



FALL 2005

## Study Shows TorsinA Protein May Protect Against Parkinson's Disease

Drs. Guy and Kim Caldwell, the husband and wife team at The University of Alabama whose research centers on studying the roundworm *C. elegans* as an animal model, have demonstrated that a specific protein – TorsinA - protects against the loss of brain neurons. The demise of those neurons leads to Parkinson's disease.

The Caldwell's study, funded in part by a grant from The Bachmann-Strauss Dystonia & Parkinson Foundation, was published in an April 2005 issue of *The Journal of Neuroscience*.

The research focuses on torsinA and its ability to protect dopamine neurons against the stresses that cause them to die. "Torsins have the capacity to function in a neuroprotective manner, thus providing an insight into their native role in dopamine neurons, while simultaneously indicating their potential therapeutic value for Parkinson's disease," Guy Caldwell said.

While torsinA appears to exhibit a protective capacity in neurons, specific defects in it can lead to another movement disorder, early-onset torsion dystonia. Thus, the findings further define a functional role for torsins in neurons, revealing key information for research into dystonia as well.

### Regulating dopamine influx

"Parkinson's disease is caused by the loss of dopamine producing neurons in the brain as people age," said Dr. Guy Caldwell, assistant professor of biological sciences at the University of Alabama and a co-author of the journal paper. "We have identified a naturally protective factor that is already in our brains, and we've shown it has the capacity to protect those same dopamine neurons from dying during the course of aging. The trick, in the future, is how do we enhance that effect?"

The study showed that torsin decreases the number of dopamine transporter (DAT) molecules on the surface of neurons. DAT molecules allow dopamine to enter the cells. "Part of torsin's role may be to regulate the influx of dopamine into neurons," says Dr. Guy Caldwell. "One of the reasons dopamine neurons die in Parkinson's disease is that dopamine itself can undergo reactive oxidation." Reactive oxidation is a biochemical process in which highly unstable molecules react with and damage components of the cell, such as membranes, proteins, and DNA. Maintaining the proper balance of dopamine in neurons may help protect them against this type of damage while ensuring that appropriate levels of neuron activity result.

*Continued on page 2*



*Kim Caldwell, PhD and Guy Caldwell, PhD in their laboratory*

## Call for Grant Applications

*We are pleased to announce that we are now accepting grant applications for clinical and basic research relating to dystonia and/or Parkinson's disease. The Bachmann-Strauss Dystonia & Parkinson Foundation is the leading organization actively looking at the interface between dystonia and Parkinson's disease.*

*Proposals can be considered high risk and may be submitted without preliminary data. We are interested in hypothesis-driven research. Final selections are made by our Scientific Advisory Board following Requests for Proposals and a rigorous review process.*

*The deadline for application is Monday, October 3, 2005. For more information and applications, go to: [www.dystonia-parkinsons.org/research](http://www.dystonia-parkinsons.org/research).*

## 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](http://www.dystonia-parkinsons.org)*

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## TorsinA Protein May Protect Against Parkinson's Disease

Previous studies from the Caldwell lab and others have shown that torsins function as "molecular chaperones" that help guide the proper folding of proteins. "Cells contain many molecular chaperones. It is interesting that torsinA is a chaperone molecule that, when defective, causes a human movement disorder," says Dr. Caldwell. "This points to the importance of these proteins in our brain cells."

It is estimated that over one million Americans are affected by Parkinson's disease, while approximately 500,000 people in North America suffer from a variety of dystonias. Additional information on these disorders and this latest discovery can be found in a feature article by the National Institutes of Neurological Disorders and Stroke at [www.ninds.nih.gov](http://www.ninds.nih.gov).



*The dopamine producing neurons in the head of the roundworm, *C. elegans*, are readily visualized using a fluorescent marker protein.*

*Photos courtesy University Relations, The University of Alabama*

## A Broader Base of Support



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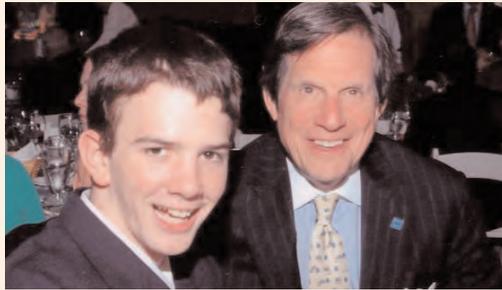
*Scientific advances are increasingly producing the kind of tangible results that enable people to understand the relationship between their philanthropic support and outcomes. Case in point is 16-year-old Michael Grater.*

*Michael has severe dystonia. But over a year ago he had Deep Brain Stimulation (DBS) surgery, which enabled him to walk better and to have more control over his legs. Three years ago, DBS was primarily used to help people with Parkinson's disease. While DBS still isn't for everyone, the continuation of medical and scientific research has made it possible for some dystonia patients to benefit from this breakthrough surgery.*

*We salute the courage of Michael Grater and the awesome fundraising efforts of 12-year old Nathan Spielberg and 16-year-old Lauren Von Der Ahe. These three are younger than members of our Young Professionals Committee, yet do an outstanding job of helping to raise awareness of our organization and broaden our base of support. We shouldn't be surprised by any of it. Throughout history, young activists have effectively mobilized support and attention to a myriad of causes.*

*As we approach the coming fall months, the impact of this support and of our funding takes center stage. This is a time when we receive and review research summaries from our past grantees and evaluate new requests for funding. We will also hold our fourth annual Think Tank, bringing together noted scientists and clinicians from around the world to discuss and debate the current and future focus of scientific inquiry.*

*Thanks to the active involvement of people of all ages, our Foundation continues to take the lead in funding research that looks at the interface between Parkinson's disease and dystonia, moving us closer every day to finding better treatments and cures.*



TOP ROW: First Place Low Net winners, from left, David Scuro, Jennifer Shim, Mark Snipe and Richard Klee of Geller & Company with Tom Strauss; Last minute practice shots. BOTTOM ROW: Dr. Emily Senay, CBS News Medical Correspondent, giving keynote speech; Michael Grater with the evening's honoree Peter Grauer; Event corporate co-chairs were key to our success: From left, Peter Hirsch and Gary Kilberg, Archeus Capital Management, LLC, Bonnie Strauss, Mashiko Kasuga, Green Stamp America, and Mark Standish, RBC Capital Markets.

## 13th Annual Golf Event Raises Record \$1.5 Million

With only two weeks to go before our 13th Annual Dystonia & Parkinson's Invitational, it became clear that we had to expand from three to four golf courses to meet the tremendous response. Our **Hedi Kravis Ruger Memorial Tournament**, which was held on Monday, June 20 in Westchester County, attracted 288 players plus 74 pros. That event, together with the evening's live auction and gala dinner, attended by 325 people, raised over \$1.5 million to benefit the work of our Foundation.

**Peter T. Grauer**, Chairman and President of Bloomberg, was honored at dinner for his ongoing support and involvement since the inception of our organization.

Keynote speaker **Dr. Emily Senay**, CBS News Medical Correspondent and Resident, Department of Community and Preventive Medicine, Mount Sinai School of Medicine, told the audience, " ... keep doing exactly what you are doing—redouble your efforts—never give up and always work with the knowledge that by reaching out you are helping others."

### Michael Grater's Personal Courage

There was hardly a dry eye in the audience when 16-year-old Michael Grater spoke about his own experience with dystonia and the Deep Brain Stimulation surgery he underwent last year.

Michael was born with a metabolic defect that resulted in dystonia and loss of control of his legs.

Discussing how he deals with the daily impact of severe dystonia, Michael's story was an example of remarkable personal strength, courage and persistence and underscored the tremendous inroads that have been made by research and the resulting new scientific technology.

### Junior Honorees Take the Spotlight

This year's dinner paid tribute to two "Junior Honorees," Nathan Spielberg and Lauren Von Der Ahe. Both have siblings with dystonia and both actively pitched in to make a difference.

Twelve-year-old Nathan developed the popular "Love Life" red rubber wristbands to help his younger brother, Jacob. As a result of his initiative, over 20,000 bracelets were sold in the first four months, generating over \$35,000.

Sixteen-year-old Lauren is a diligent and effective fundraiser. She launched a personal letter writing campaign to help her 12-year-old sister, Kristin. That effort has raised over \$32,000 and led the Tirage Gallery in Pasadena to donate a portion of the profits from their annual holiday exhibit to our Foundation.

## Advocacy Day Urges Increased Federal Funding



Congressman Danny K. Davis, D-IL, with Bachmann-Strauss Executive Director Helen Miller at the DMRF Advocacy Day luncheon on Capitol Hill.

The Bachmann-Strauss Dystonia & Parkinson Foundation joined forces with Dystonia Medical Research Foundation (DMRF) volunteers and members of the public health community for an Advocacy Day on Capitol Hill. The purpose was to raise awareness of dystonia among legislators and congressional staff, and to request a 6% increase in funding for the

National Institutes of Health (NIH) and a 6% increase for the National Institute of Neurological Disorders and Stroke (NINDS), which conducts the majority of dystonia research at NIH.

These efforts came on the heels of the President's budget request that called for a .5% increase from fiscal year 2005 (FY05) for NIH and a .7% increase from FY05 for NINDS. The House followed these modest funding recommendations in their version of the Labor, Health and Human Services and Education Appropriations bill. The Senate, however, called for a funding level of \$29.32 million for the NIH, an increase of 3.7% over FY05 funding levels.

Of the total NIH request, \$1.591 billion was appropriated for NINDS, which is an increase of \$52 million or 3.4% over FY05 levels. The bill will now go forward following the August recess and final funding levels will be set for the FY06 NIH budget.

*Photo provided with permission from the Dystonia Medical Research Foundation.*

## Young Professionals Bring New Support

Energy and enthusiasm ran high as our Young Professionals Committee gave their all in creating two very special events. Held earlier this year, these events are instrumental in raising new dollars and attracting new attention to the need to combat these neuromuscular diseases.

Our spring Young Professionals (YP) cocktail party at New York's hot spot, Bungalow 8, was sold out days in advance and raised more than \$10,000.



YP Committee co chairs. From left: Candace Tischer, Brendan Maher and Brooke Kaplan.

Earlier this year, designer Kenneth Cole was on hand at his Rockefeller Center store for a special shopping event that benefited our organization. Addressing the crowd of shoppers of all ages, Kenneth Cole spoke about the importance of getting young people involved in philanthropy. Twenty percent of the purchases made that evening were donated to The Bachmann-Strauss Dystonia & Parkinson Foundation.

*If you are between 25-35 years old and would like to join our Young Professionals, please contact 212.241.5614 or [Bachmann.Strauss@mssm.edu](mailto:Bachmann.Strauss@mssm.edu).*

Outlook is published by



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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.*

## SHARED GOALS AND COLLABORATIONS STRENGTHEN EFFORTS

### Life in Motion Awareness Campaign Launched Nationwide

More than 50 million Americans – nearly one in seven people - are now living with a movement disorder, bringing urgent need for early and accurate diagnosis and effective, up-to-date treatment.

In response to this public health problem, a coalition of more than 40 groups, including The Bachmann-Strauss Dystonia & Parkinson Foundation, has joined forces in a new national awareness campaign called Life in Motion. Announced earlier this year by the non-profit organization WE MOVE, during the American Academy of Neurology's 57th Annual Meeting, the Life in Motion campaign has already attracted interest from medical publications and Web sites, as well as from consumer media.

Campaign initiatives will continue throughout this year with additional media and community outreach, and public service announcements that will highlight real stories of people living with movement disorders.

A new Life in Motion online Resource Center at [www.life-in-motion.org](http://www.life-in-motion.org) was also launched. The Web site, which is designed for healthcare professionals and people living with movement disorders, provides valuable information and support resources.



*“The number of people challenged by movement disorders is more than twice the number of people with diabetes and more than four times the number of those surviving cancer.”*

–SUSAN BRESSMAN, MD

*Member of The Bachmann-Strauss Scientific Advisory Board*

### Banding Together to Love Life

In an effort to build support for research, we joined forces with the Parkinson Support Center of Kentuckiana this past May, selling the popular “Love Life” bracelets at their Circo Del Derby (Circus of the Derby) Eve Ball in Louisville, Kentucky.

Proceeds from the sale of the bracelets benefited our organization.

*To order “Love Life” wristbands, go to [www.dystonia-parkinsons.org](http://www.dystonia-parkinsons.org)*



*Nathan Spielberg shows the “Love Life” bracelet that he developed to help his brother, Jacob.*

### Workshop to Focus on Genetic Advances

*Intense focus will be given to “Genetic Advances in Dystonia” this coming January in Arizona. The Bachmann-Strauss Dystonia & Parkinson Foundation in collaboration with the Dystonia Medical Research Foundation (DMRF) are bringing together a group of researchers and members of both organization’s Scientific Advisory Boards specifically to examine the current science in the field.*



**THE BACHMANN-STRAUSS**  
**Dystonia & Parkinson Foundation, Inc.**

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## SAVE THE DATE 2005

**Monday, October 3**

### **Parkinson's & Dystonia Symposium**

*"New Perspectives for Treatment of Parkinson's Disease and Dystonia: Gene Therapy, Stem Cell and Deep Brain Stimulation"*

**11 a.m. - 3 p.m., Hatch Auditorium, Guggenheim Pavilion  
Mount Sinai Medical Center Fifth Avenue and 100th Street, New York City**

This free symposium enables patients, families and caregivers to hear about the latest advances and to speak directly to scientists and clinicians working on these movement disorders. The symposiums are presented jointly by The Bachmann-Strauss Dystonia & Parkinson Foundation and the Mount Sinai Medical Center Department of Neurology, Movement Disorders Program.

**Thursday, October 6**

### **Young Professionals' Fall Fête**

This fun and fabulous benefit will be held at one of New York's newest hot spots, Gypsy Tea, 33 W. 24th Street, between 5th and 6th Avenues, from 7:00 - 11:00 p.m. Raffles, hors d'oeuvres and open bar.

*For reservations or more information call 212.241.5614  
or email [Bachmann.Strauss@mssm.edu](mailto:Bachmann.Strauss@mssm.edu)*

### **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.*