

Outlook

FALL 2004

New Study Links Environmental Toxins to Parkinson's Disease

A recent study showed that laboratory animals developed Parkinson's disease features following treatment with environmental toxins known as proteasome inhibitors. This finding further supports the concept that the illness in humans occurs as a result of exposure to toxic substances that are present in the environment.



Dr. C. Warren Olanow



Dr. Kevin McNaught

The study, funded in part by The Bachmann-Strauss Foundation, was first published June 21, 2004 in the online edition of *Annals of Neurology* and then appeared in the July 2004 print issue of the journal.

Kevin St. P. McNaught, PhD and his team from the Department of Neurology, Mount Sinai School of Medicine, injected laboratory rats with naturally occurring and man-made toxins that can interfere with the proteasome. This is a vital enzyme that acts as a garbage disposal system to remove abnormal proteins within cells. Previous studies by this research group showed that the proteasome is defective in patients with Parkinson's disease.

Several weeks after the rats were treated they began to show symptoms that were similar to Parkinson's disease, including slowness of movement, rigidity and tremor. "The symptoms, which gradually worsened over several months, could be reversed with drugs that are used to treat Parkinson's disease patients," said Dr McNaught. "This is the first model of Parkinson's disease that reproduces the slowly progressive nature of the illness as it occurs in humans."

The study reports that brain scans on the live animals and autopsy studies showed dopamine nerve cell loss in the portion of the brain known as the *substantia nigra* and a reduction in the chemical dopamine that closely resemble the changes seen in Parkinson's disease patients. The rats that were exposed to proteasome inhibitors also demonstrated more subtle changes in the brain that are seen in humans with the illness.

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Save the Date:
Dystonia & Parkinson's
Disease Symposia

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Lead the Way**

SAVE THE DATE

Thursday, September 30, 2004

• Dystonia Symposium

11:00 a.m. - 12:00 p.m.

• Parkinson's Disease Symposium

1:45 - 3:15 p.m.

Hatch Auditorium

Guggenheim Pavillion

Mount Sinai Medical Center

Fifth Avenue and 100th Street

New York City

Key Information for Patients and Families

Mark your calendar now for our free symposia on Parkinson's disease and on dystonia.

This annual program enables patients, families and caregivers to hear about new scientific and medical advances, new therapies, and to speak directly to scientists working on these movement disorders.

The Parkinson's and dystonia symposia are presented jointly by The Bachmann-Strauss

Foundation and the Mount Sinai Medical Center Department of Neurology, Movement Disorders Program.

For more information or to register, please call

(212) 241-5614 or email

Bachmann.Strauss@mssm.edu.

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New Study Links Environmental Toxins to Parkinson's Disease

C. Warren Olanow, MD, FRCPC, Professor and Chair of the Department of Neurology at Mount Sinai School of Medicine and a co-author of the study, notes that "while there are a number of animal models of Parkinson's disease, none capture the features of the disease as closely as this new research. We create animal models of a disease for several reasons. They enable us to find underlying mechanisms responsible for the disease, identify targets for drug development, and test any new therapies," he said. "Our present model should facilitate accomplishing those goals in Parkinson's disease."

The next steps are to see how widespread these toxins are in the environment, how humans become exposed to them, and how these exposures correlate to the incidence of Parkinson's disease. Dr. McNaught notes that one of the proteasome inhibitors used in the study is normally produced by common bacteria which are found in soil and well water throughout the world. Proteasome inhibitors are also produced by various fungi and plants. While it is speculative at this point, living in rural areas and drinking well water have been reported to be associated with higher rates of Parkinson's disease and that could be related to higher levels of proteasome inhibitors found in those areas.

Making Positive Inroads



BONNIE STRAUSS
FOUNDER AND PRESIDENT

Recently, as we walked through the Capitol building in Washington, we spoke about the privilege of participating in the government process. We were there to press for expanded federal funding for movement disorder research and, later, to speak out about the promise that stem cell research holds for millions of people.

In the coming months, we will continue to make our voices heard. We also move into the fall with a very full calendar. Our annual symposia on Parkinson's disease and dystonia, this year on Thursday, September 30, gives patients and families the opportunity to learn the most recent information and to speak directly with medical professionals. Our third think tank on dystonia this November brings together noted scientists in a forum for sharing progress, forming collaborations, and accelerating the pace toward a cure.

Initiatives like these and our grant making programs are made possible by the generosity of so many people. We are especially honored to add the involvement of two very dynamic women – Janet Reno, who gave the keynote address at our 12th annual golf invitational, and business leader Jenny Craig, who is donating the proceeds of her book to our Foundation. My sincere thanks and admiration goes to both of them and to all of our volunteers and sponsors whose efforts make it possible for us to fund some of the most exciting, productive research underway today.

Applying for Research Grants

The Bachmann-Strauss Foundation is now accepting grant applications for clinical and basic research relevant to Parkinson's disease and/or dystonia. We are interested in hypothesis-driven research. Proposals can be considered high risk and may be submitted without preliminary data. Deadline for application is October 1, 2004. More information and application forms are available at www.dystonia-parkinsons.org/research

Jenny Craig Helps Build Awareness of Dystonia

Donates Proceeds of Her New Book to The Bachmann-Strauss Foundation

Jenny Craig, one of the world's best known leaders in the field of weight management, has become a household name. While almost everyone has heard of her, what most people don't know is that Jenny Craig suffers from dystonia.

It happened as a result of a freak accident. One evening in 1995, sitting and watching television, she fell asleep until a loud noise startled her awake. The sound was so loud that her head snapped up and her jaw locked. She had to pry her teeth apart. Her speech was impaired and her jaw dislocated, but tests showed that she had not had a stroke. She went from specialist to specialist trying to find the root of her problem. After visiting 18 different doctors, she was finally diagnosed with *oromandibular dystonia*, a form of focal dystonia that affects her jaw muscles.

Jenny told her story for the first time in her autobiography, *The Jenny Craig Story: How One Woman Changes Millions of Lives*. Published earlier this year, she is donating half the proceeds of her book to The Bachmann-Strauss Foundation.

"As a sufferer of dystonia, I know first-hand the effect it can have on people's lives," she said. "Movement disorders affect so many people throughout the world, yet there's no known cure for dystonia or Parkinson's disease. That's why I'm on board to support the Foundation's work in any way that I can."

Bonnie Strauss, president of The Bachmann-Strauss Foundation, recalls the day she and Jenny first met. "Coincidentally, we were diagnosed by the same neurologist, Dr. Mitchell Brin, and it was he who initially connected us. Jenny has secondary dystonia, caused as a result of trauma.

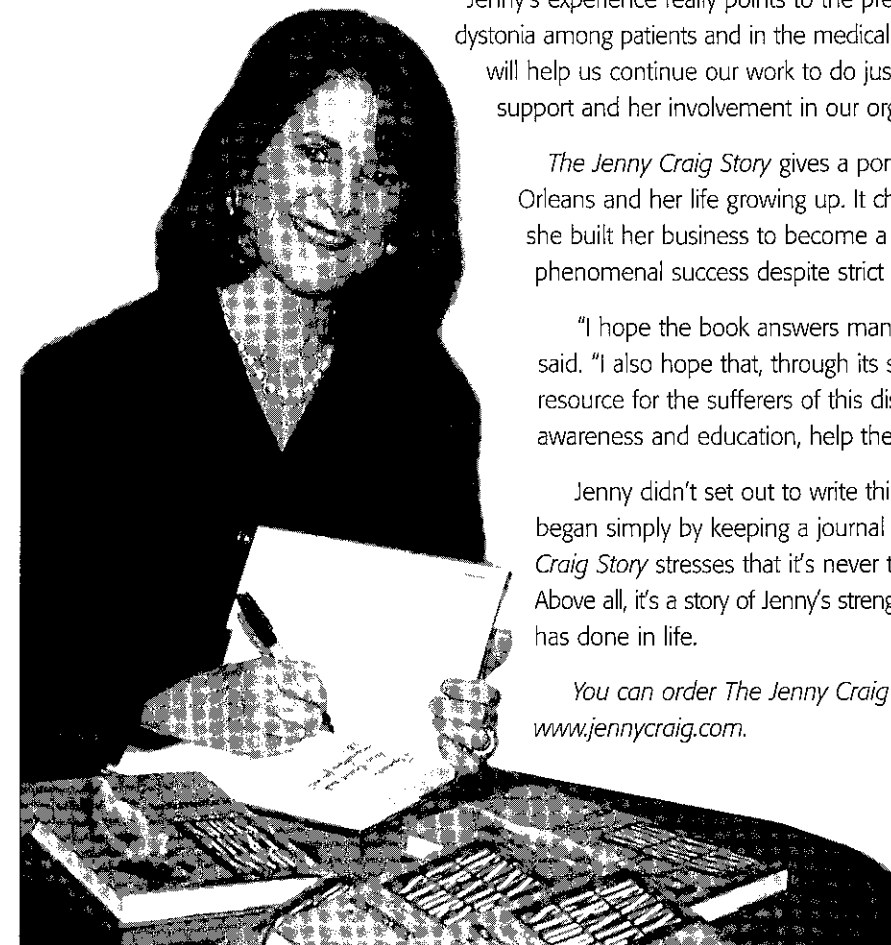
"Jenny's experience really points to the pressing need to build awareness of dystonia among patients and in the medical community. Her generous donation will help us continue our work to do just that. I'm very grateful for her support and her involvement in our organization."

The Jenny Craig Story gives a portrait of Jenny's childhood in New Orleans and her life growing up. It chronicles her career and tells how she built her business to become a publicly traded company and a phenomenal success despite strict competition.

"I hope the book answers many questions about business, she said. "I also hope that, through its sales, we can continue to be a resource for the sufferers of this disease and, through heightened awareness and education, help them to find a cure."

Jenny didn't set out to write this as an autobiography. Instead, she began simply by keeping a journal for her grandchildren. *The Jenny Craig Story* stresses that it's never too late to fulfill your heart's desire. Above all, it's a story of Jenny's strength and courage in everything she has done in life.

You can order *The Jenny Craig Story* on Amazon.com or at www.jennycraig.com.



Jenny Craig signs copies of her new autobiography at a book-signing party at the home of Bonnie and Tom Strauss.

She went from specialist to specialist trying to find the root of her problem.

Advocacy

Joining Forces to Effect Change

The Promise of Stem Cell Research

Stem cell research has become a political hot button and an issue that invokes tremendous emotional response, yet most cell biologists and other scientists believe that it is a crucial step toward helping millions of people.

Embryonic stem cells have the potential to become any type of human cell and, as such, they could lead to breakthroughs in developing new treatments and even cures. They hold high promise for Parkinson's disease, for example.

Parkinson's disease occurs when certain nerve cells or neurons die or become impaired. This degeneration occurs in the part of the brain called the *substantia nigra*, which is responsible for the control of movement. Normally, these neurons produce a chemical known as dopamine, which helps transmit signals across the nerve pathways to produce smooth, purposeful muscle activity. It is believed that if stem cells are introduced into the brain of a Parkinson's patient, they could evolve into cells that produce dopamine, enabling them to control their movements in a normal manner.

Stem cell therapy currently holds less immediate hope for dystonia patients, simply because it is not yet understood whether there is neurodegeneration with dystonia. In general, scientists' ability to explore this research has the potential to end the suffering of millions of people with spinal cord injuries, immunodeficiency diseases, and a host of other diseases like Juvenile Diabetes, Alzheimer's, and Crohn's and Colitis, to name a few.

The Bachmann-Strauss Foundation recently joined representatives of other non-profit organizations in a meeting with Senator Arlen Specter (R-PA), Chairman of the Labor, Health and Human Services, and Education Appropriations Subcommittee, to urge his continued leadership and support of this issue and to urge him to continue to press President Bush to change his position on the subject.

"Disease knows no politics," says Bonnie Strauss. "If stem cell research is permitted to move forward, then millions and millions of people stand to benefit. That's why we want to do everything we can to urge federal support."

You can add your voice to these important issues by writing to your state senator or congressional representative.

Expanding Awareness of Dystonia

With a goal of putting dystonia firmly on the Congressional radar screen, we recently joined forces in Washington, DC with the Dystonia Medical Research Foundation and a contingent of patient-advocates from around the country. Participating in an "Advocacy Day" to expand awareness of the disease and the pressing need for government funding, we visited elected representatives on Capitol Hill to emphasize several important public policy issues. Among them:

- The impact of the Medicare Modernization Act (Public Law 108-173) on reimbursement for hospital outpatient clinics for BOTOX® and other treatment therapies used by dystonia patients and the rare disorder community.
- Increased funding for the National Institutes of Health (NIH) budget, which includes the National Institute for Neurological Disorders and Stroke (NINDS) and the National Institute for Deafness and other Communication Disorders (NIDCD).
- Calling for the introduction of a Congressional Resolution to raise awareness of dystonia in Congress.

Update

As we go to press, the House gave the NIH an increase of \$726.8 million (2.6%) over FY04, an increase of \$44 million (2.9%) for NINDS, and an increase of \$11 million (2.8%) for NIDCD. All amounts are the same as the President's request. These appropriations still must be passed by the full House and the Senate still has to pass its version of this spending bill.

Congressman Danny Davis (D-IL) is expected to introduce a resolution in the House of Representatives to raise awareness of dystonia.



From left: Tom Strauss and Dr. C. Warren Olanow with The Honorable Janet Reno and WNBC-TV Medical Reporter Dr. Max Gomez



From left: Masa Kasuga, Bonnie Strauss, Nadine Kasuga, Mark Standish and Larry Fink

12th Annual Golf Invitational Beats All Records

The crowd was great, the weather was perfect and the results were simply outstanding. Our 12th Annual Golf Invitational beat all records this year, raising more than \$1.4 million to benefit dystonia and Parkinson's disease.

In all, 275 golfers and pros played at our Hedi Kravis Ruger Tournament, held at three courses in Westchester County. More than 250 people attended the evening reception, live auction and dinner. We were especially honored that former U.S. Attorney General Janet Reno came to New York to be our keynote speaker. Ms. Reno told about her own experience with Parkinson's disease and underscored the need for increased research funding.

C. Warren Olanow, MD, FRCPC, Chairman of Mount Sinai Medical Center's Estelle and Daniel Maggin Department of Neurology, was recognized for his work in the field of movement disorders and his work as head of our Scientific Advisory Board. Dr. Olanow took another honor that day. With teammates Kenneth L. Davis, MD, President and CEO of Mount Sinai Medical Center and Dean of the School of Medicine, Burton Drayer, MD, President of the Hospital, and Michael L. Brodman, MD, Chairman, Department of Obstetrics, Gynecology and Reproductive Science, they won First Place Low Net with a score of 39.

Our sincere thanks go to our event co-chairs – Nadine and Masa Kasuga, Larry Fink and Mark Standish – who helped make this invitational such a smashing success.

Young Professionals Lead the Way



YP co-chairs Margaret Johnson, Andrew Olanow and Emily Fine

They're enthusiastic, they're hard working and, collectively, they put together two terrific events for our organization this year – one in February and one in July – to help us raise funds for medical research.

Our Young Professionals group was co-chaired in 2004 by a top-notch leadership team: Emily Fine, Margaret Johnson and Andrew Olanow. Along with an active Benefit Committee they planned and organized the events, reached out to their friends and colleagues to bring additional support, and retained sponsorship and product donations.

Our thanks go to all the Committee members, to our sponsors and to everyone who attended our events.

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.

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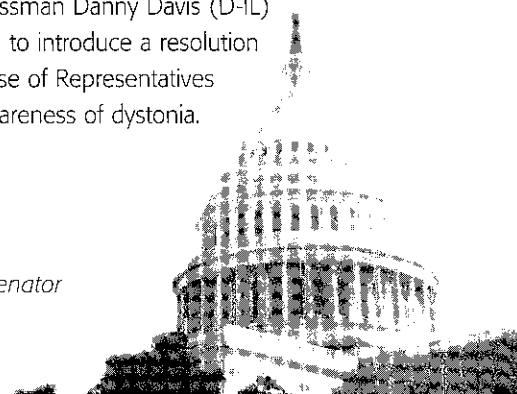
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The Bachmann-Strauss Dystonia & Parkinson Foundation, Inc. was established in 1995 to find better treatments and cures for the movement disorders dystonia and Parkinson's disease, and to provide medical and patient information. An independent, nonprofit, 501(c)3 organization, its funding is made possible through the generosity of individual and corporate contributors.





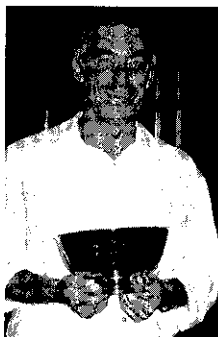
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Jeffrey M. Lederer Named 2004 Scott M. Johnson Memorial Award



*Jeff Lederer receiving
his award*

The Bachmann-Strauss Foundation is pleased to name Jeffrey M. Lederer as recipient of the 2004 Scott M. Johnson Memorial Award for Dystonia & Parkinson's Disease Research. The award is given annually to the Young Professionals (YP) Committee member who has demonstrated tremendous enthusiasm and dedication in helping the Foundation raise funds and public awareness about these neuromuscular diseases.

A member of our YP Committee since its inception seven years ago, Jeff consistently goes above and beyond, whether it's helping to get donations for YP events or giving his time to work at our annual golf invitational. In his professional life, he is founder and CEO of Organic and Nature, Inc., a company that manufactures and distributes non-toxic environmentally-safe cleaning and agricultural products. "I am personally committed to eliminating environmental links to diseases," Jeff said.

Last year, Jennifer Meltzer Geller was named the first recipient of this award. It is given in memory of Scott Johnson, the former Young Professionals Committee member who lost his life on September 11, 2001 in the World Trade Center attack.