



DYSTONIA MEDICAL RESEARCH FOUNDATION
NEW JERSEY CHAPTER

10th Annual
**NEW JERSEY DYSTONIA
GOLF INVITATIONAL**



Thursday, June 17, 2010

Green Brook Country Club
100 Greenbrook Road • North Caldwell, NJ

Joe & Kathy Grano
are proud to support
The Dystonia Medical Research Foundation
and congratulate
E. Michael Shine
on this well deserved honor.



Dear Friends,

For years, the New Jersey Chapter of the Dystonia Medical Research Foundation (DMRF) has distinguished itself as a powerhouse for supporting research. This year's honoree is a long-time, dedicated contributor to the New Jersey Chapter and I am extremely pleased to congratulate E. Michael Shine for this special acknowledgment.

The Annual New Jersey Dystonia Golf Invitational is a perennial success thanks to the generous support of patrons like you. Your support is helping the DMRF find a cure for this devastating disorder.

Your support has already changed my life. I believe in the power of dystonia research because my story is a living example of its progression. I have directly benefited from science advancements the DMRF helped make possible.

I was diagnosed with dystonia at 12 years old, after four years of unexplained symptoms. As an adult I learned I was positive for the DYT1 dystonia gene mutation, which was discovered by DMRF-funded scientists. My two sons were conceived through a form of *in vitro* fertilization that ensured they would not inherit the mutated gene. They are dystonia free, and it still takes my breath away that they were spared from the disorder that stole so much of my childhood. In 2007 I had deep brain stimulation surgery, and the results have been amazing. My wife and sons have a husband and father who, despite having dystonia, is physically able to be active and fully engaged. None of this would have been possible without the work of the DMRF.

My story is proof that the DMRF is making a difference. Dystonia research is giving people like me the chance to live without constant pain and in greater control of my own body. We must keep working until every individual with dystonia experiences the level of benefit that I have. Every year in my work with the DMRF I have greater optimism—and the science shows greater evidence—that we are on the right track toward better therapies and a cure. Your support has already helped change my life and the life of my children, and for that I am infinitely grateful.

Thank you for your continued commitment to the DMRF and dystonia research.

Sincerely,

A handwritten signature in black ink that reads "Art Kessler". The signature is fluid and cursive, with the first letters of the first and last names being capitalized and prominent.

Art Kessler
President
Dystonia Medical Research Foundation

CONGRATULATIONS TO
E. MICHAEL SHINE
PARTNER, THE GMS GROUP, LLC
ON RECEIVING THE
DYSTONIA CIRCLE OF FRIENDS AWARD



We are proud to support

The Dystonia Medical Research Foundation



DYSTONIA CIRCLE OF FRIENDS AWARD 2010 HONOREE

E. Michael Shine
GMS Group, LLC

The Dystonia Medical Research Foundation (DMRF) is pleased to honor E. Michael Shine with this year's Circle of Friends Award.

Mr. Shine has worked on Wall Street since 1975 as a municipal bond trader and salesman for firms including Dillon Read, Glickenhau, and Cowen & Company. For the past 15 years he has been a partner with GMS Group, LLC, a national brokerage firm.

A 1970 graduate of Villanova University, Mr. Shine earned a Bachelor's degree in Arts and Sciences. He went on to earn an MBA in Accounting and Taxation from Fairleigh Dickinson University in 1973.



Mr. Shine was diagnosed with spasmodic torticollis/cervical dystonia at Columbia University Medical Center in 1986, shortly after his symptoms began. For over 10 years, he shared his diagnosis with virtually no one. Approximately 12 years ago, he reached out to find a dystonia support group and became a member of the DMRF New Jersey Chapter. Since that time, he has served as a mentor for newly diagnosed patients, faithfully attended Chapter meetings, and became a passionate fundraiser. Mr. Shine has made every effort to support the DMRF in any capacity, and acknowledges what a personal help it has been in his journey with dystonia to meet others living with the disorder.

"The people of the DMRF are friends for life," says Mr. Shine. "We're trying to help each other and find the cure."

Mr. Shine resides in Morristown, New Jersey with his wife Kathy. Together they share a common goal of living with dystonia and supporting the DMRF. The DMRF is deeply appreciative of Mr. Shine's commitment and partnership.

Previous Dystonia Circle of Friends Honorees

- Dr. Michele Tagliati, Mount Sinai School of Medicine (2008)
- Dale Dirks, Health & Medicine Counsel of Washington (2007)
- Shawn Patrick O'Brien, Solstice Neurosciences (2006)
- David M. Pernock, GlaxoSmithKline (2005)
- John D. O'Neill, Clark-O'Neill (2004)

ACKNOWLEDGEMENTS

We thank all of the companies and individuals who have generously sponsored or have provided gifts or in-kind donations making this 10th annual event a success.

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Our sincere apologies to any individual or organization whose name may have been omitted in error or who has fallen victim to the evils of typographical errors.

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In support of Michael Shine
and the Dystonia Medical Research Foundation in 2010!



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*5N Regent Street, Suite 513
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in improving the lives of those
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Michael—

*Congratulations on your selection as the
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*Hope it's a fantastic
event.*

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dys·to·ni·a (dīs-tō'nē-ə)

n. Abnormal tonicity of muscle, characterized by prolonged, repetitive muscle contractions that may cause twisting or jerking movements of the body or a body part.

dys·ton'ic (-tōn'ik) *adj.*

Simply, dystonia is a *movement disorder* that causes muscles to contract and spasm involuntarily. Presently, there is no cure.

Blepharospasm affects the eyelids, causing them to close.

Oromandibular Dystonia affects the muscles of the lower face causing them to pull or contract. Blepharospasm may be present.

Spasmodic Dysphonia affects the muscles that control the vocal cords, making it difficult to speak.

Cervical Dystonia/Spasmodic Torticollis affects the neck muscles, turning the head to the side or pulling it back or forward.

Writer's Cramp is a focal hand dystonia which affects the fingers, the hand, and the forearm, and occurs when the person attempts to write or perform fine hand functions.

Generalized or Early-Onset Dystonia usually begins with the limbs, especially the foot and the arm, affecting most of the body.

Inherited forms of dystonia include:

- Early-Onset Childhood
- Dopa-Responsive Dystonia
- Paroxysmal Dystonia
- X-linked Dystonia-Parkinsonism
- Myoclonic Dystonia
- Rapid-Onset Dystonia-Parkinsonism

Focal forms of dystonia usually affect one part of the body as illustrated above.

Secondary forms of dystonia are a result of varying causes including birth injury, trauma, stroke, and drug-induced (tardive dystonia).

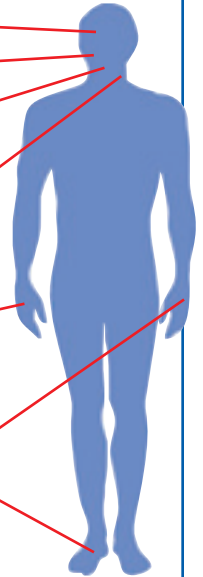
Dystonia is the **third most common movement disorder** after Parkinson's Disease and Tremor, affecting more than 300,000 people in North America.

Dystonia **does not discriminate** — any one at any time (all races and ethnic groups). It is not fatal, nor does it affect intellect.

Dystonia **can be hereditary or result from a brain injury**. Although there is no known cure for dystonia, treatments are available, including drug therapy, botulinum toxin injections, and several types of surgery.

Since its establishment in 1976, the Dystonia Foundation has funded millions of dollars in research grants, established support groups for people with dystonia and their families, and continues to battle misdiagnosis through expanding educational and awareness programs.

- **In 2010, the DMRF is funding more science than ever before**, continuing on in our commitment to make science a priority. The DMRF has been behind most of the scientific breakthroughs critical to understanding dystonia, from the identification of the DYT1 gene to the most recent genetic and protein research on various dystonia.



- Working in partnership with the Foundation for Dystonia Research, the **DMRF launched a \$1.8 million dollar research contract to identify and validate novel molecular targets for dystonia drug discovery and development.** This project is possible because of the many years of research the DMRF has supported – including the DMRF funded discovery of the DYT1 gene in 1997. The first phase of this enormous scientific project was completed in 2009.
- Additionally, the **DMRF is contracting for the development of a new animal model for dystonia.** This is also important for drug discovery/development.
- **DMRF continues to hold discussions with pharma to engage them in dystonia.** Last year, significant meetings were held and we are optimistic about the interest expressed in dystonia – developing into additional, new treatments for dystonia.
- **The Children & Family Symposium was a major success** – with many new families learning that they are not alone. This combined with our ongoing educational efforts and the fabulous support/education efforts of our support groups has provided accurate information to thousands of people.
- **The Dystonia Coalition – the clinical research program approved by NIH** is a major step forward for the community. The DMRF is proud to serve as an administrative center for this important program – providing administrative support for meetings, payments to the clinical sites, pilot projects and this past year, to have co-sponsored the Career Development Award.
- Last – but certainly not least – we are **grateful to join with our advocacy partners** the Benign Essential Blepharospasm Research Foundation, DySTonia, Inc., the National Spasmodic Dysphonia Association and the National Spasmodic Torticollis Association **in celebrating the addition of dystonia to the list of eligible diseases for funding through the Congressionally Directed Medical Research Program.**

**The Dystonia Medical Research Foundation is fighting for the
FREEDOM TO MOVE for people affected by dystonia.**



DYSTONIA
MEDICAL RESEARCH FOUNDATION

For more information, contact:

**Dystonia Medical Research Foundation
National Headquarters**

One East Wacker Drive • Suite 2810
Chicago, IL 60601-1905

Phone: 312-755-0198

Toll free: 800-377-DYST (3978)

Fax: 312-803-0138

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William Wade

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New Jersey Dystonia Golf Invitational*

Brian C. Heytink



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We are two Grandmothers.
We have many grandchildren but share only two.
Two grandchildren who live 24/7 with DYT1 Dystonia.

You bet your trifocals that we
support the efforts of the
Dystonia Medical Research Foundation
and the New Jersey DMRF Chapter.

We also offer our heartfelt thanks
to each and every individual,
company and organization that supports
DMRF in its fundraising efforts.

We know firsthand how each research dollar
benefits dystonia patients;
that through research, the DYT1 gene was identified
only two years after our grandson was born;
that the pain and twisting in our
granddaughter's hands can be halted
with a combination of therapies;
that Deep Brain Stimulation (DBS) surgery
was attempted in dystonia patients and now
gives our grandson control over his body.

He has control to walk, to sit, to stand.
Control to take a shower and play basketball.

She is regaining control to hold a pen and write.
Control to hold a knife and fork without pain and,
yes, to play basketball and softball.

for Jack and Lydia Nathans
and every grandchild affected,
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Mary Calvert Heavilin & Zita Nathans



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