Thank you for trusting the Dystonia Medical Research Foundation (DMRF) to lead the charge to find a cure and for your confidence in the scientific process to deliver the breakthroughs we are fighting for every day.

Hope keeps the DMRF moving forward. Hope is the powerful feeling of expectation that an achievement will be fulfilled. The research continually provides an abundance of hope. We see proof that the work of the Foundation is producing results. Countless lives have been changed for the better because of the vibrant research field dystonia has become and the resources DMRF makes available to patients and families every day.

Hope feeds the endurance required to seek answers, no matter how complicated the questions and despite whatever inevitable obstacles appear. DMRF-funded investigators know that families are counting on them to make meaningful discoveries and ultimately improve quality of life.

Hope is essential to living with dystonia. Hope provides the strength to manage everyday challenges, to wait and see if a new treatment approach will help, and to trust that dystonia researchers are on the cusp of the next breakthrough.

Thank you for trusting the DMRF with your hope. All of the accomplishments highlighted in this report were made possible because of you—because of your generous support and your vision for the future. We are in this together. The DMRF will not stop until a cure is available for every dystonia.

Art Kessler
President

Janet L. Hieshetter
Executive Director

“The DMRF is responsible for almost all the dystonia research that’s done today.”

Joel S. Perlmutter, MD, Scientific Director
Every member of the Board of Directors is personally impacted by dystonia—either they or a loved one has been diagnosed. The Board is acutely aware of the urgency of DMRF’s work because they experience dystonia in their own lives every day. They are tireless in their dedication to finding a cure and supporting affected individuals and families.

The dedication of the Board of Directors was reflected in the successful surpassing of personal Board fundraising goals from the previous year. Board Members were also active in supporting DMRF events such as Dystonia Zoo Walks and Advocacy Day.

“This is a more complex and richer field than I ever imagined, and one that keeps budding new flowers. We understand more and more now, and that understanding can be translated into more successful treatments.”

Mahlon R. DeLong, MD, Scientific Director Emeritus & Lifetime Honorary Board Member

Niccolo Mencacci, MD, PhD is among the 20 member Medical & Scientific Advisory Council (MSAC), which advises the DMRF Board of Directors on research matters.

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 involuntary contractions force the body and limbs into abnormal movements and postures. 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.
Mahlon R. DeLong, MD retired after 25 years of exceptional service to DMRF as Scientific Director. He remains involved as Scientific Director Emeritus and Lifetime Honorary Board Member. Joel S. Perlmutter, MD, Elliot Stein Family Professor of Neurology and Head of the Movement Disorders Program at Washington University in St. Louis, now serves as DMRF Scientific Director. Dr. Perlmutter is a long-time member of the Medical & Scientific Advisory Council (MSAC) and Co-Director of the Dystonia Coalition. As Scientific Director, Dr. Perlmutter works closely with DMRF Chief Scientific Advisor Jan Teller, MA, PhD and DMRF Vice President of Science Richard Lewis, MD in planning and evaluating the Foundation’s scientific efforts. He also serve as the Chairperson of the MSAC and offers guidance to the Board of Directors on dystonia research matters.

“...serve as President of the DMRF with Dr. DeLong as our Scientific Director. His contributions to the DMRF’s scientific program will resonate forever. We are fortunate that Dr. Perlmutter is stepping into this role, in continuance of his steadfast dedication to the Foundation. I am deeply appreciative for their leadership in the dystonia field and devotion to patients and families.”

Art Kessler, President
A healthy research field requires attracting young investigators. DMRF provides funding opportunities at strategic stages in a young researcher’s career. DMRF funded six research fellowships:

**Role of the X-linked Dystonia Parkinsonism (XDP) Causative Gene TAF1 in the Striatal Development and Maintenance**
Maria Cirnaru, PhD  
Mount Sinai School of Medicine (USA)  
Mentor: Michelle Ehrlich, MD

**CRISPR/Cas9 System Targeting Specific DYT1 Allele Mutation in Patient iPSCs: A Strategy for Phenotype Reversion in iPSCs-derived Neurons**
Lilian Cruz, PhD  
Massachusetts General Hospital (USA)  
Mentors: Xandra Breakefield, PhD & Cris Bragg, PhD

**Developmental Regulation of eIF2alpha Pathway Activity and its Significance for DYT1 Dystonia**
Ashley Helseth, MD, PhD  
Duke University Medical Center (USA)  
Mentor: Nicole Calakos, MD, PhD  
*Barbara Oliver Memorial Dystonia Research Award*

**Using the Nematode Caenorhabditis elegans to Identify Candidate Substrates for OOC-5/torsinA**
Gabriela Huelgas-Morales, PhD  
University of Minnesota (USA)  
Mentor: David Greenstein, PhD  
*Barbara Oliver Memorial Dystonia Research Award*

**A Genetic Approach towards Identifying Torsin Function in Relation to DYT1 Dystonia**
Anthony Rampello, PhD  
Yale University (USA)  
Mentor: Christian Schlieker, PhD  
*Supported by the family of Barbara and Ron Oliver*

**Impact of Microglia on Abnormal Synaptic Plasticity and Development of Dystonia in Transgenic DYT1 Mouse Models**
Lisa Rauschenberger, MD, PhD  
University Hospital of Würzburg (Germany)  
Mentor: Chi Wang Ip, MD, PhD  
*David M. Rudolph Dystonia Research Fund Award*

“The dystonia community cannot wait for new pharmaceutical and biotech companies to get interested in dystonia on their own. DMRF has a responsibility to encourage and support drug discovery efforts while we work constantly to engage pharma and industry partners.”

*Jan Teller, MA, PhD, Chief Scientific Advisor*
DMRF MSAC Member and grant recipient Roy Sillitoe, PhD is clarifying the role of the cerebellum in dystonia.
The DMRF continues to work every day to nurture and expand the field of dystonia research and partner with experts across scientific disciplines. Since 1976, DMRF has funded hundreds of research investigations. In 2019, DMRF-funded investigators pursued new treatment strategies, explored dystonia brain networks, targeted dystonia-causing genes, and studied the proteins encoded by these genes. DMRF funded the following 19 investigations:

**NEUROANATOMICAL SUBSTRATES FOR DISRUPTED eIF2alpha SIGNALING IN DYSTONIA**
Nicole Calakos, MD, PhD, Duke University Medical Center (USA)

**MYOCLOONUS-DYSTONIA, A STUDY OF MOTOR AND NON-MOTOR SYMPTOMS: IS THERE A ROLE FOR SEROTONIN?**
Marina de Koning-Tijssen, MD, PhD
University Medical Center Gröningen (The Netherlands)
Supported by Brown Family Foundation

**MACHINE LEARNING GUIDED DEEP BRAIN STIMULATION TO CURE NEUROLOGICAL DISEASE**
Jesse Goldberg, MD, PhD, Cornell University (USA)
Supported by Dorothy Feiss Scientific and Medical Research Fund

**VARIABLE EXPRESSIVITY IN SGCE-ASSOCIATED MYOCLOONUS-DYSTONIA: INSIGHTS FROM EPIGENETICS AND TRANSCRIPTOMICS**
Karen Grütz, PhD, University of Lübeck (Germany)
Supported by Brown Family Foundation

**STRIATAL NEURON ACTIVITY PATTERNS IN DYSTONIA**
ellen Hess, PhD, Emory University (USA)

**TREMOR, OSCILLATIONS, SYNAPTIC PLASTICITY, AND DBS FOR DYSTONIA**
William Hutchison, PhD, Toronto Western Hospital (Canada)
Supported by Dystonia Medical Research Foundation Canada

**UNRAVELING HIERARCHICAL NETWORK LOOPS IN ISOLATED DYSTONIA**
Xin Jin, PhD, The Salk Institute for Biological Studies (USA)
Supported by Cure Dystonia Now & Benign Essential Blepharospasm Research Foundation

**USING FUNCTIONAL CONNECTIVITY TO OPTIMIZE DEEP BRAIN STIMULATION IN DYSTONIA**
Andrea Kühn, MD, Charité University Berlin (Germany)
Supported in collaboration with Cure Dystonia Now

**BANKING OF MYOCLOONUS-DYSTONIA BIOLOGICAL MATERIALS**
Mark LeDoux, MD, PhD, University of Memphis (USA)
Supported by Brown Family Foundation

CONTINUED ON PAGE 8
Determining the Role of Torsin in Nuclear Pore Complex Assembly
Patrick Lusk, PhD, Yale University (USA)

Synaptic Plasticity in a Mouse Model of Paroxysmal Dystonia
Alexandra Nelson, MD, PhD
University of California, San Francisco (USA)

Investigating Multimodal Neuroimaging for Probing Brain Networks in Cervical Dystonia
Richard Reilly, PhD
Trinity College Dublin (Ireland)
Supported in collaboration with Cure Dystonia Now

Investigation of Striato-Pallidal Connections in a Mouse Model of DYT1 Dystonia
Giuseppe Sciamanna, PhD
University of Rome Tor Vergata (Italy)

Integrative Network and its Proprioceptive Modulation to Probe Physiology and Therapy of Cervical Dystonia
Aasef Shaikh, MD, PhD
Case Western Reserve University (USA)
Supported by Estate of Jocelyn Baker

Interregional Brain Connectivity in a Mouse Model of Cerebellar-Induced Dystonia
Roy Sillitoe, PhD, Baylor College of Medicine (USA)
Supported in collaboration with Cure Dystonia Now

Dystonia-associated Endoplasmic Reticulum Dysfunction in the (de)Regulation of Neurotransmission
Patrik Verstreken, PhD, VIB Leuven (Belgium)

Three-Dimensional Network Architecture of Dystonia
An Vo, PhD, The Feinstein Institute for Medical Research (USA)

Identification of Neuronal Mechanisms of Agency in Myoclonus-Dystonia
Yulia Worbe, MD, PhD
Pitié-Salpêtrière Hospital (France)
Supported by Brown Family Foundation

Deciphering the Sources of Myoclonus in DYT-SGCE Patients
Yulia Worbe, MD, PhD
Pitié-Salpêtrière Hospital (France)
Supported by Brown Family Foundation

Erwin Jackson, PhD is among the 20+ members of the DMRF Board of Directors who are leading the mission to cure dystonia.
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 objectives are to develop a fuller understanding of the many features of dystonia and how they change over time, to develop validated diagnostic strategies and rating tools for diagnosis and monitoring patients in clinical trials, to establish a biorepository where blood and other samples can be stored and distributed for research, to stimulate clinical trials for new treatments, and to promote education and awareness.

The Dystonia Coalition was renewed in 2019 and is funded through 2024.

The DMRF plays an integral role by providing administrative support at no cost, which means Coalition funding is directed fully to science. This has saved the Dystonia Coalition $1.5 million in indirect costs, maximizing funds invested in research. The Dystonia Coalition was renewed in 2019 and is funded through 2024.

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, including clinical trials, through the confidential collection of patient data and distribution to dystonia investigators. To date, more than 5,800 individuals have 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. Two brains were successfully recovered in 2019. DMRF extends our deepest condolences and gratitude to donors’ families for enabling these invaluable contributions to research.
Clinical fellow Noreen Bukhari-Parlakturk, MD, PhD and team are studying TMS therapy as a novel dystonia treatment.
Evaluation by a movement disorder specialist has a dramatic impact on timely diagnosis and maximizing benefit from treatment. Many patients throughout the country must travel significant distance or endure long waits for appointment openings to access a physician with the qualifications to diagnose and treat dystonia.

In response to the need for additional clinical experts, the DMRF sponsors one-year clinical fellowships to train second-year fellow physicians in the diagnosis and treatment of movement disorders with special emphasis in dystonia. The outstanding clinicians who complete training have joined movement disorder programs at prestigious institutions and begun practicing in communities previously without a dystonia expert.

Noreen Bukhari-Parlakturk, MD, PhD (2018–2019)
Duke University Medical Center (USA)
Mentor: Nicole Calakos, MD, PhD
Research: Development of Plasticity Rectifying Approaches for Therapy of Task-Specific Dystonia Using Noninvasive Neuromodulation

Abhimanyu Mahajan, MD, MHS (2019–2020)
University of Cincinnati (USA)
Mentor: Alberto J. Espay, MD, MSc
Research: Cerebellar Degeneration in Tremor-Dominant Cervical Dystonia: Clinical and Neuroimaging Cohort Study

“I want to close the gap between understanding the disease and targeting it with therapeutic trials so patients walk away feeling their treatment makes a major positive change in their quality of life.”

Noreen Bukhari-Parlakturk, MD, PhD, Clinical Fellow

The 2019 Clinical Fellowship Training Program is supported by grants from Merz Pharmaceuticals and The Allergan Foundation.
On March 26–27, 2019, the Dystonia Advocacy Network (DAN) hosted Advocacy Day in Washington, DC to encourage Members of Congress to support the DAN’s legislative priorities. Advocates asked that dystonia continue to be recognized as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program and to provide the National Institutes of Health with ample funds for the 2020 Fiscal Year. The DAN also advocated for increased funding for the Centers for Disease Control & Prevention and protections for the Americans with Disabilities Act of 1990. The DMRF continued to provide staff support to ensure the DAN implemented and achieved the legislative agenda.

The Douglas Kramer Young Advocate Award recognizes exceptional young people who are giving voice to dystonia through advocacy. Recipients in 2019 were Melissa Alvarado, Sam Ashkenas, Serina Griffin, Amy Yurchision, and Haseeb Khawaja.
Since 2010, the Department of Defense (DOD) has funded dystonia research because volunteer advocates push every year to make sure dystonia is included in its Congressionally-Directed Peer-Reviewed Medical Research Program (CDMRP). Unlike the National Institutes of Health and other federal medical research initiatives, the CDMRP only funds research into conditions that are deemed eligible for study by Congress. The eligible conditions list is renewed by Congress every year.

The hard work of dystonia advocates on this issue has resulted in $17+ million from the DOD awarded to outstanding dystonia investigators.

The DOD integrates patients and family members into the CDMRP scientific review process by assigning consumer reviewers to participate alongside research experts. The DMRF is invited each year to nominate members of the dystonia community for these important positions.

“I loved participating in Dystonia Advocacy Day. It was a great privilege to see our elected officials at work, to engage with them, and to promote awareness about such an important issue alongside such wonderful advocates and new friends.”

Serina Griffin,
Douglas Kramer Young Advocate Award Recipient

Dystonia was included in the DOD Congressionally Directed Peer Review Medical Research Program.
DMRF BROUGHT FACTS TO THE HOT TOPICS THE COMMUNITY WAS TALKING ABOUT.

Through online webinars, newsletter articles, and new brochures, DMRF offered exclusive content on issues the community wanted to know more about: the role of medical cannabis in dystonia, drug discovery efforts, deep brain stimulation, emerging treatments with non-invasive brain stimulation, and the relationship between dystonia and social anxiety. Community-wide surveys sought feedback about treatment experiences as well as perceptions and use of medical cannabis.

Access to accurate information about dystonia and treatment options is as vital to living well as access to appropriate medical care. Sharing a brochure about dystonia can be a simple but powerful act to help inform family members, educators, colleagues, and even strangers about the disorder and promote greater awareness. More than 25 brochures and pamphlets are available for free mail order or download from the DMRF website. These materials are also distributed through local dystonia support groups, educational meetings, awareness events, and in medical offices.

The DMRF offers programs and information to 50,000+ people annually.

DMRF PROVIDED FREE EDUCATIONAL MATERIALS TO PEOPLE SEEKING INFORMATION AND REASSURANCE.
1,500+ people completed a DMRF survey seeking feedback from individuals with dystonia about the diagnosis process and experience with botulinum neurotoxin injections, a common treatment.

Among the most significant findings is that individuals diagnosed with dystonia within the last five years were diagnosed faster than those diagnosed more than five years ago, suggesting that diagnosis times continue to improve.

Rushed medical appointments in which physicians have limited time with patients are not always a constructive time for in-depth learning about dystonia and the latest clinical advancements. DMRF creates opportunities for individuals to interact with clinicians and researchers in an educational setting, with ample time for interactive discussion. DMRF provided thousands of people with the latest information on living well with dystonia by organizing free educational meetings across the country. These meetings also provide opportunities for peer support and social connection. Locations included Denver, Cincinnati, Providence, Detroit, Atlanta, Las Vegas, and Omaha.

NEW WEBSITE CENTRALIZED INFORMATION FOR PATIENT AND RESEARCH COMMUNITIES.

The DMRF website was re-designed with a number of new-and-improved features including more intuitive navigation, resources for researchers, social sharing, and lots of updated content.

WWW.DYSTONIA-FOUNDATION.ORG
The DMRF partners with volunteers and support groups around the country on creative and fun events that unite the local dystonia community, promote awareness, highlight movement disorder programs, and raise urgently needed funds for research. More than 20 special events took place in 2019, raising over $525,000.

Among DMRF’s most popular community programs are Dystonia Zoo Walks, family-friendly gatherings to raise awareness and support DMRF. Thirteen Zoo Walks attracted more than 5,000 participants in 2019. Locations included Bronx/New York City, Detroit, Cleveland, Cincinnati, Los Angeles, Philadelphia, Phoenix, Pittsburgh, Portland, Providence, St. Louis, Toledo, and Twin Cities.
“DMRF is fortunate to have strong partnerships with local volunteers who are dedicated to serving their local dystonia communities. These volunteers give of themselves to run support groups, moderate online forums, and organize local awareness events. Remarkably, they do this extraordinary work while coping with dystonia themselves or alongside a loved one.”

Janet Hieshetter, Executive Director
“Having a support network is vital to coping with dystonia and in my case that starts with Shanna, my wife. There’s also a certain moral uplift that comes from connecting to a support group and being surrounded by people who are experiencing the same things you’ve dealt with.”

Brad Schmitt, Co-Leader, Minnesota Dystonia Support Group

Feelings of isolation are common among individuals and families impacted by dystonia, and can be devastating to physical and emotional health. Social connection and peer support are vital to living well with dystonia. DMRF support groups provide local peer support, offering the opportunity to gather with others who know the challenges of living with dystonia. Online forums provide connection to thousands around the country, and around the world. The DMRF volunteer network is also made up of individuals devoted to awareness, fundraising, and/or serving as area contacts.
DMRF earned the highest marks from Charity Navigator and Guidestar, highlighting DMRF’s commitment to fiscal responsibility and transparency.
MEDICAL & SCIENTIFIC ADVISORY COUNCIL

Mahlon R. DeLong, MD
Scientific Director Emeritus
Emory University School
of Medicine

Joel S. Perlmutter, MD
Scientific Director
Washington University School
of Medicine in St Louis

Nicole Calakos, MD, PhD
Duke University Medical Center

Michelle Ehrlich, MD
Mount Sinai School
of Medicine

Jesse Goldberg, MD, PhD
Cornell University

Mark Hallett, MD
National Institute of Neurological Disorders
& Stroke

Niccolo Mencacci, MD, PhD
Northwestern University

Jill Ostrem, MD
University of California,
San Francisco

Alvaro Pascual-Leone, MD, PhD
Harvard Medical School

Terence Sanger, MD, PhD
University of Southern
California

Christian Schlieker, PhD
Yale University

Thomas Schwartz, PhD
Massachusetts Institute
of Technology

Roy Sillitoe, PhD
Baylor College of Medicine

Kristina Simonyan, MD, PhD
Harvard Medical School

Cynthia Comella, MD
ex officio
Dystonia Study Group

H.A. Jinnah, MD, PhD
ex officio
Principal Investigator,
Dystonia Coalition

Codrin Lungu, MD
Federal Liaison

Jill Ostrem, MD is among the 20 member Medical & Scientific Advisory Council (MSAC), which advises the DMRF Board of Directors on research matters.

CLINICAL FELLOWSHIP PROGRAM COMMITTEE

Susan Bressman, MD
Mount Sinai Beth Israel

Cynthia Comella, MD
Rush University Medical Center

Mahlon R. DeLong, MD
Emory University School of Medicine

Stanley Fahn, MD
Columbia University Medical Center

Hubert Fernandez, MD
Cleveland Clinic

Mark Hallett, MD
National Institute of Neurological Disorders
& Stroke

Joseph Jankovic, MD
Baylor College of Medicine
THE DMRF WISHES TO ACKNOWLEDGE THE GENEROUS GIFTS RECEIVED IN MEMORY OF THE FOLLOWING:

Nathan Abbott  
Tess Ackerman  
Ann Burns Adrain  
Peggy Allen  
Robert Alosco  
John F. Anderson  
Cecilia Antonilli  
Dorothy Armstrong  
Esther Auster  
Laurie Ornstein Avona  
Bernice Baras  
Glenn Barker  
Basya Rochel Bas  
Shmuel Hirsh obm  
Mary Lou Batty  
Ethed Bean  
Shirley Bell  
David Belsky  
Lydia Bennett  
Laurel A. Bradley  
John Brookelman  
Joyce Britt Brown  
Steve Brown  
Willie Robert Brown  
James R. Bulmer  
Sharon Cadwallader  
Ray Cahill  
Ian C. Campbell  
Allen Capozio  
Melissa Anne Centrella  
Dr. David Cohen  
Martha Colombini  
Enid Columbus  
Janene Conte-Clark  
James Cooksey  
Catherine Cornetto  
JoAnna Craig  
Helene Craner  
David Cullinane  
Harold Leicester Davis  
Eulinia “Nini”  
Del Rosario  
Paul Delsandro  
Jean Demoray  
Joseph Dolce  
Robert Dufault  
Ed Dye  
John Earnisse  
Bill Eley  
Isaiah Erb-White  
Virginia Fairbank  
Shari Farber-Tritt  
Rita Farnkoff  
Rita Flanagan  
Evelyn Florjancic  
Arthur Fox  
Rosemary Frassetto  
Saul Friedman  
William Frindt  
Adele Garber  
Sharlene Gorden  
Carol Greenblatt  
Gordon Gross  
Lewis E. Halley  
Christopher Harris  
Paris Hilton  
Rhoda Hitrys  
Doris Hoffman  
Mary Ann Hohenstein  
Ron Isacoff  
Yale Kanter  
Gary Kauffman  
Margie Kelly  
Bonnie Keszler  
Miriam Kimmelman  
Novyce King  
Maciej Kocur  
Mary Kolls  
Stephanie Kopec  
Deanna Kotch  
Paul Kovacs, III  
Florence Kramer  
Rose Kremen  
Steven Lesperance  
Valerie F. Levitan, PhD  
Kevin Lorence  
Norma Maglione  
Phillip Marshall  
David McClure  
Mary Frances McMahon  
Jerilyn McNamara  
Beverly Mellon  
Joseph Nemeth  
Daniel Newmahr  
Mary Odell  
Susan Owens  
Marie Perusse  
Ginny Peterson  
Brent Petri  
Helen Carol Pieczynski  
Lev Plitman  
Sol Pollan  
Ron Reichstein  
Dee Ann Reynolds  
Carl Donald Richards  
Joann Richardson  
Annie Ritsch  
Craig R. Rosen  
Roberta Rosenbaum  
Joan Rosenberg  
Brunilda Ruiz  
Virginia Ruth  
Dr. Marty Schulman  
Bernice Schwartz  
Willard “Tommy”  
Thompson  
Virginia Thrower  
Randall Warning, Sr.  
Sol Wasserman  
Elaine Weinberg  
Madeline Werle  
Kim Weyer  
Allan Womac  
Bruce Slepian  
Sam Slepian  
Sarah Slepian  
Phil Smith  
Robert Snow  
Michael Sparish  
Caroll Spinney  
Gail Stanziale  
Murray Steinfink  
Iris Stoler  
Stephen K. Sverid  
Ronald Switzer  
Owen Thompson  
Willard Thompson  
Allan Womac
## STATEMENT OF ACTIVITIES

**DYSTONIA MEDICAL RESEARCH FOUNDATION | YEAR ENDING DECEMBER 31, 2019**

### REVENUES, GAINS & SUPPORT

<table>
<thead>
<tr>
<th>Description</th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>Total</th>
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<tbody>
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<td>Donations and grants</td>
<td>$ 1,612,398</td>
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<td>Bequests</td>
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<td>Special events, net of direct benefits to donors of $64,293</td>
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<td>Investment income</td>
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<td>Other</td>
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<td>Net assets released from restrictions</td>
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<td>Total Revenues, Gains and Support</td>
<td>3,261,937</td>
<td>(130,810)</td>
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### EXPENSES

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<th>Without Donor Restrictions</th>
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<td>Program services</td>
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<tr>
<td>Science</td>
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<td>$ 2,558,132</td>
<td>$ 1,589,368</td>
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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.
### STATEMENT OF FINANCIAL POSITION

**DYSTONIA MEDICAL RESEARCH FOUNDATION | YEAR ENDING DECEMBER 31, 2019**

#### ASSETS 2019

<table>
<thead>
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<th>Description</th>
<th>Amount</th>
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<td>Cash and cash equivalents including segregated</td>
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<tr>
<td>Equipment and leasehold improvements, less $26,918 of accumulated depreciation</td>
<td>15,809</td>
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<tr>
<td><strong>Total Assets</strong></td>
<td><strong>$5,351,796</strong></td>
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#### EXPENSES

<table>
<thead>
<tr>
<th>Description</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Science</td>
<td>55%</td>
</tr>
<tr>
<td>Awareness &amp; Education</td>
<td>16%</td>
</tr>
<tr>
<td>Fundraising</td>
<td>11%</td>
</tr>
<tr>
<td>Administration</td>
<td>7%</td>
</tr>
<tr>
<td>Membership &amp; Support</td>
<td>6%</td>
</tr>
<tr>
<td>Advocacy</td>
<td>5%</td>
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#### REVENUES

<table>
<thead>
<tr>
<th>Description</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Donations &amp; Grants</td>
<td>77%</td>
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<tr>
<td>Special Events</td>
<td>17%</td>
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<tr>
<td>Bequests</td>
<td>6%</td>
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#### LIABILITIES & NET ASSETS 2019

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
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</thead>
<tbody>
<tr>
<td>Grants and fellowships payable</td>
<td>$623,916</td>
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<tr>
<td>Accounts payable and accrued expenses</td>
<td>101,190</td>
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<tr>
<td>Deferred rent payable</td>
<td>111,538</td>
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<tr>
<td>Deferred revenue</td>
<td>73,700</td>
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<tr>
<td>Dystonia Coalition agency liability funds</td>
<td>293,952</td>
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<tr>
<td><strong>Total Liabilities</strong></td>
<td><strong>1,204,296</strong></td>
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<tr>
<td>Net assets without donor restrictions:</td>
<td></td>
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<tr>
<td>Undesignated</td>
<td>1,058,132</td>
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<td>Board designated for science</td>
<td>1,500,000</td>
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<tr>
<td><strong>Total net assets without donor restrictions</strong></td>
<td><strong>2,558,132</strong></td>
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<tr>
<td>Net assets with donor restrictions:</td>
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</tr>
<tr>
<td>Purpose restricted</td>
<td>1,589,368</td>
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<tr>
<td><strong>Total net assets with donor restrictions:</strong></td>
<td><strong>1,589,368</strong></td>
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<tr>
<td><strong>Total Net Assets</strong></td>
<td><strong>4,147,500</strong></td>
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<tr>
<td><strong>Total Liabilities and Net Assets</strong></td>
<td><strong>$5,351,796</strong></td>
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</table>
## Dystonia Zoo Walk Teams 2019

### $25,000 or More
- Team Ali’s ZooGooders/Bronx
- Team Allergan
- Team Merz

### $10,000 to $24,999
- Team Dystonia Muse/Bronx
- Team Flanagan/Cleveland
- Team Ipsen

### $5,000 to $9,999
- Team Braden’s Brigade/Pittsburgh
- Team Kristin/Toledo
- Team US WorldMeds

### $2,500 to $4,999
- Team A Twist of Ed/Pittsburgh
- Team Barrow Neurological Institute/Phoenix
- Team BillyMac/Twin Cities
- Team Chief Spencer/Phoenix
- Team E-Team/Portland
- Team Jester/Los Angeles
- Team Kohl’s
- Team Liam’s Unshakeable Ninjas/Pittsburgh
- Team Medtronic
- Team Mount Sinai/Bronx
- Team Movers & Shakers 2019/Twin Cities
- Team Olivia & Madison/Cincinnati
- Team Rawson/Los Angeles
- Team Sophia’s Squad/St. Louis
- Team X-Treme Apparel/Phoenix

### $1,000 to $2,499
- Team Allegheny Health Network (AHN)/Pittsburgh
- Team The Big Tall Guy/Pittsburgh
- Team Cedars-Sinai/Los Angeles
- Team Columbia/Bronx
- Team Dawn’s Angels/Philadelphia
- Team Dee/Portland
- Team Feinstein/Bronx
- Team Gestrich Dream Team/Pittsburgh
- Team Hakuna Matata Sweeney/Philadelphia
- Team Henry Ford Healers/Detroit
- Team JJ’s Jaunt/Providence
- Team Joanna/Philadelphia
- Team Kathy’s Krusaders/Twin Cities

### $500 to $999
- Team Alright Alright Alright/Detroit
- Team Annie/Philadelphia
- Team Awareness & Support/Phoenix
- Team BBVA/Los Angeles
- Team Blueberry/Phoenix
- Team Bowser Automotive/Pittsburgh
- Team Breanna’s Brigade/St. Louis
- Team Cailtyn/Philadelphia
- Team Captain Dystonia & the Movers/Pittsburgh
- Team Cardinal USA Fuel Oil/Bronx
- Team Carol’s Curesaders/Philadelphia
- Team Carson Strong/Cincinnati
- Team Cyara’s Pack/Phoenix
- Team Cyborgs/Philadelphia
- Team Daphne/Portland
- Team Debbi’s Tribe/Philadelphia
- Team Destiny’s Squad/Providene
- Team East River Energy/Bronx
- Team Eisel/Toledo
- Team Flamingo King/Philadelphia
- Team Glacier Tek/Twin Cities
- Team Hartford HealthCare/Providene
- Team Henry Ford Healers/Toledo
- Team IHG Walks for Johan/Bronx
- Team Impact HVAC/Pittsburgh
- Team Interpretations Dance Academy/Cleveland
- Team Jared’s Journey/Philadelphia
- Team Karen/Los Angeles
- Team Kayla/Cincinnati
Team McDonald's Archway/Cincinnati
Team Melton & Friends/Bronx
Team MGC Supports DMRF/Cincinnati
Team Montefiore Medical Center Dept of Neurology/Bronx
Team Newbold/St. Louis
Team NYU Langone Medical Center/Bronx
Team Omy's Team/Bronx
Team Overcomers/Los Angeles
Team R. W. Hemelgarn Foundation - 4 U MATT/Toledo
Team Rachel/Detroit
Team Reese's Pieces/St. Louis
Team Sigma Financial/Toledo
Team Stony Brook Medicine/Bronx
Team Tonya's Tribe/Cincinnati
Team Trowbridge Financial Services, Inc./Toledo
Team Twisted Troop/Twin Cities
Team Yale School of Medicine/Bronx

$250 to $499
Team DancingWithDystonia/Philadelphia
Team Agony of DeFeet/St. Louis
Team Allison Dahlstedt/Providence
Team Becky D's Superstars/Phoenix
Team Bellisario/Pittsburgh
Team DaCota Js/Los Angeles
Team DE LA VEGA/Los Angeles
Team DeAnne/Portland
Team Donna's Dream Team/Cincinnati
Team Double B/Providence
Team GS 463/Philadelphia
Team Jansen/Pittsburgh
Team Keith's Tribe/Cincinnati
Team Kinetic Kruses/Cincinnati
Team Liz's Team/Bronx
Team Maddy/Detroit
Team Maynard's Motley Crew/Providence
Team McLynn/Phoenix
Team Michelle/Providence
Team Moving With Dystonia/Los Angeles
Team Nancy/Portland
Team Nicko/Cincinnati
Team Pain in the Neck/St. Louis
Team Paula S/Providence
Team Poetry In Motion/Philadelphia
Team Rita's Roses/Philadelphia
Team Ruczynski/Philadelphia
Team Twitchy/Twin Cities
Team Vicki Glicken/Cleveland
Team VITA CORS/Los Angeles
Team Wood/Providence

$100 to $249
Team Anderson/Bronx
Team Arya's Red Hot Chili Steppers/Cincinnati
Team The Bad Struts/Pittsburgh
Team Bailey/Phoenix
Team Chicken Wing... Ain't No Thing!/Philadelphia
Team Cincinnati Children's Hospital Medical Center/Cincinnati
Team Cosplay It Forward/Pittsburgh
Team Go Team Goldman/Providence
Team Jan/St. Louis
Team Jean Abbott/Twin Cities
Team Kavin/Toledo
Team MJ/Phoenix
Team Mo/Toledo
Team MooMoo/Bronx
Team Movers and Shakers/Phoenix
Team Pat/Philadelphia
Team Rogers/Twin Cities
Team Sandy/Toledo
Team Solstice Sisters/Philadelphia
Team St. Louis Dystonia Support Group/St. Louis
Team Twisted Sister/St. Louis
Team Zooney/Cincinnati
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Musical Fundraiser
Rose and Arthur Perrin
Jacob Peterson/
Dystance4Dystonia

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Elaine Bridges
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The Concannon Family
CustomInk, LLC
Mark Daus/X-Treme Apparel
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Microsoft Giving Campaign
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<td>George Smith</td>
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Linda Smith
Linda and Douglas Smith
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On the cover:
Dystonia Coalition
Director H. A. “Buz”
Jinnah, MD, PhD, and
DMRF Board Members
Sandra Weil and Mark
Rudolph demonstrate
the many dimensions
of the Foundation.