

June 6, 2017



*Bringing the Parkinson's
Community Together*

*Save
the Date!*

**JUNE
4-7, 2019**



Dear WPC friends,

Our dear friend, and perhaps one of the world's leading patient advocates in the Parkinson's space, Tom Isaacs, passed away suddenly on Wednesday, June 1. Tom was just 49, and had lived with Parkinson's for 22 years, never letting it slow his work or drive. He founded The Cure

Parkinson's Trust, Parkinson's Movement, and participated vigorously in every single World Parkinson Congress since we launched them in 2006.

We were devastated by the news. You can read our full memorial about Tom [HERE](#) and you can read our blog post highlighting our favorite memories of Tom [HERE](#). Tom was hugely impactful with everything he did. He was a leader in the community and a big friend of the WPC. Tom wrote one of our first blog posts this year about the WPC and the influence it had on him personally and how he felt the WPC impacted the community. While he loved the WPC and often [recognized our work](#), we equally adored Tom and were grateful for his tireless effort to lift up the WPC and to recognize our service to the community. The respect and love was mutual and we are heartbroken by the news of his passing.

One thing is for sure, Tom would not want us to stop our work or efforts to find the elusive cure to Parkinson's or to slow our efforts to empower and engage the millions of people living with PD today. He would most likely say, "get on with it, there's work to be done."

So with great sadness, we will "get on with it" and we will keep our eyes on the goal and keep moving forward with Tom's laughter in our ear and his footprints across our hearts. If you missed the award ceremony honoring Tom at the WPC 2016, watch it [HERE](#) by registering for free to view our videos, look for the Friday 9AM video of Tom getting his award. If you missed Tom's singing performance at the WPC 2016 closing ceremony, watch it [HERE](#).

As we start our two year countdown to the WPC 2019, start thinking about how you will get yourself to Kyoto. Two years flies by, but it's enough time to make a plan to be with us in Kyoto for an inspiring program offered in one of the most beautiful cities in the world. We owe it to ourselves, and to Tom, to gather in Kyoto to show the world we are moving forward, and keeping our focus on improving treatment options and finding a cure. Tom would expect nothing less and would be the first one with the microphone in his hand ready to sing a new song and make us laugh.

See you in Kyoto.

Kind regards,

Eli



Robin Elliott at the closing game show held at the WPC 2010, hosted by Tom Isaacs & The Cure Parkinson Trust.

WPC Robin A. Elliott Award to be offered at future World Parkinson Congresses

Robin A. Elliott, CEO Emeritus of the Parkinson's Foundation, (formed by the merger of the National Parkinson Foundation and Parkinson's Disease Foundation (PDF) in summer of 2016) led PDF from 1996 to 2016. Over the past 20 years, Robin has been recognized as a leader in the Parkinson's community and lucky for us, he helped to launch the first World Parkinson Congresses by hiring our initial staff and giving us space to work.

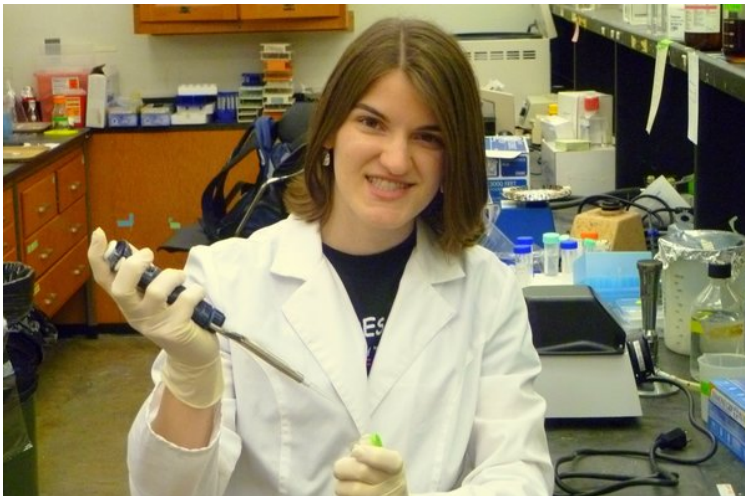
To honor Robin's incredible service to the community, the WPC Board of Directors has unanimously decided to create a new award named the **WPC Robin A. Elliott Award** to be offered at the next World Parkinson Congress and all future WPCs.

The **WPC Robin A. Elliott Award** will be offered to one person every three years at each Congress who embodies community service, commitment to supporting scientific research, and support of training junior clinicians and health professionals. This award honors Robin's tremendous work to better the lives of people with PD and to support the research and medical community, which will lead us to a cure one day.

Robin's fierce drive and dedication has inspired so many of us and to acknowledge and honor his service, we are proud to announce the new **WPC Robin A. Elliott Award**.

[Read Robin's Post for the WPC Blog here.](#)

WPC Blog Highlight



*The following is an excerpt from **Madelyn's [WPC Blog](#)** post.*

A Look Back at WPC 2016: Gait Dysfunction in Early PD and Implications for Treatment?



*The following is a summary of the abstract submitted by **Sue Lord, PhD** for the WPC 2016*

From a treatment standpoint, Parkinson's disease (PD) presents a distinct problem. Most patients are diagnosed when classic motor symptoms, like a resting tremor appear, but these symptoms don't manifest until much of the dopamine-producing neuron function in the brain has already been lost. This means that the degeneration in the brain has been progressing for a long time, sometimes decades, before the disease is diagnosed and treatment can begin. It's a "tip-of-the-iceberg" problem, where we're only treating the advanced stage of the disease that we can see. To complicate matters further, our current treatments for PD mitigate the symptoms but don't stop the actual disease progression. While there are therapies, medications, and activities that can greatly improve quality of life for people with Parkinson's (PwP), we are still left with a situation in which we don't know for sure what initially causes the degeneration to start, we don't start treating it until much of the damage has already been done, and we don't know how to stop the progression of neurodegeneration once it's underway.

The underpinnings of gait dysfunction can be motor (including visual), cognitive, and/or affective (having to do with mood or emotion.) Knowledge of gait dysfunction in early Parkinson's disease has been refined in recent years in two of these areas. The first is greater awareness of the role of non-motor aspects (principally cognition) to gait and how these influence performance. The second is through measurement of discrete gait characteristics, which allows a more nuanced approach to understanding the neural basis to gait deficit and the mechanisms that drive it. Advances in both fields influence treatment and help inform disease trajectory.

For example, some features of gait, such as step hypokinesia, respond to medication, which is the primary therapy of choice in the early stages of PD, whilst others (such as gait characteristics associated with posture control) are not responsive to medication. Similarly, physical therapy has a selective impact on gait. Understanding the non-motor and motor aspects of early gait disturbance, their change over time, and their response to treatment is important to optimize outcome.

Cognitive-based physical therapy (eg movement strategy training and cue-based

On one hand, this “tip-of-the-iceberg” problem is frustrating, but on the other, it provides an incredible opportunity for developing different and better ways to treat Parkinson’s. If the motor symptoms are only one manifestation of the disease, and a late one at that, that means there are a lot of other aspects of it that could serve as alternative and hopefully early warning signs and could also potentially offer researchers clues as to what is driving the disease pathology. Some of the non-motor manifestations of PD, such as constipation, changes in intestinal bacterial populations, and indicators of inflammation measured in the blood have led researchers to speculate that PD may not actually begin in the brain at all, but may progress from the gut or other peripheral systems to the brain.

[READ THE FULL POST](#)

interventions) is effective but may be time-limited due to cognitive decline or because motor deficit becomes too great. Of further interest is the role of secondary features that arise from reduced mobility (such as attenuated muscle strength and loss of aerobic conditioning), which is an early and persistent feature of PD. Targeting primary and secondary features of gait disturbance is critical.

[VIEW THE SLIDES FROM HER PRESENTATION HERE](#)

**Help Build the
WPC 2019 Program**

Where is Parky?



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 always 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.



Betsy Seidel from Hoquian, Washington, USA shared her photo and story with us:

"Parky is here with our seven month old grandson, Arhaan Mina. My husband and I really enjoyed WPC 2016. I volunteered all days, and Bob volunteered and attended sessions. We brought home a Parky for one of our Grays Harbor Support Group members who wasn't able to attend (after she had registered) because she fell and broke her hip right before WPC. We also brought home a Parky for Arhaan, who loves the soft toy. Here is Arhaan wearing his "Parky hat" and playing with Parky."

ORDER YOUR OWN PARKY
& SHARE YOUR PICTURE

We look forward to your suggestions.

See all of the places that Parky has been at whereisparky.org

[MAKE PROGRAM SUGGESTIONS](#)

UPCOMING EVENTS



Ho Chi Minh City, Vietnam
12 - 15 NOVEMBER 2017

XXI World Congress on Parkinson's Disease and Related Disorders

[Learn more about the event and the International Association of Parkinsonism and Related Disorders here](#)



The Brian Grant Foundation is hosting a wellness retreat in Troutdale, Oregon

When: Sunday June 25th
from 10:00 AM to 3:30 PM

Where: Yoshida's Garden
View Estate
29330 Southeast Stark
Street

[Learn more and register here](#)

Useful Links

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