



Parkinson's Association of Ireland

www.parkinsons.ie

Autumn 2020

Leon the labrador leads the way
in helping with Parkinson's



A MESSAGE FROM THE BOARD

DEAR MEMBERS

As we continue to face the challenges of the COVID-19 global pandemic, we truly hope that you and your loved ones are safe and healthy. We are grateful to the members who are fighting in the forefront of this unprecedented crisis within healthcare systems, research institutions, pharmaceutical companies, and other essential service organisations. Our thoughts are also with those many who are personally affected. This is a moment to support each other, work together on innovative solutions and use our research in response to COVID-19. It has been a difficult few months with the disruption to our usual routine of attending classes and services to help us manage our Parkinson's suddenly taken away. However, it has been great to see so many people embrace technology who would have not done before to access exercise classes via Zoom, Bluejeans etc and social chats to keep fit and stay connected. We would love to be able to help our members more but with the restrictions it is limited at present.

We are currently working to improve our IT systems and particularly our new website to enable members to stay up to date and access useful information about your Parkinson's journey.

Internal Governance and Financial Stability:

As a charity organisation, it is essential to professionalise the internal workflow and governance of the association and ensure financial stability. Some targeted ideas and options are

- already set in motion, which all branches will need to comply with in order to meet the required regulatory standards of a Charity Organisation.
- Prior to the onset of the Covid-19 crisis, our former CEO, Paula Gilmore decided to leave the Association and did so in March 2020. On behalf of the PAI, her colleagues and the Board, we wished her every success for the future and thanked her for all her work on behalf of the Association and for her contribution to its development. Since then, I, on behalf of the Board have continued on an interim basis to oversee the executive functions of the organisation.

- I am pleased to confirm that the Board has appointed Paul O'Brien to the new role of Programme Manager of the PAI. This interim role will be for a period of 4 months. Paul will report to the Chairperson and the Board and key responsibilities will include: Corporate Governance, Process and Procedures review, Communications and other duties as required by the Board.

- Regrettably for operational reasons we temporarily closed our Waterford branch mid August. This is an interim measure and member services for this period will be supported by the National Office. The PAI is fully committed to re-establishing a fully functional support structure across the South East in due course and will liaise with members on this.

- As always we want to acknowledge all branch offices and volunteer who are continuing work and provide support and services to the Parkinson community.

- We are continuing to work with research teams and advocating for better services. We are at present working with UCC to find out the most essential services needed for people living with Parkinson's in Ireland. Researchers at UCC have compiled a survey for your feedback and I would encourage you to complete this as your input is important to us. It takes about fifteen minutes to complete and paper versions are also available.

Date to Remember!

- A note to remember that the Parkinson's Association of Ireland AGM will take place on Saturday the 10 October 2020.

- Stay safe and hopefully we will get back to some sort of normality soon.

- Yours sincerely,

- *Joe Condon*

- Parkinson's Association of Ireland Chairperson on behalf of the PAI board

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MEMBERSHIP OF PARKINSON'S ASSOCIATION OF IRELAND

The Parkinson's Association of Ireland (PAI) was established in 1987. The PAI provide support for people living with Parkinson's, their families, carers and health care professionals.

We operate a Freephone helpline 1800 359 359 which is available Monday- Thursday 9am-7pm and Friday's 9am-5pm.

Other services offered are access to a Parkinson's Nurse Specialist call back service each Monday and Friday.

We have a social gathering annually where members can enjoy Parkinson's workshops, information updates, yoga, set dancing and entertainment.

We produce a quarterly magazine and provide information literature on the symptoms of Parkinson's and how best to manage them.

Our focus at National level is on increasing awareness and improving education around Parkinson's and how to provide appropriate support.

At local level, we have a branch network of 18 branches spread throughout the country, all of which are run by volunteer committees. Each branch provides a focal point primarily as a social engagement but also as a source of exercise and other physical activities to help maintain a good quality of life. These activities range from set dancing, singing groups, voice training, physiotherapy and yoga to name but a few.

Annual membership of PAI costs €25.00. We are currently updating our data base and we need to make sure we have all the contact details of our members to ensure we can provide the best service we can and be able to contact members

with ease with updates etc.

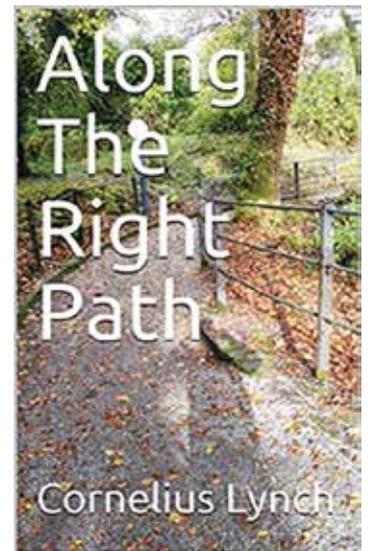
Please contact our Freephone 1800 359 359 or email nationaloffice@parkinsons.ie to ensure we have your latest contact details.

To see what is going on in your local branch please visit our website www.parkinsons.ie

ALONG THE RIGHT PATH

by *Cornelius Lynch*

This book was written primarily to deal with some issues (not health issues) which concern a lot of people and to raise funds for Charitable Organisations.



Proceeds from the sale of this book will be used to raise funds for charitable organisations which include The Parkinson's Association of Ireland. This book is available from the author's web page www.corneliuslynchautor.com and is available in e-book format and paperback format from www.amazon.co.uk.

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

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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.

LIVING WELL WITH PARKINSON'S DURING COVID-19



Covid-19 has presented unforeseen challenges and affected each and every person's life on the planet.

Over the past few months in Ireland we have had a lockdown, some of us have had to cocoon, some have been separated from families, friends and loved ones.

Some have had hospital visits postponed or perhaps replaced by a telephone call with their neurologists, GPs or geriatrician.

This disruption to our daily routine can make us feel irritable, frustrated, unsettled, disoriented and sometimes sad.

Adjusting to new circumstances can take time. The way that you approach the "new normal" can be challenging but focusing one day at a time and trying to live a healthy lifestyle with a positive outlook will help you manage your condition

Exercise

Exercise is good for everyone. It's especially good for you if you have Parkinson's Disease.

Regular exercise will improve your strength,

- balance, posture and flexibility. It will help keep your heart and lungs healthy. It can also help with sleep, tiredness, your mood and mental health.
- It's good to focus on the rewards of exercise.
- Keeping your body fit will help you carry on doing the things that matter to you.
- Exercises that work the body and mind at the same time are really good to manage Parkinson's.
- Whether you have Parkinson's or live with someone who does, there is no one size fits all approach to exercise. The best exercise to do depends on the way it affects you.

Exercise

- Maintains flexibility
- Improves balance
- Improves muscle strength
- Improves general functioning
- Improves fitness and stamina
- Provides a sense of achievement and empowerment
- Reduces stress and anxiety
- It can be enjoyable



Exercise leaflet available from the National office, call 1800 359 359 or email nationaloffice@parkinsons.ie

Visit our website www.parkinsons.ie for online exercise classes

Diet

If you have Parkinson's there is no specific diet that you should follow. But you should find it helpful to maintain as healthy a diet as you can.

Generally, the rules for following a healthy diet are:

- Eat a varied diet.
- Eat healthy portions of foods.
- Eat the right balance of food groups.
- Eat regular meals.
- Drink plenty of fluid.
- Eat at least five portions of fruit and vegetables a day.

Eating a balanced diet will improve your health and may help to ease various problems you may be experiencing, including constipation, low mood, reduced bone density and weight changes.

Visit www.parkinsons.ie for information leaflet on diet.

Medication

Each person with Parkinson's will have an individualised tailored regime depending upon his/her age, physical state, level of disease etc, therefore no two patient's medication regime will be the same.

We encourage people to take their medication "on time, every time"

Whatever your medication regime is please follow it carefully.

Look after your Mental health

Stress can affect how you feel emotionally, mentally and physically.

Stress can also affect how you behave. We can all sometimes feel overwhelmed, irritable and wound up when things are out of our control.

Stress can lead to sometimes experiencing racing thoughts, constant worrying or a feeling of low mood. Help is available. There is no need to go it alone. Talk to family, friends, contact your GP or visit hse.ie for a list of contacts to connect with mental health services.



Continue to be Active

Learn the skills needed to manage your condition by educating yourself about the condition. Studies have shown that people who educate themselves about their illness and learn how to manage it do better and have a better quality of life over time.

Adapt your activities to fit around times when you get the most benefit from your medicines.

Focus on doing the things that are important to you and your family.

Be realistic in setting goals and objectives.

Rest when you need to, particularly before a challenging activity.

In general, try to get as much sleep as you can.

It is important to continue to stay socially active following your diagnoses.

You can connect with other people living with Parkinson's through your local branch. To see branch activities please visit www.parkinsons.ie

Keep a sense of perspective and try to maintain a sense of humour. Laughter is good for your health and well-being.

Our helpline 1800 359 359 is available 9am-7pm Mon-Thurs and 9am-5pm Fri.

To avail of our Parkinson's Nurse Specialist call back service please call the helpline 1800 359 359.

The Parkinson's Nurse works every Monday and Friday.

Anxiety and Parkinson's

What is anxiety?

Anxiety can be an entirely normal feeling and is often an appropriate response to a dangerous or threatening situation. What is often understood as 'anxiety' can range from worry and stress to the bodily symptoms associated with fear and panic (the 'fight or flight' response). The bodily symptoms of such anxiety may include sweating, pounding of the heart, shortness of breath, tightness in the chest and unpleasant feelings in the stomach. Psychological symptoms of anxiety include excessive worries, ruminating thoughts and a sense of tension.

If anxiety goes on for a long time, it can also cause symptoms such as feeling worried all the time, feeling tired, over-reacting to a situation, lacking insight into the reality of a situation, poor concentration, irritability, poor sleep, muscle pain and tension. It may even lead to depression. At times, anxiety can be so severe that it interferes with day-to-day functioning. At this point, anxiety is no longer a 'normal' reaction and may be considered as a psychiatric condition. Very often, severe and unrelenting symptoms of anxiety can co-exist with the symptoms of depression. Treating the depression can sometimes clear up the anxiety symptoms and vice versa.

Anxiety and Parkinson's

In Parkinson's, anxiety may be based on the very real fear of functioning with a disability. However, at times, it can take on a life of its own and be unrelated to the physical state of the person with Parkinson's. Just like depression in Parkinson's, anxiety in Parkinson's may also be related to changes in brain chemicals, particularly in noradrenaline and serotonin.

Some people with Parkinson's have anxiety related to the 'on/off' state of their motor symptoms. When 'off' and less able to move well, they may develop significant anxiety symptoms and, at times, may even have panic attacks. A panic attack is an overwhelming feeling of fear or terror that comes out of the blue and is accompanied by physical symptoms of sweating, a racing heart and shortness of breath. The person often feels as if they are going to die and if they do not recognise what is happening to them, they may end up in A&E believing that they

are suffering from a heart attack. A typical panic attack may last up to 15 or 20 minutes, or in some cases, even longer.

What can be done about anxiety?

For those who experience mild and intermittent anxiety, conservative measures such as avoiding stimulants, including caffeinated drinks, tea/coffee, alcohol and cigarettes, may be helpful. Identifying and avoiding triggers of anxious episodes may also be helpful. Some people find other methods, such as relaxation tapes, yoga, massage, acupuncture, mindfulness and complimentary therapies beneficial.

If anxiety is specifically related to motor function, then improving the management of motor symptoms may improve anxiety symptoms. For example, an 'off' episode anxiety may improve by altering anti-Parkinson's medication regimens to lengthen the duration of 'on' episodes and reducing fluctuations in motor symptoms.

Likewise, those with no clear 'on/off' phenomena may experience generalised anxiety if their motor symptoms are under-treated.

In such cases, increasing the anti-Parkinson's medication may be beneficial. This should be discussed with their Parkinson's specialist before any changes are made.

For anxiety symptoms that do not respond to changes in anti-Parkinson's medication regimens, trying either talk therapy, such as cognitive behaviour therapy (CBT), or medications may be helpful. CBT and other forms of psychotherapy, such as relaxation therapy, have been shown to be very helpful for people without Parkinson's. However, clinical experience has shown that these methods may only work for some people with Parkinson's. Nonetheless, they have proved to be helpful in practice and most Parkinson's specialists would support their use in Parkinson's.

Psychiatric medication may have a role to play in treating those with severe anxiety that is interfering with daily functioning and impacting on quality of life. Again, as with psychotherapy and psychological treatments there is very little direct evidence that such interventions work

specifically in Parkinson's, and recommendations for their use are taken from their efficacy in treating anxiety in people who do not have Parkinson's.

The most common medications used to treat anxiety in these circumstances are anti-depressants such as serotonin reuptake inhibitors (SSRIs). These medications may improve both anxiety and depressive symptoms, particularly because the conditions often co-exist and overlap. Another medication that sometimes can be used to control anxiety symptoms in Parkinson's disease is pregabalin. Once again, the research evidence for the benefit of this medication for anxiety comes from studies in people without Parkinson's disease. Sometimes, benzodiazepines may be used for a short time in times of high stress/anxiety. However, these medications should be used with caution as they may cause excess sedation and drowsiness, unsteadiness of gait, slurring of speech and even confusion. Whereas most psychiatric medications are not addictive, the benzodiazepines can be highly addictive and after about six weeks of use, may be difficult to taper off without withdrawal symptoms.

Benzodiazepines are also used as muscle relaxants so may be helpful if muscle tension and pain is also experienced. This group of medication works very rapidly to alleviate symptoms of anxiety but does not treat the underlying abnormality in brain chemistry that is causing the anxiety in the first place. In contrast, using anti-depressants to treat anxiety takes longer (about two weeks before symptoms start improving), but will ultimately be more effective as the underlying brain changes will be improved.

Advice to family, friends and carers

Anxiety can be a very difficult problem to live with and it may restrict normal day-to-day activities, such as going out and socialising. If anxiety symptoms start to significantly affect quality of life, then a family member, friend or carer should try to encourage a discussion about this with their doctor. This may result in a referral to a mental health specialist who may recommend treatment. Helping and reminding a person with Parkinson's to undertake relaxation exercises can also be of benefit.

Acknowledgements

The PAI would like to thank Parkinson's UK for permission to use PDS Leaflet FS96 as the basis for this Information Sheet.

Our thanks to Professor Brian Lawlor, Consultant Psychiatrist in St. James's Hospital, Dublin for endorsing this leaflet.

DISCLAIMER – The information on these pages is not intended to be taken as advice. No changes to your treatment should be made without prior consultation with your doctor or allied health professional.

Parkinson's Association of Ireland

National Office: Carmichael House, North Brunswick Street, Dublin 7, Ireland.

Tel: 00 353 1 872 2234 **Fax:** 00 353 1 872 5540

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LEON THE DOG -

By Philip Bromwell

TRAINED TO HELP PARKINSON'S PATIENT WITH MOBILITY AND STABILITY



Duncan Hughes was diagnosed with Parkinson's Disease in 2003. He was in his early 30s at the time and the diagnosis obviously came as a shock. However, the accountant and married father of two from Dublin was determined to carry on with work, leisure and family life despite his diagnosis. However, Parkinson's can be a debilitating disease and one for which there is no cure. Duncan found himself with problems with movement and walking. This impacted on his well being, as well as his physical health, as in public people often stared or thought he was drunk. His consultant neurologist, Prof Tim Lynch from the Dublin Neurological Institute wanted to try something different to assist Duncan.

He teamed up with Dogs for the Disabled and its founder Jennifer Dowler in Cork for an innovative pilot project. Jennifer has been training dogs to support a variety of people with disabilities, but she had never previously been asked to train a dog to help someone with Parkinson's with their walking and mobility.

This is certainly a first for Ireland and maybe a world first. While other dogs may have been trained to be a support or companion for people

- living with Parkinsons, no other dog has been
- specifically trained to assist with mobility, stability,
- movement and gait here.
- The dog, a black labrador named Leon, was
- trained for several months at Dogs for the Disabled
- in Cork. Last December, Duncan went to Cork to
- meet this new companion and to spend a week
- with Jennifer to be trained in how to work with this
- "Stability" dog.
- After that short time, Duncan returned home to
- his family in Dublin with Leon. Now, just a few
- months later Duncan says that "This is the best
- treatment to improve my quality of life among all
- the treatments I've had for Parkinson's Disease
- over the last 17 years."
- A friend of Duncan's recently told him that he had
- never seen him walk so well as with the assistance
- of the dog. People with Parkinson's disease often
- find that their movements are "frozen" and they
- cannot emerge from that frozen position. Freezing
- of gait is a very difficult thing to manage and
- treat - there is no proven treatment. Freezing is
- associated with increased death rate presumably
- because of falls and injury. In Duncan's case,
- his feet often become "stuck" and this limits his



movements as well as being personally frustrating and sometimes embarrassing in public. Duncan's dog has been trained to help him unfreeze by moving himself on command to help activate Duncan's movement. Duncan says that he senses the movement and it helps to kickstart his own movement - rather than it being a visual cue. The dog also moves at a slower pace than Duncan usually would and this is also helpful in terms of safety and gait.

In addition to mobility, improved movement and gait the dog will also help balance and hopefully decrease falls and hence injuries, fractures and hospital admissions - while we don't have data yet to show this, Duncan feels much more confident and safe with the dog.

This is a pilot project by the DNI, a registered charity. Dogs for the Disabled, which is also a charity, used its funds to pay for the training for one Parkinson's Stability Dog (estimated to be around €15,000). Duncan and Leon have



also been assessed in the laboratory at UCD Engineering (Prof Madeleine Lowery) and had sensors placed on both of them to see if Duncan's gait is improved when walking with Leon. This data will be used for an academic publication Tim Lynch is planning, with the view to providing more Parkinson's Stability dogs to other patients who are suitable for this intervention in the future.



LABRADOR LEADS THE WAY IN HELPING DAD WITH PARKINSON'S

A father-of-two who has Parkinson's disease says his life has been transformed by a dog trained to help him with mobility and stability.

Duncan Hughes, from Dublin, partnered with Leon, a black labrador, just over six months ago. The pilot project by the Dublin Neurological Institute (DNI) at the Mater Hospital is a first for Ireland and possibly the world.

While other dogs may have been trained to be a support or companion for people living with Parkinson's, Leon is the first one to have been specifically trained to assist with mobility, stability and gait here.

Mr Hughes said: "This is the best treatment to improve my quality of life among all the treatments I've had for Parkinson's over the last 17 years."

He added: "Previously when I was walking, people used to think I was drunk or on drugs. Now they just smile. The two of us are walking more than six kilometres every day now. It has been a complete change of life."

Parkinson's is a long-term neurological condition that affects around 8,000 people in Ireland.

It affects the way the brain co-ordinates body movements, including walking, talking and writing.

While there are a number of different treatments available to help manage the condition, there is currently no cure.

Consultant neurologist Professor Tim Lynch from the DNI wanted to try something different to assist Mr Hughes.

Professor Lynch said: "While Duncan has done well over the years with his Parkinson's, he has had problems when his feet get stuck on the ground and freeze. Hence he wasn't able to go for regular walks.

"So we had a couple of ideas that a stability dog could be of use. Firstly, a fairly sturdy dog could provide support, something you could lean on if you were getting stuck, so you wouldn't fall over.

"Secondly, with movement control, a dog could provide a sensory trick if the patient's leg was

frozen, giving them a nudge to release the knee and the foot would move forward."

He approached the Cork-based charity Dogs for the Disabled, which trains dogs to support a variety of people with disabilities.

The charity's CEO Jennifer Dowler said: "It's the first time we've worked with a Parkinson's patient. We selected and trained a dog based on an assessment of Duncan's needs, wants and personality type.

"Leon is a strong dog, a great worker, with real drive and determination. He's really stepped up to the mark and it's just amazing to see how happy they are together."

Mr Hughes and Leon are also undergoing assessments at University College Dublin.

Engineering researchers have been carrying out gait analysis by attaching sensors to both of them.

"By taking these scientific measurements and using psychological tools, we are trying to prove whether there is a difference in Duncan's walking.

"As far as we know, this is the first long-term study of a patient with Parkinson's using a dog that has been trained specifically for them. Being able to

scientifically prove that it is beneficial to them would be very exciting," said Dr Cliona Buckley, a research registrar at the DNI.

Data gathered over the course of the project will eventually be published, with a view to providing training for more stability dogs, estimated to cost around €15,000 per animal.

Duncan believes other Parkinson's patients would benefit from this kind of innovative intervention.

"This isn't a medicine looking after the symptoms of my Parkinson's, it's actually making my life better.

"Leon is like a part of me at this stage. I don't go anywhere without him. He looks after me and I look after him," he said.



VHI VIRTUAL WOMEN'S MINI MARATHON

Oct 1st-10th 2020

10k in 10 days...

We want you to do it your way.
With friends, in your garden, in one go, or
maybe you'd prefer to spread the distance
over a few days - you decide!

The VHI Women's Mini Marathon is an annual 10k Charity road race which occurs each June Bank Holiday weekend in Dublin.

This year Covid -19 prevented the mini marathon from going ahead in June, however the event is going Virtual from 1st-10th October 2020.

While we cannot all be together to participate, we can still do our 10k collectively, but safely apart.

PUTTING THE FUN INTO FUNDRAISING

Each year women from all over Ireland walk, jog or run to raise awareness and much needed funds for the Parkinson's Association of Ireland. We are asking you to please visit www.vhiwomensminimarathon.ie and participate in this fun event on our behalf.

REMEMBER

- The Virtual VHI Women's Mini Marathon is supposed to be a fun and enjoyable experience.
- You could Walk around your block, loop your garden, take the stairs or walk in a local park.
- Please take pictures of your efforts and we will be happy to share them on our social media platforms.
- Follow all current government guidelines.



BRANCH NEWS

LONGFORD BRANCH



The Longford branch was launched in 2017 and a committee was formed. It comprised of Brenda Shannon, Chair, Al Shannon, Secretary, Mary Connolly, Treasurer. With just six members, we met, and the branch still meets, once every month, when we have various activities.

2018 saw an increase in numbers accessing the branch seeking information about their condition. Over time we've had the services of physios, speech and language therapists, a Parkinson's Nurse Specialist as well as singing exercises, set dancing etc. Our meetings always finish with the cuppa – tea or coffee – and it is a very important part of the night.

2019 saw a new committee formed due to the resignation of our Chair, owing to work pressures. Al Shannon became Chair, Adell Dunleavy Co-Chair, Bridget McKenna Secretary and Mary Connolly Treasurer. The committee set about organising weekly exercise classes for the members but, due to the prevailing conditions in 2020, these have had to cease. However, the branch is looking forward to resuming activities when that becomes possible.

One member who deserves special mention is our Co-Chair Adell Dunleavy who played a major role in getting the branch off the ground. Adell and a group of her friends raised much-needed funds through their participation in the Dublin City Marathon. Sadly, for personal reasons, Adell resigned from her role on the committee earlier this year but we take this opportunity to wish her well.



Oughterard Marathon finishers Coman and Kevin Feeney

A GREAT FUNDRAISING FAMILY

Mary Feeney is a Roscommon woman who has always lived in her own county and married a Roscommon man. Her husband, Tomás, looks after the farm in Kilglass where they live. Six years ago Mary was diagnosed with Parkinson's but she's well and says the medication is keeping her symptoms under control.

She joined the Longford branch, as it's the nearest to her, and enjoys going to their social events. "It's nice meeting people," she tells me.

To support Mary, and the Longford branch, her loyal family decided to put their minds, and feet, to the task of some serious fundraising. Her sons, Colman and Kevin, who both live in Dublin, set their sights on doing a half marathon. They began training and entered the Oughterard Half Marathon. On the March day of the race Mary was there to see them finish. Asked how they felt afterwards, she doesn't talk about sore legs or tiredness, only saying "They were pleased with themselves." This is clearly a family who look on the bright side of life.

Not to be outdone by the younger generation, Mary's sister-in-law and brother-in-law, Mary Rose Neary and Eamon Feeney, who are both over sixty, then decided take on the Dublin half marathon. They were joined by Eamon's daughter, Martina. When the September race came around, Mary says "I went to Dublin and I was there in the Phoenix Park to watch them."



Many families would have been content to rest on their laurels at that stage but, no. Mary Rose's son, Paul, decided he was going to put on a different kind of fundraiser. He organised a quiz similar to the TV show, The Weakest Link, which took place in a pub in the Co. Roscommon village of Rooskey. A neighbour of Mary's, Teresa Reynolds, drew up the questions and Paul was quizmaster on the night. "It was a great success," Mary tells me, "The whole village was there." Five brave local people volunteered to be the contestants and winner on the night was Vinnie O'Leary.

The net result of their mental and physical exertions was that the Feeney and Neary families presented three cheques to the Longford branch, totalling €5,521, a great achievement by everyone involved. The family requested that €1000 from their last fundraiser be donated to the PAI for the Parkinson's research being carried out in TCD.

This year, things are obviously very different and Mary has been 'cocooning' because of Covid 19. "I'd like to be able to get out," she tells me, "And for my sons to be able to get down to visit." This is a wish no doubt echoed by many people all over the country. But let's plan for the day when a pub quiz or a half marathon can take place once again and raise much-needed funds. It will happen.

Contact Al Shannon 087 764 0409

CAVAN BRANCH

Greetings to all our members in the Cavan Branch. It has been trying and a strange time for us all since

- lockdown was announced
- back in March. However as
- we gradually start to get out a
- little again hopefully it will lift
- our spirits!
- Yoga has resumed on Fridays
- at 11.00am in Castlemanor
- Community Centre beside
- Castlemanor Nursing Home.
- Masks are required to be
- worn and social distancing also applies. Contact
- Catherine 087 2944805 for more info.
- The branch recently purchased two Laser Cane
- walking sticks from Beechfield Healthcare. The
- Laser Cane is a lightweight adjustable walking
- stick which projects a bright green line across
- your path. It is specifically designed to help
- people with gait freezing or gait ignition failure
- such as occurs in Parkinson's Disease and other
- Parkinsonian conditions. It is also useful for
- abnormal gait patterns such as Ataxia and stroke
- rehabilitation. These are available for trial to paid
- up members of the Cavan Branch. If any member
- is interested in trying out the Canes please contact
- Susan Donohoe 086 8396518 or Danny Byrne 086
- 8357852.
- The branch would like to extend congratulations
- to Branch Treasurer, Seamus Minogue and his wife
- Dympna on recently celebrating their Diamond
- wedding anniversary!



Continued on page 14



Ultan Flynn, Coman Feeney, Vinnie O'Leary, Enda Beirne, Seamus Nugent, James Feeney, Mary Shannon, Al Shannon, Mary Feeney, Paul Neary, Teresa Reynolds.

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Although there are no meetings or outings at present due to COVID 19, remember the branch, Head Office and the Helpline 1800 359 359 are still there to support you. There are also exercises and speech & language exercises available on Facebook on Parkinson’s Ireland and on Cavan Parkinson’s Branch – it is really important to continue to try to do some exercises as best you can even if Physio or Speech & Language is not available. In addition please spread the word about the Parkinson’s Association and encourage people living with Parkinson’s Disease or a family member to join.

The Branch would also like to extend its sympathy to the families of the following members who passed away over the past few months: Sean Flood, Victor Ennis, Patsy mc Kevitt and Patsy Lynch – may they Rest in Peace.

Finally for anyone who hasn’t renewed their membership please send on cheque or Postal Order to Assistant Treasurer *Susan Donohoe 086 839 6518*.

DONEGAL BRANCH

Hoping you are all keeping safe and well during these difficult times. Hopefully we will be able to reconnect when HSE Guidelines allow. I hope you are continuing to enjoy exercise classes. Until we meet up again stay safe.

Contact Ann Foxe 086 1605 847

DUBLIN BRANCH

We hope everyone is keeping well and safe during these very difficult times for us all.

We know that a lot of you are missing your exercises and your contact with other people.

We are delighted that so many of you join us every Thursday at 11am for our Siel Bleu exercise classes which we have specially set up for members via



Zoom. If any other member would like to take part just email Sinéad at dublinsecretary@parkinsons.ie. Everyone is welcome!

We would like to get our exercise classes up and running again. However, safety of members remains our priority so nothing is certain yet. Members will be advised via email of the latest developments.

We, in the Dublin Branch were very sorry to see the departure of the former CEO of PAI, Paula Gilmore. We would like to wish Paula all the best for her future career. We await an appointment of a new CEO.

The Dublin Branch members wrote to their local TD’s to lobby for more funding for Parkinson’s nurses and access to essential service. We have received some favourable responses so far. We are very grateful to members for sending emails on all our behalves.

The walk we had arranged for Parkinson’s Awareness was supposed to take place in Marlay Park on Saturday 25th April, as part of Parkrun.

Unfortunately, like so much else it had to be cancelled. We asked members to do the walk themselves in their own homes and to send us photos. Many thanks to all those who did.

See some below:

We have also sent our members, details about how to use Zoom and a very interesting article about Vitamin D. These are both in the Summer edition of Dublin Branch Bulletin.

We would like to thank committee member, Sheila Fahey for





organising a face covering workshop via Zoom for our members. This class was a great success and members really enjoyed it.

Margaret Mary Byrne and Ann O'Brien have stepped down from the Dublin Branch committee after many years of service. We wish them well and assure them that they will be missed. We are delighted to welcome Mary Butler (who compiles the quarterly bulletin), Teresa Farrell and Olivia Heavey to our committee.

The committee are continuing to meet on your behalf via Zoom.

The committee members will be taking August off this year so we hope that this will not inconvenience members.

Until we meet again, stay safe and keep well and keep exercising as much as possible.

Contact Sinead 087 286 9173

CORK BRANCH

What with Covid-19 lockdown, cocooning, self-isolation, social distancing and washing our hands you'd think we would all just give up and stay quiet but not the Rebel county. When nature threw down the gauntlet we rose to the challenge as individuals and groups.

Knowing the importance of staying connected we quickly found new ways of working. From the simple things of phone calls, Whatsapp groups to the cutting-edge technology of Zoom calls. We were all just amateurs before the pandemic.

Cork Connect was born out of the need to stay connected. We knew that people would miss the regular meetings so we created a Zoom call. This now runs every Monday at 11.00 and the attendance has been amazing. We are able to get speakers on different subjects to join the call and people are finding it a great way to stay in contact while remaining safe. Some of the speakers include; Dr. Emma O'Shea (UCC) who is running the national survey, Paddy Harkin (Lisheen House) talking on Mental Health issues with plans to get more people involved including someone to cover falling & recovery (not a stunt man!) and other relevant subjects. One of our most enjoyable meetings was when we exchanged our own hints & tips for living with Parkinson's from simple things like using a pack of cards to improve dexterity in the fingers to using a long shoehorn to put on laced up shoes.

There were casualties along the way as we had to forego our regular monthly meetings around Cork. We tried to continue as a Choir over Zoom

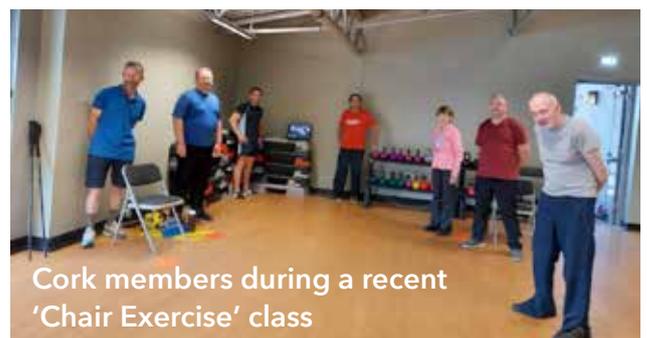
with little success. However Jerome Maune has been a whizz at keeping the WhatsApp group flowing with music, quizzes, virtual concerts to name but a few. He has also penned a heartfelt and emotional song about living with Parkinson's made all the more powerful by his beautiful voice.

We all know how important exercise is for people with Parkinson's and the closure of the Mardyke centre which hosted the PD Rebels classes was a huge loss. However, Conor O'Mullane our brilliant and proactive instructor put together a Zoom class which allowed us all to continue with our exercises from the safety of our own homes. A big bualadh bos for Conor who had the vision and confidence to do this. Our group benefitted hugely from it, not alone for the exercise but also for the camaraderie and fun during the sessions. With the easing of restrictions we had our first session back at the gym in mid-July with Conor. Having seen how useful the Zoom calls were during the lockdown we are now combining live gym session with Zoom calls which allows people not yet able or comfortable with returning to the gym to join the class remotely.

Another innovative idea has been the 'Chair exercise' class. This is the HSE chair exercise programme which we do together as a group again through Zoom on Thursdays at 11.00 am. These are gentle exercises which are chair-based so suitable for many levels of fitness and build a great sense of community and inclusiveness. We now have people joining from care homes around the county.

Among some of the unfortunate casualties was the cancellation of our AGM in April. We will reschedule it at an appropriate time taking into consideration the guidance from the Government on personal safety. The setting up of a new group in Bantry will also have to wait as will our information tours with the minibus which was due to appear at many summer shows in 2020.

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Cork members during a recent 'Chair Exercise' class

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Let's finish with THE BIG SHOUT OUT – taking the lessons learned in the past number of months we are looking at a totally new approach for the future development of the groups. Once restrictions are lifted, the plan is to hold all our group meetings (6) on the same day. The idea is the local group will go to their normal meeting place and will connect via Zoom from one machine (TV) in the room. This will allow people who cannot make the meetings in person to still join in from home. This gives everyone access to the speakers and we all get to hear the same information at the same time. It will improve participation and representation at the meetings and allow attendees to ask questions or comment. It is also a great way to bring the groups together across the great distances of county Cork.

Group development is a key focus of CPA and we cannot do it without your help and commitment. Keep safe and well in this 'new normal', keep in touch with each other and remember "because we are here nobody has to go through Parkinson's alone".

Contact Tony Wilkinson 083 864 3676.

MIDWEST BRANCH

As you can imagine we are completely restricted with the Covid 19 virus.

We are going by the rules and doing everything online.

Pat O'Dea has everyone dancing the MidWest. If anyone would like to join in just give Pat a call.

The voice club continues with Ann Blake and we hope to have it together in the Redemptorist Music Centre at the end of September--all going well.

We hope to start up in the Desmond centre asap. If there is anything you would like us to do as a group please send me some suggestions and we will get started.

Once we are allowed a group meeting we will restart our Tuesday monthly meeting. I know you are all looking forward to some normality.

We need to complete the membership list for September so perhaps you will get in touch with Eddie Butler.

Eddie has had some health issues so we would like to wish him well for a speedy recovery.

We wish our former CEO, Paula Gilmore well in her future endeavours.

Contact Una 087 251 1156

YOUNG PARKINSON'S IRELAND

OUR YEAR TO DATE

We would like to update you on some of the things we have done this year to date and what was originally planned, but hopefully will be rescheduled for a later date.

JANUARY In early January we created a leaflet about YPI for distribution to Health Professionals and Pharmacies around Ireland. This was sent to them so they could let young people living with Parkinson's in Ireland know that YPI are here to offer support and information from people who understand.

We organised an Insight event in Galway, where Dr Leo Quinlan spoke about the development of a device to help manage freezing (FOG). Also presenting was Dr Eilis Dowd who explained the developments of Cell therapies for Parkinson's. We then heard from Neurologist, Dr Tim Counihan about genetics and Parkinson's. This was a very informative evening and it was well attended by our members.

We exhibited at the Wexford Volunteer Expo to highlight YOPD and YPI. It was a well organised event and it was good to connect with other organisations that have services that could be of benefit to our members.

FEBRUARY We had a walk planned in Glendalough for 9th but due to high winds it had to be cancelled.

On the 12th we were delighted that RTE's Nationwide programme featured Rock Steady Boxing to show the great benefits people in New Ross were getting from this class. It also showed that Parkinson's affects younger people. It seemed to reach so many as the response was overwhelming and we were thankful to Helen McInerney and the Nationwide team for the work put into this programme. In particular the way the hours of footage were edited so well to get our message across.

Due to the response from Nationwide we had set up classes in extra locations. Before the restrictions came into place, we had RSB classes running in New Ross, Naas, Tullamore, Portlaoise and Kilkenny.



We had our AGM on the 15th February which included excellent presentations from Shane Breslin on DBS, Richelle Flanagan on Diet and Joe Condon on exercise for Parkinson's. These were recorded for viewing by those who could not attend on the day.

MARCH We had our first committee meeting outside Dublin which was held in Cork on the 11th and was followed by a social chat with Cork YPI members. There had been other socials held in Wexford, Dublin and Limerick before this date. The regular Cork YPI monthly Wednesday social went online using Zoom.

On the 20th March we started Rock Steady Boxing classes on Zoom, scheduling three times per week. This has been great to keep people exercising and connected with others by having a chat before and after class. This also resulted in coffee mornings, topic discussion nights and a show casing people's talents at art and crafts etc.

We were disappointed to have to cancel the training camp for coaches at the end of March. This was to be facilitated by Rock Steady Boxing team USA to bring this excellent exercise programme to other parts of Ireland. However, we will continue to work on this project to achieve this in the future.

APRIL Our committee compiled a video for Parkinson's awareness week to show how PD can affect people and how they are managing this condition. It really showed how diverse the symptoms of PD can be but exercise and staying positive helps.

We also launched the **5 for 5 for Parkinson's fundraiser** which started off as a homework exercise in Rock Steady. It has received great attention and raised a lot of funds. It is a bit of fun and you can still try it! See our Facebook page for details where you will see our committee member Ian giving a great demonstration.

MAY We were delighted to have head coach Kristy from HQ RSB Indianapolis join our class online one morning (5.30 am USA) to see the great work our coach Mirek has been doing and how well he adapted RSB to online classes at very short notice. Kristy stayed on to have a long chat afterwards and gave the history of RSB. She messaged to let us know that they used some of Mirek's exercises for hands in their class at HQ!!

JUNE On the 27th the yearly fundraiser Sunrise up Croagh Patrick for neurological conditions

took place virtually this year. Our Chairperson, Joe Condon completed this 28K walk. Great achievement Joe. This raised close to €20,000 for the three charities.

JULY We had our first all-Ireland YPI social chat on Zoom and it was so nice to see people from all around the country come together and especially good to see new people join us. We had a number of break out rooms so people got the chance to talk in smaller groups. You are very welcome to join us on our next Zoom chat.

We had a walk on Sunday the 26th at Castlecomer Discovery Park, Co. Kilkenny for a chance for people to meet up while adhering to social distancing.

We also had a soccer team ready to take part in the Cure Parkinson's Cup which was to take place the weekend of the first YOPD conference in Leicester, UK. This was scheduled for April and many of our members were looking forward to this event which I am sure would have been very informative.

We hope this gives you an idea of what YPI are trying to do to help our members. We feel we need to highlight young onset to bring more awareness so that people are aware it is not just an older person's condition.

We want to let those living with Young Onset Parkinson's in Ireland know that YPI is here for them so they don't feel isolated and they have the support of others.

We always welcome suggestions, so please get in touch. We have set up a messenger link on our public Facebook page. You may find this a quick an easy way to get in touch and we look forward to hearing from you soon.

We hope you and your families stay safe and well.

Contact Mary Casserly 051 347 473

GALWAY PARKINSON'S

Classes

We have been busy here in Galway Branch. Our classes which we held in 5 venues prior to Covid 19 had to be cancelled. Our Physio team arranged for our members to go on line and to do the classes on Zoom twice a week. These have proved to be of huge benefit both physically and socially. We are also providing Chair Yoga and Dance classes via Zoom. If any one wishes to join the classes please contact us.

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Walk

This year we were unable to have our annual Walk so we decided to have a virtual Walk, The Galway Hurdle to incorporate the Galway Races. The members walked virtually around their homes and parks. Everyone really enjoyed this and sent in some wonderful photos. Well done all.

Contact Marie 087 7783825.

EAST MIDLANDS BRANCH

We at East Midlands Parkinson's hope that all our members are keeping safe and well in these uncertain times. We are keeping up to date with

- the evolving situation and as of now we have no
- plans to return to general meetings or classes
- for the moment. We understand the stress and
- anxiety Covid 19 is having on everyone but our
- priority has to be to keep our members safe
- therefore everything remains cancelled for now.
- We the committee of East Midlands would like
- to send our condolences to all families who have
- lost loved ones at this sad time.
- Should you wish to contact East Midlands please
- do so on the following numbers:
- John Sinnott 087 2712448, Martina Sinnott 087
- 6550176, Marian Deely 085 2112973.
- Hope to see you all as soon as it is safe to do so.

FOUR WORDS

By Gary Boyle

TO THE CONSULTANT NEUROLOGY FRATERNITY...

A diagnosis of Parkinson's Disease can be overwhelming to receive. With the telling of the diagnosis, many can feel they hear a heavy steel door being shut on their future. Many people can leave their neurologist's office feeling shaken and alone.

You, the neurologist, are an expert. You have worked tirelessly around the clock, focussing your life exclusively to achieve what you now have, who you now are. Blood, sweat and tears are no strangers to you as you worked on dozens of research projects for years, achieving unquestionable peer respect from endless peer reviews. Your area of specialism is just that – your own; you are the go-to, leading practitioner; you are the one they all quote; the one they all look up to. You have rightly earned the respect and esteem you're held in. You have sacrificed everything to reach the top, where you are just about peerless. Your opinion is sought out and your stature extends well beyond the field of medicine.

Now comes the hard bit.

You will deliver many diagnoses in your career



- and your words will remain with your patients,
- your clients, long after they've moved on;
- certainly long after you have moved on too.
- Your clients will always remember how you made
- them feel the day you said 'You have Parkinson's
- Disease'. These four words cannot just fall out
- of your mouth and be delivered dispassionately
- – as much as you own your elective field of
- study, you own the delivery of your decision on
- what is 'wrong' with your client, too. Don't let
- them receive this news on their own. Show that
- you understand the life changing impact this

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diagnosis means – empathise, don't patronise. Perhaps your client is 'glass-half-full' in their outlook on life and is hoping for the best. You can never be 'glass-half-emptiness' in what you say next and how you say it. A real person stands before you, floundering, shaking, and trembling at what you have just told them. That's what a diagnosis does, and there's a person behind every one.

Don't tell them their PD will 'progress over time'. Nobody wants PD to progress. PD will cause deterioration over time, but your client will progress if they focus on what happens next; what your client can do to slow down PD. This is the start of a journey, hopefully heading away from, and slowing down the deterioration of, PD. This journey is guided by a pathway of multi-disciplinary therapy and medication, that will help your client to understand more the things they can do to help themselves. Encourage them while being realistic. Remember again, your client is hanging on your every word; waiting to hear something to soften the devastating blow you've

- just delivered. You have changed the course of
- your client's life and you can make that change
- less difficult depending on how you engage with
- each person. Listen to their fears and questions.
- Encourage them to be active – explain to them
- the significant benefits that we know result from
- the many different types of activity people get
- up to and give them real examples of what other
- clients are doing to slow down their own PD.
- Understand that your client will probably only
- take in a quarter of what you are saying to them
- on this fateful day, so follow up with them a short
- time later. Take a genuine interest in each person
- and be patient with your patients. Listen to them,
- as each one, each person, has a different story, a
- different PD infecting their brain. As much as you
- are an expert in your field, each of your clients
- will become the expert in your consultations with
- them. Their experience is your new learning.
- This is only the start of the journey for the rest of
- their life. **'You have Parkinson's Disease'** - these
- four words are the most powerful words you will
- ever say to your client.
- Let's begin.

WORRIED ABOUT FINANCES?



MABS (Money Advice and Budgeting Service) is a service available to guide people through dealing with problem debt.

MABS is free, confidential and independent. MABS helps people with all kinds of problem debt. Their advisors work with clients with a wide range of personal debts, including

- ▲ Personal loans
- ▲ Utilities arrears
- ▲ Credit Card debt
- ▲ Hire Purchase
- ▲ Rent Arrears
- ▲ Court Fines
- ▲ Catalogue debts
- ▲ Sub-prime loans
- ▲ Legal moneylenders



- If you have a problem debt, or if you are worried
- that your debt may become a problem, you can
- call their Helpline on 0761 07 2000. Alternatively
- for more information visit their website www.mabs.ie



Parkinson's Association of Ireland

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

PLEASE ATTACH THIS FORM TO MY FILE

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

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

I WILL NEED A FULL GLASS OF WATER PER PD TABLET

Name

Contact Number

Next of Kin Contact Number

Doctor/Neurologist Contact Number

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

Other Medication

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

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



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

