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Parkinson's Association of Ireland

QUARTERLY MAGAZINE

SPRING 2012



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

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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.

Through the Chair

Dear Friends,

2012 will be a big year for Parkinson's in Ireland. This is our 25th Anniversary and we have started the year with a flood of activity. In early January we signed the contracts for our forthcoming patient information meeting taking place on the 17th of June in the Convention Centre Dublin. The very impressive line-up of speakers has been announced and our centre pages are devoted to this. This event will be the largest we have ever had and it is sure to be a full house. Advance bookings are now being taken through our National Office; Freephone 1800 359 359. For those who wish to secure hotel bookings, it would be wise to book well in advance as the Eucharistic Congress is also taking place on the same weekend and hotel rooms are sure to be at a premium.

Our advocacy role received a huge boost with the Oireachtas briefing, which took place in mid-January. This was kindly arranged for us by Senator Marie Moloney from Kerry. Senator Moloney has been a great supporter of our organisation and she arranged the meeting with our CEO, Joe Lynch. Joe spoke to a full audience and outlined the five main aims of the Association in 2012:

- [More Neurology Services](#)
- [More Nurse Specialist Appointments](#)
- [Provision of a Deep Brain Stimulation Unit in Ireland](#)
- [Funding for the Association](#)
- [Medication On-Time in Hospitals and Nursing Homes](#)

This meeting was quickly followed up with a meeting between the Health Information and Quality Authority, the Parkinson's Association of Ireland, Dystonia Ireland, HSE and members of the medical profession from the Mater and Beaumont hospitals. The meeting is reported on later in this magazine.

In April we hope to host a patient information meeting in the Sligo/Donegal area to mark Brain Awareness Week. More details will follow soon on this.

Unfortunately in February our CEO, Joe Lynch, left us to take up the National Manager's position with the Irish Motor Neuron Disease Association. Over the past two years Joe has steered the Association through some difficult times and he was instrumental in the delivery of over 70% of our Strategic Plan. Joe is leaving the Association in a far better position following his two year term in office. I would like to take this opportunity to wish Joe well in his new career and thank him for his sterling work on behalf of our Association and you, its members.

Yours sincerely,

Pat O'Rourke
Chairman



Speech and Language Difficulties in Parkinson's

Speech and Language Therapists work with children and adults to assess, diagnose and treat speech, language and communication difficulties. Their work aims to enable people to improve and/or retain communication through speech, gesture and/or augmentative and alternative communication (AAC) devices. Speech and Language Therapy also makes up an essential component in the management of Parkinson's Disease (PD).

Communication

Predominantly a disorder of movement, PD can affect a range of areas of communication such as reduced facial expression, stuttering, hoarse and slurred or a monotone-sounding voice and reduced rate of speech. All these factors contribute to reduced clarity of speech. Family members often describe their relation with PD as having low vocal volume, although the client themselves may have a reduced awareness of this. This can be distressing, all too often resulting in a lot of anxiety and withdrawal from social occasions.

Speech and Language Therapy (SLT) works to enable individuals maintain and develop their communication abilities while ensuring safe and manageable healthcare throughout the stages of the disease. SLT has proved an intrinsic component in the management of PD through non-pharmaceutical interventions which can maximise a patient's quality of life, independence in daily living and communication. Alarming however, while it is documented that up to 90% of people with PD have speech and communication difficulties, less than 3% seek the advice of a Speech and Language Therapist. For those that do wish to access SLT, these harsh economic times have unfortunately further compounded these figures and reduced the already limited availability of public speech and language therapy service.

Intervention

Drug-therapy is an important treatment in PD however while retarding the progression of PD is still being researched, SLT aims to minimise the secondary complications of drug-therapy through educating clients and carers in safe eating and drinking techniques, The SLT's role in education can

thereby prolong a person's self-sufficiency and reduce the need for specialist care or hospitalisations.

A range of speech therapy approaches have been used in PD to manage its effects on the voice. One such course is the Lee Silverman Voice Therapy (LSVT) approach which I attended in Glasgow in 2009. This

approach focuses on improving a client's vocal volume, breath support for speaking, speech quality, intelligibility, pitch and clarity. It is proven to be very effective, particularly in the early stages of PD. While this approach is not for everyone, LSVT is founded on a strong evidence base and can benefit many people.



Eating, Drinking and Swallowing

Many people with PD report a fear of choking at mealtimes. A dysphagia-trained clinician can devise safe eating, feeding and swallowing strategies for people with these concerns. LSVT has also produced positive results for improving a client's eating, drinking, swallowing, facial expression and so many SLTs also employ the approach for this reason.

Undertaking a course of speech and language therapy for PD requires diligence, hard work and perseverance for achieving optimum results. Prior to commencing such a course, it is important that clients first attend an Ear, Nose and Throat Consultant to ensure they are fit to carry out voice therapy.

Aisling Keogh co-founded SpeechMatters clinic with Jonathon Linklater in July 2011. SpeechMatters offers a range of services for adults and children, including LSVT for people with Parkinson's disease at its practice in Ranelagh, Dublin and throughout the country.

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Special Feature

National Parkinson's
Conference 2012

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Front Cover Picture

Paddy Conaty (Cavan/Monaghan Branch)
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Oireachtas Members Hear From Parkinson's Association



Oireachtas Briefing with Senator Marie Moloney, Pat O'Rourke & Joe Lynch

The Association started its 25th anniversary celebrations this year with a briefing to TDs and Senators in Leinster House in mid January. The briefing was facilitated by Senator Marie Moloney, from Killarney to whom we are extremely grateful. Over forty members of the Oireachtas attended the meeting to hear the CEO of the Association, Joe Lynch, outline the lack of neurological services available to the 9,200 people with Parkinson's in Ireland.

Speaking at the briefing Joe said, "We have a particular focus on the provision of healthcare supports, advocacy, information and advice to people with Parkinson's, their families and carers in Ireland. This briefing outlines the very real difficulties that people with Parkinson's experience in the public health system. Some of our members have experienced delays in seeing a neurologist of up to two years, which is wholly unacceptable, early diagnosis and treatment is critical". Joe also told the meeting that the day to day management of the disease can be affectively administered by a Parkinson's Disease Nurse Specialist (PDNS), and that unfortunately there are only four fulltime and one part time PDNSs in the Republic of Ireland. "We can and should do much better than we are" Joe said.

The meeting was told that each year more than twenty people with Parkinson's travel to the UK for Deep Brain Stimulation (DBS) at great cost to the Irish taxpayer. The human cost of this journey to people with Parkinson's is almost immeasurable and must be undertaken many times for assessment and modification. The Association is seeking a DBS unit in Ireland as a matter of urgency.

The Association also highlighted the need for medication routines to be more flexible in hospitals and nursing homes to take account of the specific needs of Parkinson's patients. This particular issue will form discussions with HSE senior management in February. The Association informed the

Oireachtas members that it receives no state funding even though it provides information and nurse support services through their helpline to the entire country.

Speaking after the event, Senator Marie Moloney told us, 'I have been working closely with the South Kerry Parkinson's Branch for many years and more recently with the National Organisation, an organisation very close to my heart. One of the reasons that I initially got involved with this great organisation was the fact that they receive no funding whatsoever from the state. They rely fully on donations and fundraising. They are one of the few disability groups in this position, and I wanted to help in any way I could on the ground or at political level.'



Senator Marie Moloney

Having met with many organisers, volunteers, and fundraisers from the Parkinson's Association over the years I can honestly say I am always completely blown away and humbled by their tireless efforts, commitment, dedication and 'can do' attitude. Whether it's jumping out of a plane, an epic cycle ride, climbing mountains, bucket collections or coffee mornings, the dedication of the members shines through in their continued, and may I say extremely brave efforts in fundraising. I cannot commend the members of the Parkinson's Association and their family and friends highly enough.

I am acutely aware of the need for further Neurological Services throughout Ireland. There are an inadequate number of Neurologists to deal with disabilities of a neurological nature. To cite an example; there is only one Neurologist in Kerry. Access to services is a necessity for people with Parkinson's. The disease is complex and requires specialist knowledge. My ultimate long-term hope for the Association would be the acquisition of a Dedicated Specialist Parkinson's Nurse Service for patients, as there are currently only five such nurses in Ireland's public health system. The emergence of such a service cannot be overstated. The provision of this service would reduce the time people with Parkinson's need to spend with a consultant, and would also reduce the amount of time people with Parkinson's need to spend in hospital.

My second long-term hope would be to see a Deep Brain Stimulation unit set up within the Island of Ireland. At present I am aware that people requiring this surgery must travel to England or mainland Europe. This is a costly and extremely stressful time for patients and their families. I really hope that within the next few years this treatment will be available here in Ireland and I will continue to press at Government level for the establishment of such a unit.

I would like to commend Grace McCrea, of the South Kerry Organisation for her tireless dedication as a carer of someone with Parkinson's and also for her leadership, time, and dedication to the organisation. I wish Mr. Joe Lynch all the best as he heads off to pastures new, he will be dearly missed by all. However, I have no doubt that I will continue to, and look forward to, working with his successor and with Mr. Pat O'Rourke in an equally rewarding capacity.

I wish to conclude by wishing every success to the Parkinson's Association of Ireland in your endeavours for 2012, be they fundraising initiatives or providing support and advice.'



ANN KEILTHY IN CONVERSATION WITH OUTGOING PARKINSON'S CEO, JOE LYNCH



Joe with Pat O'Rourke and Minister for Health and Children, Dr. James Reilly TD

AK You will be leaving us in the middle of February, we are sorry to say. Where are you going?

JL I start working with the Irish Motor Neuron Disease Association (IMNDA) on the 13th of February. It will be a challenging job with some areas that have similarities with Parkinson's but many more that are completely new. I will be taking over the National Manager's position from Larry Joyce who has been in charge of the association for almost two years.

AK Have you achieved all that you wanted with Parkinson's?

JL I think there will always be areas that are left undone. In the spring 2010 issue of our magazine I outlined that I wished for better services for people with Parkinson's and their families. I have been working very hard with an amazing team to try and ensure that this would happen. We now have a Parkinson's Nurse, Alison Cashell, on staff and our helpline is very well used. We have a fantastic large scale conference taking place in June and we recently addressed Dáil deputies and Senators and now have better relations with the HSE and the Department of Health. Also, as can be seen in this issue of our magazine, we have engaged with the Health Information & Quality Authority (HIQA) to ensure better services. However, all of these issues are still ongoing and hopefully we will see better public services



*Joe Lynch interviewed by
RTE's Fergal Bowers*

in the near future. We have addressed almost 70% of the strategic plan we adopted two years ago. This is a good start but there is a need for more focused input into patient services.

AK What is your wish for the future of Parkinson's?

JL We now fund research on an ongoing basis, this should be grown and enhanced. The forthcoming June conference will be fantastic. It will have the world's foremost authorities on Parkinson's and I am sure it will be well worth attending.

It is within the Parkinson's Association's capacity to be able to train and provide at least five nurse specialists in areas that need them if the collective spirit of the Association is harnessed. If the government can't or won't provide this type of service, the Association can and probably should.

AK Any final words for the members of the Association?

JL I want to thank everyone who welcomed me so warmly over the past few years in every one of the branches throughout Ireland. I have a very personal interest in Parkinson's as I have a family connection, so I will keenly follow the progress of the charity and I will remain a member of the Association assisting where I can. I would also like to thank my colleagues in the national office: Pauline, Alison and Lauren, brilliant and dedicated people one and all, and every one of the volunteers in the branches around the country who are working so hard on behalf of people with Parkinson's. And finally I would ask members to encourage new members to join the organisation. To take a line from a well known advertisement – there's strength in our number!



*Joe with National Office staff
and Michael Carruth*

Editors Note: As editor of this magazine I have worked with our CEO for the past two years on the editorial team, and can attest to his energy and his passion for getting the right information out there to people with Parkinson's, and his efforts to up our profile and gain government funding. He turned his hand to anything that needed doing, and that included driving on one occasion from Belfast to help with an event one weekend, arriving in Dublin before 9am. As with anything you have a commitment to and opinion on, we had some differences of opinion, but the end product was always in the members' interests and not ours. Joe, I wish you every success; you will, in my opinion, be a hard act to follow!

Ann Keilthy



PUNDING IN PARKINSON'S DISEASE

DR SEÁN O'SULLIVAN, MRCPI, PHD, CONSULTANT NEUROLOGIST, CORK UNIVERSITY HOSPITAL, CORK.

Punding is a term used to describe repetitive and pointless activities seen in some people with Parkinson's. Punding includes repetitive manipulations of technical equipment (eg dismantling and re-assembling household appliances), the continual handling and sorting of common objects, grooming, pointless driving or walkabouts, prolonged monologues devoid of content, excessive cataloguing and computer work. A feature of punding is that it is never ending, it is disorganised and frequently leaves chaos in its wake. Punding can cause social avoidance, severe sleep deprivation, and disintegration of family relationships. In most cases it is the family members who describe the full social and functional impact of these behaviours on the persons' lives.

EXAMPLE CASE:

A 67 year old man developed Parkinson's at age 61. He was a retired statistician and always had a keen interest in solving mathematical puzzles. A few years after starting treatment for Parkinson's, his family began to notice the amount of his time spent on mathematical puzzles had greatly increased. He had also developed newer hobbies, such as Sudoku and repetitive drawings, as well as undertaking an extremely detailed household budget on his computer. He would often stay awake until after 4am, and on occasions he would remain up all night doing these hobbies. When he was engaged in these activities he would "lose sense of time", frequently forgetting to take his tablets, have his food, or any other household duties. Any attempts by his family to reduce or interrupt these behaviours were strongly resisted and were associated with arguments. He and his family discussed these excessive activities with his neurologist as he was becoming extremely fatigued during the day. His Parkinson's medications were altered, and a "contract" was made between the man and his family to limit the hobbies to less than 4 hours per day, leading to an improvement in the behaviours.

HOW COMMON IS PUNDING IN PARKINSON'S?

The frequency of punding varies widely according to the definition used, but most researchers and support group workers would agree that it can affect up to 10% of people with Parkinson's. One difficulty in diagnosing punding is that the behaviours involved are often related to previous hobbies or work-related activities (as in the example above) before the onset of Parkinson's. Similarly, sometimes behaviours can begin as being a useful task (such as drawing up a household budget), but then develop into an unnecessary one.

HOW DO I IDENTIFY PUNDING?

This can also be very difficult sometimes for the individual with Parkinson's to recognise – they may be entirely unaware of the time they spend on the behaviour, they may consider it irrelevant, embarrassing, distracting or relaxing but not harmful.

Family, carers and friends are often better placed to recognise the behaviours as being excessive. Some questions to consider when trying to decide if a pastime is excessive are listed below, but the most useful one is usually "Does your hobby interfere with sleep?" If this is the case, then the behaviour is harmful.

Suggested screening questionnaire for punding in Parkinson's

- Does your hobby interfere with sleep?
- Do you have any hobbies or activities you do repeatedly?
- When did you become interested in your hobby?
- How many hours per day do you spend on your hobby?
- Do you have difficulties in finishing your hobby projects?
- How do you feel when you are interrupted when you are engaged



with your hobby (i.e., do you ever get angry or upset)?

- Do you make a mess when you are pursuing your pastimes or hobbies?
- How many hours per day do you spend on the following?
Cleaning/tidying, Gardening or DIY, Collecting things, Repairing/dismantling, e.g., computers, television, radio
Sorting, e.g., papers, through drawers/handbag, on the computer, Crosswords/Sudoku/Puzzles

WHAT OTHER BEHAVIOURS ARE ASSOCIATED WITH PUNDING?

Punding is commonly associated with other harmful impulsive-compulsive behaviours in Parkinson's and these should also be looked for.

These behaviours include:

- A failure to resist gambling
- A pre-occupation with sexual thoughts or inappropriate sexual behaviour
- An irresistible need to buy things
- Binge eating large amounts of food in a short space of time
- Excessive hoarding of items
- Reckless generosity, even to relative strangers
- Compulsive use of Parkinson's medications, in excess of that recommended by the person's doctors

WHAT CAUSES PUNDING?

One factor that is consistently associated with punding and other impulsive-compulsive behaviours is the use of dopamine replacing medications for Parkinson's. Dopamine agonists are probably more implicated in most of these behaviours, but punding in particular can also occur on higher doses of L-dopa.

WHAT CAN I DO ABOUT PUNDING?

Recognising that the behaviours involved are harmful to the person and/or their family is the first and most important step. Many families find that some form of a "contract" can be helpful, whereby the person will restrict their pastime to certain times in the day, and allow their families to enforce this deadline if necessary.

In addition to these measures, the person should also inform his/her doctor as they might require a change in their Parkinson's medications.

Sometimes an individual may require counsellors or medications to help with their mood as depression, anxiety and sleep disturbances are commonly found in people with punding. Psychiatry services can be invaluable in helping treat other less common conditions which can resemble punding, which include obsessive-compulsive disorder or mania.



Young Onset Parkinson's Disease (Y.O.P.D.)

We ARE different or so they say. Young (under 40 at diagnosis) or Early (under 55 at diagnosis) Onset Parkinson's is apparently slightly different to that developed in those of an older age, as, according to Prof. Timothy Lynch, people with Young or Early Onset (YOPD) "may develop dyskinesias within a short few years, much earlier than those with later onset, who might develop dyskinesias only after five to ten years on Sinemet/Madopar. If you study the brains of YOPD patients, they don't have Lewy bodies, so it's a different disorder."

Apart from the physical aspects of Parkinson's, there are some issues that, to quote Dr. Raymond Murphy, "affect the younger patient that are quite different to those of the older onset patient". His list:

1. The effect on one's ability to work
2. The effect on self-esteem if the wage earner becomes unable to work
3. The increased difficulty in coping with a young family, and indeed the reaction of the child towards a parent affected by Parkinson's, particularly in a teenager: "Dad/Mum you are so embarrassing!" - does that ring a bell?
4. The way diagnosis may affect your hopes and aspirations
5. The effect on sexual function.

He says that many of these apply also to the older person with Parkinson's (PWP) but "are more acutely felt in the younger."

This seems a rather dismal outlook that may dismay some, so we asked Ann Keilthy about her views as a YOPD person diagnosed 15 - 16 years ago at the age of 44.

Nothing is ever 100% good or bad, symptoms vary, progression varies, and life always throws up challenges. When I was first diagnosed my husband Liam and I both reacted with shock, and we coped by reading about and talking about it, and over the years he has supported me always. Sometimes I get upset when he does not listen to something I am saying and I often wonder what will happen further down the line, will I be left out of things? I have to stop for a moment. What am I concerned about? The potential effect of Parkinson's on our relationship and not just Parkinson's itself. I have had Deep Brain Stimulation (DBS), and will continue to try and make sure I am as well optimised as possible not just for me but for us. I have managed for the past 15 - 16 years. I am getting older - 60 approaches this month - but I don't consider myself old - yet!

A diagnosis is a shock, but things only change very slowly, and help is at hand to manage most of it. Dr. Raymond Murphy makes the following point: "One might assume that the younger patient develops the disease the more rapidly progressive it will be; strangely, often the younger onset may have a much slower progression of disease." To see how YOPD people, like Ann, cope with their disease and treatment why not visit our 'People with Parkinson's' section on our website; www.parkinsons.ie/pwp.

References:

Consultant Neurologist Prof. Timothy Lynch in an article written for PALS and available on the PALS website www.pdpals.com. Consultant Neurologist Dr. Raymond Murphy in an article written for PALS and available from PALS upon request. Email annk@pdpals.com or phone 087 2853117.

People with Parkinson's tell their stories

Each year hundreds of people in Ireland are diagnosed with Parkinson's disease and very often the impact on their lives is huge. Each individual has their own coping mechanisms and over the coming months we will regularly update a number of different people's stories on these pages. As you will see the disease progression is vastly different and the ways in which it impacts on their lives is as different as the people themselves.

The first few people we have asked to write these pages are Margaret Mullarney, David Walsh, Geraldine McGeever, Ann Keilthy, Jerry Hurley, John Carey and Martina Sinnott. David, Margaret and Ann all live in Dublin and have differing views on life but they have an excellent attitude to Parkinson's and how to deal with it.

Margaret recently completed the Dublin City Marathon in October and the Glasgow Marathon in September. Margaret is also travelling to Branches throughout Ireland to meet people with Parkinson's and their families and she addresses these meetings to pass on her inspirational message. She also has a very successful blog that has featured in the top forty blogs for Parkinson's Awareness Week 2010.

David Walsh is in his mid forties and extremely fit. He had noticed the symptoms of Parkinson's creeping up on him from his late thirties but was not diagnosed for over two years. He is an amazing man who deals with everything life has thrown at him with natural good humour and determination. He has just come back from a solo cycle ride across America to raise funds for the association and its work, and having survived all that the elements threw at him there, his bike was stolen in Dublin!

For further information and to follow our People with Parkinson's visit www.parkinsons.ie/pwp where you will find many more stories.





National Parkinson's Conference 2012

As reported in our winter 2011 magazine the Movement Disorder Society Worldwide (MDS) are holding their 16th International Congress of Parkinson's Disease and Movement Disorders in the Convention Centre, Dublin starting on June 17th, 2012. We will be running a very special Parkinson's Information Meeting for people with Parkinson's and their carers as a satellite to the main conference. This patient meeting will be the largest single event out of our schedule of events to mark our 25th Anniversary. We have invited some of the most renowned speakers on Parkinson's to participate in this event. The agenda for the meeting is set out below and we have included profiles for each of the speakers (below and on page 9).

The cost for attending the conference is €25, which includes a light lunch, and must be paid in advance. Bookings can be made over the phone to Pauline Mahady in our National Office – 1800 359359. The weekend of the 15th – 17th of June is hectic in Dublin with the Eucharistic Congress also taking place along with the MDS conference. Hotel rooms will be difficult to find and early booking would be advised. The Maldron Hotel, Parnell Street, 01 - 871 6800, and the Maldron Hotel, Smithfield Market, 01 - 485 0900, do have a small number of rooms at this stage and we would advise those who wish to book to secure the rooms as soon as possible. Both hotels are close to the LUAS line, which runs close to the Convention Centre.

We are very grateful to Professor Tim Lynch for his assistance in securing this very special event for all of you. It is important to note that this agenda may change as we may be able to secure additional speakers in time. We are delighted to have secured all of the speakers for the conference and we hope to have over seven hundred people in attendance. Don't be left out, book early and secure your place!

Conference Agenda

TIME	TOPIC	SPEAKER
10.15	Arrival & Registration	
11.00	Welcome Address	To Be Confirmed
11.10	Parkinson's Disease from James Parkinsons to Current Day	Professor Stanley Fahn
11.30	The Drug Management of Parkinson's	Professor Werner Poewe
12.00	Questions & Answers	
12.15	Growing Old with Parkinson's - Principles and Considerations	Dr. Graham Hughes
12.45	Depression and Compulsive Behaviour in Parkinson's	Professor David Burn
13.15	Questions & Answers	
13.30	Lunch	
14.30	Deep Brain Stimulation (DBS)	Dr. Philip Starr
14.50	Future Directions of Parkinson's Disease	Professor Olivier Rascol
15.10	Questions & Answers	
15.25	Practical Advice on Day to Day living with Parkinson's	Mr. Brian Magennis PDNS
15.45	Questions & Answers	
16.00	Close of Meeting	



The Convention Centre Dublin

Meet Our Speakers



Stanley Fahn, M.D. is the H. Houston Merritt Professor of Neurology and Director of the Centre for Parkinson's disease and Other Movement Disorders at Columbia University. He is the Scientific Director of the Parkinson's Disease Foundation. He has served as a member of the Scientific Advisory Board of the Dystonia Clinical Medical Research Foundation and is currently a lifetime honorary member of its Board of Directors. Dr. Fahn has served as the founding director of the Dystonia Clinical Research Centre at Columbia University, funded by this foundation. He previously served on the Medical Advisory Board of the Myoclonus Research Foundation, the Scientific Advisory Board of American Parkinson's Disease Association, and chaired the Medical Advisory Board of the Committee to Combat Huntington Disease. He currently chairs the Parkinson's Community Research Advisory Council of the Michael J. Fox Foundation for Parkinson Research.



Professor Werner Poewe is Professor of Neurology and Director of the Department of Neurology at Innsbruck Medical University. His research interests are in the field of movement disorders with particular emphasis on the diagnosis, clinical presentation, natural history and treatment of Parkinson's disease and related disorders. Professor Poewe has served as PI or Steering Committee member of numerous multinational randomized controlled trials targeting Parkinson's disease in related movement disorders. Professor Poewe is the author or co-author of more than 550 original articles and reviews. He has served on the Editorial Board of international neurology journals, including Movement Disorders, Journal of Neurology and European Journal of Neurology and is a regular reviewer for major journals, like Lancet Neurology, Brain, Movement Disorders, Neurology and Annals of Neurology. He has served as President of The International Movement Disorder Society, as President of the Austrian Society of Neurology and the Austrian Parkinson's disease Society. He is also Chair of the European Section of The Movement Disorder Society and has been elected corresponding member of the American Neurological Association and Honorary Member of the German Society of Neurology and the Japanese Society of Neurology.



Dr. Graham Hughes is a Consultant Physician in Geriatric Medicine and General Medicine in St. Vincent's University Hospital, Dublin. He graduated from Trinity College Dublin in 1997 and received his geriatric training in the Northern Deanery in the U.K. He has particular interests in Parkinson's disease (PD) and integration of older people's care across the services interfaces. He has been a consultant with special interests in movement disorders since 2007 in the U.K. and Ireland. The Movement Disorder Service in St. Vincent's University Hospital is integrated between the Departments of Neurology and Geriatric Medicine which permits appropriate patient assessments in specialist and nurse specialist clinics, day hospitals and local nursing care facilities. He has performed research and has publications in PD and Progressive Supranuclear Palsy. Graham is an active lecturer in Movement Disorder at undergraduate and postgraduate level and has presented and chaired national meetings in this area.



Brian Magennis was the second Parkinson's Disease Nurse Specialist appointed in the Republic of Ireland and since 2003 has worked at the Mater Misericordiae Hospital, Dublin alongside Professor Tim Lynch, Consultant Neurologist and his team. Brian trained and registered as a General Nurse in 1992 and a Sick Children's Nurse in 1996. In 2000 he undertook the Parkinson's disease Nurse Specialist course in Cornwall, U.K. He completed the Postgraduate Diploma in Professional Nursing Studies at Trinity College Dublin in 2005. He is also registered with the National Council for Nurses in Ireland as a Clinical Nurse Specialist in Parkinson's disease and Movement disorder care. In 2007 Brian developed the Parkinson's disease treatment Algorithm with Prof Tim Lynch and in 2008 he co-wrote "Parkinson's disease – A Nurses Handbook" with Margaret Richardson PDNS. He has also written many articles, patient information leaflets and cards and in 2011 recorded a patient information video called "An introduction to Parkinson's disease" available to download on YouTube or can be viewed at www.parkinsons.ie.



Dr. Philip Starr is currently Professor of Neurological Surgery, and holds the Dolores Cakebread endowed chair at the University of California, San Francisco. Dr. Starr received his medical and doctorate degrees from Harvard Medical School, did his neurosurgery residency at Brigham and Women's Hospital, and completed a fellowship in movement disorders surgery at Emory University. He is founder and surgical director of the largest program for deep brain stimulation in the Western USA. His NIH funded research addresses the effects of disordered basal ganglia output on cortical function in patients with movement disorders. In addition, with UCSF colleagues Drs. Paul Larson and Alastair Martin, he has developed new surgical approaches to achieve very accurate implantation of drugs and devices at deep brain targets, using interventional MRI. Dr. Starr directs a fellowship training program in functional neurosurgery, and is past president of the American Society for Stereotactic and Functional Neurosurgery.



Dr. Olivier Rascol is Professor of Clinical Pharmacology in Toulouse University Hospital since 1993. He obtained his MD in Neurology (Toulouse, 1985) and his PhD in Neurosciences (Paris, 1992). Dr Rascol has been running the Toulouse Clinical Investigation Centre since 1994 and the Toulouse European Space Clinic since 1998 and he is also running a Research Group on Motricity in the Research Unit INSERM U825 and is the coordinator of the French Reference Centre for Multiple System Atrophy (Atypical Parkinsonism). Dr Rascol is the chair of the national network of the 56 French Clinical Investigation Centres since 2008 and the chair of the NS-Park Neurosciences Network of the French CIC since 2010. As a neuropharmacologist, Dr Rascol's main fields of interest are Parkinson's disease and movement disorders, drug development for Parkinson's disease and functional neuroimaging. Dr Rascol has been actively involved in the development of several marketed antiparkinsonian medications (ropinirole, rasagiline) and he is currently running several research programs for disease progression and symptomatic management of PD.



David Burn is Professor of Movement Disorder Neurology at Newcastle University and Honorary Consultant Neurologist for Newcastle upon Tyne Hospitals Foundation Trust. He is Director of the University's Institute for Ageing and Health, Director of Newcastle Biomedicine's Clinical Ageing Research Unit and a Senior NIHR Investigator. He qualified from Oxford University and Newcastle upon Tyne Medical School in 1985. His MD was in the functional imaging of Parkinsonism. He runs the Movement Disorders service in Newcastle upon Tyne which provides a large regional service. Research interests include dementia associated with Parkinson's disease and progressive supranuclear palsy. He was a member of the Special Interest Committee Task Force of the International Movement Disorder Society for Diagnostic Criteria for Parkinsonian Disorders (2002-03) and the Parkinson's disease Dementia Task Force (2004-6) and was appointed NIHR-DeNDRoN Associate Director/National Lead for Parkinson's disease in July 2010. Professor Burn is currently Chair of the MDS Congress Scientific Programme Committee and he has published over 180 articles on movement disorders in peer reviewed journals.



ASK OUR NURSE



Alison Cashell, RGN, Parkinson's Disease Nurse. To make an appointment to speak to Alison call 1800 359359 or email her nurse@parkinsons.ie or fill in the online form on our web site www.parkinsons.ie/advice_asktheexperts

QUESTION My mother was recently diagnosed with Parkinson's. At the time her main symptom was a tremor but lately she has started to experience changes in her mobility and balance. Her doctor said we did not need to take any action beyond getting medication but she now feels she should start to look at therapies and adaptations for her house. Can you advise what therapies would be recommended for her, and what first steps we should take to make her house more suitable? Also are grants available for house adaptation?

ANSWER Thanks for your email. I would recommend that you contact your mother's Public Health Nurse (PHN) and she can organise a community Occupational Therapist (OT) to visit. They would be the best people to advise you on any adaptations you mother may need, and how to apply for grants etc. I know that the waiting list for the grants is long, so if you were in a position to make some of the adaptations yourself (like grab rails, or shower chairs), the OT could advise you on this too. When you say therapies, what do you mean? If you mean Physio or something similar, this would be an excellent idea, as exercise can help to alleviate the stiffness and slowness often associated with Parkinson's

QUESTION My mother is 83 and was diagnosed approx 5 years ago with Parkinson's disease. Her main complaint at present is severe dizziness, poor balance and restless leg syndrome in the evenings and sometimes during the night. I was wondering if you have any helpful suggestions. Many thanks.

ANSWER Dizziness and poor balance often go hand in hand, so there are a few tips I can give... When standing, get your mum to sit at the edge of the chair before she stands, and stand up slowly. Advise her not to walk off until she feels steady on her feet. Also, it could be related to low blood pressure, so unless your mum has a restricted fluid intake for medical reasons, maybe try to get her to increase the amount she drinks during the day. Increasing her fluid intake should in turn improve blood flow and circulation. Another alternative may be to increase salt intake, but you need to speak to her GP or a dietician before doing this, as I don't know your mother's medical history. As regards the restless legs, this is effectively treated with medication, which can be prescribed by her GP or Neurologist or Geriatrician.

QUESTION My father has Parkinson's disease, he also has depression. Recently he was hospitalised for eleven weeks after getting severely dehydrated due to swallowing difficulty. He is now home with a feeding tube which is very successful. One thing I have noticed is his voice is very weak. I was wondering if there is anything we can do to improve that. Thank you.

ANSWER People with Parkinson's will often complain of a soft, quiet voice. Unfortunately, there is not a lot to do, besides vocal exercises. A Speech and Language Therapist (SLT) would be the best person to advise you on what exercises are most successful. Many of the SLT voice programmes require physical effort, so not everyone is suitable for them. There should be an SLT in your local hospital, they probably assessed your dad when he was in hospital, and recommended the feeding tube. Or there may be a community SLT in your area, and your Public Health Nurse is the link to all the community services in your area

QUESTION My mother was diagnosed with Parkinson's last year. She really has given up recently and does not go out alone and is not handling it very well. Her main problem according to her is that she only sleeps for a couple of hours at night. She does have sleeping tablets but still says she only gets 4-5 hours sleep, any suggestions?

ANSWER Sometimes sleeping tablets work, but it depends on what is keeping your mother from getting a good night's sleep. For example, is your mother waking because she is uncomfortable? Or is she waking to go to the toilet, and then can't go back to sleep? Or does it take her so long to fall asleep, that she only has a few hours before it is time to get up? Also, depression can affect sleep – it may be that if your mum is having difficulty dealing with her diagnosis, maybe this is what is causing problems with her sleep. Each of these problems are dealt with differently, and I would suggest that you should find the root of the cause of poor sleep, then speak to her doctor (her GP or Consultant), and devise a plan together.

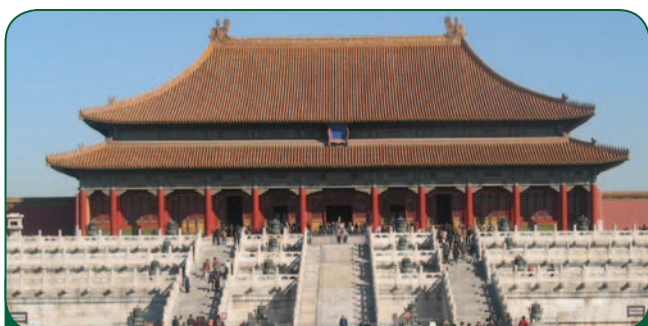
QUESTION My father has recently been diagnosed with Parkinson's. He has been seen by a specialist and is receiving a number of different medications. I was wondering if you knew of any up-coming Parkinson's treatment trials in Ireland that we could look in to? I know a number of different factors will determine whether or not he is acceptable for any of these trials however I would be particularly interested in stem cell research if that was being carried out. Any information you provide will be greatly appreciated.

ANSWER Thanks for your email. I am not aware of any specific trials that are on at the moment for straight forward Parkinson's. The specialist that your dad attends is probably the best person to ask, as they may be linked in with a particular trial or be aware of one in the pipeline. There were trials previously on stem cells taken from skin biopsies, but that trial is no longer taking on participants.



Great Wall of China Trek 2012

Every year our charity needs donations and fundraisers to enable us to run our charity and to assist with research into the Parkinson's disease. This year we have teamed up with a young Irish Company, Earths Edge, to host our largest fundraising event; an expedition to the Great Wall of China. For many people the Great Wall appears on their 'bucket list' and we hope many people will wish to take part to this expedition destination.



Traditional Chinese Temple

Each year thousands of people walk the wall and our group will be part of this great tradition. The Great Wall of China is arguably the most impressive man-made structure in the World. Construction of the 6,000km long wall began in the 5th century and finished in the 16th century. The wall formed the front line defence of Imperial China which was under attack from nomadic tribes.

Trekking the wall is truly an experience of a lifetime. On a clear day one gets a fantastic view of the wall winding through and over the beautiful mountains that once formed China's northern border. As well as walking along the wall we visit nearby villages meeting friendly locals and getting a great sense of rural life in China. After the trek enjoy a full days sightseeing in Beijing including Tiananmen Square, the Forbidden City, the Temple of Heaven and the Summer Palace. Enjoy the amazing food of Beijing which, for some people, is a greater experience than seeing the wall!

Each participant is asked to raise €4,200 and a non refundable booking deposit of €500 is required per person. All funds will be lodged directly to Parkinson's Association of Ireland fundraising account. The trek will take place in the first week of September and last around ten days. For further information please contact our national office.



The Great Wall of China

3rd Annual Parkinson's Raffle

Over the past few years our annual raffle has become an integral part of our annual fundraising.

This year's raffle is even bigger than last year with twenty prizes to suit just about everyone's tastes. Our thanks go out to the Kilkenny Ormonde Hotel and the Rochestown Park Hotel, Cork, for their kind donations of weekends away for two lucky winners. We are also very grateful to Ann Keilthy who has donated a beautiful gold necklace and Mrs. Sheila Clarke for her donation of a hand crafted throw. We also have an eclectic mix of other prizes, which make this a great summer raffle. The draw will take place in the Carmichael Centre, Dublin on Friday the 18th of May at 12 noon. We have included two books of tickets with this edition of our magazine and a freepost envelope to return the ticket stubs and payment. If you require additional tickets please don't hesitate to contact our national office for more and good luck!



Rochestown Park Hotel



Ormonde Hotel, Kilkenny

- ◆ 2 Nights B&B and one evening meal at the Kilkenny Ormonde Hotel
- ◆ 2 Nights B&B and one evening meal at the Rochestown Park Hotel, Cork (up to end of October 2012)
- ◆ 3 x €100 All4One Gift Vouchers
- ◆ Newbridge Silverware 44 piece cutlery canteen
- ◆ Newbridge Silverware 3 piece tea service
- ◆ Newbridge Silverware purse
- ◆ Gents Sekonda watch
- ◆ Ladies watch, bracelet and necklace set
- ◆ 16" Ladies gold necklace
- ◆ Vivitar 7.1 Megapixel Digital Camera
- ◆ HP Deskjet 1050 Printer
- ◆ Russell Hobbs food steamer
- ◆ Morphy Richards Café Mattino Coffee Maker
- ◆ Handmade throw
- ◆ 3 Newbridge Silverware Parkinson's Pendants
- ◆ 2 Signed Copies of Nevin Maguire's 'Country Living' Cook book



You've got to be quick to catch the Flora Women's Mini Marathon 2012



Flora Women's Mini Marathon 2012

This year is our charity's 25th Anniversary and we hope to make this our biggest Mini Marathon year yet! So dust off the running shoes and pick up the phone and call us for a fundraising pack which includes a Parkinson's Tee Shirt and sponsorship card. We can't do what we do without you! Join us on the 30th Annual Mini Marathon and help raise funds for our cause. Last year many of our regular supporters were very disappointed when entries for the Marathon closed early (almost a month early). So don't wait around, register today and then give us a call and join the dozens of women from all around the country who will take part this year.

Many people are also using Facebook and MyCharity.ie to help with their fundraising. If you need assistance, just call us for help. Oh and don't forget to join us after the race for a well deserved cup of tea and some snacks. For further details call Pauline on 1800 359359.

Hair Raising Experience

Grace McCrae, president of the South Kerry Branch, contacted us recently to tell us about a novel fundraising evening organised by Mr. Denis Desmond. Shaving bearded men in aid of local charities was Mr. Desmond's idea and several thousand Euro was raised on a wet and windy Friday evening recently when a string of volunteers were shaved for the cause. Other charities to benefit on the night were the Diabetes Federation and the Irish Cancer Society. Grace and Jack McCrae were on hand to lend

their support in the Bridge Bar, Rathmore. Well done to all the brave volunteers who had a close shave and a big thank you to Denis Desmond.



Kerry Branch members - A cut above...

Mulled Wine & Mince Pie Walk

Bailieborough local man, John Ed Sheanon contacted Sheila Clarke, one of our members from the area, just before Christmas to ask if he could raise funds for our charity in a pretty unique way; a Mulled Wine and Mince Pie Walk.



John Ed Sheanon

As you can see from the event picture it was no easy walk, but the reward of hot mince pies and warming mulled wine was irresistible to the dozens who participated. Over €1,600 was raised and Sheila was the first to congratulate John Ed for his fantastic generosity and unique idea. Most of the funds will be used to ensure that our Nurse led Helpline will continue its valuable work over the coming years. Cheers to Sheila and John Ed!

2WillDo Charity 25 Chooses Parkinson's



Mrs Browne helps with launch of 2WillDo

Charity 25 is a fully audited, low-cost organisation that has extremely low overheads run by professional volunteers. It is a charity that operates purely to raise funds for their chosen 25 Irish National Charities. They do this through a text campaign called 2WillDo. Charity 25 does not even have a salaried CEO or Directors. The organisation ensures that their operating costs are kept to a minimum, thus guaranteeing that their charity partners, of which Parkinson's Association of Ireland is now one, receive maximum funding from the 2WillDo text campaign.

Charity 25 operates by donations made to it through 2WillDo text messages ensuring €1.94 of every €2.00 raised goes directly to all 25 charity members. The remaining €0.06 is an administrative charge by the mobile phone operators. This ensures that they operate on the strictest of budgets which in turn means that if they reach their annual fundraising target of €1 million between 2011 and 2012, then our charity will receive the sum of €40,000. To donate text 2WILLDO plus your county to 57802. So what are you waiting for text now!



Parkinson's Awareness Week: 9th – 15th April, 2012

This year Parkinson's Awareness Week will take place from the 9th to the 15th of April. We hope to launch the week around the 2nd of April and we are asking all Branches to host at least one event during the awareness week. This is our second awareness week and we hope to inspire more activities and greater media attention during the whole of April but particularly between the 9th and 15th. If you have an idea about an event to mark the occasion please tell your Branch and get them to tell us! This is a great time to raise awareness and gain new members.



Parkinson's Awareness Week supporter Michael Carruth

Brain Awareness Week: 5th – 11th March, 2012



The dates have been set for Brain Awareness Week (BAW) 2012, March 5th to 11th. This event is organised by the Neurological Alliance of Ireland (NAI) to highlight neurological issues in Ireland. National Brain Awareness Week is growing in strength size each year and this is made possible by the continued dedication of all of the Neurological Alliance of Ireland member groups who organise and support the many worthwhile and beneficial events throughout the country.

Brain Awareness Week 2011 saw over 90 events take place nationwide which made it the busiest awareness week to date. To mark our participation we are hosting a pilot ten session Metronome Physiotherapy Training programme in conjunction with the HSE North Central, commencing in early March. The results of the training will be published in our summer magazine.

Health Information & Quality Authority (HIQA) Meeting

For the past two years our association has been campaigning for the introduction of Deep Brain Stimulation (DBS) unit in Ireland on an Island of Ireland basis. At the time of writing over twenty people per year travel to the UK (primarily) to have DBS implantation carried out. It must be noted that not every person with Parkinson's is a viable candidate for the DBS treatment; however a significant number, around 10% -15% would be eligible to have this form of treatment. Ireland is now one of the few countries in Europe where DBS is not routinely used in the treatment of people with Parkinson's.

In September 2011 a delegation from the Association met with the Minister for Health, Dr. James Reilly TD, and outlined the Association's contention that there should be a DBS unit in Ireland as a matter of urgency. The Minister was receptive to our approach and assured us, at that time,

that if such a unit could be established safely and within the constraints of the HSE budgets, it would be examined carefully. In late December HIQA contacted the Association to invite our CEO, Joe Lynch, to take part in an expert advisory group along with HSE officials, a member of Dystonia Ireland and leading neurologists and surgeons and a movement disorder nurse. The first meeting took place in late January with a follow up meeting scheduled to take place in May. The main issues concerning HIQA are the feasibility of the project: are the skills, equipment and staff available, would such a project be cost effective; is sending patients to the UK more cost effective than setting up such a unit in Ireland, and patient safety: is setting up a unit here safe including all of the aftercare needed.

Members of the group from the patient representative side gave examples of the difficulties experienced through having to have the surgery carried out in the UK. Interestingly it was also highlighted that some patients who were candidates for DBS may not be recommended by a neurologist based on the difficulties they would face in getting to and from the UK and their poor support mechanisms when they return. We will report further on this issue as information becomes available. HIQA has assured us that a full report will be published by them at the end of the process, towards the end of this year.



the soulstir sessions

hear the difference

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Whelans (Wexford Street Dublin)

Parkinson's Association of Ireland (PAI) All Ireland Initiative in association with

PARKINSON'S CHANGE ATTITUDES. FIND A CURE. JOIN US.

Saturday 28 April 2012 8pm

Parkinson's Awareness Week In Aid Of Parkinson's Disease

Poster design by Regene Whelans & Associates



Tipperary Branch

Happy New Year and many blessings to all our members. Well done and thanks to Irene Carey for representing the branch in the Dail on the 18th January.

Branch activities started for the New Year with a very successful afternoon of music, song and refreshments in the Ragg, Thurles. Many thanks to all our musicians and singers and members who attended this very enjoyable afternoon.

We are delighted to welcome back our Speech Therapist Evelyn Norton and congratulations to Evelyn on the birth of her new baby. Evelyn will be available on Friday 9th February, details to follow. Looking forward to seeing everyone during 2012. Contact: Mary Carey 086-3916726 or Michael Burke 087-2864798

PALS Branch

Our Christmas party was good fun, lots of good food, a Kris Kringle and a raffle! I can report that I won a prize - one of the items I brought in as a raffle prize went home with me again!!!

I want to thank the committee - Tim and Rebecca Kelly, Brian and Cathy Pollard, Eddie O'Brien and Frances O'Sullivan for all their hard work during the year, and especially for the way we all worked as a team. It was a privilege to work with each and every one.

We are starting the New Year with a talk on January 29th, in the Tara Towers Hotel, starting at 3pm, and we are delighted to report that PAI CEO Joe Lynch will relate the adventures of the group he led to the summit of Mount Kilimanjaro. This promises to be a good afternoon, and we look forward to seeing you there! Contact: Ann Keilthy 087- 2853117.

Galway Branch

We will have our next meeting on Wednesday the 21st of February 2012 at 8pm in the Clayton Hotel, Ballybrit, Galway. Our Physio, Speech & Language and Yoga will be commencing in February. All those interested in taking part please contact us. We will have various speakers at our upcoming meetings. Contact: Marie Cahill 087-7783825

Dublin Branch

The Chairperson and Secretary of the Dublin Branch attended a meeting with TDs and Senators at the Dail on the 18th January. There was a good attendance and hopefully will be followed by constructive results. A meeting of representatives from countrywide branch committees took place in the Aishling Hotel after the Dail meeting. This was very successful and informative. Another meeting is planned for April.

There will be a meeting for all members of the Dublin Branch in March. Details of this will be in the Branches Spring Bulletin.

Hopefully 2012 will be a year when many new helpful initiatives will be put in place for all persons suffering from Parkinson's disease and their carers. Contact: Isabel 01-4909646

Waterford Branch

The Waterford and SE Branch have had a fairly busy few months with good and not so good events intermingled. The good news is we have continued to fund and enjoy our classes with help from members and friends and a very



enjoyable Christmas Party was had with a "concert" in which members and tutors participated.

On the other hand we have had some members or their partners who have had a few health problems and are now making slow but sure recovery. We also had the death of one of our much valued members, Paddy Duggan who shall be sorely missed (as he rolls up his mat at 17.55pm precisely). Our condolences go to his wife May and son, daughter and wider family. Contact: Teresa Peacock 051-383685

Cavan/Monaghan Branch



Our AGM took place on Saturday 28th January in the Seven Horse Shoes in Belturbet.

We also held our annual dinner on that date with guests from the Fermanagh Branch. This event was addressed by Pat O'Rourke, Chairman

and was also attended by Seamus Funge, Director of the Parkinson's Association. We held a very successful meeting towards the end of last year in Monaghan. Pauline Mahady, Helpline Manager gave an informative talk on the work of the office. Approx 30 people attended.

We also attended the Dail briefing on 18th January, where we were able to put forward our views on the appointment of a neurologist to the Enniskillen hospital. This appointment could cover the Cavan/Monaghan area. We had an assurance from the representatives that they would take up the matter with the Northern Ireland Ministry for Health. Contact Paddy: 049-4332821

Louth/Meath Branch



We had a flag day a couple of days before Christmas in Dunleer. Many thanks to Thomas & Ann Matthews for organising that. We are holding a branch meeting on Thursday 8th March 2012. We hope to see all our members there as we have an

interesting line up for the night. We had two representatives from our branch attend the Dail briefing on 18th January. Contact: Maurice O'Connell 087-7512608

South Kerry Branch

Kathleen & Teddy Cronin made a trip back to Bristol for her DBS check up. She is still finding her life difficult and we hope she will soon feel a lot better.

We had a fantastic turnout for the walk and head shave of four men at the Bridge Bar Rathmore. Three local charities were involved. Thank you to Senator Marie Moloney of Killarney for all her hard work for the Parkinson's Association. We are so grateful to Senator Moloney and her husband Mike for their hospitality in inviting 13 branch members to the Dail on 18th January. Everyone had a day that we will always remember.



BRANCH NEWS

A very big thank you to Joe Lynch CEO and his team in the National Office for giving us a great welcome. We are sorry to lose Joe and we wish him success in his new position. We wish Noreen Kenny a speedy recovery. Contact: Grace McCrea 064-7758837

North Kerry Branch



At our pre-Christmas social evening in the Three Mermaids, Listowel, we were delighted to meet our special guests, Mary and Cliff Gore. Mary was the founder of the North Kerry Branch and was the enthusiastic and highly efficient Secretary for many years. Cliff is a talented artist

and is still busy at his easel creating his paintings. He is never happier than when he is in his garret studio working on his latest masterpiece.

We send our condolences to our Committee Member, Joan Rogers, on the recent, unexpected death of her husband, Stanley.

Congratulations to Mary Lynch who organised and ran a successful Fashion Show in Tralee recently in aid of Parkinson's.

Our next Committee meeting is at 8 o'clock on the 21st of February - a date for noting in your diary!!! Contact: Jerry 068-22089 or Mary 087-2935 787

Mayo Branch



We held our A.G.M. on Jan 29th in The Traveller's Friend Hotel Castlebar. There was a huge turnout which we were really glad to see as we had put a lot of effort in to advertising and organising the meeting. The meeting was chaired by Pat O'Rourke, Chairman, Parkinson's

Association of Ireland. We thank Pat for coming to Mayo for the A.G.M. he was very informative and offered all the help we would need from the National Organisation. Vincent McDonnell was proposed and seconded for the position of Secretary, Mary Nolan was proposed and seconded as Treasurer and Marian Newman was proposed and seconded as Chairperson.

The main topic of discussion was the lack of services available to Parkinson's sufferers in Mayo. Physiotherapy is practically non-existent. Speech therapy is not freely available and many patients had not been referred for a neurological consultation.

As the newly elected secretary I will contact the various services and relate my findings to the next meeting. As a result of our meeting and thanks to all who turned up we now have numbers to present to the HSE and show how many patients are waiting for these services which are vital for us. Hopefully as our branch expands we will have more positive and cheerful news to contribute. Contact: Vincent McDonnell 086-8305907



The Soulstir Sessions is dedicated to fundamentally shifting the awareness of Parkinson's Disease throughout the island of Ireland. Holding nights of truly great music with both established and up-and-coming musicians, we are here to make a real difference to those with Parkinson's Disease and their families. We aim to fund improved services and support research to find a cure.

Enjoy the music, hear the difference.

Working with the Parkinson's Association of Ireland and Parkinson's UK - N. Ireland Region, our intention is to hold gigs in as many towns and cities across the island as possible in as many musical genres as possible.

The first of a number of gigs will be held on Saturday 28th April 2012 in the legendary Whelan's of Wexford Street, Dublin. With a line up of really great musicians and bands from North and South playing in this intimate venue, this promises to be a night to remember. Don't miss it! Tickets available at www.whelanslive.com, via the Whelan's box office (Wav tickets) at 1890 200 078 or internationally at +353-1-4780766. From the North, as another option, tickets can also be purchased from Fa' Joes bar, Lurgan at 0044 (0)2838342335. Tickets cost €15 plus a €1.50 booking fee.





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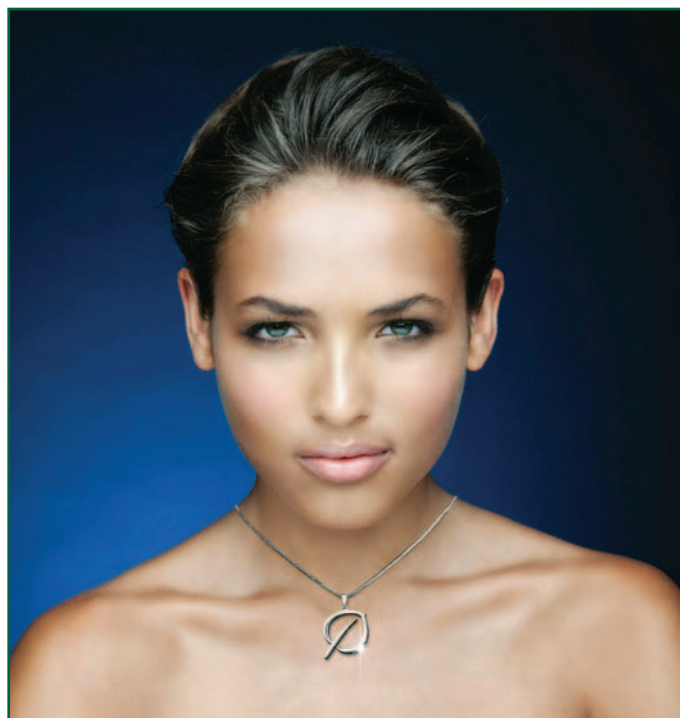
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