



The Dublin Neurological Institute

The Mater Misericordiae
University Hospital

In this issue...

- ▶ Welcome...
- ▶ The Yellow Door Project
- ▶ Dublin Neurological Institute Official Opening
- ▶ History & location of the DNI
- ▶ A unique facility
- ▶ Who are we?
- ▶ Contributions from the Staff
- ▶ Leona's Story
- ▶ Board of the DNI
- ▶ Education & Research
- ▶ The Staunton Library
- ▶ North West Neurological Institute Launched
- ▶ Future Plans & Aspirations
- ▶ How you can help

Welcome

*Prof Timothy Lynch
Consultant Neurologist*



Welcome to the Dublin Neurological Institute (DNI) Newsletter. The DNI is housed in a beautiful old Georgian building - No 57 Eccles Street - and is steeped in history. In this opening address, it is important that we highlight a great success story made possible by so many people...

We acknowledge the wisdom of the Sisters of Mercy in purchasing this magnificent building, the tireless fundraising efforts of the Mater Foundation, the HSE, the generosity of patients, their families and friends, philanthropic donations, research grants, legacies and corporate funding. The DNI is a stunning building, refurbished to its original splendour, thanks to the compassionate skills of our architect and good workmanship by the building contractors. However we are very aware that No 57 Eccles

Street is just a building and it is the people who occupy it, who are responsible for the many great achievements since we opened the doors 5 years ago. We are indebted to the unstinting commitment of our staff who have helped to fulfil a vision.

Every day patients and their families place their trust in the Mater's doctors and nurses who help them through their neurological condition. Over the last five years I have been overwhelmed by the generosity and support of so many people. As a charity we are totally reliant on the generous donations we receive which help us maintain the service we provide. This enables us to enhance the care that neurological patients at the Mater receive.



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Registration No. 9755710W

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The Yellow Door Project

Renovation of a derelict protected structure to a modern state of the art neurological centre



Originally conceived as a domestic house in 1750, it was now to be adapted for clinical and medical use. The traditional plot arrangement consisted of a three story over basement red brick house bounded to the front by granite steps and railings which defined the public space from the domestic private space.

In 2005 we acquired a seriously dilapidated building. There was severe ingress of water which had caused major decay of the timber. Many sections of the plasterwork had been destroyed. However the original plasterwork was intact in the front hallway and partially intact in the stairwell and in the first floor reception rooms. The architectural challenge was to reconcile the requirements of the Neurological Institute with the conservation of a derelict Georgian building. In particular there were challenges raised by the requirements of fire regulations and access for those with special needs.

Many interesting events, stories and discoveries came to light during the renovations. One in particular being... an issue of a journal called *Innisfail* (dated January 1895) was found by James Sweeney, the site Foreman. The journal was stuffed into a drawing room window to act as padding and support. We offered this to the National Library of Ireland who were delighted to accept it (this is the earliest edition the Library had received). *Innisfail* was an illustrated monthly journal designed “to encourage Native Arts, Industries & Manufacturers to Foster Temperance, Thrift and Mutual Aid Associations”. As yet, we don’t know a lot about this journal, but interestingly the editor’s mailing address was 58 Eccles Street – so we’re guessing that’s how it ended up as window insulation at no. 57! This issue of *Innisfail* (Vol. 1, no. 2, January 1895) can now be consulted in the National Library – NLI Ref. IK 2913 ■





(Left to Right)
Prof Tim Lynch,
 Dublin Neurological Institute,
President Mary McAleese and
Mr Declan McCourt,
 Chairman, Mater Foundation



Official Opening of *Dublin Neurological Institute -* 19 September 2008

President Mary McAleese officially opened the DNI in September 2008. The President acknowledged the great work which had been done over the years by the Sisters of Mercy and congratulated the Mater Foundation for their fundraising achievements and the doctors and nurses in the neurology team in the hospital for bringing the dream to fruition.



In her remarks the President stated:

“

I know it has been a long hard journey since 2002 when the Sisters of Mercy handed this building over to the Department of Neurology. While it was great to get a building which could in time serve as a centre of excellence for clinical care and research, you could probably have done without the added gift of the tree which was at that time growing up through the building. That such a sorely dilapidated building has been transformed into the magnificent restored Georgian edifice we see around us is a tribute to the hard work and dedication of many people.

Many people worked with a heart and a half to bring about this day and for them it really is a very proud day for not only have you transcended the huge challenges presented by the renovation but now Ireland for the first time has an important new resource for the treatment and care of those with neurological conditions. Thanks to you this Institute is set fair to be a leading provider of neurological care in Ireland.

”

History & location of the DNI

The Dublin Neurological Institute is situated on 57 Eccles Street. We are trying to trace the history of the various tenants who occupied this beautiful building over the years and we would welcome information from any of our readers who may be able to help us.

It was very interesting that one day a patient (named Anne) attended the DNI and she told Sharon (Clinical Administrator) that she used to live in this house. I phoned Anne and asked if we could meet to discuss her years here. She invited me to her home in Fairview. Anne used to live on North Circular Road with two other girls. When one of the girls got married, Anne and her friend Joan decided they would look for a place together. It was difficult to find suitable accommodation in Dublin then. Through a colleague in the Dept of Post and Telegraphs (based in the GPO) Anne heard there was a flat available in No 57 Eccles Street.

The Landlady: Anne and Joan were interviewed by the landlady, Dr Cynthia Noonan Tyler, who was married to Mr Con Tyler, pharmacist from the UK. They had no children. Cynthia was originally from Tralee and one of her brothers was Dr Brendan Noonan, another Fr Frank Noonan (Liverpool) and her sister was Sr Dymphna Noonan, Presentation Convent, Tralee. Cynthia was a lovely, fun-loving lady and when she was showing the girls around the house she was telling them about the great location they were moving to as they could walk to all the dances in the ballrooms in Parnell Square. However, Anne & Joan weren't very interested in dancing.

While Cynthia and Con didn't live permanently in No 57, they kept their own private accommodation there. The current Waiting Room was their living quarters. I understand they had magnificent furniture there. Their kitchen was where the day ward is now and their bedroom was on the first floor – now the consultant's office. Cynthia was a very decent landlady and whenever the tenants extended families were in Dublin – (particularly for the big matches in Croke Park), she allowed them use her bedroom for their guests. Cynthia and Con were good friends with the O Kennedys who owned



Ormsby Hotel visible at right of image

the Ormsby Hotel which was located on the opposite side of the road on Eccles Street. When they had guests, they were accommodated in the hotel. They used to enjoy going to the races in Leopardstown and the Phoenix Park with friends and then they used to come back to No 57 and play cards late into the night. When they were staying here there was a lady from Nelson St who used to come in to No 57 to do the cooking and cleaning for them.

Accommodation: All of the rooms were divided into flats with dividers between the bedroom and the living / kitchenette areas. They were all freshly painted and papered when Anne & Joan moved in. Their flat was where the Board Room is now. There were 2 beds in the bedroom and a living room / kitchenette. The front office (current reception area) was a smaller flat and just had bedroom and living area. So the person who occupied this had the use of Cynthia's kitchen. All flats had a fireplace and everybody bought their own fuel and stored it in the basement. In the early 70's – electric fires were becoming popular and lots of people replaced these for the open fires. There was only one bathroom for the whole house and that was located where the current bathrooms are now. There were 2 separate rooms - one with wc & washbasin and the other with a bath. Water was heated by a gas geezer. The house was comfortable and flats were easy to heat. The garden was well kept ('though not as beautiful as it is today') and the tenants used it when the weather was fine.

LOCATION	NAME	OCCUPATION
Front room, ground floor now Reception Office	Miss H	Inspector of taxes
Back room, ground floor now Waiting area	Landlady: Dr Cynthia Noonan & her husband Con Tyler	Medical doctor & Pharmacist
Front Room, 1st floor now Board Room	Anne & her friend Joan	Public servant – Dept Post & Telegraphs Assistant Secretary Dept of An Taoiseach
Back room, 1st Floor – now consultants office	Landlady: Dr Cynthia Noonan & her husband Con Tyler	Medical doctor & Pharmacist
Front Room, 2nd floor now Dolores's office	Miss O'N (left to get married) Miss RS (moved in then) Miss RS's sister	Assistant Matron, Richmond Hospital Nurse in Richmond Hospital Priest's housekeeper
Back Room, 2nd floor now Nurses office	Miss TC	Public servant – Tax office
Basement Flat 1	Miss HM	Public servant - Dept Post & Telegraphs
Basement Flat 2	Miss NB	Savings Bank

Care taker: Miss TC was Cynthia's friend and she looked after the house and ensured, with an iron fist that it was kept well. There was a beautiful table in the hallway and there was always a bunch of flowers in a vase on it. TC was a great cook and often treated the other tenants to a meal in her flat which was on the second floor (back).

The tenants: All of the tenants were female, single and most were civil / public servants. There was very little movement of tenants – it was a happy place to live

Reason for leaving: Every Summer Anne used to say to herself that she would love to have her own house and garden. In 1979 she was mugged on Dorset Street and she made up her mind then that she was moving. She bought her house in Fairview and has been very happy living there since. ■

*Regina Prenderville,
Project Manager, Dublin Neurological Institute*



A unique facility

The DNI is a unique innovative facility with links to the original Neurological Institute in Montreal and New York. A patient satisfaction survey was conducted in 2012 and demonstrated huge satisfaction with the service provided at the DNI by 95% of patients.



Patient Comments:

"What a joy to be here – pure heaven. The music is beautiful." L.M.

"Very appropriate setting for neurological assessments – brilliant – congrats !!" J.C.

"Thank you so very much for your wonderful skill and your kindness. A magnificent place here – will recommend to HSE !" J.L.



Through the Eyes of a patient

An MS patient who was one of the first to attend the newly opened DNI wrote the following ... ' I thought I HAD DIED AND GONE TO HEAVEN OR HAD GONE TO THE Mater Private Hospital by mistake. I entered the waiting room and spied sofas and comfortable looking lounging chairs. It was like entering a private salon, in a beautifully restored Georgian house, with such a relaxing ambience and in the corner of this beautiful room came the sound of music. Not your blaring, nauseating pipe music but the soft tones of a baby Grand Piano. At this stage I was in complete shock, still convinced I was in the wrong place. I whispered to the man beside me.. 'Is this the MS Clinic' and he nodded in confirmation... Lovely isn't it.. he said as he rolled his eyes and sat back in the comfortable chair.

I was gob smacked. A baby Grand, soothing music and a lift. A brilliant hat trick for patient care and comfort. I left the premises of Ireland's first Neurological Institute feeling that perhaps 'Centres of Excellence' could have a future !

Who are we?

The DNI at the Mater Misericordiae University Hospital is an independent company and charity which strives to increase access and improve care of patients with neurological problems including Parkinson's Disease (PD), Multiple Sclerosis (MS), Epilepsy, Headache, Stroke etc.

Mission, Vision & Values: The Department of Neurology at The Mater Misericordiae University Hospital as part of the Dublin Academic Health Care Centre will provide a multi disciplinary, high-quality and compassionate service to all patients suffering from Neurological conditions in a timely and efficient manner.

(extract from Mission Statement)



Our staff...

- ▶ Back row (left to right): Tim Lynch, John McKinley, Emer Fallon, Peter Kelly, Brian Magennis, Shane Smyth, David Linehan, Laura Cosgrove, Conor Fearon, Sean Murphy
- ▶ Middle row: John McFarland, Emma Fahey, Annik De Dios, Jacqui Scott, Sandra Flood, Dolores Caffrey
- ▶ Front row: Sharon Harris, Tara Daly, Jane Melling, Elaine Scally, Regina Prenderville

What has been achieved in the past 5 years

In the past 5 year we have treated approx 25,000 patients in our day ward and Out patient Department. As a result, patients with neurological problems are assessed more rapidly, diagnosed earlier and receive appropriate treatment leading to better outcomes. There is no waiting list for the day ward which is a dedicated space and we provide a service to patients with neurological conditions whose needs may not be met by the private or public health service in Ireland.

Services available

Service to Patients: The Department of Neurology at the Mater Misericordiae University Hospital as part of the Dublin Academic Medical Centre will provide a multi disciplinary, high-quality and compassionate service to all patients suffering from Neurological conditions in a timely and efficient manner (extract from Mission Statement).

Specialty Clinics: The following facilities are available to patients: Day Ward, Headache Clinic, Neuropsychiatry Clinic, Stroke/ Hypertension Clinic, Neurovascular/ Stroke Prevention, Young Onset Stroke Clinic, Neuromuscular Clinic, Neuropsychology Clinic, Physiotherapy Clinic, Relaxation

Therapy, Acupuncture Clinic, Complex Parkinsonism/DBS Clinic, Movement Clinic, Multiple Sclerosis Clinic, Complex Epilepsy Clinic, Study/Research Clinic, Parkinsons Clinic (Nurse Led), Stroke/Epilepsy Clinic, Headache Clinic (Nurse Led), Family Care Support Clinic (Nurse Led) Neuro-immunology Clinic (Nurse Led).

Holistic therapies

We are very pleased to be able to offer our patients the following holistic therapies

- ▶ Acupuncture
- ▶ Relaxation Therapy
- ▶ Psychology Service

Volunteers

The staff in the DNI and patients who attend clinics in this building, greatly appreciate the commitment given by the volunteers who provide a number of services which enhances the ambiance. The atmosphere in the clinic waiting room is tranquil and peaceful, thanks to one of our volunteers (who is a professional pianist). Other volunteers help to maintain the beautiful manicured gardens while others come here just to support our staff and patients. If you are interested in applying to become a volunteer we would be delighted to hear from you - please call (087) 637 6563.

CONTRIBUTIONS FROM OUR STAFF...

Clinical Nurse Specialist in Multiple Sclerosis, Neuroimmunology and Neurology

Jacqui Scott
Clinical Nurse Specialist

The diagnosis of MS and Neurology conditions gives rise to psychological, physical and functional consequences. It is a time of uncertainty, as the disease is so unpredictable. The new hope offered to people with Neurology conditions by disease modifying therapies have resulted in an enhanced spectrum of care that called for nurses to educate, support and advise patients from diagnosis throughout the disease continuum.

Our clinical role allows us to provide direct and indirect care to Neurology patients and their families. We actively participate in the multidisciplinary (MDT) team to assess symptoms, effectively manage treatments and refer to the necessary disciplines when the need arises. The complexity of the disablement and the multiple sites of neurological damage as in MS demonstrate the significance of the MDT and there is a mutual respect and reliance on the contribution of each team member.

It is imperative that Neurology patients need accurate, relevant and realistic information to enable them to reach informed decisions regarding therapy and to take control of their health and lifestyle decisions. Education empowers the Neurology patients and allows them to be an active participant in the management of their condition. We provide information on the consequences of a diagnosis, realistic expectations relating to lifestyle and treatment options and management of side effects as a result of these therapies. We also help to dispel misconceptions, interpret data to aid in the decision-making. Through the process of education we hope to facilitate the transition from being a young healthy adult to a person with a Neurological diagnosis as uncomplicated and effortless as possible. Elements of the Neurology Nurse educational role also extend to families, other health care professionals and the community to promote confidence in managing the condition and related complications.

It is crucial that the Neurology patients have a link with the team and reassurance that support will be available throughout the disease continuum. This ensures expert nursing care with emphasis on health promotion and prevention of complications where possible through monitoring and evaluation. The role of advocate through nursing was only recognised in the literature in the 1970's but it is critical and instrumental for us to implement as the Neurology Nurse is recognised as the health professional that interacts most with this group of patients. We collaborate with other health care professionals and community groups on the patient's behalf when necessary and develop support systems for newly diagnosed if required. With continued support we encourage and promote patient responsibility for their well being using evidence based care to guarantee improved outcomes.

Research and development is a significant aspect of our role. Through this we use research findings critically and generate questions for research arising out of practice to improve overall patient care. It also allows us to become involved in projects that develop inventive, yet practical and effective nursing services through dissemination of information with our International colleagues.

As part of the service provided we all carry out Nurse Led Clinics for patients with Neurology conditions.

In conclusion we provide holistic patient focused care in collaboration with the Neurology Physicians and teams making appropriate referrals and coordinating treatment packages. This approach broadens to community care health based professionals where Neurology conditions may not be seen often enough to be managed expertly. The Neurology Specialist Nurse conveys many possible benefits to Neurology patients, increased awareness of the condition and better access to services. Our role as Specialist Nurses is evolving and changing with each individual Patient: ultimately we endeavour to provide best quality care with the patient's interest foremost to enhance quality of life. ■

The Day Ward

Jane Melling CNM2 Neurology
Carole Goggin CNM2 Neurology

The day ward in the Dublin Institute of Neurology is open 5 days a week. Two highly trained nurse specialists cater for general neurology patients who visit the clinic to receive Intravenous medication or for diagnostic testing. Tests carried out include:

- ▶ Lumbar puncture
- ▶ Skin biopsies
- ▶ Tensilon tests

This is an excellent resource for patients - particularly those who are working or have other commitments, as appointments can be arranged to facilitate the patient.

The atmosphere in the day ward is relaxed and tranquil. While patients are being treated here, they can enjoy the views of a beautifully manicured Victorian garden, which adds to the ambience and serenity of the area. This clinical setting, away from the hospital environment, providing

expert care is a unique facility and is cherished by both staff and patients. Those with chronic conditions feel less dependent on the hospital services when they can visit a centre such as the Neurology Day Ward.

The day ward is a win win situation for all concerned

- ▶ Less stressful for patients
- ▶ Reduced waiting times for appointment
- ▶ Cost effective

Comments from patients :

“I was in hospital for 12 months before I came to the Day Ward. I have never looked back. I love the environment of the Day Ward. The staff are excellent and so efficient

“The Neurological clinic is a lovely place to come to every month to receive meds. The nurses are very friendly and highly efficient. The clinic makes an otherwise daunting experience, a very nice one”

A day in the life...

Sharon Harris

Clinic Administrator at the Dublin Neurological Institute

The Reception and Administration office at the DNI is always a hive of activity. Our patients arrive every day for their Neurology Clinics and consultations, and our phone lines are always busy. We are in constant contact with an array of people, patients, staff at the Mater Hospital, GP's, and with other Hospitals around the country.

The really interesting and challenging aspect of my job at the DNI is that every day is completely different, and I deal with new people and experiences each day. My job is very diverse, I meet people when they arrive at the DNI for their Clinic and Day Ward appointments, I make sure that the front office is running smoothly, and that the Waiting Room is comfortable for patients while they wait to be seen. It is amazing to see how little things such as having music in the waiting room, a comfortable environment and literature for patients to read can have such a positive impact on our patients experience here and can be reassuring for them. Occasionally, we even have one of our Volunteers playing the Grand Piano, which always entertains the patients. Each day, the administration staff provide administrative support

to the Consultants and Specialist Neurology and Research teams. We prepare Clinics and patient charts, deal with clinical correspondence, make appointments and follow up on patient queries. No two days are ever the same.

Patients arriving for their first visit are always impressed by how beautiful the building is, and by the friendly, comfortable and informal atmosphere here. Everyone is very caring and welcoming and our patients receive amazing care from the medical teams.

The really nice aspect to my job here is being able to get to know our regular patients very well, being able to help or reassure someone who may be here for the first time, and to see patients leave the DNI with a pep in their step after they have had great care and advice from the Doctors and Specialist Nurses.

I began working at the DNI nearly 4 years ago, and it's growing and getting busier every year. It is a unique facility for neurology patients in Ireland, and I am proud to be part of the team.

CONTRIBUTION FROM A PATIENT...

Leona's Story...

by *Leona Daly, Patient*

I was a healthy young woman when I fell into a coma while pregnant. If it wasn't for the amazing team at the Mater and Rotunda Hospitals and my loving family, I wouldn't be here today to tell my story.

Before taking ill, I had been enjoying a successful musical career as a singer/songwriter. I even sang in the Irish Eurovision Finals. My life took a sharp turn for the worse one morning in January 2011, when I woke up and it hurt to open my eyes. My ears were ringing similar to being on an aeroplane with high cabin pressure. Doctors outside the Mater diagnosed me with various ailments, such as fatigue, stress, anxiety, and depression. Despite various treatments and multiple hospitalizations, my condition worsened. I began having delusions (false beliefs), and paranoia (irrational fears). Meanwhile, in February 2011, my partner Ben and I learned that I was pregnant.

By May 2011, I started having visual hallucinations and was admitted to the Rotunda Hospital for a diagnosis of 'acute psychosis'. Like the doctors before him, psychiatrist Dr John Sheehan wondered if I might be suffering from the pitfalls and excesses associated with the music business. He sent off tests for drugs and alcohol, but I didn't abuse any substances, and the lab results came back negative.

Dr Sheehan also requested a consultation by the Mater Neurology Service led by Professor Tim Lynch and Dr Killian O'Rourke, and registrars, Dr Jennifer Dineen and Dr Allan McCarthy. This proved very timely, as within days of my admission to hospital, I began having seizures and became catatonic (stiff and unresponsive), and eventually, I slipped into a coma and needed ICU care.

After extensive evaluations, my physicians suspected Anti-NMDA receptor encephalitis, an acute and life-threatening inflammation of the brain. Normally, the immune system produces proteins called antibodies. Such antibodies usually fight foreign invaders like bacteria and viruses. My doctors deduced that my antibodies were mistakenly



Leona & Alfie

acting against my brain tissue, specifically targeting the N-methyl-D-aspartate (NMDA) receptors. These receptors are important molecules for healthy brain functions, especially memory.

The treatments for encephalitis suppress the immune system and have other pronounced side effects, so they are not administered lightly, especially to a pregnant patient. However, I was rapidly deteriorating and it often takes weeks before lab tests confirm anti-NMDA receptor encephalitis. My doctors decided to act.

They employed immunosuppressive treatments like plasmapheresis (plasma exchange), a heroic procedure in which a great deal of my blood is withdrawn, antibodies are filtered out, and the fluid is then replaced. Fortunately, the plasmapheresis eventually worked. After almost three months in a coma, I slowly began to wake up. Initially, I was confused and forgetful: I didn't know where I was, what had happened to me, who my partner Ben was, or even remember that I was pregnant. I also couldn't talk at first, so I just lay on the bed and cried with fear. The team at the Mater: doctors, nurses, physios, the porters and ladies who served me my meals, all helped and supported me with great kindness and I started to improve a little every day.

Because I had been bedbound for so long, the muscles in my legs had wasted and I couldn't walk. I took my first steps, with the help of incredible nurses Trish McAuliffe and Des O'Neill, into the arms of my partner Ben. With extensive rehabilitation and a great deal of physical and emotional support from the Mater team and my family, I was discharged from hospital near the end of August 2011.

At the end of October, eight weeks early, the best gift of my entire life decided to make a dramatic entrance into the world. Besides my obstetrician Dr Peter McKenna, the neurologist, Dr. Killian O'Rourke, also attended the birth of my baby in the Rotunda Hospital.

They really were with me every step of the way! Dr. McKenna performed a caesarean section to deliver my baby boy to a heap of huzzahs and rapturous applause. He also removed a strange-looking ovarian tumour, an abnormal growth containing many different types of cells. In the case of anti-NMDA receptor encephalitis, a teratoma containing neural (nervous system) cells triggers the immune system to produce antibodies against brain tissue. The doctors had searched extensively for such a tumour as a cause of my encephalitis, but it had been hidden by my pregnancy.

After I held my baby Alfie, Dr McKenna handed me the hairy, golf ball-sized tumour for closer inspection. Now that is a moment I am never likely to forget!

Nor will I forget what Dr McKenna, Dr O'Rourke, Professor Lynch and the soulful, Dr McCarthy and the rest of the medical team at the Mater did for me. I owe them my life. I owe them my baby's life: Lovely little Alfie is now an exceptionally strong, energetic, and cheerful two year-old boy!

- ▶ Leona Daly is a popular singer/songwriter, who is writing a book based on her experience with neurologist Anne Lipton MD, PhD. For more information go to www.leonadaly.com and www.annelipton.com
- ▶ Contact leonadaly@gmail.com



Alfie, now aged 2 years

The Board of the DNI...

The Board of the Dublin Neurological Institute is made up of 7 board members from medical and business backgrounds. Dublin Neurological Institute Board members and the Chairman of the board are volunteers who donate freely of their time, skills and experience. They are members of the public who have a passion and commitment to helping improve services to patients of the Dublin Neurological Institute and who are constantly working towards the further development of the DNI. The focus of the Board is always on the future planning of the Institute both from a service delivery viewpoint and a financial planning viewpoint. The board meets approximately four times a year and at these meetings members are presented with a Directors report from Prof Tim Lynch, Clinical Director of the charity. This report gives the Board members a breakdown of clinics in the previous quarter and helps the board to ensure that the excellent quality of care



- ▶ Back row: Pauline Ward, Micheal O Muircheartaigh, John O Connor (Chairman), Sr Margherita Rock, Christine Cole Gallagher
- ▶ Front row: Mary Day, Tim Lynch, Margaret Sweeney

to patients is maintained year on year. The Dublin Neurological Institute would like to take this opportunity to express its most sincere thanks to Board members both past and present who are so generous with their time and expertise.

Education & Research

Education & Research: The Institute will provide a centre of excellence where clinical care and research thrive together linking clinical service with the basic sciences at the Conway Institute, UCD to study Neurological degenerative diseases including Stroke, Multiple Sclerosis etc.

(extract from mission statement)



Irish Neurology Association - Prize Giving

Dr John McKinley of the DNI and Mater University Hospital received the following awards at the Irish Neurology Association meeting held in May 2014

- ▶ Dr Mark Gibson Medal in Movement Disorders
- ▶ Harold Millar Prize for best overall presentation

The staff in the DNI recognise the enormous prestige attached to these awards and congratulate Dr McKinley on his achievements.

DNI Multicenter Movement Disorders video journal club

At the DNI we have been hosting a monthly video journal club in which clinical videos are presented and discussed by a panel of specialists in Movement Disorders (in adults and paediatrics), Neurologists with other specialist interests, Nurse Specialists and doctors in training. This meeting is chaired by Professor Timothy Lynch and video conferenced 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 Hospital and Cork University Hospital.

Complex and challenging cases are discussed, especially those in which a diagnosis is rare or difficult in order to educate colleagues and develop a strategy for ongoing investigation and management to benefit patients from pooled expertise and experience.

There is a strong clinical teaching ethos at the DNI and doctors in training benefit from the demonstration of clinical signs and key points of history taking in the field of Movement Disorders at the video journal club. This should facilitate the

development of diagnostic skills with a view to bringing those back to the clinic setting for the benefit of our patients.

The multicenter nature of this meeting has helped develop links between colleagues and institutions and disseminated knowledge and expertise for the benefit of patients in all the centers involved.

Medical Education for General Practitioners

Through the Irish College of General Practitioners the DNI is conducting an E-learning programme for general practitioners where GPs will become more informed about the early diagnosis and onset of various neurological conditions.

Postgraduate Nursing Education

The DNI is currently working with the Nursing Dept in University College Dublin in drawing up a specialised educational programme for nurses interested in furthering their studies in neurology.

Education for the patient & carers

Since September 2013 information sessions for patients & carers have been hosted in the following areas: Parkinsons Disease, Stroke, Multiple Sclerosis, Epilepsy, Headaches. These sessions are very well received and we envisage they will be held on a monthly basis. If you require further information please call - (087) 637 6563

Research

Since the opening of the DNI in 2008 there have been between 50-60 peer review publications

Recent study

Deciphering the role of single mutation carriage in recessive Parkinson's disease: Temporal Discrimination Threshold (TDT) as an endophenotype.

The vast majority of typical Parkinson's disease is not due to an underlying primary genetic or inherited problem. There are however several rare 'monogenetic forms' of Parkinson's disease that are primarily due to a mutation in a gene, usually inherited from one or both parents. In the recessive forms (in which an abnormal gene needs to be passed on by each parent in order to lead to disease in their offspring), parents and some siblings of affected patients are often referred to as 'carriers' meaning that they only carry one of the two required genes that lead to Parkinson's disease. Patients with certain recessive genetic forms of Parkinson's disease tend to develop symptoms before the age of 35 and tend to have an excellent and sustained response to treatment, without the development of memory or cognitive problems over the years. Some experts believe that having one abnormal gene (in a recessive form) can predispose to the development of later-onset Parkinson's disease and this notion has created much debate in the medical literature.

At the DNI and in collaboration at St Vincent's University Hospital Dublin, the Belfast City Hospital and the Mayo Clinic Jacksonville USA, we have been undertaking a 2 year study, looking at the potential use of TDT in unaffected relatives of patients with young-onset Parkinson's disease (who are at higher risk of recessive forms such as PARK2), in order to identify



if TDT is abnormal in those who carry a single abnormal gene. If this were the case then it would strengthen the argument that having a single abnormal gene may be contributing to the development of late-onset Parkinson's disease, as TDT is known to be abnormal due to dysfunction of the basal ganglia which are responsible for automatic movement control.

The identification of a group of individuals who are at greater risk of developing Parkinson's disease, perhaps many decades before symptom onset would be extremely important as current research is focused on individuals who already have the condition. By the time someone presents with Parkinson's symptoms, many of the dopamine producing cells of the brain are already lost and thus identifying a group of individuals many decades before disease onset, would offer the potential to study disease modifying/preventative therapies and in identifying potential environmental factors which in addition to genetic factors may be contributing to the development of Parkinson's disease.

We would like to thank the patients and families who gave their time to this study, as without their valuable contribution this work would not be possible. ■

Dr John McKinley, DAMC Fellow in Movement Disorders, Dublin Neurological Institute at the Mater Misericordiae University Hospital and St Vincent's University Hospital.

The Staunton Library

Dr Hugh Staunton was consultant neurologist to the Mater Misericordiae Hospital on a sessional basis from the early 1970s up to the time of Professor Timothy Lynch's appointment in 1998. He had a keen interest in the historical aspects of neurology, and 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 in the world.

Following Dr. Staunton's death in 2012, the DNI has been privileged to come into possession of the collection which has

been housed in two specially built bookcases in the DNI boardroom. The books have been electronically catalogued and the collection is available for browsing online:

www.librarything.com/profile/HughStauntonLibrary

The library was catalogued by Dr. Anna Linehan, under the supervision of Dr. Killian O'Rourke. The assistance of Professor John Crowe, President of the Royal College of Physicians of Ireland, Ms Harriet Wheelock, Archivist RCPI Heritage Centre, and Eamon de Burca of De Burca Books is gratefully acknowledged. ■





North West Neurological Institute (NWNi) Launched

On 14 November, 2013 the North West Neurological Institute (NWNi) was launched. The NWNi is modelled on the highly successful Dublin Neurological Institute (DNI). This new facility will bring together support and services to patients, carers and clinicians across the North West of Ireland, for a wide range of challenging neurological conditions including Parkinson's Disease, Multiple Sclerosis, Alzheimer's Disease, Epilepsy and Dementia.

The NWNi will operate from a dedicated building at Sligo Regional Hospital and will serve the counties of the North West. The launch of the Institute has been made possible by Elan's commitment to provide €1.5 million over a five year period as well as support from HSE North West and Sligo Regional Hospital. The NWNi will also be seeking active help from the public, community groups and national initiatives to raise the additional annual funding needed to run the centre.

The Clinical Director and head of NWNi, Dr Kevin Murphy, Consultant Neurologist at Sligo Regional Hospital, said: "We have been inspired by the success of the Dublin Neurological Institute, which has helped to improve services for patients and carers and reduce waiting lists. There is a significant need for better access to high quality services for patients and families in the North West, with long waiting lists for new patients to receive the specialist help they need. We are grateful to Elan, the HSE and Sligo Regional Hospital for their support in making NWNi a reality and we look forward to working with the local community across the North West as we seek to help people with neurological conditions to lead better lives."

The NWNi will be based in the grounds of Sligo Regional Hospital in Molloway House. Following renovation, Molloway House will include a bright reception area, individual clinical and consulting rooms and a meeting room. NWNi will eventually provide a full range of neurology services, including outpatient support, diagnostics, a drop in information centre and alternative and complementary approaches, combined with access to a consultant neurologist and specialist nurses. Patients who previously had to travel to Dublin or Galway for specific neurology-related tests such as electromyography (EMG) will now be able to receive such tests much closer to home.

When fully operational, NWNi will aim to provide general neurology and speciality clinics with specific interest in epilepsy, Parkinson's and movement disorders; EMG / EEG clinics; physiotherapy services; nurse-led clinics; patient / family

support clinics; educational training for medical personnel; and holistic services (such as acupuncture and reflexology).

In addition to the five-year funding received from Elan and enthusiastic support from Sligo Regional Hospital and the HSE, the NWNi will seek help from local communities and others to raise the funds needed to keep the doors open.

NWNi will work closely with the Dublin Neurological Institute, which was founded in 2008 and has led research into neurological conditions, with more than 50 scientific papers published in academic journals, and contributed to the identification of two new genes that cause Parkinson's disease. It is affiliated to two of the world's leading Neurological Institutes, The Montreal Neurological Institute and The New York Neurological Institute.

Prof Tim Lynch, Clinical Director of the Dublin Neurological Institute and a Consultant Neurologist at the Mater Misericordiae University Hospital and Beaumont Hospital, and National Lead HSE Neurology programme said, "The launch of a dedicated neurological Institute in the North West is a wonderful achievement and will bring improved support and greater hope to the many people and families who carry the burden of neurological conditions. We are grateful for the financial support of Elan for the Institutes in Dublin and the North West and for the enthusiastic backing of the HSE and our partner hospitals. This launch is an integral part of the National HSE Neurology programme to improve access for patients to neurological care leading to decreased waiting times. We are optimistic that all the communities around NWNi will rally round to make sure this new not-for-profit initiative can thrive and serve the people of the North West for many years to come."

About NWNi

The North West Neurological Institute (NWNi) is a specialist, not-for-profit organisation which has been founded to help patients, families and clinicians across the North Western counties of Ireland by working in partnership with HSE and existing services. With the active support of our local communities, our goal is to drive excellence in neurological care across the North West by bringing together services for a wide range of challenging neurological conditions including Parkinson's disease, multiple sclerosis, Alzheimer's disease, epilepsy and dementia.

For further information about NWNi please visit our new website, www.nwni.ie

Future Plans & Aspirations

Overall Objective

Develop a clinical academic centre of excellence that is one of the best Irish clinical neuroscience academic unit providing the

- ▶ best clinical services
- ▶ best teaching &
- ▶ best research

How do we achieve this?

1. Develop excellent clinical holistic care of patients with neurological problems
2. Develop research in parallel with the clinical care to allow patients to avail of research studies and novel treatments in trials. Clinicians, nurses and services allied to medicine will improve standards of care via a multidisciplinary team approach
3. Increase education and awareness of clinical neuroscience to medics, nursing personnel, services allied to medicine and the Irish public
4. Promote the DNI brand nationally and internationally
5. Develop strong links with international centres of excellence in neuroscience, e.g. Neurological Institutes of New York and Montreal
6. Work with the Health Service Executive to appoint more neurologists & nurses so that we can offer more specialised clinics – e.g Traumatic Brain Injury (TBI)

Local / Regional / National Plan

In addition to developing and strengthening the DNI on the north east of Dublin, the Board of the DNI supports the development of ‘satellite’ institutes throughout the country and we hope some day our ambitions will be fulfilled.

Advantages: Increasing access for patients with neurological problems in equitable fashion around the country. A common database and biological sample

collections for biobanking of neurological disorders can be done with a network of neurological institutes. Such a network (Irish Institute of Neurology) would attract interest from pharma and other groups for research trials of products generating a source of income for the neurological institute network and provide our patients an increased choice of therapies.

Plan for 2014

- ▶ Develop new services at DNI (e.g. complex epilepsy clinic, traumatic brain injury)
- ▶ Increase patient/carer education
- ▶ Increase links with GPs, e.g. elearning with ICGP
- ▶ Engage with HSE/DOHC to ensure the “Institute” model is part of the National Neurology Programme

Funding

1. Kind funding from Elan Pharmaceuticals Inc. allowed the DNI to expand by recruiting medical and nursing staff - helping to increase services and support research.
2. Fundraising annually to sustain the clear budgetary plan in place to account for the increased expenditure over the next five years.
3. Philanthropy to be encouraged and developed. ■



How you can help...

While much has been achieved we have aspirations for so much more. This cannot be done without your support. Please give what you can - 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



Prof Tim Lynch accepts a cheque from Dr Allan McCarthy & Ms Grainne McKeown who together with Dr Brian Murray completed the Wexford Half Marathon.

Forthcoming fundraising events

21 June: East & West cycle to the Midlands

On Saturday 21 June a group of medical, paramedical staff & friends will leave the Dublin Neurological Institute DNI in Dublin and cycle to Athlone. At the same time a group of medical, paramedical staff & friends will leave the North West Neurological Institute (NWNi) Sligo and cycle to Athlone.

Prof Tim Lynch, Consultant Neurologist DNI and Dr Kevin Murphy, NWNi will present parallel presentations to local GPs and Members of the public in the Sheraton Hotel at 6pm.

26 September: Annual Golf Classic will be held in Hermitage Golf Club

This is the 13th year that the Annual Neurological Golf Classic has been held in Hermitage Golf Club. Funds raised over the years have helped us develop services and support programmes for patients and their families. Through the vital fundraising efforts of our friends and volunteers we have also been able to fund our research programme which we hope will make a difference to patients today and in the future.

November: Variety Show

Organised with the support of Mr Shay Healy - (details will be announced shortly)



The Mater Foundation will be hugely grateful for your support. If you would like to make a once off gift or a regular gift please complete either 1 or 2 below and return this form together with your CHEQUE, POSTAL ORDER or CREDIT CARD DETAILS to: The Mater Foundation, FREEPOST F4360, 54 Eccles Street, Dublin 7. Thank you.



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