

## DON'T GO IT ALONE

### Join the DMRF Community

Are you looking for support in your area or are you interested in connecting with others in the dystonia community? Visit the DMRF's website for a list of current online and local support groups:

### Local Support Groups

[www.dystonia-foundation.org/supportgroups](http://www.dystonia-foundation.org/supportgroups)

### Online Support Groups

[www.dystonia-foundation.org/online](http://www.dystonia-foundation.org/online)

### Unable to locate a support group in your area?

Contact the National Office to discuss the possibility of starting a dystonia support group and learn how you can become more involved with the DMRF.

### What is Dystonia?

Dystonia is a little-known brain 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 is the third most common movement disorder after essential tremor and Parkinson's disease, affecting no fewer than 300,000 people in the U.S. and Canada alone.

For many people, the first time they hear the word "dystonia" is when they receive the diagnosis. Many can feel isolated and alone as they begin to think about how to approach life with dystonia.

### What is the DMRF?

The Dystonia Medical Research Foundation (DMRF) is a 501(c)(3) non-profit organization that funds medical research toward a cure, promotes awareness and education, and supports the well-being of affected individuals and families.

### Dystonia Medical Research Foundation

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Connect with the DMRF on Facebook,  
Twitter, YouTube, Instagram, and Sharecare.

# FINDING SUPPORT





## The DMRF

The Dystonia Medical Research Foundation (DMRF) has been battling dystonia for over 40 years and is comprised of people who know what dystonia is and how it can impact one's life. The DMRF offers programs to keep people in the know about what is happening in the dystonia world. The Foundation's science program funds cutting-edge research to get us to better, more effective treatments and—one day—a cure for all forms of dystonia.

Providing support is an important part of the DMRF's mission because the Foundation is aware the science cannot move fast enough for those who are waiting. Being in touch with others who are living with dystonia is an important step in the progression of one's dystonia treatment.

The DMRF works with volunteer leaders across the country to develop support groups that serve as a resource for local communities. As part of this commitment to provide ongoing support to the dystonia community, the DMRF has a full-time staff member dedicated to working with groups and their leaders. DMRF support groups are run by people who know what it is like to feel unprepared for a dystonia diagnosis and not know where to turn for guidance. It is because they have been through so much that they want to make it easier for those who are just being introduced to life with dystonia. Group leaders are aware that managing dystonia may feel overwhelming at times, but they have seen how peer support can help dystonia patients thrive.

## TAKE CHARGE OF DYSTONIA: Join the Support Community

**Many people don't realize the benefits of being involved in a support community until they attend their first group meeting.**

DMRF support groups provide a safe environment for those affected by dystonia and their families to learn more about life with dystonia and to talk about their frustrations, their fears, and their triumphs with others who can truly relate.

Support groups take place both in person and online—empowering individuals by connecting them with others who have a shared understanding of dystonia. They provide information and resources to help individuals better manage their dystonia, and support them and their families in their dystonia journey.

Not only do DMRF support groups provide the opportunity to share experiences, they also give individuals the chance to learn more about dystonia research, treatments, and ways to become more active in the dystonia community. They empower individuals to tackle the hardships that come with a diagnosis of dystonia.



### Learn How to Live Well with Dystonia

Support groups provide the unique opportunity to learn about dystonia and hear from experts in the field. Guest speakers—such as movement disorder neurologists and physical therapists—are often invited to support meetings to discuss treatment options, coping strategies, research updates, and ways to live well with dystonia. Local DMRF support groups regularly host symposia and community education meetings. These events feature top medical speakers and provide life-changing opportunities for dystonia-affected individuals and families to meet, receive support, and build their personal networks.

### Stay Up-to-Date with Research

The DMRF is committed to improving diagnosis and treatment for dystonia patients. The Foundation has funded tens of millions of dollars in research, which has led to critical advancements in our understanding of dystonia. DMRF support leaders are in-the-loop on these advancements and are an important resource for dystonia patients who want to stay informed or become involved in dystonia research.

### Your Voice Matters: Become an Advocate

Many DMRF support leaders and members are active dystonia advocates who play an essential role in communicating the needs of the dystonia community to lawmakers. The Foundation works with three other dystonia organizations as part of the Dystonia Advocacy Network (DAN). DMRF

advocates help legislative leaders understand the unique challenges of living with dystonia and show them the importance of allowing federal funds to go toward dystonia research.

### Promote Dystonia Awareness

Support groups are vital to increasing dystonia awareness. In addition to improving society's recognition and understanding of dystonia, increased awareness allows the DMRF to raise more funds for research and identify individuals and families who are in need of support.

Raising awareness of dystonia helps those living with dystonic symptoms become properly diagnosed and assist them in managing the disorder. Many people affected by dystonia have never met another person with the disorder before attending a DMRF support group meeting, education symposium, or fundraising event. By reaching more individuals affected by dystonia, we can work together to help others know that they are not alone.

