



# Brain Research in Ireland Delivering on the Potential

10th March, 2015 – Trinity College, Dublin

## Introduction

The Irish Brain Council was launched in May 2013 to coincide with the European Month of the Brain, an initiative of the European Brain Council in association with the European Commission.

The aim of the Irish Brain Council is to provide a critically needed platform for policy development and advocacy in relation to brain research in Ireland. There is a strong and vibrant brain research community in this country with contributions by Irish researchers increasingly recognised throughout Europe and worldwide.

However, there are significant challenges facing the sector in terms of the proportion of research funding that goes to brain research and the need to develop the appropriate infrastructure to encourage and support research in this area.

As part of events to mark European Month of the Brain, the EU Commission organised a Europe-wide conference in the National Convention Centre, Dublin entitled "Healthy Brain: Healthy Europe: A New Horizon for Brain Research and Healthcare". The report from this conference outlines a series of key recommendations to support and develop research into brain conditions in Europe, providing an important focus for member states to develop their own national approaches to strengthen and promote research in this area.

On March 10th, 2015 the Neurological Alliance of Ireland and the Irish Brain Council, with support from Novartis, organised a half-day conference focused on bringing together all the stakeholders involved in brain research in Ireland, including patient organisations; national bodies with a remit to support, promote and develop scientific research; and representatives from the brain research community in Ireland.

It was recognised in the planning of this event that the representation from the sector should be as wide as possible, in order to ensure that perspectives in relation to patient involvement and the role of patient organisations, career pathways, funding and infrastructure to support brain research were available to the debate.

The aim of the conference was to identify the key opportunities and challenges facing brain research in Ireland and outline a clear set of recommendations to promote and develop the sector going forward. These recommendations will be developed into a position paper on supporting and strengthening brain research in this country, which will be presented to key decision makers. This paper will also form the basis for the development of a strategic plan for the Irish Brain Council.

The Neurological Alliance of Ireland agreed to take a lead role in the planning and organisation of this event with the other members of the Brain Council. The Neurological Alliance has a strong interest in developing a supportive climate for research into neurological conditions in Ireland, recognising the importance of its own network of member organisations in this regard.

The conference organisers wish to thank all the panel members and speakers for their contribution to an informative and engaging debate that provided an important direction for brain research in Ireland going forward.

**Ms Magdalen Rogers**  
**Development Manager, Neurological Alliance of Ireland (NAI)**

## Brain Research in Ireland Delivering on the Potential

On March 10th 2015, the Neurological Alliance of Ireland (NAI) and the Irish Brain Council (IBC), with support from Novartis, brought neurological charities and dozens of researchers and scientists together to discuss the future of brain research in Ireland at a special conference entitled 'Brain Research in Ireland - Delivering on the Potential'.

Opening the one-day event, **Ms Magdalen Rogers**, NAI Development Manager, explained the main aim of the meeting - to bring neuroscientists, clinicians, researchers and charities together and discuss how to support and strengthen the environment for conducting brain research in Ireland.

"Although strides have been made, such as the foundation of the Irish Brain Council, Ireland still lags behind internationally when it comes to supports for brain research," Ms Rogers said. "So the objective today is to signpost what is needed in terms of funding, networks and infrastructure and career structuring, and to promote collaboration between all the stakeholders involved."

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*“Neuroscience in Ireland is relatively young, but we punch well above our weight...We’re here to identify problems and obstacles to brain research in Ireland, examine how brain research in Ireland can be supported, and suggest solutions and plan action”*

## **Promoting and advocating for brain research in Ireland**

**Dr Richard Roche**, President of the Irish Brain Council, presented an overview of the current state of brain research in Ireland, and what needs to be done to improve it. He presented figures showing that brain research receives one-third of the funding cancer research does; and furthermore, there have been successive funding cuts since 2008 throughout the EU.

According to Dr Roche, the problem in Ireland centres on the shift of emphasis to translational or applied research at the expense of basic science; and the fact that Ireland produces some of the best neuroscientists in the world, but loses them to institutions abroad.

“Neuroscience in Ireland is relatively young, but we punch well above our weight,” said Dr Roche. “Compounding the problem, the trend towards funding ‘applied’ or commercial research appears directed at job creation and economic growth...but this is not the job of science. Neglecting fundamental research is not sustainable - balance is needed. However, there is a lot we can do to balance this problem.”

This includes informing and educating the public, politicians, and industry about the Irish Brain Council and its aims and priorities, he said, as well as becoming individually more active and engaged in advocacy, as researchers.

“This conference is another important part of improving the situation,” said Dr Roche. “We’re here to identify problems and obstacles to brain research in Ireland, examine how brain research in Ireland can be supported, and suggest solutions and plan action.”

## Brain research in Ireland: An overview of successes, opportunities and challenges

**Professor John Cryan**, Professor and Chair of the Department of Anatomy and Neuroscience at University College Cork (UCC), spoke about his own neuroscience research and gave recommendations on how to foster more such research in Ireland.

Prof Cryan has a special interest in neuroscience research that includes mental illness, especially depression.

“I think it is important to include the mind, and disorders of the mind, when we discuss further understanding the brain. One way to look at this, which is an area of research my colleagues in psychiatry and I focus on, is looking at how the brain responds to stress - in particular, stress as one of the major predisposing factors in the cause of depression,” he explained.

His Cork lab is successful, he said, partly because they collaborate where possible to engage in translational neuroscience research - they aim to make their research relevant to patients.

However, he continued, it is becoming harder to get funding.

“Ireland is probably one of the few countries where agencies are telling us to go to Europe to look for funding. That’s very much the agenda from the Government, to try and get back our investment from Europe.”

Horizon 20/20, the €80 billion research project from the European Commission, is one such opportunity. However, said Prof Cryan, Horizon 20/20 has “tough metrics in place for Ireland to deliver on”.

“We do have strengths. Neuroscience in Ireland is very collaborative and there is a large effort for us all to work together. But we need to engage in all aspects of neuroscience, whether it’s applied science or health service research. A problem we have here is there is a lot of shuffling around, to see which aspect (of neuroscience) will be prioritised. Sometimes we get obsessed about the politics a bit too much - instead of fighting over what aspect of neuroscience to fund, we should just fund excellence across the board.”

Another challenge to conducting good research is the issue of scientist contracts, said the professor.

“Many people are hired on short-term contracts, and when they apply for funding they are blocked because their contract does not extend beyond a certain time period. So on one hand, we are asking people to stay in Ireland and conduct research; but contracts are preventing them from doing that.”

*“My advice to young researchers would be to think translational; to collaborate; to engage in outreach, including social media; and to consider a niche or area of science that you can meaningfully add to”*



Furthermore, the bureaucracy and cost of doing neuroscience research in Ireland is only increasing, whereas other countries in Europe can do it a lot cheaper, he added.

“My advice to young researchers would be to think translational; to collaborate; to engage in outreach, including social media; and to consider a niche or area of science that you can meaningfully add to.”

**Professor Orla Hardiman**, Professor of Neurology, Trinity College Dublin and Beaumont Hospital, Dublin, spoke next about the challenges and opportunities facing neuroscience in the 21st Century.

“The biggest problem facing us all, and one that will worsen, are diseases of the brain and neurodegeneration. Two billion people around the world are affected by brain disease, and the cost of these is trillions of dollars. The NAI and other advocacy groups around the world have figures showing that at least 1 in 5 people will have brain disease or injury throughout their lives. The economic burden is enormous and growing,” said Prof Hardiman.

She presented figures showing that the cost of brain disease in Europe was €798 billion in 2011. Comparatively, the cost of cancer was between €200 and €250 billion.

“And yet,” said Prof Hardiman, “there is a huge focus on cancer strategies but maybe not yet an understanding that something similar needs to happen with brain disease. Cardiovascular disease, another big problem, is only a quarter of the burden of brain disease, in terms of numbers. We need to look at contributing funding to the most important health risk.”

About 700,000 people in Ireland have brain disease, according to estimates produced by the HSE. It could even be more, since that figure does not include mental illness or addiction problems. Furthermore, in Ireland, the cost of brain disease per capita is roughly €1,700. Prof Hardiman explained that to tackle brain disease, in Ireland and around the world, supporting research is vital.

“Everybody in Ireland with an interest in brain disorders of all kind should be working together. This includes developing career structures to keep the best and brightest in Ireland.”

She explained that there are three “pillars” of funding in Ireland - the Department of Health, which funds the HSE and HRB; the Department of Jobs, Enterprise and Innovation, which funds Science Foundation Ireland; and the Department of Education, which funds universities. The problem, according to Prof Hardiman, is that these pillars do not feed into each other.

“If we look at HRB funding, the amount that goes into mental health and neurology is about 16 per cent of their total budget, and cancer research is almost a quarter of all funding. Some of this is due to excellence and some is due to prioritisation. We need to up our game, be excellent, and promote networking. We have a good network in Ireland, so we should use it.



*“The biggest problem facing us all, and one that will worsen, are diseases of the brain and neurodegeneration... We need to up our game”*

“The problem is everything is very fragmented. The funding model is not connected; we should learn from other countries such as the UK. They set up the National Institute of Health Research, where the universities and clinical settings are under one umbrella, with the patient in the centre. I believe the HSE, our academic universities, and patient organisations should be under one similar umbrella. This is because good clinical practice is research and evidence-based, and good research drives good practice.”

Finally, said Prof Hardiman, Ireland needs to develop strong career tracks for young people, so those who leave the country to work abroad can come back and have jobs open for them.

“My colleagues in Europe send people away to train and then have funding available to bring them back and put them to work at home. This shows again how health, education and innovation are all silos - they need to be brought together.”



*“Patient organisations have unique insights into real life and the real needs of patients, and these need to be utilised more”*

## **Patient and charity involvement in clinical research**

**Ms Eibhlin Monroe**, CEO of the Irish Platform for Patients, Science and Industry (IPPOSI), focused her presentation on the importance of involving patients in the drive to conduct more clinical trials in Ireland.

She presented data from an IPPOSI survey of 1,000 adults, questioning them in relation to their perceptions of clinical research. When asked whether carrying out research in Ireland with the aim of curing diseases was a good idea, 60 per cent strongly agreed. Half of respondents said they would be willing to donate blood to be used for clinical research. The study also showed a need for more awareness amongst the public for the overall benefits of participating in clinical trials, which led to IPPOSI’s clinical trial awareness campaign ([www.clinicaltrials.ie](http://www.clinicaltrials.ie)).

Ms Monroe also outlined IPPOSI’s involvement in the European Patients’ Academy on Therapeutic Innovation (EUPATI), which aims to build a strong relationship between researchers, Industry, patients and regulators.

“Patient organisations have unique insights into real life and the real needs of patients,” said Ms Monroe. “And these need to be utilised more.”



*“The MRCG/HRB Joint Funding Scheme has a very high rate of healthcare innovations, due to the projects stemming from the charities’ goals”*

## The key role of charities in supporting brain research

**Ms Marie Downes**, Development Executive of the Medical Research Charities Group (MRCG), echoed these statements, explaining how important charities are in promoting brain research.

The MRCG was founded in 1998, and over a number of years met with various Government departments in an effort to secure funding for medical research for patient support charities in Ireland, Ms Downes explained.

In 2006, this campaign came to fruition, and the Department of Health awarded MRCG €1 million in the HRB allocation for the co-funding of research between the charities and the HRB.

This has continued annually since then. Unfortunately, said Ms Downes, due to Government cutbacks this figure is now €800k annually.

The majority of research projects funded by MRCG are biomedical, although there is a push towards health service and population health research, she explained.

“The MRCG/HRB Joint Funding Scheme has a very high rate of healthcare innovations, due to the projects stemming from the charities’ goals, which are improved treatments for patients – largely patient-led research,” said Ms Downes.

A new group called the Irish Health Research Forum (IHRF) originated from a study that the MRCG carried out in 2014, which asked approx. 200 researchers to identify the barriers and enablers to research in Ireland, and to identify how to improve the landscape.

The main findings of this study included:

- There are gaps in enabling research infrastructure in Ireland
- Particular important areas of research are not prioritised
- Support is focused on the earliest stages of research and on well-established researchers
- The contribution of medical research charities is not recognised in official policy documents.



**Mr Peter Murphy**, Deputy CEO of Epilepsy Ireland outlined that charity's research programme and presented some examples of work they are currently involved in.

As a Board member of the Neurological Alliance of Ireland, he also presented results of an NAI survey conducted on 14 charities online in January 2015, which aimed to explore the support provided by NAI member organisations for research into neurological conditions.

The survey asked the charities about their research goals. The main findings were as follows:

- 69 per cent have specific targets and goals in relation to research
- 43 per cent have a 'formal' research strategy
- 38 per cent have a research committee, and 43 per cent have staff with research responsibilities
- Regarding the main barriers to actively supporting research in neurology, 92 per cent said funding was the main barrier, followed by 'other commitments' (54 per cent), staffing resources (46 per cent), and lack of expertise (31 per cent)
- 75 per cent of respondents said they have an ongoing relationship with an academic or research institution that carries out scientific research
- The average amount invested per charity per annum is €50,000, typically 5 per cent of the annual budget
- 50 per cent have increased funding from five years ago, while 25 per cent have decreased funding and 25 per cent have stayed the same
- The most common type of research funded is basic science/genetics, and research into treatments, therapies, devices or technologies

Mr Murphy said the NAI survey findings show that barriers to research do exist, such as the cost of funding research, competition for resources, and a perceived lack of research expertise within charities but that nonetheless there is a strong and growing support for research among NAI members. He outlined the benefits of working with charities on research projects.

"Charities are open to partnerships and they can be a viable alternative for securing funding," he said. "We charities also need support from the wider research community, for example in establishing internal infrastructure around research and on aspects such as evaluating and deciding on proposals."



*"Charities are open to partnerships and they can be a viable alternative for securing funding"*

Epilepsy Ireland, he explained, takes a strategic approach to research. It coordinates with the Health Research Board/ MRCG Joint Funding Scheme to foster research. The charity's current research priorities include projects with an emphasis on the psychosocial aspects of epilepsy, sudden unexpected deaths in epilepsy and the genetics of epilepsy.

Mr Murphy explained their Research Funding Scheme, launched in 2009 has supported eight projects with an investment of €780,000 to date. Six of these projects are funded on a joint basis with the HRB/MRCG Joint Funding Scheme.

He then presented an example of research supported by Epilepsy Ireland. The project is entitled 'A pharmacogenomic study of chronic refractory epilepsy,' and was conducted under the HRB/MRCG Scheme from 2010-2012 by Dr Gianpiero Cavalleri of the Royal College of Surgeons in Ireland (RCSI).

The study involved 400 patients, and looked at identifying genetic predictors involved in drug resistant epilepsy and genetic factors involved in how people respond to particular medications.

The study helped identify a gene involved in Stevens Johnson syndrome, a serious side effect that occurs in some people taking a common epilepsy medication, carbamazepine, and also identified a new genetic cause in a particular type of epilepsy in people with an intellectual disability. It also confirmed the role played by the SCN1A gene in epilepsy.

Another Epilepsy Ireland-supported study is ongoing in Trinity College Dublin, carried out by Professor Agnes Higgins, who is evaluating the role of the epilepsy specialist nurse, their impact on patient quality of life and the cost-effectiveness of the positions.

Mr Murphy outlined other research activities conducted by Epilepsy Ireland, including the Epilepsy Deaths Register; communication activities such as videos and newsletters to inform members and the public of all research projects, recruitment drives and news; regular conferences; and a presence on social media.

## Panel Discussion

The panel discussion brought together a group of individuals representing the main stakeholders in brain research in Ireland, including funders; researchers, including early career researchers in both fundamental and clinical research; and patient representatives.

The panel was made up of the following members:

- Dr Graham Love: CEO, Health Research Board (HRB)
- Dara Dunican: Programme Director, Science Foundation Ireland (SFI)
- Ms Audrey Craven: Patient Representative and member of the Irish Brain Council
- Dr Niamh O Sullivan: Lecturer, School of Biomolecular and Biomedical Science, UCD
- Professor David Henshall: Professor of Molecular Physiology and Neuroscience, RCSI Ireland
- Dr Fionnuala Keane: Development Lead at the Royal College of Surgeons Clinical Research Centre
- Dr Eavan McGovern: Neurology Fellow, St Vincent's University Hospital Dublin
- Dr Eva Lindgren, Medical Director, Novartis

Professor Marina Lynch, Professor of Cellular Neuroscience, Trinity College Institute of Neuroscience (TCIN), sent her apologies, as she could not attend the conference due to illness. The panel was chaired by Dr Colin Doherty, Consultant Neurologist and Clinical Lead with the National Epilepsy Programme.

The central theme of the panel discussion - "How can brain research in Ireland be supported to deliver on its potential?" - was divided into three sub themes (funding, career structures and networks, and infrastructure) and panel members were invited to contribute a short summary of their viewpoints in advance for inclusion in the conference booklet.

1. Panel members focusing on the issue of funding for brain research
2. Panel members focusing on the theme of career structures for researchers
3. Panel members focusing in the theme of networks and infrastructure to support brain research.

Dr Doherty divided the panel debate into these three sub themes and opened the discussion by inviting the panel members to comment on the submissions they had put together, summarising their thoughts.



**Dr Eva Lindgren**, Medical Director of Novartis, said that although Ireland is a small country, other, similar-sized countries such as Denmark still manage to attract applied science research and clinical trials.

“To get treatments to patients, we need to conduct clinical trials. In Ireland in 2011 we had 185 clinical trials. In Denmark - roughly the same size as Ireland but with a very different infrastructure - there were 928 clinical trials. They have a structure in Denmark where you are rewarded for doing clinical trials, and where clinicians are expected to do research - although, importantly, they are given the time to do it. Ireland does of course have excellent people, and excellent work is being done by Prof Hardiman and her colleagues in neuroscience, for example. But Ireland could do more.”

Dr Lindgren spoke about the need for Irish networks to be honest and realistic when submitting proposals for clinical trials and that other issues such as low consultant staffing in neurology in Ireland in particular needed to be addressed. When asked by Dr Doherty what one improvement she would suggest, Dr Lindgren stressed the importance of doing trials we do get well, and being honest about not having the time to be involved, if that is the case.



*“In general, the HRB does not pick therapeutic areas themselves to fund – the best project wins out. The best applications get the funding”*

**Dr Graham Love**, CEO of the HRB, said that until recently, Ireland had not invested properly in clinical trial infrastructure. He explained that ICORG – the oncology clinical trial consortium in Ireland – has received €50 million in funding since its inception and so of course they have a lot of patients in trials, and willing to do trials, and a lot of research conducted.

“ICORG shows that if you put in the money, you get the return,” said Dr Love. “In general, the HRB does not pick therapeutic areas themselves to fund – we have a more bottom-up approach, to build the infrastructure and promote excellence generally, so the best project wins out. The best applications get the funding, and cancer applications in Ireland are of a high standard.”

Speaking from the audience, Professor Michael Gill, Professor of Psychiatry, Trinity College Dublin, and a member of the Irish Brain Council, pointed out that a large proportion of the cost of brain disorders is psychiatric. He highlighted that there are very specific initiatives focused on brain research and disagreed with the approach of the Health Research Board in not prioritising specific areas of clinical research. He pointed out that both the Brain Project led by President Obama in the US and the Human Brain Project in Europe are leading initiatives which prioritise research into brain conditions.



*“For trials in neuroscience, patient input is particularly valuable, especially when it comes to establishing real-world targets against which drugs can be assessed”*

It was pointed out from the audience that the ICORG initiative came from poor outcomes in cancer care - and there was a need to focus on developing an evidence base for poor outcomes for people in Ireland with neurological and with psychiatric conditions in order to make the case for more resources both for research and service development.

**Audrey Craven**, President of the European Federation of Neurological Associations (EFNA), the European Headache Alliance, and Migraine Association of Ireland, pointed to the launch earlier this year of the Book of Evidence for the Brain, Mind and Pain Project, an initiative of EFNA and the Pain Alliance Europe, which makes a clear case for investing in neuroscience research.

**Dr Dara Dunican**, Programme Director of Science Foundation Ireland (SFI), said that sourcing funding from outside the country is vital.

“Collaborations are so important; you build up interactions with the best researchers in Europe and create contacts and funding opportunities. This is critical. We are targeting Horizon 20/20 to try and get as much funding as we can into Ireland, and there is support from the Government and SFI to try and get this funding. “There are other supports available – whether it is enough, I’m not sure. But it’s important to engage with organisations abroad.”

Regarding the large amount of funding given to cancer research, Dr Dunican pointed out that there is a very organised cohort of cancer researchers and charities, and clinicians, driving this funding. The drive also comes from the Government itself, and therefore the HSE.

*“Collaborations are so important; you build up interactions with the best researchers in Europe and create contacts and funding opportunities. This is critical.”*



Speaking from the audience, Professor Orla Hardiman highlighted the importance of cancer as a model we should look to, not envy. She outlined that the development of ICORG was critically reliant on two things (a) the availability of a cancer register and (b) a political agenda for improved cancer care. She noted that this conference represented an example of the willingness of the neuroscience community to work together and pointed to the need for a clear plan emerging from this conference that would point to key recommendations going forward.

Dr Doherty then focused the debate on the second subtheme of the panel discussion: the importance of networks and infrastructure to support brain research.



*“The main way to improve brain research in Ireland is to build up networks and infrastructure throughout the country”*

**Dr Fionnuala Keane**, Development Lead at the Royal College of Surgeons Clinical Research Centre, said she believes the main way to improve brain research in Ireland is to build up networks and infrastructure throughout the country.

“The Irish clinical trials framework is key in this regard, and the Irish Clinical Trials Research Network has recently received approval for funding from the HRB and Enterprise Ireland for the development of a national, integrated clinical research network in Ireland. These plans aim to be operational later this year.”

Referring back to Dr Lindgren’s point, Dr Keane acknowledged that Ireland has a long way to go. She highlighted that Denmark benefits from excellent patient registries and also a national pride in clinical research and leading innovation.

Professor Hardiman, from the audience, issued a caveat about fragmented initiatives if networks like the clinical trials network are not part of an overall co-ordination structure around clinical research, like the National Institute for Health Research in the UK. In the UK, the Dendron network is integrated into other structures aimed at supporting brain research, not a stand-alone initiative.

Ms Audrey Craven (EFNA) said it is very important that patients are involved in helping to shape priorities for research that is publicly funded and, ultimately, carried out for their benefit.

“Including patients in top level priority-setting in order to close the gap between what researchers want to investigate, and what patients want researching, would be beneficial for all publicly-funded research. For trials in neuroscience, patient input is particularly valuable, especially when it comes to establishing real-world targets against which drugs can be assessed,” she said.

Involving patients and patient representative organisations in the infrastructure around brain research in Ireland benefits all stakeholders, including researchers themselves.

Dr Doherty then asked, “How close are we to having patients who don’t have a scientific background having a key role in Ireland in driving research?”

Ms Audrey Craven pointed to the work of EFNA in providing training for patients on health technology assessments and becoming involved in clinical research in association with the London School of Economics. The Book of Evidence for the Brain, Mind and Pain programme clearly outlines the benefits and strengths of patient engagement in brain research, she said.

**Professor David Henshall**, Professor of Molecular Physiology and Neuroscience at the Royal College of Surgeons in Ireland, agreed with Dr Keane. He said that to remain cutting-edge, neuroscientists in Ireland will increasingly need collaborations of significant size to bring together a broad range of expertise and techniques.

“Investment in cutting edge technology and broader interdisciplinary networks will be required to retain a competitive edge in the future,” said Prof Henshall. “Particular areas for more investment are imaging and functional tools for gene manipulation where new technology is key to high-impact science – for example, brain imaging and gene editing techniques.” He noted that Ireland is in danger of being left behind unless we can invest heavily in the technology required for neuroscience research.

Professor Henshall also recognised the importance of this conference in bringing together Neuroscience Ireland and other groups and allowing basic neuroscientists the opportunity to interact with and engage with their clinical colleagues.

Dr Doherty then focused on the final sub theme of the panel discussion - the importance of proper career pathways for researchers. He asked two early career representatives on the panel to comment.



*“Investment in cutting edge technology and broader interdisciplinary networks will be required to retain a competitive edge in the future”*



*"It should be clear that fundamental research, such as the study of synaptic function and signalling pathways, is essential to the long-term benefits of people's health"*

**Dr Niamh O'Sullivan**, Lecturer in the School of Biomolecular and Biomedical Science at UCD, echoed earlier comments made by Prof Hardiman about the importance of proper career structures for researchers.

She also said there is a strong need to support fundamental, or basic, neuroscience research.

"The high-profile failure of drug trials for certain neurodegenerative diseases emphasise the need to better understand the mechanisms behind neuronal dysfunction – for example in Alzheimer's disease – so that more effective therapeutic strategies may be developed.

"It should be clear," she said "that fundamental research, such as the study of synaptic function and signalling pathways, is essential to the long-term benefits of people's health."

Professor John Cryan noted in his earlier presentation that he asks his basic researchers to concentrate from day one on their how their research translates into a clinical perspective. Dr Doherty questioned Dr O Sullivan on this - do basic researchers need this shadow hanging over all basic neuroscience research?

"We have been saying for twenty years that basic researchers has to translate clearly into clinical implications, is this realistic in every case?" asked Dr Doherty.

Dr O Sullivan responded that it should not be a question of funding either basic or clinical research, since both need specific earmarked streams of funding. Dr O Sullivan moved back to Ireland last year from Cambridge and sees a number of positives in terms of excellent support from individual neurologists. However, there is a lack of funding and support for basic brain research and Ireland is not going to be in a position to compete for larger grants unless we support grass roots research.

From the audience, Professor Cryan noted that the award winning work done by Professor John O'Keefe would not be funded in Ireland right now through any of the existing funding mechanisms. Basic brain research has to be supported, he said.

Dr Graham Love pointed out that there needs to be debate on the right level of funding for basic research within any disease area in order for it to be effective. He acknowledged that if the overall amount of funding available for



research within a specific area such as brain research is not high enough, there will always be this tension between basic and clinical research. He noted that an international panel had advised that the Health Research Board needed to lead a “national conversation on funding basic research, because it is so critical to feed into clinical research.”

Dr Doherty joined the debate in relation to funding of basic research, and noted that: “The balancing act between fundamental and clinical research is now moving increasingly towards applied research, and basic researchers will leave Ireland in droves.”

Professor Henshall noted the erosion of basic scientific training because of the pressure to have applied research in fields such as biochemistry and pharmacology. Education at undergraduate and postgraduate level is suffering because of how research is funded - at the same time that pharmaceutical companies are withdrawing their applied funding portfolios because they recognise that basic research and understanding of brain structures is needed, he said.

The debate on the importance of funding and supporting basic brain research was reiterated throughout the panel discussion at the conference, and by many of the speakers on the day, and is clearly one of the significant issues that must be addressed going forward.

**Professor John Foxe**, Professor of Neuroscience and Paediatrics at the Albert Einstein College of Medicine, New York University, US, and Editor in Chief of the European Journal of Neuroscience, commented on career structures from the point of view of someone who left Ireland twenty nine years ago and has watched the struggles of researchers who came back.

He noted that we are a small nation, and there is only so much we can achieve, but we can still have excellence. He said that we seem to have a general inferiority complex as a country when it comes to our achievements, and pointed out that we do not project neuroscience in Ireland well enough despite the quality of the work being done here.

For example, he said, of one hundred and seventy nominations for European scientist of the year, none were made from Ireland. He highlighted that Irish universities could work together better to advance neuroscience research, pointing to the NYC genomics consortium. He believes a similar thing could happen in Ireland in relation to a neuroimaging consortium. He noted that it is a tragedy to watch very talented researchers try to come back to Ireland and have to leave again.

*“We do not project neuroscience in Ireland well enough despite the quality of the work being done here”*





*“The introduction of additional research positions for clinical neurologists is key. By creating research-specific posts, we could build a more structured mentoring programme for neurology trainees in research”*

**Dr Eavan McGovern**, neurology fellow at St Vincent’s University Hospital Dublin, concluded the discussion on the importance of career pathways for brain researchers by stating: “The introduction of additional full and part-time research positions for clinical neurologists is key. Protected research time is too frequently missed out on by the increasing demands of clinical service. By creating research-specific posts, we could build a more structured mentoring programme for neurology trainees in research, and consider the introduction of a mandatory undergraduate programme in research project development.”

Dr Doherty stated that the HSE needs to develop academic posts and that the academic lead to be appointed for each of the new hospital groups should go some way to improving this.

Dr Doherty thanked all the panel members for a lively and focused discussion and for their contributions beforehand, which were critical in guiding the debate. He stressed the importance of a clearly articulated set of proposals arising from the conference that would outline a clear set of recommendations for supporting and promoting brain research in Ireland, and said that he would look forward to the publication of the conference report and subsequent position paper.



## Themes Emerging from NAI & Irish Brain Council Conference March 2015

Overall Panel Question: “How can Brain Research in Ireland be supported to deliver on its potential?”

Sub areas for discussion:

- (a) Funding
- (b) Career Structures
- (c) Networks and Infrastructure

### Funding to Support Brain Research

Points Emerging:

1. *Limited*: Overall, limited funding opportunities for Brain Research in Ireland
2. *Diversification*: Importance of diversified funding sources e.g. charities, industry and other entities supported through partnership programmes such as SFI
3. *International*: Importance of securing international funding through collaborative partnerships
4. Strong need for funding to support fundamental research in addition to translational research
5. *Targeted Grants*: Need for condition specific grant calls which would stipulate several research elements from basic pre-clinical to clinical research that ultimately impacts on patient care. This would facilitate collaboration of researchers across different fields with a common goal
6. *Grant Duration*: Funding in the area of neuroscience research should be to support projects over a sufficient timeline to allow for translational approaches
7. *Clinical Trials as a Source of Funding*: Participation in industry sponsored clinical trials is a competitive business and Irish centres with some exceptions have not been very successful (In 2011, Denmark participated in 929 trials, in Ireland 185). Excellence in clinical trials is vital in order for Ireland to compete and secure funding from industry

### Career Structuring to Support Brain Research

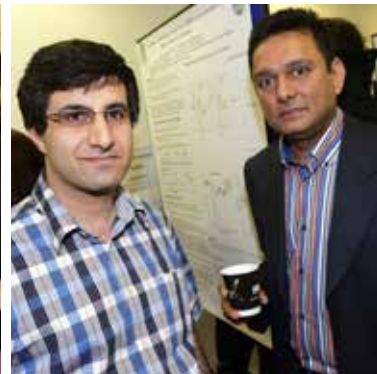
1. Funding needed to support non clinical fundamental researchers including at graduate and post graduate levels
2. Stronger collaboration between clinical and non-clinical groups
3. Importance of additional full and part time research positions for clinical neurologists in order to provide protected research time
4. Importance of creating research specific posts within clinical neuroscience

### Networks and Infrastructure to Support Brain Research

1. *Ethics Committees*: Centralised inter hospital ethics committee would be invaluable to support brain research as research frequently involves patient recruitment across multiple sites and applying to each hospital's ethics committee takes significant time, effort and paperwork
2. *Databases*: Integrated, anonymised and disease specific databases with a streamlined disease classification system are a key requirement for research into specific neurological conditions in Ireland. The existence of these databases would also facilitate the identification of potential participants for research projects.
3. *Patient Involvement*: Benefits of patient involvement in research:
  - shaping priorities for research
  - planning research protocols
  - selecting measured outcomes and establishing real world targets

However, patient involvement must be appropriate for different types of research and different patient groups. Funding applications increasingly require public patient involvement. Opportunity for Ireland to contribute to best practice in this area.

4. *Clinical Trials: Infrastructure:* Ireland's participation in clinical trials is low and problematic with low levels of recruitment in those trials which did take place here. Importance of developing excellence in clinical trials. The importance of the Irish Clinical Trial Framework as key infrastructural development in this area to:
  - promote Ireland as a high quality location for clinical research
  - provide a single point of contact for academics and industry (both pharma and device industry)
  - the network aims to provide a whole range of supports for researchers including regulatory and ethics process advice, online template documents, training and education, monitoring and audit service etc.
5. *Neuroscience Research Networks in Ireland*
  - Existing Networks:* Existing interdepartmental and inter-institutional networks of neuroscientists across a broad range from understanding brain development through to the diagnosis and treatment of neurological disorders.
  - Research Networks of Sufficient Size:* Neuroscientists will increasingly need collaborations of significant size to being together a sufficiently broad range of techniques and disciplines.
  - Access to Cutting Edge Technology for Networks:* Networks must have better access to emerging technologies; examples include transgenic/biomedical research facilities, genomics, proteomics, computational/systems biology (big data) viral gene delivery and imaging.
  - Access to Patient Samples:* Translational neuroscience research is highly dependent on patient samples (tissue, DNA, biofluids) and access to this among Irish networks is key as it is often a challenge for basic scientists.





**Members of the Irish Brain Council:**

- President of the Irish Brain Council: Dr Richard Roche, National University of Ireland, Maynooth
- Audrey Craven, President of the European Federation of Neurological Associations (EFNA) and member of the European Brain Council
- Professor Orla Hardiman, Professor of Neurology, Trinity College Dublin
- Professor Michael Gill, Professor of Psychiatry, Trinity College Dublin
- Dr Niall Pender, Senior Clinical Neuropsychologist Beaumont Hospital
- Professor Tim Lynch, Consultant Neurologist and Medical Director of the Dublin Neurological Institute
- Neurological Alliance of Ireland

**Members of the Neurological Alliance of Ireland:**

- Acquired Brain injury Ireland
- Alzheimer Society of Ireland
- Aphasia Ireland
- Ataxia Ireland
- Aware
- Bloomfield Health Services
- Epilepsy Ireland
- Cheshire Ireland
- Chronic Pain Ireland
- Dystonia Ireland
- Enable Ireland
- Headway
- Huntington's Disease Association of Ireland
- Irish Heart Foundation
- Irish Hospice Foundation
- Irish Motor Neurone Disease Association
- Migraine Association of Ireland
- Move4Parkinsons
- Multiple Sclerosis Society of Ireland
- Muscular Dystrophy Ireland
- Neurofibromatosis Association of Ireland
- North West MS Therapy Centre
- Parkinson's Association of Ireland
- Post Polio support group
- Syringomyelia support group of Ireland
- Spina Bifida Hydrocephalus Ireland
- The Rehab Group

**Associate Members:**

- Brain Tumour Ireland
- PSPA Ireland
- Irish Association of Speech and Language Therapists
- Myaware