Call to Action

TOGETHER WE CAN MAKE A DIFFERENCE

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Dear Members

We have had a number of new developments to start off the year. The new board of Directors had their first meeting and I am looking forward to us working together in 2017. The PAI opened its 17th branch. The Longford Branch meet in the Family Resource Centre ‘Teallach Iosa’ in Longford town. The group is very enthusiastic and looking forward to providing services in Longford and the surrounding counties. Young Parkinson’s Ireland (formally PALS) had a number of meetings and have now formed a committee. They are looking forward to launching this new service for people living with young on-set Parkinson’s Disease at the upcoming conference in the Teachers Club as part of Parkinson’s Awareness Week.

It is my pleasure to bring to your attention the recent development in Donegal/Sligo which is the introduction of a Parkinson’s Disease Nurse Specialist Clinic delivered by PD nurse Specialist Patrick Brown and funded by Donegal/Sligo branch on a trial basis. The aim is to develop services and establish demand for this pilot project with a view to securing long-term funding from the HSE. Clinics will be held twice a month on Sundays in Killybegs County Hospital and Sligo General Hospital. We are in the concluding stages of the negotiation process and hope to open this service in the coming months.

We look forward to seeing as many of you as possible at a number of events we have planned for Parkinson’s Awareness Week. We have secured funding for a media campaign to raise awareness about Parkinson’s and we will also be participating in a ‘United for Parkinson’s global campaign’ as 2017 marks 200 years since Parkinson’s was recognised as a health condition. The aim of this campaign is to unite the global Parkinson’s community and spread the same message on the same day all over the world. We will be working in partnership with Parkinson’s UK and European Parkinson’s Disease Association.

Parkinson’s Awareness Week events

There will be a great line-up of speakers on Saturday, 8th April at the Teachers Club in Dublin focusing on young Parkinson’s on-set. This is a great opportunity to meet the Young Parkinson’s Ireland committee and get involved. You will need to register for this event as places are limited.

On Sunday the 9th April join us for our 5th Annual Unity Walk. We are meeting at the Davenport hotel for a word from the Lord Mayor of Dublin and some warm-up exercises before we head out on the Unity walk. The Garda band will lead us around Merrion Square. There will be plenty of entertainment and a selection of speakers to take you through the afternoon. We will also ask you to sign a campaign petition called “Your Voice counts” that we will be launching at the Unity Walk with a view to securing Government funding for the PAI. Our aim is to collect 10,000 signatures and deliver them to the Minister for Health later in the year.

Join us in the Mansion House on Monday 10th April for the launch of our Device-Aided Therapies DVDs (registration needed). On Tuesday April 11th we ask you to join the Global Parkinson’s Community and # unite for Parkinson’s if you’re on social media. This campaign is to encourage a bigger focus on Parkinson’s and the need for more collaborative research and development around the world.

At least 50 countries are taking part in this campaign by using the campaign hash tag logo and messages. You will be raising awareness wherever you are in the world. We also want to encourage you to attend the Cork unity walk on Tuesday April 11th, meeting at the Parkinson’s Aspen Tree in Ballincollig Regional Park at 10.30am and afterwards at the Oriel Park Hotel Ballincollig for a cuppa and a ceili.

Work on the PAI strategic plan is nearly complete and we look forward to launching this later in the year. The PAI have been invited to attend the European Parkinson’s Disease Association event in Brussels organised to mark the 200 year anniversary of the discovery of Parkinson’s. This meeting will focus on the role of public health policy and the urgent need for investment and public funding in research, development and social policies that must support improvements in quality of life.

Due to the tremendous success of last year’s educational conferences we hope to run them again in some different locations. We will be working closely with local branches and will keep you updated when these are finalised. There are busy months ahead and I look forward to seeing you at upcoming events, Parkinson’s Awareness Week, branch meetings and conferences.

Kind Regards
Paula.
Young Parkinson’s Ireland Conference

On Saturday 8th April we will host a conference for the newly formed Young Parkinson’s Ireland Group. This conference will take place in the Teacher’s Club in Parnell Street Dublin 2pm-5.30pm.
This conference is aimed at young onset Parkinson’s patients up to the age of 55 years.

Unity Walk Sunday 9th April 2017

Our Unity Walk will take place this year on Sunday 9th April at 12noon. We will assemble at the Davenport Hotel and will walk around Merrion Square, returning to the hotel for refreshments and entertainment. Last year we had approx. 400 people walking in unity, raising awareness of Parkinson’s Disease. Please join us for a day full of fun and entertainment.

Launch of 3 Advanced Therapies DVD’s

We will be launching 3 new advanced therapies dvd’s on Monday 10th April in the Mansion House at 11am. We have been working hard to produce these dvd’s and wish to thank the three patients who generously shared their stories. Thanks to Gerry, Patricia Corscadden and John Bannion.

New Parkinson’s Disease Nurse Service for Northwest-Donegal/Sligo

On Thursday 6th April we will officially launch the new Parkinson’s Disease Nurse Service for the Northwest region. See page 8 for details.

World Parkinson’s Day Campaign
#UniteForParkinsons

Join together for Parkinson’s and help make 11th April 2017 a global World Parkinson’s Day. See page 4 for details.

Handbags for Lorna

The Dunderry Ladies circle hosted a handbag sale “Handbags for Lorna”. They raised €5,000 for the Parkinson’s Association of Ireland. Pictured are Lorna’s sister Ruth and her daughter Hazel presenting the cheque to Paula and Sabrina. Congratulations and well done on raising awareness and funds for the Association.

The Board of PAI

A big welcome to our new Board members. Our Board of Directors is made up of

Chairperson Joe Lynch.
Treasurer Nicola Clarke
Director Michael Burke Tipperary Branch
Director Professor Tim Lynch, Consultant Neurologist
Director Dave Donegan

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.
OUR SERVICES

Parkinson’s Nurse Specialist Service
Nicola Kavanagh Parkinson’s Nurse Specialist is available on our call back service every Wednesday and Friday. To avail of this service call our Freephone helpline 1800 359 359 leave your name and number and Nicola will return your call.

Freephone Helpline
The Freephone Helpline 1800 359 359 is available: 9am-7pm Monday - Thursday and 9am-5pm Fridays.
The helpline can be the first point of contact for newly diagnosed patients who can sometimes feel very vulnerable, scared and lonely. Your calls will be listened to confidently and with a listening ear.

We can refer you to resources which may be available to you in your local area, identify the kind of support you may require and provide reliable information. We have branches throughout the country which provide activities and meetings which can help support at a local level.

We have a range of information leaflets and booklets which are available on our website or which can be posted out to you.

We endeavour to answer all calls as promptly as possible.

Leaflets/Information
We have a large number of information leaflets available on many of the symptoms of Parkinson’s Disease. These leaflets are available to download from our website www.parkinsons.ie or we are happy to post them on to you if you would like to receive them please call Freephone helpline 1800 359 359. We will feature some of our leaflets in each edition of our magazine. In this Spring edition 2017 we are featuring Impulsive-Compulsive Behaviours.

Social Media
Website/facebook/Twitter.

Branch Network
We have 16 branches throughout the Country. Please check our website for a branch nearest you. www.parkinsons.ie Branch support at local level can provide meetings activities and a social outlet for many people. Some branches offer yoga/exercise classes/set dancing/physiotherapy and speech and language therapy.

Parkinson’s Awareness Week 4th-11th April 2017

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<td>4th April</td>
<td>Launch 3 Advance Therapy DVD (Brochure and Memory Stick Pack)</td>
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<td>Thurs</td>
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<td>Launch New PD Nurse Service for NorthWest- Donegal/Sligo</td>
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<td>Sat</td>
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<td>Launch Young Ireland Parkinson’s- Meeting Teachers Club Dublin 2-5.30pm</td>
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<td>Sun</td>
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<td>Unity Walk Merrion Square Davenport Hotel</td>
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<td>Launch Strategic Plan Oak Room Mansion House</td>
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www.parkinsons.ie
Young Parkinson’s Ireland Conference
Teachers Club (Club Na Muinteoiri) 36 Parnell Square, Dublin 1
Saturday 8th April 2017 at 2pm - 5:30pm

Open to all with an interest in Young Onset Parkinson’s Disease.
Meet the newly formed Young Parkinson’s Ireland Group which is a branch of the association for people diagnosed under the age of 55 years.

GUEST SPEAKERS:
- Parkinson’s Nurse Specialist - Brian Magennis Mater Hospital Dublin
- Humanistic Integrative Psychotherapist - Dee Daly
- Senior Occupational Therapist - Claire Dolan St James Hospital Dublin
- PD Warrior Instructor O.T. - Marion Slattery, Personal Health

To Register Call Freephone 1800 359 359
Free Admission

This event is run as part of Parkinson’s Awareness Week 4th-11th April.
For More Information on Parkinson’s Awareness Week and Young Parkinson’s Ireland support services visit www.parkinsons.ie

Young Parkinson’s Ireland
SOCIAL GATHERING

2nd/ 3rd SEPTEMBER 2017

We will gather again in the beautiful Hodson Bay Hotel Athlone for our annual Social Gathering, taking place this year on 2nd-3rd September.

We have decided to hold this event again this year in the Hodson Bay Hotel as the feedback we receive is that it people find it a convenient place to travel to and enjoy the experience there. Unfortunately hotel prices have jumped dramatically and the National Office have decided to subsidise the difference between this year’s rate and last year’s rate and keep the price at last year’s cost.

The cost of attending the gathering will be €99.00 pps. This includes Bed and Breakfast, Lunch and Gala Dinner and entertainment. This cost also covers our information day and events throughout the day, set dancing/yoga/drumming.

Set the date in your diary- 2nd-3rd September 2017 Hodson Bay Hotel Athlone

Please contact the hotel directly to book. Be sure to mention Parkinson’s Association of Ireland to ensure you get the correct overnight rate.

To Book, contact Hodson Bay Hotel on 090 6442005

WEXFORD CONFERENCE UPDATE

A Patient Conference was held in the Ferrycarrig Hotel, Wexford on 6th November 2016.

The conference was a great success and was well attended. Speakers included Consultant Neurologist Sean O’Riordan, St Vincents Hospital, Anne Roche, Acting Director of Nursing and Eileen Roche, Health and Fitness Instructor.

Well done to all involved. This conference was kindly sponsored by AbbVie.

www.parkinsons.ie
WHO WE ARE
Nicola Kavanagh Parkinson’s Nurse Specialist

I work as a Parkinson’s Disease Nurse in Tallaght Hospital & have done for the past 7 years. I work with 4 Neurologist. Myself & Dr Richard Walsh (Consultant Neurologist) who specialises in movement disorders, along with two registers we run a Movement Disorder Clinic every Thursday.

My role as a PD nurse is vital in caring for people with Parkinson’s Disease, as there are only 5 Parkinson’s Disease Nurses in Ireland there are a lot of areas under resourced and as Parkinson’s Disease patients have very individual needs, research has shown they benefit greatly from PD nurse input in the management of their symptoms. I also work with patients who attend the day care center in Tallaght Hospital. Part of my role involves training the staff in the day hospital & on the wards on both motor & non motor symptoms of Parkinson’s. We try to involve the family members in education & support to ensure they are receiving the best treatment available for their symptoms.

My role involves educating and support for patients and their families. This can vary from newly diagnosed patients to people living with PD for many years. I run nurse led PD clinics which help monitor for any issues they may be experiencing & may need help with. I work closely with a multidisciplinary team which includes a Physiotherapist, Occupational Therapist, Speech and Language Therapist, Neuro Psychologist and Social Worker. Patients benefit greatly from these resources and referrals for these disciplines are sent as required. A large part of my role is managing medications, this involves ensuring patients are taking their meds so they get optimal benefit from them. Again this varies from patient to patient but my role is to help them get their meds on time and educate staff so they are aware of the importance of this, and how their mobility can be affected if this is not maintained.

We also offer a follow up service, as the time between out patients appointments can be long & symptoms can occur long before they are due back to the clinic. Even telephone contact can be reassuring for patients and their families. Also knowing they have contact details for a nurse specialist is instrumental. Access to a specialist team for people with Parkinson’s Disease and their family/carers is detrimental to the management of their care.

I started working for the Parkinson’s Association of Ireland over 3 years ago. I work on the helpline which is available to anyone who has questions on symptom management, queries on medication, motor and non motor symptoms. People don’t realise symptoms they are experiencing are in fact related to Parkinson’s. This can be extremely helpful for their management as we can explain different medications used to treat symptoms. We offer an email service, which is confidential, where people can ask questions on any issues they are concerned about.

The helpline offers support for people who are diagnosed with Parkinson’s disease if they are concerned about any issues which may be affecting their quality of life. Family members and carers can also contact the helpline. If you are newly diagnosed and have any questions contact the helpline for support and education which is vital in management of issues that you may be experiencing.

As part of my role for the PAI I am asked regularly to visit nursing homes and Parkinson’s disease groups to give them education on medications mainly but also just general knowledge on ways they can manage their Parkinson’s better. This can be valuable for these patients as staff usually know very little about PD.

I also travel around Ireland to visit different branches. The feedback has been very positive & people are surprised by how much they learn about this condition and the importance of education and how this can affect their daily lives.

As part of my role, the PAI put a lot of work into organising a social gathering. I have given small group sessions where people can ask questions and these have been really well received. I am looking forward to the 2017 annual weekend trip to the Hudson Bay Hotel which can be very informative and great fun.
NEW SERVICE IN DONEGAL/SLIGO

RE: Parkinson’s Nurse Practitioner Outreach Service

The National Office in partnership with the Donegal/Sligo branch have entered into a one year contract with Galway University Hospital to provide an outreach nursing service to the Donegal/Sligo area. This pilot project will be delivered two Sunday’s per month in Killybegs County Hospital and Sligo General Hospital. The aim is to develop services on a pilot project basis with a view to securing long term funding, once need is established. This initiative was successful in Dublin’s Tallaght hospital when the Dublin branch in partnership with the National Office part funded the salary of the PD Nurse Specialist. Today this post is now permanent and fully funded by the hospital administration.

A recent development of University Hospital Galway’s Movement Disorders Advanced Nurse Practitioner Outreach Service. This service is being wholly supported by and fundraised for the Donegal/Sligo branch of the Parkinson’s Disease Association of Ireland.

This service development has come about as a direct result of needs expressed by patients and their families. It is well known that there is a difficulty for some people accessing services due to transportation constraints and the patients’ level of disability as a result of their illnesses. It is hoped to develop on the services available below, however a pilot study is required to ascertain the feasibility of this service provision.

Service available:

Referrals will be accepted from General Practitioners and Consultants for individual patient consultations, from which a liaison between the hospital-based health care provider or GP can be initiated. A record of the assessment and subsequent recommendations will be sent to the referring doctor. These assessments will be carried out in locations as convenient as possible for patients in Sligo and Donegal. Initially a clinic will be held once a month in Killybegs Community Hospital and then depending on patient dispersal will continue this way or a clinic will also be established in Sligo thus preventing difficulties with long distance transport etc.

If you are a member of the Donegal/Sligo branch and want to avail of this service contact your GP or our freephone 1800 359 359 for further information.

YOUR COMMENTS

Let us have your comments and we’ll post them here, in the next issue

Text PARKINSONS to 50300 to donate €2

Parkinson’s Association of Ireland has moved with the times and embraced mobile technology to offer you the option of SMS Text Donation, a smart way to give, where you can donate 2 to us by texting PARKINSONS to 50300. It’s as easy as that.

(Service provider Likecharity 01-4433890)

100% of your donation goes directly to Parkinson’s!

www.parkinsons.ie
Impulsive-Compulsive Behaviours

Dr. Sean S. O’Sullivan, MB, PhD, Consultant Neurologist, Cork University Hospital

Introduction
In the last decade, there is increasing awareness amongst people with Parkinson’s and their physicians that some medicines may potentially cause a change in some people’s behaviour. These changes are known as impulsive-compulsive behaviours and they are a potential side effect of commonly-used Parkinson’s medications - mainly dopamine agonists such as ropinirole, pramipexole, but also levodopa. A abnormal behaviour is characterised by an inability to resist an impulse or temptation, so the person can’t stop themselves from doing an activity repeatedly, excessively or obsessively. In most cases it is the family members who describe the full social and functional impact of these behaviours on the persons’ lives. Whilst some behaviours are associated with increased amounts of dopamine-replacement therapies, in most cases the behaviour develops in people taking standard doses. It is estimated that up to 14% of people with Parkinson’s taking dopamine agonists experience some problem with impulsive-compulsive behaviours. In a lot of cases, the behaviour is a part of character for the person. If untreated, they can escalate and lead to uncontrollable addictions that devastate people's lives. What kind of impulsive - compulsive behaviours are seen in Parkinson’s?
The most frequently described behaviours in Parkinson’s include compulsive gambling, compulsive sexual behaviour, compulsive shopping and binge-eating or compulsive eating. It is quite common for an individual to have more than one type of impulsive-compulsive behaviour.

These behaviours manifest as:
• a failure to resist gambling
• an irresistible need to buy things
• binge eating large amounts of food in a short space of time
• a pre-occupation with sexual thoughts or inappropriate sexual behaviour
• reckless generosity, even to relative strangers

Dopamine addiction
Some people with Parkinson’s become addicted to their dopamine replacement drugs. This behaviour is less frequently seen than compulsive gambling, compulsive sexual behaviour, compulsive shopping and binge-eating or compulsive eating. Here, the addiction is so powerful that they start taking more and more of the drug – exceeding the dose prescribed to control their movement. This happens even though they are ‘on’ and experience severe dyskinesia (involuntary jerking). People will often resist the advice of their doctors and families when it is suggested that they try and reduce their dopamine medications. People with this problem may also have very bad mood swings throughout the day. These can vary from feelings of depression, irritability and anxiety when they are ‘off’, all the way to euphoria and hyperactivity when they are ‘on’.

Punding
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 (e.g. 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.

Hoarding:
Excessive hoarding is commonly seen in association with other impulsive-compulsive behaviours in Parkinson’s, and this can represent a significant health hazard to some individuals in terms of fire risk and clutter in the home.

What causes impulsive - compulsive behaviours in Parkinson’s?
The precise causes are still under investigation, but it is clear that dopamine-replacing medications used to treat Parkinson’s are the major risk factor for the development of these abnormal behaviours. Other risk factors may include:
• Younger age of onset of Parkinson’s
• Higher amounts of dopamine replacement therapies
• Previous history or family history of drug or alcohol abuse

What can I do about impulsive - compulsive behaviours?
Recognising that the behaviours involved are harmful to the person and/or their family is the first and most important step. Very commonly, the person with Parkinson’s may not be aware that their behaviour is related to their medications. Even if the person or their family recognises the behaviour as being excessive, factors such as embarrassment and fear of social stigma often prevent them from discussing the problem. After the potentially harmful behaviour is identified, the person should inform his/her doctor as they might require a change in their Parkinson’s medications.

In the case of punding and related behaviours, many families find that some form of a “contract” can be helpful, whereby the person will restrict their activity to certain times in the day, and allow their families to enforce this deadline if necessary. In addition to these measures, 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 impulsive - compulsive behaviours. Occasionally, mood problems such as depression can arise when dopamine-replacing medications are being reduced, and these problems should be discussed with the treating physicians. Psychiatry services can be invaluable in helping treat other less common conditions which can resemble impulsive - compulsive behaviours, which include obsessive-compulsive disorder or mania.

With treatment, the prognosis for impulsive - compulsive behaviours in Parkinson’s is generally good, with most people making a significant improvement. Untreated, the consequences can be very dramatic and bring about terrible work, social and financial problems.
How does Smovey help people with Parkinson’s?

Smovey are a handheld devise with 4 steel balls inside it. Through movement, it creates a vibration through the handle which travels up the arm, into the spine and up to the brain and makes the dopamine in the brain more effective. The vibrations connect to the brain and send the neurotransmitter clearer signals. This is extremely effective, in particular with helping people with balance, coordination and movement. Also, as the vibrations travel through the rest of the body, it creates energy and vitalises over 100 million cells in the body which is fantastic for better circulation. By exercising with this tool, it will not only help with improving symptoms, it will also help to slow down the progression of the disease.

Do you need special training to use Smoveys?

No special training is required as it comes with a DVD and booklet explaining exactly how to use it. However, I offer a free personal demonstration or video call for each client just to get the most of it and design specific exercises to suit their special needs. For example, if somebody is having balance issues, we focus more on balance exercises, somebody with freezing issues, we focus more on exercises creating vibrations going through the body which will help preventing and reducing with freezing episodes.

Are there any classes especially for people with Parkinson’s?

Yes. I hold classes in Waterford, in Cheshire House, Johns Hill Waterford and Active Elite Gym, Commercial Marina, Cork has classes every Tuesday and Thursday at 10am. These classes are held by a physical therapist who will cater especially for the individual needs of the client.
We are looking at increasing the classes around Ireland for people with Parkinson’s, so if you know any physical therapist or personal trainer that would like to do Smovey classes, please pass me their details and I will contact them.

**How can people try them before they buy them?**

I will be at various Parkinson’s meetings throughout the country over the coming months or, if you’d like me or a colleague to come to your local meeting, you can contact me at smoveyhealth@icloud.com.

**How much do Smoveys Cost**

They cost €100 per set plus €15 postage but if your living in Cork, Dublin, Kilkenny or Waterford you can buy directly from one of my colleagues or myself and get your personal demonstration at the same time. I personally offer a 30 day money back guarantee, so if you’re not 100% satisfied you can get a full refund so there is nothing to lose but everything to gain. It sounds expensive at first but if they are used correctly and as advised, you will think they are worth every cent and more. I have many clients who have said they’d pay €1000 for them.

**TESTIMONIALS**

I have testimonials from all over Ireland, UK & America from people who found that Smovey gave them a better quality of life and would all personally recommend Smoveys to their Parkinson’s friends.

Check out www.smoveyhealth.com for a list of testimonials but few include:

I was introduced to Smovey on holidays in Lanzarote 7 months ago and I think everybody with Parkinson’s should use Smovey - I would NEVER miss my 15 minute daily workout as it gives me so much energy, relieves pain and stiffness, helps with depression and I always feel better after using it. Niall O Driscoll, Cork

I have been using Smoves 5 months and they are one of the best tools I have ever seen. I need to walk with a stick as I’ve bad balance but I can walk up to 10 miles with the Smovey without the aid of stick. It’s absolutely amazing and it has also given me great strength in my core body from the exercises. I’d give these 10 out of 10. Tony Wilkinson Cork

I love using the Smoveys as they are so easy to use and can do them 1st thing in the morning and at home, nobody needs to see them. They have increased my energy, helped me with pain in my body and I’ve suffered with IBS the past 7 years and now off medication for this thanks to Smovey I don’t suffer with my bowels anymore. Ann Quinlan, Waterford

I have been using Smovey for 8 months and find it extremely helpful for my balance, coordination, preventing freezing and helps me being more positive about my condition. I love it so much, organising classes with my local Parkinson’s group in London. Dee Oakley, London

I have been suffering with PD for 8 years and I have such negative reactions against so many PD medications that I have dedicated my life to finding natural solutions to helping people and I find Smovey absolutely top class. It’s easy to use and you can feel it helping you almost immediately. Vibration therapy is excellent and I am without doubt delighted to include it into my daily routine. Dr. Gary Sharpe UK (please feel free to follow Gary Sharpe journey on his page on Facebook “outthinking Parkinson’s”)

Smovies are used all over Austria, Germany and Switzerland by Physiotherapist to personal trainers; from nursing homes to gyms and with various support groups with clients suffering from neurological disorders. These Smovies are not only excellent for exercise and stimulation of the brain but also for relief of muscles and back pain via vibration therapy.

If you have any questions or would like to meet with me personally, please don’t hesitate to contact me on 089 2422120 or see our website www.smoveyhealth.com

**Parkinson’s Ireland - Smovey competition**

To win a set of Smovies with DVD & Booklet and 10 personal classes or video calls, please answer the following question:

Who invented smovey?

Please email your answer to smoveyhealth@icloud.com before ------ ---- and the winner will be announced in Parkinson’s Ireland newsletter, facebook page and next edition of magazine.
MAYO BRANCH

Mayo had a very busy year in 2016. We had a great launch of our awareness video in late October, it was very well received, which was quickly followed by a nomination in the Rehab Mayo people of the year awards. This meant we received some well timed publicity on local radio and in the local papers.

We continued with our Physiotherapy classes and ran up to our Christmas Party in mid December in Hotel Westport, where Mayo members danced the night away. A lovely end to our year.

We had a short break over Christmas, with a number of members joining in a St Stephens day walk organised by the Keywest Bar in Islandeady for the benefit of Mayo Parkinson’s and Islandeady Foroige. A good way to work off Christmas day excess and blow away a few cobwebs.

We returned to our normal schedule on 7th January and it’s been busy since.

A meeting was held in Belmullet to see what services and supports were needed in the area and a good turnout was had, we hope to see a local support group holding monthly meeting to be up and running shortly. This will be part of Mayo Parkinson’s Branch.

We also have some members attending manual handling and Patient handling course this month.

Our Mayo Parkinson’s Awareness walk in April is approaching and we have much work to do to get ready for it again.

Contact: Caroline McLoughlin 0879324646
Branch Email: mayoparkinsons@gmail.com
Web Site: www.mayoparkinsons.com

CORK BRANCH

Cork branch has continued to welcome new members at our coffee mornings and set dancing classes. Bandon Parkinson’s Support Group under the leadership of Tony Wilkinson held it’s first meeting in Bandon in January and 18 people attended. It hopes to meet on a monthly basis from now on. Tony moved to Cork from the UK in 2015 and was initially shocked to discover that there was no Parkinson’s Nurse available to people with Parkinson’s in Cork city or county. This contrasts with the service available in the UK where he was able to avail of regular expert advice and support.

Unfortunately Cork Parkinson’s members were recently informed that Dr. Sean O’ Sullivan, Consultant Neurologist at CUH will be leaving his post in April and moving to The Bons Secours Hospital. Sean has Parkinson’s as his speciality and while this is disappointing news for many PwPs we wish him well and are extremely grateful to him for the care he gave many of us individually and for the encouragement he gave us as a group. He will continue to speak at our annual conference. His advice is that it could take a while for a replacement will be appointed. Without doubt this will lead to delays in appointments but the remainder of the CUH Neurology team are all well experienced in Parkinson’s. For those in a strong financial position there is the option of going to the Bons Secours as a private patient. However we as a group will continue to demand that a Parkinson’s Neurologist and Parkinson’s Nurse be appointed at CUH.

Cork Branch committed itself to helping fund research in UCC which is the biggest research hub in Ireland. Prof. Aideen Sullivan is overseeing a study on “Sleep, Diet and Mood in People with Parkinson’s”. This will involve PwPs wearing Actigraph watches for seven days which can track sleep patterns and activities of daily living. There will also be a number of questionnaires to be completed. Initially volunteers from the Cork area are required but in time other branches may be contacted.

We are currently making plans for Parkinson’s Awareness Week and particularly for World Parkinson’s Day on 11th April. We will hold the 3rd Cork Unity Walk in the Ballincollig Regional Park, leaving from The Cork Parkinson’s Aspen Tree at 10.30 am. Following the walk, everyone is invited to
Oriel House Hotel in Ballincollig for a Parkinson’s Ceili and refreshments. Wexford Branch have indicated that they hope to join the Cork walk and are organising a social trip around it. Other groups and individuals are most welcome to attend.

Our annual party was held in January in Oriel House Hotel and once again it was a most enjoyable day for everyone who attended. We had excellent musicians and story telling and despite the prevalence of flus etc. over 130 attended. A relative summarised the day as follows: I am so pleased that my mother went. She had a wonderful time and met some lovely people and I will continue to encourage her to attend activities.

Contact: Ted Horgan 087 2375558

CAVAN BRANCH

The Branch held an Ecumenical service in November for deceased members of the Cavan branch and deceased family members of the branch. It was very well attended despite bad weather conditions on the night. Refreshments and food followed along with a little raffle which included a copy of Maura Renehan’s new book which Eileen from the branch had won in the Winter edition of this magazine! PAI Christmas cards were also on sale on the night.

The Cavan Parkinson’s branch Annual General Meeting will take place on Monday 27th February at 6.30pm in the Hotel Kilmore, Cavan Town. New and existing members and / or family members are welcome to join us! Geraldine Clarke from Family Carers Ireland – Cavan branch will address the meeting and food and refreshments will be served afterwards.

Membership fees for 2017 are now due and can be paid at the A.G.M. or can be posted to the Secretary. The membership fee is €25.00. Anyone who pays their membership on or before the night of the A.G.M. will be included in a draw on the night!

Yoga continues every Friday in the Community Centre beside Castlemanor Nursing Home at 11am. All yoga is done sitting on a chair apart from a few standing exercises. If any members from outside the Cavan town area are interested in attending yoga please contact Eileen 086 2426699 with a view to setting up a set of classes in some other part of the county with the assistance of Cavan Sports Partnership.

The Paul Myles Memorial Run committee has announced that half of the proceeds of their proposed run on Monday 1st May 2017 will go towards the Cavan Parkinson’s branch. We would like to take this opportunity to thank them for thinking of us. Please support them by either by taking part or spreading the word about the event.

Reminder letters about the A.G.M. and membership fee will be issued shortly.

Contact Paddy Conaty 0494332821

SOUTH KERRY BRANCH

Our November meeting was held in Our Lady of Lourdes Nursing Home where Consultant Neurologist Helena Moore gave an interesting talk. A number of nurses and carers attended the meeting also. A special thank you to Nurse Noreen Davis, Maggie & her husband for all their help at the meeting. Our Christmas dinner was a very enjoyable occasion. Our meeting in March will be held at Kilcummin in Our Lady of Lourdes Nursing Home at 7.30pm. Parkinson’s Nurse Nicola Kavanagh will speak at that meeting. Chairperson Grace McCrae broke her hip and spent 5 weeks in hospital. Thanks to all who visited her and a big thank you to Karen Burkitt and Teddy & Kathleen Cronin who looked after the branch in her absence.

Contact Grace 064 7758837

TIPPERARY BRANCH

2016 is now history and 2017 is well established, Spring is in the air with the birds singing sprightly and brightly in the garden. Time for all in the Parkinson’s family to put “A Spring in our step” as we look forward in anticipation to increased participation in all Tipperary Branch Activities across the county and beyond.

The Branch now provides a two and a half hour activity session each Monday (with the exception of Bank Holidays) in The Pastoral Centre Church Rd, Nenagh from 2pm until 4.30pm which involves PD Warrior with Occupational Therapist Marion Slattery cost is €10 per session.

3pm to 4pm Our Sing Along Club which is of great benefit to voice clarity and loudness and also improves your breathing. Well know vocalist and choir Leader Sheila Chadwick is our leader and she encourages us all to sing whether we can or not
and is ably assisted by Mary Shinnors on keyboard and her sister Rita Gleeson on Fiddle who provide the music on a “key” suitable to all. The Speech Therapist will drop in from time to time to keep us on our toes!!!!!!!!!

All activities with sing along group is voluntary and our thanks to all concerned. The words of the songs are projected on screen which ensures a good posture look up at the screen rather than down at a sheet of paper.

Presently our activities come under the heading of “The Monday Club” while we await a final title with some of the characters attending on Mondays. We anticipate some interesting suggestions. Yes the craic is mighty on Monday afternoons, sessions are serious but lighthearted with a fantastic atmosphere of comradeship and friendship and care for one another.

Recently in Limerick for an appointment we happened to meet Una Anderson Ryan a former Chairperson of P.A.I. and decided to go for a quick coffee. During the course of our chat the Sing Along Group was mentioned and we are delighted to say that the Mid West Limerick Branch is planning to have a singing group after their regular meetings. We will give every assistance with words of songs etc continuing the great spirit of cooperation between our neighboring branches. Consideration should be given to representatives of Branch Forums on a regular basis to share ideas and experiences for the benefit of all in the Parkinson’s family.

Our Variety concert in The Templemore Arms Hotel was a great success with entertainment from near and far. The local Templemore Pipe Band raised the roof as they marched into the hall giving a fantastic display. Our thanks and appreciation to all concerned and particularly to our host Dan Ward proprietor of the Hotel and his staff.

On December 2nd Nenagh Support Group held its second annual Ecumenical Candle Lighting Ceremony and Mass for members who were called to their eternal reward in the past year. In excess of twenty candles were lit in their memory.

Fr. Des Hillary PP Nenagh officiated at the Mass. The Entire Monday Group participated at the Mass. They sung the hymns, done the readings, offertory procession and Communion reflection.

WOW!! YE WERE ABSOLUTELY FANTASTIC

WELL DONE TO ALL OF YOU. Remembering the happier times following the mass we had finger food etc., and entertainment from many friends and members including Mary Shinnors, Rita Gleeson, Marion Slattery, Brendan Treacy, John Shinnors and Donal Ryan Story Teller, Jim Barry, Paddy Shoer, etc.,

Thurles Support group had a very successful Carol Service with Upperchurch Youth Choir in The Community Hospital of The Assumption prior to Christmas. They played a wonderful selection of Carols and then they travelled to Tipp FM Radio in Clonmel for the Midnight Mass being broadcast on the radio on Christmas Eve. They are a wonderful group of young people who give of their time every year and we really appreciate them for this. On Wednesday 1st February in the Community Hospital of the Assumption we had a very successful meeting with Nicola from PAI HQ addressing the meeting and a question and answer session after the talk. Our AGM will be held in the Anner Hotel on Wednesday 15th March and we hope to have our CEO Paula Gilmore in attendance.

We are also talking at present of running a bus for Unity Walk on Sunday 9th April in Merrion Square Dublin if we have sufficient members.

Roscrea Support Group are planning meetings for later in the year.

The Clonmel Support group Autumn/Winter season has also been very busy. Their calendar (Theresa Gahan & Pat Feely’s baby) was born in September. What a lovely “baby” it was. The Calendars flew out the door, all 500 of them, they re-printed another 200 and they got wings as well, at €5 each they were very good value.

Christmas came early, November 11th with a Vintage Tea Morning in Place 4U. It was indeed a lovely morning. Thanks to Noelle and all the ladies in Place 4 U.

On Friday night November 18th Mary Finnegan and her family had a great night in The Templemore Arms Hotel, Templemore where the Tipperary Branch hosted a concert, it was a very enjoyable night with sing along, and the musician were excellent. It was well worth the journey there and they wish to compliment Marion Burke, John Brown, Paul Ryan, Seamus Loughman and Kevin Lalor Fitzpatrick on the hard work, organising this wonderful evening. (Michael did his bit as well)

Their Christmas lunch was held in Raheen House Hotel, Clonmel on December 6th. There was a
great attendance 37 sitting down to lunch. The meal was excellent. They were joined by Tipperary Branch Secretary Mary Carey and Chairman Michael & Marion Burke, Tina Whyte (more than just our set dance teacher) and the helpers Helen & Mary. After lunch music was provided by Billy Fitzgerald and his band Patsy & Jim, the feminine touch was provided by Anne Walshe, who serenaded us with some beautiful old songs.

The evening was made very special for Mary Finnegan organiser and our Clonmel Support group leader when a lady expressed her thanks for the lovely lunch. She said that going out for a meal can be stressful, and not enjoyable, as she is very conscious of people looking at her, as she has involuntary movements of her body, which are Dyskinesia’s. At our lunch she was relaxed as she knew nobody would notice, and if they did, they would understand.

The Group are at present running a campaign to have the services of a Parkinson’s Nurse Specialist for the South East Region. The management of South Tipperary General Hospital met with Mary Finnegan, who saw the need for a Nurse Specialist, and assured her of their assistance where possible. The Public Representatives of the area were also approached. We have a promise of their attendance at our next meeting. Watch this space for an update on this item.

Wishing all within the Parkinson’s Family a very Happy & Busy New Year.

Contact Marion Burke 0872967296

17th branch of PAI now up and running

LONGFORD BRANCH

We are delighted to announce the opening of our 17th branch in Longford. The enthusiastic team are really excited about Parkinson’s focused services in their area.

The group will meet in Teallach Iosa Family Centre, located behind St Mel’s Cathedral Longford town. The group will have their first meeting on 13th March at 7pm. The group have formed a new committee. The chair is Brenda Shannon, treasurer is Mary Connolly and secretary Al Shannon. The group hope to meet once a month to start with a view to developing more regular services. For information about joining this group contact Al Shannon ph 086 279 1421
Parkinson’s groups all over the world will unite on 11th April 2017 to raise unprecedented amounts of awareness about the disease, using a dedicated campaign hashtag: #UniteForParkinsons.

Each year, Parkinson’s organisations and individuals across the world observe 11th April as World Parkinson’s Day. However, this year’s World Parkinson’s Day is a landmark anniversary. The date momentously marks 200 years since Parkinson’s was recognised as a health condition (following the publication of Dr James Parkinson’s Essay on the Shaking Palsy, whose birthday the day is marked on).

We will be using the #UniteForParkinsons on the day to help make the hashtag go viral on social media. You can help us to do this by sharing your thoughts, experiences, hopes and plan for the future. Below are examples of posts with the hashtag in them that you can use on Twitter and Facebook on the 11th of April. We hope our followers will help us spread the word and use the hashtag #UniteForParkinsons.

LOOKING FOR IDEAS ON HOW TO FUNDRAISE?
Why not visit our website and see our A to Z of exciting fundraising ideas
www.parkinsons.ie

www.parkinsons.ie
FACE UP TO YOGA with Renee Le Verrier. RYT

Increasingly, evidence points to yoga for helping ease symptoms of movement disorders and improve balance, increase slow movement and even reduce tremor.

As a Parkinson’s yoga instructor, I have witnessed the positive effects in individuals in my classes. As a stroke survivor with a ten-year-old Parkinson’s diagnosis, I can also personally attest to yoga’s benefits.

**Face it:** yoga is good for the body, especially the body of someone with Parkinson’s

But what about the face, especially the face of someone with Parkinson’s?

Research stops at the neck. Rigidity and range of movement measurements take arm swing, leg stride and trunk rotation into account. No surprise, really, since yoga poses for the face address anti-aging and wrinkle prevention. Only rarely does traditional yoga involve aspects of the face. Parkinson’s, however, does.

Facial masking is a common Parkinson’s symptom that stiffens the muscles that raise eyebrows in surprise or curl the lips into a smile. The face loses all expressions but for a vacant, lifeless one. The impact is not only physical – affecting chewing and swallowing – there’s also an emotional impact. The inability to react with expression is often misinterpreted as inattention or apathy.

Recent studies indicate that facial masking in Parkinson’s leads to reduced social interaction and connectedness so much so that isolation and depression become factors. Interventions still need to be studied. In the meantime, why not invite yoga up to the face?

More than forty muscles are at work from the forehead to the chin. Approach them with the same yoga techniques that have proved beneficial below the neck and note if symptoms ease. They have for me.

When I was tying my runners one afternoon, my husband asked me a question. I glanced up at him, he took a half step back and asked why I was so angry with him. I wasn’t angry at all with him. He was reading my expression – or, perhaps, lack thereof. I hadn’t spoken, and I remember only the runners, really. I’d been so focused on fumbling with the laces while being “off” that my face must have crunched up into a ball of consternation.

That day, I began incorporating facial areas into my own yoga practice as well as into my classes. I include a combination of mindfulness, stretching and massage adapted from a variety of sources. The mindfulness comes from yoga. The stretching mixes physical therapy approaches with yoga. And the most useful exercises, interestingly, derive from yoga and former actors and actresses. They’re trained to portray emotion, even if all they’re doing is tying their runners.

**TRY THIS:**

**Smile:**
Before rising each morning, even before opening your eyes, smile.

**Unclench:**
Throughout the day, notice if you’re clenching your jaw. Say to yourself, ‘Lips touching, not teeth.’

**Smooth:**
Massage your forehead.

**Soften:**
Squeeze your eyes closed. Ease the pressure. Notice the line where the top lid touches the bottom. Make that line of touch as light as you can.

**Three horses:**
Breathe in through the nose then exhale through the mouth with lips lightly touching, allowing them to vibrate and make a phhlllt sound like a horse.

For more information, resources and a link to the 2017 World Parkinson’s Congress poster presentation on Face Yoga, please visit www.limyoga.com
Our Facebook Group - ‘Young Parkinson’s Ireland’ - is up and running, with membership gradually increasing. It is a good way for easier contact for those scattered around the country. This is a closed group to maintain member’s privacy. It gives an opportunity to share ideas and concerns and support each other. As we are operating within the Parkinson’s Association, those wishing to join will need to be members of the PAI. Anyone interested please contact us at youngparkinsonsireland@gmail.com or 087 6383465 and once your details have been registered you will receive an invitation to join.

Our first social event was in the Mercantile Hotel in Dublin. It was a great success, with some members coming from Waterford, Cavan, Mayo, though mostly Dublin. Many people walked in knowing absolutely no-one (not easy to do), and walked out having made new friends and finding a lot more in common than just Parkinson’s.

It proves the value of these meetings, and the need to extend this outside Dublin. Before the summer we will organise a social meeting outside Dublin. In the meantime, we plan to have some more smaller local meetings in areas in Dublin where we have some numbers, though open to anyone who’s interested. An event is organised as part of World Parkinson’s Week, and we hope some will join us for that and maybe form a group at the Annual Unity Walk in April.

We have the Committee, but equally important we need the participation of members - this is your group, and its success will depend on how many join and participate. So please work with us and contribute your views. If you have any interest in support of any kind for ‘young onset’ Parkinson’s, this is your opportunity to come on board and influence how this group will develop.

Contact Cathy Pollard at 087 6383465 or youngparkinsonsireland@gmail.com.

Many people have started using the internet and social media platforms as their primary source for networking and information. Here are the links and information you need to follow PAI online.

**PARKINSONS.IE -**
Visit www.parkinsons.ie
The website is updated regularly. On the site you will find, information leaflets that you can download and print on a variety of topics relating to Parkinson’s disease. There is information on support networks and coping tips, types and methods of treatments, information patient videos, ask the expert section, how to get involved with the association and our latest and upcoming events. There is also a contact form on the site where you can contact us directly.

**TWITTER PAGE -**
To keep up to date on our twitter page follow us @ParkinsonsIre. The account is updated with a variety of different tweets in relation to Parkinson's disease and other relevant topics. You can also contact us directly through Twitter via messaging.

**FACEBOOK -**
To follow us on Facebook like our page Parkinsons Ireland, after you like our page our statuses and posts will then appear in your news feed. We use Facebook for sharing information on a different number topics such as, medical, research, fundraising, events and campaigns. You can also contact us through FB via messaging.
To be handed to your Doctor and used for planned or unplanned admission to hospital.

I am living with Parkinson’s Disease. I may have difficulty speaking or writing clearly. My condition may deteriorate if my medication is not taken at the correct times prescribed for me. **I WILL NEED A FULL GLASS OF WATER PER PD TABLET**

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<th>Name</th>
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<td>Next of Kin</td>
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<td>Doctor/Neurologist</td>
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**Other Medication**

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

By asking your Health Care Professional to attach this to your file you will be helping them to manage your condition while you are in hospital.
People with Parkinson’s need their medication on time, every time

GET IT ON TIME

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

www.parkinsons.ie • freephone 1800 359 359