

WPC 2019 Final Report

The 5th World Parkinson Congress (WPC 2019) took place in Kyoto, Japan from June 4-7, 2019. This was the first time the WPC was held in Asia. The World Parkinson Congress is a unique event in that it's the only international scientific gathering of the whole Parkinson's community. Neuroscientists, physicians, clinicians, rehab specialists, people with Parkinson's and families all come together to learn about current scientific updates on Parkinson's and to be inspired about how to live well with this chronic degenerative disease that is expanding in number due to the aging population and better diagnostics tools.

Even before the WPC program started, key community members in Kyoto were educated on Parkinson's disease. The WPC hosted a day of educational programs two weeks prior to the Congress to educate front of house hotel staff, convention center staff, catering staff, design team members, security and others. In total 125 participants were educated about Parkinson's disease and how to best serve this community of special delegates as part of the WPC "Parkinson's Ready" program we offer to host cities.

The WPC 2019 started on Tuesday, June 4 with a full day of five pre-congress courses. The courses each focused on a difference audience. Course 1 targeted patients and families, Course 2 targeted health professionals, Course 3 targeted people who wanted scientific updates, Course 4 targeted patients who wanted to learn about advocacy, and Course 5 was delivered to Japanese doctors by industry sponsors.

The **opening ceremony** began Tuesday evening. It was a moving ceremony that brought many people to tears with the talks while at the same time inspiring the audience with incredible performances by renowned pianist, Hidetoshi Yamada with vocals performed by Ryoichi Higuchi, a well-known singer in Japan. Both of these men live with Parkinson's disease. Their outstanding performance was flanked by the WPC Choir, made up of people in the PD community globally who came together for the first time in Kyoto and by our global dance group who trained under dancer and choreographer, Pamela Quinn, who herself lives with PD. These emotional performances really showcased how people with Parkinson's can continue doing things they love. We also announced the winner of the WPC Video Competition and the winner of the People's Choice Award. These winners hailed from Norway and Japan and their videos told moving stories that inspired the audience and brought many to tears. We closed out the ceremony with some outstanding taiko drumming.

The following three days, Wednesday through Friday, started each morning with Hot Topics, presentations by authors of outstanding posters. Just four posters each morning were highlighted orally, total of 12 in all, selected to present out of 600+ posters submitted.

Each morning, a WPC Award ceremony was held to recognize WPC Award recipients. This year awardees hailed from five countries and were selected for their outstanding contributions to the PD community.

Awardees of the **WPC Award for Distinguished Contribution to the Parkinson Community** were:

Soania Mathur, BSC, MD, CCFP from Canada, patient advocate

Lori Ramig, PhD, SLP-CCC from the USA, Founder of LSVT

Susanna Lindvall, BS Chem from Sweden, Swedish Policy Advocate and VP of European PD Association

Awardees of the **WPC Robin A. Elliott Award for Service to the Community Award** were:

Sara Lew Lai Heong from Malaysia, President of Malaysian Parkinson's Disease Association

Nancy Tingey, OAM, CF, MA, BA from Australia, Founder of Art for Parkinson's and Care Partner

After the awards, we opened the morning Plenary each day inviting world leaders to help us better understand and digest some of the most important topics in Parkinson's today. Plenary topics at the WPC 2019 covered the following subject:

Plenary Day 1 - What is alpha-synuclein?

What is α -synuclein – The biology	<i>Speaker:</i> Ronald Melki (France)
The pathology of α -synucleinopathies	<i>Speaker:</i> Peter Riederer (Germany)
Patients as living science: The importance of participating in clinical trials	<i>Speaker:</i> Soania Mathur (Canada)
Clinical trials and efficacy of clinical trials targeting α -synuclein	<i>Speaker:</i> Jesse Cedarbaum (USA)

Plenary Day 2 – Are we moving towards personalized medicine?

Heterogeneity of Parkinson's disease	<i>Speaker:</i> Connie Marras (Canada)
How are the genetics of PD influencing treatment development?	<i>Speaker:</i> Susanne Schneider (Germany)
New trial approaches to treating Parkinson's disease	<i>Speaker:</i> Olivier Rascol (France)
What's it like to live with a gene for Parkinson's disease?	<i>Speaker:</i> Benjamin Stecher (Canada)

Plenary Day 3 - The peripheral aspects of Parkinson's disease – It is not just a brain disease!

Your radical new life: Creative ways to overcome our challenges	<i>Speaker:</i> Heather Kennedy (USA)
Overview of peripheral (non-brain/CNS) abnormalities in PD	<i>Speaker:</i> Jeffrey Kordower (USA)
Does PD start outside the brain?	<i>Speaker:</i> Per Borghammer (Denmark)
Managing of the peripheral problems in PD	<i>Speaker:</i> Shen Yang Lim (Malaysia)

Each day over lunch, delegates chose from a dozen options, such as reviewing poster abstracts, joining in a special lecture, visiting authors in our Book Nook, listening to special talks on Clinical Research and more. Special Lectures at the WPC 2019 were particularly exciting this year with the following options:

Day 1 Special Lecture was split between two highly prestigious Japanese leaders who talked about *History of Parkinson's disease research in Japan: Past, present and future* presented by Dr. Toshiharu Nagatsu and *Mitochondrial energy crisis as a pathogenesis of Parkinson's disease* presented by Dr. Yoshikuni Mizuno.

Day 2 Special Lecture was a panel of globally recognized people with Parkinson's discussing how they live well with PD on: *Living well with Parkinson's disease: What's your secret?* with the following panelists: Omotola Thomas (UK/Nigeria), Yoshiko Okada (Japan), Emma Lawton (UK), Elizabeth Ildal (Denmark), Benjamin Stecher (Canada)

Day 3 Special Lecture was incredibly special as we were joined by 2012 Nobel Laureate in Physiology or Medicine, Dr. Shinya Yamanaka (right), who spoke about *Current status of iPS cells and efforts for medical application*



After lunch, sessions expanded, giving delegates many choices. Sessions were broken into larger Parallel sessions (large room, lecture style), Workshops (smaller room, interactive panel style), or even our very small Round Tables with one expert and just 11 guests.

Session Type



Basic Science



Clinical Science



Comprehensive Care

The end of each day delegates had a choice to attend the poster tours in the exhibit halls or to attend the Daily Wrap Up panel of experts.

All sessions, regardless of format, were marked with icons to showcase the level of the science expected and to declare the focus, whether basic science, clinical science, or comprehensive care. These icons help participants select the session that is best for them and helps them to understand what they can expect from the presenters before they even enter the door.

Session Levels



Minimal or no scientific background required for these sessions



Moderate-level scientific sessions



High-level scientific sessions

To maximize access to information, for our Japanese speaking patients, all sessions from 8AM through the 1PM lunch lectures, were **translated into Japanese**, as well as the Daily Wrap up session from 5:15 – 6:30PM. On Wednesday afternoon, the WPC worked collaboratively with the Japan Parkinson Disease Association to offer a Japanese Track where the talks were all delivered in Japanese. We also worked closely with the medical students at Kyoto University to offer simultaneous interpretation at 35 of the Roundtables. Each student translated for any Japanese patients who needed the support.

WPC 2019 Final Program and Abstract book can be downloaded at <https://www.worldpdcoalition.org/PastCongresses>

ATTENDANCE

A total of 2,777 delegates from 61 countries attended the WPC 2019.

Category	Attendees
Health Professionals	987
Student/Post Doc	179
PwP/Care Partners	1,092
Accompanying Person	39
Pharmaceutical/ Sponsors/ Exhibitors	356
Complimentary (Guests, Committee, Media)	125

COUNTRY OF ORIGIN

Delegates came from 61 countries, with the largest body of delegates coming from Japan. A total of 46% of the delegates came from East Asia/Central Asia & Russian Federation, including Japan (37%). At the past three congresses, representation from East Asia and Russia was 7.4% combined.

Region	WPC 2019 (Kyoto)	WPC 2016 (Portland)	WPC 2013 (Montreal)	WPC 2010 (Glasgow)
Europe	15%	6.7%	15%	72%
USA/Canada	29%	85%	78%	17%
East Asia/Central Asia & Russian Federation	46%	1.4%	2%	4%
South Asia/ South East Asia/ Australia /S. Pacific	8%	4.8%	2.5%	3.5%
Mexico, Central/ South America & Caribbean	1%	1.3%	2%	2%
Africa/ Middle East	1%	0.8%	1%	1.5%

Asian representation

Country	Delegates	Percentage
Japan	1037	37%
South Korea	55	2%
Thailand	35	1%
Taiwan	23	1%
Hong Kong	19	1%
Malaysia	19	1%
China	18	1%
India	12	0%
Singapore	11	0%
Indonesia	2	0%
Macau	1	0%
Pakistan	1	0%
Philippines	1	0%
TOTAL	1234	44%

Top 21 Countries by Number of Attendees

Country	Number of Attendees
Total countries: 61	
Japan	1037
United States	638
Australia	168
Canada	141
United Kingdom	134
South Korea	55
Norway	41
Thailand	35
Sweden	30
New Zealand	29
Germany	26
France	26
Taiwan	23
Denmark	22
Hong Kong	19
Israel	19
Malaysia	19
China	18
Italy	18
Netherlands	16
Finland	15

Self-Reported Demographic Information

WPC asks a few **optional** questions during the registration process to help us better understand the demographic make-up of the WPC and how it shifts from one Congress to another.

Ethnicity	WPC 2019 (Kyoto)	WPC 2016 (Portland)
African American	5	30
Arab/Middle East	10	13
Asian/Pacific Islander	981	222
Black (Not American)	11	15
Latino	58	102
Other	44	33
South Asian	51	49
White	972	2948

Age	WPC 2019 (Kyoto)	WPC 2016 (Portland)
Under 20	16	10
20 - 35	321	254
36 - 50	636	557
51 - 60	528	453
61 - 70	496	419
71 and Older	196	170

Wellness Way is a hugely popular area of the WPC where delegates can enjoy different activities in each room that showcase how to live better with Parkinson’s. In Kyoto we offered five rooms:

Wellness Way	Room Activity	
Renewal Room	Exercise classes including tai chi, boxing, dance, vocal classes, drumming etc.	 <p><i>Rock Steady Boxing class</i></p>
Care Partner Lounge	Roundtable talks on issues key to care partners/ family members. Led by social workers, nurses and others. A quiet space for care partners to come together, connect with others, and learn.	
Massage & Reiki Room	Daily short massages or reiki treatments offered to delegates.	 <p><i>Tai Chi class</i></p>
Quiet Room	Quiet space for delegates to sit or lie down to rest. This was hugely important! Patients get tired easily and many delegates were jetlagged. This room was constantly full.	
Table Tennis Room (NEW)	A new room for the WPC, this Table tennis room introduced the game of table tennis to delegates and also allowed for table tennis players to meet each other and to play a short tournament.	

The **closing ceremony** was attended by more than 600 delegates who remained to see who was announced as the recipient of the Stanley Fahn Young Investigator Award and to hear the location of the WPC 2022. WPC President, Dr. Jon Stoessl, thanked our sponsors, gave gifts to our invaluable local committee members, including Dr. Ryosuke Takahashi, Dr. Nobutaka Hattori, and the President of the Japan Parkinson Disease Association, Mr. Hasegawa. We ended on a high note with a drumming circle.

FACULTY

The 181 WPC 2019 faculty were global leaders who were hand-picked by the WPC Program Committee for their outstanding research, ability to “translate” their research into understandable talks to a large mixed audience, and who value and understand the importance of bringing the community together.

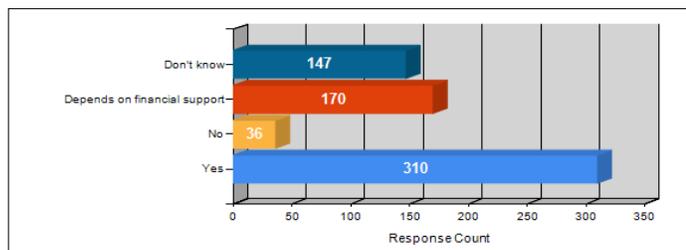
Faculty Category	Number of Faculty (181)
Physician/Researcher	119
Nurse/Rehab Specialist/ Other	37
People with Parkinson’s	23
Care Partner	3

The 5th World Parkinson Congress was a success. We believe the impact of having the WPC in Japan will reverberate for years and decades to come. Our desire to raise awareness of Parkinson’s and ensure people with Parkinson’s live the best possible lives they can, was achieved with this unique and emotional Congress.

Returning delegates

The make-up of the audience is important to the WPC experience, but not just diversity of profession, but also with returning delegates and new delegates who are attending for the first time. Of the WPC 2019 attendees, over 50% attended at least one previous congress with many of these having attended two and three previous WPCs.

When we asked delegates post WPC if they would plan to attend the WPC 2022, in Barcelona, Spain, of those who completed the survey, nearly 47% indicated yes, they would attend, with the other 48% indicating ‘maybe’.



WPC TRAVEL GRANTS PROGRAM

WPC 2019 offered 98 Travel Grants and nearly 150 Registration Grants to delegates in one of three categories: (1) junior researchers and clinicians who submit posters that are accepted for display; (2) health professionals from developing parts of the world; (3) people with Parkinson’s who are advocates.

Travel grant award amounts varied, based on the application and financial need. WPC raised money for the grants from corporate sponsors and individual giving, mainly through our unique “Pay it Forward” program where delegates who are registering are invited to help sponsor another person who may not be financially able to reach the WPC. One hundred percent of the donations that come in go out to recipients. The WPC does not take an administration fee.

Below is a breakdown of delegates who chose to donate during the registration process.

Donation Category	WPC 2019
Please use where needed	\$11,690 (145 people gave donations)
I would like to scholarship a student	\$2,700 (9 people gave \$300 each)
I would like to scholarship a PwP	\$5,100 (17 people gave \$300 each)
Total raised from ‘Pay it Forward’ program	\$19,490

- People from 17 countries donated to the Travel grants “Pay It Forward” program:
- Largest amount donated: \$1,000
- Smallest amount donated: \$10

MOBILE APP



The WPC 2019 Mobile App enjoyed a high level of engagement before and during the congress. People used the app to plan their schedule, connect with other delegates, and to generally navigate all that the congress had to offer. We used the app to have audience members submit questions, which was a great way to allow audience members who were shy, or having speech challenges, to still be able to ask their question(s).



Key numbers:

- 1,780 people downloaded the mobile app.
- 864 messages were sent within the app.
- 17,186 times delegates added sessions to their schedule within the app.
- 8,048 times delegates opened the app to view the activity feed we were posting daily. (The activity feed is a mixture of notifications from the WPC staff about current sessions and an aggregate of posts to social media using our hashtags)

VOLUNTEER PROGRAM

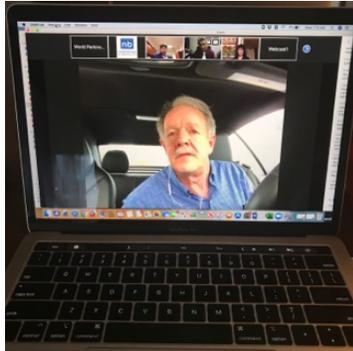
The WPC Volunteer program is a well-coordinated program whereby individuals can volunteer to work approximately 22 hours during the week of the WPC in exchange for free registration to attend sessions when not working. **WPC 2019 had 102 volunteers who worked 3,500 hours over six days and came from 14 countries.**

This is a wonderful way to engage students, care partners, clinicians and others who wish to decrease their costs while at the same time engage and socialize with the community members who attend the WPC. Volunteers work together months ahead of time communicating on webinars, discussing jobs, and planning their tasks.



Volunteer Breakdown: Who Were They?	
Caregiver, Family Member of someone with PD	26
Person with PD	20
Nonprofit employee	8
Other	3
Neurologist / Physician / Clinical Researcher	9
Occupational Therapist	1
Nurse/ Nurse Practitioner	2
Physical Therapist	3
Social Worker	5
Speech Language Pathologist	6
Student/ Post Doc	21
<i>(102 volunteers worked more than 3,500 hours)</i>	

WPC 2019 PRE-CONGRESS WEBINARS



For the first time ever, the WPC offered three pre-congress live webinars with virtual panels of experts discussing some very specific topics that were to be covered at the WPC in Pre-congress Course #3, Scientific Updates. This was a way to (1) help highlight the sessions people could attend onsite; (2) help educate our friends in the world who could not join us in Kyoto; (3) give people a taste of what they would be hearing if they participated in the pre-congress course on scientific updates.

Webinar topics & Presenters

→ Non-motor symptoms and PD

Speakers: Barry Snow (NZ), Jennifer Goldman (USA), Shen Yang Lim (Malaysia), Tim Anderson (NZ)

→ Surgical Options and PD

Speakers: Raj Pahwa (USA), Kelly Foote (USA), Elena Moro (France), Peter LeWitt (USA)

→ Motor symptoms and PD

Speakers: Raj Pahwa (USA), Simon Lewis (Australia), Stu Isaacson (USA)

Nearly 800 people from 39 countries attended the three Pre-Congress webinars hosted in the weeks before the congress. People are still accessing these webinars today on the WPC website at <https://www.worldpdcoalition.org/page/Webcasts>

Geographic demographics of viewers

Region	Percentage of Viewers
Africa/Middle East	3%
Europe	10%
Asia	10%
North America	62%
South America	1%
Oceania	14%

Registration breakdown of viewers

Category	Number of Attendees
Care Partners & Family Members	138
Neurologists/Movement Disorder Specialists	61
Non-Profit Employees	22
Nurses, OTs, PTs, SLPs, Social Workers	132
People with Parkinson's	368
Other	74

Post WPC Survey Results

In the post WPC online survey, we collected feedback from the participants, exhibitors, speakers and others to better understand what we did well and what we can improve on for future WPCs. While we had 2,777 participants at the WPC, we had just 2,300 unique emails and from the 2,300 people we invited to complete the survey, we received a complete response from 663, or 29% of total possible survey takers.

Speakers

94% of speakers rated their experience a 7-10 on a 10-point scale.

85% of speakers **would like to be considered again** as a faculty member for the WPC 2022.

60% of speakers **would like to be considered for a committee role** for the WPC 2022.

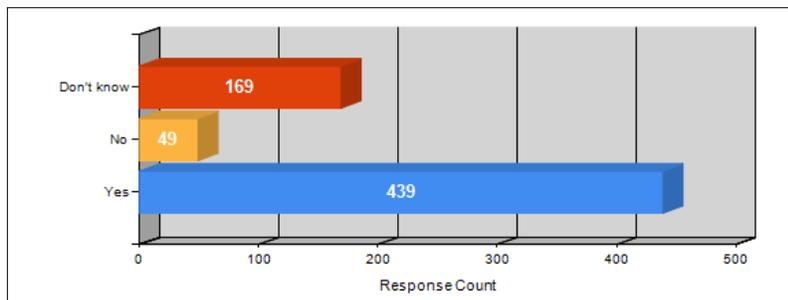
Exhibitors

80.8% of exhibitors rated their experience as a 7-10 out of a 10-point scale.

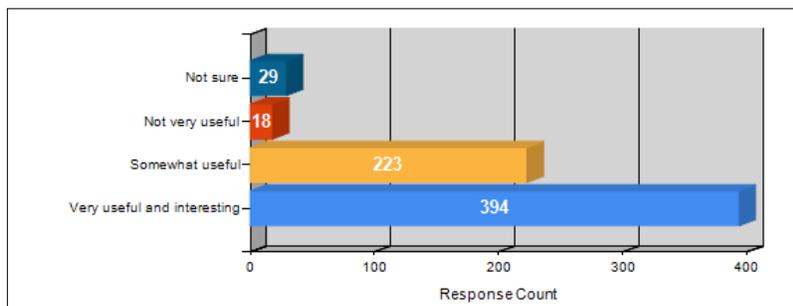
89% of exhibitors stated that **they will possibly or definitely exhibit again** at the WPC 2022.

Delegates & Speakers

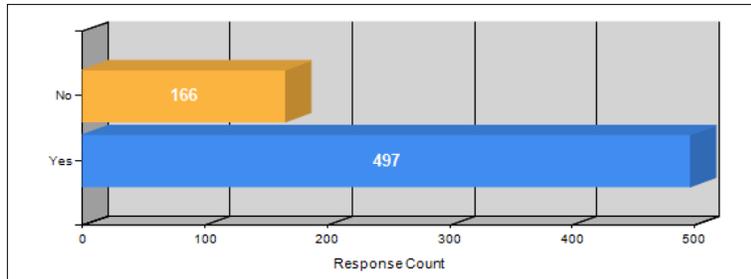
When asked, “Does the WPC fill a need/ void/ niche that other meetings do not cover?” Sixty-six percent felt the WPC filled a specific need in the Parkinson’s community.



When asked, “How did you find the discourse between people with Parkinson's, researchers and health professionals?”, ninety three percent felt it was either very useful or somewhat useful.



Based on the questions, “Did you make contacts from outside of your broad field who you plan to stay in touch with post WPC?”, seventy-five percent indicated yes, contacts were made outside their own field that they intend to keep in touch with post WPC.



Additional stats:

86% of respondents said the **length of the Congress, four days including one day of pre-congress courses**, was just the right length.

80% of respondents said the sliding scale for the **registration fee was fair and reasonable**. Registration was offered on a sliding scale. *(See details below).*

REGISTRATION FEES

All prices are in US dollars (\$US)

REGISTRATION CATEGORIES	EARLY FEES	STANDARD FEES
	Until February 27, 2019	February 28 – May 20, 2019
Physicians, Clinical Researcher, Scientist ²	\$625.00	\$750.00
Pharmaceutical Industry members	\$625.00	\$750.00
Nurse/ Physical Therapist/ Speech Language Pathologist/ Occupational Therapist/ Social Worker ²	\$425.00	\$550.00
Student/ Post Doc ⁴	\$300.00	\$350.00
Person with Parkinson	\$300.00	\$350.00
Care giver	\$300.00	\$350.00
Care giver (with PwP who has registered) ¹	\$200.00	\$250.00
Accompanying Person ³	\$150.00	\$150.00

When asked, “How likely are you to recommend to others that they attend the WPC 2022?” **76% of the respondents** rated a 8-10 out of a 10-point scale (10 being the most likely to recommend to others to attend the WPC 2022).



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