Editorial

People with Parkinson's as Partners for the Journal of Parkinson's Disease

Kevin McFarthing^a, Bastiaan R. Bloem^b and Lorraine V. Kalia^c

Pre-press 10 March 2023 Published 14 March 2023

Keywords: Parkinson's disease, editorial, patient advocate, patient participation, participatory care

The *Journal of Parkinson's Disease* (JPD) is committed to serving the broad Parkinson's disease research community which undoubtedly includes people living with Parkinson's disease (PwP). Taking people with the lived experience seriously as equal partners in both care and science is increasingly coming to the fore, but we strongly feel that this level of participation should also apply to the world of publishing. There is already a strong representation of PwP in the journal, with seven PwP recruited to the editorial board. Furthermore, our journal regularly publishes articles which are written solely by [1] or together with PwP (see e.g. [2–6], which makes us rather unique in the field of movement disorders. Still, we recognise that we could and should do more.

An important component of serving the PwP community is making the research published in JPD more accessible. JPD is a useful resource with much contemporary and historical content that is currently under-utilised by PwP. As a first step to enhance

PwP readership, JPD has transitioned to a gold open access publication, as we recently announced [7]. This means that all articles published in 2023 and onwards are immediately and permanently freely available online for PwP to view, download, and share. However, not all PwP have a scientific background, let alone the experience and knowledge to read and fully understand manuscripts published in the JPD. To address this, our next initiative is to pilot the addition of summaries in straightforward lay language for each paper, as a special service dedicated specifically to PwP. These summaries will be two to three sentences intended to offer the main message of the article expressed in plain English to describe the findings to a non-scientific audience.

In addition to this new initiative, we plan to refresh the JPD website blogs written by PwP with a new section entitled "The Person with Parkinson Perspective". We will be looking for articles that are not only interesting to PwP but that may also be useful for researchers by providing insight, inspiration, and ideas. We will encourage those PwP with writing skills to propose topics. Blog articles will be approximately 500–1000 words with a flexible structure to

^aParkinson's Research Advocate, Oxford, UK

^bDepartment of Neurology, Donders Institute for Brain, Cognition and Behavior, Radboud University Nijmegen Medical Center, Nijmegen, The Netherlands

^cDivision of Neurology, Department of Medicine, Tanz Centre for Research in Neurodegenerative Diseases, University of Toronto; Krembil Research Institute, Edmond J. Safra Program in Parkinson's Disease and the Morton and Gloria Shulman Movement Disorders Clinic, Toronto Western Hospital, University Health Network, Toronto, ON, Canada

^{*}Correspondence to: Lorraine V. Kalia, MD, PhD, FRCPC, Movement Disorders Clinic, Toronto Western Hospital, McL 7th Floor, 399 Bathurst Street, Toronto, ON, M5T 2S8, Canada. Tel.: +1 416 603 6422; E-mail: l.kalia@iospress.com.

126 Editorial

give authors the freedom to make points in their own style

We look forward to welcoming more PwP engagement with JPD, and are open to receiving further suggestions.

REFERENCES

- [1] McFarthing K (2022) Prasinezumab and Cinpanemab The Perspective of a Person with Parkinson's. *Journal of Parkinson's disease* **12**(8), 2287-2288.
- [2] McFarthing K, Rafaloff G, Baptista M, Mursaleen L, Fuest R, Wyse RK, Stott SRW (2022) Parkinson's Disease Drug Therapies in the Clinical Trial Pipeline 2022 Update. *Journal* of Parkinson's Disease 12(4), 1073-1082.
- [3] McFarthing K, Rafaloff G, Baptista MAS, Wyse RK, Stott SRW (2021) Parkinson's Disease Drug Therapies in the Clinical Trial Pipeline: 2021 Update. *Journal of Parkinson's Disease* 11(3), 891-903.

- [4] Noordegraaf MA, van den Berg SW, Bloem BR (2023) Hopamine as personalized medicine for persons with Parkinson's disease. *Journal of Parkinson's Disease* 13, 271-277.
- [5] Alonso-Canovas A, Voeten J, Gifford L, Thomas O, Lees AJ, Bloem BR (2023) The Early Treatment Phase in Parkinson's Disease: Not a Honeymoon for All, Not a Honeymoon at All? Journal of Parkinson's Disease.
- [6] Meinders MJ, Donnelly AC, Sheehan M, Bloem BR (2022) Including People with Parkinson's Disease in Clinical Study Design and Execution: A Call to Action. *Journal of Parkinson's Disease* 12(4), 1359-1363.
- [7] Bloem BR, Kalia LV (2023) The Journal of Parkinson's Disease Takes the Open Road. *Journal of Parkinson's Disease* 13(1), 1-2.