



Parkinson's

Association of Ireland

www.parkinsons.ie

Autumn 2023

CEO Shane meets the Minister for Disabilities Anne Rabbitte TD



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A MESSAGE FROM THE CEO - SHANE O'BRIEN

DEAR MEMBERS,

I'm delighted to have finally taken up my role with the PAI. At the time of writing, I have completed my first full month with the organisation.

I can already see the clear impact that PAI and its members play in improving the lives of people with Parkinson's Disease and their care partners.

Existing services:

We continue to provide our helpline service on 1800 359 359. The service provides information, support and advice. The service is provided by our dedicated nurse specialist, Lisa Wynne, and our dietitian, Richelle Flanagan.

We are recommencing our weekly Zoom classes which include mindfulness, exercise, yoga and singalong. Our PD nurse Lisa Wynne also continues to have her weekly Zoom Clinic every Thursday which covers symptoms, medications and other topics related to PD.

Please liaise with your local branch regarding services in your area and also keep an eye on our weekly e-newsletter.

I would encourage you to engage with our services if you are thinking about doing so.

Additional nurse:

In the new strategic plan, a major area of focus is to grow the services that PAI offers. This will be required over the coming years due to the increase in the number of people being diagnosed with PD. As you may have seen, one of my first actions was to start the recruitment process for an additional

- PD specialist nurse. I'm delighted to announce
- that after an extensive recruitment campaign,
- an additional nurse will be starting on the 16th
- of October 2023. I'm determined to increase our
- services over the coming years. As we receive no
- core state funding, the role will be fully funded by
- income raised through fundraising.

Advocacy:

- As you are aware, the main objective of the
- organisation has been to obtain section 39 HSE
- funding for our services. We will be submitting an
- application for funding over the coming weeks.
- Linked to this is our pre-budget submission that
- you will most likely have viewed by now. If not, you
- can view the submission in full in this magazine.
- We will continue to lobby for government funding
- using all available avenues. I'm a firm believer in
- utilising the strength of our membership. I would
- ask that you send a copy of our pre-budget
- submission to your local TDs and ask them to
- support our asks. As the general election in 2024
- is only around the corner, we will continue this
- collective advocacy work.

- We continue to support the work of the
- Neurological Alliance of Ireland (NAI) as one of its
- member charities. I attended an event to mark the
- 20th anniversary of the NAI and the retirement of
- Professor Orla Hardiman as National Clinical Lead
- for Neurology, on the 29th of August last. The
- NAI collectively advocates on behalf of people
- with a neurological condition. Among its recent
- campaigns was "Patients Deserve Better", which
- secured additional funding for specialist nurses
- around the country including Parkinson's nurse
- specialists within the HSE.

Research committee:

- The Research & Impact committee continues to
- meet on a regular basis. The committee is chaired

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by Dr. Emma O'Shea of UCC. We aim to expand the work of this committee in line with the strategic plan and increase our investment in research over the coming years. We will be issuing more detailed updates on the work of the committee to members.

UCC survey

We welcome the results of a survey which was published by UCC recently, as part of their wider mapping project. The survey sought to understand the services available to people with PD and how people with PD access them. The principal researchers were Professor Suzanne Timmons and Dr. Emma O'Shea of University College Cork. I plan to use the results of this survey to support our advocacy work over the coming years, as it clearly demonstrates the gaps in services for people with PD and the large variability in services depending on an individual's circumstances e.g. public versus private patients. 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.

Fundraising & Communications:

I will be reaching out to all members over the coming months to get your ideas on what major fundraising events we should be focusing on over the next while. As our services grow, so will the need for funds.

I will also be getting your views on some of the key awareness themes that you'd like us to focus on. As people with PD and care partners, your views are invaluable on how we educate the general public about PD.

Social event & branch meetings

Finally, I look forward to meeting any of you that are attending the social gathering in the Hodson Bay hotel.

I plan to continue to visit our branches over the coming months and to meet as many of you as possible. I'd like to thank all the members that I've met so far, and those who have contacted me directly, for making me feel so welcome.

Take care,

Shane

See our Pre-Budget Submission in the centre pages of this issue

OUR ASKS FOR BUDGET 2024 ARE:

- To be provided with HSE section 39 funding for Parkinson's Disease nurse specialists
- An increase in the number of allied health professionals in the community e.g. physiotherapists
- Investment in community neurorehabilitation teams

HOW YOU CAN HELP:

We are asking the Parkinson's Disease community to support our Pre-Budget Submission. We kindly ask that you contact your local TDs and Senators to ask them to support our submission.

If you would like hard copies of the document to be posted to your address, please contact the national office on 1800 359 359 to request same.

If you are on social media, can you also 'like' and 'share' our posts related to this topic over the coming weeks?

We appreciate your ongoing support for our advocacy work. Thank you.

Shane

UCC - Parkinson's Disease Gait Freeze Study

Team: Pádraig Cronin, Dr Lucy Collins
Stack, Prof. Aideen Sullivan



Freezing of Gait (FoG) is one of the most debilitating and pervasive symptoms of Parkinson's Disease. Freezing of Gait can be defined as "brief, episodic absence or marked reduction of forward progression of the feet despite the intention to walk". People with Parkinson's (PwP) often describe the phenomena as their feet being "glued" to the ground, blocking their ability to take a step. It primarily affects the gait of PwP, manifesting when starting to walk, in the middle of the movement, when turning or changing direction, when approaching obstacles, or in narrow spaces. Once the freezing episode terminates, the person can often walk smoothly and without impedance; however, over time people experience increasing incidences of gait freeze and falls.

Throughout the Summer of 2023, research was carried out by our team at University College Cork, in collaboration with the Parkinson's Association of Ireland and Corrib Physiotherapy, to examine FoG in Irish PwP, and to identify if freezing had a significant effect on their quality of life and wellbeing.

The study ran from June through to August 2023 and consisted of 122 participants. These participants included three groups: PwP. their

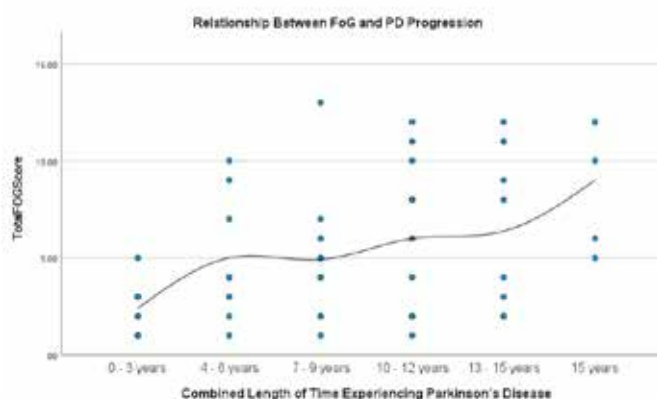


direct caregivers or supporters, and their clinical caregivers. On completion of the study, it was identified that, 27.9% of participants experienced an episode of freezing in the past month, and that FoG had an overwhelming negative impact on PwP's wellbeing. This means that the participants' overall quality of life, and how healthy and well they felt, were significantly impacted by FoG. This demonstrates the clear negative impact of this motor problem on PwP's physical and mental wellbeing, as well as their independence. Additionally, we found that people who had PD for a longer time were more likely to experience FoG. This indicates the gradual progressive nature of FoG with the disease course in PwP.

We also found that freezing episodes were associated with a number of other PD motor and non-motor symptoms, including:

- Difficulty with Balance & Coordination,
- Postural Instability,
- Rigidity & Stiffness,
- Slowness of Movement,
- Changes in Speech or Writing,
- Cognitive Changes,
- Orthostatic Hypotension,
- Weight Changes,
- Generalised Pain & Discomfort.

This compilation of symptoms observed in PD





would also impact negatively upon quality of life in PwP, and should be considered by physicians who are caring for patients experiencing significant freezing episodes.

These findings demonstrate not only the complex nature of Gait Freeze, but also the vital importance of healthcare planning and management for PwP who are at risk of falls or fractures due to episodes of FoG. In addition to the findings described above, this study has demonstrated proof-of-concept for the remote monitoring of PwP through the use of an entirely online questionnaire. This concept will allow future researchers and clinicians to effectively monitor multiple aspects of the life of PwP, including disease progression, quality of life, symptom tracking, and effectiveness of treatment, thus allowing for a tailored approach by clinicians in the treatment of PD, and opening the door to personalized PD management. Furthermore, this provides researchers with the ability to remotely study PwP outside of a clinical setting and

- without the need for frequent in-person follow-ups, reducing time constraints and maximizing population representation on a national level, to monitor and create a more personalised approach to PD treatment and clinical care.
- This study will inform larger clinical trials on the pathophysiological mechanisms behind FoG, and further research on targeted treatment strategies.
- We would like to thank each and every member of the Parkinson's Community in Ireland who partook in this study, as well as the School of Medicine at University College Cork for providing the funding required to carry out this study through the Summer Undergraduate Research Experience (SURE) Award.
- Pádraig Cronin
- Graduate Entry Medical Student
- Department of Anatomy and Neuroscience, and
- Parkinson's Disease Research Cluster
- University College Cork

CHRISTMAS IDEAS FROM THE PARKINSON'S ASSOCIATION OF IRELAND

With Christmas fast approaching we have our Christmas cards now in stock.

These bright cheerful cards include the PAI logo and are on offer for €10.00 per pack of 15 cards.

We have teamed up with Newbridge Silverware to produce these beautiful Newbridge pieces showcasing the Parkinson's logo.

**Newbridge Pendant
€35.00 plus P&P**

**Newbridge Pins €20.00
Parkinson's Lapel
plus P&P**

**Please place your
order early to avoid
disappointment by
calling the Freephone
1800 359 359**

**Many thanks for your
support**



WORLD PARKINSON'S CONGRESS

The World Parkinson's Congress (WPC) Barcelona was first and foremost an international scientific conference for Parkinson's research of the highest quality. Of course, there are also other conferences for which that is true but WPC is the only scientific conference in Parkinson's for ALL stakeholders. This means that you have researchers, clinicians, People with Parkinson's (PwP) and their Care Partners (CPs) mixing together, asking questions of each other and listening to each other. These meetings later result in new connections, new projects and new research directions all contributing to building the Parkinson's global knowledge bank. I attended as a Care Partner with my husband, diagnosed as a PwP since 2019 and was apprehensive about how I would cope with so much exposure to Parkinson's Disease (PD). I am always grateful not to have Parkinson's myself but sometimes honestly I would like to forget about PD and certainly resent it being centre-stage. However I found attending WPC a very humbling experience and it gave me perspective as I walk this path with my PwP.

People with Parkinson's become the majority at WPC and that opens you to engagement, positivity and optimism in a way that normal life doesn't. In normal life it is sometimes impossible to tell if someone you pass in the street has Parkinson's or maybe just a sore hip so connecting with others takes time and is quite guarded. The WPC experience allowed me to meet and quickly connect with positive and inspiring people such as the artist Matt Eagles (UK) who has had Parkinson's since he was 7. In conjunction with Havas Media Group he presented 'The Art Wobble' exhibition in the foyer. The 'Art Wobble' was perfectly positioned on the floor not the walls and Matt's wife and care partner invited me to step on the art and enjoy it. The WPC experience also gave me a global lens through which to view PD. For example Hellen Mwithiga from Kenya, where you are marginalised, stigmatised and persecuted for having Parkinson's Disease, presented a case study on how to replicate multidisciplinary care in low and middle income countries across the



Pen Portraits of 41 Parkinson Subtypes by Jonny Acheson MD (UK) featured, Foyer Exhibition, WPC

world. Closer to home Richelle Flanagan (Ireland) dietician and PD advocate received an award for distinguished contribution to the Parkinson Community and Jerome Maume sang with the Cork Choir in the Exhibition Hall to thunderous applause. There were really uplifting moments like Jonny Acheson MD (UK) whose talk explained what La Sagrada Familia and Anton Gaudi can teach us about Parkinson's subtypes and the need for researchers to challenge, innovate and think differently, just as Gaudi did.

Indeed there was a wide range of sessions to attend such as the main plenary, workshops, round tables, hot topics, a renewal room, a table tennis room, a meditation and mindfulness room, a film room but I decided to prioritise events run in the Care Partner Lounge. The Care Partner Lounge sessions were for Care Partners only and tissues were provided! The organisers hoped for 30 attendees or more at each session but those I attended had as few as 6 people in attendance. Possibly because the Lounge was badly signposted in the program, possibly because many of the CPs present at the conference were unable to leave their PwP for an hour session or possibly reluctant to step into the space of self care. I was unprepared for how



BARCELONA 2023

Article by Mary Mehigan

instantly I would connect with the people I met in the Care Lounge from Canada, Australia, Sweden, USA and the UK. It was because they got what it was like to live with a PwP without me having to explain everything as I usually have to do with friends and close family. I felt that my experiences were similar to those of others in the group and for the first time in a long time I felt less isolated and more part of a community. Talking with other CPs the biggest challenge faced was in the area of communication and one lecture by Angela Roberts, Asst Professor, Western University Elborn College, Canada was very humbling because it enhanced my understanding of my PwP and my appreciation of his life with PD. I attended two therapy sessions on journaling and art and found them very therapeutic particularly the one on journaling held by Rebecca Gifford (Canada) on writing to cope and connect. She is co-host of When Life Gives you Parkinson's with Larry Gifford her husband and PwP. We all know that physical touch (like, hugging or cuddling) has a beneficial effect on health, by reducing stress, decreasing emotional pain, recharging optimism and energy, and improving the quality of life of everyone. Gila Bronner (Israel) director at Tel Aviv Sourasky Medical Center passionately believes that people who live with a chronic and progressive disease, as well as their partners, have the basic right to touch, to love, to be touched and feel good. She demonstrated different types of touch, how to overcome "Off" episodes in PD, how to melt frozen masked faces, and how to express love in a delicate and effective way, without the need to say anything.

For those interested in a flavour of the Care Partner Lounge topics the WPC recorded in 2020 a four part talk series of virtual panels hosted by health professionals, care partners, and people with Parkinson's who discuss topics relevant to care partners. If you are interested, more detail can be found here <https://www.worldpdcoalition.org/page/carepartner>.



When we returned home from Barcelona both my PwP and myself were quite overwhelmed and it took a couple of weeks to process all we had experienced. The gist of what I took away from it all was to find support for myself locally because my family live far away and to spend time together with my PwP while maintaining a "seize the day" philosophy. I am running four Care Partner workshops in October in Limerick.

To participate in these workshops please contact Una Anderson Ryan. Her email is: una.andersonryan@gmail.com



Cormac & Mary Mehigan, WPC Barcelona July 2023

INTERVIEW WITH THE NEW

Tell us about your career to date.

I'm a qualified Chartered Accountant and have worked both in industry and professional practice for the past 10 years, including for Grant Thornton for nearly 5 years. I've advised individuals and companies of various sizes and from a variety of different industries. I've been involved in volunteering throughout my life. I increased my involvement in the charities sector after being diagnosed with epilepsy in 2015. I was the chairperson of the Finance & Audit committee of Epilepsy Ireland and was also on their board of directors. That work made it clear to me that I wanted to move into the charities sector. In the charities sector, you can really see the tangible impact your work makes in people's lives and there is a huge amount of job satisfaction that goes with that. My professional qualifications and the skills I've acquired will be invaluable to me in this role.

What was it about the Parkinson's Association of Ireland (PAI) that appealed to you?

Firstly, the fact that PAI is a neurological charity was hugely appealing to me. I see first hand the specific challenges that go with having a neurological condition, and I see the need for more education in that regard. I knew when I researched PAI further that it's a charity that is in a growth phase with huge potential. We know that the number of people with PD will increase over the coming years which will result in an increased demand for our services. I reviewed the strategic plan for the next 5 years and I could see that there is a huge amount that can be achieved. I have a lot of ideas for how we're going to achieve our objectives.

Meeting with the board was also very important as I could see that there was a great mix of skills and experience to support me in my role and move the organisation forward.

You mentioned the strategic plan. Will that be a major priority for you over the coming years?

Absolutely, the strategic plan is very important, particularly in a membership organisation like ourselves, where everyone has fed into the process of coming up with the plan. I'm determined that the document isn't just going to gather dust over the coming years!

Since I started, we have started the recruitment process for an additional PD specialist nurse which would increase our staff from 4 to 5 at national office. One of our biggest priorities will be trying to get the government to fund our services and we will be



PAI's new CEO, Shane O'Brien.

submitting various funding applications over the next while.

It's important not to view the various areas of the strategic plan in isolation. So, for example, it's important that we have an effective advocacy strategy which is linked to our grant/government funding applications, to give us the best chance of success. Likewise, awareness raising has a positive impact on fundraising.

On a related note, members will be able to see our pre-budget submission document in this edition of the magazine. I have appealed to members to send a copy of this to their local TDs to ask them to support our asks.

What are some of your other priorities over the coming years?

I mentioned earlier about raising awareness. That will be vital. There are so many misconceptions about PD and it's important that we bust those myths and educate the public. I will be canvassing members on what the key themes are that we need to focus on in educating the public and the members will also be at the centre of this work as we will need them to tell their stories. There is no substitute for hearing people's personal stories.

In relation to fundraising, the landscape has changed since COVID like in so many other areas. The government stability funding to charities during COVID was vital as we couldn't get out to fundraise but that is now gone. We now have this new normal where people attend more events online. While this



CEO: SHANE O'BRIEN

brings many benefits, it also means that there can be less attendance at in-person events which is obviously a challenge for fundraising. There is also the fact that people are carrying less cash than was previously the case. There is a lot of competition for the public's attention in the charity sector and it can be hard to compete with the larger charities. But, having said all of that, there are also lots of opportunities too. We have a very active membership that is heavily involved in grassroots fundraising in their communities which is not the case with a lot of other charities. The corporate sector is becoming more important for fundraising, and we are also gaining insights into the new fundraising streams that other charities are using.

Another major priority will be research. The Research & Impact committee are becoming more active, and we are hoping to increase the work that they do and bring more visibility to it. I do believe that although we are small, we have our part to play, and we need to identify a sustainable way to fund research. What I want to do is to make sure that we get value for money from any funds that we do decide to invest in research. Needless to say, it's important that any funding applications are reviewed in detail from a variety of perspectives, including independent clinical experts, to ensure that we're achieving value for money and that there is a reasonable chance of success in the research objectives for particular projects.

How do the branches fit into this work?

The branches and the members are at the centre of everything that we do. Over the past few weeks, I've managed to visit 5 branches and I can see the impact of the amazing work that is being done on the ground. Other charities would be so envious of the commitment levels of our members and the amount of time that they dedicate to PD.

I want our membership and our branch network to grow. The projects I mentioned including fundraising, advocacy and raising awareness will include our branches, so we will be working very closely together over the coming years.

Communication is hugely important, and when discussing communication, I always think of the quote: "the single biggest problem in communication is the illusion that it has taken place". We are an organisation that is distributed around the country and it's important that everyone knows what everyone else is doing, including the activities of the national office. That's why I think the quarterly meetings which involve myself, the

- Board and the branch committees are so important.
- The intention is that the attendees would then update their members on what's going on after the meeting.
- Obviously, I also do this when I'm visiting the branches and at our events also, but this brings a structure to it.
- It was a really good initiative by the board.

What are some of the challenges facing the charities sector?

- I've mentioned fundraising already and also meeting the increasing demand for our services. But growth must be sustainable. One of the other biggest challenges is compliance with our statutory obligations and adhering to best practice to reduce risks. This includes everything from compliance with fundraising guidelines, governance requirements and also financial procedures and reporting. The reasoning behind all these things is not to increase the amount of work that has to be done for the sake of it, but rather to ensure that there are procedures in place which make it very difficult for anything untoward to happen. It can be very difficult for charities to recover from reputational damage, as we've seen from some high-profile scandals in other charities. The general public have no tolerance for this and rightly so. For me, this is an area that is not negotiable. We owe it to the people that give us as much as one euro to make sure that the funds are spent as intended, and that we have the systems in place to ensure that we are responsible in our practices. PAI has always been compliant and it's about continuing to be, because the sector is evolving and the regulations are becoming tighter. These issues are also an important element of any funding and grant applications.

Finally, what will the organisation look like in five years' time?

- We will be a bigger organisation, with additional nurse specialists and head office staff and will have increased our membership numbers. We will have expanded our services significantly. We will have increased our fundraising footprint and expanded our income streams. Awareness raising will be a key part of our work and we will have ongoing advocacy campaigns.
- We will have increased the amount of research that we undertake. Finally, our branches will remain vibrant, with an expanded range of services and supports.
- All this will be made possible by our members. I want us to remember that we are all part of the one team with shared goals, no matter what part of the country we are based in or what our role is in the organisation.

OCCUPATIONAL THERAPY

How can an Occupational Therapist (OT) help?

Parkinson's Disease (PD) can change how you control your movements and thinking. Movements can be slower, restricted or you may experience additional movements e.g. tremor. These symptoms can impact your ability to complete every day occupations and tasks e.g. dressing, writing or moving in bed.

An OT can help you identify how your symptoms of PD are impacting your ability to complete these everyday tasks. The OT can support you to continue these tasks through:

Different ways to
complete
activities

Optimally setting
up your Home
Environment

Cues & Strategies
to perform
Activities

Self-
Management
Strategies

Optimising your Daily Routine

Fatigue may be an issue resulting in you feeling physically and mentally tired more quickly. An OT can help advise you to balance the demands of activities with your energy levels. An effective fatigue management programme helps to ensure your energy is used on tasks that are a priority to you. Optimal planning, pacing, prioritising and positioning allows for more controlled use of your time and effort.

Sleep Hygiene

PD can directly impact your quality of sleep and result in restless sleep. This may be due to a number of reasons such as chemical changes in the brain, medication, changes to mood or other symptoms such as pain. You may find it harder to fall asleep, have fragmented sleep or vivid dreams and nightmares.

Using Cues

In PD, your ability to control and perform automatic movements is affected. Your OT can teach you cues to help compensate for this.

Movements can become more effortful. You may experience "freezing" where your feet feel like they are stuck on the floor or cannot move. This can occur when standing up from the chair, moving through



doorways or when turning or changing directions when walking.

Hand movements can become slower or more effortful. This can impact how you write, place your arm in your sleeve for dressing or with smaller movements such as buttons and zips.

Ask the OT to teach you ways to change these movements.

Falls reduction- identification of modifiable risks

The OT may teach you alternative ways of moving to reduce the risk of fall e.g. changing how you step and turn when you are facing the sink or toilet. Along with the assessment completed by the OT in your home, there are several steps you can take to reduce your risk of falls.

Make sure there are no trip hazards or items on the floor blocking your pathway. If your therapist provides you with visual prompts, place these in the appropriate places in your home e.g. prompts for bed transfers can be stuck to the bedside locker. Sit to complete activities as required. Your therapist can advise you on steps to take if you have a fall to help you get up from the floor in the future. They may be able to give advice on use of a pendant alarm.

Setting up your Home

Sometimes even with use of strategies, you may require equipment and modifications to your home to assist with carrying out your daily activities. Your



FOR PARKINSON'S DISEASE



Primary Care Occupational Therapist will come to your home to complete this assessment. The OT can also give you recommendations on suitable grading of environmental adaptations, grant schemes and VAT rebates.

Handwriting:

Changes in hand function, especially handwriting might have been one of the first PD symptom that you noticed. Handwriting may become smaller, more difficult to read or it may require more effort to hold the pen. Some people notice that their handwriting starts off normally but becomes smaller over time. This is called micrographia.

The OT can provide various suggestions for posture, movements or types of pen. Wide grip pens, free flowing ink, bigger movements and lined paper can help.

Household Chores:

Planning can be helpful to manage fatigue. Pre-chopped vegetables or using ready-made meals on days you are feeling more tired can help. Breakdown the task into smaller steps and build in rest periods. e.g. prepare vegetables earlier in the day, do not cook straight after shopping. A perching stool might be helpful to avoid standing.

If you are experiencing difficulties in other areas of your daily routine, speak to your OT for advice on specific help or equipment to assist with this.

Driving:

- Many people continue to drive after the diagnosis of PD. Driving is a complex skill that involves physical and mental skills. These skills can be impacted by PD and it is important to discuss your driving needs with your GP or Neurologist. If you or your PD team have concerns, the OT can complete an off-road driving assessment depending on specialist services available in your area or refer you for an on-road driving assessment.

- Making daily habits such as setting regular sleep and wake times, sleeping in a dark room and getting daily exercise outside can all help. You should avoid caffeine for six hours before bedtime, long daytime naps and screen time before bed.

Memory & Everyday thinking

- There may be changes to your concentration and memory. These may include:
 - - Automatic or routine activities becoming more effortful and requiring more concentration.
 - - Repeating questions, forgetting names, losing keys
 - - Taking longer to process information.
 - - Multitasking and problem solving becoming more difficult
 - - Reduced spatial awareness which means difficulty telling how far objects are away from you.

- An OT can help you to learn to complete activities with focused attention. This may include:

- - Visualising the task
- - Using step by step self-instruction or from a carer as a mental cue.
- - Focus on one thing at a time- remove distractions. Dual or multi-tasking should be avoided.
- - Repetition is essential for learning strategies.
- - Ask a person to repeat what they are saying or to slow down when they speak.
- - Use alarms to remind you to take medication and ask your pharmacist to organise your medication into a dosette box.
- - Keep things in routine places.

Dealing with stress and time pressure

- Stress and time pressure can make your symptoms worse. PD results in a slowness in movement patterns but also reduces the speed in processing information. It takes extra time to complete tasks. Your OT will help you learn to allow extra time to complete

Continued on page 12

activities through activity scheduling, setting up the environment and use of focused attention. They can also help your loved ones to become more aware of what helps and hinders you.

Housing Adaptations:

If you are considering adapting your home and installing a wetroom, level access shower, ramp or stairlift, information on this can be gathered on your county council website. This is generally found under the housing section. Depending on the extent of work to be completed, you may apply for the mobility aids grant or housing adaptations grant. An OT assessment is required for this and it is worth checking with your primary care team whether this needs to be arranged privately, through the council or the primary care team. It is important to get advice from your OT prior to completing work to make sure it is specific to your needs and to plan for the future.

Helpful Tips for Daily Activities:

Transfers and walking:

Due to the change in movements, transfers can become more difficult. Examples include difficulty moving in bed, standing in the bath or shower, getting in and out of the car.

Changes in balance, posture and step pattern can impact walking. Performing more than one activity at a time can impact how you move. It can be helpful to minimise distractions and avoid carrying items when walking.

The OT can explore ways to improve these movements or suggest equipment to assist with these difficulties.

Eating & Drinking:

Your OT will advise on optimal posture and ways to improve completing this task. This may include modified equipment such as large grip cutlery to help with your grip or cups with lids.

Showering:

Movements can be more effective and symptoms reduce after taking your first dose of medication. It can be helpful to wait until your medication has taken effect. Sitting or using a grab rail in the shower can support your balance. Techniques regarding focused attention will also be important here.

Dressing:

You can conserve energy for dressing by being prepared. Have your clothes set out on a chair the night before. Sit to complete dressing. Use focused attention or cues provided by your therapist to assist with this. This may include instructing yourself on the specific steps in the task e.g. put your right foot into the trousers and pull up.

How do I access an Occupational Therapist?

You can request a referral to your Primary Care Occupational Therapist from your GP, Neurologist or PHN. In some areas, self-referrals may also be possible. A medical card is required in order to access equipment. A PD diagnosis can sometimes (not always) mean eligibility for LT illness card and access to equipment.

Some Outpatient Services (where you see your Neurologist) may have an Occupational Therapist as part of their team who can see you in the hospital.

Otherwise, you can organise a Private OT assessment. A list of Private OTs is available on www.aoti.ie. OTs practicing in Ireland must be CORU registered so it is worth checking this with your OT. It can be helpful to ask the therapist have they experience working with other patients with Parkinson's Disease or Neurological Disorders.

ACKNOWLEDGEMENTS:

This leaflet has been authored by Mairead Campbell (Clinical Specialist Occupational Therapist, Neurology, Beaumont Hospital, Dublin 9) and Claire Dolan (Clinical Specialist Occupational Therapist, Movement Disorder Clinic, St James's Hospital, Dublin 8)

References:

Aragon, A. & Kings, J. (2018) Occupational Therapy for People with Parkinson's: Best Practice Guidelines, 2nd Ed, London: Royal College of Occupational Therapy.

Occupational therapy can help people with Parkinson's continue to carry out everyday activities when they become difficult to do. It can benefit people at all stages of the condition.

- Ask your GP, physiotherapist, Public Health Nurse (PHN) or Speech and Language Therapist to refer you.
- Request a referral from your GP or other Healthcare Professional.

Visit Association of Occupational Therapists of Ireland www.aoti.ie



To fill out a My Medicines List you need all your medicines in front of you. Remember to include all the medicines you take regularly and

- Sain-chógaiseoir um Shábháilteacht Cógais





Parkinson's Association of Ireland

Pre-Budget Submission 2024

The Parkinson's Association of Ireland (PAI) is one of only a few major disease charities that does not receive HSE funding for its core staff.

Parkinson's Disease (PD) is one of the most common neurological disorders. It currently affects approximately 1% of people over the age of 60. The rate of Parkinson's Disease is projected to double by 2040.

The need for further services will increase rapidly over the coming years.

PAI calls on the government to invest in PD and to put PAI on an equal footing with charities for other major diseases.

Ask 1

Provide HSE section 39 funding for PAI PD nurse specialists

Ask 2

Increase in the number of allied health professionals in the community e.g. physiotherapists

Ask 3

Investment in community neurorehabilitation teams



Ask 1

Provide HSE section 39 funding for PAI PD nurse specialists

Section 39 of the Health Act 2004 provides the HSE with the power to fund community, voluntary and not for profit agencies to deliver services.

PAI is one of only a few major disease charities that does not receive HSE funding for its core staff. We ask that this disparity is ended.

PD nurse specialists play a critical role in assisting patients in their local communities. In a recent UCC national survey of people living with PD in Ireland, just 20.7% of respondents reported having any access to a PD nurse specialist. The contact hours with a nurse specialist are critical to assist people in managing their PD.

The Sláintecare Implementation Strategy envisaged a reorientation of the health service “where the vast majority of care takes place in primary and community care setting”. Our ask for funding to be provided in 2024 is in line with this vision.

Ask 2

Increase in the number of allied health professionals in the community e.g. physiotherapists

Allied health professionals such as physiotherapists, occupational therapists, dietitians, speech and language therapists and counsellors, play a key role in helping people with PD manage their condition. In a recent UCC national survey of people living with PD in Ireland, 43% of respondents only attended a consultant either once per year or less². Therefore, the involvement of a multidisciplinary team to assist in the management of PD is crucial. Recent studies show a difficulty in accessing these types of services. For example, only 15% had access to a dietitian and only 13% had access to a mental health professional².

We ask that specialist PD care delivered by allied health professionals be allocated further resources.

Ask 3

Investment in community neurorehabilitation teams

PAI supports the ask of the Neurological Alliance of Ireland for funding for community neurorehabilitation teams in each of the nine CHOs around the country. These teams will provide short-term intensive rehabilitation for people with PD to support their recovery. The multidisciplinary services include physiotherapy, speech and language therapy and occupational therapy.

PD is the second-most common neurodegenerative disease after Alzheimer's disease.

The rate of PD will double by 2040 as life expectancy increases¹

Exercise improves the quality of life for people with PD and has a beneficial effect on symptoms

1. Dorsey, E., & Bastiaan, R. (2018, January). The Parkinson Pandemic—A Call to Action. JAMA NEUROLOGY, 9-10. Retrieved from JAMA Network: <https://jamanetwork.com/journals/jamaneurology/article-abstract/2661302>

2. O Shea et al. (2023). Experiences of Health Service Access and Use for People Living with Parkinson's Disease in Ireland: A National Survey. Health & Social Care in the Community.

Summer Raffle 2023

The National Office
Would like to thank all those that
contributed to our Summer Raffle.

A big thank you to all who bought/sold tickets to
help this Annual Fundraiser.

All Winners have been notified.

Thank you.



time and effort you went into raising funds and
awareness of Parkinson's. Please remember to
send in any sponsorship.

Thank you!

Callback Services Available

To avail of our callback service from our
Parkinson's Nurse Specialist Lisa and our
Dietitian Richelle please call the Freephone
Helpline 1800 359 359 to arrange a
callback.

Resources Available through PAI.

PAI have a range of information/Literature
available to you.

Please call our Freephone Helpline 1800 359
359 if you wish to receive some of our literature/
passports/exercise charts/alert cards.

VHI Mini Marathon 2023

A very big thank you to all the ladies who
walked, jogged and ran the VHI women's
mini marathon in support of The Parkinson's
Association of Ireland. Thank you for all the



Left: Michelle O'Neill who recently
ran the Belfast Marathon to raise
funds for Parkinson's, pictured with
her uncle Michael Barrett and her
aunt Kay King, both of whom have
Parkinson's.

COVID VACCINE AUTUMN BOOSTER

BOOSTER DOSE OF THE COVID-19 VACCINE

The protection from previous vaccines or a Covid 19 infection may weaken over time. Booster doses help boost your antibodies and give you good protection from becoming seriously ill or needing to go to hospital if you get COVID-19. A first booster is recommended for all adults age 18 years and older. After this, seasonal boosters are recommended for some people.

Please check with your Health Care Provider to ask if you need to avail of the booster dose of the Covid 19 vaccine. Please visit [HSE.ie covid 19 booster](https://www.hse.ie/covid-19/booster) for further information.



SURVEY



Have your voice heard. Invitation to participate in a research study on PD

Dear member,

My name is Fran and I am conducting research in collaboration with Prof Timmons, Dr O'Shea and Dr O'Keeffe of the School of Medicine at University College Cork. This research explores the lives of people with Parkinson's disease to ultimately increase public awareness of this illness.

Considering the rate of new cases of PD has grown more than 50% in the last decade, the necessity to promote public knowledge of PD is more than ever a priority. At the individual level, the PD-related disability greatly reduces people with PD's quality of life, mental health and emotional and social functioning. Furthermore, as the more visible symptoms of PD (i.e., tremors, stiffness, slowness, walking difficulties) can be misinterpreted by uninformed onlookers, people with PD can often suffer from social stigma and contempt. In particular, slowness of movements and speech difficulties might be seen as intellectual disability, physical imbalance as inebriation and a masked facial expression as an unfriendly attitude. Therefore, collecting insights into the lives of individuals with PD could inform the development of health and social policies and educate the general public with a view to dissolving the stigma associated with PD. Up to now, research on PD in the Irish context has been lacking and this study will hopefully pave the way to more research on PD in Ireland.

I am inviting you to take part in my research study on PD to explore your quality of life and life satisfaction and how these relate to your symptoms, self-belief and social context. You are asked to complete a 20-minute survey. Your participation would be greatly appreciated and would provide an invaluable contribution to this research. Please complete the enclosed survey and return in the pre-paid envelope. Thank you for your participation

Francesca Gaiera
Post Graduate Researcher

Online Classes for Members 2023

Our online classes for members have now resumed. Details can be found at www.parkinsons.ie

Our members will have been notified via our weekly e-zine for zoom links

WEEKLY SCHEDULE

MONDAY – Meditation/
Mindfulness 7pm-8pm Dee Daly

TUESDAY – Singalong session –
11amDara McMahon

WEDNESDAY – Yoga through
the Chair 6.15pm-6.45pm Theresa
Kearney

WEDNESDAY – Yoga for YPI
Members 7pm-8pm
.....Theresa Kearney

THURSDAY – Nurse Zoom 11am
..... Lisa Wynne

FRIDAY – Exercise classes
11am -12noon Grainne McKeown

*We would encourage all our
members to avail of these online
classes.*

*Help reduce stress, lower anxiety
with mindfulness.*

*Work your voice with our singalong
sessions.*

*Increase flexibility and strength
with Yoga.*

*Access to information with our
Parkinson's Nurse zoom sessions*

*Boost flexibility and mobility with
Exercise Classes.*

DRIVING WITH PARKINSON'S

For many people who have a diagnosis of Parkinson's disease, (PD) or Parkinsonism, one of the first questions they ask is can I continue to drive?

Being able to retain personal mobility is of huge importance to people, whether you have a disability or not, and with an increase in accessible public transport, especially in urban settings, being able to go where you want to and need to, is made a lot easier nowadays.

Before diagnosis your GP may already have advised about driving. If you have already passed the 70 year old mark, your GP will have had to sign a Medical Fitness to Drive form (D501) for the National Driver Licensing Service, (NDLS), to give medical clearance to drive, before you can be issued with a new driver's licence. (This has been increased now to age 75.)

Once you have had a diagnosis the first point of contact for a person to check with is your Consultant Neurologist. I wrote in my previous article for this magazine:

'Sometimes PD has a significantly negative effect on many areas of a patient's skills, and it is important to ensure there are no medical issues that might impact on your driving skills. For the most part modern drug therapies allow people with PD to continue to live without it having a major impact on their day to day lives. But as the condition moves forward driving can become a cause of concern for the medical team'.

By the time your Neurologist feels it has reached the stage that you need to have your driving skills checked out, or to attend for an on-road driving assessment, a definite diagnosis will have been made, and the progressive nature of the disease means an assessment may be needed at any stage. Your consultant will have their team carry out

a number of checks, such as physical range of movement and strength, reaction times, eyesight, as well as cognitive screening. These are typically completed in a hospital setting, but often in rural areas, community Physiotherapists and Occupational Therapists can carry out these tests in a local clinic or perhaps in your own home.

It's not easy to predict how PD will develop, but as it may worsen over time, an in-car, on-road driving assessment is the one way to definitively establish if your Parkinson's, or your Parkinsonism, has reached a stage where driving is of concern, or indeed no longer possible.

Having tremors, even occasional tremors, resting tremors, or stiffness in a limb, as well as having a slowing of spontaneous movements or balance difficulties, may not, necessarily stop you from driving. However, people with PD are more likely to have minor accidents or encounter driving problems than their non-disabled peers, (Hunter 2009) and it is for this reason doctors are keen to refer someone for an assessment.

For many people with Parkinson's driving is still a possibility, and a possibility for many years in the future. As modern medications progress and improve the life of people living with PD, many more people are continuing to drive for longer periods. This is evidenced by an increase in referrals from consultants to driving assessment services, such as at our service at Transport and Mobility Consultants - Ireland, (TMC-I) and anecdotally, other driving assessment services report an increase in driving referrals for people with Parkinson's Disease.

If you have been diagnosed with Parkinson's or Parkinsonism, the law requires you to do two important things.

1. You must notify your car insurance company of the diagnosis, otherwise you will not have appropriate insurance cover, as you



- have not disclosed a change in your health.
2. You must also notify the National Driver Licence Service, NDLS, and your doctor(s) should complete a Driver Licence Medical Report Form (D501), where they will notify the NDLS that you are still able to drive, and it provides for them to issue you a licence for one or three years. You must submit this form within one month of your doctor completing it. More recently Ireland licensing service allows for doctors to provide advice to the NDLS to issue a restricted licence, such as only driving during daylight hours, not driving on a Motorway or some times only driving within a 30kms radius of your home. In some circumstances your on-road assessor might recommend that you only drive when accompanied by a family member or friend, especially if travelling longer distances.

Most doctors are guided through this process by following the RSA's Sláinte agus Tiomáint, Medical Fitness to Drive Guidelines. If your doctor has any concerns about your continued driving ability they are advised in these guidelines, to refer you for an on-road assessment.

SLÁINTE AGUS TIOMÁINT SAYS:

Parkinson's disease and other forms of Parkinsonism.

Permitted to drive provided the condition does not impair safe driving e.g. there is no clinically significant variability in motor function.

Due consideration should be given to medication review (with due attention to tendency to drowsiness/ sleepiness), rehabilitation, specialist on-road assessment and adaptations which may help to adapt to, or overcome, relevant cognitive and physical impairment.

If driving safety not impaired, can continue driving subject to satisfactory reports. Fitness to drive is subject to regular review.

Driver should notify NDLS.

WHAT IS AN ON-ROAD DRIVING ASSESSMENT?

An on-road Assessment is not like your learners driving test! At TMC-I we provide a nationwide service, visiting clients in their own home areas. We think it is only fair if you are having someone check your driving you

Continued on page 20

should be allowed to drive on roads that are familiar to you. Similarly, we like to see you driving in your own car; it's the vehicle you are familiar with rather than asking you to drive a vehicle that may be unfamiliar to you. We come to your home, having a short initial interview where we take note of how you are coping with PD and how it might affect you from day-to-day, check any tremors, or pausing you might have, check your eyesight, you need to be able to read from a certain distance and have sufficient fields of vision, and then we go for a drive. It usually takes about half an hour or forty minutes, and when we return, we offer our advice, which we follow-up with a written report. With your written consent we copy the report to your referring doctor or Hospital consultant. You must give us this consent before we begin the in-car assessment.

There are four possible outcomes from the assessment:

- Continue driving as you were, and we'll check it out again in a year's time
- Continue driving as you were, but restrict your driving. This might mean you can no longer drive on Motorways or dual-carriageways, you may be advised to only drive locally, perhaps within a 30kms radius of your home, perhaps you might be advised to not drive at night, and we'll check it out again in a years time
- You may be advised to drive using some type of adaptation to your car. Sometimes people can continue driving with an inexpensive adaptation, such as a wide interior rear-view mirror if they have difficulty turning their head to the right or left, or an easy release handbrake button can be a great advantage if someone can't push in the hand brake release button. Or you may be advised to change to driving a car with automatic transmission, or to using hand controls if you have difficulties using your feet on foot pedals, and we'll check it out again in a years time, or in six months if your consultant requests it

- Or finally, it may be that we have to advise you to stop driving. We would only advise this if your driving skills had reduced to such a point that you were no longer able to drive safely.

This final option would be a last resort; our aim is to enable people to drive for as long as possible. We would also advise your GP and your consultant of the outcome of the assessment and they would receive a copy of the report we would send to you.

Many people wait until after the driving assessment to notify their insurance company of the outcome, by sending them a copy of our report too. Some doctors will not complete the Medical Fitness to Drive form, (D501), for the NDLS without a driving assessment being completed first.

Apart from TMC-I assessment services, there are other organisations providing driving assessment, such as the

- Disabled Drivers Association of Ireland in Ballindine, Co. Mayo
WWW.DDAI.ie
- Southern Mobility Services in Cork
- Results Driving Service in Limerick
<https://resultsdrivingassessmentservices.ie/>
- Irish Wheelchair Association in Kildare, but you are expected to travel to their offices for an assessment appointment and you should contact them for further details on the type of services they provide.
- The Irish Wheelchair Association have a national service and a number of adapted vehicles which you can try.

If you want to apply for a driving assessment anywhere in the country you can contact us at the details below. We have OT's working as On-Road Assessors as well as several Approved Driving Instructors, (ADI's) and can provide a service at your own home. All on-road assessors are qualified to administer the MoCA Cognitive screening tool and have qualifications in On-Road Assessments from both Chester University and Oxford-Brooks University.



Transport and Mobility Consultants – Ireland
Rathnasca

Garymore Lower

Rathdrum

Co. Wicklow, A67A260

Tel: 0404 43854, or 087 263 5025

Email: tonyregan@transportandmobility.ie

daviddelamere@transportandmobility.ie

Web: www.transportandmobility.ie

References:

Hunter, J., de Vries, Jos, et al, (2009)

Handbook of Disabled Driver Assessment,
the PORTARE Working Group

The Road Safety Authority, (2020)

Sláinte agus Tiomáint, Medical Fitness to
Drive Guidelines

Tony Regan is the Director of Transport
and Mobility Consultant – Ireland, which he
founded in 2001, (and has a PGDip in On-
Road Assessments), and has been joined by

- David Delamere as a new Executive Director
- in 2018. David is an ADI and has had specialist
- training as an on-road assessor, and a PG Dip
- in On-Road Assessments.

- Tony has extensive experience working with
- older and disabled drivers for over forty years
- both in Ireland, the UK and in the USA.

- He is currently a member of the UK Driving
- Mobility, the Chartered Institute of Transport
- in Ireland and a member of the USA ADED
- organisation where he has a Certificate in
- Driver Evaluation.

- His background is in Mechanical Engineering
- and Driver Education and he holds a Dip Ed
- in Driving Education, a PGDip in Business
- Management, a second PGDip in On-Road
- Assessments and Outdoor Mobility.

- Tony was, until recently, a member of the
- faculty of Traffic Medicine at the Royal College
- of Physicians in Ireland.

- Web: www.transportandmobility.ie



FREE HELPLINE 1800 359 359
If you have any questions regarding help with
the day to day managing of your Parkinson's
symptoms or to any medical queries you might
have, we've got the information and support
you need.

Freephone Helpline
Monday - Friday
9am-5pm.
Need to speak with
our Parkinson's Nurse
Lisa or Dietitian
Richelle?
To arrange a callback
please call Freephone
1800 359 359



BRANCH NEWS

DUBLIN BRANCH

We sponsored four people — three professionals and one committee member — to help them attend the World Parkinson's Congress in Barcelona in July. They included a neurorehabilitation nurse, who's also living with Parkinson's, a researcher and a hospital speech and language therapist. We're really looking forward to hearing about their experience and what they learned at a webinar from 3pm on Saturday afternoon, 4th November. I'd really encourage members to click into it and attend. We'll send out the invitation in our next branch bulletin.

We're already starting to plan our very popular Christmas lunch so I hope many old and newer members will come along to it on Sunday 3rd December at the Marine Hotel, Sutton.

In the meantime all of our local support groups/exercise classes are back up and running. (A few took a summer break). Our thanks as always to the wonderful Siel Bleu instructors and to Adrienne in Clontarf who make exercise fun and accessible to everyone, sitting or standing.

Here are the details of our local groups which are open to all Dublin members.

CLONTARF: Mondays 2.30pm-3.30pm with Adrienne.

Venue: St. Anthony's Community Centre, St Lawrence Road, Clontarf, Dublin 3 (exit from free car park is on coast road) As Adrienne has to work occasional Mondays, contact St. Anthony's Centre 01 8335300 to make sure the class is on or email Adrienne Towell: justaido@hotmail.com

LOUGHLINSTOWN: Tuesdays 2.30-3.30pm.

Venue: Loughlinstown Leisure Centre, Loughlinstown Drive, A96 XP60 with free car park and coffee and chat afterwards Contact: Austin Hynes 086 073 6833

HAROLD'S CROSS: Wednesdays 11am-12noon

Venue: Our Lady of the Rosary Church Pastoral Centre, Harold's Cross Rd, Harold's Cross D6W KW21. Car park, free on request. Contact: Gerry Lovett 087 8133743

PORTMARNOCK: Wednesdays 1.30pm-2.30pm, followed by tea/coffee and chat from 2.30pm.

Venue: Arch Club, behind St. Anne's Church, Strand Rd, Burrow, Portmarnock, Co. Dublin. Free car park. Contact: Tony Brady 087 795 3302

ONLINE CLASS: Thursdays 11am-12noon
Contact: cormac.walsh@sielbleu.ie

TALLAGHT: Fridays 11.30pm-12.30pm

Venue: Rua Red Arts Centre, Blessington Rd, Tallaght, Dublin 24, D24 KV8N. Contact: Sean Balfe 086 815 3606 or email: dublintonline@parkinsons.ie

HUNTSTOWN: Fridays 10am-11am

Venue: Huntstown Community Centre, Huntstown Way, Blakestown, Dublin D15 EDP8. Free car parking. Contact: Kieran Connolly 083 105 9922 or email: dublinmembership@parkinsons.ie

NAVAN: This support group has a social meet-up on the last Friday of the month.

Venue: Teach Tramhrach Trim Rd Navan.

Contacts: Stella McElherron 0851677325 or Mary Burke 0872836794

To inquire about joining classes or about other Dublin Branch activities contact Mary Butler at: dublinchairperson@parkinsons.ie or on 087 2434990. The suggested payment per class is €5. The Branch pays the rest of the costs.

MIDWEST BRANCH

All our activities have started again after the summer break.





Members are delighted to reunite with the friends they have made through the sessions.

I feel it is most important to recognise special efforts made by members and so we paid a visit to present small awards to three members in the Voice Club.

Edkart Hartman received his award for his very important role as Carepartner to Barbara.

In a talk to our members last Spring he highlighted the lonely life of a Carepartner with no family support in the country. He set up a coffee morning group to meet up to chat and share some ideas to make life easier.

Two further awards went to Geraldine and Caroline from the Adult facility in Lisnagry in Limerick. In spite of their added difficulties they join in all the movements in the voice exercise group. Geraldine can be seen dancing around with her walking aid all in tune to the music while Caroline beats her drum and both with a happy smile. They are an inspiration. Well done to all.

On the 4th and 6th of September we set up an information desk in Johnson and Johnson Pharma Company in Castletroy. We were approached by David Brannigan, a team leader in the company, who has connected with Parkinson's Midwest as their chosen Charity to help raise awareness throughout the Plant. This is an initiative facilitated by the Company. They will run various activities with PD at the centre of each project. Many thanks to David and his team for choosing us as their charity.

Best wishes to all returning to this new season.

We wish our new CEO Shane O'Brien the very best in his new role and we were delighted to welcome him to our Information Afternoon on the 5th September. Only one month in his position and he has called to four branches already which he promised when appointed.

Here in the Midwest we wish him every support.

Johnson & Johnson Limerick. Led by David Bannigan ran a fundraiser around predicting

- the results of the Rugby World Cup. Frank Lynch and Brendan O'Neill attended with Una Anderson Ryan. We were amazed at the number of the staff who had relatives with PD. We were delighted with the opportunity to share our knowledge and offered leaflets on all aspects of the condition. Our thanks to David. Shelagh Ryan was the real sales person and got a great number to sign up for the competition.

• *Contact Una 087-2511156 and committee Frank, Paudie and Gerry.*

• **CORK BRANCH**

• **Do you want a local support group in your area?**

- If you do, contact us and we will help source a venue where you can have a coffee and a chat. Also if the group is interested in a class or activity we will be there to help. The services will be provided at no expense to members of PAI Cork Branch.

- We are also planning some zoom classes and we are putting together a list of people interested in providing a variety of classes.

- All we need is to hear from you, the members.

• **Perpetual Motion Choir**

- Every Monday 7.30pm-9pm Lough Parish Centre on the grounds of the Lough Church.
- All Welcome

• **Weekly Set Dancing**

- Marian Hall Ballinhassig 2-3.15pm Tuesdays

• **Kinsale Parkinson's Support Group**

- Friary Centre Kinsale
- 3rd Thursday every month
- Contact Fred Treacy ph 086-8275481

• **Glounthaune Parkinson's Support Group**

- 1st Weds every month
- Contact Jackie ph 087-2047169

• **Coffee Mornings**

- Oriel House Hotel Ballincollig
- 2nd Monday every Month 11-12.30pm

- If you are interested in participating in the following classes contact joancooney72@gmail.com

• **Mindfulness and Gentle Yoga with Brenda.**

- Email Joan. Ref Brenda

• **Physio classes with Jack.**

- Email Joan. Ref Jack

• **Contact CARETAKER TEAM**

- *joancooney72@gmail.com*

WEXFORD BRANCH

Hello to all our members

We have had an absolutely great summer with some amazing people

Oylegate Vintage Club held a Tractor Run as a fundraiser for our branch in May. We are so thankful to Henry Cosgrave, Cormac Downes and all in the club for their kind donation and hard work.

Our Singing for Health Choir led by Elizabeth Drwel performed in the National Opera House in June alongside some amazing artists, such as Joan & Co., John, Jimmy & Margaret who gave us some fabulous music, Janette Sidney & Ruth Donegan provided us with comedy Louise Jones, George Lawlor, the Cordiality Choir & 2 children from Elizabeth's other choirs provided us with some great singing talent and last but not least our special thanks to Matty Murphy our MC for the night. This event raised over €4000 we appreciate everyone that made the night such a great success.

Our weekly classes continue, Chair Yoga Class in Coolcotts Community Centre, we have Physio Classes in Murrintown Community Centre and Singing for Health Classes in Coolcotts please contact the numbers below if you would like to join us.

We have our Coffee Mornings around the County on the last Monday of each month. We would love if you would come and meet us. Our latest Coffee Morning was held in The Presentation Arts Centre in Enniscorthy

- and was a huge success, we had Aideen McGuinness Senior Dietitian from WEXICOP in attendance speaking about 'Parkinson's & Nutrition'. We also had Mr. Shane O'Brien CEO of the Parkinson's Association of Ireland in attendance we would like to thank Shane very much and we wish him every success in his new role

- Please contact us on the numbers below if you would like to attend any of our classes.

• *Chairman: Pat Lacey 087-2585992*

• *Treasurer: Breda Kennedy 087-0958984*

• *Email: wexfordtreasurer@parkinsons.ie*

OFFALY BRANCH

- The Offaly PD Support Group was incorporated into a Branch at our meeting in August '23. Since it's inception in November '22, we have arranged weekly gym sessions and monthly meetings in the Charleville Centre, Tullamore. Providing education, support and social interaction is the objective of these latter meetings. To date our speakers have included Lisa Wynne, PAI Nurse Specialist; Aoife Carolan, Senior Speech and Language Therapist; HSE, Rachel Henry, Pharmacist; Beth McCarty, Family Carers Ireland and Aisling Durkin, Neurology Specialist OT, Belfast Health and Social Care Trust.

- Due to the interest of Aoife Carolan, SSLT, we have collaborated with Clare Meskill, founder of Teletherapy. The Offaly group has functioned as the pilot group for research and development of this speech therapy application and have contributed hugely to



Wexford Branch Opera Outing.



its present form.

We also had two social gatherings during the summer with a sing along session and a board games afternoon.

We look forward to welcoming Marion Slattery, OT, Personal Health, Dublin, Specialist in the PD Warrior programme to present her workshop in September.

Members will also attend the Social Gathering in Hudson Bay Hotel, Athlone, in October which will be an opportunity to meet with members from other Branches.

Contact Jean 086-8069855

TIPPERARY BRANCH

The Tipperary branch would like to extend our sincere condolences to the Burke family on the loss of Michael Burke. Michael was heavily involved in the Tipperary branch for many many years and worked tirelessly on behalf of all our members. Michael also served on the Board of PAI giving his time, his expertise and highlighting patient views at Board level. He will be sadly missed by all in the Tipperary branch.

We would like to welcome the new CEO Shane O'Brien to his new role and look forward to him joining us at our meetings in the future.

Meetings will continue on 1st Thursday of each month in the Order of Malta Centre, Thurles

Thursday 7th September at 2pm with Music and Sing a Long.

Thursday 5th October at 2pm with Physio Maria.

Thursday 2nd November with Joan Speech Therapist.

Thursday 7th December at 2pm Christmas Party.

The Monday Club re-commenced in Pastrol Centre, Nenagh on Monday 4th Sept 2pm

Clonmel Meetings continue in Hotel Minella on 1st Tuesday of each Month at 10.30am

Contact Mary 086-3916726

DONEGAL BRANCH

It is with great sadness that branch members extend their condolences to Ann Leonard and her family, Tourlestrane, Co Sligo on the death of Peter. He was a regular and much liked at-

- tendee at the Fitness4All exercise classes in Strandhill. May he rest in peace.
- We also learned of the death of Tom Conlon from Sligo. Tom attended all our meetings and conferences. He was a great supporter of people living with Parkinson's. We extend our sympathy to his wife, Phil, and all his family.
- Elizabeth MacFadden was given a beautiful king size quilt which she raffled for our funds and raised over a thousand euro. Thank you, Elizabeth, from all the branch members.
- The summer outing to Riverstown Folk Park was enjoyed by all. The weather was perfect, and we started the outing with coffee and scones in the sunshine. The park was very interesting being in part a recreation of life in 1900 and a street in Riverstown. As life had not changed all that much between 1900 and 1950s for many of us it was very nostalgic seeing items we remembered as children, such as the mangle, but which are unheard of in homes today.
- Our former treasurer celebrated a significant birthday in June. A very happy occasion for all. Maureen has been so caring of everyone, a leading figure in the North West Branch since the early 2000s, long before she herself was diagnosed with the disease.
- Mollaway House, the neurological centre in Sligo has continued to give great backup to us during the summer. The weekly meeting with meditation, is very popular and has resumed today after a month's break.
- During that month Aideen Connolly brought in her pencils, crayons and paint and had us all busy experimenting in a fun atmosphere. Some people were very talented but even if you were not, like me, you still left each class with a sense of achievement. Anyone with a movement disorder is welcome to come and join. Just contact Mollaway House.
- Exercise classes continued for most of the summer,
- And they are now all back and running in Letterkenny, Donegal and Sligo. The yoga classes in Letterkenny and Sligo have also recommenced.
- Earlier in the summer a number of our members took part in a survey of people with Parkinson's to discover what areas of research we were interested in, how much we knew about our disease, where we obtained or are obtaining our information and what



Maureen Giblin with her husband, Paddy, and four children.

we do to try to increase our quality of life. The responses are to be used to create a free half day conference for people with Parkinson's. This will be in TCD on Saturday, 7th October, and some members have their tickets already booked.

On 2nd September, members met up at Dorian's Hotel in Ballyshannon, where we enjoyed soup and sandwiches and chat. Kevin

and Marie Fitzsimons gave us a very interesting and comprehensive account of their visit to Barcelona for the World Parkinson's Conference.

Later Kevin was elected as Deputy Treasurer of the NW Branch.

We also discussed a possible visit to a therapy centre in Italy, for a week's therapy next year.

At least two of our members have previously been there, Ronnie Gillanders and Judith McKinley.

We are now looking forward to meeting up with old friends and making new at the Parkinson's Conference in Athlone.

EAST MIDLANDS BRANCH

Summer Outing 2023

On the 6th of September a group of 25 set out on our first outing since 2019.

Our first port of call was the gorgeous Delta Sensory Gardens in Carlow. After a leisurely stroll around the gardens we enjoyed a beautiful lunch in the Centre's cafe. This set us up nicely for our onward journey to the Riverside Park Hotel in Enniscorthy. Dinner at 7 o'clock was followed by the brilliant entertainment of Maureen Culleton and her Rambling House friends who treated us to a great night of music, songs, stories and lots more.

On Thursday we visited the Kennedy Homestead where we were given an insight into the



East Midlands Branch outing.



Kennedy family and the visit of J.F.K. President of the U.S.A. in 1963. Lunch in New Ross followed before we visited Johnstown Castle, Agricultural Museum and Gardens. Returning to the Riverside Park Hotel for our second night and again enjoying a lovely dinner at 7 followed by entertainment once more by our Rambling House friends who provided us with more music, songs and laughter. Following check out on Friday morning we set off for the picturesque village of Bennettsbridge and a visit to Nicholas Mosse pottery factory and shop. From here we went on to

Kilkenny City where we enjoyed the Smithwicks Experience tour before our final dinner in Kilkenny. After another hearty meal we set out for home. A huge thank you to John our driver and everyone along the way for making our outing so successful and enjoyable. Our Yoga class will be returning soon in Newbridge for further information please contact Marian on 085 2112973 also our Movement to Music classes will be resuming in the Parish Centre Portlaoise for further information please contact John at 087 2712448.

GET THE FLU VACCINE- NOT THE FLU

Flu is a highly infectious acute respiratory illness caused by the influenza virus. Influenza affects people of all ages. Outbreaks of flu occur almost every year, usually in winter. This is why it is also known as seasonal flu. Flu can be prevented by vaccination. Flu vaccination is a safe, effective way to help prevent flu infection, avoid hospitalisation and reduce flu-related deaths and illnesses.

Get the vaccine, not the flu! The HSE is urging people in at-risk groups to get vaccinated against influenza. You should get your flu vaccination from September to be covered for flu season. The viruses change each year. This is why you need to get a new vaccine each year. People 18 and over should get the vaccine from their GP or Pharmacist or Occupational Health Department. Younger people should get the vaccine from their GP. The flu vaccine is free if you are in an at risk group but you may be charged a consultation fee, unless you have a medical card or a GP visit card.

The flu vaccine doesn't contain any live viruses - it cannot give you the flu.

How it works - The flu vaccine helps your



immune system to produce antibodies to the influenza virus. If you have been vaccinated and you come into contact with the virus, these antibodies will attack it and stop you from getting sick. The flu vaccine starts to work within two weeks.

At-risk groups - people in at-risk groups to get the flu vaccine. The vaccine is recommended if you: are 65 years of age, are pregnant, have a long-term health condition or work in healthcare, if are a carer, live in a nursing home or other long-term care facility or in regular contact with pigs, poultry or water fowl.

Don't get the flu vaccine if you have had a severe allergic (anaphylaxis) reaction to a previous dose or any part of the vaccine. Vaccination should be re-scheduled if you have an acute illness with a temperature greater than 38°C.



Parkinson's

Association of Ireland

People with Parkinson's need their medication on time, every time

PLEASE ATTACH THIS FORM TO MY FILE

To be handed to your Doctor and used for planned or unplanned admission to hospital.

I am living with Parkinson's Disease. I may have difficulty speaking or writing clearly. My condition may deteriorate if my medication is not taken at the correct times prescribed for me.

I WILL NEED A FULL GLASS OF WATER PER PD TABLET

Name

Contact Number

Next of Kin Contact Number

Doctor/Neurologist Contact Number

Name of PD Medication	Dosage	How Often
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>

Other Medication

Don't leave it until there is an emergency to fill out this form.

By asking your Health Care Professional to attach this to your file you will be helping them to manage your condition while you are in hospital.



*If people with PD don't get their meds
on time, their condition deteriorates.*



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Freephone Helpline: 1800 359 359

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We make every effort to be as accurate as possible, and in the event of a mistake being made, it is our policy to acknowledge it in the following quarter's publication.

The material herein is for your information only, and does not represent advice. No changes to your treatment regime should be made without the prior agreement of your consultant or GP.