

2021
ANNUAL
REPORT

Thanks to you!



DYSTONIA

MEDICAL RESEARCH FOUNDATION

45 Years of Service

Mission

The mission of the Dystonia Medical Research Foundation (DMRF) is to advance research for more effective treatments and ultimately a cure, to promote awareness and education, and to support the well-being of affected individuals and families.

About Dystonia

Dystonia is a neurological disorder that causes excessive, involuntary muscle contractions. These muscle contractions force the body and limbs into abnormal movements and postures, making it difficult for individuals to control their movements. Dystonia can affect virtually any region of the body including the face, jaw, eyelids, neck, vocal cords, torso, limbs, hands, and feet. Dystonia may affect a single body area or be generalized throughout multiple muscle groups. Dystonia affects men, women, and children of all ages and backgrounds. Estimates suggest no fewer than 250,000 people in the United States are affected. Dystonia causes varying degrees of disability and pain, from mild to severe. Although treatments exist, dystonia remains a chronic disorder for which there is not yet a cure.

Message from President & Executive Director



ART KESSLER
President



JANET L. HIESHETTER
Executive Director

2021 marked the DMRF's 45th anniversary. This is not a milestone we celebrate. We would much rather announce that DMRF is closing its doors for all the right reasons: because we found a cure and no person or family is ever again burdened by dystonia. Instead, we commemorate

anniversaries to practice gratitude. We acknowledge how far the dystonia community has come in raising visibility of the disorder and making a difference in the lives of those affected. This moment provides time to reflect on all that the DMRF has accomplished thanks to the generosity of our supporters.

2021 was another year to appreciate the depth of the dystonia research universe. Although there is much work to be done to better understand the biological mechanisms of dystonia and develop new and improved therapies, each year buoys our hope that we are closer than ever to achieving those goals. There was a record number of dystonia studies published in 2021. More than 1,300 scientific papers announced new discoveries, proposed improvements to existing treatments, suggested novel treatment strategies, pored through existing data to revisit unresolved questions, highlighted factors for optimal quality of life with dystonia, and meaningfully expanded dystonia knowledge overall. DMRF-funded investigators, in multiple scientific disciplines, added new insights to an increasingly advanced understanding of the disorder. As the leading global authority on dystonia, the DMRF continued to act as a central resource for investigators and powerful catalyst for leveraging every opportunity to move the science forward.

2021 was a year to again acknowledge the many invaluable individuals within the DMRF family. Our Support Leaders in particular redoubled efforts to help dystonia patients and families feel connected via local support groups and online peer support forums. Support Leaders broke through the isolation that so often hangs over a dystonia diagnosis, extending their compassion to individuals across the country and beyond. These connections are life-changing. We are thankful for the time and energy our Support Leaders invest in helping others, often while coping with dystonia themselves.

We are thankful to our legislative advocates who share their stories to educate Members of Congress. They give a face and a voice to the dystonia community, demonstrating the urgent need for federal research funding and access to affordable treatment. Thanks to the ongoing work of legislative advocates, dystonia investigators have been able to apply for, and obtain, tens of millions of new dollars in research funding so that progress toward a cure not only continues but accelerates.

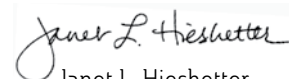
Special thanks goes as well to Cure Dystonia Now (CDN), which joined the DMRF to further our mutual goals to benefit the dystonia community. CDN Founders Robin and Marc Miller established the DMRF Cure Dystonia Now Fund in continuation of their commitment to advance outstanding research by leading dystonia investigators.

Every person who contributes to DMRF is essential for the Foundation's success. You have our gratitude. The accomplishments shared in this annual report were possible *thanks to you*.

Sincerely,



Art Kessler
President



Janet L. Hieshetter
Executive Director



“I am grateful that we have found treatments and have been able to identify the condition quicker and alleviate some of the emotional strain that dystonia has on the individual. We are diligently finding new investigators. I am looking forward to the day that we can close the door and say goodbye to the Dystonia Medical Research Foundation.”

Frances Belzberg, DMRF Co-Founder & Honorary Chair

“When there is a need in the dystonia community, whether from patients or researchers, DMRF consistently steps up to address those needs.”

Richard Lewis, MD, Vice President of Science



“The DMRF is important to me because it is helping to find a cure and funding new research for people who are fighting dystonia.”

*Danielle Sweeney
DMRF Supporter*



Thanks to you!

2021 AT A GLANCE

- ♥ DMRF commemorated 45 years of service
- ♥ 1,300 new dystonia studies published
- ♥ \$1,378,000+ invested in science
- ♥ *Dystonia* journal launched
- ♥ 12 research projects funded
- ♥ Cumulative DOD dystonia research reached \$20M+
- ♥ 1 scientific workshop
- ♥ 55,000 people received *Dystonia Dialogue* newsletter
- ♥ 4 requests for research proposals issued
- ♥ 2 clinical fellows in training



Thanks to Kaden Mendez of Team Omy for joining (and winning!) the Virtual Dystonia Zoo Day chalk challenge.



Deep gratitude to Janice and Len Nachbar for promoting awareness and supporting the DMRF mission in memory of their daughter, beloved dystonia advocate Joanna Manusov, who passed away in May.

- ♥ DMRF office responded to 1,000 new inquiries for assistance
- ♥ Online forums offered peer support to 10,000+ people.
- ♥ Global Dystonia Registry reached 6,300 sign-ups
- ♥ 12 online webinars provided expert information
- ♥ Virtual Dystonia Zoo Day raised \$361,000+ and made 185,000 online impressions
- ♥ Website visitors increased 13%
- ♥ Support groups held 119 meetings to connect dystonia community
- ♥ DMRF reached 5% more people on Facebook, 6% more on Twitter, 22% more on Instagram, and 30% more on YouTube compared to previous year



Thanks to Allison London, who joined the Board of Directors and Editorial Board. Her husband Dan London, sister Jen Goldman, and cousin Susan Greene ran the New Yorker Half Marathon in her honor.



Many thanks to our volunteers who hosted creative awareness events and campaigns, from a cooking demo, to a motorcycle ride, to mountain climbing, and more.

DMRF rose to the challenges of Covid-19.

In the second year of the Covid-19 pandemic, DMRF again made the adjustments necessary to ensure fulfillment of the mission continued. The pandemic required steady communication with dystonia investigators to monitor shutdown conditions and public health measures affecting clinics and laboratories all over the world. The DMRF continued to hear from individuals whose dystonia treatment was delayed and interrupted due to the pandemic, often resulting in weeks and months of returning or escalating symptoms. The pandemic exacerbated so many of the acute challenges individuals with dystonia have faced for decades: treatment access, social isolation, financial insecurity, and a lack of local disability services and social safety net resources. For the research and patient communities alike, the DMRF was a touchstone for essential information, assurance, and guidance.

“Without DMRF, we would not be as far along as we are today on the path to new treatments, and likely would not have developed many of the treatments we now have. The research that DMRF has promoted and funded, the advocacy, the training of investigators and clinicians, and the education for patients and families—all of these have been important components of the mission of the DMRF. The DMRF is an incredible organization of patients and families, clinicians, and investigators. We're all committed and working together.”

Joel S. Perlmutter, MD, Elliot Stein Family Professor of Neurology, Professor of Radiology, Neuroscience, Occupational Therapy and Physical Therapy, and Head of Movement Disorders at Washington University in St. Louis, Co-Director of the Dystonia Coalition, & DMRF Scientific Director



DMRF launched the first scientific journal dedicated to dystonia.

The DMRF partnered with Frontiers Media to launch *Dystonia*, the first scientific journal dedicated exclusively to the disorder. The journal will bring visibility to the growing dystonia field and highlight advancements in science and clinical practice. *Dystonia* provides a centralized, go-to publication by and for dystonia investigators. It is Gold Open Access, which means the content is available to the medical community and the public at no charge to readers.

Co-Editors-in-Chief are Aasef Shaikh, MD, PhD of Case Western Reserve University and Roy V. Sillitoe, PhD of Baylor College of Medicine. Both are members of the Medical & Scientific Advisory Council (MSAC), and Dr. Shaikh is a past DMRF Clinical Fellow.

The journal is partially supported by the Joan Miller Young Investigator Fund and Tuft Family Foundation.



Dystonia Co-Editors-in-Chief are Aasef Shaikh, MD, PhD (top) & Roy V. Sillitoe, PhD.

JOURNAL EDITORIAL BOARD

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12 research grants and fellowships supported critical dystonia investigations.

The goals of the DMRF's science program are to support the discovery of improved dystonia therapies and ultimately a cure. The DMRF is committed to providing investigators with the funding needed to address the most pressing unresolved questions in dystonia research.

RESEARCH FELLOWSHIPS

Postdoctoral fellowships support outstanding young scientists who have earned a doctoral degree and embarked on a period of mentored research. DMRF supports postdoctoral fellows who are working to fundamentally improve our understanding of brain dysfunction and molecular mechanisms underlying dystonia.

Investigating Abnormal Neurodevelopment in a Novel in vivo Model of Inherited Dystonia

Simon Lowe, PhD
University College London Institute of Neurology

Neural Signals in the Cerebellar Nuclei Gate the Manifestation of Dystonia-like Symptoms

Meike van der Heijden, PhD
Baylor College of Medicine

DYSTONIA COALITION CAREER DEVELOPMENT AWARDS

The DMRF is proud to have supported two Dystonia Coalition Career Development Awards. The goal of the program is to facilitate career development for junior investigators interested in clinical and translational research relating to dystonia, or to provide a mechanism for more senior investigators from other fields to get involved in dystonia research.

Non-invasive Neuromodulation to Study Long-term Plasticity Mechanisms in Task-specific Dystonia

Noreen Bukhari-Parlakturk, MD, PhD
Duke University School of Medicine

Immune Mechanisms in Cervical Dystonia

Laura Scorr, MD
Emory University School of Medicine

GRANTS & CONTRACTS

Research grants are available in support of hypothesis-driven research at the genetic, molecular, cellular, systems, or behavioral levels that may lead to a better understanding of the pathophysiology or to new therapies for any or all forms of dystonia. Contracts provide the opportunity to direct research through the identification of specific, milestone-driven projects conducted by identified investigators.

Genetic Modifiers of Penetrance in DYT1 Dystonia – 2nd Year

David Arkadir, MD, PhD
Hadassah Medical Center and Hebrew University of Jerusalem

Role of Cerebellar Network Excitability and Plasticity in the Pathophysiology of Dystonia

Antonio Pisani, MD
University of Pavia

Normalizing DYT1 Cholinergic Neurons by CRISPR Disruption of Mutant TOR1A Allele

Xandra Breakefield, PhD
Massachusetts General Hospital

Targeting the cAMP Pathway in the Striatum to Treat Dystonia

Emmanuel Roze, MD
Paris Brain Institute

A Next Generation Sensing Neural Interface Study for Adaptive DBS in Dystonia

Simon Little, MBBS, MRCP, PhD
University of California, San Francisco

Cholinergic Interneuron Dysfunction in a Phenotypic Mouse Model of Dystonia - 2nd Year

Mariangela Scarduzio, PhD
University of Alabama at Birmingham

The Role of Cholinergic Neurons in Isolated Focal Cervical Dystonia – 2nd Year

Scott Norris, MD
Washington University School of Medicine in St. Louis

Connie and Jim Brown Early Stage Investigator Award Cerebellar Repetitive Transcranial Magnetic Stimulation in Monogenic Myoclonus-Dystonia

Anne Weissbach, MD
University of Lübeck



Several research teams reported major advances in the development of new drugs to treat movement disorders including dystonia.

In one of these preclinical studies, a team at Vanderbilt University School of Medicine led by past DMRF Medical & Scientific Advisory Council (MSAC) member P. Jeffrey Conn, PhD and colleagues Aaron Bender, PhD and Jerri Rook, PhD identified several compounds that retained the beneficial effects of anticholinergic drugs like Artane® in mice while eliminating side effects.

A team of researchers at Duke University led by past DMRF grant recipient and current member of the MSAC Nicole Calakos, MD, PhD successfully corrected dystonic brain abnormalities in mice with an antiviral drug that is already approved by the US Food & Drug Administration for use in humans to slow HIV infection. Also from Calakos Lab, DMRF grant recipient Ashley Helseth, MD identified a specific cellular pathway that may be a potential target for novel treatments.

The Vanderbilt and Duke studies were supported in part by funding from the Department of Defense (DOD) Peer Reviewed Medical Research Program, which began offering funding to dystonia investigators in 2010 at the urging of the Dystonia Advocacy Network led by DMRF.

Moehle MS, Bender AM, Dickerson JW, et al. Discovery of the First Selective M4 Muscarinic Acetylcholine Receptor Antagonists with in Vivo Antiparkinsonian and Antidystonic Efficacy. ACS Pharmacol Transl Sci. 2021 Aug 2;4(4):1306-1321.

Spock M, Carter TR, Bollinger KA, et al. Discovery of VU6028418: A Highly Selective and Orally Bioavailable M4 Muscarinic Acetylcholine Receptor Antagonist. ACS Med Chem Lett. 2021 Aug 2;12(8):1342-1349.

Caffall ZF, Wilkes BJ, Hernández-Martínez R, et al. The HIV protease inhibitor, ritonavir, corrects diverse brain phenotypes across development in mouse model of DYT-TOR1A dystonia. Sci Transl Med. 2021 Aug 18;13(607):eabd3904.

DMRF-funded investigators developed a new approach to studying motor control.

DMRF grantee Jesse Goldberg, MD, PhD of Cornell University developed a groundbreaking new approach to studying dystonia and other movement disorders.

Much of what is known about the complexities of human movement control comes from the study of reaching and grabbing in monkeys. Dr. Goldberg and his team, however, discovered that the movements of a mouse's tongue licking water from a spout are neurologically comparable to a primate reaching an arm to grab an object. Through a series of meticulous experiments, Dr. Goldberg created a new tool to study normal movement as well as the neural basis of movement disorders like dystonia. The hope is that this will provide a superior method for examining mouse motor control with the necessary precision to clarify dystonic abnormalities in mouse models, which are critical for strategizing and testing new treatment approaches.

DMRF supported Dr. Goldberg's lab in partnership with the Dorothy Feiss Scientific and Medical Research Fund.

Bollu T, Ito BS, Whitehead SC, et al. Cortex-dependent corrections as the tongue reaches for and misses targets. Nature. 2021 Jun;594(7861):82-87.

“We connected with the DMRF in 1978, shortly after our son Art was diagnosed with generalized dystonia. It has been very rewarding to see how the DMRF has grown over the decades and the advancements that have taken place. The DMRF has had a profound positive impact on our family.”



*Dennis & Barb Kessler, DMRF Board of Directors
Dennis is DMRF Past President and Past Vice President of Development. Barb Kessler is Vice President of Awareness & Education and Chair of the Editorial Board*

Investigators discovered that novel treatment strategies may be time-sensitive.

A debilitating type of childhood onset dystonia occurs when a protein called TorsinA cannot function properly. Symptoms typically begin at approximately 9–12 years of age. This suggests there is something about the young developing brain that makes it vulnerable to dysfunctional TorsinA.

William Dauer, MD of UT Southwestern Medical Center investigated whether TorsinA function is uniquely necessary during a critical period of brain development, and whether genetic therapies similarly might only be effective during a specific age window. They found that suppressing TorsinA caused dystonia-like symptoms in young mice, but not adult mice. Furthermore, the ability to correct the TorsinA dysfunction and reduce dystonia symptoms was only possible during specific periods of mouse brain development. These important findings demonstrate that normal TorsinA function is critical to young brain development and suggest that TorsinA-based therapeutics may need to be targeted early in the course of this type of dystonia.

Dr. Dauer is a past DMRF grant recipient and past member of the Medical & Scientific Advisory Council.

Li J, Levin DS, Kim AJ, Pappas SS, Dauer WT. TorsinA restoration in a mouse model identifies a critical therapeutic window for DYT1 dystonia. J Clin Invest. 2021 Mar 15;131(6):e139606.



The circulation of the *Dystonia Dialogue* is 55,000+. The *Dystonia Dialogue* was partially supported by AbbVie Foundation and Revance Therapeutics.

“DMRF support came at a critical point in my career, and I am so grateful for the support then and ongoing support now... DMRF funding allowed me to spend two years as a postdoctoral research fellow during which time I learned about clinical DBS [deep brain stimulation] research, built expertise in management of dystonia, and secured funding to start my own laboratory.”



Sijetlana Miocinovic, MD, PhD, Assistant Professor in the Department of Neurology, Movement Disorders Section, at Emory University School of Medicine & Past DMRF Clinical Fellow and Mentor

Clinical Fellowships helped train two new movement disorder specialists.

In response to the pressing need for additional movement disorder specialists, the DMRF sponsors one-year clinical fellowships to train second-year fellow physicians in the diagnosis and treatment of movement disorders with special competence in dystonia. The fellowships focus on training in both the clinical evaluation and care of patients with dystonia and clinical research on dystonia.

The following clinical fellowships were underway in 2021:

Jessica Frey, MD (2021–2022)
University of Florida
Mentor: Aparna Shukla, MD

Margi Patel, MD (2020–2021)
Emory University
Mentors: Stuart Factor, DO
& Sijetlana Miocinovic, MD, PhD

DMRF is proud to note that mentor Sijetlana Miocinovic, MD, PhD is a past DMRF Clinical Fellow.

The Clinical Fellowship Training Program was supported in 2020-2021 by grants from Merz Pharmaceuticals, Ipsen Biopharmaceuticals, and Allergan Foundation.

Advocates rescued Department of Defense research funding for dystonia.



Dystonia Advocacy Network

Dystonia advocates acted swiftly to protect a critical source of research funding for dystonia investigators. The Dystonia Advocacy Network (DAN) was alerted that dystonia was not included in the list of conditions eligible for study through the Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP) for fiscal year 2021. Because of the work of the DAN, dystonia has been included on this exclusive list of conditions annually since 2010, resulting in more than \$20 million awarded to dystonia investigators.

In response, the DAN mobilized dystonia advocates in key districts. Thanks to their quick action, dystonia was added as a condition eligible for funding, avoiding a potentially devastating disruption to dystonia research supported by DOD.

DAN held Virtual Advocacy Day on March 3, 2021. Hundreds of dystonia advocates contacted their Members of Congress to educate them about dystonia and the needs of the dystonia community. In advance of Advocacy Day, every newly elected member of Congress received a personalized letter and information about dystonia. The DAN reaches out to new members following the start of every Congress.

“What do we need to establish new treatments? We need cooperation among experts and engagement from people who have dystonia, we need a good understanding of dystonia, we need good tools to measure new treatments and know if they work or not, and we need new approaches—new ideas for treatment and new experts to help study dystonia. The Dystonia Coalition is filling gaps in all these areas.”

H.A. “Buz” Jinnah, MD, Professor, Departments of Neurology and Human Genetics at Emory University School of Medicine and Director & Principal Investigator of the Dystonia Coalition

The Dystonia Coalition advanced global research progress.



The Dystonia Coalition is a collaboration of medical researchers and patient advocacy groups supported by the Office of Rare

Diseases Research in the National Center for Advancing Translational Sciences and the National Institute of Neurological Disorders & Stroke (NINDS) at the National Institutes of Health (NIH). The mission is to advance the pace of clinical and translational research in the dystonias to find better treatments and a cure.

The DMRF plays an integral role by providing free office and staffing support for the Coalition as an administrative center, maximizing funds invested in research. This has saved the Dystonia Coalition \$1.7 million in indirect costs. Dystonia Coalition Director H.A. “Buz” Jinnah, MD, PhD presented an update on activities and accomplishments in a webinar hosted by DMRF in June.

Investigators had access to shared data for studies.



The Global Dystonia Registry is a collaborative research initiative that depends on the DMRF for

operational and administrative management. The Global Dystonia Registry supports future dystonia studies through the confidential collection of patient data and distribution to dystonia investigators. As of 2021, more than 6,300 individuals joined.

The Dystonia Brain Collective is another DMRF-led collaborative effort among participating dystonia organizations. The purpose is to promote brain donation registration in support of research and provide investigators with access to tissue samples. DMRF extends our deepest gratitude to donors’ families for facilitating these invaluable contributions to research.

Virtual meeting supported DMRF Support Leaders.

A Virtual Leadership Conference took place on April 17, 2021. The event provided an opportunity for DMRF support group leaders and online moderators to connect with one another and get updates on DMRF activities. Break-out discussion sessions sought feedback from support leaders to ensure DMRF is providing appropriate resources to support them in their roles. Support was provided by Ipsen Biopharmaceuticals and Supernus Pharmaceuticals.

50+ support groups and moderated online forums created social connection.



Feelings of isolation are common among individuals and families impacted by dystonia, and can be devastating to physical and emotional health. DMRF support groups offered 119 meetings via video conference, providing the opportunity to gather virtually with others who understand the challenges of living with dystonia.

Online forums continued to provide connection to more than 10,000 people around the country, and beyond. The DMRF volunteer network is also made up of individuals devoted to awareness, fundraising, and/or serving as area contacts.

\$5Cure4Dystonia surpassed \$100K raised for research.

Dystonia awareness all-stars Mike Delise and Jason Dunn continued their tireless efforts to promote dystonia awareness and support research through \$5Cure4Dystonia. Launched in 2017, the campaign has cumulatively raised more than \$100,000 in support of DMRF's science program. \$5Cure4Dystonia was once again covered by reporter Deena Centofanti of FOX 2 Detroit, and Michigan Governor Gretchen Whitmer issued a proclamation recognizing Dystonia Awareness Month in September in recognition of the campaign.

A Virtual Dystonia Educational Symposium shared the latest dystonia updates from an expert panel.

The DMRF is committed to providing the dystonia community with access to educational opportunities with leading experts. A distinguished panel of speakers, most of who were past DMRF Clinical Fellows, participated in the Virtual Dystonia Educational Symposium on November 13, 2021. Medical speakers included Andres Deik, MD, MEd of Penn Medicine; Sijetlana Miocinovic, MD, PhD of Emory Healthcare; Scott Norris, MD of Washington University in St. Louis; Victor Patron Romero, MD of Rush University; and Harini Sarva, MD of Weill Cornell Medicine. DMRF Vice President of Public Policy Carole Rawson presented on getting involved in legislative advocacy and Brain Bank Liaison Martha Murphy spoke about registering as a brain donor. The program was moderated by DMRF President Art Kessler. More than 300 people tuned in for the live broadcast, and the recording pegged over 1,000 views. Ipsen Biopharmaceuticals provided support for this program.

“The DMRF turned 45 this year and so did I. What a wonderful time to be a part of such an important organization. When I was first diagnosed, the DMRF gave me hope. The information and support they gave me and my family was imperative to navigating this diagnosis of dystonia. I'm 27 years in on this journey and the DMRF has been there the entire time.



“Being a Support Leader and involved with the Pittsburgh Zoo Walk and becoming a legislative advocate for the DMRF has given me a sense of purpose. Playing an active role in my dystonia has made a positive difference in the way I handle my dystonia. Thank you to the DMRF.”

MaryRae Nee, DMRF Support Leader

DMRF extended special outreach to musicians with dystonia.

The family of the late musician Keith Emerson donated proceeds from sales of a 2016 concert film and album, “Fanfare for the Uncommon Man: The Official Keith Emerson Tribute Concert,” to benefit DMRF. The disc set was released in 2021 to commemorate what would have been Emerson’s 76th birthday. DMRF provided an educational video about musician’s dystonia that was added to a reunion video featuring musicians who performed in the tribute concert. In the educational video, movement disorder expert Steven Frucht, MD of NYU Langone Health provided a brief medical description of musician’s dystonia, and musicians Glen Estrin and Billy McLaughlin shared their stories. Dr. Frucht and Mr. Estrin are Co-Founders of The Leon Fleisher Foundation for Musicians with Dystonia, a program within DMRF.

DMRF also created a private “Musicians with Dystonia” Facebook Group as a peer support resource for professional musicians impacted by dystonia.

New new online forum provided support for individuals treated with DBS.

Deep brain stimulation (DBS) is a surgical procedure applied to treat an increasing number of dystonia patients. DMRF created the “Dystonia & Deep Brain Stimulation” private Facebook group as a peer support resource for individuals considering DBS or at any stage of the treatment process. The group is moderated by DMRF Support Leader and Community Leadership Council member Dee Linde and Andi Elliott.



“DMRF brings together people who feel alone. I have met some of my best friends through the DMRF.”

Amy Yurchison, DMRF Member

THANKS TO YOU!

DMRF offered virtual programs to address community concerns.

A schedule of webinars addressed topics ranging from dystonia research updates to treatment access and mental health. The following programs were broadcast live and most made available as lasting resources on the DMRF website and YouTube channel:

- ***Dystonia is More than a Movement Disorder: Depression & Anxiety***
Guest: Brian Berman, MD, MS, Virginia Commonwealth University Health
- ***Virtual Advocacy Day Training***
Guests: Dystonia Advocacy Network Chair Carole Rawson & Philip Goglas II, Health & Medicine Counsel
- ***Dystonia Research Funded Through the Department of Defense***
Guest: David Peterson, PhD, University of California, San Diego
- ***Connecticut Dystonia Educational Meeting***
Guests: Duarte Machado, MD & Megan Rood, MSPT, CSRS, CBIS of Hartford Healthcare
- ***Deep Brain Stimulation from the Patient Perspective***
Guests: Joan Miravite, DNP, Mount Sinai, Board Member John Downey, & Support Leader Dee Linde
- ***Dystonia Research Extra Access***
Guests: Scientific Director Joel S. Perlmutter, MD, Washington University in St. Louis, Ellen Hess, PhD, Emory University School of Medicine, & Aasef Shaikh, MD, PhD, Case Western Reserve University
- ***Dysport® Co-Pay Program***
- ***Update on the Dystonia Coalition***
Guest: Principal Investigator H. A. “Buz” Jinnah, MD, PhD, Emory University School of Medicine
- ***Botox® Co-Pay Program***
- ***Xeomin® Co-Pay Program***
- ***Dystonia & Cerebral Palsy***
Guests: Bhooma Aravamuthan, MD, DPhil, Washington University in St. Louis & John McGuire, MD, Froedert & Medical College of Wisconsin

2021 ANNUAL REPORT



Dystonia Virtual Zoo Day engaged 20% more participants.

DMRF hosted the second Virtual Dystonia Zoo Day on September 25, 2021. National Sponsors were Allergan, an AbbVie Company; Merz Therapeutics, Ipsen Biopharmaceuticals, and Revance Therapeutics. The National Organizing Committee included Kristin Cinglie, Jacquelyn Coello, Ed Cwalinski, Beth Farber, Karen Flanagan, Caleb Metherell, Shanna Schmitt, Paula Schneider, Pam Sloate, Brian Smuda, and Julia Wall.

An Olympic-style Dystonia Zoo Day torch traveled virtually across the country, handed off to a DMRF supporter in a new city each day of September leading to the event. The torch ultimately reached DMRF President Art Kessler and Executive Director Janet Hieshetter for the opening ceremony. Sessions included zoo keeper chats with Toledo Zoo & Aquarium and Como Park Zoo, appearances by puppet Lolly Lardpop performed by Leslie Carrara-Rudolph, inspiring stories from DMRF Board Member Jon Davis, DMRF supporter Kim Robinson, DMRF supporter Stacey Steinmetz and her son Daniel moderated by Julia Wall of Henry Ford Health System, an exercise demonstration with physical therapists Chelsea Richardson, PT, DPT, NCS and Lincoln Beal, PT, DPT, and a dance party with Interpretations Dance Academy Dance Team.

The event raised over \$261,000 in support of the DMRF mission. Team donations were eligible to be matched by a generous anonymous donor, generating an additional \$100,000.



“Twelve years ago, our daughter Allison received a diagnosis. The term applied was ‘dystonia’—something we had never heard of before. The myriad of specialists she had seen for years had also given their diagnoses, and many of them treated her for those ailments. Unfortunately, none of those previous doctors were correct. This, we learned, is an all too common occurrence, one that the Dystonia Medical Research Foundation has strived to eradicate.

“As the only organization solely focused on education, awareness, and the unceasing drive for better treatments and the elimination of all types of dystonia through research, the DMRF stands very tall. It has unfailingly served the dystonia community through its work to improve the lives of all those suffering with the multitude of symptoms that form what dystonia is and what it means to those affected.

“Since joining the Foundation several years ago I cannot help but marvel at the dedication and determination that every single member of the organization puts forth every day. That goes for both staff and volunteers. All have the common goal of making it so the Foundation can close its doors when the cure is found.

“So, on the 45th anniversary of its founding, I cannot say anywhere near enough about what wonderful work, what terrific people, and how much the

DMRF means to our family and the entire dystonia community.”

Ron Hersh, DMRF Vice President of Development



Statement of Activities

Dystonia Medical Research Foundation | Year Ending December 31, 2021

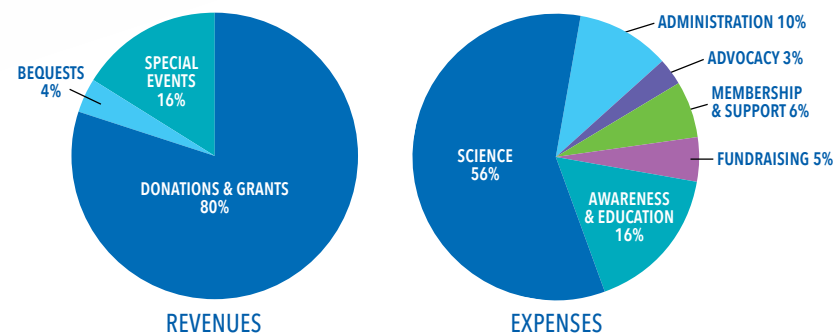
| | WITHOUT DONOR RESTRICTIONS | WITH DONOR RESTRICTIONS | TOTAL |
|---|----------------------------------|-------------------------------|------------------|
| REVENUES, GAINS & SUPPORT | | | |
| Donations and grants | 1,010,237 | 661,711 | 1,671,948 |
| PPP SBA grant | 144,660 | | 144,660 |
| Cure Dystonia Now funds received | 400,000 | | 400,000 |
| Bequests | 123,366 | | 123,366 |
| Special events, net of direct benefits to donors of \$686 | 444,085 | | 444,085 |
| Investment income | 357,825 | 29 | 357,854 |
| Other | 48,112 | | 48,112 |
| Net assets released from restrictions | 207,372 | (207,372) | - |
| Total Revenues, Gains and Support | <u>2,735,657</u> | <u>454,368</u> | <u>3,190,025</u> |
| EXPENSES | | | |
| Program services | | | |
| Science | 1,378,133 | | 1,378,133 |
| Awareness and education | 389,889 | | 389,889 |
| Membership and support | 139,582 | | 139,582 |
| Advocacy | 73,441 | | 73,441 |
| Total program services expense | <u>1,981,045</u> | | <u>1,981,045</u> |
| Supporting services | | | |
| Administration | 251,284 | | 251,284 |
| Fundraising | 236,883 | | 236,883 |
| Total Expenses | <u>2,469,212</u> | | <u>2,469,212</u> |
| Change in Net Assets | 266,445 | 454,368 | 720,813 |
| Net assets, Beginning of Year | 2,884,156 | 1,781,401 | 4,665,557 |
| Net Assets, End of Year | <u>3,150,601</u> | <u>2,235,769</u> | <u>5,386,370</u> |

Statement of Financial Position

Dystonia Medical Research Foundation | Year Ending December 31, 2021

| ASSETS | 2021 |
|---|---------------------|
| Cash and cash equivalents including segregated Dystonia Coalition cash of \$318,053 in 2021 | \$ 1,017,081 |
| Investments | 5,760,796 |
| Unconditional promises to give | 35,997 |
| Other current assets | 73,469 |
| Equipment and leasehold improvements, less \$33,792 of accumulated depreciation | 11,576 |
| Total Assets | <u>\$ 6,898,919</u> |
| LIABILITIES & NET ASSETS | |
| Liabilities: | |
| Grants and fellowships payable | \$ 817,754 |
| Accounts payable and accrued expenses | 61,480 |
| Deferred rent payable | 104,762 |
| Deferred revenue | 210,500 |
| Dystonia Coalition agency liability funds | 318,053 |
| Total Liabilities | <u>1,512,549</u> |
| NET ASSETS WITHOUT DONOR RESTRICTIONS | |
| Undesignated | 1,650,601 |
| Board designated for science | 1,500,000 |
| Total net assets without donor restrictions | <u>3,150,601</u> |
| NET ASSETS WITH DONOR RESTRICTIONS | |
| Purpose restricted | 2,235,769 |
| Total net assets with donor restrictions | <u>2,235,769</u> |
| Total Net Assets | <u>5,386,370</u> |
| Total Liabilities and Net Assets | <u>\$ 6,898,919</u> |

A complete copy of financial statements audited by Barnes, Givens & Barnes, Ltd. is available upon request from the Dystonia Medical Research Foundation, One E. Wacker Drive, Suite 1730, Chicago, Illinois 60601.



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The background of the entire page is composed of several broad, horizontal brushstrokes in various shades of blue, ranging from light sky blue to deep navy blue. The strokes are layered, creating a sense of depth and movement. At the bottom, there is a solid dark blue horizontal band that serves as a backdrop for the organization's name.

Dystonia Medical Research Foundation

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