



Parkinson's Association of Ireland

www.parkinsons.ie

Spring 2019



Call to Action

PARKINSON'S
AWARENESS
WEEK CALL
TO ACTION.
SCHEDULE
OF EVENTS
ENCLOSED

Parkinson's Awareness Week 2019 April 8th - 14th



Dáil Protest

Unity Walk

Awareness Raising

Online Conference

Local Branch Events

**PROGRAMME
OF EVENTS
NATIONWIDE**

 **Parkinsons.ie**
Parkinson's Association of Ireland



Please support the Parkinson's Association of Ireland by participating in this year's VHI WOMEN'S MINI MARATHON. Calling all walkers, runners, joggers to help raise funds and awareness for the association. You can register online at www.vhiwomensminimarathon.ie or via The Herald entry form which will be in the Herald from early March. Thanks for your support.



Membership of the Parkinson's Association of Ireland

THE PARKINSON'S ASSOCIATION WAS ESTABLISHED IN 1987.

The association has grown over the years to now having 19 branches throughout the country.

It is estimated that approx. 12,000 people are living with Parkinson's in Ireland.

We operate a Freephone helpline 1800 359 359, produce a quarterly magazine and now have a Parkinson's Nurse on staff two days per week.

Branches run meetings and classes in their localities and the National Office organises information days and an annual social gathering. We also organise activities during Parkinson's Awareness Week.

The Parkinson's Association receive no Government funding and we rely on donations, sponsorships and annual memberships to allow us to continue our work.

Membership of the association costs €25.00 per year.

PLEASE CONTACT YOUR LOCAL BRANCH TO RENEW YOUR MEMBERSHIP.

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.

GARY BOYLE: TAKING A STEP AWAY FROM PARKINSON'S



Sitting in a restaurant near his home in North Dublin on a cold January day, Gary Boyle told me about the challenges he has faced since being diagnosed with Parkinson's Disease when he was 44.

The date of diagnosis, 2nd September 2009, is etched in Gary's memory. "I knew something wasn't right," he said, "But I wasn't expecting that". Gary had noticed that his hand would sometimes freeze, and his writing had become smaller, but he managed to ignore these for a while. Receiving his diagnosis was life-changing. "It threw me off course," Gary said, "I struggled with the diagnosis, and all my confidence seemed to evaporate."

Gary feels those early days could have been better if he had received more information. He remembers the doctor delivering the diagnosis in a casual manner, apparently without a thought for how he was feeling.

At a later consultation, Gary's wife Joan asked the doctor if he had considered the impact of what he said to her husband and asked him to think about how he delivers diagnoses. Gary says that Joan's support is as strong today as it was then and that the love and support of his family mean so much to him.

Gary and Joan married in 1992 after meeting through mutual friends. Gary moved from the construction business into Human Resources after completing a degree in Management and European Law in 1998. In 2004, Gary, Joan and their children Daire and Bronwyn moved to Oregon, USA, for two years, as Gary was appointed Salaries and Benefits Manager for a global business group.

When Gary received his diagnosis, he was in complete shock, and initially only told his wife and brother Patrick. Gradually he told his children and his family, who were all very supportive. "Parkinson's gets into everything, it changes everything so utterly, and it's hard", Gary said, "But I looked at my life around me, and I knew I had to find a way to move on".

By Judy Williams

However, there were difficult days to come when Gary eventually disclosed his diagnosis to his employer. The following year was extremely stressful, and his neurologist was alarmed by the deterioration in Gary's health and signed him off work in 2015.

Nowadays, Gary has a positive and proactive approach to his diagnosis. He exercises regularly and is careful about his health. Since he gave up work, he has learned to cook and loves to have dinner ready for his family whenever he can. "You can't be positive all the time," Gary said, "But I try to look for the positives in everything and to keep a sense of humour if I can. Humour is so important; it has really helped me," he added.

Gary describes his brother Patrick as a rock. "Patrick lives around the corner from me, and is my running buddy," he said, "He helps to keep me motivated about exercising".



It didn't sound like Gary needed encouragement as he listed off his activities, including cycling, walking, running, pilates and dancing, but he said it is his supportive network of family and friends that keep him motivated. His daily mantra is 'Every step I take is a step away from Parkinson's taking over'.

Gary is an active member of the Parkinson's Association of Ireland (PAI). He is on the committee of Young Parkinson's Ireland and he has been a member of the Board of Directors since 2017. CEO Paula Gilmore explains why Gary's contribution to the Board is so important, "Gary brings his lived experience to the board," she said, "He is constantly available to get involved with Board issues and gives an enormous amount of his time. He is also the Data Protection Officer and played a leading role in implementing procedures that enabled PAI to comply with new data regulations."

As Gary leaves, he tells me he has a PAI Board meeting that afternoon and a dance class that evening and I can't help but feel inspired by his tenacity and positivity.



DUBLIN BRAIN BANK

Dublin Brain Bank was founded in 2008 by Professors Michael Farrell and Francesca Brett, in Beaumont Hospital's Neuropathology Department. It offers the opportunity to support medical science in a very tangible manner by donating one's brain to research. By studying brain tissue from patients with and without neurological disorders, researchers aim to develop our understanding of the genetic and physiological mechanisms underlying disorders such as Parkinson's Disease and Parkinsonism. This will facilitate improved diagnostic techniques and treatments, ultimately leading to higher quality of life for patients.

Many brain banks specialise in a particular neurological disorder, collecting tissue only from patients with that condition. However, Dublin Brain Bank is a generalised brain bank, accepting tissue from donors with a range of neurological disorders, as well as healthy donors. By accepting tissue from patients with a range of disorders, Dublin Brain Bank allow a greater number of patients to contribute to the future of biomedical research.

The donation process relies on the consent of the donor and their next-of-kin. It is therefore important that the donor discuss the process with their next-of-kin, and make their wishes known. After the death of a donor, a post-mortem examination of the nervous system is conducted. The brain tissue is retrieved and preserved for future use. The final results of this post-mortem examination are made available to the next-of-kin, if they wish to receive it. This information may be important if there is a hereditary component to the disease, but can also provide a sense of closure, particularly where the diagnosis was complex or changed over time.

Dublin Brain Bank are consistently struck by our



donors' generosity and desire to help future patients, and always do our best to honour a donor's wishes by facilitating their donation. Dublin Brain Bank are also deeply appreciative of our donors' families, who are tasked with facilitating their loved one's donation at such a difficult time. Dublin Brain Bank strive to ensure that there is minimal delay to the family's own funeral arrangements, and all costs relating to the donation are borne by the Brain Bank.

After a final diagnosis has been made, the tissue is made available for study. Scientists who wish to access tissue from Dublin Brain Bank must submit a research proposal for approval by the Dublin Brain Bank Tissue Advisory Board. Another positive outcome of the decision to remain a generalised brain bank is that Dublin Brain Bank contribute to a variety of studies. In 2018 alone, Dublin Brain Bank contributed to studies in Ireland, the UK, and the USA.

The decision to donate should be considered carefully, and a member of the Brain Bank team will always be willing to answer any questions donors may have. If you or someone in your family is considering brain donation, or if your community support group would be interested in an information session, then please don't hesitate to contact our project coordinator, Jennifer Lorigan, at brainbank@rcsi.ie or on 01 809 2706.

As part of Brain Awareness Week 2019, Dublin Brain Bank and the Parkinson's Association of Ireland will be holding a table quiz on Monday 11th of March at 7:30PM in Ruin Bar, 33 Tara Street, Dublin 2. Entry is €10 per person, maximum four people to a team. The venue is wheelchair accessible. If you would like to reserve a table, please call 01 809 2706.

PROGRESS IN PARKINSON'S

For this instalment of "Progress in Parkinson's", we look at three recent studies covering on new medical therapies, how singing may help Parkinson's, and the emergence of 3D neural networks

- A team of Tufts University-led researchers has developed three-dimensional (3D) human tissue culture models for the central nervous system that mimic structural and functional features of the brain and demonstrate neural activity sustained over a period of many months. The new 3D brain tissue models overcome a key challenge of previous models -the availability of human source neurons. This is due to the fact that neurological tissues are rarely removed from healthy patients and are usually only available post-mortem from diseased patients. With the ability to populate a 3D matrix of silk protein and collagen with cells from patients with Alzheimer's disease, Parkinson's disease, and other conditions, the tissue models allow for the exploration of cell interactions, disease progression and response to treatment.
- Singing may provide benefits beyond improving respiratory and swallow control in people with Parkinson's disease, according to new data from Iowa State University researchers. The results from the pilot study revealed improvements in mood and motor symptoms, as well as reduced physiological

By Jake McDonnell



indicators of stress. Elizabeth Stegemöller, an assistant professor of kinesiology, cautions this is preliminary data, but says the improvements among singing participants are similar to the benefits of taking medication. She presented the work at the Society for Neuroscience 2018 conference.

- A promising new therapy to stop Parkinson's disease in its tracks has been developed at The University of Queensland. UQ Faculty of Medicine researcher Associate Professor Trent Woodruff said the team found that a small molecule, MCC950, stopped the development of Parkinson's in several animal models. MCC950 effectively 'cooled the brains on fire', turning down microglial inflammatory activity, and allowing neurons to function normally. The findings provide exciting new insight into how the spread of toxic proteins occurs in Parkinson's disease and highlights the important role of the immune system in this process.

Attention PAI Members – We need your participation:

The Dublin Branch has put together a short online survey and want as many PAI members as possible to complete it. The survey, done anonymously, simply inquires which activities (i.e. Pilates, dancing, yoga) members partake in to help with Parkinson's, and how helpful each activity is. It should take no longer than 5 minutes to do!

So why are we doing this and why do we need as many Parkinson's Ireland Members to partake?

- TO HAVE YOUR VOICE HEARD
- To pro-actively allocate resources in the future
- To identify areas of need for extracurricular activities
- To help Parkinson's Ireland obtain Government Funding

Please head over to the Parkinson's Association of Ireland website at www.parkinsons.ie where you will find the survey. Results of the study will be made openly available to each branch. We cannot stress enough how incredibly important the information we gather from this study will be, and how much of a step forward it will provide for the organization.

*The study will be funded and managed by the Dublin Branch.



MID-WEEK SOCIAL GATHERING

18th to 20th September
Hodson Bay Hotel Athlone

Please contact Hodson Bay Hotel directly to book your accommodation 090 644 2005

THIS YEAR OUR SOCIAL GATHERING TAKES PLACE FROM 18th to 20th SEPTEMBER 2019

The offer includes:

- Two nights Bed and Breakfast
- Lunch
- Two nights Gala Dinner and entertainment
- Full use of spa/pool/leisure facilities

Full day conference to include:

- Nurse clinic, Neurologist, Set Dancing, exercise, yoga, to name some of the activities we hope to include.

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Thursday 19th September 2019

1 Night B&B with Lunch and Dinner €110.00 per person sharing or €130.00 single

OR

Wednesday 18th and Thursday 19th September 2019

2 Nights B&B with lunch and 2 Dinners- €199.00 per person sharing or €239.99 single

All activities and entertainment included
Day attendee Rate is €30.00 per person
Rooms available from 3pm on 18th. Workshop starts from 4pm

NUTRITIONAL STRATEGIES TO TARGET PARKINSON'S DISEASE

My name is Dr. Conor Kerley. I am a doctor of nutrition, award winning nutrition researcher, leading dietitian, consultant and lecturer.

I have long had an interest in nutrition and neurological conditions, including Parkinson's disease. My interest stems from my own diagnosis of multiple sclerosis when I was aged 15. I think nutrition plays a huge and often under appreciated role in neurological conditions, including Parkinson's disease.

PD is a progressive degenerative disorder affecting the central nervous system, primarily the motor system. PD is due to decreased dopamine, a neurotransmitter in the brain. Dopamine helps connect thoughts about movement to muscle activity, hence when dopamine is reduced (for example in PD) the major symptoms are movement-related: shaking, instability, tremors, slowness, rigidity, and difficulty walking. There is no known cause of PD, and no cure currently. When I ran an online scientific search (on PubMed) for nutrition and PD, I found 944 articles but when I ran a search for nutrition and diabetes, I found over 33,000 articles! If you have PD and are interested in nutrition, please read on and then speak to your health care team.

It is thought that long term inflammation and oxidative stress are involved in PD, for example by increasing the loss of neurons which produce dopamine. It is well known that nutritional factors can influence inflammation and oxidative stress. In fact, a growing body of research suggests that what individuals eat and drink may affect PD.

Evidence for diet and PD

One interesting study from Harvard University looked at nearly 50,000 men and over 80,000 women who did not have PD. The researchers followed these people for 16 years and found

By Conor Kerley (PhD, BSc, H. Dip)

that a diet high in fruit, vegetables, legumes, whole grains, nuts and soy, and low in saturated fat (found in fatty meat, cheese, cream, butter) was associated with a 22% decreased risk of PD compared to a 'Western' diet which was high in red meat, processed meat, refined grains, French fries, desserts, sweets, and high-fat dairy products. Legumes, nuts, fish, and poultry seemed to be beneficial sources of protein compared to red meat (e.g. beef and pork) and processed meat (e.g. bacon, ham, sausage). Mediterranean and Japanese type diets high in vegetables, seaweed, pulses, mushrooms, fruits and fish were also found to reduce the chances of developing PD.

Berry good news!

Another study demonstrated that certain compounds called flavonoids in plants like fruits, vegetables and legumes were associated with a 40% reduction in PD. Rich dietary sources of flavonoids include parsley, onion, tea (green, black or oolong tea), citrus fruits and berries such as strawberries, blueberries etc. In fact, in this study those who ate 2-4 servings of berries each week had a 23% decreased risk of PD compared to those who ate less than one serving per month!

Nicotine: peppers over cigarettes

Some studies have actually reported that cigarette smoking may protect against PD! Nevertheless, no guidelines recommend that anybody with PD should smoke. Smoking clearly increases risk of cancer, heart disease and many other health conditions. However, a possible protective effect in PD is interesting because some foods contain small amounts of tobacco and/or tobacco like substances. For example, Solanaceae vegetables come from the same botanical family as tobacco and include peppers, tomatoes, aubergine and potatoes. A group of researchers from the University of Washington





examined the association between total vegetables as well as Solanaceae vegetables specifically and PD. Solanaceae vegetables, but not overall vegetables, were related to a 19% decrease in PD. In this study, a protective effect of peppers was also observed whereby eating peppers every day was associated with a 50% decreased PD risk compared to eating peppers less than once a week. It turns out that even a small amount of nicotine can saturate brain receptors.

Fats of life

An early study of fats in the diet and PD reported that saturated fat and cholesterol were associated with increased PD odds. Another study reported a 32% lower PD risk associated with high intake of fats found in avocado and olive oil and a 34% lower PD risk associated with high intake of fats found in flaxseeds/linseeds, walnuts and oily fish, like salmon and sardines. Another large study reported one specific fat called omega-3 found in flaxseeds/linseeds, walnuts and oily fish, like salmon and sardines, was particularly protective and associated with 60% decrease in PD odds.

Healthy bowls to help maintain healthy bowels

Constipation is a frequent and bothering symptom in PD. Constipation can also decrease the effectiveness of PD medications such as L-Dopa. There is evidence the constipation can occur before PD is diagnosed. One study reported 400% more PD in men with bowel movements less than daily compared to those with daily bowel movements.

This has led to the suggestion that a healthy gut may help prevent and treat PD. As a dietitian, when I think of constipation I think of dietary fibre, fluid and exercise. Dietary fibre to provide bulk to stools and fluid to soften the stool and exercise to boost the circulation. Dietary fibre comes from fruits, vegetables, legumes (e.g. chick peas, lentil, kidney beans), nuts (e.g. walnuts), seeds (e.g. linseeds or flaxseeds) and whole-grains (e.g. oats/porridge).

Fluids from water, tea, coffee, fruits, vegetables, potatoes. Exercise can include walking, swimming and many other activities. In fact, there are lots of studies demonstrating benefit of exercise in

- PD and it is recommended
- that you seek personal
- advice regarding what type(s)
- of exercise may be appropriate
- for you.

- A really interesting study from over 25 years ago reported that just 2 weeks of a diet high in insoluble fibre could increase the amount of L-Dopa in the blood in PD and after 2 months the amount doubled! This resulted in decreased PD symptoms. Insoluble fibre is found mainly in whole grains (e.g. oats/porridge, barley, brown rice) and vegetables/fruit (especially the skins).

Gut feelings and the magical microbiome

- Until recently we assumed that fibre was most helpful for maintaining healthy bowels. Because humans can't digest fibre, its importance was not fully understood. However, new research demonstrates that fibre can be broken down by microorganisms in the human gut. Furthermore, when bacteria break down fibre, other active substances are released which have beneficial effects all over the body. It is known that diet and exercise play a major role in determining the gut microbiome.

Water, water everywhere

- Drinking enough fluids is important for everyone to maintain hydration but also for helping prevent and treat constipation. One study reported that those with PD drank less fluids than those without PD but also that those with PD were less thirsty. Some people with PD may not find themselves thirsty but it is important to take enough fluids throughout the day.

- There are lots of ways to increase fluid intake - but remember tea and coffee are mostly water and may have additional benefits in PD (see below) and fruits, vegetables, potatoes can be 90% water!

Tea and coffee: Mrs Doyle says 'go on, go on, go on'

- Evidence has been accumulating that caffeine consumption is associated with less PD and less severe PD symptoms. The major sources of caffeine are tea (green or black) and coffee. I do not recommend caffeine supplements or energy drinks as sources. However, tea and coffee can be healthy and enjoyable!



One review which looked at 26 different studies found a 25% lower risk of PD among tea and coffee drinkers compared to non-consumers. One 6-week trial included 61 adults who all had PD. 30 subjects were assigned to the caffeine group (about 2 cups of coffee per day), while 31 were assigned to the placebo group. The caffeine group experienced decreased sleepiness and much improved PD movement symptoms.

High consumption of tea and coffee, especially in the evening time can result in decreased sleep quality. However, because the effect varies from person to person there are no set rules. In general, try to avoid coffee and tea after 6pm (and earlier if you find that these drinks can affect your sleep).

Other research

L-Dopa can be transported into the brain but it seems that certain components of dietary proteins 'compete' with L-Dopa and that consuming protein rich meals (e.g. high in meat) can decrease the effectiveness of L-Dopa. On the other hand, there is more research being carried out which demonstrates that eating a low protein breakfast and lunch can increase the effectiveness of L-Dopa while a higher protein evening meal can ensure the person gets enough protein in the diet. Currently there are no specific recommendations to have a low protein diet but this is an interesting concept.

Putting it altogether

I read a scientific article about a 53 year old dietitian who was diagnosed with PD.

After her diagnosis, the dietitian started a diet of

- mostly fruits, vegetables, whole grains, extra virgin
- olive oil, nuts, seeds, tea, coffee and only skim
- milk products. After 6 months the lady added in
- foods containing N-hexacosanol and fisetin (e.g.
- strawberries and other whole fruit/vegetables) and
- this new diet led to marked improvements in PD
- symptoms. The clinical improvement has persisted
- for at least 10 years.

- Italian researchers then actually studied the effect
- of a plant rich diet on PD. In their study they
- asked 12 people with PD to follow a plant-food
- menu and another 13 people with PD to follow an
- omnivorous menu. After only 4 weeks the people
- in the plant rich diet had greater reductions in PD
- symptoms.

Supplements

- As a dietitian I focus on dietary means to increase
- nutrient intake as opposed to supplements.
- However, low vitamin D has been linked to
- increased PD. Vitamin D is an interesting nutrient
- because unlike other nutrients the major source
- of vitamin D is not from the diet but from sunlight.
- Yes, this even includes those of us living in Ireland!
- This is why in Ireland, vitamin D levels are highest
- at the end of summer and then start to decrease
- throughout winter until the sun is strong enough
- and we start to produce the vitamin again. One
- trial demonstrated that 1,200 units of vitamin D
- for one year stabilised PD. 1,200 units of vitamin
- D is very difficult to get from diet. For example
- this would require a person to drink over a litre of
- vitamin D fortified milk...every single day! Vitamin
- D supplements are cheap, widely available and
- worth considering. Speak to your GP, neurologist
- or dietitian regarding vitamin D.

- I am hoping to commence research relating to the
- effects of certain nutritional strategies, including
- specific supplementation to benefit brain health,
- decrease inflammation and oxidative stress which
- would be expected to have multiple benefits in
- Parkinson's disease. So watch this space!

Swallowing problems

- Some people with PD may have trouble
- swallowing due to involuntary muscle movements
- that make eating difficult. This can cause food
- or liquid to get into the lungs, which can lead
- to serious complications. If you experience
- any difficulties in swallowing or if you feel your



swallowing process has changed, seek medical attention, including from a speech and language therapist as well as a dietitian.

If you have any other specific issues, seek help and guidance from a dietitian. Although most people with PD do not experience nutritional difficulties, some may experience issues. For example, loss of appetite, constipation, loss of smell, swallowing difficulties or excess weight

- loss/gain. Others may experience medication interactions or changeable symptoms.

• **Conclusions**

- There are many unknowns concerning nutrition and Parkinson’s disease. However, as you can see from the above article evidence is accumulating regarding the protective effect of certain foods listed in table 1:

Table 1: Foods associated with PD benefits and harms			
BENEFICIAL		HARMFUL	
What	Example	What	Example
Fruit	Berries, apples, oranges etc.	Saturated fats	Fatty meat, cheese, cream, butter
Vegetables	Broccoli, spinach, carrots, mushrooms etc.	Cholesterol	Egg yolks, beef, pork
Solanaceae vegetables	Peppers, tomatoes, aubergines, potatoes.		
Legumes	Chickpeas, kidney beans		
Wholegrains	Oats, barley		
Nuts	Walnuts, hazelnuts		
Soy	Soy milk, tofu		
Insoluble fibre	whole grains, vegetables/ fruit with the skin on		
Omega 3	Linseeds/flaxseeds, walnuts, oily fish		
Oily fish	Salmon, sardines		
Fluids	Black tea, green tea, coffee, water		
Vitamin D	Sun, supplements		

While there’s no guarantee that eating a diet high in fibre and antioxidant-rich plant foods is effective in relieving constipation or reducing symptoms of Parkinson’s, there are virtually no negative side effects of including them and we already know these foods are protective for other conditions. Enjoy a variety of these foods for overall health and Parkinson’s health.

Wishing you the berry best but don’t forget to veg out and go nuts sometimes!

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TED'S PERSONAL JOURNEY

Timing is Everything. That short statement could easily be attributed to my Camino Trek between 14th and 19th October 2018 last.

It all began when I received the Spring 2018 Parkinson's magazine containing the first advertisement for the Camino walk due to take place in October 2018. I immediately contacted Sabrina in head office for a brochure. When it arrived it was read and reread as I toyed with the idea of walking it myself. However at that time it seemed a step too far for a person in their 14th year living with Parkinson's. I set about finding participants from within Cork Parkinson's Association.

With a little encouragement we recruited 4 family members of People with Parkinson's. Unfortunately 3 of this quartet had to drop out for health, fitness and personal reasons. My wife had good reason to question my ability to walk 100km in a foreign land. A conversation-inducing question at the family dinner table, (who thinks Dad could walk the Camino) elicited a 3 word 6 letter response: No, No, No. After that resounding vote of no confidence from the people I love, I thought they were probably right even though I didn't like to admit it.

Looking back on 2018, there were a number of events which equipped me/encouraged me and ultimately convinced me to embark on the Camino Trek. In early April I was offered a place on a Parkinson's Self-Management Course, excellently presented by 2 HSE Occupational Therapists. A lot of useful snippets of information were gleaned from this course. A local Pharmacist corrected one or two misconceptions I had and also encouraged me to get my meds in blister packs to ensure correct timing of utilisation. After all, timing is everything.....

In May I was contacted by Teresa, a HSE Physiotherapist who had completed a LSVT BIG training course and offered me the option of undertaking the LSVT BIG programme. We agreed to set it up for September. I went on a sun holiday in June and found that the warm weather helped me to be 'on', most of the time. I was able

By Ted Horgan

- to walk comfortably at the same pace as my wife
- and children. When I returned home, Ireland was
- basking in sunshine which went on and on.
- Enter West Cork Anne, a good friend, very practical
- and very positive, and a Camino Veteran. "I really
- believe you could do it, Ted" she said. Timing is
- everything a shot across the bows at just the
- right time.
- Enter Pope Francis. What has Pope Francis got to
- do with a mere mortal like me going to walk the
- Camino? Well, this mere mortal as a member of
- the local Parish Assembly was entrusted with the
- honour of representing the parish at the Festival
- of Families Event in Croke Park during the Pope's
- visit. I personally look back upon the Pope's visit
- as an uplifting experience. In advance I considered
- it to be a benchmark of my fitness and stamina. If
- I could survive the anticipated amount of walking,
- standing, hardship, could I consider myself a
- genuine Camino pilgrim?
- And I did survive it. I walked about 24 kilometres over
- the 2 days of the Pope's visit, all at a fairly fast pace.
- As well as my intuitive feelings. I decided I needed
- more reassurance. I had got that reassurance and

even though my wife and family were naturally concerned about my welfare they could sense my desire, my ambition, my growing confidence and my determination and supported my decision to go on the Camino. On 11th of September 2018 (9/11), I confirmed my booking for the Trek less than 5 weeks before departure. A final warm up was a trip to the first day of the Annual Ploughing Championships being held in Tullamore. It was a very enjoyable day and I used the opportunity to visit 2 Camino companies and I posed the question "do you think I could walk the Camino?" Again they replied in the positive.

I set up an online donation to help look after the financial aspect of





the trip. I was delighted by the response I received from old UCD Agricultural Science classmates, from friends, from work colleagues and from within Cork Parkinson's and the encouragement and good wishes I received definitely helped me when I struggled on the route although they added a little more expectation.

The timing of my decision to go on the trek coincided with the intensive LSVT BIG programme which gave me huge confidence that, against all odds, I would Walk the Camino. While it was inevitable that I would tire as the week went on, at least if I was fresh at the start, I would give it my best shot. My preparations included a moderate amount of walking covering distances varying from 4kms to 12kms but as my Parkinson's meds would be the petrol in my engine, as long as my arms and legs were flexible I would be happy. Other preparations included selecting 2 pairs of walking shoes, getting appropriate creams and bandages, selecting 2 nordic poles for the trek which proved to be absolutely essential, purchasing a poncho at the Ploughing Championships, visiting my chiropodist the day before departing to ensure my feet were in the best condition possible and, consuming regular portions of my wife's fabulous brown bread to help my constitution. And another "secret weapon" - a small portion of Coconut Oil.

And so the day dawned. A 6.45 am departure from home required a very short interval for meds to click in. My Camino trek started with a crawl from bed to toilet to kitchen. If my wife had seen the efforts this crawl involved she would have been justified in cancelling my Camino trek for the good of my health. With a few minutes to spare my meds started to work and I was on track. A quick goodbye to my wonderful children, Declan and Caoimhe, who were charged with management of my small farm enterprise in my absence and I was off with my wife Bernadette, who took on the entire management of the family unit, to meet my fellow traveller Kate and travel onwards to the bus for Dublin. While Kate rested on the journey, my brain was active. John Lonergan ex-Governor of Mountjoy had spoken at a meeting in Kinsale 36 hours before my departure and I decided to email him.

"Morning John,

I was at your talk on Thursday night which was excellent. I am now on a bus to Dublin to catch a plane to SANTIAGO to walk 100km on the Camino in aid of Parkinson's Research. So what

you might say? Well I'm living with Parkinson's for 14 years, I need medication to get out of bed, I need medication at 5 other times every day, I qualify for a parking permit and I hope to walk 100Km over the next week. Would you be interested in a small bet? In the unlikely event that I complete the walk will you make a small donation (€10+) to my fundraising page www.idonate.ie/TedtoCamino and in the likely event that I fail to walk it, I will buy your book!

Regards

Ted"

"Good morning Ted, well done, hope you have a most enjoyable walk and trip. I will indeed make a donation to your fundraising page, no problem. Sorry I missed talking with you on Thursday night. Very best wishes for now.

John."

And so we arrived at Dublin Airport. Paula Gilmore and myself embraced warmly and she introduced us to our travelling companions. Mary O, Mary M, Miriam and David L, Ann D, Fiona, Nicola K, Yvonne S, Kate W and Louise. As we waited at the Departure gate I almost had to pinch myself to see if this was really happening. Then the call to the gate was announced. There was no going back now!

In Santiago Airport we were met by our guide, Emmanuel and ferried by minibus to Sarria. We were struck by how long it took to reach our destination. The following morning, at 8a.m I headed for breakfast which was in a coffee shop 500 metres from the accommodation or Pension. I set out in semi darkness. My brain froze and I came to a halt. Half joking/half serious I said to Paula that I would pass her out on the walk later on in the day. I ran out of the freeze and reached the door of the coffee shop. Again I froze badly which was exactly what I didn't want to happen. Some of the group looked frightened at my disability. I wondered should I have come on this trip at all. I need food to get me moving every morning and a pre-breakfast stroll is a luxury that has long since dropped off my radar. I used a bit of mindfulness to get out of that freeze. Paula assured me that every other



morning breakfast would be nearby, which it was. I had put the relic of St. James, which a kind lady gave me a loan of for the trip, safely in my rucksack. We set off for Portumarín firstly getting our pilgrim passports stamped in the church in Sarria. Almost immediately on departure it started to rain and my poncho was pressed into action.

Along the route we saw hundreds of pilgrims at various stages of the journey and we were struck by the number of young people among them. The first thing I noticed was the willingness of my fellow pilgrims to assist me wherever necessary. The first morning was probably the wettest we encountered. When we arrived at our lunchtime venue, Cafe Seneda, we were drenched. The cafe owner promised a sandwich which would be the best we ever had and it certainly lived up to our expectations. 3 members of the group headed off and I set off to catch up with them. However, I didn't catch up and after a kilometre or so I realised I had wandered off the Camino. I used Google Maps to confirm that I was going in the right direction and I marched on. I used this time to send a few short texts. "Greetings from wet Portumarín, Santiago de Compostella, Northern Spain on the first day of my Camino 100km Trek". Within minutes the weather changed and I felt a bit of humour wouldn't go astray so another text said "Correction, the rain in Spain has gone to the Plain and the Sun is now shining on the Camino! " After about an hour "off Camino" I rejoined the Camino route and walked on to Portumarín. Amazingly I hadn't met any other member of the Parkinson's walking party for the previous 3 hours. Those who arrived ahead of me cheered on my arrival at our night's accommodation. A very enjoyable evening followed with a nice meal and we continued to gel as a group. I slept well, medicated around 7am and I was second down for breakfast fully mobile. I was confident that I could last the pace for the day ahead. A kilometre or two into the walk, we started a long up-hill walk and almost simultaneously heavy rain arrived. Nicola had prepared a sandwich at breakfast time and she gave me half. The lunch time stop was in a very quiet location with beautiful soup being served. The walk on day 2 seemed a little shorter and within sight of our destination we stopped at a cafe for refreshments. Nicola shared her bowl of soup with me as it was huge. As we relaxed in the afternoon sun we were joined by 3 girls from Dublin. We swapped suggestions on exercises to keep us walking. On to our accommodation for the night which was superb. After a beautiful meal I

- sang but nobody else followed!
- Day 3 we departed the guesthouse which was shrouded by early morning mist. We were now slowly becoming experienced endurance athletes. I was a special category athlete requiring medicine, food, water and determination in generous quantities. We stopped for lunch where I had the most enjoyable bacon, egg and chips and Mary M told us about her friend who was related to Jedward. Yes, they seem to be as mad in real life as when they perform. Energised by this high calorie meal we continued to our next stop off, a small hotel. I stopped for water a kilometre from the night's accommodation and I struggled to get going. I ran out of my difficulty and reached the hotel more off than on. I posed for an action photo outside the hotel and then struggled to my bedroom. The group had now gelled and my comment the previous night that I felt we were all making 11 new friends was being validated. I had breakfast with this member the following morning with a limited conversation. Conversation was more forthcoming that evening when I said "At breakfast this morning I was thinking you have a great appetite!" Day 4 had been a very enjoyable experience starting with a walk with two others where we spoke As Gaeilge. Almost without realising it, I now had 80km walked and I was within sight of completing the 100km goal. However, I struggled badly from the evening meal to my bedroom and there were real concerns within the group as to whether I could continue any further. I slept well and on waking I WhatsApped the group for someone to bring some water to Ted, the 100km Man! I knew why I was struggling, I had Parkinson's after all. I had no intention of pulling out now and spending the rest of my life regretting it. I was gung-ho starting off, however, a steep uphill climb caused me to struggle. A natural stone paving walkway followed and suddenly my left foot started to lock. I could stand but I couldn't walk. I thought about all who had wished me luck on the trip. If I ever needed luck I needed it now. I started counting in English and Irish in an effort to get moving without success. Kate, whose assistance was crucial throughout, started counting in French. We started singing. We sang 4 or 5 songs to no avail. However, with my next singing effort I struck gold. Ar nAthair got me moving and mentally I breathed a sigh of relief. I walked on, had a few 'feet up on a chair' stops at a couple of cafes and reached a cafe for lunch, Nicola and Kate and I had a very welcome lunch. Nicola needed assistance to eat half her burger so I obliged once again.



This lunch really energised me and even though Nicola and Kate set off at a reasonable pace, I felt it wasn't fast enough. I had developed a number of walking styles, the fastest of which was what I might describe as a lower limb speed walk which I reserved for when my medication was working best. I took off and over perhaps 2km I barely hit the ground. I passed out walkers who were walking at a brisk pace and also passed out the strong walkers who were overtaking the brisk paced walkers. I would conservatively estimate that I overtook in the region of 200 people. For a brief 8 to 10 minute period I have no doubt I was the fastest person walking (excluding runners) on the entire Camino.

I was delighted to push aside memories of the episode earlier in the morning when for 5 or 6 minutes I was probably the slowest person on the entire Camino apart from people who were actually stationary. As I approached a vehicular crossing my balloon burst when Emmanuel came into my wide range view. How did he do that I asked myself. I discovered later he actually had to run to catch up with me. At least he now knew that I could move well, most of the time.

Many times during my preparations for the Camino I had wondered what would it be like to reach the 100km mark. It was appropriate that Paula Gilmore was my companion at the time I realised my dream. The moment crept up on us as we chatted about anything under the sun. I asked Emmanuel, the guide, how far more to the 100km mark. He said congratulations you are there just now. I raised up my arms in celebration. The truth is I could do no more. I was physically drained and walking on adrenalin. I couldn't jump up and down with excitement as newly crowned GAA All-Ireland champions might do. It didn't matter that I used the wall of our guest house to support myself as the celebratory picture was being taken. I had reached my goal. I had walked the Camino. I was going home full of pride, full of passion, full of satisfaction that no one can ever take this from me. I may appear frail on the outside but inside so strong, inside so strong. I moved slowly to my bedroom in what was a beautiful guesthouse. I was just drifting off to sleep when an extremely loud fire alarm broke the silence. Soon Paula was at the door to tell me that it was a false alarm and asking if I was ok. I shared with her the theory that if you tell a Person with Parkinson's there's a fire they will be able to run. Jokingly Paula said there is a fire. I was so tired I could not have run out of the building even if I was paid to.

- Timing is Everything as I said before. Now it was
- time to inform my family of my achievement.
- My wife, Bernie, and daughter, Caoimhe were
- thrilled at my news, as was Declan who sent me the
- most beautiful WhatsApp message "I am so proud
- of you, Dad, well done on walking it all, ring me
- later.." WOW it's not every day a parent gets such
- praise or indeed encouragement to phone their
- teenage offspring, it certainly was a Moment in
- Time for me.
- Cheers rang out when I arrived at the dinner table
- that evening. Though I walked an additional 5k
- to the city boundaries the following morning,
- reaching the 100k mark was my dream come true.
- I was honoured to attend the pilgrim Mass in the
- beautiful Santiago De Compostella Cathedral. I
- sent a picture home with the message: Greetings
- from Hotel Luz, Santiago De Compostella, After
- 106km my Camino trek is complete, Veni, Vidi, Vici.
- Time to put the feet up. The following 24 hours
- were for relaxation and recovery and Paula, Nicola
- and Kate helped as I re-adjusted to a slower pace of
- life. I was happy to come to Spain and even happier
- to leave Spain. Pilgrimage complete. Homeward
- bound. On arrival home my wife commented "you
- look better than I expected." I slept well that night.
- I had to be pulled out of my bed the following
- morning but I thought to myself very few people
- are pulled out of bed in a state of euphoria! Two
- hours later I went for a family walk. After a short
- distance my wife told me to stop galloping!
- It was the experience of a lifetime. Many times
- over the past 13.5 years of my Parkinson's journey, I
- have been unable to walk even one metre. To walk
- 106000 metres was God's blessing on me. If you
- have a dream, an ambition, a bucket list of 1 before
- 100, or 40 before 40,
- go for it, Every
- step is a
- Victory.



BRANCH NEWS

DUBLIN BRANCH

Dublin Branch has plenty going on over the coming month!

We have our AGM on 23rd February which will be followed by a talk from Cathal Phelan, Speech Therapist from Personal Health. It promises to be very informative.

On Saturday 13th April Dublin Branch will hold a mini Unity Walk in Harold's Cross. This will start at 11am at the main entrance gates to the Park in Harold's Cross and the walk will follow the Harold's Cross walking trail. The walk should last about 40 minutes with a break mid-way! The walk will be led by local historian Tony McDermott.

We will finish up in McGowan's Pub for tea/coffee/soft drink and sandwiches. All are very welcome and we hope to have a great turn out on the day. We will have t-shirt and beanies for everyone. We will also have an information stand in the park with information for the general public.

We are delighted that we now have 4 Siel Bleu Exercise classes running in the Dublin area – in Swords, Portmarnock, Harold's Cross and Loughlinstown. Please see website for contact details for all these classes. These are in addition to our two exercise classes in Clontarf and Donnybrook.

We have 4 support groups – Swords, Portmarnock, Harold's Cross and Navan.

Our Summer members meeting will take place in the Marine Hotel in Sutton on the 9th June.

We keep our members informed by email and a quarterly bulletin which we are starting to send by email and by post to those who have no email.

Contact Sinead 087-2869173

Dublin Branch have been busy preparing the survey for research - details in this edition of the magazine.

LOUTH/MEATH BRANCH

The Louth/Meath Branch are continuing to run their monthly support group meetings alternating with Dundalk & Drogheda and held on the last Monday of each month at 3 pm. For further details of meeting please contact Delma on 0872893685.

As in previous bulletins the Navan support group continues once a month on the last Friday also.

Both these groups are well attended and the people attending same feel they are of great value in that they can share their experience with each other at a casual event and also avail of any up-to-date therapy, news or information that might be available on the day. These meetings are free to people who attend.



Gene Rice and Denis Leahy

We were delighted to welcome Dr. Ciaran Wynne, Senior Clinical Psychologist, Our Lady of Lourdes Hospital, Drogheda, who spoke to a large crowd in the Partnership Offices Dundalk on the 15th



Maurice O'Connell

October, 2018. Dr. Wynne spoke on the subject "Living with Parkinson's – a guide to good Mental Health" in which he covered areas such as Neurological Changes, How Parkinson's can affect your mental health, Treatment and Tips for Caregivers. A good crowd attended this meeting and everyone appeared to get something out of it. We were very grateful to Dr. Wynne for giving his time to speak at our public meeting.

Our Christmas gathering was held in December in the Crowne Plaza Hotel, Dundalk and was well attended by Members of our Group. The Hotel provided delicious sandwiches and mince pies on the day and the room was beautifully decorated. Background music was provided and it was felt that the event was a success in bringing people together to celebrate the Christmas Season.

Our next public meeting is scheduled for the 8th April, 2019 in the Boyne Valley Hotel, Drogheda and a talk will be given by Dr. Conor Kerley, Dietician & Nutrition Researcher. This talk will be part of the "Parkinson's Awareness Week". Members of the Branch will receive letters



informing them of this talk in due course. Again we look forward to having a good attendance on the night.

We wish all our Members in the Louth/Meath Branch a very Happy 2019 and look forward to seeing you at our next support group meeting

Contact Eamon 042-9336267

TIPPERARY BRANCH



Well Santa has been and gone and we welcome 2019 with the hope that it will be a good year for all in the Parkinson's family. There is both a breath of Spring in the air and a bounce in our step

- April in The Pastoral Centre, Church Rd, Nenagh
- at 7pm. The hour long programme consists of
- music song and chat and the choir will contribute a
- few numbers. The Monday Club and branch were
- delighted to facilitate the attendance of two UCC
- Speech & Language students at our meeting on
- Monday 11th February. As part of their degree in
- Speech & Language Therapy at UCC they needed
- to carry out a research study. The study investigates
- the experiences of persons with Parkinson's
- Disease and communication impairment in the
- health care system, as well as the experiences of
- health care professionals in working with persons
- with Parkinson's disease and communication
- impairment. As future Speech Therapists they
- were interested in communication barriers and
- strategies in the health system. We also welcome
- Marion Quigley a new volunteer to our Monday
- Club team. C.E.O. Paula Gilmore and Board



as the snowdrops fade and daffodils burst into blossom as we wait the advent of the bluebells. Quite similar to Parkinson's Disease with highs and lows. The Monday Club returned early in January and Marion Slattery OT has put a bounce back into our activities with a refreshing exercise programme. We are jumping like Spring Lambs. When it's Springtime in Alaska reminds us of our Sing Along Choir who every Monday banish away the blues of overcast days with a variety of songs which are enjoyable and beneficial to members speech. Sheelagh Chadwick M.D. has introduced a series of breathing exercises and scales which members' also practice at home. Sheelagh is supported by our musicians Brendan Treacy, Rita Gleeson & Mary Shinnors.

Part of Tipperary Branch awareness week is a recording of Tipp FM programme "Down your Way" with Eamon O'Dwyer on Wednesday 3rd

- member Michael Burke were invited by Boston
- Scientific in Clonmel to make a presentation re
- Parkinson's organisation to members of the team
- who manufacture the DBS unit at the plant. We
- wish to acknowledge the courtesy and hospitality
- of the management and staff of Boston Scientific.
- We would also like to congratulate Michael Burke
- our Branch Chairperson on being re-elected to
- the Board of PAI as Vice Chairperson. Well done
- Michael.
- Thurles Support Group opened their New Year
- with a time to reflect and set your New Year's
- intentions for 2019 in a peaceful setting with
- Brid Harty Reiki Practitioner in the Community
- Hospital of the Assumption on the 17th January.
- Brid is making a second appearance on Thursday
- 28th February at the Hospital of the Assumption
- at 2pm and on Friday 12th April Parkinson's Nurse

Specialist Nicola Kavanagh, Tallaght Hospital and Parkinson's Headquarters, will be in attendance. Please contact Mary Carey on 0863916726.

Clonmel Support Group resumed the New Year with Dr. Sabine Eggers. Sabine gave a very good presentation on achieving optimum Mental Health. Some of the issues included Depression, Anxiety and other mental health issues are part of Parkinson's. To achieve optimum mental health it is important that we have a balanced diet, take regular exercise and get involved in an activity that you enjoy. Dr. Sabine also stressed the importance of knowing and accepting that there is no shame in experiencing a mental health problem. Clonmel Support Group have organised a Charity Auction as part of awareness week on Friday 12th April in Minella Hotel, Clonmel. Please support with items for auction or by attending. We are also holding an awareness day on Friday 5th April in The Bank of Ireland in Clonmel.

Dr. Helena Moore, Neurologist will give a talk in the Pastoral Centre, Nenagh on Wednesday 17th April at 7pm.

Contact Mary Finnegan re these on 0861224283. Marion Burke

Tipperary Branch PRO 08721967296

CAVAN BRANCH

Yoga has resumed after the Christmas break every Friday at 11am in the Community Centre, beside Castlemanor Nursing Home, Cavan. Cost €5.00 per session.

All yoga is done sitting on a chair apart from a few standing up exercises occasionally. There is no pressure to do all the exercises. Please contact any member of the committee for more information. Finally the committee are appealing for more help particularly with secretarial duties as membership has almost doubled in the last few years. If any family of a member would be interested in helping, please let the committee know.

Contact Paddy 087-2798811

CORK BRANCH

Since the last issue we have rebranded and are now Cork Parkinson's Association rather than 'Support Group'. This change became necessary because we successfully started a number of support groups throughout the county.

In November, Ted Horgan and Kate Wilkinson

were congratulated and rewarded at a special lunch hosted by the committee for representing Cork in their completion of the Camino Way with PAI.

Our groups are working closely with CUH, HSE and UCC in a number of separate research projects. One is related to sleep and activity aspects of Parkinson's. Participants completed questionnaires and wore a digital watch for a week monitoring sleep and activity. This was returned to the department for collation. Another is a digital glove which gleans information from the participant (stiffness, movement, dexterity etc) in real-time and relays it from anywhere in the county back to the hospital. This is to help with assessing future treatment and timely interventions. We are getting a lot of requests to help with Parkinson's-related research because we have built up a strong network of groups spread across the county who are actively supportive of trailing new technology and contributing to improving diagnosis and treatment.

Tony and Kate Wilkinson took part in a radio interview with John Green on his well-known 'Where the road takes me' show on C103 radio station. (Podcast WTRTM-11.11.18). Tony did a talk on bee-keeping in Bandon Town Hall to help raise funds for Kate's Camino Way walk. Kate did the walk, Tony did the talk! John heard people raving about the bee talk and knowing that Tony has Parkinson's thought it would make a very interesting mix. Tony and Kate saw this as an opportunity to raise awareness of Parkinson's and how it impacts the lives of those around them. In addition we talked about the role of our 4 lovely hens and a couple of beehives in our North London garden and how in the early days of diagnosis their presence kept the dark clouds at bay.

All our groups celebrated Christmas in style and the Cork city group had fierce competition for the best Christmas Jumper – the winners were Sr Bridie and Sr Bernadette. Well done! Towards the end of January we had our annual Christmas party in the Silver Springs Hotel. Ted Horgan, Chairman, gave a review of the past 12 months and listed the great achievements; fund raising, raising the profile of Parkinson's, visits to the Dáil, getting Parkinson's on the political agenda, group development and the purchase of a Mini bus. He



also spoke about his personal challenges and achievement in completing the Camino Way. Well done Ted, you are an inspiration to us all.

Tony Wilkinson put on his 'Mr Motivator' hat and spoke about the year ahead and what we have to look forward to. Top of the list and to gasps of surprise from the audience, Tony mapped out the vision for using the Mini bus to further expand and develop new groups in more rural areas. This will be achieved by hosting information days in local towns, for example, Castletownbere, Bantry, Charleville etc. The bus will be branded with the Cork Parkinson's Association livery and will be kitted out for mobile Events. He then described how our stepping stone project has been so successful – the bus will allow us to develop at a faster pace. He explained how growing groups = growing membership = growing awareness which in turn leads to growing fundraising and funds for PWP. Parkinson's Awareness week in April was next on his list to tackle. A number of events are taking place around Cork including the Cork GAA Mile challenge representing one mile for each of the 156 GAA pitches in county Cork. Good luck Kevin O'Donovan – go along and support him at your local GAA pitch. We want to get our members to run a mile with Kevin with the view to clocking up 1,250 miles each mile representing a person with Parkinson's in Cork. A list of times and places will be available.

Finally, we learned about the 'Rebel Express' bus leaving Cork on Thursday April 11th heading to the Dáil in Dublin to be part of the big protest organised by PAI. This is part of Awareness week and the aim is to draw attention to the lack of services throughout the country experienced by

- PWP. It will also highlight our ongoing call for
- specialist nurses in the community.
- Kate Wilkinson followed and gave a very open
- and honest account of how living with someone
- with Parkinson's changes your life. She spoke of
- how important it is to have access to local support
- groups where others share the same experience
- and the urgent need to develop groups particularly
- in remote or isolated rural areas. The themes
- raised resonated with people and confirmed they
- were not alone in their thoughts and feelings.
- We were thrilled that one of the PAI directors,
- Gary Boyle, came down from Dublin for the event.
- He openly shared his own experience when he
- was first diagnosed, the anxiety and the denial
- which chimed with many of us. The big take-
- way from his very constructive talk was to have
- your list of questions ready when you meet your
- consultant. Work your way through the list and
- make sure you get them answered satisfactorily.
- Do not be 'fobbed off' and do not be constrained
- by time – this is your appointment, your time and
- your health. It takes as long as it takes to get your
- questions answered. Great advice Gary, thank you
- very much.
- The staff at Silver Springs Hotel were attentive and
- accommodating and looked after us very well. We
- had music and set-dancing and a performance
- from the amazing Crosshaven Ukulele players as
- well as impromptu songs from guests. The general
- feedback was this was the best we've had. Thank
- you to Margaret and Mary for organizing this, the
- bar is set high for next year!
- *Contact: Ted Horgan 087 237 5558*



Parkinson's Online

If you would prefer to view online and not to receive a copy in the post, please contact the PAI office on 01 872 2234 for more details.

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