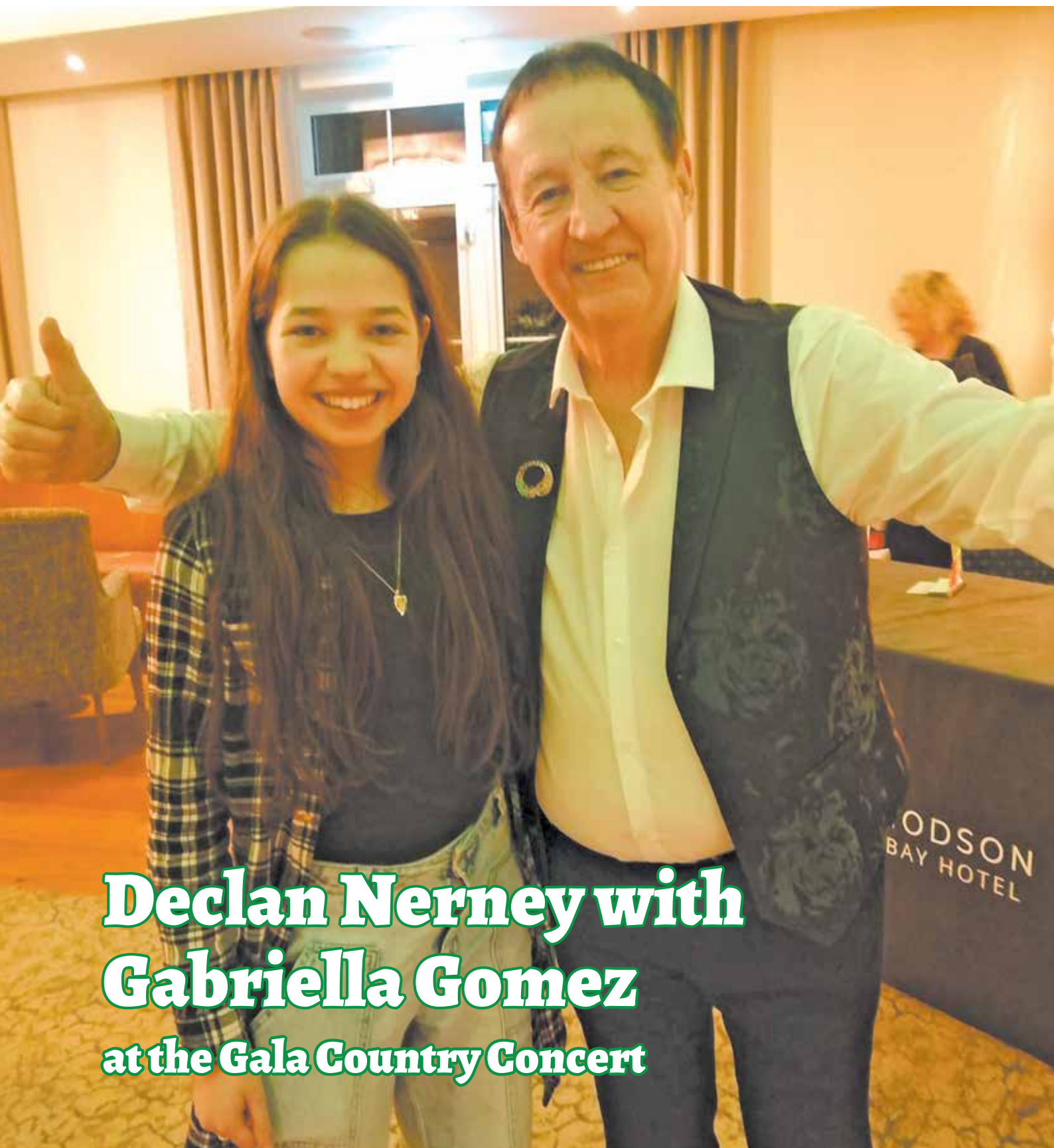




Parkinson's Ireland

www.parkinsons.ie

Spring 2024



**Declan Nerney with
Gabriella Gomez
at the Gala Country Concert**



A MESSAGE FROM THE CEO - SHANE O'BRIEN

Dear members,

Welcome to the first edition of our magazine for 2024. I'd like to take this opportunity to wish you all well for the year ahead.

There is a huge amount of work going on at the moment but for this edition, I'm going to provide an update on our three key areas of focus for Parkinson's Awareness Week in 2024: Awareness, Advocacy and Education.

Awareness Campaign – 'Different for Everyone':

By now, many of you will have seen our new awareness campaign which focuses on the variety of symptoms in Parkinson's Disease (PD) and the fact that PD is different for everyone.

The phrase 'Different for Everyone' is the most common thing that I hear from member's when they speak to me about PD. Towards the end of last year, we surveyed members on a variety of issues. This included the misconceptions about PD. The biggest theme arising from this question, was the lack of understanding among the general public on the range of symptoms in PD. I'd like to thank our members for their engagement with this, and I want to use our members to continue to inform and guide our work in the future.

We partnered with Havas, a leading creative and media company, on designing the campaign and obtaining the advertising. I'd like to thank Gareth Fitzpatrick and all in Havas for the work they put into the campaign and the significant amount of work that they did pro-bono, without which the campaign would not have come into fruition. I'd also like to thank our sponsors: Abbvie, Bial and Clonmel Healthcare.

The campaign is the biggest awareness campaign that Parkinson's Ireland has ever undertaken, and will include advertising on national radio, national newspapers, outdoor advertising and digital media such as Spotify. The campaign will reach hundreds of thousands of people.

PD is a sometimes-hidden condition and I hope that this campaign will go towards increasing the general public's understanding of the condition, and the prevalence of PD.

Advocacy:

At the time of writing, we are working on preparing our 2024 election campaign document. Although a general election is not expected until the Autumn, we feel that Parkinson's Awareness Week is the most opportune time for us to release this document, given the additional publicity that we receive during this period. These documents tend to get lost in the ether when they are released by the various organisations all at once.

Again, we have used our members survey to inform our 'asks' for this campaign. The options ranked as most important in the survey were: additional PD nurse specialists in the HSE, additional allied health professionals such as speech therapists, and the full rollout of the new HSE Community Neurorehabilitation Teams in all areas.

Our five asks in the election campaign are as follows:

- 1 Government funding for our services including our PD nurses, and funding for other allied health professional services such as physiotherapy, speech therapy, counselling and dietitians.
 - 2 The full rollout of the Community Neurorehabilitation Teams in all regions by the end of 2025.
 - 3 Additional neurologist outreach services in 5 hospitals which don't currently have a neurologist: Letterkenny, Wexford, Bantry, Portlaoise and Castlebar.
 - 4 Funding for additional PD nurse posts has been announced in recent budgets. We ask that these posts are filled as soon as possible.
 - 5 Investment into research on the links between exposure to pesticides and PD. In addition, investment should be made into education around safety measures which should be taken when using pesticides such as the wearing of masks and gloves.
- We will be working with members closer to the general election on helping us with this campaign. This will involve contacting the candidates running for election in their local area and speaking about these issues.
- At the time of writing, we don't have an update on our HSE funding application. We are told that there is no additional budget for Parkinson's Ireland for 2024, but we have yet to receive confirmation in writing of this. We need to bring visibility publicly to the overall low level of funding that PI receives. PI receives less than 10% of its overall income from the HSE and no funding for the vast majority of areas. The other neurological



charities receive over 50% of their income from the HSE. This disparity needs to end, and we need to be fearless in bringing visibility to this issue publicly. People with PD deserve the same community supports as people with other neurological conditions. With the rate of PD continuing to grow, government action on committing funding, rather than words and referendums is now what's needed.

Education:

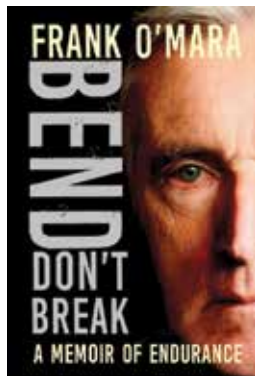
Our annual education conference takes place online on the 13th of April. There are talks from a variety of health professionals on a range of topics relevant to PD.

We recently had an event specifically for women with PD. This was held on International Women's Day and was delivered by our dietitian, Richelle Flanagan. Many of you will have seen our new website by now.

- The website has been completely redesigned and
- rebranded. We have worked on making information
- easier to find and putting the person with PD at
- the centre of how we lay out the information. For
- example, information on understanding PD and
- our service offering are now the first sections on
- the website. The clinical information has also been
- updated by our PD nurses.
- Finally, I'd like to thank everyone who supported our
- recent Declan Nerney fundraiser in the Hodson Bay
- Hotel. Everyone who attended really enjoyed the
- event and it was great to see so many of you in such
- great spirits.
- We have exciting plans for the year ahead which we
- will continue to keep you updated on.
- Take care,
- Shane

FRANK O'MARA BEND, DON'T BREAK

Limerick man Frank O'Mara competed for Ireland in three Olympic Games and broke Irish and world records. He was twice World Indoor champion in the 3,000 metres. He has recently published a book on his journey with Parkinson's disease titled 'Bend, Don't Break: A Memoir of Endurance'.



Frank made his way to the top of the telecoms industry after retiring from running. He was diagnosed with early onset Parkinson's Disease at age 48. Frank's book recounts his battle with Parkinson's and how he used the strength that made him successful as an athlete and in business, in order to 'bend, but not break' as he faced Parkinson's head on.

Frank's story is an inspiring one, and details how he has faced adversity with grace and courage. His primary motivation for writing the book is to raise awareness of Parkinson's Disease and to help



Pictured is Frank with our CEO Shane O'Brien.

people with Parkinson's.

Frank has very kindly offered a donation from his author's royalties to Parkinson's Ireland. Parkinson's Ireland is very appreciative of this kind gesture.

The book is available to purchase online and in all good bookstores.

Ruth Delaney talks to Parkinson's Ireland member

MARY-ITA O'CONNOR about her PD journey

Parkinson's Ireland spoke to Limerick born Mary-Ita O'Connor, who featured on RTE's 'The Big Life Fix' in search of a new and improved rollator for her park runs.

Mary-Ita was born in 1963 and grew up in West Limerick, but now lives in Co Cork. She has three daughters and still follows local Limerick hurling.

Mary-Ita loves running too, but this was a newfound joy that only became part of her life once Parkinson's kicked in. "It's a great saviour for me," she explained. When Mary-Ita was 39 years of age, she was diagnosed with Parkinson's Disease. "I didn't want to know about it, the consultant said yes you have it but I said leave it, forget about it, don't talk about it."

After a few falls, Mary-Ita received her diagnosis and said for the first while she was "feeling sorry" for herself and lost her confidence: "I couldn't go for any walks really. I'd try to go up the road for a walk and I'd freeze."

Crossing the road was the hardest job for her: "I'd freeze if I heard a car coming or if people were walking towards me I'd freeze. I lost my confidence completely then."

Mary-Ita kept going, and after gaining confidence on the treadmill at home, she took part in her first run in April 2016, a fundraiser where she linked arms with two of her daughters the whole way. Her daughter then suggested trying a park run, which were local in Newcastle West: "I said okay, so we signed up for it. It was 5km and I was only up to 3km on the treadmill". Mary-Ita agreed to push herself and ran the whole 5km.

"I met lovely people, special people, I'm still friends with them. I do the runs as often as I can."

Mary-Ita does 10km runs now also, with her dear friends Leila and Patsy.

Running helped Mary-Ita get her confidence back, it's "great for the head," she said: "When I cross the finish line, I still get the same buzz now as I did back in 2016. I love crossing that finish line. No matter how slow or how tired we get, we won't walk, we keep running slow. I can't give in".

After Covid, Mary-Ita needed a new rollator. She



sought the names of engineers from 'The Big Life Fix' to see if they could make one for her. However, she was told she would have to take part in the television show. "Forget that!" Mary-Ita laughed. She kept trying, and when they asked her to do the show again she agreed: "Go on so, I will!"

Filming began in 2021 and she said those involved were "smashing people". Mary-Ita met inventor and rocket scientist David McKeown and he created the prototype for her new rollator: "I broke it of course that day! But he came back with a stronger one. He has a brilliant mind."

Mary-Ita also told RTE that McKeown knew she was interested in Limerick GAA, "so he put all the years they won the All-Ireland on it, and all my family names on it. It's beautiful."

Mary-Ita intends to keep going for as long as she can and has a list of runs planned in various counties such as Clare, Galway, Kerry, Cork and Limerick. She remains extremely optimistic, but the one word she doesn't want to hear is "inspiration". "I go mad when I hear that word. I have it (Parkinson's), I've got it, get on with it."

When asked what advice she would give to people with Parkinson's Disease, Mary-Ita said to keep going no matter what: "Just keep going. If we're out running and the girls are waiting on me and I slow down, I say keep going, I'll catch up."

"The other thing I will say is to have faith. I have great faith in my prayers. Faith is a good friend, and just keep going and don't give in."



SOCIAL GATHERING 2024

Parkinson's Ireland are delighted to announce our Social Gathering will take place this year from

Monday 7th October - Wednesday 9th October
Hodson Bay Hotel, Athlone

Please join us for this gathering in the beautiful surroundings of the Hodson Bay Hotel.

THE OFFER INCLUDES

- Two Nights B&B
- Lunch
- Two nights Gala Dinner and entertainment both evenings.
- Full Day Conference to include

An exciting line up of speakers, workshops, set dancing and yoga.

Price includes all of the above

€225 per person sharing

Or

€333 per single room.



**CONTACT THE HOTEL DIRECTLY ON 090-6442005 TO BOOK.
EARLY BOOKING IS ADVISED TO AVOID DISAPPOINTMENT.**

RESEARCH IN THE DELTA NEUTROPHIL INDEX (DNI)



Research in the Delta neutrophil index (DNI) has really ramped up this year with the expansion of our Research Team and the beginning of some new and exciting research projects. Over the year more than 150 people have volunteered to participate in a number of ongoing research studies with themes including, eye tracking, Parkinson's Assistance dogs, Balance and Brain activation, as well as Deep Brain Stimulation. While some studies kicked off during the year, others were wrapped up, and the results of these research projects were shared far and wide through conferences, congresses and even radio programmes!

During the Summer, Research Registrar, Dr Amy Gallagher shared some preliminary findings of her research into Eye movements, in Parkinson's disease and Parkinson's related conditions, alongside our Canadian collaborators from Queen's University, Ontario at the annual Movement Disorder Congress in Copenhagen. The findings so far, show some changes in the speed of eye movements across different neurological conditions, however, the research is still ongoing so watch this space!

In September, with your help and participation, Rex Lloyd completed his Masters in Neuroscience with flying colours! His research focused on understanding how the brain controls balance in people with Parkinson's Disease and Progressive Supranuclear Palsy. Through his research, he discovered while levels of stability may be similar between groups, different strategies for maintaining balance are at play, which is reflected in different patterns of brain activation! These findings can be used in future to help tailor rehabilitative interventions for particular conditions to improve balance. He is pictured (left) presenting his work at the annual Movement Disorder Society Congress

Also, Nicola, a dedicated research volunteer shared her experience of being paired with her companion dog, Nemo, as part of our ongoing research with Dogs for the Disabled and UCD, into the potential for assistance dogs to improve mobility in people living with Parkinson's Disease. She spoke to the Leinster Leader and Kfm radio about how Nemo has helped her to stay active.

<https://www.kfmradio.com/on-air/podcasts/kildare-today1/episode/wednesday-4th-october-2023-hour-2/>



Scan QR Code for Nicola's interview which starts at 9 minutes and 15 seconds.

The upcoming year also looks to be full of innovative research endeavours spanning new research themes and using novel technologies. This year we are joined by Master's Student, Tom, from Trinity College Dublin, who will carry out research into causes and predictors of Falls during activities of daily living using motion sensors and pressure sensing insoles. As well, Research Registrar, Eoghan, will begin his



MD research through the exploration of new novel technologies in optimizing treatments and assessing the benefits of Deep Brain Stimulation.

We have a number of exciting research opportunities for people to take part in during the coming year, covering a wide range of topics.

- Falls Modeling: Explaining and predicting the cause of Falls in People with Neurological Conditions.
- Understanding challenges in Battery Charging in Rechargeable Deep Brain Stimulators.
- Evaluating differences patterns of Eye Movement in Parkinsonian Related Conditions.
- Quantifying Changes in Speech and Gait with Deep Brain Stimulation, using Novel Technology

If you are interested in taking part in any of our ongoing research projects, or would like to hear more about them, please don't hesitate to contact our Research Coordinators John Inocentes and Clodagh O'Keeffe by phone at +08032645 or by email at research@dni.ie

Trinity College Dublin TRINITY CENTRE FOR BIOMEDICAL ENGINEERING The State's Neurological Institute

Cognitive Interference in Postural Control as a Diagnostic and Prognostic Biomarker in Parkinsonian Disorders

*Rex Lloyd^{1,2}, Conor Fearon³, Clodagh O'Keeffe¹, John Inocentes¹, Tim Lynch³, Richard Walsh³, Richard B. Reilly^{1,2}

Introduction

- Postural deficits are an important landmark in the progression of PSP and PD and may be a useful marker to differentiate these two conditions [1].
- Postural control is associated with higher order networks, and thus increased cognitive load may cause enhanced postural instability in PSP patients [2].
- Neural correlates of postural control have not been explored in PSP. The Anterior Cingulate Cortex (ACC) is involved in error detection, generating an 'error signal' characterised by fronto-medial (FM) theta activity [3].
- Reduced FM theta may reflect ACC dysfunction and a reduced ability to detect and manage instability.
- Hypothesis: Cognitive interference may cause increased postural sway, particularly in the medio-lateral (ML) direction.
- These changes may be reflected by cortical abnormalities, specifically in FM theta activity.

Methods

Postural Sway Data Collection

- 10 PD, 4 PSP, and 10 HCs.
- Sway data acquired using a force platform and analysed through Centre of Pressure (COP) characteristics:
 - Area
 - Path Length
 - Velocity (AP & ML)
 - Amplitude (AP & ML)

EEG Data Collection

- Wireless 24-channel electrode array.
- Resampled at 200Hz.
- Parkinsonian Related T-APIC.
- Artifacts were identified through ICA and removed.

Time Frequency Analysis

- Data divided into 2s epochs (50% overlap).
- Theta frequency extracted (4-7Hz).
- Absolute power averaged over electrodes in each of the four ROI (frontal, FM, central, and parietal).

Postural Tasks and Conditions

1. Eyes Open (EO)
2. Eyes Closed (EC)
3. Attention task (SART)
4. Inhibition Control task (ICWT)

Results

Dual Task - Cognitive Tasks

Postural Sway

EEG

Discussion

- PSP patients demonstrate impaired executive functioning, particularly inhibitory control, consistent with the frontal dysexecutive syndrome [4].
- Increased cognitive load precipitates increased postural instability in both groups. PSP patients exhibit further increased sway compared to PwP during the SART condition.
- These findings suggest dysfunction of specific cognitive-motor domains which compete for limited attentional resources in PSP.
- Reduced FM theta in PSP compared to PD suggests reduced ability of the ACC to generate an error signal which facilitates instability detection. Reduced FM theta supports findings of atrophy of the ACC and impaired functionality of brain networks incorporating the ACC in PSP [5]. Reduced ACC activity may therefore contribute to postural instability in PSP patients, particularly during dual cognitive-motor tasks.

References

Acknowledgments

VHI WOMEN'S MINI MARATHON 2024



12.30pm
Sunday
2nd June

Parkinson's Ireland are looking for women to support them by participating in this year's VHI Women's Mini Marathon.

The event is open for entries now. Please visit www.vhiwomensminimarathon.ie for details

Walk, jog, run to help raise funds and awareness for Parkinson's.

Contact ruth@parkinsons.ie

We are happy to help set up an idonate page and to send t-shirts and sponsorship cards to participants.

Thank you for your support

Did you know that neurological disorders affect up to 1 billion people worldwide, nearly 1 in 6 of the world's population?

According to the World Health Organisation, 1 in 3 people will experience a neurological condition in their lifetime.

The HSE's five steps to good brain health include: physical activity; eating well; regular blood pressure checks; quitting smoking; and keeping socially engaged.

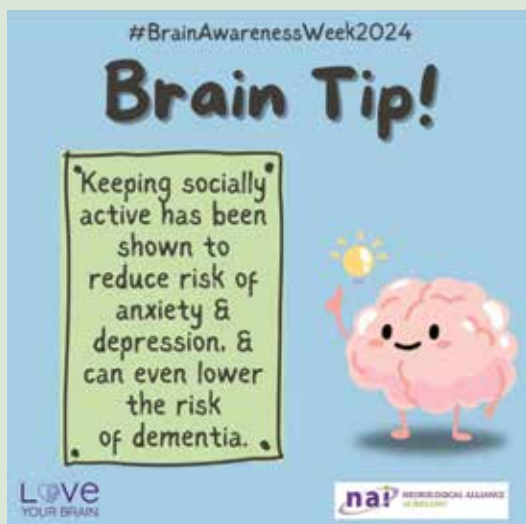
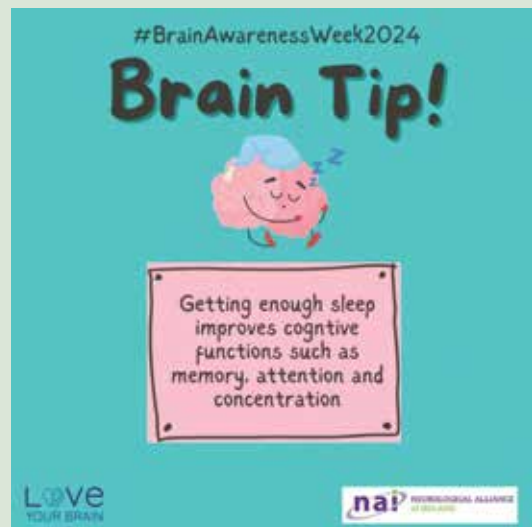
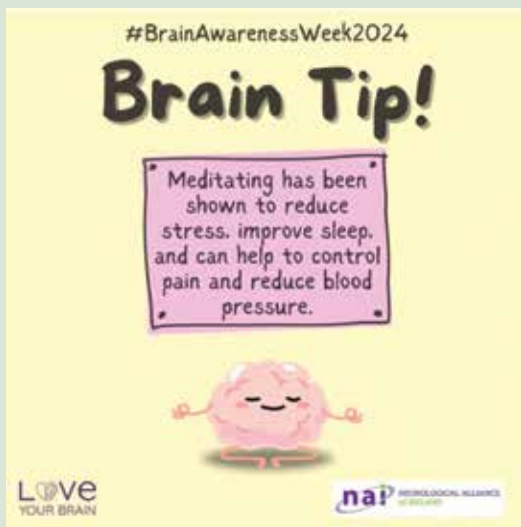
Making an effort to be socially active, exercising regularly, meditation and getting enough sleep can have a positive benefit in our brains in the long

term.

Parkinson's Ireland joined the Neurological Alliance of Ireland in support of Brain Awareness Week from the 13-17th of March to promote greater awareness of the brain and brain conditions, along with the need for more investment in services, research and prevention.

This year's theme was "The Changing Brain", a great reminder to us all of just how amazing our brains are and their ability to change and adapt. It really is never too late, or too early, to start looking after your brain!

The NAI shared plenty of key tips throughout the week for keeping your brain healthy:





DELIRIUM is often temporary and treatable

What is Delirium?

Delirium is a sudden change in cognitive baseline. It often involves sudden onset and can fluctuate in severity. Delirium is not a specific disease but rather a set of symptoms that can be caused by various underlying medical conditions or factors.

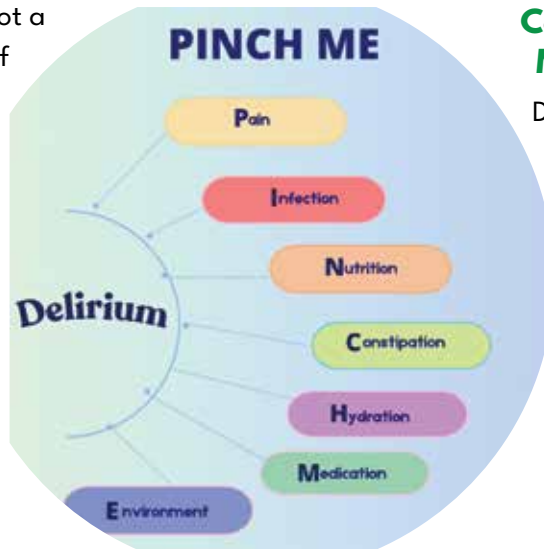
What might you notice:

1. Episodes of new or increased confusion
2. Hallucinations
3. Change in behaviour
4. Rapid Onset
5. Fluctuating Symptoms

Common causes of Delirium:

PINCH ME

**Pain Infection Nutrition
Constipation Hydration
Medication Environment**



Delirium requires prompt medical attention to identify and address the underlying cause. It is important to distinguish delirium from other cognitive disorders, such as dementia, and to treat the root cause to improve the person's cognitive function and overall well-being. If someone is exhibiting symptoms of delirium, it's important to seek medical help.

MEMBERSHIP OF PARKINSON'S IRELAND

Parkinson's Ireland was established in 1987.

Parkinson's Ireland has grown over the years to now having many branches throughout the country.

It is estimated that between 15,000-18,000 people are living with PD in Ireland.

We operate a Freephone helpline 1800 359 359, produce a quarterly magazine and a weekly e-zine.

We now have 2 Parkinson's Nurses and a Dietitian call-back service available to our members.

Our Parkinson's Nurses also travel to branch meetings to reach as many people as possible.

The National Office run online classes for members on week days including, mindfulness, singing, yoga through the chair, yoga for YPI members, nurse zoom meetings and exercise classes run by a Physiotherapist.

Branches run meetings and classes in their locality and the National Office organise information days and an Annual Social Gathering. We also organise

- activities and a National Conference during Parkinson's Awareness Week.
- The National Office have a large number of resources available to members- Information leaflets, Information booklets, Parkinson's Passports, nutrition booklets, Parkinson's Alert Cards and exercise leaflets.
- Parkinson's Ireland receive no core Government funding and we rely on donations, sponsorships and annual memberships to allow us to continue our work.
- To ensure all members are receiving their e-zine and magazine We are asking members to update their information by calling Freephone 1800 359 359 and update information if necessary – it may be a new address/ email address/contact number
- Membership of Parkinson's Ireland costs €25.00 per year.

PREPARING FOR SPRING WITH PARKINSON'S

TIPS FOR DAILY LIVING BY KATHY FOLEY PNS

As winter melts into spring, you may be realizing that your exercise routine suffered through the cold season. You probably know already that exercise is a vital component to maintaining daily living activities and mobility for people with Parkinson's disease (PD).

Studies have shown that high-intensity exercise can improve motor function while dance improves balance and walking stability.

Now is a great time to kick back into gear, but make sure you do so safely. Below are some tips for easing into a new exercise routine:

Talk to Your GP

- Your doctor knows your condition and can refer you to a physical therapist who can give you specific exercises based on your health and symptoms.
- Did you know that people with Parkinson's are at a higher risk for osteoporosis (a medical condition that makes bones weak and brittle)? Research has found that people with PD have lower bone mineral density (BMD) than their peers. Vitamin D shortage increases your risk. Ask your doctor about a BMD test before you begin a new workout plan and get outside.



Start Slow

- Try returning to a previous routine, if you had one, do it at a lower intensity.
- If you're just getting started, try working fitness into your daily routine. For example, walk to the post box. Next, try parking far from the entrance when running errands. When that's easy, take a longer walk. Increase your distance as you go, try joining a walking group or trying new walking trails.
- Work in an extended warm up and cool down time to protect yourself from any injury.
- Each week, assess your progress and see if you're ready to take it to the next level!

Safety First

- Wear comfortable shoes and clothing that provide good support.
- Make sure you have the proper safety equipment for your activity — like walking sticks or a helmet if you are cycling.
- Do NOT continue an exercise that causes pain. All movement should be done in a controlled manner to prevent injury.
- If you push too hard one day, take a break from your exercise routine the following day so you can heal and restore your energy.

Don't Do It Alone

- Having someone there if you need an extra hand is always a good idea, however it is vital if you're learning your new starting point and you're just getting started again.
- While exercise is vital for people with PD, it's important for everyone! Ask a friend, a family member or a neighbour to be your workout buddy.



You'll be more likely to stick to your plan if you have someone else working out with you.

Never been interested in fitness? Here are some great activities that don't feel like exercise:

- Check out <https://www.parkinsons.ie/exercise-and-flexibility-chart/>
- Hike with friends. With great spring weather, it may not even feel like a workout to the nature



- lover, and it means getting plenty of fresh air too.
- Play with your children or grandchildren outdoors. Make memories and break a sweat! Trying to keep up with them in the garden or in the playground, that should do the trick.
- Spruce up your garden. Since gardening combines lifting, stretching, pulling and pushing, you get a functional exercise. Don't have a garden? Join your local allotment or gardening club
- Try a new dance, set dancing, yoga, or Tai Chi class — all four benefit balance and mobility. You may even have a Parkinson's-specific class near you. Want to try it at home? Try different videos on YouTube until you find one you enjoy.
- Play Nintendo Wii Sports with your grandchild or a friend. The Wii gaming system gets you up and moving with games like tennis, golf and bowling.

Additional Resources

See our website for our exercise classes online.

So go on, take that leap and get that Spring in your step.

Saturday 13th April

14:00 - 14:05	Meeting Chair, Ms Annmarie O'Connor
14:05 - 14:15	Welcome Opening Mr Shane O'Brien, Parkinson's Ireland CEO
14:15 - 14:45	PD Update Prof Graham Hughes (Geriatrician)
14:45 - 15:10	40 + Parkinson's Symptoms Ms Kathy Foley Parkinson's Ireland (PD nurse Specialist)
15:10 - 15:35	Stronger and Better Together, acknowledging the difficulty of Moving and Communicating in Mazes, towards creating more simplified, accessible, assistive & integrated Links for People with Parkinson's & others. Ms Joanne Reilly (Speech & Language Therapist)
15:35 - 15:50	BREAK
15:50 - 16:15	Mind and Movement – unravelling the cognitive and emotional aspects of Parkinson's Prof Iracema Leroi (Geriatric Psychiatrist)
16:15 - 16:35	TITLE TBC Ms Marion Slattery (Occupational Therapist)
16:35 - 17:05	Eat well to feel well with Parkinson's Ms Richelle Flanagan (Dietician)
17:05 - 17:30	O&A & Close

abbvie



Kindly sponsored by Abbvie & Clonmel Healthcare



**Parkinson's
Ireland**

Gala Country Concert Fundraising Night

Parkinson's Ireland recently held their first Gala Country Concert Fundraising Night.

The Hodson Bay Hotel was chosen as a venue for a wonderful evening of music and dancing in the company of Declan Nerney and his wonderful band.

The crowd were entertained, sang and danced along to hits old and new. Parkinson's Ireland wish to thank everyone who supported us to get this event off the ground.

Below are some pictures that captured the night.



GALA COUNTRY CONCERT WITH DECLAN NERNEY



Gabriella Gomez pictured with Declan Nerney. Gabriella attended the concert with her grandparents and danced the night away.



PD & EXERCISE

Physical Benefits

Strength
Stretch
Balance
Gait
Rigidity
Relieving constipation
Level Of Fitness
Cardiac Benefit
Decreases Falls Risk

Exercise is a crucial piece to the jigsaw of living well with Parkinson's. In Parkinson's Ireland we put a huge emphasis on the benefits of exercise backed by evidence-based research. The research within the field of PD and exercise is a fast evolving and exciting area. The guidelines as per The Parkinson's Exercise Framework (UK) recommends – 2.5 hours of aerobic exercise per week, of a varied regime and intensity. If this sounds like a lot, remember you must start somewhere so something is better than nothing. When we exercise we know of the fitness benefits but also remember that through exercise we release endorphins (happy hormones) including the very important ones: dopamine and serotonin.

Exercise has many benefits for motor and non-motor aspects of PD, for example:

Neuroplasticity is the ability of the brain to compensate. Our nervous system has the capability to change its activity in response to stimuli by reorganizing its structure, functions, or connections, thus creating new pathways. Repeated practice helps in the strengthening of these pathways. Physical exercise has a huge role in enhancing neuroplasticity

Psychological Benefits

Builds Confidence
Increases Serotonin
Mood
Sleep
Stress/Anxiety Levels
Decreases fear of falling
Social interaction

& overall brain health. Over the last decade there has been increasing evidence promoting exercise and its benefits in neuroplasticity for PD. Some research shows exercise may have the potential to slow the disease progression in PD, more research is needed but this is extremely promising.

As part of a Health Ireland campaign, the Department of Health published National Physical Activity & Sedentary Guidelines on March 15th 2024. The key recommendation is to limit sedentary activity. The guidelines reiterate the evolving research we know about in relation to Parkinson's Disease but applies it to all age groups and ability. This includes a recommendation of 2.5 hours of aerobic exercise per week, of moderate to vigorous intensity with a variation of exercises with perhaps a focus on balance, addressing falls prevention and cognitive challenges.

What exercise is best for PD?

There is no evidence that one particular exercise is more beneficial than another. The truth is that if you enjoy it you will benefit hugely, so pick something that interests you and that you enjoy. Be it the social aspect or actual exercise that provides the dopamine hit, try new things or practice what you know, all exercise is beneficial for you. There is evidence that exercise has a role within falls prevention by addressing issues such as balance, freezing of gait and building confidence to manage fear of falling. These are just



Every Move Counts

National Physical Activity and Sedentary Behaviour Guidelines for Ireland



some exercises you may never have considered, apart from conventional exercises, that are showing great benefits to PD.

Dance therapy according to a systematic review carried out by Lavinia et al (2019) demonstrates the ability of dance to induce both structural and functional neuroplasticity. Ismail et al (2021) carried out a review explores the evidence of dance for Parkinson’s with regard to disease severity, cognition and physical benefits. The outcome showed significant reduction and improvement in motor, balance and gait through rating scores. Dance is seen as a form of natural expression, a source of sensory enjoyment, initiating body awareness and a peer community activity. It focuses on rhythmic choreographed steps, emphasis on amplitude of each step and of co-ordinating movements with each piece of music.

Paddle sports require co-ordination, multitasking, movement and speed of movement but over short distances. A non-pharmacological approach which has led to the development of world ping pong championships for PD. In 2020 Japanese researchers in Fukuoka University studied a small group of people with Parkinson’s for a period of three months. There was improvement seen in speech, handwriting, walking and tremors. Ping Pong Parkinson’s was established

in 2017, the idea originated from a gentleman with Parkinson’s who experienced the benefits - in terms of PD symptoms - of playing ping pong on his PD symptoms.

Aquatic therapy is a way of exercising your body in a different environment to dry land. Aquatic therapy provides buoyancy, reducing stress on joints, natural resistance, assisting in strength, and relaxation. Research carried out by Dr Louise Carroll in the University of Limerick showed that aquatic therapy can have positive outcomes for those with PD. Symptoms accessed included gait, balance & falls. Dr Carroll developed guidelines for health professionals including recommended dose of therapy and safety aspects to deliver optimum therapy to those with PD. Sea swimming has also been reported to be hugely beneficial for a temporary increase in endorphin levels, if you’re brave enough to get into the sea!

Where can I access exercises? Within P.I. we offer regular exercise focused classes including yoga & physio led exercises. Our branch network provides local in person classes throughout the country including dance, aquatic therapy and chair based exercises. It is also recommended that your regime is personalised and adapted to your level of ability and fitness. Consider asking your GP or physician for a referral to HSE-led Parkinson’s programmes run locally or the Living Well sessions run by HSE. See details below or contact your local Parkinson’s branch.

Four key messages surrounding physical activity:

- Some is better than none.
- Enjoy it- If you enjoy you are more likely to persist.
- Start somewhere & build it up.
- The more you do the greater the benefit.

Recommended Websites:

- www.parkinsons.ie
- Get Ireland Active
- HSE Living Well Programme LSP Contact
- Finder | Sport Ireland Home - Age & Opportunity (ageandopportunity.ie)
- References on request.)

BRANCH NEWS

MIDWEST BRANCH

The Midwest branch continues to thrive with some new members joining our committee - Brendan O'Neill, Mary McMahon, Margaret Woods and Jim Quinlivan.

We are holding our AGM on Tuesday 2nd May. A new team of officers will be elected at the meeting. We will have another great speaker on the day.

A new Aqua Therapist Dolores Whelan has joined our Hydrotherapy sessions. Dolores has brought great energy and enthusiasm to the group.

Frank O'Mara, a great athlete, has launched a new book called "Bend not Break," A Life of Endurance. He had a very successful book launch in Limerick recently and it was sold out in a short time. Frank lives in the USA but comes home to Limerick regularly.

On his next visit he will come to meet the members of our Branch and will tell his story, his years as an athlete and his journey living with Parkinson's. We will have his book available for signing on the day. On reading the book Jim Quinlivan wrote that it was not a great book, It was AMAZING!!! His talk will be on Tuesday 6th June at our Information Afternoon.

We are very grateful to all the people who gave generous donations to the Branch recently. It makes it possible to have all the activities free of charge to members.

Prof Audrey Tierney, Diet and Nutrition, spoke at the March

Information Day and in April we have two speakers from Family Carers Ireland, talking on your rights and entitlements while living with Parkinson's.

On World Parkinson's day 11th April there will be an information day in Ennis organised by a group of therapists more details will be posted to you.

Take care and keep active.

Contact **Una Anderson Ryan on 087-2511156**

ROSCOMMON BRANCH

Our 1st Physio Session for 2024 finished recently and members are availing of a well-earned rest. It's hoped to have our Chair-Yoga and Dance Classes back soon.

We are getting ready to launch our annual Walk at Oran 2024 at the end of March with the event taking place at Oran GAA Pitch at 2.00pm on Sunday 14th April
Contact Eddie ph 086-1011438

EAST MIDLANDS BRANCH

East Midlands Branch held a very successful meeting on the 24th of February. The Community Centre Monasterevin was the venue.

Our guest speaker on the day was Parkinson's nurse specialist Kathy Foley who gave a fantastic presentation on all aspects of Parkinson's disease followed by a very successful question and answer session. The meeting concluded with refreshments and as always a chat!!

Our Movement to Music classes

continue in the Parish Centre Portlaoise on Thursday mornings and Yoga classes on Tuesday mornings in the Parish Centre Newbridge both at 11am.

We have also commenced Mindfulness classes in The Community Centre Monasterevin on Monday mornings at 11.30am.

On the 4th of April East Midlands Branch will be taking part in the Live Well expo in Portlaoise College where we will be one of 70 groups and organisations who help to provide services for people with disabilities and the elderly.

For further information on any of the above please contact:

John on 087 2712448 or Marian on 085 2112973

DUBLIN BRANCH

More than ninety people attended our first Branch Meeting of the year in Tallaght on Saturday afternoon, 10th February which was an amazing turnout and there were a good number of new faces.

Membership Secretary Kieran Connolly spoke first about how the World Parkinson's Congress in Barcelona last year benefitted clinicians, researchers and people living with Parkinson's and their care partners because each cohort gained from mixing and learning from the others. He also gave a number of examples of research projects into things as varied as whether Chinese medicine or altitude training would benefit people with Parkinson's.

Then Lisa Wynne, PI's own PD Nurse



Specialist gave an interesting talk about how to improve your sleep and ways to motivate yourself, while pointing out that apathy, or a lack of a sense of get-up-and-go is being recognised more as a symptom of Parkinson's. In other words, it can take more effort to get going and to take on things



Lisa Wynne, PD Nurse.

when you have Parkinson's. On the other hand, getting out and doing things does have real benefits. Lisa was more than generous with her time, taking numerous questions from the floor and speaking to other people during the social part of the afternoon, the all-important tea, coffee and biscuits.



Membership Secretary Kieran Connolly.

At the end of January, Treasurer Sean Balfe and Chairperson Mary Butler were invited to a morning of music by the Templeogue Men's Sheds at which the group presented the Dublin branch with a cheque for €4,585 – the proceeds of both their calendar sales and their pre-Christmas carol singing outside their local Orwell Shopping Centre. We are truly grateful for the Men's Shed huge support again this year and the sing-song was most enjoyable too.

We held an awareness day on 21st March at the Ashfield Shopping Centre on Cromwellsfort Road,



Members of Templeogue Men's Sheds making a presentation to Dublin branch.

Walkinstown. We raised more than €700. Thanks to our Treasurer, Sean Balfe, for organising. We are also holding two informal get-togethers for a coffee and chat during Awareness Week. Southside: Tuesday, 9th April, 1130-1230 Milano's Restaurant, Crofton Rd, Dun Laoghaire, A96 DA02. Northside: Thursday 11th April 11am-1230pm Croke Park Hotel, Jones' Road, Drumcondra, D3, D03 E5Y8. Please note that our Clontarf class will have an earlier start time of 2pm from 25th March.

For more information about Dublin branch activities, contact Mary Butler at: dublinchairperson@parkinsons.ie or 087 243 4990.

GALWAY BRANCH

We have been busy with lots of events happening in Galway. Valentine Coffee Morning - We had a lovely Valentine Coffee morning on 14/2/24 in the Clayton Hotel. Everyone was feeling the love and enjoyed a cuppa and love biscuits. Physiotherapy Classes: Our Physiotherapy classes are going strong in Galway City, Barna, Tuam, Athenry, Ballinalsoe and Clifden. The numbers are growing and the benefits are great.

Speech Classes We are delighted to be working with Rebecca and Roisin from the HSE who are delivering Speech Classes to members once a month. There are three sessions and the attendance is wonderful. They are currently taking part in the Clayton Hotel but we hope to be able to roll out same to Tuam, Ballinasloe and Clifden in the near future.

Declan Nerney in Athlone: We had

a great night in the Hudson Bay with Declan Nerney and Band. We enjoyed a night of great music and dancing.

Golf Classic: We are delighted to be having a Golf Classic Fundraiser Weekend 3rd May to 6th May in Loughrea Golf Club. This promises to be a great weekend. We are very grateful to John Reddin and Pat Loughnane for organising this event. If you wish to take part please contact John 087 1346692. Choir Factor : our choir took part in the annual SCCUL Choir Factor on Saturday 2nd March 2024 in Kilcoran. What a wonderful night we had. Our choir had been practising each week and it paid off. Under our wonderful Choir Mistress Michelle Tully the Choir lifted the roof and every one enjoyed their melody of tunes. Well done all. Our choir are going to continue to meet up monthly and are looking forward to their next outing.

If you wish to contact the Galway Branch for more details on our services please call

Marie 087 7783825 or Caroline 086 2566655 or check out our facebook page.

OFFALY BRANCH

Offaly Branch Quarterly Report March 2024.

The AGM was held in January with a good attendance and four new members were elected to the committee. At the following committee meeting, the Chairperson, Jean Durkin, Secretary, Nuala Jones, Treasurer, Edel Healion and vice chair Larry Bane were elected to these positions. The other members elected to the committee were, Carmel Bane, Stephanie Connor, Andy Galvin, Rosemary Grogan, Sadie Keating, Yvonne Lane and Danny Owens.

The Offaly Branch continues with their weekly gym classes supervised by two local physiotherapists.

We hold monthly Branch meetings for all members, care partners and supporters on the third Wednesday of each month in the Charleville Centre, Tullamore. In February,

Kathy Foley, Parkinson's Nurse Specialist spoke to the group. In March we have the local Speech and Language therapist attending. The HSE (CHO8) has sanctioned the use of the Telea App for all persons with Parkinson's disease in our area and the SLTs have trained in its use.

The Tullamore Lions Club are holding a Golf Classic in aid of the Offaly Branch. This takes place in the New Forest Golf Club, Higginstown, Tyrrellspass, Co. Westmeath on Thursday 25th April. We are currently looking for sponsors for tee boxes (€50) and holes (€100). All funds raised will give support to people with Parkinson's in the greater Offaly area. The presentation of prizes will take place in the Brewery Tap, Tullamore on that evening with music, an auction and a raffle. We hope all our members and friends will attend the afters.

We are advertising our Branch locally and our numbers are growing with approx 60 members, including care partners, on our



Choir practice with Wexford branch members.



books. The Physiotherapists, OTs and SLTs are aware of our group and are referring to us also.

Contact numbers are: Jean Durkin 0868069855 or Nuala Jones 0879706231.

WEXFORD BRANCH

Hello to all our members

Our coffee mornings continue each month around the County we really would appreciate your attendance to keep our branch going from strength to strength

Our Singing for Health Choir is really doing well. We now have 18 members and have performed in the Riverside Park Hotel, Enniscorthy as part of a fundraiser. We also have another concert coming up in Horse and Hound, Ballinaboola, New Ross in March please see photo attached of our Choir and of this fundraiser Chair based Physio Classes are held in Murrinctown Community Centre on Fridays at 11.30am. Research shows that exercise is very good for you



Wexford branch members with Verona Murphy TD.

Chair Yoga Classes in Coolcotts Community Centre every Friday at 11am

Thank you to Anne St Ledger for her kind donation from her Coffee Morning held recently in New Ross Credit Union.

We would like to thank everyone who has paid their membership and all those who have made donations. We really appreciate it

to keep our classes running every week.

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



Coffee morning in Brandon House.

Parkinson's Ireland are looking to set up a new Cork Committee and would welcome anyone who would like to volunteer in the Cork area.

Please call our Freephone 1800 359 359 or email nationaloffice@parkinsons.ie if you are interested in volunteering your time. In the meantime, services are continuing in the Cork area as always.

Services in Cork area for members of Parkinson's Ireland Cork Branch:

Perpetual Motion Choir

Every Monday at 7.30pm – 9pm (excluding Bank Holidays) at the Lough Parish Centre on the grounds of the Lough Church. All are welcome.

Set Dancing Classes

Held on Tuesdays from 2.00pm – 3.15pm at the Marian Hall, Ballinhassig

Kinsale Support Group

A meeting of the Kinsale Parkinson's Support Group is held on the third Thursday of every

month from 11.00 am – 12:30 pm in The Friary Centre, Kinsale. For more details phone Fred Treacy 086 8275481

Local support group – Glounthaune

Meet with your local support group in Glounthaune – all welcome First Wednesday of every month

For further information please contact Jackie on 0872047169

Coffee Morning Oriel House Hotel Ballincollig. Time 11am to 12.30pm, the second Monday of every month.

Come along for the chat.

For members who cannot get to these activities please remember Parkinson's Ireland have online zoom classes daily. Please visit www.parkinsons.ie to see classes.

We also provide a Parkinson's Nurse Callback Service and a Dietitian Callback Service- please call our Freephone 1800 359 359.

ZOOM ONLINE CLASSES 2024

OUR ZOOM ONLINE CLASSES TAKE PLACE DAILY

Please visit www.parkinsons.ie for details

There is also a short video to assist people who may have difficulty in accessing these classes on our website.

Our members are sent a weekly e-zine each Friday with the links to access the online zoom classes.

Links are also available on the website.

Our online zoom classes are

Mondays - Mindfulness

Tuesdays - Singing

Wednesdays - Nurse CLINIC

Thursdays - Yoga through the Chair and Yoga for YPI members

Fridays - Physio classes

Please come along and join in these wonderful classes





BY JEROME MAUME FACILITATOR - CORK BRANCH CHOIR

The Cork branch choir “Perpetual Motion” formed in 2019 by Ted Horgan and Jerome Maume is still singing to help its members fight Parkinson’s. We meet to sing together every Monday from 7.30 pm to 9.00 pm with a tea break (excluding public holidays and in the event of severe weather).

Everyone can sing! Group singing is scientifically proven to have many health benefits particularly for those with Parkinson’s. 90% of people with Parkinson’s will have voice issues.

The group is currently facilitated by Jerome Maume who has early onset Parkinson’s disease but also over 30 years of choral experience and is a grade 8 qualified classical singer. We currently have about 18 active members (14 of whom have Parkinson’s) with care partners and other family members also joining us from time to time.

- After an initial chat we spend about 20 minutes doing physical and vocal warmups followed by some simple songs and chants. We have a tea break and then work on repertoire chosen by the members or with some performance objective.
- About 20 of us enjoyed participating in the Focus Ireland carol singing event in Kent railway station fundraising for the homeless followed by a gathering for tea, coffee and scones.
- We are currently practising to sing for the fourth time at the Cork branch annual mass in Rochestown Church on April 17th and are exploring other future performance opportunities.
- The emphasis however is on fun singing and good vocal health.
- EVERYONE WITH PARKINSON’S IS WELCOME REGARDLESS OF SINGING ABILITY OR EXPERIENCE.



Taking a break from choir practice for Cork branch members.



Parkinson's Ireland

FUNDRAISING

RUTH DELANEY

Parkinson's Ireland relies heavily on fundraising, not only for donations but to raise important awareness. We are lucky to have incredible volunteers along with people who are affected by Parkinson's, who organize and participate in fundraisers for us all over the country. Over the past few months, we have seen some fantastic efforts to raise funds and awareness for Parkinson's Ireland and our local branches.

We have put together a short summary of five fundraisers completed in aid of Parkinson's Ireland. This is only a spotlight on a handful of the fundraisers people do for us, and we would like to take this opportunity to give thanks and recognition to every single person who takes the time to help us in our goal to assist people with Parkinson's, their families, carers & health professionals.

1. Verona Gannon and Ciara Healy decided to grow their hair and donate it to Little Lady Locks, which is a charity that makes wigs for children with cancer.

Verona said: "While doing this, we decided we would make it worth something and decided we would raise money for a charity. We chose Parkinson's because it is a charity close to our hearts as my uncle has Parkinson's".

The pair cut their hair in January and donated their ponytails to Little Lady Locks, all while raising €1370 between them for Parkinson's Ireland. Well done to Verona and Ciara, we are extremely thankful, and the short hair looks great!



2. Aine Moore set herself a challenge of running 60K for the month of January, all to raise money in aid of Parkinson's Ireland. Aine quickly surpassed her original goal and decided to push it out to 100km.



Aine said: "My dad, Brian, was diagnosed with Parkinson's 17 years ago and has been living with the condition ever since, which comes with its own challenges.

Parkinson's Ireland provides significant help and much-needed support. For example, providing information, access to dedicated specialist nurses, nutritional advice, physiotherapy, and speech therapy, among other things, while continuing to lobby for improved services - more neurologists, nurse specialists and more access to proven ancillary services."

Aine raised €1,860 for Parkinson's Ireland, and tracked her runs over on her Instagram: @ainem_ She also welcomed friends and family to join her for company and support to pass the KM's. Well done and thank you Aine!

3. Sophie Barnwell raised fantastic funds in support of her Dad, Paul, who is a member of our YPI branch





and was diagnosed with Parkinson's Disease in 2021.

Sophie ran every day throughout the month of January and completed the Galway mini-marathon on the 5th of February. On the 15th of February, Sophie handed over a cheque of €7,000 to our CEO Shane O'Brien alongside her Dad, Paul and Mother, Shirley. The amount has now reached €8,050 and we want to give a huge heartfelt thank you to Sophie for her amazing work. To see more about Sophie's fundraising, please see her Instagram page: @runforpb



4. Aoife Leahy decided to walk 5km a day for 78 days, in memory of her Dad, Denis Leahy. Aoife said: "My lovely Dad, Denis Leahy, passed away, age 78, at the end of November 2023 from Parkinson's Disease.

"Just before Christmas I started to walk in his memory. My aim was to walk 5km a day for 78 days (bar illness or injury or red weather warning!)

"In doing so, I would like to raise funds for Parkinson's Ireland. All money raised will go towards research into this progressive neurological disorder and also to support people who have this disease.

Aoife has raised €4,841 and we are extremely grateful and touched by her efforts to support Parkinson's in her Dad's memory. Aoife's Mother,

Fidelma, was very involved with the Louth-Meath branch for many years and made a huge contribution to the running and support given to the members. Their family's support means the world to us.

5. Aine Herr and her family organised a raffle fundraiser in aid of Parkinson's Ireland just in time for Christmas 2023. Aine's godfather was diagnosed with Parkinson's 15 years ago and her extended family have a long family history of the disease. To raise funds for research, Aine raffled off a Prada bag worth €2500 selling tickets for €10 each.

Aine said: "My Godfather Ivan Bishoff was diagnosed with Parkinson's at just 58 whilst leading one of the world's largest brands L'oreal Ireland. 15 years later, Ivan still lives a busy and joyful life with Parkinson's but fatigue, immobility and hallucinations are just some of the daily struggles he lives with.

"Ivan is not the only one in our family who suffers from Parkinson's. Ivan's sister was diagnosed this year, my late Grandmother lived with Parkinson's for 20 years, my uncle in law Paddy was diagnosed just 3 years ago and my cousin in law Steve was diagnosed at just 40 years old. Watching loved ones suffer and feeling useless in their journey is never easy, that's why last Christmas, my family and I hosted a raffle to raise money for Parkinson's Ireland where all proceeds went towards more research into the causes of Parkinson's to hopefully find a cure one day."

Aine's raffle raised an amazing €10,370. We would like to thank Aine and all her family for their incredible support.





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.



Parkinson's Ireland, Carmichael House, North Brunswick Street, Dublin 7 Tel: 01 872 2234 Email: info@parkinsons.ie Web: www.parkinsons.ie
Freephone Helpline: 1800 359 359
Company registered in Ireland No. 123532, CHY No. 10816
Registered address as above

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.

