



First Dystonia Center of Excellence to Open

New York City's Beth Israel Medical Center will be the site of the nation's first ever Bachmann-Strauss Dystonia Center of Excellence. Slated to open in September 2009, Susan Bressman, MD will head the new facility, which will bring together clinical care, research, fellowship training, and easier access to care for dystonia patients. Dr. Bressman is Chairman, The Alan & Barbara Mirken Department of Neurology, Beth Israel Medical Center, and Professor of Neurology, Albert Einstein College of Medicine, New York City.

The Bachmann-Strauss Dystonia Center of Excellence was made possible through a single \$475,000 gift by an anonymous donor. These funds, to be used over a two year period, provided seed money to establish the Center. Beth Israel will raise additional money to continue the program.



Dr. Susan Bressman talks with a patient.

At the end of January our Foundation sent out a "Request for Proposal" (RFP) for the creation of the new site. Applications from around the country were evaluated by our Scientific Advisory Board in early spring and awarded to Dr. Bressman, a noted specialist in

movement disorders.

While centers of excellence do exist around the country for Parkinson's disease and Alzheimer's, this is the first of its kind for dystonia.

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Breakthrough Study Identifies Cause of DYT6 Dystonia

A recent research study identified mutations in the THAP1 gene as a cause of primary torsion dystonia (DYT6 type) in Amish-Mennonite families and cited another mutation in a non-Mennonite family showing that THAP1 causes dystonia in other ethnic groups. A second study found that a substantial proportion (25%) of families of European ancestry with non-DYT1 early-onset dystonia have mutations in this new gene.

Both studies, which were funded in part by the Bachmann-Strauss Foundation, contribute to better understanding of this little-known disease and may lead to development of new therapies.

Study co-investigators: Susan Bressman, MD, Chairman, The Alan & Barbara Mirken Department of Neurology, Beth Israel Medical Center; Professor of Neurology, Albert Einstein College of Medicine, New York City. Laurie Ozelius, PhD, Bachmann-Strauss Professor and Associate Professor of Genetics and Genomic Sciences and Neurology at Mount Sinai School of Medicine, New York City.

Exploring the Overlap between Parkinson's Disease and Dystonia



At a recent meeting hosted by The Michael J. Fox Foundation for Parkinson's Research, Ted Dawson, MD,

PhD, led a discussion among scientists urging them to focus on dystonia along with their study of dyskinesia.

Dyskinesia is an involuntary, uncontrollable movement that is a frequent side effect of treatment and that is distinct from the tremors commonly associated with Parkinson's disease.

"It's important to see what scientists can learn from one another in this area and there's a good rationale for scientists to study it," said Dr. Dawson, Director of the Parkinson's Disease and Movement Disease Center, Johns Hopkins University School of Medicine. "Potential new treatments for dyskinesia may well be beneficial for dystonia since both are hyperkinetic movement disorders and many patients with dyskinesia also have dystonia."

The Bachmann-Strauss Foundation is the lead partner with The Michael J. Fox Foundation in the study of dyskinesia. Ultimately the Foundation hopes to leverage dyskinesia research into new treatments for dystonia.

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This multidisciplinary center will bring together neurologists, surgeons, psychiatrists, genetic counseling and other therapists as needed to confer about a patient's diagnosis and a treatment plan. "It has been sorely needed for some time," says Dr. Bressman. "There's no place else where you can get that for dystonia."

By combining it with an onsite research component and training, Dr. Bressman points out that it will help to move the science forward since the patients will be invited to participate in research and clinical trials. "By training fellows so they acquire clinical and research skills, we will be carrying our mission forward, developing the next generation of dystonia experts," she says.

It is hoped that the Bachmann-Strauss Center of Excellence will be replicated around the country in years to come.

The Roots of Progress

The growth of our research investments and its solid outcomes are tribute to our supporters who make it all possible. As a result of *your* trust and *your* generosity, we are helping some of the most talented researchers in the field of movement disorders to gain more insight into dystonia and Parkinson's disease and achieve progress that wouldn't otherwise be possible.



BONNIE STRAUSS
FOUNDER AND PRESIDENT



HELEN MILLER
EXECUTIVE DIRECTOR

Funding early stage research has proven ability to move science forward – and that, after all, is our goal. We actively follow the careers of the scientists who received Bachmann-Strauss funding, and are gratified by their ability to leverage our funding and make more progress in their work as a result.

It is very exciting to be at the point where we can apply knowledge gained in a research lab to help patients. The opening of the first Bachmann-Strauss Dystonia Center of Excellence brings together expert patient care with research and training. It fills a critical need and will serve to expand our knowledge even further. It is, we hope, the first of many nationwide Centers.

This newsletter reports on an increasingly diverse level of support that makes these roots of progress possible. A large, one-time grant enabled the creation of this premier Center. Individual supporters of our signature golf event, TEAM Bachmann-Strauss marathon runners, and the tremendous grassroots commitment behind Jake's Ride and other local events fund research grants and every other aspect of our work. Our heartfelt thanks and admiration go to those of you who are helping us to help so many people now and in the future.

Foundation Research Portfolio Broadens

Growth and development is particularly tough during hard economic times, but our Foundation ends the third quarter of this year with an expanded research portfolio. An innovative drug discovery program, a range of new grants, many of which explore the link between dystonia and Parkinson's disease, and the establishment of a model center for dystonia research, treatment and care (see cover story) are part of this portfolio.

"There is a powerful combination at play," says Helen Miller, the Foundation's Executive Director. "We are fortunate to have continued, loyal support and an unwavering focus on providing seed money so researchers have the opportunity to explore new ideas to help combat these terrible movement disorders."

Six months into our AntiDystonia Drug Development Program, Principal Investigator Ellen Hess, PhD, Professor of Pharmacology and Neurology, Emory University School of Medicine, Atlanta, GA has recruited two high-level technicians and is moving forward on various technical aspects of program development including prioritizing compounds for study.

This past spring marked the first time that our Foundation moved from an annual to a biannual schedule of grant awards. This enables us to respond more quickly to promising new developments on the path to finding better treatments and cures.

"Bachmann-Strauss is currently funding 26 grants. The breadth and depth of this research is phenomenal and spans all the way from fundamental biology to clinical trials to drug discovery," says Ted Dawson, MD, PhD, chair of our Scientific Advisory Board.

Six new grants awarded

Steven Clapcote, PhD
University of Leeds, Leeds, England

The role of Na⁺,K⁺-ATPase α 3 in motor control: clues to the pathogenesis of rapid-onset dystonia-parkinsonism



Working under the theory that the Na⁺,K⁺-ATPase α 3 (sodium-potassium pump) gene is linked to rapid-onset dystonia-parkinsonism (RDP), this study will examine mice with normal and defective genes to learn more about the role of Na⁺,K⁺-ATPase α 3 in nerve cells and in muscle control. The aim

is to also learn the location of the sodium-potassium pump in the brain and spinal cord and obtain clues about the causes of RDP.

Michelle Ehrlich, MD
*Mount Sinai School of Medicine
New York, NY*

Pan-neuronal mouse models of DYT6 THAP1 dystonia

THAP1, the protein mutated in DYT6 dystonia, is a transcription factor, i.e. a protein that regulates the expression of other proteins. This study will make transgenic mouse models of THAP1 DYT6 dystonia in order to assess motor and gene expression abnormalities, and to help identify a common mechanism causing these genetic dystonias, which may also be relevant to focal dystonia.

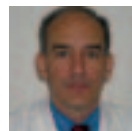
Stewart Factor, DO
Emory University, Atlanta, GA

Anterocollis in Parkinson's disease and other Parkinsonian syndromes: what is the underlying etiology?



Many patients with Parkinson's disease and Parkinsonian syndromes have forward displacement of the head, some with such severity that their chin falls to their chest. Dr. Factor's hypothesis is that the deep flexor muscles of the neck become dystonic and secondary muscle changes occur in the neck extensors. His study will look for the underlying causes and develop novel techniques useful in diagnosis and therapy of dystonic conditions.

Mark LeDoux, MD, PhD
*University of Tennessee,
Health Science Center, Memphis, TN*
Developmental Neurobiology of THAP1



Dr. LeDoux's experiments will look at the developmental expression of THAP1 in the brain. A mouse model of

DYT6 dystonia will be generated by "knocking out" the THAP1 gene in mice to test the hypothesis that THAP1 is critical for the normal development of various neurons in the cerebellar cortex.

Susan Lindquist, PhD
*Whitehead Institute for Biomedical
Research, Cambridge, MA*

Utilizing Saccharomyces cerevisiae to understand the relationship between TorsinA, Protein trafficking and folding defects and alpha-synuclein



Building on her previous study of Parkinson's disease, Dr. Lindquist will create a yeast model to study how the normal and mutant versions of the torsinA protein function in the cell and lead to dystonia. This will enable the creation of screens that wouldn't be possible with more complex organisms, and will enable testing of most of the yeast genome (6000 genes) to look for genes that alleviate or enhance toxicity associated with the expression of mutant torsinA.

Laurie J. Ozelius, PhD
*Mount Sinai School of Medicine
New York, NY*

Knock-out and conditional knock-out mouse models of THAP1 (DYT6)



Dr. Ozelius recently discovered the THAP1 gene as the cause of DYT6 dystonia. Mouse models targeting this gene will be generated to clarify the underlying mechanisms of dystonia and provide the foundation for devising novel treatments. The study will develop mice with only a single copy of this gene and mice where the gene has been "turned off" in neurons in the brain. Chemicals, cells and proteins in the brain of these mice will be compared to control mice and both groups assessed for behavioral differences.

The next grants will be awarded by year's end. Requests for Proposals are due September 21.

Collaborations

Second Annual Jake's Ride Takes Off



From left, Alex Ferrer, Jake Silverman and William Wenik at the first Jake's Ride.



David Gardner developed this successful event.

Thirteen-year-old Jake Silverman was the inspiration behind the creation of a bike ride and walk to benefit dystonia research launched last year. Jake's Ride for Dystonia Research, the popular event that demonstrated the best of

community spirit, will be held again this fall on Sunday, October 4th at the Glenwood School in Short Hills, NJ. Participants can ride their bikes through the Millburn/Short Hills area from one to 20 miles or walk a one mile loop.

The gourmet food store chain Eden Gourmet/Garden of Eden has joined in the effort, providing generous support. From September 8 through October 6, shoppers will be asked at the checkout counter if they would like to donate \$1 to \$5 to benefit our organization. Eden Gourmet/Garden of Eden has six stores: two in New Jersey, located in South Orange and Hoboken; three in Manhattan, located in Chelsea, Union Square and the Upper West Side, and one in Brooklyn Heights.

We are grateful to the Garden of Eden Markets for their in store promotion of Jake's Ride September 8 – October 6.

New Jersey: South Orange and Hoboken

Manhattan: Chelsea, Union Square and the Upper West Side

Brooklyn: Brooklyn Heights



Jake was diagnosed with childhood onset dystonia when he was only 11. He missed a year of school because he was too ill but now, thanks to Deep Brain Stimulation surgery, he is back in class. Despite significant progress he is often in pain and remains unable to use his hands to write and perform other fine motor skill functions.

David Gardner, a residential and commercial developer in New Jersey and Pennsylvania whose son goes to school with Jake, developed the event which raised more than \$275,000 last year – funding four research grants.

To join in or to learn more go to www.jakesride.org.

Foundation is Again an Official Charity Partner in ING NYC Marathon

Our organization has once again been selected as an official charity partner in the ING New York City Marathon. Scheduled this year for Sunday, November 1, we have a guaranteed 40 slots in the world famous race. Members of our team, comprised of men and women from all over the country, will raise money to benefit dystonia and Parkinson's disease.

Our goal is to raise \$150,000, which will provide funding for research grants.

Rob Lefkowitz, a second year runner on our team, is serving as this year's chairman.

TEAM Bachmann-Strauss was created in 2006 by Brian Dugan to help his mother and others like her with Parkinson's disease. This year five of Brian's friends will run in honor of his mom, who passed away in January.

To add your support, go to www.teambachmannstrauss.kintera.org.



TEAM Bachmann-Strauss 2008 runner Alice Stopkoski.

A New Way to Say Thank You

It's always a special occasion when you help others. With that in mind, we have created a meaningful token to thank the guests who attend your parties. In place of party favors at your next occasion, consider making a donation in your guests' name. This notable, lasting gift will contribute greatly toward finding better treatments and cures for dystonia and Parkinson's disease.

Our new, personalized Occasion Cards, ideal to be given at weddings, bar/bat mitzvahs, showers and other parties, will let your guests know that you have made a contribution in their honor.

A pack of 10 cards is \$20 and you may choose from a number of inscriptions.

Sample inscriptions:

*Thank you for joining us at Jane and John Doe's celebration
Monday, August 24, 2009
In honor of your presence we have made a donation to
The Bachmann-Strauss Dystonia & Parkinson Foundation*

*Thank you for sharing this day with us.
In recognition of your love and support,
we have made a donation in your
name to The Bachmann-Strauss
Dystonia & Parkinson Foundation.*



To find out more about our Occasion Cards go to www.dystonia-parkinson.org or call 212-682-9900.

One for the Record Books

17th annual golf invitational raises over \$1.1 million

Despite the troubled economy and the second wettest June in history, hundreds of people rose to the challenge to do whatever they could to combat dystonia and Parkinson's disease by supporting our signature fundraising event.

Our Hedi Kravis Ruger Golf Tournament, held Monday, June 22, raised over \$1.1 million. Barbara Israel and William Thompson did an outstanding job as co-chairs of this 17th annual pro am tournament. Jamie Niven, auctioneer par excellence, generated more than \$116,000.

All photos read from left to right.



Event co-chair Barbara Israel with Bonnie Strauss.



Bonnie Strauss with Jake Silverman, who told our dinner guests of his life with dystonia.



Our entire audience gave Jake a standing ovation. Among them, pictured here, Morris and Nancy Offit, Tom and Ann Johnson.



Winners of men's tournament – 1st place low net–Wayne Silberstein, Jay Price, Frank Ritter and Joe Falgaras.



John Kirby and Susan Cullman, winners of the women's/mixed tournament, with Tom Strauss.



Judith Eisenberg, Amy Regan and Nancy Rackoff.

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Louis Bachmann (1916-2000)
Bonnie Strauss

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Gina Tordella, Mark Standish and Kim Baker.



Broadway star Christian Hoff entertained our guests with songs from *Jersey Boys*

Mark Foresi Honored with Scott Johnson Award

Special tribute was paid to 28-year-old Mark Foresi at our golf invitational dinner when he was presented with the Scott M. Johnson Memorial Award for Dystonia and Parkinson's Disease Research.

Mark became involved with our Foundation because his father has Parkinson's disease and he wanted to help raise money to find a cure. He joined our Young Professionals (YP) group and was a dedicated volunteer.

Last fall, when a YP fundraising event wasn't scheduled because of the economic downturn, Mark wanted to do what he could to ensure that revenue for research would continue. Taking the initiative, he launched a personal campaign by writing to friends, family and co-workers and raised \$10,000 on our behalf. Citizen's Bank, where he worked as an assistant vice president in the Commercial Real Estate department, helped maximize contributions made by his colleagues through their corporate matching gift program.

This award was established in memory of Scott Johnson, a former member of our Young Professionals group who lost his life on September 11, 2001 in the World Trade Center. It is given each year to a Young Professional who has made an outstanding contribution to the Foundation and who is recognized as embodying Scott Johnson's generous spirit.



Mark Foresi with Bachmann-Strauss Executive Director Helen Miller.



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SAVE THE DATE

Wednesday, October 28, 2009

Parkinson's and Dystonia Symposium

The Graduate Center CUNY, New York, NY
This free symposium enables patients, families and health care providers to hear the latest information about treatments and research.

Sunday, October 4

Jake's Ride for Dystonia Research

Glenwood School in Short Hills, NJ
Bike ride with routes ranging from one to 20 miles in honor of Jake Silverman and other children with dystonia. To find out more go to www.jakesride.org.

Sunday, November 1

ING New York City Marathon

Cheer on TEAM Bachmann-Strauss running to benefit our Foundation. Add your support now at www.teambachmannstrauss.kintera.org

Monday, June 21, 2010

The Hedi Kravis Ruger Memorial Tournament

18th Annual Dystonia & Parkinson's Pro-Am Golf Invitational

For reservations or more information, call 212.682.9900 or go to www.dystonia-parkinson.org

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.