The Dublin Neurological Institute at The Mater Misericordiae University Hospital

DNI NEWS

Volume 1 : Issue 3 : February 2017

Contents:

Concert in aid of the DNI
There is only love !

It is our pleasure to invite you to a very special event, a concert of Samuel Gaine's music. This is the first screening of an original project, one that is comprised of musicians and singers from all around the country. The original tracks, as written by Samuel Gaine, have been arranged by both Samuel and Claire Crehan and include cello, percussion, piano, low whistle and guitar, as well as a 25 piece choir. This is the first time that Samuel's music has been heard in public and is a wonderful opportunity to be part of something extremely unique and exquisite.

This event takes place in the Chapel of the Mater Misericordiae University Hospital - entrance to the Chapel is from the North Circular Road Gate. Admission to the event is free of charge; donations towards the Dublin Neurological Institute will be accepted on the night.

We are indebted to Samuel Gaine, his wife Saedbh and their friends who have organised this event in aid of the DNI. There are over 700,000 people in Ireland affected by a neurological disease. This includes 1 in 5 hospital medical admissions and 1 in 8 GP attendances. Many of these brain, spinal, nerve and muscle disorders are increasingly treatable but access to diagnosis and treatment in Ireland presents a challenge.

There are only 34 Consultant Neurologists in Ireland to cater for these patients. This number is far below European and International standards.

The DNI is an unique innovative facility with academic links to the original Neurological Institutes in Montreal and New York. By offering a multidisciplinary team approach – patients travelling distances can be seen on the same day, not only by a doctor but also by a clinical nurse specialist, physiotherapist and other professionals allied to medicine.

Our statistics show that from January – December 2016 there was a footfall of almost **5,000** attending neurology clinics in the DNI. The total number attending clinics here in 2015 was **4,430.**

Our sponsors play a crucial role in helping us deliver and expand this service while continuing to maintain the highest standards of excellence. We avail of funds via multiple sources including the Mater Hospital, fundraising events, philanthropy, legacies and other donations.

Sustainability of the DNI requires a constant injection of funds to ensure that Irish citizens can access the best neurological care.

Prof Timothy Lynch
Consultant Neurologist & Clinical Director
Dublin Neurological Institute

ADVANCES IN RESEARCH

Research

Irish research is unlocking the dark secrets of dementia

A cure for the disorder is five to 10 years away, according to neurologist Tim Lynch

Article by Paul Cullen, Irish Times

Prof Tim Lynch said a cure for dementia is five to 10 years away

Two groundbreaking discoveries by an Irish scientist, separated by almost 20 years, have shed significant new light on the causes of dementia and Parkinson's disease.

Back in 1994, Prof Tim Lynch was training as a neurologist in the United States when his research team made a landmark finding of the first mutation of the tau gene that causes a form of dementia.

Working in Columbia-Presbyterian Medical Center, New York, the team discovered the mutation responsible for frontotemporal dementia – a form of the disease occurring in the part of the brain behind the forehead and ears – in an Irish-American family.

This discovery changed the science and direction of dementia research across the globe, including work on Alzheimer's disease, because the tau protein is also abnormal in the brains of Alzheimer patients.

At the time, the team predicted all the sites within the stem loop of the gene where mutations over time would be found, and also predicted no mutations would be within the loop region. In the years that have passed, all but one of the predicted tau mutations were found, thereby further unlocking the mysteries of brain degeneration.
It wasn't until two years ago that the final mutation was uncovered and, in the words of Lynch, "the loop was closed".
This happened on the other side of the Atlantic when a man presented to his neurology clinic at the Dublin Neurological Institute at the Mater Misericordiae University Hospital in Dublin with short-term memory loss and a changed personality.

Peculiar clinical pattern

The 44-year-old farmer showed signs of disinhibitation and impulsivity, but was also apathetic and lacked motivation, according to the report published recently in Brain journal. His sense of humour was altered and he enjoyed playing practical jokes.
"I had been waiting for something like this for over 15 years, to complete the circle that started with the initial research in the US.

"The patient had a family history of neurodegenerative diseases that had been previously labelled as Alzheimer's but the clinical pattern was peculiar," says Lynch.
The Mater team examined a number of the man's siblings, who were found to have either personality change or atypical parkinsonism, thereby indicating the importance of the tau gene for Parkinson's disease as well as dementia.
"Thanks to our previous work and recognition of the importance of the 'missing tau mutations' we were in a position to realise that we had found the missing tau mutation and that this gene change was causing the disorder in the family."
Lynch says Ireland is an ideal country in which to carry out neurological research because the population is genetically homogenous yet large enough to accommodate a sufficient variety of conditions.
Researchers also appreciate the traditionally large size of Irish families as the large families make identification of causative genes in brain conditions easier.
The tau loop mutation causes frontotemporal dementia, which accounts for roughly one in five dementia cases, behind Alzheimer's and stroke.

"It's a particularly nasty form of the disease, one that robs patients of their personality.

“It differs in this respect from Alzheimer’s, where the personality is preserved. It’s also a tricky diagnosis, often mistaken for other issues,” says Lynch.

Amyloid protein mutations

In recent years, much research has focused on mutations in the amyloid protein as the potential cause of degenerative diseases in the brain.

Lynch, though, believes tau offers greater potential for unlocking the dark secrets of dementia and other neurological disorders.

Given the fact that more than 700,000 people in Ireland suffer from some form of neurological condition, with this number set to increase as the population ages, the importance of brain research cannot be underestimated.

A cure for dementia is perhaps five to 10 years away, he estimates.

“We can now stop multiple sclerosis in its tracks using biologic agents, and we hope to be doing the same with dementia in the next 10 years.”

Even delaying the onset of dementia by five years would confer an enormous financial benefit on a hard-pressed health system, he points out.

“The result of this research will be used to bring new awareness to this particular field of neurology and result in new interest and funding for the development of much-needed novel treatments.”

The experience of the first Adult Neurogenetic Clinic in Ireland

Diane Olszewska, Prof Tim Lynch, DNI, Terri McVeigh, Dr Gregory Pastores, Genetics Dept, MMUH

Diane Olszewska, Research Fellow to Prof Tim Lynch, Dublin Neurological Institute

Introduction:

Genetics is the backbone of medicine, and particularly Neurology, where a number of disorders have a genetic aetiology. Some of these disorders are complex and make management difficult, requiring a dedicated Neurogenetics clinic. At least one designated consultant post each within clinical genetics and

neurology is recommended per 2,000,000 patients[1]. Genetics in the Republic of Ireland is under-resourced, with the lowest number of consultants per million of population in Europe[2].

Methods:

In November 2014, we established the first and only monthly adult Neuro-Genetics clinic in Ireland, staffed by 1 consultant neurologist, 1 consultant geneticist, 1 neurology registrar and 1 registrar in Clinical Genetics. The clinic is attended by patients and families with complex rare neurological conditions of an unknown genetic aetiology. We performed a retrospective cohort analysis after one year, reviewing data regarding symptoms and diagnostic work-up.

Results:

Twenty-five patients attended a pilot clinic over 12 months. Complex conditions encountered included: Parkin-related Parkinson's disease, leucodystrophy, ataxia (pure, familial and spastic), Fronto-temporal lobar degeneration (FTLD), Spino-cerebellar Ataxia (SCA) 6, and ataxia-telangiectasia. Identification of pathogenic mutations directed screening and treatment, and facilitated onward referral of family members for genetic counselling (n=8, 33%). A number of novel mutations were identified in MAPT ("missing tau" mutation)[3], SLCA1 and Progranulin. A number of patients had phenotypic features not previously reported; e.g. writer's cramp in SCA6; paroxysmal myoclonus in GLUT1 deficiency. Appropriate referrals were made for non-neurological sequelae of genetic mutations, e.g. breast cancer screening for carriers of ATM mutations. New treatments were considered based on genetic diagnoses, e.g. triheptanoin in GLUT1 deficiency. We appropriately referred undiagnosed complex patients (n=2) to international experts.

Conclusion:

The establishment of a joint Neuro-genetics clinic has addressed a gap in service provision for complex families with neurogenetic disorders, has allowed identification of rare and atypical diagnoses. These complex disorders have a unique psychological burden, and ideally, the clinic should be expanded to include input from psychology.

References:

1. Genetic Services for Neurological Disorders, ABN and Clinical Genetics Society Report, 2003.

2. https://www.eshg.org/111.0.html.

3 Brain. 2015 Oct;138 (PT 10):3100-9

Educational Events

It is vitally important for doctors in training, neurology nurse specialists and members of our multi-disciplinary team to keep up-to-date with advances in Neurology. Through the Catherine McAuley Education Centre in the Mater University Hospital, the DNI organises regular teaching events. As well as weekly teaching events – we were honoured to have the following speakers visit the Dublin Neurological Institute and made presentations:

Prof Anthony E Lang
Director Division of Neurology, University of Tor*onto, Canada*

Presentation: Functional Movement Disorders

Was presented on 12th February 2016

In 2011 Prof Lang was listed as the most highly cited investigator in the field of Parkinson's disease for the decade 2001-2010 and in 2013 he was recognised as one of the most influential (top 400) living core biomedical researchers based on publications between 1996-2011. In 2014 he was elected by the International Parkinson and Movement Disorder Society as an honorary member 'in recognition of his extraordinary contribution to the field of Movement Disorders'

Dr Andrew McKeon
Consultant Neurologist, Mayo Clinic,
Rochester, Minnesota, USA

Presentation: Antigen-specific neurology autoimmunity

Was presented on 15th March 2016

Andrew McKeon was born in Dublin, Ireland. He obtained his medical degree from University College Dublin (2000). He completed internal medicine and neurology residencies in Ireland, including one year at the Mater University Hospital before coming to the United States in 2006. He completed fellowships in Movement Disorders, Autoimmune Neurology at Mayo Clinic, Rochester, MN, before joining the Mayo staff in 2009. He has a joint appointment in the Departments of Neurology, and Laboratory Medicine and Pathology, where he is co-director of the Neuroimmunology Laboratory. He is an Associate Professor of Neurology, and Laboratory Medicine and Pathology in the College of Medicine, Mayo Clinic. Dr McKeon's research and clinical interests pertain to the evaluation and treatment of patients with autoimmune neurological disorders.

Prof Niall Quinn
Emeritus Professor of Clinical Neurology,
University College Limerick &
Honorary consultant Neurologist at the
National Hospital for Neurology & Neurosurgery,
Queen Square, London, UK

Presentation: Young on-set Parkinson's disease revisited

Lecture was presented on 2nd June 2016

Prof Quinn is the former Secretary of the Movement Disorder Society, Past Chairman of its European Section, and an Honorary Life Member of the Society. He has over 400 original peer-reviewed publications on movement disorders and has served on multiple scientific advisory boards and on the editorial boards of leading journals including JNNP, Lancet Neurology, Journal of Parkinson's Disease and Movement Disorders Journal. His major interests are in diagnosis, investigation & treatment of movement disorders, especially Parkinson's disease, multiple system atrophy, & progressive supranuclear palsy, including surgical approaches & neural transplantation.

Prof Serge Przedborski
Professor of Neurology & Neuroscience,
Columbia, University, South America

Presentation: Parkinson's Disease & energy
200 years of the Shaking Palsy and the Mitochondria

Lecture was presented on 8th December 2016

Serge E. Przedborski, MD, PhD, an internationally recognized clinician-scientist in the neurobiology of disease, is the inaugural director of the Columbia Translational Neuroscience Initiative (CTNI). His work on the cellular and molecular mechanisms of neurodegeneration in Parkinson's disease and amyotrophic lateral sclerosis exemplifies the potential of interdisciplinary, basic, and translational science to effect meaningful advances in the diagnosis, prevention, and treatment of neurologic disease. A native of Belgium, Dr. Przedborski earned his medical and PhD degrees at Université Libre de Bruxelles in Belgium and came to Columbia in 1989 as a movement disorders fellow. He joined the P&S faculty in 1991 and was promoted to Professor with tenure in 2002. Currently, he is the Page and William Black Professor of Neurology (in Pathology & Cell Biology), vice chair for research in the Department of Neurology, and co-director of Columbia's Motor Neuron Centre.

The DNI Parkinson's Disease Masterclass

Sponsored by UCB Pharma

A **Masterclass Expert Day for Parkinson's Disease** was held on 18th November 2016 in the Catherine McAuley Education Centre, Mater Misericordiae University Hospital. Pictured above (left to right) are expert speakers:

Dr Timothy Counihan, Consultant Neurologist, Galway University Hospital

Prof Elan D Louis, Professor of Neurology & Epidemiology, Yale University, USA

Prof Timothy Lynch, Consultant Neurologist & Clinical Director, Dublin Neurological Institute, Mater University Hospital

Prof Angelo Antonini, Director Parkinson's Disease & Movement Disorders Unit, Padua University Hospital, Italy

Dr John McKinley, Consultant Neurologist, Royal Victoria Hospital, Belfast, N. Ireland

Also participating were (left to right) Ms Yvonne McNelis Senior Physiotherapist & member of the Riverdance Troupe, Dublin Neurological Institute, Mater University Hospital, (Speaker) Dr Joanne Shanahan PhD Physio, UL Limerick & Dr Diane Olszewska,Research Fellow, Dublin Neurological Institute, Mater University Hospital

In his invitation to attendees Prof Tim Lynch wrote:

"Parkinson's disease and movement disorder are the focus of this event. Our faculty for the day are all experts in their field who will cover various "hot topics", the latest clinical data, practical aspects relevant to your practice, with the opportunity to hear new insights into Movement Disorders and to review case studies with your peers. Attendees are welcome to participate and interact with the speakers. We expect our panel of excellent local and international speakers to cover many different aspects of Parkinson's disease but also other movement disorders including Young Onset Parkinson's, Basal Gangila Disease & the Mind, the role of Irish dancing and PD rehabilitation, Continuous Drug Service can Impact Motor & Non-Motor Symptoms, A,B, C & Zs of recognising & diagnosing Tremors, Sorting out the inherited Ataxais."

The event drew an attendance of 127 delegates. It would be remiss of us not to mention the enormous support given to us in the organisation of this event by Ms Maeve O Sullivan, Academic Programme Manager in the Postgraduate Medical Centre of the Mater University Hospital.

Prof Tim Lynch, Mater University Hospital & Mr Tony O Brien, HSE

National Framework for Model of Care in Neurology

A new model of care for neurological services in Ireland developed by Edina O Driscoll, Programme Manager, National Clinical Programme for Epilepsy, Neurology & Rehabilitation Medicine, HSE, Prof Tim Lynch (Consultant Neurologist and UCD Full Clinical Professor) was launched by HSE Director General, Mr Tony O'Brien at the Mater Misericordiae University Hospital. Mr O'Brien was joined by Dr Aine Carroll, HSE National Director for Clinical Programs, a number of patients, past and present, who outlined their neurological conditions.

The publication of a new "Model of Care for the National Clinical Programme of Neurology" was developed by Prof Tim Lynch who is Clinical Lead in the National Clinical Programme for Neurology and the neurology programme. The programme aims to define the future set up of acute and chronic neurological services in Ireland and hopes to have such services delivered in an efficient, equitable and cost effective manner by supported, skilled, professionals working in a multidisciplinary manner using a person-centred approach to care.

Mater Neurologist Develops National Framework for Model of Care in Neurology

Article from UCD website

At a recent meeting held in the Mater University Hospital on the Development of a National Framework for Model of Care in Neurology, Mr Tony O'Brien, HSE Director General said,

"This model of care for neurology is a blueprint for the future set up of both acute and chronic neurological care services for Ireland. In agreeing this Model of Care for Neurology in the Irish health services, the National Clinical Programme has focused on where we can take concerted and specific actions, at all levels of the health service, to improve the management of neurology diseases. The plan supports us to capitalise on our influence, our governance and decision-making, and our powerful workforce, to improve care for persons living with neurological conditions."

Patients with neurological conditions need access to services from all areas of the health service - acute hospitals, mental health, social care, primary care and health and wellbeing via an integrated approach. The National Clinical Programme for Neurology aims to provide equitable access to a high quality service to provide accurate diagnosis, appropriate treatment, and management for all neurological conditions. We aim for excellence in neurology care and the best outcome for our patients.

The *Model of Care for Neurology* provides a framework for neurology services using international best practice and describes care provision using an integrated service approach. It covers the full spectrum of care provided in hospitals (in-patient & out-patient) and makes specific recommendations to the type of care considered best practice in the management of patients with long term neurological conditions in the community.

"Integrated care is an approach characterised by a high degree of collaboration and communication among health care professionals and the people they care for. The model of care for Neurology, which is being launched today, reflects the principles of integrated care, with doctors, nurses, health & social care professions, patients, families and patient organisations working together in a collaborative way to improve the patient journey for those with neurological conditions. I want to thank the National Clinical Programme for Neurology for leading on this excellent piece of work", said Dr Aine Carroll, HSE National Director for Clinical Programs.

Prof Tim Lynch, National Clinical Lead for Neurology said,

"The brain is the most important organ of the body and we need to encourage understanding and approaches to brain health in Ireland. This model of care is intended to ensure we provide excellent care for patients with neurological illness and also to stimulate teaching of and research into clinical neurology. There is no medicine like hope. We hope we will give hope to people with neurological illness with the publication and implementation of this model of care."

PROFESSIONS ALLIED TO MEDICINE WITHIN THE DNI

Physiotherapy and Parkinsons Disease

By: Grainne McKeown
Chartered Physiotherapist in Neurological Rehabilitation
Dublin Neurological Institute

Introduction

With over 12,000 people with Parkinson's Disease (pwp) in Ireland, providing optimal care for this complex neurodegenerative disorder is a key priority for neurological physiotherapists.

In the last 15 years there has been an emergence of evidence supporting the role of physiotherapy in Parkinson's disease (PD) with more than 100 international publications. In order to ensure clinical implementation of this research, colleagues from 19 European countries collaborated to develop the **First European Physiotherapy Guidelines for Parkinson's Disease - 2015.**

This guideline recommends early access to physiotherapy, outlines best practice for physiotherapists working with pwp and stresses the importance of physical exercise from initial diagnosis through all stages of the condition.

Role of Physiotherapy

PD is a complex movement disorder with a variety of motor symptoms affecting physical capacity, transfers, dexterity, balance and walking. These are core areas affected by movement impairment which are amenable to physiotherapy interventions. Our scope of practise is therefore broad, changing through the course of the condition depending on disease progression and patient capability but importantly it is patient specific, focused on optimising quality of movement and preserving independence.

Assessment

Seeing a Neurophysiotherapist specialising in Parkinson's on initial diagnosis is crucial. It provides a basis for tailored treatments specific to ones needs. Early intervention also gives a person the chance to discuss any concerns they may have and movement related issues can be addressed. The importance of physical activity and self-management strategies are highlighted.

To help manage movement related problems pwp are encouraged to complete a **Pre-assessment Information Form** (PIF) prior to seeing a Physiotherapist. This is an excellent tool. It helps patients consider their key problems. It provides the physiotherapist with greater insight into patients concerns, level of function and physical capacity. PIF form can be found on www.parkinsonnet.info/guidelines

Exercise

The evidence supports exercise as a primary treatment for PD, secondary only to medication, with emphasis that it commences on initial diagnosis. The exercise components that need to be evaluated are:

- Balance
- Flexibility
- Gait analysis
- Complex Movement sequences
- Muscle Strength
- Endurance

However we know PWP exercise one third less than their healthy peers and have a tendency towards a more inactive lifestyle. Furthermore preserving physical capacity is vital to prevent secondary deconditioning, falls, musculoskeletal pain and further functional limitation.

Exercise therefore should be integrated into patient education programs and become a lifetime habit based on a person's needs, lifestyle and capability. In my clinical experience those who exercise do better in relation to cardiovascular fitness, function and mood. Aerobic training and progressive resistance training have been particularly identified as key forms of exercise beneficial for pwp.

Unfortunately research has found that under dosing tends to be the norm. To ensure an ongoing training effect exercise needs to be structured, modified on a regular basis with incremental changes (which may include alterations in loading, repetitions and speed), and close monitoring of the patients response by a skilled Physiotherapist.

Movement Strategy Training

When a person has difficulty performing complex automatic tasks e.g. walking, turning in bed, getting out of a car the rehabilitation focus shifts to performing learned strategies (i.e. breaking down complex movements and using specific techniques) to compensate for movement control deficits.

Movement Strategy Training is effective to initiate and guide movement. It usually requires attention and use of external cues (e.g. visual, auditory and tactile cues). The choice of movement strategy is specific to each functional deficit (e.g. the movement strategy employed for turning will be different to the strategy to initiate gait). Studies have shown that walking stride can be maintained following a period of training and when cues are removed. This would imply that the motor ability to generate a step is not lost but the difficulty lies with activation and coordination of the motor control system. These strategies are valuable tools and provide opportunities for rehabilitation.

DNI Physiotherapy

At the Dublin Neurological Institute pwp are referred to the physiotherapy clinic on initial diagnosis. Treatment, advice and monitoring are provided on an individual basis. Research studies at DNI have looked at dance as a therapy for PD and management of the common, but debilitating symptom – freezing. We have also commenced exercise classes specifically for pwp run by two experienced neurophysiotherapists. This is a very dynamic class aimed at improving physical capacity whilst importantly providing peer support. It is an area we hope to develop further.

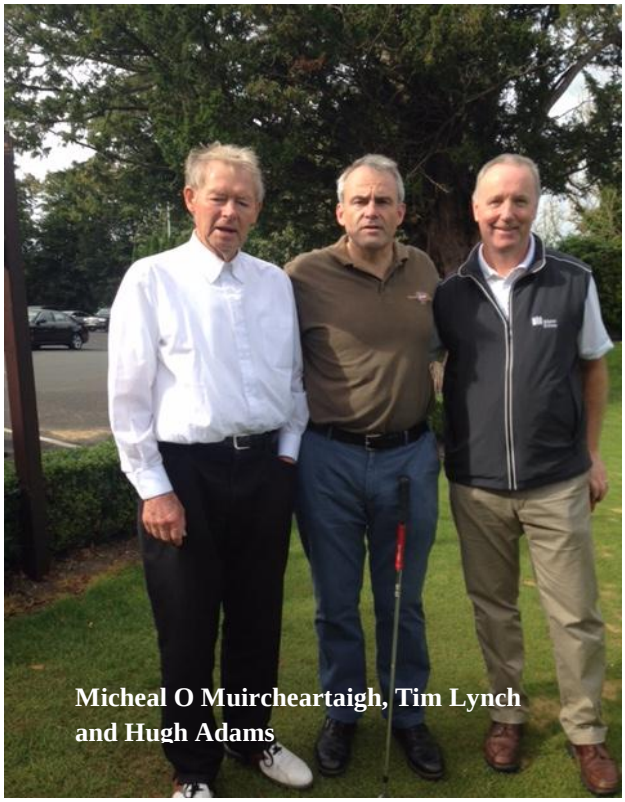
FUNDRAISING

The Dublin Neurological Institute is a registered charity and a centre of excellence for the care of patients with neurological disease. To ensure we provide a continued flow of care and maintain our existing services to the thousands of patients who enter the DNI each year, we need an annual budget of at least €200,000 per annum.

Annual Golf Classic

In September 2016 we held the 15th Annual Golf Classic in Hermitage Golf Club. As always, it was a most enjoyable afternoon and evening. We have been blessed with good weather since this event started in 2001. The 2017 golf classic will be held at the same venue on Friday 22nd September. We are currently inviting teams to participate. Thanks to the generosity of our supporters we raised €20,000 last year.

First prize in the raffle attracted great interest. We acknowledge the support from Friends of the DNI who so generously contributed to the prizes.



Micheal O Muircheartaigh, Tim Lynch and Hugh Adams

Pauline Ward, who together with her husband Ray were the founders of this great event. Ray unfortunately passed away in 2013

We were indebted to the Malin corporation who were our title sponsors in 2016.

Dermot Lee, Pauline Ward, Tom & Maud Nally

Chairman of the DNI: Micheal O Muircheartaign prepares to tee off

Hugh Adams, Dolores Caffrey & Tim Lynch

Pauline Ward presents the Ray Ward perpetual trophy to the winning team from Saltan Properties team

The Mater Does Strictly

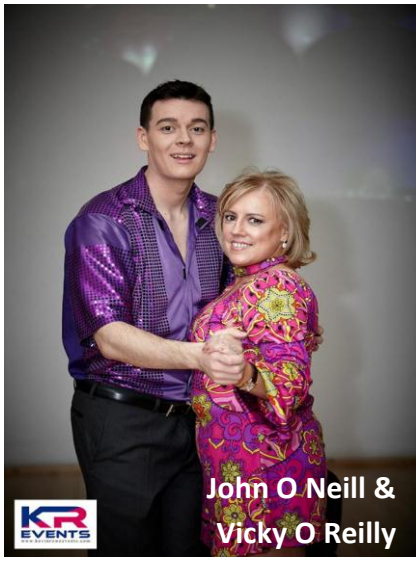
The BBC's ***Strictly Come Dancing*** and RTE's ***Dancing with the Stars*** would not hold a candle to the magical event that was held in The Helix in November 2015. All dancers were staff members – (not one professional dancer in the crew) and were they impressive!!! Over an 8 week period, the 15 couples received training for 2 hours per week with a professional choreographer and then they practiced and practiced on corridors, in store rooms and disused areas. The evening started with a group dance performed by 15 dancers which really got the crowd into the mood. Then the audience was treated to exhibitions of the Quick Step, Cha Cha, Waltz, Tango, Jive etc etc. Our own Parkinson's Clinical Nurse Specialist – Mr Brian Magennis danced the Charleston with his partner Mich Vartulli. Brian certainly demonstrated that that he has more strings to his bow than the talents he demonstrates in the DNI.

The atmosphere in the Helix was electric on the night with banners, posters and balloons encouraging the success of colleagues. In the end the results were very very close and we had to endure a nail biting experience of a re-count. In the end Colette Denham, Executive PA to the Chief Executive and James Connell, Medical Scientist were the winners with their magical performance of the Swing. It was a night we in the Mater Hospital will never forget!!

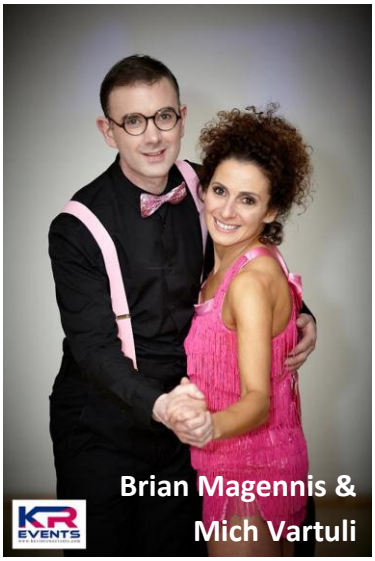
We in the DNI are so very grateful to the dancers, the sponsors and of course the Committee who organised this amazing event. It was a humbling experience to witness the diligence of our colleagues supporting the Dublin Neurological Institute.

In their performance of the Charleston - The DNI's Clinical Nurse Specialist Brian Magennis together with his dance partner Mich Vartuli, Information Analyst demonstrated talents we have never witnessed in clinic !!

Introducing our Strictly contestants……



John O Neill &
Vicky O Reilly

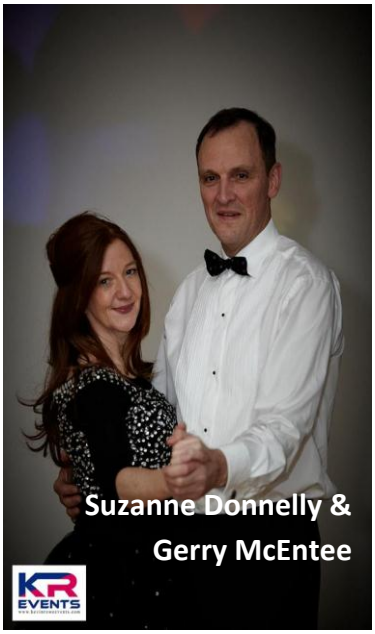


Brian Magennis &
Mich Vartuli

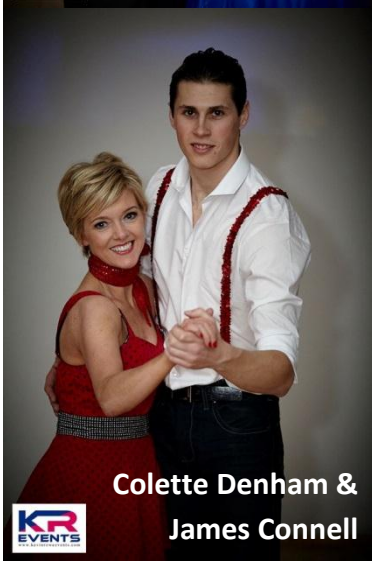
Keith Synnott &
Tanya King

Conor Galvin &
Anne Marie Corcoran

Sean Paul Teeling &
Mairead Casserly

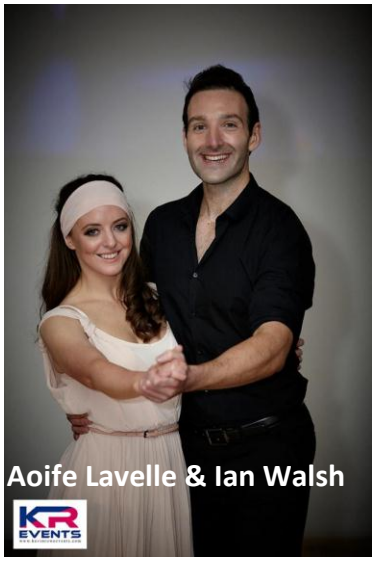


Suzanne Donnelly &
Gerry McEntee

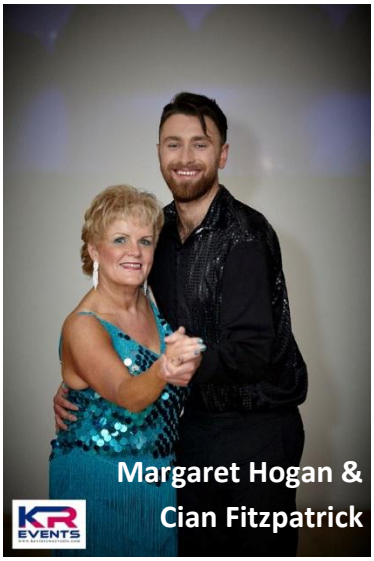


Colette Denham &
James Connell


Brian Cosgrave &
Bernadette Mee


Aoife Lavelle & Ian Walsh


Mary Kenny &
Michael Oyuga


Margaret Hogan &
Cian Fitzpatrick


Carl Hubbard &
Comfort Chima


Robbie Keogh &
Christine Quinn


Cian O Bradaigh
&
Sharon Toal


Rico Laguna & Teresa
Loughnane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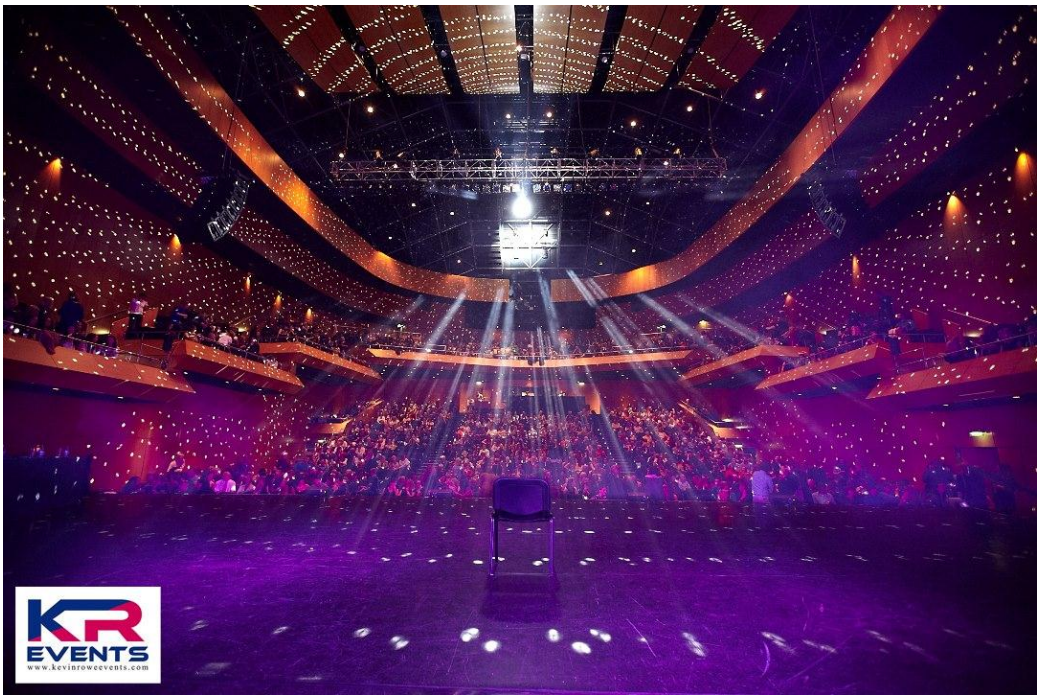
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Be With You
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And the winners were…….

1st place:

The Swing

Colette Denham
Executive PA, CEO Office
James Connell
Medical Scientist

2nd place:

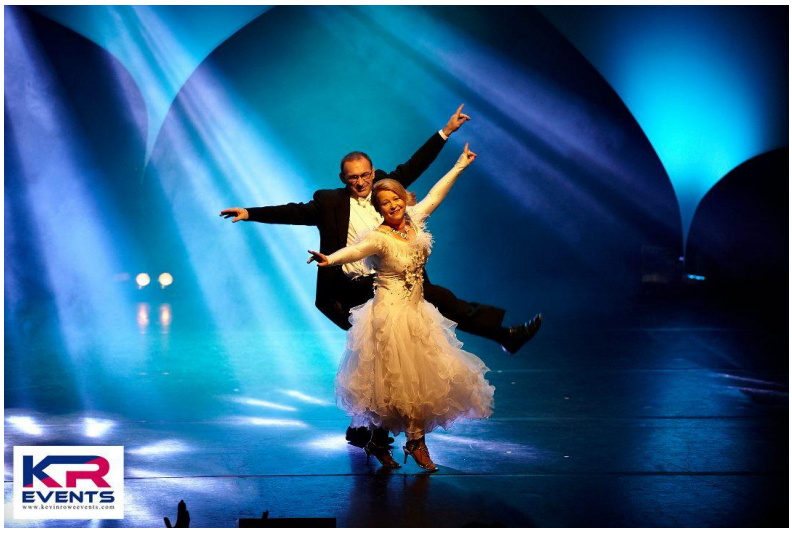
Dirty Dancing

Aoife Lavelle
Specialist Registrar, Anaesthesia &
Ian Walsh, Lab Aid, Laboratory

3rd place:

American Smooth

Tanya King, Director of Nursing
& Keith Synnott, Consultant
Orthopaedic Surgeon



Patient perspective of Parkinson's Disease
By Sean MacEntee

I was diagnosed 7 years ago with Parkinson's Disease, in fact I think I had it for 3 years before I was finally diagnosed. Perhaps one would think my reactions would have been anger, frustration, fear but strangely enough I accepted the diagnosis with a very positive attitude. I believe the secret of well-being is 'Staying Engaged' and to remain Curious about life and what is going on around us. I read up about Parkinson's Disease and was determined I wasn't going to let it get me down. Thankfully I'm still able to play golf (one might say badly) but I was never going to be a threat to Rory McIlroy! I'm also a member of four Boards of Directors which keeps my brain active and necessitates a lot of reading.

I was born in Shercock, Co Cavan and received an education for life from my Mother. Both she and my Father ran a business in the town – like many country establishments in those days, our business consisted of a pub, an undertakers, a grocery shop and also a hardware shop. My Father *worked* in the business but my Mother *ran* the business. Every penny was accounted for. As children and young adults – whenever we were home – we were on duty to help out, whether it was helping a family to choose a coffin or just to pull a pint. My Mother was rigorous in her pursuit of efficiency. She did not tolerate wastage and if by chance one bottle of stout was lost through breakage – we were reminded that we must sell 6 more bottles to make up for the profit lost. It was good to instill this awareness in country lads.

My Mother told my brothers and me that she would fund our Secondary School education but if we wanted to go to University, we must pay our own fees and accommodation. When I completed my Leaving Certificate I went off to Birmingham where I worked as a bus conductor. As I was preparing to go home with adequate funds to sustain my education, bed board etc, I received a telegram from my Mother informing me that I had won a Scholarship to UCD – so I considered myself to be quite flush but invested my extra money wisely. My investment was a source of interest to my brother who was studying Medicine in UCD and I can honestly say that I funded his *courtships* during his years in College. My years in UCD were happy ones and our laboratories were in Merrion Square (now the office of An Taoiseach). I graduated as an Electrical Engineer and in 1974 I married Miriam Deery – a Secondary School teacher. We spent some time in the UK. When we returned home I worked as a sound engineer in RTE. At night I studied for an MBA. For over 20 years I had my own business in Dundalk. Miriam and I were blessed with four great children.

Having had a very active career and working very hard to achieve what we did, Miriam and I were looking forward to retirement. Then in 2010 it was confirmed - **I had Parkinson's Disease.** I have always been a very positive person and I decided that I cannot change the fact that I have this disease but I can change my attitude to it. I am very grateful to God for the life I have had and perhaps he's testing me with this illness. I am determined it won't get me down. I know if my Mother were alive she'd tell me *'there's work to be done and get on with it'*……..so Miriam and I have enrolled with ALONE to help senior citizens who may feel isolated, forgotten and may indeed also have Parkinson's ?

A lot of energy is wasted with anger and resentment. We are given one life and it's so much easier to make the most of it and look at all of the positive things around us in this wonderful world.

Remember to

Stay Engaged
Remain Curious &
Be Happy

STAFF NEWS

We were sad to say good-bye to the following staff members:

Ms Emma Fahy who was the Administrative Manager in the DNI
Ms Emer Fallon was the Clinical Research Administrator in the DNI

We wish both Emma & Emer well in their new roles

We welcome

Ms Clare Leatham who has been appointed Administrative Manager & Support to the Clinical Director
Dr Michael Murnane, Consultant Neurologist, Mater Misericordiae University Hospital – special remit Teleneurology
Dr Shane Smith, Consultant Neurologist, Mater Misericirordiae University Hospital & Mullingar Regional Hospital

Congratulations to:

Ms Jane Mellott, Clinical Nurse Specialist on the birth of her second son Oliver who was born on 18th April 2016
Ms Carole Goggin, Clinical Nurse Specialist, who gave birth to her second son Conor, on 1st August 2016

COURSE FOR CARERS

Thanks to the great support given to us by the Friends of the DNI, we are in a position to organise the following bespoke course for the carers of those with a neurological disease. We recognise that the diagnosis of a loved one with a neurological disease can be a life changing experience, not only for the patient, but also for their spouse / partner who often becomes the carer of their loved ones. Many experience emotional, social and financial changes when it is not only the patient who can no longer participate in the workforce. We are planning a formal programme of education and training to support carers of people with a neurological disease. The course will be held over five weeks and will include the following topics:

- Introduction to the disease
- Responding to changes / behavioural pattern
- Nutrition and eating well while engaging in life activities
- Personal care and safety in the home
- Looking after Yourself as a carer and accessing information regarding help that is available

Further information from: Regina Prenderville, Dublin Neurological Institute – 087 637 6563

Your ongoing support is vital

The DNI is a centre of excellence which provides a clinical holistic care to patients with neurological problems. We constantly strive to provide, not only the best clinical service but also the best teaching and research facilities for our young doctors, nurses and professions allied top medicine. To facilitate the expansion of our services and to sustain the clear budgetary plan we must continue to fundraise.

Some of the ways you can help:

- Consider making a donation to the Dublin Neurological Institute (DNI). By making a monthly donation, we can plan for the future which means you are supporting the DNI all year long. Please complete the donation form attached
- Organise a local fundraising event such as a coffee morning or a table quiz
- Take part in a fundraising event – for example participate in a Fun Run, Marathon, Triathlon or a Sponsored Walk
- Consider remembering the DNI in your Will – **please call 01 8303 482 for further information.**