



# Parkinsons.ie

## Parkinson's Association of Ireland

THE QUARTERLY MAGAZINE OF THE  
PARKINSON'S ASSOCIATION OF IRELAND

AUTUMN 2011



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Pat O'Rourke  
Chairman  
Board of Directors  
Parkinson's Association of Ireland

## Chairman's Report

Dear Friends,

It has been a long summer during which all the branch committee members have been planning activities for the coming winter months. As a board we would like to show our support for their work and ask you to keep us informed so the magazine will reflect their great efforts.

We hope to meet most of you at our Social Weekend in Galway. We have arranged some key speakers to provide information on different aspects of Parkinson's, and as usual some music to enjoy the evenings. If you would like to attend or if you want further information on the event just call the office on our free phone number 1800 359 359.

There have been some special events during the summer months. Michael Carruth and his entire family organised the Austin Carruth Memorial Pitch and Putt Classic and evening entertainment in memory of their father Austin, on the 19th of August. It was a great success with Olympic gold medalists, Ronnie Delaney, along with former world boxing champion, Bernard Dunne and former Irish soccer manager Brian Kerr all taking part to show their support for Parkinson's. On behalf of the board, I would like to thank the Carruth Family for organising this outstanding event to help raise funds for our association.

Michael gave a heartfelt speech at the launch of Parkinson's Awareness Week when he told us how he felt about his father Austin who had Parkinson's disease. As you all know, taking medication on time is essential and Michael told us how their family felt when they realised their father was not taking his medication on time. Michael felt that we should learn from their lesson and be aware of the importance of doing so. A special thanks to the entire Carruth family.

I would like to acknowledge the great spirit of those who climbed Kilimanjaro with Joe Lynch, our CEO and David Donegan, Board Member, for Parkinson's. We will have a full report in the next issue of our magazine with photos to capture the atmosphere of the event. All those who have worked hard to fundraise despite the recession, deserve our thanks.

The ladies who participated in the Mini Marathon for Parkinson's did so well again this year. We appreciate all those who take part every year and we welcome those that ran or walked for us for the first time. The fun on the day helped everyone go that extra mile. Pauline Mahady is the main coordinator of this event for the association. Thank you Pauline for her great work and thank you to the participants.

Finally, I would like to announce that Mr Noel Lappin has taken over as Vice Chair of the association. Una Anderson Ryan has stepped down from the role having spent so many years guiding the association to the level it has reached to date. I would like to thank Una for her unerring commitment over many years. She will remain on the board and will also continue her work in the Midwest. I look forward to working with Noel who has great experience to bring to the role.

Sincerely,

*Pat O'Rourke*

Chairman

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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.



## MARGARET MULLARNEY ON TRAINING FOR THE DUBLIN CITY MARATHON, GOOD NUTRITION AND THE PROTEIN EFFECT

THE TRAINING for the Dublin City Marathon is really beginning to hot up, and in between training for the marathon I am also playing on a golf team for my club and our team has reached the final which is played over two days. One of the final legs will be played while I am in Scotland (more about that shortly) and the second leg was played on my home course on the 11th September.

So last week my marathon training consisted of a 3 hour trek up Ticknock in Dublin and then 3 days of one, to one and



a half hour walks during the week, followed by 3 hours on Sunday. My trainer Jason was away last week so I was left in the capable hands of my friend Kate and my son David who doubles up as my physiotherapist.

We are off to Scotland next week to do a half marathon in Glasgow - "The Great Scots Run" - to raise awareness about Parkinson's, with Bryn

William's of Wobbly Williams fame [www.wobblywilliams.com], an inspiring guy who opened the World Parkinson's Congress in Glasgow last year and who was diagnosed with Parkinson's at 37. This half marathon will be a good indicator of my projected time. This year the Dublin marathon route will only be open for 7 hours (usually it's 8 but the marathon is being televised so will start later and the roads have to be reopened by a specific time) and we have to get over that finish line within that time otherwise we will be completing it on our own!! Note that I am walking, not running, in these marathons.

GOOD NUTRITION for me is key to completing the marathon and I am being guided around that by my trainer. I am really learning and beginning to understand the huge importance of food and drink and the incredible difference it can make in the management of Parkinson's. I learned my lesson the hard way when, having completed one three hour stint I had not taken in enough water and food so my body did not respond to the medication for 7- 8 hours. For anyone with Parkinson's water is essential and we should all use the time we take our tablets to get a glass of water into us and I try to drink 7-8 glasses a day. If you are not drinking water regularly introduce it gradually and again take medical advice if you are not sure.

I try to eat as much organic food as I can. I often find I have very little appetite so I have to remember to eat. Also my sense of smell has been dampened by Parkinson's so that takes away another reminder of when you are hungry.

FINALLY, I HAVE TO BE VERY CAREFUL with my intake of protein. Protein interferes in some cases with the efficient absorption of some Parkinson's medication i.e. Sinemet/ Madopar. When I first started taking it, through trial and error, I realised that if I ate a protein meal before the medication, the medication would not work, so for me I have to leave eating protein for at least one hour after taking medication and once I eat it I have to wait 2 hours before taking another dose. This means that for me, the management of my medication in terms of protein interference is essential. I also find that eating smaller meals more often also helps the medication to work better. Not everyone will have this problem with protein but if you do, talk to your Parkinson's nurse specialist or your neurologist about it.

Keep the fingers crossed that the training continues to go well and watch this space, with more to report in the next edition.

In the meantime if anyone would like to sponsor me they can log onto [www.mycharity.ie/event/move4parkinsons/](http://www.mycharity.ie/event/move4parkinsons/) or send your donations to Joe Lynch at Parkinson's Association of Ireland, Carmichael House, North Brunswick Street, Dublin 7.

*Photo's show Margaret in action at the Austin Carruth Memorial Pitch & Putt Classic*



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Austin Carruth Memorial  
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#### Front Cover Picture

Joe Lynch, CEO, Ann Keilthy, Board Member  
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Memorial Pitch & Putt Classic

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Parkinson's Association of Ireland



## Critical Illness Cover And Parkinson's Disease

by Raymond Noone, partner in Kelly Noone & Company Solicitors



It is important when dealing with insurance companies in relation to serious illness cover that you are aware of the full extent of the cover provided by your policy. We are aware from previous experience that in some cases insurance companies have refused to pay out on foot of the policy in place even though the policy holder has been clinically diagnosed with Parkinson's disease.

In these cases the insurance company tend to rely on the definition of Parkinson's disease on the policy to decline payment. It is most important that you know your rights in this regard.

On two separate occasions in the last few years we were contacted by two different clients with Parkinson's disease. In both cases the insurance company had refused to pay out under the insurance policy. A separate insurance company was involved in each case. On the first occasion the insurance company immediately backed down when challenged regarding their interpretation of the policy. On the second occasion we had to engage in a series of correspondence between the insurance company and medical experts before the insurance company bowed to the threat of legal proceedings and paid out under the policy.

If you have Parkinson's disease and have serious or critical illness cover you should make a claim under your policy. If this claim is rejected by the insurance company and you are unsure as to whether or not they were entitled to do so you should consult with a solicitor before finally accepting the decision.

*Raymond Noone, a partner in Kelly Noone & Company Solicitors of Taney Hall, Eglinton Terrace, Dundrum, Dublin. 01-2965144.*

## The Long Term Illness Book

If you are diagnosed with Parkinson's, you can apply for a Long Term Illness Book, which allows you to get "drugs, medicines, and medical and surgical appliances directly related to the treatment of your illness, free of charge". It does not depend on your income or other circumstances and is separate from any other scheme. The HSE website, from which the quotations are taken, says that "if you already have been given a Medical Card, you do not need to apply for a Long Term Illness book", unless you become ineligible for a Medical Card.

Note: while the Medical Card covers most items, it does not for instance cover CoQ10, for which you need a Long Term Illness Book. The prescription must be written by a consultant and you apply for it – it is not automatically granted. Also, no brand must be specified. We can stand corrected on this but this is the information we received.

"To obtain a Long Term Illness Book, you must be ordinarily resident in Ireland and hold a PPSN. There is no income requirement or means test."

"A Long-Term Illness book will be issued to you if you are approved for the scheme. This book contains the type and quantity of the drugs or medicines you need for your prescribed illness. Your doctor will sign it and you can then bring this to the pharmacy when you need any of the items. If your doctor or occupational therapist prescribes a medical or surgical appliance, it will be supplied to you from your Local Health Office. There is no separate application form for medical/surgical appliances - your doctor lists the type of appliance in your book and signs it."

Other prescription medications may be obtained under the Drug Payment Scheme, where you are liable for the first €120 per month per family. If your prescription medication is not listed on the allowable drugs under this scheme, e.g. prescribed food supplements, you will have to pay for them, but you can get a partial refund on your income tax return, only if prescribed, at the end of the tax year. This is the situation going to print.

In summary, once on the Long Term Illness Scheme, you should not under any circumstances have to pay for any medication prescribed for Parkinson's. You can however continue to use your Medical Card, if you have one, but if you do not have one, you should apply for the Long Term Illness Book.

Forms are available from your local Health Centre, or in some instances your pharmacist. The HSE Info Line is 1850 241850, and the web page address is: [www.hse.ie/eng/services/Find\\_a\\_Service/entitlements/Long\\_Term\\_Illness/](http://www.hse.ie/eng/services/Find_a_Service/entitlements/Long_Term_Illness/)





# David Walsh's Trans-American Journey



The day was finally here, after ten months of fundraising and preparation and a year of training with a specially commissioned cycle, it was not the bike ride that was troubling me, it was the flight from Dublin to Los Angeles, arriving in the early hours of the morning on 4th of April, alone, unmedicated and solely responsible for my own movements, and as we all know movement is the problem. But still I collected my bags and made my way to Gerry's Motel in a rundown part of LA.

the Arizona desert, alone with my own thoughts, rarely seeing anyone except for American Indians on the reservations as I passed through. Interestingly access to water on the reservations is strictly prohibited unless a tribe member allows it!



From there it was a steep climb of approximately 7,000 feet over forty miles to Flagstaff where I soon learned the difference between low and high deserts. It was very cold at the top. From there on I had to travel on the famous Route 66, which stretched on through Colorado and I finally left Route 66 heading for New Mexico into Kansas where I jumped onto the I 40 motorway for about 1,000 miles through Missouri, Illinois, Indiana and Ohio, through some very nasty weather caused by tornadoes coming up from Memphis. All along the way I kept updating my Facebook page and surprisingly my use of medication decreased from where it would have been had I not been cycling. Leaving Ohio and heading onto Northern Pennsylvania, I started to recognise the terrain a little more as I approached the east coast. Now I was travelling through some big cities, skirting Pittsburgh heading in the general direction of northern New Jersey. I passed through several small towns where I was welcomed and shown some great hospitality. Finally resting in Haslet from where, unfortunately, I picked up a bacterial infection. For a day and a half I was riding the bike with a very dodgy tummy and feeling none too well. I then took the Henry Hudson trail to the shores of New Jersey, north of Manhattan, from where I took a ferry for the last 20 miles.



After a good night's rest, purely from exhaustion, I then headed to Hollywood boulevard to spend some time with Freddie Roche, a boxing coach who has trained four world champions. Freddie has been diagnosed with Parkinson's for more than eighteen years. He pushes himself to the limit for 16 hours a day training some of the best professionals in the world today, and he was inspirational!

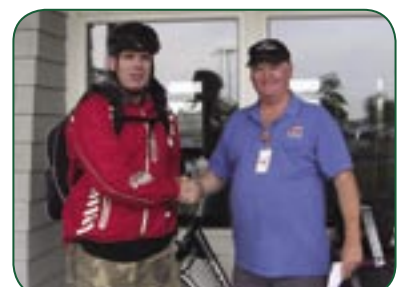
This was a good start. It was very uplifting to be in the company of such a positive hard working person. Two days later I made my way to Ocean Side, San Diego and not long after that I began the cycle. Lake Henshaw was my first stop - and it was almost my last stop - as I met the lovely Lyndsey



Hearst - a wonderful waitress with a bubbly personality. Reluctantly I left the next day and did two days travelling in one, reaching Parker, Arizona, a total of 130 miles from California, where a chance meeting with a fantastic couple who owned a radio station, turned into a great opportunity to spread the Parkinson's message. They insisted that they interview me to raise awareness of Parkinson's. From there it was four days cycling through

After six weeks I was dropped off in my final destination in midtown Manhattan. I had made it! My six week journey was all summed up in one evening in a typical Irish way, in a bar where everyone was drunk around me, and there I was having given up the drink! I was treated with respect and kindness by everyone I met along the way and they were all interested in hearing about Parkinson's and how it affects me.

This was a very personal odyssey for me and it reinforced my self belief. I now know that Parkinson's doesn't define me but makes me more determined to challenge my perceptions and the perceptions of others about people with Parkinson's.





# Pedal for Parkinson's mega cycle ends at Ringaskiddy



Limerick Chronicle columnist, Richard Lynch (Right) and members of Parkinson's Midwest Branch meet Pedal for Parkinson's volunteers and fundraisers (l to r) Eddie Butler (PMB), Val Valance, Neil Manning, Una Anderson (PMB), Nigel Mc Vean, Sid Reillis (PMB), David Greaves and Billy Rice (PMB)

As reported in "EPDA Plus": "A six-man team of cyclists – most of whom live with Parkinson's – has completed a 2,000-mile cycle across the UK and Ireland to raise funds for Parkinson's UK. The team set off on their ride from Lizard Point in Cornwall on 15 June and cycled to Dunnet Head in Scotland – the most northern point on the mainland."

"David Greaves, 66, from North Yorkshire, who was diagnosed with Parkinson's more than seven years ago, said:

'The cycle ride has been a great experience. When you see friends with Parkinson's on a daily basis struggling to do things such as getting dressed, you know what they are going through. They are real people with real issues. The cycling challenge wasn't just about riding bikes. It was about helping to fight Parkinson's and together ultimately finding a cure.'

Ann Keilthy continues the story: Midwest Branch Chairperson Billy Rice got word of their arrival in Ireland when they were en route to Athlone and quickly moved to notify and coordinate with the National Office, and found himself on Athlone Community Radio an hour later! Thanks to Billy's swift action, they got a proper Irish welcome in Limerick, South Kerry and Cork, where each branch met, fed and entertained them. They left Ringaskiddy in Cork with hampers presented to them by the Cork Parkinson's branch, and perhaps more importantly, they also took with them some well-drawn posters from Lily Power and Emer O'Shea!

The cyclists were featured in the Limerick Chronicle by columnist Richard Lynch who also took the time to meet the cyclists, and they were interviewed extensively on local radio. And to top it off, David Greaves is returning to South Kerry in October to give a talk.

Our thanks to all concerned. Cooperation works...





## What is 'Wearing Off?'



an article by Brian Magennis

An article in the summer edition of EPDA Plus caught our eye. Written by Brian Magennis, a Movement Disorder Nurse Specialist in the Dublin Neurological Institute, it looks at the phenomenon of wearing off.

astute person who is well informed and motivated about their condition would ring the clinic and suggest they are experiencing wearing off. Otherwise you might have a people with Parkinson's, spouse or carer calling to say that the medication isn't working as well as it did before."

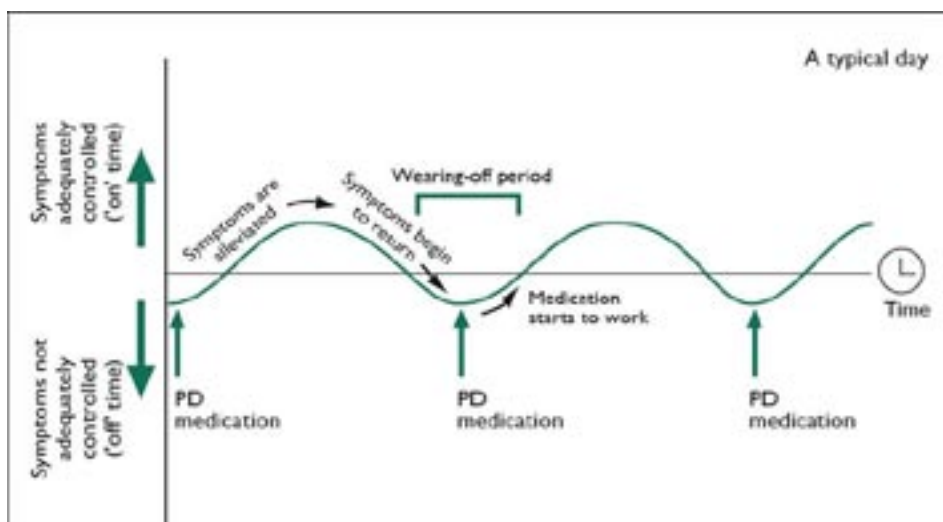
Brian says "I always advise people with Parkinson's that being predictable and reliable in taking their medication will help to obtain predictable and reliable control of their Parkinson's symptoms."

This troublesome phenomenon has had books written about it, but the principle is simple – the medication wears off before the next dose is due; over time it wears off faster and for longer and more deeply.

"Diaries and questionnaires can help a people with Parkinson's identify when wearing off occurs." Brian stresses the importance of the way you take your medication, and he stresses the need to make sure the medication is being absorbed and rule out constipation.

PDNS and neurologists "will always be a helpful source of information", Brian says, and adds that by talking to other people with Parkinson's, "people with Parkinson's can learn a lot about their condition and can identify and then solve problems".

He recommends that if you think you might be experiencing wearing off, that people with Parkinson's "should talk to their PDNS or doctor because there is help out there once wearing off is identified."



'A Typical Day; with Permission from the EPDA

Brian says that "most of the time it is the wearing off that people with Parkinson's would describe as the worst thing, because they can get both motor and non-motor symptoms." He also says that "some people with Parkinson's might want to avoid levodopa therapy altogether because they have been frightened by what they have heard about dyskinesia and wearing off..." And yet, he adds, "most people with Parkinson's will experience very good control," and "notice a difference in their stiffness, slowness and tremor", he says, once they have gotten over the initial side effects.

He agrees though that it is the fluctuations that develop that are the least liked and "the most distressing."

### DESCRIBING WEARING OFF -

Brian describes wearing off as follows: "It is the emergence of Parkinson's symptoms, both motor and non-motor, before the next levodopa dose is due." Your wearing off symptoms can be related to your current situation – "Someone with a tremor-predominant condition would probably experience tremor first with wearing off, whereas someone prone to anxiety attacks would probably [start to] feel anxious..."

"I would estimate that about 50% to 60% of people with Parkinson's are aware of wearing off. If you have an

To see and hear Brian talking about wearing off, please visit our web page; [www.parkinsons.ie](http://www.parkinsons.ie) and scroll through the available videos on the home page.

Local contact  
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**Ireland Support Group**  
Thursday 13<sup>th</sup> October, 2:00pm – 4:00pm  
Dun Laoghaire, Royal Marine Hotel  
(please contact George Hunter above)

We would like to invite you to the next Ireland support group meeting for people with MSA. The group aim to link people with MSA, and their carers and offers a forum for discussion, support and information in an informal and friendly setting.

If you are interested in attending the meeting then please reply by e-mail to [Lyn.Stone@parkinsons.ie](mailto:Lyn.Stone@parkinsons.ie) or post the reply slip below to Lyn Stone, Multiple System Atrophy Trust, Southbank House, Black Prince Road, London, SE1 7UL. Or you can call us on 020 7942 4056. Or you can contact George at the details above.



# MICHAEL CARRUTH

## TALKS FRANKLY ABOUT HIS FATHER'S PARKINSON'S



Ann Keilthy set out to interview what turned out to be a fast moving target, what with the duties of the day at the Spawell Complex. In the end she succeeded, and Michael put two chairs together in the middle of the comings and goings and we had a revealing insight into the former Olympic Champion's mind.

**A.** Michael, how did this whole event come about?

**M.** I rang Joe, CEO on a day when I wasn't feeling so good. My Dad, Austin, had Parkinson's and died in February of this year. We knew we wanted to do something as a family but didn't know what. However, pitch and putt was one of his true loves and this day is the result.

**A.** Tell us about your Dad, Michael.

**M.** Dad started his boxing at age 12 in St. Francis in Usher's Quay, met his future wife at age 14 and after they married they moved to Greenhills where he founded the Greenhills Boxing Club. From there in 1979-1980 he became boxing coach at Drimnagh Boxing Club. Over the years he went from bell keeper to one of the most successful boxing coaches in Ireland.

He was a family man, and to put this day together we worked as a family. My Dad was proud of all of us – family came first, and he saw us all married and staying married.

We are now a part of the Parkinson's family. We have given ourselves a target to increase awareness. People are walking in here today from all walks of life, and about 500 will have played. If you take the figure that one person in 500 will develop Parkinson's, then one of the people here today will go on to have Parkinson's.

I am in this for the long term going forward, and will organise one or two events a year, will keep approaching people, encouraging the ladies to do the Mini Marathon for Parkinson's. I am not a bullshitter; I said I would organise this day and I did. I stuck with it.

**A.** What about today – a huge amount of work involved?

**M.** We decided to do a Pitch and Putt Classic, picked a date and here we are. My family were a tremendous help. The Carruths as a family are well known and respected in this area and we drew on that by locating it here and keeping the interest in the area. I'm only sorry I didn't do more while my Dad was alive. Sometimes you need a push to make you see, but it was great that my brothers and sisters were all able to be involved. I am a little relieved it is going well, although to be honest, it wasn't hard to organise, and I probably could have sold this three times over. We Carruths do better each time.

Michael spoke with obvious pride about his team, made up of boxer Bernard Dunne, his father in law Bernard Johns and Olympic Gold Medallist Ronnie Delaney. He repeated several times that he was in this for the long term, and wanted the next event to be a White Collar Boxing Show.

**A.** I indulged in my curiosity and asked him if he still boxed:

**M.** I have been back coaching for the past five or six years. I spar with the kids – with any of the kids who think they are big enough to get into the ring with me, or tough enough to have a go. When I won Olympic Gold I was 24; I'm 44 now.

**A.** My thought as he walked away, busy with the responsibilities of the day was: Always a Champion.



*Former Irish soccer manager Brian Kerr and Olympic gold medallist Ronnie Delaney in conversation*



Our association is constantly surprised by the offers of good will and support from the general public and when we received a call from Olympic gold medallist Michael Carruth earlier this year, it was to offer the support of his family for our organisation. Michael is renowned for tireless work for many different charities that are often 'below the radar'.

Michael offered to host the first annual Pitch & Putt Classic in memory of his father Austin, in aid of our charity. Some very rapid planning took place and to be very honest, our input was small as the whole Carruth family swung into action and organised the venue, prizes, teams, evening event, music and yet more prizes for a fantastic raffle. All in all a mammoth effort by some very special people in memory of a very special father.

The family pitched up (no pun intended) at around 8am on a dull, but thankfully dry morning on the 19th of August. Teams had booked in from all over the country and, understandably, there was a very strong representation from the boxing community. The first team was out at 9am sharp and from then on the day flowed wonderfully. The rain tried its best to come down but for the most part it held off.



Among those who helped Michael to make the day a great success were Bernard Dunne and Ronnie Delaney

Brian Kerr, former Ireland and current Faro Islands manager came along to show his support. Michael Carruth's team consisted of Olympic gold medallist, Ronnie Delaney and former WBA Regular Super Bantamweight World Champion and European Super Bantamweight champion, Bernard Dunne, along with Michael's father in law Bernard Johns. However, all that fire power did not get anywhere as Michael's youngest brother, Robert and his team scooped the top spot on the day.

There was a hole in one during the course of the day and there were many holes in double digits, our CEO, Joe Lynch being one of those high achievers! The Templeogue course was excellent and everyone treated the day as a bit of fun. The evening event was hosted by the Nugent family who own Darcy McGee's pub in the Spawell Complex and it would be remiss not to thank them and their staff for all their help.

The staff and management of the Spawell Pitch & Putt course also deserve a big thank you for all their unerring assistance from the early hours of the 19th. Over seventy teams took part. Sponsorship from Unilever, Dunnes Stores, Osprey Hotel, George Moran AVA, Mooney's, Priory Clinic and Adidas and many more Irish companies, is hugely appreciated. Finally, a huge thanks to all of the Carruth family for their dedication, immense good humour and professionalism in running the whole event.



Thank you, Rebecca, Austin, Siobhan, Orla, Martin, Michael, William, Mary, Fergal and Robert.



# Apomorphine helps to manage the symptoms of Parkinson's effectively

In Parkinson's disease (PD), there is a lack of dopamine in the brain. When a person is diagnosed with PD, it is thought that they have already lost between 60%-80% of their dopamine. There is currently no cure for Parkinson's, but we can try to manage the symptoms effectively with different medications. There are a couple of ways to do this – you can replace the dopamine (with levodopa), or you can mimic it (with dopamine agonists). Because of the nature of Parkinson's, everyone will be on a different regime of different medications at different times, so please keep this in mind when reading this.

Apomorphine is a Dopamine Agonist (DA) which mimics natural dopamine by directly stimulating dopamine receptors in the brain, and therefore can help alleviate the symptoms of PD. Some people take dopamine agonists on their own and others take them with levodopa therapy, or other medications.

Apomorphine is an injectable dopamine agonist, and is used primarily in the treatment of motor fluctuations (wearing off, dyskinesias, or freezing) and has been available in Europe for the last decade. It has been very successful and can be used as a fast acting rescue therapy, working within 5-15 minutes, or as a continuous infusion, usually administered during waking hours.

Apomorphine is usually prescribed by a specialist who will decide, in consultation with their hospital team, which is the most appropriate system to use. No one delivery system is right for everyone. The choice will depend on factors such as frequency of dose, manual dexterity, lifestyle and availability of help.

If your doctor feels that prescribing Apomorphine would be of benefit to you, this will require hospitalisation for a few days while you are given a trial of the drug. If you are started on the rescue pen, you will need to learn how to work the pen and how you give yourself the injections in a safe and appropriate manner. Similarly with the infusion, you will need to learn how to work the

pump and insert the needle into your stomach. Your partner or carer may also need education. The hospital will make arrangements for education by the Apomorphine nurse in your area.

A common misconception is that Apomorphine is a form of morphine. This is not the case. Apomorphine does not contain any morphine and is not a narcotic. However, it is worth noting that dopamine agonists have been linked with obsessive and impulsive behaviours, such as gambling, excessive shopping or generosity, hyper-sexuality and binge eating, particularly sweet things at night time. This not to say that all who use dopamine agonists will develop these behaviours, but please be aware of these possible side effects. If you are concerned that your medication is causing you to do any of these activities, please contact your GP, Consultant or Parkinson's Nurse.



The Apomorphine drug is injected, or infused, into areas of fatty tissue, like the tummy or outer thighs. It is important to change the site every day, and ensure that you massage the area after use, to prevent sore or hard nodules forming under the skin.

We asked Paddy Conaty, Chair of the Cavan Monaghan branch about his experience of using the apomorphine pump. He has been using it now for two years and finds it brilliant. He says he has been able to halve his medication. One tip - apomorphine stains clothes but we have been told lemon juice is an effective remedy for this.

*This article is for information only, and not a promotion of the product or endorsement by the PAI.*

## Deep brain stimulation (DBS)

Deep brain stimulation (DBS) is a surgical procedure used to treat a variety of disabling neurological symptoms - most commonly the debilitating symptoms of Parkinson's disease (PD), such as tremor, rigidity, stiffness, slowed movement, and walking problems. The procedure is also used to treat essential tremor, a common neurological movement disorder. At present, the procedure is used only for patients whose symptoms cannot be adequately controlled with medications.

DBS uses a surgically implanted, battery-operated medical device called a neurostimulator-similar to a heart pacemaker and approximately the size of a stopwatch-to deliver electrical stimulation to targeted areas in the brain that control movement, blocking the abnormal nerve signals that cause tremor and PD symptoms.

[www.ninds.nih.gov/disorders/deep\\_brain\\_stimulation/deep\\_brain\\_stimulation.htm](http://www.ninds.nih.gov/disorders/deep_brain_stimulation/deep_brain_stimulation.htm)

On October 1st a conference takes place in the Conference Centre, Croke Park, Dublin 3 on the subject of Deep Brain Stimulation covering several topics including programming. The cost of attendance is €20.

The programming of the neurostimulator or neuromodulator can pose problems for some people, with speech volume and clarity on occasion sacrificed for greater walking ability. This conference seeks to demystify the process and confirmed speakers include: Prof Erwin Montgomery Jr., one of the world authorities on programming and Karen O'Sullivan who is the senior programmer in Frenchay Hospital in Bristol. Some of the talks may be more technical and more suited to electronic engineers, who are coming also, but we are running some back to back and there will be something for everyone.

Within the Parkinson's arena, it will suit those with DBS or those who are thinking about it, or the more technically minded. A great lineup also including Dr. Kinley Roberts of the DNI. Book via [www.dbsdublin.com](http://www.dbsdublin.com) or phone Niav from Conference Organisers at 01 - 2859033 about conference arrangements or Ann Keilthy 087 - 2853117.



## Flora Women's Mini Marathon 2011

We extend a big thank you to all our Flora Women's Mini Marathon participants who took part in the event this year. Once again it was a huge success with almost one hundred women from all parts of Ireland taking part. Thirty ladies met up after the marathon in the Russell Court Hotel, for well deserved refreshments and chat. Some commented that other friends and relations would have liked to take part but due to the huge numbers who registered with the marathon organisers, they were too late to enter. The registration process closed almost a month earlier than was advertised and left a lot of people disappointed. For next year we would advise early registration to avoid disappointment.



Each year the marathon helps to fund our helpline services, which has been enhanced with the addition of our Parkinson's Nurse, Alison Cashell. Last year we received over one thousand calls from people with Parkinson's, their carers, friends and family as well as health professionals. This is undoubtedly a vital part of our services to people with Parkinson's and without your help we could not reach these people.

To anyone who has not yet returned their sponsorship cards and funds please forward to us as soon as you can. A very sincere thanks once again to all who took part and we hope to see you next year.



## Motor Cycle Fun Run



In June Ray White and a group of his friends took to the highways of Ireland to raise funds for the association. Ray's mother, Patricia, in the centre of our picture with Ray, has Parkinson's and he wanted to raise funds in aid of the association's services. Ray and seven of his friends saddled up on one of the few sunny summer days before heading off to Galway. Unfortunately the good weather broke just outside Dublin and Ray tells us "It was like a scene from Lord of the Rings, it poured with rain for the whole trip and we returned early the next day due to the poor weather." He hopes to make the sponsored motorcycle ride an annual event in aid of the association, though hopefully next year the weather will be kinder.

## Midwest Fundraising Schedule

The Midwest Branch of the association is moving ahead with some very interesting projects to raise awareness and funds for the various projects in their area. The Branch set up a Parkinson's Nurse Specialist Service some years ago. The success of the service, run by Mags Richardson, meant that more of her time was going to paperwork leaving a restricted amount of time for patient's visits. The Branch decided to appoint and pay for a secretary, Pauline Conway, to support Mags. Pauline makes appointments, records all the patient data on a special database provided by the Branch and operates a help line. She also arranges our monthly patient meetings on the 1st Tuesday of every month.

Date	Event
16th Sept	Bucket collection in O'Connell Street, Limerick
17th Sept	Parkway Shopping Centre Table Collection
9th Oct	Crescent Shopping Centre Table Collection
16th Oct	Limerick Leader Limerick Women's Mini Marathon
26th Nov	The Aspen Gala Evening, Red Carpet Event, Pery's Hotel, Limerick City
Christmas 2011	Launch of the 2012 Sporting Calendar celebrating the City of Sport - Limerick. 12 different sports have allowed our photographer to take a suitable photo highlighting their sport. We hope that other branches will take some of the calendars to help us.



# ASK OUR NURSE



## Alison Cashell, RGN, Parkinsons Disease Nurse.

To Make an appointment to speak to Alison call 1800 359359 or email her [nurse@parkinsons.ie](mailto:nurse@parkinsons.ie) or fill in the online form on our web site [www.parkinsons.ie/advice\\_asktheexperts](http://www.parkinsons.ie/advice_asktheexperts)

**QUESTION** I heard that CoQ10 helps slow down Parkinson's. Is there any information on that.

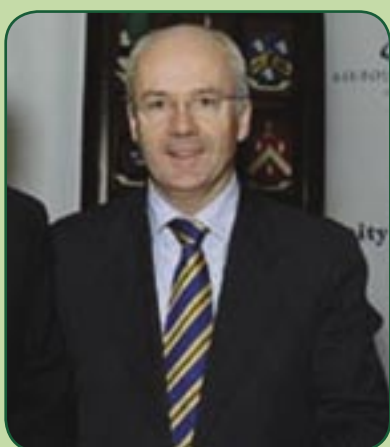
**ANSWER** Thank you for your email. The research so far shows that CoQ10 may have a neuro protective quality, and so may help slow down disease progression. CoQ10 is licensed for use for treatment in PD, and therefore you can have it prescribed into your long term illness medication booklet, and receive it for free.

**QUESTION** I'm on Stalevo 200mg x 4 times a day. I have found that I get more on time if I don't eat meat fish etc food high in protein. Is this good or bad because I love meat and fish and find it really hard to stay off them? Have you any suggestions?

**ANSWER** Thanks for your email. It is true that protein rich foods can interfere with the Levodopa in the medication. This is because the Levodopa is a synthetic protein, and your body will absorb the natural protein (from dairy products or meat, etc.) before it absorbs the synthetic protein. What we recommend is that you avoid these protein rich foods around tablet time (take the tablet 40mins before food or 1.5hours after). We would never recommend that you cut protein out completely, but it may be helpful to eat smaller portions. I have an information booklet about diet which I can post out to you if you want. Let me have your postal details and I'll organise it for you.

**QUESTION** I've had Parkinson's disease for the last few years. I am taking Sinemet 62.5mg three times a day, and one Half Sinemet CR every day. I take one Sinemet and the Half CR at 9.30 after my breakfast, the next Sinemet at lunch time, and then the last Sinemet at dinner time. I don't feel that they are helping very much. I feel slower now than I did this time last year. I am also having difficulty at night time – I am finding it hard to get comfortable and turn over. Can you give me any advice?

**ANSWER** Thanks for your question. I have a couple of things that I think you could try. Firstly, we should look at your tablet timing. I would suggest that you try taking your Sinemet around 40 mins before your meals, rather than with or afterwards. Also, it may be beneficial taking the Sinemet CR at bedtime, rather than in the morning time, as this may allow you to sleep better. The CR tablets are designed to give a longer, sustained release that many people find improves their night-times. It will also be beneficial if you ensure that you take each Sinemet with a full mug full of water, or juice (not milk). This will help the tablets get to where they need to go, and get to work. I would try these couple of changes, and if you feel no improvement, speak to your doctor. You may benefit from an addition of more Sinemet or another medication.



**ASK THE EXPERT** – question one is answered by Consultant Neurologist Prof. Tim Counihan of UCHG, who is one of the guest speakers at our social weekend in October.

**QUESTION** What do you think the future holds for stem cells of any sort? Do you think they will be THE treatment that finally eradicates Parkinson's? We hear and read so much that is hopeful, so what would be a realistic assessment?

**ANSWER** Stem cell therapy for PD has been studied for at least twenty years. Although none of the research to date has lead to a "cure", there have been several very important advances that confirm that cell replacement therapy is possible: importantly it has been found that stem cells implanted in the brain can survive and produce dopamine. In addition, cells can act as vectors (steering treatments such as gene therapies) to the exact site in the brain where they are needed). The major problem with cell-based therapies has been the difficulty preventing the cells from going out of control.

In my opinion, we have found an excellent way to deliver the treatments for PD, but we have yet to find a plausible protective agent or drug to stop the disease from progressing. I would be confident that in the next few years we will have identified a meaningful treatment to slow progression of PD. While it would be premature to call this a cure, nonetheless it would be a fantastic advance on our current treatment options



# EVENTS

## Parkinson's Social Weekend 14th-16th October, 2011

**It's not too late to book!**

This year's Social Weekend is in the wonderful Ardilaun Hotel, Salthill, Galway. The Speaker line up for Saturday morning has now been confirmed:

**Dr. Tim Counihan**, Consultant Neurologist, Galway University Hospital

**Fiona Rogers**, Speech & Language Therapist, Galway University Hospital

**Alison Cashell**, Parkinson's Disease Nurse, Parkinson's Association of Ireland

**Olanrewaju Olawale**, Senior Physiotherapist, Dublin North Central, HSE

**Margaret Mullarney**, Inspirational Speaker, Person with Parkinson's

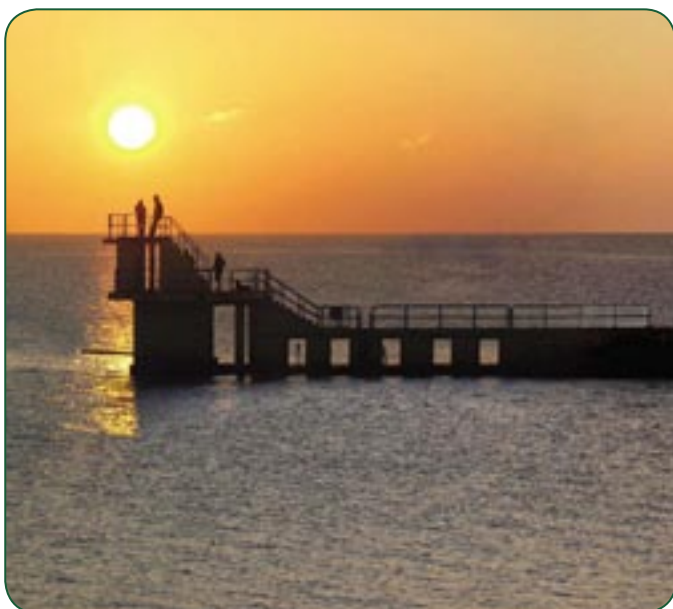


The weekend takes place from 14th-16th October, 2011. The Hotel offers luxury 4 Star accommodation in a tranquil setting with beautifully landscaped gardens, a superb leisure centre with 18 metre swimming pool and the latest gym technology. Its location in Salthill, close to Galway city centre and Galway Bay makes the Ardilaun Hotel an ideal place to relax and unwind for people with Parkinson's, partners, carers or family members. There are different booking options available to suit everyone and dinner on Friday and Saturday evening will be followed by music and dancing and a chance to catch up with friends from last year's weekend.

The cost of the various social weekend packages are:

<b>Option 1 (Full Weekend):</b> Twin/Double Room €420	Single €250
<b>Option 2 (Saturday Only):</b> Twin Double €240	Single €160
<b>Option 3 (Conference):</b> Conference & Lunch €20	Conference & Dinner €60

We would encourage everyone to plan ahead for this weekend. It promises to be a special occasion to learn about Parkinson's and an opportunity to socialise, relax and make new friends. Please call our Freephone 1800 359 359 to reserve your place.



## PAI Christmas Concert

Each year as part of our social events we organise a Christmas concert to provide a social outlet for people with Parkinson's. Last year's concert was a huge success with over two hundred people attending to hear a fantastic performance from the Army No.1 Band. This year we have



lined up George Hunter and the Galaxy Swing Band with special guest, the legendary Sil Fox. We are delighted to be holding the concert in the great hall of the wonderful Clontarf Castle Hotel, Dublin. Tickets will go on sale at €15 each from the end of September and can be purchased from our National Office 1800 359359.

Clontarf Castle are offering a special deluxe room rate of €109 bed and breakfast for a twin or double room and they are also offering a pre concert two course meal from 5.30pm in their restaurant from €19.95pp. (Contact the hotel on 01 8332321 for more information). The concert is sure to be a fantastic event with some excellent swing music that will have everyone's feet tapping and there are sure to be laughs all the way from the master of high spirits, Sil Fox.





## Galway Branch

We hope all our members enjoyed the Summer break. We held our first Autumn meeting on Wednesday 21st September 2011 at the Clayton Hotel, Balybrit, Galway at 8pm. All new and old members are always welcome.

We hope to start physiotherapy and speech and Language classes at the end of September. Anyone interested in these classes, please contact me.

We have a number of speakers who will come and talk at our meetings in the months to come.  
Contact Marie 087-7783825

## Donegal Branch

We had our first meeting after the Summer recess on 25th September in Letterkenny. It is the start of Reflexology week and some reflexologist will be in attendance to give members some treatments.

They are doing this free of charge and the branch is very grateful to them. We also hope to have one of our members give a talk on surgery he has had recently and also get feedback from his wife.  
Contact Ann 074-9128063

## East Midlands Branch

East Midlands Parkinson's branch will resume Yoga classes for the first four weeks of October in both Abbeyleix on Saturday's and Sunday's in Naas.

All members are urged to attend.

We will hold a general meeting in early October and we hope to have two special guests speaking about their Kilimanjaro trip.

So that's one not to be missed.

Contact Marian 087-0638364

## Cavan Branch

The Cavan/Monaghan branch had a most enjoyable Summer outing this year. We travelled to the American Folk Park, Omagh, Co. Tyrone. The highlight of our outing was a tour of Donegal Bay by cruiser.

We wish every success to Hugh and Orlagh Cormack and Brian Lee taking part in the Kilimanjaro challenge.

We will resume our meetings again in September, members will be notified.  
Contact Paddy 049-4332821

## Louth/Meath Branch

A meeting was held in the Fairway's Hotel, Dundalk on Wednesday 21st September at 7.30pm. The speakers were Kathy Maher, Pharmacist, who regularly appears on Four Live on RTE 1 and Jacqueline Milliman a representative from the Carer's Association. Looking forward to seeing you at our next meeting in October.  
Contact Maurice 087-7512608

## Midwest Branch

An information meeting for patients and carers took place on 6th September in Greenhill's Hotel, Ennis Road from 2.30pm-3.30pm. The topic of the meeting was the role of Occupational Therapy services in Primary Care. Tea/coffee/biscuits were served after the meeting.

Dates for our Bridge Evening and our next Golf Classic haven't been confirmed yet. If anyone would like to help us in anyway with the various activities, just call one of the committee members. A special thanks to Tina O'Gorman who has come forward to help our fundraising and a very special thanks to Richard Lynch who has put the Midwest Branch out into the public eye. His Mum Florence has Parkinson's and so he has a special insight into the right approach to raise awareness.

Contact Una 087-2511156

## Tipperary Branch



We would like to thank the Upperchurch/Drombane Youth Club for organising a very successful fund raising mid summer's night walk on behalf of the branch. €1,837.56 was raised.

Our next meeting is scheduled for Tuesday 27th September at the Parochial Centre, Nenagh. Our thanks to Alison Cashell for travelling from Dublin to meet our members.

Hope all our members had a good summer.  
Contact Mary 086-3916726

## Cork Branch

Activities have now restarted after the Summer break. Our Annual tour took place on July 3rd – this year visiting Bunratty Folk Park and the picturesque village of Adare. Very favourable feedback was received from participants. This year we provided a bus with wheelchair access which proved beneficial.

Catryn Power and CPSG colleagues met the Pedal for Parkinson's Team (on their cycle from land's end to John O'Groats, across to Ballycastle and down to the Dingle peninsula and Mizen Head) when they visited Ringaskiddy where they left on the ferry for Swansea on July 10. We provided them with some food and a wave off.



Family Fun Day Sun September 4th organised by the Morrissey family jointly in Aid of Cork Parkinson's Support Group and Enable Ireland.

The Harte family organised a successful fundraiser in Carrignavar – particularly commendable in view of the death of their father having occurred about that time.  
Cork Parkinson Support Group Flag day organised for:  
Fri Sept 23 – Midleton, Glanmire, Fermoy, Youghal, Kinsale, Bandon  
Thu Oct 6 – Cork City, Bantry

Some dates subject to confirmation. Anyone who can help may contact John Curtin 0861731773 or Pat Walsh 0872460853

Regular two monthly meeting took place at Sacred Heart Hall on September 11 at 3.00pm and was addressed by Michael Gannon (SHB Physiotherapist)  
Contact John 086-1731773



## Dublin Branch

As usual there was little or no branch activity over the summer. The branch committee met on 13th September to discuss arrangements for the autumn and Christmas. There will be a members meeting on Sunday 2nd October at the Tara Towers Hotel, Booterstown. Phyllis Prior will give a talk on Exercise and Keeping Fit. Members will be notified in advance.

Already plans are under way for our annual Christmas lunch which will take place on Sunday 4th December at the Marine Hotel Sutton. Readers may recall that last year the inclement weather caused the cancellation of this event so here's hoping mother nature will be kinder this year.

Exercise classes for members at Donnybrook and Clontarf have resumed after the Summer recess.

Congratulations are due to Declan Moriarty who in recent times has undergone a DBS operation. We wish Declan continued improvement and a bright future.  
Contact Ann 01-2851833

## PALS Branch

After one of the worst summers on record I am sure we are all delighted to have the opportunity to meet indoors!

Our next meeting will be on October 23rd (Sunday) at 3pm in the Tara Towers Hotel. We have invited a speaker and are awaiting confirmation. We look forward to meeting old friends and new, and a chat over a cup of tea.  
Ann Keilthy, Chairperson Contact 087 2853117

## South Kerry Branch

We are delighted that Kathleen Cronin's DBS operation was a success.

300 Honda motor cycles met in Killarney for a rally around the ring of Kerry and the proceeds were given to the South Kerry branch.



Kinsale Harbour

28 of our members had a beautiful day trip to Kinsale and had lunch in the Blue Haven.

40 members sat down to a dinner at Darby O'Gill's, Killarney, at our Summer recess.



SOCIAL DINNER: South Kerry Parkinson's Society who had a social dinner in Darby O'Gills, Killarney, front l-r: Mary Moynihan, Jerry O'Sullivan, Grace and Jack McCrae, Jean Ritchie, Kathleen O'Keefe. Back l-r: Denis Moynihan, Tom and Geraldine Templeman, Noreen O'Sullivan, William Leavey, Karen O'Shea, Kathleen Lynch, Eileen Moynihan, Michael Moynihan, Laurie and Muriel O'Mahony, Ed Ritchie and Michael O'Keefe

We entertained 4 cyclists from pedal for Parkinson's research, U.K. Each of them had Parkinson's. They cycled from Cornwall to Killarney, Mizen head and back to London. A donation from South Kerry branch was presented to them by Grace McCrae. The leader of the team will visit us for our October meeting to talk about his trip and research.

The tree planted in the Methodist Church grounds for Parkinson's is growing well.

Our thanks to Senator Marie Maloney for all her help and kindness to our branch. A thank you also to Larry O'Mahoney for his singing and prayers at our meetings.  
Contact Grace 064-7758837



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Dublin, Ireland  
October 1, 2011

Croke Park  
Conference Centre

