

# WORLD PARKINSON COALITION







## **BACKGROUND TO THE PROJECT**

Our purpose, as BestCities Global Alliance, is to harness the power of collaboration and community to create positive impact through business events. Our research, initiatives such as Incredible Impacts and the Madrid Challenge, our interactions with clients and destinations - all tell us that education is a priority if the industry is to understand the positive impact that can be created from events and their role in making it happen.

We have created several case studies which we hope will provide inspiration and learning about how a destination has benefited from hosting an international Congress and how the association has moved closer to its mission as a result of holding the Congress.



## BACKGROUND TO WORLD PARKINSON COALITION

The World Parkinson Coalition (WPC) helps advance understanding of Parkinson's disease by creating and hosting the only totally inclusive international gathering for the community to share knowledge and spark new research agendas across the Parkinson's field.

WPC is, in itself, an example of long-term impact resulting from a community meeting in Washington, DC in 2002. Dr. Elias Zerhouni, the then head of the National Institutes of Health, asked some of the leaders in the community why a meeting inclusive of all those touched by Parkinson's did not exist and suggested that they consider hosting one. The World Parkinson Coalition Inc. was formed in 2004 and the first Congress was held in February 2006 in Washington, DC. This groundbreaking Congress brought together, for the first time, the patient community, the scientific community, the clinical community and the advocacy

community together under one roof.

The WPC has evolved over the years – its initial purpose of hosting a Congress was to bring the Parkinson's communities together to create awareness and bring attention to the disease. It has developed into a global hub for Parkinson organisations to connect and intersect. WPC undertakes a number of different activities but the Congress remains its key tool to deliver on its mission. Planned, intentional legacy activities, which result in long term impact are woven into each and every Congress. Measuring the success of these activities and the progress towards the overall mission as a result of the Congress comes through the stories from the people who have made connections at the Congress and the things they have gone on to do. This case study charts some of the amazing work and legacy outcomes from the six Congresses held to date.




## THE CONGRESS

The World Parkinson Congress is a triennial event that rotates globally and attracts between 2,700 to 4,500 delegates. The first Congress was held in Washington in 2006, moving to Glasgow in 2010, Montreal in 2013, Portland in 2016, Kyoto in 2019 and most recently in Barcelona in 2023.

When the Coalition was first launched as an organisation, the founders were very purposeful about not repeating what other organisations were already doing and doing well - there was no reason to

duplicate. The purpose behind the 2006 Congress was to create a space where the Parkinson community could cross pollinate to advance understanding of Parkinson's. And by community this meant healthcare professionals, scientists, people with Parkinson's and care partners. To have people with Parkinson's (PwP) attend the Congress and meet with the scientists was a first, it had never been done before. Today, 20-25% of delegates who attend the Congresses are people living with the disease - in a conference of over 4,000 that's 1,000 delegates.



*I have been truly moved by the opportunity to speak and interact with people living with Parkinson's disease. Undoubtedly, this experience will profoundly influence the way I conduct research in my lab and mentor my students and postdocs. Thank you very much!*

**Chiara Zurzolor, MD, PhD**  
**Professor, Institut Pasteur, Paris, France**

ATTRACTS BETWEEN

# 2,700 to 4,500

DELEGATES



1ST CONGRESS



## 2006

### WASHINGTON



2ND CONGRESS



## 2010

### GLASGOW



3RD CONGRESS



## 2013

### MONTREAL



4TH CONGRESS



## 2016

### PORTLAND



5TH CONGRESS



## 2019

### KYOTO



6TH CONGRESS



## 2023

### BARCELONA



1,000 OUT OF 4,000

## 20-25%



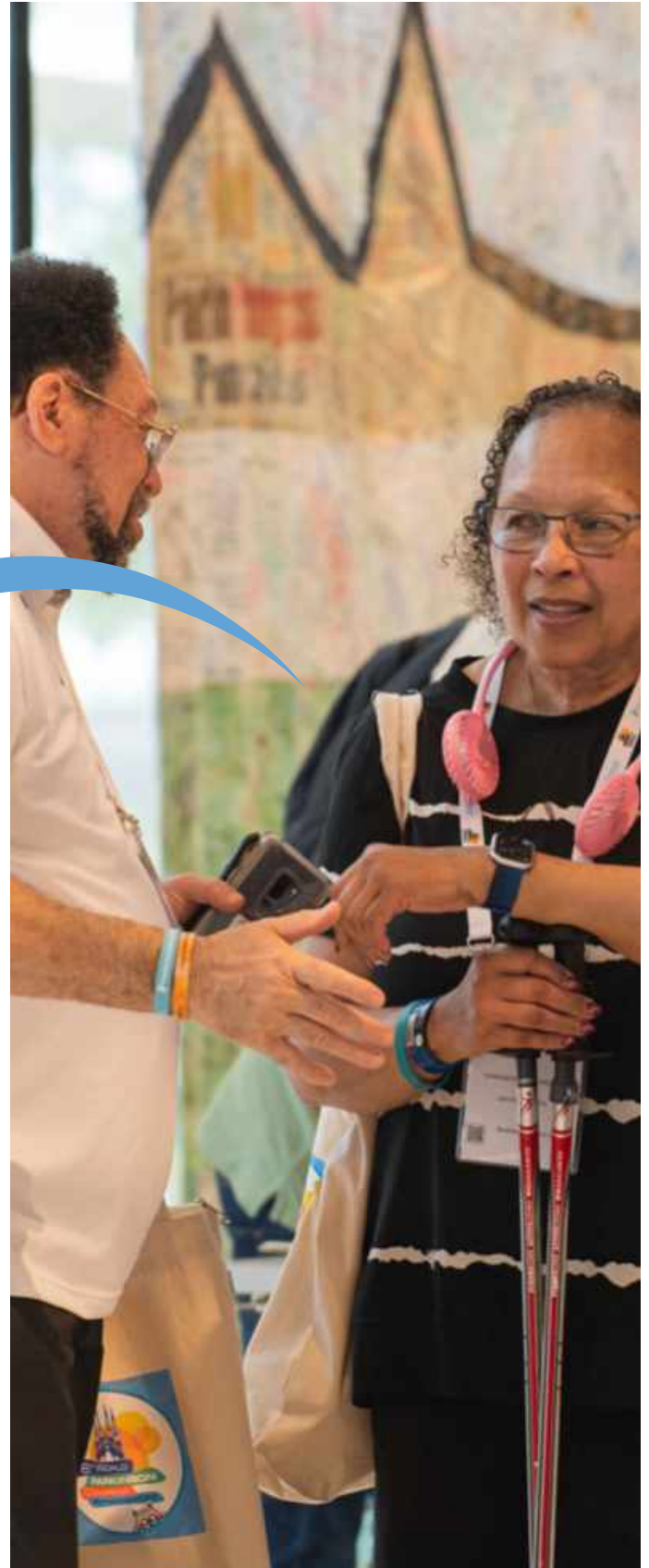
TODAY, 20-25% OF DELEGATES WHO ATTEND THE CONGRESSES ARE PEOPLE LIVING WITH THE DISEASE - IN A CONFERENCE OF OVER 4,000 THAT'S 1,000 DELEGATES.



# LEGACY OUTCOMES AND LASTING IMPACT

WPC has helped change the direction of research. The question was asked of the researchers and scientists at the Congress, "How are you curing a disease if you don't even know what it looks like or what it feels like, how it impacts those with the condition?" When WPC was first formed, Parkinson's was seen exclusively as a movement disorder. Scientists were focussing on how to cure the movement symptoms that were clearly visible in patients. By speaking to patients at the Congress they learned that what was as important to patients was research into other aspects of the disease such as the non-visual, non-movement symptoms that they encountered in their daily lives. They wanted to seek cures for sleeplessness, depression and pain associated with the disease. The realisation that patients have multiple

challenges, which are not purely associated with tremors and movement, widened the scope and direction of the research, and was expedited and elevated as a direct result of the Congress.



*... that first meeting, creating that interdigitated audience, gave us space to have those conversations when it had never happened before in that way and wouldn't have happened had the Congress not taken place.*

**Eli Pollard,  
Executive Director,  
World Parkinson Coalition**



# A SPRINGBOARD FOR ACTIVISM

WPC considers everyone who comes to the Congress an advocate, “By making a choice to come to a scientific Congress about a disease that you live with, by nature, you are an advocate”. They challenge delegates to do something with their role as advocates. By planting this seed, the Congress becomes a springboard for activism. Many delegates have been inspired to take that leap from advocacy to activism.

A great example of this advocacy came out of a meeting at the Kyoto Congress in 2019. WPC runs a buddies programme whereby people with Parkinson’s are matched up with a “Buddy”. Going to a foreign place or country, coming to a scientific meeting particularly if you’ve never been, can be intimidating and scary and WPC wanted to make sure people with Parkinson’s had someone else they at least knew when they got there.

In Kyoto in 2019, one such match involved two women with Young Onset Parkinson Disease (YOPD), one a registered Nutritionist from Ireland and the other a Nurse from the US. The lady from the US introduced a buddy from a previous Congress, the trio met at the Congress and became firm friends. They started talking about the challenges young women with Parkinson’s have around hormone changes and menstruation and why their medication during their menstruation cycle doesn’t work as effectively as it does when they’re not menstruating. There had never been any research into this, and they wanted answers. After meeting in Kyoto, they started a program called [MyMovesmatter.com](https://www.mymovesmatter.com), created an award-winning app and have been leading research into this area.

Richelle Flanagan, one of the trio, explains how she was “inspired by other people with Young Onset PD to speak out to drive change in treatment, care, and research for people with PD”. She was

an ambassador for the World Parkinson Congress in Barcelona, 2023 and recently co-authored a paper on the unmet needs of women with Parkinson’s. A huge and positive legacy outcome from the Kyoto Congress that continues to deliver positive long-term impact for the YOPD community.

A second example of this leap from advocacy to activism is a delegate who attended Glasgow 2010. Sara Riggare, PhD was so inspired that she left her career in chemical engineering and moved into the field of Health and Technology achieving a PhD along the way. Diagnosed with Young Onset Parkinson’s she started tracking her disease in an effort to stay as healthy as possible. As she explains on her website: <https://www.riggare.se>, she is the only person with the whole picture about her condition. The tracking of her disease has enabled her to get the best out of her interactions with neurologists and other members of her medical team. Her work has demonstrated how patients can be empowered by tracking their disease; monitoring what affects how they are feeling and what is helping them and assisting their medical team in understanding what’s happening and how best to manage it. She is a regular speaker at WPC Congresses and continues to inspire and empower others.





# PRE-CONGRESS ACTIVITIES

As with many legacy oriented Congresses, WPC has an engaging pre-Congress programme. The award-winning Parkinson's Ready Program addresses one of the biggest challenges for people with Parkinson's - travelling comfortably and safely. Training is offered to staff in all service industries in each host destination to understand Parkinson's disease and how to give the best and most appropriate welcome and at the same time ensure a safe experience for delegates. When the Congress is over this knowledge and understanding remains in the city to the benefit of all travellers

with movement disabilities. A fantastic example of a Congress leaving a city better off than when it arrived.

The program itself, an Incredible Impact Awards Winner in 2017, has evolved beyond the Congress and WPC is partnering with local associations to deliver training in cities around the world in 2024, even though the Congress is not being held in those cities. This gift of knowledge enables local staff from the police and fire departments, hotels, airports, and local transportation to better serve future guests to their city.



# THOUGHTFULLY STRUCTURED NETWORKING

The WPC is the only time when the non-profit organisation leaders are together. A networking lunch for non-profit organisation leaders in Glasgow 2010 was so successful that it evolved into the Pre-Congress Leadership Forum in Montreal 2013 and has continued ever since. Its purpose is to bring the non-profit organisation leaders together to discuss issues affecting them.

The non-profits range from the small e.g. the Icelandic Parkinson Association

servicing a very specific, smaller community to the much larger, well-funded organisations such as the Michael J. Fox foundation for Parkinson's Research. Needs are therefore very different. In Barcelona 2023 the topic was stigma. The stigma that can come with a diagnosis of Parkinson's can be a barrier, globally, for many people with the disease. The outcomes of these discussions, and what can be done to address this, are being distilled and will be published in due course.

# AMBASSADORS PROGRAMME

Launched for the first time in Montreal 2013, the WPC's Ambassador programme is a nominated group of individuals living with Parkinson's who are involved in promoting, engaging and encouraging people to come to the Congress. The WPC Ambassadors are available to the host destination and global community to deliver talks to local support groups, write articles in local papers or on social media blogs. Raising the awareness of the disease in this manner leaves a lasting legacy within the host destination. Their mandate is to represent the WPC and help drive up awareness of Parkinson's, the World Parkinson Congress, and to mentor and support other PwPs.

In Kyoto 2019, an Ambassador, sensing that the YOPD delegates were feeling very disconnected, arranged a meeting at the Congress for them to come together. The feeling in the room was one of anger

and frustration. Those with YOPD felt that no one was serving their needs. They are a minority of less than 10% of the global PD population, yet they live the longest with the disease and have to navigate very complicated decisions since they are often mid-career and raising young children. The outcome of the meeting was the creation of the PD Avengers. PD Avengers is a patient led organisation which now has non-profit status and a global network of over 8,000 people living with YOPD. Their mission is to raise awareness, engagement and hope. Their mantra - Think Globally and Act Locally. A secondary outcome from the meeting and hearing the views of the YOPD delegates, was a pledge from WPC to do more for YOPD and create a space for them in future Congresses which came about in 2023 as a pre-Congress course designed by and for people with YOPD.

## CONNECTIONS AND COLLABORATION

A lot of conferences talk about knowledge exchange and bringing the scientists and people with Parkinson's together but what results from it is often not reported or recorded. WPC can attest to several examples of connections that would not have been made had it not been for the Congress and have resulted in meaningful collaborations.

One example is the outcome from a matching of a researcher from Switzerland and a patient from the US which resulted in a Review Paper on Shame in Parkinson's Disease. Until this paper was published shame was not openly discussed or researched to any great degree but is experienced by many people with Parkinson's. The paper has helped to raise the awareness of shame and its effect on the quality of life of Parkinson's patients and is urging the development of effective interventions to reduce its impact.

*"Shame is an underrecognized symptom, rarely explored in clinical practice and in PD research. It emerges from PD motor and non-motor symptoms as well as from a self-perception of inadequacy due to increasing loss of autonomy and need for help, and from the deterioration of body image. Shame can have a significant negative impact on health-related quality of life. It may contribute to social isolation, depression and anxiety"*

**Reference** : Shame in Parkinson's Disease: A Review by Julio Angulo, Vanessa Fleury, Julie Anne P'eron, Louise Penzenstadler, Daniele Zullino and Paul Krack - 2019.

# CREATIVITY

Evidence based research shows that the arts can be used to solve problems in health, well-being and learning. The Congress embraces this by cleverly weaving creativity into the programme with video competitions, music and art. Not only is this a fun aspect of the

Congress, it has a wellness and health benefit e.g. using dance as rehabilitation for maintaining balance and flexibility or using vocal training for maintaining speech and swallowing. The overall wellness of the body and mind is a major part of the Congress experience.


# CREATING AWARENESS

The work undertaken by World Parkinson Coalition includes many other activities in addition to the Congress. "Where is Parky" is an initiative that invites people living with the disease to share their pictures and stories using the WPC mascot raccoon Parky. It is a means of connecting the community and raising awareness of Parkinson's.

The Parkinson Tulip Project (PTP) was held in the years leading up to the WPC 2023 and invited Parkinson's community members to come together through photographic images of people in the Parkinson's community with tulips, the official Parkinson's flower. These images were then displayed at a beautiful museum quality exhibit at the 6th World Parkinson Congress, the aim was to give

a face and name to those impacted by Parkinson's, whether living with it themselves, caring for someone with the disease, or treating someone living with it.

WPC runs both an international video competition and hosts a Film Room to help raise the awareness of what is a very complex disease. The winner of the competition receives a free registration and accommodation to attend the Congress where the winning video is shown at the Opening Ceremony. One film, first shown in Barcelona 2023 is one of the most powerful films to come out recently on the stigma of Parkinson's and is now making the rounds to film festivals where it is winning awards: [Shaking Hands with the Devil](#).



*WPC was the best conference I ever attended. It was small enough I didn't feel overwhelmed. I loved the opportunity to hear from clinicians, basic scientists and especially patients- it was a great reminder why I come to work every day.*

**Laura Volpicelli, PhD, Associate Professor, University of Alabama, Parkinson Association of Alabama Professorship**



## INCREDIBLE IMPACTS AWARD 2017

WPC was one of the first recipients of the Incredible Impacts Award, an initiative run by BestCities Global Alliance and ICCA (International Convention and Congress Association) to recognise and reward inspiring legacy initiatives. The grant was \$7,500 USD and was used to provide places for two delegates from Africa and one delegate from South Asia at Kyoto 2019. These were delegates who would not

have been able to attend the Congress had the grant not been made available to them. Since Kyoto the engagement with the African Parkinson's community has shot up and resulted in the creation of Parkinson's Africa, an umbrella organisation to serve the African continent. The young woman at the heart of this lives herself with YOPD and now sits on the WPC Board.

# CONCLUSION

WPC is about the science. It's a Congress that strives to attract a very strong showing of clinicians and researchers. Without that it loses its purpose. A meeting of patients, about the people with Parkinson's and Advocacy, is not sufficient. The key success of this Congress is that it brings all the communities together, delivers an incredible scientific program and at the same time it showcases positive living.

Is WPC intentional about legacy? The answer is a resounding yes. The Congress provides the platform for things to happen. It is designed and planned in such a way to create endless opportunities for people to make an impact. Encouraging delegates to use their advocacy status effectively has resulted in initiatives that positively impact people with Parkinson's and carers lives. Ensuring host destinations are Parkinson's Ready creates a greater awareness and a better understanding of the needs of people with all types of movement disabilities resulting in destinations that are safe and welcoming. Changing the direction of research has opened the eyes of many and channelled it into the areas where the patient needs help. Raising the awareness of the difficulties of living with Parkinson's disease, breaking down barriers and connecting globally to move the science forward creates the most amazing long term positive impact. Without this Congress, progress would not happen so quickly, and it certainly would not include all stakeholders.

When asked what three things have led to

the success of the WPC that others could consider adopting, Executive Eli Pollard gave the following advice:

1. Cross-pollination of the community is paramount to building alliances and breaking stakeholders out of their silos. This is most easily achieved with the support of recognized leaders in the space who declare that it's the way forward, forcing others who may be in doubt to accept the direction. You may lose some leaders along the way, as they won't buy into the "cross-pollination" model, but eventually they either come around or leave the space making room for up and coming leaders who embrace the inclusionary model of scientific meetings
2. Making sure that the core of the Congress and work is always about the science. Whether basic research or clinical research, the science has to remain at the center of the work.
3. Inclusion of people with Parkinson's in all components, including the planning committees, as faculty and presenters, and as members of the audience. For people with Parkinson's, seeing other PwPs who are committee members and presenters from the stage this can be a transformational experience, seeing themselves in future leadership positions.





*World Parkinson Congress was more than a meeting of the minds. Back from the World Parkinson Congress with three regrets; 1) that I missed the opportunities to attend the conference in previous years 2) that I did not bring the entire team, and 3) that I did not sign up to be a volunteer.*

*The scientific program was exceptional by all measures. The presence and active participation of the most important voices and experts in the battle against Parkinson's – the patients themselves, their families and patient advocates, their courage, grace, stories, insights, and resilient spirit were profoundly moving and inspirational.*

*It was more than a meeting of the minds. It was a symphony of moving and inspiring stories, a testament to the resilient human spirit and an affirmation of our shared commitment to fighting Parkinson's disease. It brought to the fore the lived experiences of those affected by the disease reminding us that what we do matters and how do it matters and that at the core of our work lies human lives, each worth our dedication and sacrifices. Today we have a collective responsibility to put aside our competition and work together to accelerate that to new therapies and better disease management treatments.*

**Hilal Lashuel, PhD, MD, Professor of Neuroscience, EPFL, Switzerland & Founder and CSO at ND Biosciences**



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