Dear WPC friends,

Happy New Year! We at the WPC are constantly reminded that the work we do, bringing the community together, has powerful results. We hear from scientists who are moved by their WPC experience and have found ways to include people with Parkinson’s in their trial design, we hear from people with Parkinson’s about how their WPC experience gave them hope and inspired them to do big things in their communities. (See our recent blog post by Elisabeth Ildal in Denmark who ran for her local political office, and won, despite her Parkinson’s). Our very own Sara Riggare and Jon Stamford, both past WPC Ambassadors, wrote a response blog post to the November article in JAMA about Parkinson’s being a pandemic. Sara and Jon’s post got the community fired up and reminded others that people with Parkinson’s are helping to move the dial on Parkinson’s research and care, well beyond just raising money for clinical trials.

We recently sent out the WPC 2019 Sponsor & Exhibitor prospectus. As we gear up for fundraising to make the 5th World Parkinson Congress as amazing as the past four WPCs, people often ask us, “If I am not working at a company, how can I
help?” While the support we get from the pharma industry and our non-profit supporters is paramount to the success of the WPC, individuals who believe in the WPC can make a difference in a few simple ways:

1. Add a WPC graphic to your email signature (Download images here.)
2. Request brochures and posters to give out at your support group / local PD events. Email: info@worldpdcoalition.org for materials.
3. Start a fundraiser in your own community to build a local delegation for WPC 2019
4. **Sponsor a junior researcher/ junior clinician/ person with Parkinson’s to attend WPC 2019.** Even a donation of $25 will help get a future leader to the WPC. The travel grant recipient you help fund, may be the one who unlocks the mystery to Parkinson’s. Help a young person get to the WPC, make sure they stay inspired by the Parkinson’s community so they continue working with us until a cure is found.

If you do work with a company that would like to support the WPC 2019, thank you for supporting our work. Don’t wait to find the right sponsorship item for your company. Many items in the prospectus are offered to just one sponsor exclusively, such as the opportunity to support the www.WPC2019.org website, allowing your company prime real-estate in front of thousands of visitors to our website starting now through 2019. **Check out pg. 27 for details.**

As we launch into 2018, we look forward to a good year, one with success in scientific research, a strong advocacy movement across the global landscape, and a year when people with Parkinson’s and their families get top-notch care in order to live their best.

Warm regards,

Elizabeth "Eli" Pollard
Executive Director
Patient Advocates Respond to the PD Pandemic

by Sara Riggare, MSc, PhD candidate and Jon Stamford, BSc, PhD, DSc

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

The call to the PD community to speak up is appreciated and as patient advocates as well as researchers living with the condition, we think the article is both timely and well argued.

When it comes to the silence of the PD community, the irony is not lost on us that this article is published behind a paywall, thus not allowing it to reach the intended audience. We strongly recommend always publishing open access, including viewpoints and opinion pieces but especially research reports. Patients cannot engage in research we are not aware of and few patients have access to publications behind paywalls.

Furthermore, the lack of action perceived by the authors can in part be explained by aspects of PD itself. One of the main effects of the condition, apart from the motor symptoms, which of course makes action physically more challenging, is the debilitating anhedonia and apathy.
The comparison with the work of the HIV/AIDS community is an interesting one and well worth building on. But where HIV/AIDS was a new and deadly disease, PD has been known for centuries as a slowly progressing disease mainly associated with the elderly. Possibly as a result of a highly politicized demographic, the cause and disease mechanisms for HIV/AIDS were identified in a short time, whereas the cause and disease mechanisms of PD have, except in the broader sense, eluded detection, perhaps reflecting the lack of urgency alluded to by the authors.

Nevertheless, we would argue that PD advocacy has made significant progress, despite these challenges. Notable examples include the work of Elizabeth “Eli” Pollard of the US-based World Parkinson Coalition (WPC) in bringing all stakeholders of the PD community together, including physicians, neuroscientists, a broad range of other health professionals, care partners, and people with PD. Pollard identifies the real successes of that effort as being: “(1) the involvement of people with Parkinson’s in research and educational agendas, (2) the evolution of interdisciplinary care, and (3) embracing self-care”. We would encourage everyone involved in PD research, from basic science to clinical practice, to attend the WPC. It is likely to have an impact on the quality of the research being conducted as well as improving the knowledge of important research in a wider community. This is patient advocacy at its most incisive, decisive and constructive.

Of course, advocacy is only of value if translated into action. An example of the results of PD advocacy is the innovative Linked Clinical Trials program designed for the repurposing of drugs 5. This model, which incidentally can be applied to a wide range of conditions, was developed to identify drugs developed for different conditions, that had potential interest for modifying the progression of PD. The program was spearheaded by the late Tom Isaacs, patient advocate and founder of the Cure Parkinson’s Trust. This is not idle theorizing but a practical and potent example of how patient advocacy can lead an international drug development program.

Read The Rest Here . . .
Sponsor The 5th World Parkinson Congress!

As a subscriber to the WPC eNews, you already know that the World Parkinson Congress is the only high level scientific congress that brings the entire Parkinson community together under one roof. The triennial congresses provide the only opportunity for the whole Parkinson community to learn about the latest developments in the field and to network with each other over four powerful days.

Why wait to sponsor the upcoming WPC 2019? There are exciting exclusive sponsorship items, meaning once they are gone, that's it!

Download the full prospectus here.

Sponsor the WPC 2019 Video Competition

With over 250 past video submissions and more than 500,000 YouTube views, the WPC Video Competition is unprecedented in its ability to raise awareness of PD through story telling. Sponsor this unique item and get your company recognized globally through out the Parkinson's community.

Learn more on page 16 of the WPC Prospectus

Sponsor the WPC Podcast Program

The countdown to WPC 2019 will be aided by the WPC Parkinson Podcast Program, a lively and intelligent podcast series to launch in June 2018 and run monthly until WPC 2019. This is a follow up program to the wildly successful WPC 2016 Countdown podcast program that attracted nearly 28,000 listeners and continues to attract subscribers today.

Learn more on page 17 of the WPC Prospectus
What Form(s) of Alpha-Synuclein is Transmitted from Cell to Cell? Evidence from Animal Models

by Veerle Baekelandt, PhD

Misfolded protein aggregates represent a continuum with overlapping features in neurodegenerative diseases, but differences in protein components and affected brain regions. The recent discovery of the transmissible nature of amyloidogenic proteins suggests a hypothesis of a pathogenic trigger which might spread throughout the nervous system underlying the progression of the disease. Furthermore, evidence is emerging that these protein aggregates can adopt distinct conformations or ‘strains’ with remarkable differences in structural and phenotypic traits. Alpha-Synuclein aggregation is considered to play a central role in multiple neurodegenerative diseases, such as Parkinson’s disease (PD), Multiple System Atrophy (MSA) and Dementia with Lewy Bodies (DLB). These synucleinopathies are determined by the deposition of Alpha-synuclein aggregates but segregate in distinct pathological phenotypes and diagnostic criteria. Alpha-Synuclein is recently shown to aggregate into different polymorphs or ‘strains’.
This has led to the hypothesis that strains might account for the distinct clinicopathological traits within synucleinopathies. We have shown that alpha-synuclein strain conformation and seeding propensity lead to distinct histopathological and behavioural phenotypes. We assessed the properties of structurally well-defined alpha-synuclein assemblies (oligomers, ribbons and fibrils) after injection in rat brain. We proved that alpha-synuclein strains amplify in vivo. Fibrils seemed to be the major toxic strain, resulting in progressive motor impairment and cell death, whereas ribbons caused a distinct histopathological phenotype displaying Parkinson’s disease and multiple system atrophy traits. Additionally, we showed that alpha-synuclein assemblies cross the blood–brain barrier and distribute to the central nervous system after intravenous injection. Our results demonstrate that distinct alpha-synuclein strains display differential seeding capacities, inducing strain-specific pathology and neurotoxic phenotypes. These distinctive neurotoxic and pathological prion-like effects of alpha-synuclein strains might provide a basis for the heterogeneity observed in synucleinopathies and open new therapeutic opportunities such as targeting the degradation of alpha-synuclein higher molecular weight species.
Video is a great way to capture and share the power of science, hope, humor, and inspiration. It's also a great way to encourage discourse about a disease that is often misunderstood. We launched the first video competition for the WPC 2010 and were overwhelmed by its success. The competition has grown significantly and draws a great number of submissions as well as YouTube views. View past submissions on our YouTube Channel.

The WPC 2019 invites ALL members of the global Parkinson’s disease community to make a video for the WPC 2019 Video Competition about their experiences living with, treating, researching or caring for people with Parkinson's. While it's early, submission for the competition opens July 9, 2018. We wanted to get this on your calendar, so you can start thinking about what you will submit.

Read more about the video competition here
Where's Parky?

Parky and WPC 2019 Ambassador, Cherry Vogt-Ward, on their way to speak at the University of the West Indies at Barbados.

Getting Kyoto Parkinson's Ready

Kyoto Mayor Daisaku Kadokawa greeted WPC Executive Director, Eli Pollard, and WPC Local Organizing Co-chairs, Professors Nobu Hattori and Ryosuke Takahashi in Kyoto in late November.
Spilberg at Victoria Falls in Zimbabwe.
See all the places that Parky has been on [whereisparky.org](http://whereisparky.org).

By ordering your own Parky, you are supporting the WPC Travel Grants Fund for the next World Parkinson Congress. 100% of the profit is used to bring junior researchers, junior clinicians, and people with Parkinson’s to the 5th World Parkinson Congress.

**Order Your Own Parky Here**

**Share Your Parky Photo Here**

The Mayor was excited to hear about the Fifth World Parkinson Congress and our plans for making Kyoto "Parkinson's Ready". He also liked our WPC 2019 baseball hat and welcomed Parky the Raccoon with a big smile.

Useful Links

- View online version
- Forward to Friends

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