

DNI NEWS ISSUE 02 SPRING 2015

IN THIS ISSUE:

- > OPENING OF THE HUGH STAUNTON LIBRARY
- > SPECIALITY CLINICS
 - Epilepsy
 - Migraine
 - Deep Brain Stimulation
- > LETTER FROM A PATIENT
- > CARER'S CLINIC
- > INFORMATION DAYS FOR PATIENTS & CARERS
- > STAFF NEWS
- > RESEARCH & EDUCATION
- > HISTORY OF OUR BUILDING
- > IRISH HEALTHCARE AWARDS 2014
- > FUND-RAISING



Welcome

Welcome to the second edition of the Dublin Neurological Institute (DNI) newsletter. The DNI is a registered charity, a business and a Centre of Excellence for the care of patients with neurological disease including Parkinson's disease, Stroke, Epilepsy, Multiple Sclerosis, Headache, Neuropathy, Myopathy and Muscular dystrophy. We aim to provide high quality care to our patients provided by consultants, non-consultant hospital doctors, clinical nurse specialists and services allied to medicine. By offering this multidisciplinary team approach, patients travelling distances can be seen not just by a doctor but also by physiotherapist and other services. Hand-in-hand with good clinical care we are increasing education and research in clinical neuroscience. The marriage of both clinical care and academics leads to better care for patients. For example the DNI runs regular monthly educational talks for patients with different neurological problems given by



either a clinical nurse specialist or the consultant. We also have a number of research projects ongoing some which are highlighted in this newsletter studying different aspects of gait, reaction times, skin sebum production in Parkinson's disease in addition to other studies looking at genetics and biomarkers for Parkinsons Disease and drug discovery in neurodegenerative disease including Parkinson's and frontotemporal dementia.

The DNI can only be a success if we have sustained funding to retain staff and expand our services. I would welcome and urge people to help support some of our fundraising efforts throughout the year and welcome any thoughts and advice you may have with regard to how we can continue to expand, develop and maintain our services now and into the future.

Prof Tim Lynch

Consultant Neurologist & Clinical Director The Dublin Neurological Institute

For further information visit www.neurologicalinstitute.ie or Call 01 854 5035

The Dublin Neurological Institute | Mater Misericordiae University Hospital 57 Eccles Street, Dublin 7. | Tel: 01 854 5035 | Email: info@dni.ie DNI Charity registration No. CHY 19722 | Registration No. 9755710W





OPENING OF THE HUGH STAUNTON LIBRARY



Prof Timothy Lynch and Sam Staunton (Grandson of Dr Hugh Staunton) unveil the plaque in the Staunton Library. Also in photo is Dr Staunton's son – Gabriel)

The official opening ceremony of the Hugh Staunton Library was performed by Sam Staunton (Dr Staunton's grandson). Dr Staunton was an avid collector of rare and antique texts written by the founders of the discipline such as Gordon Holmes, John Hughlings Jackson and Samuel Kinnier Wilson. His collection is undoubtedly one of the finest private neurological antique book collections and we are very privileged to have this prestigious collection in the Dublin Neurological Institute.

Born in Westport, Co Mayo, Dr Staunton graduated in medicine in University College Dublin (1960), proceeding to B Sc in UCD (1962), MRCPI (1965), Ph D at University of Edinburgh (1966), MRCP and FRCP (1968) and FRCPI (1975). His research and post-graduate training in medicine and neurology led him through Edinburgh, the Richmond Hospital in Dublin, the Max Planck Institute in Frankfurt and the National Hospital for Neurology, Queen Sq, before his appointment at age 34 as a consultant neurologist in the Richmond Hospital in 1971.

He was universally respected as a diagnostician and clinical teacher and he pioneered the development of seizure surgery for refractory epilepsy, as well as maintaining a broad clinical practice. For many years he shared the provision of neurology consultation in Richmond, Mater and Beaumont Hospitals with Dr Sean Murphy. In addition to a busy clinical practice he published over 60 papers and a book chapter. He edited the Irish Medical Journal from 1983 to 1986. He mentored and guided a number of neuropsychologists and neurologists to doctorates and was a generous and influential teacher to his housestaff as well as in preparatory



Dr Killian O Rourke & Sr Attracta Kavanagh



Gabriel, Maeve, Lucy & Sam Staunton



Dr Ray Murphy, Dr Rory O Donnell & Dr Killian O Rourke

courses for the MRCPI. He served as Dean of the Richmond Institute of Neurology and Neurosurgery (1986 -1989), Co-chairman, Richmond Brain Research Foundation (1993-1998) and as Fellow, Department of Psychology, University College, Dublin (1997-2000). In addition to epilepsy, his clinical and research interests spanned a broad spectrum from disorders of brain, peripheral nerve and explorations of the fundamentals of consciousness and dreaming. Personal memories of Hugh Staunton were given by Drs Ray Murphy (Dean IICN) and Donal Costigan, Consultant Neurologist and Rory O Donnell, Consultant Haematologist

SPECIALTY CLINICS

Over the past number of years the DNI has developed a number of specialty clinics to support patients and family members.

EPILEPSY

By Elizabeth (Noddy) Dempsey Candidate ANP Epilepsy

Epilepsy, a very common neurological condition - 50 million people worldwide are diagnosed. In Ireland 1 in every 131 people over the age of five are effected totalling 37,000 people (Linehan et al. 2010). An epileptic seizure is a transient occurrence of signs and symptoms due to abnormal neuronal or electrical activity which can effect level of awareness. Partial seizures occur in a specific part of the brain and may not effect level of awareness, whereas generalised seizures effect the whole brain and can cause loss of consciousness. with neurological, psychological and cognitive concerns for some people.

The Epilepsy service in the Mater Hospital has developed with the guidance of Professor Tim Lynch in order to provide service for both in patients and outpatients. We currently have two dedicated Epilepsy clinics monthly. These clinics are for both newly diagnosed patients with seizures and also return patients with diagnosis of epilepsy where updates of their seizure management and lifestyle are addressed. Medication treatments with possible side effects are discussed, seizure triggers, safety and driving are central to all clinic discussions. Concerns for people diagnosed with Epilepsy include frustration and many psychological concerns which impact on daily life in addition to the medical diagnosis.

Dr Ronan Kilbride Consultant Neurologist/Neurophysiologist commenced the Complex Epilepsy Clinics in February 2014. These Epilepsy clinics for Mater Hospital patients are located in the DNI. These complex clinics are for existing epilepsy patients with more difficult to control or possible refractory seizures. Assessment for medication management, additional diagnostic work up, possible epilepsy monitoring and also consideration for surgery are all evaluated at the Complex clinic.

Epilepsy at the Mater Hospital is also part of the National Epilepsy Clinical Care Programme (NECCP) which is linked with Beaumont Hospital. Beaumont is the National Epilepsy Centre for Leinster North East region. This NECCP link with Dr Kibride and the Complex Epilepsy clinic is key for access to the Epilepsy monitoring services and also Epilepsy surgery for Mater Hospital patients. We also have established links with maternity services in particular with the Rotunda and Holles Street Hospitals.

Epilepsy in the Mater Hospital like other Neurology conditions, has a team approach in that we have many disciplines and specialist areas that work together for diagnostics to ensure best plan of care for each patient. Administration services at both the DNI and Neurology department are a very significant part of the Epilepsy service.

From a Nursing perspective our presence as Epilepsy Nurses is across the full trajectory of care with Epilepsy patients. In the Mater Hospital we are involved both with inpatients and at the OPD clinics. The Epilepsy phone support service currently runs from Monday to Wednesday for our patients where daily issues and concerns are managed, thereby minimising presentations either to the Accident & Emergency Department and also reducing urgent OPD review. Epilepsy Nursing has also developed in the Mater Hospital through the NECCP with the Candidate Advanced Nurse Practitioner (cANP) role established where autonomy in Nursing practice continues to evolve with research and leadership being core competencies

also. This new National model of Epilepsy Nursing promotes better access for people with epilepsy and thus minimises unnecessary costs with reduced hospital admissions. The already established weekly Epilepsy Nurse Led clinics, Epilepsy phone support and soon to be expected sanctioning of Nurse prescribing, helps to facilitate continuity of Mater Hospital Epilepsy patient care.

Epilepsy Ireland, (previously known as Brainwave), service with information booklets are displayed in the DNI. Epilepsy Ireland is a great resource for patients and staff with comprehensive website, quarterly newsletter and many other user friendly resources. Epilepsy Ireland also adopt T.E.A.M. approach to seizure management;

- T. take care to protect the person
- E. Ensure you stay with the person
- A. Allow the seizure to run its course

M. Move the person onto their side when the seizure is over

Seizures and Epilepsy in 80% of cases can be well managed; the expectation for all our patients is no seizures, nor side effects from medications with good quality of life.



Ms Noddy Dempsey, Candidate Advanced Nurse Practitioner Epilepsy (cANP)

MIGRAINE

By: Jane Melling Clinical Nurse Specialist.

THE DNI HEADACHE CLINIC

The headache clinic in the Dublin Neurological Institute was opened in January 2010 by Dr Martin Ruttledge (Consultant Neurologist) and Ria Bhola (C.N.S. headache). The clinic runs every Wednesday on a weekly basis and continues to grow each year. To date the headache clinic has treated more than 3000 patients.

In 2011 the headache service was audited by the headache team here in the DNI. They clinically analysed 200 patients who were new referrals to the headache clinic between January 2010 and January 2011. The results were presented at E.H.M.T.I.C . (European Headache and Migraine Trust International Congress, in 2011).

Over two thirds of patients were referred to the Headache clinic by primary care physicians with the remaining 30% being referred by other medical specialties. The majority of patients referred were female, 120 were under the age of forty while only 5% of new referrals were over sixty. All but 3 patients were reviewed and examined by a consultant neurologist. Ninety three percent of patients were diagnosed with migraine (70% chronic and 30% episodic). The remainder of the patients who attended were diagnosed with trigeminal autonomic cephalgia, temporal arthritis, trigeminal neuralgia or headaches with a structural cause. Medication overuse headache was present in 52% of our cohort with the majority overusing Paracetamol and Codeine based medications. Almost three quarters of patients attending the clinic who were diagnosed with migraine had never been on prophylactic therapy. 148 patients attending our clinic were started on prophylactic agents-the most commonly prescribed being Amitriptyline, followed by Topiramate and Flunarazine.

Migraine was significantly the most common headache type encountered in the clinic. Review of treatment patterns used prior to the initial clinic evaluation suggests that management of migraine in Irish primary care is suboptimal. The fact that so few migraine patients have ever been on a preventative clearly established the need for a specialist headache clinic.

The most common reason for referral to the headache continues to be for migraine management. Migraine is a recurrent headache disorder which manifests in attacks lasting 4-72 hours. Typical characteristics of the headache are unilateral location, pulsating quality, moderate or severe intensity, aggravation by routine physical activity and association with nausea and/or photophobia (light sensitivity) and phonophobia (noise sensitivity). IHS (2011)

Migraine is among the most common disorders of the nervous system. There are approximately 12%-15% of Irish people who suffer with migraine at any given time. This accounts for over 500,000 people i.e. 137 in every 1000 people. 25% of woman will experience migraine during their life time and the World Health Organisation (2012) has ranked it in the top 20 of all conditions in relation to disability worldwide. Chronic migraine is associated with personal & societal burden of pain, disability, damaged quality of life and financial cost. Despite regional variation, migraine is a worldwide problem which affects people of all race, age, income levels and geographical areas. The average migraineur in Ireland misses 1-5 days per year due to migraine attack with a significant cost to the economy (estimated at over 200 million per year). Migraine remains undiagnosed and undertreated in at least 50% of patients with less than 50% of migraine patients consulting a physician (W.H.O.:Lifting the burdon 2011)

At the headache clinic we focus not only on management of symptoms through medication but encourage patients to identify possible triggering factors and implement lifestyle modifications, which may help limit or reduce attacks and ultimately improve quality of life. Common trigger factors include diet, sleep, exercise, hormones and environmental factors. Prior to consultation at the clinic, new patients attending are asked to fill out a migraine diary. The migraine diary is an important tool, which allows the patient to document their headache frequency and severity, to establish a headache pattern and identify possible triggering factors. We continue to utilise the diary at each clinic visit, to track their progress. The migraine diary developed by the migraine association of Ireland is available through the Migraine Association of Ireland/ www.migraine.ie.

The role of the headache nurse is evolving rapidly. Originally the role primarily involved patient support and education. Although this remains the cornerstone of the position, it has also expanded to include patient consultation including headache history taking and assessment. As a headache nurse, I work closely with the medical team and Neurologist to provide high quality care for the patients. To facilitate patients who are working, I run a nurse led evening clinic on the 1st & 3rd Tuesday of the month to ensure continuity of care, monitor patient progress, educate and ensure prescribed medication is tolerated. I provide phone based support and a point of contact for patients who have queries or concerns regarding their treatment plan. Patients who require an appointment to this clinic should contact their GP and ask for a referral letter to the Headache Clinic in the DNI. Letters should be addressed to: Headache clinic, Dublin Neurological Institute, Mater Misericirdoae University Hospital, 57 Eccles Street, Dublin 7.



Ms Jane Melling, Clinical Nurse Specialist

DEEP BRAIN STIMULATION

By: Prof Tim Lynch, Consultant Neurologist, Mr Brian Magennis & Ms Carole Goggin, Clinical Nurse Specialists.

The DBS clinic started in Dublin Neurological Institute of the Mater University Hospital in January 2009, it is the first clinic of its kind in Ireland. It was established by Professor Tim Lynch who runs the clinic along with DBS Nurse Carole Goggin, Brian Magennis and 2 neurology registrars.

The purpose of the clinic is to assess patients for a possible DBS procedure and for the follow up care of post DBS patients. Patients attend the clinic from all counties in Ireland. They are referred from the Mater Movement Disorders Clinic and from various neurological centres across the country.

The majority of patients assessed have IPD, ET, Dystonia. or other neurological disorders. DBS is not an available service in Ireland at present, therefore patients must travel abroad for the procedure mainly to the U.K. The DBS clinic has strong links with Oxford and Bristol where most of the patients are referred for surgery.

A new DBS service has been established in Belfast. Some of our patients have travelled there recently for a change of battery in their stimulator. Funding is obtained from the HSE Treatment Abroad scheme.



Mr Brian Magennis & Ms Carole Goggin



Deep Brain Stimulation Team Ms Carole Goggin, Prof Tim Lynch & Mr Brian Magennis

DBS CLINIC AUDIT JAN 2009 - DEC 2013

NO. OF ATTEN New Patients Returns: 130	S: 128	58	57 MAL		43 % FEMA	
36% FROM DUBLIN	FI	64% ROM OUTSIDE	PATIEI	NTS RED FOR DBS	249 PATIENTS REFERRE	
AGE GROUPS:	4%	9%	18%	42%	24%	1%
20'S % Patients I	30'S Referred	40'S Fo clinic:	50'S	60'S	70'S	8''08
	BRIS	TTOL: 59		4% 1%		1% 1%

% DIAGNOSIS ATTENDING THE CLINIC PD: 59% ET: 14% DYS: 12% FXTAS: 2% HOLMES TREMOR: 3% ATYPICAL PARKINSONISM: 3% RESISTANT DEPRESSION: 1% MS TREMOR: 1% TOURETTES: 1% ORTHSTATIC TREMOR: 1% FUNCTIONAL: 1% ATAXIA TELANGIECTASIA: 1% TARDIVE DYSTONIA: 1%

REASONS WHY DBS NOT PERFORMED:

- 1. OPTIMISE ORAL MEDICATION
- **2. PATIENT DECLINED SURGERY**
- **3. PATIENT NOT L-DOPA RESPONSIVE**

MOST COMMON POST-OP COMPLICATIONS

1. POST-OP INFECTION

- 2. ELECTRODE RE-SITED TO OPTIMISE RESPONSE
- **3. LEAD FRACTURE**

RELEVANCE OF DEEP BRAIN STIMULATION

A letter from a patient: Bernadette Corrigan

Dear Friends,

I hope my story is of interest to those of you who suffer from Dystonia. Please forgive me if I cannot remember correct dates as my story goes back a long, long time...

I was about 8 years old when I started to drag my left leg. At the time the doctors thought it was Polio. I was sent to an Orthopaedic Hospital in Coole, Co Westmeath. I was there for about a year getting dozens of X-rays. The doctors didn't have a clue what it was. I came home for a year or so and then a new Surgeon came to Coole – he was supposed to be great. I went back to the hospital for another year but nothing happened – the new doctor didn't have a clue what my complaint was.

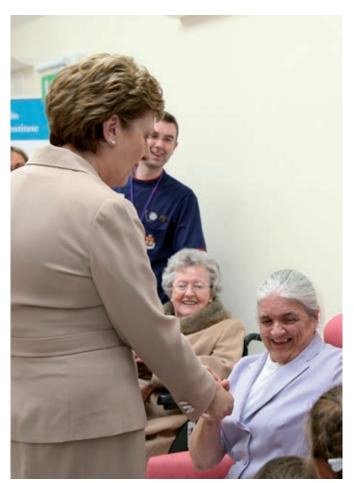
I was then referred to Our Lady's Hospital in Crumlin, I was under the care of Professor Ward and had more tests and X-rays – they came up with nothing. All I can tell you is that I was treated to the best and I did like being there.

Then I was sent to the Meath Hospital. I was under Professor Gatenby, he was very kind to me and he thought I had Wilsons Disease. I was on Artane tablets – I can remember the name because of the Artane Boys Band. The Professor said he would like if I would see a surgeon in the Richmond Hospital – his name was Mr Lanigan (another gentleman) and he came to the Meath Hospital to see me.

I was on the move again, this time with high hopes I went to the Richmond where Mr Lanigan operated on me. I had an operation on both sides of my neck and a major operation on the back of my head and neck. I had to lie flat on my back for 6 weeks. I was so disappointed that there was no improvement. There was a long time after this when I had no treatment at all.

Now I'm coming to the best part...the best is always left until last. I can remember so clearly the first day I met Professor Timothy Lynch. I was called into his consulting rooms. I was with my nephew Padhriac. The Professor took one look at me and he said Dystonia (Idopathic torsion). It was such a relief that I got a name for my complaint. I remember Prof Lynch saying to his team that he would do everything he could to help me since I had gone through so much. He tried all kinds of drugs but they didn't have much effect on my Dystonia.

Prof Lynch sat down with me one day and asked if I would go for Deep Brain Stimulation. I said I would and he told me he had a good friend in a hospital in Oxford names Prof Tipu Z. Aziz, MD FRCS. Prof Tipu was another gentleman and treated me very well. I had to make 3 trips to see him before my operation to make sure I was suitable – which I was.



At the official opening of the DNI -Bernie met with President Mary McAleese

On my return to the Mater Hospital, Prof Lynch put everything in motion – there were lots of forms to be filled in etc and he did all of this for me – he is so good.

I go over to Oxford every year for a check up and I get a battery every two years. I would love if it could be carried out in the Mater Hospital.

Dystonia cannot be cured but the shaking can be improved a lot. I would not be able to cope on my own without my wonderful carers. Of course I cannot forget my other two great friends of course. They are the Nurses in the Dublin Neurological Institute in the Mater Hospital -Jacqueline Scott and Elizabeth (Noddy) Dempsey. They are always in good humour and always there for me - nothing is too much trouble for them. I am so lucky to have them at all times.

I want to appeal to our Department of Health to please carry out deep brain stimulation surgery for Dystonia patients in Ireland.

Thanking you Bernadette Corrigan (Bernie)

PARKINSON'S DISEASE CARERS CLINIC

By: Brian Magennis, Clinical Nurse Specialist

The family & carers support clinic organised for family members / carers of patients with Parkinson's disease and movement disorders is a new nurse led initiative at the Dublin Neurological Institute, Mater Hospital.

When you are caring for others it is easy to forget about yourself. It's often difficult to find time to focus on yourself and your needs.

Getting to know more about the person's neurological condition will create a better understanding, provide better care and will avoid the need for crisis intervention. More than anything else the Family & Carer Support Clinic provides the carer with an opportunity to sit down and talk, knowing that their needs will be understood and that they can express their feelings and anxieties without fear or guilt. This is a major step in linking hospital and community services.

Some of the services the family & Carer Support Clinic can provide:

- > Giving you time to talk in confidence and at your own pace
- > Education on all aspects of Parkinson's disease and movement disorders
- > Information sheets on all aspects of each condition
- > Advice and advocacy
- > Invitation to join local Carers Groups
- > Information on benefits and services entitlements through the Carer support groups.

INFORMATION SESSIONS FOR PATIENTS & CARERS

The staff members in the DNI are very aware that a neurological illness can affect the lives of more than just the patient. The partners and family members can often feel isolated and helpless. Many experience feelings of anger, sadness, loss and frustration.

Through the DNI we organise regular informal meetings for patients & their carers / family members. These information sessions are presented by the multi-disciplinary teams involved with the various specialities. Feedback from each session has been excellent and we will continue to organise these in 2015. Patients and carers appreciate the informal setting whereby they can ask questions and discuss their own feelings / side effects of medication etc. Each session lasts approximately 1.5 hours and we finish up with tea / coffee. New friendships have been formed by people who find it therapeutic to meet with others who are in the same situation.

For further information call 01 854 5035 or 087 637 6563.

The following information sessions have been planned for patients & family members:

13 APRIL '15 Multiple Sclerosis	20 APRIL '15 Myasthena Gravis	19 MAY '15 Headache	TBC Epilepsy
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STAFFNEWS



Emma Fahey has been appointed Administration Manager & Support to the Clinical Director at the Dublin Neurological Institute. In this role Emma will help us to streamline, support and expand the services of the DNI.



Annik de Dios commenced working in the DNI in January 2015, as a CNM2 in General Neurology and Research. In addition to assisting with Clinical Nursing in the DNI Annik assists with pharma studies and works with our research co-ordinator and the neurology team involved in neurological research at the Dublin Neurological Institute & the Mater University Hospital



FAREWELL TO SHARON!

We were so sad to say good-bye to **Sharon Harris** who has worked in the Reception Office of the DNI for the past 4 years. Sharon was a very loyal & fun loving colleague. Her efficiency and commitment to details was exemplary and we will miss her friendly smile each day we come through the door of No 57. Thankfully Sharon hasn't gone too far away - she has moved to work in the Neurology Department in the Mater Hospital. We wish her well in her new position.

RESEARCH:

Freezing of gait in Parkinson's Disease Study



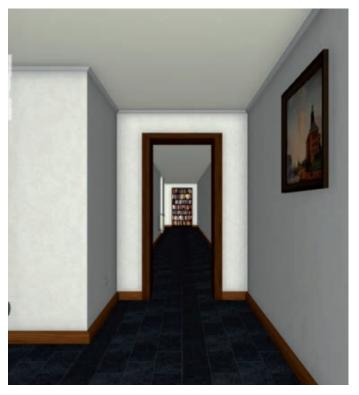
Dr Conor Fearon, Research Registrar, Dublin Neurological Institute, 57 Eccles St, Dublin 7. Email:cfearon@mater.ie



Patient participating in the study

Freezing of gait is a disabling symptom which occurs in patients with parkinsonism where they feel as though their feet are momentarily glued to the floor. This can lead to falls, hospitalization and even mortality. Research is currently being undertaken at the Dublin Neurological Institute in order to better understand why freezing of gait occurs in these patients. This information will be used to develop a training tool for use in the home designed to reduce the frequency and severity of freezing episodes and improve overall gait in those patients affected by this problem.

The research is a collaboration between the Dublin Neurological Institute and the Trinity Centre for Bioengineering. The cause of freezing of gait is poorly understood and this is because its unpredictability makes it difficult to study. We have developed a system which allows us to provoke freezing of gait in order to study it. By stepping in place on a balance board and moving through a virtual reality corridor we are able to examine



Virtual reality corridor

gait and brainwaves simultaneously in order to better understand why freezing of gait occurs. To date over 40 patients have participated in this study.

We have also commenced a training programme in an effort to improve freezing of gait. The programme consists of eight 20 minute sessions of stepping in place through a maze which is also focused on cognitive training. Twenty patients have completed this programme to date. Participants have found that they have improved confidence in walking and in some patients with severe freezing of gait, a temporary reduction in freezing.

We are continuing to recruit any patients with (idiopathic) Parkinson's who experience freezing of gait at least once per week. We are also recruiting any patients with Parkinson's disease who do not experience freezing of gait for comparison purposes.

Identification and Characteristics of Voice Tremor in idiopathic Parkinson's Disease (PD)

Dr. Patricia Gilivan Murphy, Clinical Specialist. Speech & Language Therapist

This descriptive study was carried out as part of a doctoral thesis under the auspices of the Dublin Neurological Institute with Professor Timothy Lynch as the principal investigator. The Ethics committee of the Mater Misericordiae University Hospital (MMUH) granted approval for the study.

Background

Voice problems are strongly associated with PD. They may present early in the disease, and negatively affect quality of life. It is important to evaluate the disordered voice features in order to develop effective voice treatment methods.

Parkinson's disease is classically associated with tremor, slowness, stiffness, poor balance, stooped posture, a soft voice and sometimes voice tremor. Few studies have specifically examined voice tremor features in pwPD, therefore its characteristics are unknown. Voice tremor is also associated with the normal ageing process, a population from which pwPD come. Therefore, it is unclear if voice tremor is related to PD, to normal ageing or to both conditions. The main objective of the study was to determine if voice tremor was a feature of PD relative to neurologically healthy age-sex matched controls and to describe its characteristic features.

Methods

Thirty pwPD (22 males; 8 females) who satisfied the exclusion criteria for the study were recruited through the out-patient Movement Disorder Clinic at the DNI. The mean age of the pwPD group was sixty one(range 34-76) years and the mean number of years since PD diagnosis was five (1-12) years. Twenty eight agesex matched neurologically healthy controls were also recruited to the study. A range of measures were carried out to evaluate disease symptoms, and speech, voice and tremor characteristics (Figure 1)Testing was carried out in the morning before medication was taken. All participants gave written consent to be involved in the study.

Results

A mild degree of tremor was perceived in the voice of pwPD, when speech and language therapists (SLT's) not involved in the study rated the voice recordings. The difference in voice tremor ratings between pwPD and controls was not statistically significant. It may be the case that it is difficult for listeners to discern subtle tremor differences between pwPD and people without PD especially when the disease is mild.

In pwPD, tremor was identified in the soft palate, the larynx, vocal cords and the tongue by SLT's who rated video recordings (sound removed) of the endoscopy exams. The main anatomical location was the soft palate and the larynx structure. The degree of tremor in the vocal tract was greater in pwPD than in controls with statistical significance.

A novel finding in this study was tremor in the soft palate in pwPD which has not been reported before. The computerised tremor measures showed that the mean rate (Hz) of voice tremor differentiated the groups with a 4.94 Hz tremor in pwPD and a 2.85 Hz tremor in controls.



Figure 1. Disease related, speech and voice measures carried out.



Dr Patricia Gilivan Murphy poses as a patient in the Speech & Language Therapy Dept.

The magnitude (extent) of acoustic voice tremor was higher in pwPD than controls. There was a lot of variability in the tremor measures across a number of trials which may have contributed to the statistically non-significant findings for tremor magnitude. There were further important additional findings including:

PwPD had greater voice disability than controls with statistical significance. This finding highlights that pwPD perceive themselves to be negatively affected in their daily lives by their voice symptoms. It is important to note that a disordered voice was not a prerequisite for entry into the study, and pwPD were not receiving voice treatment at the time of the study.

Another important finding is that pwPD had statistically significant higher levels of anxiety relative to controls.

Conclusion

Voice tremor was identified in a group of pwPD with mild disease severity. There were some similarities and some differences with neurologically healthy controls. Tremor movement was present in a number of different structures in the vocal tract, particularly the soft palate and the larynx as a unit.

The rate of voice tremor may be a useful measure for identifying voice tremor related to PD. Voice symptoms resulted in voice disability for pwPD.

Acknowledgments

We wish to thank the following:

The patients who agreed to take part in the initial screening and the study evaluations.

Professor Tim Lynch, and the staff at the DNI who facilitated patient recruitment.

The Speech & Language Therapy Department

Maggie Garvey for assistance with the endoscopy examinations.

The Mater Hospital Postgraduate College, for grant contribution towards study costs.



EDUCATION:



ICGP Education focus on Neurology

Prof Timothy Lynch has recorded an online education programme which will help General Practitioners to diagnose neurological conditions. As part of the ICGP Education growing catalogue of eLearning modules, the latest module focuses on neurology and neurological conditions in primary care.

This module is part of a series of modules to assist general practitioners in diagnosing neurological conditions and ongoing co-management of patients.

The initial module focuses on the initial neurological assessment and breath of conditions with lessons on: **Overview of neurological conditions / Neurological examination / Red flags in neurology**. All ICGP Education modules are free of charge to ICGP members, are CPD accredited and qualify for GMS study leave. The Neurology Module was developed in association with the Dublin Neurological Institute.

The module will be supported by disease specific modules over the coming years including modules on: Parkinson's disease / Multiple sclerosis / Migraine / Epilepsy / Stroke / Headache.

In house Education

Multi disciplinary teaching sessions are held on a weekly basis in the DNI. We also host a monthly video journal club in which clinical videos are presented and discussed by a panel of specialists.

This meeting is chaired by Prof Timothy Lynch and sent via a video conference link to other centres with expertise in Movement Disorders and neurodegenerative diseases such as the Addenbrooke's University Hospital in Cambridge (UK), the Belfast City Hospital, Galway University and Cork University Hospital. Complex and challenging cases are discussed, especially those in which a diagnosis is rare or difficult.

There is a strong clinical teaching ethos at the DNI and the video conference method is beneficial to all of the team. Doctors in training benefit from the demonstration of clinical signs and key points of history taking in the field of Movement disorders. This facilitates the development of diagnostic skills with a view to bringing those back to the clinic setting for the benefit of our patients.

Nurse specialists who play a key role in the success of the DNI are an integral part of the team's ability to pool expertise and experience while developing strategies for ongoing management of the patient.

The multicentre nature of our teaching programme helps to develop links between colleagues and institutions and has helped to disseminate knowledge and expertise for the benefit of patients in all the centres involved.

Launched February 2015.

HISTORY OF OUR BUILDING NO 57 ECCLES STREET Regina Prenderville Project Manager

We are privileged that the Dublin Neurological Institute is based in a beautiful Georgian building – 57 Eccles Street. This house was built circa 1750. While trawling through records in the various libraries and museums in Dublin, the earliest tenant we have located is Mr John Adams who was living here in 1847.

Mr John Adams - Barrister

Mr Adams was born in Dublin on 4 June, 1802. He was the 5th son of Samuel Adams and Eliza Filgate. He had two sisters named Alicia Anne and Anne Elizabeth. His brother Rev Anthony Adams from the Vicarage, Collan, Co Louth owned No 57 Eccles Street and John was his tenant. He also had a brother Robert, who was a medical doctor of great renown and had a practice in St Stephen's Green Dublin. John was educated in Trinity College Dublin and later attended The King's Inns. He was called to the Barr in the Michaelmas Term of 1828. The Dublin Statistical Society was established in Trinity College Dublin in November 1847 for the purpose of promoting the study of Statistical and Economical Science in Ireland. John Adams is recorded as being a founder member of this first committee. John appeared to have been a wealthy man and owned property in 43 & 44 Lower Leeson Street and also Ardee, Co Louth. We have records of the Co Louth 1865 voting register and John Adams from 57 Eccles Street was named as a Landlord in the Barony.

He died on 4 February 1869 and his estate was valued at almost £7,000

Mr John Gallagher - Retired Publican

John Gallagher is recorded as being the owner of No 57 Eccles Street from 1876. John Gallagher was born in Co Wicklow in 1831 and his wife Johanna Egan was born in Co Tipperary in 1839. They were married in the Pro Cathedral Dublin on 27 November 1872 by Fr T.J. O Reilly. Before their marriage John lived in Phibsboro Road and Joanna lived in Gardiner Street. John was a publican and his premises was located on 36 Phibsboro Road. A licenced premises at this address still exists - now called The Phibsborough House. They had six children named Michael, Mary, Margaret, Joanna, Elizabeth and Catherine. All six were baptised in St Paul's Church, Arran Quay – Margaret & Joanna were twins. The 1911 Census records John Gallagher as being the head of the household in No 57 Eccles Street. At this stage he was 80 and Johanna his wife was 72. The Gallaghers shared the building with Bridget Connolly, aged 47 from Longford. Bridget was listed as a domestic servant and had in 1911 been married for 23 years with only two of her six children still alive.

None of the persons registered at 57 Eccles Street were listed as having any of infirmities classified in the census - "deaf and dumb" "dumb only" "blind" "imbecile or idiot" or "lunatic". The building was listed as a 1st class house based on the number of rooms (13) the quality of the roof and building material (non-perishable) and the number of windows in the front of the house - 13 in total. John Gallagher died on 16 September 1912. His daughters Mary & Margaret were the Executrices of his Will. His estate was valued at £3.735.1s.9d. He left £50 to his son Michael and all of the residue of his real and personal estate to his wife and daughters. His daughter Joanna who was born on 19 May 1876 is listed as being a tenant in No 57 Eccles Street in the 1960s.

Dublin Neurological Institute

INNISFAIL MAGAZINE



This issue of the journal Innisfail (dated January 1895) was found by Mr James Sweeney, the site Foreman during the renovations of No 57 Eccles St.

It was used as padding and support for a window in the drawing room.

This is the earliest known copy and the National Library of Ireland were delighted to accept it. Innisfail was an illustrated monthly journal

designed "to encourage Native Arts, Industries & Manufacturers to Foster Temperance, Thrift and Mutual Aid Associations".

The full journal can be viewed in the National Library and we also have a copy of this in the DNI.

It is interesting to note that the mailing address of the editor of Innifail was 58 Eccles Street we're guessing that's how it ended up as window insulation at no. 57!

IRISH HEALTHCARE AWARDS 2014

At the 2014 Irish Health Care Awards on November 6th in the Shelbourne Hotel, the Mater Hospital Stroke Team won the Best Hospital Project Award for their Lean Green Belt Project 'Door to Needle' (DTN). The award was accepted by Professor Sean Murphy and Leona Higgins Acting CNM2 (Stroke) on behalf of the team.

Since December 2013 the team has achieved a drop in median Door to needle time from 80 minutes to 48 minutes, an improvement of 40% in the thrombolysis administration time. Correspondingly, the median Door to CT time has decreased from 47 to 16 minutes, an improvement of 66% in the door to CT time.

Professor Murphy has led this Project with great drive and the Project involved engagement with over 750 Stakeholders. The award of Best Hospital Project is a testament to the frontline multidisciplinary staff who have enacted and maintained the fantastic results of the Lean Project.

WHAT IS DOOR TO NEEDLE?

The earlier stroke thrombolytic therapy is given in acute ischaemic stroke the better the functional outcomes for the patient. 'Door to needle time' is an important key performance measure.







OVERVIEW

The Acute Stroke Service in the Mater Hospital developed a new streamlined stroke thrombolysis pathway aiming to shorten door to needle time for acute stroke thrombolysis in December 2013. The Project to develop this pathway, which is called 'Door to Needle' (DTN) was originally established by Professor Sean Murphy and a multidisciplinary team, both internal and external, with the goal to reduce the median Door to Needle time for Acute Ischemic Stroke patients attending the Mater Hospital Emergency Department from 80 minutes to 60 minutes.

Prof. Sean Murphy

With the support of Prof Mary Day CEO Mater Hospital and Prof Conor O'Keane, it was agreed that the Project at the Mater should be supported by the Mater Lean Academy. The Mater Lean Academy was delighted to take the Lean Six Sigma helm of the Mater Lean 'Door to Needle' Project from March 2014 onwards and to support Professor Murphy, the Acute Stroke team and the frontline staff in supplying Lean Six Sigma guidance and support. The Project is now in the Control Phase.

THE NEW PATHWAY

Key new and enhanced features in this updated pathway include the following:

- The Ambulance Service Paramedics who identify a possible acute stroke case using the Face Arm Speech Test continue, as previously, to pre-notify the Mater ED of an incoming FAST positive patient.
- Patients are pre-registered on Patient Centre, ahead of arrival in ED, using a pseudo-MRN (Medical Registration Number) which allows pre-ordering of CT & CT angio tests. Registration staff amalgamate the pseudo-MRN with the patient's true MRN once the patient's details have been gathered.
- Upon pre-notification of the ED of an incoming FAST positive patient, the on-call Stroke Consultant, Stroke or GIM SpR and CT are immediately alerted.
- During normal working hours, the FAST positive patient is brought directly to CT upon arrival in ED Resus. The initial history taking and expedited clinical examination takes place on the CT table but without delaying acquisition of CT/CT angio.
- Out of hours, the Stroke Consultant can utilise the telemedicine system to expedite off-site clinical assessment of the patient and to review the CT imaging on NIMIS.
- The Stroke SpR or GIM SpR act as Team Leader during the initial expedited assessment of the FAST positive patient supported in person by the ED SpR.
- Initial blood tests, from ED Resus, use the Red Stickers which signify to Laboratory staff the urgency of getting test results back.

RESULTS

Since baseline readings in December 2013 there has been a corresponding drop in median Door to needle time from 80 minutes to 48 minutes, an improvement of 40% in the thrombolysis administration time. Correspondingly, the median Door to CT time has decreased from 47 to 16 minutes, an improvement of 66% in the door to CT.

These early indicators illustrate that this new pathway has made a big impact in expediting the acute initial assessment off suspected stroke patients in the Mater Emergency Department.

The Mater Lean Academy is delighted to have supported front Line staff in their continued consolidation of this Project since March 2014, and to have many of its Green Belt graduates directly involved in the Project Implementation. At the end of the day, the Project reflects the Mater ethos of Person Centred Care.

"The enormous amount of work that was required and huge number of stakeholders that were consulted and encouraged to change the way they do things, took time, dedication, and energy by the whole team." Prof. Sean Murphy,

The Mater Misericordiae University Hospital, 57 Eccles St, Dublin 7. Phone: 01 803 2000

FUNDRAISING:

Annual Neurological Golf Classic 2014

The 13th annual neurological golf classic was held in Hermitage Golf Club on Friday 26 September 2014. On a magnificent autumn day, we were delighted to welcome members of the 27 participating teams.

Thanks to the generosity of our many sponsors and players we raised €12,464 on the day.

The golf classic in aid of the DNI has been running since 2002. Since then, there has been one person in Hermitage who has ensured the annual golf classic went without a hitch and that is Dermot Lee. In his own silent way Dermot ensures that



Mr Dermot Lee, Hermitage Golf Club & Prof Tim Lynch

tee time sheets, scores, results, prize giving etc run smoothly and we are indebted to Dermot for his tireless work. We must also acknowledge the Lord above who once again blessed us with a glorious day. Since 2002 we have never had a bad day for this event. Winning teams were organised by the following: James Marshall, Limerick City of Culture, Mullingar Four Ball, John Sheehan. Front Nine winners - Mater Private Hospital : Back Nine Winners - Home Instead

14TH ANNUAL NEUROLOGICAL GOLF CLASSIC

Join us on Friday 25th September 2015 at Hermitage Golf Club, Lucan

In aid of the Neurological Appeal at the Mater Foundation helping to fund excellent patient care at the Dublin Neurological Institute

BOOK YOUR TEAM TODAY

Last year we were delighted to sell out.

This year reserve your team early by calling **01 830 3482** or email our events team at **mmadden@materfoundation.ie**

As a charity we are totally reliant on the generous donations we receive which helps us maintain the service we provide.

The generosity of our supporters enables us to enhance the care that neurological patients receive in the Dublin Neurological Institute.

SUPPORT FROM PATIENTS & FAMILIES

We are very grateful to patients and their families who support the DNI which is a registered charity.

SATURDAY & SUNDAY: 2 & 3 MAY 2015

On the May Bank Holiday weekend, Rhode, Co Offaly will be a busy place with budding entrepreneurs working on behalf of the DNI. We are very grateful to Pamela Murphy and her family for organising these forthcoming events:

2 May 2015

A fun run / walk will be held in Rhode. The Murphy family have rounded up their friends and neighbours to participate

3 May 2015

Pamela's brother Willie who has had long dark curls for the past 15 years and has been the envy of many ladies in Co Offaly will part with his tresses for a great cause. Willie has agreed to undergo a sponsored head shave in aid of the DNI. Thank you Willie for this great commitment.



KNITTING FOR THE DNI Not to be outdone by her aunts and uncles Emma Murphy knit these little minions and has sold them in aid of

the DNI. To date she raised over €600

MONDAY 1 JUNE, 2015 LADIES MINI MARATHON

By: Mich Vartuli

My husband, Austin Cush was diagnosed with Motor Neurone Disease and passed away in 2011. I am so grateful to the Dublin Neurological Institute (with particular thanks to Prof Tim Lynch) and the Irish Motor Neurone Disease Association who supported our family during his illness. Now I'd like to say thank you by raising as much money as possible for these charitable organisations. My aim is to run the VHI Women's Mini Marathon on the June bank holiday. I would also be delighted if there is anyone else interested in joining me on the day, the more the merrier, to walk/jog the 10 kilometres and then celebrate the achievement afterwards! I have set up a "my charity" page to receive donations. This is my link: http://www.mycharity.ie/event/mich_vartulis_event/



Austin Cush R.I.P.

19-24 SEPTEMBER 2015 PARIS 2 NICE CYCLE

Paris2Nice is a unique and exceptional experience that has raised almost €2m for charity in 4 years from 244 amateur cyclists.

Now is your chance to become part of the leading fundraising, social and fitness event in Ireland and make 2015 a year to remember. To date 5 cyclists have signed up to complete the cycle on behalf of the Dublin Neurological Institute (DNI). Not only will Paris2Nice challenge your fitness but it will also provide you with a great social and motivating experience.

The total distance is just over 700km which will be completed in 6 days. The cycle is designed with all abilities and ages in mind. Participants in the race



vary in ages, level of fitness and cycling experience. With regular and gradual training and the support of the Paris2Nice team, you will not only complete the challenge but you will love the experience too.

Paris2Nice 2015 is limited to 75 participants. If you are interested in participating visit <u>www.paris2nice.com</u> for full details. We hope you will choose the Dublin Neurological Institute as your chosen charity.

MESSAGE FROM THE BOARD

The DNI is a charitable Institute and as such is governed by a Board, the members of whom bring differing skills to the table including business, medical and financial skills. There is also representation from patient and family members. All members of the Board of the DNI give their time voluntarily and freely. No Directors of the DNI are paid a salary for their membership and for this the Institute is very grateful. They meet regularly to review current services and to plan for future development of the Institute both in service provision and in business development. The members apply themselves to the meetings with commitment and energy to ensure that patients and families of the DNI receive the best service and support possible.

The DNI, under the guidance of the Mater Foundation has always sought to work within the best practice of governance guidelines. The Clinical Director produces a clinic activity report, including attendance figures, new initiatives etc. There is an audit committee in place to review finances and this committee submits a report to the full board.

HOW CAN YOU HELP?

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 to medicine.

We recognise the importance of support to the carers of our patients and we will continue to provide regular educational meetings for patients, carers & family members.

To facilitate the expansion of our services and to sustain the clear budgetary plan we must continue to fundraise.

Some of the ways in which you can help are:

- > Consider making a donation to the Dublin Neurological Institute (DNI). By making a regular donation per month, we can plan for the future which means you are supporting the DNI all year long. Simply complete the donation form below.
- > 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 Dublin Neurological Institute in your Will - just call 01 830 3482 for more information.

