Dear Friends,

The story behind the establishment of the DMRF remains very much at the heart of what we do. Almost 40 years ago, Sam and Fran Belzberg finally had a diagnosis for their daughter but quickly realized it was just the beginning of what was required of them to help her. Few physicians at the time had the knowledge to recognize dystonia, let alone offer treatment. There was nowhere to go for peer support. The Belzbergs vowed to do whatever it took, for however long, to get researchers interested in studying dystonia and to create support resources for all affected individuals and families. Few forces in nature are stronger than the instinct of a parent to protect a child, and this passion permeates everything the DMRF represents to this day.

2014 was a remarkable year for the growing visibility of dystonia. The Dystonia Moves Me campaign mobilized hundreds of volunteers across the country to educate tens of thousands of people about dystonia by sharing their powerful personal stories. Critical dystonia research discoveries supported by the DMRF were published in high-impact journals and created a buzz in the scientific community. Devin McClernan's documentary film Dystonia Devin won the Grand Prize at the annual American Academy of Neurology Neuro Film Festival and premiered to an audience of 5,000 neurologists. The DMRF's letter to the editor in The New Yorker, which has an average circulation of over one million readers, was one among dozens of media successes in national, local, and online markets.

The DMRF is grateful to each of you for supporting the Foundation. We hope you take pride in the many accomplishments described in this report. We do not take the responsibility of your trust lightly and are privileged by your belief in our mission.

The DMRF funds cutting edge research, advocates for the needs of the dystonia community, stimulates public awareness, and provides support resources for individuals and families affected by all forms of dystonia. This has been the commitment from day one, and the DMRF will work tirelessly until there is no longer a need. Your support ensures that our progress continues.

Sincerely,

Art Kessler  
President

Janet L. Hieshetter  
Executive Director
Volunteers promoted awareness throughout the country and beyond by participating in Dystonia Moves Me.

DMRF-funded investigators developed a mouse model of DYT1 dystonia that mimics the human disorder.

Several teams of DMRF-funded researchers published discoveries that are critical to better understanding the role of the cell protein TorsinA in dystonia.

BiP was identified as the first known TorsinA chaperone protein by DMRF-funded investigators.

DMRF organized two scientific workshops, Receptor Neuropharmacology in Dystonia and Integrative Approaches to Dystonia, each of which resulted in a request for research proposals.

Research investigations funded in 2014 represented topics as diverse as gene silencing, examining proteins associated with newly discovered dystonia genes, seeking additional dystonia genes, receptor neuropharmacology, and developing assays to test potential drug targets identified through previous DMRF-funded efforts.

Educational events were held throughout the country in partnership with local volunteers. Educational webinars were made available online.

Support groups and online forums provided a lifeline to affected individuals and families.

The Clinical Fellowship Training Program accepted three outstanding second year fellow physicians.

DMRF applauds Scientific Director Mahlon DeLong, MD for earning the 2014 Breakthrough Prize in Life Sciences and 2014 Lasker-DeBakey Clinical Medical Research Award.

A team of runners representing the DMRF and the DMRF Central Jersey Dystonia Support & Action Group competed in the TCS New York City Marathon.

Thanks to generous support from the Kramer family, the DMRF named four Douglas Kramer Young Advocate Awards.

Dystonia investigators were awarded funds through the Department of Defense Congressionally Directed, Peer Reviewed Medical Research Program thanks to the efforts of Dystonia Advocacy Network volunteers to ensure dystonia continues to be among the conditions eligible for study.

Charity Navigator, America’s largest and most popular independent evaluator of charities, awarded the DMRF the prestigious 4-out-of-4 star rating for good governance, sound fiscal management, and commitment to accountability and transparency. Only one quarter of the charities received the highest rating, indicating that the DMRF outperforms many other charities in America.
Dystonia is a movement disorder, and it also moves people to action. During Dystonia Awareness Month, volunteers used their stories to increase public awareness through the Dystonia Moves Me campaign. Dystonia Moves Me encouraged volunteers to share how the disorder impacts their lives with the people they encounter on a regular basis: neighbors, colleagues, acquaintances. The goal was to help the public put a face to the word “dystonia.” The challenge was to educate 30 new people about dystonia during the 30 days of September. Many volunteers far surpassed the challenge, expanding the reach of the campaign further than anticipated.

Volunteers reported back to the DMRF with photos and videos detailing their awareness adventures. Some gestures were grand, others more understated—all were effective. Tricia Bono of Connecticut, whose teenage daughter Sullivan has dystonia, partnered with her employer East River Energy to emblazon one of their fuel trucks with the Dystonia Moves Me emblem. The very first person Sullivan reached during the campaign was Hillary Clinton, former United States Secretary of State, Senator, and First Lady, whom Sullivan met at a book signing. Jason Dunn took a moment to educate Detroit Lions kicker Nate Freeze about dystonia during a pre-season practice. Dee Linde and Valentino Ramirez Lopez informed the server (in Spanish, no less) at a favorite neighborhood restaurant in Oregon. Other volunteers educated their hair stylists, store clerks, bowling league buddies, choir members, family members, and more.

Public figures lent their support including Congresswoman Jan Schakowsky, Georgia Governor Nathan Deal, guitar great Tommy Emmanuel, WGN news anchor Mark Suppelsa, and MasterChef cast member Jaimee Vitolo. Major League Baseball and the Chicago Cubs partnered with the DMRF to host Dystonia Day at Wrigley Field.

The DMRF distributed over 500 Dystonia Moves Me awareness kits. The campaign reached tens of thousands of people who learned about dystonia for the first time or gained a better understanding of the disorder.

“I believe in the mission of the DMRF. Awareness is so important. Supporting the needs of affected individuals and their families is essential—and most importantly, continued research is needed for treatments and discovering a cure.”

—Karen Flanagan and family hosted the 3rd Annual Dystance4Dystonia Zoo Walk in 2014. The inaugural event three years ago provided a model that has been replicated in communities across the country. Karen is diagnosed with rapid-onset dystonia-parkinsonism.
**Research Highlight**

**Chipping Away at the Mystery of TorsinA**

When DMRF-funded investigators discovered the DYT1 gene responsible for childhood onset torsion dystonia in 1997 it was a pivotal moment for the field and precipitated a wave of progress that continues to this day. The discovery initiated one of the biggest mysteries in the field: The DYT1 gene encodes the protein TorsinA, which had never been seen before. It was an unusual protein and no one knew the function it served. Since that time, researchers have begun putting the pieces together. Although questions remain as to its exact function, several recent discoveries have shed important light on this important protein:

**Researchers Reveal Details of TorsinA Structure and Function:**
A study led by DMRF grant recipient Thomas Schwartz, PhD provided insights into the function of TorsinA by using specialized techniques to analyze its structure and relationships with other proteins. Proteins interact by binding, so clarifying the structure of TorsinA is critical to uncovering the other proteins with which it can interact. By understanding TorsinA’s interactions, researchers begin to piece together its function. TorsinA belongs to a family of ATPase proteins which help cells generate the energy needed to accomplish the many processes and activities within the cell. Previous studies have shown that TorsinA has a relationship with two proteins, LAP1 and LULL1, but the nature of their interactions required clarification.

Researchers at Massachusetts Institute of Technology revealed that LAP1 and LULL1 activate TorsinA. The data show that a mutation in LAP1 reduces its ability to interact with TorsinA. This work is helping to uncover the biochemical chain reaction of how TorsinA causes dystonia.

**TorsinA Variants Play a Role in Dystonia Development:**
An international team of researchers revealed that variants of the human protein TorsinA may be implicated in the development of dystonia. Childhood onset torsion dystonia occurs when a mutation in the DYT1 gene makes TorsinA shorter by one amino acid. As a result, the mutated TorsinA functions abnormally. While the causative role of this particular mutation has been well established, human variants of TorsinA have been discovered and it was initially unclear whether these variants contribute to disease.

Through a series of sophisticated analyses comparing biochemical and cellular effects of normal and variant TorsinA proteins, DMRF-funded researchers led by Flávia Nery, PhD revealed that these new variants are strikingly similar in their properties to the previously known TorsinA mutant. These findings provide functional evidence that these rare mutations in the DYT1 gene may directly contribute to the development of dystonia. The approach developed in this study provides new methods to assess the role of rare TorsinA variants and may lead to validation of novel therapies.


“I hope that by people understanding dystonia, they can better understand me and others with disabilities. And that they will donate to research for a cure. I spread awareness so that other people don’t go through what I had to go through.”

—Thirteen year old Sullivan Bono began experiencing dystonia symptoms at age seven. The very first person she reached as part of Dystonia Moves Me was Hillary Clinton.
DMRF Leaders Recognized for Excellence

DMRF Co-Founder and Chairman Sam Belzberg was honored by Weizmann Canada during its 50th anniversary gala dedicated to recognizing Canadian men who exemplify philanthropy and success.

Sam Belzberg is a real estate developer, philanthropist, and financier. He and wife Fran founded the DMRF in 1976 shortly after their daughter was diagnosed. For 40 years Sam has remained steadfastly dedicated to the Foundation and the dystonia community. In 2001 Sam founded Action Canada, an institution that partners with the Government of Canada to endow 20 fellowships a year for individuals who are making a positive difference in Canada.

DMRF Scientific Director Mahlon DeLong, MD, William Timmie Professor of Neurology at Emory University School of Medicine, was one of six recipients of the 2014 Breakthrough Prize in Life Sciences. Dr. DeLong was recognized for defining and characterizing the circuits in the brain that malfunction in Parkinson’s disease; these same circuits are abnormal in dystonia.

Dr. Delong also earned the 2014 Lasker-DeBakey Clinical Medical Research Award. Dr. DeLong shares this award with Dr. Alim Louis Benabid of Université Joseph Fourier in Grenoble, France for their roles in developing deep brain stimulation of the subthalamic nucleus.

Scientific Workshops are Engines for Progress

The DMRF continued to host scientific workshops on the most pressing topics in the field, and each workshop in 2014 resulted in a request for relevant research proposals. *Receptor Neuropharmacology in Dystonia* took place February 27-28, 2014 in Miami. Chaired by Jonathan Brotchie, PhD of Toronto Western Research Institute and P. Jeffrey Conn, PhD of the Vanderbilt Center for Neuroscience Drug Discovery, the meeting brought together leaders from academia, industry, and the National Institutes of Health to discuss current trends in receptor neuropharmacology in dystonia and related movement disorders. In the wake of the meeting, the DMRF released a request for proposals and funding began in the summer. Receptors are an important topic in dystonia research because they are convenient targets for drug development. (Receptors are the gatekeeper proteins that control how neurons receive signals from one another.) The workshop was part of the DMRF’s efforts toward drug discovery and development, running parallel to efforts to identify existing therapies that are applicable to dystonia.

*Integrative Approaches to Dystonia*, took place October 30–31, 2014 in Chicago. Chaired by Joel Perlmutter, MD of Washington University of Medicine and Jan Teller, PhD of the DMRF, this meeting addressed integrative and systems-level approaches to dystonia relevant to recent progress and research perspectives in brain imaging, genetics and functional studies. The meeting covered systems-level neurophysiology, novel functional imaging techniques, the role of the cerebellum and basal ganglia in dystonia, receptor interaction at the systems-level, the role of genetic background and its neurologic consequences, deep brain stimulation, and accepted mechanisms of dystonia based on clinical and basic research. The goal was to stimulate more integrative approaches to dystonia and break scientific and organizational barriers that hamper progress. A request for research applications sought collaborative, interdisciplinary studies that ask provocative questions and use unconventional approaches. Grant announcements were made in 2015.
Novel DYT1 Dystonia Animal Model Mimics Human Disorder

A team of researchers at the University of Michigan led by William Dauer, MD published a comprehensive study linking abnormal TorsinA resulting from a mutation in the DYT1 gene to loss of cells in specific brain structures responsible for movement and overt dystonia symptoms in mice. Dauer focused on developmental aspects of DYT1 childhood onset dystonia, which typically starts between the ages of 8 and 11 years. However, even if a child has the DYT1 gene mutation, if he/she reaches adulthood without symptoms the likelihood of ever developing dystonia is reduced to nearly nothing. This suggests that specific changes in the early stage of brain development make the nervous system vulnerable to the effects of the genetic mutation.

Dauer and team developed a genetic mouse model of DYT1 dystonia that mimics the human disorder. These genetically engineered mice demonstrate overt movement symptoms of dystonia, marked by patterned twisting and fixed postures in the limbs. The mouse reveals a period of subtle neurodegeneration in specific brain structures involved in movement control that coincides with the onset of dystonia symptoms. Even a small number of brain cells from specific structures in the brain could disrupt the development of circuits critically involved in movement. The study makes a critical, experimentally testable connection between impaired TorsinA function, neural circuits, and dystonia symptoms—a tour de force of experimental neuroscience that opens up countless opportunities for future studies. The mouse model will be available to other researchers to help accelerate a better understanding of all forms of dystonia and the search for treatments.

In 2006, Dauer was the very first recipient of the DMRF’s Stanley Fahn Award. Co-author Lauren Tanabe, PhD, was awarded a two-year DMRF research fellowship in 2011.


“We are at a time of major progress in the development of new drugs. I believe we may see, after many years of waiting, some real breakthroughs. The DMRF is doing everything possible to encourage progress through supporting research and clinical translation. The rate-limiting factor is funding, which is now in short supply, relative to all the research opportunities available.” —Mahlon DeLong, MD, DMRF Scientific Director and William Timmie Professor of Neurology at Emory University School of Medicine, earned the 2014 Breakthrough Prize in Life Sciences and 2014 Lasker-DeBakey Clinical Medical Research Award.
2014 Research Projects Represent Targeted and Diverse Areas of Study

The DMRF invites scientists from all over the world to apply for funding to support research on dystonia. The Foundation also negotiates research contracts to enlist partners to work on a specific project or address a knowledge gap in the field. This would not be possible without the support of DMRF donors and years of investment in basic science.

The DMRF funded the following outstanding research investigations in 2014, some of which continued from previous years. These projects addressed issues as diverse as silencing dystonia-causing gene mutations, examining proteins associated with newly discovered dystonia genes, seeking additional dystonia genes, receptor neuropharmacology, and developing assays to test potential drug targets identified through the DMRF’s multi-year partnership with BioFocus.

**STANLEY FAHN AWARDS**
The Stanley Fahn Award is presented to young investigators who conduct groundbreaking dystonia research with a focus on improved treatments. The DMRF established this award in honor of Stanley Fahn, MD who has made visionary and lasting contributions to the field of dystonia.

“Regulatory RNA Networks in Inherited Dystonia” – 3rd year
Pedro Gonzalez-Alegre, MD, University of Pennsylvania

“Development of Novel Reagents to Augment Cholinergic Signaling in Dystonia”
Randy Blakely, PhD, Craig Lindsley, PhD, J. Scott Daniels, PhD, Vanderbilt University Medical Center

“D2 Dopamine Receptor Signaling Alteration in a Mouse Model of DYT1 Dystonia: A Novel Rescue Approach” – 3rd year
Antonio Pisani, MD, Fondazione Santa Lucia, University of Rome

“Structural Characterization of Torsin1A with its Interactors at the Nuclear Envelope” – 2nd year
Thomas Schwartz, PhD, Massachusetts Institute of Technology

“Cellular Screening Assay of RNAi in Dopaminergic Neurons Using Induced Pluripotent Stem Cells” – 2nd year
Chang-Hyun Song, DVM, PhD, Daegu Haany University, Republic of South Korea

“Evaluation of the Effects of a Novel Nicotinic Agonist, AZD1446, on Neurochemical and Electrophysiologic Endpoints in DYT1 Mouse Models”
David Standaert, MD, PhD, University of Alabama, Birmingham, Antonio Pisani, MD, University of Rome

**RESEARCH GRANTS & CONTRACTS**
Research grants are available in support of hypothesis-driven research at the genetic, molecular, cellular, systems, or behavioral levels that may lead to a better understanding of the pathophysiology or to new therapies for any or all forms of dystonia. Contracts provide the opportunity to direct research through the identification of specific, milestone-driven projects conducted by identified investigators and closely monitored by the DMRF’s Chief Scientific Officer.

“Development of Novel Reagents to Augment Cholinergic Signaling in Dystonia”
Randy Blakely, PhD, Craig Lindsley, PhD, J. Scott Daniels, PhD, Vanderbilt University Medical Center

“Structural Characterization of Torsin1A with its Interactors at the Nuclear Envelope” – 2nd year
Thomas Schwartz, PhD, Massachusetts Institute of Technology

“Cellular Screening Assay of RNAi in Dopaminergic Neurons Using Induced Pluripotent Stem Cells” – 2nd year
Chang-Hyun Song, DVM, PhD, Daegu Haany University, Republic of South Korea

“Evaluation of the Effects of a Novel Nicotinic Agonist, AZD1446, on Neurochemical and Electrophysiologic Endpoints in DYT1 Mouse Models”
David Standaert, MD, PhD, University of Alabama, Birmingham, Antonio Pisani, MD, University of Rome
RESEARCH FELLOWSHIPS
Research fellowships are designed to help post-doctoral fellows establish careers in research relevant to dystonia.

“Identification of Genetic Causes of Dystonia in a Homogeneous Population” – 2nd year
Kristoffer Haugarvoll, PhD, Haukeland University Hospital, Norway

“Targeted and Genome Wide Analyses of Factors that Modify TorsinA E” – 2nd year
Lucia Zacchi, PhD, Fundacion Instituto Leloir, Argentina

MYOCLOONUS DYSTONIA RESEARCH PROGRAM
Myoclonus dystonia is a movement disorder characterized by a combination of myoclonus (rapid, brief muscle contractions) and/or dystonia. Collaborative studies funded by the DMRF Myoclonus Dystonia Research Program supported by the Brown Family Foundation advanced progress by focusing on genetics:

“A New Gene and a Novel Pathway Leading to Myoclonus Dystonia”
Dennis Bulman, PhD, Children’s Hospital of Eastern Ontario Research Institution

“Whole Exome Sequencing in Families with Myoclonus-Dystonia Syndrome without SGCE Mutations from Turkey and Germany”
Thomas Gasser, MD, University of Tübingen, Germany

RESEARCH HIGHLIGHT
Brain Donors Prove Essential for Research Progress
The Dystonia Brain Collective is a DMRF-initiated, collaborative effort among US dystonia patient organizations to promote brain donation registration in support of research and facilitate access to clinically characterized tissue samples for dystonia researchers. The DMRF serves as the administrative center for the Dystonia Brain Collective, and the Chief Scientific Officer chairs the steering committee that oversees the distribution of tissue to researchers. The Brain Bank Liaison works with families from all participating patient groups to register donors and ensure smooth initiation of the tissue procurement process.

Proof of the importance of the Dystonia Brain Collective was starkly evident in a 2014 study that upheld the widely accepted—but recently challenged—premise that primary torsion dystonia is a disorder of brain circuitry, not brain damage.

For decades, neuropathological studies in clinically diagnosed cases of DYT1 dystonia (also called primary torsion dystonia) have revealed no specific abnormalities in brain structures or brain cells. Dystonia is widely understood as a problem of brain circuitry, not brain damage. However, ten years ago a team of investigators reported finding cell abnormalities in the brainstem which called into question whether this could be a new hallmark of DYT1 dystonia.

Using the largest series of subjects reported to date, a separate team of researchers set out to identify whether they could find these same abnormalities. This study included samples from seven donors registered through the DMRF and the Dystonia Brain Collective. The investigators did not find brain cell abnormalities in the brainstem or in other areas of the brain implicated in dystonia. The new data supports previous findings that in primary dystonia there is no overt neurodegeneration or cell loss like there is in, for example, Parkinson’s disease. The study reinforces that understanding the biochemical changes in the brain present in dystonia may be more relevant than anatomical changes in DYT1 (and other isolated/primary dystonias) for efforts to develop new therapies.

Clinical Fellowship Training Program Supports Next Generation of Experts

As part of a commitment to nurturing the next generation of dystonia experts, the DMRF sponsors one-year clinical fellowships to train exceptional second-year fellow physicians in the diagnosis and treatment of movement disorders with special competence in dystonia. The training is patient-oriented and includes hands-on experience in clinics as well as participation in professional meetings. The clinical fellowship encourages participants to be involved in the activities of the Dystonia Coalition and participate in clinical research. Merz North America and the Allergan Foundation supported the Clinical Fellowship Training Program in 2014. Merz announced a commitment to award up to $1 million in grants to support program over three years.

The impact of the DMRF Clinical Fellowship Training Program is reaching communities across the country. Past clinical fellows have earned positions in the movement disorder programs at prestigious institutions such as University of Pennsylvania, Brown University, and University of Texas Southwestern. Others are filling gaps in communities previously without movement disorder experts with special experience in dystonia such as Bakersfield, California. DMRF clinical fellows have partnered with the DMRF by organizing community education forums, speaking at support group meetings, and reviewing educational materials. As future clinical fellows complete the program, additional communities and patient populations throughout the country will benefit from these outstanding movement disorder clinicians.

The following clinical fellowship recipients entered the program in 2014:

- **Erin Deegan, MD**
  Beth Israel Medical Center
  Mentor: Rachel Saunders-Pullman, MD, MPH

- **Svjetlana Miocinovic, MD, PhD**
  University of California, San Francisco
  Mentor: Jill Ostrem, MD and Phil Starr, MD

- **Pichet Termstarsab, MD**
  Mount Sinai School of Medicine
  Mentor: Steven Frucht, MD

“The DMRF clinical fellowship offered me an extraordinary mentored opportunity to refine clinical examination skills while gaining expertise in the diagnosis and management of dystonia. The fellowship offered exclusive opportunities to interact with patients, advocacy groups, and international experts—all of which positively influenced my confidence and skills to care for dystonia patients. Additionally, introduction to the Dystonia Coalition allowed me to cultivate research interests and develop lifelong relationships with experts in the field. Upon completion of the fellowship I successfully transitioned into a busy academic practice that largely focuses on caring for patients with dystonia and conducting cutting edge research in the field.”

—Scott Norris, MD is Assistant Professor, Division of Movement Disorders, in the Department of Neurology at Washington University. He is one of fourteen exceptional physicians who have completed the DMRF’s exclusive Clinical Fellowship Training Program.

Global Dystonia Registry Provides Data Sharing for Investigators

The DMRF manages the Global Dystonia Registry, a voluntary patient registry owned and operated by collaborating dystonia patient organizations. The purpose is to support future dystonia studies, including clinical and research trials, through the collection of data from individuals affected by dystonia. Over 4,000 participants from more than 60 countries have enrolled. Data is available to investigators who apply. One of the challenges of clinical research in dystonia is having access to large numbers of patient volunteers for studies, and the Global Dystonia Registry is an important tool for remedying this challenge and informing future research.
BiP is First Identified TorsinA Chaperone Protein

Since 1997, scientists have known that a mutated protein called TorsinA causes one of the most severe childhood onset torsion dystonias, but the function of the protein remains unknown. Jeffrey Brodsky, PhD and Michal Zolkiewski, PhD co-led a DMRF-supported study that used a sophisticated yeast cell model to investigate several proteins that interact with normal TorsinA and its dystonia-causing mutant. The cell proteins belong to a family of chaperones, which are molecules that help other proteins take shape and function properly or, in case of faulty proteins, disassemble and deactivate them. BiP stabilizes both normal and mutated TorsinA structures when they are exposed to stress. When TorsinA is mutated, it becomes a target for chaperones—and especially for BiP, which also appears to have an essential role in degrading mutant TorsinA when it ceases to function properly. It is the first identified chaperone to act on TorsinA. BiP is a molecular chaperone that participates in protein transport and folding processes in the endoplasmic reticulum, an area of the cell in which mutated TorsinA tends to accumulate.

The function of BiP is well-understood, and development of potential treatments based on its interaction with TorsinA may now be possible.

The next step is to identify other cellular helpers that impact TorsinA. This work is underway by DMRF Research Fellow Lucia Zacchi, PhD at Fundacion Instituto Leloir in Argentina, formerly a post-doctoral researcher in the Brodsky lab.


Running for Those Who Can’t at NYC Marathon

A team of runners representing the DMRF and the DMRF Central Jersey Dystonia Support & Action Group competed in the 2014 TCS New York City Marathon. Thirteen runners from across the country volunteered their time, energy, and legs to raise research funds and awareness for dystonia.

Team DMRF included Andrew Chang, Abraham Cohen, Alejandro Gomez, Rodrigo Gomez, Hector Guerrero, Christina Hoenisch, Bethany Hornstein, Ardeshr Khademi, MD, David Malver, Emily Miller, Damaris Rosich-Schwartz, Daniel Sacke, and Tony Sharp. They ran in honor of family members and friends while supporters cheered them on from the sidelines. Supporters in the crowd traveled from Alabama, California, New Jersey, New York, Pennsylvania, Rhode Island, and DMRF headquarters in Chicago.
Advocacy Efforts Protect Federal Research Funding & Treatment Access

During the annual visit to Washington, DC, DMRF advocates joined other volunteers affiliated with the Dystonia Advocacy Network (DAN) to ask lawmakers for increased funding for the National Institutes of Health, inclusion of dystonia in the Department of Defense (DOD) Peer Reviewed Medical Research Program, and protections for access to treatment. During Dystonia Advocacy Day, April 8–9, 2014, advocates participated in 150 meetings with Members of Congress and staff.

Douglas Kramer Young Advocate Award recipient Stefanie Zaia presented Senator Richard Durbin with the Dystonia Advocacy Network Distinguished Public Service Award. Senator Durbin was instrumental in increasing the amount of funding available for research through the DOD Peer Reviewed Medical Research Program from $50 million in the previous fiscal year to $200 million in FY2014.

In addition to convening on Capitol Hill each spring, the DMRF and other DAN member organizations work throughout the year on relevant legislative and policy matters. In 2014 advocates in key States were asked to make visits to the district offices of their Senators during the summer recess. These visits by advocates in Florida, Massachusetts, Minnesota, New York, and Oregon were instrumental in getting dystonia included in the DOD Peer Reviewed Medical Research Program.

Dystonia investigators have been funded through the DOD Peer Reviewed Medical Research Program every year dystonia has been included, beginning in 2010. In 2014, Drs. Pedro Gonzalez Alegre and Charles Harata were funded at $1.3 million each, each of who have received DMRF grants.

The member organizations of the DAN are Benign Essential Blepharospasm Research Foundation, DySTonia, Inc., the Dystonia Medical Research Foundation, the National Spasmodic Dysphonia Association, and the National Spasmodic Torticollis Association.

“We need to inform government officials about dystonia by sharing our personal journeys and gaining their support on important issues. My time on Capitol Hill was truly one of the highlights of my life, but my biggest take away was that you don’t have to be in DC to be heard and you don’t have to be already politically savvy to advocate. DMRF and DAN set you up for success by providing you with the tools you need to make a difference.”

—Rosemary Young’s son was diagnosed with generalized dystonia two years ago. Rosemary and family organized the first— and extremely successful—Dystance4Dystonia Detroit Zoo Walk. She attended Dystonia Advocacy Day in Washington, DC for the first time as one of four recipients of the 2014 Douglas Kramer Young Advocate Award.
Possible Genetic Risk Factor for Dystonia Discovered

A team of researchers led by DMRF grant recipient and past DMRF Medical & Scientific Advisory Council (MSAC) member Mark LeDoux, MD, PhD identified a variant of the THAP gene as a possible risk factor for adult-onset primary dystonia. Volunteers participating in the study represented cervical dystonia, spasmodic dysphonia/laryngeal dystonia, oromandibular dystonia, blepharospasm, and other adult onset dystonias.

THAP1, also referred to as DYT6, is a gene associated with torsion dystonia of mixed age type and variable age of onset. Further investigations may clarify the role of this new THAP variant in dystonia across populations, perhaps ultimately leading to diagnostic or other clinical applications. Because dystonia occurs with so many clinical variations and causes, there is no single agreed upon protocol for diagnosis. It is currently possible to test for only a handful of known dystonia-causing genetic mutations and the probability of testing positive in sporadic cases is less than 1%.

Among others, Dr. LeDoux collaborated with current MSAC member Joel Perlmutter, MD and Zbigniew Wszolek, MD (past grant recipient in a joint project with Dr. LeDoux), and MSAC member and Director of the Dystonia Coalition H.A. Jinnah, MD, PhD.

Patient Education is Essential to Combat Misinformation

The DMRF is contacted every day by people who have questions about living with dystonia. Misleading information about dystonia is easy to find, not only on the internet but in media stories and even from sources that claim to be authorities on dystonia. The DMRF stands out as a credible source of accurate information on dystonia, treatments, and research updates. The website was redesigned and updated with a new look, mobile-friendly design, improved navigation, and expanded content. The DMRF’s collection of educational materials is continually updated and medically reviewed for accuracy.
Volunteers throughout the country reached out to state and local governments to promote awareness. Support group leader Debbie Wilkinson met with Georgia Governor Nathan Deal.

Access to Expert Speakers Provided Locally and Online

In 2014 the DMRF held a number of community education meetings. These programs provided the latest information on dystonia and treatments as well as a platform from which to organize or reinvigorate support groups. Meetings were held in Bakersfield, CA, Baltimore, MD, New Haven, CT, Philadelphia, PA, and Washington, DC. The Philadelphia meeting resulted in a new support group that began operating in 2015.

The DMRF hosted three live educational webinars, all of which were broadcast live and made available online as lasting resources.

- Research Update with Jan Teller, MA, PhD
- Dystonia Overview & Treatment Options with Allison Brasher, MD, Ihtsham ul Haq, MD, and Jessica Tate, MD Wake Forest Baptist Medical Center
- Dystonia in Children & Adolescents with Jonathan Mink, MD, PhD, University of Rochester Medical Center

“Support groups are vital, whether you are newly diagnosed or have lived with dystonia for a long time. Who else understands, and where do you go to find answers and share with others? Realizing that a lot of people living with dystonia had nowhere to go, had no one who shared the same experiences—that is what motivated me to start a DMRF group. I see members grow in confidence, gain knowledge, sustain and encourage each other, and with that greater awareness and understanding they become better advocates on their own behalf. Inspiring!”

—Lynda Dome founded the Silicon Valley Dystonia and Essential Tremor Support Group in Gilroy, California to provide a local resource for individuals impacted by movement disorders. She developed a head tremor and cervical dystonia following an auto accident.
Board of Directors
Stanley Fahn, MD
Lifetime Honorary Director
Samuel Belzberg
Chairman of the Board/Co-Founder
Art Kessler
President
Richard Lewis, MD
Vice President of Science
Barbara Kessler
Vice President of Awareness & Education
Rosalie Lewis
Vice President of Public Policy
Karen K. Ross, PhD
Vice President of Support
Dennis Kessler
Vice President of Development
Mark Rudolph
Treasurer
Sandra Weil
Network Liaison
Paula Schneider
Leadership Chair
Frances Belzberg
Director/Co-Founder
Donna Driscoll
Director
Nancy Harris
Director
Marilynne Herbert
Director
Erwin Jackson, PhD
Director
Deborah Kilpatrick, PhD
Director
Diane Rudolph
Director
John Symonds
Director
Mahlon R. DeLong, MD
Scientific Director, ex officio
Billy McLaughlin
Awareness Ambassador, ex officio
Janet Hieshetter
DMRF Executive Director, ex officio

Medical & Scientific Advisory Council
Mahlon R. DeLong, MD
Scientific Director
Emory University School of Medicine
David Cristopher Bragg, PhD
Massachusetts General Hospital
Bogdan Draganski, MD
University of Lausanne
Rose Goodchild, PhD
University of Leuven – KU Leuven
Phyllis Hanson, MD, PhD
Washington University School of Medicine
N. Charles Harata, MD, PhD
University of Iowa
Kamran Khodakhah, PhD
Albert Einstein College of Medicine
Coro Paisan-Ruiz, PhD
Mount Sinai School of Medicine
Joel Perlmutter, MD
Washington University
Yoland Smith, PhD
Emory University
Philip Starr, MD, PhD
University of California, San Francisco
Peter Strick, PhD
University of Pittsburgh
Michele Tagliati, MD, FAAN
Cedars-Sinai Medical Center
Michal Zolkiewski, PhD
Kansas State University
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
MSAC Federal Liaison

Clinical Fellowship Program Committee
Susan Bressman, MD
Beth Israel Medical Center
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

Editorial Board
Barbara Kessler, Chair
Vice President of Awareness & Education
Ed Cwalinski
Paul Kavanaugh
Dee Linde
Diane Rudolph
Paula Schneider
Todd Spotti

The DMRF publishes three issues of the Dystonia Dialogue each year under the guidance of the Editorial Board.
Dystonia Medical Research Foundation

Statement of Financial Position December 31, 2014

Assets

Cash and cash equivalents including segregated
Dystonia Coalition cash of $189,968 in 2014 $ 214,322
Short-term investments 2,445,431
Unconditional promises to give 108,927
Other current assets 32,093
Equipment and leasehold improvements, 3,902
less $32,128 of accumulated depreciation 5,500
Total assets $ 2,810,175

Liabilities and Net Assets

Grants and fellowships payable $ 427,736
Accounts payable and accrued expenses 62,410
Dystonia Coalition agency liability funds 189,968
Total liabilities 680,114

Net assets - unrestricted 843,965
Net assets - temporarily restricted 1,286,096
Total net assets 2,130,061

Total liabilities and net assets $ 2,810,175

Dystonia Medical Research Foundation

Statement of Activities for the year ending December 31, 2014

Revenues, gains and other support

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donations and grants</td>
<td>$ 1,687,428</td>
<td>$ 601,408</td>
<td>$ 2,288,836</td>
</tr>
<tr>
<td>Special events net of</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>direct benefits to</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>donors of $62,193</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Investment income -</td>
<td>333</td>
<td>316</td>
<td>649</td>
</tr>
<tr>
<td>interest</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>12,716</td>
<td>12,716</td>
<td></td>
</tr>
<tr>
<td>Net assets released</td>
<td>567,226</td>
<td>(567,226)</td>
<td></td>
</tr>
<tr>
<td>from restrictions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total revenues, gains</td>
<td>2,430,577</td>
<td>34,498</td>
<td>2,465,075</td>
</tr>
<tr>
<td>and other support</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Expenses

Program services

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Science</td>
<td>1,217,037</td>
<td>1,217,037</td>
<td></td>
</tr>
<tr>
<td>Awareness and education</td>
<td>348,102</td>
<td>348,102</td>
<td></td>
</tr>
<tr>
<td>Membership and support</td>
<td>128,160</td>
<td>128,160</td>
<td></td>
</tr>
<tr>
<td>Advocacy</td>
<td>132,625</td>
<td>132,625</td>
<td></td>
</tr>
<tr>
<td>Total program services</td>
<td>1,825,924</td>
<td>1,825,924</td>
<td></td>
</tr>
</tbody>
</table>

Supporting services

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration</td>
<td>182,256</td>
<td>182,256</td>
<td></td>
</tr>
<tr>
<td>Fundraising</td>
<td>215,370</td>
<td>215,370</td>
<td></td>
</tr>
<tr>
<td>Total expenses</td>
<td>2,223,550</td>
<td>2,223,550</td>
<td></td>
</tr>
</tbody>
</table>

Change in net assets

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>207,027</td>
<td>34,498</td>
<td>241,525</td>
</tr>
<tr>
<td>Net assets at beginning</td>
<td>636,938</td>
<td>1,251,598</td>
<td>1,888,536</td>
</tr>
<tr>
<td>of year</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>$ 843,965</td>
<td>$ 1,286,096</td>
<td>$ 2,130,061</td>
</tr>
</tbody>
</table>

A complete copy of financial statements audited by Gail L. Mathews & Associates LLC is available upon request from the Dystonia Medical Research Foundation, One E. Wacker Drive, Suite 2810, Chicago, Illinois 60601.
Thank you, 2014 Donors!

$50,000 or more
Allergan Corporation
Allergan Foundation
Frances and Samuel Belzberg
Brown Family Foundation
C. Northrop and A. Mariner
Pond Foundation
Cure Dystonia Now
Family Alliance Foundation
Estate of Joseph F. Grundle
Barbara and Edward Holtzhufer
Barbara and Dennis Kessler
Wendy Bloom and Arthur Kessler
Rosalie and Richard Lewis, MD
Merz Pharmaceuticals, LLC
Estate of Gloria Tyson Dwyer
Sandra Weil

$25,000 to $49,999
Dr. Mary and Mahlon Delong
Stefanie and Erwin Jackson PhD
Pipe Dreams of Tallahassee, LLC
Janney Montgomery Scott LLC
Deborah and Roger Lebbin
Diane Brandt and Martin R. Lewis
Rose and Arthur Perrin
Melissa and Roger Phelps/
Dystance4Dystonia Zoo Walk
Karen Ross, PhD and John Symonds/
Symonds Foundation

$10,000 to $24,999
Anonymous
Anonymous
Cathy and Pat Brogan/Help Find a
Cure 4 Dystonia/MS Meets Dystonia
Golf Tournament
Charles and M.R. Shapiro Foundation, Inc
DMRF Western PA Dystonia Support
Group/Dystance4Dystonia Zoo Walk
Donna and Tom Driscoll
Jean and Wayne Erickson
DMRF MN Golf Classic
Farber Family/Basket Bash
Flanagan Family/Dystance4Dystonia Zoo Walk
Heymann-Wolf Foundation
Independent Charities of America
Patrice Kabram
Cassie and James Metherell/
Toss for Dystonia
Ruth Nussdorf
Weinberg/Newton Family Foundation
William R. Lewis Charitable Foundation
Rosemary and Edward Young/
Dystance4Dystonia Zoo Walk

$5,000 to $9,999
Morris Belzberg
Vicki Berman
The Henry and Marilyn Taub Foundation
Samuel Huntley
Mary Janis
Constance and Harvey Krueger
Debra and Joel Margolis/
Dystance4Dystonia
Mary R. Gilbert Trust
Medtronic Foundation Employee
Giving Charitable Program
Diane and Mark Rudolph
Florence K. Ferguson and E. Michael Shire
Kay and Steve Shraiberg
Team Kavin/Dystance4Dystonia
Zoo Walk

$500 to $999
Team Olivia and Madison/
Dystance4Dystonia Zoo Walk
Team Sydney/Dystance4Dystonia
Zoo Walk
US WorldMeds, LLC

$50,000 or more
Allergan Corporation
Allergan Foundation
Frances and Samuel Belzberg
Brown Family Foundation
C. Northrop and A. Mariner
Pond Foundation
Cure Dystonia Now
Family Alliance Foundation
Estate of Joseph F. Grundle
Barbara and Edward Holtzhufer
Barbara and Dennis Kessler
Wendy Bloom and Arthur Kessler
Rosalie and Richard Lewis, MD
Merz Pharmaceuticals, LLC
Estate of Gloria Tyson Dwyer
Sandra Weil

$25,000 to $49,999
Dr. Mary and Mahlon Delong
Stefanie and Erwin Jackson PhD
Pipe Dreams of Tallahassee, LLC
Janney Montgomery Scott LLC
Deborah and Roger Lebbin
Diane Brandt and Martin R. Lewis
Rose and Arthur Perrin
Melissa and Roger Phelps/
Dystance4Dystonia Zoo Walk
Karen Ross, PhD and John Symonds/
Symonds Foundation

$10,000 to $24,999
Anonymous
Anonymous
Cathy and Pat Brogan/Help Find a
Cure 4 Dystonia/MS Meets Dystonia
Golf Tournament
Charles and M.R. Shapiro Foundation, Inc
DMRF Western PA Dystonia Support
Group/Dystance4Dystonia Zoo Walk
Donna and Tom Driscoll
Jean and Wayne Erickson
DMRF MN Golf Classic
Farber Family/Basket Bash
Flanagan Family/Dystance4Dystonia Zoo Walk
Heymann-Wolf Foundation
Independent Charities of America
Patrice Kabram
Cassie and James Metherell/
Toss for Dystonia
Ruth Nussdorf
Weinberg/Newton Family Foundation
William R. Lewis Charitable Foundation
Rosemary and Edward Young/
Dystance4Dystonia Zoo Walk

$5,000 to $9,999
Morris Belzberg
Vicki Berman
The Henry and Marilyn Taub Foundation
Samuel Huntley
Mary Janis
Constance and Harvey Krueger
Debra and Joel Margolis/
Dystance4Dystonia
Mary R. Gilbert Trust
Medtronic Foundation Employee
Giving Charitable Program
Diane and Mark Rudolph
Florence K. Ferguson and E. Michael Shire
Kay and Steve Shraiberg
Team Kavin/Dystance4Dystonia
Zoo Walk

Team Olivia and Madison/
Dystance4Dystonia Zoo Walk
Team Sydney/Dystance4Dystonia
Zoo Walk
US WorldMeds, LLC

$2,500 to $4,999
Anonymous
Sandy and Wes Alumbaugh
Helen Capparel/Dystance4Dystonia
Phyllis Ellis
Gannett Foundation
Joann Gerardi, PhD/Alexandra and
Martin Symonds Foundation, Inc
Joan Gordon
Treacy Henry/Dogs4Dystonia
Virtual Dog Walk
Janet Hiesheter and Eric Greenberg
Larissa and Aaron Horton
Humbolt Family Foundation
Joyce Jenereaux
David Malver/Dystance4Dystonia
Massimo La Rosa
Billy McLaughlin
Medtronic, Inc.
Emily Miller/Dystance4Dystonia
Susan Miller and Daryn Packy
Movers & Shakers Young Professionals
Terry Neville
Frances and Jerry Newberg
Carole and Doug Rawson
Leslie Richman
Arlene and Robert Subin
Team Huser/Dystance4Dystonia
Zoo Walk
Anna Voytovich and Steven Rudolph
Binbin Wang, MD and Aaron Lewis, MD

$1,000 to $2,499
Susan and Marino Aguilera
A L. & Jennie L. Luria Foundation
Arlene and Joseph Taub Foundation
Michael Ballantyne
DeAnne and Dan Bean
David Malver/Dystance4Dystonia
Catherine and James Berges
Marilyn and Howard Berman
Harnett Blumencranz and Paul Willensky
Boost, LLC
Eileen Bridges
Brownlee-Morrow
Car-O-Liner Company
Michele Carruzzo
Andrew Chang/Dystance4Dystonia
Susan and Howard Code
Kay and James Cooksey/Letter Writing
Barclay and Richard Darden
Arlene and Kenneth Davidson
Carol and Joel Davis
Jan and Charles Davis
Janet and Roger DeBard/
Dystance4Dystonia
DMRF Birmingham, Alabama
Dystonia Support Group
DMRF South Carolina Support Group
Dominion Foundation
Alyssa Dver/Dogs4Dystonia
Virtual Dog Walk
Harold Eegensperger
Sally and Maynard Engel
Ann and Mike Erickson
Timothy Esson
Harlis Ellis and Joel Farber
Kathleen and Timothy Flanagan
Bellardia and Michael Foster
Mati and Aaron Friedman
Denise and Bill Gibson/
Dystance4Dystonia
Sally Gill/Dystance4Dystonia
Irene Ginsburg
Vicki and Ernie Ginter, Jr.
Anna Graves
Bernice and Sam Greenberg
Pam Hall/Dystance4Dystonia
Greg Hartmann
Marlynne Herbert
Ruth Hietz/Dystonia Moves Me
Maureen and Raymond Hiller
Christina Hoenisch/Dystance4Dystonia
Michael Holloway
Virginia and Timothy Hornsby
Bethany Hornstein/Dystance4Dystonia
Maggie Hunt
IBM Employee Services Center
Aresheh Khademi MD/
Dystance4Dystonia
Pamela and Gregory Kintzler/
Dystonia Moves Me
Kirkland & Ellis Foundation
Jonathan Kovler/Blum-Kovler Foundation
Barbara and Harry Lehr/
Dogs4Dystonia Virtual Dog Walk
Tricia and Brian Lewis
Regala and Jacob Lichy, MD
Jeffrey Lipsett and Lisa Tabak
Lone Oak Grill LLC
Louise Chazan Banon Family
Charitable Trust
Jane Marks
Carol and John McGrath
Emily and Thomas Naughton/
Dogs4Dystonia Virtual Dog Walk
Microsoft Giving Campaign
Henry & Rose Moskowitz 1999
Family Foundation
Susan and William Murray
Lindsay Nemeth/Dystonia Moves Me
Frances and Elliot Lehman
Henry Nessley
John Nittolo/JNP Consultants, LLC
Fredelle and Martin Ohihausen
Stacey and Mark Overton
Joe Oxlman, PhD
Mary Pitman
Nancy and Larry Present
Krista and Ronald Reed
Rochester Institute of Technology
Rosen Family Foundation, Inc.
Carol Rowberg
Rubens Family Foundation
Betty and Edward Rudolph
Karen and Daniel Sacke/
Dystance4Dystonia
Susan Saril
Michele Schuster
Ilana Scott
Patricia and Howard Self
Rebecca and Tony Sharp/
Dystance4Dystonia
Cynthia Smith
Frederick Smith
Judith Soley
Solomon Family Foundation, Inc
Rise Stenico
Jacob Stone/Dystonia Moves Me!
Happy Valley Blended Products, LLC

Team Kayla/Dystance4Dystonia Zoo Walk
Team Rachel/Dystance4Dystonia
Zoo Walk
Team Sherry/Dystance4Dystonia
Zoo Walk
Team Twisted Troops/Dystance4Dystonia
Zoo Walk
Gregory Troy/Dystonia Moves Me
UBS Employee Giving Programs
Walmart
Jean and John Walter
Daniel Weinberg
Sally Weinman
Sherri and Mark Weinman
Brian Weinstein
Carol and Lawrence Weissenberg
Linda and David Westfall
Ken Williams

$500 to $999
Adele & Leonard Block Foundation, Inc
The Alice Ghostley Foundation
Joanne Antoniou and Jack Weingold
Sandra Aresta and Michael Katz
Bruce Austin
Bank of America Charitable Foundation
Dr. and Mrs. Irving Baras
Bear Peak Fund
Kathleen Behner and David Powell, MD
Deborah Bender-Palaniuk and
Gary Palaniuk
Patricia and Andrew Beran
Lydia and Robert Blake
Tracey Blowers/Dystance4Dystonia
Ronald Borden
Lisa Breedveld
Janice Brown
Karen Brown
Anne Bryan
Virginia Bryan/Dogs4Dystonia
Virtual Dog Walk
Luannette and John Butler
Dera and Jeffrey Byers
Kay and Ronald Cabay, DDS
Janet and Charles Carlton
Jon Carnahan
Lisa and Stephen Cartolano
CentraState Healthcare Foundation
John Chen
Cheryl and Brian Rothman Charitable Fund
of the Ayco Charitable Foundation
Dale and Peter Claman
The Community of the Sisters of St. Anne
James Conway
CTG Rentals Inc
Diddy and John Cullinan
Shirley Diamond
John Downey
Catherine Emery
Doris and Stephen Faber
Janet Fairbank
Matthew Felton
First Presbyterian Church at Caldwell
Yale Fishman
Mr. and Mrs. J.M. Fox
Lynn and Arthur Freedman
Sally and Robert Gardner
Barbara and Edward Gartside
Give with Liberty
Gerald Goldberg
Marvin Goodfriend
Adam Goitbetter
Tanya and Tony Guidi
Patrick Gutierrez
Happy Valley Blended Products, LLC
Deborah and James Harlow
Helen Hausmann
Hazleton Owls Rod & Gun Club
Heather Harris
Henry Ford Health System
Stacey Henderson
Joyce Hirsch
Jean and Donald Hockman
Joyce Hirsch
Julie Higgins
Katherine and Benjamin Humphrey/
Deborah Kilpatrick, PhD and
Norma and David Lefkowitz
Carolyn and Arthur Levine
Elaine and Shaul Levy
Gail and Howard Miller
Michael Mackley
Cindy and Thomas Metherell
Michael Klik Memory Fund of the
Community Foundation of New Jersey
Michell & Norman Lattman
Charitable Foundation
Michigan Head and Spine Institute
Wendy and Leonard Kaye
Bert Maron
Bob Mayer/Dystonia4Dystonia
Janet McDaniel
Laura and Curtis McGriff
Wayne Melko
Cindy and Thomas Metherell
Michael Klik Memory Fund of the
Community Foundation of New Jersey
Michelle & Norman Lattman
Charitable Foundation
Michigan Head and Spine Institute
Nan and Howard Miller
Nicola Moreau
Vicki and Steven Morris
Brenda and Lee Moss/
The Erdle Foundation, Inc.
Germaine J. Mulhern CPA
Deborah and Robert Myman
Janice and Len Nachbar &
Joanna Manusov/Dogs4Dystonia
Virtual Dog Walk
National Fuel Gas Company Foundation
Network for Good
Newedge USA, LLC
John T. Nothnagle, Inc.
Bernadette and Thomas Olson
Susan Ovens
Susan Peste
Patrice and Jeffrey Pierce
Kimberly and Jeffrey Platek
Lynn Pombonyo
Pomeroy It Solutions Inc
Naomi Prell
Marvin Rabbiner
Karen and William Rabin
RBC Capital Markets Corporation
Rehoboth Beach Running Company/
Rehoboth Beach Marathon
Riverhills Healthcare Inc
Ruth and Stanley Roberts
Ralph Rose
Maxine and Gerald Rosen
Susan and Samuel Sandberg
Charlene and Howard Schwartz
Allen Selling
Dale Shine
Mitchell Siegelman
Donna Small
SRA International Corporation
Carole and Joel Steiger/A.L. Levine
Family Foundation, Inc.
St. Elizabeth Hospital
Ronna Stamm and Paul Lehman
Mary and John Stone
Donna and Glen Sutter
Cindy and James Tanner
Team Aidan Fox/Dystonia4Dystonia
Zoo Walk
Team Alysson/Dystonia4Dystonia
Zoo Walk
Team A Match Made In Evan/
Dystonia4Dystonia Zoo Walk
Team Anthony/Dystonia4Dystonia
Zoo Walk
Team A Twist of Ed/Dystonia4Dystonia
Zoo Walk
Team Breanna/Dystonia4Dystonia
Zoo Walk
Team CBRE/Dystonia4Dystonia Zoo Walk
Team Connor/Dystonia4Dystonia
Zoo Walk
Team Gillman/Dystonia4Dystonia
Zoo Walk
Team Hippenstein/Dystonia4Dystonia
Zoo Walk
Team House of the Rohr-ing Suns/
Dystonia4Dystonia Zoo Walk
Team Jarvis/Dystonia4Dystonia
Zoo Walk
Team Kashat/Dystonia4Dystonia
Zoo Walk
Team Keagan/Dystonia4Dystonia
Zoo Walk
Team Krist/Dystonia4Dystonia Zoo Walk
Team Maddy/Dystonia4Dystonia
Zoo Walk
Team Patrick/Dystonia4Dystonia
Zoo Walk
Team PJ Brigade/Dystonia4Dystonia
Zoo Walk
Team Steeb/Dystonia4Dystonia
Zoo Walk
Team Twisted Humor/Dystonia4Dystonia
Zoo Walk
TeamUnderstanding Dystonia/
Dystonia4Dystonia Zoo Walk
Team Valerie/Dystonia4Dystonia
Zoo Walk
Team Vincoski/Dystonia4Dystonia
Zoo Walk
Jean and Dan Thompson
Traci and Jamie Trapp
Travelers Community Connections
Mark Tricelli
United Way of Buffalo and Erie County
United Way of Greater Portland
Christina Venstra
Andrea Weisbrot
Julie and David Weisman
Cynthia and Larry Weissblum
Sherry and Douglas Whiteley
Susan and David Williamsen
David Wilson
Gail and Morris Yamner
Marian and Ted Zachary
Zaia Family/Dogs4Dystonia Virtual
Dog Walk
Petier Zandt
Patricia Ziner
Mary Jo Abbott
Beth Abney
Carole and Kenneth Adashek
Aetna Foundation, Inc.
Freyda and Jeffrey Albin
Angie and Louis Amato
Kerry and Mel Armstrong
Alex Bahrke
Deborah and Richard Bailine
Anthony Barrett
Rita and Guido Battaglini
Robert Bencks
Erica Bender
Patricia Biedess
Anni and Henry Black
Esther and Charles Bley
James Blue
Darin Besak/Dystonia Moves Me
Lorraine and Gregory Bost
Shirley Bradley
Marjorie Brandenburg
John Brigham
Brnstol-Myers Squibb Foundation
Roger Brooks
Mary Brown
Tracy Buseman-Carlstrom
Christine Bynum
Nabil Cabbabe
Canterbury Park Holding Corp
Natalie Caplin
Yvonne Carney
Edward Carnvale
Roberto Casanova
A. Chodoroff
City of Bridgeport
Collaborative Advantage Marketing
Jennifer and Paul Colone
Daniel Consigo
Constellation Energy Group/
Exelon Foundation
Cranmore Food & Beverage, LLC/
Cuz N’Joes
Paul Copeland
Credit Union One
Carolyn Cruz
Kenneth Cunningham
John Curry
Susan Dangora
Deborah and Douglas Darby
Greg Davis
William Denner/Dogs4Dystonia
Virtual Dog Walk
DMRF Greater Washington, DC
Support Group
Kandi and Tom Doffing
Reese and Glycence Doffing
Francine Donner
Douglas Dugdigeon
Marcia and Richard Eisenberg
Regina and Greg Eitzen
Margaret and Leon Ellin
John Epeky
Jessica and Adam Erickson
Judith Erickson
Lawrence Erickson
Carolyn and Kenneth Erickson
Keith Erickson
Camela and Thomas Evanko
Heidi Evans
Mr. and Mrs. John Evers, Jr.
Anna Faraguna
Beth Farber and Steve Laser
Jessica Feeley/Dogs4Dystonia
Virtual Dog Walk
Rhona and Leonard Feigenbaum
Julie and Barry Farr
Thomas Fischer
Karen and Jane Ann Flanagan
Carol and Luther Flynn
Debra and David Folmar
Fortune Fish & Gourmet
Joe Fowler
Gallatin Steel Company
Judith Garber
Paul Garnett
Givalke
David Glasser
Carol and Peter Goldman
Jody and Charles Goldman
Gail and Donald Goldstein
Rodrigo Gomez/Dystonia4Dystonia
Tina Gordon
Kathleen Grano
Great Vest Side Club
Joyce and Ronald Greenberg
Melissa Greenberg/Dogs4Dystonia
Virtual Dog Walk
Shawn Greenlee
Zee Jay Gregsplan
Honi and Dennis Greenwald
J Brian Greis, MD
Asgal Guadi
Martin Gutenplan
Heather and Isaac Hagler
Gordon Hansen
Paul Hart
Robert Hartman
Stephen Harwood
Jennifer and Barry Haubracht
Karen Hazleton, CPA, PC
Margo Heath-Chiozzi and
Richard Chiozzi
Emily Hellesen
Michael Herko
Paul Herrick
Lynda Hess
Sylvia and John Hine
Eric Hochstadt
Gladys Holmes
Scott Hopping
Diane and Allen Horwitz
Susan and Jim Huser
Frank Jansen
Antoinette Jarvis
Teresa and James Joerger
Matthew Jones
Anita and Michael Kaplan
Davide Kaplan, CPA, PC
Jerome A. Kaplan & Deena L. Kaplan
Family Foundation, Inc.
Gaidaa and Ayad Kashat
Nolita Kashat
Susan and Richard Kellin
Gail and Mark Kelley
Roslyn Kesten
Pamela and Richard Kilany
Miriam Kimmelman
Violet and Chandis Klinger
Norie Knezevic
A. Roy Knutsen
Randolph Kraft
Florence Kramer
George Kramer
Mr. and Mrs. Robert Kramer
Sallie Krass
Jeffrey Kruger
Brian Kuroko
Robin and Stuart Lazarus
Joel Lehman
Florbela Lei
Douglas Lightbohound
Suzanne Lubell
Carolyn Maier
Manning & Napier Advisors, LLC
John Markel, Inc.
Deanna Johnson
Edith Johnson
Emile and James Johnson
Jane and David Johnson
Maurine and LeRoy Johnson
Trevor Johnson
Jean Jones
Linda Jones
Charlotte Jorgensen/Dogs4Dystonia
Virtual Dog Walk
Renée Kahn
Sheri Kahn
Barbara and Harvey Kallick
Barbara and Paul Kamens
Claudia Kania
Daryl and Charles Kaplan
Marla and Larry Kaplan
Nolan Kaplan
Sondra Kaplan
Kelly Karas
Kass Logistics
Charlotte and Charles Katulka
Diane Katz
Jennifer and Gregory Kaufmann
Patricia Kavanagh
Paul Kavanagh
Connie Keatinge
Kelly Kelley
Timothy Kelly
Michael Kempiak
Marcia and Howard Kent
Cathleen and John Kernen
Amy and Robert Kerstein
Joyce and Donald Kessler
Karen and Howard Kessler
Marilyn and Mark Kessler
Sharyn and Ronald Kessler
Keystone Rustproofing Inc.
Sharon and John Kick
John Killick
Margaret and Jimmy Kilpatrick
Andrew Kim
Kin Klub
Tammy and Les Kinder
Megan King
Michael Kinney
Candy Kirkendall
Karen Klauseger
Ann Klayman
Linda and Richard Knab
William Knoble
Donna Amann and Raymond Knoss
Laura Korch
Robert Koch
Andrea Kole
Myra Koltun
Cassandra Kopech
Phyllis and Martin Korn
Keeley Kosoff
Linda and George Koukourakis
Laurie and Lawrence Kraft
Candiss Kraft-Barnaba
Gary Krahn
Stephen Kraus
Ina Kraus
Virginia Kreiner
Lawrence Krizansky
Kroger
Jeremy Kronman
Janet and Jason Kruelee
Rodger and Kathryn Krull
Lisa-Kim Kuan
Brenda Kulick
Victor Kunakowski
Sandra and Kenneth Kuska
Cathy and Joe LaBlance
Way Lacy
Gary Lagler
Eugene Lai
Donna Lee Lampert
Gail Lande
Diane Langle
Judith and Deno Langis
Phyllis and David Lapin
Angela and Adam Rosen/
Lappen Family Foundation
Susan Lashinsky
Nicole and Michael Latoft
Noell and Anthony Latoft
Sheri and Jeffrey Laveroni
Stephen Layman
Leader Services
Learning Designs
Mark LeDoux, MD, PhD
Todd Leinbach
Zela and Ralph LeMarr
Dellaphine Leono
Lynda Lepore
Barbara and John Leschisin
Karen and William Levine
Martha Levine
Sandra Levine
Toni Lichman
Shaynee and Michael Lichtenstein
Rosann Liebman
Alexander Lifson
Dee Linde and Wayne Johnson
Jack Litz
Bruce Loeher
Sylvia Logerquist
Mary Lomax
Dorothy and William Long
Judy Looney
Robert Losk
Donald Lowe
Shana Lowitz
Theresa Luce
Frank Lunn
Andrea and Steven Lunie
Celia Macias
Patricia and Randall Mack
Brian Maddux
Shelley Madonia
Lorin Madow
Martha Maeder
Patricia Magee
Ellen and Cletus Magsemagen
Arthur F. and Suzanne Mahler
Family Foundation, Inc.
Sheelah D. Malamud
Michael Malver
The Mandel Foundation
Marcstone, LLC
Jean Margolis
Mark’s Wholesale Inc
Camille Marrarbun
Mr. and Mrs. James Martin
Dottie and Dan Mathers
Kathryn Matheson
Christopher Mathews
Deborah and Ben Mathews
Gail Mathews, CPA
Thomas Mathews
Elaine Matson
Matthew A. Dancy Funeral Home, Inc.
Ann and James Mattson
Roberta and Daniel Matson
Alisa and Edward Matsushke
Brittany Maung
Chris McCarthy
Mr. and Mrs. Lee McClary
Matthew McCleskey
Kristin McCormish
Mary Kay McCoy
Rick McCracken
Bonnie and Jeffrey McCray
Heath McDaniel
Carla and Robert McFadden
Lisa and Patrick McGuigan
Mr. and Mrs. Peter McInnes
Suzanne McIntyre
Kathleen and William McIntyre
S. McKidd
Robert McMenamin
Donna McMyne
McNeals Insurance Services Inc.
Kathy McPeters
Karen McPherson
Scarlett McPherson
Jacqueline Meisengen
Clara Melman
Thomas Mendelson
Steve Meray
The Merrick Group, Inc.
Diane Merritt
Sarah and Richard Messick
Kathleen Messina and Bernard Beck
Michelle and Wendell Mettey
Amanda Meyer
Rochelle and Dennis Meyer
Ronald Mezick
Michele Miles
Sharon and Louis Miles
Eileen and Andrew Miller
Ellen and Ralph Miller
Jency and Vernon Miller
Kerri and Dustin Miller
Nadine Miller
Minges Creek Salon & Spa LLC
Marla and Robert Mishler
Mary Jo Miske
Beth Mitchell
Deborah Mitchell
Sally Mitchell
Barbara Mittleman
Deborah and John Mieczko
Modern Therapeutics
Michael Molino
Jennifer Molski
Ellen and Bruce Mondschein
Janell and Gary Monetti
Barbara Montgomery
Reta Moore
Rose Moore
Jean and Robert Moorhead
David Moskovitz MD
Karen Moss
MotorWorld
Adelita and Juan Moya
Rebecca and Kenneth Muller
Nancy Mundy
Corinne and Mark Murashige
Jane and Mack Murphy
Patricia and Milo Murphy
Chad Murray
Pamela and David Murray
Iona Myers
Joyce Nachbar
Lisa Nachbar
Madeline Nagel
Sandra and Robert Nathans
Stephanie Neale
Samantha and Jason Neaman
Jennifer Nee
Debbie and Ed Nelson
Stephen Nemeth
Anita and Anthony Nepola
Paul Nepola
Mr. and Mrs. David Nester
Iva Nicosia
Anita Nolan
Jane and Roger Norkoli
North Suburban Synagogue Beth El
Carol Norton
Lisa Nouse
Cyndy Novak
Angel Nunez
Linda and John Oberkofler
Cheryl and Michael O’Brien
Shirley O’Connell
Deborah O’Connor
Christina and Jerry O’Connor
Patricia Joan O’Connor
John O’Donnell
Robin O’Donnell
George Ogden
Robert O’Grady
Lucinda O’Kelley
Paula and Richard Okolowicz
Neil Olson
Gary Oltmans, PhD
Alice Marie Oldus
Judith and Mel Oppen
Ali Orlov
Joan and John O’Rourke
Carl Oshrain
Goly Ostovar and Paul Rickerson
Lisa Otsosvky
Ronald Bock, MD
William O’Toole
Barbara Overson
The Pampered Chef
Robin Pape
Robert Paradise
Victor Parente
Judith Parker
Parma Professional Firefighters
Local #639
Christine and Samuel Parry
Janice and Robert Parsons
Debra and Joel Pasternack
Kathy and Stephen Pastrick
Patient Services, Inc. Administration
Brenda and Greg Patterson
Katharine Pearce
Rosie May Peavey
Vicki and Schuyler Peck
John Pelligrina, MD
Susan Pensel
Jennifer Penske
Lucia and Robert Peralta
Gilbert Perez, Jr.
Patricia and James Perkins
Leslee Perlstein
Kimberly and John Peroni
Marlene Peroutka
Kathleen Perry
Ludovic Perseghini
Penelope and Carl Person
Mr. and Mrs. Gregory Pestine
Jamie and Matt Pestine
Selena and Boris Pestine
Mr. and Mrs. Bernard Peter
Elizabeth and Randall Peterson
Gloria and Ron Petri
Heather and Theodore Petrovich
Pamela Phelps
Phillips Funeral Home Inc.
Mr. and Mrs. Kale Phillips
Margaret and Henry Phillips
Willard Phillips
Gail Piphs
Man Pierce
Matthias Piasky
Monica and Richard Pirozzi
Susan and Bob Pitts
Charles Plante
Gina Polcator
Virginia and Bannie Pomerance
Lisa Plonske
Harish Porecha, MD
Judith and Jeffrey Posner