Dear WPC friends,

Are you a cathedral thinker? I spent time recently with a number of others in the meeting industry who plan conferences and global congresses. They were curious about how the WPC plans its meeting and how we successfully engage people with Parkinson’s.

In one session we discussed how we can work in our professional spaces to encourage people to take on projects while engaging in cathedral thinking. The term cathedral thinking refers to many centuries ago when architects and stone masons would design and start building cathedrals and other massive structures that they knew would not be finished in their life times. They would take on the task knowing that others would finish their work.

During this meeting I was asked, what could you do in your space that could be more in line with cathedral thinking and it dawned on me, we already do this! We in the Parkinson’s community are incredible cathedral thinkers, which is why I admire the Parkinson’s community so much.

There are many cathedral thinkers in the Parkinson’s space starting with the neuroscientists who spend their lives studying Parkinson's at the cellular level to unlock the mysteries. They are striving for the cure, but they realize that their work may not yield it. They recognize that someone else may take their work and expand it to get us to the cure. The clinicians, who work day in and day out caring for people with Parkinson's and their care partners, are doing their part to empower people with Parkinson’s to take control of their lives. These clinicians can’t cure PD, or stop the progression, but they are making sure people with Parkinson’s are living well until we find that cure.

This brings me to the people with Parkinson's who are volunteering in clinical trials to help us get closer to a cure, knowing that they are one of many people donating their bodies in ways that are sometimes uncomfortable and exhausting. Yet they do this because as people with a chronic degenerative disease involved in clinical trials, they are innately cathedral thinkers. They are considering the generation after them and the generation after that generation, knowing that their enrollment in a clinical trial may not end PD in their life time, but it will end it in someone’s life time.
The entire Parkinson's community is engaged in cathedral thinking in more ways than I could list here and it was at that moment, in that meeting I attended, that I was reminded of how incredibly proud and honored I am to be part of this community of brilliant, generous, and engaged people who aren’t focused only on themselves, but on the successes of everyone involved in the Parkinson’s space.

Thank you for your service to the community.

Warm regards,

Elizabeth "Eli" Pollard
Executive Director

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**WPC Blog Highlight**

Re-purposing Old Drugs for New Treatments for Parkinson's Disease: Can an Asthma Drug Slow Progression of PD?

by John G. Nutt, MD

The following is an excerpt from his blog post. The link to the full blog post is below.

Drug discovery, that is taking a new chemical compound from the laboratory to a FDA approved drug, is a long, expensive and risky process. Most potential drugs fail to reach market; only 1% of compounds leaving the laboratory will reach the market. Many potential drugs fail in the prolonged toxicological studies in animals and in human studies when unforeseen risks emerge.

A clever scheme to speed up the process of developing new treatments is to focus on the over 1,400 FDA-approved drugs and other natural products, thus bypassing the time-consuming toxicity studies in animals and humans and simultaneously avoiding the risks of unexpected toxicity. In this scenario, FDA-approved compounds are screened in test tubes or cell cultures for effects on cellular processes that are thought to underlie development of PD. For example, in PD, alpha-synuclein, a normal cell constituent, is produced in higher quantities and is not cleared from the cell producing toxic accumulation of the protein. Thus, screening for drugs that affect the production, accumulation, aggregation and
elimination of alpha-synuclein is an obvious target. Compounds that appeared promising in laboratory testing could then be tried in animal models of PD. Clinical trials could proceed relatively quickly because the drug would have already been proven safe in humans, although for a different purpose. This strategy of testing old drugs for new purposes is termed “repurposing” or “repositioning” drugs.

Read the Rest . . .

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popular model of decision-making. We found that patients with Parkinson’s disease on medication were impaired at using prior information to guide choices in the presence of sensory uncertainty and that this impairment resulted from a failure to adjust their starting point of evidence accumulation, consistent with an impairment in adjusting the amount of evidence needed to make a decision. A change in the starting point of evidence accumulation reflects an asymmetric adjustment in the amount of sensory evidence that needs to be collected for each of the options before committing to a choice. Interestingly, patients were able to adjust their drift rate according to the prior experience, consistent with an ability to learn from feedback and in some cases this adjustment was sufficient to overcome the “frozen” starting point of evidence accumulation leading to some benefit of the prior experience. Together these results suggest a general impairment in decision-making in patients with Parkinson’s disease when those decisions require the combination of multiple sources of information; in this case sensory and previously learned information. Furthermore, the general deficit patients exhibited in adjusting their starting point of evidence accumulation could explain some of the motor symptoms seen in patients such as paradoxical movement and freezing of gait and may represent a common mechanism underlying dysfunction in patients with Parkinson’s disease.

Download all the WPC 2016 Abstracts here

Hot Topics from WPC 2016

In July we will start accepting original abstracts for the 5th World Parkinson Congress in Kyoto, Japan. Scientific and Living with Parkinson's abstracts will be considered for acceptance. **Scientific** abstracts will cover a range of topics from basic science, clinical science, and comprehensive care, while **Living with Parkinson's** abstracts are open to those involved in education or advocacy related to Parkinson’s. The top twelve scientific abstracts will be selected for Hot Topics, and the authors will be invited to orally present their work in front of up to 1,000 people, including many leaders in the field.

Many of our Hot Topics from WPC 2016 have been busy! Fortunately for us, four of them have written posts for the WPC Blog. **Dr. Richard Smeyne** wrote a post about how the flu may be a risk factor for PD. **David Leventhal** wrote about the expansion of his Dance for PD program. **Dr. Ignacio Mata** spoke about the importance of having diverse populations involved in clinical trials. **Dr. Marion Delanclos’** post went up just this week and explored how new investment into PD research will change how that research is approached. Be sure to read these excellent posts and if you wish to watch their talks, you can do so on our webcast!
Watch the twelve Hot Topic presentations

SAVE THE DATE
Abstract submission dates: July 9, 2018 to November 23, 2018.

Click here to learn more.

It was the birthday of James Parkinson, most famous for publishing ‘An Essay on the Shaking Palsy’ in 1817, which established Parkinson’s as an internationally recognized medical condition.

Together with EPDA and Parkinson’s UK, we are asking everyone to use #uniteforparkinsons on April 11 to share their stories and to raise global awareness of the disease.

Learn More

The 24th Annual Parkinson’s Unity Walk will be on Saturday, April 28, 2018 (Rain or Shine)

Sign up for a gentle 1.4 mile walk in Central Park and be sure to visit the WPC booth to share your advice and inspiration with the Parkinson’s community and enter our raffle.

100% of donations to the PUW go to Parkinson’s research at five major Parkinson’s foundations.

We hope to see you there!

Learn More

Parky The Raccoon became our official mascot in 2013. Raccoons are creative and resilient, just like people with Parkinson’s. One hundred percent of proceeds from Parky go to the WPC Travel Grants Program.

Order Parky the Raccoon

Visit WhereIsParky.org to see his adventures.

Meet the WPC 2019 Delegate Leaders
Delegate Leaders work with the WPC to coordinate a group of people interested in attending the congress. Once registration opens in September of 2018, Delegate Leaders will work with their local group to coordinate travel plans and
to ensure that registrants meet important deadlines. A limited number of Delegate Leaders will be selected based on the applications.

Learn more about becoming a Delegate Leader here.

**Shirley Burke (United States):** Hello everyone! My name is Shirley and I am 41 years old. I am happily married with a 13-year old son. I currently live in West Des Moines, Iowa. Since my official diagnose of young onset parkinson’s in 2013, I have been actively involved with the American Parkinson’s Disease Association Iowa Chapter young onset Parkinson’s support group. I am excited to be selected as the program lead, because it will give me an opportunity to be connected with others within the Parkinson’s community, and be able to take what I learned from others and share with members of my group here in Iowa!

**Melissa Rehm (United States):** Melissa lives with Secondary Parkinsonism, Ataxia, and Dystonic Tremor. She began her journey at the age 41. After years of multiple doctor visits, exams, and tests, she received a diagnosis of Young Onset Parkinson’s Disease (YOPD) in 2012. Though it came during a challenging time of being a wife, with two young daughters, and working in the school district, having a label was welcomed. In 2017, the diagnosis was changed to Secondary Parkinsonism with Ataxia and Dystonic Tremor.

In 2015, Melissa started a support group online, Never Give Up PD, to share and learn tips with other People with Parkinson’s (PwP’s) and their loved ones. Today, it’s known as Parkinson’s International - Never Give Up (PINGU).

**Alyson Blanks (Australia):** Alyson is an Exercise Physiologist and has lived in Sydney Australia most of her life. She is a mother of two, and a carer for two 90 year old’s and works for Parkinson’s New South Wales.

Alyson first became involved with Parkinson’s New South Wales (NSW) when a client, who had Parkinson’s, came to her for an exercise program. Alyson has now worked at Parkinson’s NSW for 5 years and is currently designing and implementing an exercise initiative, to be delivered all across New South Wales, to compliment the suite of support services offered by Parkinson’s NSW.
Alyson became involved with WPC when organising a group of Parkinson’s NSW delegates to attend the Portland Oregon WPC in 2016. She is very excited to again be involved with WPC in Kyoto.

**Sukhee So (United States):** Sukhee So is a physical therapist living in Portland, Oregon (USA). She has a passion working with people with Parkinson’s Disease both in the clinic and with the Parkinson’s Resources of Oregon (PRO) in her town. She truly believes the importance of movement based activities and incorporates this with the people she works with on a regular basis. When she can, Sukhee also enjoys competing in triathlons and traveling, and looks forward to participating in the 2019 WPC in Kyoto!

**Ginette Trottier (Canada):** I was first exposed to Parkinson’s disease almost 15 years ago with a cousin who had Parkinson's disease. As my career grew in the health field, I got to know and work with a multitude of people living with PD. I joined the Parkinson Canada team in 2010 and have been inspired ever since. I had the opportunity to attend WPC 2013 in Montreal and WPC 2016 in Portland. The experiences were amazing and I look forward to meeting new people and learning new developments in PD treatments and research in Kyoto next year. In my spare time I enjoying rescuing cats and give them a better life.

**Philip Bungay (United Kingdom):** from Rochester, Kent, England is the lead coordinator for the Parkinson’s UK Medway Working Age Group, Co-chair of the Medway Neurological Network and a member of the Young Parkinson’s Alliance, which is hosted by Parkinson's UK and is an umbrella group for several different Parkinson’s charities in the UK for PwPs who were diagnosed with Parkinson’s at 45.