



Dear friends,

As the year comes to a close and I look back on 2019, so much has been accomplished that we can be proud of in the WPC community. Across the globe, new treatments are coming out to help ameliorate Parkinson's symptoms, nonprofit groups are collaborating on international initiatives, and studies are getting published on major findings on topics such as the economic burden of PD, which you can read about in the abstract highlight below in this eNews. Understanding the economic burden in the U.S. will allow groups to better showcase the need for more funds to be directed to Parkinson's disease when speaking with the government and funding agencies. This data should also be valuable for those outside the

U.S. to use as leverage when speaking to their own governments or as they look at the economic burden in their own countries.

The blog post we received from Drs. Maetzler and Espay on the topic of technology and Parkinson's highlights electronic health records (EHR) and mobile health technologies (MHT) shows that we are on the cusp of a change that will eventually allow for individuals to collect and manage their own health data in a way that has never occurred before. What that means for people with PD is not clear, but what is clear is that we need to have a better understanding of these technologies and how to "read" the data so that it's useful to the end user. Data is only useful if you can understand it, so we look forward to seeing the future research around data in the Parkinson's space. It's not only the collection of the data we are interested in, but understanding how the health community will use it, and how the end users will be included in the discussion and trained to use their own data.

I am excited to see the launch of the first ever **YOPD Fundraiser Campaign** for the WPC to help to get more people with young onset Parkinson's disease to the next World Parkinson Congress. This campaign was designed by Larry Gifford and Becca Miller, who both live with YOPD, and is being carried out the entire year of 2020. Learn more below about this year long fundraiser and if you are not on Facebook, but want to support the fundraiser, you can read more about it [HERE](#) and can support it at [WPC Travel Grant Support](#).

It's an honor being a part of a community that spends so much time and energy supporting each other and inspiring each other to live well. Wherever you are in the world, thank you for your support. Thanks to our basic scientists for working toward slowing, reversing, and eventually

curing this disease. Thank you to our clinical researchers for their efforts to find better ways to treat Parkinson's, and our clinicians for caring for the community day in and day out. To the care partners for staying supportive and strong, thank you, and to our community of people with Parkinson's, thank you. Thank you for showing us how to live well and overcome the challenges we face each day. You are not alone, we are in this together.

Happy Holidays!

Kind regards,



Elizabeth "Eli" Pollard

Executive Director

WPC Blog Highlight - Technology & Parkinson's

Perspectives on the Future of Technologies in the Care of Parkinson's Disease

by Walter Maetzler, MD & Alberto Espay, MD

We live in a digital world. Technology increasingly influences our individual activities, our choices, and our interactions with others – and is bound to dramatically change living with, and caring for, Parkinson's disease. Two cornerstones of the integration of technology into the assessment and monitoring of Parkinson's disease will be the electronic health records (EHRs) and the home-based mobile health technologies (MHTs), allowing the assessment and evaluation of our physiological state and of features associated with Parkinson's.

EHRs will enable patients to collect and manage individual health data, including that obtained from the treating physicians and the allied health care teams. EHR owners may, in addition, upload their own data obtained from MHTs as related to health, fitness, mobility and nutrition. These EHRs of the future will enhance communication between users and clinics, doctors and other healthcare professionals, consolidate hospital- and practice-derived data and implement population health analytics to inform about disease risk and prevention in an individualized manner.

[Continue Reading](#)

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. Over the summer they worked hard planning 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

The economic burden of Parkinson's disease (PD) in the United States

Brian Fiske*¹, Carlie Tanner², Roger Albin³, Nabila Dahodwala⁴, E. Ray Dorsey⁵, Wenya

Yang⁶, Laura Schmiel⁶, Inna Cintina⁶, Catherine Kopil¹, James Beck⁷, Jamie Hamilton¹

1. *The Michael J Fox Foundation for Parkinson's Research, New York, NY, USA*
2. *University of California-San Francisco, San Francisco, California, USA*
3. *AD/R, VAAAHS GRECC, Ann Arbor, Michigan, USA*
4. *University of Pennsylvania, Philadelphia, Pennsylvania, USA*
5. *University of Rochester, Rochester, New York, USA*
6. *The Lewin Group, Falls Church, Virginia, USA*
7. *Parkinson's Foundation, New York, NY, USA*

Objective: To provide a comprehensive assessment of the direct and indirect medical costs of PD in the US Background: In addition to the debilitating symptoms of PD itself, people with PD (PWP) also experience injuries from falls and other comorbidities. As a result, PWP have higher medical needs, often miss work, retire early and require caregiver assistance. PD prevalence is predicted to increase in coming decades. Comprehensive information on the economic burden of PD is needed.

Methods: Multiple data sources were used to estimate the different components of the cost of PD, including: The US Census population projections combined with Medicare Current Beneficiary Survey (MCBS) and the Medical Expenditure Panel Survey (MEPS) data; claims data from Medicare Standard Analytical File (SAF), nonacute care and prescription drug components from the MCBS, CDC Wonder data, average earnings data from Bureau of Labor Statistics, and one of the largest claims databases for the privately insured. Other indirect and non-medical cost components were estimated using a primary survey that was designed and implemented for this study. Costs were determined for an estimated 1 million Americans with PD using 2017 costs.

Results: The estimated total medical cost attributable to PD is just over \$25 billion in the US. Nearly 90% of the total direct medical cost of PD are borne by Medicare and its beneficiaries with PD, with inpatient and non-acute institutional care representing the largest shares of the total direct cost. The average per-person direct cost was \$22,671 for the privately insured PWP (65 years of age) with PD. The average indirect and non-medical cost per PWP is \$18,229 for PWP alone and \$24,149 for PWP combined with unpaid care partner burden. The estimated total indirect and non-medical cost of PD is \$25.05 billion in 2017, with \$18.9 billion attributed to PWP and another \$6.1 billion to unpaid care partners.

Conclusions: This is the most comprehensive US study to-date in examining the overall economic burden of PD. Our findings underscore the significant burden of PD to society, payers, people with PD and their care partners.

[Download the WPC 2019 Abstract Book](#)

Parkinson's Community Corner

Contact 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.

Shop the WPC Store



Useful Links

[View online version](#)

[Forward to Friends](#)

© 2019 World Parkinson Coalition®

About This Email

You are receiving this email because you subscribed to receive the WPC eNews. To unsubscribe, click [@@unsubscribe_url@@](#).

