



Dear friends,

Just last year, a mere seven months ago, we held the WPC 2019 in Kyoto, Japan. It's always fun and rewarding to see what happens after each WPC, to learn about the [articles](#), programs, projects and research that comes OUT of each gathering of the community. The theme we are seeing this month from the WPC is definitely Young Onset Parkinson's disease (YOPD). Because of conversations at the WPC 2019 we have seen plans emerge for genetic studies around YOPD, plans emerge for an [international YOPD event in UK in April called PDVision2020](#), designed and lead by people living with YOPD, and the exciting launch of a YOPD Fundraiser to raise money for travel grants to support more YOPD to attend the WPC 2022. The WPC YOPD Facebook fundraiser is off to a great start. The goal is to raise \$50,000 by the end of the year that we can give out to YOPD friends to support their journey to Barcelona in 2022. Even if you are not on Facebook, [you can support this PwP led campaign through the WPC website](#) or even pledge to match the funds raised by one or more of the fundraisers. Help us send more YOPD to Barcelona!

While we are busy building out the Program Committee and raising funds, the WPC 2022 Local Organizing Committee (LoC) in Barcelona is working out their plans to ensure the biggest turnout at a WPC yet and to make sure the Spanish speaking communities across the globe show up! LoC Co-chairs, Dr. Eduardo Tolosa and Dr. Miquel Vila invite you to Barcelona. Read their welcome letter in [English](#) or [Spanish](#) and be sure to save the date now on your calendar.

Did the WPC change your research focus? Open doors for you that were previously closed? Lead you to a new collaboration? Tell us about it and we might write up your story in our [World Parkinson Connections](#) section of our blog.

Kind regards,

*EAPollard*

Elizabeth "Eli" Pollard  
Executive Director

#### WPC Blog Highlight

##### Interpersonal, Intrapersonal, and Organizational Intersections: A Socio-Ecological Discussion of Adapted Tango Dance for People with Parkinson's Disease

by Madeleine E. Hackney, PhD with Allison Bay, MPH

##### Introduction:

**Adapted Argentine tango (adapted tango) has been shown to be effective at improving motor, cognitive and psychosocial function in individuals with mild-moderate Parkinson's disease in several studies over the last decade.**

Adapted tango is a powerful form of therapy because it integrates traditional exercise content with social dance. Engaging and fun, social dance is acceptable across cultures and may address intrapersonal, interpersonal and organizational spheres. Historically, health interventions have had single-level targets focused on intrapersonal factors and largely resulted in improvements for only short durations. As societal norms and environmental contexts influence behavior, leveraging interpersonal, intrapersonal, and organizational levels of participants' socio-ecological realms can increase an intervention's impact.

##### The Interpersonal Level:

Relationship-related goals are important to older adults. The World Health Organization's International Classification of Functioning, Disability and Health emphasizes social participation among individuals with mobility and other challenges. An individual's functioning and participation in activities is an interplay between health condition, environment, and personal contextual factors. The caregiver/care recipient dynamic influences the person with PD, and the physical and psychological health of the caregiver.

Adapted tango may help people with PD re-attain and retain healthy relationships with family. Social dance benefits may extend to caregivers of people with PD by reducing stress and its downstream physiologic correlates, and re-establishing connections with loved ones.

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#### Young Onset PD Advocates Support WPC

A group of people with YOPD (Young Onset Parkinson's Disease) at the 5th World Parkinson Congress spontaneously came together to discuss issues unique to those with YOPD such as working with PD, raising young families or taking care of elderly parents while living with PD.

Two of the people who attended that meeting, Larry Gifford (Canada) and Rebecca Miller (USA), were inspired afterward to help get more YOPD friends to the next 6th World Parkinson Congress. They felt that their WPC experiences influenced them heavily as advocates and inspired them to live their best lives with YOPD. They wanted others to have that spark and get to experience the WPC. They have planned a special WPC Facebook Travel Grants Fundraiser that will hopefully support at least 40 people with YOPD to attend the WPC 2022.

Larry and Rebecca, along with 24 others from around the world, will host 26 two-week fundraisers back to back starting January 1, 2020 on Facebook through December 31, 2020. Their goal is to help bring more people with YOPD to WPC 2022 in Barcelona. We hope that you will join us in supporting their efforts! If you are not on FB, or prefer to give in other ways, you can donate right through the [WPC website](#) or send in a check to support the WPC Travel Grants program for people with Parkinson's, junior clinicians, junior basic scientists. Your support of this program is valued, no matter the amount you give.

#### Meet the January 2020 Fundraisers, Larry and Heather!



I was diagnosed with Parkinson's at age 45. Since my diagnosis in August 2017, I've launched the podcast "When Life Gives You Parkinson's." Since that time I have had the opportunity to talk to a lot of amazing people and to attend my first World Parkinson Congress. One of the things I have learned is that everyone can do something to help raise funds or awareness of Parkinson's. I decided to start this fundraiser because getting a diagnosis of Parkinson's disease in the prime of your life is a punch in the gut. The more you can connect with people who understand that you are going through, the easier it is to move forward. I'm committed to help bring more people with YOPD to WPC 2022 because they deserve the chance to share their stories and to build connections in the PD community.

My fundraiser will be held from January 1 to 14 on my [Facebook page](#).



The WPC has been dubbed the parkie jamboree, because it unites us with one another and with the researchers and geneticists and companies in support. My entire life I've been searching for my tribe. Always feeling disjointed and apart, the odd one out, and most lonely in a crowd, so it is most healing on a number of levels to just to be accepted as I am. Without this meeting I might've succumbed to crippling depression, or limited the scope of my interactions with PwP in the US alone. In a typical week, I now collaborate with friends in Norway and Sweden and Canada and the UK and Spain and various countries in South America and Africa. I have met people I call friends and family, people whom I adore and cannot wait to see again. I am participating in this fundraiser because I want other people to have this experience.

My fundraiser will be held from January 15 to 28 on my [Facebook page](#).

[Learn More About the Fundraiser](#)

#### WPC 2019 Abstract Highlight

##### How to maintain a good voice for people with PD: A fun vocal exercise

Merrill Tanner  
Glenrose Rehabilitation Hospital, Edmonton, AB, Canada

As a speech language pathologist, voice therapist and singer who works with people with PD, I recommend this simple but effective home exercise at least 2 times per day to help you maintain a strong and healthy voice, in addition to LSVT LOUD® or Speak OUT® exercises.

- You need a straw, a glass ¼ full with water.  
Put your straw in and blow air into the water in the glass. Notice the bubbles that are produced.  
Say "hello" in your normal voice (to see how your voice sounds and feels before the exercise).
1. Now blow into the glass through the straw and make sound at the same time. It might happen right away or you might have fiddle until you can do it.
  2. Prolong a sound as long as you can. Repeat 5 times or more. Check in and say "hello". How does your voice feel? How does it sound?
  3. Slide from low pitch to high pitch as smoothly as possible. Don't skip notes.
  4. Now slide down from high pitch to low pitch.

**WHY DOES IT WORK SO WELL?**  
This exercise is a type of semi-occluded vocal tract (SOVT) exercise. SOVT exercises have been shown to reduce vocal fatigue and vocal cord swelling and train healthy breathing, better resonance and more efficient vocal fold vibration. The lip seal you make with the straw helps your lips pucker which in turn helps to lower your larynx making it easier for the vocal cords to approach each other and vibrate together.

The puckered lips also encourage more forward resonance which makes your voice carry. It also keeps your facial muscles more active and may help reduce flat affect. The straw extends the length of your vocal tube, causing more resistance and making your breathing muscles work harder than you would normally. You also receive visual, auditory and kinesthetic feedback about your voice and breath.

[Download the WPC 2019 Abstract Book](#)

## Parkinson's Community Corner

Contact [info@worldpdcoalition.org](mailto:info@worldpdcoalition.org) about putting your information here.

**IAPRD**  
07-10 June 2020  
Prague, Czech Republic

Abstract submission is now open for #IAPRD2020 World Congress on Parkinson's and Related Disorders in Prague, 7-10 June 2020. Be part of the scientific program! Click [HERE](#) to learn more about abstract submission.

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