



## WHAT DEFINES Quality Care for Parkinson's Disease?

**H**ow can someone living with Parkinson's disease know if they are receiving quality health care? What measures would tell someone if they are living with the highest quality of life possible? NPF has launched a new initiative, the Quality Improvement Initiative (QII), which will explore these questions and contribute to an understanding of what constitutes the best possible care for Parkinson's disease (PD).

While many Parkinson's patients and their doctors may have opinions about what constitutes good care in the management of PD, the reality is that no one really knows. Although there may be research about PD drugs and their individual effects on patients, there is little comparison between the treatments themselves and how PD patients fare over time. Since Parkinson's disease has many aspects and can cause different symptoms in different people, we need more data on large numbers of people to draw conclusions.

NPF's Quality Improvement Initiative will define and develop sound measures of quality care, build evidence-based best practices and innovations in Parkinson's care, and then disseminate such

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information. Project outcomes include the first-ever multi-center Parkinson's disease clinical database. This database will track the health of PD patients who receive care in each of NPF's 43 Centers of Excellence. Together, there are currently about 50,000 PD patients treated in these centers. Each one will be asked to be part of this new initiative.

"NPF's Quality Improvement Initiative is truly groundbreaking," stated Michael S. Okun, MD, NPF's National Medical Director. "NPF Centers have many of the leading clinicians in the world. Our goal is to leverage this expertise to collect information about what treatments patients receive and how they are doing. Over time, we will paint a portrait of what is excellent care for patients at every stage of the disease."

While other diseases have long tracked this data — particularly cancer and heart disease — there has long been a gap in the field of Parkinson's disease. Other PD databases tend to be confined to one institution, collect inconsistent information, or were developed for clinical trials and thus exclude many types of patients and do not represent "real world" patients or clinical practice.

Advising NPF on this initiative is a core working group led by John G. Nutt, MD, Medical Director of the NPF Center of Excellence at Oregon Health & Science University and Andrew Siderowf, MD, MSCE, Fellow at the University of Pennsylvania Institute on Aging and Medical Director of the NPF Center of Excellence at the University of Pennsylvania Parkinson's Disease and Movement Disorders Center. The external advisors are Gerald T. O'Connor, PhD, ScD, Professor of Medicine and Associate Dean, Dartmouth Medical School, and Elaine M. Olmstead, Research Analyst, at the Dartmouth Hitchcock Medical Center. Gerry and Elaine have had extensive experience in database design and reporting. They have worked closely with the Northern New England Cardiovascular Disease Study Group. Gerry has also collaborated for the past 10 years with the Cystic Fibrosis Foundation. Dartmouth is a recognized leader in the study of health outcomes and disparities in health care. Other members of the Steering Committee include: Mark Guttman, MD; Eric Cheng, MD, MS; Tanya Simuni, MD; Laura Marsh, MD; Sotirios Parashos, MD, PhD; Nir Giladi, MD, Bastiaan Bloem, MD, PhD; and Michael S. Okun, MD.

The types of information NPF will collect include: age, height, weight, gender, date of diagnosis, severity of disease, other conditions besides PD, change in treatments and several tests for mobility, cognitive state and how patients fare with activities of daily living. The goal is to eventually have data on every single patient treated in NPF Centers of Excellence: "one patient, once a year."

### Phase 1 of the project will include six NPF Centers of Excellence:

- Markham Stouffville Hospital (CAN)
- Northwestern University (IL)
- Oregon Health & Science University (OR)
- Struthers Parkinson's Center (MN)
- University of Florida (FL)
- University of Pennsylvania (PA)

The collection of this information will help clinicians and researchers see trends over time in the health of people with Parkinson's. It will help create care guidelines, design clinical trials to test new therapies and compare the effectiveness of various treatments, all ultimately geared to improving the quality of care. The database will also allow NPF centers to benchmark their performance against other NPF Centers on key measurements.

Initial findings will be presented at NPF's annual Centers Leadership Conference in December 2009 in Miami. In 2010, the Quality Improvement Initiative will expand to 15 centers, with the full roll-out of a web-based portal anticipated next year.

By answering the question, "What defines quality care?" NPF's goal is to raise the bar for care and the quality of life for the millions of people living with Parkinson's disease worldwide.