Dear WPC friends,

I had the recent pleasure of visiting Kyoto for the World Congress of Neurology where I met with many of the 8,000 delegates, mostly neurologists, to share details of the 5th World Parkinson Congress. Their meeting was held in the same venue where the WPC 2019 will be held so our team spent time walking the pavement, exploring the rooms, and working out details to ensure the WPC delegates' experience will be as rich and as memorable as it should be. As the first WPC to take place in Asia, we look forward to the powerful impact the 5th World Parkinson Congress will have on the Parkinson's community in Japan and across the region. If you haven't already started making plans to be with us in Kyoto, please start thinking now about your plans and how you might be able to inspire others from your community to attend with you.

The WPC blog has had some exciting posts this month. Leading patient advocates, Andy McDowell and Dr. Julio Angulo, shared insights on the preparations people with Parkinson's need to make for the challenges that lie ahead, and the acceptance when the end goal isn't reached. Andy's message of having a "Plan B", and accepting Plan B when needed, really resonated. Julio's post on dealing with shame was touching and powerful. It included tips for addressing shame and moving through this emotion to a healthier place in life.

Professor Andrew Lees' post highlighted his desire for doctors to maintain a "curiosity to answer with more precision the questions every doctor is asked by patients and to acknowledge that patients can inspire valid research through their own observation." His understanding of how researchers can find inspiration
outside of their field offered a fresh perspective to the community. We love that the proceeds from his new book are going to The Cure Parkinson Trust.

Dr. Jeffrey Kordower and Dr. Patrik Brundin's response to the recent FDA decision to crack down on unscrupulous stem cell clinics in the USA brought attention to the critical issue of clinics delivering stem cell therapies that are potentially dangerous to patients. Their post opened the eyes of our readers to the risks associated with these stem cell therapies. Stay vigilant in where you get your information!

As we in the northern hemisphere head into the fall season and pull out our quilts and warm hats, our friends in the global south are entering their spring and warmer days. Wherever you call home and whatever season you are experiencing, we are all connected in this Parkinson's space, you are not alone! Have a great month and be sure to watch for our new exciting blog posts and our upcoming details on the WPC 2019 Video Competition.

We hope you'll join us in Kyoto!

Kind regards,

Elizabeth "Eli" Pollard
Executive Director

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**WPC Blog Highlight**

*Advice For Those With A Curiosity To Find A Cure For The Shaking Palsy*

by A.J. Lees MD, FRCP, FMedSci
Between 1958 and 1964 the BBC broadcasted a television documentary called Your Life in their Hands. It was the first time in the United Kingdom that cameras had been taken into the operating theatre and the programme became popular prime time viewing. There was one particular episode that I filed subconsciously in my brain attic. The presenter Doctor Charles Fletcher began by informing the viewers that Parkinson’s disease was a fatal degenerative brain disease of unknown cause and for which no medical remedy had been found. A new surgical treatment called thalamotomy had recently changed the outlook for many patients although it was far from a cure. He then introduced a sixty-year-old bank clerk who the brain surgeons considered a suitable case for treatment. Mr S had been forced to retire from his work because of an intrusive trembling of his right hand.

With Mr S sedated but still conscious a vital probe was inserted deep into his brain through a metal frame that had been attached to his cranium. Once the desired target had been reached and a few thousand brain cells cooked his shaking had stopped abruptly. Further footage then showed the relieved man demonstrating to his doctor how he could hold a spoon in his hand and feed himself for the first time in years.

Ten years later I made my first acquaintance with William Seward Burroughs. The hard man of hip agreed to allow me to qualify as a doctor provided I listened closely to what he had to say about the medical profession, universities, governments and the pharmaceutical business.

I used L-DOPA for the first time in 1970. Within two weeks my patient could walk again. It was a magic moment and it was at that time that the Your Life in Their Hands episode rose to the surface. The shaking palsy was now associated with the supernatural. How was it possible that making a hole in the head or administering an innocuous amino acid present in broad beans could lead to such miracles?

By the time I began my quest to find better remedies for Parkinson’s disease it was no longer considered a death sentence but L-DOPA had proved to be no panacea. I had not forgotten my Faustian pact with Burroughs and continued to read his books and letters.

Burroughs taught me to be open-minded and non-judgemental and run with what life threw my way. He looked at the literature in a slanted and unusual way and helped me to read between the lines.
Those of you who have attended previous World Parkinson Congresses understand the magic that comes from having thousands of people whose lives are deeply connected with Parkinson's disease together in the same place. Some of you reading this newsletter have not yet attended a World Parkinson Congress, but you understand the importance of a scientific conference where people with Parkinson's (PwP) are involved at every level of the event.

Word of mouth is the most powerful tool that we have to convince people that the triennial WPC should be added to their calendar. This is where we need YOUR help in making the fifth World Parkinson Congress a success.

- If you are a PwP, encourage your neurologist, doctor, or anyone involved to your care to attend the congress. Health professionals and researchers are invited to many congresses each year. If your doctor is unable to go, encourage her/him to send a junior member of their staff. Explain that as a person living with the

The following is the abstract submitted by David Burn FRCP, MD, MA, MB BS for the WPC 2016

Up to 40% of people with early Parkinson’s (PD) will display cognitive deficits on formal testing, but in a majority these deficits have little impact upon activities of daily living. “Mild cognitive impairment (MCI)” associated with PD affects different cognitive domains (e.g. memory, attention, visuospatial function). PD-MCI affects quality of life in the person with PD and their carers. Attentional impairments may be most important in determining poorer quality of life. The pathophysiological substrate underpinning the early cognitive deficits in PD is varied both neurochemically and neuropathologically. Cognitive deficits mediated by dopaminergic dysfunction (particularly via the caudate nucleus) are common but may not necessarily predict cognitive decline. The role of norepinephrine is yet to fully established, but is likely to be important in mediating attentional function. Perhaps the most “malignant” substrate relates to cholinergic deficiency, which is also a key player in the symptoms of dementia associated with PD. Progression to dementia in PD is by
disease, it is important to you that they attend the WPC.

- If you are a clinician or researcher, and you cannot attend yourself, please send your junior staff member(s) to the congress. Help inspire the next generation to research and treat Parkinson's.

- We will be accepting abstracts starting on July 9th, 2018. Those involved in research, education, or advocacy related to PD are encouraged to submit an abstract. Clinician and researchers should apply and encourage their junior staff to apply.

- Depending on where you live in the world, getting to the congress can be expensive. If you are planning to attend, it is a good idea to start putting aside money now. For those of you interested in making a bigger impact, build a delegation from your area including PwP and a mix of local healthcare providers and start fundraising to send your group to the WPC. Your group can then bring what they learned back to your community and better serve people living with Parkinson's disease.

Thank you for helping us spread the word! Email info@worldpdcoalition.org to request some brochures and/or a poster to hang in your local clinic.

no means inevitable, but occurs around six times more commonly than in age-matched people without PD. Current age is the biggest risk factor for dementia in PD, but other factors, including motor phenotype and genotypic background are also involved. Research has focused upon phenotypic, “wet” (e.g. cerebrospinal fluid, CSF) and “dry” (e.g. neuroimaging) biomarkers that may more accurately predict and monitor cognitive decline in people with PD. Although progress has been made there remain issues with regard to predictive value in the individual subject, rather than in a group setting, as well as the availability (and to some degree acceptability) of some investigations. From the phenotypic perspective, a postural instability-gait difficulty motor pattern, autonomic dysfunction and presence of REM Sleep Behaviour Disorder appear to predict cognitive decline. Low levels CSF beta-amyloid, above median retention of 11C-PIB on PET scanning, and reduced inhibition of short-latency afferent inhibition, amongst others, may all indicate a greater likelihood of dementia. Future research should focus upon establishing more robust biomarkers that may be applied widely, with high levels of acceptability. Ultimately, identifying individuals at high risk of dementia will allow earlier and more focused use of disease-modifying treatments.

Download The Slides Here
Where's Parky?

Parky the Raccoon joined WPC 2019 Ambassador Alejandra Borunda at the Polynesian Cultural Gala to fundraise for the annual PD walk in support of the Muhammad Ali Parkinson Center in Phoenix, AZ.
All profits from the sale of Parky the Raccoon are used to fund the WPC Travel Grant Program to bring junior researchers, junior clinicians and people with Parkinson's to the 5th World Parkinson Congress. Visit the [Where Is Parky website](https://www.worldparkinson.org/where-is-parky) to learn more about our mascot.

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