

May 3, 2017



*Bringing the Parkinson's Community Together*

*Save the Date!*

**JUNE  
4-7, 2019**



Dear friends,

As we wrap up our activities from the Parkinson Awareness Month in April, it's great to reflect on all the amazing things that we saw happening in the community and in our own office.

We launched the new [WPC Blog](#) with posts by a number of leaders in the field, including Dr. Fahn, our founder, and Tom Isaacs, one of the recipients of the WPC Award in Portland last year. This month I am excited to share that blog posts will cover topics such as the exciting research being done by Dr. Ted Dawson on the c-Abl protein and Dr. Ray Chaudhuri on personalized medicine. We'll also hear from Dr. Richard Smeyne who will update us on the work he presented on at the WPC 2016 on viruses and Parkinson's. Keep the link to our blog handy, you'll want to stay on top of these inspiring weekly posts!

I had the pleasure of visiting Japan in the month of April, to meet members of the Local Organizing Committee and attend the 2nd Japan Parkinson Congress. Leaders in the Parkinson's community were so inspired by the WPC 2013 in Montreal, that they returned to Japan and launched their own Japan-based WPC called the Japan Parkinson Congress, or JPC, in 2015. They host this meeting bi-annually and it was so exciting to see the meeting last month with a diverse audience of around 800 people from across Japan. My dream would be for every leading national organization to launch their own domestic version of the WPC. Why wait three years for the WPC to occur when you can start making it happen in your country today?

We have new marketing materials for the WPC 2019. If you'd like brochures or posters for your clinic, support group, or upcoming meeting, write to [info@worldpdcoalition.org](mailto:info@worldpdcoalition.org) and let us know how we can help you.

As always, thank you for your support.

Kind regards,

Elizabeth "Eli" Pollard  
Executive Director

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## **A Look Back at WPC 2016:**

# What can you do with this information and what will it do to you?

*Presented by Dr. Jason Karlawish*



During the WPC 2016 Dr. Jason Karlawish spoke at the Thursday morning plenary, "*Genes and Mechanisms of Sporadic PD.*" During his lecture, he spoke about the discovery of biomarkers and ethical challenges for clinical trial participants in what to do with the information they learn during their clinical trial, and

what it all means for them. Balancing a desire to contribute to science, but also protecting one's own data from other, can be a complex and complicated decision-making process for clinical trial participants. Read about his talk below, and then watch his presentation via the WPC 2016 webcast program.

The definition of sporadic PD has historically been grounded on the solid foundation of a clinical disorder defined by signs and symptoms such as troubles walking, a tremor and a response to dopamine replacement therapy. The discovery of the genes and mechanisms, also called biomarkers, of sporadic PD are remodeling this foundation. Researchers are creating a new definition grounded in the presence of genes or biomarkers and their response to a drug intervention. This definition is essential to develop method to prevent PD. Progress to achieve this presents patients both short and long term challenges. Short term challenges engage matters of research ethics. Studies that enroll persons on the basis of their genetic or biomarker profiles present potential subjects an ethical dilemma over whether to enroll in the study. If they enroll, they will advance progress in diagnostics and therapeutics but learning gene or biomarker information may be harmful. If they don't enroll they will avoid leaning this information but also not help to advance the field. Making this decision engages values about risk tolerance and also understanding how this information may affect an individual's affective and neuropsychological function. Long term challenges include how society interprets this new model of sporadic PD. Interpretations will shape how patients experience their diagnosis. They may, for example, find the information threatening to relationships and therefore information they choose to keep private from family and friends. They may also experience changes in how they perceive themselves and their abilities. Other challenges of a biomarker-based diagnosis in an otherwise asymptomatic person include the way people and society responds to the person, causing, for example, discrimination in the workplace or insurance, and changes in social interactions

**[Watch Dr. Karlawish's presentation from the WPC 2016](#)**

*WPC 2016 webcast made possible with support from Biogen.*

## WPC Blog Highlight



*The following is an excerpt from **Dr. Tiago Fleming Outiero's** [WPC Blog](#) post.*

For the past few years we have been studying how the age-associated process of glycation (the chemical reaction of sugar molecules with proteins) affects the

## Meet the NEW WPC Blogger Partners



Meet our new WPC Blogger Partners. Each of them brings their unique perspective on how to navigate life with Parkinson's disease. We look forward to working with this outstanding group of community bloggers who hail from seven countries.

- [Allison Toepperwein](#)
- [Sharon Kischer](#)
- [Mariette Robijn](#)

aggregation and toxicity of one of the central players in Parkinson's disease (PD), the [alpha-synuclein](#) protein. Glycation is an unavoidable process, a bit like "rusting", since it happens spontaneously, once the levels of the glycating agents are high enough, and the targets of glycation (e.g. proteins) are in the vicinity. Neuronal cells in our brains are highly dependent on the enzymatic breakdown and metabolism of glucose for energy. Alpha-synuclein is a long-lived protein, and is known to accumulate in insoluble deposits in the brains of patients with PD and other similar disorders. The close proximity of the glucose the brain uses for energy and the alpha-synuclein protein, create an environment where glycation may happen easily.

- [Benjamin Stecher](#)
- [Elisabeth Ildal](#)
- [Tamami Nose](#)
- [Kirk Hall](#)
- [Allison Smith](#)
- [Heather Kennedy](#)
- [Joe Lacy](#)
- [Debbie Shapiro](#)
- [Bruce Ballard](#)
- [Brian Lowe](#)
- [Gary Ballenger](#)
- [Natasha McCarthy](#)
- [Tim Hague](#)



[READ THE FULL POST](#)

**Help Build the  
WPC 2019 Program**

**Where is Parky?**

Eli Pollard. WPC Executive Director traveled



As we prepare for the 5th World Parkinson Congress, we want to know what type of sessions you would like to see.

The WPC program is designed BY the community FOR the community. In the link below you will have the opportunity to suggest a session title, speaker(s), and learning objectives. As you can imagine, the process is complex, but your input as a community member is paramount to the success of designing a great program.

**Ideas may be typed directly into our system OR uploaded in a word document.** Visit the link to download the template.

We look forward to your suggestions.

Recently, the Executive Director traveled with Parky the Raccoon to Japan to prepare for the 5th World Parkinson Congress. She met members of the Local Organizing Committee who are eager to welcome the Parkinson's world to Kyoto in June 2019.



**ORDER YOUR OWN PARKY**  
**& SHARE YOUR PICTURE**  
**See all of the places that Parky has**

## MAKE PROGRAM SUGGESTIONS

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