



# Outlook

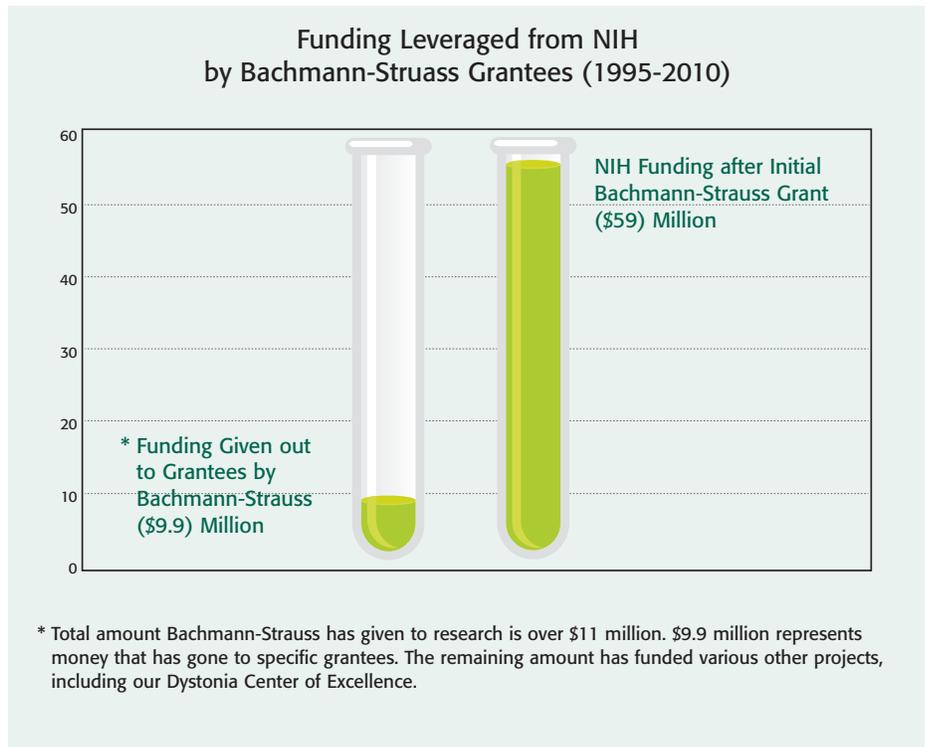
FALL/WINTER 2011

## Your Contribution Keeps On Giving

Many researchers dedicate their entire lives to finding a piece of the puzzle that can lead to a cure for an illness. It takes more than a great idea, brains and a stellar team of scientists to achieve this potential cure - it also takes significant monetary support. The Bachmann-Strauss Dystonia & Parkinson Foundation is unique because we provide seed money to scientists, enabling them to explore their most promising hypotheses, which is needed, in order to leverage additional funding.

The Bachmann-Strauss Foundation has given \$9.9 million directly to grantees in the field of dystonia and Parkinson's disease. Our grantees leveraged this money into \$59 million in NIH funding due to our initial investment in their research.

Xandra Breakfield, PhD is a perfect example of how our grants assist researchers in obtaining future funding for their research. Dr. Breakfield stated, "Currently The Bachmann-Strauss Foundation is funding our work on understanding the function of torsin in a fly model system. These studies will also form the basis of a grant application to NIH in the coming year. I have also served on several NIH Study Sections which review applications. It has become imperative to have preliminary



data demonstrating feasibility of the proposed experiments, as well as showing some experimental support for your hypothesis."

The importance of our unique grant award system is that every dollar contributed from someone like you has the ability to turn into approximately 600 times more than its original value. Thanks to your generous contributions, great research ideas that would ordinarily go unnoticed by the NIH now have a chance to make a tremendous impact

in the scientific world of dystonia and Parkinson's disease. Our hope is that one day our Foundation will be the one that funds the scientist who holds the key to the cure for both diseases.

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Visit us at [www.dystonia-parkinson.org](http://www.dystonia-parkinson.org)

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**Complimentary Dystonia & Parkinson’s Disease Medical Advice for You:**

Now you can get complimentary medical advice 24 hours a day, 7 days a week, with a click of a button. If you have any questions regarding dystonia and/or Parkinson’s disease, “Ask Dr. Marta” and she will gladly answer your medical questions via email. This special service is provided to you by The Bachmann-Strauss Dystonia & Parkinson Foundation, through our website.

Marta San Luciano, MD sees patients with Parkinson’s disease, tremor, dystonia and other movement disorders. She is currently an Assistant Professor of Neurology at the State University of New York (SUNY) Downstate Medical Center. She received her M.D. degree from The University of Navarre in Spain, and her MS in clinical research methods from Albert Einstein College of Medicine.

To “Ask Dr. Marta” your dystonia and/or Parkinson’s disease medical questions visit: [www.dystonia-parkinson.org/AskDrMarta](http://www.dystonia-parkinson.org/AskDrMarta)

Upcoming Think Tank Set to Explore the Connection between Dystonia and 2 Different Parts of the Brain

The Bachmann-Strauss Think Tank, taking place this December in New York City, will include some of the most prestigious scientists and researchers from around the world. They will discuss the latest scientific findings



David Standaert, MD, PhD



Henry Paulson, MD, PhD

in dystonia and Parkinson’s disease. Co-chairs, Henry Paulson, MD, PhD and David Standaert, MD, PhD have determined the focus of this year’s Think Tank will be **“Connecting the Dots: How can we relate the circuit–and systems-level mechanisms of dystonia to the genes and proteins which trigger it?”**.

They will discuss how two areas of the brain, the basal ganglia and cerebellum, contribute to the development of dystonia. Co-chair Henry Paulson, MD, PhD stated, “We have invited basal ganglia and cerebellum experts together to bridge this gap and explore the possible connections underlying dystonia.” These discussions can potentially lead to more effective pharmacological or surgical approaches to prevent or treat dystonia, which is one of the main objectives to holding this Think Tank. Furthermore, it will also bring progress within the field of Parkinson’s disease since 40% of Parkinson’s patients live with dystonia.

“I have no doubt this will be a very exciting day of science! Not everyone sees eye to eye on the possible causes of dystonia, which guarantees we will have a stimulating discussion on key points,” stated by co-chair Henry Paulson, MD, PhD.

**Visualizing the Future**



Bonnie Strauss, Sandy Cahn

As we approach the end of another successful year at The Bachmann-Strauss Dystonia & Parkinson Foundation, we are proud of our record of achievement. We have once again funded extraordinary research and continue to do so with esteemed scientists and investigators from all over the world.

Our Bachmann-Strauss Dystonia Center of Excellence at Beth Israel Medical Center is thriving and self-sustaining. We are now looking forward to launching a special campaign in 2012 called **20/20: A Clear Path to the Future**, which will help fund a new Movement Disorder Center of Excellence. We have learned wonderful lessons from our first initiative at Beth Israel—we know that early diagnosis, superb translational holistic treatment of patients in one place, and quality research is a winning combination that works.

This year our Foundation has increased awareness of dystonia and Parkinson’s disease through considerable exposure on television, numerous articles in publications and higher visibility on the internet. As always, without your support we couldn’t do any of the work we do. We appreciate all of you and hopefully you noticed our front cover story and you can see how effective we can be together!

Bonnie Strauss  
Founder and President

Sandra F. Cahn  
Executive Director

**WATCH OUR SCIENCE ONLINE**

You can now watch all of the medical specialist’s presentations from our 2011 Patient Symposium FREE on our website! These videos are a great educational tool to gain insight on the latest treatments, trends, findings and general medical information about dystonia and Parkinson’s disease.

In addition, Medical Reporter, Dr. Max Gomez of WCBS Channel 2 News has featured the Dystonia & Parkinson’s disease Patient Symposium’s Unconventional Therapies and how they can benefit the daily lives of people living with dystonia and Parkinson’s disease.

To view the videos and CBS segment visit, [www.dystonia-parkinson.org/symposium2011videos](http://www.dystonia-parkinson.org/symposium2011videos)

# The 2011 Interactive Dystonia & Parkinson's Disease Patient Symposium

Imagine a room filled with a variety of medical professionals, therapists and instructors that specialize in dystonia and Parkinson's disease, and their sole purpose is to help people related to these disorders? This dream became a reality at The Bachmann-Strauss Dystonia & Parkinson Foundation's Patient Symposium on May 2, 2011. The Foundation's goal was to help dystonia and Parkinson's patients and caregivers with **"Finding Balance: Treatments, Therapies, Coping Techniques and Current Research for People Living with Dystonia and Parkinson's Disease."**

Located at The Graduate Center in New York City, over 200 participants from the tri-state area attended. This full day event, FREE to the general public, was divided into two separate sections: one for dystonia patients/caregivers and one for Parkinson's patients/caregivers.

## Speaker Presentations

Audience members had the opportunity to listen to specialists including neurologists, neurosurgeons, researchers, psychiatrists and physical therapists and new information was learned. For example, Neurologist, Claire Henschliffe, MD from Cornell Medical



Claire Henschliffe, MD presenting to patients and caregivers.

Center spoke about a new procedure for Parkinson's disease diagnosis that is soon to be introduced into the United States, "This is called a Beta CIT SPECT Scan, and it's a wonderful way of looking at the dopamine producing areas of the brain to see if there's been any impairment there, any damage, that might show up if one has Parkinson's disease that can help with diagnosis with Parkinson's and different types of parkinsonism's." In addition, Psychiatrist, Mark Groves, MD from Beth Israel Medical Center explained "The type of illness one has, whether its cancer or dystonia or Parkinson's, does not predict the individual's response. Individuals' responses to illness vary tremendously and the personality style, coping strategies, life history, relationship dynamics, a lot of different things can explain why one person has a certain type of reaction than another." After the group of specialists presented, the audience was able to ask them questions about the disorder(s).

## Interactive Workshops

The second part of the day offered interactive workshops to experience complimentary therapies such as



Pharmaceutical companies distributing information to attendees about dystonia and Parkinson's disease.

Nutrition, Yoga, Massage Therapy and Meditation/T'ai Chi Chih. These workshops provided practical exercises and methods that these patients/caregivers could take home to improve their quality of life. An attendee stated, "Dividing the program into two sessions, one devoted to dystonia and the other to Parkinson's disease, allowed for the best use of time and provided for a more meaningful experience for those attending. It also allowed for a hands-on experience of different therapies one might not have ordinarily explored."

*This Patient Symposium had the generous support of pharmaceutical companies: Allergan, Medtronic, Merz and Teva Neuroscience. They not only provided monetary support, but also attended the event in order to inform guests on the latest drugs and programs that they offer for people living with dystonia and/or Parkinson's disease.*



Participants doing Yoga exercises at the Interactive Workshops.

# YOU Can Lead a Path

## Community Building

Two teenage brothers, Jeremy and Josh Mosier, from Austin, Texas brought their community together for a cause that was close to their heart. Their first cousin, Jacob Spielberg, was diagnosed with dystonia at age eight and grandfather, Bernie Friedberg, is living with Parkinson's disease. In honor of their cousin and grandfather, they organized a local annual automobile show to raise money for our cause. This fundraiser attracted a tremendous amount of exotic and classic cars, which led to raising \$20,000 for research over two years. By bringing the community together, we are steps closer to a cure.



## Raising Awareness

A group of young professionals who have a specific interest in our Foundation came together to help raise funds, plan events, and network with others to heighten awareness of the critical need for more research dollars to help people with dystonia and Parkinson's disease. This Professional Philanthropy Group created an array of upcoming events for young professionals including speakers from the worlds of finance, ethics, journalism, entrepreneurship, and fashion/beauty. These events leave individuals with a fuller understanding of this amazing Foundation and the diseases it's fighting to cure! For more information about the Professional Philanthropy Group, contact Marissa Schaevitz at [mschaevitz@bsdcpf.org](mailto:mschaevitz@bsdcpf.org).



## Company Collaborations

Several years ago, Tirage Fine Art Gallery in Pasadena, California received a letter from Lauren Von Der Ahe, the teen-age daughter of one of their clients, describing her class project to raise funds to battle dystonia in honor of her sister, Kristin. Since the touching story of Kristin's daily life with dystonia struck a nerve with gallery owners, Kevin Casey and Karen Hackett, they decided to join forces with The Bachmann-Strauss Dystonia & Parkinson Foundation. Now through March 30, 2012, Tirage Fine Art Gallery will donate 10% of the gallery retail price to the Foundation when The Bachmann-Strauss Foundation is mentioned at the time of purchase, either in person, by telephone, or through the extensive gallery website of more than 2,000 artworks, [www.tirageart.com](http://www.tirageart.com).



## WHAT'S YOUR PART?

"Each of these people has created their own path to contribute to fighting dystonia and Parkinson's. YOU CAN TOO! There is therefore any idea you have, if you have an idea, help support the cause. contact Chris at [cpepi@bsdcpf.org](mailto:cpepi@bsdcpf.org)

# to the Cure!

## OUR PATH

se individuals  
n special way to  
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kinson's disease.  
The sky's the limit,  
ea is a great one!  
dea and want to  
finding a cure,  
stina Pepi at  
sdpf.org."

### Use your Talent

Jared Shadkin always had a passion for painting. Jared who is now 11 years old, was diagnosed with dystonia when he was only nine. To express all that he is going through, Jared decided to give back to the dystonia community by donating 50% of sales from each of his original paintings to The Bachmann-Strauss Dystonia & Parkinson Foundation. Since starting this project, he has already raised \$4,000. To purchase one of Jared's paintings visit [www.jaredspaintings.com](http://www.jaredspaintings.com).



### Social Responsibility

Many Synagogues encourage or require students to participate in or initiate a "Mitzvah Project" in order to contribute to the community and to help the less fortunate. Throughout the years, pre-teens from all over the country have chosen our Foundation as the beneficiaries of their projects. From selling carabineer clips in every state for Clips for a Cure, to selling bike magnets for Jake's Ride, these driven pre-teens have raised thousands of dollars for dystonia and Parkinson's disease medical research. It is because of people like them that our mission to cure these diseases becomes clearer!



### Entrepreneurship

15 year old, aspiring pop/rock artist, Anya Parker-Lentz of Short Hills, NJ wrote and composed a song in honor of her good friend Jake Silverman, who has dystonia. Determined to find a cure for Jake, Anya is giving all the proceeds of her iTunes sales from her song "Mission Possible" to Jake's Ride for Dystonia Research which took place September 25, 2011. To download Anya's song "Mission Possible" on iTunes visit [www.anyaparkerlentz.com](http://www.anyaparkerlentz.com). To find out more about Jake's Ride visit, [www.jakesride.org](http://www.jakesride.org).

# 19th Annual Golf Invitational Raises \$1.35 Million for Research

When people come together to help a cause, it is a beautiful thing, and that's just what happened on June 21st! Over 200 friends of The Bachmann-Strauss Dystonia & Parkinson Foundation raised \$1.35 million for dystonia and Parkinson's disease research. DeMarco Morgan, Anchor and Reporter, WNBC 4 New York, emceed the event, and Sotheby's auctioneer, Jamie Niven helped raise over \$200,000 at the Live Auction. Guests were treated to a live performance by Anya Parker-Lentz, who sang her original song, "Mission Possible." It was an emotional evening and a huge success for The Foundation! Thank you to all who attended and supported this important event.



James Regan, Tom Strauss Treasurer and Vice President, CJ Reeves, Sam Evans and Philip Waterman.



Golf Co-Chairs, Jason Spacek & Kimberly Smith Spacek.



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Ned Offit and Morris Offit



President and Founder Bonnie Strauss, Laurie Ozelius, PhD, Susan Bressman, MD.



Singer/Songwriter Anya Parker-Lentz, WNBC Anchor and Reporter DeMarco Morgan who emceed the dinner program and Jake Silverman.



## A Special Honor Awarded to a Special Man

Dan London, an active supporter and advocate for The Bachmann-Strauss Foundation for over 2 years, was awarded The Scott M. Johnson Award during our 19th Annual Golf Invitational. This admirable award was given to Dan, recognizing his endless dedication to our cause. Specifically, Dan was part of our ING New York City Marathon team, TEAM Bachmann-Strauss in which he raised \$35,000 in 2010. Being the superstar philanthropist that he is, he will once again be running this year's ING New York City Marathon with yet another ambitious goal. He is also an active participant in our Professional Philanthropy Group. Our cause is a personal one to Dan because his wife lives with dystonia. He continues to bring strength and hope to our Foundation due to his ceaseless passion to find a cure.



Dan London with Bachmann-Strauss Executive Director Sandy Cahn

The Scott M. Johnson Memorial Award for Dystonia and Parkinson's Disease Research was established in memory of a member of our Young Professionals Committee who tragically lost his life on September 11th at The World Trade Center. It is given annually to a Young Professional who signifies Scott Johnson's extraordinary enthusiasm and dedication in assisting the Foundation to raise funds and public awareness about dystonia and Parkinson's disease.

### TEAM Bachmann-Strauss Running the ING NYC Marathon



Our Foundation is once again a charity partner for the ING NYC Marathon on November 6th! We have 40 motivated runners who are not only training to run 26.2 miles, but also raising a minimum of \$2,500 for dystonia and Parkinson's disease research. For a second time, RBC Capital Markets has partnered with the Foundation and has over 20 employees running in the race. Our goal this year is to raise \$300,000 and fund four research grants! To support our marathon runners go to <http://teambachmannstrauss.kintera.org> to make a donation.

### Our Very Own Tom Strauss to Walk the ING NYC Marathon

The Foundation's very own Vice President & Treasurer, Tom Strauss, will be walking the ING NYC Marathon this year as one of the official participants of TEAM Bachmann-Strauss. Tom's goal is to raise \$100,000 towards funding a second Center of Excellence in 2012. Completing the ING NYC Marathon has been a life-long dream of Tom's and though he is unable to run due to a bad back, he has been given approval by his surgeon to walk the famous 26.2 mile course. He looks forward to walking "where many greats have run" and is happy to have the opportunity to do something personal for the Foundation.

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Louis Bachmann (1916-2000)  
Bonnie Strauss

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## SAVE THE DATE

**Sunday, November 6, 2011**  
**ING New York City Marathon**

Come cheer on TEAM Bachmann-Strauss running to benefit our Foundation. Show your support now at <http://teambachmannstrauss.kintera.org>

**Tuesday, February 28, 2012**  
**Educate and Empower Patient Symposium**

A free event, located in NYC, offering lectures and interactive classes for dystonia and parkinson's disease patients/caregivers. To learn more, visit [www.dystonia-parkinson.org/symposium2012](http://www.dystonia-parkinson.org/symposium2012)

**Monday, June 18, 2012**  
**The Hedi Kravis Ruger Memorial Tournament**

20th Annual Dystonia & Parkinson's Pro-Am Golf Invitational

*For reservations or more information, call 212.682.9900 or go to [www.dystonia-parkinson.org](http://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.*

Thank you to our generous sponsors who provided funding for this newsletter:

