



# Newsletter January 2023

Welcome to our first newsletter of the year and a warm welcome to our new readers and we hope you find the information below helpful.

We have been in touch with MSD and have been informed that there is no issue with the supply of Sinemet in Ireland as of January 2023.

We are delighted to let you know that Prof. Richard Walsh will update us on the latest advancements for PD, DBS etc at an information night in Lucan, on the 24th February at 6.30pm. This will also be available to attend online. Details to follow or contact at [joecondon@eopd.ie](mailto:joecondon@eopd.ie).

The Board of Directors had a workshop recently to draft our strategic plan. see picture below. We will be inviting you to hear your views and suggestions soon.

We are meeting up next Tuesday in Dublin, please see details below.

Looking forward to the year ahead, as we try to enhance the lives of people in our community.

Kind regards,  
Mary Casserly  
(Chairperson EOPD.ie)



## Patients Deserve Better

EOPD.ie are part of this campaign, Patients Deserve Better. EOPD and MS were two of the conditions that speakers were invited to give their lived experience at the launch of CHO 5. See Video below.

[View Video](#)

The National Strategy for Neuro-Rehabilitation states that 9 teams are required for a multi disciplinary approach, but only 2 have been delivered. Everyone deserves access to a community neuro-rehabilitation team. Visit [www.patientsdeservebetter.ie](http://www.patientsdeservebetter.ie) .It only takes a few minutes to contact your local political representatives in your area to highlight the need for better services. Click on link below to take action now.

[Take Action Now](#)



## Parkinson's community Awareness of Research; emphasis on Knowledge and Information Exchange

The following survey is being conducted by the Caldwell Research Group in Trinity College Dublin, The University of Dublin. This survey was created through input from St. James's Hospital, the Mater Private Hospital, the Neurological Alliance of Ireland, and Early Onset Parkinson's Disease Ireland. Professor Maeve Caldwell, Professor Jean Fletcher, Professor Timothy Lynch, Professor David Bradley, Magdalen Rogers, Joseph Condon, and Fiachra O'Higgins were all involved in the survey's creation.

In this survey, we want to **discover how much people with Parkinson's know about their condition**, particularly the potential role played by the immune system. We also want to discover what areas of research into Parkinson's they consider important to them.

We will do this by co-creating a survey to answers these questions. We also want to discover **where people with Parkinson's get their information from**, who do they listen to and who do they discuss their condition with.

Furthermore, the survey will also determine **what activities help them deal with their condition and increase their quality of life**.

This survey will not collect any personal or identifying information and all responses will be stored by Trinity College Institute of Neuroscience.

The responses to this survey help create a conference to help inform people with Parkinson's Disease about topics they are interested in learning more about and provide information about resources available to them online and in Ireland.

If you would like to be involved in the focus group please send your details to [joecondon@eopd.ie](mailto:joecondon@eopd.ie) by the Monday the 30<sup>th</sup> of Jan.

## PHONE SURVEY

We recently conducted a phone survey of our members in which the overall opinion was they were happy with EOPD.ie to date.

Some comments/suggestions were:-

- Increase membership for a stronger voice for EOPD.
- More awareness for this hidden disability.
- Additional research and looking into the other drugs not available in Ireland. Members were happy to hear we campaigned for Ongentys, which had already been England for 5 years.
- More in person get togethers for peer support.

We would like to thank those who took part. If you have missed the notification to participate in this survey and would like to give your input please contact [kieranfallon@eopd.ie](mailto:kieranfallon@eopd.ie).



## Update from Cure Parkinsons on 2022 Clinical Trials

**Parkinson's Disease:- Dr. Simon Stott's research highlights from 2022 & what's in store for 2023**

Featured on the No Silver Bullet YouTube Channel - Check out the video below.

[View Video](#)

# Focus on Exercise

It's the new year again and many of us will make a renewed effort to exercise and get or stay fit. Exercise is one of the only proven ways to slow Parkinson's progression and this recent article also reiterates other benefits of

exercise. **Parkinson's: NI man shows how exercise can alleviate symptoms.**

Click on link to read his story.

[Read full article](#)

We have listed below some providers of exercise programs. Please seek professional advice if starting a new exercise regime and always exercise to your own ability to avoid injury.

- University of Limerick online classes by Physiotherapy Students, starting beginning of February contact marie.murphy@ul.ie
- Exercise classes for people living with Parkinsons:-
  - New Ross, Farrell Fitness. Contact Robbie at 087 7759716.
  - Mullingar- K & S Fitness. Contact Ken at 086 1676358
- Rock Steady Boxing online classes <https://www.eventbrite.ie/e/rock-steady-boxing-classes-fighting-back-parkinson-tickets-491205136787> and in person classes on Saturday's at Portlaoise Combat Academy
- ' Minding Me' is a free online exercise and health education programme <https://edufit.ie/programmes/minding-me/>
- Exwell run classes for people with health conditions in certain locations around Ireland [Home \(exwell.ie\)](http://Home.exwell.ie)
- Dance for Parkinson's <https://www.danceireland.ie/whats-on/events/dance-classes-for-people-with-parkinsons-1>
- HSE videos of Pilates Classes <https://www.hse.ie/eng/about/who/healthwellbeing/exercise-videos/pilates-videos.html>
- There are also many organisations that run exercise programs in each county. Check out your local sports partnerships. e.g South Dublin County Sports Partnership <https://sdcsp.ie>

## Upcoming Events



### Dublin meet up

We would be delighted if you are available to join us Next Tuesday 31st January at 12.00 pm in Leopardstown  
Contact [marycasserly@eopd.ie](mailto:marycasserly@eopd.ie) or [kieranfallon@eopd.ie](mailto:kieranfallon@eopd.ie) for details, hope to see you there.

## Parkinson's Games

June 23 – 25, 2023

Eindhoven Netherlands

- International Multi-day Sports Event for people with Parkinson's disease and their carers/partners
- Originated by analogy with the Paralympics and Special Olympics

### Why join The Parkinson Games

- Sports and exercise are good ... it stabilizes and slows down Parkinson's disease
- Connecting people with Parkinson's disease and their carers internationally
- Participation contributes to fundraising for fundamental research into Parkinson's

[Visit The Website](#)

## World Parkinson's Congress

The 6th World Parkinson Congress (WPC 2023) will be held in Barcelona, Spain from July 4 – 7, 2023. Details are available on <https://wpc2023.org/>. We have decided that EOPD.ie will not be represented at the congress this year. Please see the website below for more information on this event.



[Find Out More](#)



Facebook



Instagram



Twitter



Email

### Our mailing address is:

Authorized representative: Mary Casserly

Email address: [newsletter@eopd.ie](mailto:newsletter@eopd.ie)

Phone: +35315252994

Address: 77 Lower Camden Street, Dublin 2

Registered Charity Number (RCN): 20206267

Revenue Number (CHY): CHY22875

Want to change how you receive these emails?

you can [update your preferences](#) or [unsubscribe from this list](#).