



# PARKINSON

## REPORT

1-2

Building Your  
Parkinson's  
Care Team

3

Tips for  
Communicating with  
Your Health Care Team

4

Quality Improvement  
Initiative

5

What's Hot in  
Parkinson's Disease?

6-7

Top Questions  
and Answers from  
"Ask the Doctor"

Tips for Daily Living

8

Fall 2012  
Event Calendar

9

Parkinson's  
Superstars

10

Join Team Hope

11

Support NPF

## Building Your Parkinson's Care Team

Get the care you want and the information you need



Ruth Hagestuen, RN, MA

**O**ver the years, many people with Parkinson's disease have told me how dramatically their lives have been impacted by a particular healthcare professional, team or doctor. Getting the personal attention they needed from a caring health professional or group of knowledgeable healthcare professionals who understand the challenges faced by those living with Parkinson's proved to be life changing.

Parkinson's disease is a complex, chronic illness that can impact every aspect of your life. For this reason, NPF has long promoted a multidisciplinary, comprehensive approach to Parkinson's care. Comprehensive care is a strategy that takes into account the health of the whole person—including physical, emotional and spiritual health. An ideal Parkinson's healthcare team will include individuals (see page 2) who are highly qualified in different disciplines and who work closely with you, and other members of your team, to meet your changing needs and goals.

To enable you and your care partner to achieve optimum health, NPF has developed a worldwide network of Centers of Excellence (COE), medical centers across the U.S. and abroad where expert teams—including movement disorder specialists, nurse specialists and social workers—come together to provide comprehensive medical care to patients and their families. To be designated an NPF COE, each center must be guided by an

...continued on page 2

## Tips for Communicating With Your Health Care Team

"The main ingredient in any successful partnership is communication..."

...continued on pg 3

## The Power of Parkinson's Superstars

"I want people to know that, yes, I have Parkinson's, but I still love life..."

...continued on pg 9

## Join Team Hope

Run to Beat  
Parkinson's!

...continued on pg 10

## Building Your Parkinson's Care Team

### Get the care you want and the information you need

...continued from cover

expert in Parkinson's disease and be engaged in four areas: comprehensive care delivery, professional education, patient outreach services and research on new therapies.

Whether you live in a small town or big city, you can draw upon one of these centers to get the best level of Parkinson's care possible. On the other hand, you may want to seek professionals knowledgeable about Parkinson's care closer to home. Remember, there are multiple solutions to your problems, but it's up to you to take the next step. Don't be afraid to ask questions and to seek the support and care now available to you and

your family. You can begin to be part of every decision about your Parkinson's care. And even start enjoying a better quality of life.

**Author:** Ruth Hagestuen, RN, MA

Co-Director of Struthers Parkinson's Center, NPF Center of Excellence, and Director of NPF's Allied Team Training for Parkinson.

**To locate NPF resources in your area, call NPF's Helpline 1-800-4PD-INFO(473-4636) or e-mail [helpline@parkinson.org](mailto:helpline@parkinson.org).**

## THE PARKINSON'S HEALTHCARE TEAM

**Neurologist:** A neurologist is a doctor who specializes in the brain and nerves. Parkinson's disease (PD) specialists are neurologists who get extra training in movement disorders.

**Nurse:** Supports the doctor and provides patient care and education; is usually team coordinator and main contact.

**Social Worker:** Connects you with PD resources and community support.

**Physical Therapist:** Provides PD movement training and exercise programs.

**Speech-language Pathologist:** Helps with communication, soft speech, swallowing concerns and memory.

**Occupational Therapist:** Helps you maintain independence in normal daily activities.

**Care Partner:** Should accompany you to appointments to listen and take notes.

**Primary Care Physician:** Will continue to monitor and address your broader healthcare needs.

**Other Specialists:** Psychologists, pharmacists, dietitians and others also can be very helpful. If you're considering deep brain stimulation (DBS) surgery, a neurosurgeon and neuropsychologist will become members of your team.

**Complement your Parkinson's Care:** Get involved in exercise and support programs offered in your community.



## TEAMWORK IN ACTION

**Theresa Snoeyenbos, 50,** was diagnosed with Parkinson's disease when she was 32 years old, but it was over a decade before she got the real help she needed. For years, Theresa's treatment primarily consisted of a fistful of medications she

swallowed each day. "I ended up getting really sick, suffering from depression and being hospitalized for 12 days," she said.

Eventually, the Wisconsin mother-of-three and her husband were forced to sell their family-run motel. She took a desk job, but her symptoms interfered with work so she resigned. "I felt pretty worthless," she said. After job loss, divorce and a move, "lock, stock and barrel," to her parent's home in suburban Minneapolis, the nightmare finally ended. Theresa got an appointment with a top neurologist at Struthers Parkinson's Center, an NPF Center of Excellence.

"Dr. Martha Nance took me off of every med I was on and had me start completely over again. I went from 12 meds to three," she said. "And her wonderful staff treated the whole person. They taught me all kinds of things to help myself, and it's made a big difference." Since her diagnosis 18 years ago, Theresa earned a black belt in Taekwondo. More recently, she reached another turning point. "I had DBS surgery in May," she said. "It's given me such hope."