Dystonia Dialogue

Join the global effort to find a cure.

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What is Dystonia?
Dystonia is a disorder that affects the nervous system. Improper signaling from
the brain causes muscles to contract and twist involuntarily. Dystonia can affect
a single body area or multiple muscle groups. There are several forms of dystonia,
and dozens of diseases and conditions include dystonia as a significant symptom.
For more information visit: http://www.dystonia-foundation.org

On the Cover:
This is a time of unprecedented discovery in brain research
that has the potential to advance what is known about
dystonia and provide exciting new tools for researchers.
For example, through the “Brainbow” project at Harvard
University, scientists are able to color-code individual
neurons, providing an extraordinary view into interactions
among different regions of the brain. The dots and trails
of color on the cover of this issue are neurons inside a
mouse brain. The human brain is made up of billions of these individual
cells. Neurons conduct electrical signals across complicated networks that likely
hold the key to finding a cure for dystonia.

See page 12 to learn more about the growing global interest in brain research and
implications for the dystonia community. And be sure to check out the research
projects funded by the DMRF in 2013 on page 8.

Brainbow image courtesy of Tamily Weissman.

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and The Medtronic Foundation.

The Dystonia Dialogue is the magazine of
the Dystonia Medical Research Foundation (DMRF). It is published three times a year to
provide information to individuals affected by
dystonia, family members, and supporters of
the DMRF.

The Dystonia Medical Research Foundation (DMRF) is a non-profit, 501c(3) organization
founded in 1976. The mission is to advance
research for more effective treatments and a
cure, to promote awareness and education,
and to support the well being of affected
individuals and families.

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The Dystonia Dialogue reports on developments
in dystonia research and treatments but does not
endorse or recommend any of the therapeutics
discussed. Individuals are urged to consult a
physician with questions and concerns about
their symptoms and care.

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Foundation Update

Dear Friends,

By participating in the DMRF you are taking an active role in creating a better future for yourself and affected individuals and families everywhere. While dystonia may limit the ability to be in full control of your body, it does not limit your ability to fight back.

The most powerful tool at our disposal is medical research. The science demonstrates that if we continue our current trajectory of progress, a cure is inevitable. It is more important than ever that we keep investing in research and that we cannot be satisfied with anything less than achieving our goal.

In this issue of the Dystonia Dialogue, we are pleased to share the research investigations that you make possible through your support of the DMRF. By being a member of this organization, you are part of a global effort toward improved therapies and a cure. The DMRF is funding projects throughout the United States as well as in Italy, Norway, India, and other countries around the world. Your participation in research is as vital as the scientists in the labs and the clinicians conducting clinical trials. Your financial contributions are the fuel in the engine of progress. See page 7 to learn about the numerous ways you can participate in research.

Advocacy is essential to our ability to accelerate the development of improved therapies and a cure. In this issue, you will read about the volunteers who traveled to Washington, DC for face-to-face meetings in Congressional offices for Dystonia Advocacy Day to tell their stories and convey the needs of the community. Individuals with all manner of dystonia diagnoses, parents, spouses, and caregivers put themselves out there—quite literally—by showing up and putting a face to dystonia for the legislators who create the policies that impact the community. Read how dystonia advocates are making a difference on page 12.

The DMRF is effective because of the willingness of our members to participate in the mission. You inspire us every day with your enthusiasm and passion to be a part of shaping a brighter future for yourselves and others impacted by this disorder. Everyone has something to contribute; any one can make a difference. Thank you for your support.

Sincerely,

Art Kessler
President

Janet L. Hieshetter
Executive Director
DMRF Chief Scientific Officer Receives DIA Patient Fellowship Program Award

Chief Scientific Officer Jan Teller, MA, PhD was recognized as a Drug Information Association (DIA) Patient Advocate Fellow and will represent the DMRF at the DIA 49th Annual Meeting, June 23–27, 2013 in Boston. Dr. Teller is one of 19 representatives selected from nationally recognized patient organizations for rare or underrepresented diseases.

Fellows will meet on the discovery, development, and management of pharmaceuticals, biotechnology, medical devices, and additional clinical applications. Fellows will also have opportunities to develop and strengthen collaborations with policymakers, health professionals, industry representatives, and research institutions. The Patient Advocate Fellowship is an opportunity to continue the DMRF’s leadership in pushing the envelope toward innovative dystonia therapies and better quality of life for all affected individuals and families. The DMRF is proud to be a part of this important event.

Show Your Support with New DMRF T-Shirt

The DMRF received so much positive feedback on the cover artwork of the spring Dystonia Dialogue, we designed a t-shirt featuring a variation of the design. You can raise awareness everywhere you go by ordering one of these stylish black, high-quality cotton shirts. Only $20! Order yours today and help promote the global effort to find a cure: http://dystonia.donorshops.com/

Experts Exchange Ideas and Discuss Future Research at 2nd Myoclonus Dystonia Workshop

Certain forms of dystonia serve as important areas of focus for research because they provide a unique opportunity to examine an element that all dystonias share; every form of dystonia provides lessons to be learned for the field as a whole. Myoclonus dystonia is an inherited movement disorder characterized by a combination of rapid, jerking muscle contractions (myoclonus) and the sustained twisting and repetitive movements that result in dystonia postures. Although this form is relatively rare, increased interest in myoclonus dystonia is revealing insights into the dystonia mechanism and genetics of all inherited forms.

Supported by a grant from the Brown Family Foundation, the DMRF hosted the 2nd Myoclonus Dystonia Workshop April 4–5, 2013 in New York, New York. Susan Bressman, MD of the Alan and Barbara Mirken Department of Neurology at Beth Israel Medical Center and Thomas Gasser, MD of the Hertie Institute for Clinical Brain Research at University of Tübingen, Germany chaired the meeting. Movement disorder experts gathered to review clinical aspects of myoclonus dystonia including genetics, brain imaging, and treatment as well as to examine experimental approaches. The meeting provided a constructive platform to exchange ideas and formulate plans to facilitate and inspire novel future research.

While the research continues, the DMRF serves individuals and families affected by myoclonus dystonia by providing resources for information and support. See the article “Hope and Gratitude: Reflections from a Patient Observer at a Dystonia Workshop” on page 5 to learn what it was like for DMRF member Ginny Bryan to attend this meeting.
Hope and Gratitude

Reflections from a Patient Observer at a Dystonia Workshop

Ginny Bryan of Buffalo, New York attended the 2nd Myoclonus Dystonia Workshop (April 4–5, 2013 – New York) as an observer. Ginny has lived with symptoms of myoclonus dystonia, an inherited type of dystonia, since infancy but was initially misdiagnosed with cerebral palsy.

To be honest I was a little scared and anxious to attend the workshop because I had no idea what to expect. I just thought I would listen and soak it all in. I have so much respect for all the people in that room. What blew me away was that I had no idea how many people were so interested in dystonia and how far along the research is. It was almost like music to hear it all. I thought, Wow. It was jaw-dropping.

I had only read about grants in the newsletter, and to see the people who are making it happen was amazing: people who work for 14 hours a day on the research. To see how hard they work, how much they care. These researchers were from all over: New York but also France and the United Kingdom. The amount of “buzz” in the room was inspiring—to see them excited and sharing. It’s not just their job, it’s their passion.

The experience exceeded my wildest expectations. I had no idea how much hope I would feel. How much dedication, generosity, and collaboration there was in the room. It made me speechless. It improved my quality of life to attend this meeting. Most people don’t get to see the researchers in action like this. It was one of the best weekends I’ve had in a while. I have so much gratitude for everyone involved.

As patients, a lot of the time we have to be our own advocates. This meeting helped me realize how lucky we are to have the DMRF and scientists around the world working so hard.

I wish every patient could have this hope. I wish they could know there are so many people around the world working on this disorder. There are so many people collaborating on the research, and the DMRF brings all these people together. It’s amazing.

There are no quick fixes, but I’m in this for the long haul. And the researchers are in it for the long haul. I want the researchers to know all the long hours they put in are noticed. What they do really matters. They give us hope. When I’m having a tough day or feel frustrated, I remind myself of how much there is to be thankful for and it makes me try ever harder.

Attending this meeting was a gift, like a present. I feel so fortunate to have been a part of it.

See page 4 for more information on the 2nd Myoclonus Dystonia Workshop.
“An Ingenious Way to Live”
Catching Up with Outspoken Advocate Neil Marcus

For decades, disability activist Neil Marcus has used his life and his art to challenge how society categorizes and reacts to individuals with disabilities. He became an iconic figure in the disability culture movement that coalesced in the late 1970s and 1980s by using theatre, dance, poetry, and contemporary art to express his unique vision: “Disability is not a brave struggle or ‘courage in the face of adversity.’ Disability is an art. It’s an ingenious way to live.”

Although there is no shortage of Neil’s recent projects, his early work continues to attract new audiences. His self-published underground magazine from the 1980s, *Special Effects: Advances in Neurology*, was featured in an exhibit entitled “Humans Being II” at Woman Made Gallery in Chicago throughout May and June of this year. Neil describes his publication: “It is all about bringing art and culture (as well as humor) into the political sphere. *Special Effects* was distributed as I traveled around town in street zine fashion and also had a mailing list. The advent of the computer helped me develop other kinds of expression: theater acting skills, scripts, text (no longer typewriter and razor blade).” A special collection of *Special Effects* was published by Publication Studio in 2011.

Another of Neil’s latest projects is the like-titled *Special Effects* with collaborator Stephen Lichty. This work is an improvisational dance performance with rocks and fire. Both Neil and Stephen have been diagnosed with forms of dystonia, and they use verbal cues, body positioning, and external objects to re-articulate their dystonic movements into dance. “Working with Neil is a challenge; he is a Zen kōan,” explains Stephen, comparing Neil to a vessel for inspiration and wisdom. “From our first meeting three years ago, I recognized Neil as kin, a brother. He makes it look easy, but it’s not; Neil is a master of empathy.” Neil and Stephen have been performing together since 2012.

Neil lives and works in Berkeley, California. He developed generalized dystonia at age eight. Neil has danced internationally since the 1980s, received a United Nations Society of Writers Medal of Honor for his play *Storm Reading*, and is included as a seminal voice in the National Endowment for the Arts Oral History Project. He is frequently recognized on the street for his appearance on the hit television show, *ER*. He has published numerous books, and his poetry has been published internationally. Recent projects and performances in partnership with Petra Kuppers include *Burning: Cells, Transformation, Energy Transfer*, an installation with The Olimpias, Berkeley, 2009 and *Journey to the Holocaust Memorial in Berlin*, Pustervik, Gothenburg, 2011.

**Did You Know?**

One of the benefits of DMRF membership is the annual “Promise & Progress” science report mailed each spring to provide information on the DMRF’s latest research activities. To join the DMRF and start receiving this informative publication, go to: www.dystonia-foundation.org/membership or call 800-377-DYST (3978) or 312-755-0198.
DMRF Hosts Workshop on Development of New Dystonia Treatments

One of the most important outcomes from the last decade of dystonia research is that drug discovery efforts are now possible. Years of investment in basic research, simultaneous advancements in technology, and a growing global interest in dystonia are creating new opportunities to accelerate progress toward new therapeutics.

The DMRF partnered with Tyler’s Hope for a Dystonia Cure to host a scientific workshop entitled Toward Discovery of Novel Treatments for Dystonia, April 25–26, 2013 in Atlanta, Georgia. Yuqing Li, PhD of the University of Florida Center for Movement Disorders and Neurorestoration, and Jan Teller, MA, PhD of the DMRF chaired the workshop.

This workshop brought together dystonia patient advocacy organizations, researchers, pharmaceutical industry leaders, and federal agencies to brainstorm and collaborate on the continuing push for new dystonia treatments. Sessions addressed the neurobiology of dystonia, drug target development, pharmacology, accelerating progress, and areas for collaboration.

Participants will meet regularly to accelerate progress in drug development through collaboration and pooling resources.

How Can I Participate in Dystonia Research?

You can support dystonia research discoveries in more ways than one. Consider these opportunities to make an impact:

Ask your Doctor
Your movement disorder specialist may be participating in a clinical trial that needs volunteers.

Search Online for NIH Studies
Search for dystonia clinical studies supported by the National Institutes of Health at http://www.nih.gov/health/clinicaltrials/

Register as Brain Donor
Individuals with dystonia as well as unaffected family members are urgently needed. See page 15 to learn why DMRF member Melinda Wrens is passionate about this program.

Join a Patient Registry
Share your dystonia history with researchers through the Global Dystonia Registry: http://www.globaldystoniaregistry.org/

Check out Dystonia Coalition Studies
The Dystonia Coalition is recruiting for several projects. Go to http://rarediseases-network.epi.usf.edu/Dystonia/ and look for “Join a Study.”

Donate
Financial contributions to the DMRF support cutting-edge research by the world’s foremost thought leaders and up-and-coming experts.

Use the envelope enclosed in this newsletter to make a gift or donate online at http://www.dystonia-foundation.org/donate
The DMRF believes the best service it can provide the dystonia community is to work every day toward improved therapies and a cure. The DMRF invites scientists from all over the world to apply for funding to support research on dystonia. Our research funding provides relatively modest grants that allow investigators to do the preliminary work required for larger grants from agencies like the National Institutes of Health (NIH). In many cases, the DMRF helps young investigators establish careers in dystonia.

The DMRF does not only fund research proposals submitted by investigators. Through research contracts, the DMRF enlists partners to work on a specific project or address a knowledge gap in the field. This would not be possible without the DMRF’s years of investment in basic science.

The DMRF is proud to announce this year’s outstanding research investigations, some of which are continuing from 2012. Congratulations to this year’s award recipients, and infinite thanks to our supporters for making this research funding possible.

### 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 of Columbia University who has made visionary and lasting contributions to the field of dystonia.

“Regulatory RNA Networks in Inherited Dystonia”
Pedro Gonzalez-Alegre, MD, University of Iowa

Now in the second year of a three year award, this project is advancing our understanding of the dystonia mechanism by closely examining neurons for the consequences of dystonia-causing mutations in the DYT1 and DYT6 genes. TorsinA, the protein associated with the DYT1 gene for early onset dystonia, is believed to have a role in monitoring other proteins in cells. THAP1, the protein associated with the DYT6 gene for early and late onset primary dystonias, is believed to influence how torsinA functions. One of the aims of Dr. Gonzalez-Alegre’s work is therefore to characterize the precise disruptions in neurons linked to both mutated torsinA and THAP1.

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

Dr. Pisani previously identified a link between the DYT1 dystonia-causing gene mutation and changes in specific receptor proteins in the brain. Now in the second year of a three year award, his latest work further explores the effects of this mutation on specific neurotransmitters. Using electrophysiological techniques, he and his team have managed to pinpoint and characterize specific brain activity changes in rodent models of DYT1 dystonia.
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 to be conducted by identified investigators and closely monitored by the DMRF’s Chief Scientific Officer.

“Identification of Novel Drug Targets for DYT1 Dystonia”
BioFocus DPI, The Netherlands
This continuing project, which began in 2009, is the first step toward the rational design of dystonia therapeutics by identifying new drug targets. The major objective is to identify genes and proteins that modify the effects of the DYT1 dystonia mutation on torsinA, the protein coded by the DYT1 gene. Several hundred hits have been identified from a library of more than 4,500 candidates. These hits represent proteins and genes that potentially can rescue cells from lost torsinA function, which is believed to be the primary cause of DYT1 dystonia. The next step of the project is to identify a small number of the most promising targets to be used in drug discovery efforts. The DMRF is proud to partner with Tyler’s Hope for a Dystonia Cure on this project.

“Comprehensive Examination of Motor Circuit Activity in Awake Behaving DYT1 Knockin Mice”
Nicole Calakos, MD, PhD, Duke University
Dystonia can be caused by many factors, including lesions to a variety of different regions in the central nervous system, peripheral trauma, drug exposure, and defined genetic mutations. One hypothesis is that what all of these diverse insults to the nervous system have in common is that they interfere with the brain networks responsible for movement. In this study, Dr. Calakos is seeking a defined connection between the DYT1 dystonia mutation and these brain networks.

“Assessing the Role of GNAL Pathway Genes in Primary Dystonia”
Tatiana Fuchs, PhD, Mount Sinai School of Medicine
GNAL is one of the latest genes discovered to cause primary dystonia. This gene plays a role in how neurons receive signals. Dr. Fuchs and her team are examining other genes involved in this process. This research has the potential to reveal additional genes for primary dystonia, contributing to our understanding of the dystonia mechanism and providing a basis for development of new therapies.

“Morphological-Functional Analysis of the Endoplasmic Reticulum in a Mouse Model of DYT1 Dystonia”
N. Charles Harata, MD, PhD, University of Iowa
This project is designed to identify how dystonia changes the way neurons function. Dr. Harata is also taking a close look at a possible link between dystonia and calcium ions, which play a critical role in the function of cells.

“Encoding of Interhemispheric Interactions in Mirror Dystonia: A Window to the Physiology of Dystonia”
Asha Kishore, MD, Sree Chitra Tirunal Institute for Medical Sciences and Technology, India
Dr. Kishore and team are using transcranial magnetic stimulation (TMS) to examine the phenomenon of “mirror dystonia” and gain a better understanding of the changes in brain activity associated with dystonia movements. Mirror dystonia occurs when, for example, an individual with writer’s cramp in the dominant hand attempts to write with the opposite hand, and yet dystonia symptoms persist in the unused hand.

“Structural Characterization of Torsin1A with its Interactors at the Nuclear Envelope”
Thomas Schwartz, PhD
Massachusetts Institute of Technology
Dr. Schwartz’s project seeks to learn more about the function of the dystonia protein torsinA by defining its three-dimensional structure. Within the atomic structure lie the clues to fully understand its function and the ability to influence this function by developing specific drugs.

“Patient-specific Induced Pluripotent Stem (iPS) Cells as a Model for DYT1 Dystonia”
Nutan Sharma, MD, PhD and Cris Bragg, PhD
Massachusetts General Hospital
The objective of this work is to establish a collection of dystonia cell models as a public resource for the research community. These models enable multiple dystonia research groups to study defects in neurons affected by the DYT1 gene mutation associated with early onset dystonia.
RESEARCH FELLOWSHIPS
Research fellowships are designed to assist post-doctoral fellows establish careers in research relevant to dystonia.

“Identification of Genetic Causes of Dystonia in a Homogeneous Population”
Kristoffer Haugarvoll, PhD
Haukeland University Hospital, Norway
Dr. Haugarvoll and team are investigating the relationship between cervical dystonia and essential tremor by studying families impacted by both. There is ongoing debate among experts whether cervical dystonia and essential tremor are different disorders or part of a spectrum.

“Targeted and Genome Wide Analyses of Factors that Modify TorsinA∆E”
Lucia Zacchi, PhD
University of Pittsburgh
One approach for developing new dystonia therapies is to identify cellular processes or genetic factors that selectively affect the protein torsinA, which is known to be abnormal in individuals with specific dystonias. Dr. Zacchi’s work will identify new genetic factors that affect normal and abnormal torsinA, and could eventually lead to therapies designed to reduce the effects of abnormal torsinA while enhancing the effects of normal torsinA.

CLINICAL TRAINING FELLOWSHIPS
The DMRF is fostering the next generation of dystonia leaders by offering one-year fellowships to support training of neurologists in preparation for a clinical career in movement disorders with special focus on diagnosing and treating dystonia. Congratulations to this year’s fellows and their mentors:

Umer Akbar, MD
Fellowship Institution: University of Florida
Mentor: Michael Okun, MD

Raminder Parihar, MD
Fellowship Institution: Beth Israel Deaconess Medical Center
Mentor: Daniel Tarsy, MD

Jung Park, MD
Fellowship Institution: National Institute of Neurological Disorders & Stroke
Mentor: Mark Hallett, MD

Harini Sarva, MD
Fellowship Institution: Beth Israel Medical Center
Mentor: Susan Bressman, MD & Rachel Saunders-Pullman, MD, MPH

Aasef Shaikh, MD
Fellowship Institution: Emory University
Mentor: H.A. Jinnah, MD, PhD

Cheat Sheet: Genes & Mutations
Mutations in specific genes cause certain types of dystonia. Each gene is linked to a protein. Here is a chart of genes mentioned in this article, the proteins with which they are associated, and forms of dystonia.

<table>
<thead>
<tr>
<th>Gene</th>
<th>Protein</th>
<th>Dystonia</th>
</tr>
</thead>
<tbody>
<tr>
<td>DYT1</td>
<td>torsinA</td>
<td>Early onset primary dystonia</td>
</tr>
<tr>
<td>DYT6</td>
<td>THAP1</td>
<td>Primary dystonia with prominent symptoms in face and upper body</td>
</tr>
<tr>
<td>DYT25</td>
<td>GNAL</td>
<td>Primary dystonia of varied anatomical symptoms and age of onset</td>
</tr>
</tbody>
</table>

A complete list of known genes associated with dystonia is available at http://www.dystonia-foundation.org/genechart
Definitions & Concepts

**Brain network/neural network** – A circuit of neurons in the brain that conducts brain activity.

**Disease mechanism** – The origin and development of a disease or disorder. Ideally, treatments target the disease mechanism.

**Drug target** – A protein involved in the disease mechanism that can be manipulated by a medication or therapy.

**Early onset/Late onset** – Movement disorder experts make a distinction between forms of dystonia that typically begin prior to about age 28 (early onset) and forms that typically begin after about age 28 (late onset). Early onset dystonia tends to become generalized; late onset dystonias are more likely to remain focal.

**Genes & Proteins** – Genes are the building blocks of living things. Most genes contain a code of DNA that corresponds to a protein. Proteins participate in virtually every process of the human body. When a gene becomes mutated, this changes the protein associated with that gene and how that protein functions. When a protein cannot properly fulfill its function, this may disrupt normal biological processes and lead to a disease or disorder.

**Neurons & Receptors** – A neuron is a nerve cell or brain cell. Signals between neurons must cross a small gap called the synapse. A neurotransmitter is released from one neuron and crosses the synapse. The neurotransmitter then may be accepted by the next neuron at its receptor.

**Neurotransmitter** – A chemical in the brain that transmits signals from one neuron to another.

**Penetrance** – The percentage of people with a disease-causing gene that actually develop symptoms of the disease. For example, approximately 30% of people who have the DYT1 mutation develop symptoms. The remaining 70% of people with the mutation never develop dystonia. This is referred to as reduced penetrance.

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**Volunteers Needed**

*Researchers Seek Patients with DYT1 Dystonia and Asymptomatic Carriers*

Researchers at Columbia Medical Center in New York are recruiting individuals with DYT1 dystonia and asymptomatic carriers of the DYT1 mutation for a clinical study. The study involves performing short auditory and visual tasks on a laptop. The exercise takes an hour to complete, and eligible volunteers can participate from home or at Columbia Medical Center. Participants will be asked several questions regarding their medical history and current medications.

**The enrollment criteria for this study are:**

1. Asymptomatic (no dystonia) or symptomatic (with dystonia) carriers of a DYT1 mutation.
2. Age 18-45 years old.
3. No prior neurosurgical surgeries for dystonia such as deep brain stimulation (DBS), pallidotomy, or thalamotomy.

If you are interested in participating in this non-invasive study or require additional information, please contact Dr. David Arkadir at 212-305-3767 or da2501@columbia.edu

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**Sign Up for DMRF Updates to Your Mobile Phone**

Text DYSTONIA to 90999.
Dystonia Advocates Challenge Cuts to Federal Research Funding & Push Forward on Key Issues

On April 30–May 1, 2013 nearly 100 volunteers representing the Dystonia Advocacy Network (DAN) gathered in Washington, DC to give dystonia a voice to Congress. Against the backdrop of sequestration, advocates from across the country made over 100 visits to Congressional offices in support of continued and increased funding of dystonia research at the federal level and protecting patient access to treatment.

The DAN also used this opportunity to recognize US Representative Chris Van Hollen of Maryland and Senator Ron Wyden of Oregon for their attention to issues affecting the dystonia community.

This year’s legislative agenda includes:

• Support of a $32 billion budget in FY2014 for the National Institutes of Health (NIH). The NIH is losing $1.6 billion this fiscal year due to across-the-board cuts to particular categories of federal spending that began early this year, popularly known as sequestration. The NIH is the country’s largest supporter of basic research. This cut and previous erosion to NIH’s budget equates directly to fewer new research projects, stalling existing research, and a loss of scientific advancement—not just in dystonia but across all medical research.

These cuts to NIH come at a time of unprecedented discovery and high interest in brain research on a global scale that has the potential to advance what is known about dystonia and provide new tools for researchers. The NIH BRAIN Initiative (Brain Research through Advancing Innovative Neurotechnologies) is part of a new focus aimed at revolutionizing science’s understanding of the human brain. In total, NIH intends to allocate $40 million in FY2014. Simultaneously, the European Union’s Human Brain Project is making a better understanding of the human brain a stated scientific goal of the 21st century. As a neurological disorder, this global interest in brain research is a boon to the field of dystonia and any obstacle to this momentum threatens progress toward new therapies and a cure.

• Continuing to include dystonia as a condition eligible for study in the Department of Defense’s (DOD) Congressionally-directed Medical Research Program. Since 2010, as a result of action taken by DAN advocates, dystonia investigators have been invited to apply for research funding from the DOD—and a number of dystonia projects have been funded. However, the list

From L to R, advocates Paula Schneider, Dee Linde, Bruce Austin, Diane Zaia, and Stephanie Zaia (front row) were one of the teams of volunteers who spent the day meeting in Congressional offices in support of the dystonia community.
of conditions of concern to the DOD changes each year, and advocates must perennially work to insist that dystonia remains included.

• **Protecting patient access to dystonia therapies through a permanent solution to Medicare physician reimbursement.** Doctors increasingly are not able to afford to treat Medicare patients due to a serious flaw in the rate at which they are reimbursed by the Centers for Medicare and Medicaid Services. This jeopardizes access to healthcare for large number of patients including individuals with dystonia, and a permanent solution is urgently needed.

Advocacy is a year-round process; dystonia advocates will continue to work on these issues throughout the year and plans have already begun for Advocacy Day in 2014.

For more information on how you can get involved in legislative advocacy on behalf of the dystonia community, contact the DMRF at dystonia@dystonia-foundation.org or 312-755-0198.

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**How Does the NIH Support Dystonia Research?**

The vast majority of federally funded dystonia research is conducted through institutes and centers of the National Institutes of Health (NIH) including:

- National Institute of Neurological Disorders & Stroke (NINDS)
- National Institute on Deafness & Other Communication Disorders (NIDCD)
- National Eye Institute (NEI)
- Office of Rare Diseases Research (ORDR)

The NIH dystonia research portfolio is growing, but this growth is dependent on funding appropriated to NIH by Congress.

The groundbreaking Dystonia Coalition is part of the Rare Diseases Clinical Research Network conducted by ORDR. The Dystonia Coalition is a collaboration of medical researchers and patient advocacy groups that is working to advance the pace of clinical and translational research in the dystonias to find improved treatments and a cure. The Dystonia Coalition has made tremendous progress in preparing the field for clinical trials and supports research pilot projects and awards for young investigators. The DMRF serves as the administrative center for the Dystonia Coalition.

The DMRF has worked with the NIH on groundbreaking dystonia workshops, program announcements, and a memorandum of understanding to review well-rated dystonia research grant applications submitted to NIH agencies but not awarded due to lack of funding.

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**Why Does the Department of Defense Fund Dystonia Research?**

The Department of Defense (DOD) supports research on conditions that affect military personnel through the Peer-Reviewed Medical Research Program (PRMRP). Traumatic injury can cause dystonia, and traumatic brain injury is not uncommon among service men and women. Dystonia is becoming increasingly prevalent among combat veterans and especially those returning from the Afghanistan and Iraq wars—and the DOD has taken notice. Relatively little is known about the mechanism of dystonia in relation to traumatic injuries, and research in this area is urgently needed to supplement the work being done at the National Institutes of Health—both for the benefit of our military service people and the greater dystonia community. The DMRF is committed to continuing to work through the Dystonia Advocacy Network to ensure the DOD continues to fund dystonia research.
DMRF Names Three Douglas Kramer Young Advocacy Award Recipients

Thanks to generous support from the Kramer family, the DMRF named three Douglas Kramer Young Advocate Awards this spring. This award is given to individuals between the ages of 20 and 35 who have demonstrated a commitment to making a difference for those affected by dystonia through advocacy.

Congratulations to our Young Advocates:

Nicole Dean developed cervical dystonia at age 17 as a senior in high school. Having never heard of dystonia prior to her diagnosis, she pushed through the fear and uncertainty to learn all she could about the disorder and available treatments. She began attending a support group and writing a blog to promote greater awareness among her family and friends. She is a “Face of Dystonia” on the DMRF website and has contributed to the Dystonia Dialogue. Now 22, she is working toward a college degree.

Nicole states: “I want to be a voice for those who are unable to speak for themselves due to the crippling nature of this disorder. I am hoping advocacy will lead to awareness, awareness to funding for research, research to answers, and ultimately answers that will give us a cure.”

Melissa Phelps was “blindsided” when her then 16-month-old daughter was diagnosed with dopa-responsive dystonia after several misdiagnoses. Just months ago, her 5-month-old was also diagnosed with the same syndrome. Melissa has advocated with multiple organizations for rare disorders and has special passion for promoting dystonia in all the forms it can occur. She is planning a walk at the Cincinnati Zoo on September 14, 2013 to raise awareness of dystonia and support the work of the DMRF. See page 19 for details.

Melissa explains: “Our family had to educate ourselves about this rare disorder. I felt so alone when I realized that many people do not understand this disease or have never even heard of it. I have been my daughters’ voice ever since. I am willing to be the voice of those who can’t speak for themselves.”

Allison London was 26 years old and a graduate of Georgetown Law when she began experiencing symptoms of truncal dystonia affecting her torso and posture. For the past three years she has promoted awareness and fundraised for medical research.

Allison was nominated by her mother June Hersh, who explains: “Allison has an incredible spirit and has put a positive face on this illness, winning people over with her warmth and smile and convincing energy. Her law school training and role as a litigator have perfectly positioned her to carry a message to a broad and diverse community.”

The DMRF looks forward to working throughout the year with these stellar volunteers to advance the dystonia community’s legislative and policy agenda.
Give a Gift to Research That Costs Nothing at All

Become a Brain Donor and Make a Difference

“Donating my brain is the most amazing gift I can give to research,” says Melinda Wrens, who developed generalized torsion dystonia in her mid-30s. “So many people donate their organs through their driver’s license, simply because they want to help people. Brain donation is something special we can do for dystonia research.”

You can make a significant contribution to dystonia research by registering as a brain donor. The study of brain tissue provides researchers with unique opportunities to gain a more thorough understanding of the disorder, develop improved treatments, and advance closer to a cure.

The DMRF is part of the Dystonia Brain Collective, a collaboration among several dystonia patient organizations, in partnership with the Harvard Brain Tissue Resource Center (HBTRC) at McLean Hospital in Belmont, Massachusetts. Individuals residing in the United States who are diagnosed with dystonia as well as unaffected family members are encouraged to register.

“It’s a personal decision. I received paperwork from the DMRF and shared it with my family. Talked about it with my friends. My daughter had questions—and I reassured her they didn’t need my brain right away,” Melinda jokes. “I just explained why it was important to me. I explained that researchers need normal brains too—family members don’t need to be jealous that they only want my brain. It’s ok to laugh, to help put others at ease.”

The registration process is easy. There is no cost. The recovery process does not interfere with funeral or memorial services or affect the outward appearance of the donor.

Individuals considering brain donation must discuss their intentions with family members because the next-of-kin or legal representative will be responsible for notifying the HBTRC when the donor passes away as well as granting permission for recovery to take place and for the donor’s medical records to be sent to the HBTRC. The recovery process must be completed within 24 hours from the time of death, so time is of the essence.

“I don’t want to be defined by dystonia,” explains Melinda. “I’ve learned you have to advocate for yourself. The same year I was diagnosed I registered as a brain donor. I want to help other people, and I trust in the DMRF to help find a cure. My definition of hope is not only about a cure. It is anything that provides relief of a symptom, greater awareness, better understanding, or—maybe the most important—educating the medical field in recognizing and diagnosing dystonia.”

Melinda’s family and community have supported the DMRF by selling homemade crafts, performing music benefits, and working year-round to promote greater awareness.

If you wish to learn more about brain donation, the DMRF is happy to mail you information about the program and answer questions. Contact DMRF headquarters at 800-377-3978 or email Martha Murphy, Brain Bank Liaison, at brainbank@dystonia-foundation.org. You may also visit the DMRF website to download an informational brochure and registration form: www.dystonia-foundation.org/brain
**PEOPLE ON THE MOVE**

*The DMRF is deeply grateful for our grassroots volunteers who work year round to promote dystonia awareness and fundraise for medical research. Every effort and every volunteer makes a difference! We appreciate your support.*

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Early this year, Helen Capparell ran the Disney Marathon in Orlando, Florida to support the DMRF in honor of brother-in-law Pat Brogan. Pat is a longtime dystonia advocate whose story was featured in the documentary, *Twisted*.

Dena Sherry ran the Napa Valley Marathon on behalf of the DMRF on March 3 in honor of her daughter Jana Sherry who has generalized dystonia. She says the race was “beautiful, amazing, hard, and painful.” She raised over $2,500! Dena also spoke at this year’s Dystonia Advocacy Day in Washington, DC to encourage new participants and assist in their orientation.

Mandi Guilfoyle hosted the second Dystance4Dystonia – Walk for a Cure on May 11 in Fitchburg, Massachusetts. Mandi is diagnosed with dystonia and has twice undergone deep brain stimulation. Thank you, Mandi!

Paula and Don Gates and their loyal committee raised over $23,000 at the sixth and final “Return to Margaritaville” dinner dance on April 19 in Danvers, Massachusetts. The DMRF is extremely grateful for so many years of dedicated support. Pictured are committee member Maureen Gillis (left) and Don and Paula Gates. *Photo by Myrna Fearer.*

Beverly Benson, Jason Dunn, Kym Kell, Debbie Severson, Madison Williams, and Chris Wygergangs participated in a patient panel to share their experiences with dystonia with second-year medical students as part of “Clinic Day” at Wayne State University School of Medicine in Detroit, Michigan. Family and friends Diane Garchow, Marla Garchow, and Mike Delise attended to show their support. Special thanks to Dr. Edwin George, Dr. Natalya Shneyder, Krystal Parker, and Tamara Taylor of Wayne State for supporting this important effort.

Lydia Nathans has been a member of the Caldwell, New Jersey First Presbyterian Church choir for 13 years. Over the Easter holiday, the choir honored her longtime service by doing a special collection for the DMRF that raised over $250.

Kym Kell organized a “Soup Sampler for Dystonia” fundraiser in April in partnership with Deb’s Diner located in Windsor, Ontario, Canada. Kym is diagnosed with tardive dystonia and has undergone successful deep brain stimulation. Great job, Kym!

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*Check the DMRF website for upcoming events at www.dystonia-foundation.org/events*
Susan Strawgate Code hosted a fundraiser at Holbrook Cottage in Briar Cliff Manor, New York on May 2. Attendees shopped for home décor and gourmet food gifts, and a portion of proceeds were donated to the DMRF. Susan organized this event in honor of her nephew David Rudolph. Special thanks to shop owner Sue Taub.

In January, David Peterson, PhD of University of California, San Diego spoke at a meeting of the Dystonia Support & Advocacy Group of San Diego County led by Martha Murphy. In May, acupuncturist Rose Thomas, Lac. was the featured speaker. Stephanie Kallay from Merz Pharmaceuticals also attended the May meeting.

In celebration of Mother’s Day, the Verville family and music teacher Patricia Bergeron held their 8th Hands for Movement Freedom piano recital in Vermont to benefit the DMRF. There was so much interest in this event, that organizers hosted two concerts to accommodate all the interested guests. Sixteen-year-old Alexandre Verville, whose diagnosis inspired this annual concert, was among the pianists who performed.

Founders and leaders of the Central Jersey Dystonia Support and Action Group, Len and Janice Nachbar and Joanna Manusov, are spreading awareness throughout New Jersey: They secured dystonia awareness proclamations from the Monmouth County Board of Chosen Freeholders, Freehold Mayor Barbara J. McMorrow and governing board, and Governor Chris Christie. Well done!

Pat and Bill Wyatt visited the office of Alabama Governor Robert Bentley where he signed a proclamation in support of dystonia awareness. Pat leads the Dystonia Support Group of Alabama. Image courtesy of Governor Robert Bentley.

Dystance4Dystonia is a program for volunteers interested in participating in local marathons, runs, and/or walks in support of the DMRF.

A Dogs for Dystonia Dog Walk is a fun way to bring family, friends, and the community together in support of the DMRF.

For more information about Dystance4Dystonia or Dogs4Dystonia, contact the DMRF at 312-755-0198 or dystonia@dystonia-foundation.org
Three years ago, parents Marci and Steve Goldstein’s wish for their daughter Emily was that deep brain stimulation (DBS) surgery would give her the ability to simply stand up from her wheelchair and possibly use her hands. The surgery was far more successful than anyone imagined: this spring, Emily ran the Los Angeles Marathon, without any indication that dystonia ever slowed her down.

“I was more prepared than I thought,” said Emily who trained for months in advance of the race. “I ran non-stop for about the first 15 miles. At around 18 miles I started feeling worn down. And then I sprinted the last mile and a half because I just really wanted it to be done!”

Emily was a healthy, able-bodied child until age nine when her beautiful cursive handwriting began to deteriorate and her foot started to turn inward. She soon lost control of both hands, required a wheelchair full-time, and her speech began to slur. It took two years for Emily to be properly diagnosed. Marci and Steve were beside themselves. Steve explains, “I found myself worrying, Will she ever be independent? Will she have a boyfriend? You want your kids to experience love and fun, and I was worried about her survival.”

Emily underwent DBS at age 12. The benefits of DBS are neither guaranteed nor immediate. Emily began to see subtle improvements about a month out of surgery. Within two months her wheelchair was collecting dust, and after four months she was taking dance classes. Her symptoms are now 90% gone.

As dedicated supporters of the DMRF, the Goldsteins had hoped Emily’s participation in the Los Angeles Marathon might help improve awareness of dystonia, and a local television affiliate interviewed Emily during her last practice before the race. “The interview was really fun,” she says. “And my teammates were really excited for me—it was adorable.” Emily’s story aired the Friday before the race. Emily also did a text fundraising campaign so that family and friends could support the DMRF in her name. The Goldsteins also hope Emily’s story can provide encouragement to other dystonia-affected families.

Marci explains, “We went two years without a diagnosis for Emily. We have to make dystonia more well-known. Especially because in some cases the earlier you do DBS the better the results. The clock is ticking. We need awareness.”

The DMRF congratulates Emily on this amazing accomplishment!
**When Life Gives You Lemons, Make Lemonade—and Cookies!**

Sisters Catherine (age 15) and Grace Mulshine (age 9) and cousin Elizabeth Puntillo (age 15) raised $50 for the DMRF selling lemonade and homemade gingerbread cookies. They did so in honor of Catherine and Grace’s dad Brendan Mulshine who has cervical dystonia that affects his neck. Catherine says, “Day to day we can see the struggle he has, and we want to help him. We hope our donation can help you find a cure for dystonia soon!” Thank you Catherine, Grace, and Elizabeth!

**9-Year-Old Girl Uses Birthday Party to Collect Donations for DMRF**

Mackenzie Brown learned about dystonia by accident. While watching videos online, she came across a television special about a man named Jason Dunn. Jason has generalized dystonia and is well-known in the dystonia community for promoting awareness. “I thought about it, and I wanted to help,” says Mackenzie.

She was so impressed with Jason that, instead of accepting gifts for her ninth birthday, she asked party guests to make a donation to the DMRF in his honor. Mackenzie and her friends raised $100!

Mackenzie’s mom Tiffany Lyon says, “She has such a compassionate heart. She is amazed at how Jason lives his life to the fullest and does not let dystonia stop him. I hadn’t heard about dystonia until she told me—I learned too. I am so proud of Mackenzie.”

When the DMRF informed Jason of Mackenzie’s actions, he reached out to the family to personally thank them. The DMRF is extremely impressed by Mackenzie’s generosity and grateful for her support!

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**Upcoming Events**

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<th>Event Details</th>
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<td>Dystance4Dystonia &lt;br&gt;“Don’t Be Jealous of Our Moves” &lt;br&gt;Rigby, ID</td>
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<td><strong>September 14, 2013</strong></td>
<td>Dystance4Dystonia &lt;br&gt;Cincinnati Zoo Walk &lt;br&gt;Cincinnati, OH</td>
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<tr>
<td><strong>September 28, 2013</strong></td>
<td>Toss4Dystonia Cornhole Tournament &lt;br&gt;at Frontier Field &lt;br&gt;Rochester, NY</td>
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<tr>
<td><strong>October 5, 2013</strong></td>
<td>Dystance4Dystonia &lt;br&gt;Cleveland Zoo Walk &lt;br&gt;Cleveland, OH</td>
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<td><strong>October 20, 2013</strong></td>
<td>Dogs4Dystonia – “Howl-O-Ween” &lt;br&gt;Woodland Hills, CA</td>
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<td><strong>October 27, 2013</strong></td>
<td>Chicago Basket Bash &lt;br&gt;Chicago, Illinois</td>
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<td><strong>November 3, 2013</strong></td>
<td>Team Dystance4Dystonia at NYC Marathon &lt;br&gt;New York, NY</td>
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Visit [http://www.dystonia-foundation.org/events](http://www.dystonia-foundation.org/events) for a complete list of events and support group meetings as dates are confirmed.
Out of Control
Finding Peace of Mind When Your Body is Running Your Life

“I feel I maintain a sense of balance, but in some fashion dystonia is always in control. I have to take meds every six hours and breakthrough meds sooner if I start to feel an attack coming on. My dystonia is well controlled, but I always feel like it’s calling the shots to some degree because I cannot predict whether or not an attack will happen.”

~ Jenelle Dorner, PhD, Neuroscientist & diagnosed with secondary dystonia due to mitochondrial disease

Dystonia takes away a person’s ability to be in complete control of his/her body. The brain—the body’s command center—is overridden by chaotic signals that cause the muscles to contract and move involuntarily. The chronic, unpredictable nature of symptoms can make individuals with dystonia feel as though the disorder is the prominent force governing their lives. The dystonia experience may include mobility problems, communication difficulties, pain, medication side effects, and inconsistent response to treatment. These complications intensify the universal challenges of family, relationships, work, school, and everyday living.

Research has shown there are three particularly challenging psychological stressors that commonly face people with a chronic disorder: a sense of powerlessness, loss of control, and a loss of hope. A spiral into depression and helplessness can be both physically and mentally debilitating. Protecting against these negative effects can help promote a greater sense of peace and balance.

Life Turned Upside Down
“There are no easy adjustments when your life is turned upside down,” shares DMRF Vice President of Support and psychologist, Karen K. Ross, PhD. “Our family was overwhelmed with my son’s diagnosis of early onset dystonia more than 35 years ago. We didn’t have the DMRF or support groups—or even doctors who knew about dystonia. I think everyone in the family suffered from shock and feelings of helplessness.”

Adjusting to life with a chronic illness is a grief process, much like mourning a death. Dr. Ross recommends embracing a “patient active” concept (adapted from the cancer support community) as a guide for how individuals and families impacted by dystonia can navigate the experience. “The patient active concept is about feeling and acting empowered to do whatever is required to improve the quality of your life,” she explains. “A patient active approach is made up of the feelings, actions, and attitudes that move a person from being a ‘patient’ to an ‘active’ participant in their health and in their life.”

Stress management is critical. Dr. Ross explains, “It’s essential to find ways, on a daily basis, to calm the chemical reactions going on in your body when stress is triggered. We need to do this for our body and for our brains.” Physical exercise, for example, as a beneficial physiological effect. There are more tools for overall wellness available now than ever before: numerous styles of stress reduction and meditation, adapted exercise programs, web-based videos and podcasts, and even counseling and coaching via phone or online.

“My belief is that anyone going through a major change in their life, such as dealing with a physical disorder, can benefit from some kind of professional help,” says Dr. Ross. “A therapist, online coach, or spiritual leader can provide empathy, support, and feedback to help you achieve a sense of well-being and help you nurture compassion for yourself.”
Finding the New Normal

For 20 years, Reverend Mike Beck has been “living in a body with a mind of its own.” He is diagnosed with several focal dystonias, each with distinct symptoms and challenges. He developed spasmodic dysphonia (dystonia of the vocal cord muscles) in 1992, and hand dystonia about a year later. In 2003, blepharospasm appeared (causing excessive blinking and forced closure of the eyes) and oromandibular dystonia followed (causing involuntary movements in the jaw and face). Just as he would adapt to one diagnosis, the dystonia surfaced in another set of muscles. His relationship with the disorder began to resemble a chess match: two opponents trying to outmaneuver the other, his body the playing board.

Continued on page 22
“You have to learn to live one day at a time,” he says. “And that is not easy.” As a church leader, Rev. Mike had devoted his life to a busy vocation that required him to speak before crowds of parishioners, drive to the hospital in urgent situations, and attend to families in distress. Dystonia eroded his ability to do all of these by making his voice unreliable, impairing his vision, and even diminishing his range of facial expressions. Despite years of managing dystonia through proactive medical care and creative problem-solving, he stepped down from leading his congregation in 2006. “The decision to leave my ministry wasn't an easy decision to make, but the dystonia really made the decision for me. I didn't want to do it, but I didn't have a choice.”

And so, as he had done for years prior, Rev. Mike was once again faced with the challenge to re-invent himself to accommodate dystonia. He says, “In terms of dealing with the ups and downs, the first thing to realize is that life will never be the same after the diagnosis. It's going to be hard. You have to try to keep a positive state of mind. Ask yourself, will this experience make me bitter or better? Is my life half-empty or half-full?”

Later in 2006, several months after deep brain stimulation (DBS), Rev. Mike was facing one of the darkest periods in his life. After an exhilarating—but brief—reprieve from his symptoms immediately following surgery, the process for finding his optimal DBS settings was proving long and daunting. He recalls an appointment with his programming nurse: “She realized how discouraged I was. She taught me something critically important. She said, ‘You'll probably never be able to do what you did before, but you still have value. You are not your illness.’” Rev. Mike recalls this as an extremely influential moment that provided a sense of peace and helped reset his outlook for the future.

After a year of adjustments to the DBS settings, the blepharospasm and oromandibular symptoms improved somewhat. Rev. Mike continues to receive botulinum neurotoxin injections in his vocal cord muscles, eyes, and hand. He remains involved in ministry by guest speaking, leading workshops, and teaching short-term classes. He channeled the creativity he once put into writing sermons into authoring books. He credits dystonia with fortifying his capacity for gratitude, humility, and sense of humor.

“Finding your new normal, it takes time to get there. There will be numerous times you'll get discouraged. When it comes to feelings, we tend to think of ‘good’ feelings and ‘bad’ feelings. Feelings are just feelings—what you do with them is what's important.”

Karen K. Ross, PhD serves as the Vice President of Support on the volunteer Board of Directors for the DMRF. She is a clinical psychologist and marriage and family therapist formerly in private practice in California. Karen began working with the DMRF since the very early stages of the organization, soon after her son was diagnosed. She authored the book Holding the Hope: A Parent's Guide to Living with Dystonia. She created two relaxation/meditation audio programs for dystonia-affected individuals and caregivers, available through the DMRF. She is a frequent contributor to the Dystonia Dialogue and presenter at DMRF events. Her son is grown and benefitted greatly from deep brain stimulation surgery.

Rev. Mike Beck earned degrees from Taylor University, Butler University, and Asbury Theological Seminary. For 25 years, Rev. Mike served churches in Greensburg, Corydon, and Franklin, Indiana. He is the author of No Longer Silent: Doing Pastoral Ministry with Excellence and Grace. His second book, Living in a Body With a Mind of its Own: The Emotional Journey of Dystonia, is scheduled to be published in the summer of 2013. Rev. Mike and his wife Mickey have been married for over 40 years. They have two sons and four grandchildren.
PERSONAL PROFILE
Meet Jerome Hansen

Jerome lives in Muskego, Wisconsin with his wife of 10 years Amy and his 9-year-old son Xaiver. He serves as a volunteer administrator for the DMRF’s new “Parenting with Dystonia Support Forum” on Facebook.

When and how did your symptoms begin?
In 2007, I was 29 years old. I was working as an EMT [emergency medical technician]. I went to bed and woke up with a stiff neck. The spasms continued and got so strong I went to the emergency room that afternoon. The ER doctor diagnosed me with cervical dystonia. A neurologist confirmed it.

What treatments have helped you?
I was getting botulinum neurotoxin injections every 12 weeks. I’ve exceeded the recommended dosage so I’m waiting to be evaluated at a major movement disorder center to see if I am candidate for DBS [deep brain stimulation] or denervation surgery. I’ve been without botulinum neurotoxin for about four months. I have pain and a lot of pulling to the left. If you asked me before I stopped the botulinum neurotoxin, I didn’t think it was doing much for me. Now that I have gone without, it did more than I realized, including controlling some of the pain.

How has dystonia impacted your life?
After I was diagnosed, I refused to listen to anyone. I became a firefighter and then advanced to Firefighter II training, a more advanced certification. I did tactical EMS training and was SWAT team certified. And then joined the dive rescue team. After a while, I could still do the job but I refused to bet someone’s life on it.
I was having increasing pain and spasms, but they were overridden by adrenaline. I was always re-evaluating my limitations. I left the fire service. As a firefighter, I accept risk for myself but will not accept added risk for my crew. It was the hardest decision of my life. I truly miss it.
I now work as an EMT in the private industry. My son, who is nine, loved that his dad was a firefighter; he was always so excited. That hit me the hardest. I’m coming around to accept it.

What helps you cope?
I concentrate on my family. We were on vacation in Orlando, and my wife made a comment that she had her husband back. It hurt to realize I had been making everyone else miserable too. Since then, making family memories with my family is the most important thing. I know my wife misses who I was before I was in pain, but I know she loves me and will do whatever she can do to help me feel better. My parents Rick and Fran Hansen play a very important role in helping me cope. I have a tattoo on my back that also helps me cope with dystonia. It is a set of lyrics from the artist Pink and the song “Try.”

What have you learned?
I thought I was in good hands with my doctor. Until one day my pain management doctor, who was doing my injections, said I was maxing out on the dose and the only future for me was long-term narcotics. So I started doing research on clinics that specialized in dystonia and picked the one closest to me. Now a whole new set of options is open to me. I learned about medications my previous doctors never considered. They also suggested I could be a good candidate for surgery, so we’re exploring those options.

Any advice for others with dystonia?
Don’t stop. Get a doctor who you feel has your best interest at heart. Always ask questions. Remember dystonia is now part of your life but not all of your life. Refuse to accept a lack of options even if means you have to change doctors. Surround yourself with people who know, love, and support you. I became a firefighter because I just refused to let dystonia define me. I wanted to be able to look at my accomplishments, not think about what I wish I had done.

For links to the Parenting with Dystonia Support Forum and additional online groups, visit: http://www.dystonia-foundation.org/online
DMRF Partners with eBay for “One of a Kind” Auction

The DMRF has partnered with eBay Giving Works to provide supporters with a unique opportunity to support dystonia programs at the Foundation. In June, we launched a one-of-a-kind auction of unique items donated by friends of the DMRF. Items include original artwork by Aaron Bauers and Patricia Evangelista and the signed script from a TV show pilot episode. Throughout the year, Giving Works allows individuals to list and sell their own items on eBay with a percentage (10-100%) of the final sale directed to DMRF. Sellers like Sharon McMyne have listed hundreds of items on eBay, raising important funds for research.

If you sell items on eBay and wish to donate a portion of proceeds to support the DMRF, or to bid on donated items, visit: http://givingworks.ebay.com/charity-auctions/charity-information/