matters critical to dystonia.
- Advancing medical research toward improved therapies and a cure.
- Promoting greater awareness of dystonia.
- Educating patients and families.
- Providing support resources for patients and families.

**The Dystonia Medical Research Foundation (DMRF) is working hard to put itself out of business. Our proudest moment will be the day we close our doors forever because a cure has been discovered and no individual or family is ever again burdened by dystonia.**

Since 1976, the DMRF has worked tirelessly to expand scientific understanding of dystonia and offer patient programs. The mission is to advance research toward improved treatments and a cure, promote public awareness and patient education, and provide support resources to affected individuals and families.

Decades of investing in dystonia research have produced a vibrant research field brimming with new opportunities for medical discoveries to improve lives. Because a cure cannot happen fast enough for those who are waiting, the DMRF provides a safety net of information and support for everyone affected by this life-changing disorder.



## JOIN US!

Curing dystonia is an ambitious goal, but our progress is proof our strategy is working. There are many ways you can help:

- Become a member of the DMRF and join forces with others committed to finding a cure.
- Join the Dystonia Advocacy Network and give dystonia a voice.
- Support or sponsor a DMRF event.
- Join or start a support group, and become a local hero to others with dystonia.
- Register to be a brain donor.
- Donate today and help us move closer toward a cure.

## CONTACT US

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*Find the DMRF on Facebook,  
Twitter, YouTube, and Sharecare.*

# MOVING TOWARD A CURE





## RESEARCH

The DMRF supports research projects while acting as a catalyst to strengthen and expand the field of dystonia science. The acceleration of dystonia research and countless medical advancements prove our strategies are working.

- **Expert Advisors:** The Medical & Scientific Advisory Council represents pre-eminent clinicians and scientists from institutions across the USA and abroad.
- **Strategic Planning:** The DMRF's science plan is reviewed annually to inform the focus and scheduling for research funding cycles.
- **Research Funding:** DMRF has supported hundreds of research investigations related to the causes, mechanisms, prevention, and treatment of dystonia.
- **Scientific Workshops:** Bringing researchers together generates new ideas, leads to collaborations, and attracts new experts to work in dystonia.
- **Pharma/Biotech:** The DMRF has formed alliances with pharmaceutical partners to speed-up the development of new therapies.
- **Clinical Fellowships:** DMRF has invested in training physicians in the diagnosis and treatment of movement disorders with special expertise in dystonia.
- **Research Collaborations:** The DMRF provides staff support for research initiatives such as the Global Dystonia Registry and Dystonia Brain Collective.
- **Chief Scientific Officer:** A full-time staff scientist gives the DMRF a unique asset to advance science goals.

For more information on the DMRF's research activities, visit [www.dystonia-foundation.org/research](http://www.dystonia-foundation.org/research)

### RESEARCH DISCOVERIES

Major recent advancements in dystonia could not have been possible without direct support from the DMRF or the research environment the DMRF painstakingly built piece by piece, year after year.

- Multiple types of dystonia identified
- Dystonia-causing genes discovered
- Botulinum neurotoxin and deep brain stimulation have provided life-changing relief for thousands of patients
- New treatments are being pursued
- Pathophysiology of dystonia is being clarified



## AWARENESS & EDUCATION

The DMRF offers awareness and education programs to help patients make informed treatment decisions, identify the mis/undiagnosed, improve timely diagnoses, and improve societal understanding of dystonia.

- **Dystonia Awareness:** The DMRF mobilizes volunteers across the country to promote dystonia awareness locally and via social media.
- **Educational Resources:** The DMRF offers a newsletter, printed educational materials, a detailed website, and online webinars.
- **Meetings & Events:** Communities across the country host dystonia educational meetings every year. Volunteers organize and participate in public events to represent dystonia and the DMRF.

Sign up to receive email updates about DMRF news and events at [www.dystonia-foundation.org/email](http://www.dystonia-foundation.org/email)



## ADVOCACY

The DMRF works to improve quality of life of those living with dystonia by educating elected officials about dystonia and the policy needs of the community.

- **Dystonia Advocacy Network:** The DMRF is a member and provides the staff support for the DAN, which gives the dystonia community a voice to Congress and federal policymakers.
- **Collaboration with Government Agencies:** The DMRF is in ongoing communication with federal research and medical agencies to represent the dystonia community and advance research goals.

To learn how you can become a dystonia advocate, visit [www.dystonia-foundation.org/advocacy](http://www.dystonia-foundation.org/advocacy)

## SUPPORT

No one should have to endure dystonia alone. The DMRF reduces social isolation by offering peer-to-peer support programs that help patients and families connect with one another.

- **Individual Support:** DMRF staff are available by phone, email, web, and social media to those seeking information and support.

- **Support Groups:** Local support groups are resources for coping support and access to credible information. Search for support groups at [www.dystonia-foundation.org/support\\_groups](http://www.dystonia-foundation.org/support_groups)

- **Internet Support Forums:** Online groups are available 24/7 and offer a sense of belonging regardless of geography or mobility. Find links for online forums at [www.dystonia-foundation.org/online](http://www.dystonia-foundation.org/online)