

Commentary

People with Early Onset Parkinson's Disease: Empowered to Improve Care

Josefa Domingos^{a,b,c}, Maria do Carmo Teixeira Bastos^c, Rui Couto^c, Ana Rita Cameira^c, Ana Leal Cardoso^c, Alexandre Reffóios^c, Susana Magalhães^{c,d}, João Massano^{c,e} and Tiago Fleming Outeiro^{c,f,g,h,i,*}

^a*Department of Neurology, Donders Institute for Brain, Cognition and Behavior, Center for Medical Neuroscience, Center of Expertise for Parkinson and Movement Disorders, Radboud University Medical Center, Nijmegen, The Netherlands*

^b*Egas Moniz Physiotherapy Clinic and Research Centre, Centro de Investigação Interdisciplinar Egas Moniz (CiiEM), Portugal*

^c*Young Parkies Portugal, Porto, Portugal*

^d*Institute of Research and Innovation in Health of the University of Porto (i3S-UP), Porto, Portugal*

^e*Department of Neurology, Centro Hospitalar Universitário de São João and Faculty of Medicine University of Porto, Porto, Portugal*

^f*Department of Experimental Neurodegeneration, Center for Biostructural Imaging of Neurodegeneration, University Medical Center Göttingen, Göttingen, Germany*

^g*Max Planck Institute for Multidisciplinary Sciences, Göttingen, Germany*

^h*Translational and Clinical Research Institute, Faculty of Medical Sciences, Newcastle University, Framlington Place, Newcastle Upon Tyne, UK*

ⁱ*Scientific Employee with an Honorary Contract at Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE), Göttingen, Germany*

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Abstract. Patient organizations play an ever-growing role in modern societies by providing organized resources for patients and care partners. Importantly, patient organizations enable patients to define and share their needs and views. In Parkinson's disease (PD), patient organizations play significant roles in different countries. However, there is limited support and resources tailored for people with early onset Parkinson's disease (EOPD). These individuals face unique social, professional, and personal challenges that are often not accounted for by general PD organizations, which play very important roles for a significant proportion of individuals with PD. In Portugal, this was the situation until 2022, when Young Parkies Portugal (YPP) was founded to allow people with EOPD and various stakeholders to join forces to cover their specific needs. In this manuscript, we aim to share our experience in building an association for people with EOPD, reflecting on the reasons for

*Correspondence to: Tiago F. Outeiro, Department of Experimental Neurodegeneration, University Medical Center Göttingen, 37073 Göttingen, Germany. E-mail: touteir@gwdg.de.

this need, the activities developed thus far, challenges in implementation, and future directions. In summary, we believe that nonprofit organizations like YPP play an essential role in shaping the care and support of people with PD care and should be considered key partners of care alongside the larger multidisciplinary team. We are confident that sharing our experience can inspire and guide the implementation of similar initiatives in other countries.

Keywords: Parkinson's disease, early-onset, neurodegeneration, parkinsonism, patient association

INTRODUCTION

Parkinson's disease (PD) is the second most common neurodegenerative disorder and is increasing in prevalence due to the aging of the human population [1, 2]. The age cutoff for early onset Parkinson's disease (EOPD) has been heterogeneously defined in the literature. Still, recent expert consensus recommended that it should be used for cases starting between 21 and 50 years of age [3].

Given that EOPD poses significant, and unique, social, professional, and personal challenges to patients, their families, care partners, as well as healthcare systems, there is an urgent need for the development of teams that combine a unique set of expertise and resources to provide adequate support during the various stages of the disease. However, there is still no systematic information on the specific needs of people with EOPD. There has been limited research and resources specifically designed for this population, who often search and navigate nonspecific resources online, generated mainly by nonprofit groups.

Nonprofit organizations play essential roles in the care and support of people with PD care and should be considered partners of care alongside the wider multidisciplinary team. Patient involvement in such organizations brings unique and vital viewpoints to the healthcare process, ensuring that scientific and clinical advances are patient-centered and relevant.

Herein, we share the motivation for creating a patient association tailored to the needs of EOPD individuals—Young Parkies Portugal (YPP), as a tool for providing specific information and care in the Portuguese PD community.

EMPOWERMENT: YOUNG PARKIES PORTUGAL AS A VEHICLE FOR PROVIDING SPECIFIC INFORMATION AND CARE

YPP was created from the perceived absence of support that three people living with PD (Carmo, Rui,

and Alexandre) felt when diagnosed in their 30s and early 40s.

Carmo was 44 years old when she was diagnosed with PD in 2018. Married, mother of three teenagers, and with a solid career in investment banking, Carmo's first initiative was to search for information about her condition. She was shocked by the estimated number of people with this condition in Portugal (around 3,000) and by the absence of information in Portuguese. Her experience during the first couple of appointments with the neurologist also showed flaws in the system: how can a patient be adequately supported if the stakeholders (doctors, researchers, physiotherapists, psychologists, etc.) do not share adequate information and knowledge?

Rui was 36 years old when he was diagnosed with PD. In 2010, he started complaining about difficulty raising his right hand when moving the computer mouse, his arm dragging on the desk, and having difficulty brushing his teeth. Rui was facing episodes of fear of movement in activities he used to master, like skiing, and constantly feeling stiff. Due to traveling a lot for work, it was getting harder to meet his doctors regularly. The diagnosis was made in June 2012, and by that time, his right arm did not swing—this was a solid indicator for the neurologist. He describes the diagnosis as a shock and found limited help in his community, particularly in Portuguese, his mother tongue.

Alexandre was diagnosed with PD at the age of 37. Father of 4 children, and a professional architect, he noticed a slight tremor in his fingers and decided to seek a neurologist. The diagnosis came as a shock, but he quickly started a daily routine where work, wife, children, and physical exercise gained an even more significant presence. As he searched for more information, he found scarce resources and support for young people with PD.

These three people with EOPD quickly realized that something had to be done to create the help they needed and assist others like them, who also needed specific support. In 2021, YPP was born to Inform, Integrate and Assist (2IA) people with EOPD and their families. YPP promotes cooperation between all

stakeholders, from caregivers to doctors, researchers, physiotherapists, etc. The ultimate mission of YPP is to create a sense of community, providing people with the tools and the motivation to pursue an active, confident, and healthy way of living with PD.

STEPS TAKEN AND CHALLENGES ENCOUNTERED

As a new association, we first defined an action plan to ensure YPP would strive and serve its mission. We assembled a core multidisciplinary team that could cover essential areas of activity. The founding team included people with EOPD, a neurologist, a basic scientist, a physiotherapist, a sociologist, and communication and financial specialists. We realized we needed a broad group of people to ensure the association would achieve its goals and serve its role in the modern society we live in. A clear communication strategy and strong presence in social media was considered essential.

We identified areas where additional information was necessary, specifically for people with EOPD in Portugal, as we realized people are left to navigate nonspecific resources online, mainly on websites in English, making it less accessible for those with limited language knowledge. In response, we created a digital platform (<https://www.youngparkiesportugal.org/home/>) that provides expert-validated information to obtain input and insight from our members and deliver tailored care for the Portuguese PD community.

We initiated online activities through various digital platforms. These included webinars, which we named Parkie Talks (available on YouTube and Spotify), specialized physical activity classes for EOPD individuals, yoga classes, and a psychological support group, where family members are also welcome and encouraged to join, as this is a key element in the process of care. We created and implemented a yearly 2-day ‘YPP Bootcamp’ to engage people in person so that experiences, fears, and hopes can be shared in person. The lack of resources and funding is a constant challenge. This requires a defined goal-oriented strategy to ensure we expand our activities in a sustainable manner. Nevertheless, fund-raising activities and the generosity of most of those we have approached have allowed us to deliver all the above activities at minimal or no cost, to participants, which we consider paramount.

As our visibility grows, we have been approached by other stakeholders to disseminate initiatives and research studies conducted in Portugal, thereby enabling us also to stimulate new collaborations and interactions with existing research groups.

In 12 months, 183 people registered as members of YPP. Of these, 154 were people with young-onset PD. From the young-onset PD group, 83 are married, 86 are still working, 46 live in Lisbon, 22 live in Porto, and 86 live in other areas of the country.

Social media metrics were assessed and demonstrated a strong impact of YPP in just one year: 351 newsletter subscribers; 69 subscribers of the Young Parkies Facebook group; 20.000 users <https://www.youngparkiesportugal.org>; 9.015 Instagram followers ([youngparkiesportugal](https://www.instagram.com/youngparkiesportugal/)); and 1.017 Facebook friends ([youngparkiesportugal](https://www.facebook.com/youngparkiesportugal/)).

Our priority is to constantly identify the specific needs of the members to define possible actions to help support and fulfill those needs. As such, we are currently designing a research study to assess the needs of our community using scientific methodology and artificial intelligence support. The ongoing challenge with such studies is to employ adequate assessment tools that can provide a detailed understanding of needs while avoiding overloading the participant with questions. A digital questionnaire is being built based on pretest methods involving ten people with PD. Given the wide variety of topics (demographics, understanding of PD, work-related issues, family issues, genetic awareness, access to care, etc.), a well-designed set of questions must be defined. Special considerations will be made for issues regarding women with EOPD (factors affecting pregnancy, hormones, menopause, etc.) and to raise awareness about genetic testing. Other patient associations and groups can be key partners in research studies. They can help access patient populations often dispersed, raise awareness for further research, share meaningful areas of interest for research, and help researchers get more funding opportunities [4].

IMPLICATIONS FOR PATIENT CARE AND OUTLOOK

Patient organizations can be focused on the local or regional, national, continental, or broader international level. They echo the voice and needs of the various patient communities. In this context, we are confident that YPP can serve as an example of how

people with EOPD are making a difference. The best assistance one can provide to others is to empower them to fulfill their needs according to their views and input. Our goal has been to create an environment that enables EOPD individuals to take their needs into their own hands and, thereby, shake the status quo and improve our society.

We also aim to engage as active research collaborators, assisting research teams set priorities and accessing people with EOPD for various research studies, ensuring their involvement from the initial stages of the projects.

In conclusion, we strongly believe that nonprofit organizations, like YPP, play an essential role in the support of people with EOPD, and should, therefore, be considered partners of care alongside a wider multidisciplinary care team. We are confident that sharing our experience may inspire and guide the further implementation of similar initiatives in other countries.

CONFLICT OF INTEREST

Tiago F. Outeiro is an Editorial Board Member of this journal but was not involved in the peer-review

process nor had access to any information regarding its peer-review.

REFERENCES

- [1] Massano J, Bhatia KP (2012) Clinical approach to Parkinson's disease: Features, diagnosis, and principles of management. *Cold Spring Harb Perspect Med* **2**, a008870.
- [2] Dorsey ER, Sherer T, Okun MS, Bloem BR (2018) The emerging evidence of the Parkinson pandemic. *J Parkinsons Dis* **8**(s1), S3-S8.
- [3] Mehanna R, Smilowska K, Fleisher J, Post B, Hatano T, Pimentel Piemonte ME, Kumar KR, McConvey V, Zhang B, Tan EK, Savica R; International Parkinson and Movement Disorder Society Task Force on Early Onset Parkinson's Disease (2022) Age cutoff for early-onset Parkinson's disease: Recommendations from the International Parkinson and Movement Disorder Society Task Force on Early Onset Parkinson's Disease. *Mov Disord Clin Pract* **9**, 869-878.
- [4] Raffai F, Timmis O (2017) Building the patient community. *Gene Ther* **24**, 547-550.