

Welcome to this week's e-newsletter. Please note that our Freephone Helpline 1800 359 359 is open from 9am - 5pm Monday to Friday. If you wish to avail of our Nurse led call back service with Lisa Wynne (PDN) or a call from the Dietitian Richelle Flanagan please phone the Helpline to arrange a call



Message From CEO: Job Opportunity

We have started the recruitment process for an additional Parkinson's Disease Nurse. This is due to the exceptional demand for our services and as part of the implementation of the 'Healthcare and Wellbeing' section of our strategic plan. As we receive no core state funding currently, the role will be fully funded by income raised through fundraising and in that regard, we are appreciative of the ongoing fundraising efforts of both members and the general public.

Details of the role can be found here: [Job Opportunity – Parkinson's Disease Nurse – PAI \(parkinsons.ie\)](#)

If you know of anyone that may be interested in applying for the role, please forward the above link to them.



Research update: UCC Survey

The Parkinson's Association of Ireland (PAI) welcomes the results of a survey which was published by UCC this week, as part of their wider mapping project. The survey sought to understand the services available to people with Parkinson's Disease (PD) and how people with PD access them. The principal researchers were Prof. Suzanne Timmons and Dr. Emma O'Shea of University College Cork.

There were over 1,400 responses to the survey, 68% of which were current or former members of PAI.

The results of note included:

Diagnosis:

For 1 in 5 respondents, it took longer than 12 months to receive a diagnosis. 22% said that how the diagnosis was relayed was unacceptable.

Early-onset:

People with early-onset PD were significantly less satisfied.

Access to consultants:

43% of respondents only attended a consultant either once per year or less. Those attending a private consultant were seen significantly more frequently.

Access to other services:

There was an overall lack of access to nurse specialists and clinical therapists.

Urban versus rural:

Participants in rural areas were more underserved than those in urban areas.

Speaking to PAI this week, Dr. Emma O'Shea commented: "What the results tell us is that PD care is significantly under-resourced which affects diagnosis and ongoing care."

The results of this survey will assist PAI in it's calls on senior decision makers to prioritise PD care.

PAI would also like to thank the efforts of it's Cork branch members for their role as patient advocates as part of the study.

The project was fully funded by the Health Research Board in 2019 and PAI was delighted to be the co-applicant on the funding application.

A Collection of Quarterly Parkinson's Webinars



Next Webinar
WPC 2023 HIGHLIGHTS
5:30-6:30 p.m. BST | 12:30-1:30 p.m. ET
Wednesday 6th September, 2023
Only 500 Spaces Available - Register Now!

Brought to you by



Overview of WPC: What it is and why it's an important event:

World Parkinson Congress (WPC) is the only meeting that brings together scientists and researchers, people living with Parkinson's and their loved ones, and clinicians and healthcare professionals.

But WPC is more than a meeting it's an extraordinary educational event where healthcare professionals and researchers have the opportunity to learn from each other as well as from people living with Parkinson's and where people living with Parkinson's have the opportunity to present posters, books, lead talks and sessions, share ideas and advice. WPC is where international collaborations and friendships are forged.

The Barcelona meeting saw teams cycling from the UK, Italy and Spain to attend the conference, and one individual even ran all the way from the UK – an incredible achievement!

During this webinar, chaired by The University of Edinburgh's Professor Tilo Kunath, we will hear from our panelists about which WPC sessions they found most useful and why they found them so motivating. For further information you can visit the website here -

<https://cureparkinsons.org.uk/2023/08/upcoming-webinar-world-parkinson-congress-insights/>



Dublin Branch Autumn Meeting Deferred

The Dublin Branch Autumn Meeting, due to take place at St. Anthony's Parish Centre Clontarf 3pm on 7th October has been deferred due to a clash with a conference being organised by Trinity College on the same day.

We will re-organise the meeting and let members know the new date as soon as we can.

Mary Butler,

Chairperson Dublin Branch PAI.

EATING WELL WITH PARKINSON'S DISEASE



Nutrition and Parkinson's Disease

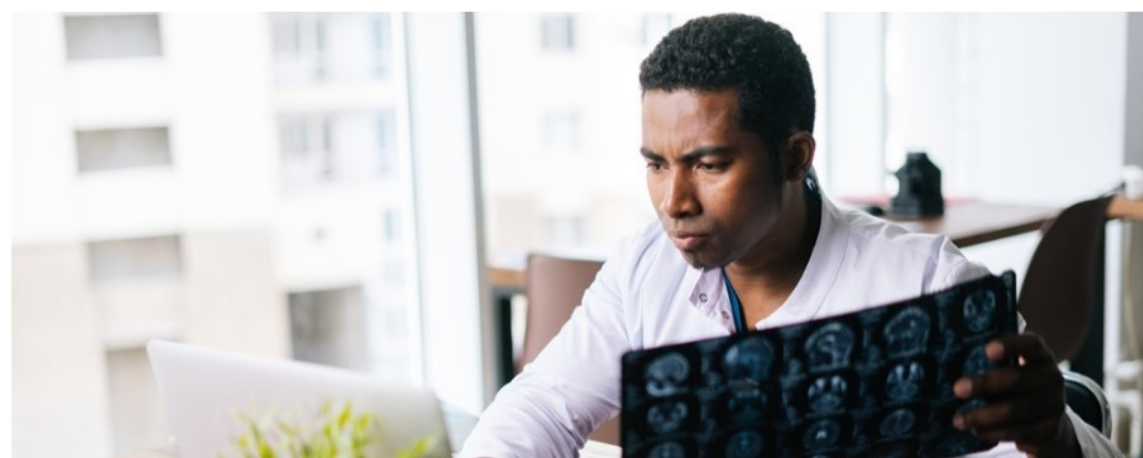
Whilst there is no specific 'PD diet', research to date is showing that healthy diets are beneficial to people living with PD. Diet can also play a role in improving some of the symptoms people with PD may experience such as: • Unintentional weight loss or gain • Chewing and swallowing difficulties • Constipation • Dehydration • Osteopenia and osteoporosis You should be referred to a Dietitian soon after your diagnosis and have ongoing reviews throughout your Parkinson's journey. Your Dietitian can assist you with maintaining a healthy weight and muscle mass, ensuring good hydration status, and reducing your risk of constipation. Your Dietitian can help you to manage dietary issues related to your PD and advise on the best diet to maximise the effect of your PD medications.

PAI have a call back service with Dietitian Richelle Flannagan. If you would like to arrange a call with Richelle call 1800359359 and she will talk you through any questions you might have.

PAI have a booklet that you can download free of charge from the website to have a read through here -

<https://www.parkinsons.ie/wp-content/uploads/2022/05/1440-INDI-Parkinsons-FINAL-full.pdf>

Alternatively you can give us a call on 1800359359 and we can pop it out to you in the post.



Preparation for Neurologist Visit

To help people get the most from your visit with your neurologist, below is a link to a PDF file with some questions to be considered and bring to your meeting. We recommend printing this document and filling it in prior to the meeting.

[Questionnaire for Meeting with Neurologists Report](#)

If you have any news that you would like to be included into the newsletter, send it into Sabrina at fundraising@parkinsons.ie