

September 8, 2017



*Bringing the Parkinson's
Community Together*



Dear WPC friends,

As we enter the month of September, when many families around the world send their children or grandchildren back to school with excitement, our thoughts are

with our friends and colleagues who live in locations around the world that are being battered by serious hurricanes, mudslides, forest fires, and other treacherous environmental events.

We are keeping our focus on Texas, all of South Asia, West Africa, the western parts of the US dealing with forest fires, and now the Caribbean and Florida, which are facing Hurricane Irma. For our WPC friends who are living and working in these regions, we hope you are safe. We also hope that if you are living with Parkinson's you have the medications you need and the support network around you to help you through these challenging times. If you haven't already done so, be sure to save the phone number of a Help Line for your local or national Parkinson's organization. If you can, stock up with some extra medications, just in case the floods or fires last longer than anticipated and you are unable to get to the pharmacy. Be prepared!

On a lighter note, if you haven't visited the WPC Blog yet, this is a great way to take your mind off floods and fires! This month includes topics on sex and Parkinson's by past WPC presenter, Gila Bronner from Israel, next week we'll post a blog by WPC Video Competition Grand Prize winner, Andy McDowell, and in the middle of the month a post by the most published Parkinson's author on the planet, and WPC 2010 Co-chair, Professor Andrew Lees will go up. Don't miss these great posts! [Sign up to get notified each time we put up a new post.](#) These posts are designed to keep you "in the know" on some key Parkinson's topics and to whet your appetite for the kinds of sessions we will offer at the WPC in Kyoto, Japan in June 2019.

We hope you will be inspired to join us in Kyoto!

Kind regards,

Elizabeth "Eli" Pollard
Executive Director

WPC Blog Highlight

Personal Intimacy and Sexuality in Parkinson's Disease

by Gila Bronner, MPH, MSW



The World Parkinson Congresses have been a special opportunity for me, as a sex therapist. I've been active as a speaker in the second congress in Glasgow, Scotland, the third congress in Montreal, Canada, and the last one in Portland, Oregon. These meetings enable a unique experience: one meets physicians and health professionals, as well as persons with Parkinson's disease (PwP), spouses, partners, and family members. We can communicate ideas during workshops, in roundtable sessions, during breaks and in the challenging

exhibition hall. Frequently, I found myself sharing practical tips how to handle intimate problems and sexual dysfunction. But, more and above all- I've learned a lot from others. Listening to the voices of PwP and their families, while being aware of their sexual difficulties and their coping strategies, enriched my professional world. Some of you talked about creative solutions and your personal ways to protect intimacy and sexual life, when confronted with such a very challenging disease.

Yes, it is not simple to talk about sex. Most people in the world are not relaxed when talking about sex, peculiarly even not with their intimate partners. While talking about sex, we actually invade an uncertain emotional territory. It is so personal and so private, that people prefer to hide or ignore it and act as if it does not exist at all.

Is it really important to discuss sexuality? Well, yes!! As you probably know, physical intimacy and emotional intimacy are essential aspects of wellbeing and general satisfaction from life. This is a basic human need that accompanies our life from birth to death. You probably know the powerful effect of a close hug, when you try to calm a child or a crying baby. The same occurs with adults. We all need to love and be loved, to hug and be hugged, to touch and be touched, to feel close, and to live with affectionate, empathic and caring relationships. When this physical and emotional intimacy exists in our life, we may better accommodate life's challenges and overcome moments of frustration, pain and despair.

So, what is the role of Sex? Problems in sexual activity, known as sexual dysfunction, are common among adults around the world, not only among

people with chronic or progressive disease. For example, approximately 20% of men suffer from premature ejaculation, about half suffer from erectile dysfunction and about one third of the women complain of reduced desire and inability to reach orgasm. Obviously, the frequency of sexual problems increases significantly in the presence of a multi-dimensional disease like PD. The consequences of these sexual problems are feelings of frustration, misery and hopelessness, followed by increased marital tension, ending with a cessation of any physical, relaxing and loving touch. It happens even in couples who care for and love one another.

Quite often, when I meet couples with PD, I'm overwhelmed by the amount of love and care that they have towards one another. However, coping with the disease is so exhausting and strenuous, that they can't continue maintaining their intimate and sexual life anymore. Sometimes, they need a professional session with a health care provider or an expert in couple or sex therapy. Openly discussing intimacy and sexuality may contribute to reducing their stress and improving their relationship. It is enough, just to express to each other their craving for touch or a hug, and how much they miss their intimate and sexual life.

I would like to share with you, PwP and spouses, some tips to improve intimate life:

1. Change your mindset and your approach, when you deal with intimacy and sexuality.

[Read The Rest Here . . .](#)

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Let's Meet In Person!

Highlight from WPC 2016:

The WPC Will Be At The Following Events

Allocating Scarce Resources: Care vs. Cure



Event: [World Congress of Neurology](#)

Date: September 16 - 21, 2017

Location: International Conference Center, Kyoto, Japan

While everyone in the Parkinson's community, from research scientists to clinicians to those living with the disease and their families, is focused on the importance of finding

Center, Kyoto Japan

Who's Going? Elizabeth "Eli"
Pollard,
WPC Executive Director

Event: [Walk & Talk](#)

Date: September 23, 2017

Location: Zug, Switzerland

Who's Going? Cherry Vogt-Ward,
WPC 2019 Ambassador

Event: [NWPF HOPE Conference](#)

Date: October 7, 2017

Location: Bellevue, Washington,
USA

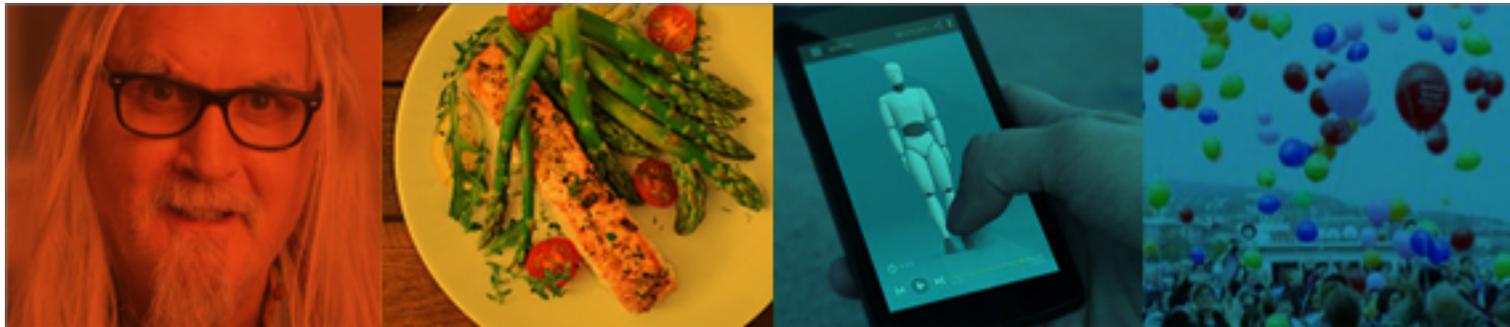
Who's Going? A.C. Woolnough,
WPC 2019 Ambassador

a way to alter disease progression, there's another key question that doesn't receive the same attention: Are we doing enough to provide the best ongoing care options for people with Parkinson's? By "care options" we mean both the need to develop better drugs for symptomatic treatment as well as the need to provide exercise and physical or movement therapy opportunities. It's a key question for anyone who is at mid or late stage disease since disease modifying therapies aren't likely to be on the market any time soon. For these individuals, really good care options, for all practical purposes, are disease modifying. It's understandable that funding disease modifying research has been a priority, but has it come at the expense of developing improved Levodopa delivery systems or providing adequate access to exercise facilities or other therapeutic approaches? This isn't so much a debate over "care vs. cure"

as it is an exploration of what more we can do to make sure the “care” part of the equation isn’t neglected.

[Watch the full presentation on this topic at the WPC 2016 for free by registering here](#)

Have You Seen EPDA's Newsletter?

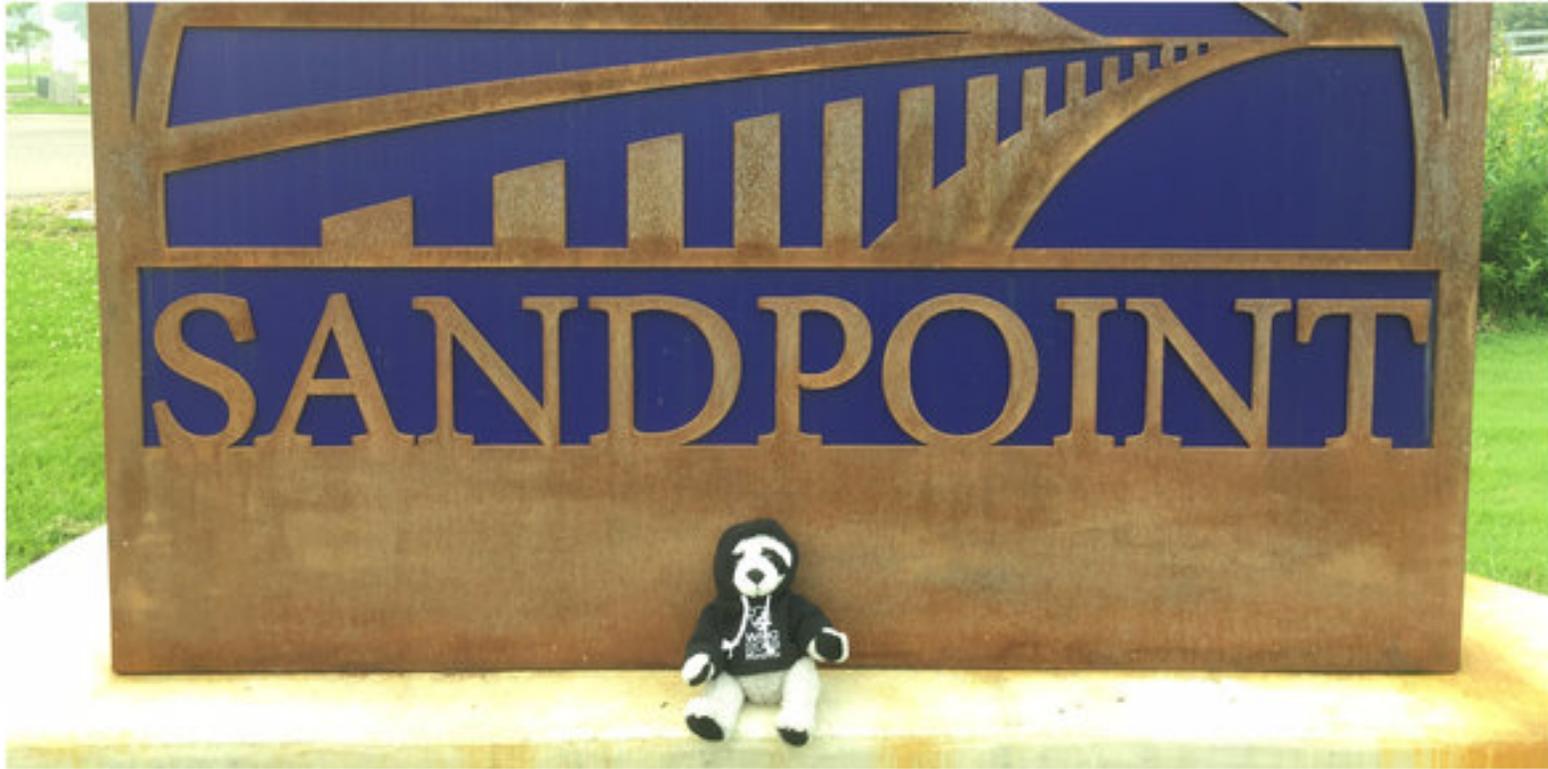


Parkinson's Life

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Where Is Parky?





Pictures and story were sent to us from our WPC Ambassador, AC Woolnough.

Sandpoint, Idaho had the dubious distinction of having the worst air quality in the country this week due to the fires in Washington, Oregon, Idaho, Montana, and Canada. Therefore if the sky is not very pretty in any of the pictures, you know why. Parky still had fun!

All proceeds from the sale of Parky the Raccoon goes to the WPC Travel Grant Fund which helps people with Parkinson's and junior researchers attend the World Parkinson Congress.

[VISIT THE WHERE IS PARKY WEBSITE](#)

[TAKE HOME PARKY THE RACCOON](#)

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