Depression Drives Quality of Life in Parkinson’s:
NPF Releases New Report to the Community

Although Parkinson’s disease (PD) impairs many aspects of movement, it’s the disease’s impact on emotions that has the greatest effect on quality of life. The first report to the community from the National Parkinson Foundation’s Quality Improvement Initiative, part of the Parkinson’s Outcomes Project, has found that depression is the number-one factor influencing health status. Based upon this report, and other research, NPF recommends that all people with Parkinson’s get screened for depression at least once a year.

What Works Best in Parkinson’s Care?
The Parkinson’s Outcomes Project was created to help researchers identify what treatment and care strategies have the greatest impact on lessening the symptoms of Parkinson’s by studying the differences in care provided by leading experts. At the project’s core is a comprehensive database of information on more than 5,000 patients, who have been evaluated in the clinic by expert neurologists, and followed in 20 NPF Centers of Excellence around the country and the world.

“Through this report, we wish to start a conversation with the patient community about what works best in Parkinson’s care,” said Joyce Oberdorf, NPF’s President and CEO. “We believe that the best expert care can mitigate the impact of Parkinson’s disease and significantly improve quality of life. Ultimately, the goal of the Parkinson’s Outcomes Project is to make it possible...continued on page 2
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for every person with Parkinson’s to gauge how well their care measures up and to choose treatments based on solid evidence, not guesswork.”

**Key Findings:**

1. **NPF has found that patients at some centers fare better than similar patients at other centers.** We don’t know why this is, but we believe it is a combination of two things: doctors at some centers are getting referred patients who are simply doing worse to begin with, and the centers with the best outcomes are providing a superior level of care that leads to better outcomes.

2. **NPF has found that most centers use medication differently.** Once Parkinson’s advances, physicians rely on their best judgment in managing drug regimens. As a result, patients who seem to be very similar can be on very different prescription regimens. What we have found is that some neurologists opt for more complex and individualized medication strategies, while others prescribe simple treatment plans of one or two medications.

3. **Finally, NPF has found that centers also refer patients to allied health professionals differently.** Sometimes this is due to varied philosophies about the range of care they offer their patients and at other times it is due to issues surrounding access to care. We have found that depression, for example, seems to be treated best when patients are referred to a counselor, yet not all centers follow this approach.

**Depression: Too Often Untreated**

Referring a patient diagnosed with depression to a therapist for treatment is paramount because negative mood and depression are the most important factors contributing to the health and wellbeing of someone living with Parkinson’s (see chart in next column). For doctors, however, diagnosing depression can be difficult because some symptoms of Parkinson’s—such as a masked facial expression, sleep problems and fatigue—overlap with symptoms of depression. In fact, studies show that the majority of people with Parkinson’s will go unrecognized or undertreated for depression.

That’s why individuals must understand that depression is a disorder, not a character flaw, and discuss even subtle changes in mood with their doctor as soon as they arise.

Parkinson’s disease affects chemicals in the brain that are responsible for the way we feel, so depression can be caused by the underlying disease process. Ongoing stress, sadness and social isolation that result from living with a chronic disease can also trigger, or worsen the condition.

“It’s very important that depression is considered just as important as any of the other physical symptoms of Parkinson’s,” said Michael Okun, MD, NPF’s National Medical Director. “As this report shows, improving mood is one of the most significant ways to address the other aspects of Parkinson’s.”

NPF recommends a comprehensive, holistic approach to depression. Treatments with antidepressant medications, independently, or in combination with exercise, psychotherapy, and behavioral techniques, are very effective. “Cognitive behavioral therapy—teaching coping strategies, building on self efficacy, and thinking positively—is a very important part of a person’s overall wellness,” Dr. Okun said. “Each individual’s treatment plan should be tailored to their symptoms, preferences and other illnesses.”

As NPF researchers continue to analyze this growing collection of data, they will establish a standard of care that has been “tried, true and tested,” and can inform proactive treatment plans. Ultimately, the purpose of the Parkinson’s Outcomes Project is to help people who have Parkinson’s to not only live longer, but also healthier, more active lives.

To read the full report to the community, NPF’s Parkinson’s Outcomes Project, visit www.parkinson.org/outcomes.
Caring for the Caregiver

Where do most people with Parkinson’s disease live? At home—where loved ones provide most of the care. If you are a primary caregiver feeling stretched beyond your limits most days, that outflow of time and energy may be putting you on the road to burnout and depression. Not surprisingly, research from NPF’s Quality Improvement Initiative shows that Parkinson’s caregivers of all ages experience high levels of strain, which can lead to caregiver burden—an alteration in one’s emotional and physical health. As the disease itself progresses, the burden of caring for your loved one increases as well.

Focusing on your loved one’s needs to the exclusion of your own is a formula for failure, said Kara Barton, MSW, LCSW, a social worker at the Center for Psychological Excellence at the University of Southern California, an NPF Center of Excellence. In order to be able to succeed in your role, you need to care for yourself even as you care for your spouse or parent. “If the caregiver collapses, everyone loses,” Barton said. Here are some ways to ease the burden:

✔ Seek out rehabilitation services. Research shows that improving the functional status of the person with Parkinson’s is an effective approach for relieving caregiver strain. Physical therapy, occupational therapy and assistive devices can all make a difference for both you and your loved one.

✔ Learn to be interdependent. Bring more balance into your life by relying on community resources such as transportation services, in-home aides, adult day care and local caregiver groups. “Shift your thinking from independence to interdependence, and look at yourself as someone who is going to function in a new way—giving and receiving,” Barton said.

✔ Assess yourself. If you are struggling with resentment and anger, or are just feeling bad most of the time, you must make some changes in order to turn this emotional scenario around. “Ask yourself, what can I do to feel good about myself again?” Barton said. “Work on becoming more mindful, paying attention to what you are doing and feeling in the moment, so you can better take care of yourself.”

✔ Face forward. If the thought of your future fills you with anxiety and trepidation, begin to look for ways to increase control in your life. “Plan ahead and start taking simple steps to address those fears, instead of just being terrified,” Barton said.

✔ Find out if your loved one is depressed. When people who have Parkinson’s suffer with depression, their caregivers report higher levels of caregiver burden than caregivers whose loved ones are free from the condition. Since depression is common in people with Parkinson’s, make sure your loved one is screened and, if diagnosed, getting the right treatment.

WHEN TO SEE A DOCTOR—SYMPTOMS OF DEPRESSION:

- Ongoing, sad anxious feelings
- Feelings of hopelessness, guilt or worthlessness
- Irritability or restlessness
- Loss of interest in pleasurable activities
- Difficulty concentrating, remembering details, or making decisions
- Insomnia or sleeping all the time
- Overeating or loss of appetite
- Thoughts of death or suicide
- Ongoing aches and pains, headaches, cramps, or digestive problems that do not ease with treatment
- Call NPF’s Helpline, 1-800-4PD-INFO, to speak to a trained PD specialist today.
**Living with Parkinson’s for the last four years, Marty Gershe, 71, knows first-hand the importance of being prepared for a hospital stay. His many trips to the hospital often left him frustrated with staff who did not fully understand the complexities of Parkinson’s and the importance of getting him his medications on time.**

“It was a constant battle to get my meds on time,” he said. “And when I don’t get my meds on time, I can’t function—my speech is affected, my walking is affected and my general well-being is affected.”

Along with the reminder slips Marty explained that another item included in the kit, the *Aware in Care Hospital Action Plan* (a booklet designed to help people with Parkinson’s prepare for a hospital stay) was essential to his visit.

"The parts of the booklet that discuss that you should be vocal, persistent and assume that each person you meet has little experience with Parkinson’s are so true,” Marty said.

Using these tools, Marty was better prepared to speak with the nurse manager and the head pharmacist after moving from the emergency room to the hospital’s main care unit. “After going through everything with them they got the schedule timed perfectly, and for the first time I got my medications on time and every time I was supposed to,” he said.

By educating himself, Marty was also able to share critical information with hospital staff about Parkinson’s and his particular requirements. His positive experience reflects the main intent of the *Aware in Care* campaign—to empower patients and help healthcare professionals understand Parkinson’s better.

“Having the *Aware in Care* kit has made a world of difference in the treatment I received when I had to go to the hospital,” Marty said. “Everyone with Parkinson’s should have one.”

Watch the online video of Marty talking about how he used the *Aware in Care* kit in the hospital. Visit NPF’s Video Library, [www.parkinson.org/videos](http://www.parkinson.org/videos).

For more information about the *Aware in Care* campaign or to share your thoughts about the kit online, please visit [www.awareincare.org](http://www.awareincare.org).
What’s Hot in Parkinson's Disease?
Caffeine May Improve Motor Symptoms in Parkinson's Disease

Here’s some good news for coffee lovers. Several recent studies have suggested that caffeine may lower the risk of developing Parkinson’s disease (PD). Now, another new study suggests that it could also help improve motor symptoms in people who have PD.

The aim of the latest study, published in the Aug. 1, 2012 online issue of the journal *Neurology*, was to assess the effect of caffeine on wakefulness. When Canadian researchers from the Research Institute of the McGill University Health Centre in Montreal followed 61 people with PD for six weeks, they found that those who received caffeine supplements (a 100 mg dose twice a day for three weeks and a 200 mg dose twice a day for another three weeks), compared to those who got a drug-free placebo pill, experienced an approximate 5-point improvement in their movement symptoms. The change was measured on the Unified Parkinson Disease Rating Scale (UPDRS), a standard scale of PD symptoms used by doctors to track disease progression and response to therapy. No significant improvement in daytime sleepiness was reported.

Since the study was small, the results should be interpreted with caution, and will need to be replicated in larger studies. But these findings suggest that caffeine may have an impact on motor impairment, including severity of tremors and speed of movement. Because the results have been mirrored by several smaller studies, paying attention to the link between caffeine and PD could be beneficial for patients.

The idea that caffeine may play a role in PD began with a series of epidemiological studies that suggested a reduced risk for PD when caffeine intake was increased over a lifetime. And, several large studies have uniformly concluded that higher caffeine intake seems to be closely associated with a lower risk of developing the disease.

Further, several other human and animal studies, as well as anecdotal observations, support the view that there is a mild to moderate benefit from caffeine consumption for people with PD. The benefit is believed to result from caffeine’s action in blocking the adenosine A2A brain receptor. Several A2A blocking drugs have either been studied, or are currently being studied.

What’s the take home message? The mild motor benefit of consuming 100mg to 200mg of caffeine twice daily, the equivalent of about two to four cups of coffee, seems to be real. Those wishing to benefit from this discovery will need to calculate their daily caffeine intake, and also remember that caffeine comes in many forms—tea, soda and chocolate.

Also, keep in mind that the study did not examine higher doses of caffeine, and it’s possible that caffeine’s effects on tremor and other symptoms could worsen at higher doses. Finally, be aware that in most studies participants develop tolerance to the effects of caffeine, which could cancel the benefits. The true value of this recent study will be in spurring future development of new therapeutic targets and drugs for the treatment of PD.

Selected reference:

Author: Michael S. Okun, MD, NPF National Medical Director

Read Dr. Okun’s monthly column, “What’s Hot in PD?” online at www.parkinson.org/whats-hot.
Top Questions and Answers from NPF’s “Ask the Doctor” Forum

This November, NPF is celebrating caregivers during National Family Caregivers Month. Many experts agree that the most important factor for living successfully with Parkinson’s disease is having an empathetic and supportive spouse or caregiver. For this issue of the Parkinson Report, we focus on commonly asked questions about Parkinson’s from our “Caregiving” forum, an unmoderated forum open to all. We encourage you to visit www.parkinson.org/forums and take advantage of this informative and free resource.

Q How do I decide if my father who has Parkinson’s disease (PD) should come live with us?
A Deciding whether to move a loved one with PD into your home can be a difficult decision. There are many important factors to consider before making such a major change. Here are some suggestions on how to proceed:

- Have an occupational therapist complete an inspection of your house and do a comprehensive evaluation of your father and your family. You’ll need to determine the precise activities of daily living your father will need assistance with and then find out whether you and your family will be able to meet those care demands. The occupational therapist should also assess the safety of your house. Often, some remodeling is necessary in order to improve conditions.

- Consult with a neurologist about the challenges your family will face as the disease progresses. If you are not psychologically prepared, these challenges could put undue stress and strain on your family resources and dynamics. Caregivers of individuals with PD have high rates of depression and other problems. To learn how to prevent caregiver burnout or burden, talk with a licensed clinical social worker.

- Consider how the move will affect your father (friends, weather, happiness, etc.). The fact that you are considering moving your father into your house shows your devotion, but make sure you have a “big picture” look at his circumstances, and all the individual caregiving obligations, before making this decision. You want to be sure that this move will improve matters for him.

Q My husband was diagnosed with Parkinson’s 13 years ago, but his hallucinations have gotten worse in the last few months. Is there anything I can do to help manage this problem?
A To start, make your house safe by storing ladders, knives, firearms and other dangerous objects in a secure place. Next, contact your neurologist to arrange an in-person evaluation. During that visit, his medication should be reviewed and optimized. Occasionally, hallucinations are benign, and do not require any changes. But in most cases, caregivers will need to work closely with their doctor to implement medical and behavioral interventions. Some common changes can include reducing medications, adding drugs used to treat hallucinations such as quetiapine (Seroquel) or clozapine (Clozaril) and improving sleep. Be aware that when hallucinations set in, accompanying confusion may lead to “out of character” statements from sufferers. You should be psychologically prepared for these disturbing outbursts, and understand that the person has an illness that is beyond their control.

www.parkinson.org
**Q** My mother lives with me and has had Parkinson’s for about seven years. She suffers from confusion and falls. What do you suggest?

**A** There are many underlying problems such as dementia and medication side effects which can cause confusion and increase your mother’s risk of falls. To prevent falls, your mother’s neurologist and primary physician will need to identify and treat the underlying cause of her confusion. Further, her medications should be carefully reviewed and optimized, because sedatives and other drugs can worsen balance or cause dizziness. A physical therapist can recommend an appropriate assistive device such as a cane or walker for your mother. (For ideas on how to make your house safe, see Caregiver Tips for Daily Living.)

**Q** My spouse, like 18 percent of those with Parkinson’s, has developed an impulse control disorder. What is the best way to resolve this problem?

**A** Some common impulse control disorders associated with PD include excessive shopping, overeating, gambling, and hyper-sexuality. So it’s critical that you and your spouse see a neurologist about resolving this issue immediately. If your spouse is taking a dopamine agonist, the first line of therapy is to work with your doctor to taper off the agonist from the medication regimen. This weaning must be performed very slowly to avoid a withdrawal syndrome. In many cases, the dopamine agonist will need to be replaced with carbidopa/levodopa to control PD symptoms. If this approach is ineffective you may need to obtain a second opinion from a Parkinson’s specialist, because an additional medication may be necessary (e.g., clozapine, valproic acid). It’s also possible that an impulse control disorder can occur while a patient is on other PD medications.

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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.
Thirty-four years ago, Rick Weeden received a diagnosis of Young-onset Parkinson’s disease. His wife and caregiver, Betty Weeden, will never forget how the doctor delivered the news, “It could be a lot worse, deal with it.” Betty and Rick have done more than just “deal” with Parkinson’s; they have carved out a full life of travel and adventure, including RVing up and down the Eastern Seaboard, camping, tandem biking and sailing.

Betty, a former operating room nurse turned full-time caregiver, has the hard-working and matter-of-fact outlook of a New England native. She tackles each day head-on and barely stops to think about her circumstances, preferring to “live each day like it’s your last.” With her contagious laugh and unrelenting sense of humor, she fully embraces the challenges of this disease and what she has seen it do to her beloved husband.

As Rick’s advocate, Betty does not take no for an answer—from her husband or from a doctor. She continually looks for new treatments (e.g., Botox, pool therapy) to help with symptoms and she helps Rick exercise on a daily basis, even if it’s just for a short walk around the neighborhood. “Caregivers don’t realize how strong they are,” Betty explained. Despite Betty’s indomitable strength, she has realized over the years that she can’t be there for Rick 24/7 or her own health starts to suffer. Therefore, she has hired nursing assistants to help her with Rick three days a week. This has freed up some time for her to join a support group for caregivers, meet friends for lunch and to take up quilting as a hobby.

This year, Rick’s brother, Curt Weeden, is releasing a new mystery novel entitled, Dutch Island. Rick and Betty are feature characters and it is set in their hometown of Portsmouth, Rhode Island. In this novel, Betty is a courageous, RV-driving heroine and Rick is not defined by his Parkinson’s, but by his vast sailing knowledge. Betty has been reading the novel out loud to Rick daily and they are both flattered that Curt thought of them when writing this book.

“I never thought that anybody realized what we go through, but after reading this book, I realize that Curt did and that meant the world to me,” Betty exclaimed through tears.

Betty’s advice to caregivers like her is to:
find a network of help, whether it is professional or family; always face each day with a sense of humor; maintain your own hobbies; and tend to your other relationships with friends for support.

The book, Dutch Island, is available on Amazon.com for $11.95. The author is donating all proceeds from the sale of this book to the National Parkinson Foundation.

For more information or to order a copy of the book, please visit www.parkinson.org/dutchisland.

FREE SUBSCRIPTION TO CAREZONE

CareZone and NPF have partnered to offer you free access to the CareZone utility for caregivers—it’s a safe place to get organized, store important information and share access with family. CareZone helps the people in charge of caring share the burden, and enable others to help out. Sign-up for your free account at https://carezone.com/npf.
Amy Ardman Shea and Marty Ardman, both of Weston, FL, are leading a caravan of family and friends to participate in the first-ever Moving Day Miami, on October 7, 2012 at Bayfront Park. This daughter-father duo are the energy behind Team Ardman. Although they both created the team for different reasons—she to support her father who has Parkinson’s disease (PD), and he to be an advocate for the community—they share the same goal: help raise awareness of PD and the importance of movement in improving quality of life.

Moving Day Miami is one of 16 walks taking place in cities across the United States in 2012; however, it is the first major event on the National Parkinson Foundation’s (NPF) home turf of South Florida. The foundation has been based in Miami since 1957 when founder Jeanne Levey established the organization to help improve care for everyone living with PD.

Remaining true to this mission, while taking the effort one step further, NPF’s Moving Day is the first grassroots campaign that spotlights Parkinson’s on a national level. Working with the NPF South Florida Chapter, which serves Miami-Dade and Broward counties, this event is expected to draw more than 1,000 walkers.

Both Amy and Marty hope to contribute to the success of Moving Day, while expanding the reach of NPF’s community of support. “There is a large elderly population in South Florida who are unaware of the early warning signs of Parkinson’s and of the myriad of support services that NPF offers,” Amy said. “We need to raise awareness and get more people involved with the NPF South Florida Chapter.”

Marty, 73, has been involved with the foundation as a volunteer for more than a decade; he received an award from NPF for his countless hours of volunteer service. His goal for Team Ardman is to raise $10,000, most of which will go back to the NPF South Florida Chapter to help fund local Parkinson’s services and educational outreach.

When asked what advice he has for others living with the disease, Marty doesn’t hesitate, “Keep moving. Don’t sit idle.” He certainly follows his own advice—staying in shape by taking a physical therapy class, playing tennis and working with a personal trainer once a week. And he is always sure to work out his mind as much as his body, engaging in challenging mental exercises.

Everyone has a different answer when asked, “Who moves you?” on Moving Day, but for Amy the answer is crystal clear.

“My dad greets each day with strength and perseverance and is determined to win the battle against Parkinson’s,” Amy said. “I am walking for my father and for others living with the disease to help them live their best life.”

To learn more about Moving Day, please visit www.npfmovingday.org.
To learn more about the NPF South Florida Chapter, please visit www.npfsouthflorida.org.
Free NPF Webinar Series

If you or a loved one has been diagnosed with Parkinson’s disease (PD), you probably have a lot of unanswered questions. To help you get the answers you need, NPF has put together a series of interactive webinars. Featuring presenters who are experts in their field, the presentations address a host of issues of concern to the Parkinson’s community.

The following webinars were a success. Did you miss them? NPF has archived the presentations and made them available to all for free.

➡ Relationships, Parkinson’s and You
Our guest, Kara Barton, MSW, LCSW, a social worker at the Center for Psychological Excellence at the University of Southern California, Keck School of Medicine, discusses the impact of PD on interpersonal relationships. Topics covered in this webinar include personal identity and needs, common relationship challenges and appropriate ways to disclose a Parkinson’s diagnosis to friends and employers. This presentation will help you learn how to cope with some of the major life changes that accompany a Parkinson’s diagnosis. Barton explains how getting past common Parkinson-related problems such as embarrassment, social isolation and feelings of helplessness can lead to a greater sense of freedom and confidence. Viewers will get practical suggestions on how to assess personal needs, communicate more effectively and stay engaged in life.

➡ Non-Motor Symptoms of Parkinson’s Disease—Depression
If you have Parkinson’s, or are caring for someone with the disorder, then it is critical to learn about two important non motor symptoms of PD—depression and anxiety. In this webinar, Anthony Santiago, MD, Associate Professor of Neurology and Director of Clinical and Translational Research at the Muhammad Ali Parkinson Research Center and Movement Disorders Clinic, provides an overview of depression and anxiety in PD, as well as specific pharmacologic and non-pharmacologic treatment options. Since these symptoms often fly under the radar of both patients and physicians, people who are concerned about mood changes must do several things in order to receive correct treatment. They need to discuss the uncomfortable details of their emotional state with their doctor, ask specific questions about their symptoms and consult with a dedicated team of specialists knowledgeable about PD. Caregivers and support groups are also essential to this team approach.

To view archived webinars, please visit www.parkinson.org/webinars.
Stay tuned for the 2013 webinar schedule.

SAVE THE DATES—UPCOMING NPF EVENTS

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<td>Young Onset Parkinson Conference (YOPC)</td>
<td>November 16-17, 2012</td>
<td>Cincinatti, OH</td>
<td><a href="http://www.parkinson.org/yopc">www.parkinson.org/yopc</a></td>
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<td>Allied Team Training for Parkinson’s (ATTP)</td>
<td>March 6-9, 2013</td>
<td>Denver, CO</td>
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<td>NPF Wellness Retreat at Kripalu</td>
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Help NPF Beat Parkinson’s!

Please consider making a gift to NPF now or prior to the end of the year. Your support will help NPF improve the quality of care for those living with Parkinson’s disease.

Federal tax policy related to estate and gift tax exemptions are due to revert back to their 2000 levels on January 1, 2013. In light of this it is certainly worth contemplating, depending on your financial situation and net worth, a planned gift to NPF before December 31st.

There are many ways to give that are meaningful to you and will positively impact those living with Parkinson’s.

- Consider making a bequest and designating NPF in your will
- Consider creating a Living Trust
- Learn about the benefits of creating a:
  - Charitable Gift Annuity
  - Charitable Remainder Unitrust
  - Charitable Remainder Annuity Trust
  - Charitable Lead Trust

For more information on all of these planned giving opportunities, please visit www.parkinson.org/plannedgiving.

Contact David Weiss, Senior Director of Development, at dweiss@parkinson.org or 305-243-8113.

Note: NPF does not offer tax or legal advice. Please consult your own advisor with any legal or tax-related questions.

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Palais des congrès | October 1–4, 2013 | Montréal, Canada

Science, Community, Hope | Science, Communauté, Espoir

The 3rd World Parkinson Congress will bring together the full spectrum of people who live with Parkinson’s disease and those who serve the Parkinson community. We hope this cross-pollination of delegates helps find a cure and better treatment options for people living with Parkinson’s.

Attendees will include:
- Neurologists • Researchers • Geriatricians
- Nurses • Rehabilitation Specialists • People with Parkinson’s
- Carepartners • Family members • Representatives of industry and government

Important Dates

November 5, 2012  Video competition opens
December 3, 2012  Abstract submission opens
January 2, 2013  Registration opens
April 15, 2013  Abstract submission closes

www.worldpdcongress.org The official language of the WPC 2013 is English.