



# Dystonia is a Journey

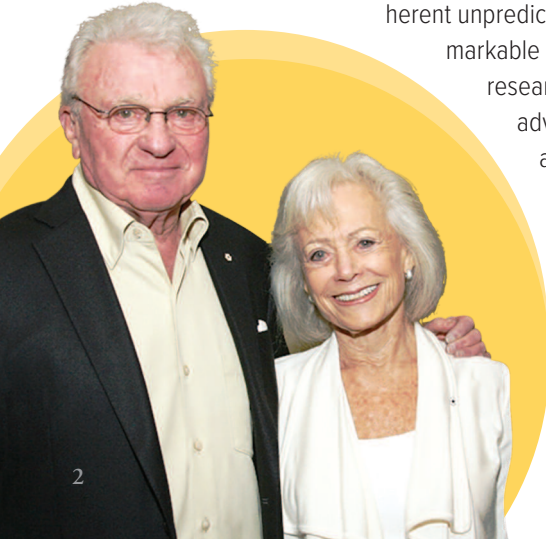


**DYSTONIA**  
MEDICAL RESEARCH FOUNDATION  
2018 ANNUAL REPORT

## Message from Leadership

Dystonia is more than a diagnosis in a medical record. It is a life-changing journey, not only for those affected but for the entire family. Your support of the Dystonia Medical Research Foundation (DMRF) ensures that no one has to face this journey alone. For nearly 45 years, DMRF has supported people through the dystonia experience while advocating on their behalf and stimulating medical research to improve lives.

The DMRF's mission to cure dystonia is also a journey. The organization has evolved dramatically since its founding in 1976. The promise to find a cure has not wavered, and we continue to transcend the many obstacles between our vision and the cure, including limitations in funding and the inherent unpredictability of science. The remarkable expansion of dystonia research and flow of medical advancements prove our approach is working, and we continue to be inspired by the constant progress.



**Sam and Fran Belberg founded the DMRF in 1976. The Foundation has since transformed the field of dystonia research and the resources available to affected individuals and families.**

We suffered a difficult loss in 2018 with the death of Co-Founder and Chairman Samuel Belberg. His wise guidance and tenacious enthusiasm for pursuing our mission are sorely missed. Yet his legacy continues. The strength of the DMRF and the undeniable impact the Foundation has had on dystonia research and patient resources is a testament to Sam's vision and the unconditional commitment he and Frances Belberg made to the dystonia community. We are grateful Fran agreed to step into the role of Honorary Chair, and the Board of Directors is as determined as ever to fulfill the promise of a cure.

Our progress in 2018 simply would not be possible without your support. Every accomplishment highlighted in this report was possible because of *you*. Thank you for being a part of the DMRF's global effort to find a cure.

Sincerely,

Art Kessler  
President

Janet L.  
Executive Director

“  
Sam’s impact on dystonia research and those affected by it was immeasurable. He literally kick-started the field of dystonia research. Through his determination to unravel this mystery, he inspired countless others to tackle it. Like so many of us, Sam never accepted defeat to dystonia. Our dystonia family lost a great crusader, but his legacy will live on and we won’t let him down.

—Art Kessler, DMRF President,  
on the passing of Co-Founder &  
Chairman Samuel Belzberg

”

## 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 awkward 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.

Each of the 20+ members of the DMRF Board of Directors is personally affected by dystonia, either diagnosed themselves or a loved one is diagnosed.



# Making great strides for dystonia research

## 15 DYSTONIA RESEARCH INVESTIGATIONS ADVANCED CUTTING EDGE SCIENTIFIC WORK.

Since 1976, DMRF has funded hundreds of research investigations, each one an investment in expanding the dystonia field and pushing closer to a cure.

In 2018, DMRF-funded investigators pursued bold new treatment strategies, explored dystonia brain chemistry, examined non-motor aspects of dystonia, and embarked on clinical studies to improve diagnosis and treatment.

### Neuroanatomical Substrates for Disrupted eIF2alpha Signaling in Dystonia

Nicole Calakos, MD, PhD  
Duke University (USA)

### Myoclonus-Dystonia, a Study of Motor and Non-Motor Symptoms: Is there a Role for Serotonin?

Marina A.J. de Koning-Tijssen, MD, PhD  
University of Groningen (The Netherlands)  
*Supported by the Brown Family Foundation*

### Machine Learning Guided Deep Brain Stimulation to Cure Neurological Disease

Jesse Goldberg, MD, PhD  
Cornell University (USA)  
*Supported by the Dorothy Feiss Scientific and Medical Research Fund*

### 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*

### Determining the Role of Torsin in Nuclear Pore Complex Assembly

Patrick Lusk, PhD, Yale University (USA)  
*Supported in part by Dystonia Medical Research Foundation Canada*

### Synaptic Plasticity in a Mouse Model of Paroxysmal Dystonia

Alexandra Nelson, MD, PhD  
University of California, San Francisco (USA)

### An International Study to Investigate the Non-Motor and Psychological Impact of Myoclonus-Dystonia

Kathryn Peall, MD  
Cardiff University (United Kingdom)  
*Supported by the Brown Family Foundation*



**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 the Estate of Jocelyn Baker*

**Dystonia-associated Endoplasmic Reticulum Defects and 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 the Brown Family Foundation*

**James C. Kilik Memorial Research Awards**

**Modulating the Functional Connectivity of the Cerebellum in Musician's Dystonia**

Robert Chen, MD, PhD  
Toronto Western Hospital

**A Study to Identify Kinematic and Force Measures Capturing Impairment in Musician's Dystonia among String Players and Improvement with Retraining Therapy**

Christine Kim, MD  
Columbia University

**Dystonia is one of the network disorders, and I'm trying to understand how different nodes of the network talk to each other and how we can modulate the network in a counter-intuitive way. If something is broken, we don't focus on what is broken. We make up for what is broken with something that is working.**

*—Aasef Shaikh, MD, PhD,  
DMRF Grant Recipient & Past Clinical Fellow*

## 4 YOUNG DYSTONIA INVESTIGATORS RECEIVED RESEARCH FELLOWSHIPS.

Dystonia research requires a constant flow of new people and new ideas.

DMRF provides funding opportunities for young investigators, at strategic stages in a research career, designed to help foster the next generation of dystonia innovators.



**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  
Mentor: David Greenstein, PhD

**CRISPR/Cas9 System Targeting Specific DYT1 Allele Mutation in Patient Induced Pluripotent Stem Cells (iPSCs): A Strategy for Phenotype Reversion in iPSCs-Derived Neurons**

Lilian Cruz, PhD  
Massachusetts General Hospital (USA)  
Mentors: Xandra Breakefield, PhD  
& Cris Bragg, PhD

**Role of the X-linked Dystonia Parkinsonism (XDP) Causative Gene TAF1 in the Striatal Development and Maintenance**

Maria Daniela Cirnaru, PhD  
Mount Sinai Beth Israel (USA)  
Mentor: Michelle Ehrlich, MD

**A Genetic Approach towards Identifying Torsin Function in Relation to DYT1 Dystonia**

Anthony Rampello, PhD, Yale University  
Mentor: Christian Schlieker, PhD  
*Supported by the family of Barbara and Ron Oliver.*

Mahlon DeLong Young Investigator Award recipient Aloysius Domingo, MD was invited to present at the annual Medical & Scientific Advisory Council meeting. Pictured with MSAC Member Kristina Simonyan, MD, PhD, Dr. med.

## DMRF LEADERSHIP MET WITH NINDS TO IDENTIFY OPPORTUNITIES FOR DYSTONIA RESEARCH.



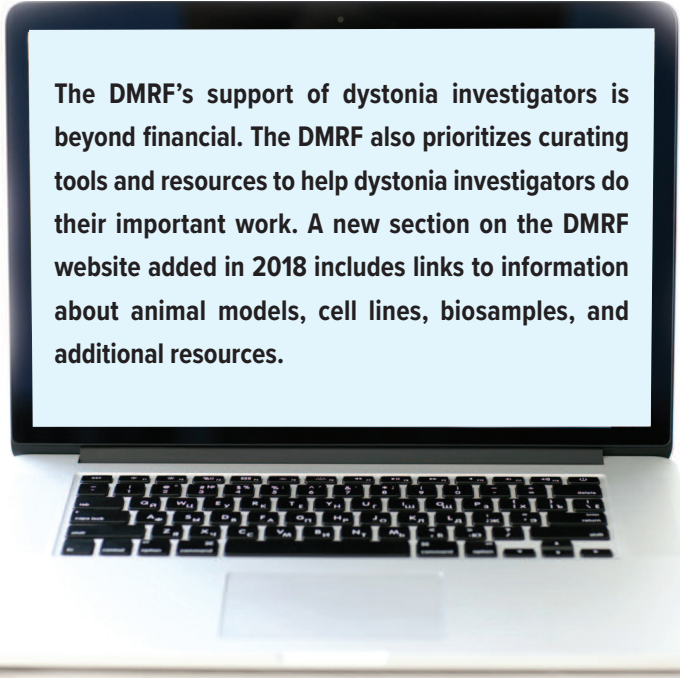
National Institute of  
Neurological Disorders  
and Stroke

“Defining Emergent Opportunities in Dystonia Research” was the title of a meeting organized by

the National Institute of Neurological Disorders & Stroke (NINDS), October 29–30, 2018, in Bethesda, Maryland. The meeting convened world renowned dystonia experts and brought increased visibility of dystonia to a critical federal medical research agency. Director of NINDS, Walter J. Koroshetz, MD, opened the meeting which was co-chaired by Laurie Ozelius, PhD of Harvard Medical School and David G. Standaert, MD, PhD of University of Alabama at Birmingham. DMRF Chief Scientific Advisor Jan Teller, MA, PhD was among the presenters.

The program agenda included a detailed review of advancements in dystonia research and discussion of future research priorities.

## A NEW SECTION OF THE DMRF WEBSITE CENTRALIZED RESOURCES FOR INVESTIGATORS.

A photograph of a silver laptop with a black keyboard, viewed from a slightly elevated angle. The laptop screen is the central focus, displaying a light blue background with black text. The text on the screen reads: "The DMRF's support of dystonia investigators is beyond financial. The DMRF also prioritizes curating tools and resources to help dystonia investigators do their important work. A new section on the DMRF website added in 2018 includes links to information about animal models, cell lines, biosamples, and additional resources." The laptop is positioned in the lower right quadrant of the page, with a thin orange line extending from the top right corner of the page down to the top of the laptop's screen area.

**The DMRF's support of dystonia investigators is beyond financial. The DMRF also prioritizes curating tools and resources to help dystonia investigators do their important work. A new section on the DMRF website added in 2018 includes links to information about animal models, cell lines, biosamples, and additional resources.**

## 5 CLINICAL FELLOWS RECEIVED EXPERT TRAINING TO QUICKEN DYSTONIA DIAGNOSIS AND TREATMENT.

Evaluation by a movement disorder specialist can have a dramatic impact on quickening dystonia diagnosis time, increasing treatment options, and maximizing outcomes from treatment. Many patients throughout the country must travel significant distance and/or endure long waits for appointment openings to access a physician with the necessary 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 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.

*The Clinical Fellowship Program was funded by grants from the Allergan Foundation and Merz Pharmaceuticals.*

### CLINICAL FELLOWS AND MENTORS ACTIVE IN 2018 INCLUDED:

- **Noreen Bukhari-Parlakturk, MD, PhD** – Duke University (2018–2019)  
Mentor: Nicole Calakos, MD, PhD  
Research: Using transcranial magnetic stimulation (TMS) in patients with writer’s cramp (focal hand dystonia) to reduce dystonic movements.
- **Avram Frait, MD** – Rush University Medical Center (2017–2018)  
Mentor: Cynthia Comella, MD  
Research: Feasibility, reliability, and satisfaction of post-botulinum toxin injection telemedicine assessment in patients with cervical dystonia.
- **Christopher Groth, MD** – University of Colorado Denver (2017–2018)  
Mentor: Brian Berman, MD, MS  
Research: Exploring possible correlation between reduced GABA receptor availability in global pallidus and susceptibility to developing cervical dystonia.
- **Shabbir Merchant, MD** – National Institute of Neurological Disorders & Stroke (2017–2018)  
Mentor: Mark Hallett, MD  
Research: Investigating frequency of anxiety and depression in dopa-responsive dystonia.
- **Lindsey Neimand** – Icahn School of Medicine at Mount Sinai (2017–2018)  
Mentor: Rachel Saunders-Pullman, MD, MPH, MS  
Research: Exploring differences in the pathophysiology of dystonia associated with complex regional pain syndrome compared to organic focal hand dystonia.



“

I was fortunate to find a movement disorder specialist through DMRF. Thank you so much. If it wasn't for the Foundation I would be stuck using a pain clinic with very little knowledge of dystonia.

—Jason Padden,  
DMRF Supporter

”

Drs. Christian Schlieker, David Peterson, and Roy Sillitoe were among the guest presenters at the 2018 Medical & Scientific Advisory Council meeting.

## INVESTIGATORS HAD ACCESS TO DATA AND SAMPLES FOR NEW STUDIES.

The Global Dystonia Registry is a community-based research initiative that depends on the DMRF for operational and administrative management. The Global Dystonia Registry supports future dystonia studies, including clinical and research trials, through the voluntary collection of patient data. To date, more than 5,300 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. Three brains were successfully recovered in 2018. DMRF is deeply grateful to the donors' families for facilitating these invaluable contributions to research.



## EXPERTS FROM ACROSS THE GLOBE GATHERED FOR SCIENTIFIC MEETINGS.

With support from the Brown Family Foundation, the 4th DMRF Myoclonus-Dystonia Workshop took place September 27–28, 2018 in Paris. The meeting was chaired by Marina de Koning-Tijssen, MD, PhD of University Medical Center Groningen (The Netherlands) and Marie Vidailhet, MD, PhD of Salpêtrière Hospital (France). An international cohort of experts presented the latest myoclonus-dystonia research and brainstormed next steps to accelerate research progress.

DMRF organized a workshop entitled “Targeted Drug Discovery for Dystonia,” November 8-9, 2019 in Chicago. Meeting participants included seasoned dystonia investigators and non-dystonia experts experienced in protein-based drug discovery. The workshop was co-chaired by Christian Schlieker, PhD of Yale School of Medicine and Thomas Schwartz, PhD of Massachusetts Institute of Technology. The goal of the meeting was to summarize and discuss recent efforts to identify drug targets for dystonia.

The Joan Miller Young Investigator Scholarship Award supported up-and-coming dystonia researchers by providing travel stipends to attend DMRF workshops and meetings. Participation in these workshops and meetings is particularly important for young researchers because they provide opportunities to present their work to expert audiences and develop useful connections with thought-leaders in the field.

Research grants awarded by the Foundation along with its dedication to raising public awareness make me truly hopeful that finding a cure for all forms of dystonia is possible.

—Ed Gewirtz, DMRF Supporter





## THE DYSTONIA COALITION RECEIVED FREE STAFF AND ADMINISTRATIVE SUPPORT.



**DYSTONIA  
COALITION**

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 DMRF plays an integral role by providing free logistical and planning support for the Coalition as an administrative center, for example managing payments to clinical sites and supporting the renewal grant to the NIH. This has saved the Dystonia Coalition \$1.5 million in indirect costs, maximizing funds invested in research.

## Increasing awareness & advocacy



### THE DYSTONIA ADVOCACY NETWORK MADE 150 VISITS TO MEMBERS OF CONGRESS TO EDUCATE THEM ABOUT DYSTONIA.

On March 19–20, 2018, 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 Congressionally Directed Medical Research Programs and to provide the National Institutes of Health with ample funds for the 2019 fiscal year. The DAN also collaborated with like-minded organizations to ensure pre-existing condition protections are not eliminated from federal healthcare policies. The DMRF continued to provide staff support in 2018 to ensure the DAN implemented and achieved the legislative agenda.



The Douglas Kramer Young Advocate Award recognizes young people who are giving voice to dystonia through advocacy. Recipients in 2018 were Rachael Mathews, Sophia Taylor, and Melissa Rentfrow. Special thanks to the Kramer Family for generously supporting this award.

“The time I spent with the Dystonia Advocacy Network was a tremendous turning point for me. Being with other people who had been through similar experiences made me feel like I wasn't alone anymore.”

—Mike Cahall, DMRF Supporter & DAN Advocate



## **DYSTONIA WAS INCLUDED IN THE DOD CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAMS.**

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 Medical Research Programs (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 \$14 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.

**DAN advocates presented Senator Susan Collins with a Distinguished Public Service Award to recognize her support of the dystonia community.**



## TEAM DMRF RAISED AWARENESS AT THE TCS NYC MARATHON.

In honor of those struggling with dystonia, Team DMRF has competed in the world famous TCS New York City Marathon since 2013, literally running for those who can't. In 2018, Team DMRF included Amy Amendola, Heather Barskaya, Ginny Bryan, Jaime Dimitri, Larry Dubill, Stephen Gebeloff, Jim Metherell, Marissa Rozenfeld, Carrie Siu Butt, and Carole Tordi. Dozens of supporters gathered on the sidelines to cheer them on.



I would never run for any organization except for the DMRF. The research they fund changes lives, including mine and my sister's. This organization changed my life!

*Carrie Siu Butt, Team DMRF,  
TCS NYC Marathon*

# Empowering patients with information & support

**50,000+**  
**PEOPLE RECEIVED**  
**INFORMATION & RESOURCES.**

The DMRF is here for you when dystonia turns life upside down. Every member of the DMRF's Board of Directors is navigating the dystonia journey, either themselves or beside a loved one. We are reminded every day of the urgency of our work because we see and feel the impact of dystonia in our own lives. We are all on this journey together.

## **50+ SUPPORT GROUPS AND MODERATED ONLINE FORUMS REDUCED ISOLATION AND INCREASED SOCIAL CONNECTION.**

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.

Support groups provide a space for those of us with dystonia to share our stories and struggles in a safe and accepting environment. We feel less alone and more understood. We become better informed about our treatment choices and walk away with useful information to support us in our journey with dystonia.

—Alli Feeley, Founder & Leader of Greater Chicagoland Dystonia Support Group





The Central Indiana Dystonia Support Group held its first meeting in 2018.



## DMRF PROVIDED THOUSANDS OF FREE EDUCATIONAL MATERIALS TO PEOPLE SEEKING INFORMATION, RESOURCES, AND REASSURANCE.

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 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.



## 8 EDUCATIONAL MEETINGS PROVIDED THE LATEST INFORMATION FROM TOP EXPERTS.

Hurried medical appointments in which physicians have limited time with patients are not a conducive space for in-depth learning about dystonia and the latest clinical advancements. DMRF creates opportunities for individuals to interact with expert 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 meeting across the country. These meetings also provide opportunities for peer support and social connection. Locations included: Albuquerque, Boston, Chicago, Cleveland, Gig Harbor (Washington), Los Angeles, Phoenix, and St Louis. Allergan provided a generous educational grant in support of the meetings.

## 20+ community events

### PATIENTS, FAMILIES, AND HEALTHCARE INSTITUTIONS UNITED IN THE MISSION TO FIND A CURE.

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.

Among DMRF's most popular community programs are Dystonia Zoo Walks, family-friendly events to raise awareness and support DMRF. Thirteen Zoo Walks attracted more than 5,000 participants in 2018. Locations included: Bronx/New York City, Detroit, Cleveland, Cincinnati, Fresno, Philadelphia, Phoenix, Pittsburgh, Portland (Oregon), Providence (Rhode Island), St Louis, San Diego, and Twin Cities.

(L to R) Allison Hersh London and June Hersh led “Ali’s Zoo-Gooders” at the Bronx Zoo Walk. US Congressman Dwight Evans is pictured with organizers of the Philadelphia Zoo Walk. Team BillyMac participated at the Twin Cities Zoo Walk. Scotty Tritley made a new friend in St. Louis. The Young Family traveled to Cleveland to support Karen Flanagan and her event. Ed Cwalinski and MaryRae Nee were recognized at the Pittsburgh Zoo Walk. Mary Stone lead team “Rolling Stones” in Phoenix. The Baron Family is pictured at the Providence Zoo Walk.







## Board of Directors

Samuel Belzberg  
*(1928–2018) Co-Founder*

Frances Belzberg  
*Honorary Chairperson & Co-Founder*

Stanley Fahn, MD  
*Lifetime Honorary Director*

Art Kessler  
*President*

Richard A. Lewis, MD  
*Vice President of Science*

Barbara Kessler  
*Vice President of Awareness  
& Education*

Karen K. Ross, PhD  
*Vice President of Support*

Rosalie Lewis  
*Vice President of Public Policy*

Dennis Kessler  
*Vice President of Development*

Sandra Weil, *Network Liaison*

Mark Rudolph, *Treasurer*

Jon Davis, *Director*

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Donna Driscoll, *Director*

Nancy Harris, *Director*

Marilynne Herbert, *Director*

Ronald Hersh, *Director*

Erwin Jackson, PhD, *Director*

Stefanie Jackson, *Director*

Carole Rawson, *Director*

Liz Rawson, *Director*

Diane Rudolph, *Director*

Paula Schneider, *Director*

Pamela Sloate, JD, *Director*

Mahlon R. DeLong, MD  
*Scientific Director, ex officio*

Billy McLaughlin  
*Awareness Ambassador, ex officio*

Janet Hieshetter  
*Executive Director, ex officio*

## 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*

## Dystonia Dialogue Editorial Board

Barbara Kessler, *Chair*

Paul Kavanaugh

Diane Rudolph

Elizabeth Schultz

Ed Cwalinski

Dee Linde

Paula Schneider

Todd Spotti



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



The DMRF has been a wonderful community of families who have walked the path. We followed those who went before us, and now there are people following us. We pay it forward through the DMRF.

—Diane Rudolph,  
DMRF Board of Directors



### *Medical & Scientific Advisory Council*

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

Jesse Goldberg, MD, PhD  
*Cornell University*

Mark Hallett, MD  
*National Institute of Neurological  
Disorders & Stroke*

Charles Harata, MD, PhD  
*University of Iowa*

Jill Ostrem, MD  
*University of California, San Francisco*

Coro Paisán-Ruiz, PhD  
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*Harvard Medical School*

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*Washington University School  
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Christian Schlieker, PhD  
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Thomas Schwartz, PhD  
*Massachusetts Institute of Technology*

Kristina Simonyan, MD, PhD  
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Yoland Smith, PhD  
*Emory University*

Peter Strick, PhD  
*University of Pittsburgh*

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

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

Beth-Anne Sieber, PhD  
*Federal Liaison*

### *Community Leadership Council*

Ginny Bryan

Karen A. Flanagan

Melissa Phelps

Beth S. Farber

James A. Metherell

Rosemary Young

# Statement of Activities

DYSTONIA MEDICAL RESEARCH FOUNDATION | YEAR ENDING DECEMBER 31, 2018

	Without Donor Restrictions	With Donor Restrictions	Total
Revenues, Gains and Support			
Donations and grants	\$ 1,549,619	\$ 359,478	\$ 1,909,097
Bequests	10,000		10,000
Special events, net of direct benefits to donors of \$68,163	466,881		466,881
Investment income	(193,320)	195	(193,125)
Other	4,834		4,834
Net assets released from restrictions	302,302	(302,302)	-
Total Revenues, Gains and Support	<u>2,140,316</u>	<u>57,371</u>	<u>2,197,687</u>
Expenses			
Program services expense -			
Science	1,534,744		1,534,744
Awareness and education	419,167		419,167
Membership and support	190,386		190,386
Advocacy	122,586		122,586
Total program services expense	<u>2,266,883</u>		<u>2,266,883</u>
Supporting services expense -			
Administration	174,785		174,785
Fundraising	299,679		299,679
Total Expenses	<u>2,741,347</u>		<u>2,741,347</u>
Change in Net Assets	(601,031)	57,371	(543,660)
Net assets, Beginning of Year	2,555,579	1,662,807	4,218,386
Net Assets, End of Year	<u>\$ 1,954,548</u>	<u>\$ 1,720,178</u>	<u>\$ 3,674,726</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.

# Statement of Financial Position

DYSTONIA MEDICAL RESEARCH FOUNDATION | YEAR ENDING DECEMBER 31, 2018

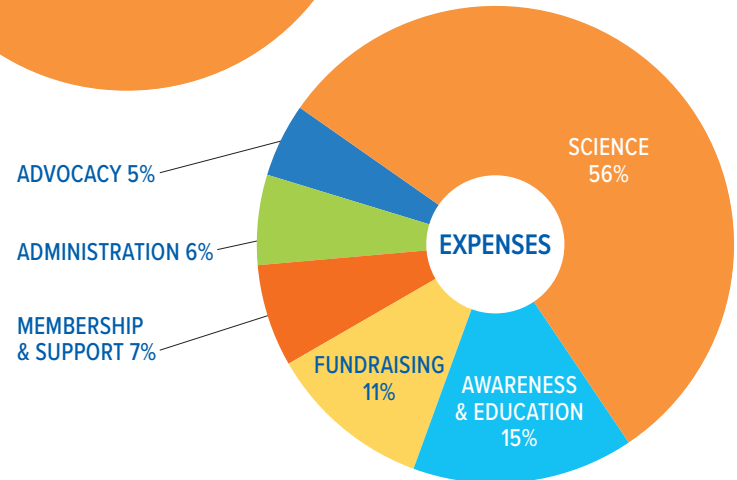
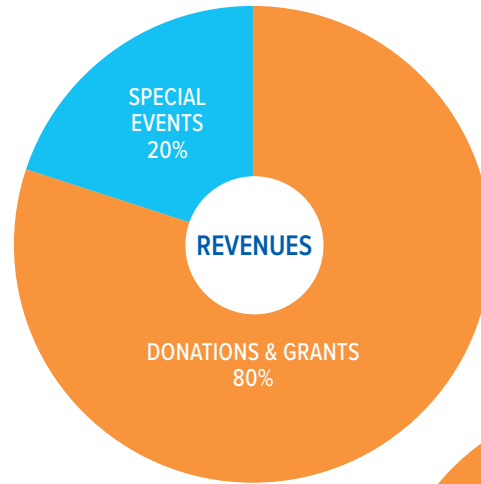
Cash and cash equivalents including segregated Dystonia Coalition cash of \$198,578 in 2018	\$ 743,578
Investments	3,796,524
Unconditional promises to give	90,286
Other current assets	20,526
Equipment and leasehold improvements, less \$38,973 of accumulated depreciation	11,547
<b>Total Assets</b>	<b>\$ 4,662,461</b>

## LIABILITIES

Grants and fellowships payable	\$ 558,947
Accounts payable and accrued expenses	115,691
Deferred rent payable	114,519
Dystonia Coalition agency liability funds	198,578
<b>Total Liabilities</b>	<b>987,735</b>

Net assets without donor restrictions:	
Undesignated	454,548
Board designated for science	1,500,000
Total net assets without donor restrictions	1,954,548
Net assets with donor restrictions:	
Purpose restricted	1,720,178
Total net assets with donor restrictions:	1,720,178
<b>Total Net Assets</b>	<b>3,674,726</b>

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# *In memoriam*

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Jacqueline Taylor  
Team Anna's Bananas/  
Cincinnati Dystonia Zoo Walk

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Team Champion/Fresno Dystonia Zoo Walk	Team Movers & Shakers/Phoenix Dystonia Zoo Day	Marie Torres Perez	James Wagner	Katherine Bryan White and Justin White	Alana Zinn and Jeremy Beyda
Team Cincinnati Children's Hospital Medical Center/Cincinnati Dystonia Zoo Walk	Team Moving Disorderly/Twin Cities Dystonia Zoo Walk	Barbara and Thomas Trager	Annette Waite	Courtney and Kay Whitlock	Sara Beth Zivitz
Team Cornell/Bronx Dystonia Zoo Walk	Team Muck Family/Pittsburgh Dystonia Zoo Walk	Mollie and Ken Traub	Joanne and Samuel Walker	Catherine Wieland	Katie Zlotnick
Team Cris/Fresno Dystonia Zoo Walk	Cities Dystonia Zoo Walk	Carol and Clifford Trenton	Emily Walker-Robbins	Shirley Wilkinson	Marie Zuidema
Team Dave's Co-Pilots/St. Louis Dystonia Zoo Walk	Team Muck Family/Pittsburgh Dystonia Zoo Walk	Shirley Trettenbach	Emily Walker-Robbins/C.O. Pigs in Space BBQ	Monika Willging	Bonita and Michael Zurek
Team Dinos for Dystonia: Making Dystonia Extinct Phoenix Dystonia Zoo Day	Team Penn/Philadelphia Dystonia Zoo Walk	June Tritley	Team Ladies	Brian and James Williston	
Team Dys-won't-ia/San Diego Dystonia Zoo Day	Team Reno/Providence Dystonia Zoo Walk	Anita Ann Trudell	Lisa Walter	Lesley and Raleigh Willson	
Team Extreme Attitude/Pittsburgh Dystonia Zoo Walk	Team Rick and Friends/Pittsburgh Dystonia Zoo Walk	Natalie Trunzo	Eileen and James Warburton	Mary Ann Wilson	
Team Hope for a Cure/Twin Cities Dystonia Zoo Walk	Team Seismic Activity/Twin Cities Dystonia Zoo Walk	Jane Tucker	Linda Warren	Zulma and Jake Wilson	
Team Jefferson/Philadelphia Dystonia Zoo Walk	Team Southwest Synapse	Tuesday at Ten Bible Study	Irvina and Sherwyn Warren	Charles Wilster	
Team Jens walkers 4 hope/Cincinnati Dystonia Zoo Walk	American Association of Neuroscience Nurses/Phoenix Dystonia Zoo Day	Karen and John Tuozzolo	Barbara Warrick	Alice Wiltshire	
Team Kayla/Cincinnati Dystonia Zoo Walk	Team Tall Drinks of Water/Phoenix Dystonia Zoo Day	Wendy and Jeffrey Turk	Elizabeth Watson	Lesley Winslow	
Team Laurie's Luck/Bronx Dystonia Zoo Walk	Team TD4Life/Bronx Dystonia Zoo Walk	Anthony Turner	Louanne Watson	Rick Winslow	
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Team Missy's Keep Your Eye On The Prize/Detroit Dystonia Zoo Walk	Team UMN Nerds/Twin Cities Dystonia Zoo Walk	Carol and Douglas Twedt	Elizabeth Webb	Jill Fink and Jerry Wise	
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*Pictured on the cover:  
US Congresswoman  
Jan Schakowsky and Mike  
Caball, the Sorley Family,  
Ginny Bryan, Marilynne  
Herbert and Mayor Esther  
Manheimer, and Aasef  
Shaikh MD, PhD.*

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