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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:
Christina Thorpe, who lives with cervical dystonia, attended the 6th Children & Family Dystonia Symposium (August 19–21, Chicago) with partner Patrick Rogers and son Christian. This was the first Children & Family Symposium to include sessions for dystonia-affected adults. Read more on page 6.

Partial support of the Dystonia Dialogue is provided by educational grants from Allergan, Inc., Ipsen, The Medtronic Foundation, and Merz Pharmaceuticals.
Foundation Update

Dear Friends,

Thirty-five years of serving the dystonia community have taught the DMRF leadership that access to accurate information is as essential to living well with this disorder as seeking the appropriate medical care. Individuals impacted by dystonia can empower themselves by being as knowledgeable as possible.

We all know you cannot always rely on information you find on the internet to be accurate, and this includes descriptions of dystonia and other movement disorders. To those of us who live with dystonia every day and who know the importance of promoting awareness, few things are more frustrating than a media story or online blog that disseminates incorrect information about this already frequently misunderstood disorder.

The DMRF applauds a recent letter to the editor in the *New England Journal of Medicine* entitled “Movement Disorders on YouTube—Caveat Spectator” that addresses this matter. Physicians are reporting that a growing number of individuals with movement disorders are coming to them with inaccurate portrayals of these disorders from the internet, especially from the video sharing website YouTube. These videos are causing many people undue concern by providing inaccurate depictions of movement disorders (including dystonia) and suggesting treatments and cures not backed by trustworthy sources.

The DMRF echoes the *New England Journal of Medicine* in reminding those with dystonia to seek out credible sources for medical information. We encourage you to verify the sources of information about treatment options and to rely on those backed by solid scientific study and endorsed by a qualified physician trained in movement disorders.

The DMRF will continue to take very seriously our efforts to provide accurate, timely information about dystonia and the latest news in treatments and research—an effort we have undertaken for 35 years. This year we published updated versions of several of our most popular brochures and will continue doing so in 2012. The articles we bring you in each issue of the *Dystonia Dialogue* are monitored by the volunteer Editorial Board and medical articles are reviewed by members of our Medical and Scientific Advisory Council. The DMRF is privileged to work closely with the world’s top thought leaders in movement disorders and most knowledgeable figures in the dystonia community to make sure the information we provide is sound.

It is unfortunate that there are people who take advantage of a platform like YouTube, which can do so much good, and use it in a manner that is harmful. This does not in any way diminish the tireless work of our volunteers who are promoting awareness—including through social media websites like YouTube and Facebook—and helping the un- and misdiagnosed access the information and resources they need. Now more than ever, we need to make sure individuals impacted with dystonia know where to go for good information.

If you have suggestions for resources you would like to see the DMRF develop or improve, we want to hear from you—please do not hesitate to contact us.

Art Kessler
President

Janet L. Hieshetter
Executive Director
Critically-acclaimed guitarist and DMRF Awareness Ambassador Billy McLaughlin is the newest member of the DMRF Board of Directors.

“The DMRF is an organization that's making great progress in research to better understand and cure this disorder—and to bring visibility to the devastating impact of dystonia on those of us who are diagnosed,” says Billy. “I’m thrilled to continue being a part of this work.”

Billy gained critical acclaim and a loyal fan base for his unique style of placing both hands on the fretboard, creating a harp-like effect on the acoustic guitar. In 2001, he was diagnosed with focal hand dystonia. Against doctors’ recommendations, Billy began the daunting journey of teaching himself to play in his signature style, left-handed. In 2004 a film crew began following McLaughlin’s desperate attempt to regain his career. Billy has since published a limited release of *Into the Light*, a concert recording of compositions for acoustic guitar with string orchestra, and has resumed a vigorous touring schedule.

Billy was appointed DMRF’s Ambassador of Awareness in 2009 for his efforts to educate the public about dystonia. The documentary about his journey, *Changing Keys*, began airing on PBS stations across the country in 2010. That same year, he received the American Academy of Neurology Leadership in Public Neurology Award. Billy is a frequent speaker at DMRF events, leads a support group, and has been an active legislative advocate on behalf of the dystonia community for the past two years.

“Billy is as energetic and enthusiastic about making life better for people with dystonia as he is about his music, which is truly inspiring. It’s an honor for the DMRF to have him be a part of our team,” says Executive Director Janet Hieshetter.
Esther Goodhart Brings Dystonia to the Smithsonian

Member of the DMRF, Esther Goodhart, is featured in a special exhibit at the Smithsonian’s National Portrait Gallery. The exhibit, entitled "Portraiture Now: Asian American Portraits of Encounter," is on display through October 14, 2012.

This exhibition is the Smithsonian’s first major showcase of contemporary Asian American portraiture. Through the work of seven artists from around the world, the exhibition offers provocative expressions of the Asian American experience against and beyond the common stereotypes associated with being Asian in America.

“I’m Korean, I’m Jewish, I’m handicapped, and I’m proud of who I am,” says Esther. “It’s a thrill for me to be in the Smithsonian. Living in America gives us the luxury to say what we want and be who we are. I don’t have to be shy about my dystonia or any part of who I am.”

Esther’s portrait, taken from the new book Kyopo by Cindy Hwang, is a fierce depiction of perseverance. She stands regally, holding the canes she uses to walk as proudly as if they were scepters.

Esther’s dopa-responsive dystonia first surfaced as a toddler as she struggled to learn to walk. She was not properly diagnosed until she was 14 years old.

Create Your Plan

Planning ahead can allow you to support the DMRF as generously as you wish, often without impacting your current financial situation. Creating your plan is now easier than ever with the new Wills Planner on the DMRF website. It will help you organize your family and estate information using our secure online system. To get started, go to http://dystoniagifts.org and click on “Create Your Plan.” Questions? Contact Tammy Reed at 312-755-0198 or treed@dystonia-foundation.org. We look forward to helping you plan your future.
6th Children & Family Symposium Attracts Record-Breaking Crowd

Weeks in advance of this year’s John H. Menkes Children & Family Dystonia Symposium, the DMRF’s Facebook and social media pages were peppered with exchanges about the event. The anticipation was clear. Status updates like “14 days until the symposium—can’t wait!” and “Who else is going to Chicago?” and “So bummed I can’t make it this year :-(” ricocheted across the web.

The weekend of August 19–21, families from across the country and beyond convened in Chicago, Illinois for the 6th Children & Family Dystonia Symposium. Nearly 200 people were in attendance, the largest number for any Children & Family Symposium to date.

The event was made possible by the generous support of Allergan, Medtronic Foundation, Merz Pharmaceuticals, U.S. WorldMeds, Paula and Don Gates and the Friends of the DMRF, and an anonymous donor.

These biannual meetings provide a special program for children and teens affected by dystonia and their families. This year, the programming was expanded to begin including sessions for dystonia-affected parents and members of the community in their 20s and 30s.

Nearly 30 speakers representing a wide spectrum of expertise participated in separate tracks for children under 13, teens, parents of affected children, and dystonia-affected adults. Medical speakers included Cynthia Comella, MD of Rush University Medical Center, Larissa Pavone, MD of Rehabilitation Institute of Chicago, and Jerrold Vitek, MD, PhD of University of Minnesota. DMRF Science Officer Jan Teller, PhD provided a research update. In addition to educational lectures on dystonia and treatments, the agenda offered discussion circles, coping sessions, and break-out groups on topics as varied as family dynamics, service dogs, disability rights, and genetic counseling.

The children and teens shot their very own dystonia awareness videos which will appear in DMRF’s online social media in the near future.

DMRF members Jason Dunn and Mike Delise of Warren, Michigan were presented with DMRF Star Awards for their dedication and success in promoting dystonia awareness. Jason and Mike have partnered to bring extensive dystonia awareness to their hometown in the Detroit metropolitan area and appeared on the television program, Extraordinary Humans: Muscles, which was partially shot at the 2009 Children & Family Symposium and aired internationally on the National Geographic Channel in 2010 and 2011.

First-time participant Christina Thorpe, who has cervical dystonia and attended with her partner Patrick Rogers and son Christian said, “It was a memorable experience for us all. It was personally great for me to hear others’ stories who also live with dystonia. I met wonderful people.”

As a result of the symposium, the DMRF launched a Dystonia & Special Education blog authored by attorney Roberta Senzel, a special education expert and mother of a grown daughter with dystonia who served as a guest speaker at the event (http://dmrfspecialed.blogspot.com/). Roberta’s daughter Marcie Povitsky, who has lived with dystonia since childhood, is partnering with the DMRF to create the “Dystonia 20/30” Facebook group, which is a special online forum for 20- and 30-somethings in the dystonia community. Stay tuned for details about this new resource.

The DMRF extends a heartfelt thanks to the families, speakers, sponsors, volunteers, and special guests who made the Children & Family Symposium such a successful and fun event.

Rachel Rudolph’s design was selected to appear on the bag given to all attendees.
Nearly 200 people attended the 2011 Children and Family Symposium.

Siblings Fréderick Côté-Verville (left), Catherine Côté-Verville, and Alexandre Verville are loyal symposium attendees.

This year’s symposium included sessions for children, teens, parents of affected children, and dystonia-affected adults. Jeannie Soto-Valencia of Beth Israel Medical Center was a guest speaker.

Below: Chair of the UK Dystonia Society Fiona Ross (left) traveled from Scotland to lead a session for children and teens. She is pictured with DMRF President Art Kessler and Executive Director Janet Hieshetter.

Above: Billy McLaughlin and Kimberly Hough led a first-ever discussion session for dystonia-affected parents.

Alex John (second from right), who shared her story on the TV show The Doctors, and mother Pat John (second from left) of California attended for the first time along with mother-daughter pair Brenda Gillis and Macy Nalley from Oklahoma.
In Memoriam: Jim King

The DMRF regrets to report that Jim (“Jimmy”) King of Startex, South Carolina passed away in July after a battle with cancer. Jim and his wife of 59 years, Novyce King, were leaders of the South Carolina DMRF Support Group, and have served as a source of support and information for dystonia-affected individuals and families for 20 years. Jim was diagnosed with cervical dystonia in 1985 after years of undiagnosed symptoms. His experiences fueled his and Novyce’s passion for promoting dystonia awareness and reaching out to those who are affected.

Jim was a graduate of Westminster High School and Clemson A & M College, Class of 1956. He retired from the textiles industry as plant manager of Spartan Mills after working at Startex Mills. Jim was a former member of North Spartanburg Rotary Club and Startex Ruritan Club. He was an Explorer Scout leader and a Little League baseball coach. For 53 years he was a member of Startex United Methodist Church.

The South Carolina Support Group holds an annual flea market, holiday poinsettia sale, and partners with local retailers to fundraise in support of the DMRF year round. They meet regularly, publish a newsletter, and have a mailing list that extends throughout the state.

The DMRF extends condolences to Jim’s surviving family and friends. The dystonia community has lost a dedicated and compassionate advocate.

Click! Moments of Clarity in the Dystonia Experience

Finding Your Niche
After my diagnosis of adult onset generalized dystonia 12 years ago, I began my search for support. I attended support group meetings, I hopped on every online bulletin board I could find. There just wasn’t a place that felt quite right for me.

I managed on my own and did very well, but still longed for that supportive feeling. Then one day, I found the DBSforDystonia Online Bulletin Board. I made a post introducing myself to the group. Man, within hours I had so many posts welcoming me!

Now, I’m a regular. I can honestly say every member is my family. There is so much knowledge, so many caring people. Most of all there is humor, which this girl can’t go without.

I can proudly say the DBSforDystonia Bulletin Board has filled a void in my life by connecting me with people who know what it’s like to live with dystonia. It gave me family that I never knew I had, including my “twisted sister,” Dee Linde who founded DBSforDystonia.

Our family is never big enough! Come and join us at: http://health.groups.yahoo.com/group/DBSforDystonia/

Shellie Gray
Tulsa, Oklahoma

What realizations have you made in your journey with dystonia? What ‘clicked’ for you?
Email us at dialogue@dystonia-foundation.org
5th International Symposium Represents a Global Effort to Understand Dystonia

At the time of printing, over 500 dystonia experts from around the world were preparing to gather at the 5th International Dystonia Symposium, October 20–22, in Barcelona, Spain for an extensive, global exploration of what is known about dystonia, new questions to be pursued, and future strategies to grow the field.

This unique conference for dystonia specialists, clinicians, and researchers is a joint effort of the European Dystonia Federation, Dystonia Coalition, and the DMRF.

This meeting represents the latest chapter in a definitive series of truly international dystonia meetings hosted by the DMRF, the last of which was held nine years ago in Atlanta with 150 attendees. The 5th International Dystonia Symposium brings together renowned researchers and clinicians to deliver an extensive program of dystonia topics including clinical issues, functional anatomy, pathophysiology, genetics and molecular biology, treatments, and the very latest developments in treatments. The Symposium is the most thorough, comprehensive examination of dystonia to date.

The purpose is to expand knowledge in all areas of dystonia beyond current boundaries and to encourage the open discussion and debate which will yield further advances for the benefit of people who live with this debilitating disorder.

A report on 5th International Dystonia Symposium will be included on the DMRF website and information will be shared in future issues of the Dystonia Dialogue.

Dystonia 101

Dystonia can be a confusing disorder to understand. It never hurts to brush up on the basics:

- Dystonia is a neurological disorder. It affects the nervous system’s ability to control voluntary muscle movements.
- Dystonia does not affect smooth muscles, such as the heart.
- There are many forms of dystonia. It can affect a single body area or multiple muscle groups.
- Dystonia can exist on its own, or be a symptom of another neurological or metabolic disorder.
- In primary dystonia, the affected person has no other neurological symptoms and the dystonia is known or suspected to be genetic.
- In secondary dystonia, the symptoms can be attributed to an insult to the brain such as physical trauma, drug-exposure, or other diseases/conditions.
- People with secondary dystonia often have other neurological symptoms, some of which may affect more than just muscle movement.
- Each case of dystonia is classified by: the age symptoms started, whether it can be classified as primary or secondary, the body parts affected, and the presence or absence of other disorders.
- Treatment options include oral medications, botulinum neurotoxin injections, surgery, and less invasive methods such as physical and occupational therapy, and relaxation practices.
- Stress does not cause dystonia, but symptoms may worsen in stressful situations.
- Dystonia is not a psychological or psychiatric disorder.

For more information, visit http://www.dystonia-foundation.org
I am in seventh grade and I go to middle school in Massachusetts.

Dystonia makes my arms twitch and spasm uncontrollably. At times, my right hand is worse than the left which is lucky because I am left handed. Because of the dystonia, I have to stand up and clutch a pencil or pen with both hands when I write. When I play on my Nintendo DS, I must flip my right hand over so it won’t shake and mess up my game. I can’t always do other normal things because my arms shake. For example, I can’t lift certain items when setting or clearing the table, I have trouble carrying two or more things at a time, and I can’t participate in certain sports such as archery, darts, etc.

I have learned that dystonia is a hurdle. I’ll be confronted with it many times, but each and every time I will have to overcome it. There are some positive parts about dystonia. At school I get to use a netbook laptop and some groovy pencil grips. Sometimes, my teachers or group members write for me if I’m having a challenging time or when I can’t keep up when there is a lot of writing.

I have been playing tennis for over half a decade now. I am determined despite my dystonia because tennis involves hand and eye coordination. I also play the trombone which is sometimes a struggle. Recently, despite how challenging it is to draw, I started creating comics called “Noodle Warrior” and “Noodle Ninja.” I do a lot of other things too that aren’t affected by my dystonia like rollerblading and playing catch with my dog Georgie.

I would like the world to know that dystonia is just an obstacle and can be overcome. Plus, it’s only an obstacle for some things, not everything.

My advice is not to give up just because you may not be able to do one of your passions. If you keep going at it and (as I say) “don’t look down,” you’ll find a way to do it despite your dystonia so you can do anything you crave.

When I grow up, I hope to be a very inspirational person. I can do this by informing people about dystonia very openly so they can deal with it if they have dystonia themselves or know someone else who does.
Service Dog
By Joanna Manusov

My dad, who didn’t want another dog, got me a dog, sight unseen. A cute little black Pomeranian/Chihuahua mix.

It’s very funny to see my dad walking out of the laundry room with a tissue full of poop muttering, “Thank goodness I love this dog.”

Her name is Nicki and she puts my mom, dad, and me to shame. She’s too smart, and she knows it.

I once put her on my chair in my computer room so now, because she’s allowed on my chair, in her mind that seems to mean any unoccupied seat is fair game. After dinner most nights, we all migrate to the couch, always in the same order: dad’s first, mom’s second, and eventually I am third. One night dad looked at Nicki and then at us and said, “Why are we all squished on this couch?” Mom or I didn’t understand the question. Dad said, “Look at Nicki!” The dog was stretched out on the other couch, all by herself.

Dad got Nicki to eventually become my service dog. When I get anxious or stiff, just put Nicki on my lap and you can see me calm down. It’s not easy for me to speak, so she will start barking like a mad dog to tell the person I am with that I am going to have a dystonic attack. One thing that a service dog must be able to do is stay quiet. She tries, but it’s difficult. It just takes one person to stop and pet her and she becomes all excited and loony. Nicki may not always be in the mood to perform the tricks we taught her, or do her business outside, and she may not look like the assistance dogs we see trained for people in wheelchairs or people who are visually impaired, but we bonded very quickly. She kisses my face. Nicki is my service dog, and I love her very much.

Dynamic Duo

Sixteen-year-old Jessie Wolthius and 17-year-old Casey Gillett have used their musical and singing skills to raise money in support of the DMRF. They have performed for donations and have distributed DMRF brochures at public events. Jessie’s mother Melinda Wolthius is diagnosed with dystonia, and the entire Wolthius family are dedicated dystonia advocates.
PEOPLE ON THE MOVE

One of the most important strengths of the DMRF is the amazing nationwide team of volunteers in local communities. The DMRF is extremely fortunate to benefit from the hard work of individuals and families across the country who promote awareness and fundraise. Every effort and volunteer makes a difference! Sincere thanks to all our grassroots volunteers and supporters.

In July, Tammy Kinder held a dystonia information and donation booth in partnership with the Viet Nam Vets and Legacy Vets Motorcycle Club, Chapter “A” of Miami. Tammy’s booth was one of many at a benefit event for a local mission serving homeless and addicted veterans. The Viet Nam Vets Motorcycle Club donated $200 in support of the DMRF, and Tammy raised nearly $500 total. Wonderful work, Tammy!

Alice Schloen of New York lived with dystonia and essential tremor since early childhood but was not diagnosed until age 60 when her granddaughter Allison Peralta—and then daughter Carol Ann Peralta—were diagnosed with DYT1 dystonia. When Alice passed away earlier this year, the Peralta family asked mourners to donate to the DMRF in lieu of sending flowers. “My mother was a strong role model for myself and Allison. She proved that you can do whatever you want when you put your mind to it,” says Carol Ann. The DMRF extends deepest condolences and gratitude to the family of Alice Schloen for honoring her through such gracious support of the Foundation.

Inspired by his mother Yvonne McClanahan, Dystance4Dystonia volunteer Mark McClanahan of Colorado represents “Team Dystonia” in bike races throughout the state. His goal is to “start a team with jerseys that will be known across the country for dystonia.” Learn more about Yvonne’s experience with dystonia on page 18.

Wayne Erickson organized and hosted the 3rd Annual Minnesota Dystonia Golf Classic on August 19 in Hastings, Minnesota. Many thanks to Wayne and his committee for another successful event and his dedication to supporting the DMRF.

Nancy Present of St. Louis, Missouri conducted a letter writing campaign in August inviting family, friends, and colleagues to support dystonia research.

Dystance4Dystonia volunteer Tracy Jo Blowers of Minneapolis, Minnesota raised $1,500 this summer at the Urban Wildland Run in support of the DMRF, tripling her $500 goal. Tracy is diagnosed with cervical dystonia and uses her blog to promote awareness with regular “Dystonia Awareness Moments.”

Many thanks to Brittnie Ingo, Donna and Dave Haney, and their committee who organized and hosted their annual fundraising pub event in Naperville, Illinois in September. The event included an extensive raffle, great food, and lots of fun.

Pat Brogan of Hazleton, Pennsylvania, who appeared in the dystonia documentary film Twisted, competed in the Dewey Beach Sprint Triathlon on September 17. Pat reports, “Swim was tough, waves were huge, bike was great, run was wrenching, but after 1 hour and 15 minutes, Dystance4Dystonia wins!”

WINTER 2011
At a September meeting of the Dystonia Support and Advocacy Group of San Diego County led by Martha Murphy, movement disorder specialist Jennifer Friedman, MD and the Beery family were the guest speakers. Fifteen-year-old twins Alex and Noah Beery were diagnosed with dopa-responsive dystonia 10 years ago and recently underwent sophisticated genetic testing to customize their treatment plans, maximizing results. Parents Retta and Joe Beery are working to promote greater awareness of and access to this potentially life-changing therapeutic approach to genetic disorders.

Martha Murphy and fellow support group member Bette George staffed a table at the annual “Jobtoberfest” in San Diego, which is a job fair for individuals with disabilities. Approximately 1,500 people attended this year.

The 5th Annual Dystonia Golf and Tennis Classic and Banquet was held October 3 at Bretton Woods Country Club in Potomac, Maryland. DMRF Board Member Donna Driscoll and husband Tom Driscoll and their committee have worked extremely hard to make this event a success every year and have made significant contributions to the DMRF. The event included live music, silent and live auctions, and a gourmet menu.

The 2nd Annual Alabama Dystance4Dystonia 5K Run & Walk, which took place in September, was organized by the Dothan, Alabama Dystonia Support Group.

Rebecca Sharp and her parents Timothy and Virginia Hornsby spearheaded the planning for this event in acknowledgement of Timothy’s dystonia diagnosis in 2006. Many thanks to Rebecca and the Hornsby’s for their dedication to promoting awareness and raising funds for research. Timothy appeared on a local television news program to spread the word about the event and dystonia.

Walking doesn’t come easily to DMRF volunteer Joey Tehle of Boise, Idaho but she is having no trouble getting around on her trike. “It’s so slick and moves faster than a speeding bullet. I can adjust the speeds of the electric assist. I can just pedal too,” she explains.

On September 26, Joanna Manusov and parents Len and Janice Nachbar accepted a ceremonial resolution issued by the New Jersey Senate in the New Jersey Senate chamber, recognizing them for the work of the Central Jersey Dystonia Support and Action Group, which they lead. At the same time, Senator Jennifer Beck introduced a resolution to designate June as Dystonia Awareness Month in New Jersey each year. Terrific work!
Dystance4Dystonia is a program for volunteers interested in participating in local marathons, runs, and/or walks in support of the DMRF.

Dogs4Dystonia Dog Walks are a fun way to bring family, friends, and the community together in support of a good cause. Organizing a Dogs4Dystonia Dog Walk may just be up your alley.

For more information about Dystance4Dystonia or Dogs4Dystonia, contact Tammy Reed, Director of Development at 312-755-0198 or treed@dystonia-foundation.org

The Central Jersey Dystonia Support and Action Group also hosted the “6th Annual Dogs for Dystonia...a dog walk and so much more” October 9 at Turkey Swamp Park in Freehold Township. This event gets bigger and better every year. Activities included a dog walk, pet adoptions, costumed dog and child photographs, games, contests, demonstrations, vendors, and prizes.

Stacey and Mark Overton of Pennsylvania, whose 14-year-old son Jake Overton has dystonia, challenged friends and family to contribute to the DMRF’s Difference4Dystonia Challenge Grant. The Overtons invited their contacts to make a donation in support of the $100,000 matching grant, and in return the Overton’s offered to make a donation of equal amount to a charity of their friend or family member’s choosing. Cheers to the Overtons for finding such a creative way to support the DMRF! For more information on the Challenge Grant, see the back cover of this newsletter.

Carrie Siu Butt, Lizabeth Dunn, DMRF President Art Kessler, and Doug Walgren crossed the finish line at the Bank of America Chicago Marathon in October, running for Dystance4Dystonia. Inspiring!

Changing Hands: An Evening of Acoustic Guitar with Billy McLaughlin took place October 1 in Asheville, North Carolina to benefit the DMRF. This special concert was organized by board member Marilynne Herbert. Billy was elected to the DMRF board of directors earlier this year.

Many thanks to Carmelita De LaGuardia for organizing the 2nd Omaha Dogs4Dystonia Dog Walk, inspired by her sister Antonella Gosselin’s experience with dystonia.

“Faces of Dystonia” is for Families

The DMRF has created a mosaic of faces and stories from the dystonia community at http://www.dystonia-foundation.org/faces_of_dystonia. Individuals with all forms of dystonia are invited to participate by sharing a photo and completing a brief interview form. Family members are also invited to submit their stories. New profiles are posted every Tuesday.

To add your story to “Faces of Dystonia,” visit http://www.dystonia-foundation.org/faces
FDA Promotes Health Fraud Awareness

The US Food & Drug Administration (FDA) defines health fraud as the deceptive sale or advertising of products that claim to be effective against medical conditions or otherwise beneficial to health, but which have not been proven safe and effective for those purposes.

In addition to wasting billions of consumers’ dollars each year, health scams can lead patients to delay proper treatment and cause serious—and even fatal—injuries. Since the 1990s, peddlers of fraudulent “health” products have used the internet as a primary tool to hawk their wares.

Protect Yourself

In spite of efforts from the FDA and other agencies to protect people from health fraud, it is ultimately up to the buyer to beware of suspicious vendors. Be aware of the potential for health fraud and learn about the common techniques and gimmicks that fraudulent marketers use to gain your attention and trust.

For instance, testimonials from people who say they have used the product may sound convincing, but these can easily be fabricated. These "testimonials" are not a substitute for scientific proof.

Never diagnose or treat yourself with questionable products. Always check with your doctor before using new medical products.

Beware of Red Flags

Look out for these indications of potential fraud or false claims:

- Claims that a product is a quick, easy, effective cure-all for a variety of ailments
- Promotions using words such as “scientific breakthrough,” “miraculous cure,” “secret ingredient,” and “ancient remedy”
- Impressive-sounding words for a product or concept such as “cellular hyperstimulation point” and “deficient interneurological synthesis”
- Undocumented case histories by consumers or doctors claiming amazing results
- Limited availability and advance payment requirements
- Promises of no-risk, money-back guarantees
- Claims that the product is “natural” or “non-toxic.” This doesn’t necessarily mean safe.

Don’t be fooled by professional-looking websites. Avoid websites that fail to list the company’s name, physical address, phone number, or other contact information.

For additional information, go to http://www.fda.gov/ForConsumers/
There have been job gains in professional and business services, healthcare, leisure and hospitality, and mining. Employment in manufacturing has continued to trend up. So opportunities remain available, but the competition is stiff.

The Approach
Job seekers with dystonia need to be aware of what they want to do, their skills, and how the disorder affects them. Once that has been determined and you are aware of your strengths and limitations, begin looking for employment. Be sure your resume is up-to-date and professional, and take advantage of multiple resources to learn about job openings: websites, newspaper listings, Department of Labor offices, and word of mouth.

Once you get an interview don’t hesitate to ask for any accommodations that may help you during the interviewing process. After the interview you may want to tell the potential employer that you have dystonia and how it affects you. If you choose to do this, reassure them that you are capable of doing the job and that the dystonia does not hinder you from doing the work that may be asked of you.

There is no legal obligation for you to disclose a disability to a potential employer although there may be advantages in doing so. You must use your own judgment.

Legal Rights
The Americans with Disabilities Act (ADA) makes it illegal for employers to refuse to hire or promote disabled people and from discriminating against them in working conditions, wages, or benefits. Employers are prohibited from asking any job applicant medical questions or from putting such questions on job applications.

After you accept an offer of employment, the employer may ask medical questions or require a physical exam,
and may rescind an offer of employment if you would be unable to perform the essential functions of the job with or without reasonable accommodations. An employer must ask the same questions or require the same medical examination of all applicants for that job category.

A reasonable accommodation is a change or adjustment made to a job that allows a person with a disability to perform the essential tasks of that job. An employer must make a reasonable accommodation unless it causes undue hardship to the employer, which is defined as an action that is significantly difficult or expensive. If the cost of the accommodation will impose an undue hardship on the employer, the person with a disability must be given the option of paying that portion of the cost that would constitute the hardship for the employer.

**Employed But Job May Be in Jeopardy**

For many of us, jobs can easily become in jeopardy. Whether the job is being eliminated or your dystonia is becoming worse and you feel it is difficult to perform work related tasks, there are options for you.

If you feel the dystonia is hindering your ability to work you should talk to your employer to see if there is anything that can be done. Such things could be changing up work tasks, allowing for additional breaks, or working fewer hours.

If you feel your job is going to be eliminated you will likely qualify for unemployment benefits. In order to qualify for unemployment benefits, you must have worked a minimum amount of time at the job. If awarded unemployment, you will receive a percentage of what you made and you will have the option to keep insurance.

If you are unable to work because of your disability you may qualify for Social Security Income (SSI) or Social Security Disability Insurance (SSDI).

**Social Security Income (SSI) & Social Security Disability Insurance (SSDI)**

SSI is a United States government program that provides stipends to low-income people who are 65 or older, blind, or disabled. Today the program provides benefits to over 8,000,000 Americans.

SSDI is a payroll tax-funded, federal insurance program of the United States government. It is managed by the Social Security Administration and is designed to provide income supplements to people who are physically restricted in their ability to be employed because of a notable disability, usually a physical disability. SSDI can be supplied on either a temporary or permanent basis, usually directly correlated to whether the person’s disability is temporary or permanent.

Unlike SSI, SSDI does not depend on the income of the disabled individual receiving it. Most SSI recipients are below an administratively-mandated income threshold, and these individuals must stay below that threshold to continue receiving SSI, but this is not the case with SSDI.

**Resources**

While the current economic state is not ideal for anyone, especially those with disabilities, there are programs and groups that can provide assistance. One of the most important things is not to give up and not to allow dystonia control your life.

For a listing of links for additional information and guidance, visit www.dystonia-foundation.org and look under “Dystonia Dialogue.”

*Matt Lawrence is a career consultant with special expertise in advising individuals with disabilities. He has presented at DMRF educational events and been featured in DMRF publications. Matt has lived with early onset dystonia since childhood and resides in Austin, Texas.*
True Grit
Dystonia Treatment is a Journey

Even in the mildest or most manageable cases, dystonia is life-changing. Most people faced with dystonia encounter difficult, disorienting moments at one time or another. The trial and error period of treatment can be among the most trying moments. A therapy like deep brain stimulation is typically reserved for severe dystonia and there is often a lot at stake for those who undergo it. Individuals typically wait weeks or months to experience beneficial effects from the procedure, even in the best case scenarios.

The word “resilience” has become one of the latest buzz words used to describe how ordinary people adapt to extraordinary—often difficult—experiences. Resilience is that intangible quality that fuels optimism and perseverance, even against daunting odds. It’s that inner fire that allows some people to rebound from bad circumstances stronger than before, rather than letting failure devastate them. They find a way to get up and brush themselves off, with an open heart for what the next day will bring.

Psychologists have identified some of the factors that make a person resilient: a positive attitude, optimism, the ability to regulate emotions, and the ability to see hardship as a learning experience. The research suggests that while some people seem naturally resilient, resilience can also be learned.

Stephanie Zaia and parents John and Diane frequently attend DMRF events.

Since Yvonne McClanahan’s diagnosis, her son Mark has dedicated himself to promote awareness.
Yvonne

“I started my fight when I was 58 years old,” says Yvonne McClanahan of Michigan when describing the onset of her dystonia. Her eyes began to close involuntarily, eventually for several seconds at a time.

She could no longer drive safely, and had to abandon her career in real estate.

For four years Yvonne was referred from one doctor to another. In 2007, shortly after she was diagnosed with blepharospasm (dystonia of the eye lid and brow muscles) and began botulinum neurotoxin therapy, her head twisted to the right and fell forward toward her chest. She experienced involuntary movements in her mouth and tongue. The symptoms had spread to include oromandibular and cervical dystonias. “I felt like giving up,” said Yvonne. “You get to a point where you’re just exhausted.” After nearly another three years of escalating symptoms, additional referrals, new specialists, and the growing risk of requiring a feeding tube for nourishment, deep brain stimulation (DBS) was recommended. “Was I afraid? Yes, definitely,” says Yvonne. “No one wants two holes drilled in their head.” Yvonne and her son Mark (whom she refers to affectionately as her Medical Advisor) researched the neurosurgeon and sought out additional medical opinions before opting for the surgery.

Yvonne understood that the effects of DBS for dystonia are not immediate and that it may take weeks or months of adjustments to find the best setting. After 13 adjustments and no positive relief, she began to lose hope. “I again felt like giving up, but I couldn’t do it.” In March of 2011, Yvonne’s neurosurgical team recommended one more settings adjustment. “If this didn’t work after one week, I was to turn off the stimulator, wait another week and call him. We all crossed our fingers.” After the appointment, Yvonne and her husband visited the hospital cafeteria for lunch. “My neck started to straighten up as we ate,” Yvonne recalls. “By that night, I was pretty much straight and my eyes were not closing. I got my life back on March 10, 2011. I am able to drive. I have not felt this good since 2003. I am so thankful. Miracles do happen. Don’t ever give up!”

Yvonne is partnering with the DMRF to start a support group in her area and has inspired her son Mark to become an active fundraiser for research.

Stephanie

After four years of escalating symptoms, Stephanie Zaia of Massachusetts was diagnosed with idiopathic early onset, generalized dystonia in 2007. The progression was so severe she was cleared for deep brain stimulation (DBS) surgery within months of the diagnosis. The once athletic, active teenager had to depend on a wheelchair for mobility and her college search now included universities with solid resources for students with disabilities, not just outstanding academic programs.

Following the DBS, Stephanie explains, “At first I was doing well and I was ecstatic. I imagined getting out of my chair, walking, and even going back to competitive swimming.” 2007 was also the year Stephanie attended her first DMRF Children & Family Symposium in Chicago and met others her age with dystonia for the first time. The Symposium helped buoy her spirits even more.

Three weeks into her first semester at the University of Illinois, Stephanie experienced a dystonic storm so severe that doctors put her in a medically-induced coma in hopes her body would relax. Intense physical therapy followed, but overall her dystonia worsened. By the time Stephanie attended her second Children & Family Symposium in 2009, she was able to sit upright in her power chair aided by restraints and enjoyed the symposium even more than two years prior. A year and a half of hard work had led to steady improvements. Inexplicably, another dystonic storm in 2009 resulted in two weeks in the hospital and a month in a rehabilitation center. “My
post-storm situation hasn’t changed much in the last two years,” Stephanie now reports. “I am still unable to sit up at all and am forced to use a back brace and a neck brace so I don’t arch out of my power chair. I am on high doses of medications plus the DBS is still on and working. My right arm is the only part of my body that has become stronger.”

And yet, Stephanie insisted on attending the 2011 Children & Family Dystonia Symposium in August to meet up with friends from previous meetings and enjoy the unparalleled company of others who know dystonia firsthand. “Neither of the dystonic storms have stopped me from pursuing what I want in life,” says Stephanie. “Much of the coverage of DBS at meetings and in articles stress the success stories of those who have had DBS—as they should. But I want people in the dystonia community who don’t see the results they hoped for to realize they can still have a life, even with continuously active dystonia. And to know they are not alone. I want to help children and adults alike to understand that the hardships endured by someone with dystonia do not define what any of us can accomplish.”

Throughout her struggles, Stephanie has only missed three semesters of college. She continues to attend the University of Illinois, and will graduate in three semesters with a major in Community Health with a focus on rehabilitation and a minor in Speech and Hearing Science.

**Building Resilience**

Yvonne and Stephanie teach us that anything is possible, even against daunting circumstances. While diagnosis and treatment of dystonia have made undeniable strides in the past decades, finding the optimal treatment plan for each individual, even under the care of a dystonia expert, continues to be a process that unfolds over time.

The DMRF is pursuing all promising roads to new and improved treatments. The ultimate goal is a cure, and at the very least a new line of minimally invasive therapies that are safe, effective, and affordable for all individuals with dystonia. The DMRF acknowledges this reality cannot come soon enough.

For more information on developing resilience and navigating difficult times, see [http://www.dystonia-foundation.org](http://www.dystonia-foundation.org) under “Dystonia Dialogue.”

**Sources**

American Psychological Society
Mayo Clinic – Adult Education
Psychology Today

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**Genetic Researchers Need Your Help**

Finding genes associated with dystonia may be the key to understanding how to better treat or cure the disorder. A collaborative team from Beth Israel Medical Center and Mount Sinai School of Medicine is conducting a study aimed at finding these genes. If there are two or more living individuals in your family with any form of dystonia you may be eligible to volunteer for this important study. Participants will be asked to complete a short questionnaire and medical record release form, sign study consents, and give a blood sample. Your information will be kept strictly confidential.

You can help to unlock the mysteries of dystonia. For more information please contact:

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DMRF Partners with Harvard Brain Bank

You too can go to Harvard! But hopefully not for a long time. The DMRF is working with the Harvard Brain Tissue Resource Center (HBTRC) located at the McLean Hospital in Belmont, Massachusetts to establish a dystonia brain repository. The purpose of the repository is to advance important research, help researchers better understand this complex disorder, and ultimately find a cure. The donation of your brain, upon your death, may help unravel the mysteries of dystonia.

Frequently Asked Questions about Brain Donation

Is there a cost involved to participate as a donor?
No. The DMRF assumes all costs, so there is no expense to the family.

Do I need to live near Massachusetts to enroll as a potential brain donor?
No, but you must live in the United States in order to participate in this program. The Harvard Brain Bank works in conjunction with pathologists and funeral homes throughout the United States and will communicate with the specialists who actually collect the donated brains. They are then transported to the Brain Bank, preserved, stored, and made available for analysis.

Do you only need donated brains from dystonia-affected individuals?
No. In fact, we need brain donations from persons who have dystonia and those who do not. The latter are used for comparison purposes and are referred to as control subjects. So please encourage your family members and friends to also pre-enroll as donors.

If I sign up to be a brain donor, does that prevent me from donating other organs?
It may, depending on how long the procedure takes for retrieving the donated organs and how long the donor was on a respirator.

Does the Harvard Brain Bank accept whole body donations?
No. The facility is not equipped to receive such donations.

Will being a brain donor interfere with funeral arrangements or memorial services?
Absolutely not. You may have any sort of service or remembrance that you and your family desire. The brain recovery process is performed very discreetly and does not alter the outward appearance of the donor or cause any disruption in those plans.

Will the family of the donor receive any communication from the Harvard Brain Bank after their loved one has passed away?
Yes. The family will be asked to complete a questionnaire about the donor and will also be asked to grant permission for the donor’s medical records to be sent to the Brain Bank. The medical history and questionnaire are both important so the Brain Bank can reliably give researchers the correct tissue samples needed for their specific studies. When this information is received and after the tissue has been analyzed by the neuropathologist, the family will receive a copy of the final neuropathology report.

If someone has had the deep brain stimulation (DBS) surgery or another type of brain surgery, does that prevent them from participating as a brain donor?
No. Researchers want to study these brains and the donors’ medical records will provide needed information for researchers.

For more information about the DMRF’s brain donation program, go to: http://www.dystonia-foundation.org or contact us at 800-377-3978 or brainbank@dystonia-foundation.org
When and how did your symptoms begin?
In 2009 I began noticing that my head would pull down towards my right shoulder when I felt stressed or nervous. I had noticed a lot of tension in my neck, lower back, and hips for several years. By November I was tense, nervous, agitated all the time, and did not feel in good health. By December, my head began to shake at the end of the workday. I got worse and began to shake more during the day, uncontrollable spasms of my head, arms, back and hips. It was becoming dangerous to drive and impossible to perform my work duties. In March 2010, I was diagnosed with cervical dystonia. I had to leave my job. I began learning as much as could about this disorder. I found out my wife was pregnant with our fourth child and all I could do was rest most of the day.

How does cervical dystonia affect you in your daily life?
I got botulinum neurotoxin shots for the first time in 2010 which made things worse for a while, but subsequent shots have made me much better. My spasms are under control now, and I can drive and do more things. I get tired pretty quick and have to rest during the day. My biggest problem is that I don’t feel well a lot of the time and feel very cross. That is the worst—I try not to be crabby but am not always successful. I don’t feel I can keep a regular job. I may feel good one day and the next, who knows. I cannot go back to my career in chemical sales. I am totally sensitized to most chemicals now. They bother me and make me feel bad, and my symptoms worsen. I’m not really sure what I’m going to do at this point.

What have you learned from living with dystonia?
I’ve learned to slow down. I didn’t realize how busy I was until I got sick. My haunting hobby has been a great coping mechanism. I am a prop maker and I get to working on a new project, and I forget that I am sick and in pain. It’s great. I was able to make lots of new pieces for Halloween this year, but I work when I feel good for a couple of hours then have to rest. My wife is the best, helping me to stay positive.

Why is it important for you to be involved with the DMRF?
Dystonia turns a family’s life upside down. That person struggles with just basic tasks and cannot do as much. Taking care of small children is very difficult. I want people to know what dystonia is. I’m glad to talk about it. Promoting awareness is important to me. I’m very excited about our haunted attraction—I think it will get people asking questions.

If someone really knew you, what would they understand about you?
I refuse to let dystonia define who I am. Dystonia has been a blessing and a curse. I have lost my health and my career, but I have gained more peace in my life as has my entire family. We eat dinner together every night, and I got to watch my kids all summer. My wife’s schedule is easier because I take care of things at home, especially with the kids and their school.
FOCUS ON DOPA-RESPONSIVE DYSTONIA

Meet Jamie Klein

Jamie Klein is a 16-year-old junior in high school who, despite dopa-responsive dystonia, recently made Captain of the track team.

When and how did your symptoms begin?
From the day I started walking, I had “pigeon toed” feet, meaning my feet pointed inwards. I never grew out of it. My feet became very painful. If I tried to untwist my legs, they would not budge. I went from doctor to doctor. In eighth grade I was miserable. I went through painful physical therapy, lots of tests. My legs grew worse. No one understood my pain. My physical therapist believed that I was faking it. I had to sit out of gym. I came home crying from physical therapy and just begged for surgery to fix my legs. I had been seeing an orthopedist who was collaborating with a neurologist. He had run dozens of tests. In 2010 he diagnosed me with adolescent onset, dopa-responsive dystonia.

What medical treatments help you the most?
I started going to a movement disorder clinic in New York City which specializes in dystonia. My doctor started me on a medication regimen. We experimented with different dosages until we found the one that gave me the most success.

What helps you cope?
When I started high school, I joined the cross-country team. I wanted to do a sport and decided that I would not let my disability stop me. I ran five miles a day like every other girl. I endured the pain, and it was worth it. I had a passion for the sport, something I had never truly had for anything else. I never sat out no matter how much pain I was in. Everyone would ask me how I run with my feet twisted, and I would always reply, how do you run with your feet straight? I was so determined. I made some of my closest friends on track. I impressed my coaches that I never used my disability as an excuse.

How does dystonia affect your daily life?
After my doctor found a medication that worked for me, I ran every morning over the summer with a goal to be one of the ten girls to make varsity cross-country. After lots of hard work and determination I made the varsity team. I then made the conference championship team, which only seven of the ten varsity runners make. Conference Championships was one of the best moments of my life, running through the finish line, people were cheering my name. I have become extremely strong and nothing can stop me from reaching my goals. I live every day knowing I am dystonic, but that’s just who I am and I don’t let it define me.

Why is it important for you to be involved with the DMRF?
I want my story to help other people not let anything get in their way. Anything is possible! Whatever hurdles you face, with determination you will always be able to jump over them. I am extremely lucky that I have done so well with my treatments, most people don’t which is why research and awareness for the disorder are essential. I wish everyone with the disorder could respond as well as I did.
Difference4Dystonia: Every Gift Makes a Difference

As we go to press, the DMRF is closing in on the Difference4Dystonia Challenge Grant goal of $100,000! All new donations up to the $100,000 goal will be matched dollar for dollar by a generous anonymous donor, doubling the total amount raised.

Many thanks to those of you who have stepped up to the challenge and made a donation toward this effort. Your generosity is making a difference. If you have not yet responded, there is still time! Please consider supporting the work of the DMRF and the Difference4Dystonia Challenge with a gift.

How does the challenge grant work?
For every new dollar raised, the DMRF will receive a matching amount. So, if you raise $10, the DMRF will receive an additional $10. If you raise $250, the DMRF will receive an additional $250. If you raise $5,000, the DMRF will receive an additional $5,000.

What does this grant mean?
The DMRF is putting your donations to work and doubling the amount of money raised in support of the programs that are taking us one step closer to a cure.

For more information on how you can contribute to the Difference4Dystonia Challenge Grant campaign, please contact Tammy Reed at treed@dystonia-foundation.org or 312-447-5098, or visit http://www.DMRFevents.org/event.php?457209