Expanding Our Reach

After President Bush vetoed legislation this summer to expand federally funded embryonic stem cell research, two states – California and Illinois – came forward with funds to enable research in this area to continue. Stem cell research currently holds great promise for Parkinson’s disease patients. If injected into the brain of a Parkinson’s disease patient, stem cells have the potential to evolve into cells that produce dopamine, in turn enabling patients to control their movements in a normal way. It is believed that scientists’ ability to explore this research has the possibility to help millions of people with spinal cord injuries, immunodeficiency, juvenile diabetes, Alzheimer’s and many others, including dystonia. We believe that too much is at stake to turn away from such great hope.

As we work toward finding better treatments and cures, we continue to expand our horizons through collaborations, many of which are highlighted in this newsletter. Sharing knowledge, exchanging ideas and heightening awareness are paramount to achieving our goal. Our fifth annual Think Tank, upcoming on November 15-16, will center on the “Latest Developments in the Pathophysiology and Imaging of Dystonia.” The Think Tank brings together an international group of many of the best and brightest scientists working on dystonia today and provides a rare opportunity to exchange information and foster collaboration.

We begin our busy fall season by welcoming Dr. Ted Dawson of Johns Hopkins University Medical Center as Chair of our Scientific Advisory Board (SAB). We are pleased to have him at the helm of the SAB to lead us in new directions and we are thrilled to include him in our Foundation’s family.

Our fundraising efforts, which have now expanded well beyond New York and the east coast, are vital to encouraging new research. We want to take this opportunity to thank all of you who have made a financial commitment to our Foundation. Our 14th Annual Golf Invitational held in June brought a tremendous show of support. Every person and every dollar makes a huge difference. Thanks for being part of this journey.

Workshop Highlights Genetic Advances in Dystonia

The finding almost ten years ago that the DYT1 gene causes early onset torsion dystonia inspired many geneticists and neurologists to search for other genes responsible for various forms of dystonia.

While 14 other genes have either been isolated or mapped in recent years, more progress on the genetics of primary dystonias is needed. The major stumbling blocks include lack of well-characterized multi-affected families and the reduced penetrance associated with most forms of dystonia. Reduced penetrance is when an individual carries the defective gene but does not show any clinical features of the disease.

Continued on page 2
We are pleased to announce that we are now accepting grant applications for basic and clinical research in dystonia and the interface between dystonia and Parkinson disease.

Proposals can be considered high risk and may be submitted without preliminary data. Proposals designed to collect pilot data in preparation for a Federal grant or other large grant applications are encouraged. Funding will be for work conducted in 2007. The maximum award will be $50,000.

The application deadline is Monday, October 2, 2006. For more information and applications, go to www.dystonia-parkinsons.org.
All eyes were on Father Tom Hartman of the popular cable TV series, “The God Squad” when he gave the dinner Keynote address and spoke of his own struggle with Parkinson’s disease. “Why do I have Parkinson’s disease? Maybe I have it to help find the cure,” he said.

Seventeen-year-old Michael Sharp, who recently underwent Deep Brain Stimulation surgery for dystonia, thanked the audience for their kindness and generosity in supporting the kind of research that turned his life around. “Thankfully, I can stand in this perfect condition in front of you today…,” he said. “People usually do not appreciate what they have until they lose it. Until the age of 13, I didn’t realize how important it is to be able to stand upright or walk. And now, I’ll never forget it!”

14th Annual Golf Invitational Brings In $1.5 Million

Our 14th Annual Golf Invitational was so popular that, for a second year in a row, play was expanded to four golf courses in Westchester County, NY. Thanks to the generosity and support of all those who attended the day of golf, followed by dinner and a live auction, our Hedi Kravis Ruger Memorial Tournament raised $1.5 million.

The event, which was held on Monday, June 19, attracted over 270 golfers and 66 pros.

WNBC-TV’s Senior Health and Science Correspondent Dr. Max Gomez was honored at dinner for his work in heightening awareness of dystonia, Parkinson’s disease and other movement disorders.

A live auction, conducted by Gary Schuler of Sotheby’s, featured fabulous golf and spa packages around the globe, as well as creative travel packages, including one that featured a visit to the hit TV series, “Desperate Housewives.” The auction alone raised over $200,000.

Telling Their Stories

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Advocacy Day Presses for Federal Increases and Change

The Bachmann-Strauss Dystonia & Parkinson Foundation joined the Dystonia Medical Research Foundation (DMRF) and other advocates from across the country earlier this year to press for increases in federal funding, to preserve access to dystonia therapies and to pass genetic non-discrimination legislation.

Funding increases were requested for the National Institutes of Health and some of its agencies including the National Institute of Neurological Disorders & Stroke. Currently the appropriation bills are pending before Congress. It is likely that NIH will receive a modest increase in funding for fiscal year 2007.

While the Medicare Modernization Act assured an adequate reimbursement rate for therapeutic Botox injections for calendar years 2004, 2005, and 2006, we still need to preserve access to necessary medical drugs and treatments such as botulinum toxin injections after 2007. In addition, the CMS National Coverage Policy was urged to provide inclusion of Deep Brain Stimulation (DBS) whenever it is deemed medically necessary.

Congressional action to pass the Genetic Information Nondiscrimination Act this session and to send a bill to the President is essential to ensure that Americans will not be discriminated against because of their genetic information.
Generous 8th Graders Raise $1,000 for Dystonia Research

Students at the Mayfield Junior School in Pasadena, CA are noted for their generosity and charitable giving throughout the year. As the end of each school term approaches, the class evaluates different giving options and determines where the money they raised should be donated. This year, 8th grader, Caroline Nutt, made a presentation about the work of our Foundation and about her friend, Kristin Von Der Ahe, whom she called “one of the bravest people I know.” Kristin, who has severe dystonia, has strong muscle spasms and is unable to use her mouth to speak. She is also blind.

“We have become very good friends,” Caroline told her classmates. “We have gone to the beach, had dinner and lunches together and I love seeing her laugh. We are giving $1,000 to The Bachmann-Strauss organization in honor of Kristin. This organization is working hard to find a cure for dystonia …this money will go towards research and every dollar counts.”

Dress Down Day is Fundraising Success

When 11-year-old Jacob Spielberg returned to his class at The Kentucky Country Day School after missing five months of school, he asked the headmaster if he could run a fundraiser for dystonia. On the Friday before school ended, the middle school held a “dress down day” which meant that each child could pay $1 to dress out of uniform. The result was nearly $400 raised to benefit The Bachmann-Strauss Dystonia & Parkinson Foundation.

“It was great,” said Linda Spielberg, Jacob’s mother. “It gave everyone an opportunity to see that Jacob was back and doing fine. They all pitched in and many kids gave much more than $1 each.”

Jacob, who recently underwent Deep Brain Stimulation surgery for dystonia, is now doing so well that he is able to go to day camp. According to his mother, shortly after he went back to camp he decided to sell the red “LoveLife” wristbands that his brother Nathan had developed in his honor.

“Jacob sold $200 in bands in two weeks,” said Linda Spielberg. “The counselors and kids all wanted to help! They remembered him and what a hard time he’s had. They know that whatever they're giving is helping him. They’ve seen it for themselves.”

You can purchase “LoveLife” wristbands at www.dystonia-parkinsons.org

Organization’s Web Site is Revamped

A fresh new look was recently given to The Bachmann-Strauss Dystonia & Parkinson Foundation Web site – www.dystonia-parkinsons.org. Providing a user-friendly resource, it features a range of topics including overviews of funded research, information about dystonia and Parkinson’s disease, and downloadable grant application forms.

Tickets to our special events may be purchased on our Web site and supporters may make donations. One of our Young Professionals, Brian Dugan, is taking advantage of this new Web site to gain support for his New York City Marathon team. Brian wants to raise money to benefit The Bachmann-Strauss Dystonia & Parkinson Foundation in tribute to his mother, Joan Dugan, who has a severe form of Parkinson’s disease.

To find out how you can help, visit www.dystonia-parkinsons.org
**THE BACHMANN-STRAUSS**
**Dystonia & Parkinson Foundation, Inc.**

Mount Sinai Medical Center
One Gustave L. Levy Place, Box 1490
New York, NY 10029

Phone: 212. 241.5614
Fax: 212. 987.0662
www.dystonia-parkinsons.org

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**SAVE THE DATE 2006**

**Wednesday, September 27**
**Parkinson’s & Dystonia Symposium**
“Advances in Dystonia and Parkinson’s Disease”
Lighthouse International
111 East 59th Street, New York City
10 a.m. - 3:30 p.m.
This free symposium is for patients, families and health care providers.

**Wednesday, October 4**
Virginia Zabriskie will host an exclusive visit to three artist’s studios followed by a reception at her New York City art gallery. Fee is $100. Proceeds benefit The Bachmann-Strauss Dystonia & Parkinson Foundation.

**Wednesday, October 18**
**Film showing – “Twisted”**
The Walter Bruno Theater
111 Amsterdam Avenue at 65th Street
6:30 p.m.
Screening of the recently-released film “Twisted” about people with dystonia. Jointly sponsored by Bachmann-Strauss and DMRF. Admission is $20. Reservations necessary.

**Sunday, November 5**
A team of people, headed by Brian Dugan, are running in the New York City Marathon to help raise funds for our Foundation. Go to www.dystonia-parkinsons.org to cheer them on by adding your support.

*For reservations or more information call 212.241.5614 or go to www.dystonia-parkinsons.org*

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**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.