

Parkinson's IRELAND

THE QUARTERLY MAGAZINE OF THE
PARKINSON'S ASSOCIATION OF IRELAND

AUTUMN 2010

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Una Anderson Ryan
Chairperson
Board of Directors
Parkinson's Association of Ireland

“Services provided by the HSE for our patients are becoming more limited because of poor funding, which means that our branches must work harder to offer support and help”

through the chair

Dear Friends.

During the summer break for branches, the Management Committee has been busy working on some exciting plans for the future.

With the Strategic Plan completed it is now time to start its implementation. We are setting up some sub-committees to help with this important work. We would be delighted if any members from the branches who have some time would volunteer to share the work on some of these committees.

With the grateful assistance of the Tipperary Branch a delegation met with the Minister of State with responsibility for Disability, Mr. John Moloney TD, and the Minister of State with responsibility for the Elderly, Máire Hochtóir TD. Mr Pat O'Rourke represented the PAI Board and Joe Lynch, CEO and I represented the Management Committee. I would like to thank Mr. Michael Burke, Tipperary Branch Chairperson for arranging the meeting where we gave a full report on what the Association has done in 2009 and what we intend to do through 2010/11. Minister Moloney offered to do what he could to help with our funding application.

Our CEO, Joe Lynch, prepared our application for core funding from the HSE. While we are aware that money is quite scarce in Government circles, we still feel that there is scope for some funding in 2010. Services provided by the HSE for our patients are becoming more limited because of poor funding, which means that our branches must work harder to offer support and help. One of the central themes of our Strategic Plan is for PAI to reach more people with Parkinson's. This in turn will create a stronger and more effective organisation. While Joe will formulate this plan it will be up to each of us to encourage other people with Parkinson's to join our organisation, so that our demand for proper services in all areas is heard.

Joe and I attended a meeting with Maebh Reynolds of the HSE's Disability Section, to give further details of our work and why we need funding. Maebh was very generous with her time and it was great to be able to give an explanation in detail of what we need and how we plan to use the funds, should we secure them.

On September 3rd the Board of Directors invited the leaders of all our Branches to attend a conference to help with various aspects of running a good organisation. A full report on the conference will be covered in the next edition of our magazine. I hope those who attended the meeting found it helpful and I would like to assure all of your leaders that the National Office is there to help you and you can call us at any time.

An Information Day will take place in the Keadeen Hotel, Newbridge on the 13th of October and in November we will hold one in Cork. The Cork Information Day is only at the very early stages of planning so we will notify you as soon as we confirm the details. We are also attending the World Parkinson Congress from the 27th of September to the 1st of October in Glasgow and we are delighted that quite a few branches are sending their representatives too. This is a wonderful opportunity to hear some world renowned speakers giving up-to-date information on the condition. If you have not booked and you would like to do so Joe, our CEO, would be delighted to help.

Fundraising is getting more and more difficult but we will continue to try. Joe is planning to lead a group to climb Kilimanjaro in September 2011. If some of the younger members of PAI or family members would like to try this great event, call Joe for more details. In November we are planning a concert featuring the No. 1 Army Band. This will be quite spectacular and the supporting artists will be well worth hearing.

If you are planning some of your Christmas shopping, we have some ideas. Our logo has been made into a very attractive pendant and also a lapel/tie pin by Newbridge Silverware. Both make ideal Christmas gifts. You can order one through your branch or from the office by calling 1800 359359. We would like to thank Newbridge for helping us so generously with this project.

So you can see how busy we have been and I hope you will enjoy what we have planned. If we can help you in any other way it is important to let us know about it. We are there to help people with Parkinson's so do let us hear from you.

Our association has heard with sadness of the death of Mr Tom Fleming, Chairperson of the Cork Parkinson's Support Group. I wish to extend our deepest sympathy to his family. Mr Fleming had worked for many years for people with Parkinson's in the Cork area and people with Parkinson's in Cork benefited greatly from his help and guidance. I would like to offer my help in anyway to the new Chairperson and look forward to meeting the Cork group in the near future. We all have one common aim: to support people with Parkinson's when they most need advice, information or just a listening ear. May Tom rest in peace.

Sincerely



Una

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

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

Parkinson's Association of Ireland
Carmichael House,
North Brunswick Street, Dublin 7

Tel: 01 872 2234
Email: info@parkinsons.ie
Web: www.parkinsons.ie
Freephone Helpline: 1 800 359 359 Mon - Fri 9am-9pm

Company registered in Ireland No. 123532 CHY No. 10816
Registered address as above

Contributors

Editor
Ann Keilthy 087 2853117
A.Keilthy@parkinsons.ie

Photography
Ann Keilthy
Joe Lynch
AIM Billy Galligan

Editorial Team
Ann Keilthy
Una Anderson Ryan
Joe Lynch
Pauline Mahady
Ed Rice

Feature Story
Professor K. Ray Chaudhuri

Living
Dr. Peter J. McGonigal, BDS

Ask the Experts
Dr. Tim Counihan
Dr. Michael Reardon
Patrick Browne, PDNS

Front page photo
Irish Entrepreneur
JP McManus

PAI Meeting with Ministers

On July 7th, a delegation representing PAI met with Minister of State with responsibility for Equality, Disability and Mental Health at the Department of Health and Children, John Moloney TD and Máire Hocter TD, Minister of State with responsibility for the Elderly, to highlight the lack of funding currently being experienced by PAI. The delegation consisting of the National Chairperson, Una Anderson Ryan, CEO Joe Lynch, Board Member Pat O'Rourke, Mr. & Mrs. Michael Burke and Mr. & Mrs. Oliver Nolan of the Tipperary Branch, presented Ministers Moloney and Hocter with copies of our newly launched Three Year Strategic Plan along with a copy of our 2009 Annual Review. PAI stated that while we understood the current financial constraints the Government was under, PAI was in a position to help relieve some of the strain on the public health system through rigorous application of any funding received. A follow up meeting has also taken place with the HSE Disability Section to discuss our application and to ensure that our case is brought to the forefront of the HSE's thinking.



(L to R, CEO Joe Lynch, Pat O'Rourke, Minister John Moloney TD, Minister Máire Hocter TD, Michael Burke, Oliver Nolan, Chairperson Una Anderson Ryan)



Flora Women's Mini Marathon 2010

The Flora Women's Mini-Marathon, which took place on the June bank holiday Monday, was a fantastic success once again, raising over €18,000 so far for PAI. It is a wonderful way to increase awareness and much needed funds for the Parkinson's Association. We would like to thank everyone who participated on the day for their enormous hard work and stamina. Ladies travelled from Donegal, Galway, Louth and Mayo, to name but a few locations, and added to a very colourful day in Dublin. A very special word of thanks goes to Emma Doyle (below right), who was shortlisted for the "Flora Heart



Hero" for 2010. Emma appeared on TV3's Ireland AM show and showed great enthusiasm on the day despite the dreadful weather conditions, and finished the marathon in good form before joining us for refreshments in the Russell Court Hotel. Our photographs show that the wet weather did not dampen our ladies' spirits!

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.



A Fundraising Family

During July, PAI CEO, Joe Lynch, met up with Eddie O'Brien, a member of the PALS Branch and physiotherapist Elizabeth Laffin to receive a very generous donation of over €24,000 which had been raised over the last few years through golf classics.

"Many thanks go to Eddie, Elizabeth and Emma for their enormous efforts on our behalf"

Elizabeth and Eddie explained that they wished to see the funds put to use for direct service provision within PAI. Eddie also took the opportunity to present Pauline Mahady, our Helpline

manager, with another cheque for over €4,000 from his daughter, Emma, who had completed the Ladies Mini Marathon in June. Many thanks go to Eddie, Elizabeth and Emma for their enormous efforts on our behalf.





Parkinson's 2011 KILIMANJARO Challenge



Parkinson's is heading for the roof of Africa in September 2011. The trip is being organised by our CEO, Joe Lynch, and will last about 11 days. The total amount that needs to be raised for each person is €4,200 and includes flights, accommodation and food. Joe says "I have been to Kilimanjaro twice and loved every single minute of the journey. This is not for the faint hearted, but will suit people with reasonable levels of fitness who can continuously walk for up to 8 hours a day".

PAI hopes to have up to twenty people on the trek and there will be a minimum of ten people required to make it viable. The trek gives people the opportunity to see Kenya, Tanzania and, of course, Kilimanjaro. This unique trip is exciting and uplifting, while at the same time giving people an opportunity to raise funds for Parkinson's. Most of those who complete the trek leave vowing to come back and do it again!

An information leaflet has been included in the magazine for you to read, and, while we know that the trek will not suit



everyone, we would be delighted if you could pass the leaflet on to anyone you may think would be interested, and even more delighted if you were willing to support one of our participants. For an information pack contact Joe in our National Office on 1800 359359 or Email: kili@parkinsons.ie



Christmas Concert

Since our Holy Thursday concert in 2009, many people have asked when we intend to hold our next concert. We are delighted to confirm that the Army Number One Band has agreed to entertain us on Thursday the 18th of November in the D4 Ballsbridge Inn Hotel, formerly Jury's Hotel. The concert was suggested to us by PALS member, Ray McDonnell, who is a member of the band. The concert featuring the Army Band will be conducted by Commandant Mark Armstrong and it will be a magical night with one of the few professional big bands in Ireland. The entertainment won't end there, and with the able assistance of a great friend of PAI's, George Hunter, a dance band will follow the concert to entertain us into the small hours of Friday morning. Tickets are priced at just €25 each and will be on sale from our National Office from September 15th and they can also be purchased through your local Branch. We have also negotiated a special rate with the hotel for an overnight stay and a delicious pre-concert dinner; all the details will be on our web site and will be sent to Branches in the coming weeks. Why not make this your Christmas night out! All in all this will be a terrific night of



Irish Army No. 1 Band

entertainment and we look forward to seeing you there. Our special thanks go out to Ray McDonnell for organising the concert for us and to Commandant Mark Armstrong for agreeing to bring the band together for PAI. Please book early as tickets are sure to go quickly.



JP McManus - The most generous Irishman that has ever lived?



helped with fine-tuning the proposal and worked with the Branch, the HSE and others, and in the end funding was granted for a state-of-the-art Neurological Centre and Acute Stroke Unit, to be built onto Ward 3B at Limerick Regional Hospital.

To date around €65,000,000 has been raised through his remarkable efforts

To most people, JP McManus remains an enigma, an inspiration, and a source of continued fascination. However, few would argue against the suggestion that he is probably the most generous Irishman that has ever lived.

His relatively humble background in Limerick is well documented, and this has always had a huge influence on his philanthropic endeavours, the scale of which will probably never be fully known. The most public and remarkable of these is the JP McManus Pro-Am Golf tournament which is held every 5 years - bringing to Limerick a field of world-class golfers to rival any major championship, and an array of celebrities to rival the Cannes Film Festival. To date around €65,000,000 has been raised through his remarkable efforts. For the many organisations JP McManus supports in the Mid West region, he has been a life changing Godsend.

In 1999, the Mid West region had no neurologist and no specialist services for people with a neurological condition. Una Anderson Ryan and Sid Rellis established the Special Projects Committee of the Mid West Branch of PAI in order to service a rapidly growing and indeed urgent need in the region. Initially, they put together a proposal for the provision of essential Parkinson's Nurse Specialist services in the region, and set about making this happen.

The HSE agreed with the initial proposal, but requested that the Mid West Branch match the funds they provided 50/50. This was never going to be an easy demand for any organisation, but the timing was fortuitous as JP McManus was holding his Pro-Am the following year. Una & Sid explained the situation to JP's people and somehow managed to persuade them to make the Mid-West Branch a key beneficiary of the 2000 event.

With the huge success of the Parkinson's Nurse Specialist provision, the JP McManus organisation was now open to all suggestions and before the 2005 Pro-Am, the Mid West Branch put forward a proposal for a multi-million euro Specialist Hydrotherapy Unit. The JP McManus organisation

After much consultation with technical, educational, social studies and social media experts, a request for funding for what will be known as 'The Clever Centre' has now been submitted. This will be a support system that will be easily accessible to all, and make full use of existing technologies to engage and stimulate the minds of those with neurological conditions, while helping to alleviate the social isolation that can result from their condition.

By integrating and using everything from basic email, TV, mobile phone and chat technology, it is hoped that the centre can build and connect together a vibrant online community of people with neurological conditions to inspire them to embrace communications tools that can greatly enhance their lives and provide social, entertainment and creative outlets for them to use, especially those who are relatively immobile.



The proposal has delighted bodies such as the European Parkinson's Disease Association (EPDA), and the President of the European Federation of Neurological Associations (EFNA), Mary Baker, MBE, acclaimed it as "groundbreaking" and "essential". The proposal has also had the support of those with neurological conditions in the region, and the response from the JP McManus organisation has been positive thus far. The Mid West Branch looks forward to working together with them again, to fine-tune the proposal to fully meet their funding requirements.

The 2010 JP McManus Pro-Am took place last July, and needless to say it was a huge success - with everyone from Tiger Woods, to Samuel L. Jackson giving it huge compliments and praise. On day one, the expected 30,000 spectators exceeded 45,000, and the €50 tournament entry caps they were using ran out. This kind of response is typical of the support and affection that the people of the Mid West feel towards JP McManus and the work he does for charities, sports, arts and voluntary organisations in the region. To all who know him and benefit from his big-hearted ways there is good reason to reflect on and celebrate the endless philanthropic works of a great man and hope they can continue long into the future.



BY CATHERINE SHEEHAN



Catherine was a massage therapist until tendonitis set in, and in her search for another form of massage that would suit her better she discovered the Bowen Technique, and her story goes from there.

I have been working with the 'Bowen Technique' for nine years and it continues to amaze me, fascinate me and surprise me. It is a very gentle non-invasive system of stimulating muscle groups and reminds the client's body how to activate and utilise its own healing ability.

I worked as a massage therapist for twenty years, doing massage for relaxation and working with people with injuries, eventually working with teams of Gaelic and rugby players where often the perception is the deeper you go, the harder you hurt, the better the treatment. As a result of working at that physical intensity I developed tendonitis, that cut short my career as a deep tissue therapist. I looked for another modality that would be painless for me and effective for the client, and I discovered the 'Bowen Technique'.

The 'Bowen Technique' is named after Tom Bowen, an Australian who developed the work through trial and observation. He was also an advocate of 'less is more' and 'why do five moves when one will be more effective'. He also believed in the innate ability of the body to heal itself and for the therapist to step back once a small degree of assistance has been given, hence the 'breaks' but more on that later!

A Bowen move can be done over light loose clothing or on the skin, the client can be sitting or lying down, but the main thing is to ensure that the client is comfortable and therefore the body is more receptive to the treatment.

There are three parts to a 'Bowen' move

1. Moving skin slack, the therapist puts her fingers on the highest point or 'belly' of a relaxed muscle or tendon or ligament and gently tractions the skin off the muscle to one side of the muscle
2. The challenge - a gentle push against the side of the muscle. This move is made as the client breathes out
3. The move is made by pushing horizontally across the muscle with slight pressure in the direction of the challenge at the end of the exhale.

The Science Book says: 'A Bowen move activates proprioceptors at multiple tissue levels creating a dynamic effect in the peripheral and the central nervous system leading to postural realignment, regulation of autonomic nervous system, fascial release and ultimately facilitates the body in accessing its intrinsic ability to heal itself.'

A Bowen treatment can last between 20 minutes and an hour, the duration depending on how the client's body is processing the treatment. Rule of thumb is: the worse you feel the less we do.

During a treatment the therapist will do a series of moves and then leave you for approximately two minutes. The reason for the breaks is that the body goes through a process of release and

integration. This happens mainly through the autonomic nervous system and it is important that time is given for it to complete its natural cycle of approximately 90 seconds, which is needed for the body to respond to sensory information.

Autonomic reactions can include feeling cold, sweaty, tearful or tingly or even sometimes reviving memories of old injuries or operations. If any of these reactions happen it may be confusing or distressing or even interesting for a client but it is always seen as a good sign by the therapist. If the client does not experience any reactions it does not mean that the treatment is not working but that it is being processed differently.

Reactions to look out for after or during a treatment include: Feeling hot or cold, tingling or numbness, feeling frozen, not wanting to move. Some clients can also feel flushing or pallor and clamminess in skin, stomach gurgling, sleepy or wide awake and feeling withdrawn.

After your Bowen treatment you will be given 'homework:'

1. Drink water. This is important for the hydration of fascia which surrounds all the muscles ligament and tendons. Fascia is primarily made up of collagen fibres which are hollow tubes filled with fine fluid similar to cerebro-spinal fluid. It has a unique property in that water molecules are attracted to it; this quality allows a high degree of fluidity in the fascia which is essential for free movement and glide between groups of muscles and organs and also for effective inter-cellular communication. The conductivity of collagen is strongly dependant on hydration.
2. Walk for approx 20 minutes every day. This enables the body to eliminate any toxins that may have been released in the treatment.
3. Wait a week. The body will process the 'Bowen' information for about five days after the treatment. Throughout that week there may be changes happening that are obvious and some that are more subtle. At the end of the week the body will be ready to process more 'Bowen' information.
4. On the day of the treatment do not sit for longer than half an hour at a time. This is because it is important to keep the circulation and the information moving in the nervous system so that the effects of the treatment will last for a few days. When we sit for longer than half an hour everything slows down, although I do this treatment on people in wheelchairs and it seems to be effective.
5. No rubbing, no poking, no massage, no heat or ice packs and no other treatment at the same time. Through the 'Bowen' treatment your body has been stimulated to activate its own healing capacity. By massaging or using any other modality at the same time as 'Bowen' the information that the body has to integrate is confused and therefore the real effects of a 'Bowen' treatment cannot be properly demonstrated.

The 'Bowen Technique' is a growing therapy and there is nothing that we therapists won't have a go at treating! The usual treatment schedule is 3-4 treatments. Then if the problem is resolved the client may decide to have a 'top up' treatment once a month. As the effects of the 'Bowen' are so individual, so also is the schedule of care. Sometimes the symptoms presented are not the root of the problem, and when this happens it is imperative that the client be aware of any changes or sensations that take place during the treatment, and that the following week they relay them back to the therapist. My advice to anybody who is curious about 'Bowen' is to give it a go!

There is a lot of information on the internet particularly www.bowen-technique.co.uk. This is the organisation that I trained with and they adhere strictly to the teaching of Tom Bowen.



TREATING NON-MOTOR SYMPTOMS

An Interview with Professor K Ray Chaudhuri



Professor K. Ray Chaudhuri is a Consultant Neurologist and Professor in Neurology/Movement Disorders at King's College and Institute of Psychiatry. He is a recognised teacher and active researcher within the Guy's, King's and St Thomas' School of Medicine, London, UK and is the medical director of the National Parkinson Foundation International Centre of Excellence at King's College, London. He also serves as Chairman of the International Parkinson's Disease Non-Motor Group and is the author of 190 papers including reviews and book chapters. He was the co-editor of four books on Parkinson's disease and Restless Legs Syndrome and is credited with over one hundred and fifty published peer reviewed articles.

"Restless Leg Syndrome (RLS) is one distressing non-motor symptom of Parkinson's Disease that adversely affects patients"

Professor Chaudhuri recently visited Ireland to deliver talks to neurologists, geriatricians and doctors in Dublin and Cork and PAI took the opportunity to ask him some questions relating to non-motor symptoms in Parkinson's Disease.

Restless Leg Syndrome (RLS) is one distressing non-motor symptom of Parkinson's Disease that adversely affects patients and we asked Professor Chaudhuri about the effects of, and treatments for this particular symptom. Professor Chaudhuri said, "Restless leg syndrome affects about 10% of the general population; however this rises to 20% among Parkinson's patients." Professor Chaudhuri advised that many patients diagnosed with RLS are being given sleeping tablets or quinine for treatment and he stresses that this is unacceptable as RLS is entirely treatable and some sleeping tablets actually make RLS worse. RLS often presents with insomnia (difficulty in sleeping) and if you have this and your GP suggests a sleeping tablet, make sure you ask about alternative treatments for RLS first. Professor Chaudhuri went on to say that "The rotigotine [Neupro] skin patch is a new form of dopamine agonist treatment and this drug, delivered through a patch that is worn for 24 hrs, is a new and effective development in the treatment of RLS."

Falling and unsteadiness are features of Parkinson's and this is borne out from our helpline where about 10% of calls relate to unsteadiness among Parkinson's patients. Professor Chaudhuri said that exercise can be an effective tool in the treatment of balance issues within Parkinson's. A simple regime of daily classes of exercise such as yoga or Tai Chi can help to correct imbalance in some patients." Recent studies also cite



A simple regime of daily classes of exercise such as yoga or Tai Chi can help to correct imbalance in some patients

dancing as a particular exercise that is both fun and helpful with co-ordination.

Professor Chaudhuri was at pains to point out that non-motor symptoms are complex in Parkinson's. They include such symptoms as sleep problems, depression, apathy, anxiety and sexual problems. The main issue when dealing with these problems is around non disclosure and clinicians simply not asking about them at all. Professor Chaudhuri commented that "most patients are not asked about non-motor symptoms and unfortunately these patients do not disclose these symptoms through lack of awareness that they can be treated or even embarrassment with the problem."

PAI asked Professor Chaudhuri how we could encourage patients to discuss their non-motor function and what part clinicians played in this? Professor Chaudhuri responded that this was actually the key issue when dealing with non-motor symptoms, information. He said "If a clinician is aware of the problems that a patient is experiencing a treatment programme can be worked out. It is important to supply your doctor or neurologist with as much information as possible."

SYMPTOMS IN PARKINSON'S DISEASE



Recent studies also cite dancing as particular exercise that is both fun and helpful with co-ordination

“If a clinician is aware of the problems that a patient is experiencing a treatment programme can be worked out”

Non-motor symptoms questionnaire

Name: _____ Date: _____
 Centre ID: _____ Male Female

Non-movement problems in Parkinson's
 The movement symptoms of Parkinson's are well known. However, other problems can sometimes occur as part of the condition or its treatment. It is important that the doctor knows about these, particularly if they are troublesome for you. A range of problems is listed below. Please tick the box "Yes" if you have experienced it during the past month. The doctor or nurse may ask you some questions to help decide. If you have not experienced the problem in the past month tick the "No" box. You should answer "No" even if you have had the problem in the past but not in the past month.

Have you experienced any of the following in the last month?

	Yes	No		Yes	No
1 Dropping of saliva during the day	<input type="checkbox"/>	<input type="checkbox"/>	16 Feeling sad, 'low' or 'flat'	<input type="checkbox"/>	<input type="checkbox"/>
2 Loss or change in your ability to taste or smell	<input type="checkbox"/>	<input type="checkbox"/>	17 Feeling anxious, frightened or panicky	<input type="checkbox"/>	<input type="checkbox"/>
3 Difficulty swallowing food or drink or problems with choking	<input type="checkbox"/>	<input type="checkbox"/>	18 Feeling less interested in sex or more interested in sex	<input type="checkbox"/>	<input type="checkbox"/>
4 Spitting or feelings of acidness (reflux)	<input type="checkbox"/>	<input type="checkbox"/>	19 Finding it difficult to have sex when you try	<input type="checkbox"/>	<input type="checkbox"/>
5 Constipation (less than three bowel movements a week) or having to strain to pass a stool	<input type="checkbox"/>	<input type="checkbox"/>	20 Feeling light-headed, dizzy or weak standing from sitting or lying	<input type="checkbox"/>	<input type="checkbox"/>
6 Bowel (faecal) incontinence	<input type="checkbox"/>	<input type="checkbox"/>	21 Falling	<input type="checkbox"/>	<input type="checkbox"/>
7 Feeling that your bowel emptying is incomplete after having been to the toilet	<input type="checkbox"/>	<input type="checkbox"/>	22 Finding it difficult to stay awake during activities such as working, driving or eating	<input type="checkbox"/>	<input type="checkbox"/>
8 A sense of urgency to pass urine makes you rush to the toilet	<input type="checkbox"/>	<input type="checkbox"/>	23 Difficulty getting to sleep at night or staying asleep at night	<input type="checkbox"/>	<input type="checkbox"/>
9 Getting up regularly at night to pass urine	<input type="checkbox"/>	<input type="checkbox"/>	24 Intense, vivid or frightening dreams	<input type="checkbox"/>	<input type="checkbox"/>
10 Unexplained pain (not due to known conditions such as arthritis)	<input type="checkbox"/>	<input type="checkbox"/>	25 Talking or musing about in your sleep, as if you are 'acting out' a dream	<input type="checkbox"/>	<input type="checkbox"/>
11 Unexplained change in weight (not due to change in diet)	<input type="checkbox"/>	<input type="checkbox"/>	26 Unpleasant sensations in your legs at night or while resting, and a feeling that you need to move	<input type="checkbox"/>	<input type="checkbox"/>
12 Problems remembering things that have happened recently or forgetting to do things	<input type="checkbox"/>	<input type="checkbox"/>	27 Swelling of the legs	<input type="checkbox"/>	<input type="checkbox"/>
13 Loss of interest in what is happening around you or in doing things	<input type="checkbox"/>	<input type="checkbox"/>	28 Excessive sweating	<input type="checkbox"/>	<input type="checkbox"/>
14 Seeing or hearing things that you know or are told are not there	<input type="checkbox"/>	<input type="checkbox"/>	29 Double vision	<input type="checkbox"/>	<input type="checkbox"/>
15 Difficulty concentrating or staying focussed	<input type="checkbox"/>	<input type="checkbox"/>	30 Bloating (things are happening to you that other people say are not)	<input type="checkbox"/>	<input type="checkbox"/>

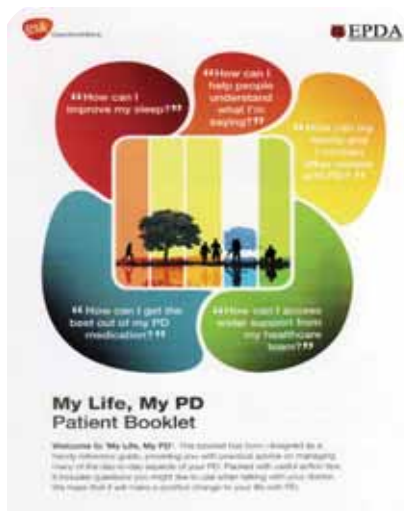
All the information you supply through this form will be treated with confidence and will only be used for the purpose for which it has been collected. Information supplied will be used for monitoring purposes. Your personal data will be processed and held in accordance with the Data Protection Act 1998. Developed and validated by the International PD Non-Motor Group.

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Chaudhuri said “it empowers the patient to tell us [doctors] because otherwise he or she is dominated with motor

treatments and in some cases non medical treatments. Other non-motor symptoms can be more intractable and need the introduction of novel non-dopaminergic drugs,” he concluded. Professor Chaudhuri hopes to visit Ireland again in the near future and PAI will endeavour to have him attend an Information Day for our members.



Parkinsons UK [formerly the Parkinson's Disease Society] has developed a questionnaire in conjunction with Professor Chaudhuri, that assists with this process and they have given kind permission for PAI to use this. The questionnaire is now available to download from our web site, www.parkinsons.ie and it contains thirty questions to which the patient ticks either “yes” or “no”, and this in turn gives the clinician a snapshot of the patient's non-motor profile. Professor

problems and we don't always have time to ask about sexual health and other issues they may have.”

“Some non-motor symptoms, including depression, constipation, pain, genitourinary problems and sleep disorders can be improved with available

A booklet entitled “My Life, My PD” has been developed by the EPDA in conjunction with a European panel of healthcare professionals and people with an interest in Parkinson's, and provides practical advice on managing some of the real life challenges that face people with Parkinson's disease on a daily basis, such as sleeping difficulties and relationships with family and friends. The booklet is divided into five areas, each one including suggested questions that people with Parkinson's can use when talking with their doctor and useful tips to help them prepare for their consultation. PAI has four hundred copies which can be requested though our helpline, 1800 359 359. An online version is also available through our web site, www.parkinsons.ie.



Editor's note: we will have Mags Richardson PDNS back in our next issue



Dental Health

Dr. Peter J. McGonigal BDS (NUI), Dip. Clin. Dent (U.Dub), MGDS RCSI, FFGDP RCS.
166 Pembroke Road, Ballsbridge, Dublin 4

“The dentist chosen for treatment should have a complete understanding of performance limitations imposed by the disease ”

The most important factor in managing dental health for any person with Parkinson's is a high standard of personal oral hygiene achieved daily in the home. This must be supplemented by regular dental checkups, in order to nip trouble in the bud, and also by more frequent visits to a dental hygienist (three to four times a year).

The two major problems with care in the home are:

1. an increasing lack of manual dexterity and hand-mouth coordination, and
2. a lack of the tools to do the job

Both of these contribute to a greater incidence of cavities and accumulation of plaque, gum inflammation and periodontal disease.

The Tools for the Job

The best piece of equipment for cleaning teeth is the electric tooth brush. This does not require muscular force and can be successfully guided around the mouth by the person with Parkinson's or by a carer. Incidentally, carers must remember to maintain absolute infection control by using a hand gel (e.g. Spirigel) and gloves (e.g. latex powder-free examination gloves). A fluoride mouth wash once a day is a good idea and people with Parkinson's with drug-induced xerostomia (dry mouth) can use an artificial saliva solution as a dry mouth is very susceptible to disease. A coarse cloth dipped in an antiseptic mouthwash and rubbed around the teeth and gums can augment a less accurate tooth brushing technique. A small tooth brush handle can be bulked out by tape for ease of grip (or by a sponge pen grip).

In addition, if the person is in the more advanced stage of Parkinson's, the designated carer should be talked through the optimum daily dental care routine and the importance of adhering to this should be stressed.

Choose Your Dentist with Care

The dentist chosen for treatment should have a complete understanding of performance limitations imposed by the disease and of the time requirements for all aspects of treatment. Essentially this means that appropriate treatment should be delivered in a timely fashion. Anxiety makes the underlying condition worse and it is a good idea to keep waiting time and appointment durations short. Bite blocks to

help keep the mouth open, tongue guards to help control an “unruly” tongue and a rubber dam to protect the airway all have a role to play in individual cases.

Wheel chair access to the dental practice should deliver the person with Parkinson's to clinical chair side where an easier transfer to the dentist's chair can take place. This allows the dentist to use the usual equipment. The dental surgery is not really suitable for more advanced Parkinson's as there are issues with maintaining the airway while working. The person with Parkinson's can attend the dental hospital or general hospital where a crash team is available in case of emergency, and routine maintenance can be facilitated by a domiciliary visit from a dentist or hygienist.

Dentures will become a poor fit as time passes. This is quite often exacerbated in people with Parkinson's who have xerostomia. Ulceration, sometimes severe, can occur and action should be taken as soon as possible to minimise pain. One of the main contributing problems to speech impairment is poor dental health, especially loose or missing teeth, and defective dentures. Badly fitting dentures not only distort the consonants but also the vowel sounds, and the resultant anxiety about being understood increases the speech difficulty. Loose dentures do not allow effective control of saliva. Dentures can be relined to improve the fit and sometimes it is appropriate to use a flexible, cushioning liner for greater comfort, or a lot of dental fixative.

If it would not be suitable to have a filling or extraction or other work done in the dental practice, perhaps because of tremor or dyskinesia, the Dublin Dental Hospital is the only facility available as far as I know that will cater for this. The Department concerned is called Special Needs. Most anaesthetists favour sedation rather than a general anaesthetic - if possible and if it works.

Finally, with advancing Parkinson's, swallowing may become an issue. It is vital that teeth are maintained in a healthy state, as this allows the continuation of proper chewing. This in turn facilitates easier swallowing, and the intake of a healthy variety of food. A speech and language therapist may be able to recommend strategies to improve swallowing.



Neurologist Dr. Timothy Counihan,
Geriatrician Dr. Michael Reardon and
PDNS Patrick Browne form our panel of experts

You can send questions to:
Ask the Expert,
c/o Parkinson's Association of Ireland,
Carmichael House, North Brunswick Street, Dublin 7
or email expert@parkinsons.ie

Another selection of questions and
answers may be found on our website
www.parkinsons.ie



Patrick Browne PDNS



Dr. Timothy Counihan



Dr. Michael Reardon

Q I've heard that there are two new versions available of Mirapexin and ReQuip. Now my consultant wants me to take Mirapexin in the one-a-day formulation rather than three a day as at present, but I do not want to upset the applectart. I am having a good reaction to the ordinary version. Have you any patients who made the switch and how did they get on, and if I decide to switch what is the transition like? Many thanks for the answers in other editions of the magazine. I find them very useful.

A You are right; ReQuip and Mirapexin both now come as once-a-day formulations, and the switch over is straightforward. However, the old maxim, "if it ain't broke, don't fix it" applies to your situation, and I agree there is no need to upset the applectart. The only real advantage to once a day tablets is the fewer pills taken over the day. I have had a few patients switch to the controlled release formulations, and in most there has been no problem; one or two patients have reverted to the three times a day. Stay on what you are on would be my advice.

Q I was diagnosed with Parkinson's about three years ago but am getting worse faster than I thought I would, and now my consultant has suggested it might be something else called Multiple Systems Atrophy. I have to think of the future and want to know the implications of such a diagnosis. Would there be surgery offered for it do you know? It is the uncertainty I find hard to deal with and my wife too.

A As you may be aware, there are several forms of "parkinsonism"; the most common by far would be what we traditionally refer to as idiopathic (meaning cause unknown) Parkinson's disease. However, in some patients, over a couple of years, it becomes clear that their parkinsonism symptoms are "atypical"; perhaps the symptoms do not respond well to the standard Parkinson's treatment, or perhaps other symptoms emerge, such as dizziness, trouble swallowing or falls. Multiple Systems Atrophy, or MSA, is the name given to a condition where other symptoms such as the above develop in someone who was thought initially to have Parkinson's disease. This diagnosis may be difficult to confirm in the first few years of symptoms. I think it is important that you discuss with your consultant how certain they are regarding the diagnosis, and whether

they feel you have a milder or more severe form. They should be able to guide you regarding the future to some extent. MSA is more challenging to treat but there are some treatments available for specific symptoms. Surgery is unfortunately not an option in MSA.

Q What can I do to help my husband who has just been diagnosed as having dementia as well as Parkinson's? I am in two minds but don't want to question the word of the neurologist. I went on the internet and found a recent article suggesting that type 2 diabetes plus depression can, when taken together, be mistaken for early dementia and maybe I am grasping at straws but I need to know if this is a possibility. My husband has had Parkinson's now for about 16 years and has had some hallucinations that he has found troubling. I can't remember anything about the article except that it was written this year. Any help would be greatly appreciated. I do not want to start looking around for a nursing home but it may come to that and it would break my heart really it would. There are plans to put him on something for the dementia but would this cause more problems?

A Firstly, there is no harm in questioning the word of your neurologist! We are all human and make mistakes. However, it is true to say that for many (not all) patients with Parkinson's for more than 15 years, hallucinations and cognitive (memory) impairment can become a problem. It is essential that your neurologist look in detail at your husband's overall condition: this includes All medications that he may be taking, any possible infections or other medical conditions (you mentioned diabetes), and any psychiatric conditions (you mentioned depression). It is essential that all other potential causes of hallucinations and dementia be excluded, before a diagnosis of Parkinson's dementia is reached. Even if this turns out to be the case, there are treatments and medication adjustments that can minimize the degree of disability and allow your husband to remain at home for some time to come. Of course it has to be acknowledged that the condition is in general progressive, and that it can become ultimately impossible for families to care for their loved ones at home indefinitely. But your husband sounds like he needs a complete medical and neurological overhaul first. Don't give up.

Q This Neupro patch, can it cause psychiatric side effects, only my wife has suddenly been making very strange accusations that I am finding hard to dismiss and hurtful. She is on the 6mg patch. Thank you for the help in advance.

A You need to have her see her specialist urgently. Dopamine agonists, including Neupro, can be associated with serious changes in behaviour; the doctor will most likely recommend discontinuing the drug to see if it has caused the problem, but you should be sure to contact them before stopping it.



Newbridge Silverware

For over seventy years, Newbridge Silverware has designed and produced homeware products, continuously innovating and producing items that are relevant to the lifestyles of each new generation of customers. The unique history of the company provides a wealth of tradition, craftsmanship and experience. Contemporary and fresh designs have made Newbridge Silverware one of Ireland's real success stories. Their showrooms display simple and stylish designs for both homeware and jewellery, which meet the requirements of all ages.

While attending the General Assembly of the EPDA in Budapest last year, the Chairperson of the East Midlands Branch of PAI, Marian Deely, first saw a potential connection between Newbridge Silverware and our association in the modern and elegantly redesigned PAI aspen leaf logo, and talked to our Chairperson, Una Anderson Ryan about it.

The next stage of the project was to see if Newbridge Silverware could see what we had seen. Marian met with the Production Manager, Mr. Cliff English, and made the initial

contact on behalf of PAI. The Managing Director Mr. William Doyle soon became involved, and following the production of some samples and a very warm meeting between some of PAI's Management Team and Newbridge Silverware, where Marian's pride in her hometown was very much to the fore, the project has now taken off. This is the first partnership of a charity with Newbridge Silverware.



One of the main objectives for PAI with this collaboration was that the pins and pendants would be completely manufactured in Ireland. We now have beautiful lapel pins and pendants for sale, which we hope you will purchase and wear with pride. Each box will contain a brief explanation of our aspen leaf logo, which will help to raise awareness around Parkinson's. The pins and pendants represent great value for money and are fabulous Christmas gifts. A special launch of the pins and pendants will take place in the Newbridge Silverware showrooms in October.

To purchase, please use the order form insert with this magazine, or call Pauline on 1800 359359 for details.

Meet Our Board



Mary Reynolds

Mary joined our Board in May and currently heads up National Fundraising at the Society of St. Vincent de Paul. Previously she held senior management roles with the Irish League of Credit Unions, Motorola and McDonald's and

has provided marketing and business development support in both the commercial and not for profit sectors.

Mary holds a BBS (Hons) Degree from Trinity College Dublin, a Certified Diploma in Accounting and Finance from ACCA, a Diploma in Digital & Online Marketing from Digital Marketing Institute and a Diploma in Public Relations from Public Relations Institute of Ireland. Mary is an active volunteer having been involved with Plato Network; Chernobyl Children's Project International and is VP Public Relations with Kildare Toastmasters.

Mary hopes to utilise her Communications and Public Relations skills and experience to contribute to increasing awareness of both PAI and Parkinson's.



Pat O'Rourke

Pat is currently the Chairman of Livestock and Meat Commission (LMC) for Northern Ireland in which he has been involved in a major review of the organisation. Prior to joining LMC, Pat was Marketing and Public Relations Manager for the Irish Concrete Federation, responsible for the

development and implementation of a nationwide industry marketing strategy involving the New Building Energy Rating system introduced by the E.U.

Pat has also served as President of the Irish Creamery Milk Suppliers Association (ICMSA) and during his term of office he was a member of the Irish delegation at the World Trade Talks in both Cancun, Mexico in 2002 and Hong Kong in 2005. He is a former director of Bord Bia, the Irish Dairy Board and the National Dairy Council and is currently a member of the local County Development Board in Longford. Pat hopes to bring his vast experience to the Board, ensuring that PAI becomes as effective as possible when lobbying the HSE and Government for services for people with Parkinson's.



Seamus Funge

Seamus is a native of Gorey, County Wexford. Throughout his career he has acted as Finance Director and Company Secretary for some well known companies and he has operated as a consultant for many years, concentrating largely

but not exclusively on agribusiness. This involved working closely with Government, farm organisations, the media and all relevant agencies in this country and in Brussels, in the implementation of policy and achievement of strategic aims and objectives.

Seamus is a Past Chairman of the Chartered Institute of Management Accountants in Ireland and he has also served as Chairman of Comhlucht Gaeloideachais Naithi Teo, an all Irish school, and was a member of the Board of the Irish Youth Foundation for a number of years.

In recent years Seamus has completed a Master's Degree in Applied Irish and Translation.

Bernadette Coleman



Bernadette began her career as a Secondary Teacher and then moved to work in the IT industry followed by a number of years in Management Consultancy.

A senior manager and trainer with over 15 years experience in hands on management of a wide variety of assignments and projects. Bernadette combines strong technical and commercial skills with experience in training, mentoring and coaching across a variety of industries and sectors. She holds an MBA, BA, H Dip Ed, Graduate Diploma in Computing and a Diploma in Professional Coaching. Bernadette has worked in the UK, the US, Canada and Europe and adds value to the PAI Board by bringing her management and Board experience to the Association. She has already taken on the role of Governance Officer with the Board and was involved in the organisation of our recent Leaders Conference in Limerick.

Bernadette is originally from Dundalk, County Louth and she now lives in Kilkenny where her business is based.



Parkinson's Carers Report Launched

The Parkinson's Association of Ireland in conjunction with Care Alliance Ireland, launched their report entitled, 'The Caring Reality of Family Carers' in June this year. The report was commissioned by the two organisations as a collaborative exploration of the health status of family carers of people with Parkinson's. The author, Ann Stokes, told the launch meeting that "A carer is defined in the 2006 census as someone who provides regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability."

The report highlights the substantial contribution that family carers provide within Ireland, often to the detriment of their own health. Ann said that most people "spoke of the severe physical demands and responsibilities of the caring role. She spoke of "the emotional support which they provide and as the condition progressed, the physical care that they gave, which also increased." The report shines a light on the often difficult and unwanted position that carers are placed in. Some interviewees told Ann that they used a range of coping techniques, such as setting aside some time for themselves, and termed these as being essential for their wellbeing. Most carers found great solace through informal support mechanisms, such as family members taking over their role for a while, though they often didn't feel they had a right to ask for this kind of help. "There is often a huge feeling of guilt when a carer has to use respite care even where the carer needs time to recuperate from an illness themselves," Ann said.

Throughout the report it is very clear that couples often felt robbed of their future plans by Parkinson's. However almost all of the carers interviewed were so dedicated to their family members, that they were prepared to continue caring

even when illness had taken over their lives. The main findings of the report are that:

- there are inadequate home supports in place to assist carers,
- respite care places need to be more readily available,
- families need to have a full assessment regime in place to assess their needs,
- a health promotion and public awareness programme is needed, and that,
- there should be a 24 hour phone line for people to call when they need a listening ear or when they simply cannot cope.

The full report and the executive summaries are available online from www.parkinsons.ie and copies were also sent out to each Branch earlier in the summer.



(L to R) Una Anderson Ryan, PAI Chairperson, Joe Lynch, PAI CEO, Ann Stokes, Carers Report Author

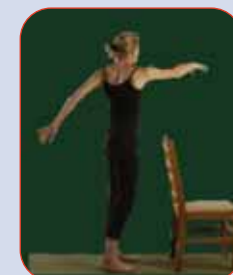
World renowned Yoga instructor to launch Movement Disorders DVD in Dublin



October 3rd sees the visit to Ireland of Renée Le Verrier, the yoga expert who wrote the excellent book on Yoga for Movement Disorders, sold from our national office! She is launching a companion DVD to her book, and the Dublin Branch has kindly facilitated this. So, on October 3rd, at 2.30pm, Renée will be taking the attendees through some

gentle exercises, and following on that with a short talk, to be followed at 3.30 by Dr. Raymond Murphy, neurologist at Tallaght Hospital. So that's October 3rd, 2.30pm in the Tara

Towers Hotel, and members of other branches are also welcome to attend. Renée will be coming here en route home to the USA from the World Parkinson Congress in Glasgow. People may be interested to note that Renée had a stroke a few years ago which affected her on one side of her body, and was diagnosed more recently with Parkinson's on the other side. This, says Renée, has had the effect of balancing out her body quite nicely! We hope to have her DVD for sale on the day, with the cost price to be determined but somewhere in the region of €10 and €15. Once again the Dublin Branch has extended an invitation to other branch members.





Midwest Branch News

We would like to thank Brendan Sheridan for a generous cheque, the proceeds of his cycle around the ring of Kerry with his son in support of the Midwest Branch. Brendan's mother has Parkinson's and they were delighted to do it for her. Brendan raised the money through his friends and through MyCharity.ie and this was then matched by Bank of Ireland, thus doubling the amount raised.

We would also like to draw attention to another fundraising opportunity taking place in Limerick in October. The Limerick Ladies Mini Marathon is to take place in the grounds of the University of Limerick on the 3rd of October. If any member would like to ask a family member or friend to run on our behalf we would very much appreciate it. We supply T-Shirts and sponsorship cards. Just call a committee member and we will get you organised. Great news has been received about our project in the Regional Hospital. Our Neurological Centre/Acute Stroke Unit has now moved to the planning stage and work should commence before Christmas. This is a very exciting project and we look forward to its completion. We are now looking forward to our Monday afternoon sessions in the Greenhills Hotel which were missed over the summer months. Finally we are all delighted that Teresa Rellis is recovering after her recent illness. Teresa we wish you well and our prayers are with you for a full recovery. For further information please contact Una Anderson Ryan: 087-2511156.

Kildare East Midlands Branch News



East Midlands Branch wish to inform their members that Yoga Classes will resume on Saturday 25th of September at 3.00pm in The Red Cross Hall in Raheen Abbeyleix, and will continue for four weeks at the same time and venue. Yoga Classes will

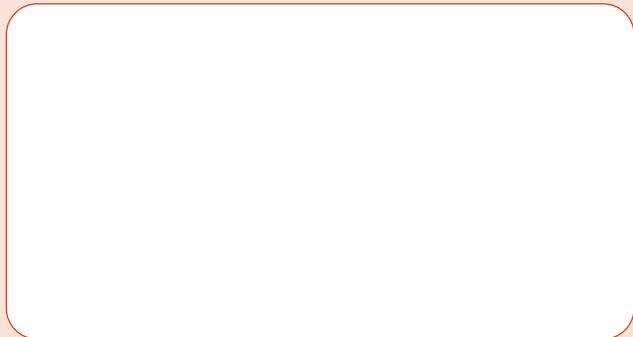
resume on Sunday 26th of September at 3.00 pm in The Day Care Centre, Newbridge Road, Naas, and will continue for four weeks in total. All members are urged to attend. Shane Barry recently completed a mini marathon on behalf of PAI and our picture shows Shane and his mother, Moira presenting a cheque to Pauline Mahady. For further information please contact Marian Deely: 045-435024.

South Kerry Branch News

Our members' sympathy goes out to Mr Willie Carson on the death of his wife Georgina, a member of our group who helped us in many ways. Our branch members recently travelled to Áras an Uachtaráin to a garden party hosted by President Mary McAleese and all were given a very big welcome and had a lovely day. Our branch also enjoyed a great day out to Blarney Castle and Fota Wild Life Park during the summer and on our return to Killarney there was a delightful dinner and dance at Darby O'Gill's Hotel for 40 members which every one enjoyed.

We hope to hold a meeting in Caherciveen where Dr. Tim Lynch will give a talk.

We will be starting back on the 13th September when we hope to have a representative from the Gardaí speaking on security. Planning will start soon for our annual Christmas dinner and dance. For further information please contact Grace McCrae: 064-7758837 or Eileen Hobbs: 087-2995882.



(L – R) Michael Moynihan, Eileen Moynihan, Denis McAleese, President Mary McAleese, Jerry O'Sullivan, Noreen O'Sullivan, Eileen Hobbs, Richard Hobbs, Muriel Knight. Missing from picture: Kathleen O'Keeffe.

Galway Branch News

Galway Parkinson's Branch will resume after the summer break on Wednesday the 22nd of September at 8pm in the Clayton Hotel, Ballybrit, Galway and all are welcome. There will be a Social Worker at our October meeting to explain all about the Fair Deal issue in relation to nursing homes. This will be a very interesting talk. There are other talks and events planned over the coming months and branch members will be advised as they come about. For further information please contact Marie Cahill: 087-7783825 or Caroline 086-2566655.

Waterford Branch News



The Waterford Branch continues to meet on the last Thursday of the month in the meeting room at the Waterford Cheshire, John's Hill, Waterford City at 11am for a coffee morning gathering or alternatively with a guest speaker. All are welcome. Our summer outing this year was a joint venture with the

Kildare/East Midlands Branch and we went to Powerscourt House/Gardens. This was a great success. We managed to have a picnic and view the waterfall in between showers. Many thanks to the Kildare/East Midlands Branch for co-hosting the day & evening meal. We hope to return the invite to somewhere in the Sunny South East next year. Our programme for the winter is being organised, including local events and our Christmas party in December. Keep in touch to get up to date information! For further information please contact Mary Keane: 051-355764, Teresa Peacock: 086-3585738 or Nicky Clarke: 087-5942927.



PALS Young Onset Branch News

After a long break for the summer, we will be holding our first meeting after the World Parkinson's Congress in Glasgow. Some of our Committee will be going and will be reporting in detail to our members upon our return! For further information please contact Sinead O'Kane, Chairperson, Mobile 087-2869173.

Donegal Branch News



The summer months are usually very quiet for our branch. However we still had some kind people doing fundraising for us. Three local golf societies, the Drum Bar Golf Society, the

Central Bar Golf Society and the Glencar Inn Golf Society, organised a golf tournament and presented Geraldine McGeever with a cheque for €865. Some of our members were busy too in recent months. Madeline Doherty organised a dance and gave the proceeds, €2,600, to the branch at our final meeting before the summer. Our picture, above, shows L-R Madeline Doherty, Patricia O'Gara, Maureen Giblin and Ann Foxe. Kathleen Durcan held a Quiz and at the same meeting she presented the Branch with a cheque for €550. The Branch extends a sincere thanks to all for their generosity. Finally Ellen Doherty, one of our members, and her husband James recently celebrated their Golden Wedding

Anniversary. They decided that rather than receive gifts the guests at the celebration could make a donation to the Branch. In July Ellen presented Ann Foxe with €800. Congratulations to James and Ellen and many thanks for your kindness and generosity. For further information please contact Ann Foxe: 074-9128063.

Dublin Branch News

Dublin Branch Committee members have each been enjoying our glorious summer each in his/her own way. We hope all members have been doing likewise. Our activities restart in the autumn with exercise as Phyllis Prior resumes classes at St. Anthony's community Centre in Clontarf, on Monday 13th September at 2.30 pm. Ann Walsh will re-open classes at The Sisters of Charity Donnybrook on Thursday 9th of September at 2.00 pm. Classes last one hour and the fee per class is €5. There is no need to book a place, just come along and you will feel the benefit of some light exercise and a bit of company.

The Committee has organised an autumn meeting for all members or others interested at the Tara Towers Hotel Booterstown for October 3rd at 2.30 pm. The speaker will be Dr. Raymond Murphy, Consultant Neurologist at Tallaght Hospital. This meeting will also include the launch in Ireland of a DVD on yoga by Renée Le Verrier, whose excellent book on yoga is available from the National Office.

Editor's Note: The Dublin Branch have very kindly allowed the National Office to piggyback on their meeting, thus allowing a busy Renée to come and launch her DVD en route home from the World Parkinson's Congress in Glasgow.

Christmas Gift Ideas from PAI!

Prices

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