It has been a year since I was appointed as Chair of the umbrella and it has certainly been an eventful and challenging year. Each of our organisations has very separate needs and challenges, based on the unique requirements of the people we represent. However, that still leaves room for a strong common agenda that we can deliver on most effectively through the combined strength of our organisations.

The advocacy agenda of NAI is more important now than it has ever been. The economic situation is placing enormous pressure to reduce the health spend. However, the irony is that there has never been a greater focus on neurological care and the need to develop services and supports in this area. The long NAI journey from the publication of the Standards of Care, through the Comhairle na nOspideal and the Laffoy reports has at last resulted in targeted programmes in the areas of stroke, epilepsy, neurology and rehabilitation.

2012 was a very busy year for NAI that started with a very successful lobby day in Leinster House. Brain Awareness Week in March was the most successful to date, with over one hundred events held nationwide. The development of a new NAI website provides a vital resource to publicise and promote the work of the umbrella and its members. The NAI continued to work closely with the national clinical programmes in neurological care on the development of a model of care, pathways and guidelines to support effective delivery of services. This year saw NAI working in partnership with Care Alliance, the Disability Federation of Ireland and the Irish Hospice Foundation to broaden and deepen our awareness of the needs of people with neurological conditions and our capacity to respond to those needs. The introduction of a Policy Advocacy and Campaign Forum aims to empower and support NAI members to share ideas and information and strengthen the response of the neurological sector.

What is our vision for the coming year? As a Board we will sit down and review our 2012 workplan and make our plans for 2013. The clinical programmes in stroke, epilepsy, rehabilitation and neurology have to be an important focus for NAI, both in terms of advocating for investment and in our role as watchdog, to make sure that the models of service they put in place meet the needs of the people we represent. With Ireland as the host country for the Month of the Brain, we have a huge opportunity to highlight many of our key issues under the message that we need to do so much more to meet the needs of Irish citizens with neurological conditions and that we lag far behind the rest of our European partners in this area.

I would like to thank the staff and the Board for their support throughout the year and I hope that all our members will continue their commitment to the work of the NAI in the coming year.
European Month of the Brain May 2013

The European Commission has designated May 2013 as the European Month of the Brain. As Ireland holds the EU presidency at this time, Ireland will be the host country for Brain Month. This represents a vital opportunity to highlight issues affecting people with neurological conditions in this country.

The NAI Board has taken the decision to make the most of this opportunity by moving its annual Brain Awareness initiative to May 2013, with events to take place throughout the month.

NAI is working closely with its members to ensure that Brain Month delivers important messages about neurological care in Ireland and the vital role played by the not for profit sector in supporting people with neurological conditions and their families.

Visit our website www.nai.ie to view our special Brain Month section including our online calendar of all the events happening during Brain Month. You can have your own event added by contacting sineadnai@gmail.com.

Clinical Programmes Update

Neurology Clinical Programme

The aim of the National Neurology Programme is to improve access and quality of care for patients with neurological conditions in Ireland.

It is intended to achieve this objective through:

- improved referral management;
- development and implementation of care pathways and care bundles,
- early diagnosis and treatment;
- increased OPD capacity
- appointment of additional Consultants.

Ten additional Consultant Neurologist posts have been approved for adult services. Seven new consultants are in post, and the remaining three posts are in various stages of recruitment. An additional consultant post for paediatric neurology in CUH and a paediatric neurophysiologist in each of Our Lady's Hospital Crumlin and Temple Street have also been filled.

National Rehabilitation Medicine Programme Update

Model of Care:
The Model of Care document for the rehabilitation medicine programme is currently in draft format and going through internal review with the Model of Care, Working and Consultants’ Clinical Advisory Groups. The final draft of this document will be ready for wider consultation in early 2013.

Patient and Family Involvement:
The Rehabilitation Medicine Programme is planning a series of “World Café Conversation” events. This new initiative will be innovative in developing solutions for rehabilitation and will give service users a real opportunity to guide the work of the Programme. The inaugural event took place on Wednesday 26th September 2012 in Dun Laoghaire. Minister Kathleen Lynch, Minister for Disability lent her support to the World Café initiative by attending the inaugural event. She stated that ‘I welcome this innovative project. Promoting local input to a National Programme at events like this demonstrates a clear and practical way for service users to have their views represented”.

The Neurological Alliance of Ireland (NAI) which is the national umbrella organisation for groups representing views and concerns of those affected by neurological conditions were also involved in organising the event. The Chair of the NAI, Mr. Chris Macey welcomed the initiative stating ‘Engaging people and their family members affected by a neurological condition in informal events like this is an important development.'
Clinical Programmes Update

Workstreams Update:
The Programme currently has workstreams involving expert clinicians nationally who are drafting sets of national guidelines for Acquired Brain Injury; Spinal Cord Injury and Limb Absence Rehabilitation. These workstreams are also developing associated care pathways and care bundles, which will be central to the implementation of the programme’s Model of Care in 2013.

Standards and Guidelines for the Procurement of Prosthetics, Orthotics and Specialist Footwear:
The Programme has also been developing a set of standards and guidelines, which will be central to the procurement of HSE approved prosthetics, orthotics and specialist footwear in Ireland. The Programme, in collaboration with HSE’s national procurement office engaged with relevant stakeholders in a public consultation in July 2012 and an expert group has now been established to review submissions and to make a set of recommendations for services nationally.

Managed Clinical Rehabilitation Networks:
The programme has developed a standard operating procedure for the management of clinical rehabilitation networks and hopes to pilot this initiative regionally in 2013. This will result in health professionals and organisations from primary, secondary, and tertiary care, working in a coordinated way that is not constrained by existing organisational or professional boundaries to ensure equitable provision of high quality, clinically effective care to patients, families and carers.

Rehabilitation Medicine Programme Holds World Café event

The rehabilitation medicine programme held the first of what they aim to be a series of world café events with rehabilitation service users in Dun Laoghaire on 26th September 2012.

The event was aimed at hearing directly from services users themselves about their experiences of rehabilitation services.

NAI was on hand to promote awareness of the event and to help out on the day.

The event was opened by Minister of State Kathleen Lynch who spoke about her own experience of rehabilitation in childhood and her awareness of the difficulties and challenges faced by Irish people in accessing rehabilitation services. She spoke warmly of the aims of the rehabilitation medicine programme and the NAI and their work to secure better access to rehabilitation services.

The director of the Clinical Programme, Dr Aine Carroll, spoke of her interest in hearing what people had to say, positive and negative. She stressed that this event was about really listening, not just paying lip service to people’s views. The report on the day will be integral to informing the ongoing work of the programme, including the submission to the 2013 HSE service plan. Dr Carroll recognises the huge challenges that lie ahead, in trying to develop rehabilitation services in a recession. However, the programme has a clear plan in place and the energy and commitment to achieving change.

Chris Macey, Chair of NAI, spoke about the commitment of the NAI to achieving better access to rehabilitation services. The umbrella group is working closely with the programme, as well as working actively to promote awareness and lobby political representatives about the need for investment in rehabilitation. Chris outlined the statistics that 5 out of 6 people who need to cannot access specialist rehabilitation and Ireland continues to have the lowest number of rehabilitation consultants in Europe. Chris noted that the NAI will launch a rehabilitation manifesto in 2013 which will aim to put the spotlight on Ireland’s rehabilitation services.
Rehabilitation Medicine Programme Holds World Café event

Attendees discussed and debated a series of three questions, namely:
(a) What is good about rehabilitation services
(b) What is bad about rehabilitation services
(c) What one thing would you change

Positive aspects included the expertise and commitment of staff. There was a view that when you were “in the system” you received excellent care. Attendees spoke of excellent initiatives by the not for profit sector such as MS Ireland’s “Getting the Balance Right” programme which allowed them to access physiotherapy at a level that they would not otherwise have been able to receive.

Negative experiences pointed to the sheer dearth of services at all stages. There was a particular emphasis on the lack of longer term care, with very little available in the community. Attendees spoke about the lack of clear signposting, with family members having to navigate a complex web of entitlements and information. Sometimes, families find out about a service, only to realise that the criteria are very tight and they are not eligible.

Recommendations for changes to rehabilitation services ranged from better communication among service providers to providing more access to therapists in the community.

A full detailed report on the event is being prepared by the Rehabilitation Programme and will be available in the New Year. The NAI looks forward to report being made available as it will provide a valuable insight into the views of service users and their own recommendations as to what changes need to be put in place.

Launch of the New Health Strategy: Future Health

The Government’s new plan for health reform Future Health: A Strategic Framework for Reform of the Health Services 2012 was launched on 14th November 2012.

The report details the new structures and arrangements that will take place to deliver on the health reforms outlined in the Programme for Government.

The new strategy is based on four key inter-dependent pillars of reform:

1. A focus on health and wellbeing including the establishment of a health and wellbeing agency and policy framework, representing a whole of government approach to addressing health issues
2. Service Reform: moving towards a new model of care which aims to treat people in a way that is safe, timely, effective and as close to their homes as possible. This will represent a change from the current hospital centred model of care which reacts when people become very ill, toward a more preventive and planned approach
3. Structural Reform: The strategy outlines a series of changes that will take place including the establishment of new hospital groups and a new Child and Family Support Agency to improve service delivery
4. Financial Reform: The strategy outlines the introduction of a new Money Follows The Patient (MFTP) model that will facilitate money following the patient out of the hospital system and into primary care and other related services. Funding of the new health service will be progressed through phased introduction of universal health insurance and reform of private health insurance and through improved financial control procedures within the health services.
The strategy outlines the changes that will occur in three main areas of the health system:

**Primary Care:** There will be a focus on the development of primary care through capital investment in primary care centres, development of the primary care workforce, removal of fees to improve access to GP care and improved ICT and reporting structures within primary care to allow greater communication between team members.

**Hospitals:** The strategy provides for the continued work of the Special Delivery Unit to achieve more responsive and equitable access to care, the establishment of a hospital groups and the publication of the framework for the development of smaller hospitals.

**Social and Continuing Care:** Measures include the reform of the Fair Deal Scheme to allow more people to live at home as they would wish. Reform of disability services will be in line with the recent Value for Money and Policy Review. The strategy also points to a greater community focus for mental health and the rollout of commissioning in relation to service provision. The introduction of individualised budgeting is also highlighted.

**What will all these reforms mean for people with neurological conditions?**

The NAI is closely examining the report for its implications for people with neurological conditions. While the emphasis on primary care is welcomed, this has to take account of the need for provision of specialist services to those with complex needs. The NAI welcomes the proposed development of a chronic disease framework for neurological conditions and will be learning more about how this will be designed and implemented. Reforms to ensure prompt access and shorter waiting lists for hospital based specialist care are to be welcomed. The proposed reforms of social care will have to be carefully examined as to what they will mean for people living with a neurological disability.

The NAI will be engaging with its members and with other organisations in the health and disability sector over the coming weeks to examine the strategy and what it means for people with neurological conditions and their families.

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**New NAI Website**

The long awaited new NAI website is now up and running at [www.nai.ie](http://www.nai.ie). The website aims to provide access to a range of reports and publications on neurological care, both Irish and international. A dedicated campaign centre provides up to date information on NAI's advocacy activities and how supporters can become involved. The Brain Awareness section provides a user friendly guide to Brain Awareness Week, including a county by county search for events happening in your area. NAI are using the opportunity to contact a wide range of target groups, including political representatives and healthcare staff to highlight the new website and the range of activities carried out by the umbrella.

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**Protect Neurological Care 2013**

In advance of December’s budget, the NAI has requested member groups to display a link to this item on the NAI website. We have also e mailed all TD’s and Senators in relation to this information.

**Neurological Alliance of Ireland**

**Call to Protect Supports to People with Neurological Conditions in 2013**

The Neurological Alliance of Ireland (NAI) is calling on the government to protect services and supports to people with disabilities in Budget 2013. The umbrella group represents over 30 not for profit organisations, working with people with conditions such as epilepsy, Alzheimer’s disease, multiple sclerosis, acquired brain injury and Parkinson’s disease. Over 700,000 people in Ireland are living with a neurological condition, many of which have a chronic disabling impact on their lives.

In October 2012, the NAI joined with eight national umbrella bodies in highlighting the impact of the Government’s economic measures to date on those with disabilities and the hardship that will be caused by any further cuts in December’s budget.
Effects of cutbacks on people with a neurological disability
Five successive years of cutbacks have affected key supports for people with a neurological disability. Just some examples of the wide range of cuts that have been imposed include cuts in disability welfare payments and housing adaptation grants, reduced income threshold for the drugs payment scheme and introduction of prescription charges. Cuts to home care support continue to impact significantly on people with neurological conditions.

In addition, people with a neurological disability face significant increases in the cost of living due to the introduction of a range of charges and levies including the universal social charge and the proposed household charge.

The Neurological Alliance of Ireland first national survey of carers of people with neurological conditions earlier this year found that over one third reported a significant impact of government cutbacks on their ability to care for the person with a neurological condition.

“We have to pay privately for the therapies (physiotherapy, speech and language therapies) he needs, with cuts in child benefit and more and more charges, how can we do that?”

Chris Macey, Chair of the NAI, notes “I’m not sure if people realise just how vulnerable people with a neurological disability are. They are critically dependent on the support provided by not for profit organisations. Ireland’s neurological care services are drastically underdeveloped. Recent figures from the HSE showed over 5000 people waiting for over a year to see a neurologist. The message has to be clear, once they get that diagnosis, there is very little available to them and what is available is being steadily undermined”.

Cutting funding for not for profit organisations has a disproportionate impact on people with neurological conditions
Not for profit organisations which provide specialist services and support to people with neurological conditions have sustained funding cuts of up to 14% in recent years. These organisations are often the only source of support available. Groups have been forced to cut back on essential services such as respite, home care support and helpline hours as a result of cutbacks. Fundraising by charities has been significantly impacted by the recession. A survey by the Disability Federation of Ireland showed that half of disability organisations had suffered a 17% drop in their fundraised income.

NAI’s call to protect supports for people with neurological conditions in Budget 2013
The NAI have joined with eight other national disability organisations in calling for the following steps to be taken by the Government in relation to this December’s budget:

1. A halt in reductions in the basic standard of living of people with disabilities requiring welfare supports. People with disabilities are most likely to experience real poverty because on top of the recent cuts in benefit levels and new charges, they also have to continue to pay for extras required due to their disability.

2. Ensure funding for the services needed by people with disabilities. Cutting the services required by people with disabilities not only undermines their lives, it also leads to a growing public burden in terms of hospital stays and expensive care costs. In terms of neurological disability, most of these services and supports are provided by not for profit organisations who are struggling to maintain services. In the words of one individual “Without my charity, I have no service”.

Profile of New NAI Members

We are pleased to welcome two new members to the NAI umbrella

The Irish Hospice Foundation
The Irish Hospice Foundation is delighted to become a member of the Neurological Alliance of Ireland, as it will assist us in delivering on our mission to achieve dignity, comfort and choice for all people facing the end of life. Building on one of the key objectives in our Strategic Plan, working with NAI will assist us to build capacity with patient and disease specific organisations to identify and respond to the end-of-life and bereavement care needs of people with advancing neurological disease, as well as enhancing support to their families and carers in this domain of care.
Move 4 Parkinsons
Based on her own experiences of Parkinson’s, Margaret Mullarney established Move4Parkinson’s in November 2011 to help People with Parkinson’s (PWP’s) achieve a better quality of life. The charity works to engage and support the PWP community through activities like yoga and a choir, as well as providing education and information through their patient empowerment days and website. They also raise awareness of Parkinson’s through advocacy. Central to everything they do is their Five Elements framework, which has been developed as a guide to the self management of Parkinson’s. More detailed information is available on their website www.move4parkinsons.com

Self Management

The NAI is keen to explore self management as a valuable tool for people with neurological conditions in managing the impact of their condition as well as an important framework to describe the vital services and supports provided by NAI member groups.

A joint seminar, hosted by NAI and DFI on 25th November, pointed to the key role of not for profit organisations in supporting people to self manage their condition. Entitled “Self Management: A Key Niche for Voluntary Sector Organisations” the seminar was focused on bringing together the experiences of a number of organisations which have embraced self management on behalf of the people they represent.

Mags Rogers, NAI Development Manager outlined what both umbrella groups view as the core strengths of the not for profit sector when it comes to supporting self management:

1. They have a close relationship with the person with a chronic condition or disability, often remaining in contact and working with them over a long period of time
2. They have an insight into all the aspects of the persons life in living with their condition as they take a holistic approach
3. They can provide peer to peer contact and other supports that maintain and reinforce self management thinking and behaviours over time
4. Their work is informed and led by people with the condition, so they have a track record of working with people to identify the aspects of their condition that they wish to be more involved in managing on a day to day basis.

Dr Joanne Mc Carthy, Head of Health Policy in the Disability Federation of Ireland, spoke of the importance of positioning organisations to highlight the crucial role they play in supporting people to live with neurological and other chronic conditions. Self management provides a framework and a language to outline these supports.

Dr Pat Doorley, National Director for Population Health, HSE gave the opening address on the day. He highlighted the international evidence for self management, pointing to the success of self management programmes in leading to improved quality of life, improved confidence and self efficacy, improved control over symptoms and a reduction in pain, anxiety and depression. The HSE, in co-operation with a group of patient organisations, has developed a national framework for self management. Dr Doorley noted that the publication and rollout of this framework has yet to be decided, but he recognised the key role of patient organisations in supporting its delivery.

Grainne O Leary, Director of Education and Support Services in Arthritis Ireland, outlined the details of her organisations self management programme “Living Well with Arthritis”. The Arthritis Self-Management Programme is a programme that was developed in Stanford University in the USA and is delivered by Arthritis Ireland, under licence from Stanford University. People with arthritis are trained as peer led trainers, to provide a six week course to arthritis sufferers. Research to evaluate the success of the programme has demonstrated the following impressive results.
Self Management

Those who attended the training:

- Improved their ability to cope with pain by 50%.
- Increased their amount of regular exercise by 72%.
- Improved their attitude towards living with their condition by 63%.
- Increased their knowledge of their condition by 59%.
- Showed a significant reduction in their visits to hospital and their reliance on their GP in relation to their arthritis.

The post polio support group and Move 4 Parkinsons spoke about their own experiences of self management within their own organisations. A number of critical points were made by both groups, noting that:

- Self management must be an ethos that informs all the activities of the organisation. It is not enough just to send people on a course, staff and volunteers should be trained in self management techniques and principles so that they can provide ongoing support.
- Self management courses provide a vital tool for people in managing the effects of the their condition but could they be delivered in an online or teleconference format to support people who cannot travel to a course.
- All over the world, developments and initiatives are taking place in relation to self management. Ireland needs to embrace this potential.

Discussion and questions and answers on the day referred to the importance of recognition by the HSE, both at policy level and in individual service level agreements, of the role of not for profit organisations in supporting self management.

NIA and DFI are working on a joint project plan aimed at supporting organisations to develop their capacity around self management and hope to announce details of this project early in the New Year.

Report on Deep Brain Stimulation Published

The Health Information and Quality Authority have published a health technology assessment on the provision of deep brain stimulation services in Ireland.

Deep brain stimulation is a surgical procedure for the management of motor function symptoms in people with movement disorders, including Parkinson’s disease, essential tremor and dystonia, that can no longer be adequately controlled by drug therapy. There is also the potential that this treatment can be used for other conditions.

Currently in Ireland, people are referred to DBS centres abroad for assessment, surgery and follow up care. The Irish health service funds this treatment under the European E11 (Treatment Abroad) scheme, (TAS). Since 1997 it is estimated that over 130 adults have been funded to receive DBS care through this mechanism.

The disadvantages of the scheme are that individual patients incur travel costs and significant inconvenience associated with receiving a procedure and follow up care in another country. People who are otherwise eligible may not be able to receive the treatment due to the costs and burden associated with travel.

An expert advisory group and an evaluation team from HIQA undertook the following research:

- a review of the scientific literature to summarise the available clinical evidence on the effectiveness of DBS technology and to identify guidelines and service standards for its provision in other healthcare systems
- data were obtained from a range of Irish and international experts, including dossiers submitted by commercial companies manufacturing DBS devices
- the likely costs and budget impact over five years for the Irish healthcare system was assessed
HIQA report into Deep Brain Stimulation Published

The report concludes that a national DBS service will cost the HSE more per patient treated (€20,900 more over ten years) and result in an increase in the overall cost of the service (€1.84 million more over five years) compared to the estimated €4.9 million to treat the same number of patients abroad using the current scheme. The report points out that a key factor in this analysis is the impact of private health insurance. The report recognises the current inconvenience, difficulty and distress for people having to travel overseas, but also points the demands that a DBS service would place on already overstretched neurosurgical and neurology services.

The NAI is very aware of the distress and difficulties experienced by individuals in travelling abroad for surgery and follow up and the need to make this surgery a viable option for more of those individuals who are otherwise eligible but cannot incur the cost or burden associated with travel to another country. The NAI encourages the HSE to review the recommendations carefully in this context.

Member News

Irish Heart Foundation 3rd Annual Stroke Awards

Three children aged four, seven and 10 years of age were among 14 stroke heroes honoured on the 20th November at the Irish Heart Foundation’s 3rd annual Life After Stroke Awards sponsored by Boehringer Ingelheim in the Gibson Hotel in Dublin.

The annual event hosted by Marty Whelan with special guest Dana Rosemary Scallon whose mother suffered a stroke at 91, recognised the courage of patients and their carers in their recovery from stroke. An estimated 10,000 strokes happen in Ireland annually which is more than one person struck down by stroke every hour.

Four-year-old Rebecca Lawlor from Tyrrellstown in Dublin was the youngest stroke champion to receive an award. In January this year (2012), Rebecca suffered a serious stroke which saw her spend a month in hospital followed by four months of intensive rehabilitation learning to walk again. According to her mum Irena, Rebecca’s resilience and positivity has been nothing short of inspirational. The mother of three, said: “I'll never forget the day it happened. The children had had chicken pox in December but Rebecca didn’t really show too many signs at the time. Then one day in January she fell asleep in the middle of playing which is not like her, she’s usually full of beans. We realised she had a temperature and when we placed her in a cool bath, she had a seizure so we called the ambulance.

“Rebecca was rushed into Temple Street hospital on 11th January and moved to the national rehabilitation centre in Dun Laoghaire on 7th February. Throughout her hospital stay, she had to have scans and injections but she never once complained, not even when she was in a wheelchair. We were told her recovery would take a long time but it’s amazing what they can do. By April Rebecca had started walking again. I never thought we’d get through it, but we did. She responded really well to musical therapy and we’re now closer as a family. I don’t think I’ve met anybody as brave in my life. Our Rebecca is one in a million.”

Joint Children’s Courage Awards were also presented to 7-year-old Oisin Ryan-Blake from Limerick and to 10-year-old Abby O’Keeffe from Waterford. Just one month after Rebecca’s stroke, young Oisin collapsed with a severe pain in his head which medical experts later described as a catastrophic event involving a bleed to the brain. His grandfather Denis spent every waking minute by Oisin’s bedside for 11 weeks straight, to see his grandson through a double craniotomy and eight weeks of rehabilitation. Denis said: “Oisin’s sheer willpower and determination for one so young is incredible and he keeps striving to get back to what he loves most, his sports – soccer, rugby and hurling. The last six months have been tough but Oisin has kept his mum, family and me going with a smile and joke for everyone, no matter if he was on his way to theatre or waking up after one of his procedures.”
In Waterford, 10 year-old Abby O’Keeffe only just made it home in time for Christmas last year following a gruelling recovery from stroke earlier that summer. Now Abby is learning to write again with her left hand and is back at school full time. Her mum Paula said: “Abby’s stroke completely turned our worlds upside down and has left Abby without the use of her right hand. But Abby has such an amazing spirit and this is really what has kept us going through our darkest days. Homework is a challenge and fatigue hits her hard but we just take each day as it comes. Abby never gives up and this keeps me and the rest of the family going.”

According to Barry Dempsey, Chief Executive of the Irish Heart Foundation, there are nearly 50,000 stroke survivors in Ireland today. He said: “Stroke affects tens of thousands of families every year in this country but we hardly ever hear their story. Our charity is proud to host the national stroke awards to bring to light the daily miracles and heroic efforts happening around the country in overcoming stroke. Our award winners are inspirational and they represent the strength of all stroke survivors nationwide. We hope their stories will dispel the myths that stroke only happens to older people or that it is a sentence of death. There is life after stroke, and we have the heroes to prove it.”

Marathon man Alan Corcoran from Waterford, received the Boehringer Ingelhiem Stroke Champion Award after completing 35 marathons back to back to raise awareness of stroke and raise funds for charity. The 21-year-old was inspired to take on the gargantuan challenge after watching his father, former FAI President Milo Corcoran, battle to recover from stroke. In the course of his 35-day epic run, Alan put stroke on the map not only for his father, but for thousands of survivors and their families nationwide.

Ken Murphy from Boehringer Ingelheim said: “We are very pleased to be associated with today’s event honouring those of all ages who have fought hard to overcome the effects of a stroke and those who tirelessly care and campaign for those who may have suffered a stroke. We believe Alan Corcoran’s incredible achievement running a lap of Ireland is an incredible testament to the endurance and will needed by stroke survivors in their recovery to rebuild their lives. At Boehringer Ingelheim we work hard to deliver innovative treatments to help prevent and reduce the impact of serious conditions like stroke and together with the important work of the Irish Heart Foundation, we strive to see a future with less strokes in our population.”

A further 10 awards were presented at the heartwarming event hosted by Marty Whelan to mark the incredible courage and determination of stroke survivors in Ireland, with support from special guest, iconic former Eurovision winner Dana Rosemary Scallon whose mother suffered a stroke aged 91. The award recipients included Fair City actor Jim Bartley, better known as Bela Doyle, who received the Stroke Ambassador Award for his willingness to share his own personal stroke story to raise awareness of the serious illness. Jim suffered a stroke in June 2011 when he had an operation on his carotid artery. Three months later he was back at work at his second home, the fictional town of Carrigstown.

Unable to attend the event due to filming commitments, the Irish Heart Foundation surprised Jim with his award (on Sat 17 Nov) at rehearsal when a tear-filled Jim said: “I don’t know what to say. Thank you. I am very honoured and touched to receive this Stroke Ambassador Award. We all have our tough times and there are so many stroke survivors who are equally deserving of this award and I believe this is a joint award for me and for them.”

Meanwhile thrill-seeking 72-year-old Dave Henshaw from Athy, Kildare received the Life After Stroke Award in recognition of his ‘can-do’ attitude after abseiling down buildings for charity. The active pensioner has not only survived a stroke in his life but also a heart attack and brain tumour. While paramedic Joe O’Donoghue, 50, from Clonmel in Tipperary saw the tables reversed four years ago when he became the emergency after being struck down by stroke. Now Joe is a stalwart supporter of his local stroke support group helping to spread the Irish Heart Foundation’s vital Act FAST message.
Member News

A Joint Carer’s Award went to Margaret Donoghue, 61 from Dublin for her unending support in caring for her 31-year-old daughter Karen after stroke and fellow carer Noel Kerrigan from Navan in Meath, has gotten to grips with women’s fashion and accessories to make sure his wife ‘Tiny’ of nearly 60 years is kept in the style to which she is accustomed. In Cork, Mary J Foley received the Stroke Support Group award for her dedication and tireless effort in bringing stroke survivors together in the city.

While joint winners of the Young Person’s Courage Award went to 26-year-old Rachel Dufficy from Leixlip in Kildare and to 18-year-old Ronan O’Keeffe from Trim in Meath. Both Rachel and Ronan have endured tough challenges in order to regain their mobility and get back to where they were before their strokes so they can start living independent lives. Wicklow man Brian Quinlan, aged 70 who can no longer speak, was honoured for his inventiveness in creating his very own brand of communication using nothing but a photobook, diary and a map and he received the Adult Courage Award for over 65s. In Kildare, Graham Macken didn’t hesitate to act FAST and get his wife Aisling to hospital when she went numb down one side just two weeks after giving birth to their first baby. For three months, Graham donned the dual role of both father and mother to their baby boy Karl as his young wife regained her strength and mobility. For his quick-thinking that may have saved Aisling’s life, Graham was awarded the Act FAST Award.

Brainwave Highlights Risk Associated with New Health Legislation

Brainwave The Irish Epilepsy Association held an event in Leinster House last week, urging members of the Oireachtas to support their call to exclude epilepsy medications from the upcoming Health Bill 2012.

The Health (Pricing and Supply of Medical Goods) Bill is due to be enacted before the end of the year and allows for the substitution of patent drugs with a generic equivalent.

Brainwave have highlighted that epilepsy should be a special case for exemption as there are particular side effects associated with substitution of epilepsy drugs.

Consultant Neurologist Norman Delanty outlined that while the composition of generic substitutes was the same, the way they are absorbed in the body can differ with the risk of seizures. The cost differential associated with generic substitution in epilepsy is small and is outweighed by the risk to the patient and increased risk of hospitalisation and intervention.

Brainwave point out that internationally, anti epilepsy drugs are excluded from generic substitution. A report by the HSE & Department of Health and Children in (Moran Report) recommends the exclusion of AED’s (anti epilepsy drugs) but the current Health Bill ignores this.

Over 33 TDs attended the event which received coverage in the media, including the Irish Times Health Supplement.
Migraine Association: Report on International Headache Congress

The European Headache and Migraine Trust International Congress (EHMTIC) took place last September in London. This is a biennial event where opinion leaders and researchers present the latest data on headache research and discuss and debate current topics.

It is considered one of the foremost international events for neurologists, physicians, scientists, researchers, and international experts and healthcare professionals with an interest in migraine and headache disorders. Since 2007 Audrey Craven (President of the Migraine Association of Ireland) has chaired the EHMTIC Board and she had this to say about the event:

“As a patient advocate and a person living with migraine, it was my privilege to say a few words at the opening ceremony.”

“I spoke about the fact that ‘Headache’ should be positioned so that those responsible for ordering priorities allocate resources appropriately. To make this happen I called for a ‘ Coalition of the willing’, meaning all stakeholders working in unison to ensure a more equitable distribution of limited funding. Stakeholders include patients, researchers, health professionals, scientists, industry representatives and policy makers.”

“In order to influence key opinion leaders and those ordering priorities I said we must agree to collaborate in a strategic way and to make our case based on evidenced based data.”

This year Audrey received an award in recognition of her tremendous work over the last five years. The next congress will take place in Copenhagen 2014. For more information visit www.ehmtic2014.com

Generic Substitution of Neurological Drugs

The Department of Health and Children held a stakeholders meeting on 21 November to discuss the upcoming Health (Pricing and Supply of Medical Goods ) Bill which will allow for generic substitution of patent drugs with a generic equivalent.

Presentations from this meeting can be viewed on the Department of Health and Children’s website at http://www.dohc.ie/issues/reference_pricing/

The NAI has consulted with its member organisations on this issue and has offered its support to members who have individual concerns. NAI is aware that an exemption list is available in other jurisdictions where such legislation has been passed, including in Northern Ireland. No such exemption list has been proposed in an Irish context.
Tea Party for MS Ireland

MS Ireland hosted a Thank You Tea Party on the 21st November for all those who took part in our Access To Treatments campaign which aimed to improve access to various MS therapies. The campaign ran around World MS Day at the end of May and raise awareness about an infusion therapy only available in a few places around the country and a new oral therapy not being funded at all.

MS Ireland and our members and friends wrote and contacted many TDs, Senators and government and HSE officials about the issue. We asked people with MS to speak to the media about their experiences and we worked closely with many organisation who shared our belief that therapies should be available to people with MS if they are approved and licensed and deem appropriate for them by their neurologist.

Our campaign - and the work of many other organisations - meant that the oral therapy became available in September. We are now in talks with the HSE on how to fund all therapies and generally improve the care received by people with MS through the healthcare system.

The campaign hinged on a successful partnership approach and worked with many organisations like the Irish Pharmaceutical Healthcare Association, The Neurological Alliance of Ireland, The Irish Platform for Patient Organisations, Science and Industry and the pharmaceutical industry.

MS Ireland wishes to thank Novartis for sponsoring the event, Prof Orla Hardiman for supporting the campaign and speaking at the event and Grainne Kelly, a person with MS who spoke about her journey with MS.
We look forward to bringing you our next newsletter with all reports and photos from Brain Month. In the meantime, please continue to check out our website, www.nai.ie for frequent updates. You can also find us on Twitter (@_naireland) and Facebook (Neurological Alliance of Ireland)