

PRESS RELEASE

Parkinson's community throughout Europe urges more progress in the management, treatment and awareness of Parkinson's

Europe: 20 October 2022

Today (20 October 2022) sees the launch of 'A Parkinson's Manifesto for Europe, 30 wishes from the Parkinson's Community'. The Manifesto has been developed following a series of workshops and surveys and represents the view of people from the Parkinson's community (including people with Parkinson's, their caregivers, family members and health care professionals) in 39 countries in Europe and beyond.

It's the first document of its kind to describe the hopes and wishes of people across Europe – 200 years since the disease was first identified. It aims to help shape the Parkinson's agenda in Europe on what truly matters to the Parkinson's community, guiding those working in health, research and policy areas.

Information collected has been shaped into 30 wishes covering awareness; training; diagnosis; research; and quality of life. Some examples include:

- increasing awareness of gender and age differences among people with Parkinson's to create a more accurate representation of the variety of people the condition affects;
- improving all health professionals' understanding of Parkinson's so they can better manage symptoms and support those with the condition;
- supporting the adoption of a holistic care system that takes into account the whole person: their emotional, physical, mental and social wellbeing; and
- offering clear, timely and consistent access to licensed treatments that provide increased efficacy, better pain relief and fewer side effects, as well as the opportunity to take fewer medications.

Millions of people across the world have Parkinson's (a conservative estimate is 10 million but it's likely to be much higher than this). It's the fastest-growing neurological disease of the century and no cure exists. More important still, the Manifesto symbolises a pressing need for more progress in improving the quality of life of those living with the condition.

Russell Patten, Director General at Parkinson's Europe, said:

“Our 30th Anniversary felt like the right time to consider the question: how has treatment and prevention of Parkinson's progressed over the last 200 years since the condition was medically described? And who better to consult than the Parkinson's community themselves.

"From our perspective, the manifesto is a distillation of what the Parkinson's community really feels about the evolution of progress relating to the condition. And the message is clear: they want more investment in five key areas: awareness; training; diagnosis; research; and quality of life.

"In a world where more and more people are being diagnosed with Parkinson's, the progress being made to improve the condition is absolutely unacceptable. Very often other diseases win the day when it comes to investment in research, treatment and quality of care. Parkinson's is a ticking timebomb and it's time for policymakers, health professionals and society in general to be proactive. We hope this 'wish list' will be a springboard for guiding and shaping this proactivity over the coming years.”

Elisabeth Ildal from Denmark, a person with Parkinson's who took part in one of the workshops, said:

“I was keen to give my view, particularly as a woman with Parkinson's. The condition is too often portrayed as the shaking old man. We feel this shows a lack of understanding. People with Parkinson's often don't recognise themselves in what's reflected back to them in public. We need increased awareness of gender and age differences among people with Parkinson's to create a more accurate representation of the variety of people the condition affects.”

Notes to Editors

- For interviews or quotes, please contact Tara Nabili at tara@parkinsonseurope.org +44 7717442315
- Copies of the Manifesto as well as a recording of a webinar presenting it can be found from 20th of October (PM) at www.parkinsonseurope.org/manifesto.
- The Manifesto is available in nine languages: Czech, Dutch, English, French, German, Italian, Portuguese, Slovenian and Spanish – with more translations planned.
- Parkinson's Europe is a non-profit organisation and the only European Parkinson's umbrella organisation. We have been championing and working with the global Parkinson's community for 30 years and are the voice for people with Parkinson's in Europe. Visit our website at www.parkinsonseurope.org