

Annual Report 2011



Find answers. Change lives. **Beat Parkinson's.**

## About the Foundation

Founded in 1957, the National Parkinson Foundation (NPF) is a leading, national organization with an extensive network of Chapters, Support Groups, and Centers of Excellence 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 \$164 million in research, education and support services.

NPF programs touch more than one million people a year through our 39 U.S. Chapters and 900 Support Groups, patient conferences, and our online resource Parkinson.org.

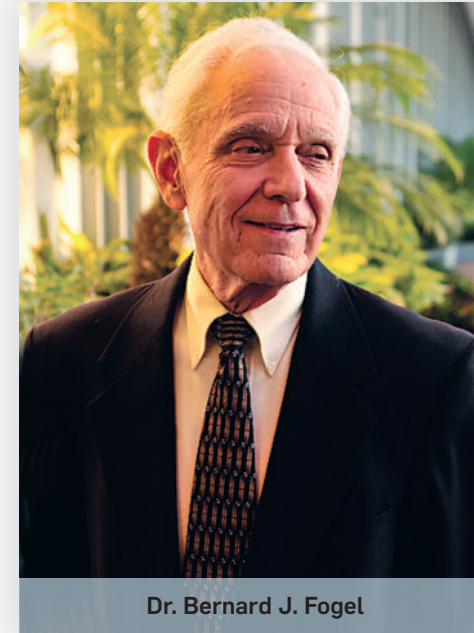
NPF drives breakthrough research by bringing together the thought leaders at NPF Centers of Excellence – 43 leading medical centers around the globe that deliver care to more than 50,000 Parkinson's patients. NPF continues to be a major funder of research programs, such as our Quality Improvement Initiative, to change the course of the 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 help us beat Parkinson's.



*The mission of the National Parkinson Foundation (NPF) is to improve the quality of Parkinson's care through research, education and outreach.*

## Chairman's Message



Dr. Bernard J. Fogel

I have had the pleasure of serving as chairman of the NPF board for the past three and a half years, and I am proud to say that our efforts to reorganize the foundation have allowed us to become the leader in improving the quality of care for people with Parkinson's disease. On a daily basis, I am inspired by the hard work of NPF's extremely dedicated team of individuals under the leadership of NPF's President and CEO, Joyce Oberdorf.

With all of our successes in the past year, I am most proud of our national outreach efforts to launch *Moving Day*, NPF's signature walk for Parkinson's. NPF is thrilled to

have Katie Couric as the honorary national chair of the *Moving Day* campaign. With this national event, we are beginning to change the world for people with Parkinson's. The slogan of *Moving Day* is "People Who Move Change the World" and we are helping people to stand up and declare that movement is beautiful.

In these pages, you can read about some of the cutting-edge programs we have created to provide the best treatment and care options for people living with Parkinson's. NPF truly is creating a new day for Parkinson's. Your generosity makes our work possible.

I would like to extend my special thanks to our loyal supporters who help us to bring help and hope to the millions of people living with Parkinson's disease and their families every single day. Together, we will find answers, change lives and beat Parkinson's.

Warm wishes,

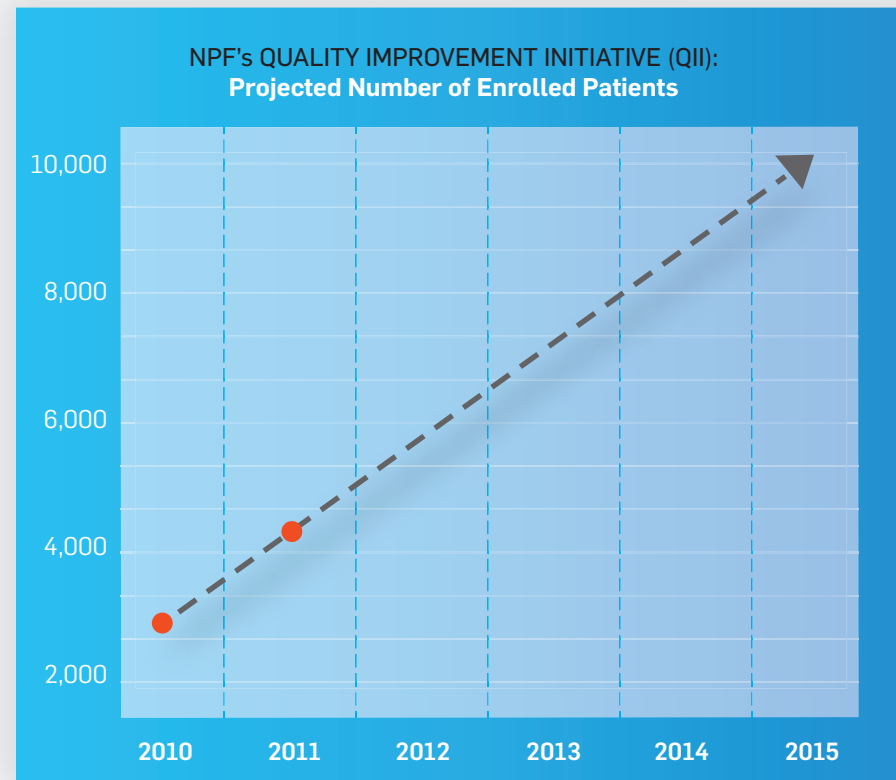
A handwritten signature in black ink, appearing to read 'Bernard J. Fogel'.

Bernard J. Fogel, MD – Chairman of the Board

### Finding What Works Best

Bringing the same high-quality care to every patient diagnosed with Parkinson's — that is the goal of NPF's Quality Improvement Initiative (QII). Since it was established in 2009, the project has expanded to include more than 4,500 patients at 19 Centers of Excellence, making it the largest Parkinson's outcomes registry in the world. Ultimately, our goal is to track and monitor the care of each patient within the NPF Center of Excellence network.

As this collection of real world data continues to grow, physicians will be able to use this resource to evaluate and improve therapeutic strategies within the clinical setting. In 2011, NPF used the data to learn more about what predicts and prevents falls, what works best in treating depression, and how to gauge medication usage in deep brain stimulation (DBS). Today, over 15 studies like this are under way and will help us to redefine Parkinson's care.



# NPF is finding answers.

*“ We are amazed by what we are finding in the Quality Improvement Initiative (QII) database; these associations have never been seen before, and I think it’s the power of QII that makes this possible. ”*

**Sotirios Parashos, MD, PhD**  
 Director of Research, Struthers Parkinson's Center,  
 NPF Center of Excellence



Dr. Carlos Singer and Dr. Aleksandar Videnovic, NPF grant recipients studying sleep and Parkinson's

*“ By supporting sleep research, the National Parkinson Foundation is bringing this issue to the forefront. As we pool together resources and leverage expertise, we will make a real impact on the lives of people with PD and their caregivers. ”*

**Aleksandar Videnovic, MD, MSc**  
 Parkinson's Disease and Movement Disorders Center,  
 Northwestern University, NPF Center of Excellence

### Sleep Research Lays Foundation for Future Progress

Three-quarters of people with Parkinson's experience sleep-related problems. In 2011, NPF hosted a symposium for specialists in sleep and Parkinson's, exploring REM sleep behavior disorder (RBD). RBD, in which people act out their dreams during the rapid-eye movement phase of sleep, is now thought to be one of the earliest signs of Parkinson's.

During the two-day conference in April, researchers designed a clinical trial with a practical therapeutic

application for treatment of RBD. Furthermore, NPF funded two clinical research studies on sleep. One will document the prevalence of sleep disordered breathing (SDB) in patients with Parkinson's and test the effectiveness of a common treatment, while the other will investigate how a therapy known as transcranial magnetic stimulation (TMS) could improve motor learning, which consolidates during sleep, and potentially reduce falls. Taken together, these research studies demonstrate how NPF can have an effect on understanding new aspects of Parkinson's.

### Getting Answers, Finding Support

One of NPF's most valuable resources is our staff of exceptional Parkinson's disease information specialists. In July 2010, NPF launched a toll-free Helpline to assist people with Parkinson's, caregivers and health professionals get answers to their many questions. Since then, NPF's national Helpline has responded to more than 5,000 telephone and email inquiries. Last year, when a NPF survey showed that few Hispanics are aware of the early signs of Parkinson's, we started a program to help the Hispanic community access the resources they need. Today, NPF's information specialists are bilingual, answering questions, providing referrals and suggesting community resources in English and Spanish. One new resource is: *10 Signos de Alerta Temprana Sobre la Enfermedad de Parkinson (10 Early Warning Signs of Parkinson's Disease)*. More Spanish resources, including booklets and videos, are available on NPF's Web site, [www.parkinson.org/espanol](http://www.parkinson.org/espanol).



The NPF Helpline Staff (clockwise from left): Sharon Metz, Anna Hedges, Paula Weiner, Joan Gardner. Not pictured: Adolfo Diaz

# NPF is changing lives.

*“ Thank you for all the information. It has brought great relief knowing that there are resources and support for my family. ”*

**Inez**, a Spanish-speaking Helpline caller directed to an Adult Day Care facility catering to Hispanics



Katie Couric filmed a *Moving Day* public service announcement for NPF

*“ I watched in awe as my father bravely battled Parkinson's disease, and I know that he greatly benefited from high-quality care, which significantly minimized his symptoms by addressing all aspects of his well being. ”*

**Katie Couric**  
Honorary National Chair of *Moving Day*

### Community + Movement = Good Medicine

People who move change the world. That is the theme of *Moving Day*, a national grassroots campaign NPF launched to promote awareness of Parkinson's through local annual fundraising walks. Katie Couric, who lost her father due to complications of the disease, took on a new role as Honorary National Chair of the campaign. In October 2011, three pilot *Moving Day* walk events were held in Pittsburgh, PA; Washington, D.C.; and Rome, GA. About 2,500

people participated, bringing in more than half a million dollars to fund Parkinson's research and NPF chapter programs. Because studies indicate that physical activity plays an important role in managing the symptoms of the disorder, each event also featured a "movement pavilion" with stations demonstrating beneficial ways to exercise. The aim is to encourage people to stay active and move for better health. Fourteen *Moving Day* events will be held around the country throughout 2012. Learn more at [www.npfmovingday.org](http://www.npfmovingday.org).



### A Hands-on Approach to Better Care

Because about 50 percent of Parkinson's care is done by primary care physicians, it's important to design tools to improve their ability to identify and treat some 60,000 individuals diagnosed with Parkinson's every year, and countless others who go undiagnosed. Increasingly, doctors are turning to smartphones and the web for answers. In 2011, NPF created the *Parkinson's Toolkit*, a free mobile-enhanced Web site with a companion smartphone application. It is the first app reference tool specifically for Parkinson's that is geared to how busy family doctors practice.

Now, clinicians have access to best practices in Parkinson's care to promote early intervention, and help close the gap between what people with Parkinson's need and what health professionals actually give them.



Dr. Janis Miyasaki and Dr. John Morgan, neurologist members of the Parkinson's Toolkit steering committee



The NPF Parkinson's Toolkit mobile app

# *NPF is beating Parkinson's.*

**The Parkinson's Toolkit features:**

- More than 100 topics in Parkinson's care, including issues that are often overlooked, such as melanoma screening and sleep disorders
- Criteria for determining whether a patient requires a consultation with a specialist
- Latest developments in Parkinson's treatment
- Parkinson's reference tools and patient resources

*“ An important part of advancing Parkinson's care is innovation, finding new ways to extend our impact on the community. Now, with the tap of a finger, clinicians can better understand complex aspects of Parkinson's care as they navigate their daily practice. ”*

**Janis Miyasaki, MD, MEd, FRCPC**  
Toronto Western Hospital, University of Toronto,  
NPF Center of Excellence

# Honor Roll 2011

The National Parkinson Foundation gratefully acknowledges the following individuals, corporations, foundations and organizations who have contributed \$1,000 or more between July 1, 2010 and June 30, 2011. Their giving assists research, education and outreach initiatives. Thank you for your support.

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## Gifts of \$250,000 and above

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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 people with Parkinson's live better lives in the years to come. We would like to recognize the following Legacy Society members:*

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## National Parkinson Foundation Community Fundraisers



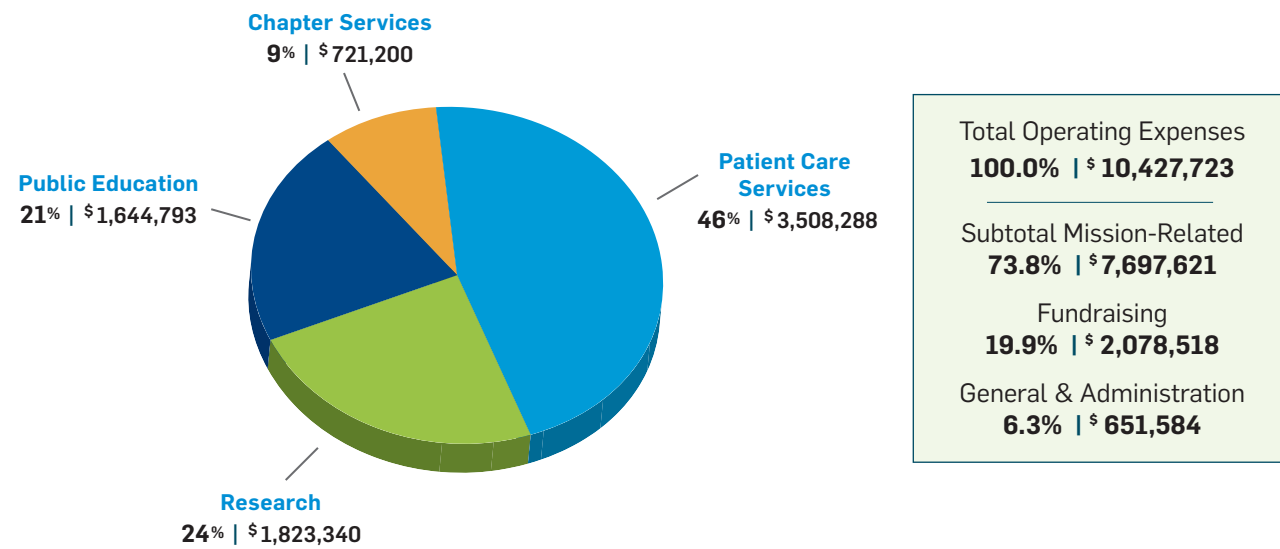
*Every year, thousands of people participate in community fundraisers to increase awareness of Parkinson's disease and raise funds for the National Parkinson Foundation. We would like to extend our sincerest gratitude for their creativity, energy and commitment:*

Veronica Anderson	Kelly Guliano	Morgan Stanley Smith Barney of Coral Gables, FL
Kelly Arney	Adam Hart	Robin Nagel
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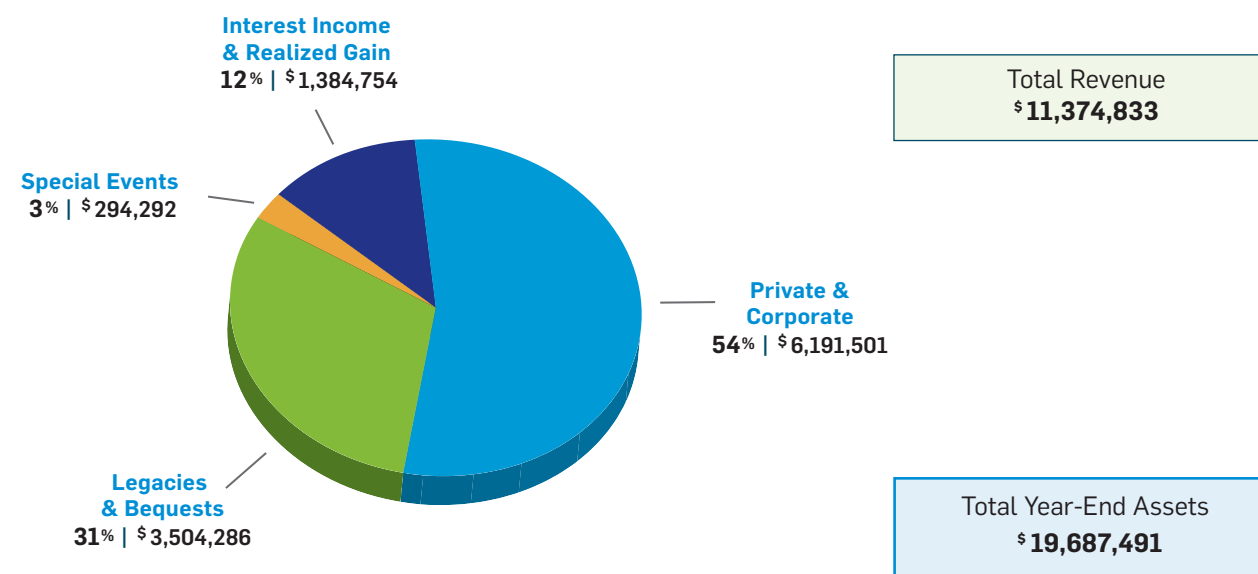
## Financial Highlights

### Expenses by Category | 2010-2011

As illustrated below, the National Parkinson Foundation directed 74% of its 2010-2011 spending on mission-related activities and 26% on fundraising and management combined.



### Revenues by Category | 2010-2011



## Board of Directors

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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Annual Report 2011



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