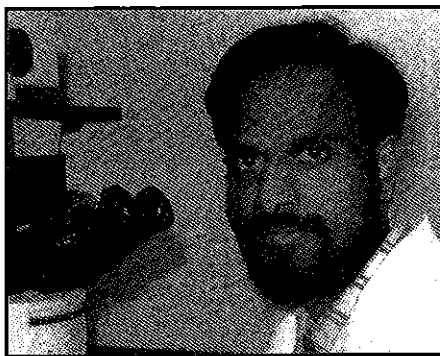


# Outlook

The Newsletter of The Bachmann-Strauss Dystonia & Parkinson Foundation, Inc. • Volume 1, Number 1 • Spring 2000

## New Beginnings



Dr. Pullanipally Shashidharan's development of a torsinA antibody represents an important step in learning how the brain malfunctions in dystonia.

For too long, dystonia and other movement disorders have been little known among the general public and little understood by science, as Bonnie Strauss, the founder and president of The Bachmann-Strauss Dystonia & Parkinson Foundation knows all too well.

C. Warren Olanow, M.D., F.R.C.P.C., Chairman of the Department of Neurology, and Mitchell F. Brin, M.D., Director of the

Movement Disorders Program, and members of The Bachmann-Strauss Foundation's Board of Directors will readily confirm that Bonnie is that most admirable sort of citizen — the kind who discovers a problem and steps right up to organize the search for a solution. Drs. Olanow and Brin consider themselves fortunate to have found such a tireless advocate and fundraiser working beside them in the search for cures for both dystonia and Parkinson's disease.

Just as Dr. Shashidharan's exciting discovery of a torsinA antibody signals an important step in the progress of research, this inaugural issue of *Dystonia & Parkinson Outlook* constitutes another step in the search for answers — a way of keeping the Foundation's friends and supporters abreast of new developments in research, as well as up-to-date about the activities of The Bachmann-Strauss Foundation.

The Foundation is proud to support the work of scientists at Mount Sinai's Movement Disorders Program. Their work focuses on discovering the fundamental causes of

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## Golf Tournament Tees Off A Great Fundraising Event

It turned out to be one of the hottest days in June — but this year's Dystonia Invitational was a success in every way. Over 240 golfers (plus 60 pros) took part in The Hedt Kravis Ruger Memorial Tournament, playing on four courses, the Century Country Club, Golf Club of Purchase, Old Oaks Country Club and Braeburn Country Club. More importantly, this tournament helped us raise over \$1.1 million to support research at The Mount Sinai Medical Center Movement Disorders Program and through the Dystonia Medical Research Foundation.

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Keynote speaker Perri Peltz, correspondent ABC News - 20/20, and Dr. Les Kaplan, our 1999 Honoree, President, Research and Development, Allergan.

### The Bachmann-Strauss Dystonia & Parkinson Foundation, Inc.

The Bachmann-Strauss Dystonia & Parkinson Foundation, Inc., was established in 1995 to raise funds to support research, provide treatment and promote medical and patient education. These efforts are designed to "make a difference" for those with dystonia and other movement disorders.

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Louis Bachmann (1916-2000)

#### Board of Directors

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Sharon G. Epstein  
Executive Director

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# research notes...

Highlights of the research funded by The Bachmann-Strauss Dystonia & Parkinson Foundation at the Mount Sinai Medical Center include:

## DYSTONIA

**Biochemical characterization of human torsinA:** A critical area of dystonia research involves the torsinA protein. Despite many recent advances, exactly how the brain malfunctions in dystonia is still poorly understood. Our investigators were among the team that recently identified the gene for one of the most severe types of inherited dystonia. This gene, the DYT1 gene, was found to make the newly discovered protein termed torsinA. The majority of patients with childhood onset dystonia share a specific gene mutation, or abnormality, in this protein. The protein is present in all of us, and in nematodes (primitive worms) and fruit flies as well, indicating that it is a fundamental protein preserved through evolution.

There is minimal information about the normal function or possible dysfunction of this protein, and additionally, very little information on the cellular and sub-cellular localization of the protein. Now that the protein has been identified, after 10 years of investigation, researchers need to learn exactly what it does, first in people without the gene mutation, and then in patients with the mutation. Solving this mystery may lead to more effective therapies for the disease.

The first step is to explore where the protein is located within the cell, and also which brain regions express this protein. In order to conduct this exploration, we needed a tool to identify, visualize, and measure the expression and activity of the protein. Our investigators have developed an antibody, which labels ("marks") human torsinA and enables them to determine its localization in rat and human brain tissue. The development of this antibody is a most important discovery. Their report has been published in the journal, *Brain Research* and one of the figures demonstrating neurons expressing torsinA was featured on the cover of the journal.

**Myoclonic dystonia:** One of the major focuses of current dystonia research is to identify the genes responsible for the disease in its different forms. For example, in one recent study, members of a certain family who had myoclonic dystonia all had the same gene mutation, while 300 randomly selected subjects did not have this mutation. Now that this gene mutation has been identified, researchers are trying to discover why the mutation is associated with the disease.

## PARKINSON'S DISEASE

**Role of D2 receptors in apoptosis:** Neuronal apoptosis, or cell death, may contribute to Parkinson's disease. Some agents that activate D2 dopamine receptors reduce

apoptosis in animal and tissue culture models of Parkinson's disease. This study is designed to gain further understanding of how the use of dopamine-like drugs could prevent nerve cell death in Parkinson's disease.

**Mechanisms of growth factor-induced neuro-protection during oxidative stress:** It is believed that excessive amounts of oxygen free radicals in the brains of Parkinson's disease patients may be responsible for the damage done to the dopamine neurons. Continued free radical damage may contribute to the pathogenesis and progression of the disease. This project will study the mechanisms involved in the protective action of growth factors against oxidative stress. Information obtained from these studies will result in an increased knowledge of the events that lead to growth factor induced protection of dopamine neurons.

With the support of the federal government and the pharmaceutical industry, additional clinical trials are ongoing at Mount Sinai Medical Center in collaboration with other research centers:

**Botulinum toxin:** Following on the success of Botulinum toxin as a drug therapy for dystonia patients, researchers are conducting clinical studies of each of the toxins in the hope of finding other, possibly more effective treatments.

**Deep brain stimulation:** The use of deep brain stimulation as a possible therapeutic intervention for intractable dystonia, in addition to its use in Parkinson's disease, is currently being investigated.

**Early vs. late levodopa:** Levodopa is the most effective drug now used to treat Parkinson's disease. After two-five years on levodopa, however, patients develop an erratic response to the drug. Researchers are now studying whether levodopa enhances progression, slows progression or does not influence progression of Parkinson's disease.

**Fetal cell implantation:** This study, now in its fourth year (and renewed for another five) seeks to determine whether dopamine-rich fetal cells grafted into the brains of Parkinson's patients can improve the symptoms of the disease. The first results will be analyzed in about two years.

**Genetic study of siblings with Parkinson's:** Researchers at medical centers across the country are collaborating to find pairs of siblings with Parkinson's disease. By collecting and studying blood samples, the researchers are able to study the entire genome of each sibling, and to seek genetic features that seem to be linked to Parkinson's disease. This, researchers hope, will lead to a better understanding of the genetic basis of the disease.

If you wish to participate in a clinical trial, please call 212-241-4253. ☆



**Q:** What is dystonia?

**A:** Dystonia is a neurological muscle disorder affecting about 300,000 Americans of all races. Dystonia produces uncontrollable, painful muscle spasms in one or more parts of the body. Different forms affect the face, neck, throat, eyelids, arms, legs and torso. There is no known cure.

## We Will Remember...

Louis Bachmann, Jr., a philanthropist active in support of Jewish causes, higher education and medical research died at his midtown Manhattan home of natural causes on Wednesday, January 26, 2000. He was 83. Memorial services were held at Mount Sinai's Goldwurm Auditorium on February 11.



Mr. Bachmann grew up in New York City where he attended the Ethical Culture School. After graduating from the Phillips Academy Andover, Mr. Bachmann attended MIT. He then joined L. Bachmann & Co., the firm founded by his father in 1898. He rose to become President of the firm's successor company, Bachmann Uxbridge Worsted, Co. Following a series of mergers involving Bachmann Uxbridge, Mr. Bachmann became Vice President and Director of Amerace Corporation, a position he held until the company was sold in 1984.

An active philanthropist since 1948, Mr. Bachmann served on the Boards of the Federation of Jewish Philanthropies and Elmira College. Over the years, Mr. Bachmann dedicated a growing portion of his philanthropic commitment to the support of medical

research, in particular involving work at Mount Sinai toward the treatment of dystonia. In 1993, he was named an Honorary Trustee of the Dystonia Medical Research Foundation, a position he held until his death. Since 1995, he also served as a Board Member and Secretary of the Bachmann-Strauss Dystonia & Parkinson Foundation, founded by his daughter, Bonnie Strauss. In 1998, Mr. Bachmann, along with his daughter, Bonnie, and son-in-law, Tom Strauss, named and endowed the Bachmann-Strauss Chair in Neurology (Dystonia) at The Mount Sinai School of Medicine. Dr. Mitchell F. Brin was its first recipient.

John W. Rowe, M.D., and President & CEO of Mount Sinai NYU Health, said about Mr. Bachmann: "His philanthropy was exceptionally well targeted and led directly to decreased suffering and enhanced function for many patients with dystonia and Parkinson's disease."

Mr. Bachmann is survived by his daughter, Bonnie Strauss, his son-in-law, Tom Strauss (former President of Salomon, Inc. and currently Managing Member and Co-Founder of Ramius Capital Group), three grandchildren, Tracey M., Elizabeth B., and Peter B. Strauss.

## Personal Profile

### Rebecca Serdans: Nurse, Author & Dystonia Patient

One of The Bachmann-Strauss Foundation's primary goals is to spread public awareness of dystonia, so that people suffering from its symptoms will be able to get accurate diagnoses and effective treatment without having to wait for years. A major triumph in this arena was a story broadcast in October on NBC's *Dateline*, which profiled Rebecca Serdans, an Intensive Care Unit nurse who has cervical dystonia (also called spasmodic torticollis). Rebecca herself was instrumental in bringing this story to *Dateline* viewers. "It took me a year, but it proves that anything is possible — even with dystonia," Rebecca says.

"It's a very difficult disease to live with on a daily basis," Beka told the NBC science reporter. "You wake up in the morning and it never leaves. It's always there." This is apparent watching her on her morning walk to work. While her body moves in a straight stride, her neck deviates to the left. Her hands, crossed, help to support her neck. Aside from the physical pain and discomfort of this affliction is the overwhelming emotional self-consciousness it causes. Beka, the oldest of three girls in a family of Latvian descent, is the only one to suffer from the disease. She left her family back in Rochester two years ago to seek treatment in New York.



Rebecca Serdans

*Dateline* included an interview with Dr. Mitchell F. Brin, Director of Mount Sinai's Movement Disorders Program, who diagnosed Beka. Dr. Brin explained the mechanism behind Botox (botulinum toxin type A), the most effective drug now available to treat dystonia: It prevents signals from the brain from reaching the affected muscles — "like cutting the wire," he said.

Soon after her botulinum toxin injection, her posture markedly more relaxed, Beka enjoyed an on-camera meal in a restaurant. "It's heaven not to be in pain," she confided. "It's heaven not to have twitches and tremors." The tremendous relief the injections bring lasts about 6-12 weeks, followed by returning symptoms and time for another injection.

The story concluded with her riding a bike in the park — proof that, although there is no cure for dystonia yet, the condition can be managed.

Beka has also co-authored a booklet with Dr. Brin called, *Demystifying Dystonia: A Guide for Managing Your Dystonia*. She is now working on several other publications for the Bachmann-Strauss Foundation, including a booklet for children. ☆



## Symposia for Patients & Families

Each year, The Bachmann-Strauss Foundation sponsors a symposium on Parkinson's Disease and another on dystonia. Both are designed to bring patients, families and caregivers up-to-date on the latest breakthroughs in medical research. This year's Parkinson's symposium, held at The Mount Sinai Medical Center on October 8th, featured a presentation by Dr. Tony Schapira (of the Royal Free and University College Medical School in London, and a member of the Foundation's Scientific Advisory Board) on recent research into new treatments, as well as talks by Drs. C. Warren Olanow and Mitchell F. Brin on medical and surgical therapies.

The Dystonia Symposium on November 5th featured three researchers from Mount Sinai, all of whom hold Bachmann-Strauss research grants for dystonia: Drs. Mitchell F. Brin, Ruth Walker and Colum MacKinnon. The attendees were especially eager to hear about new treatment options. ☆



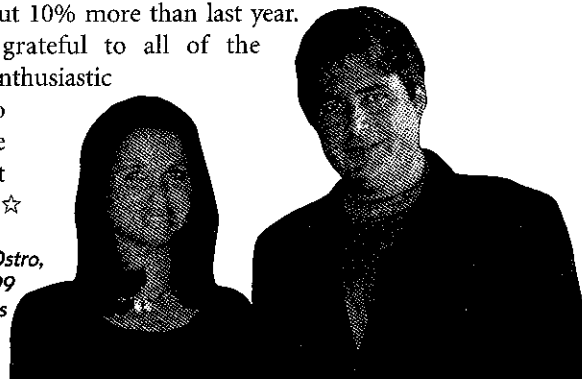
Symposia speakers included (l. to r.) Drs. Mitchell F. Brin, Anthony Schapira and C. Warren Olanow.

## Young Professionals Raise Awareness — And Funds



The Grand Havana Room at 666 Fifth Avenue was the site of this past July's second Young Professionals event. Co-chairs Marilyn and Scott Ostro, working with a network of over 60 committee members and organizers, brought more than 275 of their friends and co-workers to this elegant evening of cocktails, dinner and dancing. Ticket sales, a journal and a raffle of over 25 prizes raised more than \$45,000 — about 10% more than last year. We are truly grateful to all of the dedicated and enthusiastic individuals who worked to make this year's event such a success. ☆

Marilyn and Scott Ostro, co-chairs of the 1999 Young Professionals event.



### Q: What is Parkinson's Disease?

A: Parkinson's is a neuro-degenerative disease affecting approximately one million Americans. Parkinson's is caused by a change in the part of the brain that controls movements such as walking and balance. Symptoms include tremor, slowness of movement, muscle tightness and problems with balance.

## The President's View



Hundreds of thousands of Americans should not have to suffer a lifetime of pain and discomfort when, even now, treatments are available that can greatly ease the symptoms of dystonia and Parkinson's disease.

It took me five years before my dystonia was correctly diagnosed by Dr. Mitchell F. Brin. My frustration at the lack of knowledge about movement disorders was matched by the difficulty pioneers like Dr. Brin encountered in obtaining research funding. Both led to my determination to change an intolerable situation by establishing The Bachmann-Strauss Dystonia & Parkinson Foundation.

The Foundation works to raise awareness of dystonia and Parkinson's among the general public and in the medical community. In this way, the Foundation, together with the Movement Disorders Program, have the potential to make a real difference in hundreds of thousands of lives. Progress and, ultimately cures, will result from medical research. By raising funds to support scientists at Mount Sinai's Movement Disorders Program and the Dystonia Medical Research Foundation, we help these researchers make important discoveries. Furthermore, published reports on successful studies draw attention to this field of research, which I hope will attract some of the country's top researchers to the search for cures.

Our fundraising achievements have gone far beyond anything I imagined back when I organized the first Dystonia Golf Invitational. Through annual events such as the Invitational, theater benefit and young professionals benefit, we've raised more than \$6 million since 1993. Of course I'm proud of this, but even more, I'm overwhelmed with gratitude to the many friends who have contributed their time, their talents and their enthusiasm to the success of these events. It inspires me to see what people can achieve when they combine their commitment and determination.

With this first issue of *Outlook*, our new newsletter, The Bachmann-Strauss Dystonia & Parkinson Foundation hopes to accomplish several goals: to keep dystonia and Parkinson's patients informed about the latest advances in research, to recognize the hard work and achievements of those who take part in our fundraising efforts, and to raise awareness about both dystonia and Parkinson's disease.

You can help in two important ways: First, through your ongoing generosity, you can help fund desperately needed medical research. Second, you can pass this newsletter on to someone else when you finish reading it. By that simple act, you'll be furthering our mission and, quite possibly, saving someone from years of unnecessary suffering. ☆

Bonnie Strauss  
President and Founder



Benefit Committee Chairs Patti Kenner and Bonnie Strauss present Drs. C. Warren Olanow (left) and Mitchell F. Brin (right) with a check for \$70,000, representing the proceeds of our Parkinson's disease theater benefit.

## Kiss Me, Kate Performance Benefits Bachmann-Strauss

Another successful fundraiser, another night of fun. On November 10th, an audience of 220 people enjoyed a performance of this season's critically acclaimed *Kiss Me, Kate*, starring Marin Mazzie and Brian Stokes Mitchell, at the Martin Beck Theater. The Cole Porter show, based on Shakespeare's *The Taming of the Shrew*, features familiar songs like *Another Op'nin', Another Show*, *So In Love* and *Wunderbar*.

The event — our third theater benefit — raised \$70,000 for Parkinson's disease research at Mount Sinai.

Our sincere thanks to all of the dedicated friends who served on our Theater Benefit Committee for a job well done. ☆

## Friends of the Foundation Awards & Grants Named

A special "thank you" to a few remarkable individuals who made significant contributions to the Foundation's efforts in the past year. These individuals help to *make a difference* for those with dystonia and Parkinson's disease. Awards and award-winners include:

Corporate Fundraising:	Harvey R. Blau
Dystonia Volunteer of the Year:	Sharon Baron
Parkinson's Disease Volunteer of the Year:	Patti Kenner
Young Professionals Award:	Marilyn and Scott Ostro
Media Awards:	Beka Serdans and Nancy Roth
Outstanding Research Award:	Dr. Pullanipally Shashidharan

For their outstanding fundraising work, grants have been named in honor of The Zames Family and Young Professionals Group.

The Zames Family Parkinson's Disease Research Grant has been presented to William Tatton, M.D., Ph.D., for *Catecholaminergic Receptors for the Reduction of Apoptosis in Parkinsonian Models*. Board member Jonathan D. Zames and his family have had outstanding success in raising funds for Parkinson's disease.

The Young Professionals Research Grant has been presented to Mitchell F. Brin, M.D., for *Genetics and Phenotypic Expression of Idiopathic Dystonia*. This grant is named in honor of the extraordinary accomplishments of a group of dedicated young professionals. In two years they have raised almost \$100,000.

The Foundation is pleased to acknowledge the efforts of all our award winners and grant honorees. ☆

## Golf Tournament Tees Off A Great Fundraising Event

(continued from page 1)

The tournament's reputation keeps growing — we actually had to turn people away this year! And despite the heat, nine courageous souls played tennis.

At dinner that evening, nearly 300 attendees enjoyed a touching talk by ABC News correspondent Perri Peltz about the importance of getting involved with nonprofits. Les Kaplan, our honoree, is President of Research and Development at Allergan, the manufacturer of Botox, a therapeutic treatment that has improved the quality of life for many dystonia patients.

The dinner also included an auction of wonderful packages, including trips to Hawaii, the Caribbean and Europe, an internship at Bloomberg LLP and fabulous jewelry.



Bonnie Strauss, President of The Bachmann-Strauss Dystonia & Parkinson Foundation, Inc., with (left to right) Corporate Chairs Harvey Blau, Burt Ehrlich, Fran Ehrlich and Loren Katzovitz.

Corporate Chairs Harvey R. Blau, Fran and Burt Ehrlich and Loren M. Katzovitz deserve our gratitude for their hard work and effectiveness in making this year's event such a success. Special thanks to every one of you who supported the 1999 Invitational! ☆



THE BACHMANN-STRAUSS  
DYSTONIA & PARKINSON  
FOUNDATION, INC.

The Mount Sinai Medical Center  
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**In Support of  
Movement Disorders  
Research**

*Address Correction Requested*

**New Beginnings** *(continued from page 1)*

dystonia and Parkinson's disease, and developing strategies for relieving symptoms and ultimately curing these diseases. Mount Sinai's researchers already have made important advances in understanding and treatment — playing a major role, for example, in developing surgical treatments as a possible novel therapy for dystonia and Parkinson's patients. Additional dystonia research is funded through the Dystonia Medical Research Foundation, based in Chicago.

The Movement Disorders Program staff also pioneered the use of Botulinum toxin in the treatment of dystonia, and have been exploring the delivery of drugs directly into the cerebrospinal fluid in order to relieve dystonia patients' uncontrollable spasms. Researchers recently have been exploring high-frequency deep-brain stimulation as a treatment for many of the symptoms of Parkinson's disease and dystonia, as well as testing a variety of drugs that may help the disorders.

Each year, The Bachmann-Strauss Foundation supports several research projects at Mount Sinai.

**Dystonia grantees for the year 2000 include:**

Joan C. Borod, Ph.D.  
*Postdoctoral Neuropsychology Fellowship*  
Mitchell F. Brin, M.D.  
*Genetics and Phenotypic Expression of Idiopathic Dystonia*  
Christine Eng, M.D.  
*Genetic Epidemiology of Idiopathic torsin Dystonia in the*

George Huntley, Ph.D.  
*Synaptic Physiology of Motor Circuits in Transgenic Mouse Models of Dystonia*

Stuart Sealfon, M.D.  
*Regulation of torsinA mRNA in Living Cells*

Lawrence Shapiro, Ph.D.  
*Structure-Based Functional Analysis of torsinA*

Pullanipally Shashidharan, Ph.D.  
*Biochemical Characterization of Human torsinA*

Jeremy Silverman, M.D.  
*The Phenotypic Expression of Myoclonic Dystonia*

William Tatton, M.D., Ph.D.  
*Subcellular Localization as a Guide to the Function of torsinA*

Ruth Walker, M.D.  
*Immunohistochemical Studies of torsinA in Rat & Human Brain*

**Parkinson's research grantees for 2000 include:**

Paul Good, Ph.D.  
*Cytoskeletal Protein Phosphorylation in Parkinson's Disease*

Catherine Mytilineou, Ph.D.  
*Mechanisms of Growth Factor-Induced Neuroprotection During Oxidative Stress*

Stuart Sealfon, M.D.  
*Levodopa vs. DA agonist: Gene Changes in Mesencephalic Neurons Assayed by Microarray*

William Tatton, M.D., Ph.D.  
*Catecholaminergic Receptors for the Reduction of*