Dear friends,

In this month's WPC eNews, we are highlighting some amazing things that took place at the WPC 2016. While it's been nearly six months since we all met up in Portland, plenty of work is still being done in the community. For example, in this month's message we highlight the WPC Leadership Forum presenter, Erica Branch, Executive Director of the Parkinson Support Center of Kentuckiana. Their work building a mentor program for medical students to meet people with Parkinson's is having an impact in their community, and is something we intend to watch long-term. We need more Movement Disorder Specialists in the world to treat people living with PD and evidence shows that people with PD who see trained Parkinson's specialists get better care. What's happening in Kentucky is an interesting model for introducing Parkinson's to medical students before they make a decision on which area of medicine they will pursue. Let's catch these student while they are young and inspire them to join our community.

In this eNews, we also highlight travel advice for those living with DBS, share the summary of the Roundtable talk from the WPC 2016 on Young Onset PD, and give you an excerpt from our moving book that came out in December, Face of Parkinson's: Global Reflections on PD. We still have copies for sales, but they are disappearing fast!
We wrap up this eNews with a glimpse of the fabulous Parky the Raccoon, who we hope you have in your home. If you don't have your own Parky, now's the time to get one! One hundred percent of the profit from Parky sales goes to the WPC Travel Grants program. Because of the generosity of the community, we were able to offer travel support in the form of free/discounted registration, hotel, or travel support, to hundreds of delegates totalling over $300,000! Thank you to those who supported our Travel Grants program and to those who continue to support this program. Your support matters! If you'd like to scholarship a student or person with PD to attend the WPC 2019, it's never too early to show your support.

Kind regards,

Elizabeth "Eli" Pollard

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A Look Back at the 2016 Leadership Forum

On the Monday before the 4th World Parkinson Congress started in Portland, Oregon we invited our nearly 200 Organizational Partners together to network and learn from each other at the first ever WPC Leadership Forum. The Forum allowed our partners to talk about their outreach, fundraising, educational, and advocacy efforts and to strategize with each other on how to improve their work and better serve the community.

Erika Branch (Pictured above), Executive Director of the Parkinson Support Center of Kentuckiana spoke about their program of pairing first year medical students with people with Parkinson's (PwP) who live in the community. The goal of this program is to introduce medical students to Parkinson's so they can better prepare for caring for someone with the disease, but even more importantly, it puts a face on the disease and may inspire these students to go on to be Movement Disorder Specialists.

One of the challenges of implementing this program was designing it in a way that proved to the medical school that the program was worth the students' time. Twenty-five first-year medical students were recruited from University of Louisville Medical School and paired with a PwP. The students were given a short test on their knowledge of PD before meeting the PwPs. The students attended monthly lectures and mentoring sessions about Parkinson's and were required to keep a journal about the experience. At the conclusion of the program, surveys were given to the students and PwP's about the experience and how it could be improved. Everyone involved participated actively and
rated the experience as positive. In addition students improved their PD knowledge significantly. It was exciting to hear about Parkinson Support Center of Kentuckiana's work in the community. We look forward to seeing the long term impact of this program on the medical students who were selected to participate and encourage other organizations who are interested in starting a similar program to watch Erica's talk from the Forum and to reach out to them to learn how to start a similar program in your community.

VIEW ERICA'S TALK FROM THE LEADERSHIP FORUM HERE, ALONG WITH THE OTHER TALKS.

We'd like to thank the sponsors that made the WPC Leadership Forum possible, Adamas Pharmaceuticals and Acorda Therapeutics. We look forward to continuing to bring the community of global Parkinson's organizations together in the future and to advancing the programs and services for the communities of people living with PD.
Tell us about an amazing program that is changing your Parkinson's community by writing to info@worldpdcoalition.org.

Roundtable Highlight:

The following is a summary of the roundtable that took place at the WPC 2016 on “Tools for living with young-onset PD” with Jon Stamford, PhD & Ruth Hagestuen, RN, MA. Roundtables took place daily at the WPC allowing for small group discussion with experts on topics of interest.

For physical symptoms the principal tools are exercise, diet and medication. Of those three, the most important for young onset PwPs is exercise. It is easier to maintain physical health than it is to regain it. Therefore exercise, if started early, significantly benefits overall well-being in addition to relieving symptoms such as rigidity and bradykinesia. There is ongoing discussion on which form of exercise is best. For now, the best exercise you can choose is the one that you will continue to do.

Diet is another important part of maintaining physical health. People with PD have a tendency to get constipation and careful attention to diet can help relieve this as well as ensuring that medication is most effective. Medication itself is of course vitally important.
and again, attention to timing and impact helps manage and minimize drug side effects.

Taking care of your mental health involves three tools: support networks, education, and communication. First and foremost is support. Young Onset PD carries a significant burden of isolation even within the PD community. It is important to build your own support network as early as possible. Knowledge about the condition is empowering and has been shown to improve long-term outcomes. Finding reliable sources of information and building a PD specialized care team to assist you as the disease progresses are essential.

Communication cannot be underestimated. PwPs in general and Young Onset PwPs specifically need to find ways of communicating their needs and expectations to those around them whether these are family members, work colleagues or the general public.

DOWNLOAD ABSTRACTS FROM WPC 2016 SESSIONS

An excerpt from 
Faces of Parkinson's: Global Reflections of PD
Jean Burns, United States, Person with PD

It has been thirteen years since my PD diagnosis in 2003. I honestly don’t remember the person I was prior to that. What were my goals?

In this life, as an advocate, I have written, edited, and produced; I have lobbied, petitioned, inspired; I have spoken out and organized; I have championed national and international recognition of the Parkinson’s tulip

Tips for Traveling with DBS
co-authored by Jean Burns & Alice Templin, BSc

Excerpt from the WPC 2016 Toolkit:
There is no need to give up traveling long distances, just because you have DBS. There are different DBS systems; if yours does not require a charger, your DBS will be an easy travel companion. If you have a system that does require a charger, there will be just a few things to be aware of.  
1. What to take with you:
symbol; I have volunteered and I have participated. In *this* life, I have helped many others, especially in the research community, especially by donating my data to science. In *this* life, I have participated in 25+ clinical research studies and trials. I have signed 25+ “informed consents,” none of which protected me in the event I was injured during the trial. Now, I say to the research community, isn’t it time to recognize, protect, and thank all of the human volunteers who have given so much to research? We are your most precious commodity. Support no fault insurance including long term care for your human subjects who may be injured during research. We deserve no less.

**ORDER YOUR COPY HERE**

- A DBS identification card – this wallet-sized card supplied by the manufacturer of your stimulator describes the DBS system and medical warnings. It should be shown to security personnel at the airport.
- The “operating manual” for your system.
- Your patient controller/ programmer. Carry it with you in your handbag or backpack. Extra batteries (AAA or AA) for the controller.
- Battery recharger.
- A cord that connects your charger to a power point.
- An electrical adaptor.

2. Battery Recharger is bulky and heavy but if you are going to be away for a week or more, you must have it with you. The large bag supplied by the manufacturer for carrying the charger is cumbersome. You might find it easier to put the charger into a smaller toiletry bag and pack that into your overnight bag – you’ll have one less bag to carry! The frequency of recharging the battery will vary from 1 to 3 weeks. When it is time, recharging will take an hour or two, so you will need to plan when to do that. Recharging the battery provides a good time to recharge yourself too. Take time to rest, watch TV, or write in your journal.

3. You may want to wear a medical-alert bracelet that states you have a DBS system; it could also state that you have a wallet card with special warnings and emergency contact phone numbers.

4. At the airport: Your neurostimulator device will activate the metal detector / set off the alarm, and the security equipment at the airport may turn off the neurotransmitter. Most airports will make special accommodations for people with medical devices, and will allow them to bypass the metal detector.

5. Show the security personnel your medical card explaining the neurostimulator and how it may be affected by the detector. While security personnel
may not be familiar with DBS, they will understand if you call it a “pacemaker”.

He's so vain. He probably thinks this article is about him.

Did you take home a mischievous Raccoon at the WPC 2016? (If you didn't, you can still get one with a blue hoodie here, but they are almost gone!) Stay tuned for our announcement when we start selling the Parky with the new stylish hoodie for Kyoto. All profits go to the WPC Travel Grants Program.
Share your Parky pictures here and we will post it on the Where Is Parky? global map.