



*Serving the Dystonia Community Since 1976*

## **Plans for 2018**

### **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.

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

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

We at DMRF strongly believe that it is our moral duty to help everyone affected by dystonia. 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 and esoteric at times, 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 dystonias worldwide. We strongly believe this is achievable. Research is the key to our going out of business.

#### **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 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. The DMRF regularly organizes scientific meetings on specific topics to focus current research and to identify future opportunities for research and collaboration. In 2018, the DMRF will:

- Support and monitor cutting-edge research aimed at expanding the knowledge of the genetic, molecular, physiologic and pathologic basis of dystonia.
- 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.
- Engage, recruit to the field, and support young investigators pursuing dystonia-focused research through fellowships and grants
- Support improvement of clinical treatments for those affected by dystonia.

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

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

Despite being the third most common movement disorder, dystonia is not 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, healthcare professionals and to raise awareness of dystonia with researchers and the public.

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. 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 2018, the DMRF will:

- Develop and implement a new and improved website to serve as a resource in all awareness activities.
- Use social media to increase awareness of dystonia and DMRF programs.
- 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?**

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. The DMRF believes strongly that no one should go through the dystonia journey alone. 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 available 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 2018, the DMRF will:

- Work with local leaders to host 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.

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

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

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. 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.

### **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 2018 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 2018, the DMRF will:

- Work with the Dystonia Advocacy Network to develop and host Advocacy Day 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 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. The Foundation has been serving the community for over 40 years and we feel strongly that we have a responsibility to the people who have come to depend on the DMRF to provide support, education, fund important research and push for answers. 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 2018, 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 local events that raise funds in support of our mission, provide awareness of dystonia and the DMRF and invite others to join the fight against dystonia.
- Work with corporate partners to support approved program initiatives.

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

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

The administrative and legal responsibilities and requirements of operating a national organization such as the DMRF are numerous and important to do correctly. 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. 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. In 2018, the DMRF will:

- Identify and engage an independent auditing firm to conduct an audit of 2018 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 (two in-person) of the DMRF Board of Directors.
- Regularly identify and implement cost-saving measures.