



# Parkinson's Association of Ireland

[www.parkinsons.ie](http://www.parkinsons.ie) Autumn 2019



Parkinson's  
Wellbeing  
Weekend  
2019



Paula Gilmore

## A WORD FROM OUR CEO

- Parkinson's disease. We have lobbied the HSE on your behalf seeking clarity about the availability of this treatment.
- As many of you know I have served as an observer to the board of directors for the European Parkinson's Disease Association for the past year and I will seek nomination to the board at the General Assembly in November. My aim is to advocate for positive proactive dialogue in partnership with all the EPDA stakeholders with the goal of improving the lives of the 1.2 million people and their families across Europe and ensuring that people with Parkinson's in Ireland have a voice in Europe.
- Thank you to all who have supported the national summer raffle and all who participated in the VHI mini-marathon raising much needed funds for the national office and the local branches.
- We continue to lobby for nurses across Ireland and are working with individual branches, local politicians and decision-makers on an ongoing basis. If you need to talk to a nurse, Nicola is available two days per week and the support line is available Monday to Friday. You can contact the support line on 1 800 359359.

Regards

Paula

### BREXIT AND MEDICATION

#### A statement recently published by the Disability Federation of Ireland

Public urged not to panic over medicine supplies. Ireland's pharmaceutical industry has said there are always two to three months' supply of medicines in the system and these stocks will help absorb any short-term delays that could arise from a disorderly Brexit. The association said it is satisfied that arrangements are in place to mitigate against a shortage of medicines, in the event of a disorderly Brexit.

## CONTENTS

- 2 A Word from our CEO  
Paula Gilmore
- 3 Michael J Fox Funding
- 4 Parkinson's Disease and Self Expression  
Denis Murphy
- 5 YPI Sunrise up Croagh Patrick

- 6 Cork GAA Mile Challenge
- 7 World Parkinson's Congress
- 8 Meet the Board
- 10 Paddling the 60th Liffey Descent
- 12 PAI Wellbeing Weekend
- 14 Branch News

**Text PARKINSONS to 50300 to donate €2**

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# IRISH PARKINSON'S DISEASE RESEARCHERS GET FUNDING FROM ACTOR MICHAEL J FOX'S FOUNDATION

AN IRISH drug firm has received \$1m (€885,000) in funding from the Michael J Fox Foundation for Parkinson's Research.



Dublin-based Inflazome was set up by academics Professor Luke O'Neill, from Trinity College, and Professor Matt Cooper, from the University of Queensland, in 2016.

The grant will be used to support the development of a brain imaging probe for diagnosing patients, as well as the development of drugs to treat neurodegenerative diseases, including the two most common, Alzheimer's and Parkinson's.

In Ireland, around 55,000 people suffer from dementia, the most widespread form of which is Alzheimer's.

There are approximately 12,000 people living with Parkinson's here.

According to the company, scientific data indicates that the NLRP3 inflammasome is overactive in a broad range of serious medical conditions driven by harmful inflammation.

These diseases include neurological disorders such as Alzheimer's and Parkinson's, as well as inflammatory bowel disease and cardiovascular diseases.

Prof Cooper, who is also chief executive of Inflazome, said yesterday: "The Michael J Fox Foundation is a fantastic organisation with a passionate commitment to new science, science translation and candidate therapies for Parkinson's.

"We are fully aligned in our shared goal to help patients with Parkinson's and other debilitating

neurodegenerative diseases, for which there are inadequate therapies and no cures."

The news of the funding from the foundation comes after the company completed a €40m Series B funding round last November.

Best known for his role in the 'Back to the Future' film series, Michael J Fox (57) was diagnosed with Parkinson's in 1991.

## Attention PAI Members – We need your participation:

The Dublin Branch has put together a short online survey and want as many PAI members as possible to complete it. The survey, done anonymously, simply inquires which activities (i.e. Pilates, dancing, yoga) members partake in to help with Parkinson's, and how helpful each activity is. It should take no longer than 5 minutes to do!

So why are we doing this and why do we need as many Parkinson's Ireland Members to partake?

- TO HAVE YOUR VOICE HEARD
- To pro-actively allocate resources in the future
- To identify areas of need for extracurricular activities
- To help Parkinson's Ireland obtain Government Funding

Please head over to the Parkinson's Association of Ireland website at [www.parkinsons.ie](http://www.parkinsons.ie) where you will find the survey. Results of the study will be made openly available to each branch. We cannot stress enough how incredibly important the information we gather from this study will be, and how much of a step forward it will provide for the organization.

\*The study will be funded and managed by the Dublin Branch.

**Front cover picture:** Maureen Culleton, set dancing teacher with PAI members.

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

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

# PARKINSON'S DISEASE AND SELF-EXPRESSION

**By Denis Murphy**



**My name is Denis Murphy and I live in a little village called Riverstown in Co. Sligo.**

I was born and reared in Cork city where I grew up in the 60's and 70's. I was always shy and introverted by nature, preferring the world of books and my vivid imagination to the real world.

At school I loved history and geography, but also enjoyed English literature, especially short stories and prose. However poetry for the life of me, I could not grow to either like or appreciate. My mind seemed to switch off and my imagination would wander once Shakespeare or Milton made their appearance in class. Even today, I rarely read poetry. All the more reason I am astounded that it is through poetry I have found a way to express my feelings, emotions, fears and hopes.

A major turning point in my life came in 2007 when, at the age of 48, I was diagnosed with early stages of Parkinson's Disease. As anyone who suffers from Parkinson's Disease, or has a family member who does, will know and understand that it brings about drastic changes, both physically and mentally.

It can be very difficult for people with Parkinson's to express their emotions, feelings and to cope with their loss of power and independence.

One of the many physical conditions is called "The MASK". This is when the face muscles become stiff and rigid and expressionless. The eyes appear to lose their sparkle and the mouth seems to be permanently in a "sad" position. To the outside world this appears as if the person with Parkinson's Disease is uninterested, bored and apathetic.

However, behind this stern facade lies a sea of feelings and emotions

Another symptom of Parkinson's is a problem with vocal expression. The voice can become weak and we lose our strength and with this we begin to lose confidence in ourselves. We find it more difficult to express our opinions and ideas in public as we struggle to be heard. So between difficulties with facial and vocal expression we can withdraw into ourselves and stifle our emotions. All the more need for an outlet to express these emotions, feelings and fears.

So many people living with PD find this through art,

- be it painting or crafts or writing.
- While Parkinson's Disease severely restricts our physical and mental activities, there is one advantage.
- Whether it is the disease itself or the side effects of the medication but it seems to stimulate the creative areas of the mind. So it is only in the last four years
- I have begun to compose and express my feelings through my poetry.
- I have written over a hundred poems to-date, not all on P.D. of course ! I write about Nature, Social issues, Mythology, History, Philosophy, Life and Death.
- Parkinson's Disease has made a huge difference to my life, not only in health matters. It has made a profound difference in my attitude, relationships and my whole approach to life.
- I no longer take things for granted. Even the loss of the simplest things like...driving, going for a long walk alone, a trip to the cinema or a concert, or a social event with too many people. Even just being able to run down to the local shop or take away.
- All those little things we don't miss until it is too late... But every cloud has a silver lining. There are some advantages.
- I can sit back, think about, observe the world around me and how I relate to people, places and situations.
- It has taught me how to appreciate life's gifts and the people in my life. I try to live in the present and make the most of the moment. That is not to say I don't think about the past, have regrets, or worry about the future, that is only normal, but I do try my best to be as positive as possible, even on some dark days when all I want to curl up and stay in bed.
- I have found an inner strength and determination to do the best that I can in any given moment.
- Without seeking anyone's approval or permission to express myself. I have become more "selfish" and "self-centred" but not in the negative sense.
- I have learned over the past 12 years or so that if you try to fit in with the world and people and their schedule, you are on a hiding to nothing. The most important person in your life is you !. and the world must revolve around you !! That is one of the hardest and most important lessons I have learned.
- The second is I not only have a responsibility to myself but to others. Through my poetry I have found a new medium not only to express myself but to help others to come to a better understanding.
- We get so caught up in our own little worlds that we forget that we are not the only ones affected



by this disease. Our friends, families, spouses and loved ones are also suffering. At times they can only stand by and watch, feeling helpless and powerless, so it is vital that we reach out to them and that is where my poetry is so important as a medium for communication and information and not just a means of self-expression. I am a very lucky man to have such an understanding wife. She has had M.S. for over thirty years. So she has great patience, empathy and understanding through her own

- experiences. Without her support, encouragement and love, my life would be an awful lot darker. So despite having a crippling, degenerating disease, I try to look at the positive things I have discovered or uncovered about myself. And one of these my poetry.
- For more information please check out my website [denismurphy.blog](http://denismurphy.blog). My Facebook page is Denis Murphy's Poetry. Thank You.

## Bent, Battered but never Broken by Denis Murphy 24th May, 2017

I suddenly stir and begin to wake  
As my body and mind try to integrate  
Bedroom full of shadows and dappled light  
Day has chased away the night  
As I slowly move this tired body  
I've slept for a few hours but still feel weary  
But I will not admit defeat  
As I struggle to stand and get to my feet  
Like an old man I stagger and sway  
As I slowly and carefully make my way  
Creaking bones on creaking floor  
And freeze for a moment by the bedroom door  
Some day I feel like I am ninety three  
Trapped in a cage, struggling to break free  
Like a pacing tiger in a gilded cage  
Moving so slowly like a man twice my age  
Chronic fatigue affects both body and brain

Aching muscles and darting pain  
Like electric shocks on aching bone  
I wish for one day they would leave me alone  
Some days I just feel like crying  
But inside, I'm still alive and dancing  
I am still that child, that strong young man  
So I will continue to do all that I can  
Someday I will be just bones and dust  
Life goes on as it surely must  
Parkinson's has robbed me of a lot  
But I can still dream and scheme and plot  
I still have things to do and places to be  
People to meet and many wonders to see  
And still many words left unspoken  
I may be bent and battered, but I will never be broken.

## SUNRISE UP CROAGH PATRICK YPI EVENT 2019

**Beautiful Clew Bay with its sparkling collection of islands, the town of Westport glistening on the horizon, and the Western Atlantic Ocean lapping up gently on the rugged Mayo coast.**

There is nowhere else to view this panoramic vista other than the challenging slopes of Croagh Patrick, Ireland's 'holy mountain'; a place of pilgrimage for centuries.

Of course, all of these spectacular sights were visible to everybody that joined Young Parkinson's Ireland on June 29th when we assembled for what was a lovely summer's walk to the summit on a beautiful sunny day.

Thanks to the Sunrise Up Croagh team for an excellent event and I look forward to working



- Huntington's Disease Association of Ireland and Irish Motor Neurone Disease Association in the future.
- Date for the diary 2020 Sunrise up Croagh Patrick
- 27th June 2020. **JOE CONDON**

# CORK GAA MILE CHALLENGE

By Kevin Donovan



**When I came up with the idea of doing the Cork GAA mile challenge, little did I know what effect it would have as it went on. The idea was based on when I used to listen to podcasts on BBC radio 1, I heard about 2 guys who ran a mile at every football league ground in England (that's 92 pitches). Geography is an interest to me so that attracted me doing something similar. I felt that the GAA route was the way to go since it is a sport where you get to every community in the county and country. This is where Cork GAA pitches came in, since there was a total of 157 pitches.**

I am someone who likes to take on challenges, for example I did a 32-county challenge in 2017

- where I ran a race in each county. I also like to do it in a way that would benefit charities from an awareness viewpoint.
- For my wife, Mary, it was important to get Parkinson's Ireland involved and the Cork Branch. It was to get the awareness out there and we have achieved that in Cork.
- I really enjoyed going around to all the pitches and the various welcomes we got. What we really enjoyed is when a club went out of their way to welcome us and get a large group of people to run or walk. One unique welcome spring to mind is the Pipe band at Castleyons, it was something I truly enjoyed. Another club, Ballyphehane issued out certificates for the kids to say they ran the mile with me. I also enjoyed the last pitch at Russell Rovers in Shanagarry as they really put a lot of effort into the day, as they made it a family day.
- There were days where it was a challenge to keep going, as I did up to 7 pitches in one day. When you consider the logistics, it a major undertaking but was confident that this can be done. It was terrific that I had Mary at my side and got through this together. It is especially when her late father, Michael O'Callaghan had Parkinson's that spreading the awareness was very important.
- We managed to raise just over 14,500 euros in total which is split between Parkinson's and Cork Deaf Association. This was way beyond our expectations as I never imagined we would raise such a large amount. I would like to thank both charities that supported us in any way. Like to thank in particular Ted and Tony for making a big effort for spreading the word about the challenge. This challenge was much more satisfying and I hope it inspires people to come up with their challenge in a way that would help them.



## LOOKING FOR IDEAS ON HOW TO FUNDRAISE?

Why not visit our website and see our A to Z of exciting fundraising ideas

**[www.parkinsons.ie](http://www.parkinsons.ie)**



# WORLD PARKINSON'S CONGRESS 2019



12 years ago a group of people with Parkinson's, and people looking to halt Parkinson's disease, organised the first World Parkinson's Congress (WPC). It has since been held every 3 years at various venues around the World. In June 2019 the 5th WPC was held in Kyoto in Japan.

Over 2,000 people attended the event and amongst them were 4 representatives from Ireland, Paula Gilmore (CEO PAI), Joe Condon (PAI Board member), Richelle Flanagan (YPI member) and Shane Breslin (YPI committee member). Given the long journey and the difference in time zones we decided to arrive a day or two before the start of the Congress itself. This gave 3 of us a chance to do a quick tour of some of the Temples and Shrines for which Japan is famous. We also happened by chance on one of the two Irish pubs in Kyoto so that finished our first day in Kyoto nicely.

The Congress consisted of an optional additional 1st day of lectures on the Tuesday and then 3 days of the actual Congress itself. The format was:

- Each morning common presentations and lectures were held;
- Each afternoon had 6 parallel sets of lectures as well as a series of workshops;
- There was a comprehensive "Poster" hall where tours were organised to look at the subject matters which varied from academic research papers to the likes of a fitness campus dedicated to people with Parkinson's,
- There was an option available to all attendees to take part in exercise and dance classes which ran concurrently with the lectures each day.

The audience was a mix of medical practitioners (doctors, nurses, occupational therapists, physiotherapists, dieticians and nutritionists etc.), people of various ages at different

stages in their journey with Parkinson's, family members and carers.

As you can imagine the presentations and workshops were varied in terms of the subject matters and their technical level. There was almost too much to take in. We tried to split out the afternoon parallel sessions so that we covered as much as we could. For instance, Richelle is a consultant dietician, so she took the opportunity to attend the majority of the lectures associated with food and dietary habits. The keynote lecture was on the morning of the last day when the research team at Kyoto University presented the latest information on injected induced Pluripotent Stem (iPS) cells - which have the potential to develop into any cell in the body. It reported on the status of the current human trials on Parkinson's sufferers. Overall the Congress was very well organised and highly informative in all aspects of on-going research, current medical treatments, non-medical ways of addressing the disease, and supports for those with the condition. One additional positive outcome of the Congress arose from an informal meeting of Young Onset Parkinson's sufferers who were attending the Congress. It was acknowledged that this group really requires detailed discussion around the specific challenges and needs of Young Onset Parkinson's and as a result of this a 2-day international seminar is being organised for April 2020 in Leicester, England.

Unfortunately, the lecture presentation packs have not (to date) been made available to the attendees and we are working on that! We hope to be able to share some of that information as soon as it's available.

The 6th WPC will take place in Barcelona in Spain in 2022. Given the relative proximity compared to Japan, we would hope for a larger number of Irish attendees, both sufferers and members of the medical profession, at this next Congress.

Shane Breslin



# MEET THE BOARD OF PAI



## MICHAEL BURKE

Michael is Chairperson of the PAI Board since 2019. He has served two terms as a director to the Board. Michael is also Chairperson of the Tipperary Branch. Michael lives with Parkinson's Disease.



## GARY BOYLE

Gary joined the board in 2017.

Although Gary Boyle was born in Dublin in May 1965, he lived all his early life in the midland town of Carlow. After a brief period of 3rd Level study, Gary moved to London in the mid-80's and stayed there until 1990. By then Gary had met Joan (Duffy) and they married in 1992. A couple of years living and working in Clonmel, Co. Tipperary preceded a move back to Dublin where Joan and Gary still live, along with their son, Daire and daughter, Bronwyn.

In Gary's early career he spent 10 years working in various roles within the construction industry. In 1997 he made a significant career change into Human Resources and the following year

- he completed his studies with the award of BSc. Management (European Law). Gary enjoyed a wonderful career with a large U.S. multinational, working at the leading edge of HR, both in Ireland and also for a couple of years in the U.S. Then, in 2009, life changed utterly for Gary when he received a diagnosis of 'Young Onset' Parkinson's Disease – a deteriorating health problem that was as unexpected as it is rare for any 44 year old. The following 5 years proved increasingly difficult as Gary's health worsened, and, given the state of his health by the end of 2015, Gary was admitted onto his employer's 'Income Protection' insurance plan.
- The impact of this change in status for Gary has been quite dramatic. He has embraced the positive benefits of exercise in a way that has quite literally transformed his life. Gary has become a champion for an 'inter-disciplinary' approach in dealing with Parkinson's, and indeed all neurological conditions. For Gary the combination of exercise, diet, medication and rest, along with the loving support of Joan, Daire and Bronwyn, is what keeps him sane, happy and healthy – deteriorating neurological condition aside!

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Gary has made it his mission to drive Patient Advocacy forward so that in all medical consultations the Patient is always placed first; is always considered the expert in whatever condition is diagnosed. The frustrations Gary may sometimes experience with his mission in life are all forgotten when he listens to music, especially Robert Plant and Led Zeppelin; when he gets on his bike and cycles through the Phoenix Park, or when he goes for a run with brother and best buddy, Patrick.



### MIRIAM JENKINSON'S

Miriam joined the board in 2019 as a Director. Retired primary school principal, wife of David and mother of four.



### JOE CONDON

Joe was elected to the Board in 2019 and is a Governance Trustee. Joe is the current Chairperson of Young Parkinson's Ireland. Joe previously had a successful career in the IT industry, working as an IT Consultant. Joe has a keen

interest in sport. Since then Joe has combined love of sport and community engagement to raise funds and awareness for both local and national charities. Over the past few years he's thrown himself into walking, run, boxercise and cycling. Joe was diagnosed with Parkinson's in 2013. He's passionate about exercise, which he finds helps to limit the impact of the condition. He decided to take the Income Protection policy to better balance work and non-executive roles, with spending more time on fitness and with family and friends. He's also able to use his voice and experience to support increased awareness and action for people living with Parkinson's, their families and carers.



### DR. RICHARD WALSH

Dr Richard Walsh joined the Board in 2017. Dr. Walsh began his training in neurology with a Research Fellowship in Movement Disorders and Dystonia with Prof. Michael Hutchinson in St. Vincent's University Hospital. Since 2012, Dr. Walsh has run the Tallaght Movement Disorders Unit where he works with a Parkinson's Disease Nurse Specialist and a Movement Disorders Fellow.



### DENIS O'RIORDAN

Denis joined the Board in 2019 and has since taken up the role of Treasurer.

After leaving school in 1972 after completing my leaving cert.

My first job was working in an electrical shop Murdoch's who had about 10 branches in Dublin.

I fell into the financial services business after the death of Con Smith who had the Renault Franchise for Ireland. The new management team decided to dispose of Murdoch's and set up a finance company in 1975 to support the funding of the Renault dealers selling the cars. I was appointed franchise manager with responsibility for the garage funding.

I left the company in 1985 went to government owned ICC having responsibility for developing a motor finance business.

I made my final move in 1992 when I was asked to join the Ulster Bank in their installment credit division. Retired in 2010 from the bank.

I set up my own consulting business which was successful until my health got to bad to manage it.



### MIKE O'BRIEN

Michael joined the Board in 2019. Michael has extensive experience in retail management. Since retiring immersed himself in many volunteering roles both locally and also with the County Council.



### PAULA GILMORE

Paula is CEO of PAI since 2015. She has an MA in Voluntary Sector Management. Paula has over 20 years' experience in the voluntary sector. She is also Secretary on the Board.



### MAEVE CALDWELL

Maeve is a Professor in Neuroscience in Trinity College, she joined the Board in 2019. Maeve's other interests include Stem Cells and Regeneration; she was also a Senior Research Fellow in the University of Bristol.

# PADDLING THE 60th LIFFEY DESCENT

When Paul Laing came to Ireland for a job in the mid-1990s, he had no idea how completely it would change his life.

Laing is a professional – and much sought after – wallpaper hanger based in Cheltenham and he was employed with a crew to help decorate a large house near Skibbereen in Co Cork.

"It was the job from hell and it was raining all the time. We were told that we'd be lodged in a hotel, but then they told us we'd be staying in a B&B. I was wasn't pleased – until we got to the B&B which was an amazing place."

Although English, Laing has some Irish roots. "My great-grandmother Annie Kelly was born in a workhouse. She was the only daughter of Anne Kelly, who came from the Portlaoise area I think."

While staying in west Cork, Laing met Jim Kennedy who had started running sea kayaking courses in the area. Jim brought him out for a paddle and Laing, who had done a little rowing in his youth, was immediately hooked.

## PAUL LAING

- "I had never been in a canoe although I grew up beside a river – my parents thought canoeing was dangerous! Jim taught me how to paddle, and when he noticed I was a bit competitive, he taught me how to compete as well. Only seven or eight months later after I started canoeing, Jim suggested I come over again to Ireland and do this little race they had near Dublin – he was referring to the Liffey Descent!"
- That's the legendary 17 mile river race from Straffan to Islandbridge which takes in a number of challenges including ten weirs and a stretch known as "The Jungle", with good reason, along its way. First of those weirs is one of the most challenging – and it comes soon after the race start at Straffan.
- "Straffan was my first ever weir, and if you're at the back of the race, you see bits of boat and debris scattered all over the place. It's terrifying."
- Suffice it to say that Laing survived the experience





# DESCENT FOR PARKINSON'S

and has come back many times for more. "I've done 21 Liffey now usually in a touring double or a single, if I can't get anyone to pair up with me." Among those he has paired up with is one of his three daughters; all of them paddle.

He's no mean paddler having taking three third places down the years. In 1999, and then again in 2001 and 2002, he was third in the masters wild water category, with his fastest time of 2 hours 35 minutes coming in 2002.

"I've also wrecked a lot of boats – at least four of them – and in two cases the boat was so badly damaged that I couldn't go on!"

In recent years, Paul faced an even more daunting challenge than the carnage at Straffan when he was diagnosed with Parkinson's Disease at the age of 50. For some years, he had been complaining of problems with the left side of his body. "I knew I was seriously ill in my late 40s, but found it hard to face up to it. I was stubborn in denial. I was finally diagnosed on 7 November 2008. I had spent six years having tests and I got up one day and my legs were paralysed."

The diagnosis had an immediate effect, since hanging wallpaper is a skilled job that requires both good balance and strength.

"It meant I couldn't work – I'd been fighting with wall paper for 30 years after I discovered I'd a flair for it and I travelled the world. But I found that canoeing is one of the best exercises for keeping Parkinson's at bay. You don't get the same natural rigidity associated with the disease. At the end of a day when I've been paddling, I don't need to take medication because my body has created its own dopamine."

Laing has kept a record of his Parkinsonian symptoms using the same markers. "For instance how I use a knife and fork. I can do that now, whereas for a long time, I was eating with my hands. The canoeing helps build new patterns in the brain – remapping my doctor calls it."

He paddles as often as he can on the Severn and other rivers near his home. "If I don't keep canoeing, the Parkinson's catches up with me since I have no muscle memory." Interesting, he

- finds it easier to paddle backwards – as rowers do.
- Last year, Laing was forced very reluctantly to opt out of the Liffey Descent because of a medical procedure which didn't give him enough time to get fit again. In the four weeks after the procedure he practised tai chi, which strengthens the muscles and although it proved difficult, he was soon back in a boat.
- On Saturday 14 September, a gloriously sunny day, he and partner Charles Early, supported by driver and bank support James Simson, a resident of Montpellier in France, completed the 60th anniversary race in 3 hours 52 minutes 55 seconds. At 67, he was one of the oldest participants in the race.
- "It was enjoyable, although I left part of me in the river! We took three swims – including one at the "Ghost Weir" which we weren't expecting. Will I be back next year? We'll see! I like to enjoy my canoeing and I hope to keep it going for as long as I can."

Paul is also raising funds for Parkinson's charities through his efforts. If you wish to donate, see <https://www.justgiving.com/fundraising/paul-laing10>  
To donate directly to the Parkinson's Association of Ireland, go to <https://www.parkinsons.ie/donate>



# WELLBEING WEEKEND



Parkinson's  
Association of Ireland



Our Health and Wellness Gathering this year was a great success with a packed agenda, entertainment, good food and we were also blessed with plenty of sunshine for members to enjoy the beautiful surroundings of the hotel.

Our gathering started with Ann Blake, Music facilitator who encouraged us to sing our hearts out working on breath work, singing and gentle movement.

We were entertained by the Reynolds Academy of Irish Dancing and Katie Henshaw and friends on Wednesday evening.

Thursday's agenda was a full day of nurse clinics and talks.

We kicked off the day's agenda with a talk from Dee Daly Psychotherapist, who spoke on resilience. This was an uplifting and encouraging talk.



Conor Kerley, Doctor of Nutrition spoke on nutrients and Parkinson's.

Dr Suzanne Timmons gave a presentation on research to support the health service to meet your needs. This is very exciting research which our members were asked to participate in.

We stretched, laughed and danced with Maureen Cullen, Maureen is a set dancing teacher who manages to get everyone up on their feet enjoying themselves through movement.

Grainne McKeown held a physio clinic with our members who were able to avail of her advice and expertise as a physiotherapist.

We finished the day with Theresa Kearney, Yoga instructor who gently guided us through chair yoga. A beautiful, gentle way to round off our busy day.





# WELLBEING WEEKEND

Parkinson's  
Association of Ireland



Thursday evening, we were entertained by Bernard and Patrice Coyle, who had us all up on our feet by the end of the evening with their wide range of music to suit every taste.

Nurse clinics were held again on Thursday giving everyone the opportunity to speak with the nurse in an intimate setting.

Friday morning and to set us off on our journey home Dee Daly gave a relaxing session of mindfulness. A way to calm the mind, body and centre yourself before embarking on the journey home.



Again there was an opportunity to speak with the nurse before leaving the hotel on Friday.

The feedback we have received was very encouraging.

We are always looking for feedback and ideas that you feel may work for our Health and Wellness Gathering.

Please call our Freephone 1800 359 359 or email [nationaloffice@parkinsons.ie](mailto:nationaloffice@parkinsons.ie) with your comments/ideas.



HODDSON BAY ATHLONE 2019

# BRANCH NEWS

## YPI BRANCH

### Parkinson's Disease in the land of the Midnight sun!

Take 10 people who have never met before, sign them up for a 1,385km relay cycle race around Iceland, add in the fact that the course has to be completed within 3

days (72hrs.) or their efforts don't count, plus the fact that 5 of the Team are living every day with Parkinson's Disease, and what do you get? Surely an impossible task, one that's doomed to heroic failure from the outset? This thing is over before it starts.

Well, incredibly, that is not what happened with this adventure and it has turned out to be one of the greatest events in my life. From the beginning the 10 of us 'clicked' at our 'virtual' (Skype) meetings that started back in early January 2019, and when we finally met in person in Reykjavik Airport on June 23rd. last, we sort of felt we knew each other pretty well already.

We called our Team 'Parkinson's Power' and I have to say this whole experience gave me a real sense that we all can have 'Power' despite the limitations we have – or maybe now I should say despite the limitations we think we have! Each of us played our part and rode our bikes into the ground (literally in many cases!), and the result was something quite extraordinary, a real achievement; something that caught us all on an emotional high. I don't have space to even begin to go into detail of the 3 days we spent close together, jumping off and jumping on to our bikes at the appropriate times to ensure we were always moving, staying awake through the night. Actually, Iceland in June means no night time: the Sun barely dips below the horizon before sunrise starts the day up again.

And what a feeling the 10 of us shared crossing the finish line just outside Reykjavik that particular Saturday morning just before 4am: we did it! Our time was 56hrs. 57mins. 55sec., quite literally awesome. I will forever be grateful to Yvonne and John from Scotland; Sue and Susan (yes, both of them!) from Canada; Snorri, Einar and Birgir from Iceland; Neil representing Isle of Man, and PJ; originally from Tullamore but now committed to a life in Scotland! We had 3 goals as a Team: to finish the race; to finish within the time allowed; and to have fun. We comfortably achieved all



3. And we comfortably took care of the idea that some things are just impossible – it's truly amazing what we can achieve when we put our minds to the task in hand!

Finally, a really big 'thank you' for the sponsorship I received from so many people over the past few months. I managed to raise over

- €3,500 which I'm delighted to say is on its way to the 2 charities we supported on this adventure - the Michael J. Fox Foundation in the U.S, and the Cure Parkinson's Trust in the U.K.

• Who knows what will happen next year!

## GARY BOYLE

### Parkinson's disease researchers at NUI Galway awarded Michael J. Fox Foundation funding:

- Congratulation to Dr. Eilis Dowd and her team in Galway on the awarding of MJF funding

#### What are NUI Galway doing?

- research conducted by Dr. Eilis Dowd and her team in Galway over the next two years can radically improve the process of transplanting healthy cells into the human brain and even help to reverse the process which causes Parkinson's disease.
- MJF is hugely impressed by the research carried out by Dr. Dowd's team, whose breakthrough relating to brain repair and the survival of transplanted cells generated global headlines in November 2017.
- The research will allow the Galway team to spearhead research into a special gel which would allow healthy brain cells to survive following a transplant and provide life-changing hope to patients all across the globe.

#### NUI Galway trial

- What they are doing at NUI Galway, which nobody else is doing, is using biomaterials to provide a supportive environment for cells after they have been transplanted into the brain. Biomaterial is a material which has been engineered to safely interact with human tissue
- The cells are dying because you are taking them out of their normal tissue environment, breaking



them up into single cells in order to inject them into the brain. So you are taking them out. This gel provides them with this matrix or scaffold which helps them to survive."

- Dr. Dowd explains that the gel being developed by the Galway-based team could result in non-invasive surgery which could result in the brains of those with the condition being repaired. The "scaffold" or "matrix" being developed in Galway could allow Parkinson's to be reversed

What the research is trying to resolve?

- The roll-out of brain repair therapy has been hindered, so far, by the poor survival rate of transplanted cells.
- "Eilis hope is this implant will tackle Parkinson's disease at its source in the brain and give people back their quality of life. This involves very simple surgery, which involves drilling a small hole, and the patient is usually awake. It's a dental drill, like you'd use with a tooth. It's a liquid at room temperature which forms into a gel in the brain, which has the same consistency as the human brain. The cells can then live happily in that gel,"

## JOE CONDON

### EXERCISE CLASSES:

#### MOVEMENT THERAPY TO IRISH MUSIC

##### Dublin

##### Move4parkinsons Classes

Sandyford Community Centre, Lamb's Cross, Dublin 18. Wednesday Mornings 10.30am -12.00noon  
(Advanced Class)

Cost €10 per class

Belarmine Community Centre, Belarmine Plaza, Belarmine, Stepaside, Dublin 18 Wednesday Afternoons 2.00pm-3.30pm, (Beginners class)

Cost €10 per class

Parkinson's Association of Ireland

St Bridget Parish Hall, Blanchardstown, Dublin 15 Wednesday Afternoons 4.45pm-6.00pm, (Beginners class)

Cost €10 per class

##### Limerick

Location Desmond Centre Newcastlewest Monday morning 10:30 -12:00. Class starts the 16th of September

Cost €10 per class

Location Dromkeen East Limerick Monday afternoon 14:30 -16:00

### ROCK STEADY BOXING

#### Wexford

- Location KBX Kickboxing Club New Ross. Date and time to be confirmed
- Cost €10 per class
- For more please contact local branch or Young Parkinson's Ireland on 012544410 or email [ypiinfo@parkinsons.ie](mailto:ypiinfo@parkinsons.ie)

### SOCIAL EVENTS:

#### Dublin

- Location: Clayton Hotel Dublin Airport (Was Bewley's Hotel)
- Date Friday the 13th of September 8PM
- Cost Free

#### Wexford

- Location Maldron Hotel Wexford
- Date Friday the 18th of October 8:30PM
- Cost Free

#### Cork

- Location Clayton Hotel Silver Springs Cork
- Date Second Wednesday of the month @ 8PM

### FILM

#### Cork

- The New Music Premier
- Indie Cork
- Date 06 to 13th of October. Venue, date and time to be confirmed
- **For more please contact local branch or Young Parkinson's Ireland on 012544410 or email [ypiinfo@parkinsons.ie](mailto:ypiinfo@parkinsons.ie)**

### DUBLIN BRANCH

The next meeting of the Dublin Branch is Saturday 19th October at 3pm in the Avila Centre, Bloomfield Avenue, Donnybrook.

The speaker will be Siobhan Ryan, Parkinson's Nurse, St Vincent's Hospital. All welcome.

#### Women's mini Marathon

Congratulations and thank you to Ursula Andrews and Kay McParland- nieces of member Rita Andrews, branch member who



raised €825 for the branch. Thank you very much to Rita and Ursula and Kay.

#### Exercise classes

Our Donnybrook exercise class resumes Thursday 5th September

Our Clontarf exercise class resumes on Monday 3rd September

#### Siel Bleu classes

We are delighted to announce that we have a new Siel Bleu class starting on Wednesday 11th September at 11am in Huntstown Community Centre Dublin 15.

Please contact Sinead if interested. (0872869173).

Loughlinstown will be restarting on Tuesday 3rd September 2019 at 2.30pm

Harold's Cross will restart on Wednesday 4th September at 11am.

Swords will restart on Tuesday 3rd September and will be running fortnightly until Christmas on a trial basis.

Portmarnock continued through the summer and will return to Naomh Mearnóg from 3rd September.

#### June Meeting

We had a very successful meeting in June at which Isabelle Kelly, a Dublin Branch member, shared her experiences with us. Thank you, Izzy it was very interesting. The Branch was also given a cheque by Tony Brady from the Portmarnock Singers for €2540. Thanks very much Tony and the Portmarnock Singers.

#### Donation

We received a very generous donation of €500 for the branch from Brid Mannion in memory of her husband Bernard (Tony), a member of the Dublin Branch who sadly passed away in January this year. Thank you

very much Brid and to her daughter Siobhan who arranged collection of same.

#### Donation from Tesco

We are very grateful to the person who submitted our name to Tesco in Kilcoole where we received a donation of €166.67. Sinead accepted the cheque the cheque from Tara, store manager



at the end of July.

Interested in attending Choir or set dancing classes? The choirs are held in Balally and Dun Laoghaire and the step dancing is held in Belarmine Community Centre, Stepaside. Contact Move 4 Parkinson's on 01 2950060.

Information contact Sinéad O'Kane 087 2869173

#### CORK NEWS

Cork Branch has been busy on many fronts in the Spring and Summer of 2019.

Parkinson's Awareness Week was extremely successful due to the encouragement and guidance we received from the PAI office and due to the efforts of the committee and individual members. On 5th April, Kevin and Mary Donovan launched a Cork GAA Club 156 Mile Challenge, where they set off from Pairc Ui Chaoimh and travelled to every GAA club in Cork city and County and ran or walked a mile. Indeed, at many clubs they were accompanied by club members and occasionally by PwPs and/or family members. A huge crowd welcomed them at their final club venue, Russell Rovers, Shanagarry, which was Kevin's home club. The proceeds of more than €13000 were divided between the Cork Deaf and Cork Parkinson's. While this was a significant fundraising achievement, the biggest success of the mammoth challenge was the amazing Parkinson's Awareness that was achieved with more than 1000 people walking or running with Kevin and Mary throughout Co. Cork. We thank them most sincerely for their commitment over a 6 month period as scheduling this event was no easy task.

More than 30 people travelled from Cork to the gates of Leinster House on the 11th April to lobby the Minister for Parkinson's nurses, for Deep Brain Stimulation surgery and reviews within the Republic of Ireland as well as for direct Government funding. The sight of this group of people with Parkinson's and various levels of disability, dressed in red, walking down Kildare Street like warriors going in to battle is a memory which will live long with this writer. The public representatives present as well as the media acknowledged our presence and listened attentively to our account of our struggles and our needs for the future.

Ted Horgan was requested by PAI to do an interview on RTE Countrywide which was broadcast on 23rd March last to talk about farming with Parkinson's. Ted says, apparently I was articulate, confident, and inspirational during this interview. My statement



that "I'm Living With Parkinson's and Suffering From Optimism" was well received. RTE decided to repeat some of the interview on Playback, while the Bishop of Cork & Ross John Buckley (now Emeritus) contacted to say that he was an example to everybody and that "half the country" were talking about him. The Bishop wouldn't be a true Cork man if he wasn't prone to a little exaggeration, I suppose!

The Bishop we invited him to attend our Annual Parkinson's Mass in Early May. We were delighted that he came, but equally delightful was the singing of the Cork Parkinson's Choir (Aka "Perpetual Motion") which under the leadership of Jerome Maume and with a few guest musicians and singers made its debut performance. After many years on our wishlist the idea of a choir has finally been realised! We now have weekly choir practice and have around 20 participants each week. We hope to appoint a Choir Master shortly.

The annual tour has always been an enjoyable day out and this year's trip did not disappoint. We departed from the Viaduct Inn, Cork and travelled to Courtmacsherry Hotel for Coffee and Scones. We then travelled on to the Michael Collins Centre near Clonakilty which was most interesting and explored the link not just between Michael Collins and West Cork but also between Henry Ford and West Cork and JFK and East Cork. We had a wonderful meal in The Celtic Ross Hotel and as the afternoon was a little overcast we stayed on and had a great sing song lead by Jerome and his friend Michael.

Unfortunately, we have had to say goodbye to a number of members in recent months, may they rest in peace. We will hold their memories close to us, and enjoy ourselves as they would like us to. Best wishes to our member Sean C who is back in action after being hospitalised for 5 months with a brain infection.

Congratulations to anyone who has done something to improve their own quality of life while living with Parkinson's. A special word to those of you who haven't attended any of our coffee mornings, information days, set dancing, exercise classes or choir practices, Give it a try, contact us now.

**Contact 087-2375558**

## **WEXFORD BRANCH**

Autumn AGAIN!!! Where has the summer gone we at The Wexford Branch have had a busy summer heading away to Killarney in June for 3 nights where we had a ball, day trips to Killorglin, and Dingle dinner and dancing it was a very special few days and we thank everyone that joined us.

Our Chair Yoga classes will resume in September on Fridays in Coolcotts Community Centre, please contact us if you would like to join in. Our Physio

- classes are continuing in Murrintown Community Centre on Thursday mornings with Mairead McDaid physiotherapist who is excellent at what she does we now have 2 sessions up and running.
- We celebrated our 5th birthday back in May where we had dancing, food and singing, we all have a fantastic afternoon.



We are planning more support meetings and some fundraising events soon namely our Annual Raffle so we would appreciate your support in any events we may run. We would also like to thank everyone that has donated to our branch, we really appreciate it.

If you would like any information about the group, please do not hesitate to contact us

**Chairman: Pat Lacey**

**Treasurer: Breda Kennedy 087-0958984**

**Secretary: Betty Sweeney 089-4351103**

**Email: wexfordtreasurer@parkinsons.ie**

## **TIPPERARY BRANCH**

Autumn has arrived and Tipperary Hearts are beating with pride as Liam McCarthy returns to the County. Congratulations to the players and management on winning the 2019 All Ireland Hurling Final. While "Slievenamon~" will be our No.1 choice for our sing along choir on Monday Jim Barry gives a good rendition of The Rose of Mooncoin. The choir is not parochial in its repertoire as we have members attending weekly from Offaly, Limerick, Clare Laois etc.,

Nenagh Support Group. The Monday Club resumes its weekly schedule from September 16th except Bank Holidays, after the Summer recess and the venue is The Pastoral Center, Church Rd., Nenagh from 2 pm until 4.30 pm. with exercises, sing along choir, cuppa, chat and craic. The Monday Club is fortunate in having Sheelagh Chadwick to do the sing along choir ably assisted by musicians Brendan Treacy, Mary Shinnors

& Rita Gleeson, and not forgetting our Occupational Therapist Marion Slattery who puts us all through our paces doing the exercises. We have two excellent Volunteers helping out the Club in Marion Quigley & Michael O'Brien who make the tea and hand out water and assist any patient during the exercises. Not attended Monday Club previously? Come on give it a try! You will receive a hearty welcome. Uneasy about moving out and meeting people is a symptom of Parkinson's Disease. Do not let it best you. Enjoy the comradeship and friendship of fellow members and volunteers. Please remember you are not alone and family members and carers are also welcome to attend. In May 2019 our new Caring Services were launched at Loreto House Kenyon St, Nenagh which are available to all with Parkinson's. Daily respite care which allows Parkinson's carers time for appointments, shopping, some personal time for themselves etc., It is a home from home voluntary service in relaxing atmosphere. Meds on time be administered at correct times. If you are wishing to avail of our daily respite services, please contact Marion Burke, 0872967296 in advance of date. We have a wonderful group of volunteers but it is essential that their time is managed to the best advantage for the benefit of all concerned.

Thurles Support Group resumes its activities as follows:- Friday 27th September in Thurles Community Hospital of the Assumption Speech Therapist Joan will give a talk and presentation and in the first week of November we have Parkinson's Nurse Specialist Mags Richardson, date and time to be confirmed. For further details please contact Mary Carey on 0863916726.

### **"Remembering".**

On behalf of the members and friends of the Tipperary Branch we wish to extend our deepest sympathies to Paula Gilmore, CEO, P.A.I. on the recent death of her father Lawrence (Larry) R.I.P. Sympathy is also extended to the family of Fr. Tom Seymour, Presbytery Church Rd, Nenagh a native of Portroe, Co. Tipperary and his fellow priests in Nenagh and Killaloe Diocese. Ar dheis De go raibh a anam.

The branch wishes to acknowledge it appreciation of donations received from the families of the late Paddy Shoer & Sean Cawley both members of the Monday Club. Also cheque for €330 from Tesco Nenagh raised from the Blue Token collection.

Congratulations to Marion Slattery OT at our Monday Club on her recent engagement to Andrew every good wish for the future.

Clonmel Support Group have been very busy and as Mary Finnegan Facilitator says Volunteers do not necessarily have the time they just have the heart. They

- had the heart and they brought heart and soul to the meetings and their Parkinson's sufferers benefited greatly from their efforts. There was a good attendance at the June/July meetings. Raising awareness of the existence of the support group, fund raising, lending support and an ear to listen are the main objectives of the group. To this end, we had an awareness day in the Allied Irish Bank, Clonmel with the help and support of management and staff. Knowledge and information were given freely, based on the experiences of those present, all of whom had Parkinson's or were caring for someone with Parkinson's disease.
- Much discussion took place re date and destination of the Summer outing. It was decided to visit Wexford and stay overnight in The Talbot Hotel. It was planned to leave Clonmel at 9.30am, and stop at the RhuGlen Hotel for breakfast, and then visit the most haunted house in Ireland, Loftus Hall. Dinner and a cosy chat with the addition of music was the order of the evening. The chat is very important, it gives people a chance to discuss, and share a Parkinson's problem, or just have a "good old chinwag". On the return journey there was a visit to The Kennedy Homestead. It was interesting, but there was no audio visual, as there was an electrical breakdown. We did manage to have tea/coffee. A good Samaritan got boiling water in a flask for us. All those who traveled really enjoyed the experience and were asking about a winter outing.
- There have been no developments in the quest for a Parkinson's Nurse Specialist. The residents of Cherry Mount Estate donated €200 towards the funds. Details and information on the Social Weekend in Athlone in September 18th to 20th 2019 were discussed. The next event on the calendar is the Clonmel flag day which is on Friday 2nd August. Mary wishes everyone a nice, relaxing break and will see us all in September.

### **Contact ph 087-2864798**

### **MIDWEST NEWS**

September has arrived and we are putting plans in place for the Autumn Programme.

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## **THANK YOU**

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To celebrate their 55th Wedding Anniversary Liam and Mary Forde requested donations in lieu of gifts to celebrate.

They have requested that all donations go towards research. Thank you to everyone who contributed to making this a great occasion.

### **Bequest**

The Parkinson's Association of Ireland would like to thank the Family of the late Bernadette Duggan from Wicklow who left a bequest to the association.

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The Voice Club starts on Friday 30th August at 10.30 in the Redemptorist Music Centre at the back of St Mary's Church in Corbally. Aidan O'Connor is looking after this. His number is 0868828304

Set-dancing is in full swing with Pat O'Dea out in An Teach His number is 0872577761.

We hope to have a new term starting soon for the Hydrotherapy in St Gabriels. Eddie Butler looks after this and his number is 0876776446.

We had a very interesting session with two Physio Students in UL. The lead girl Sophie invited 8 patients for a discussion about living with PD. She had lead questions to open the chat. All the patients were very forthcoming about their difficulties and also the benefits of exercise and other therapies.

We finished the meeting with a cup of tea and we were amazed how they all felt a session such as this was very useful and asked if we could have them again.

We have found over the last year Parkinson's is high on the agenda of numerous areas in UL and we appreciated how the awareness of the condition was widely discussed and indirectly was very beneficial.

Our Branch contacted all our politicians to get the funding of the Duadopa Drug solved. We were very impressed how they all responded to help to put the matter on the table for discussion at Government level. We are looking forward to a positive outcome.

We have good news for our patients in the Newcastlewest area. We are starting the set-dancing on Monday 16th September at 10.30 in the Desmond Complex. We have formed a small committee of local

## SUMMER RAFFLE

The National Office would like to thanks all those who contributed to our Summer raffle.

Thanks to all those who bought/sold tickets to help with this annual fundraiser. All winners have been notified



## VHI MINI MARATHON

A very big thank you to all the ladies who walked, jogged and ran the VHI women's mini marathon in support of The Parkinson's Association of Ireland. Thank you for all the time and effort you went into raising funds and awareness of Parkinson's. Please remember to send in any sponsorship.

- members to get this sub branch off the ground. For further information contact Una Anderson Ryan 087 2511156.

- We wish everyone a healthy Autumn and hope you will all come to our meetings in the Greenhills to learn more about your condition which will make living with PD a little easier.

- Mags Richardson will notify everyone. First meeting will be on Tuesday 6th September.

- We would like to extend our deepest sympathy to our CEO Paula who's father sadly passed away. Most of us know how difficult it is to loose a parent.

**Contact ph 087-2511156**

## DONEGAL BRANCH

- The Branch would like to acknowledge and thank the following people for their generous donations:

- Mrs White and family €450 received in lieu of flowers following the death of her husband, Thomas. We would also like to extend our sincere sympathy to the White family.

- Seamus Ginty, €1005 who completed a walk in Glenveagh National Park.

- Sean Callaghan €1330. Sean recently celebrated his 70th birthday and the donation was given in lieu of gifts and also money received from the Daniel Callaghan Memorial Darts Competition.

- Edel Fahy (Giblin) €2030. Edel completed the Women's Mini Marathon in June to raise funds for the North West Branch. Well Done Edel and thank you for your generosity.

- We look forward to meeting everyone in Athlone in September.

**Contact ph 087-2869173**



# CHRISTMAS IDEAS FROM THE PARKINSON'S ASSOCIATION OF IRELAND

With Christmas fast approaching we have Christmas cards now in stock and also some jewellery gift ideas.

These bright cheerful cards are on offer for €10.00 per pack of 15 cards

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

Newbridge Pendant €35.00  
Newbridge Pins €20.00

Parkinson's Lapel Badges €3.00

PRICES DO NOT INCLUDE P&P

