

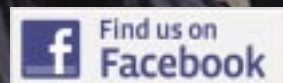


Parkinsons.ie

Parkinson's Association of Ireland

QUARTERLY MAGAZINE

WINTER 2011



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

Through the Chair

Dear Friends,

Over the past year I have been in a position to meet many people with Parkinson's and their families and it has been both educational and inspiring. With Christmas approaching it's often a good time to look back at the year that is almost past and reflect on what we have achieved in 2011 and look forward to 2012. One of the most important occurrences of the current year was the employment of a Nurse with a very good knowledge of Parkinson's disease. Alison Cashell took up her post with us in February and she stepped up to the plate very quickly with a TV interview on RTE on just her second day with us! Since then Alison has been visiting Branches and taking call and emails from people with Parkinson's throughout the country.

In March our National Office moved to new office space within the Carmichael Centre. During the year we had three very well attended Patient Information Days in Clonmel, Bantry and Dublin. A huge number of people, over three hundred and seventy, attended these events. Many thanks go to Orion Pharma for their assistance and all of the speakers and organisers who gave so freely of their time. April marked our first Parkinson's Awareness Week. Olympic Gold Medallist, Michael Carruth, launched the week for us and he also took the opportunity to join the association and sign the World Parkinson's Pledge. A large debt of gratitude is owed to Shay Healy, who graciously put together a fantastic radio advert that was played on Newstalk and Today FM throughout Awareness Week. We also re-launched our very successful website, www.parkinsons.ie, in April. A great achievement for all involved. In May all of our co-opted Directors and three new Board members, David Donegan, Declan Moriarty and Nicola Clarke were elected to our Board.

The Carruth family hosted the first annual Austin Carruth Memorial Pitch and Putt Classic in the Spawell Complex in memory of their late father. This was a hugely successful event and the current total from it stands at over €12,000. In September nineteen brave souls set off for the heights of Kilimanjaro and in the process they raised over €93,000. A huge debt of gratitude is owed to all those involved in all the fundraising activities for Branches and the National Office throughout the year. In October we held our Annual Social Weekend in the Ardilaun Hotel, Galway, which everyone enjoyed. A new Dáil was formed earlier this year and in October we took the opportunity to lobby TDs and we met the Ceann Comhairle, Sean Barrett who assisted us in arranging a meeting with the Minister for Health, Dr. James Reilly TD. We presented a number of ideas to the Minister and he asked for more information from us, which we are now preparing for him. We are ending the year still raising awareness with our 'Understanding Parkinson's Disease – It Makes Sense' campaign. For more on this see page 4 of this magazine or visit our web site.

2012 is shaping up to be a big year for the association. Next year will mark our 25th anniversary and we aim to deliver more services and supports to members. A special mention must be made of the World Movement Disorder Society's (WMDS) conference, which will take place in Dublin from the 17th to the 21st of June 2012. As you will see later in this edition, we have achieved a huge success by arranging to host a very special Patient Information Day on the 17th of June in the National Convention Centre alongside the WMDS' conference. The speaker line-up has yet to be announced; however we do know that world authorities on neurology, drawn from the speakers at WMDS conference, will be on the list. We will be carrying out a patient survey early in 2012 and we are also carrying out two pilot studies that we hope will be of benefit to people with Parkinson's. If successful it is our intention to roll these out nationwide. It would be remiss of me not to thank my colleagues on the Board and our National Office staff, Pauline, Alison and Lauren, under the direction of our CEO, Joe Lynch, who have all worked so diligently on our behalf throughout the year. I also want to thank all of the Branch officers who give their time and effort so willingly to keep all our Branches working and who provide badly needed services to our members all year round. Finally huge thanks to every one of our members for your support of our association and all of our events throughout the year. I wish you a very happy Christmas and healthy New Year.

Yours sincerely,

Pat O'Rourke

Chairman

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

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

This issue of our magazine was supported by Abbott Pharmaceutical



Christmas & New Year Closing Times

The management and staff of our National Office would like to thank all of the Branches and members for their continued support for the association throughout 2011. Our National Office will be closed from Friday the 23rd of December until Tuesday the 3rd of January. Please note, our helpline will also be closed during these times.

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Special Feature

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Front Cover Picture

Top of the world: Parkinson's trek to the top of Kilimanjaro in September.

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Neven 'Nose' Best: Top Chef Launches Parkinson's Awareness Campaign



Aimee Casey, Pat O'Rourke, Neven Maguire, Joe Lynch

Campaign highlights lesser known 'invisible' symptoms of Parkinson's

Awareness of Parkinson's is not high in Ireland and in November we teamed up with Lundbeck Ireland to raise awareness of the Non-Motor aspects of Parkinson's. Celebrity chef Neven Maguire is lending his distinguished nose to an educational campaign which seeks to highlight the lesser known non-motor symptoms of Parkinson's disease.

The 'Understanding Parkinson's Disease – It Makes Sense' campaign aims to raise awareness of the non-motor symptoms associated with the disease which can include:

- ◆ Loss of smell and taste
- ◆ Constipation
- ◆ Depression
- ◆ Sleep disturbances.

These non-motor or often 'invisible' symptoms require long-term management in the community, usually with the assistance of a GP or nurse, and are known to impact on the quality of life for people with Parkinson's. Commenting on his involvement in the campaign, Neven said: "It is the small things that matter and I know I would

find it not only frustrating, but impossible to do my job if my sense of taste or smell began to deteriorate. The sensory experience with food - the colours, the tastes, and smells - combines to create the enjoyment with food". Speaking at the launch of the campaign our CEO, Joe Lynch, said "Parkinson's disease is well known for the classic symptom of tremor but there are many other non-motor symptoms that take close management and have a huge impact on the quality of life for the Parkinson's patient."

"Management of these symptoms is long term and happens in the community which is why the Parkinson's Association of Ireland has branches throughout the country to provide support and resources for those with Parkinson's disease and their carers."

Our Parkinson's Nurse, Alison Cashell, handles queries from patients around the country and she points out that non-motor symptoms would feature quite frequently in the disease, "Parkinson's patients have to carefully manage their medication, diet, exercise, and sleeping habits. Even the smallest change to their routine can have a knock on effect on their day-to-day living. Management of non-motor symptoms are the key to the living well with Parkinson's disease post-diagnosis." Lundbeck Ireland is delighted to be supporting this awareness campaign particularly as non-motor symptoms can sometimes be the precursors of the disease. These symptoms are often the ones that we cannot see but they can have a profound impact on the quality of life.



Meeting with Minister for Health - Dr. James Reilly TD

Following the formation of the 31st Dáil our association made contact with every Dáil deputy and all of the members of the Seanad to highlight our associations needs on behalf of our members. In September a small delegation, led by Pat O'Rourke and Joe Lynch, met the Ceann Comhairle, Sean Barrett TD and several other members of the Oireachtas. Mr. Barrett facilitated us with a meeting with the Minister for Health, Dr. James Reilly TD and members of his department and the HSE.

Pat and Joe met with the Minister and his officials in late October this year. The meeting concentrated on a number of important issues: the provision of funding to the association, better treatment regimes through the provision of more neurologists, training of Parkinson's Nurse Specialists, setting up a deep brain stimulation unit in Ireland and a 'Medication on Time' campaign to be rolled out to hospitals and nursing homes. The Minister was receptive to some of the issues raised and there has been some movement by the HSE in relation to the DBS unit. In November our CEO was invited to take part in a small committee of the Health Information and Quality Authority (HIQA) who are tasked with investigating whether the unit is necessary, if it would be safe and if it would be viable in the long term. This committee commences its work in January.

The Minister also asked our association to complete a mapping exercise in relation to locations for Nurse Specialists. This work has commenced we hope to bring our report back to the Minister in the second quarter of 2012. Meetings are also scheduled with the HSE to role out the 'Medication on Time' campaign and we will report on our progress as it happens.



Pat O'Rourke, Dr. James Reilly, Minister for Health & Joe Lynch

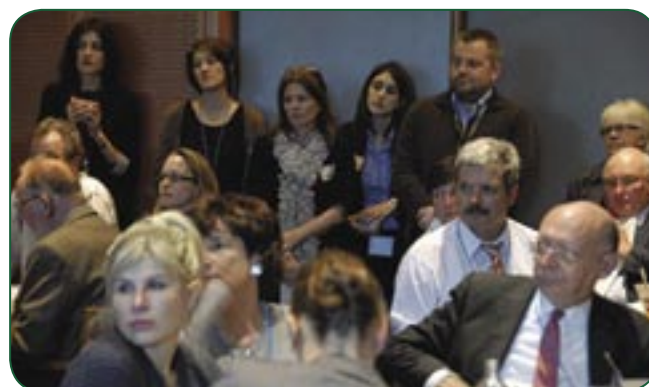
EU Debate on Parkinson's has Irish MEPs out in force

The EPDA is the only European umbrella organisation for Parkinson's disease and represents 45 member organisations, of which Ireland is one, advocating for the rights and needs of more than 1.2 million people with Parkinson's and their families.

Its vision is to enable all people with Parkinson's in Europe to live a full life while supporting the search for a cure. The EPDA seeks to achieve this by raising awareness and reducing inequalities in the treatment and management of Parkinson's disease across Europe. An EU lunchtime debate to help raise awareness of Parkinson's at a European level was held in Brussels on November 22, arranged with the assistance of ex-MEP, John Bowis, with the EPDA providing the content.

This included the EPDA Standards of Care Consensus Statement, launched at this debate, which said that they

"Support initiatives that ensure people with Parkinson's receive equal access to good quality, specialised care across Europe, reduce inequalities in the treatment and management of Parkinson's and improve funding for Parkinson's research and define research priorities." It also asked that the EU, "invest in optimum



treatment and maintenance strategies, increase public and professional awareness of Parkinson's, minimise stigma and discrimination, strengthen the level of neurological care within European healthcare systems, and provide adequate funding that supports the continued work of national Parkinson's Organisations."

Ireland's MEPs were by far the largest group by country who were there, and the EPDA's Secretary General, Lizzie Graham says the whole event was truly memorable. The event really was standing room only and we hope that the awareness raised among our MEPs will translate into something worthwhile for people with Parkinson's both here and in Europe. We congratulate them and our CEO, Joe Lynch (who worked hard to arrange the Irish MEPs' attendance) on an excellent turnout!

The EPDA will have a full report on this groundbreaking meeting in their next edition of EPDA Plus.



Acceptance and Commitment Training (ACT) for Parkinson's - Aisling Curtin



Aisling Curtin & her Dad, John

Nobody wants a cure for Parkinson's more than I do. However, how are you going to live your life every day until this cure is found? I ask this question as a Counselling Psychologist. But perhaps even more importantly, I ask this question as the daughter of one of the most kind, considerate and loving men that I know. A man who was diagnosed with early onset Parkinson's at the age of 47.

I remember when my father's diagnosis was confirmed, the tears and the fears for the future. A similar experience, I imagine, to many of those reading this article right now. I remember wishing things could be different and wishing for a cure for Parkinson's so badly. How could this have happened to my father? How could this have happened so young?

Some say a cure is not too far into the future and I sincerely hope this is true. What will those living with Parkinson's do in the meantime? My life's work lies in how can we possibly make the most of each and every day? To be even more precise, how can we make the most of each and every moment especially when that moment brings up many unwanted thoughts, emotions and bodily sensations?

I have specialised in an area of psychology called Acceptance and Commitment Training (ACT), which derived from Acceptance and Commitment Therapy. The basic idea behind ACT is that we all struggle with unwanted thoughts and uncomfortable emotions. ACT teaches people Mindfulness

skills to manage these unwanted thoughts and emotions more effectively. Mindfulness is a current buzz word in psychology, which refers to skills that teach us to connect more with the "here and now" and with what truly matters to us.

All too often we are preoccupied with what is going wrong for us and all the things that we wish were different. We are mourning the past or worrying about the future. ACT helps us by teaching practical skills to make the most of each and every day. ACT cannot cure Parkinson's. I really wish that it could. However, ACT can help us make the most of the life that we have right now and the relationships that matter to us.

There is a lot of research attesting to the usefulness of ACT and Mindfulness for:

- * Depression
- * Anxiety
- * Chronic Pain
- * Improving your Quality of Life
- * Improving your Life Satisfaction
- * Improving the quality of your relationships
- * Addictions
- * Social Phobia
- * Health concerns such as epilepsy and diabetes

Many of us spend about 90% of our time and energy on the 10% of our life that is outside of our control. Needless to say, this leaves very little time left for the 90% of our life that is within our control. Acceptance doesn't come naturally for most of us. In fact I often joke with people saying we normally only ever come to acceptance when nothing else works. Acceptance doesn't mean that we need to like, want or love how we are feeling. What it does mean is that we are no longer willing to spend all of our time and energy fighting a battle that we cannot possibly win. This frees up our time and energy for the people and things that mean the most to us.

In my professional capacity, I have had the good fortune to introduce approximately 1000 people to ACT. ACT has helped these people to gain a different perspective on their lives. This doesn't mean that they never feel stressed or down. However, the vast majority say that they become less overwhelmed by their emotions and that they are pushed around less by their thoughts. There is a huge emphasis in ACT on really connecting to what matters most. Most of these people notice themselves consistently making small changes that amount to big changes in their quality of life over time.

I was delighted when Grainne Fleming approached me about doing her M.Sc. Applied Psychology research on ACT. I have wanted to develop a 2-day workshop specifically aimed at those with Parkinson's and their family members and/or carers for quite some time. This is a subject that is very near and dear to my own heart for obvious reasons. I was 19 when my father was diagnosed with Parkinson's. I have had a strong desire to help people in similar circumstances since then. Our hope is to initially offer two workshops in Dublin for 20 people in each workshop in February and May 2012. We want to look at how these workshops may potentially help those living with Parkinson's. This is very much a 'pilot project' and we want to learn how we can improve the workshops even further with a view to taking nationwide in the coming



years. This is a project for which I am both incredibly enthusiastic and grateful to be embarking on. I hope I will get the chance to meet many of you in the months and years to come.

An ACT Information Evening will be held with Aisling Curtin and Grainne Fleming on Wednesday the 25th of January from 6:30-7:30pm in Carmichael House. The first 2-day ACT for Parkinson's workshop will be on Friday February 17th and Saturday February 18th 2012 in Carmichael House, Dublin. A second workshop will be held in May. There are initially only 40 places available open to people with Parkinson's and their family members/carers across these two workshops and there is a small €10 contribution sought for each workshop. The Parkinson's Association will be underwriting the cost of literature, room hire, lunches, etc. If you are interested in finding out more about ACT and these events, please call Grainne on 087-7790670 or e-mail our Assistant Psychologist yasmin@actnowireland.com. Places will be reserved on a first-come, first-served basis. However, we hope to offer more workshops in the future in different locations throughout Ireland.

Aisling Curtin, B.A. (Psych) Hons., Dip. Coun., M.Sc. Coun. Psych., is a Counselling Psychologist and the director of ACT Now Ireland. She works in an Adult Psychiatry setting with people with depression, anxiety, bipolar, addictions, eating disorders and psychosis. She also gives ACT workshops and professional trainings around the world. She specialises in developing and facilitating ACT groups and workshops.



ACT Now Ireland
ACT Now: Get Unstuck

ACT

I heard about this act scene,
I wonder what could it be.
My friend John said he'd book me in,
To, come and look and see.
He spoke to me of mindfulness
And sharing how you feel.
He said that living in the now
Was really the only deal.
I said I'd bring my friend along
He's been really very ill.
This act sounds better to me,
Than any bloody pill.
John's daughter Aisling tutored us
And when she rang her little bell,
Silence overtook the hall.
She really did it well
She thought to us many new techniques
That could help us all to cope
With any trauma in our lives
It really gave me hope.
And though I went for my friend
It was obvious to me, that,
ACT is not just for the ill
It's for you, everybody and me

Pat Walsh (A person with Parkinson's who attended a 2-hour ACT Workshop)

Yoga for Parkinson's Reconnect with Yoga to Support the Body

Saturday 14th January 2011, 12.30pm

The practise of yoga aims to reduce stiffness and increase strength. Yoga helps to calm the mind through breath work and introduces relaxation. The class will focus on body awareness and breathing as well work with balance and coordination. Classes consist of a sequence of postures which are taught whilst sitting on a chair using adaptations and modifications, so regardless of the severity of your symptoms postures can be adapted to suit you.

Taught by Patricia O'Connor, who began practicing Hatha yoga almost 15 years ago and qualified as a yoga instructor with Yoga Therapy Ireland (YTI) in 2004. Patricia has a strong interest in yoga therapy and completed a post graduate diploma with YTI in 2006. Patricia uses the physical postures, breath work, and relaxation of hatha yoga to make it assessible to people of all ages and abilities.

This 4 week course is suitable for all levels of ability, even newcomers to Yoga.

Cost: €55 for 4 weeks. Breathing Place is located upstairs on Main Street, Clane, Co. Kildare.

Call 045 893755 or book online at www.breathingplace.com





Something Very Special Coming to Ireland

The Movement Disorder Society Worldwide (MDS) are holding their annual conference in the National Convention Centre, Dublin on the 17th June 2012. This is sure to be a huge event for neurologists, neurosurgeons, scientists and consultants of all kinds who care for people with Parkinson's.

Professor Tim Lynch was instrumental in securing this high profile conference during the Year of Science in Ireland and we must acknowledge his efforts in doing so. On his recommendation, the organisers of this conference have allowed us to run a very important patient meeting as a satellite of the main conference. It is a coincidence that the Parkinson's Association of Ireland are celebrating our 25th anniversary during 2012 and this patient meeting will be the largest single event out of our schedule of events to mark this occasion. We have invited some of the most renowned speakers on Parkinson's to participate in this event. We are greatly honoured that the International Chairperson for MDS,

Professor David Burn who heads up the Clinical Ageing Research Unit, Newcastle University, has already accepted our invitation and we look forward to hearing him and other specialists.



While the list of agenda topics has not been finalised the draft agenda is as follows:

- Parkinson's Disease from James Parkinson to Current Day
- Drug Management of Parkinson's
- Growing Old with Parkinson's-Principles and Considerations
- Depression and Compulsive Behaviour in Parkinson's
- Deep Brain Stimulation
- Future Directions of Parkinson's Disease
- Practical Advice for Day to Day Living with Parkinson's

The main conference will be one of the largest in Europe during 2012 and it will certainly be the largest in Ireland. The venue is extremely spacious and comfortable and we have been very fortunate to have secured both the venue and a line up of international experts and well respected speakers for what is sure to be a sell out conference. The convention centre is close to the O2 stop on the Luas line and there are ample car parking spaces locally. We hope to encourage every Branch around the country to facilitate their members by running a special bus to the event, as well as encouraging new members to join our association. In addition we will be running a media campaign to ensure that the event is well publicised. Watch this space for more information in the New Year but in the meantime mark the date on your calendar.

1st Irish Deep Brain Stimulation Conference

About 70 people attended the very successful 1st Irish Deep Brain Stimulation (DBS) conference, and heard speakers talk on the topic of programming of the implanted pulse generator (IPG) post-operatively. There were a huge number of questions asked and answered. Dr Madeleine Lowery, a Senior Lecturer in the Dept. of Electronic and Electrical Engineering in UCD, provided an introductory overview from an engineering point of view, and dealt with some of the terminology that would be encountered. She was followed by Professor Erwin Montgomery on theoretical considerations and best programming practice in DBS. Karen O'Sullivan, clinical nurse, detailed the Frenchay selection methods, their screening for DBS and the programming process they use.



Professor Montgomery then talked about the development of an algorithm for programming. Dr. Kinley Roberts brought the conference up to date with the DBS work being conducted in the Dublin Neurological Institute. Finally, Dystonia DBS patient Christine Nally spoke movingly about her DBS for Generalised Dystonia, and Ann Keilthy did similarly for Parkinson's disease.

Joe Lynch, CEO of Parkinson's Association, chaired the meeting and the organisers are grateful to Joe and all the speakers for donating their time and energy to make the conference a huge success. Not forgetting the delegates whose intelligent and considered questions led to informed

and lively debate. There were breaks for coffee and lunch and Joe encouraged the delegates to mingle, and introduce themselves, as many had DBS already, and could talk about their experiences to date with those who were considering the procedure. The conference was closed by Maria Hickey, Chair of Dystonia Ireland, who made the closing remarks on behalf of the committee.

The conference was the brainchild of Gearóid Ó Néill, and the steering committee which he chaired included Aine Kearns, Mags Richardson, Ann Keilthy, and Maria Hickey. Special advisors to the committee were Stephen Butler and Roisin Hynes, and the sponsors were Medtronic, GlaxoSmithKline, Parkinson's Association of Ireland, PALS and Dystonia Ireland.





Co Enzyme Q 10

Following our last magazine, there has been a high volume of calls, and much confusion around the subject of Co Enzyme Q 10.

Co Enzyme Q 10 (CoQ10) is believed to improve the function of the mitochondria, the energy maker in cells. It is also believed to help with "cleaning up" waste products during normal cell metabolism, and this is due to its antioxidant properties. Previous studies have showed that people with PD have a lower level of CoQ10 in their cells, and that their mitochondria don't work as well as people without PD.



A medical trial involving CoQ10 and PD ("Effects of Coenzyme Q10 in Early Parkinson Disease") was done in North America in 2002 by Dr.

C Shults with a team of doctors and researchers. Their aim was to find out if taking CoQ10 could help people with PD and possibly slow down the progression of their disease. They enrolled 80 people in the trial. These 80 people had been diagnosed within the previous 5 years and were on no medication for their PD. They were divided into 4 groups: 1st received 300mg/day of CoQ10, the 2nd received 600mg/day, the 3rd received 1200mg/day, and the 4th group received a placebo (an inactive pill). None of the participants knew which group they were in. The study lasted for 18 months, and the participants were seen regularly over this time. They were assessed using different PD measuring tools, such as the UPDRS, and other tests such as the Mini Mental State Examination and time tapping score.

At the end of the study, the author of this study, Dr. Shults found that "CoQ10 appeared to slow the progressive deterioration of function in PD, but these results need to be confirmed in a larger study".

In 2007, Dr. A Storch conducted a study on 106 people in the mid stages of PD and Coenzyme Q 10. The trial lasted 3 months, and the participants took 300mg/day of CoQ10. Dr. Storch concluded that he "did not support the hypothesis that restoring the impaired energy metabolism of diseases dopaminergic neurons leads to symptomatic benefits in PD".

In December 2008, Dr. Shults started a larger study ("Effects of Coenzyme Q10 (CoQ) in Parkinson Disease") in America, and this new study had 600 patients with PD. Dr. Shults was hoping to replicate his positive finding from his smaller study with the new, larger group. This time they were divided into 3 groups; the 1st received 1200mg/day of CoQ, the 2nd group received 2400mg/day of CoQ and the 3rd group received the placebo.

The data that was produced by the study found that there was no major difference between the high doses of CoQ10 and the placebo. The trial was terminated after 16 months on the



recommendation of the Data Safety Monitoring Board, as they felt "the investigational drug is unlikely to demonstrate efficacy over the placebo for this indication. However, no safety issues were discovered". This study, which was due to conclude in August of this year, was stopped in May.

Therefore, the latest scientific evidence shows that CoQ10 has no major impact on Parkinson's disease; it has not been proved that it contains any properties for slowing down or altering the disease process. That said, there are ongoing trials into taking CoQ10 in different forms and doses, so there remains a possibility that it may still have some beneficial properties for people with PD.

For this reason, many health boards and pharmacies are now no longer covering CoQ10 on the medical card or long term illness book. The studies showed that the consumption of CoQ10 did no harm to the individuals who took the supplement.



The antioxidant properties CoQ10 can be replicated by eating a diet that contains fresh meat and fish (not fried), oils (eg. sesame, soybean and rapeseed), nuts and seeds (eg. peanut, sesame seeds, pistachios, and walnuts). Fresh fruit and vegetables also contain small amounts of natural CoQ10. For people who are taking Levodopa medication (Sinemet, Madopar and Stalevo) please bear in mind that a lot of these food groups are high in protein, so avoid them at tablet time.

Our "Simple Handbook for healthy eating with Parkinson's" is available free of charge from the main office in Dublin, and contains some recipes, advice and information.

References available upon request.

Clarification

Following the publication of the Autumn edition of the magazine, it has come to our attention that many Chemists around the country are no longer in a position to supply Co Enzyme Q 10 as a treatment for Parkinson's disease. This is because there is currently no scientific evidence that it has neuroprotective qualities, which is what was once thought.

However, by eating a balanced diet, including fresh fruit and leafy green vegetables, you should get all the antioxidants that you need.



Kilimanjaro 2011 – Serious Fun

Introduction

The economic downturn has had a profound effect on a lot of charities in Ireland. It's not that people are less generous; it's just that they have less to give. In September of 2010 our CEO, Joe Lynch, asked the Board of our association to set a very ambitious target for one fundraising event in 2011 of eighty four thousand Euro of which thirty eight to forty thousand Euro would be generated for Parkinson's projects when travel, food and guide expenses were deducted. This was a very large target in any climate but particularly where Ireland's economy is today. Articles appeared in our Parkinsons.ie magazine, the event was posted on our web site, leaflets were printed and amazingly eighteen people signed up for the trek along with Joe.



The group were from all walks of life and as one of the group leaders, John 'Ginger' O'Leary put it, 'We couldn't have been as lucky if we had selected people from a lucky bag'. The group ranged in age from 18 to 69, men and women, some with family connections to Parkinson's and some without and we had two people with Parkinson's on the trek. **Joe Lynch takes up the story from here**, 'The morning of the 4th of September in Dublin Airport marked the first meeting of the entire

group. There was a little nervousness and apprehension from everyone, particularly me as this was very much my gig, but to a man and woman everyone helped with bags and tickets and it was clear from the start that we would have a very good trek'.

Everyone had brought along their personal belongings, trek gear and a special bag (or two) of children's clothing. We had decided from early on that we would visit the slum areas of

Nairobi and the projects being run by Irish missionaries as well as supporting a Parkinson's Project in Tanzania. I could feel it, right from the beginning; this was going to be something special.

Following a very long flight from Dublin to Nairobi, changing planes and terminals in Paris, we arrived in a warm and slightly humid Nairobi to be met by our driver for the fortnight, Hamishi. Everyone was allocated their rooms and most had a small drink before an early night.

The second and third days of the trek involved seeing what true poverty is and seeing what a difference a handful of dedicated people like Sister Barbara, who runs an enormous primary school and food project and Sister Mary Killeen, who brings families out of the poverty trap through training and education, can make with very few resources. Both of these Irish nuns are Sisters of Mercy. They exude confidence and deliver their projects from an ethos of no handouts without a commitment to work to get out of the poverty trap. We parted company with over 100 kilos of new and very good quality second hand clothes to these dedicated Irish nuns. The group also visited a small hidden orphanage set up and run by Justina from Poland. We next visited an Arts and Crafts centre run by Wexford man David Redmond who ensures that the arts and crafts made in the centre provide income for the people who made them. Our trekkers donated \$500 to each project.



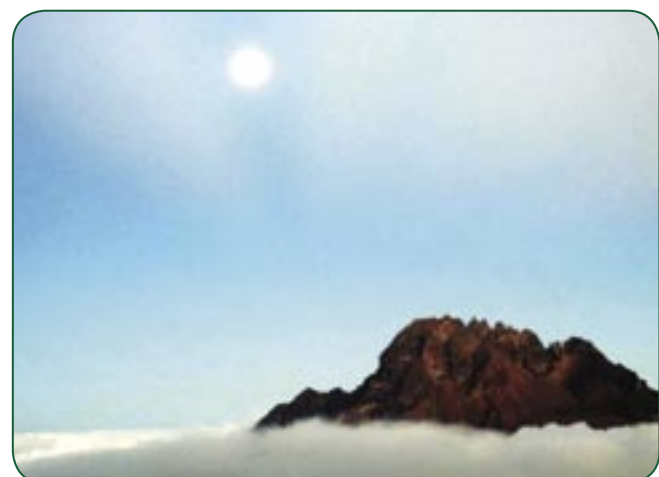


Following an early start we made our way from Nairobi encountering a family of reticulated giraffes along the way. We crossed the busy Kenyan – Tanzanian border and made our way to our base in Tanzania; the bustling town of Moshi. We met the Parkinson’s regional co-ordinator for the area, Jane Rogathi, who was overcome with the generosity of the group who donated \$2,500 towards their drugs programme being run by Professor Richard Walker, Consultant Physician at North Tyneside General Hospital who visits the area often to assess patients and advise on treatments.



From there we approached the Marangu gates at the start of our trek through Kilimanjaro National Park. After a seven hour hike we reached the Mandara huts, tired but exhilarated. Night falls very quickly near the equator and just after 6.30pm we were in complete darkness. The huts were basic but exhaustion took over and everyone slept well. An early and misty start the following day signalled a seven to ten hour climb to Horombo huts. This was a very arduous trek that took us through the clouds and, for some, it brought the first signs of altitude sickness. Horombo was to be our home for the next two nights to help with acclimatisation. The camp also gave us our first real sight of the peak. It still looked so far away! It was truly amazing to be standing on solid ground looking down on the clouds. Days and particularly nights were getting very much colder.

After two nights rest eighteen out of our nineteen strong group pressed on to Kibo huts which would be our final stop



before the climb to the top. We all noticed the lack of oxygen as any physical effort immediately brought on heavy breathing and a lot of us developed headaches. After a long walk to Kibo huts we were greeted with the most amazing views of the African plane and the recently passed Mawanzi peak. We were high above the clouds with Mawanzi peak across from us and we were looking down on it! After a short rest and food, we gathered just after midnight in sub zero temperatures and darkness, only alleviated by a full moon, to climb for the next six hours to the very top of the highest peak in Africa. This proved very difficult for everyone. Many thought about giving up and returning to Kibo but seventeen still managed to get to Gilman’s point and fourteen of these pressed on to Uhuru peak four hours further on and 120 metres higher. The views were spectacular with the sun breaking over the clouds, Mawanzi peak far below us and the glacier on top of the Kilimanjaro glistening in the early morning sun. We had made it!



Over the course of our trek we had covered around eighty kilometres and climbed over 3,500 metres to a total height of 5,895 meters, for those, like me who need to convert from metric, this is 19,385 feet. This was an amazing achievement for everyone and one which most would not have missed. The descent was almost as hard as the climb! There were plenty of aching bones, painful feet and sore backs, but everyone was smiling and delighted with their achievements. Our arrival back to Ireland was delayed by twenty four hours due to a fault with the plane but we were greeted by family and friends and our Chairman, Pat O’Rourke was on hand to extend the best wishes of the association to all who took part. On my own behalf, I met some great people who were generous with their time and patience and who lifted my spirits on more than one occasion. Remarkable people one and all, I say roll on next year and our next trek to the Great Wall of China.



Research – The Irish Connection

One of the strategic aims of our association is to find a cure for Parkinson's disease. To put not too fine a point on it, we would like to go out of business through finding a cure! Each year millions of Euro pours into research foundations around the world for this singular aim. Several years ago our association donated €50,000 to research in Trinity College through a bequest and unfortunately we were not in a position to follow that donation with another, until this year. The Board has taken the decision to fund Dr. Gavin Davey's stem cell research in Trinity College with an annual bursary of at least 20,000 per annum, if these funds are available. This year we asked Branches and individuals to assist us in this work and on the 27th of September last a small group of people led by our Chairman, Pat O'Rourke, met with Dr. Davey in the new Biomedical Sciences Institute on Pearse Street to formally hand over our contribution to his work.

Dr. Davey gave the group a guided tour of the facility and informed them about his work on behalf of the association. Over the next few years we hope to be in a position to increase the amounts donated to research and it is our hope that we can be a conduit for future research projects into the causes, and hopefully, cures of Parkinson's disease. If you wish to contribute to next year's fund please ensure that you explicitly state that you wish your contribution to be used for research purposes.



Many thanks to all the Branches and individuals who have made this year's bursary possible. Our membership form for 2012 has an additional donation option specifically for research and donors should note that every cent donated for research will be given directly to research.

Waterford Community Physiotherapy Service, Parkinson's Disease Exercise Programme: "Up and Running" since 2008!

Parkinson's disease (PD) is a chronic, progressive disorder of the nervous system. Parkinson's disease affects a person's muscular coordination and symptoms include tremor (shaking), rigidity in some muscles, slow movements, and problems with maintaining normal posture. The disease is caused by the death of cells in one of the movement control centres of the brain. These nerve cells control body movement.



Physiotherapy plays a key role in the management of PD, helping to maximise the independence and functional potential of the client, and to minimize secondary complications.

As part of the 2008 Waterford Physiotherapy Service Business Plan, a number of initiatives targeting chronic disease management were planned. One of these was to develop a PD exercise and education programme for Service Users in the Local Health Area. Physiotherapists Siobhan Fitzpatrick, Suzanne Rath and Chris Morrissey designed, coordinated and delivered the first programme in Waterford, in April 2008.

The programme aims to improve posture, range of movement, walking, balance and transfers among the class participants. The educational component empowers participants and their carers to understand and manage their condition. The class is a great social outlet for people to meet and chat with other Parkinson's sufferers and their families.

Since 2008, this program has been run on 6 occasions, with a total of 32 patients participating. A variety of outcome measures have been used over the years, including the Elderly Mobility Scale, Berg Balance Scale, Timed Up-and-Go, Unified Parkinson's Disease Rating Scale and two quality of life questionnaires, the PDQ-39 and SF-36.

The eight week programme began in St. Patrick's Hospital, and was moved to St. Theresa's Unit at Waterford Regional Hospital in 2010. Each class consists of an exercise session, followed by an educational talk. The exercise component is a circuit-based class with 8-10 different stations, each challenging the participants in a variety of ways. The education component involves input from the Consultant in Elderly Medicine, the Physiotherapist, Occupational Therapist, Nurse, Pharmacist and Speech and Language Therapist. Family members/carers are invited to these sessions.

The clients and their carers are enjoying the social aspect of the class, and we are further developing our group work skills. In addition, in each of the 4 years, there has been an improvement in each of the outcome measures as mentioned previously, with further research taking place currently to determine the statistical significance of these results. We regularly distribute Parkinson's Association charts and literature to our clients, with thanks to the local Branch and the association's national office.



ASK THE EXPERTS



Alison Cashell, RGN, Parkinsons 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



Questions answered by Consultant Neurologist Prof. Tim Counihan of UCHG

QUESTION Would Yoga and Meditation help with my Parkinson's?

ANSWER A lot of people find that doing yoga and meditation can help with some symptoms. The overall health benefits of doing exercise are well known, and because yoga is a gentle form of exercise, it can be very useful for people with Parkinson's. The National Office has DVD's and books by Renee Le Verrier, a lady with Parkinson's, and book and DVD takes you through gentle step by step yoga movements specifically for people with neurological conditions.

QUESTION Can you get withdrawal symptoms from medication when your tummy is upset?

ANSWER I am not entirely sure what you mean when you say "withdrawal symptoms" but certainly if you have diarrhoea from a stomach upset your medication may not be absorbed as well as normal, so you may not be as active or your movements may become impaired. As well as that, we know that when someone is sick, this can cause a deterioration of their Parkinson's, causing a sudden worsening of symptoms. However, once the illness subsides, and routine is restored, their Parkinson's should go back to normal.

QUESTION Reducing protein, red meat etc., in diet – would it help in mobility?

ANSWER We now know that eating meals that are high in protein around the same time as taking Levodopa medication (Sinemet, Madopar, and Stalevo) can reduce its effectiveness. Protein is found in red meat, chicken, fish, nuts, eggs and all dairy products. It is not advisable to cut out protein from your diet altogether, but try to be mindful of your portion size, particularly if it is close to medication time. So if your tablets are working to the best of their ability, one would hope that this has a positive effect on your mobility. The things to remember are to time your levodopa medication 30-40mins before meals, or 1 and a half hours after meals, and ensure that you drink a full glass full of water with them.

QUESTION Does smoking Marijuana help?

ANSWER Smoking marijuana is not legal, therefore we could not advocate its use for any purpose, medicinal or otherwise.

QUESTION What is the name of the TB drug and where is the study being carried out on it?

ANSWER The name of the TB drug is Rifampicin. I am not aware of any ongoing clinical studies in patients with PD. The drug is of interest because it seems to prevent build up of alpha synuclein, the protein that accumulates in cells in patients with PD. Although the drug is used to treat TB, it can have serious side effects. It is too early to know whether it is safe or effective in PD patients.

QUESTION I get tremors which are severe and can last for hours with no definite pattern.

ANSWER "Tremors" can mean different things to different patients, so it is important (although sometimes difficult) to try and distinguish between true tremors and other involuntary movements, referred to by the doctors as "dyskinesias". True tremors are what many patients with PD experience early in the condition. They consist of a fairly rhythmic shake of a hand or leg; by rhythmic, I mean that the shake occurs at a constant frequency, like a fast drum beat. Often this tremor disappears when the patient uses the hand, although it may reappear, such as when holding a newspaper.

Patients who experience such rhythmic tremors are described as being in the "off" state, meaning the medication is not working, or has worn off. It is very useful to try and determine if there is any pattern at all regarding when the tremor is at its worst, because the solution involves adjusting the medication upwards. However the other type of involuntary movement, known as dyskinesia, is different. This movement usually occurs when there is too much medication in the body. The movement is usually more dance-like than a rhythmic drum-beat. The treatment for this movement is usually to spread out the medication doses a bit.

I would recommend that you keep a careful hourly diary of your tremors for a few days in a row to try and establish a pattern of when they are worst. Write down how you feel at those times: "are you stiff and slow to get around? Or are you pretty mobile despite the shake. Your PD nurse or doctor should have sample diaries that they can give you, and they will advise you further when they establish the type of "tremors" that you have.



Social Weekend

Our annual social weekend was held in the Ardilaun Hotel in Galway in October. As always the weekend was well attended and over one hundred and twenty people enjoyed the talks on Saturday and all of the social activities arranged by our national office. Many commented on the large attendance and everyone enjoyed meeting old friends and new.

We were entertained by Ray Lynam on the Friday night, and the Ardilaun house band played some great floor fillers on the Saturday night. Both nights were a great success with plenty of people on the dance floor. There was a great atmosphere, and even after the official entertainment ended, certain people held their own concert after hours!

We had an information update on Saturday, with Dr. Tim Counihan from Galway University Hospital. The questions and answers session after Prof. Counihan's talk turned into a dialogue between him and his audience. This was something special to see. We also heard from our Parkinson's Nurse Alison Cashell about her role in the association and she was followed by Speech and Language Therapist, Fiona Rogers. The afternoon was rounded off with an inspirational talk and breathing exercise from Mags Mullarney who gave an account of her journey with Parkinson's. Mags also engaged the audience with her relaxation methods and this proved



particularly useful to at least one member of the audience whose dyskinesias reduced visibly with Mags calming influence. Finally we had an unscheduled short talk from David Greaves from the UK group 'Pedal 4 Parkinson's', who had cycled the length of the UK and Ireland earlier this summer for research, encountering our hospitality in the Midwest, Kerry and Cork. He spoke movingly about the need to have hope.

On Sunday morning, Fr. Jennings from Galway celebrated Mass, which took place just before departure. All the donations from the collection were given directly to the local church. This weekend followed in the footsteps of previous social weekends and it was terrific to see all our Branches represented and many friends from Northern Ireland joining us once again.

Wynn's Hotel Patient Information Day

The Friday afternoon of a bank holiday weekend is not an ideal time to host an information meeting especially in Dublin. However one member thought it was perfect, and how right she was. Mags Mullarney with Elaine Quinlan, organised a hugely successful meeting in Wynn's Hotel, Dublin on the 28th of October. Over one hundred and thirty people attended the meeting to hear Dr. Jon Stamford (pictured right), a renowned neuroscientist, who also has Parkinson's, speak about a new organisation and web site that has been designed and is being run by and for the benefit people with Parkinson's. Jon was followed by Mags Mullarney who delivered her own unique and accessible breathing and relaxation techniques. The calmness in the room was very palpable.

During the meeting Mags was informed by her daughter that she had won the inaugural Mayor's medal for her forthcoming participation in the Dublin City Marathon. Patricia O'Connor took the whole room through a gentle 'yoga in a chair' routine and the feedback from those who attended was excellent.



Web Update & Social Media

Our new web site, which was launched in April, has just passed the 18,000 'hits' mark making it one of the most successful means of communicating with people with Parkinson's. Our home page is updated regularly and we have linked the site to all of our 'social media' channels. Since our online 'shop' launch in August almost

one thousand euro worth of cards, books, videos and Newbridge Silverware, has been sold. A special word of mention for our new 'Patient Advocate Panel' page. This page is where people with Parkinson's can tell their stories and if they are willing they will be a source of information for media if needed. Why not visit them on www.parkinsons.ie/pwp.



The social media phenomenon has gripped many people with millions worldwide communicating and receiving their information through this medium. The Parkinson's Association has developed channels on Facebook, Twitter, Flickr and Youtube. While for many the internet and all of these web sites are not new to them very many people are only becoming aware of their possibilities. Over the past few months the level of interest in our Facebook page has escalated and we now have almost one thousand 'friends' following us on a regular basis. Our Twitter account is @parkinsonsire and we tweet regularly. All of our tweets appear on our web page and our facebook page so add us as soon as you can, tell your friends and keep up to date with the latest information for our association.



Austin Carruth Pitch & Putt Classic



As previously reported on, the Austin Carruth Pitch & Putt Classic was an outstanding success. At the end of September Joe Lynch and Pat O'Rourke met up with Michael Carruth and his sister

Orla to accept the handover of a cheque for €12,250. Michael tells us, 'This is not the end of it, we intend to keep going and make as much as possible for the association and raise awareness into the bargain.' Our Chairman was understandably delighted with the contribution made by all of the Carruth family. Pat said, 'This is an unbelievable achievement, far in excess of what we might have imagined.' The Carruth family have also organised the first ever Austin Carruth cup through the Lucozade Powerleague football tournament. More on that soon.

Irish Parking Association - Conference Lunch

The IPA Conference Lunch takes place every two years, and more recently has incorporated the IPA Quality in Parking Awards/Irish Parking Awards. These recognise quality in the Irish Parking Industry and are a keenly contested and worthy showcase for all that is best in the Irish Parking Industry.

For the last two biannual events the association has held an 'envelope' charity giving appeal in aid of the Parkinson's Association of Ireland and this year the amount raised reached over €1,000. Our sincere thanks go to everyone involved.

A big Donegal Thank You!

The Donegal branch would like to thank Raymond Kyle from Fanad for his generous donation of €6,600. Also a big thank you to our own Kathleen Durcan who participated in the Ladies Mini Marathon and presented us with a cheque for €1,086 at our last meeting. Well done Kathleen! Finally a big thank you to James McIntyre, Sarah Meehan and Barney who swam across



Donegal Bay to raise some funds for us. They raised €3,670 and this was presented to us in Ballyshannon on Sunday 27th October. All of this money is put to good use to benefit our members and is all greatly appreciated.

New York Marathon



In July of this year we were contacted by Zeb Austin who was getting fit for the New York Marathon. Zeb takes up the story from here, 'I got an entry into the NYC marathon via work (Telefonica), as part of the charity work they do for the Amigos de Proniño, which is a charity for under privileged children in South America. However I wanted to raise money separately for something very personal. My grandmother, who died earlier this year, had suffered with Parkinson's for a number of years. She was resident in the UK and the Parkinson's society there gave her lots of help, so really that is why I wanted to help. The run itself was fantastic, just being in New York is a great experience but to run all the way from Staten Island to Manhattan (taking in all 5 boroughs) was brilliant! This was my second marathon but felt just as hard as the first! The crowds were great, with lots of music playing and endless New Yorkers screaming and shouting to keep going! I hope things continue well for Parkinson's Association of Ireland in the future.' Zeb used a MyCharity.ie page to raise funds for the association.

Watch the First Step!



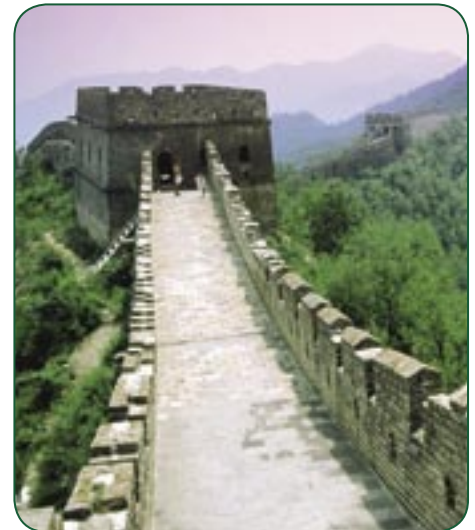
Sky diving is not most people's idea of a good day out. But Chris Bowe chose this method to raise funds for the association. Chris tells us, 'I wanted to raise funds for your charity, as my mother was diagnosed with Parkinson's in 2008. So I performed my sky dive during the late summer and it was an unbelievable experience. It was an absolute pleasure

to raise money for the Parkinson's Association and Skydive Ireland will be sending you on the funds soon. Thanks for your support and help.' We want to thank Chris for his help for us and we wish him all the very best in the future.



Trek the Great Wall of China

The 2011 trek was a difficult one and next year we have decided to tackle an 80 kilometre section of the Great Wall of China. This is a moderate trek that will suit most people and we have added a leaflet in with this magazine that we hope you might pass on to anyone that would be interested. The climb will have some steep sections so a reasonable level of fitness is required. We have also maintained the fundraising target at the 2011 level, €4,200. We hope to present the trek details at a special launch early in 2012 with our travel partners Earth's Edge. For further details contact Joe Lynch on 1800 359359 or email fundraising@parkinsons.ie.



Spread Your Wings Songwriting Competition

A very innovative way to raise awareness and funds has been launched by the Midwest Branch. An online song writing competition in aid of Parkinson's Association of Ireland is being run by Music4you.ie. The hope of the organisers is that it will put Parkinson's out onto the airwaves where more people will talk about the condition and reach new patients who need support. The event is organised by Music4you.ie with the aid of Ilovelimerick.com, the song writing competition is sponsored by the Limerick Leader, Limerick's Live 95FM, Music Therapy Ireland, Red Door Productions, Maurice Gunning Photography, music and www.Buildermonkey.com.

This online event will engage songwriters from all parts of Ireland. The prize is valued at €10,000, giving the winner an opportunity to hone their musical skills and image through various mediums including a state of the art web site, a full photo promo shoot with renowned Limerick photographer Maurice Gunning, a style makeover, a video shoot with Ilovelimerick.com and the winning song will be recorded and produced by Dave Keary of Red Door

Productions in Limerick City. The winner will also receive a PA system sponsored by XMusic.

The talented panels of judges include singer songwriter John Spillane, acclaimed writer and former Eurovision Song winner, Shay Healy and singer and journalist Leanne Moore. For more details go to www.facebook.com/music4you.ie and see 'Song Competition' for more details. The winner will be announced on March 1st 2012.

The banner features the Parkinson's Ireland logo at the top left. The main text reads 'SPREAD YOUR WINGS Songwriting Competition in aid of Parkinson's Association of Ireland'. Below this is a yellow cassette tape. A button says 'To find out more. Click here'. At the bottom, there are logos for sponsors: 95FM, MTH (Music Therapy Ireland), Limerick Leader, Website Buildermonkey.com, Music4you.ie, Maurice Gunning, and XMusic.



A Christmas Thought – Maura Renehan

As the family put the final touches to the preparations for the big feast day coming up the next day. There was a loud banging at the front door. My husband Jim answered. There was a lot of whispering in the hall which seemed to go on for a long time but really it was our anxious curiosity which made it seem so. As we were about to collapse with worry, we could hear the echo of many loud footsteps approach the living room. Looking in the direction of the door I nearly fell with shock, to see my husband accompanied by a policeman and our next door neighbour carrying and pulling a little frail old man, who was covered in blood and clay. I got a cushion and throw over and they put the poor man on to the couch.

My daughter and I washed him as best we could and dressed his cuts. Thankfully he wasn't as badly injured as we first thought. While we had been cleaning the poor man, the policeman had been busy on the phone enquiring as to the identity of the stranger.

It turned out he was a man of the roads, but his people were from the locality. We gave him some tea and toast and he seemed a little brighter. After some discussion with the guard and my family we decided to leave him rest for the night on the couch.

Next morning we were all going to early mass. My eldest daughter and her friend offered to stay with our guest whom they had decided to call Noel. On our return from mass we were surprised to find the two girls and Noel busy preparing Christmas dinner. They seemed to have taken a shine to Noel. He seemed to be in great spirits and little worse for his ordeal the previous night, which seemed to be as a result of

a little seasonal over indulgence. The girls then offered us drinks of various strengths which helped to warm and relax us. At this stage Noel was fitting in with everyone like an old sock.

Soon we made our way to the Christmas tree, there were presents exchanged and Noel hadn't been forgotten. At about three o'clock we sat down to dinner. We all relaxed for some time after our dinner. Noel asked if we had an accordion, sure enough my daughter had one in her room which she gave him. The music that he brought from it was varied and beautiful and nothing short of the touch of the master's hand.

At the end of the day we all agreed that it was the best Christmas we ever had. Noel departed the next day as the call of the roads would always be in his blood. We will never forget him and I hope he will call if he passes this way again. It really taught our family that Christmas has nothing to do with big spending, but more about thinking and sharing with others. If you stretch out your hand in friendship you receive back a hundred fold.



Lord Mayor's Medal - Margaret Mullarney Inaugural Winner

The medal was presented to Margaret Mullarney before the start of this year's National Lottery Dublin Marathon on Monday 31st October. Organisers of the National Lottery Dublin Marathon and the Lord Mayor of Dublin, Councillor Andrew Montague sought nominations for the inaugural

"Lord Mayor's Medal" earlier this year. The specially commissioned medal will be presented from this year onwards to an individual or individuals who are deemed to have either overcome incredible odds to take part in the Dublin Marathon or have an unusual marathon story to tell.

Margaret spoke at our recent patient meeting in Wynn's Hotel, about the effect



of positive thinking and the use of exercise in Parkinson's, and was given the news that she had won the Lord Mayor's Medal by her daughter during the meeting. Margaret completed the Dublin Marathon in just under 7 hours. She also appeared on RTEs Four Live recently publicising the event and raising awareness of Parkinson's. Congratulations go to Margaret and her family, who have been so supportive of her fantastic efforts and achievements, and our best wishes are extended to Margaret and her team for their achievement in the marathon.



Waterford/South East Branch

The Branch has been keeping busy continuing to raise funds to keep classes and events going. We enjoyed a very pleasant if busy day out with the members of the Kildare Branch and I believe everyone got something out of the trip. We have also been trying to bring the branch and other health services etc. into closer contact by meeting up and discussing how we can inter-relate and inform other people with Parkinson's (or families or carers) of our existence.

Last month we were very pleased to have Dr Paul Crowley accept an invitation to come and talk to us, he did this without accepting any fees. He first gave a talk on all the choices of treatment and the criteria generally used for each method. He discussed the progress, hopefully, being made and was very balanced in his view as to the outlook. He then took questions from the floor which varied widely from how to deal with "freezing" to voice production and the roll of exercise in Parkinson's. Everyone present was impressed by his delivery and we can only hope to continue such cooperation whilst he informed us is looking forward to eventually having a clinic where a specific day will be for Parkinson's patients and all other related services will be present.

Contact: Teresa Peacock: 051-383685

Dublin Branch

In October, six members of the Dublin branch attended the Social Weekend in the Ardilaun Hotel, Galway. All agreed that it was a great success with a mix of good food, leisure activities, and interesting speakers. We are looking forward to the next event in 2012—maybe back at the Ardilaun? A collection for Parkinson's was arranged for 24th, 25th and 26th of November in the Frascati Shopping Centre, Blackrock. Shoppers were in a very generous mood! We hope everyone enjoyed our Christmas lunch on 4th December at the Marine Hotel, Sutton and we wish all members and the hard working staff of the Parkinson's Association a Happy Christmas and a peaceful New Year

Contact: Isabel Somerville 01-4909646

Tipperary Branch

Many thanks to the Citizens Advice Bureau for updating our members on benefits and entitlements available to them. We would like to once again welcome and thank our wonderful Parkinson's Nurse Specialist, Mags Richardson, for coming to speak with our members on 1st December. Our best wishes for a speedy recovery to Michael Burke, our Chairperson. We were delighted to have our very own John Carey highlighted on the Parkinsons.ie website. Visit John and all of the other people who are telling their stories there on www.parkinsons.ie/pwp. Finally we would like to wish all our members a very Happy Christmas and hope that all our members will join us for a special social event which is planned for 6th January 2012. Details will be sent to our members.

Contact: Mary Carey 086-3916726

Donegal Branch

Our September meeting was a huge success as it took place at the beginning of Reflexology Week a group of reflexologists and massage therapists attended the meeting. They offered treatments to our members and many of them availed of the treatments throughout the afternoon. All treatments were free of charge. Our sincere thanks to all the therapists involved. We concluded the meeting and all members had a meal before going home.

Friday the 14th October. We were going to the Information Weekend in the Ardilaun Hotel. Some stops had to be made along the way to pick up more passengers and all in all there were twenty of us altogether. We had a bite to eat in The Yeats Tavern and continued on our way to Galway. Friday evening music was provided by Ray Lynam and everyone



danced the night away until the early hours! On Saturday we attended some talks and question and answer sessions which were very informative. Business concluded at 4pm and members were free to do as they wished. Some used the time to relax while others headed off shopping. Dinner was at 7.30pm and our entertainment was provided by a band from Galway who were excellent and members thoroughly enjoyed the music all night never leaving the floor empty which really impressed the musicians. We returned home on Sunday the 16th October having had a brilliant weekend.

Contact: Ann Foxe 086-1605847

North Kerry Branch

We held a very successful Patient Information Evening in the Three Mermaids in Listowel on 21st of November. Our guest speaker on the night was our association Nurse, Alison Cashell. In spite of some little organisational glitches we had a good turnout and Alison's calm and informal approach struck just the right note. Questions came freely from the floor and were dealt with sensitively and comprehensively. She also remained for some time after the meeting and spoke to each person individually who wanted a personal word. We send a big thanks to Alison and PAI for their cooperation.



Our next venture was our Christmas Social Evening which took place on Friday the 2nd of December in The Three Mermaids, Listowel. Carers and patients joined us for a bite and a sup and we had a little entertainment as well.

We must acknowledge the Trojan work our Secretary, Mary Thornton, has put in to get the Information Evening off the ground. She has also brought her whirlwind organising abilities to bear on the Christmas Social Evening so an enjoyable night was assured. In other news, committee member, Joan Rogers, is helping with a fashion show in The Earl of Desmond, in Tralee in aid of Parkinson's. More news of that event in due course.

Contact: Liam 086-3771844



South Kerry Branch

Our condolences go to Mrs. Noreen O'Sullivan and her family on the death of her husband Gerry, a much loved member. A guard of honour was formed at the Church by the Parkinson's group.

We send our best wishes to Teddy & Kathleen Cronin and hope all goes well for them. David Greaves and his wife Kath, Parkinson's Research, U.K., enjoyed their recent visit to Killarney with a dinner with all our members. We held a Carol Service in Killarney for all our Parkinson's patients, carers and friends and were delighted to have our CEO, Joe Lynch, and his lovely wife, Wendy, with us on the night for this service.

We also recently had an enjoyable evening arranged by the manager of Our Lady of Lourdes Nursing Home, who invited us for a day visit. We are all looking forward to our Christmas dinner when 45 members will be present along with Senator Molloney and her husband Mike.

Contact: Grace McCrae 064-77-58837

East Midlands Branch

We held our Annual Christmas Party on Sunday 11 December at the Day Care Centre, Naas, Co. Kildare for all members of East Midlands Parkinson's. We look forward to a carol service and a ceremony of appreciation for deceased members which will be taking place shortly.

We in the East Midlands Branch would like to take this opportunity to thank all who have helped us in any way during 2011. We wish our fellow Branches throughout the country a very Happy Christmas and good health and happiness for 2012. We also wish all in our National Office a very happy Christmas and a bright and productive New Year.

Contact: Marian Deely 085-2112973

Louth/Meath Branch

Our Branch has been fundraising over the last two months and Kathleen Molloy held a draw at the launch of her niece's latest single in the Crowne Plaza Hotel Dundalk and raised over €600. Thanks to Kathleen and all her family for their help. On the 22nd and 23rd of December we are holding a flag day in Dunleer and any volunteers would be most welcome. Please call Anne Matthews, 086-1779697, if you can help. Branch meetings to start again in early February and we will write to everyone notifying them of the time and date of the next meeting. We wish everyone a very happy Christmas and peaceful New Year for 2012.

Contact: Maurice O'Connell, 087-7512608

Mid West Branch

Members of the Mid West Voice Club were both happy and sad at the news that Aisling O'Gorman, our much loved Vocal Coach has moved to Dublin. Aisling takes up a prestigious new position with 'The Ark' Children's Project in Temple Bar as Music Programmer. During the past 3 years Aisling has become familiar with the foibles, the offs and ons, the lethargy and enthusiasm of the 'movers and shakers' of our little group. Her unfailing high spirits and commitment brought us



to a point where we dared to perform on occasions like the Christmas lunch and the Information Day in Ennis. Apart from the importance of learning how to "speak up", the Voice Club became a source of energy and was an important social outlet for all of us.

We have also recently recommenced our aqua aerobics classes again and these are well attended. Our picture, above, looks a little out of place in the current cold weather, but the sessions are well worth attending.



Contact: Billy Rice 087-6410406 or 061-228003

Galway Branch

The Branch held its December meeting on the 14th in the Clayton Hotel, Ballybrit, Galway. We have also launched our new website and Facebook page www.galwayparkinsons.com. The Speech & Language classes are continuing and the Physiotherapy classes will commence at the start of February. We have decided to have our Christmas mass and party in January 2012 (date to be advised). We wish everyone a very Happy Christmas and all the best for the New Year and look forward to seeing new and old members in 2012.

Contact: Marie Cahill 087-7783825

PALS Branch

Our October 23rd meeting had Tom Mathews as speaker. Although nervous, Tom is a born raconteur and we had a wonderful afternoon, full of laughter and shared experiences. Tom recently had the Duodopa Pump fitted, having had DBS previously, and so has benefit from both, and gave a witty and moving account of his journey. Mags Mullarney spoke for a few moments to introduce herself and to publicise the meeting in Wynn's Hotel. In November Ann, Cathy and Brian presented a cheque for €4,000 to the National Office to assist with the running costs of the helpline.



Our Christmas lunch took place in the Goat Grill on Sunday December 11. It was a lovely afternoon with many members in attendance.

January 29th sees the Association CEO, Joe Lynch presenting on the Kilimanjaro trip which he led this year. Having seen some of the photos, this will be an afternoon to remember! Tara Towers Hotel, 3pm.

May we wish all our members a Happy Christmas

Contact: Ann Keilthy 087-2085117 pdpals@eircom.net



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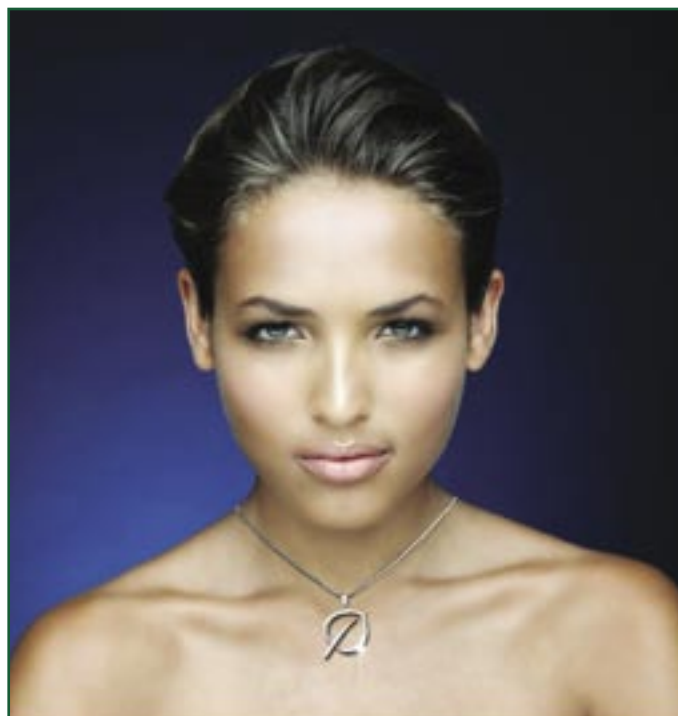
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