



*Serving the Dystonia Community Since 1976*

## **Plans for 2022**

### **Mission**

The mission of the Dystonia Medical Research Foundation (DMRF) is to promote and support basic, clinical and translational research into the causes and mechanisms of the dystonias with the goal of developing more effective treatments and ultimately a cure; to promote dystonia awareness and provide educational resources; and to support the needs and welfare of affected individuals and their families. The DMRF has served the dystonia community for over 45 years and remains steadfast in our dedication to achieving our mission.

### **Achieving our mission through RESEARCH**

#### **Why Do We Promote and Support Research?**

**Research is the key to our going out of business.**

The DMRF leadership believes strongly that it is our moral duty to help everyone affected by all forms of dystonia. The everyday suffering of dystonia patients, the lack of effective treatments and appropriate medical care as well as numerous societal obstacles and burdens faced by patients drive our continuous efforts to spearhead scientific initiatives and to financially support medical research. Although scientific research may seem complex, we never lose sight of our ultimate goal - to create a base of knowledge and skills that will expedite not only better scientific understanding of dystonia but will successfully translate into strategies to reduce the burden of all forms of dystonia worldwide. We know this is achievable.

#### **How Will We Do It?**

Supporting dystonia research requires a robust, multi-layered scientific program. It involves continuous interaction with scientific leaders to identify gaps in our knowledge, stimulate dystonia worldwide research, and create an environment that fosters effective and productive collaboration among investigators. For more than forty-five years the DMRF has been funding breakthrough research on the dystonias through several mechanisms: regular research grants and fellowships awarded on a competitive basis, as well as milestone-driven research contracts. In 2022, the DMRF welcomes the leadership of Cure Dystonia Now (CDN), a long-time partner in funding research. The melding of the DMRF and CDN will enhance support for funding the best research to advance understanding of dystonia and accelerate progress toward a cure.

In 2022, the DMRF will:

- Support and monitor cutting-edge research aimed at expanding the knowledge of the genetic, molecular, physiologic and pathologic basis of dystonia.
- Promote and publish, *Dystonia*, an open access journal dedicated to dystonia research.
- Support collaboration and sharing of results and research resources to advance worldwide dystonia research. This includes providing administrative support to the Dystonia Coalition, the Global Dystonia Registry and the Dystonia Brain Collective.
- Engage and interact with industry and academic partners in supporting discovery and development of dystonia therapies.
- Organize and participate in scientific meetings to assess progress, promote creative dystonia research and foster collaboration, including a DMRF hosted meeting on the non-motor symptoms of dystonia.
- Engage, recruit to the field, and support young investigators pursuing dystonia-focused research through fellowships and grants.
- Support the training of clinicians and improve treatment experience for those affected by dystonia through support of the clinical fellowship program.
- Support improvement of clinical treatments for those affected by dystonia.
- Support global scientific collaboration through the development of the Samuel Belzberg 6<sup>th</sup> International Dystonia Symposium to be held in Dublin, Ireland in June 2023.

### **Increasing dystonia AWARENESS and EDUCATION**

#### **Why Do We Promote Dystonia Awareness and Education?**

**Access to accurate information about dystonia from credible sources is critical so that affected individuals and families understand the diagnosis and can make informed treatment decisions.**

Despite being the third most common movement disorder, dystonia continues to not be well known to the general public, to some healthcare professionals and members of the research community. Most people first hear the word ‘dystonia’ when they or a loved one is diagnosed. Feelings of loneliness and frustration are common among those living with dystonia because of social stigma and lack of understanding. Misdiagnosis is common because of a lack of awareness among medical professionals. Greater awareness of dystonia is needed to accelerate diagnosis, lessen feelings of isolation among those affected, and encourage support for dystonia research and programs. Greater awareness of dystonia is also critically important to our reaching and engaging the brightest young researchers. The need for increased awareness is key if we are to achieve our mission. The DMRF is committed to providing timely, accurate information for patients, their families, health care professionals and to raise awareness of dystonia with researchers and the public.

Research has demonstrated that an informed patient has better treatment outcomes. There is a wealth of inaccurate and misleading information available on the internet, from news outlets, and even from parties that claim to be authorities on dystonia. The DMRF is dedicated to providing

educational resources that empower those affected by dystonia so they can have the best outcome from their treatments, successfully manage their dystonia, and improve quality of life.

### **How Will We Do It?**

The DMRF will use multiple formats and communication strategies to create easy access to the information needed to make good treatment decisions and to stay informed on advancements and to convey how people may participate in the dystonia community. Increasing awareness of dystonia for healthcare professionals and the general public is more challenging and we are up for the challenge. The DMRF will look for every opportunity and utilize a multitude of media platforms to work with our volunteer leaders, our network of dedicated physicians and researchers to communicate the programs and activities of the Foundation, develop relationships with media outlets to help people understand what dystonia is and how it changes lives.

In 2022 the DMRF will:

- Develop and distribute the *Dystonia Dialogue* to keep the community apprised of relevant news, inspiring personal stories and opportunities for engagement.
- Utilize social media more frequently to increase awareness of dystonia, help create better understanding of dystonia research, and promote DMRF resources and programs.
- Develop videos to demonstrate the impact of dystonia.
- Promote awareness through local and web-based news media by announcing DMRF achievements and programs.
- Provide members of the dystonia community easy ways to promote awareness among their social and community contacts.
- Promote greater awareness of dystonia among healthcare professionals to support expedient movement disorder referrals.
- Provide easy access to information and global experts through print and web-based publications, webinars, host education and support meetings.

**SUPPORTING those who are affected by dystonia.**

### **Why Do We Encourage Individuals and Families to Connect with the Larger Dystonia Community?**

**The DMRF believes strongly that no one should go through the dystonia journey alone.**

Dystonia can be a very isolating disorder. It may take more than five years to get a diagnosis and when it is finally given, although there is relief at finally having an answer, it is something that few people are familiar with. There is benefit in having a network of well-informed, empathetic people who can provide moral support, and the opportunity for people to give back by supporting others on this same path. We know that the research can never progress fast enough for those who are struggling. Support is designed to be help now.

### **How Will We Support People Affected?**

Utilizing the dedicated, selfless peer support leaders who volunteer tirelessly with the DMRF to support others with dystonia, the Foundation has created a national network of support groups and on-line forums for networking, sharing information and providing support to one another. The DMRF is committed to growing the support program and to meeting the needs of the dystonia community. We feel strongly that all affected persons deserve the opportunity to live life to the fullest while the research advances toward a cure.

In 2022, the DMRF will:

- Work with local leaders to host virtual support meetings that provide accurate information, access to area experts, opportunities to get involved with the community, and opportunities to share personal experiences in a safe environment.
- Support on-line support forums available to all who are affected by dystonia regardless of geography and the ability to travel. These forums, like support groups, will provide accurate information, access to area experts, and create opportunities to share personal experiences in a safe environment.
- Develop new support resources to meet the needs of the dystonia community.
- Support the leaders who work tirelessly to serve as a resource for others in their communities by providing access to educational resources, technology to hold virtual meetings and organize a leadership conference to provide training and networking opportunities.

### **Addressing the MENTAL HEALTH NEEDS of the dystonia community.**

**Why do we encourage the community to be aware of the emotional and mental health aspects of living with dystonia?**

**The DMRF believes that mental health care is an important part of any dystonia treatment plan.**

Research is demonstrating that non-motor symptoms of dystonia can negatively impact quality of life as much as, and sometimes more severely, than the motor symptoms. The mental health needs of persons affected by dystonia are often overlooked or not recognized. It is critically important that mental health considerations be included in the overall healthcare plan for individuals in the dystonia community. People need to be empowered to seek help and be informed about the best way to get the complete healthcare they need.

### **How Will We Address the Mental Health Needs?**

By engaging mental health care professionals, physicians and representatives of the dystonia community, the DMRF will identify the resources needed to elevate and encourage conversations regarding mental health needs. We will work to spotlight this important issue in educational programs, print resources and within the DMRF support network.

In 2022, the DMRF will:

- Appoint a Mental Health Advisory Council to work with the Foundation to identify and develop resources for the community to utilize in addressing mental health needs.
- Work with the DMRF science team in developing the scientific workshop to address the non-motor symptoms of dystonia.
- Work collaboratively with the DMRF Awareness & Education and Support programs to integrate relevant mental health considerations into programs and activities planned for this year.

### **ADVOCATING for those affected by dystonia.**

#### **Why Do We Engage in Advocacy for the Dystonia Community?**

**The DMRF believes strongly that we have an obligation to those living with dystonia and to those who have dedicated their lives to curing dystonia, to turn over every stone in pursuit of access to treatment, to fight discrimination of those who have dystonia and to ensure funding opportunities for research that will lead us to our goal.**

We have a responsibility to make sure that our policy and decision makers are aware of what dystonia is, how it changes lives and how they can support those affected.

#### **How Do We Advocate for the Community?**

Working collaboratively with three other dystonia patient organizations, the expert legislative consultants and the dedicated dystonia advocates across the country, the DMRF will develop and implement a legislative agenda for 2022 that reflects current policy priorities, is responsive to proposed policies at the federal and state levels and proactively works for inclusion of dystonia on the Department of Defense Peer Review Medical Research Program and increased funding for the National Institutes of Health.

In 2022, the DMRF will:

- Work to promote dystonia research funding opportunities through the National Institutes of Health and the Department of Defense Peer Review Medical Research Program and the Veterans Administration.
- Work with the Dystonia Advocacy Network to develop and host Advocacy Days in March, presenting advocates with training and the information needed to meet with Members of Congress and their staffs regarding dystonia.
- Communicate to advocates about issues requiring their action in opposition to or in support of matters affecting the dystonia community.
- Partner with other organizations as needed to support the needs of the dystonia community.
- Work to ensure patient and physician access to all approved treatments for dystonia.

### **FUNDING the DMRF programs/services offered to the community**

#### **Why Do We Fund Raise?**

**The Foundation has a strong commitment to the people who have come to depend on the DMRF to provide support, education, fund important research and push for answers.**

The work of the DMRF is essential to the dystonia community. The DMRF is an internationally recognized leader in dystonia matters because of its unique capabilities and expertise. It is a privilege to serve those affected by dystonia and to invite others to join us in this cause.

### **How Do We Raise Funds?**

The DMRF Board of Directors, professional staff and hundreds of dedicated volunteers all work together to develop diverse revenue streams to ensure our research momentum continues uninterrupted and that the DMRF will be there to provide information and support to every individual and family who struggles with every form of dystonia.

In 2022, the DMRF will:

- Work with individuals and foundations to create giving opportunities to support the work of the Foundation.
- Work with local volunteers in the development and implementation of in-person and virtual events that raise funds in support of our mission, provide awareness of dystonia and the DMRF.
- Invite individuals to join the fight against dystonia and support the important work of the DMRF.
- Work with corporate partners to support approved program initiatives.

### **Securing and maintain the public trust**

#### **Why is Organizational Capacity Important?**

**The DMRF takes very seriously our responsibility to those affected by dystonia, their families, the researchers we work with and the generous people who financially support our work.**

The administrative and legal responsibilities and requirements of operating a national organization such as the DMRF are numerous and important to do correctly. Receiving and maintaining the trust of our community by compliance with all that is required of a non-profit organization is critical to our being able to our achieving our mission.

#### **How Do We Maintain Trust?**

The DMRF has a professional staff experienced in establishing and monitoring compliance with the policies approved by the Foundation's Board of Directors, the procedures and systems in place to assure effective and efficient use of resources and the legal requirements of being a charitable organization. The DMRF has a 3-star rating from Charity Navigator and a Platinum Rating, Seal of Transparency from Guide Star.

In 2022, the DMRF will:

- Identify and engage an independent auditing firm to conduct an audit of 2021 and 2022 finances and activities.
- Comply with all state and federal laws and requirements for a 501(c)3, charitable organization in good standing.
- Monitor compliance with DMRF approved policies and procedures.

- Hold four meetings of the DMRF Board of Directors.
- Identify new persons to serve on the Board of Directors who are committed to the DMRF's mission.
- Regularly identify and implement cost-saving measures.
- Share our financials and plans for the year with our members and the public.
- Work to maintain the highest ratings from charitable watchdog organizations.

### **Keeping People Safe**

The DMRF plans to host in-person meetings in 2022. However, should circumstance with COVID-19 call for these plans to pivot to virtual events, the DMRF will do so in an effort to protect the community during the continuing challenge of this global pandemic. These decisions will be made in advance of the scheduled dates of DMRF events.

1/26/2022