transforming Parkinson’s Disease care
informing Parkinson’s Disease patients
reforming Parkinson’s Disease beliefs
forming Parkinson’s Disease hope
Founded in 1957, NPF is a leading national organization with an extensive network of Centers of Excellence, chapters and support groups in the United States, Canada and internationally. Unique among the national Parkinson’s organizations, NPF is the only organization with a singular focus on improving the quality of care in Parkinson’s disease. Since 1982, NPF has funded more than $155 million in research, education and support services.

NPF drives breakthrough research by bringing together the thought leaders at NPF Centers of Excellence – 43 leading medical centers around the globe that deliver care to more than 50,000 Parkinson’s patients. Through the centers network, NPF creates a community of health care professionals dedicated to improving clinical care in Parkinson’s disease.

In everything we do, NPF promotes our passionate belief that the best care is a comprehensive approach that addresses the whole person and the full range of symptoms, while continuously searching for the next insight that will change the course of this devastating disease.

The mission of the National Parkinson Foundation (NPF) is to improve the quality of Parkinson’s care through research, education and outreach.
On July 7, 2010, the National Parkinson Foundation said goodbye to our Chairman Emeritus, Nathan Slewett; a dear friend and visionary leader. The foundation is indebted to Nathan for his unwavering commitment, not only to research, but also to care for those living with Parkinson’s.

Nathan served as the volunteer President of the foundation for several years and was elected Chairman of the Board in 1992. He continued to serve as Chairman Emeritus until 2010 and came into the Miami office nearly every single day of his 40-year tenure. He took on this important role after befriending NPF’s founder, Mrs. Jeanne Levey, without compensation and without personal or familial connection to the disease.

His accomplishments during his tenure are remarkable—because of his leadership, the National Parkinson Foundation has funded more than $155 million in research and support services since 1982; established a Centers of Excellence network housed at leading universities throughout the world and garnered international recognition.

Although he did not live to see a cure for Parkinson’s disease, his legacy lives on in the many researchers and neurologists whose careers started because of Nathan Slewett.

Nearly half of our centers, which were established with Nathan’s help, have implemented NPF’s Quality Improvement Initiative (QII), under the leadership of our President and Chief Executive Officer, Joyce Oberdorff. In this report, you will read more about the new approach to studying Parkinson’s disease that promises better understanding of how it progresses, better data about which treatments are most effective for which patients and a wealth of knowledge to help spark further innovation. This exciting initiative has the potential to transform the way Parkinson’s care is delivered.

On behalf of all of us at NPF, we express our thanks to you for allowing us to fulfill our mission of bringing help and hope to the one million people living with Parkinson’s disease and their families in this country alone.

Warm wishes,

Bernard J. Fogel, MD
Chairman
Better research means better treatment. Better treatment means better lives. That’s why the National Parkinson Foundation’s Quality Improvement Initiative (QII) is so important. QII is the first large-scale comprehensive study to track how Parkinson’s disease progresses and how various treatments affect outcomes. It will help doctors make evidence-based decisions about the best care for each Parkinson’s patient and spur innovation.

The vision of this initiative is to:

- Identify correlations between therapeutic choices and improved outcomes
- Establish an evidence base as a foundation for future innovation
- Improve the body of research to support evidence-based medicine decisions

“[The Quality Improvement Initiative should help define what is optimal care, no matter where you receive it, and produce the research to back it up.]”

Mark Guttman, MD, FRCPC
Markham Stouffville Hospital, Markham, ON, Canada
Parkinson’s disease is a neurodegenerative disease that affects about one million Americans. But NPF research has shown that the average patient is much sicker than those typically included in clinical trials, with a higher percentage of comorbid conditions such as arthritis, heart disease and diabetes. How do treatments fare in real-world settings? QII will help find the answers.

The database includes an annual screening that is likely to elevate care, as patients are asked about demographics, diagnosis, disease progression, comorbidities, medications, exercise, depression, caregiver strain and cognition.

“NPF is closing the gap between the knowledge that arises out of clinical trials and everyday practice. This project will enable physicians to track performance of various treatment approaches and evaluate new treatments in a real-world setting.”

Joseph Jankovic, MD  
Baylor College of Medicine, Houston, TX
By December 2010, the QII registry included 3,000 Parkinson’s patients. This is expected to expand to 10,000 patients by the year 2015.

Preliminary data has already identified frequent reports of cognitive and psychiatric issues among people with PD. To date, 17 NPF Centers of Excellence in the United States, Canada, Israel and Europe are participating. In 2011, NPF will continue to roll out the QII program to Centers of Excellence across the United States, Canada and internationally. Data collection will be standardized through robust electronic medical record systems. The long-term goal of QII is to create feed-forward clinical decision making that will help people with Parkinson’s manage their symptoms and keep life at a high-functioning status.

“Cognitive issues are major factors in Parkinson’s and the ones likely to be most troubling to a patient and their families. By including an annual screening for cognitive issues, QII will lead to earlier detection and better treatment.”

Laura Marsh, MD
QII Advisor, Michael E. DeBakey VA Medical Center, Houston, TX
The Quality Improvement Initiative, the first and largest of its kind for Parkinson’s disease, is merging the art and science of care to elevate the management of the disease.

Preliminary data has already shown:

• A high incidence of other diseases and chronic conditions
• Early indications of the positive effects of exercise programs
• Distinct variations in the way that physicians are treating PD

QII offers the possibility of closing these gaps as well as decreasing the disparities that exist in certain ethnicities.

“The greatest benefit of QII may be the opportunity it provides us to closely study the centers that are doing the best job of improving and extending the lives of people with Parkinson’s and share that knowledge with clinicians around the world.”

Daniel Tarsy, MD
Beth Israel Deaconess Medical Center, Boston, MA
In 2010, NPF joined two other Parkinson’s organizations, the Parkinson Disease Foundation (PDF) and American Parkinson Disease Association (APDA), in a collaboration geared toward imparting greater awareness of Parkinson’s and training for nurses. Nurses can take the online course, “Parkinson’s Disease Across the Lifespan: A Roadmap for Nurses,” and receive continuing education credits for their work.

As NPF continues to study the 21st century health care needs for people with Parkinson’s, we will identify ways to improve care. We will continue to forge the path to new advances in treating this debilitating neurological disorder, which is second only to Alzheimer’s disease in the number of Americans it affects.

“As our population ages, the number of people with Parkinson’s is expected to skyrocket. Nurses are on the front line of clinical care, and the need for more training in Parkinson’s is a critical unmet need.”

Julie Carter, RN, MS, ANP
Oregon Health & Science University, Portland, OR
The National Parkinson Foundation gratefully acknowledges the following individuals, corporations, foundations and organizations who have contributed $1,000 or more between July 1, 2009 and June 30, 2010. Their giving assists research, education and outreach initiatives. Thank you for your support.

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- South Palm Beach County Chapter of NPF

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Legacy society members are a select group of donors who have recognized the National Parkinson Foundation in their wills, trusts, estates and other planned gifts. Their generosity and forethought will help thousands of Parkinson’s patients live better lives in the years to come. We would like to recognize the following Legacy Society members:

- E. Richard and Meme Alhadeff
- Eugene M. Bane Charitable Trust
- A. Jeffrey Barash
- Virginia C. Barrett
- Chinowth Charitable Lead Trust
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- Sally & Robert Webb
- Michael L. & Antoinette H. Wilkerson
- Freeman A. Wolfe
Every year, thousands of people participate in community fundraisers to increase awareness of Parkinson’s disease and raise funds for the National Parkinson Foundation. We would like to extend our sincerest gratitude for their creativity, energy and commitment:

American Junior Golf Association
Anne Joyce Memorial Foundation
Baker Elementary School
Sarah Battaglia
Anita Blenke
Nikki Carr
Catch The Cure
Linda M. Cibula
City of Littleton, CO
Debbie Cuppernell
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Emily Luther
Ramon E. Martinez
Kevin Corbett and Patrick Matthiessen
Mt. Vernon Knights of Columbus Club, Inc.
Alicia Myers
North Florida Parkinson Awareness Group
Jama Oliver
Matt O’Mansky
Parkinson Association of South Dakota
Parkinson’s Support Group
Of Upstate NY, Inc.
Leilani Pearl
Merle Perlow
Vincent & Maria Pfeifer
Jim Posen
Jeffrey and Marjorie Rugg
The Society of Friendly Fellows
Sara Solomon
Jason Stein
Johnny Strange
Ryan Strayhorn
TruMark Financial Credit Union
Mason Walker
Whisconier Middle School
FINANCIAL Highlights

2009-2010 Mission-Related Expenses
The National Parkinson Foundation directed over $6 million of 2009-2010 total expenses on mission-related activities.

2009-2010 Revenues by Category

Total Year-End Assets | $17,768,764
The National Parkinson Foundation is privileged to have an outstanding and dedicated group of volunteers who generously donate their time and talents by serving on the NPF Board of Directors. Without their selfless efforts, the work of the Foundation would not be possible.

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Senior PROFESSIONALS

These are the people who work daily to carry out NPF's mission:

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President and Chief Executive Officer

Michael S. Okun, MD
National Medical Director

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Chair, Clinical & Scientific Advisory Board

Robin Boettcher
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