

Parkinson's Association of Ireland

www.parkinsons.ie

Spring 2018

WALK WITH US

15th April 2018

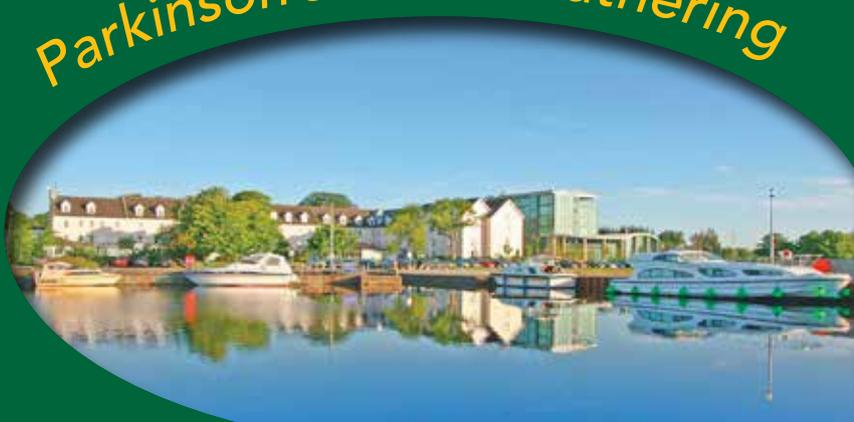
MAKE
EVERY
STEP
COUNT



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Parkinson's Social Gathering





Paula Gilmore

A WORD FROM OUR CEO

Dear Members,

It is time to show our dissatisfaction with the health services, or lack of them.

Despite our best efforts, and a meeting with the Minister for Health, Simon Harris, last year The Parkinson's Association still has no direct government funding. There is no commitment on a nationwide Nurse Specialist service and our members still have to travel abroad for DBS (Deep Brain Stimulation) surgery.

We are organising a protest in advance of Parkinson's Awareness Week and want as many of you as possible, along with your families', to take part. Marian Harkin, Independent MEP, who is also the EU Ambassador for people with Parkinson's

- plans to be there to support us. The lunchtime
- protest will take place at 1pm on Thursday
- 29th March outside Leinster House. We will
- hand in a letter to the Minister for Health,
- Simon Harris, appealing for funding, along
- with our petition signed by thousands of
- people.
- Please spread the word about the protest
- on Thursday March 29th. Join in to make our
- voices heard.
- Parkinson's Awareness Week runs from
- Monday 9th to Sunday 15th April. The annual
- Unity Walk will take place on Sunday 15th
- April. The theme for 2018 is 'People's Lives.
- Living with Parkinson's'. A photographer will
- also be asked to get portrait photos of six to
- eight members with PD which can be used
- to highlight the theme. We hope that Brain
- Awareness Week in March may also attract
- publicity. In partnership with the Dublin Brain

Call to Action

Dear Members,

It is time to show our dissatisfaction with the health services - or lack of them - for our members and their families.

Despite our best efforts - and a meeting with the Minister for Health, Simon Harris, last year - the Parkinson's Association still has no direct government funding, no commitment on a Nationwide Nurse Specialist service and our members still have to travel abroad for DBS (Deep Brain Stimulation) surgery. When combined with the chronic/critical shortage of Neurologists in this country, it seems we are the poor relations in the Irish health service.

So, we are organising a protest in advance of Parkinson's Awareness Week and want as many of you as possible, along with your families' to take part. Independent MEP, Marian Harkin, who is also the EU Ambassador for people with Parkinson's plans to be there to support us. The lunchtime protest will take place at 1pm on Thursday 29th March outside Leinster House. We will hand in a letter to the Minister for Health, Simon Harris, appealing for funding, along with our petition signed by thousands of people.

We will also demand the Nurse Specialist service we need, and deserve, as a so-called First World country. It is not too much to ask that the twelve thousand people

in this country with Parkinson's Disease should have access to a Nurse Specialist within their area. There are only five such positions across the entire country and one of the posts is vacant. In the North West, the Nurse Clinic is funded entirely by members of the Parkinson's Association. The Support Line Nurse is funded by PAI. Four nurses for twelve thousand people's long-term needs is grossly inadequate.

Travelling abroad for surgery is costly for the state and difficult for patients and their families. If DBS surgery was available here it could be more cost-effective and, crucially, more people with Parkinson's Disease could avail of it.

A Nationwide Nurse Specialist Service and direct funding would save the government money in the long-term as it would reduce the number of bed nights our members need to spend in hospital. (This is borne out by the Specialist Nurse Service for those with epilepsy). The Parkinson's Association, with its knowledge of people's needs, could target funding and services where they are most needed. Long Term Illness should not mean being deprived of surgery and nursing care in the long term.

Please spread the word about the protest on Thursday March 29th. Join in to make our voices heard.

Sincerely,

Paula Gilmore



bank, PAI will host a pub quiz and an awareness campaign as part of BAW. The pub quiz is on 5th March in the Ruin Bar, Tara Street. Also in Partnership with Neurologic Alliance of Ireland we will be supporting the Invest in Neurology Campaign calling on the government for:

- Immediate investment to address critical deficits in neurology staffing, including neurologists, nurses and allied health professionals to recommended levels
- Long term investment in neurology services to support implementation of the Neurology & Epilepsy Models of Care.
- Establishment of all Ireland deep brain stimulation service for people with Parkinson's disease and other neurological conditions. We have received information that there has been a development on a DBS service and as soon as we have more information we will update you.

The members social gathering will take place the 5th-7th September in Athlone, all details are on

- page 9. We have decided this year to go with a mid-week break and have two nights and two evening meals. That will give us more time to enjoy the hotel and each other's company .

• **Camino De Santiago fundraiser for the National Office**

- This fundraiser will take place from 13th-20th October and I would love as many of you as possible to join me and some board members on this upcoming fundraising challenge. Please tell your family and friends to consider doing this 100km challenge to raise much needed funds for the Parkinson's Association of Ireland's national office.

• 

• *Sincerely*
• *Paula*

PARKINSON'S AWARENESS CAMPAIGN

The Parkinson's Association of Ireland are involved in an awareness campaign to highlight the need for services for its members.

Friday 2nd /Saturday 3rd March - Headspace - Dementia & Neurodegeneration Network Ireland Parkinson's Association will attend and have a stand at the event. For further information and booking <http://www.creativeageinginternational.com/events/BrainAwarenessWeek>

Monday 5th March - Parkinson's Association in Collaboration with the Dublin Brain Bank will hold a Pub quiz in Ruin Bar Tara St Dublin 2 at 7pm. €10.00 a head. All Welcome

Tuesday 6th March - Irish Brain Council and Neurological Alliance of Ireland Conference, Royal College of Physicians Kildare. See website www.nai.ie

Wednesday 7th March - Launch of the Harold's Cross Support Group, Our Lady of the Rosary Pastoral Centre Harold's Cross at 11am.

Saturday 10th March - Dementia and Neurodegenerative Disease Conference UCC Cork Parkinson's Association will have a stand at this event.

• **PROTEST OUTSIDE LEINSTER HOUSE**

- **Thursday 29th March** - Join us at 1pm for a silent protest along with Marian Harkin MEP, EU Ambassador for people with Parkinson's. We will hand in a letter plus our petition to Simon Harris, Minister for Health.

• **PARKINSON'S AWARENESS WEEK**

- The theme for this year's week is 'People's Lives, Living with Parkinson's Disease'.
- Our media representative, Mary Butler, will be promoting this theme throughout the week to raise awareness about living with Parkinson's Disease in Ireland today.

- **Wednesday 11th April** - Parkinson's groups all over the world will unite on 11th April 2018 to raise awareness about the disease, using a dedicated campaign on social media, hashtag: #UniteForParkinsons.

- **Sunday 15th April** - Join us to celebrate our **Unity Walk**. We will meet in the Alex Hotel, Dublin 2 at 11:30. Walk begins at 12 noon. We will walk around Merrion Square and return to the Alex Hotel for lunch and an afternoon of entertainment.





DUBLIN BRAIN BANK

Dublin Brain Bank was established in 2008, and is today based in Beaumont Hospital, Dublin, in the Royal College of Surgeons in Ireland Smurfit Building. The aim of the Brain Bank is to facilitate the donation of brain tissue to medical and scientific research, and to provide Irish and international researchers with access to brain tissue to conduct research into neurological disorders.

Dublin Brain Bank offers the opportunity to support medical science in a very tangible manner. Through the study of this precious brain tissue, researchers aim to develop our understanding of the mechanisms underlying neurological disorders such as Parkinson's disease and Parkinsonism. This, in turn, will enable improvements in the diagnosis and treatment of these disorders, ultimately leading to increased quality of life for patients. We also encourage people with no neurological disorder to consider registering in our donor scheme; while healthy tissue is essential as a point of comparison, many brain banks have difficulty obtaining sufficient 'normal' tissue.

Since the opening of the Brain Bank, over five hundred people have registered as donors, and over three hundred donations have been received. Of the neurological disorders represented, the most common tissue samples are Alzheimer's disease cases, followed by Motor Neurone Disease, with Parkinson's disease plus syndromes accounting for the third largest portion of tissue samples. The courage and generosity of our donors and their families paves the way for treatments, cures and reduced suffering for patients with Parkinson's disease or other neurological disorders in the future.

The donation process relies on consent on the part of the donor and their next-of-kin. As is the case

for other forms of organ donation, Irish law does not permit an individual to consent to the donation of their own organs; it is therefore important that the donor discuss the process with their next-of-kin, and make their wishes known. To register for donation, the donor completes an 'Intention to Donate' form, while the next-of-kin complete a 'Consent to Post-Mortem' form, granting permission for tissue to be taken.

After the death of a donor, a post-mortem examination of the nervous system is conducted as soon as possible. The brain tissue is recovered during this examination, and is preserved for future use. The donor's body is typically released to the undertaker on the same day so that funeral arrangements are not delayed. All costs relating to transport for donation are borne by the Brain Bank.

The decision to donate should be considered carefully, and a member of the Brain Bank team will always be willing to answer any questions donors may have. Donors can withdraw from the donor registry at any time, without having to give a reason. Donation to the Dublin Brain Bank is strictly confidential and information regarding the tissue will only be provided to relevant parties with the consent of the family.

If you or someone in your family is considering Brain Donation then please don't hesitate to contact the Project Coordinator for more information via the following:

**Ms. Jennifer Lorigan,
Project Coordinator,
Dublin Brain Bank,
Neuropathology Department,
Beaumont Hospital,
Dublin 9.
www.brainbank.ie
Phone: 01 8092706
24 hr messaging service: 01 7974757
Fax: 01 8092955
E-mail: brainbank@rcsi.ie**

Join us on the

13th - 20th October 2018

Camino Way



Parkinson's
Association of Ireland

WALK FOR PARKINSON'S

Join us this October for the trip of a lifetime to the Camino de Santiago in Northern Spain.

From 13th to 20th October 2018, make it your goal to get fit and active and join us on the walking trip of a lifetime along the world famous, Camino de Compostela, in Northern Spain.

Each day our group will walk on average 20km, with a mid-day break for lunch in the cafes and restaurants that dot the trail. And in the evenings, break bread with new friends while enjoying home-cooked meals in the guesthouses and hotels that have been carefully selected to add to your Camino experience.

ITINERARY:

- Sat 13th Fly Dublin to Santiago and transfer by coach to Sarria
- Sun 14th Walk Sarria to Portomarin (23km)
- Mon 15th Walk Portomarin to Palas de Rei (25km)
- Tue 16th Walk Palas de Rei to Melide (15km)
- Wed 17th Walk Melide to Arzúa (14km)
- Thur 18th Walk Arzúa to Amenal (22km)
- Fri 19th Walk Amenal to Santiago (22km)
- Sat 20th Morning free & transfer to Santiago Airport mid afternoon.

TRIP COSTS €2,200 AND INCLUDES:

- Return flights Dublin to Santiago
- Bus transfer Santiago to Sarria and to the airport
- Seven nights in two and three star accommodation
- All breakfasts and dinners
- Daily luggage transfers
- Route maps/Pilgrim Passport

BOOKING DEPOSIT €250

At least
60% of your
donation will
go to PAI

CONTACT US ON 01 872 2234 FOR SPONSORSHIP PACK

'EVERY DISEASE IS A MUSICAL PROBLEM;'

Creative art therapies, which allow individuals to experience and express themselves through the arts, are a valuable treatment option for individuals with Parkinson's disease. The creative art therapies foster resilience and exploration of creativity in a supportive environment. They offer reassurance, encouragement, and potentials to adapt, flourish and cope.

The British Association of Art Therapy define the arts as being "committed to understanding and utilising the therapeutic potentials of both psychological therapy approaches and the art form employed. In bringing together the aesthetic and psychological domains, the resulting practice is unique" (2010). Creative arts therapies are practiced throughout Ireland and in more than 40 countries worldwide. The umbrella term includes the following four professions:

- Art therapy
- Music therapy
- Dance therapy
- Drama therapy

Creative arts therapists work with individuals and groups in a variety of settings. In health and social care settings, therapists can be found working in hospitals and rehabilitation centres, nursing homes, hospices, and in centres treating mental health, substance misuse and offering social care. In educational settings therapists work in early intervention, schools and special schools, vocational training centres, and disability services.

• Music therapy

• Music therapy is an evidence-based profession that uses music to help with physical, emotional, cognitive, and social needs at any age. There are two types of music therapy: 'active' which involves the use of instruments and voice, and 'receptive' which involves listening to music. Music therapists are trained to design specific programmes for individuals or groups according to their emotional, physical, social and cognitive abilities. Sessions may include instrument playing, listening to music, song writing or singing.

• Music therapy and Parkinson's disease

• Oliver Sacks once said, "music... is a remedy, a tonic, orange juice for the ear. But for many neurological patients, music is even more – it can provide access, even when no medication can, to movement, to speech, to life. For them, music is not a luxury, but a necessity." (Sacks, 2007, p. 156)

• Parkinson's disease gives rise to movement-related dysfunctions as well as other symptoms, mainly of a psychological and cognitive nature. Aarsland,





EVERY CURE IS A MUSICAL SOLUTION'



Påhlhagen, Ballard, Ehrt and Svenningsson (2011) report that depression is experienced by 35% of individuals with Parkinson's disease, whereas Richard (2005) indicates that anxiety is found in 40% of cases. Playing and listening to music modulates emotions, behaviours, communication and movement. Music can produce substantial effects on psychological symptoms as well as movement-related ones in Parkinson's disease by some of the following;

- reducing stress
- improving movement
- improving breathing
- improving verbal and non-verbal communication
- promoting self-expression
- promoting a sense of well-being

Cork Parkinson's Branch music therapy groups

Music therapy sessions with the Cork Parkinson's Branch began in May 2017. Weekly music therapy groups are held in Ballincollig and Middleton. These groups provide members with the opportunity to work on breathing and vocal exercises, singing and relaxation. The breathing and vocal exercises improve diaphragm and chest extension, and therefore, improve breath-depth and stability of posture. Singing has all the benefits mentioned so far, and it is particularly helpful in improving speech that may be slurred as a result of Parkinson's disease. Furthermore, music therapy groups incorporate the following goals:

- sustaining the voice
- increasing and controlling volume
- varying pitch and expression
- controlling vocal speed

Group members have said that music therapy "... helps me to forget my problems for an hour" and that "...it is very relaxing." Others have said that "it makes me more aware of my breathing and projecting my voice" and that "the emphasis on breathing properly" is useful. If you would like more information on the groups that are running in Cork, or you would like to get involved, please contact Ted Horgan on 087 237 5558 or you can email tedhorgan3@gmail.com.

In Summary

Interventions that involve music can offer important starting points in the rehabilitation of Parkinson's disease. Don't be put off by thinking that your symptoms might make engaging in music therapy difficult. There are many different techniques that can help you. And remember, in all creative therapies, no prior knowledge or experience is necessary. Many people try new activities after being diagnosed with Parkinson's disease and derive so much pleasure from them that they wonder why they didn't start before!

*Jess O' Donoghue, BSc, MA
Music Therapist
odonoghuejessica@gmail.com*



References

- * Aarsland, D., Påhlhagen, S., Ballard, C. G., Ehrt, U., & Svenningsson, P. (2012). Depression in Parkinson disease—epidemiology, mechanisms and management. *Nature Reviews Neurology*, 8(1), 35–47.
- * British Association of Art Therapy (2010). *What are the art therapies?* Retrieved from <http://www.baat.org/ArtsTherapies2010Flyer.pdf>
- * Richard, I.H. (2005). Anxiety in Parkinson's disease. *Advances in Neurology*, 96, 42-55.
- * Sacks, O. W. (2007). *Musicophilia: Tales of music and the brain*. New York, N.Y.: Knopf.

INVEST IN NEUROLOGY CAMPAIGN

This campaign is being run by The Neurological Association of Ireland.

The PAI is a member of the NAI.

800,000 Irish people are living with neurological conditions such as migraine, epilepsy, multiple sclerosis, stroke and Parkinson's Disease as well as rare and genetic conditions.

A nationwide audit of neurology services published in 2016 showed critical gaps in neurology services and staffing across Ireland, including:

- ❑ The recommended ratio is one consultant neurologist per 70,000 population, this was exceeded within every hospital group and in one hospital group (Mid West) the ratio is 1:200,000

- ❑ Less than two thirds of the minimum recommended number of dedicated inpatient neurology beds available to support the service nationwide

- ❑ Number of specialist nurses is significantly below what is recommended for our population with less than half the number of MS nurses and less than a third for Parkinson's Disease (recommendations British Assoc Neurologists)

People can wait up to 2 years to see a neurologist. We have 34 neurologists for our population, we should have a minimum of 72.

The first patient experience survey of over 200 service users of outpatient neurology services, carried out in 2017, found that:

- ❑ Over one third of patients who responded were concerned at the length of time until their next appointment

- ❑ Over one fifth of respondents reported waiting more than 6 months from the time they were referred by their GP and when they saw a neurologist for the first time with one in ten respondents waiting more than 12 months.

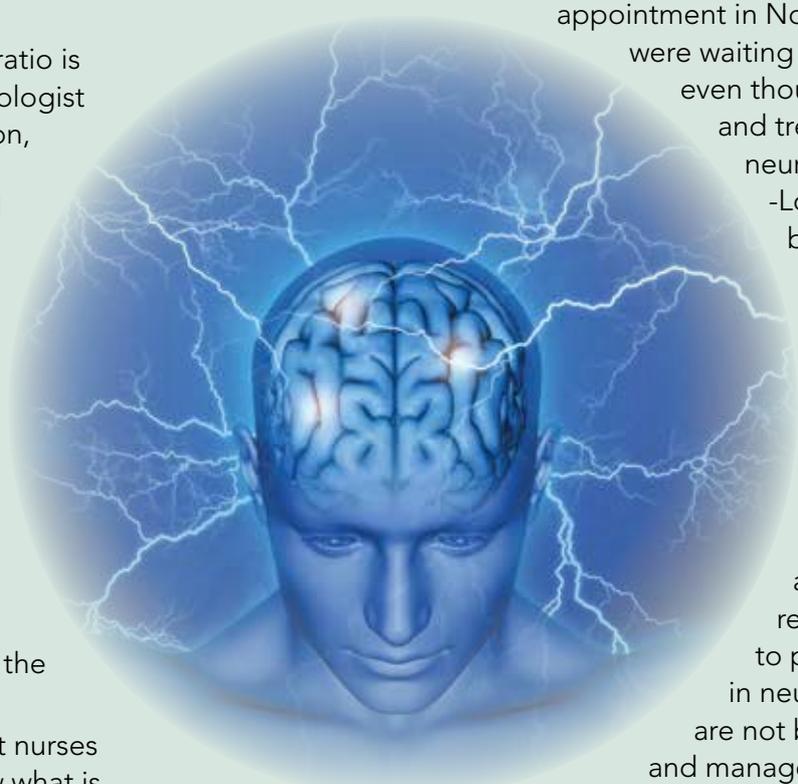
Failure to invest in neurology services has led to:
Long waiting times for first outpatient appointment to see a neurologist (NTPF figures showed that over 19,000 people were waiting for a first appointment in November 2017, 11,000 were waiting more than 6 months), even though early diagnosis and treatment is essential for neurological conditions.

-Long waiting times between appointments and lack of access to specialist nurse and therapy services

Increased pressure on other areas of the health and social care system such as home care services, personal assistance services and rehabilitation services due to preventable deterioration in neurological conditions that are not being properly monitored and managed.

The Invest in Neurology campaign is calling for Government commitment for:

- ❑ Immediate investment to address critical deficits in neurology staffing, including neurologists, nurses and allied health professionals to recommended levels
- ❑ Targeted long term investment in neurology services to support implementation of the Neurology & Epilepsy Models of Care
- ❑ Establishment of all Ireland deep brain stimulation service for people with Parkinson's Disease and other neurological conditions





MID-WEEK SOCIAL GATHERING

5th and 6th September 2018.
Hodson Bay Hotel Athlone.

Please contact Hodson Bay Hotel directly to book your accommodation 090 644 2005

THIS YEAR OUR SOCIAL GATHERING TAKES PLACE ON THE FIRST WEDNESDAY AND THURSDAY IN SEPTEMBER

The offer includes:

- Two nights Bed and Breakfast
- Lunch
- Two nights Gala Dinner and entertainment
- Full use of spa/pool/leisure facilities

Full day conference to include:

- Nurse clinic, Neurologist, Set Dancing, exercise, yoga, to name some of the activities we hope to include.

COST:

- **OPTION 1** (Contact Hotel) 5th & 6th September
€190 per person sharing for two nights
€230 per single room for two nights
- **OPTION 2** (Contact Hotel) 6th September
€105 per person sharing for one night
€125 per person single for one night
- **OPTION 3** (Contact Parkinson's Head Office 1800 359 359) 6th September
€35.00 per person day attendee, to include lunch and full day conference

TO BOOK OPTIONS 1 OR 2 - CALL HODSON BAY 090-644 2005

- Dedicated resources to support the development of clinical pathways for headache, multiple sclerosis, Parkinson's Disease and other neurological conditions.

The Invest in Neurology Campaign is supported by the PAI. To find out more about this campaign visit www.nai.ie/go/campaign-centre

1. INVESTMENT IN STAFFING

- Providing full multidisciplinary teams (neurologist, nurse and allied health professionals) in each neurology centre nationwide would:
 - ▲ address unacceptable waiting times for outpatient appointments
 - ▲ Lead to improvement in key outcomes such as length of stay and readmission.

Specialist nurses recruited as part of the Epilepsy Clinical Programme have led to reduced length of stay and admissions to hospital

2. INVESTMENT IN DEDICATED NEUROLOGY BEDS

- Ireland has less than two thirds of the minimum ninety dedicated neurology beds needed for its population
- Investing in dedicated beds to support neurology services nationwide is vital to enable these conditions to be properly managed
- Dedicated neurology wards have been shown to improve outcomes, reduce length of stay and need for rehospitalisation

3. DEVELOPMENT OF CLINICAL PATHWAYS FOR HEADACHE, MULTIPLE SCLEROSIS, PARKINSON'S DISEASE AND OTHER NEUROLOGICAL CONDITIONS

- Clinical pathways have been shown to improve co-ordination of care, reduce fragmentation, improve patient outcomes and reduce costs of unnecessary admissions and complications.

BRANCH NEWS

CAVAN BRANCH

The Annual General Meeting of the Cavan Branch of the Parkinson's Association of Ireland was held in The Hotel Kilmore, Cavan on Monday 19th February at 6.30pm.

We welcome new members and people living with Parkinson's who would like to join. Their spouses or family members who would like to join are welcome to contact our branch.

There was a talk by Barry Murphy, Community Mental Health Nurse on "Looking After Our Mental Health".

Yoga has resumed after the Christmas break every Friday at 11am in the Community Centre, beside Castlemanor Nursing Home, Cavan. Cost €5.00 per session.

All yoga is done sitting on a chair apart from a few standing up exercises. There is no pressure to do all the exercises. Please contact any member of the committee for more information. If any members think there might be an interest in getting some yoga classes in their area for a period say of 6 weeks please contact Eileen 086 242 6699.



The Cavan branch had a very enjoyable Christmas dinner in the Errigal Hotel and a number of the Monaghan branch joined us for the occasion. A presentation from the newly elected Mayor of Cootehill, one of our members – Danny Byrne was made to the branch from his fundraising campaign for which the branch is very grateful. Sincere thanks to Danny and his wife and team for all their hard work! Also, a big thank you to Margaret Fox, another member who ran a very successful sponsored walk as part of Danny's campaign. Thank you also to member Helen Cunningham who along with her family ran a table quiz and to Jim O'Leary who nominated the branch for a donation from the Cavan Rugby Club Male Voice Choir!

Congratulations to Mary Flood who recently won the title of Best Granny in Ulster in a competition run by Specsavers. Mary was nominated by her granddaughter Yasmin. Mary is the wife of Sean, one of our members!

Well done to our Chairman Paddy Conaty who recently spoke so eloquently to Joe Finegan on Northern Sound Radio about living with Parkinson's disease following the announcement that singer Neil Diamond had been diagnosed with Parkinson's. There were a number of messages sent to the radio station after the interview stating what a wonderful inspiration Paddy is to us all! Well done Paddy!

Contact Eileen 086 842 6699.

MIDWEST BRANCH

On Tuesday, December 5th the AGM of Mid West branch was held followed by mass for deceased members.

At the AGM, the following positions were filled. **Chair** - Kathleen Conran. **Vice Chair** - Aidan O'Connor. **Secretary** - James Broderick, **Treasurer** - Eddie Butler. We pass along our sincere thanks and gratitude to Billy Rice and P.J. O'Driscoll who have provided great service, support and guidance to the branch and people with Parkinson's over the past number of years. We also extend our thanks to all committee members who have contributed to the success of the branch.

Our end of year mass was celebrated by Fr. Harry Bohan. He delivered a powerful and inspirational homily and we are very grateful for his contribution. We finished off our evening very socially with a chat tea/coffee and mince pies. Wished each other a Happy Christmas and Healthy New Year.

Our regular monthly meeting resumed on Tuesday, February 6th at 2.30pm in the Greenhills Hotel. The monthly meetings are open to all people with Parkinson's Disease and their Carers. We have tea and coffee and a chance to meet Mags, our Parkinson's nurse specialist after the informative guest speaker.

A number of members continue to attend dance classes delivered by Pat O' Dea. We hope to have music therapy classes recommence in the



near future. Hydrotherapy classes resumed on February 7th, because of the increase in numbers we have had to arrange a second class. The first class commenced at 1.00pm and the second at 1.45pm. For further details and to register contact Eddie Butler, Hon Treasurer. Physiotherapy, with final year students from UL will be held for the next six weeks on Thursdays and Fridays, commencing on Thursday, January 25th.

We started 2018 with our annual lunch in the Greenhills Hotel which was a great success. Thanks to all who attended and Eddie Butler for organizing a wonderful event.

Contact Kathleen 087 634 4023.

WEXFORD BRANCH

2017 was a very active year for our Branch with regular, well attended Coffee Mornings/Support Meetings at various hotels around the county. Yoga classes at Coolcotts Community Centre continued to be very popular and were always well supported, we hope this will continue for 2018. We also had some great trips where we laughed, danced and most of all, made great friends



We are planning a 3 night trip to Killarney Co. Kerry in May, visiting Muckross House & Gardens and taking a Jarvey and Boat trip. In view of the pleasure and support derived from these outings we would be pleased to hear from other Branches with similar plans, especially any involving a visit to the Sunny South East, in order that we might arrange some suitable hospitality. For those of you not familiar with our region – we encourage you to pay us a visit.

Please contact us if you would like to be included on the Parkinson’s Course that is run by Wexford General Hospital where you will receive lots of information and support. You will be in contact with a nurse, have access to physiotherapists, occupational and speech therapists. Please contact us for details.

This opportunity is taken to express on behalf

of our Branch, our thanks to Paula Gilmore and the staff at the National Office for their continued support and good work which is much appreciated

Chairman: Gerry Peake 053 9367638

Breda Kennedy 087 0958984

Email: paiwexford@gmail.com

CORK BRANCH

Since our last branch news was submitted we have been quite busy on a number of fronts. Eight people from Cork represented the Branch at the Social Gathering in Hodson Bay Hotel in Athlone. Indeed 2 couples extended their stay at the hotel for an extra few days to relax after the fast moving, but most enjoyable weekend. The Cork Parkinson’s committee set a goal for the branch to bring support closer to people who live some distance from Cork. Tony Wilkinson spearheaded this initiative. Tony was diagnosed with Parkinson’s in the UK about 3 years ago and had the benefit seeing at first hand the level of support available to newly diagnosed Parkinson’s Patients in the UK from both Parkinson’s Nurse Specialists and Parkinson’s Support groups. Through his efforts and with the support of his wife, Kate, and many others whom he has enlisted along the way, including radio stations, newspapers, volunteer organisations, UK trained Parkinson’s nurses and People with Parkinson’s in West Cork, we now have a Bandon Parkinson’s Support Group, A Skibbereen Parkinson’s Group and plans for a group in either Schull or Bantry. These are local support groups run by people in the localities. Tony also plans to set up a Mallow Parkinson’s Support Group and to help people in Fermoy to get their group firmly established.

As well as monthly coffee mornings we now have 3 different weekly classes running in Ballincollig Community Centre. On Mondays, Voice and Music Therapy, Tuesdays Set Dancing, Thursdays Exercise classes. We also have a Voice and Music Therapy class in Market Green, Middleton on Mondays. The Voice and Music Therapy classes are presented by Jessica O’ Donoghue, who spoke at the Social Gathering mentioned above as well as all the Parkinson’s Patient Conferences last year. Jessica is a qualified Speech and Language Therapist and also a Music Therapist and is now a lecturer on the Music Therapy Course at UL. Her classes focus on improving the strength and clarity of speech through breathing control, voice projection, upper body exercises and end with a relaxed singing of a favourite song and discussion about the song’s

meaning. In Bandon on Thursdays the Bandon Movers and Shakers Exercise class has been running for the past 8 months. In Ballincollig the exercise classes started in early January 2018, they are physio- led exercise classes and have been well attended and very enjoyable. We also hope to have a number of information meetings a conference and social outings during the year.

We had our Annual Party on 21st January 2018, more than 150 people were in attendance at the Clayton Silversprings Hotel/Events Centre, Cork. This was a new venue this year and everybody enjoyed it. The function room was extremely comfortable with huge windows letting in natural light and views of the new Pairc Ui Chaoimh, the most modern Sports Stadium in Ireland. We were treated to a feast of excellent food served efficiently. We were then treated to a feast of music during the afternoon from two local bands who came together to play for the group free of charge. We also got an opportunity to display the set dancing skills we have learned with the much appreciated assistance of Ballincollig Comhaltas. We were entertained also by Mary B, Billy, Declan and Caoimhe. Paula Gilmore was unable to attend due to another commitment. We congratulate Paula on the excellent 5 year strategic plan produced under her guidance. It is excellently formulated and concisely written. It enables branch leaders to show that alongside the generous

• volunteer spirit of each branch there is a well
• managed, dynamic, functional organisation which
• is very much in touch with needs of Parkinson's
• patients nationally and locally.

• We continue to strengthen our links with the
• UCC Parkinson's research hub and are presently
• involved in 2 separate research projects. We are
• also having discussions with Professor Aideen
• Sullivan of the Neuroscience Department about
• getting involved in an Open Day at UCC in
• March on Neurodegeneration. We live in hope
• that all the Parkinson's research worldwide will
• soon deliver either a cure or a treatment that will
• greatly improve our quality of life. May the year
• ahead be memorable for all the right reasons!

• **The Cork Unity Walk will take place on**
• **Wednesday 11th April at 10:30 in Ballincollig**
• **Park followed by refreshments at Oriel House**
• **Hotel.**

• **Contact: Ted Horgan 0872375558**

• **TIPPERARY BRANCH**

• The campaign for securing a Parkinson's Nurse
• Specialist and support services will continue
• unabated to cover the catchment area of
• Clonmel General Hospital and University Hospital
• Waterford. The Branch will be actively supporting
• the long ongoing National Campaign to obtain
• improved services for Parkinson's patients and
• Government funding for P.A.I. This campaign will



Tipperary Branch members gathered for the Christmas Dinner in the Monella Hotel



involve a protest outside Leinster House at 1pm on Thursday 29th March 2018.

Tipperary Branch will organise travel for all who wish to join in a show of strength highlighting the lack of Health Services for people suffering from Parkinson's Disease. Contact Marion Burke PRO 087 296 7296.

Pre Christmas activities included the Annual Christmas Dinner of Clonmel Support Group in the Monella Hotel. Congratulations to Mary and the Committee. Guests were Branch Chairman Michael Burke, Secretary Mary Carey & PRO Marion Burke.

The Annual Christmas Carols in the Community Hospital of the Assumption, Thurles with the Upperchurch Youth Choir which played at Knock Shrine earlier in the season followed by refreshments.

The Annual Ecumenical Candle Lighting Service for members who were called to their eternal reward in the past year was held on Friday night 15th December in the Pastoral Centre, Church Rd., Nenagh. Participating Celebrants were Rev. Roderick Smyth, Church of Ireland Rector and Fr. Des Hillary PP Nenagh. The Monday Club choir under Musical Director Sheelagh Chadwick with musicians Mary Shinnors and Rita Gleeson made a significant contribution with appropriate and well known hymns. Later joined by all present the choir sang a selection of popular Christmas Carols. Our appreciation to all who assisted in serving the very large attendance with hot finger food, and plenty of goodies. Member Leslie Blackwell provided us with delightful and tasty home made apple drinks. Our thanks and appreciation to all the singers and musicians who voluntarily gave of their time on the night.

International singer Nora Butler Swan attended with her husband Pat a well known drummer. Pat suggested himself and Nora perform their renowned duet which brought the house down with rapturous applause. What a shock to all when Pat died suddenly a few days later. We all remember with affection Pat & Nora's duet. Our deepest sympathies to Nora and all his relations. In the early years of Nenagh Support Group there was another local singer who entertained us and that was Johnny Starr. Sympathies to his wife Teresa and family, also our sympathies to Ann Ryan on the death of our story teller Donie Ryan.

What the Monday Club provides to its members and their contribution is beneficial exercises in a serious and light-hearted atmosphere from

walking to button opening and closing, writing etc., singing and breathing exercises. The list is endless. Members participate to the best of their ability with absolutely no pressure. Be warned, this is a light-hearted group with wit, good humour, craic and comradeship. A place where people who enjoy life despite having Parkinson's disease can share their experiences, showing concern when a fellow member or carer is not present or ill. Celebrating birthdays, our senior member is presently 84 years young but then age is just a number. Coming from all walks of life they are most positive in their outlook. Newly diagnosed members who attend for the first time are amazed and surprised at the friendly care and atmosphere of the group. All are welcome to visit and see for oneself the benefit of the Club's two and a half hour weekly get together. OT Marion Slattery meets new members privately to assess their condition etc., prior to commencing exercises. Please come and join us for a session and see how you feel then.

On Friday 9th February at Littleton, Thurles Active Retirement Centre a Coffee Morning, organised by Breeda Fanning, was held in aid of Tipperary Parkinson's Group.

On Wednesday 14th February (Valentines Day), Nicola Kavanagh, Parkinson's Nurse Specialist at gave a very informative talk in The Community Hospital of the Assumption.

UPCOMING DIARY DATES.

Weekly Monday Club (except Bank Holidays) 2pm to 4.30pm Pastoral Centre, Church Rd, Nenagh. Contact Marion Burke 0872967296

Wednesday 28th March same venue Citizens Information Group.

Clonmel Support Group meets on 1st Tuesday of the Month in The Monella Hotel, Clonmel 10.30am to 12 noon. Guest Speaker for February is Tina Whyte Set-Dance Instructor.

June 2018. Nenagh Support Group fundraiser Clay Pigeon Shoot competition at Jim Barry's Newtown Nenagh. More details later. Contact Jim Barry on 0872736559.

Open Meeting in Nenagh with Neurologist Dr. Helena Moore (Date to be confirmed).

Dates for awareness week, also to be confirmed.

CLONMEL SUPPORT GROUP NOTES.

The group have been busy preparing for The Health and Wellness EXPO which took place in The Park Hotel on January 27th and at which the Clonmel Support Group had a stand. The attendance

surpassed all expectations of the organizers and sponsors Tippfm. Answering queries and handing out information leaflets kept those at The Clonmel Support Group stand very busy indeed. The leaflets soon vanished, it was now time to speak, and share our experiences of the disease. These symptoms can be compared to the 'designer dress', no two people share the same experiences. Those who manned the stand at the EXPO, went home tired but happy with a good day's work and felt that people were now more aware of the existence of the Clonmel support group, and had a more positive attitude towards Parkinson's disease.

To keep the group in existence, a fund-raising table quiz in the Goatenbridge Lounge, which has now become an annual event, took place on Friday February 23rd 2018. 'Twinkle Toes' herself gave a talk at the February meeting on the benefits of set-dancing to Parkinson's people. Tina Whyte is the person to whom I am referring, her dancing 'shanos' is like poetry in motion.

YOGA AND ART CLASSES WILL RE-COMMENCE IN MARCH.

Billy Fitzgerald (our resident musician) and yours truly Mary Finnegan will be interviewed on Tipp Today with Fran Curry on Thursday morning at 11am.

- **UPDATE ON PARKINSON'S NURSE SPECIALIST ON SECURING A NURSE SPECIALIST FOR SOUTH-TIPPERARY GENERAL AND UNIVERSITY HOSPITAL WATERFORD**

- To date there is positive interest from the Neurologists in Waterford University hospital, and from the Geriatrician in South Tipperary General Hospital, Four (out of five) politicians attended one of our monthly meetings, and promised a lot, Jackie Cahill is very interested in the issue, and has so far attempted to raise the issue at cabinet meetings.
- Paula Gilmore, CEO of Parkinson's, will assist in any way she can.

- **Marion Burke PRO 087 2967 296.**

- **LOUTH/MEATH BRANCH**

- Our very successful coffee/tea support group meetings continued during the summer months. The final one of the year had a festive theme and was held in the Crowne Plaza Hotel, Dundalk on Monday 27th November and was very well attended by most of our regulars.

- Our winter branch meeting was held in the Boyne Valley Hotel, Drogheda on Wednesday 6th December. The guest speaker on the night was Ms. Nicola Kavanagh, Parkinson's Nurse Specialist. Nicola gave a very informative talk about medications and other therapies used in the



Louth/Meath Branch members enjoying get together at the Boyne Valley Hotel, Drogheda



treatment of Parkinson's, followed by a question and answer session. During the tea break people had an opportunity to talk to Nicola privately to discuss problems they were having with their medications.

The first Coffee afternoon of the New Year was held in the Boyne Valley Hotel, Drogheda on Monday 29th January, and the next one will be held in the Crowne Plaza Hotel, Dundalk, on Monday 26th February at 3.00pm. These coffee afternoons are proving to be a great success with attendees who are building up strong friendships from regular attendance. The coffee afternoons are open to all members of the Branch. A text is sent out every month prior to the meet-up. If you do not receive a text please contact Secretary, Fidelma Leahy 0872893685

We also plan to have a public meeting of the Branch in early March, speaker to be decided.

YOUNG PARKINSON'S 2018 PLANS

Young Parkinson's Ireland (YPI) is looking forward to a busy 2018 with regular events to support its members. The committee has committed to help its members by being a source of information, by providing support and by advocating for better services for people with Young Onset Parkinson's. We will do this by hosting events and promoting our ideals. Our monthly informal meeting provides a setting for members and family members to get together and share information and experiences in a relaxed social setting. At our speaker events we invite speakers who can provide insight to living well with Parkinson's. We especially welcome new members. Keep an eye out for our events on the website, we look forward to seeing you!

YOU CAN FOLLOW YPI EVENTS:

Web: www.parkinsons.ie

Twitter: #ypievents2018

Contact us: phone/text 01 2544410 (Skype Phone)

Email: youngparkinsonsireland@gmail.com



WESTPORT 30TH JUNE 1ST JULY SOCIAL EVENT

All roads lead to Westport to climb Croagh Patrick, with walks for all levels catered for on 30th of June and cycle event on Sunday 1st of July from Achill to Westport for all levels. Members, family, friends all welcome to join in for all or any part of this event, including meeting up for a social in the evening.

3 Charities are coming together for this event.

- Huntington's Disease Association of Ireland,
- Irish Motor Neurone Disease Association
- Parkinson's Association of Ireland.

EVERYBODY IS WELCOME.

You can follow Westport event and check out our progress here:

Web: www.sunriseupcroaghpatrick.com

Facebook: <https://m.facebook.com/events/338550579891753?>

Twitter: #ypievents2018

THE NEW MUSIC FILM



The New Music is an Independent, no budget and non profit feature film which follows the life of Adrian, a young pianist of rare talent, who gets diagnosed with Young Onset Parkinson's disease. Unable to cope and in denial, Adrian runs away from home and comes to Dublin, where he becomes friends with Will, David and Jodie, who play in a punk band. Their attitude and lifestyle slowly infect Adrian and give him a new perception of life and music. Their friendship helps him to redefine himself and realise that, despite the illness, there will always be someone there for him and music to be played.

From the pre-production phase, the young film makers decided to get involved with Young Parkinson's Ireland and to make The New Music a non-profit film since the main aim of the film is to help shine a light on Young Parkinson's as a rare condition. Partnering with the Association helped them to understand Young Parkinson's better and their support has been essential to ensure they were moving in the right direction with their story.

The New Music was filmed by a team of volunteers

throughout the Summer of 2017. In September a crowdfunding campaign was launched to help cover the post-production phase. 20% of the raised funds are being devolved to Young Parkinson's Ireland, and any future profits from the film will go to YPI. Gofundme: www.gofundme.com/thenewmusic

YOU CAN FOLLOW THE FILM AND CHECK OUT OUR PROGRESS HERE:

Facebook: The New Music – Feature Film
Twitter: @thenewmusicfilm
Instagram: thenewmusicfeaturefilm
YouTube Channel: The New Music Feature Film

NEXT SOCIAL EVENT:

When: Friday, March 9, 2018
Where: Skeffington Arms, Eyre Square, Galway
Informal Social meeting for coffee/drinks/bar food and mostly chat (+1's welcome).

CONTACTS FOR RSVP IF POSSIBLE PLEASE:

Email: youngparkinsonsireland@gmail.com
Phone: 01 254 4410

MAYO BRANCH

The Mayo Branch had a very busy end to 2017, having had a very successful year with our physiotherapy classes and speech and language classes.

Our Christmas party in the Broadhaven Hotel, Belmullet was thoroughly enjoyed by those who attended.

We also had a fun day in both Belmullet and Castlebar where games, challenges, mince pies and Christmas cake were enjoyed by all.

A huge thanks to Donna and James of Corrib Physiotherapy for the great activities they came up with. Looking forward to a very busy 2018 and new projects for the group.

Contact Caroline 087 932 4646.

NORTH KERRY BRANCH

The North Kerry branch missed some recent news entries in our magazine and we wish to bring our branch up to date. Unfortunately, we lost some members in the recent past - namely Mary Gore, Jerry Hurley, Eamon O'Connor and Eamon Mulvihill, RIP.

We held an evening in their memory, Fr Tom Mahon celebrated Mass at our new meeting place, Aras - Curamh in Listowel Hospital grounds. We welcomed their widows, Clare Hurley, Mary O'Connor and Dana Mulvihill.

We had a very pleasant evening, if a little sad. Refreshments were served and it was a social occasion appreciated by all.

Our Christmas Party was held on 17th December at Listowel Arms Hotel. A very enjoyable event with good wishes all round for Christmas and New Year.

Contact Liam 086 377 1844.

EAST MIDLANDS BRANCH

Ben Ryan, Author, Artist and all round good guy, who is a long time member of East Midlands Parkinson's Branch was awarded "Person of the Year Award" for 2017 in Duleek Co. Meath.

We extend our heartiest congratulations to Ben for this well deserved recognition.



Mayo Branch members enjoying their Christmas Dinner held in the Broadhaven Hotel



Membership of the Parkinson's Association of Ireland



THE PARKINSON'S ASSOCIATION WAS ESTABLISHED IN 1987.

The association has grown over the years to now having 18 branches throughout the country.

It is estimated that approx. 12,000 people are living with Parkinson's in Ireland.

We operate a Freephone helpline 1800 359 359, produce a quarterly magazine and now have a Parkinson's Nurse on staff two days per week.

Branches run meetings and classes in their locality and the National Office organise information days and an annual social gathering. We also organise an annual Unity Walk during Parkinson's Awareness Week which attracts a large volume of patients taking to the streets to be visible and raise awareness of their condition.

The Parkinson's Association receive no Government funding and we rely on donations, sponsorships and annual memberships to allow us to continue our work.

Membership of the association costs €25.00 per year.

PLEASE CONTACT YOUR LOCAL BRANCH TO RENEW YOUR MEMBERSHIP.




The VHI Women's Mini Marathon is moving to **SUNDAY 3rd June!** Entries will open 7th March so make sure you enter early and support Parkinson's on Sunday 3rd.



YOUR COMMENTS

Let us have your comments and we'll post them here, in the next issue



Parkinson's Association of 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.

Posture, Walking and Falling

Parkinson's Disease is a movement disorder, which may affect posture, balance and walking.

Safe and effective performance in these areas is a basis for all activities in daily life. This leaflet gives some advice about managing these difficulties, if they should occur.

Posture

As your Parkinson's progresses, your posture can change – you may become more stooped and your muscles may become more rigid. This inflexibility can increase your risk of falling, because it's more difficult for your body to move, and for you to protect yourself if you lose your balance.

This can be worrying or frustrating, but there are some things you can do to help overcome balance problems.

To check or correct a stooped posture, try standing with your back against a wall, heels touching the wall then try to get your shoulder blades back against the wall and tuck your chin in so that the back of your head touches the wall. Or try facing the wall, with your feet a few inches back from the wall, place hands overhead, palms on the wall and lean into it – hold the stretch for 20 to 30 seconds.

Walking

Walking, an essential activity for maintaining independence and overall health can be affected by Parkinson's. The most common problems with walking include

- ★ festination or shuffling (this is made worse by a stooped posture), where steps become shorter and you have to take lots of quick steps to stop you from losing your balance because your centre of gravity is too far in front
- ★ freezing, where the feet get stuck to the ground and knees may be flexed and heels are off the ground;
- ★ getting started and turning can also be problematic for some

To help overcome these difficulties, focus only on walking:

1. Try to concentrate on taking long steps, placing heels down first (saying to yourself – HEEL – HEEL with each step can help).
2. Eliminate sharp turns in the environment. When you have to turn, keep the feet apart and turn in a semicircle, always moving in a forwards direction.
3. The use of rhythm (a tape or CD with a catchy beat, or a metronome) can help you get started and to keep going.
4. Visual cues such as lines or tiles on the floor, or a strip of tape at a doorway can help prevent freezing.

Falls

It's important to get help and advice about avoiding falls. If you have fallen over before, anxiety or fear of falling can increase the likelihood of it happening again. Your GP, specialist or Parkinson's nurse can offer advice on how to avoid future accidents, or refer you to a physiotherapist or occupational therapist.

The physiotherapist may work with you on balance training and improving your ability to walk. This training will improve your confidence and help to reduce any fear of falling. They can also teach techniques to help you get up if you fall. Often a physiotherapist will work with an occupational therapist to make sure your home is hazard free.

Though it might be tempting, try not to restrict all your activities to prevent falls, as this is likely to cause joint stiffness or muscle weakness. This can actually increase your chance of having a fall because your body won't be used to moving and maintaining its balance.

It's important to try to stay as active as possible and to exercise regularly to help you maintain your mobility and prevent falls.

Some people with Parkinson's fall because they have problems starting to move or they 'freeze' while they are moving. Freezing is when you stop suddenly, and it can last for a few seconds or minutes. If this happens, you might feel as though your feet are stuck to the floor or that you can't move easily, which can make you feel unsteady. This can increase your risk of falling over. If you have difficulty with your medication wearing off before your next dose is due, you might find freezing becomes worse.

If falls are a problem, a physiotherapy assessment can help determine the cause. In some cases, balance activities and strengthening exercises can help to reduce the occurrence of falls.

Some useful suggestions

- ★ Remove rugs or low lying obstacles from pathways inside or outside the home
- ★ Install handrails especially along stairways
- ★ Use a cane when necessary
- ★ Avoid using stepladders or stools to reach high objects
- ★ Slow down when you feel yourself in a hurry
- ★ Before rising from bed or your bath, pause for a moment when you are in a sitting position.
- ★ Stop walking or sit down if you feel dizzy.
- ★ For some people, wearing hip protectors (specialised undergarments with padding over the hip areas) can be useful in protecting the hip bones from fracturing as a result of a fall.

If necessary, physiotherapists can recommend mobility aids.

- ❖ Wheeled frames tend to help the flow of movement
- ❖ Baskets and trays can often be attached and can eliminate the need to walk and carry items at the same time

These may be available through your local Public Health Nurse at your local health centre.

Acknowledgements:

Parkinson's Association of Ireland would like to thank David Hegarty Chartered Physiotherapist for endorsing this leaflet.

Other Relevant Information Sheets:

EX1: Physiotherapy and Parkinson's



FUNDRAISER IN AID OF PARKINSON'S ASSOCIATION OF IRELAND AND THE DUBLIN BRAIN BANK, AS PART OF BRAIN AWARENESS WEEK 2018.

 Parkinson's
Association of Ireland



DUBLIN
BRAIN
BANK



PUB Quiz

Table of 4
€40 or €10
per person

7pm

Monday
5th March

RUIN BAR
Tara Street,
Dublin 2

RUIN BAR

All Welcome



xxx Spot Prizes on the Night xxx

To Guarantee A Table
Call FREEPHONE 1800 359 359



Parkinson's Online

If you would prefer to view online and not to receive a copy in the post, please contact the PAI office on 01 872 2234 for more details.



Parkinson's Association of Ireland

We are asking you to pledge your support to the
Parkinson's Association of Ireland campaign to access direct
Government funding.

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*Please gather as many signatures as possible and return Petition(s) to Parkinson's Association of Ireland, National office at Carmichael House, North Brunswick Street, Dublin 2 **by 26th March**. Thank you.*

Photocopies of this form are acceptable