

DNI News



In this issue...

- ▶ *Expert on DBS joins staff*
- ▶ *Research on Parkinson's*
- ▶ *Fundraising Events*
- ▶ *Patients' Stories – nothing is impossible*
- ▶ *How Parkinson's patient interprets his condition through art*
- ▶ *Restoration of Victorian garden seats*
- ▶ *A day in the life of DNI staff members*
- ▶ *Family expression of gratitude*
- ▶ *Fundraising appeal*
- ▶ *How music can be beneficial to the brain*

The Dublin Neurological Institute
 Mater Misericordiae University Hospital
 57 Eccles Street, Dublin 7
 Tel: 01 803 2871
 Email: info@dni.ie
www.neurologicalinstitute.ie
 DNI Charity registration No. CHY 19722
 Registration No. 9755710W

Editor of DNI News:
 Regina Prenderville,
 Dublin Neurological Institute

Welcome

Welcome to the Spring 2020 edition of DNI News. Since our last Newsletter the world has changed and we are living through extraordinary times. We at the Dublin Neurological Institute (DNI) are focusing on helping our patients (with and without COVID 19) to the best of our abilities. It seems that those with the virus are prone to acute neurological problems so we anticipate being very busy in the Mater over the coming weeks and months.

The Coronavirus pandemic, is not only a public health crisis with an attached economic disaster but in its wake, it will leave slim pickings for charitable organisations such as ours. Unfortunately, three major fundraising events for the Centre for Brain Health at the DNI were cancelled this year, the Breakfast in Croke Park, Fairyhouse Festival Lunch and Afternoon Tea in Trim Castle. These events were scheduled for April, May & June. However we have faith in the medical & scientific expertise of our counterparts throughout the world and hope and pray that before too long we will turn the tide on COVID19

The 19th annual golf classic will be held in Hermitage Golf Club on Friday, 18th September 2020 and we hope we will receive support from all those who have participated in the past. Last year's event was an amazing success – we had 32 teams for the afternoon timesheet. The generosity of those who played and supported the raffle was phenomenal. To those who made monetary donations and donated prizes, we are extremely grateful to you for your ongoing commitment to this event. We are seeking a major sponsor for this year's fundraising golf classic. Over the years this has proved to be an extraordinarily positive event – we would welcome any suggestions or ideas regarding sponsorship.

Over time Education, Research and Innovation in neurology are key to improving the care of patients. The DNI has an active programme of teaching and education, including an annual Neuroimmunology conference which is always well attended. This year's conference was held in February 2020 and we had presentations from

continued on page 2 >

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www.neurologicalinstitute.ie or Call 01 803 2871

the following international speakers – Dr Anastasia Zekeridou, & Prof Sean Pittock from the Mayo Clinic USA, Prof Simon Rinaldi, Dr Patrick Waters, Prof Angela Vincent & Prof Sarosh Irani from the University of Oxford UK. Presentations were also given by Prof Mary Keogh, Beaumont Hospital and Dr Roisin Loneragan & Prof Tim Lynch from the Mater University Hospital. Our annual Parkinson's disease and Other Movement Disorders conference takes place in October and this is always a very well attended event. Research projects are ongoing looking at the skin in Parkinson's disease (PD) and determining if it can be used as a diagnostic marker, developing an integrated care approach for patients with PD and studying movement control and gait in Parkinson's. These and other studies are funded by grants awarded by the Health research Board and Michael J Fox Foundation.

The above activities would not happen without the ongoing funding we receive from our many supporters and we greatly appreciate this commitment to the DNI. Neurological disease affects almost 800,000 people in Ireland and occurs more frequently as we age. However a prompt diagnosis

can make an enormous difference. This can be a problem in Ireland due to limited investment in neurological services. The funds we raise are vital to ensure we can provide a service to those who suffer with conditions affecting the brain and the spine.

Tim Lynch FRCPI FRCP (London) Consultant Neurologist & Clinical Director Centre for Brain Health Dublin Neurological Institute

If you would like to make a Donation to the Centre for Brain Health at the Dublin Neurological Institute online readers can click on the DONATE button below and you will be taken to our Donation page (credit card or Paypal)



Or alternatively please visit:
www.neurologicalinstitute.ie/how-to-donate

Expert on DBS (Deep Brain Stimulation) joins staff of the DNI



Dr. Richard Walsh joined the team at the DNI in March 2020 to lead the deep brain stimulation service (DBS) in a post shared between Tallaght University Hospital and the Mater Hospital. Dr Walsh has been a consultant Neurologist in Tallaght University Hospital for the past 8 years. He completed his neurology training in Ireland in 2010, during which time he worked in the Mater under the mentorship of Prof.

Tim Lynch. During his training in Ireland he also completed a clinical research fellowship in dystonia under Prof. Michael Hutchinson in St. Vincent's Hospital.

He left Ireland to work in Toronto Western Hospital where he completed a clinical fellowship in Parkinson's Disease under supervision of Prof. Anthony Lang and an additional Fellowship in DBS with Prof. Elena Moro. Dr Walsh established the Tallaght Movement Disorders Unit in 2012. Within this service he treats patients with dystonia and other hyperkinetic movement disorders with botulinum toxin and also runs a complex Parkinson's disease clinic aimed at optimising function in patients with advanced Parkinson's disease. Dr. Walsh co-directs the National Ataxia Clinic in Tallaght Hospital where he supervises an MD candidate with Trinity College. He is actively involved in research of Parkinson's disease genetics and epidemiology,

the genetics of familial ataxia and neurophysiological biomarkers in deep brain stimulation.

His aim over the next 5 years is to build on the work of Prof Tim Lynch in placing the Mater Hospital at the centre of a national deep brain stimulation network which will include a functional neurosurgical centre to serve Irish patients with complex movement disorders, to build on the very strong teaching history in the Dublin Neurological Institute and to further develop collaborations with colleagues and academics around the country within neurology and related fields.



Research Steps towards Parkinson's Disease

Parkinson disease (PD) is the second most common, non-curable, neurodegenerative disease and leading source of disability worldwide. This is a very complex disease associated with motor (e.g. tremor, bradykinesia, rigidity and freezing of gait) and non-motor (e.g. fatigue and anxiety) features. The prevalence of the disease ranges from 41 people per 100,000 in the fourth decade of life to more than 1,900 people per 100,000 among those who are 80 and older.

In Ireland, approximately 12,000 people have been affected by this disease and about 6.1 million globally, which is estimated to be doubled by 2030. There is only 1 neurologist for 115,000 population and 5 PD nurse specialists in Ireland to provide this complex care. However, it has been felt that innovations in diagnosing and creation of care facilities to improve quality of life (QoL) for patients and care partners are in urgent need.

Dublin Neurological Institute (DNI) has initiated some research activities to address this issue, which are:

1. Skin biomarker study in Parkinsonian syndromes:

Dr. Dimitra Khalil Chaity, Neurology Research Registrar



This is a collaborative research between DNI and University College Dublin (UCD). Our goal is to look for early and non-invasive diagnostic marker for Parkinson's disease and differentiate it from other parkinsonian disorders such as multisystem atrophy (MSA), progressive supranuclear palsy (PSP), diffuse lewy body disease (DLBD), corticobasal degeneration (CBD) and fronto-temporal dementia (FTD). We will collect skin samples with sebatape and punch biopsy, as well as blood samples will be taken to examine the expression of proteins associated with the above mentioned diseases and establish skin as a potential biomarker.

2. Freezing of gait in Parkinson's disease study:

Dr Cliona Buckley, Neurology Research Registrar



This research is currently being undertaken at the DNI in collaboration with Department of Neural Engineering, Trinity College Dublin (TCD). The study aims to better understand walking problems such as freezing of gait and trip related falls, as it is known to be disabling in patients with PD. We have been gathering this information to develop potential home-designed tool with a view to reducing the frequency and severity of freezing episodes, leading to improve overall gait in those patients affected.

3. Integrated Parkinson Care Networks (i-CARE PD):

Dr Aoife Lafan, Consultant Neurologist, NDTP Aspire Fellow in Deep Brain Stimulation



A multicentre European Union collaborative research programme focuses on shifting outpatient care to home and community based care with self-management support and technology enabled health care for PD, which will be cost-effective and sustainable. It is a multiphase study that will start with patient and care partner's interview on their lives with this disease to recognise the main concerns related with care and the potential use of virtual technology to address the issues. Besides, we will be recruiting people with PD experiencing motor and non-motor symptoms, with or without freezing of gait, as well as MSA, PSP, DLBD, CBD and FTD patients for the said research. Participation of patients in these studies are voluntary. Any interested patient can contact us, Dr. Dimitra Chaity and Dr. Cliona Buckley (neurology research registrars) on 01-8545038 for further information and participation.



Since we first opened the doors of the DNI we have been inspired by the following words

*"Start by doing what is necessary,
then do what is possible and
suddenly you are doing the impossible"*

- St Francis of Assisi



Online readers can donate by clicking here

Thanks to the generosity of our supporters we continue to achieve the impossible every day

Set Dancing Classes haven't been affected by Restrictions

An uplifting story by Gary Boyle

In 2009 I was diagnosed with Young Onset Parkinson's Disease. I was completely shattered by this diagnosis; it came literally out of the blue. I was 44, at my career best and was healthy and active. I thought I would have to at least 74 to get Parkinson's Disease, but as I have since learned 'Young Onset' Parkinson's Disease affects about 10% of the PD population. So there I was – officially 'Young' and also in a pretty exclusive group. Life can be funny like that, and with PD you eventually get used to these little ironies. Well, I spent the next 5 years trying to ignore PD but it being the deteriorating condition it is, I was heading down a path where life was becoming very difficult. I walked with my right leg dragging behind me. My right arm didn't move - at least in a way that I wanted it to. I had a constant tremor and things like getting dressed or finishing the food on my plate were becoming a nightmare. I was losing weight; my clothes (if I got them on!) were falling off me. In actual fact I was miserable and I was very worried. My stress levels were very high and that in itself was a serious problem with the receding Dopamine levels in my Brain.

And then in May 2014, Prof Tim Lynch advised me of a pilot project he was involved with for Parkinson's patients, together with an Italian Neurologist, Prof Daniele Volpe of Venice and the Physiotherapy Department in the University of Limerick. When he mentioned Irish Set Dancing Classes, I thought he was out of his mind and I most certainly wasn't too impressed with the suggestion that I should take up this 'ridiculous form of therapy' I very reluctantly attended a few classes in 2014. They were actually great fun! And what's more, they helped me with my balance and gait. Well I can tell you I went all in for Irish Set Dancing! It was beginning to change my life, in a good way! Along with a very significant Speech and Language Therapy programme, I have fully embraced Irish Set Dancing, and our Dance classes



• Set dancing class in Dun Laoire Library



• L.to R: Gary with his wife Joan, daughter Bronwyn & son Daire

have been going from strength to strength – thanks to Move 4Parkinson's.

Of course now, with the onset of Covid19 – everything has changed and we are living in unprecedented times. I'm trying to shine a light on some positive things that are happening despite the pain and anxiety we're all experiencing at the moment. Understandably the coronavirus is the only story we hear about today. Not just a health story, Covid19 is resetting our lives and its impact is keenly felt as the death toll continues to rise. The

sadness and heartbreak for the bereaved feels manifestly unfair. And yet, there is a bright spot that I'd like to share with you, a shining light in the midst of all of this anxiety.

Despite living with Young Onset Parkinson's Disease – thankfully, I am very much alive and I can tell you that although I may not be cured, I am a lot better than I was 5 years ago! One of the reasons for the lack of my demise is because I attend Irish Set Dancing classes every week. Set Dancing is still one of the few recognised therapies for Parkinson's (PD). Our classes cover all age groups, I'm not the oldest 'dancer' in the group, as I'm 'only' 54! Most of our Dance classes are made up of people in their late 60's, 70's and 80's. These are wonderful people who know how to enjoy themselves!

So, when the restrictions on movement were introduced it seemed that this would be the end of our classes, for the foreseeable future at least. At our last class some weeks ago Pat O'Dea (who is a 'Sean Nós' Set Dancing teacher from Limerick) and I suggested to the group that maybe we could try to go online with our dancing. Well, I have to say the groans were very audible and many in the room were positively disdainful towards the internet. Rather than viewing technology as something that could help us, it was being looked upon as a barrier to any further dancing, and I began to worry about the loss of exercise and social interaction, so critically important for those of us living with PD.

Well, I was wrong, well wrong! In the most uplifting and moving way, people have embraced technology and our Set Dancing classes online are proving to be an enormous hit! We are meeting 3 days a week, with 2 sessions each day and the classes are full of eager participants. There is delight on the faces of many who only a few weeks ago thought well, that's the end of the Dancing. Now all of us dancers are positively thrilled with the opportunity to display our new found '4C' savvy, complementing our 8-beats per bar Irish Set Dancing dexterity! It seems that people have put aside their technological misgivings in order to learn a new skill. And they are delighted to have done so, as now we're all connected up again and everyone is thoroughly enjoying the experience. It's not perfect; it will be fantastic to

get back together again when finally (and hopefully) Covid19 is defeated. In the meantime what is happening with our Irish Set Dancing just confirms for me that putting labels on people that they are 'young' or 'old' is utterly meaningless - when people are motivated there is little that cannot be achieved.

There have been a few (very funny) hiccups along the way but I can tell you that people are taking part, getting wonderful exercise and clearly having fun in a way that I never could have expected. And believe it or not, we now have more people 'Dancing online' than we did when we met together in our groups! It's so uplifting; it is truly a bright spot amidst the darkness that currently surrounds us, something we can shine a light on; one that will bring hope into people's hearts. I just wanted to share this for the smile it will bring and hopefully for greater awareness of what's possible, despite living with Parkinson's Disease!



Living with Parkinson's - The Lighter Side "Wallpapering the back bedroom" by Eileen O'Brien

I have lived with Parkinson's Disease or Mr Parkinson (as I like to call him) for the past 20 years. Despite the huge nuisance factor he imposes on me, my family and friends, we generally get on quite well together. We can achieve quite a bit if we cooperate, but like any other team, we can over estimate our capability from time to time and land ourselves in trouble. The following description of our attempt at hanging wall paper was, I am glad to report relatively successful. Yes there were a few hitches but with a pioneering spirit and loads of spare wallpaper – we did it !!

You know how it is, you paint a bedroom a single colour and somehow it looks dull and uninteresting. This happened to me just before Christmas last year. Determined to brighten up my guest room, I tried a contrasting colour on the wall behind the double bed. I now had a powder blue on three of the walls and a mid blue on the wall behind the bed..... But no it still didn't look right. So suddenly I had a brilliant idea. I went to the book shelf in my kitchen and pulled out the very glossy and expensive Home and Garden magazine which I had borrowed from my neurologist's waiting room during my last visit. The answer jumped out at me from a magnificently glamorous photo of a bedroom so dissimilar to mine – it was like comparing Kim Kardashian's boudoir to a bedroom in a backpacker's hostel in Oz. The answer to brightening up my guest room was to wallpaper behind the bed.

I considered this for a few moments. I consulted my body companion, Mr Parkinson and we convinced each other that this could be done. I should mention of course that I had never wallpapered before. I consulted YouTube & watched a video on 'Practical Wallpapering for Beginners' - It all looked very simple. I gathered a check-list – I needed wallpaper, paste, a brush, something called a plumb line and the kitchen table. Now the table is downstairs and the back bedroom is upstairs but the video made it look so easy – I didn't envisage a problem.

Idiots have done this, I told myself – it cannot be that difficult. I measured and cut a length of paper, placed it on the table,

patterned side down. I discovered some readymade paste in the utility room press. I brushed on the paste with generous aplomb, having neglected to read the detailed instructions to use sparingly. I carefully folded the two ends of the paper noting a few bulges and bubbles forming but told myself that this could be sorted with a brush and a cloth. So I carefully lifted it and proceeded to the bottom of the stairs.

Unfortunately, I failed to notice that as I progressed into the hallway, the bottom of the paper was slowly unfolding. As it unfolded, it started to wrap itself around my legs, waist and chest and stuck fast to my clothes. At this stage of course the prospect of making it upstairs was out of the question. I stood for a moment, wrapped from head to toe in a blue and white floral print wallpaper, just like an oversized gift. I thought of Queen Cleopatra who wrapped herself in a carpet and had herself delivered to Mark Anthony. I scoured my mind briefly to pick a possible candidate to whom I could dispatch myself, but thought better of it – after all Sean

Connery might not appreciate taking delivery of a quivering 63 year old wrapped in flowery wallpaper.

So I proceeded to peel off the sticky paper along with my top and my jeans. Then I caught a glimpse of my postman approaching the front door. I quickly made my escape upstairs as fast as Mr Parkinson would permit. 'This will not defeat me' I vowed as I pulled on my old tracksuit and started again. After a considerable number of slight hitches, which included sticking a length of paper to my step ladder and almost pasting my cat Daisy to the wall – the job was finally completed.

I took photos of myself and a somewhat disgruntled cat having had paste washed from her fur in the shower. The look on my adult children's faces when they visited was my supreme reward. 'How did you manage that' they said staring at the perfectly papered wall 'Easily' I replied nonchalantly. 'I had a little help from Cleopatra and the rest was a piece of cat - cake I mean!'



DNI FUNDRAISING EVENTS

The DNI is an independent company and charity (CHY 19722). There is no charge to patients who receive treatment here.

We depend solely on various fundraising events, philanthropy, legacies and grants.

We strive to increase access and improve care to patients with neurological problems including Stroke, Alzheimer's disease, Parkinson's disease, Multiple sclerosis, epilepsy, head trauma including concussion, brain tumours, motor neurone disease, spinal injury and headaches (including migraine).

We worked tirelessly throughout the year by organising events etc – however the support we receive from patients and their families is invaluable. We greatly appreciate the support given to us by patients and their families. It is always extremely gratifying for our staff when we receive positive feedback. The following are some of the fundraising events which took place on our behalf in 2019

■ Dublin City Marathon

In recognition of the work carried out by our team - brothers Robert & Mark D'Arby from Co Meath ran the 2019 Dublin City Marathon on our behalf. Their sister Rachael was at the finishing line to support the boys' achievement.

This was Robert's 3rd and Mark's 4th marathon and we are extremely grateful to them for choosing the Centre for Brain Health, Dublin Neurological Institute as their chosen charity. They raised €1,782.69



ABOVE: Robert & Mark D'Arby at the finishing line celebrating with their sister Rachael

LEFT: Pictured at the cheque presentation were Prof Sean Murphy, Robert D'Arby, Rachael D'Arby and Dr Michael Marnane

■ KCR Festival 2019

This festival has been an annual event for the past 10 years and has been organised by Tony Swaine, his wife Noirin, Robert Delaney and their late friend Kay Byrne RIP. Over the years they have raised over €35,000 and have supported numerous charities with money received through the generosity of their supporters.

Each year the organisers come up with novelty events to raise money. We in the DNI were delighted to be the recipients of part of the money raised during the 2019 Festival Week. We were awarded €1,425 by the KCR Festival Week Committee who buried 2 men in a sand filled skip. The unfortunate men were then the victims of a sponsored cream cake throwing exercise.

We are honoured that we have been nominated to be one of the major recipients of funds raised during the 2020 Festival Week. The main fundraising activity this year will be the election of the Lord Mayor of Harold's Cross. The KCR Public house in Kimmage will nominate people to participate. There will be 4-5 contestants who will each organise various fundraising activities. The person who raises the most money will be awarded the prestigious title of Lord Mayor of Harold's Cross.

Fundraising Events

■ Longford supports the DNI

ICA (Legan Branch) organise Cake Sale on our behalf

We are most grateful to the ladies of the Legan Branch of the ICA for their generosity. They raised €2000 by organising a cake sale. On behalf of the ICA, Mrs Margaret Quigley travelled to Dublin to present the cheque for €2000 to Prof Tim Lynch.

Ballymahon Vocational School – forfeit Kriskindle

The pupils and staff of Ballymahon Vocational School took part in a walk to support the Centre for Brain Health. This walk was done in memory of Maria Harte-Bars - Mother of Chris who was a past pupil of Ballymahon Vocational School. Brigid Harte, also deceased was Chris's Aunt and Eugene Harte who was her grandfather. Sadly Maria, Brigid and Eugene passed away as a result of a form of frontotemporal dementia call pallido-ponto-nigral degeneration (PPND/FTD). Frontotemporal dementia (FTD) is a terrible form of dementia that affects younger people. It is the second most common cause of dementia, after Alzheimer's disease, in those less than sixty-five. FTD is difficult to diagnose as it often presents with insidious personality and behavioural change, language problems, parkinsonism and in some people motor neuron disease. Moreover healthcare professional may not have heard of FTD and hence it is unrecognized. Being diagnosed with dementia and personality change at a younger age presents a real challenge to the patient, family, carer/spouse and health service. Often the patients may still be working, have financial commitments or dependent children, and need greater services and support. Moreover we have shown that the patient often has limited insight into his or her condition and the stress for carers when dealing with FTD is much greater than when dealing with Alzheimer's disease.

FTD occurs when nerve cells in the frontal and/or temporal lobes of the brain degenerate and die. Some of the chemical messengers that transmit signals between nerve cells are also lost. Over time, as more and more nerve cells die, the brain tissue in the frontal and temporal lobes shrinks.

Research on an Irish-American family in the 1990s resulted in identifying multiple families with familial forms of FTD called frontotemporal dementia and parkinsonism linked to chromosome 17 (FTDP-17). This work led to a crucial discovery

of the causative gene called microtubule associated protein tau (MAPT) that led to a sea change in dementia research. Pallido-ponto-nigral-degeneration is one of the FTDP-17. Patients with this type can present with personality change and memory problems but also they present with parkinsonism that mimics Parkinson's disease making the diagnosis very difficult. Tragically we do not have therapies that slow the stop of FTD or PPND yet. It is hoped and expected that research studying these tau-related disorders (tauopathies), including research at the DNI in collaboration with Columbia University New York, will lead to new insights into these disorders and new treatments.

To acknowledge the work of the staff in the Centre for Brain Health, the children and the teachers made contributions in lieu of their Christmas Kriskindle. This innovative and generous undertaking was greatly appreciated.



■ IRES – Dragons at the Dock Event

The Irish Property Industry organises an annual fundraising event - titled 'Dragons on the Dock' in aid of the Simon Community. Each major sponsor can nominate a charity of their choice to receive a donation from the funds. In 2018 IRES nominated the Centre for Brain Health as a recipient of this special donation. In early 2019 we were most grateful to receive a donation of €8,500 from the staff of IRES.

See next edition of DNI News for details of the very successful DNI 150K Frontline Run which has now gone global

Fundraising Events

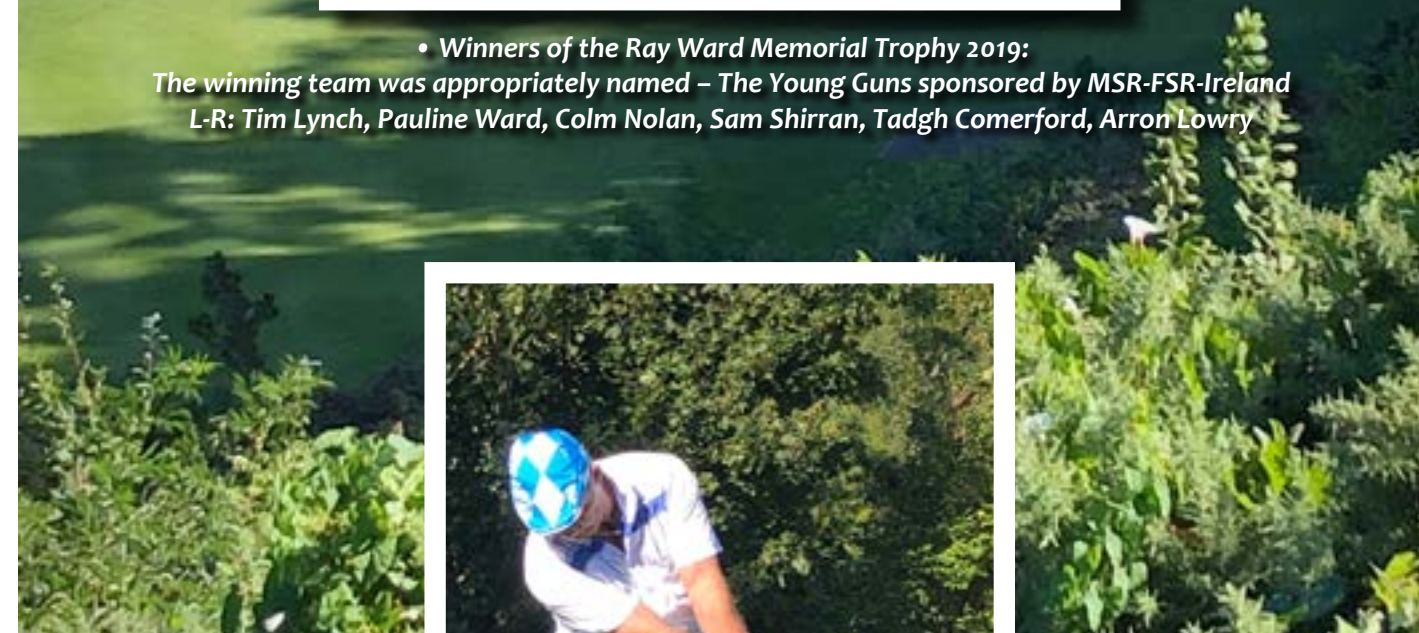
ANNUAL GOLF CLASSIC

The 18th Annual Golf Classic in aid of the Centre for Brain Health, Dublin Neurological Institute was held in Hermitage Golf Club on Friday, 20th September. As in other years we were blessed with a glorious Autumn afternoon. The course, though challenging, was in splendid condition and we greatly appreciated the wonderful support we received from the staff of Hermitage. We had a busy time-sheet with 32 teams playing. We are most grateful to those who have supported us since we started this event in 2001 and we welcomed many new teams who have committed to support us in the future.

The raffle was a huge success and we never cease to be amazed with the generosity of our supporters who donate prizes and purchase tickets.



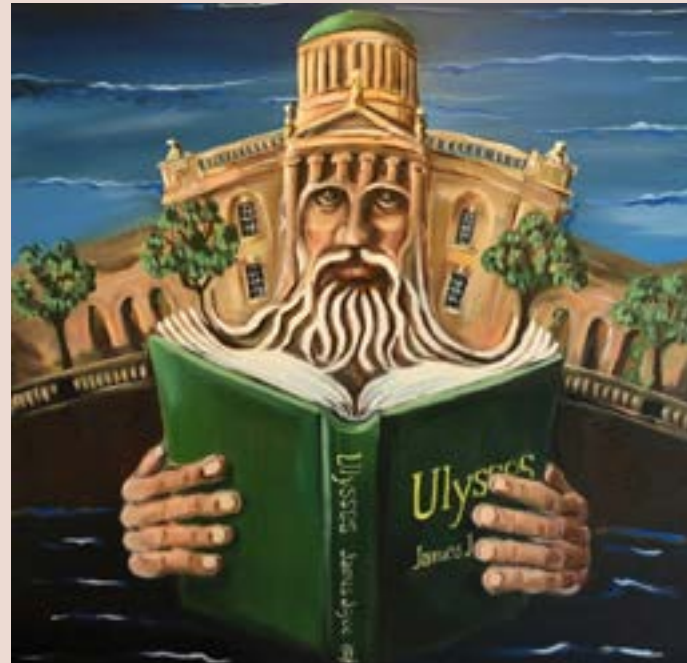
• **Winners of the Ray Ward Memorial Trophy 2019:**
The winning team was appropriately named – The Young Guns sponsored by MSR-FSR-Ireland
L-R: Tim Lynch, Pauline Ward, Colm Nolan, Sam Shirran, Tadgh Comerford, Arron Lowry



Fundraising Events

■ Art Exhibition

An exhibition of art was displayed in the Board Room of No 57 Eccles Street from 25th – 28th November 2019. Invitations to submit artwork was sent to patients and friends of the DNI. We were amazed by the quality of work received & we wish to acknowledge the work and commitment from Ms Carmen Neary (volunteer) who organised this event on our behalf. The main advertising feature of the event was the painting on right (Ulysses) by Jimmy Burns



An interview with artist Jimmy Burns

Many of Jimmy's paintings depict his battle with what it is like to live with Parkinson's.

The following Q/As help to interpret his paintings.

Question 1: What is life like living with Parkinson's?

I often console myself by thinking that life could be a lot worse..... Parkinson's is not nearly as bad as having illnesses like terminal cancer or Motor Neuron Disease. What is unusual for me is that my wife, Trish, was diagnosed with Parkinson's in 2011, so I was aware of what to expect when I developed symptoms in 2014. As a couple we try to live each day to the full and to the best of our ability. Pat O'Dea's set dancing/ sean- nós dancing class once a week has been inspirational and invaluable both for containment and shared hope. I have a shake in my left hand, which has got noticeably worse over the years. Thankfully, my Parkinson's has progressed very slowly, so I still have a good quality of life. However, when I lay down my head most nights, my tremor is a reminder of the future I am facing with emphasis on two words 'progressive and incurable'.

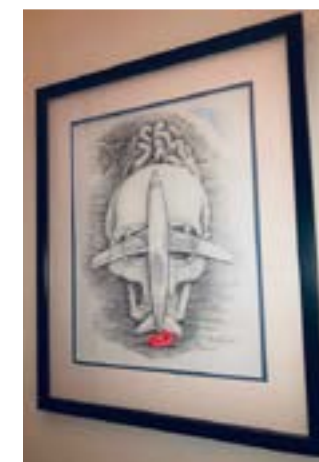
Question 2: Has Parkinson's disease had any effect on your art work since being diagnosed?

Not at all if anything, I'm more productive than ever - helped by two factors... retirement and my new studio! In the past year I have illustrated two books, taught a few adult art classes a week, and will hold my 10th solo Art exhibition, entitled 'Eye to Ear - a visual homage to Music' in December. Since my Parkinson's diagnosis, I have been keen to interpret my thoughts on Parkinson's through the medium of paint - hence the three pictures in the Neurological Institute.

Question 3: Does painting relieve any of your Parkinson's symptoms?

I like to think that it does! Keeping my mind and body busy at the same time is a good distraction and an exercise in multitasking - as is also the case with set dancing and riding a bicycle! The answer to this question might change somewhat if and when the tremor moves to my right hand. Jimmy Burns

Jimmy Burns Paintings donated to the DNI



"Brain Storm"

A visual interpretation for the detection of Parkinson disease. The pilot (usually male) encounters a (brain) storm and crashes!

Only on recovery of the 'black box' can investigators establish the cause of the crash.

Similarly with the Parkinson's patient the symptoms can be established on examination of the Basal ganglia gland of the brain, when the patient crashes (dies!). -Jimmy Burns



"Topsy Turvy"

Topsy Turvy is about being positive in the calm... but still the same person in the stormy! - Jimmy Burns



"Taking Flight"

The birds take flight in the night from the old tree. The old man/tree is now alone with part of his life missing ... a bit like a Parkinson person... alone in the dark to deal with the oncoming storm clouds on the horizon. Already the leaves are beginning to shake, a promotion of the oncoming upheaval. But life goes on in this beautiful world with Nature carrying on regardless.

-Jimmy Burns



Restoration of Garden Furniture The Victorian Garden Seats

By: Barry Dunbar

Nestled in the busy city centre on Eccles Street lies the garden at the rear of the Dublin Neurological Institute and tucked in the garden were two old garden seats. I learned they were in bad repair and needing the timber slats replaced. Their sorry state apparently depriving patients and staff of the opportunity to sit and enjoy this beautiful quiet oasis amongst the turmoil of daily life and offering some comfort when dealing with the news of challenging neurological conditions.

Having heard of their plight I volunteered to replace the timbers to get them back in use, how difficult could that be? I thought to myself and arranged to go see & measure them so as to arrange collection. I wasn't prepared for what greeted me on arrival that beautiful sunny day, two equally beautiful cast iron seats, 5ft wide with a lovely oak and ivy pattern in need of much attention. Once collected & taken home to begin work I quickly realised simply replacing the timber slats wouldn't be enough, the flaked paint and aggressive rust needed attention.

This was going to be more challenging task than expected and before starting I needed to ensure I restored them in manner that respected their heritage and set about researching their background more.

Turns out these cast iron seats with oak leaf and ivy design with acorns and having had seven wooden slats as the seat, have a heritage dating to the 1870's. The original design number I'm reliably informed it seems was registered and patented by the Coalbrookdale Iron Foundry at the UK's Public Record office in 1859, and is apparently seat number 30A in their 1875 Castings Catalogue. Its original was designed by the sculptor John Bell,

one of Coalbrookdale's principal designers. The back of the two sets from the DNI is the same as the original catalogue reference, with different side arms. As with all items from this time line being precise is a challenge, but they certainly seem to be from that era and if weight is any barometer weighing in at 100kg each certainly gives them that feel of authenticity.

Having carefully disassembled them I quickly learned that stripping the old paint by hand wasn't going to be practical or indeed easy on such an intricate cast iron pattern. Back to the laptop for some research and after several phone calls & emails I secured the invaluable services of dipstrip.ie and I am eternally grateful to Tony Duddy there for his help and soon got the seats back ready for the next phase of work.

Again professional advice sought on best practice for painting cast iron seats of this vintage Cornmarket, Dublin 8, for their advice and expertise. And so began the tedious application of rust primers and white finishing coats on the metal work over long bright summers evenings and sunny weekends. In the meantime I had ordered the 14 timber slats in and thanks to the staff in MRCB Iroko timber as I needed something both durable and sustainable and once received coated several times with the recommended clear finishing oil to preserve them long into the future.....and then final assembly.

In a small deviation from tradition I felt the original white paint finish on the cast iron didn't really do justice to the original oak and ivy design which I felt needed highlighting. So after much pondering I decided to paint a very small circular pattern on each seat end a lovely gold colour which was indicative of the oak its natural environment in autumn gold. And in some small way paralleling the autumn of our lives in which neurological

conditions often manifest themselves and in some small way mirror the experience of those who may sit in these seats into the future when returned to the tranquillity of the DNI garden.

So finally all done and dusted, time to return the two finished seats to their home, funnily I don't want to part with them now having gotten to know every detail of their fabric over some 60 hours of restoration.

Now back in their rightful place and hopefully those attending and working in the Dublin Neurological Institute can enjoy the garden in the comfort of these lovely old seats long into the future.

And I trust that patients continue to benefit from the oasis of care the DNI provides that wraps like a blanket around those in need of its invaluable services.



Left: Seat 1 before restoration begins

Right: Seat 2 carefully dismantled ready for work to begin

Below: the finished projects



Note: Prof Tim Lynch is delighted with the renovation of these beautiful Victorian benches. He bought them on a whim over 15 years ago in Mullens Auction House hoping they might be suitable for the DNI back garden.... Thank you Barry we are extremely grateful to you for your unwavering commitment to this project. **It should be noted that Barry provided all of the materials and his time free of charge.** These beautiful pieces are greatly appreciated & will be cherished forever.

Working in The DNI - Two very different Roles

The Reception Office A day in the life of a DNI staff member

By Rebecca McDonnell

No day is ever the same in the Reception office at The Centre for Brain Health, DNI. In the front office there are a number of aspects that make up our day, whether it is answering calls, greeting patients, pulling charts or making appointments..... the list goes on. The variety of work involved is what makes my job so enjoyable.

The structure and set up in the Centre is always being complemented by patients who say it doesn't feel like they are in a hospital but more like being in a hotel or a private clinic! What makes The Centre for Brain health so special is that once a patient comes through the yellow door, they soon become friends as we get to know each other with each visit.

What I personally appreciate about The Centre for Brain Health is that while I am fully exposed to the effects of Neurological diseases and the impact it has on a person's life – it never ceases to amaze me that the patients are always smiling and in form for a chat as they pass through the front office. It really makes one appreciate how precious our health is. As each day comes to an end I appreciate my ability to perform everyday tasks – like walking up the stairs etc.

When my work day in No 57 Eccles Street comes to an end - that is when I start, what I consider is my second full time job. I play Gaelic football for Clanna Gael Fontenoy in Dublin 4 and at the moment I am on the Dublin Senior Ladies Team. I have been playing football



since I was 10 and have been playing with Dublin at underage level since 2012. In May 2018 I tore the Anterior Cruciate Ligament in my knee and reluctantly I had to take a step back from county football. In August 2018 (shortly after my ACL injury) I began working in the Centre for Brain Health. The support I received from my colleagues made my return to fitness so much easier.

The Centre for Brain Health is an amazing place to work. It is a privilege to work with the multi disciplinary team, the patients and the volunteers. We are all part of one big team effort, working in a great environment with even greater people.

Music to the ears of our Resident Pianist

By Pauline Johnson

"Music to the ears" is a phrase used to rejoice in some good news, but it has literally been proven to be very beneficial to the brain. Many studies are available to read on line relating to this very subject. I recently read an Irish Times article about findings in the Journal of Neuroscience which stated that playing an instrument alters brainwaves in a way that improves listening and hearing skills over a short period. Since discovering the Journal of Neuroscience, I have become an avid reader of articles on this subject and have noted that an overview on Music and Dementia states "Music appears to be a unique and powerful stimulus for reaffirming personal identity and social connectedness in individuals with dementia"



As the resident pianist in the Centre for Brain Health, Dublin Neurological I encourage patients who once played an instrument, to take it up again, or if they have never played an instrument – I encourage them to 'try it for the first time'. I am delighted to have this opportunity to share the following story which illustrates my point.....

Last year, a 90 year old retired missionary priest said to me "Pauline, I missed out badly in life by not learning to play the piano" Well I replied ... "Better late than never" and there and then I introduced him to a small keyboard of mine. I put the letters of the notes on the keys. I asked him to give me the name of songs he liked and we took it from there. After a week's trial, he hastily got his own keyboard and from then on "Hey Presto" After one year he now has a repertoire of songs he loves and last week he brought me a list of 12 war songs – to see if I knew any of them !!

We celebrated his 91st birthday recently and I asked him how he was - he replied "Never Better – not a dull moment and plenty of music to the ears" I thought to myself "Seemingly a tune a day – keeps the doctor away".

I feel very passionately about this subject and if anybody reading this article has the same ambition, I would be happy to take you on !

Contact: Volunteer Pauline, Resident Pianist at 57 Eccles Street, Dublin 7
Or email: paulinejohnson986@gmail.com

A study by Dr Bernard Ross of the Baycrest Centre for Geriatric Care Toronto said "Music has been known to be beneficial to the brain, but there's limited understanding into what it is about music that makes a difference". His study showed the action of creating music leads to a strong change in brain activity. Researchers now hope that older people could even ward off dementia related conditions if they learned to play an instrument. I firmly believe this is true.

Family Gratitude...

We always appreciate when we receive a letter of gratitude from patients & family members.

The following was received recently (names have been removed)

Dear

On behalf of my father and the family of, I wish to confirm that today we made a donation to the Dublin Neurological Institute bank account.

My mother attended the Dublin Neurological Institute under Prof Tim Lynch since 2014. We live in the Midlands, where there are no regional neurology services available. Without the input of Prof Lynch and all the team at DNI we would have been absolutely lost in trying to access help and care for Mum. Expertise in Lewy Body Disease, and in particular, medication management of this complex illness was something we found to be completely absent at local level and it was only through the DNI that we got the help that we needed to allow our Mother live at home as long as possible, with as much dignity as possible.

Through Brian Magennis and Catriona McLoughlin, Movement Disorder Nurse Specialists, we received so much support and guidance over the phone and in person throughout the years.

My mother passed away peacefully surrounded by her husband and family at Cluain Lir Community Nursing Unit, Mullingar. As her lasting legacy she donated her brain to the Brain Bank at Beaumont Hospital, something that Prof Lynch suggested to her at one point, and which we, as a family are enormously proud of.

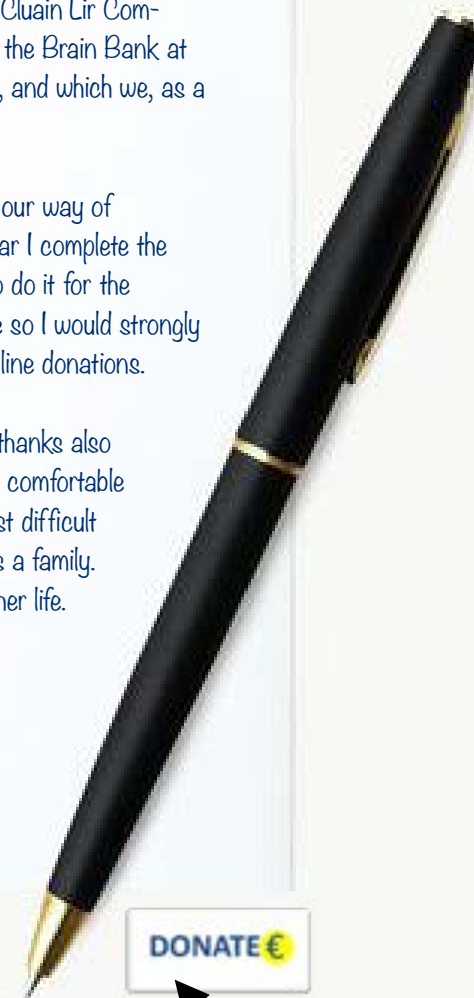
We hope this donation will go some way towards the running of DNI and it is our way of saying thank you for helping us when we were so desperate for help. Each year I complete the Dublin Marathon in October for a specific charity and this year I would like to do it for the Dublin Neurological Institute. Generally I receive about half of donations online so I would strongly urge you as a charity to develop a donation platform to facilitate access to online donations.

Once again, thank you to everyone who helped us at DNI. A special word of thanks also to Pascal who went out of his way at the last appointment to make things as comfortable as possible for Mum. He always had a cheery and kind word, even at the most difficult times. We will never forget the DNI for all you did for my mother and for us as a family. Your support allowed us to care for her at home up to the last six months of her life.

For that we will always be grateful.

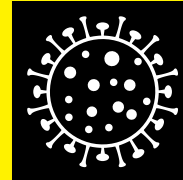
Yours sincerely,

NOTE: Since we received this letter, we have organised a DONATE BUTTON on our website - it is now possible to donate online by credit card or Paypal. Online readers can click the **DONATE** button (right) Or alternatively please visit: www.neurologicalinstitute.ie/how-to-donate



Online readers can donate by clicking here

Coronavirus **COVID-19**



Coronavirus
COVID-19
Public Health
Advice

Please Help !

Due to Covid-19 The DNI has had to cancel its fundraising activities so far in 2020. Your emergency donation is urgently needed to help keep our services running.

Please donate if you can!

DONATION METHODS

By Debit/Credit Card:

Online readers can donate by clicking here:



By Cheque/PO/Draft:

Make payable to The Dublin Neurological Institute & mail to
**Dublin Neurological Institute 57, Eccles Street
Dublin 7**

(please supply contact details so that we can acknowledge donation received)

By EFT:

Bank:	Bank of Ireland
Account Name:	The Dublin Neurological Institute
IBAN:	IE58BOFI90051970494077
BIC:	BOFIE2D

If you would like to make a Donation to the Centre for Brain Health at the Dublin Neurological Institute, online readers can click on the DONATE button above and you will be taken to our Donation page where you can contribute a suggested amount or choose your own donation value (by credit card or Paypal).

Or alternatively please visit: www.neurologicalinstitute.ie/how-to-donate