Dystonia is a neurological muscle disorder that causes uncontrollable, painful spasms in one or more parts of the body. Different forms of the disease affect the face, neck, throat, eyelids, arms, legs, or torso. Some people can maintain a relatively normal lifestyle, while others permanently struggle in wheelchairs or with crutches—some unable to talk, others unable to see—often needing full-time assistance.

Parkinson's disease is a disorder of the central nervous system caused by a change in the part of the brain that controls movements, like walking and balance. Symptoms include tremor, slowness of movement, muscle tightness, and problems with balance. Parkinson's may appear at any age, but it's most common in people over 50 and rare in those under 30.
In simplest terms, dystonia and Parkinson’s disease both entail involuntary muscle activity characterized by a malfunction in the brain’s basal ganglia, which helps coordinate the movement of muscles. It’s speculated that research findings of one disease will help further the understanding of the other.
The harsh reality for people affected by dystonia or Parkinson’s disease is that, right now, no one really knows the exact cause or cure.
MESSAGE FROM THE PRESIDENT AND FOUNDER

BONNIE STRAUSS

From the time we established our Foundation in 1995, we encouraged scientists and neurologists to work together to look at the root causes of dystonia and Parkinson's disease. We're now beginning to see that encouragement result in solid progress.

The inspiration behind this focused view—the inspiration for establishing our Foundation—was my father, Louis Bachmann. He guided our early steps and helped make our vision a reality. While there's still a long, long way to go before we find the cure that will help millions of people worldwide, this year we've seen unparalleled inroads. Not only is research making headway, but more information in the field is being shared than ever before and real connections between various factors relating to both Parkinson's disease and dystonia are being identified.

Thanks to the generosity of hundreds of individual and corporate contributors, The Bachmann-Strauss Dystonia & Parkinson Foundation awarded $875,854 towards medical research. This year we expanded our efforts to educate doctors and scientists alike about the signs and treatments of these debilitating diseases. We also reached out to patients and families and the general public to ensure that more people find the best treatments.

Our next steps are clear—quite simply, to continue to fund the kind of cutting edge research that's making a difference and to facilitate the synergy among various research studies so we can help develop better treatments and find a cure for dystonia and Parkinson's disease.

I thank you for your continued support. My heart goes out to each of you for helping to make such great advances in the field.

Bonnie Strauss, president and founder of The Bachmann-Strauss Dystonia & Parkinson Foundation, went from doctor to doctor for five years before she found Dr. Mitchell F. Brin, who diagnosed that she had a form of dystonia. Her work ever since has been to fund research that will help find a cure. After her mother was diagnosed with Parkinson's disease in 1997, she decided to also raise funds for Parkinson's disease since it, like dystonia, affects the brain's basal ganglia.

Bonnie Strauss has dedicated her life to expanding the base of knowledge about these two debilitating diseases among the medical and scientific community and the general public.
MESSAGE FROM THE EXECUTIVE DIRECTOR

MARGIE J. WALDEN

While the important progress our organization made this year was against a backdrop of economic uncertainty and the tragic bombings of the World Trade Center, which saddened our entire nation, we remained focused on our fundraising efforts to help find a cure for dystonia and Parkinson’s disease. We were joined by a tremendous show of support from over 100 volunteers. Individual and corporate contributions also increased by 5.6 percent, and the number of people who attended our events increased by 5 percent.

We also fine-tuned our administrative and fiscal management in 2001, adding needed staff to help coordinate and manage our special events. We improved our Web site, www.dystonia-parkinsons.org, and published two newsletters to help build awareness and provide a valuable information resource for the medical community and general public alike. In addition, we held two symposia for patients, family members, and caregivers on current research and treatments.

The true bottom line of all our efforts this year is the medical research and breakthroughs made possible by your support. It’s only through scientific inquiry that we are able to further our understanding and provide hope to so many people affected by dystonia and Parkinson’s disease.

This report highlights examples of the dynamic connections that were made this past year. We’re proud to share with you our accomplishments and exciting plans for the future, along with our sincere thanks for your help.
Because so few people—including physicians—have heard of dystonia, the disease is often undiagnosed or misdiagnosed.

THE ROAD TO A CURE

Countless hours spent analyzing small, seemingly unrelated cells can add up to major breakthroughs. And for millions of Americans who suffer from dystonia and Parkinson's disease, those incremental steps can translate into the kind of treatments that will change their lives forever.

In 2001, The Bachmann-Strauss Dystonia & Parkinson Foundation support of medical research made great progress. As a result, the medical and scientific communities are beginning to gain greater knowledge about the causes of these neuromuscular diseases. And more people who live with the painful, often debilitating impact of these diseases are able to look forward to the development of better treatments and to the day when there's a cure.

Approximately one million Americans have Parkinson's disease. And while there's greater awareness of Parkinson's disease than dystonia, we still have a long way to go to uncover the cause and find a cure.

Over 300,000 Americans suffer from dystonia, about one-third of whom are children. Some estimates say 500,000 people are affected—more than with Muscular Dystrophy, Huntington's disease, and Lou Gehrig's disease combined.
As a result of The Bachmann-Strauss Dystonia & Parkinson Foundation funding, cutting-edge research projects are beginning to shed some very promising light. The following are the most recent highlights.

**Recent Breakthroughs**

Understanding the TorsinA protein has become an important key to finding a cure for dystonia. Research investigators, funded by The Bachmann-Strauss Dystonia & Parkinson Foundation, were part of the team that identified the DYT1 gene, which is responsible for one of the most severe types of inherited dystonia. It was also found that the DYT1 gene encodes the newly discovered protein called TorsinA. While everyone has this, the majority of patients who develop dystonia in childhood share a specific gene mutation or abnormality in this protein.

**Next Steps:** To learn the crystal structure of the TorsinA protein; to find out exactly what it does in people with and without the gene mutation; to find out why symptoms are limited to movement disorders and why these symptoms develop in only 30–40 percent of those who carry the mutated gene.

- **Development of the transgenic mouse model** this year is considered to be an essential step in trying different therapies to find a cure for dystonia. Researchers generated a colony of mice; 55 percent of the transgenic mice developed abnormal movements and postures at the age of one month. The further development of this animal model will allow us to understand the underlying cause of dystonia.

- **A new Parkinson’s disease study** undertaken this year is looking at a mechanism by which dopamine cells may be damaged. This may lead to ways to protect dopamine cells from oxidative stress. Initial experiments have supported the theory that arachidonic acid, a common signaling molecule, plays an important role in this mechanism.

*Terminology:*

- **Medical research** at Mount Sinai Medical Center
- **TorsinA** accumulation in Lewy bodies in sporadic Parkinson’s disease
- **Dr. C. Warren Olanow FRCP**; Professor and Chairman, Department of Neurology, Mount Sinai Medical Center
**Further Progress and Hope**

Our steadfast commitment to ongoing research in the field is strengthened by a number of collaborative relationships.

- A research team has been coordinating and implementing studies to find the gene(s) responsible for dystonia and Parkinson's, as well as to better define the clinical pictures of various types of dystonia. The team has produced nearly a dozen papers on their work, broadening the base of knowledge.

- Dr. Matt Brodsky was selected in June 2001 as the first recipient of the Mitchell E. Brin Fellowship in Movement Disorders. The fellowship, funded by Allergan in cooperation with The Bachmann-Strauss Dystonia & Parkinson Foundation and the Mount Sinai Medical Center, Department of Neurology honors Dr. Brin’s exceptional commitment and research in the field of movement disorders. Dr. Brodsky will use the fellowship to continue his research at Mount Sinai Medical Center's Department of Neurology.

**Building Knowledge**

Broadening awareness of dystonia and Parkinson's disease continued to be key to our efforts this year. Two important symposia, one on Parkinson’s disease and the other on dystonia, were sponsored at Mount Sinai Hospital in New York. Attended by patients and families, researchers discussed current treatment alternatives, clinical trials and new research currently underway.

**HELP ONLINE**

Thousands of people turned to our Web site this year for vital information about living with these diseases, about clinical trials and other research that's underway as a result of our funding, and for links to others who suffer so greatly.

[www.dystonia-parkinsons.org](http://www.dystonia-parkinsons.org)
Bonnie Strauss created the Annual Dystonia Invitational, which first took place in September 1993 at the Century Country Club in Westchester, New York. In the past nine years, she has raised more than $8 million for medical research and has increased awareness of dystonia.

**ANNUAL BENEFITS**

The very tangible connection between the work of our volunteers and the results of their help was more evident than ever before this year. Over 100 men and women lent their time and talent to our organization, enabling us to reach more people and raise money for the kind of vital, targeted research that’s making progress.

During this year, thanks to the direct efforts of these generous volunteers, our three primary events raised a record of more than $1.5 million to support local research.

**Our Ninth Annual Dystonia Invitational** raised more than $1.3 million. Over 250 amateur golfers and 70 pros took part to help fund research projects for the Movement Disorders Program at the Mount Sinai Medical Center and other national research projects in collaboration with the Dystonia Medical Research Foundation. Mary Cirillo Goldberg, Chairman and CEO, OpCenter; Jay Goldberg, Partner, Hudson Ventures; and Loren Katzowitz, Managing Director, RBC Dominion Securities, were the Corporate Chairs of the event.

Bank of America Private Bank and Allergan, Inc. served as this year’s Corporate Sponsors. GlaxoSmithKline and Pharmacia generously provided additional underwriting.

**Speakers at the 2001 Parkinson’s Disease Symposium—**
Dr. Dan Perl, Professor of Pathology, Mount Sinai Medical Center; Susan Dolan, Clinical Research Coordinator, Jewish Home & Hospital Association; Jean Michel Gracies, Assistant Professor, Department of Neurology, Mount Sinai Medical Center; Dr. Cheryl Waters FRCP(C), Professor and Chief of Clinical Practice Services, Department of Neurology, Columbia University, College of Physicians & Surgeons

**9th Annual Dystonia Invitational—** Bonnie Strauss thanking the Corporate Chairs Jay Goldberg, Mary Cirillo Goldberg, and Loren Katzowitz.
STRAIGHT FROM THE HEART

Our Fourth Annual Young Professionals' Benefit, held at The Boathouse in Central Park, raised an outstanding $52,690 for dystonia and Parkinson's disease research at Mount Sinai Medical Center. Young Professionals range in age from 25–35 years old. More than 300 people attended the event, which was co-chaired by Emily Kanders and Elizabeth Kohn. More than 25 volunteers helped organize the event, produce a journal, acquire more than 35 raffle prizes, and get an abundance of gifts from local corporations for all the attendees.

At our Fifth Annual Parkinson's Theater Benefit, 190 theater-goers attended dinner and a performance of the new Broadway musical, "Thou Shalt Not," in support of Parkinson's disease research. Thirty-two people on our Benefit Committee worked together to make this event successful, raising $100,846.
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. An independent, nonprofit 501(c)3 organization, its funding is made possible by individual and corporate contributors.

Since 1995, 61% of our funding has gone directly to the research and education of dystonia and Parkinson's disease.

*Figures are projections as of September 30, 2001. Copies of our audited financial statements are available upon request by writing to The Bachmann-Strauss Dystonia & Parkinson Foundation, Inc., The Mount Sinai Medical Center, One Gustave L. Levy.
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<th>Contribution/Role</th>
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—Bonnie Strauss
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**DYSTONIA RESEARCH**

- Jean-Michel Grecois, MD, PhD
  Donald Weisz, PhD
  Rapid Alternating Movements in Human Subjects: Establishing Normative Data for Quantitative Testing in Dystonia and Parkinson's Disease

- Colum Mackinnon, MD, PhD
  Cortical Control of Agonist-Antagonist Muscle Activity in Patients with Primary Dystonia

- Stuart C. Sealfson, MD
  D2 Receptor Mutation Linked to Myoclonus Dystonia

- P. Shashidharan, PhD
  Catherine Mytilineou, PhD
  A Transgenic Mouse Model of DYT1 Dystonia

- Lawrence Shapiro, PhD
  Structure-Based Functional Analysis of TorsinA

**DYSTONIA—CORE CLINICAL RESEARCH**

- Fabio Danis, MD
  Genetics and Phenotypic Expression of Idiopathic Dystonia, Parkinson's Disease, and Other Movement Disorders

- Ruth Konreich, PhD
  Jianli Dong, MD, PhD
  Richard Desnick, MD, PhD
  Determination of the Carrier Frequency and Penetrance of the 946delGAG Mutation in the Torsion Dystonia (DYT1) Gene in the Ashkenazi Jewish Population

- Jeremy Silberman, PhD
  The Phenotypic Expression of Myoclonic Dystonia

**PARKINSON'S DISEASE RESEARCH**

- Catherine Mytilineou, PhD
  The Role of Arachidonic Acid in Neurodegeneration Oxidative Stress

- P. Shashidharan, PhD
  Torsin-A Over Expression in Dopamine Neurons and Sporadic Parkinson's Disease in a Mouse Model
The Bachmann-Strauss Dystonia & Parkinson Foundation, Inc.

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