



WINTER 2005

Scientists Review Clues in Latest Findings at Dystonia Think Tank

Noted scientists and clinicians recently came together in New York for a one day Think Tank that centered on the pathophysiology of dystonia. Organized for a third year by The Bachmann-Strauss Dystonia & Parkinson Foundation, this important forum enabled researchers from around the globe to share knowledge and discuss new research developments in an effort to better understand what causes this devastating disorder.



From left: Drs. Andres Lozano and José Obeso with Think Tank co-chair C. Warren Olanow, MD.

Key to their focus was the recent discovery of protein clumps found in an area of the brain around the area known as the pedunculopontine nucleus or PPN in some people with dystonia.



Think Tank co-chair Susan Bressman, MD with Xandra Breakefield, PhD

The experts reviewed and discussed the need to better understand the PPN and determine what role this aggregation plays. They also spoke of the necessity of continuing research to see whether the disease might result from a failure of signals in the brain. Sharing data and techniques and synthesizing multiple data sources to see where the pieces of the puzzle fit together will be key to advancing progress. Most important will be the availability of more research resources, particularly post-mortem brain tissue from people with dystonia.

Teva Neuroscience generously provided funding for the 2004 Think Tank.

New Study Sheds Light on Early-Onset Dystonia

Newly-conducted research, recently published in "Human Molecular Genetics", produced a genetically-altered mouse model with early-onset dystonia. Demonstrating behavioral and pathologic features similar to patients with early-onset dystonia, this important finding may help to better understand the pathophysiology of this disorder to develop more effective therapies. Dystonia that occurs in humans from childhood up to age 26 is classified as "early-onset."

Funded by The Bachmann-Strauss Dystonia & Parkinson Foundation, this breakthrough research was conducted by a team led by Dr. P. Shashidharan of the Mount Sinai School of Medicine.

Billy Crystal Draws Top Showing



From left: Bonnie Strauss, Dr. C. Warren Olanow, and Patti Kenner.

With a waiting list to join us for Billy Crystal's "700 Sundays", our fall theater benefit generated a record \$120,000 in support of Parkinson's disease research at Mount Sinai Medical Center.

Parkinson's disease is most common in people over 50. The size of the 50+ population is expected to more than double over the next 35 years, bringing increased urgency to fund aggressive research.

Many thanks go to all those who joined us. Special thanks to Patti Kenner, and to Billy Crystal and Harper Collins who donated copies of Billy Crystal's new children's book, "I Already Know I Love You" to our guests.

How Can You Help?

Your support makes all the difference. Please make a generous tax-deductible contribution in the enclosed envelope or online at www.dystonia-parkinsons.org

Symposia Links Patients and Families to Latest Information

Anyone who comes to our annual symposia gets a very poignant view of the urgent need for help. This fall showed a 30% increase in attendance as patients, families and healthcare professionals came to learn about the latest research and treatments and pin their hopes on cures.

Held at Mount Sinai Medical Center in New York City, the free symposiums – on Parkinson's disease and on dystonia – featured presentations by specialists and a rare opportunity for patients to ask direct questions of the doctors. Speakers' topics focused on what goes wrong in dystonia, surgical approaches to dystonia, the genetics of dystonia and Parkinson's disease, and pain in Parkinson's disease: mainstream and alternative approaches.

We are most grateful to Teva Neuroscience and Medtronic for funding this event. Our appreciation also goes to Ron Alterman, MD, Susan Bressman, MD, Alan Carver, MD, Horacio Kaufmann, MD, and C. Warren Olanow, MD for their participation.

A Strong, New Look Forward

Since the founding of our organization a decade ago, we have steadily invested in scientific investigation that has expanded knowledge of Parkinson's disease and dystonia.

These tangible results include finding the gene that causes DYT1 dystonia and broadening the understanding of the function of the protein, torsin A, that is mutant in DYT1 dystonia. It has enabled development of a genetically-altered mouse model to help understand the mechanism responsible for dystonia and develop new treatments that prevent or reverse this problem; and to detect the site of pathology in DYT1 dystonia, unknown up until now.

While cures for these devastating diseases still remain elusive, we are getting closer every day. Thanks to the support of so many friends, we start the new year with tremendous promise.

As we enter this new decade of our growth I am pleased to welcome our new Executive Director, Helen Miller. Under her leadership and enthusiasm, we will look at new initiatives and continue to build effective, alliances that bring positive, measurable results.

I thank each of you for your support and your involvement and extend my thanks and warm wishes for a strong, healthy New Year.



BONNIE STRAUSS
FOUNDER AND PRESIDENT

Helen H. Miller Takes the Helm as Executive Director



HELEN MILLER
EXECUTIVE DIRECTOR

Helen Miller comes to the Foundation with a solid healthcare background. Prior to joining us she developed and managed the Cancer Prevention and Wellness Program at Memorial Sloan-Kettering Cancer Center in New York and, previously, she was Director of the HealthOutreach Program at The New York Presbyterian Hospital – Weill Medical Center.

Helen holds a Masters in Social Work from Columbia University. An avid sailor, she has top notch skills in executive/administrative management and in building successful collaborative efforts.

Her focus will be to enhance the Foundation's ability to fund cutting-edge research and to expand its leadership role in this country and abroad. Key to this goal will be developing new revenue streams and strengthening its educational component.

New Grants Awarded

The Bachmann-Strauss Dystonia & Parkinson Foundation recently awarded \$850,000 to further understanding of dystonia and Parkinson's disease. This funding includes support to individual researchers working in laboratories around the world, a grant to the Dystonia Medical Research Foundation to augment their grants and funding to The Michael J. Fox Foundation to continue our collaborative studies. Following highlights 11 new grants awarded for study in 2005 based on recommendation by our Scientific Advisory Board.

DYSTONIA RESEARCH

Pradeep G. Bhide, PhD

Massachusetts General Hospital, Charlestown, MA

Developmental Origins of Dystonia

This investigation centers on whether early-onset dystonia, which may appear in children one-10 years of age, stems from defective developmental processes caused by mutations in the gene responsible for this disease.

Guy A. Caldwell, PhD and Kim A. Caldwell, PhD

The University of Alabama, Tuscaloosa, AL

Proteomic Analysis of Torsin Effectors & Functional Interactions Pertaining to Dystonia

At least 14 hereditary dystonias are known to exist but not all the genes responsible have mutations. Using the roundworm *C. elegans* as an animal model, this research will identify possible genes for human geneticist's study.

Kevin McNaught, PhD and C. Warren Olanow, MD, FRCPC

Mount Sinai School of Medicine, New York, NY

★ Neuropathology in DYT1 Dystonia

A severe form of dystonia is caused by a defect in the DYT1 gene which results in an abnormal form of the protein torsinA. This project will determine if mutations in DYT1/torsinA causes nerve cell death in the brainstem and other regions in patients with DYT1 dystonia.

Laurie Ozelius, PhD, Albert Einstein College of Medicine, Bronx, NY

and Susan B. Bressman, MD, Beth Israel Medical Center, New York, NY

Studies Aimed at Identifying a Gene for Cervical Dystonia

Cervical dystonia, characterized by twisting contractions of the neck muscles, is the most common form of dystonia in adults. This study looks at the genetic links and commonalities among 20 families.

P. Shashidharan, PhD and Ioanna Armata, Graduate Student

Mount Sinai School of Medicine, New York, NY

Characterization of Transgenic Mice Expressing Wildtype and Mutant TorsinA

TorsinA, the protein discovered to be encoded by the DYT1 dystonia gene, will be further examined to determine how it impacts cellular function in transgenic mice.

Sigurlaug Sveinbjörnsdóttir, MD and John Hardy, PhD

Landspítali University Hospital, Reykjavik, Iceland

Genetic & Epidemiological Assessment and Analysis of Idiopathic Dystonia

This aims to map the annual incidence of dystonia in Iceland, looking at genetic linkages and whether there is a genetic defect causing non-generalized dystonia.



Ruth Walker, MD and P. Shashidharan, PhD
Mount Sinai School of Medicine, New York, NY

Neuropathology of TorsinA Transgenic Mice

Further studies on transgenic mice will look at the connections between neurons in different brain regions to see if cells have died and if there are signs of cell damage to the brain and to better understand how the dystonia gene affects the brain.

Zhenyu Yue, PhD

Mount Sinai School of Medicine, New York, NY

★ Generation of Dystonia Mouse Model by a BAC (Bacterial Artificial Chromosome) - Mediated Transgenic Approach

Using a newly-developed strategy of studying biological functions, this investigation on a mouse model will help identify the primary neuron types that are affected and responsible for human dystonia symptom and will also examine possible cellular dysfunction and stress.

PARKINSON'S DISEASE RESEARCH

Kevin McNaught, PhD and C. Warren Olanow, MD, FRCPC

Mount Sinai School of Medicine, New York, NY

Can Environmental Proteasome Inhibitors Cause Parkinson's Disease?

This project aims to determine if exposure to environmental toxins derived from plants and food can cause Parkinson's disease symptoms in rats, since this represents a likely means by which humans may be exposed.

Venugopalan Nair, PhD, Stuart C. Sealfon, MD and C. Warren Olanow, MD, FRCPC

Mount Sinai School of Medicine, New York, NY

Studies on Neurotoxin Induced Early Signaling Mechanisms

This investigates how neurons respond to toxins before the cells have died or show symptoms of neuronal dysfunction.

Jan-Willem Taanman, PhD and Anthony H.V. Schapira, DSc, MD, FRCP

Royal Free University College Medical School, London, England

PINK1: Distribution, Function and Effects of Loss-of-Function

Study of the function of the PINK1 gene aims to determine under which circumstances this gene modifies proteins and unravel how mutations of the gene result in disease.

★ *These grants were funded through the generosity of the Spielberg family of Louisville, KY in honor of their son Jacob, who has dystonia.*

New Members Appointed to Foundation's Boards

We are pleased to welcome Masahiko Kasuga, President and CEO of Green Stamp America, to our Board of Directors.

Joining our Scientific Advisory Board are: Susan Bressman, MD, Chair, Allan and Barbara Mirkin Department of Neurology, Beth Israel Medical Center, and Xandra Breakefield, PhD, Professor of Neurology, Massachusetts General Hospital. (See photo on page 1.)

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The Bachmann-Strauss Dystonia & Parkinson Foundation, Inc. was established in 1995 to find better treatments and cures for the movement disorders dystonia and Parkinson's disease, and to provide medical and patient information. An independent, nonprofit, 501(c)3 organization, its funding is made possible through the generosity of individual and corporate contributors.

“Love Life” Wristbands Raise Support for Dystonia Research



When Jacob Spielberg (left) was diagnosed with dystonia his family pulled together and began a letter writing campaign to support vital research. Now 12-year old Nathan Spielberg is expanding their outreach in a new venture to help his younger brother, Jacob.

Nathan wanted to make a bracelet that he could sell to his friends and help raise awareness of dystonia. “This is a cause that is very close to my heart,” he said simply.

Imprinted with the words “Love Life”, the bright red rubber wristbands are already a big hit. His idea was so successful that 10,000 wristbands sold out in the first four weeks. A second shipment has been ordered. At \$1.00 each, the bands come in packets of 10, 25, 50 and 100. Proceeds benefit The Bachmann-Strauss Dystonia & Parkinson Foundation.

To order “Love Life” wristbands, go to www.dystonia-parkinsons.org.



Shared Goals and Collaborations Strengthen Efforts

Michael J. Fox with Bonnie Strauss at “Breaking PARKinson’s,” his Foundation’s golf outing to benefit Parkinson’s disease research. For the past two years The Bachmann-Strauss Dystonia & Parkinson Foundation has collaborated with the Michael J. Fox Foundation to study dyskinesia – the uncontrollable movements that often result from Parkinson’s disease treatment. These movements are similar to the muscle spasms seen in dystonia.



Supporters of stem cell research came together at a bi-partisan pre-election cocktail reception at the home of Bonnie and Tom Strauss to meet Senator Arlen Specter (R-PA), who has been a staunch advocate for government funding of stem cell research. From left, Tom Strauss, Vicki Modell, Bonnie Strauss, Joan Specter and Fred Modell. The Modells established the Jeffrey Modell Foundation, dedicated to curing primary immunodeficiency diseases.

Renowned pianist Leon Fleischer with Helen Miller, Executive Director of The Bachmann-Strauss Dystonia & Parkinson Foundation, at New York’s Symphony Space in celebration of his new CD, “Two Hands.” The event was sponsored by the Dystonia Medical Research Foundation. This new recording marked Mr. Fleischer’s return to playing with both hands since he lost the use of his right hand to focal dystonia in 1965. Now, thanks to treatment advances, he recently regained its use. He is actively helping to increase understanding of the disorder and its debilitating impact on many musicians.





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SAVE THE DATE 2005

Monday, June 20
The Hedi Kravis Ruger Tournament

Mark your calendar now for the 13th annual Dystonia & Parkinson's Pro-Am Golf Invitational at the Century Country Club in Purchase, NY.

For reservations or more information call 212. 241-5614 or email Bachmann.Strauss@mssm.edu.

Kenneth Cole Hosts a Night of Shopping

As we go to press, fashion designer Kenneth Cole will hold a night of shopping in his Rockefeller Center store on Thursday, February 3, donating 20% of the evening's sales to benefit our Foundation. The event is sponsored by our Young Professionals Committee and is open to people of all ages.

DID YOU KNOW...

Dystonia is a neurological disorder that causes uncontrollable, painful spasms in one or more parts of the body. An estimated 500,000 Americans suffer with dystonia and one third of all patients are children. Dystonia affects more people than Muscular Dystrophy, Huntington's disease and Lou Gehrig's disease.