

The ParkinsonNet Concept:

Comprehensive Care Networks for Parkinson's Disease



Bastiaan R. Bloem, MD, PhD

The complex nature of Parkinson's disease (PD) warrants comprehensive management, including both medical services and allied health interventions. It is crucial for people with Parkinson's disease to be seen and treated by an expert in the disease; however, in many countries, including the U.S., this is a problem. There is increasing evidence of the effectiveness of specific interventions delivered by physical therapists, occupational therapists and speech therapists in Parkinson's disease. Unfortunately, care is often suboptimal because allied health therapy is usually provided by professionals that lack PD-specific expertise.



Marten Munneke, PT, PhD

Recognizing that specific, well-informed care provided by allied health professionals was lacking in communities distant from academic medical centers, the initial ParkinsonNet concept was developed in 2004 in the city of Nijmegen, the Netherlands, led by Bastiaan R. Bloem, MD, PhD, and Marten Munneke, PT, PhD, both from the Radboud University Nijmegen Medical Center,

NPF International Center of Excellence. They selected a small group of therapists in the vicinity of eight community hospitals and trained them to become experts in PD.

According to Munneke, "It is the complex nature of the condition that prompted us to develop ParkinsonNet. In the Netherlands, we saw that many patients went to a neurologist once in three months or once in half a year and only saw a neurologist for 5-10 minutes. Sometimes patients were referred to a physical therapist or an occupational therapist, but it was not structured. Our aim is to provide every person with Parkinson's in the Netherlands with qualitative care given by experienced health professionals."

In this issue:

April is Parkinson's Awareness Month

The ParkinsonNet Concept 1-3

Exercise Tips 3

Why Dance for PDSM? 4

New and Improved Parkinson.org 5

Top Questions from "Ask the Doctor" 6-7

What's Hot in PD? 8

Paddling for Parkinson's 9

A Conversation with Rudi 10

Support NPF 11



“If you want to provide quality of care, you need an experienced and multidisciplinary team.”

To boost the quality of allied health care for PD, ParkinsonNet implemented regional networks of motivated health professionals with specific expertise in treating PD patients. The multidisciplinary networks are composed of a small number of highly motivated, community-based physical, occupational and speech therapists selected and trained by the staff of the Nijmegen Medical Center. Also central to the ParkinsonNet concept are 1) delivery of care according to evidence-based guidelines; 2) continuous education and training of ParkinsonNet therapists; 3) structured and “preferred” referral to ParkinsonNet therapists by neurologists, enabling each therapist to attract a large enough number of patients to maintain and increase expertise; 4) optimal communication between ParkinsonNet and hospital professionals, via use of a “ParkinsonWeb” and electronic patient records. A certification system was developed to guarantee the quality of therapy provided by health professionals participating in these networks.

More than 64 regional ParkinsonNet networks now exist in the Netherlands, with over 1200 specialty-trained physical, occupational and speech therapists providing services. In these regions, the PD knowledge of professionals, quality of communications and the referral process has markedly improved. In fact, in a large randomized clinical trial involving 700 patients, eight regions in Holland with ParkinsonNet were compared to eight other regions without such a network and the results showed that the quality of care increased, the volume of patients per therapist doubled, and the health-care costs were reduced substantially in ParkinsonNet regions. The results were published in the prestigious journal, *Lancet Neurology* in January 2010.

“Even though the goal of this concept was just to increase the number of experts on PD, we have now come to the realization that, if implemented on a national level, this concept would provide a cost savings of millions of dollars,” explained Bloem. “It is

my personal conviction that if you first improve the quality of care, health care costs go down as an inevitable consequence.”

“Now, we hope to extend this concept to other countries and to develop comparable systems for other chronic diseases.”

Inspired by the results achieved in the Netherlands, the team from NPF's Center of Excellence at Oregon Health & Science University (OHSU) demonstrated the scalability of the model by deploying their own ParkinsonNet Oregon. OHSU faculty have provided training to three regions outside of the Portland area.

Elements of the ParkinsonNet Concept:

- Selection of a restricted number of motivated therapists
- Improving the expertise of the selected therapists
- Stimulating communication and collaboration with referring physicians
- Promoting visibility of the available expertise for both patients and professionals

Visit the new Video Library on www.parkinson.org to hear Prof. Bloem describe the ParkinsonNet Concept, “What are some strategies to improve the quality of community care for PD patients?”

ParkinsonNet: Creating a Sea Change in PD-Related Care

A very important article recently appeared in *Lancet Neurology* featuring research from one of NPF's Centers of Excellence in the Netherlands (Center Director: Bastiaan Bloem, MD, PhD). Munneke and colleagues from that center introduced the ParkinsonNet concept; a framework aimed at igniting a sea change in PD-related care. The idea is simple: deliver Parkinson's disease care through an integrated network (that may be geographically dispersed across a country), that would provide a more convenient and more integrated experience for patients.

ParkinsonNet has substantial promise for improving the shortcomings of current care models. The concept is powerful, potentially modifiable, and exportable to other regions and other countries.

This group performed what is referred to as a cluster-randomized trial (699 patients) within community-based hospitals and they assigned patients to ParkinsonNet care or usual care and followed them for six months. The stated goals of the authors were "(a) to evaluate the implementation of this change in the healthcare system; (b) to record the consequences of implementing ParkinsonNet care by measuring the health benefits for patients; and (c) to evaluate the influence on societal costs of this new organization of care."

Physical therapy is the most popular and widely utilized form of allied healthcare for PD-related motor and mobility issues. In fact, the number of published PD physical therapy and exercise trials has increased by over 500% in recent years. Exciting findings from exercise-based animal studies have hinted at neuroplastic changes, and even the possibility of disease-modifying effects. Several clinical trials have suggested that physical therapy may significantly enhance both motor performance and quality of life. Unfortunately, these findings have yet to penetrate into community-based practice.

AUTHOR: MICHAEL S. OKUN, MD, NPF National Medical Director

References: Munneke M, Nijkrake MJ, Keus SH, Kwakkel G, Berendse HW, Roos RA, Borm GF, Adang EM, Overeem S, Bloem BR; ParkinsonNet Trial Study Group. Efficacy of community-based physiotherapy networks for patients with Parkinson's disease: a cluster-randomized trial. *Lancet Neurol*. 2010 Jan; 9 (1): 46-54. Epub 2009 Dec 1. Hass CJ, Okun MS. Time for comprehensive care networks for Parkinson's disease. *Lancet Neurol*. 2010 Jan;9(1):20-2. Epub 2009 Dec 1.



David Zid giving exercise tips at the Young Onset Parkinson Conference in Dallas, Texas (October 2009).

The Role of Exercise in PD Management

Developed by **Struthers Parkinson Center**,
NPF Center of Excellence

Exercise is Important!

- Research shows exercise may protect brain cells, slowing degeneration.
- Regular exercise helps to maintain functional movement.
- Exercise is an active way of coping with Parkinson's. Establishing early exercise habits is an important component of overall management.

What types of exercise should I consider when planning my program?

- Flexibility exercises minimize effects of stiffness.
- Aerobic exercises help with endurance.
- Posture exercises help with alignment.
- Balance exercises reduce fall risk.
- Strengthening exercises counteract effects of disuse.

Exercise Guidelines

- Perform simple stretches and posture exercises daily.
- Follow a varied routine incorporating other components (strength, balance) several times per week.
- Aim for aerobic exercise (walking, biking, swimming) at least 3 days a week for a minimum of 20 minutes.
- Keep intensity at a level that feels "somewhat hard" for you.
- Try exercise videos or home exercise equipment if it is difficult to get out.
- Consider joining an exercise class or group.
- Music can enhance performance by providing rhythm to coordinate movement.

Involving Your Team

- Check with your physician if you have health concerns that affect your ability to exercise.
- Seek a physical therapy referral for help in planning your exercise program.

More printable checklists available on www.parkinson.org.

Why Dance for PDSM?

Nine years ago, the Brooklyn Parkinson Group (BPG), a NPF chapter, and the Mark Morris Dance Group (MMDG) started a collaboration to develop Dance for PDSM classes and offer them, free of charge, to persons with Parkinson's disease in Brooklyn, New York. The program, partially funded by NPF, has become so successful that they now help other groups start their own Dance for PDSM collaborations throughout the United States, Canada, England, Germany and Scotland.

Olie Westheimer, the founder and executive director of BPG, recognized the need for members of her support groups to participate in a highly social and joyful activity unrelated to therapy — away from clinics, hospitals and therapists' offices. Her main aim was to combat obvious depression among people with PD and their caregivers.

That activity became weekly Dance for PDSM classes led by dancers and faculty from Mark Morris. Dance was chosen because Westheimer recognized that professional dancers and persons with PD both have to explore how to make their bodies move, and dancing is inherently engaging and joyful.

In 2006, the collaboration added a customizable teacher-training component to help teachers gain a deeper understanding of the disease and how dance can improve the lives of people with PD. The Brooklyn Parkinson group, in collaboration with Mark Morris and neurologists, also conducts research on the effects of their classes.

For people living with PD, exercise is a vital component to maintaining a sense of well being, balance, mobility and daily living activities. There is a growing interest in this type of exercise intervention to benefit individuals with Parkinson's disease, both nationally and internationally.

Research indicates that patients enrolled in exercise programs for longer than six months have shown significant gains in functional balance and mobility. There is also growing evidence from animal models that exercise may help the brain to maintain old connections, form new ones and restore lost ones.

Based upon interviews, Dance for PDSM participants felt that their quality of life had improved because they felt active, social, physically fit and more vigorous; they also



*Jazz Across the Studio
(Credit: A.S. Merkens)*



*Improvisational mirroring
(Credit: K. Tanaka)*

gained a deeper understanding of themselves and their bodies. Recent research, not yet published, shows improvement in gait and tremor, and that the effect of the classes also relates to improved motivation. Now ask yourself this: Why dance for PD? What are you waiting for? Get involved in your community!

Why Dance for PDSM?

- Dancing is joyful, especially to live music.
- Dancing is a social activity.
- Dancing is excellent exercise. A dance class provides a complete workout. Dancing stretches, strengthens, and relaxes muscles.
- Dancing is, first and foremost, a mental activity. Dancing involves using the brain as well as the body to control movement. The brain gets a complete workout too.
- Dancing makes use of the senses. Conscious use of vision, hearing and touch makes moving easier for persons with PD, just as it does for dancers.

The Brooklyn Parkinson Group received a NPF chapter grant in 2006 to develop a DVD, "Why Dance for PDSM?" NPF is also supporting the development of a web site to encourage more Dance for PDSM programs.

Dance for PDSM classes are now offered in the following states: CA, CT, FL, GA, ID, IL, MA, MD, NY, SC, TN, TX, VA and WA.

*For more information, visit
www.danceforparkinsons.org,
e-mail: oliewestheimer@brooklynparkinsongroup.org,
or info@mmdg.org, or call 646-450-DFPD (3373).*

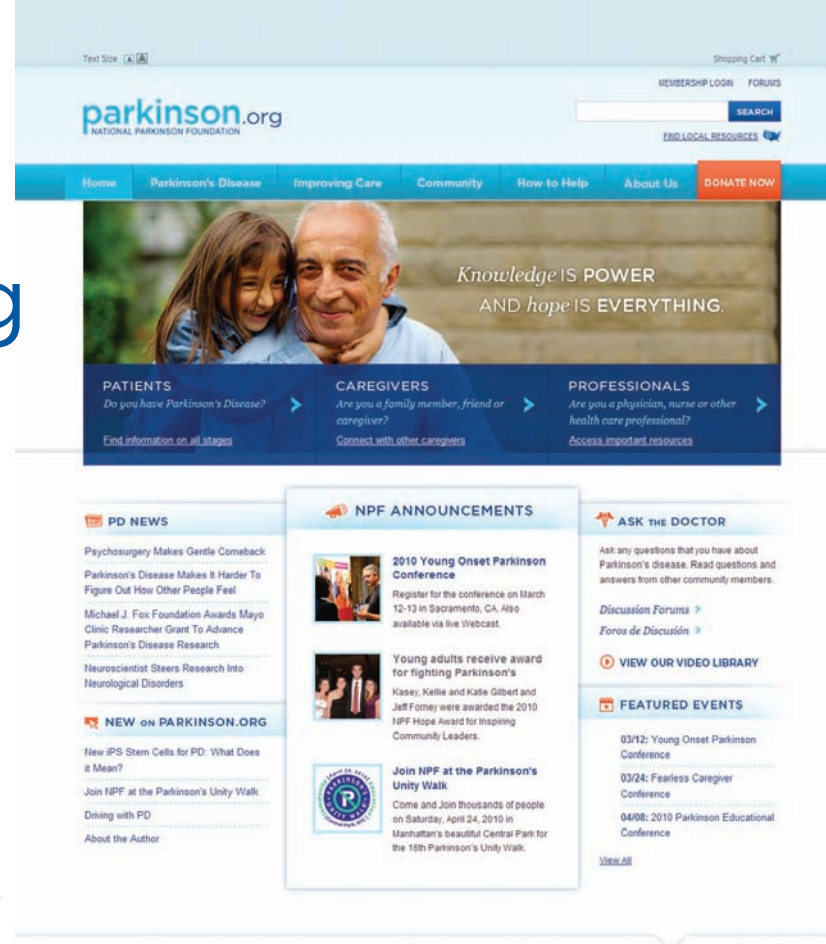
The New and Improved parkinson.org

NATIONAL PARKINSON FOUNDATION

Parkinson.org is the newly-redesigned online resource for the more than four million people worldwide living with the disease, their families and health care professionals. It is sponsored by the National Parkinson Foundation (NPF) and is the official web site of the organization. NPF is dedicated to “Improving care, Improving lives” through research, education and outreach.

THIS NEW WEBSITE HELPS PEOPLE:

- **Understand their disease.** A user-friendly primer for people living with Parkinson’s disease, their families and caregivers. Hundreds of new pages for patients and caregivers covering a wide range of topics from how the disease is diagnosed and treated, to how to live well and care for someone with the disease.
- **Learn about the latest in PD research.** Read Dr. Michael Okun’s “*What’s Hot in PD?*” monthly blog. Dr. Okun is NPF’s National Medical Director and a leading neurologist in movement disorders research.
- **Connect with others.** Read inspiring stories or share your own journey. Volunteer at a local chapter or attend a support group meeting.
- **Get access to educational materials.**
 - Printable checklists on an array of topics that patients can bring to their doctor’s office.
 - Hundreds of brochures, books and DVDs on PD available for free or for purchase.
 - Free NPF Educational Manuals to download or order on nutrition, exercise, caregiving, etc.
 - Free Educational Webcasts.
- **Find local resources.** An extensive list of Parkinson’s disease centers, support groups, health care professionals and events in your neighborhood.



- **Have their questions answered by experts.** Users can *Ask the Doctor* in English and Spanish. They can also *Ask a Nutritionist*, *Ask a Surgeon*, *Ask a Speech Clinician*, or *Ask a Pharmacist*. Plus, forums for Caregivers and Young Onset patients make sharing experiences easy.
- **Listen to advice from health care professionals.** In the new video library, leaders from NPF’s Centers of Excellence answer common questions on topics ranging from depression to deep brain stimulation:
 - What is Parkinson’s disease?
 - What are treatment options for Parkinson’s disease?
 - What should family members know about Deep Brain Stimulation?
 - How does Parkinson’s disease affect memory?
 - What are some tips for talking to a Parkinson’s doctor about depression?
 - What are some of the common misconceptions about Parkinson’s disease?
 - What do caregivers need to know about hospital stays and complex medication regimens?
 - Important information on music and exercise, falls prevention, comprehensive care and much more!

Top Questions and Answers from NPF's "Ask the Doctor" Forum



AUTHORS:

Top: Michael S. Okun, MD
Hubert H. Fernandez, MD

Bottom: Kelly D. Foote, MD
Ramon L. Rodriguez, MD

This issue of the *Parkinson Report* coincides with an important annual event for persons with Parkinson's disease, Parkinson's Awareness Month. Our web-based forums continue to provide patients and families with access to PD experts. Remember you can ask a question at any time on our web site at www.parkinson.org by joining our free forum. Even though the forum has a new look on the re-designed Parkinson.org, the format of the discussion corners remains the same. In fact, we have added an important discussion corner called, "Ask the Pharmacist." Mark Comes, RPh, joins the NPF forum to answer all of your questions on the subject of medication management in controlling Parkinson's disease symptoms. We are happy to present a sample of the top questions from the forum below.

Q If Botulinum toxin (Botox) helps patients with dystonia, does it help those with Parkinson's disease?

A Botulinum toxin therapy has long been a mainstay of treatment for muscle contractions in a disease called dystonia. Interestingly, dystonia can occur in Parkinson's disease (curled toes, turned foot, clenched hand, eyelid closure/blinking, etc.), and botulinum toxin for this type of specific deficit can be an effective treatment for well-selected cases. Additionally, carefully injected botulinum toxin into the region of the salivary glands can serve as an effective treatment for some Parkinson's disease patients with particularly severe drooling issues. Botulinum toxin sounds like a scary approach, but patients should know it is very safe when given by an experienced clinician.

Q Is it true that Glutathione failed to show efficacy in the recently published trial?

A Glutathione acts as an antioxidant, and has been found to be reduced in the brains of patients with Parkinson's disease. It is important for patients to be aware of several important facts about existing glutathione therapies: first, there is a lack of evidence it actually works; second, the therapy requires an intravenous line which has both short and long term risks; and finally, insurance does not cover the costs of this therapy.



Some doctors have chosen to offer glutathione infusion for a fee. There exists no compelling evidence that intravenous glutathione results in any meaningful clinical improvement in Parkinson's disease patients.

Q Should I go to Germany or China for stem cell therapy?

A There are significant problems with stem cells in their current form. First, when you take a cell and make it divide you must be able to turn it on and off. If you cannot control growth of the cells, then they have the potential to form cancers. This limitation of stem cell therapy is an area that has drawn increasing attention from researchers and funding organizations, and pairing stem cell therapy with gene therapy, for example, may help to alleviate this issue. The other major issue with stem cell therapy is that it fails to address the complexity of Parkinson's disease. Parkinson's disease was long thought to be a simple loss of dopaminergic cells in an area of the midbrain called the substantia nigra. We are now aware that there is a much greater level of complexity to this disease and that multiple motor and non-motor circuits and regions throughout the brain area are affected. Additionally, Parkinson's disease may actually be multiple diseases with similar manifestations. This issue of multiple regions, as well as the issue of addressing multiple motor and non-motor symptoms, may prove limiting for stem cells or for any transplantation strategy. An important area of research therefore, is the investigation of "how to encourage stem cells" to repopulate and

repair multiple brain circuits in many brain regions. So in short, save your money as stem cells are not ready yet for the treatment of Parkinson's disease.

Q Do certain jobs (occupations) put one at risk for the development of Parkinson's disease?

A There have been many questionnaire and survey studies that have examined the risk of working certain types of jobs and the development of Parkinson's disease. There has been a tremendous amount of controversy surrounding this area of research especially with regard to welders. The jury is not completely in, and studies have been conflicting, but there are several occupations that may potentially be associated with Parkinson's disease. In a study by Goldman and Tanner, "the medical records of 2,249 consecutive patients from three centers were reviewed for the primary lifetime occupation. Physicians, dentists, farmers, and teachers were significantly more common amongst Parkinson's disease patients, as were lawyers, scientists, and religion-related jobs. Computer programmers had a younger age at Parkinson's disease diagnosis, and risk of diagnosis less than or equal to 50 was greater in computer programmers and technicians." They concluded that healthcare, teaching, and farming were common occupations in Parkinson's disease patients,

but welders were not over-represented in their sample (Goldman, Tanner et al. 2005). Larger studies are needed as there have been conflicting results.



The information published in this "Ask the Doctor" Forum is not intended to replace, and should not be interpreted or relied upon as, professional advice, whether medical or otherwise. Accordingly, please consult your own professional for all advice concerning medical, legal, or other matters published in connection with this Forum. NPF assumes no liability of any kind for the content of any information transmitted to or received by any individual or entity in connection with their use of the "Ask the Doctor" Forum on the NPF web site, and NPF does not endorse or recommend any such information.

"PD Across the Lifespan: A RoadMap for Nurses"

Friday, May 21, 2010 from 8:25 AM - 5:30 PM

New York Academy of Sciences, New York, NY

**An educational symposium and webcast presented by:
American Parkinson Disease Association (APDA), National Parkinson
Foundation (NPF), and Parkinson's Disease Foundation (PDF)**

For more information contact PDF at 800-457-6676 or info@pdf.org.

What's Hot in Parkinson's Disease?

Is Parkinson's Disease a Prion Disorder?



Prion illustration courtesy of: Cedric Govaerts, Holger Wille and Fred E. Cohen, University of California, San Francisco.

There have been more than a few theories over the span of many years regarding the cause of Parkinson's disease (PD). Recent findings have implicated problems with mitochondrial dysfunction, oxidative stress, and protein misfolding along with genetic and environmental issues. Additionally, PD is now thought to be more than a single disorder, and is now considered a syndrome that may have multiple underlying causes usually occurring with similar clinical manifestations. Still, there is always a humanistic draw to attempt to outline a single unifying hypothesis underlying the cause of PD. Recently, in an issue of *Proceedings of the National Academy of Sciences (PNAS)*—Desplats, Olanow and Prusiner all discuss a new “prion disease” hypothesis.

It is widely accepted that in PD, there is an accumulation of misfolded proteins (i.e. usually alpha-synuclein). Alpha-synuclein formulates an important part of the Lewy body that is pathologically present in many motor and non-motor regions within the PD brain. Why these inclusions occur and how they spread from one brain region to another remains unknown.

Recent post-mortem brain samples from PD patients treated with embryonic cell transplants revealed the presence of Lewy body protein inclusions within previously disease-free transplant cells. This observation sparked a great deal of speculation as to how unaffected cells might acquire PD. This is where the story has become very interesting from a scientific perspective. Diseases such as Creutzfeldt-Jakob and Bovine Spongiform

Definition of Prion: A disease-causing agent that is neither bacterial, fungal, nor viral and contains no genetic material. A prion is a protein that occurs normally in a harmless form. By folding into an aberrant shape, the normal prion turns into a rogue agent. It then co-opts other normal prions to become rogue prions.

Encephalopathy (e.g. Mad-Cow Disease) are caused by the propagation of misfolded proteins that are referred to as prions. Desplats and colleagues reported in *PNAS* that nerve cells found to over-express tagged alpha-synuclein could change their conformation and transmit themselves from cell to cell. These investigators posited a prion hypothesis to explain the spread of PD, and also suggested that specific targeting of alpha-synuclein misfolding may provide a viable treatment for the disease.

It is important to keep in perspective that hundreds of expert investigators have been hard at work for many years on these issues. It is the work of the collective PD scientific community that has provided the backdrop for the protein-misfolding hypothesis. The addition of the notion that alpha-synuclein may act like a prion protein and potentially explain the progression of PD is, however, a relatively new idea. Like all new ideas, PD as a prion disease has its champions and its critics. The important thing is that we move, as a PD community, toward a better understanding and toward better treatments for this disabling condition.

Read Dr. Okun's monthly column, "What's Hot in PD?" online at www.parkinson.org.

AUTHOR: MICHAEL S. OKUN, MD, NPF National Medical Director

Selected References: Desplats P, Lee HJ, Bae EJ, Patrick C, Rockenstein E, Crews L, Spencer B, Masliah E, Lee SJ. Inclusion formation and neuronal cell death through neuron-to-neuron transmission of alpha-synuclein. | *Proc Natl Acad Sci U S A*. 2009 Aug 4; 106(31):13010-5. Epub 2009 Jul 27.

Olanow CW, Prusiner SB. Is Parkinson's disease a prion disorder? *Proc Natl Acad Sci U S A*. 2009 Aug 4; 106(31):12571-2. | Epub 2009 Jul 28.



Paddling for Parkinson's by Joseph Forrester

In 2005, my grandfather, Joe Forrester Sr., was officially diagnosed with Parkinson's and in July of 2009, my grandfather's brother died from complications due to Parkinson's disease. My grandfather has an incredible legacy; not only has he taken care of his six sons and daughters, he also has supported his nephews and grandchildren in times of need. Moreover, he has always been extremely supportive of my own personal adventures.

What is "Paddling for Parkinson's"? It was my solo kayak descent of the Missouri-Mississippi River to increase awareness about Parkinson's disease with a goal of raising \$20,000 for the National Parkinson Foundation. On June 2nd 2009, I entered the Missouri River at its headwaters in Three Forks, MT. My journey would take me 3,461 miles down the fourth longest river in the world, through 13 states, and would serve as a tribute and thanks to my grandfather.

Just over three months after entering the Missouri River in Montana, I arrived, at the end of the Mississippi River, exhausted. My journey took me through the northern plains, the Midwestern heartland, and much of the southern United States. I had the opportunity to not only share my family's experience with Parkinson's, but also to listen to the experiences of others. I expect that when I look back late in life on what I learned from this trip, these are the experiences that will have a lasting impact on me.

While I had the pleasure of meeting so many people, one in particular stands out. In Pierre, SD, after completing Lake Oahe, a 240 mile long reservoir, I was met by a gentleman named Kelly Lane. Kelly is 58 years old and was diagnosed with Parkinson's in 1997. What made my bond with Kelly so unique was that before he had been afflicted by Parkinson's he had been an extremely

active kayaker, rock climber and science teacher—passions I also enjoyed. Watching him move, understanding what had been taken from him really impacted me; I could only imagine the frustration he experienced losing these activities. Kelly was undeterred by Parkinson's, and even though so much of what he loved had been taken, he fought back with equal tenacity holding onto what he could and adapting to what he couldn't. He was truly an inspiration.

Personally, I experienced an incredible voyage, not only through America, but also into myself. Alone for so long, I had to face my own fears, had to push myself past the point of pain, and reject failure with the conviction that I would eventually savor the sweet smell of the Gulf salt water. I knew that my grandfather, family, friends and so many followers believed that I could complete the trip; their support, care and kind words helped me through the many dark hours.

I would like to thank the National Parkinson Foundation for all of the support they provided during this experience and all of the people that donated along the way to help me exceed my fundraising goal.

***Joseph Forrester is a medical student
at the University of Virginia.***

***Visit his web site www.paddlingforparkinsons.com
to read his blog entries throughout the trip.***

Left Photo: Joe Forrester, Joe Forrester, MD, and Grandpa and Grandma Forrester before the trip started.

Center Photo: Joseph Forrester kayaking.

Right Photo: Kelly Lane helping Joe with kayak repairs in South Dakota.

A Conversation with Rudi Schmid

Rudi Schmid was diagnosed with PD at age 63 in the fall of 2005. He participates in the Berkeley, CA, Parkinson's Support Group.

How does exercise help you manage your PD?

I have always been physically active and appreciative of the general effects of exercise: cardiovascular health, weight control, stress release (exercise is a good time to escape from pressures of events and just meditate). The PD-relevant benefits of exercise that I've experienced include: (1) increased flexibility and movement ability to counteract the rigidity resulting from PD; (2) improved sleep, if one suffers from the sleep fragmentation common to PD (as well as common to other ailments such as benign prostrate enlargement in older men); (3) less severe constipation, a common side effect of many PD medicines; (4) help in getting through the off or down time when the PD medications are wearing off.

How do you manage to remain physically active?

It is important for me not to give in to various pressures and stresses, from both PD and other events in life, which may decrease time devoted to exercise. Enforced activities are helpful. We have two dogs that like to be walked and my wife and I often take long hikes with them. Gardening, including weeding, is a lifetime habit that I have maintained. I've always preferred stairs over elevators, and purposefully park my car some distance from the entrance of the store, necessitating walking. I take walks with friends, which allows me to talk to them in a more meaningful manner than on a cell phone.

The best type of exercise is on the trips that I plan with my daughter, who lives in Massachusetts, several times a year to go hiking, mountain climbing and snowshoeing. (Tip: Get hiking poles, which aid the hiking effort and also provide better balance.) I used to run avidly about 30 miles a week. My PD ended my running as the toes on my left or right foot would curl up badly, making running impossible—this is my biggest regret about my



Rudi Schmid hiking through Redshanks Chaparral, San Jacinto Mountains, California. (Credit: Mena Schmid)

PD. However, I bought a recumbent exercise bicycle so that I could improve my cardiovascular fitness, which has been diminished by both age and lack of running.

How does exercise affect your mental outlook?

I've found that it is critical to maintain a positive and optimistic outlook about the management of your PD and to realize that you can have a long and productive life. Yes, having PD is a major annoyance, but it does not have the stigma of imminent mortality as many cancers and some other serious diseases do.

Rudi's exercise advice to people with Parkinson's:

- Use a varied exercise routine to avoid boredom.
- Participate in a blend of activities, both outdoors in fresh air, and indoors with television, radio, and stereo.
- Invest in a good quality exercise machine, and think ahead. For example, a recumbent exercise bike may be more usable than an upright exercise bike down the line.
- Exercise with a non-PD person, or a younger PD-person, at least some of the time, because you are more likely to be "pushed" (or pulled) to higher degrees of exercise.
- Schedule important activities during the times of the day when you are mentally at your best.
- Above all, maintain a sense of humor and a positive outlook.

SUPPORT NPF TO IMPROVE CARE AND LIVES

Leave Your Legacy to NPF Through a Bequest

Help the National Parkinson Foundation improve care for the next generation by including us in your will.

A bequest to NPF qualifies for an estate tax charitable deduction.

Your gift will create a lasting legacy and will help NPF end the suffering caused by Parkinson's for future generations.

To learn more about bequests and other planned giving opportunities, contact 800-327-4545 or e-mail: contact@parkinson.org.



JOIN ONE OF OUR FREE ONLINE "ASK THE EXPERT" FORUMS

For detailed, step-by-step instructions for registering and logging into the forums, visit www.parkinson.org.

Recipients of the 2010 NPF Hope Award at the 53rd Annual Gala for Hope

OUTSTANDING CORPORATE PARTNER:

Medtronic Foundation

Accepted by David D. Etzwiler — Vice President of Community Affairs and Executive Director of the Medtronic Foundation

ACCOMPLISHED CHAPTER LEADER:

Irving Layton — President of the South Palm Beach County Chapter of NPF

INSPIRING COMMUNITY LEADERS:

Joseph Forrester — Paddling for Parkinson's

Kasey, Kellie, Katie Gilbert & Jeff Forney — The Anne Joyce Memorial Foundation's Playing for Par

Mary Ann Kelly MacDonald — John D. Kelly 5K

Sara Solomon — ING Miami Half Marathon

Thank you to our generous 2010 Gala Sponsors:

Daniel and Ehrla Cantor; The Diller-Von Furstenberg Family Foundation; Medtronic, Inc.; New River Communications; Teva Neuroscience, Inc.; Paul F. Oreffice & Jo Ann Pepper Oreffice; Morrison, Brown, Argiz & Ferra; Allsup, Inc.; FG Wilson Miami; Donor Care Center, Inc. and Southern Wine & Spirits.

ASK THE DOCTOR:

A team of Parkinson's specialists answers medical questions about Parkinson's disease.

ASK THE PHARMACIST:

Mark Comes, RPh, fields questions about medication management.

ASK THE SPEECH CLINICIAN:

A team of experts answers questions regarding speech and swallowing.

PREGÚNTELE AL MÉDICO:

Ramon L. Rodriguez, MD contesta preguntas con respecto a la enfermedad de Parkinson y materias relacionadas.

parkinsonREPORT

NATIONAL PARKINSON FOUNDATION

NATIONAL PARKINSON FOUNDATION, INC.

1501 N.W. 9th Avenue/Bob Hope Road
Miami, Florida 33136-1494

800-327-4545 • www.parkinson.org

PRSRT STD
NON PROFIT
U.S. POSTAGE
PAID
COLUMBUS, WI
PERMIT NO. 73

Tell us what you think of
the Parkinson Report.

Send your comments to
contact@parkinson.org.

*For just \$25 a year, become
a member of NPF today
to continue receiving issues
of the Parkinson Report.*

Become a fan of
NPF on Facebook 



2nd WORLD PARKINSON CONGRESS

Glasgow, Scotland, UK
September 28 – October 1, 2010

Join more than 3,000 international clinicians, researchers,
allied health care professionals, and people
living with Parkinson's at this global Congress.
This novel meeting, supported by more than 135 Organizational
Partners from 38 countries, is the only meeting that
has representatives from all areas of the Parkinson's community
creating unique opportunities for collaboration
and innovation in science, care and advocacy.

Important Dates:

June 30 – Discounted pre-registration deadline

July 5 – Late-breaking abstract deadline

Learn more at www.worldpdcongress.org.

NPF | NATIONAL PARKINSON FOUNDATION

Improving care, Improving lives

The Parkinson Report is published by
the National Parkinson Foundation, Inc.

Headquarters 1501 N.W. 9th Ave./Bob Hope Rd.
Miami, Florida 33136-1494

President & CEO Joyce A. Oberdorf

Chairman Bernard J. Fogel, MD

**National
Medical Director** Michael S. Okun, MD

Editor Leilani Pearl

Editorial Team Adolfo Diaz
Sharon Metz, RN, MPH

Design Lucky 3 Creative

Although we attempt to ensure accuracy, the publisher cannot accept responsibility for the correctness of the information supplied herein or for any opinions expressed. Articles received and published may be edited at the editors' discretion.

Information provided in reference to medical diagnosis, treatment, and research reflect the views of the authors and should not be taken as endorsements by the National Parkinson Foundation. In case of medical issues, an individual should always check with his or her personal physician. The National Parkinson Foundation does not advertise, but rather offers information it feels will be helpful to patients, caregivers, and families.

Every effort is made to avoid duplication of mailing labels; however, occasional duplications are inevitable. If you receive an extra copy of the Parkinson Report, please pass it along to a friend or colleague. If you do not wish to receive further issues of the Parkinson Report, please contact us by e-mail or by phone as listed immediately below, and your name and address will be removed from our mailing list.

Comments? Questions? Contact us.

contact@parkinson.org

Toll-free 800-327-4545

In Miami, Florida 305-243-6666

On the Internet www.parkinson.org