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.

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.

“DMRF is outstanding. I know you are always there. I call if I have an issue or a question, and knowing you are working on dystonia has provided a level of support for me. It helps to know you’re not alone.”

Susan Aguilera, DMRF Legacy Society
Message from Leadership

The health and wellness of the dystonia community have always been at the heart of the DMRF mission. 2020 only reinforced this priority as we carefully considered how to manage programs during the Covid-19 pandemic while avoiding unnecessary risk. We kept focus on our absolute commitment to all who depend on and support our work. We rose to the challenge, supporting the community in staying safe and staying connected.

Covid-19 intensified circumstances that individuals and families affected by dystonia already experience on a regular basis: the uncertainty of grappling with a serious illness, the care with which we select sources of information to help make health decisions, the disappointment of missing social gatherings, financial fears, and the strain of adapting to a new normal. The pandemic has taken a hard toll on the dystonia community. We are grateful so many connected with DMRF for assistance, trusting the DMRF as the go-to organization concerned for their behalf. We mourn those in the dystonia community lost to the pandemic and extend our deepest condolences to every grieving family.

Throughout 2020, the work of the DMRF did not stop. We adapted. We made the inevitable decisions to cancel in-person events and local support group meetings, but vowed that our outreach would not diminish. We were reminded it is more important than ever to nurture relationships and connect socially, even from a physical or geographic distance. No one should have to face dystonia alone, and DMRF is committed to making sure no one does.

The push for a cure did not stop. Oddly enough, the challenges presented by Covid-19 only strengthened DMRF’s relationships with research leaders and investigators throughout the dystonia field by replacing the in-person meetings that traditionally bond research and clinical communities with more frequent communication by phone and virtual technologies. There has been no shortage of discussing, brainstorming, and planning important new projects.

DMRF could not have weathered this year without our loyal and generous community. Despite the overwhelming challenges of 2020, supporters like you stepped up to make sure the mission continues. Thank you for staying connected and supporting our work.

Art Kessler
President

Janet L. Hieshetter
Executive Director
4 research fellowships supported young dystonia investigators.

A healthy research field requires a constant influx of bright new people and ideas. DMRF provides funding opportunities at strategic stages in a young researcher’s career, designed to foster the next generation of dystonia leaders.

<table>
<thead>
<tr>
<th>Fellowship Title</th>
<th>Investigator</th>
<th>University</th>
<th>Mentor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental Regulation of eIF2alpha Pathway Activity and its Significance for DYT1 Dystonia</td>
<td>Ashley Helseth, MD, PhD</td>
<td>Duke University</td>
<td>Nicole Calakos, MD, PhD</td>
</tr>
<tr>
<td>Barbara Oliver Memorial Dystonia Research Award</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A Genetic Approach towards Identifying Torsin Function in Relation to DYT1 Dystonia</td>
<td>Anthony Rampello, PhD</td>
<td>Yale University</td>
<td>Christian Schlieker, PhD</td>
</tr>
<tr>
<td>Supported by the family of Barbara and Ron Oliver</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using the Nematode Caenorhabditis elegans to Identify Candidate Substrates for OOC-5/TorsinA</td>
<td>Gabriela Huelgas-Morales, PhD</td>
<td>University of Minnesota</td>
<td>David Greenstein, PhD</td>
</tr>
<tr>
<td>Barbara Oliver Memorial Dystonia Research Award</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact of Microglia on Abnormal Synaptic Plasticity and Development of Dystonia in Transgenic DYT1 Mouse Models</td>
<td>Lisa Rauschenberger, MD, PhD</td>
<td>University Hospital of Würzburg</td>
<td>Chi Wang Ip, MD, PhD</td>
</tr>
<tr>
<td>David M. Rudolph Dystonia Research Fund Award</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

“The DMRF has had an incredible influence on dystonia research over the years. DMRF has been a major game changer in grants funded by the National Institutes of Health and work leading to major findings in phenomenology, genetics, pathophysiology, and treatment.”

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 & DMRF Scientific Director
DMRF responded to the impact of Covid-19.

As long as individuals are diagnosed with dystonia, the DMRF will continue pushing the research forward and attending to the needs of those affected. The dystonia community struggles with access to effective treatment, social isolation, and the societal challenges so many with disabilities and chronic health conditions face on a daily basis. Covid-19 exacerbated these challenges for many.

DMRF launched an online survey to seek feedback about the impact of the pandemic. The survey asked about treatment delays, how people were feeling physically and mentally, and what DMRF programs and activities were of highest interest. The results reported widespread disruption of dystonia-related medical appointments, self-reports of worsening dystonia symptoms, self-reports of worsening mental health, and high interest in virtual DMRF programs. DMRF redoubled efforts to address these issues in our programs and activities.

2 clinical fellows received training in dystonia diagnosis and treatment.

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 outstanding clinicians who complete training have joined movement disorder programs at prestigious institutions and begun practicing in communities previously without a dystonia expert.

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

**Margi Patel, MD (2020–2021)**
Emory University
Mentors: Stuart Factor, DO & Svjetlana Miocinovic, MD, PhD
Research: Evaluating Quantitative Response and Temporal Profile of Improvement of Dystonia across Multiple Body Regions to Bilateral Deep Brain Stimulation in Isolated Non-Acquired Dystonia Patients

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

_The Clinical Fellowship Training Program was supported by grants from Merz Pharmaceuticals, The Allergan Foundation and Ipsen._
11 research investigations pursued critical scientific advancements.

DMRF-funded investigators pursued new treatment strategies, explored dystonia brain networks, targeted dystonia-causing genes, and studied the proteins encoded by these genes. Covid-19 safety precautions affected research at academic institutions around the world, in many cases temporarily suspending lab work. This includes DMRF-funded research. DMRF worked with investigators to revise research schedules and stay informed of re-openings. Fortunately, time away from the lab provided added time to analyze data collected prior to the shutdown and prepare important papers for publication.

Genetic Modifiers of Penetrance in DYT1 Dystonia
David Arkadir, MD, PhD
Hebrew University of Jerusalem
Supported by Cure Dystonia Now

Octanol Effect on Symptoms and Network Dysfunction in Myoclonus-Dystonia: An Intoxication-Free Therapy?
Cecile Gallea, PhD, Pitié-Salpêtrière Hospital
Supported by the Brown Family Foundation

Machine Learning Guided Deep Brain Stimulation to Cure Neurological Disease
Jesse Goldberg, MD, PhD, Cornell University
Supported by the Dorothy Feiss Scientific and Medical Research Fund

Unraveling Hierarchical Network Loops in Isolated Dystonia
Xin Jin, PhD
The Salk Institute for Biological Studies
Supported by Cure Dystonia Now

Using Functional Connectivity to Optimize Deep Brain Stimulation in Dystonia
Andrea Kühn, MD, Charité University Berlin
Supported by Cure Dystonia Now

The Role of Cholinergic Neurons in Isolated Focal Cervical Dystonia
Scott Norris, MD
Washington University in St. Louis

Banking of Myoclonus-Dystonia Biological Materials
Mark LeDoux, MD, PhD, University of Memphis
Supported by the Brown Family Foundation

Investigating Multimodal Neuroimaging for Probing Brain Networks in Cervical Dystonia
Richard Reilly, PhD, Trinity College Dublin
Supported by Cure Dystonia Now
“I started my laboratory in 2009, and began right out of the gate working on dystonia. To this day dystonia remains our focus. The pandemic certainly presented challenges and we had to close the lab for some time. When we re-opened we had to take into consideration public health guidelines. But we found a very good way to deal with the situation, operating in shifts and keeping social distancing, switching from in-person lab meetings to working remotely. And we learned a few things by working remotely that, even when we can return to working without restrictions, we may continue for efficiency. So that has been positive.”

Christian Schlieker, PhD, Associate Professor of Molecular Biophysics and Biochemistry and Associate Professor of Cell Biology at Yale University School of Medicine & DMRF Medical & Scientific Advisory Council Member

Cholinergic Interneuron Dysfunction in a Phenotypic Mouse Model of Dystonia
Mariangela Scarduzio, PhD
University of Alabama at Birmingham

Interregional Brain Connectivity in a Mouse Model of Cerebellar-Induced Dystonia
Roy Sillitoe, PhD
Baylor College of Medicine
Supported by Cure Dystonia Now

Identification of Neuronal Mechanisms of Agency in Myoclonus-Dystonia
Yulia Worbe, MD, PhD
Pitié-Salpêtrière Hospital
Supported by the Brown Family Foundation
Almost overnight, physicians who treat dystonia had to acclimate to telemedicine to continue to deliver good, consistent clinical care. Our patients shared our growing pains. Observation, the art movement disorder neurologists pride ourselves on, had to adapt to the limitations of a computer screen. Even telemedicine, surprisingly effective as it has been, could not help with certain aspects of care. Procedures like botulinum toxin injections and deep brain stimulation programming required us to see each other in-person. The warmth of a familiar face was replaced by personal protective equipment. Some of us were deployed to inpatient Covid-19 units or infected ourselves, and were not able to take care of our patients in clinic, which we so enjoy doing.

“The Covid-19 pandemic has changed the way we live for over a year. Most of us have suffered directly and/or along with friends or family. But we have endured. Necessity has been the mother of invention. Whether with careful in-person visits or through telemedicine, doctors and patients have strengthened their bond and established new ones. With vaccination and continued vigilance, there is a light at the end of the tunnel.”

Abhimanyu Mahajan, MD, MHS, Assistant Professor of Neurological Sciences, Section of Movement Disorders, at Rush University Medical Center & DMRF Clinical Fellow (2019-2020)
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 pro bono staff 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. In 2020 the DMRF hosted the June annual meeting, co-funded a career development grant, and partnered on development of a patient-reported outcomes smartphone app to track response to treatment.

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. More than 6,000 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. DMRF extends our deepest gratitude to donors’ families for facilitating these invaluable contributions to research.
DMRF offered virtual programs to address community concerns.

Local educational meetings were unfortunately cancelled due to Covid-19. In order to ensure continued educational outreach to patients and families, DMRF offered an expanded schedule of online webinars. The following programs were broadcast live to a total audience of 5,800 and remain available on the DMRF website and YouTube channel:

- **Dystonia & Sleep** – January 14  
  Guest: Danette C. Taylor, DO, Mercy Health Hauenstein Neurosciences

- **Dystonia Genetics & Genetic Counseling** – February 27  
  Guest: Deborah Raymond, MS, CGC, Mount Sinai Beth Israel

- **Dystonia & Covid-19: Your Questions Answered** – April 1  
  Guests: Mark Hallett, MD, National Institutes of Neurological Disorders & Stroke and Robert Chen, MA, MSc, MB BCh, MB BChir, University of Toronto  
  *Joint program with DMRF-Canada*

- **Telemedicine & Dystonia** – May 5  
  Guest: Harini Sarva, MD, Weill Cornell Medicine

- **Untangling the Complexity of Dystonia: 40 Years of Research Achievements** – May 28  
  Guest: Joel S. Perlmutter, MD, Washington University in St. Louis, DMRF Scientific Director

- **Merz Co-Pay Program** – June 2

- **Ipsen Co-Pay Program** – June 23

- **Allergan, an AbbVie Company Co-Pay Program** – July 14

- **Dystonia Educational Meeting** – October 20, 2020  
  Guests: Pravin Khemani, MD and Carter Gerard, MD, Swedish Neuroscience Institute  
  *Joint program with Swedish Neuroscience Institute*
Dystonia was included in the DOD Congressionally Directed Peer Reviewed Medical Research Program.

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 drafted 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 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 am passionate about advocacy because I come from a multi-generational family with dystonia. My father had dystonia. I have dystonia. My daughter has dystonia. It is my hope and prayer that we can wipe it out for future generations. With everyone’s help, I believe we can.”

Carole Rawson, DMRF Chair of Public Policy & Chair of Dystonia Advocacy Network

Hundreds took action to educate Congress.

The Dystonia Advocacy Network’s (DAN) Advocacy Day on Capitol Hill planned for March 24–25, 2020 in Washington, DC was cancelled due to Covid-19, but the virus did not prevent the dystonia community from reaching out to Congress and giving voice to the needs of affected individuals and families.

Hundreds of people reached out to their US Senators and US Representatives via phone and email to push the DAN legislative agenda—far exceeding the number of advocates typically able to attend in-person Dystonia Advocacy Day. DAN unites around legislative and policy issues of concern to the dystonia patient community.
2,500 Virtual Dystonia Zoo Day supporters raised awareness and funds.

Virtual Dystonia Zoo Day on September 12, 2020 was a powerful demonstration of unity. This first-ever event connected thousands of individuals from all 50 states and nine countries—an unprecedented scope for a DMRF community program. The event promoted dystonia awareness and raised funds to benefit DMRF. Among the special guests were Lolly Lardpop, a puppet performed by Emmy-nominated entertainer Leslie Carrara-Rudolph, best known for her performance of Abby Cadabby on the iconic children’s television program, Sesame Street. The program included a live zoo keeper chat with Toledo Zoo & Aquarium, research update with Medical & Scientific Advisory Council Member Christian Schlieker, PhD and DMRF Barbara Oliver Research Fellow Anthony Rampello, PhD of Yale University, children’s programming, chair yoga with Richard Sabel, MA, MPH, OTR, GCFP, and Q&A with a panel of movement disorder experts: Joanna Blackburn, MD of Northwestern Medicine, Rachel Saunders-Pullman, MD, MPH, MS of Mount Sinai, and Michele Tagliati, MD of Cedars Sinai. The program closed with a sing-a-long with Awareness Ambassador and Emmy Award-winning musician Billy McLaughlin and band. National Sponsors were Allergan, an AbbVie Company; Merz; and Ipsen Therapeutics.

Many thanks to National Planning Committee members Jacquelyn Coello, Ed Cwalinski, Beth Farber, Karen Flanagan, Shanna Schmitt, Paula Schneider, Pam Sloate, and Brian Smuda.
“When someone dear to my heart got diagnosed with dystonia I had no idea what that meant. I witnessed his journey and the more I learned the more I felt compelled to share with others how important it is to shine a light on the research. When Lolly and I participated in zoo day and got to know the community, and other families affected by dystonia, I knew I would forever be dedicated with all my heart to this foundation and make sure people know how important it is for people to know about it.”

Leslie Carrara-Rudolph, Special Guest,
Virtual Dystonia Zoo Day
Non-profit rating organizations acknowledged DMRF excellence.

DMRF earned the highest marks from Charity Navigator and Guidestar, highlighting DMRF’s commitment to fiscal responsibility and transparency.

Untangling the Complexity of Dystonia: 40 Years of Research Achievements is a 20-page report that highlights dystonia advancements attributed to the DMRF’s 40+ years of investment in research.

Cheri Tannenbaum, daughter of Founders Samuel and Frances Belzberg, publicly shared her story in numerous news outlets following release of her memoir, Woman of Few Words: My Creative Journey With Dystonia.

The Samuel Belzberg 6th International Dystonia Symposium in Dublin, Ireland was rescheduled for June 1–3, 2023.

Musicians With Dystonia was renamed The Leon Fleisher Foundation for Musicians with Dystonia to honor the late piano maestro and dystonia spokesperson who died in 2020.
Clinicians strengthened educational resources.

DMRF partnered with past Clinical Fellow Harini Sarva, MD to create the Clinical Educational Resources Committee, an advisory group of physicians to review patient education materials. DMRF educational brochures and resources are always medically reviewed, and this committee further ensures the quality of the content by inviting feedback from physicians.

The committee members are Harini Sarva, MD (Chair) of Weill Cornell Medicine, Abhimanyu Mahajan, MD, MHS of Rush University Medical Center, Christopher Groth, MD of University of Iowa, and Lindsey Neimand, MD of Caremount Medical (NY).

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. Covid-19 exacerbated these feelings for many, underscoring the need for social connection and peer support. DMRF support groups pivoted to hosting meetings via video conference, offering the opportunity to gather virtually with others who understand the challenges of living with dystonia. Virtual meetings attracted participants who had previously never attended a local meeting. Online forums continued to 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.
### STATEMENT OF ACTIVITIES

**DYSTONIA MEDICAL RESEARCH FOUNDATION | YEAR ENDING DECEMBER 31, 2020**

<table>
<thead>
<tr>
<th>REVENUES, GAINS &amp; SUPPORT</th>
<th>WITHOUT DONOR RESTRICTIONS</th>
<th>WITH DONOR RESTRICTIONS</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donations and grants</td>
<td>$1,409,297</td>
<td>$544,490</td>
<td>$1,953,787</td>
</tr>
<tr>
<td>PPP SBA grant</td>
<td>142,797</td>
<td>142,797</td>
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<tr>
<td>Bequests</td>
<td>22,052</td>
<td>22,052</td>
<td></td>
</tr>
<tr>
<td>Special events, net of direct benefits to donors of $686</td>
<td>337,484</td>
<td>337,484</td>
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<tr>
<td>Investment income</td>
<td>323,629</td>
<td>424</td>
<td>324,053</td>
</tr>
<tr>
<td>Other</td>
<td>3,779</td>
<td></td>
<td>3,779</td>
</tr>
<tr>
<td>Net assets released from restrictions</td>
<td>352,881</td>
<td>(352,881)</td>
<td>-</td>
</tr>
<tr>
<td>Total Revenues, Gains and Support</td>
<td>2,591,919</td>
<td>192,033</td>
<td>2,783,952</td>
</tr>
</tbody>
</table>

### EXPENSES

- **Program services**
  - Science: 1,199,379
  - Awareness and education: 384,641
  - Membership and support: 143,633
  - Advocacy: 83,764
  - Total program services expense: 1,811,417

- **Supporting services**
  - Administration: 189,920
  - Fundraising: 264,558
  - Total Expenses: 2,265,895

### Change in Net Assets

- 326,024
- 192,033
- 518,057

### Net assets, Beginning of Year

- 2,558,132
- 1,589,368
- 4,147,500

### Net Assets, End of Year

- $2,884,156
- $1,781,401
- $4,665,557

*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, 2020**

<table>
<thead>
<tr>
<th>ASSETS</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents including segregated Dystonia Coalition cash of $323,019 in 2020</td>
<td>$701,885</td>
</tr>
<tr>
<td>Investments</td>
<td>5,252,235</td>
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<tr>
<td>Unconditional promises to give</td>
<td>33,481</td>
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<tr>
<td>Other current assets</td>
<td>72,614</td>
</tr>
<tr>
<td>Equipment and leasehold improvements, less $29,605 of accumulated depreciation</td>
<td>11,551</td>
</tr>
<tr>
<td>Total Assets</td>
<td>$6,071,766</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>LIABILITIES &amp; NET ASSETS</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Liabilities:</strong></td>
<td></td>
</tr>
<tr>
<td>Grants and fellowships payable</td>
<td>$816,189</td>
</tr>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>66,576</td>
</tr>
<tr>
<td>Deferred rent payable</td>
<td>108,925</td>
</tr>
<tr>
<td>Deferred revenue</td>
<td>91,500</td>
</tr>
<tr>
<td>Dystonia Coalition agency liability funds</td>
<td>323,019</td>
</tr>
<tr>
<td><strong>Total Liabilities</strong></td>
<td>1,406,209</td>
</tr>
</tbody>
</table>

| **Net Assets without donor restrictions:** | |
| Undesignated | 1,384,156 |
| Board designated for science | 1,500,000 |
| **Total net assets without donor restrictions** | 2,884,156 |

| **Net assets with donor restrictions:** | |
| Purpose restricted | 1,781,401 |
| **Total net assets with donor restrictions** | 1,781,401 |
| **Total Net Assets** | 4,665,557 |

| **Total Liabilities and Net Assets** | $6,071,766 |

**REVENUES**

- Donations & Grants: 85%
- Special Events: 14%
- Bequests: 1%

**EXPENSES**

- Science: 53%
- Awareness & Education: 17%
- Fundraising: 12%
- Administration: 8%
- Advocacy: 4%
- Membership & Support: 6%
- Membership: 6%
- Support: 4%

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DMRF distributed 110,000+ copies of the Dystonia Dialogue.
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

Jean-Francois Daneault, PhD
Rutgers University

Michelle Ehrlich, MD
Mount Sinai School of Medicine

Alfonso Fasano, MD, PhD
Toronto Western

Jesse Goldberg, MD, PhD
Cornell University

Mark Hallett, MD
National Institute of Neurological Disorders & Stroke

Ellen Hess, PhD, Emory University

Niccolo Mencacci, MD, PhD
Northwestern University

Jill Ostrem, MD
University of California, San Francisco

Terence Sanger, MD, PhD
University of Southern California

Christian Schlieker, PhD
Yale University

Aasef Shaikh, MD, PhD
Case Western Reserve University

Roy Sillitoe, PhD
Baylor College of Medicine

Veronique VanderHorst, MD, PhD
Harvard University

Cynthia Comella, MD - ex officio
Rush University Medical Center/Dystonia Study Group

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

Codrin Lungu, MD, Federal Liaison

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:

Nikki Abramson
Louis Amato, Sr.
Ken Anderson
Stewart Babb
Ruth Bader Ginsburg
Sara Bakst
Basya Rochel Bas
Shmuel Hirsh obm
Jerry Bassininski
Karen Bean
David Belsky
Samuel Belzberg
Michael “Beno” Benoit
Faye Bernstein
Ernest Bersami
Karen Blacksburg
Leo E. Boisvert
Dr. Gerald Bowling
Phyllis Breit
Willie Robert Brown
Beverly Brownstein
James R. Bulmer
Ian C. Campbell
Natalie Caplin
Jane Meads Cassin
Joseph Choroser
Carrie Conroy
James Cooksey
Paula Cooper
JoAnna Craig
Mary Crompton
David Cullinane
Hal Davis
Eulilia “Nini” Del Rosario
Marcella Dayne
John Earnisse
Harriett Farber
Shari Farber-Tritt
Roslyn Feigenbaum Gold
Mark Feldman
Morty Fine
Beverly Fitzgerald
Rita Flanagan
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Marjory Jean Flynn
Rosemary Frassetto
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Pete Frates
Clare Frees
David Funt
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Robert Gay
Norman Gebeloff
Edward M. Genson
Mary Rita Geraghty
Randy Gestrich
Robert Gilbert
Vera Gilbert
Pearl Goldsands
Arlene Golebiewski
Shirley Goodno
Joyce Greenberg
Art Greenfield
Carroll Greenfield
Katharine Gugliuzzi
Patrick Gutierrez
Bruce Hainsfurther
Leon Handler
Christopher Harris
Jeff Harris
Marie Harris
Martin Hart
Robert Hart
Michael Hausauer
Gloria Heisdorf
Stuart Hess
Lillian-Leona Hietther
Mary Ann Hohenstein
Roberta Ann Hopper
Terry Horowitz
Pamela Houck
Barbara Hughes
Franklin Jones
Thom Joyce
Tammy Karen
Katherine Kaye
Mattie Kemp
Don Kessler
Miriam Kimmelman
Cynthia Kirwan
Leonard Koll
Stephanie Kopec
Paul Kovacs, III
Douglas Kramer
Florence Kramer
Gene Kramer
Seymour Krinsky
Armand Lavallee
Laura Lewis
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Helen McCulla
Vincent Paul Migliore
Joan Miller
Shoshana Munzer
Ronald Nash
Frances Newberg
Jenny Newberg
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5. Discoveries
8. Support
10. Hope
11. Awareness
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1. Fellowships
3. Movement disorders
4. Policy
6. Virtual
7. Donors
9. Grants
Horizontal
2. What the DMRF is committed to finding.
5. Dystonia investigators make these.
8. Helps individuals and families cope with dystonia.
10. The feeling of expectation and desire for a dystonia cure.
11. Public understanding of dystonia.

Vertical
1. DMRF offers these awards to fund clinical training and/or research.
3. Clinical fellows are trained to diagnose and treat these.
4. Legislative advocacy can influence this.
7. DMRF is very grateful for these.
9. Awards from DMRF to fund a research project.