

Parkinson's Ireland Cork Branch Newsletter March 2025

Come and visit PI Cork Branch stand at; ' My Moving Brain' event

Mayfield Sports Complex March 22nd 1.30-5.00pm



MY MOVING BRAIN

Join us to hear from inspiring speakers, try inclusive sports & get hands-on with fun science activities at our Community Connect Event in Cork!

FAMILY FRIENDLY EVENT!

Our Speakers

 <p>Dr Daniel Costello</p>	 <p>Bernie Hart</p>	 <p>Eoghan Kenny TD</p>
 <p>Michael McKillop MBE</p>	 <p>Ian O'Brien</p>	 <p>Stephanie Mac Sweeney</p>

Living with a Brain Condition: Insights from a Neurologist
Dr Daniel Costello, Clinical Neurologist, Cork University Hospital

Seizing Control: Winning with Epilepsy
Michael McKillop MBE, Paralympian & Motivational Speaker

Marching Forward with Epilepsy: A Parent's Perspective
Bernie Hart, parent of a child living with an epilepsy

Eur-Up-Ian - Promoting the Benefits of Exercise for PD
Ian O'Brien - person living with early on-set Parkinson's

Sport and Physical Activity for All
Stephanie Mac Sweeney, Strategic Operations Manager, Active Disability Ireland

Panel Discussion - Making Sports Accessible - Opportunities and Obstacles

The event aims to bring together people & families impacted by brain conditions, sports clubs, coaches, teachers, healthcare professionals, advocacy organisations & anyone with an interest to join the community conversation on brain health and inclusion in sport.

Scan the QR code to register now!

22nd March 2025, 1.30-5pm **Mayfield Sports Complex, Cork**



Revitalised Youghal Support Group

New 'first' Friday monthly social gathering





We are absolutely delighted to report that a fabulous inaugural meeting of the re-vitalised Youghal Parkinson's support group was held on Friday February 21st at Youghal Community Health Centre. There were about 12 local members in attendance with local HSE workers, Charlotte Deasy Parkinson's Ireland Cork based specialist nurse and Jerome Maume, Secretary Parkinson's Ireland Cork branch. We are forever grateful to our local members and HSE local workers for bringing back to life the excellent support group that used to meet monthly in Youghal before covid.

A special word of thanks to Ann Power, Glenn Rankine and Michael McCarthy for their efforts to set up monthly gatherings again in various locations and for recently approaching Nicola Lucey, Community worker HSE and Pamela Smyth, Occupational Therapist, East Central Cork primary care team based in Youghal for their support.

A very special thanks to Niamh Herbert community health worker HSE who kindly promoted, hosted and facilitated the gathering and supplied the refreshments. Charlotte kindly travelled to meet the group and outlined the new specialist nurse service. she now meets for up to an hour by appointment at Carrigaline Community Care Centre Parkinson's patients public and private and carers from all parts of Cork to provide useful information and advice.

Jerome brought information leaflets and outlined activities of Parkinson's Ireland Cork branch. He outlined how other monthly coffee gatherings are organised and supported. Ann kindly indicated she enjoyed the monthly meeting in Glounthaune and tai chi classes but would like to have such activities closer to home mentioning our tai chi instructor is originally from Youghal!

Nicola and Niamh offered the use of facilities at the Youghal family health centre for future meetings and the consensus among members was to hold such meetings there on the '**First Friday**' of each month at 11.00am. The group finished up with vocal exercises and a song!

Possible new exercise classes, tai chi, singalong group, information about local HSE etc



First meeting 7th March with tea, coffee, biscuits and chat - guest speakers .

All people affected by Parkinson's welcome!

**11.00 to 12.30 Youghal Community Health Project Centre,
Blackwater Heights, Youghal Lands, Youghal , Co. Cork
(parking is available by Bru na Si -building with green fence
to right of bollards at end of private road past entrance to**

GAA grounds, Magniers Hill p36 tx68,



A walk in the Park for Parkinson's Parkinson's International awareness month



Walk in the park for Parkinson's Saturday 5th April, Sacred
Heart Parish Hall (T12 TN80) to Fitzgerald's Park (T12
AW6R)/North Mall,

1.45 Welcome & warmup

2.00 Group set off

2.15 If preferred rest & picnic in Fitzgerald's Park or continue via Mardyke
walk the past skate park over river lee and on Cumann na mBan walk to St. Vincent's pedestrian
bridge on north mall (c.2km) and return.

3.00 to 3.30 - Busking in Fitzgerald's Park by perpetual motion Parkinson's Ireland Cork branch
choir & friends (subject to permit - if weather is bad there will be a short singalong concert
instead in sacred heart parish hall)

4.00 return to sacred heart parish hall for tea & biscuits 5.00 event ends



Memories of 2024 - Walk in the Park



Alternative/Additional fundraiser for north Cork members:-

Mary Ita O'Connor is organising a 5km run/walk on Sunday, 13th April at 11am in the Demesne, Newcastle West, Co. Limerick. registration to take part in the run/walk can be paid on the day (see further details below) and all other donations can be made through Mary Ita's 'gofundme' page.

5km run/walk details:

- Date: Sunday, 13th April 2025
- Time: 11am
- location: the Demesne, Newcastlewest, Co. Limerick, V42 KD35
- registration: 9:30am in the community centre
- Price: adults €15, children €5, families €30



Thanks a million Mary Ita & family you are a star!



Parkinson's Ireland Cork branch Annual Mass, Ecumenical Service and Anointing followed by tea and biscuits and a chat

Sacred Heart Church, Victoria Cross, Cork eircode T12 CA34 Easter Monday April 21st 7.00 pm

Please come along with your families and friends to this beautiful spiritual and social occasion to:

- remember members who have passed on RIP;
- pray for the success of Parkinson's research to find a cure or a way to slow and reverse progression of Parkinson's and better treatments.
- pray for our care partners, carers, clinical teams, supporters, friends and families;
- receive the Sacrament of Anointing if you wish
- sing with perpetual motion Parkinson's Ireland Cork branch choir

All welcome to join the choir to practice lough parish centre 7.30 to 9.00 on Mondays (back of Lough Church car park-park by centre)



Information on meeting No 3 was held at Sacred Heart Parish Hall, Victoria Cross Cork on February on 16th February.

The afternoon of Sunday 16th February saw a great turnout of about 70 members and families to hear 5 excellent speakers at our third information on meeting in Sacred Heart parish hall Victoria Cross, Cork.



Charlotte Deasy, Parkinson's Ireland Specialist Nurse

First speaker was our super new Parkinson's specialist nurse Charlotte Deasy. Charlotte outlined her experience as a Parkinson's advanced nurse specialist for over 6 and a half years with the NHS in the UK and other experiences as a qualified nurse working in various hospitals before deciding to specialise in Parkinson's because she could see the need for this in treating the kind patients she encountered with this complex and long-lasting condition. She also experienced first-hand her own grandmother having Parkinson's. Charlotte's service focusses on the needs of the Parkinson's patient and carers. she regards it as "their appointment" not hers and can listen for up to an hour. Unfortunately due to Irish regulations she cannot prescribe as she did in the UK but she can provide advice and general assistance and if authorised consult with the patient's clinical team.



Jill Murphy, Cork University Hospital, Parkinson's Specialist Nurse

The second speaker was Jill Murphy Parkinson's specialist nurse with Cork university hospital. Jill explained how she qualified as a nurse in Dublin and on coming across people with Parkinson's also decided to specialize. she applied for a post in Cork as a general neurology nurse and became a Parkinson's specialist nurse. she provides a telephone consultation service with patients of the 7 neurologists now based in CUH and also assists patients with Parkinson's who become inpatients of CUH. she has drafted a number of important policy and practice guidelines such as in relation to the importance of Parkinson's patients receiving medication on time and certain medicines that are contraindicated and could cause issues for Parkinson's patients.



Dr. Ruth McCullagh, Senior Lecturer in Physiotherapy, UCC

The third speaker was Dr Ruth McCullagh, senior lecturer in MSc physiotherapy who spoke briefly about the benefits of exercise for people with Parkinson's and asked members present to complete a short questionnaire regarding a possible research project regarding the benefits of more targeted exercise programs for people with Parkinson's. There was a fantastic response to Ruth's request and hopefully this will lead to further valuable research.



Leanne Ahern, Physiotherapist, HSE Cork North Community Services

After a very sociable tea/coffee break we received an invigorating presentation from Leanne Ahern, physiotherapist with HSE who is carrying out a phd with Ruth as her supervisor into the benefits of targeted exercise for people with Parkinson's. Ruth runs an excellent class in the north of Cork city and has also been involved in other similar targeted "neurogym" sessions in West Cork. Leanne showed a very powerful video of Parkinson's patients performing some beneficial exercises to improve step distance, gait, balance and overall fitness and most importantly big smiles! We all sincerely hope that such exercise classes continue and that they will be supported by the HSE and attended by as many people with Parkinson's as possible to improve our health, fitness and symptom management and to hopefully slow Parkinson's progression. We are deeply grateful to Leanne for her assistance in the development of this program and for all her interest and support of those of us with Parkinson's which we hope will continue. Leanne did not let us go without an exercise to help us stretch and move!



Sile Hunt, Trainer, Department of Social Protection

The final speaker was the truly excellent Sile Hunt, trainer with the department of Social Protection who made a very complex but extremely important subject both interesting and somewhat comprehensible! Sile is a great friend to those of us with Parkinson's and gave a similar talk online to young Parkinson's Ireland. Her experience and insights is invaluable and her delivery of her excellent presentation was warm and insightful.



Jerome ended a very full and positive afternoon with a sincere expression of thanks to all the excellent speakers for giving their time on a Sunday afternoon and making such excellent presentations. He thanked Jackie, Tara and Marie and all those who had helped with teas and coffees or helped in any way. He also thanked all members and carers for attending, especially those who had travelled from such far flung places as Newmarket, Mitchelstown and Kinsale. New members were welcomed, especially those newly diagnosed and said we were there to support in any way we could.

Jerome also outlined upcoming events including the future neuro event on 22nd march, walk in the park with Parkinson's during Parkinson's Awareness month - starting from the Sacred Heart parish hall on 5th April at 2.00 and the Annual Mass and Ecumenical service also in the Sacred Heart on Easter Monday 21st April at 7.00pm.

Some of the slide presentations are available on request.

Information Meeting No 4 May 11th in Sacred Heart

parish hall 2.30 to 5.00pm

The next information meeting **on may 11th** will feature; Dr Diana Olzewska, Movement Disorders Specialist Neurologist and research scientist Also, TBC, a Psychologist specialising in neurological issues to talk about the cognitive issues arising with Parkinson's.

We would like to welcome all our new and returning members

As January is the month for joining or renewing membership of Parkinson's Ireland (PI) we are sending you this reminder.

If you have already renewed your membership, we thank you and you do not need to take any further action.

Membership is for a person living with Parkinson's or a carer or a health professional.

Fee: Full Membership €25 per annum

You can join as members via the website: www.Parkinson's.ie or can pay at any of the events/classes they attend.

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**Volunteers
needed**

Please get involved to help establish local support groups to meet and arrange further support activities in your own locality as well as joining in branch events activities & classes

Speech & language rescheduled information day

Speech and language students and staff in UCC kindly offered to hold an information morning for members of Parkinson's Ireland Cork branch at the Brookfield building on the morning of Monday 19th February 2025.

This had been re-scheduled from the proposed information day in January which was correctly deferred due to snow and ice. A full capacity of over 20 members and carers attended. The students in groups of 4 gave three excellent sets of presentations about various issues relating to Parkinson's disease and how voice issues can be helped by specialist speech therapy. Some very interesting and valuable information was also given as to swallowing issues which also comes within the remit of speech and language therapy. A video was shown as to the structure of the physical systems relating to speech and swallowing with one of the students excellently substituting as narrator due to technical issues. Slides were shown of useful aids to avoid food spills, foods with the potential to make swallowing issues worse. One student gave a practical demonstration of a special powder to help thicken liquids to help minimize the risk of choking issues without overly affecting the taste.

There was a lively exchange of information throughout question-and-answer sessions with Dr Emma Gleeson who was well known to many members from her previous experience as HSE speech and language clinician.

Professor Nicole Muller head of the school of clinical therapies gave some kind words of welcome and thanks.

There were many individual chats between groups of members and students especially during the warm and welcoming tea/coffee break with breakfast buns which were protected from other ravenous students in the college. Each member was invited to attend breakout interviews to complete referral forms for HSE speech therapy sessions under the guidance of expert tutors with speech and language therapy clinical experience.

Ongoing research projects were highlighted and many members volunteered to help or had already done so. Hopefully this event will be repeated many times in the future and lead to great co-operation between Parkinson's Ireland Cork branch and HSE speech and language therapy services and UCC school of clinical therapies.





Dates for your diaries

Saturday March 22nd - 1.30 to 5.00

As outlined in the information leaflet on the first page all members and families are invited to attend the future neuro "My Moving Brain" event in Mayfield sports complex. This event was previously successfully held in Dublin. There will be a range of inspirational speakers and information stands hosted by local sports and community organisations including Parkinson's Ireland Cork branch (volunteers to help at the stand are welcome!) and our friends from Munster table tennis.

The event is open to everyone especially those affected by neurological conditions and their families. The event aims to open conversations about brain health and wellness, particularly addressing barriers that may prevent individuals with neurological conditions from participating in sports.

April is Parkinson's awareness month for online webinars: check www.Parkinson's.ie and other reputable Parkinson's charities

'Walk in the park for Parkinson's fundraising and awareness event on 5th april 2.00 departure sacred heart to Fitzgerald's Park/North Mall

Annual Mass, Anointing and Ecumenical service easter Monday 21st April at Sacred Heart Church

(watch out for familiar faces on social media parkinson's is #different for everyone)

Sunday May 11th (nb: this is the new and correct date) 2.30- 5.00pm information Meeting no.4 Sacred Heart parish hall featuring: Diana Olszewska movement disorders specialist CUH (other speakers to be confirmed)

June -date to be confirmed

Parkinson's disease research cluster open information afternoon in UCC Western Gateway building with expert speakers and stands for Parkinson's & Alzheimers

Summer outing suggestions and offer of help appreciated.

Some ideas include: Youghal - Cobh - return to Kinsale - West Cork tour by bus, Spike Island – Gougane Barra

July-date to be confirmed

Saturday September 27th Sacred Heart parish hall- AGM - (open forum and social gathering)






Nurse Specialist Service, Co Cork

This Parkinson's Nurse Specialist service is available to offer in-person advice to those with Parkinson's and their care partners in all of County Cork.

Based in Carrigaline Primary Care Centre, Kilnaglery, Carrigaline, Co. Cork.

This service is **appointment only**.
To book, please call 1800 359359
or email nurse@parkinsons.ie

 nurse@parkinsons.ie  1800 359359  www.parkinsons.ie