EJS ACT PD
Accelerating Clinical Trials in Parkinson's
The Edmond J Safra ACT PD initiative

EJS ACT-PD – The Next Generation of Clinical Trials for Parkinson's

A call for people with Parkinson's and their carers/partners to contribute

Help us to continue the success of the recently launched trial for Parkinson's by joining EJS ACT-PD as part of the wider network of patient and carer representatives!

What is EJS ACT-PD?

The Edmond J Safra Accelerating Clinical Trials for Parkinson's Disease (EJS ACT-PD) initiative is an exciting project that was set-up to improve how we deliver research for Parkinson's. In stage 1 (2021 – 2024) the initiative designed the EJS ACT-PD trial which aims to speed-up how we find treatments that can slow or stop the progression of Parkinson's disease. The trial will do this by using a multi-arm, multi-stage (MAMS) design which tests multiple treatments at once, removes ineffective treatments early, and can add new treatments without needing to stop the trial. The first two treatments have started testing this Autumn, with a third drug starting in 2026.

In stage 2 (2025 – 2029) the initiative will work alongside the trial, with a focus on making sure the trial continues to improve and can continue running for as long as needed until we find a treatment that works. You can read more about the EJS ACT-PD project here: www.ejsactpd.com.

Occasionally, there are topics that the group would like to receive further input on, to understand a wider perspective from the Parkinson's community. We are therefore looking for people with an interest in research to form a wider patient and carer/ partner network for the EJS ACT-PD project.

Members of this network would agree to be contacted by the EJS ACT-PD team with requests for input when they arise. The range of input requested from members will vary, but may include being asked to complete online surveys, to vote on different decisions or being invited to take part in focus groups or discussions.

Network members would be under no obligation to respond to every request but would agree to their contact details being stored and used for this purpose. The topics in question would be related to the discussions within EJS ACT-PD's Working Groups, which were set-up to help design the trial and now to ensure its continued success:

1) Reiterating and improving the **Treatment Selection** strategy
2) Selecting innovative new **Outcome Measures**
3) Identifying and applying for **Funding** sources.
4) Developing a **Communication** and engagement strategy

Network members would provide a crucial additional input to help present the critical viewpoint of people living with Parkinson's and their care partners.

We are looking for individuals who:

- Are passionate about improving Parkinson's research

- Are willing to contribute as and when needed, in a variety of different ways
- Are willing to link other interested individuals to the EJS ACT-PD network where possible

EJS ACT-PD will retain the wider network's contact details for the purposes of the EJS ACT-PD trial and Initiative only. All personal information will be stored securely within the UCL or University of Plymouth's password protected servers, and only approved members of the EJS ACT-PD team will have access to them.

If you would be interested in joining the EJS ACT-PD wider network of people with Parkinson's / carers and partners, please complete and return the short application form at the end of this document.

Applications should be sent to the EJS ACT-PD team at: ejs-act-pd@ucl.ac.uk. If you have any questions or need any further information, please feel free to contact the team.

Kind regards,

Georgia Mills
Project Manager, EJS ACT-PD

Dr Kevin McFarthing,
PPIE Working Group Chair

Title		Name		Surname	
Gender			Ethnicity		
e-mail			County		
Do you have Parkinson's or are you a carer/partner?					
When were you/the person you care for/partner diagnosed with Parkinson's?					
At what age were you diagnosed with Parkinson's?					