The Parkinson’s Outcomes Project

The mission of the Parkinson’s Outcomes Project is to determine what works best in treatment and care with an aim toward slowing the impact of the disease. At its heart is an all-inclusive, international database that will follow patients over time. Currently tracking more than 5,500 patients in four countries, the Quality Improvement Initiative (QII) study will grow in the coming years to follow tens of thousands of patients worldwide.

The Project will:

- Fund comparative research to determine best treatments and why some people respond better to some therapies than others;
- Create transparency about what strategies produce the best results and how specific centers measure up;
- Allow individuals to compare their health and treatments to that of similar people; and
- Inform education and outreach efforts for both families and professionals.
To Our Parkinson’s Community:

A little over three years ago, the National Parkinson Foundation (NPF) launched an unprecedented research collaboration: the Quality Improvement Initiative (QII), part of the Parkinson’s Outcomes Project. It is the largest clinical study of Parkinson’s disease ever conducted, and the first with the primary goal of identifying and explaining factors that result in longer, better, and more active lives for people with Parkinson’s.

The result is the deepest pool of Parkinson’s data ever collected, from some 5,500 people in four countries. If you have Parkinson’s, there is almost certainly someone like you participating in the study. Some are thriving; others are not doing as well. Our goal is to determine what makes that difference. We can now consider the interplay of factors that produce different results in different people, and likely paths toward better outcomes.

Unlike prior studies, this initiative encompasses the entire spectrum of Parkinson’s disease. No one was too sick or too advanced, or too young or too old, to be included. More than 1,400 participants are now between 55 and 65 years old, the ages when most people are diagnosed. But participants also include more than 440 with onset before age 40, and more than 100 with onset after age 80, making it the largest prospective study of both young- and late-onset Parkinson’s ever conducted.

Our study is equally inclusive in terms of the experience of individuals with Parkinson’s. More than 650 participants manage at least two other serious illnesses—a group almost always excluded from other clinical studies. Our data includes an assessment of medications and other treatment, as well as motor symptoms, cognition, anxiety and depression, and caregiver burden.
This comprehensive evaluation reflects the complicated nature of Parkinson’s, which over time can affect nearly every part of a person, as well as their loved ones.

Our study encompasses individuals at 20 leading centers for treating Parkinson’s, all part of NPF’s Center of Excellence network. By studying the “best of the best,” NPF plans to delve into the key differences in treatment and outcomes because every person with Parkinson’s deserves “best practice” care, no matter where they are treated.

When we study how disease affects individuals, we talk about your “health status,” and much of this report concerns the health status of people in our study. Health status is important because it encompasses much more than just the disease. Our goal as physicians is to not just help you function better, but to help you feel better. There is a difference between function and feeling, and we have found that how people with Parkinson’s feel—their mood and depression—is a critical factor with a tangible impact on overall health. We have also identified some of the steps that we as doctors, and you as patients, can take to change this. These opportunities for all of us to improve health are the highlight of this inaugural report.

We all hope that the next major breakthrough in Parkinson’s disease will be a treatment that slows down biological progression. When we achieve this, optimizing care will be even more important: though symptoms may be reduced, they must be addressed over a longer life expectancy. We will still need to work together to prevent falls, treat depression, and address
other factors that can speed the deterioration in your health status. As breakthroughs are achieved, care will become more personalized, so that the best therapies are applied to your particular genetic and environmental factors. In short: our goal is not only to optimize today’s care, but to help guide tomorrow’s.

On behalf of NPF and our affiliated centers and institutions, we express our gratitude to those who have shared our vision and supported our efforts. In particular, we thank the patients, caregivers, clinicians, and researchers whose participation is steadily filling gaps in our understanding, and supporting a brighter future in the fight against Parkinson’s. We look forward to future reports to you, the Parkinson’s community, on our progress.

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The Quality Improvement Initiative: Who Participates?

The centerpiece of the Parkinson’s Outcome Project is the Quality Improvement Initiative (QII) study. The study represents the broadest and most inclusive patient demographics ever assembled in a clinical study of Parkinson’s disease.

By studying the most effective care across the full spectrum of patient age, gender, age of onset and other variables, we seek to identify with ever-increasing precision exactly which factors lead to better outcomes for all people with Parkinson’s.

This international study, which was started in 2009, includes participants from across the United States as well as Canada, Israel and the Netherlands. Individuals with a confirmed diagnosis of Parkinson’s disease are enrolled at each of the 20 participating centers.

Since 2009, more than 5,500 individuals have joined the study, representing more than 9,000 clinic visits.
The severity of Parkinson’s disease has long been assessed using a 5 point scale of mobility impairment. On this Hoehn and Yahr scale, stages one and two represent early disease, three is mid stage, and stages four and five are advanced Parkinson’s where typically it is difficult to stand unassisted.

This study represents a true cross-section of people with Parkinson’s disease, with participants ranging from 25 to 95 years old.

Parkinson’s disease is diagnosed more commonly in men than in women. Women in the study are slightly older and have slightly more advanced disease than men.
**Young-Onset Parkinson’s**

The QII study includes data from the largest cohort of young-onset Parkinson’s of any study to date. Already, differences are emerging in how younger people experience Parkinson’s itself, and how they perceive the effectiveness of their care.

For example, we have identified that people with young-onset Parkinson’s often progress slowly but feel their symptoms more intensely, perhaps because they are aware of how their visible symptoms set them apart from their peers. In particular, they typically assign a greater weight to the impact of decreased mobility on their lives. Establishing such differences is a first step toward developing best practices for treating individuals who develop Parkinson’s at an early age.

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**Young-Onset Parkinson’s Disease**

![Bar chart showing the number of participants by age group. The chart indicates that the largest number of participants fall between 37-40 years old, with significantly fewer participants in the younger age groups.]

*This is the largest clinical study to date of people with young-onset Parkinson’s. Almost 400 people with onset before 40 are providing unprecedented insight into this seldom-studied group.*
**Long-Duration Parkinson’s**

This study is also the first to include more than 350 subjects who have lived with Parkinson’s for more than 20 years. These people tend to be doing better than we would have predicted based on the trajectory of people with shorter-duration disease. In particular, they tend to be more active and have better cognition. By following these survivors and their care over time, we hope to learn what factors have kept them in better health.

*Why do some people continue to thrive, in some cases, for decades? Study participants include more than 350 people who have had Parkinson’s for more than 20 years.*
While the participants in our study are unusually diverse, they share one thing in common: they all have received care at specialty clinics in academic medical centers designated by NPF as Centers of Excellence. These centers are recognized leaders in Parkinson’s care and meet rigorous criteria for research, care and outreach, evaluated in a peer-review site visit.

The benefits of expert care are well established: those who see an expert neurologist live longer, better lives than those who don’t. However, even specialized centers have different approaches to care, and achieve different outcomes.

What, exactly, do various centers do differently? Measuring those differences is our first goal. Are those differences the real reason for better outcomes? Testing those explanations is our second goal. And finally, what is the best way to share these findings with everyone who provides Parkinson’s care?

Ultimately, the Parkinson’s Outcomes Project is a cycle of learning. Physicians and therapists need to teach what they’ve learned, learn what others have to teach, then repeat. Together, we can help everyone committed to discovering, understanding and sharing the most effective ways to treat Parkinson’s.

### Varieties of Care:
**Inconsistent Results, Even at Expert Centers**

Centers varied in patient-reported health status for their patients, with the average health status varying by as much as 13 points after adjusting for disease severity.
Referral rates to physical, occupational, speech and other therapists varied by as much as 50% in our study for similar people with mid-stage, uncomplicated Parkinson’s.

In many cases, there is little evidence to support one choice of medication over another. As a result, medication use can vary substantially from one neurologist to another, even for similar patients.
MANAGING MOOD:
The Importance of Addressing Depression and Anxiety

A clear finding of the study is that, taken together, depression and anxiety have the greatest impact of health status. In fact, in a study of QII data presented at a Parkinson’s conference in 2012, scientists showed that the impact of depression on health status is almost twice that of the motor impairments universally associated with Parkinson’s.

At least 50 percent of people with Parkinson’s experience depression, and anxiety is also frequently reported. Depression can be disabling, resulting in difficulty with work or engaging in activities like exercise that can help manage symptoms. Yet physicians often have trouble recognizing anxiety and depression, or their roles in hampering efforts to treat Parkinson’s.

As previous studies have found, addressing depression can positively impact levels of disability, relapse and quality of life. Indeed, participants in clinics with the most active approach to counseling reported the lowest rates of depression. For many people with Parkinson’s, acknowledging depression is a critical step toward more effective treatment, and better health status overall.

OVERALL CONTRIBUTION TO HEALTH

Mood/depression and mobility are the most important contributors to overall health status for people with Parkinson’s, and should be priorities in evaluating patients and developing care plans.
Depression in Parkinson’s disease is mainly caused by a chemical imbalance in the brain; however, it can also arise from the simple sadness associated with the diagnosis of the disease.

Antidepressants are often effective in reducing symptoms, but they should seldom be used in isolation. A mix of medication, exercise and counseling is typically most helpful in addressing depression, and may help further engage patients and families in other critical aspects of managing care for Parkinson’s.

**NPF Recommends:**

- Physicians should screen you for depression at least once a year.
- You should discuss any change in your mood with a healthcare professional, and make sure that your Parkinson’s doctor is aware.
- You should bring a family member with you to your doctor’s office and he or she should be encouraged to discuss any changes in your mood.
Mobility: Second Most Important Driver of Health Status

Bradykinesia, or slowness of movement, is present in all cases of Parkinson’s. Indeed, impaired mobility in general is considered a defining element of the disease, and it was the second most influential factor on health status among study participants.

The impact of mobility problems can be serious. They can affect your balance, your ability to walk, and even everyday tasks such as feeding and bathing. These problems can result in falls, injury and even death. In addition, difficulty walking can keep you from doing things that are important to you. Withdrawal from familiar activities can affect personal relationships, and even how you think others perceive you.

The best way to protect your motor function is to use it regularly. A well-designed exercise plan can significantly improve almost everything about your health, including stabilizing your walking, calming tremor, improving mood, and possibly even slowing progression of the disease. Regular exercise is typically associated with a lower care burden, as well. Even as motor symptoms progress, many respond well to medical and surgical treatment. But staying active remains absolutely critical.

Regular exercise (more than 2.5 hours per week) provides many benefits to people with Parkinson’s. It is associated with lower degrees of mobility impairment, caregiver burden, and impairment in everyday activities.
Mobility and Motor Control: Findings of the Quality Improvement Initiative

Although mobility impairment is a central challenge of Parkinson’s, early data from the QII study suggests the importance of a holistic approach. People who addressed mood and mobility together, and who used a full complement of elements including medicine, surgery and exercise, were the most successful in managing the mobility aspects of their condition.

Your symptoms are connected. Better mobility reduces depression, treating constipation helps with mobility, and so on. Talk to your doctor about whatever is bothering you.

NPF Recommends:

• To feel good enough to exercise regularly, take your medications on time. Keep to your schedule.
• Exercise can help improve all your symptoms. Any exercise you can do safely will help.
• Talk with your doctor about both exercise and physical therapy. On your next visit, discuss the type of program you should pursue.
• If your symptoms become hard to manage, talk to your doctor about your options. There are many ways to try to control difficult symptoms.
• A physical or occupational therapist who understands Parkinson’s can be a great resource between your physician visits.
The Future of Parkinson’s: The Evidence We Need to Personalize Care

No two people face Parkinson’s in quite the same way. People vary substantially in their combination of symptoms, rate of progression, and reaction to treatment.

It may be that no two doctors approach Parkinson’s in quite the same way, either; unlike many other diseases, there are no clearly established standards for treating a person with Parkinson’s in a particular circumstance. As a result, two neurologists who might prescribe identical therapies for similar patients with Alzheimer’s disease would likely recommend different strategies for similar patients with Parkinson’s.

The reason is that, despite many prior studies on specific elements of the disease, none has successfully evaluated the full range of factors that bear on the experience of the disease. The Parkinson’s Outcomes Project is beginning to change that.

By embracing the diversity of people with Parkinson’s, we are gathering the most complete data set ever assembled. By involving the world’s best neurologists at NPF Centers of Excellence, we are developing the best insights into individual care. And by working together, we will define standards of care for people with Parkinson’s everywhere.

For many people, one issue stands out as the most challenging part of Parkinson’s. Over half the people in the study had one aspect of Parkinson’s that was much more troubling than the others. Everyone’s journey is different.
The QII, part of the Parkinson’s Outcome Project, is overseen by a steering committee of the lead investigators at each participating NPF Center of Excellence and a group of leaders in care quality from the broader community.

At the 20 participating centers, 153 physicians, supported by 96 research assistants, have participated in delivering care to the more than 5,500 people with Parkinson’s in the study. Each of these individuals is engaged daily in delivering the best care they can to people with Parkinson’s, and each joins us in our goal of changing the course of Parkinson’s.

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The main findings reported in this document are derived from the QII study and presentations and publications based on its information. These publications include:


In addition to the QII study, important points and recommendations concerning Parkinson’s are drawn from a range of publications, including:


QII Study Support

Over the past two years, the National Parkinson Foundation has invested more than $2 million in this study. This important research initiative is made possible by the support of thousands of people like you who made a donation to support the National Parkinson Foundation, and generous support from the following foundations and corporations:

Abbott

Braman Family Foundation, Inc.

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Parkinson Association of Minnesota

Parkinson’s Unity Walk

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St. Jude Medical

Teva Neuroscience, Inc.

The Greenberg-May Foundation, Inc.

The Kinetics Foundation

The Leir Charitable Foundation

The Thompkins-Broll Family Foundation
About the National Parkinson Foundation

Unique among the Parkinson’s organizations, the National Parkinson Foundation (NPF) has a singular focus: our mission is to improve the quality of care through research, education and outreach.

We have created a global network serving the needs of the Parkinson’s community including:

• 41 Centers of Excellence at top medical centers around the world, including 26 in the U.S. and 15 internationally

• An extensive network of chapters and support groups across the U.S., serving more than 100,000 people with Parkinson’s and their families

• Website and educational materials that reach more than 1 million people each year.