

Parkinson's Association of Ireland

www.parkinsons.ie

Summer 2017

CALL TO ACTION



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- Staff Recognition Award
- Cork Patient Conference
- New Service for Donegal/Sligo

Parkinson's Unity Walk





Paula Gilmore

A WORD FROM OUR CEO

Dear Members

2017 marks the 200th anniversary of the discovery of Parkinson's disease and this was reflected in this year's media campaign. The total readership/listenership including the website was 99,476,649 (media report). The nationwide media campaign aimed to profile people with Parkinson's and their lived experiences. A special thanks to all the branch members and everybody who participated in our media campaign to raise awareness. We also used this opportunity to call on the Government to put in place more resources and supports for the Parkinson's Association of Ireland (PAI). We highlighted the need for the much-needed neurologists and nursing staff to alleviate the long waiting times for access to diagnosis and treatment and we highlighted, through press releases, the significant increase in the demand for the PAI services. The personal testimonies shared with the media received coverage in local papers right across the country. Many of the national papers, including the Irish Times and the Irish Independent covered our campaign.

The PAI also took over Dublin landmark the Ha`Penny Bridge to highlight the lack of services. Thank you to all the people who gathered at the Ha`penny Bridge ahead of Parkinson's Awareness week, and a special thank you to RTE broadcaster Eileen Dunne for her support and contribution to raising awareness. Thank you to Abbvie for funding the campaign. We took this opportunity to raise awareness of PD and the impact it has on the 12,000 Irish patients and their families. We called on the general public to participate in the 'Unite for Parkinson's' worldwide campaign. The campaign was an unprecedented success worldwide with 30,000 visits to its website from 180 countries and more than 6,000 users of the hashtag on World Parkinson's Day. The Campaign was also endorsed at the European Parliament in Brussels which I attended with participants from 30 other countries. As a result of this meeting, organised by the EPDA and Parkinson's UK, Parkinson's was declared a European priority. I also got an opportunity to discuss the work of PAI with MEP Marian Harkin, ambassador to people with Parkinson's and brain disorder in Brussels.

A meeting took place in April with the Minister for Health Simon Harris. Joe Lynch chair of the board and Declan Moriarty also attended this meeting with me. It was a very positive meeting and we are in the process of seeking state support for the PAI's work. We are also asking you to sign a campaign petition that

- was launched at the Unity Walk. All branch committees
- have received the petition and our aim is to collect as many
- signatures and deliver them to the Minister for Health later in
- the year.
- Parkinson's Awareness Week kicked off with our 5th Annual
- Unity Walk and a series of activities to highlight difficulties
- experienced by the 12,000 people living with Parkinson's in
- Ireland. Following the walk we all enjoyed presentations,
- entertainment and set dancing. Congratulations to the
- Cork and Mayo branches that also had a very successful
- Unity Walk. As part of the weeks activities Young Parkinson's
- Ireland had a very successful conference in the Teachers Club
- Dublin. This group is very energetic and have a number of
- social events planned in the coming weeks.
- The member's social weekend is a great way to catch up
- with some other branch members. The weekend will be held
- in the Hudson Bay hotel on 2nd -3rd of September. A very
- exciting programme has been planned with something for
- everyone.
- The Munster conference is the first of the national
- conferences for 2017 and will be held at the Oriel House
- Hotel in Ballincollig on Tuesday 20th June and this is being
- organised by the Cork branch. This will be followed by the
- Cavan and Kerry conference in September and October.
- (dates to be arranged).
- We are also planning a number of smaller meetings around
- the country that will focus on the recently launched Device
- Aided Therapy. The PAI, in collaboration with Dr Richard
- Walsh, Neurologist at Tallaght Movement Disorder Unit have
- developed a series of three DVDs. The national office will
- provide a nurse specialist to attend your area and facilitate
- the showing of these DVDs. The nurse will be there to answer
- any questions you may have. The DVDs were designed to
- help alleviate concerns from patients as they begin their
- journey with advanced treatments. The DVDs will show
- interviews with Irish patients and their families. Dr Richard
- Walsh will help you understand the challenges, side-effects
- and potential benefits of each treatment option. Nurse
- specialist Paddy Browne, University Hospital Galway, will be
- contracted to deliver this programme to local branches.
- I wish you all a lovely summer and look forward to seeing you
- in the coming months.

Kind regards

Paula

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DATES FOR YOUR DIARY



- The Parkinson’s Association of Ireland have secured funding to deliver 3 National Conferences and 15 Branch Meetings with Parkinson’s Nurse Specialist Paddy Browne throughout the country in the coming months.
- Three areas have been selected to host full day conferences which are Cavan, Kerry and Cork. The remaining areas will have mini conferences.
- Paddy Browne PNS will be included on the agenda for all of these conferences to speak on device aided therapies.
- Dates for conferences to be confirmed.
- Website will be updated as dates for conferences are announced and branches will be informed.
Cork..... 20th June 2017
Cavan..... October 2017
Kerry..... To be announced

Thanks to Abbie for sponsoring the PAI Education Programme 2017.

- Another date to plan for is our Social Weekend 2-3rd September in the Hodson Bay Hotel Athlone
- Paddy Browne PNS will speak on Sunday 3rd September in the Hodson Bay for those who attend the social weekend. Please note conference will continue to Sunday morning for Paddy’s presentation

SMOOVEY RETRACTION

In the Spring edition of our magazine we ran an article on Smoovey’s.

Having consulted with Chartered Physiotherapists and Neurologists we wish to retract claims made in this article that by exercising with this tool it will slow down the progression of Parkinson’s.

As there is no clear evidence to support this claim we wish to advise that smoovey is an aid to fitness only.

Although there has been no clinical trial on this product we have received a number of calls from people living with Parkinson’s Disease stating they found enormous benefits from this product.

Many branches of PAI are establishing smoovey classes and people living with Parkinson’s have also trained as certified trainers as they have found personal benefit.

The Parkinson’s Association of Ireland support all forms of physical activity to maintain mobility

Parkinson’s Association of Ireland, Carmichael House, North Brunswick Street, Dublin 7 Tel: 01 872 2234 Email: info@parkinsons.ie Web: www.parkinsons.ie Freephone Helpline: 1800 359 359

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



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.

TRAVELLING WITH PARKINSON'S

Travelling abroad for summer holidays is meant to be a happy occasion, but for some, it can be very stressful.

Every year millions of people take to the air to visit families and friends in far off places, or just to take that well deserved annual holiday. We contacted the Dublin Airport to see what their advice is for people who may have impaired movement or a requirement for some assistance. Dublin Airport has a specifically dedicated section which provides maximum access for people with reduced mobility (PRMs).

How to request Assistance

Knowing how to request assistance can often be the key to getting through the airport with as little fuss as possible. It is imperative that people with reduced mobility contact & notify their airline, travel agent or tour operator with details of their assistance requirements at time of booking their flight or at least 48 hours in advance of the departure of their flight. Your assistance requirements will then be passed to our service provider OCS, who will ensure that the assistance you require is made available to you. It is very important that persons with reduced mobility ensure that they contact their airline, travel agent or tour operator directly as otherwise their onward travel may be affected by the safety rules an air carrier applies to the carriage of persons with reduced mobility.



Help Points

On arrival at Dublin Airport, passengers can use one of the many Help Points (blue or yellow boxes with an intercom button or tall grey and black poles with button and handset) located throughout the campus to gain assistance or can go to the OCS reception desk on the departures floor in Terminal 1 (to the right hand side when entering through door 2) or in the check-in level in Terminal 2, adjacent to the dedicated drop-off zone for reduced mobility passengers.

If you require any further information, contact us at the following:

Email: prm@daa.ie

Phone: 01 8144692 (Mon - Fri 9 to 5)

OCS Assistance Requests: 01 944 6104 (Mon – Fri 9 to 5)



8th ANNUAL PARKINSON'S SUMMER RAFFLE

Our Annual Summer Raffle has become a hugely important part of our fundraising calendar.

Every ticket you buy gives you a chance to win one of our super prizes.

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DID YOU KNOW?

1 ticket (€5) would help pay the cost of sending out an information pack to a newly-diagnosed person with Parkinson's

A book of 5 tickets (€20) would help pay for providing our Parkinson's helpline and nurse support for 1 hour.

Every ticket you buy or sell will make a positive difference to the lives of people with Parkinson's in Ireland.

HERE ARE SOME OF OUR FANTASTIC PRIZES –

- ▲ €500.00 Cash
- ▲ €250.00 Cash
- ▲ Overnight stay in Hodson Bay Hotel for two people with dinner
- ▲ One Night stay in the Limerick Radisson Hotel with Breakfast
- ▲ Original Harold Huberman Painting
- ▲ 3 x €50.00 one4all voucher

★ ★ ★
Plus lots more prizes
★ ★ ★

Parkinson's Association of Ireland ANNUAL NATIONAL DRAW 2017
REGISTERED CHY NO: 10816

1st Prize €500 Cash • 2nd Prize €250 Cash
3rd Prize Overnight in the Hodson Bay Hotel with B&B and Evening Meal
• One Night B&B in the Limerick Radisson Hotel
• A signed Harold Huberman painting to the value of €250 • 3 x €50 One4All vouchers
• A Newbridge Silver Pendant • Newbridge Silver Pin
★★★ And many more prizes ★★★

Draw will take place on 21/07/2017 @ 12 Noon in Carmichael Centre, North Brunswick Street, Dublin 7. Permission Granted.

€5 EACH OR €20 FOR A BOOK OF 5

Name: _____
Address: _____
Phone No: _____
Email: _____
No: _____



THANKYOU FOR MAKING #UNITEFORPARKINSONS GO GLOBAL



"WHATEVER YOUR CONNECTION, WHEREVER YOU ARE, UNITE FOR PARKINSON'S"

World Parkinson's Day, Awareness Week and the #UniteForParkinsons campaign have all been and gone, which means it is the time for reflection.

Firstly, we would like to thank all of our members and followers on social media who helped spread the word about Parkinson's disease and took part in the #UniteForParkinsons campaign on April 11th.

Together, we posted an endless stream of amazing messages, pictures and videos that exceeded all of our expectations – we even managed to make the hashtag trend on Twitter!

For the first time, the global community united on World Parkinson's Day with a single, clear message – that we must join forces if we are to defeat Parkinson's. The support of each of you was invaluable to achieve this result. **Thank you.**

POLICY WORKSHOP BRUSSELS 29TH MARCH 2017

To mark the 200th year anniversary of the discovery of Parkinson's Disease the European Parkinson's Disease Association (EPDA) held a high level policy workshop in the European Parliament in Brussels to discuss cross-cutting challenges to timely diagnoses and individual treatment and care.



Marian Harkin MEP (Ambassador for people with Parkinson's and Brain Disorders, Brussels), Paula Gilmore CEO Parkinson's Association and Professor Bas Bloom Neurologist, The Netherlands

Together with MEP Marian Harkin, attendees identified areas where EU can add real value, including measures to reduce discrimination in the workplace and inequalities in access to treatment and healthcare. It was agreed that the EU can also provide much-needed research funds for data collection, new treatments and services that improve quality of life.

The workshop convened 30 high-level stakeholders from EU institutions and across the Parkinson's community. Paula Gilmore, Ceo attended this meeting.

The #Unite4Parkinsons was endorsed at this meeting.



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.

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.



Saturday 2nd

Information morning
Activity based afternoon
(including aqua session for those who are interested)
Gala Dinner
Ceili Mor/
Light Entertainment

Sunday 3rd

Morning Mass
followed by
Advanced Therapies
11.15-12.30pm



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

Hodson Bay Hotel contact number : 090 6442005

Remember to bring your swimwear this year and enjoy some aqua exercise!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!

Come and enjoy this wonderful break away with us in these tranquil surroundings. Our line- up for the weekend includes Top Speakers on neurological Conditions, Nurse led clinics, afternoon sessions to include Set Dancing, Parallel Sessions including Yoga, Sing a long sessions, Aqua class in heated pool. Gala Dinner with Ceili Mor and light entertainment.



Remember to bring your swimwear this year and enjoy some aqua exercise!

SELF CARE OF CARERS

Carers Week takes place from 12th-18th June 2017

NOW YOU ARE A CARER:

TAKING CARE OF YOURSELF

The caring role makes many demands on you the Carer, it is therefore extremely important to look after your own physical and emotional health.

Below are some helpful tips on how to take better care of yourself:

GETTING OUT

If it is possible, continue with activities you enjoy outside the home, as it is important to follow your own interests outside your caring role. Some Carers feel guilty when they leave the house to enjoy an activity without the person they care for. If you are finding it difficult to get out, talk to other family members, your local Carers Resource Centre Manager, your Public Health Nurse or G.P.

REDUCE THE ISOLATION

It's easy to become isolated when you are a Carer. You may become too busy to keep up with friends and family, people may visit you less and thus loneliness often becomes the worst part of being a Carer. Sometimes just talking to someone who understands what you are going through can be a great help. Your local Carers Resource Centre and Support Groups can put you in touch with other people who share similar experiences.

KEEP HEALTHY

By taking time for regular exercise this will help you feel more energetic and provide a break from your daily activities. Always try to have



healthy and regular meals. It is not always easy to do but in the long term it is important for your health and well being.



Exhaustion can often add to the stresses of caring it is vital to get enough sleep and rest.

TAKE TIME FOR YOURSELF

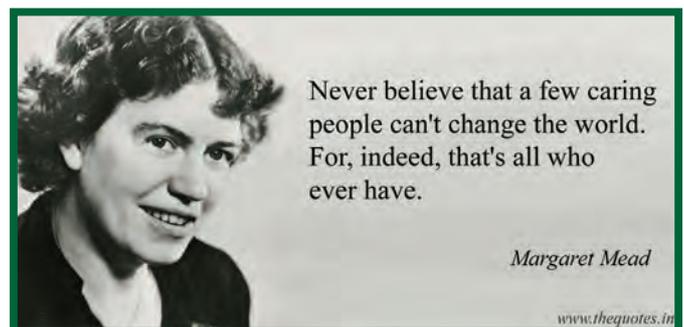
Getting in the habit of making time for yourself as a regular part of the day is important. Don't feel guilty about this time as it is for you.

Planning ahead and pacing yourself will also help. Although it can be easier said than done you need time to yourself every day to relax.

TAKE A BREAK FROM CARING SITUATION

Breaks can be taken in your home or away from it. They might be for hours, a day, and a week. You can use this time to sleep, do shopping, have a holiday yourself or just to "do nothing" – a luxury that Carers rarely if ever enjoy.

Respite Care is provided by many different organisations and is depending on the age and condition of the person being cared for as well as the location where you live. Contact your local resource centre for information on respite available near you.



Most Carers will tell you that they have times when they feel weighed down and unable to cope. If you are feeling this way it is vital to speak with someone about it such as family, friends, GP or contact your local Carers Association Resource Centre or call

Freefone Careline 1800 24 07 24 or visit www.familycarers.ie

Posture, Walking and Falling

Parkinson's Disease is a movement disorder, which may affect posture, balance and walking. Safe and effective performance in these areas is a basis for all activities in daily life. This leaflet gives some advice about managing these difficulties, if they should occur.

Posture

As your Parkinson's progresses, your posture can change – you may become more stooped and your muscles may become more rigid. This inflexibility can increase your risk of falling, because it's more difficult for your body to move, and for you to protect yourself if you lose your balance. This can be worrying or frustrating, but there are some things you can do to help overcome balance problems. To check or correct a stooped posture, try standing with your back against a wall, heels touching the wall then try to get your shoulder blades back against the wall and tuck your chin in so that the back of your head touches the wall. Or try facing the wall, with your feet a few inches back from the wall, place hands overhead, palms on the wall and lean into it – hold the stretch for 20 to 30 seconds.

Walking

Walking, an essential activity for maintaining independence and overall health can be affected by Parkinson's. The most common problems with walking include

- ★ festination or shuffling (this is made worse by a stooped posture), where steps become shorter and you have to take lots of quick steps to stop you from losing your balance because your centre of gravity is too far in front
- ★ freezing, where the feet get stuck to the ground and knees may be flexed and heels are off the ground;
- ★ getting started and turning can also be problematic for some

To help overcome these difficulties, focus only on walking:

1. Try to concentrate on taking long steps, placing heels down first (saying to yourself – HEEL – HEEL with each step can help).
2. Eliminate sharp turns in the environment. When you have to turn, keep the feet apart and turn in a semicircle, always moving in a forwards direction.
3. The use of rhythm (a tape or CD with a catchy beat, or a metronome) can help you get started and to keep going.
4. Visual cues such as lines or tiles on the floor, or a strip of tape at a doorway can help prevent freezing.

Falls

It's important to get help and advice about avoiding falls. If you have fallen over before, anxiety or fear of falling can increase the likelihood of it happening again. Your GP, specialist or Parkinson's nurse can offer advice on how to avoid future accidents, or refer you to a physiotherapist or occupational therapist.

Acknowledgements:

Parkinson's Association of Ireland would like to thank David Hegarty Chartered Physiotherapist for endorsing this leaflet.

DISCLAIMER – The information on these pages, whilst professionally sourced or assessed, is not intended to be taken as advice. No changes to your treatment should be made without prior consultation with your doctor or allied health professional.

The physiotherapist may work with you on balance training and improving your ability to walk. This training will improve your confidence and help to reduce any fear of falling. They can also teach techniques to help you get up if you fall. Often a physiotherapist will work with an occupational therapist to make sure your home is hazard free.

Though it might be tempting, try not to restrict all your activities to prevent falls, as this is likely to cause joint stiffness or muscle weakness. This can actually increase your chance of having a fall because your body won't be used to moving and maintaining its balance.

It's important to try to stay as active as possible and to exercise regularly to help you maintain your mobility and prevent falls.

Some people with Parkinson's fall because they have problems starting to move or they 'freeze' while they are moving. Freezing is when you stop suddenly, and it can last for a few seconds or minutes. If this happens, you might feel as though your feet are stuck to the floor or that you can't move easily, which can make you feel unsteady. This can increase your risk of falling over. If you have difficulty with your medication wearing off before your next dose is due, you might find freezing becomes worse. If falls are a problem, a physiotherapy assessment can help determine the cause. In some cases, balance activities and strengthening exercises can help to reduce the occurrence of falls.

Some useful suggestions

- ★ Remove rugs or low lying obstacles from pathways inside or outside the home
- ★ Install handrails especially along stairways
- ★ Use a cane when necessary
- ★ Avoid using stepladders or stools to reach high objects
- ★ Slow down when you feel yourself in a hurry
- ★ Before rising from bed or your bath, pause for a moment when you are in a sitting position.
- ★ Stop walking or sit down if you feel dizzy.
- ★ For some people, wearing hip protectors (specialised undergarments with padding over the hip areas) can be useful in protecting the hip bones from fracturing as a result of a fall.

If necessary, physiotherapists can recommend mobility aids.

- ❖ Wheeled frames tend to help the flow of movement
- ❖ Baskets and trays can often be attached and can eliminate the need to walk and carry items at the same time

These may be available through your local Public Health Nurse at your local health centre.



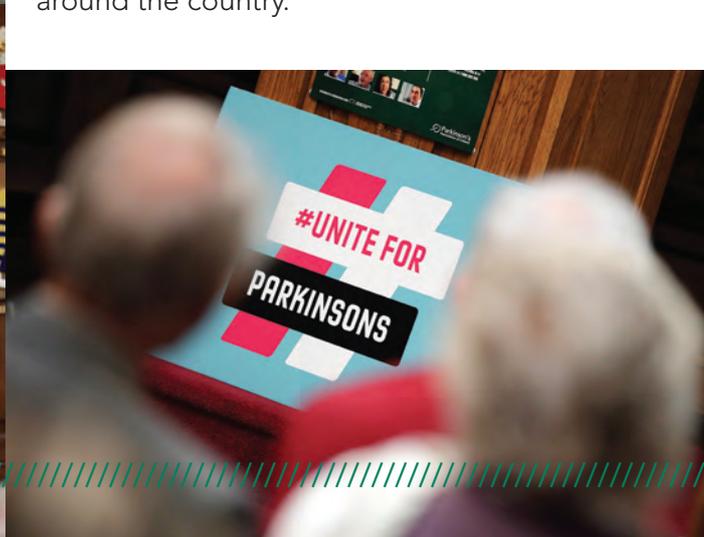
LAUNCH OF DEVICE AIDED THERAPIES

On Monday 10th April 2017 we launched our new device aided therapies dvd's for Parkinson's - Duodopa, Apomorphine and Deep Brain Stimulation (DBS) at the Mansion House, Dublin.

The Parkinson's Association of Ireland, in collaboration with Dr Richard Walsh (Neurologist, Tallaght Movement Disorders Unit) have developed a series of three videos, designed to help alleviate concerns and prepare patients as they begin their journey with these advanced treatments.

Paddy Browne PNS Galway University Hospital launched these dvd's on the day.

They have been distributed to Neurologists, Geriatricians, PNS and Parkinson's Clinics around the country.





#Unite for Parkinsons

On Monday 3rd April we gathered at the Halfpenny Bridge in Dublin to Launch Parkinson's Awareness week 2017.

Parkinson's Awareness week 2017 was very a special one as it marked the 200th anniversary since Dr James Parkinson discovered the shaking palsy and the Halfpenny Bridge in Dublin had recently celebrated its 200th Anniversary.

- Eileen Dunne graciously gave her time to come along and raise awareness for the association.
- We were also joined by many members, friends and the transition year student boys from St. Paul's CBS Brunswick St.



Parkinson's Association of Ireland UNITY WALK

On Sunday 9th April we gathered in the Davenport Hotel Merrion Square for our annual Unity Walk.

Members came from many branches throughout the country to walk in unity on this important date in the Parkinson's calendar.

We were joined by the Lord Mayor of Dublin Brendan Carr who walked the route with us. The Garda band led the walk with their upbeat tunes to keep the rhythm going.

We were also joined by drummers Wassi Wassi who helped us keep in step.

Following lunch we enjoyed some movement breaks with Marion Slattery and set dancing with Pat O'Dea.

Unity Walks also took place in Mayo and Cork where there were very positive turnouts.



Lord Mayor Brendan Carr & his son Jason lead off the march with Paula Gilmore (CEO Parkinson's Association).



Joe Lynch addressing the crowd



The start of the Mayo Unity Walk



Anne Belton, Physiotherapist



Christy Crowe & Terry Murphy (East Midlands Branch)



Cork Branch members attended their Unity Walk in Ballincollig Regional Park



Wexford Branch members attending the Cork Unity Walk



The Barry Family from Tipperary



Tipperary Branch of the Parkinson's Association



Tony Howard, Carmel Howard and Billy Young
(All Dublin / North Side / Swords)



Members of the East Midlands Branch of the Parkinsons Association



Martina Brady, Eileen Burke Smyth, Reg Thompson & Susan Donohoe (All from Cavan) & Stella McElherron & Frank McElherron (Both from Dunshaughlin).

BRANCH NEWS

MID-WEST BRANCH

Monthly meetings have had good attendance and positive feedback from members.

In March, Naturopathic Consultant, Jennifer Allen gave a talk on importance of diet in supporting general health and Parkinson's wellbeing. The principle behind Naturopathy is very simple. The key tenets are that your food is your medicine and that prevention is so much better than a cure.

In April, we had talk on incontinence and strategies (diet, exercise and medication) in managing issue.

In May, we had representative from Smovey Healthcare, Ireland give a talk and demonstration of Smovey rings. Smoveys' are a hand held device with four steel balls inside. We will endeavour to support the creation of a "Smovey exercise group" in the mid-west.

We have held numerous fundraising events. Church gate collections, bridge tournament, golf outing, coffee morning and sale of art work. Sincere thanks to all for organising and supporting these successful events.

Contact Billy Rice 061-228003



Tribute to Sid Rellis

SID RELIS RIP

Sid was one of the founder members of Parkinson's Midwest and served as the Chairperson of the Board of the National Association.

He achieved so much for the association in a quiet, respectful way. He was one of the first patients to travel to Bristol for DBS.

Our sympathy goes to his wife Teresa, his son Paul and five daughters Deirdra, Fiona, Sinead, Laura and Claire.

May he rest in peace.

YOUNG PARKINSON'S BRANCH

It has been a busy Spring for YPI. In April we had a social meeting in the Clarion Hotel, and were delighted to welcome travellers from outside Dublin as well as those more local. We had a Young Parkinson's Conference in Dublin in May in association with the National Office as part of Parkinson's Awareness Week. The speakers were excellent, and there was a very positive and uplifting vibe. We also had a good presence at the Unity Walk in Dublin.

Our next social event was held in Limerick on May 27th. It was on a Saturday afternoon, giving the option for those further afield to make a day trip, and bar food or snacks were available as required. As we are a nationwide group, we plan to hold meetings in different areas around the country, depending on numbers and interest.

Our Facebook Group is getting lots of member input and discussion. Anyone interested in joining, please email youngparkinsonsireland@gmail.com with a bit of background information and we will link you in.

Other events in the pipeline:

On Saturday, June 10th, we plan to take part in Bike Week Food Cycle. This is a collaboration between the Dublin Cycling Campaign and the Dublin Community Growers Association and has been held for a number of years. It is a great social event involving cycling at a leisurely pace and visiting a number of gardens and tasting the wares. Participants get a choice of a north or south route and everyone meets up at the end.

A day or overnight trip to Glendalough is being considered for the weekend of 9th/10th September. Details later.

A number of our members will be attending and anyone is welcome to join us, for the cycle or stop-offs / end-point, including family/friends. Confirmation of final routes and location at the end where everyone will meet up will be available on parkinsons.ie - or keep an eye on dublincycling.ie or follow dublin cycling on Facebook.

Any suggestions for an activity in your area are welcome. We would also love to have a few



additional committee members or volunteers, including people from outside Dublin (to reflect our nationwide status and give local input). No need to travel to Dublin for meetings - it is possible to dial in to participate from home.

Contact us at youngparkinsonsireland@gmail.com or 087 6383465 (Cathy). See parkinsons.ie for event updates, or request updates by email.

Croagh Patrick Climb



On the 1st of July, Young Parkinson's Ireland and Parkinson's Ireland are coming together with Huntington's Disease Association of Ireland, Motor Neuron Disease Association and Motor Neuron Disease Research UK to climb Croagh Patrick near Westport, Co Mayo. The idea is to gather together and have a fun weekend in Westport and raise some funds for the Charities involved.

The weekend is not about the climb, it is about members coming together, sharing stories and supporting friends. The event is open to all PAI members, family and friends of all level of fitness. It is not about reaching the top it is about doing what you are able to do and providing support and encouragement to one another.

The climb will start at 10 am from the car park at the Information Centre subject to weather conditions. It is advisable to take sturdy footwear, rainwear and some drinking water. On Saturday evening, we plan to have a social gathering in Westport at a location to be confirmed. Everybody is welcome to join us.

Anyone interested in attending the event please contact us at youngparkinsonsireland@gmail.com

https://give.everydayhero.com/ie/July_1st#/?_k=l2kyo8

Contact: Joe 086-2676371

SOUTH KERRY BRANCH

The branch enjoyed the visit of Nicola Kavanagh PNS to our Lady of Lourdes Kilcummin.

The staff also enjoyed the talk given by Nicola. Neurologist Dr Helena Moore from Tralee also paid a visit and so much knowledge was taken in by the nurses and carers.

Jack McCrae RIP

Grace McCrae wishes to thank Nurse Noreen Davis and her staff for all the care they gave to Jack who passed away on Good Friday. Jack had Parkinson's for 18 years and did so much for Parkinson's in the area. Thank you to everyone who sent cards, flowers and to those who took the time to call. Thanks to the National Office for cards and calls from Grace.

Contact Grace 064-7758837

CAVAN BRANCH



Denise Buggy signing petition along with Margaret Conaty and Margaret Flanagan.

The Cavan Branch recently had a get together for afternoon tea in the Lavey Inn followed by a talk by the Parkinson's Specialist Nurse, Nicola Kavanagh. Over 40 people attended and as usual Nicola's talk was very informative and helpful.

A special thanks to one of our volunteers Margaret Flanagan and her husband Ronan who held a very successful Coffee Morning in their home on Easter Saturday in aid of the Cavan Parkinson's Branch. A special thanks to Cavan Bowls Club who recently presented our Chairperson Paddy Conaty with a donation from their fundraising activities to the Cavan Parkinson's Branch.

A number of our members attended the Annual Unity Walk in Dublin and a good day was had by all. Even the weather was kind to us on the day! Thank you to Paula and all the staff and Abbie for organising the event.

The Cavan Branch have been busy collecting signatures for the petition to be submitted to the Minister for Health for more direct supports and services for the Parkinson's Association of Ireland. So far we have over 700 signatures collected. A special thanks to Cavan Gaels Bingo for allowing us to pass petition sheets around before and after Bingo and also to the Paul Myles Memorial Run who similarly allowed us to collect signatures at their run on 1st May.

A reminder to let Eileen know as soon as possible if you wish to travel to the Annual Social Gathering in Athlone in September – so far we have ten people interested in going.

The committee will be meeting shortly to organise another get together and details will be sent out to all registered members. There are a few memberships still outstanding and the committee would like to collect the remaining memberships as soon as possible in order that all memberships can be paid over to Head Office. Speaking of membership – a warm welcome to all our new members who have recently joined us in 2017. We hope you will benefit in some way from the support and information we strive to provide and also forge some new lasting friendships.

Finally the Chairperson, Paddy Conaty is proud to announce that Cavan has been picked as one of the three counties in Ireland to hold a One Day Conference on Parkinson's. This is a wonderful opportunity for the people of County Cavan living with Parkinson's and the surrounding counties to hear speakers on various subjects in relation to Parkinson's disease. More information to follow!

Contact Eileen 086-2426699

Cork Branch



Ballincollig Regional Park

The Cork Unity Walk was our biggest ever with the 120 participants enjoying perfect weather conditions in Ballincollig Regional Park. Wexford Branch travelled to Cork specially for World

Parkinson's Day and the group of 40 stayed overnight at The Riverside Hotel, Macroom. A number of our committee members joined them for a meal and took part in an impromptu Table Quiz afterwards. The winners and runners up tables had the benefit of sitting with a Cork Branch member which gave them a decisive edge!

The walk itself was attended by Seamus McGrath, Mayor Of County Cork and by Paula Gilmore, CEO, Parkinson's Association Of Ireland. Paula highlighted the fact that there are only 5 Parkinson's Nurses in Ireland even though having another nurse would actually save the HSE money. Councillor McGrath praised the group for the support we provide to People With Parkinson's, particularly newly diagnosed people. The walk was very sociable and some people would have liked to walk even further as they enjoyed the company so much. The overwhelming feeling throughout the morning was that there is no reason why People With Parkinson's can not lead very normal lives and have some fun along the way!



After the Walk it was on to Oriel House Hotel for a World Parkinson's Day Ceili. This proved very enjoyable with Helen Kelly helping the Cork members to show their prowess at Set Dancing. Michael Looney got a little sing song underway and by 2.30pm it was time for the Wexford bus to depart for home. They came as strangers and went home as friends. We look forward to meeting them again.

The final event of the day was a Parkinson's Awareness Meeting in Bandon. This was attended by 44 people and group leader Tony Wilkinson gave an excellent talk on living and coping with Parkinson's. A number of display stands at the meeting added to the variety of information available on the night.

Preparations are continuing for our 2017 Conference and visitors from any province in Ireland are welcome to come either individually or as part of a group and we have scheduled the



timings to allow travel to and from Cork outside of peak traffic times. None of our speakers (with the exception of the Conference Chairman ,Dr. Sean O’ Sullivan) has spoken at a Parkinson’s Patient Conference in any part of the country previously yet each one of them has a wealth of knowledge and expertise to share with us. Speakers include Anne Glover, Neurology Nurse, Bons Secours , Cork, Jessica O’ Donoghue , Music Therapist , Cork & Limerick, Prof. Tom Foltynie, Honorary Consultant Neurologist at the Unit of Functional Neurology at UCL Institute of Neurology (London), an International Speaker; Tony Wilkinson (Person With Parkinson’s, Bandon, Co. Cork and formerly London), Physio Team, Bons Secours Cork with a closing talk by Paula Gilmore.

Professor Foltynie, who is a leading authority on Deep Brain Stimulation will discuss a number of device assisted therapies and possible future treatments. We look forward to welcoming many of you on the day to a very interesting conference..

As Conference Numbers are limited, booking is preferable. Please Contact 087 218 9572 by 16th June to reserve your place.

Ted Horgan 087 2375558

TIPPERARY BRANCH

Summer greetings from all in Tipperary Parkinson’s family. Thurles Support group kicked off the Spring meetings with a visit from Nicola Kavanagh, Parkinson’s Nurse Specialist . Well done and thanks Nicola. Our Secretary Mary Carey organised a four week session of medical yoga classes with East West oriental Specialist Dheai Ilsaaid. These classes were very well attended and because of the good response she may repeat them again in the Autumn. Dheai believes that “Healing is a matter of Time, but it is sometimes a matter of opportunity”, and also that “Worrying does not empty tomorrow of its troubles it empties today of it strengths.”

Our Annual Summer Mass took place in the Hospital of the Assumption on Tuesday 30th May with the Upperchurch Youth Choir participating.

“The Monday Club” continues weekly in The Pastoral Centre, Church Rd, Nenagh from 2pm to 4pm with exception of Bank holidays. PD Warrior with Marion Slattery OT and Sing Along under the tutelage of Sheelagh Chadwick followed by cuppa, goodies and chat. A very special welcome to our new members. Exercise to suit all stages of

Parkinson’s Active, Chair and wheelchair friendly exercises Congratulations to our Musical Director Sheelagh Chadwick who is M.D. of Silvermines Choir who are presently visiting Rome and participating in Mass at St. Peter’s Basilica in Rome well done to all. (A vision that our sing along group may aspire to)!!!

Congratulations to Noel McMahon from Shinrone on borders of Offaly & Tipperary who launched his third book on St. Mary’s Catholic Church, Shinrone a must have book for anyone with Shinrone connections,and not forgetting Paul Ryan, from Roscrea who has published a number of books of stories and poetry.

Clonmel Support Group at the invitation of TD Jackie Cahill organised a visit to the Dail on Tuesday 21st March with lunch in the members restaurant. Our thanks and appreciation to Jackie and his sister Pauline for their hospitality. 44 members and carers from Clonmel and Nenagh’s Monday Club travelled on the day. Local TD’s Alan Kelly, Seamus Healy & Mattie McGrath also came and chatted with the group and all Oireachtas Members from Tipperary committed to campaign for a Permanent Parkinson’s Nurse Specialist to cover Mid & South Tipperary & Waterford.

ACTIVITIES OF THE CLONMEL SUPPORT GROUP

Our condolences are offered to the family of the late **Tommy Cunningham, RIP**, a Parkinson’s patient who very seldom missed a meeting. Rest in Peace Tommy.

Fund-raising flag days, Sponsored walks, An overnight stay in Kinsale, attendance at the launch of Cairdeas, a Kilkenny Parkinson’s Choir, which has in its fold, a member of the support group/ The concert was excellent as voiced by those who attended same.

The April and May meetings concentrated on diet and exercise in preparation for summer.

The April meeting had Consultant Dietician, Ellen Roache who gave an informative presentation on the importance of a healthy, varied diet in Parkinson’s disease. At the May meeting, Irene Tracy demonstrated the Smovey as part of a healthy exercise programme for those with Parkinson’s disease.

KINSALE TRIP

On Monday May 8th 11 members of the support group embarked on a trip to Kinsale. It was an



overnight stay. Taking in the scenic views of Kinsale harbour with a boat trip.

A delicious dinner was enjoyed at Acton's hotel, in which we over-nighted, followed by a sing-song accompanied by music by our resident musician, Billy Fitzgerald, himself a Parkinson's person.

The following day, after breakfast, the group visited and took a tour of Charles Fort.

Knockmealdown Actives fund-raiser for the group. And also 1/3 to go to The Neurological Research Department of The Mater Foundation.

Sponsored walks, 3 different walks of varying distances, along the base of the Knockmealdown mountains, organised by (The Knockmealdown Actives, a group of walkers) to be shared by The Clonmel support group of The Tipperary Branch of Parkinson's and the Neurological Research Department of The Mater Hospital, Dublin, is well on its way to becoming a reality. This event will take place on Sunday, May, 21st. Sponsorship cards are available from Mary Finnegan @086 1224283.

Our AGM was well attended in The Anner Hotel, Thurles with Guest Speaker C.E.O. Paula Gilmore. Appreciation was expressed to outgoing Vice Chairperson of the branch Oliver Nolan who with his wife Marie have moved to Dublin. Both were great ambassadors for the Branch and our good wishes and thanks go with them.

A cheque for €250 was presented to our treasurer John Carey by John Murphy from Kilkenny who had done Operation Transformation in his workplace a big thank you John for remembering our branch. Paula Gilmore C.E.O. in her address complimented the members on the branch activities and the success of the support groups which are key to providing activities in member's local areas. Thanks to Margaret McMahan for organising a special

surprise Easter presentation to the organisers and helpers of the Monday Club Thank you Margaret it was appreciated by all. Our After Easter party held in the Pastoral Centre, Nenagh on Friday night 21st April which included musicians, song and story telling Congratulations to Paula Gilmore and team for a splendid array of events for Awareness Week. We are gathering signatures for the petition to Government seeking permanent financial funding for P.A.I.

Tipperary Branch activities do not stop for a Summer break. Visit our Monday Club or perhaps join us for a day trip during the Summer

Contact Marion Burke 0872967296.

LOUTH/MEATH BRANCH

The AGM of the branch was held in the Lisdoon Arns, Dundalk on 27th February 2017 and the following people were elected:-

Chairperson: - Eamonn Johnston (outgoing)

Secretary: - Fidelma Leahy (outgoing)

Treasurer: - Patrick Walsh

The chairman, on behalf, of members, extended to Kathleen Molloy, (outgoing treasurer), their appreciation and thanks for her trojan work as treasurer for the branch.

The guest speaker on the night was Marie Hayes from the Citizens Advice Centre, who gave a very informative presentation, followed by a question and answer session.

We hold an informal get together with coffee in the Louth area on the last Monday of each month. These meetings alternate between Ballymascanlon Hotel, Dundalk and The Boyne Valley Hotel, Drogheda and are held at 3.00pm which is a quiet time for the hotel.

For Parkinson's Awareness Week we organised an information stand in The Marshes Shopping Centre, Dundalk, to raise awareness of the disease and the existence of the Louth/Meath branch

The Chairperson of the branch was interviewed on LMFM local radio about the disease and the work of the branch during Parkinson's Awareness week

The branch was represented by the chairperson and members of his family at the annual Parkinson's Unity Walk which was held in Dublin on 11th April in bright sunshine the Garda Band led us round Merrion Square. On arrival back at the Davenport hotel refreshments awaited us, followed by exercise and set dancing workshops.



Once again this year I would like to thank Kathleen Molloy and her sister May who ran a very successful fundraising pop up shop for the branch in the Long Walk Shopping Centre Dundalk.

The Meath support group meet on the last Friday of each month in the Ardboyne Hotel Navan at 12.30pm.

Contact Frank McElherron 085-1547987

WEXFORD BRANCH

We at the Wexford Branch continue to welcome new members at our Coffee Mornings/Support meetings. Our Yoga Classes which are a great success not just with our Members but also members



of the public these classes will continue until the 28th of July will then take a break for the summer and recommence in September. We travelled to Cork to on the 10th of April to join the Cork Branch in the Unity Walk on the 11th were we were welcomed with opened arms and we would like to thank Mr Ted Horgan and his committee for being so kind to us. 40 of us stayed in the Riverside Park Hotel in Macroom where we enjoyed Dinner and Dancing and had a great time.

Following on from such a successful trip we are looking at arranging another one for September to Dublin.

We really would welcome and encourage members to attend our Coffee Mornings/Support meetings to meet other people. We are very lucky in Wexford to have a Parkinson's Course that is run by Wexford General Hospital where you can speak to a nurse and have access to physiotherapists occupational and speech therapists please contact us for details

Chairman: Mike Murray 087-2690999
Email: paiwexford@gmail.com



A large group from the Wexford Branch attended the Cork Unity Walk and made a weekend of it

STAFF RECOGNITION AWARD FOR PARKINSON'S DISEASE WORKING GROUP



The foresight and vision of University Hospital Limerick Group (UHL) and the Mid-Western branch of the Irish Parkinson's Assoc. in 2014 is reaping rewards in 2017 at UHL.

In 2014 a group made up of nurses, physiotherapist and a pharmacist working in UHL went to London South Bank University to study modules of the "Parkinson Disease Nurse Specialist" course and today the knowledge skill and awareness for the disease can be seen in the exceptionally high standard of care experienced by sufferers of Parkinson's Disease on the newly opened Neurological/Stroke Centre , Ward 3B, in UHL which incorporates a dedicated suite to care for patients with Parkinson's Disease.

In January of this year the hard work and progress the group has made was recognised by the

- University Hospital when the group was nominated for "Best Quality Improvement" award at the annual Staff Recognition Ceremony held at The Strand Hotel in Limerick earlier this year . On hand to receive the award were Edel Hennessy (Senior Neuro Physio) and Michael O'Halloran (RGN) representing the multi-disciplinary group .
- A working group focusing on the care of Parkinson's Disease patients is now fully functioning in the Neurological Centre and it aims is to provide up to date evidenced based, efficient, optimal care to Parkinson's patients admitted to the Centre. This will be done by
- ▲ Working as Parkinson's patient advocates
- ▲ Working as a resource to colleagues and patients through dissemination of information
- ▲ Providing formal and informal education sessions to staff .



▲ Promote campaigns within the Centre aimed at improving Parkinson’s patient care

The remit of the working group will initially be to the Centre with dissemination throughout the hospital once established.

Parkinson’s Disease is a progressive, fluctuating neurological disorder. It occurs when the cells in the part of the brain that control movement are lost.

These cells produce Dopamine, a chemical that enables people to perform smooth co-ordinated movements. Without enough Dopamine in the brain, everyday activities including walking, swallowing and even smiling are affected.

The main treatment for Parkinson’s Disease is medication and there are specific which work by replacing or mimicking the actions of Dopamine. Often people will be on a number of drugs, each of which must be taken throughout the day at specific times. These stimulate a carefully timed release of chemicals into the brain to allow a person with Parkinson’s to control their movements.

The symptoms and progression of Parkinson’s Disease is unique to each individual. It may have taken a long time for the patient and specialist to establish the best individualised drug regime.

Once a medication regime is disrupted it may take hours, days or even weeks for a person’s Parkinson’s to stabilise .This can have serious consequences for ward management and the treatment for which the person was originally admitted.

The patient is likely to require a higher level of care and an extended hospital stay, at a significant cost in both time and resources . There is an increased risk of accidents and falls, and in some cases the originally planned treatment may no longer be possible. The patient may also feel a loss of dignity and independence as well as the ability to communicate and exercise choice in their care.

The National Institute for Health and Clinical Excellence (NICE) guideline on the management of Parkinson’s Disease (June 2006) stated;

If a person with Parkinson’s is unable to take their prescribed medications at the right time, the balance of chemicals in their bodies can be severely disrupted and this will lead to their Parkinson’s symptoms becoming uncontrolled.

To prevent using up of vital resources and the unnecessary extended hospital stay for patients, the Parkinson’s Disease Association of Ireland’s “Get it on Time” campaign has been launched at UHL

The campaign involves training all members of staff on 3b in the awareness and importance of why the timing of drugs is so crucial. A poster campaign along with an educational DVD presentation is running on the ward for all staff and patients to get a better understanding of the issue. Parkinson’s nurse specialist Mags Richardson is also running teaching sessions for staff.

The “Get it on Time” campaign is just the first of planned initiatives by the Parkinson’s focus group at the university hospital which makes Limerick a leader in developing excellence in care for patients with Parkinson’s and in time it is hoped other hospitals will follow the leadership shown by the Mid-west Branch of the Parkinson’s Association of Ireland and management and staff at UHL.

The Parkinson’s Association of Ireland launched their “Get it on Time” campaign last year.

We have distributed thousands of posters to hospitals, neurologists clinics, Parkinson’s clinics and continually run the campaign through our quarterly magazine.

Article by Michael O’Halloran



Cork Parkinson's Patient Conference 2017

Oriel House Hotel, Ballincollig, Co. Cork
Tuesday 20th June 2017 at 11.00 am to 3.45pm
(With Lunch and Refreshments)

BOOKINGS BY 16TH JUNE TO 087 218 9572

GUEST SPEAKERS

Prof. Tom Foltynie - Consultant Neurologist, UCL
Institute of Neurology, London (Device Assisted
Treatments)

Anne Grover - Neurology Nurse,
Bons Secours Hospital Cork

Dr. Sean O'Sullivan - Consultant Neurologist,
Bons Secours, Cork

Jessica O'Donoghue - Music Therapist,
University Of Limerick
Bons Secours Physiotherapy Team, Bons Secours, Cork

Tony Wilkinson - Person With Parkinson's,
Cork and formerly London

Paula Gilmore - CEO, Parkinson's Association Of Ireland



YOUNG PARKINSON'S IRELAND CONFERENCE 2017

On Saturday 8th April 2017 as part of Parkinson's Awareness week the newly formed Young Parkinson's Ireland enjoyed the YPI conference in the Teachers Club in Parnell Square Dublin.

The event was well attended with a great line up of speakers including, Brian Magennis PNS, Clare Dolan OT, Dee Daly Psychologist and Marion Slattery Personal Health PD Warrior programme.

It was also an opportunity for YPI members to socialise and continue to grow from strength to strength.



NEW SERVICE IN DONEGAL / SLIGO

RE: PARKINSON'S NURSE PRACTITIONER OUTREACH SERVICE

The National Office in partnership with the Donegal/Sligo branch recently have entered into a one year contract with Galway University Hospital to provide an outreach nursing service to the Donegal/Sligo area. For two Sunday's per month, this pilot project will be delivered in Killybegs County Hospital and Sligo General Hospital. The aim is to secure long term funding, once need is established.

A recent development of University Hospital Galway's Movement Disorders Advanced Nurse Practitioner Outreach Service.

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 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 contact our freephone 1800 359 359 for further information.



Parkinson's Association of Ireland

We are asking you to pledge your support to the
Parkinson's Association of Ireland campaign to access direct
Government funding.

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*Please gather as many signatures as possible and return Petition(s) to Parkinson's Association of Ireland, National office at
Carmichael House, North Brunswick Street, Dublin 2.*

Photocopies of this form are acceptable