

The World Parkinson Coalition® Announces Six Recipients Of Its WPC Awards For Contribution To The Parkinson Community

WPC Awardees to be honored during the 6th World Parkinson Congress in Barcelona, Spain.

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They exemplify how to break down barriers, knock down the silo walls around research, and work collaboratively to reach the common goal of better care and treatment for people with Parkinson's." *Elizabeth (Eli) Pollard* Parkinson Coalition (WPC) is proud to announce six recipients of the WPC Awards for 2023. Four awardees will receive the Robin Elliott Award for Distinguished Contribution to the Parkinson Community and two will receive the WPC Distinguished Collaborative Research Award. These awards are granted just once every three years to individuals whose efforts best embody the goals and ethos of the World Parkinson Congress. Recipients have been nominated by community members and selected based on their work that inspires community building and collaboration in research regarding Parkinson's in any one or more of the following areas:

advancement of science, improvement of quality of life, education about Parkinson's, and innovation in clinical care.

The Awardees will be honored at the 6th World Parkinson Congress in July 2023 in Barcelona, Spain. The judges, after reviewing strong nominations from 10 countries, selected six recipients for this year's award from the USA, UK, Netherlands, Uganda, Ireland, and Spain.

Marie-Françoise Chesselet, WPC President and Roger Barker, WPC Vice President, state, "We are honored to present these awards, and humbled by the excellence and dedication of this year's award recipients. Their collective work has made living with Parkinson's easier for many in this community as well as furthered the drive for more inclusive research needed to study and advance our understanding of this complicated disease."

"We are pleased to recognize these individuals whose hard work and dedication help the global Parkinson's community," adds Elizabeth (Eli) Pollard, executive director, WPC. "They truly exemplify how to break down barriers, knock down the silo walls around research, and work collaboratively to reach the common goal of better care and treatment for people with Parkinson's no matter where they live in the world."

The WPC Robin Elliott Award for Distinguished Contribution to the Parkinson Community is being given to the following four individuals:

Richelle Flanagan (Ireland) Diagnosed with Young Onset Parkinson's in 2017, Richelle wasted no time in becoming a Parkinson's advocate. At the time of her diagnosis, she was working full-time as a dietitian while bringing up a very young family of two children together with her

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husband. She attended the 5th World Parkinson Congress, not really knowing many others in the PD community and was inspired when she returned home to help put Parkinson's on the map in Ireland. She has focused on educating health professionals and people with Parkinson's about the importance of diet and nutrition, she has addressed government committees, pushed tirelessly for better multi-disciplinary care for PwPs in Ireland, has raised support monies for Parkinson's causes, such as the WPC travel grants program when she raised more than \$15,000 to support other YOPD folks to travel to the WPC 2023. On top of this work, she co-founded, My Moves Matter, a digital health app to the meet the specific needs of women living with PD and also co-founded the Women and Parkinson's Project to raise awareness of the research and care needs of women living with Parkinson's.

Kabugo Hannington Tamale (Uganda)

In a country with limited resources and very few Parkinson's trained clinicians, Hannington has created a community clinic, brought Parkinson's identification and diagnostic training to health clinics and hospital staff members across Uganda but perhaps more importantly, he has elevated awareness of Parkinson's in Uganda and the organization he runs, Parkinson Si Buko (Parkinson's is not witchcraft) helps educate people about PD and works to ensure individuals living with PD get support and are not isolated after their diagnosis, as Hanny's mother was after her diagnosis. Hannington works tirelessly to inform and educate Ugandans on the realities of Parkinson's disease. Working to shift perceptions and protect others from the decline that comes with untreated Parkinson's, 🛛 Hannington is committed to removing the stigma around this condition. 🗋

Lizzie Graham (UK)

Starting her Parkinson's work in 1989, Lizzie joined the UK Parkinson's Disease Society (now Parkinson's UK where she worked full time as she helped to establish the European Parkinson's Disease Association (EPDA) from 1990 to 2001. From 2001 onwards, Lizzie worked exclusively with the EPDA in various roles, most prominently as Secretary General and then as Executive Director from 2006 to 2018. Lizzie's impact on Parkinson's care continues today in the form of the Parkinson's Disease Nurse Specialists (PDNS) program in the UK, a program that continued today ensuring thousands of people with PD in UK get access to trained Parkinson's clinicians. This UK PDNS model was replicated in several European countries. In 1992, the Parkinson's community was a different place – with neurologists and healthcare professionals taking the limelight and the 'voices' of ordinary people with Parkinson's (PwPs), their families and caregivers relegated to the background.

As a champion of patient engagement, Lizzie was always supporting and encouraging the involvement of people with Parkinson's in conversation that were relevant to them and helped lead multiple surveys collecting data early on inviting PwP to help define what they saw as biggest contributors of their own quality of life.

Vincent "Enzo" Simone (posthumous) (USA/Italy)

As an outstanding Care Advocate both for family members living with Parkinson's and Alzheimer's disease Enzo became a passionate advocate in spreading awareness about these diseases. He launched a film project "10 mountains, 10 years" which received multiple awards and has been screened around the USA and Europe. Enzo made it his life's mission to raise awareness and funds to find a cure for PD and Alzheimer's, when his mother was diagnosed with Alzheimer's in 2002 and in short succession his father-in-law found out he had Parkinson's. Enzo formed a group called the regulars and climbed 10 mountains in 10 years. He did many other International fundraising events via radio and television and formed a group called Pilgrimage to Enlightenment, hiking on the Magna Via Francigena from Palermo to Agrigento to the temple of Asclepius, the birthplace of healthcare. He raised awareness on PD by talking to people along his journeys and doing television and radio interviews. Vincent R. Simone, passed away suddenly on May 22, 2020 leaving behind a legacy that continues to touch people today.

The WPC Distinguished Collaborative Research Award is being given to the following two individuals:

Ignacio "Nacho" Mata (USA/Spain)

Ignacio, or 'Nacho" as his friends call him, has helped launch an international effort to bring the Hispanic community to the forefront of genetic research in Parkinson's disease (PD). He created a consortium comprised of doctors, researchers, patients and family members from more than 40 institutions in 14 countries across the Americas and the Caribbean that provides education about PD genetics/research and genetic testing for Latinos who have PD. Dr. Mata works with the Michael J. Fox Foundation/ASAP-GP2 and the Parkinson's Foundation to help research groups

in Latin America create independent labs by mentoring researchers in genetic testing, analyzing the data through bioinformatics, and helping secure all the necessary resources. Through his work he has helped drive up the inclusion of under-represented Latino populations in research and is a prime example of a researcher that exudes passion for improving the future of research for minority populations and providing a framework for researchers to connect with one another.

Dr. Mata has not only been a pillar in the Hispanic community but has also championed research looking at women with PD to understand their experiences in PD etiology. Dr Mata's passion is contagious, not only among his peers but also among patients all over the world.

Marina Noordegraaf (posthumous) (The Netherlands)

Marina was a patient researcher and accomplished visual artist living with Parkinson's disease in The Netherlands. She was diagnosed with Parkinson's 6 days after her 49th birthday in March 2018. A native to The Netherlands where she studied organic chemistry and lived with her family, she ran a business in Communications. Her gift to the community and the world was her ability to improve and expand on the communication between people with Parkinson's and researchers, as she had an exceptional ability of translating between the lived expertise of living with PD and the learned expertise of PD that clinicians and researchers have. Marina was convinced that open access was the best way to change the world, which means that we can continue using her amazing work even though she is no longer among us. With the publication of her book 'Ommetjes door het Parkinson brein' in March 2022, she fulfilled her dream to "Create new connections, 'human chemistry' in Parkinson's research, healthcare and community to give a glimpse of hope in speeding up discovery, increasing understanding and improving the quality of life of patients with neurodegenerative diseases." She said, "I want to uncover meaningful questions and increase knowledge and understanding by designing the sparks that help this learning process most. There is no fun and meaning in having Parkinson's without the sparks".

About the World Parkinson Coalition[®] and WPC 2023

The World Parkinson Coalition Inc. is a nonprofit organization that provides an international forum for learning about the latest scientific discoveries, medical practices, care partner initiatives and advocacy work related to Parkinson's disease. The World Parkinson Coalition[®] launched the first Congress in 2006 to provide a space for the global Parkinson's community of researchers, clinicians, health care professionals, people with Parkinson's and their care partners to meet in person, network and to share advances in Parkinson's research, improve understanding and promote advocacy worldwide, and to potentially shape future research, treatment and care.

From its modest beginning to nearly 20,000 delegates who have participated in the previous triennial Congresses, the WPC 2023 is expected to attract nearly 4,000 delegates. To learn more about the 6th World Parkinson Congress, please visit: wpc2023.org

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