



# Outlook

SPRING 2011

## An Evening with Anne Hathaway

On a night we will always remember, Anne Hathaway stood before a crowd of Bachmann-Strauss Foundation supporters and recounted how playing the role of a young woman with Parkinson's disease in the movie "Love & Other Drugs" changed her life. The Academy Award nominated actress said she now has a new appreciation for the millions of people who live with a movement disorder and how she was determined to make a difference in helping to find a cure. That determination, combined with the generosity of our supporters, resulted in a record-breaking fundraising event in November.

*"I hope by being here with you tonight and supporting what The Bachmann-Strauss Foundation is doing, we can get closer to understanding the diseases and raise the funds needed to research, raise awareness and find the cure," Anne said.*

The evening began with Anne hosting an intimate dinner at Il Postino, followed by a private screening of her movie for a larger group at The Japan Society.

The movie graphically depicts what happens to Parkinson's patients over the course of a lifetime and reveals the



At the movie screening (left to right) Thomas W. Strauss, James C. Marlas, Anne Hathaway, Bonnie Strauss, Marie Nugent-Head Marlas

difficulty of diagnosing Anne's character's symptoms as dystonia or Parkinson's. "Very few people understand dystonia and Parkinson's are so closely related," Anne explained, "and Bachmann-Strauss is unique because it researches the overlap between the two diseases."

Anne graciously greeted everyone at the dinner and expressed how good she felt that she could do something to support our organization. At the preview she spoke of her introduction by Jim Marlas to Bonnie Strauss, the Foundation's founder and president, and what it meant to her to learn of Bonnie's life's work to raise money for research into the treatment and cure of Parkinson's and dystonia while actually living with dystonia herself.

To prepare for the challenging role in the movie, Anne attended multiple Parkinson's disease support groups where she met many inspiring people. She recalled hearing one person say, "I miss just being able to crumple a piece of paper." In an emotional ending to her remarks, Anne crushed a piece of paper in her raised hand and said, "This is for you!"

We are forever grateful to Anne Hathaway.

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## Exciting New Medical Discovery Funded by Bachmann-Strauss Finds a Key to Parkinson's Disease

Johns Hopkins scientists just announced a major medical breakthrough: the discovery that a protein called PARIS facilitates the most common form of Parkinson's disease, which affects about 1 million Americans.

"These findings could lead to important new targets for treatment that could someday slow or stop the progression of Parkinson's disease, said Ted Dawson, MD, PhD, and Chair of The Bachmann-Strauss Foundation's Scientific Advisory Board., who headed the Johns Hopkins team as the Scientific Director of the Johns Hopkins Institute for Cell Engineering.

The study was funded by the National Institutes of Health and The Bachmann-Strauss Dystonia & Parkinson Foundation.

The scientists discovered that mutations in the parkin gene can cause a build-up of PARIS, which can then kill off brain cells and permit the progression of Parkinson's. "The fact that we can prevent parkin-associated brain cell death by blocking PARIS gives us a promising new drug target," explained Dawson.

*For a complete description of the discovery, please visit [www.dystonia-parkinson.org/parkinsonnews](http://www.dystonia-parkinson.org/parkinsonnews)*

## Two New Members Enhance the Board

We are pleased to welcome Felice Axelrod, a consultant to Bloomberg, and Ron Hersh, President of Authenticity Lighting, to our Board of Directors. Both have long been engaged in charitable activities.

"Since joining the Board, they have demonstrated their commitment to dedicate their time and experience to our work," said Bonnie Strauss, Founder and President of The Bachmann-Strauss Dystonia & Parkinson Foundation.



Felice Axelrod

Felice is an influential connector with great ideas and creativity. She managed special events for the Bloomberg for Mayor campaign in 2009 and has worked at Lehman Brothers, Mount Sinai NYU Health, the Mount Sinai and NYU Schools of Medicine, the Museum of the City of New York and the New York Public Library.

Felice is a Board member of the Brooklyn Academy of Music and the Mount Sinai Adolescent Health Center. She is the immediate past President of the Council of Protocol Executives.

Ron Hersh has a special connection to The Bachmann-Strauss Foundation. His daughter, Allison, who has dystonia, is a co-chair of our Professional Philanthropy Group. Ron's passion to find a cure along with his business skills and experience greatly enhances the progress we are making toward achieving our goal of finding a cure.



Ron Hersh

Prior to Authenticity Lighting, Ron was with the Murray Feiss Import Corporation. He is a past Lighting Board Governor of the Dallas Market Center.

He is a Board member of the New York Chapter of the Israel Cancer Research Fund, a benefactor and past Co-Chair of the Annual Event at the Museum of Jewish Heritage in New York City, and long-time supporter of Morry's Camp.

## 2011: Looking Ahead



Bonnie Strauss, Sandy Cahn

We at The Bachmann-Strauss Foundation know what we **must** do in the year ahead: we **must** fund more research grants in dystonia and Parkinson's disease because we **must** find a cure. Too much is at risk for too many. We cannot allow government cuts in research spending or the pace of the economic recovery to stand in our way.

In order to remain a dynamic organization and laboratory for change, we need to expand new leadership and engage more people in supporting our Foundation. With your assistance, we can get the word out about who we are, what we do, and why it is so vital to fulfill our mission to find a cure.

Your support allowed us to significantly expand our scientific portfolio, develop educational and treatment programs, and be the leading organization exploring the connection between dystonia and Parkinson's disease.

We have our work cut out for us. Be assured, we at The Bachmann-Strauss Foundation continue to move ahead with purpose, determination, enthusiasm and creativity.

Bonnie Strauss  
Founder and President

Sandra F. Cahn  
Executive Director

# Think Tank Maps out Future Direction of Research for Bachmann-Strauss

While it has long been recognized that dystonia shares several features with Parkinson's disease, what is less clear is how lessons learned from one disorder can be applied to the other. The commonalities and differences between the two disorders and ideas on where future research should be directed were discussed by the group of 42 preeminent, international scientists and clinicians at the November two-day summit in New York.

Joel Perlmutter, MD, of Washington University in St. Louis, noted that about 40% of young onset parkinsonism begins with dystonia, which can also be a side effect of Parkinson's disease treatments, specifically from the drug levodopa. Conversely, some dystonia symptoms improve with levodopa, and the drug also can be used to treat certain subtypes of dystonia.

Other drugs and treatments have demonstrated benefits across both conditions. Dopamine, for example, is part of the link that explains the overlap between Parkinson's disease and dystonia and is an effective treatment



The "Interface between Parkinson's Disease and Involuntary Movements" was the focus of the ninth annual Think Tank on Dystonia at a gathering in New York of some of the world's noted movement disorder experts

for dopa-responsive dystonia. Abnormal dopamine metabolism also plays a role in DYT1, the most common hereditary form of dystonia.

Jeffrey Conn, PhD, of Vanderbilt University, noted a number of drug candidates in development for Parkinson's disease that might also play a role in dystonia treatment. Acknowledging that it may take several more years for a truly targeted dystonia drug to emerge on the market, participants highlighted specific areas for

future research. Consensus emerged that more work is needed to better understand the steps leading to dysfunction in dystonia, as well as the exact role of dopamine.

Participants also acknowledged that a number of pharmaceutical compounds might be needed to address all the subtypes of dystonia. And, finally, once clinicians have a number of treatments at their disposal, comparative studies will help them choose the most appropriate therapies.

## In Memoriam: Suzy Zimmerman

We all lost a valued friend and colleague, Suzy Zimmerman, at the beginning of this year. Suzy was known to many of us as the Foundation's interim Executive Director, working with the Board of Directors, the Scientific Advisory Board, supporters and staff, and numerous others. Throughout the years, she wrote and produced many of our publications, including the *Outlook* newsletter and annual report.

A communications professional with many industry awards, Suzy specialized in nonprofit consulting for such organizations as the Leukemia & Lymphoma Society and the National Hemophilia Foundation. She held staff positions with the Institute for Student Achievement, The Lighthouse, United Way of New York City and United Way of Tri-State. She also operated her own public relations business in London, England.

"Suzy was a truly dedicated and very talented woman who cared deeply about the programs and research we support," said Bonnie Strauss, the Foundation's Founder and President. "Suzy worked for our Foundation for over a decade in many capacities. She passionately believed in the work we did and encouraged the people she worked with to do their best. She will be sorely missed."



Suzy Zimmerman

# 2010 Research Portfolio

Funding innovative science and research in dystonia and Parkinson's disease is the hallmark of our grant program. In 2010, our 15th year, The Bachmann-Strauss Foundation supported nine individual researchers from around the globe engaged in projects that bring us closer to the cure for these disorders. And building on the progress of past years, the Foundation continued funding for three important programs.

## RENEWING OUR SUPPORT

**Bachmann-Strauss Dystonia Center of Excellence at Beth Israel Medical Center** is the first to provide patients with a multi-disciplinary comprehensive and coordinated approach to diagnosis and treatment. In its second year, the Center continued to see over 100 dystonia patient visits a month. The Center also includes an onsite genetic research component to explore the causes of dystonia, and features a training program to develop the next generation of movement disorder specialists.

**The Anti-Dystonia Drug Discovery Program**, under the direction of Ellen Hess, PhD, of Emory University School of Medicine, completed a third year of research studies to identify drugs that can either move directly into clinical trial or be put forward for product development by a bio-technology or pharmaceutical company. The drug screening protocol created in the first phase of development has transitioned to the testing of new compounds to alleviate dystonia symptoms in mice. The Bachmann-Strauss Foundation continues to fund this important project and is enthusiastic about the potential outcomes.

**The Michael J. Fox Foundation** received a second year grant for Dr. Danna Jennings, principal investigator, to explore the function of the neurotransmitter glutamate, and to evaluate the impact of glutamate antagonists, medications with the potential of reducing

dyskinesia in Parkinson's disease patients. This study has strong potential for developing novel medications that could benefit both dyskinesia and dystonia symptoms. Bachmann-Strauss has partnered with The Michael J. Fox Foundation for many years and continues to be their lead partner in the study of dyskinesia.

## INDIVIDUAL GRANTS

**Joshua Berke, PhD**  
University of Michigan  
Ann Arbor, MI

*Real-time monitoring of striatonigral and striatopallidal cells in mice with levodopa induced dyskinesias*



Prolonged levodopa therapy for Parkinson's disease frequently results in uncontrolled movements called levodopa-induced dyskinesias (LIDs). The brain changes responsible for LIDs are currently unknown. Using state-of-the-art techniques to monitor and manipulate individual neurons, Dr. Berke will test the hypothesis that one specific subtype of basal ganglia cell shows altered activity leading to LIDs. The results are expected to be extremely helpful for the generation of new therapies that either prevent or suppress LIDs.

**Xandra Breakefield, PhD,**  
**and Naoto Ito, PhD**  
Massachusetts General Hospital  
Cambridge, MA

*Exploring the role of Drosophila dtorsin gene in regulating dopamine metabolism*



This study aims to clarify the role of torsin in dopamine metabolism

by evaluating dtorsin-deficient flies that the researchers created. Because *Drosophila* (fruit fly) has one dtorsin gene similar to human DYT1, which is defective in early onset dystonia, the research should aid in evaluating the potential usefulness of drug modulation of dopaminergic neurotransmission in DYT1 patients.

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

*Regulation of TorsinA in a knockin model of DYT6 dystonia*



DYT6 is one of the inherited dystonias, caused by one of several mutations that have been identified in the gene THAP1, which is present in the developing and adult mouse brain. This study will create a genetically accurate mouse model of DYT6, in which regulation and levels of THAP1 will be under normal control in order to determine if this mutation alters the regulation of other genes that are known to play a role in dystonia.

**Phyllis Hanson, MD, PhD**  
Washington University  
School of Medicine  
St. Louis, MO

*Reversing the mislocalization of TorsinA*



This study builds on Dr. Hanson's discovery that localization is a property of TorsinA regulated in the cell and by earlier findings showing that

TorsinA is frequently mislocalized. The new study will design a screen to identify new genes that regulate TorsinA activity by controlling where it is located in the cell, looking for new candidates and pathways that may be targets for therapeutic intervention in dystonia.

**Christine Klein, MD**  
University of Luebeck  
Luebeck, Germany

*Application of next generation sequencing to identify a new dystonia gene*



Using the genomes of a family with eight members affected by spasmodic dysphonia, the study seeks to identify a new dystonia gene by applying

genome-wide linkage analysis and the latest sequencing techniques to be followed by mutational analysis of the newly identified gene in other dystonia patients. By identifying a novel genetic cause of dystonia, the study may explain many forms of the disease and lead to new therapies.

**Antonio Pisani, MD**  
Fondazione Santa Lucia  
Rome, Italy

*Evaluating the Role of thalamic activity in the pathogenesis of dystonia*



In his previous research into DYT1 dystonia, Dr. Pisani discovered a profound impairment in the synaptic plasticity of the

striatum, a brain region involved in motor control. Dr. Pisani now seeks to determine whether the aberrant synaptic plasticity of the corticostriatal pathway might lead to an imbalance with the other means of striatal cholinergic transmission, the thalamostriatal pathway. These experiments might have relevant implications for the pathophysiology of dystonia.

**Jan-Willem Taanman, PhD**  
Institute of Neurology, University College  
London, England

*Converting laboratory-created stem cells into rapid-onset dystonia-parkinsonism neuronal cells*



A major barrier to the study of dystonia and Parkinson's in the laboratory has been the inaccessibility of neuronal cells from patients. Now that there

is a new technique for creating stem cells, Dr. Taanman will attempt to convert stem cells into neuronal cells affected by rapid-onset dystonia-parkinsonism. This work can open the door to a thorough investigation of the disease mechanism of rapid-onset dystonia-parkinsonism and potentially screen for drugs.

**Enrique Torre, PhD**  
Emory University School of Medicine  
Atlanta, GA

*The Impact of Mutant TorsinA on the Axon Function*



More than 50% of carriers of mutant TorsinA never manifest early onset torsin dystonia (DYT1), but recent imaging studies suggest a deficit in the

quality or number of fibers in the axon (the projection of a nerve cell that conducts electrical impulses away from the neuron's cell body or soma). Dr. Torre will investigate the hypothesis that neurons become vulnerable to stress when expressing a

mutated TorsinA, leading to a dysfunctional and/or dystrophic axon unable to sustain normal synaptic communication or plasticity. These studies will help to understand the role of TorsinA in the normal function of axons and the connections they establish, and to design better targeted treatments.

**Aziz Ulug, PhD**  
The Feinstein Institute  
for Medical Research  
Manhasset, NY

*Determination of Brain Pathways Involved in Dystonia Using a Mouse Model*



Employing a novel experimental approach to validate and expand upon the findings of the human imaging study conducted in DYT1 carriers

of dystonia, Dr. Ulug will image DYT1 knockin mice in vitro and ex vitro in order to visualize the white matter pathways that pass through the abnormal brain regions identified in his earlier scans. This study will allow for the direct assessment of the effect of the DYT1 mutation on the structure and function of brain motor pathways.

*Since its founding in 1995, The Bachmann-Strauss Dystonia & Parkinson's Foundation has allocated more than \$11 million dollars to over 210 grants around the world. These grants have helped to bring greater insight into the causes and cures for these diseases.*

# Joining Together



Bikers set off at the start of the Annual Jake's Ride for Dystonia Research



Left to right, Jake Silverman, Otis Livingston, WCBS Sports anchor and the event emcee, and Ben Schmidt



Joanna Parker-Lentz waves at the Bachmann-Strauss cheering section at the New York City Marathon

## Jake's Ride: Mission Possible

Jake's Ride for Dystonia Research, held in September in Short Hills, New Jersey, raised an amazing \$216,000 for the Foundation, funding three research grants. Over 1000 participants rode bikes or walked to raise funds in honor of 14-year-old Jake Silverman and other children with dystonia. Jake's Ride has raised over \$700,000 and funded ten research grants in the three short years since its inception. Inspired by Jake and his journey, his classmate Anya Parker-Lentz wrote an original song, "Mission Possible," that she sang at the opening ceremony. This community event continues to inspire, raise important funds, and celebrate life!

## TEAM Bachmann-Strauss Breaks All Records

Forty-five runners raised a record \$232,000 at the ING New York City Marathon, funding four research grants.

Lead sponsor RBC Capital Markets underwrote the Team and fielded 15 runners, led by Dan Rosenbaum. Together they raised \$73,000. Dan London ran in honor of his wife Ali, who was recently diagnosed with dystonia, raising \$35,000. Dan said, "Running the Marathon enabled me to fulfill a life-long dream while also raising awareness and research funds for dystonia, a very personal cause."

These are just a few of the remarkable stories from TEAM Bachmann-Strauss. Every runner had a special reason for running this race whether for personal glory or to honor someone they love who is living with dystonia or Parkinson's disease. Huge kudos to all of our runners and their supporters for helping them cross the finish line!

## Playing For a Cause

Sixty-five poker players enjoyed an elegant evening due to the extraordinary generosity of Omega and Tourbillon, which undertook all the costs of hosting a lavish Texas Hold 'Em Tournament and Fundraiser at their luxurious Wall Street boutique. We gratefully thank them for selecting our Foundation as the charitable beneficiary of this year's event. The evening raised \$20,000, all of which will benefit the Foundation. Special congratulations to Mark Clyman, the overall winner of the Poker Tournament!

# Interactive Symposium Offers Latest Updates

Hands-on classes and discussion with top specialists combine to give patients, families, caregivers and health care professionals the latest information on treatments, therapies, coping techniques and promising research.

Yoga/Pilates, meditation/Tai chi, nutritional counseling and massage therapy. Sounds like a fancy spa, but it's actually the expanded and interactive portion of our annual symposium on dystonia and Parkinson's disease taking place at the CUNY Graduate Center in New York on May 2, 2011.

A prestigious panel made up of a neurologist, neurosurgeon, researcher, physical therapist and psychiatrist will round out the program in a discussion of the latest advances and innovative techniques for patients suffering from dystonia and Parkinson's disease, their caregivers and professionals.

This is a unique networking and educational opportunity with plenty of time to ask questions of the top specialists in the field, and partake in the interactive classes which will offer "take home" value.

Our keynote speaker is Susan Bressman, MD, Beth Israel Medical Center, New York City.

*The symposium is **free**, but space is limited. Sign up today by calling Beth Pfeil at 212.682.9900 or email her at [bpfeil@bsdcpf.org](mailto:bpfeil@bsdcpf.org). You can also check our website: [www.dystonia-parkinson.org/symposium2011](http://www.dystonia-parkinson.org/symposium2011).*

## Finding Balance: Treatments, Therapies, Coping Techniques And Current Research For People Living With Dystonia And Parkinson's Disease

May 2, 2011

at the CUNY Graduate Center  
365 Fifth Avenue, New York City  
Between 34th and 35th streets

*Sponsorship opportunities are still available.*

*For information go to our website:*

*[www.dystonia-parkinson.org](http://www.dystonia-parkinson.org) or contact*

*Beth Pfeil at [bpfeil@bsdcpf.org](mailto:bpfeil@bsdcpf.org), 212.682.9900*



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*Join us as we do our part...*

**Save the Date**  
**Monday, June 20, 2011**

*for the Annual Bachmann-Strauss Foundation Golf Tournament  
at Century Country Club in Purchase, NY*

*...and take a swing at dystonia & Parkinson's disease*

For reservations or more information, call  
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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.*