



Epilepsy News

Shining a light on epilepsy

Epilepsy Ireland Issue 76 Spring 2017

Over 500 cyclists get
'on their bike' for
Saddle Up For Epilepsy



IN THIS ISSUE:

- Epilepsy Ireland's new Strategic Plan
- Launch of SENSE study
- The return of #iseebeyond
- A Smell of Burning excerpt

CONTENTS

3. News Update
4. Strategic Plan
5. #iseebeyond phase two
7. Lorraine Lally – would you employ me?
8. SENS E Launch
9. Model of Care Launch
10. Smell of Burning extract
11. Kate Maher
12. Puppet Workshop
13. Film Workshop
14. Fundraising
15. Regional Events

NOTE FROM THE EDITOR

Conor Culkin



Welcome to the first issue of Epilepsy News for 2017. Since our winter edition there have been many significant events that have contributed to the hard work of Epilepsy Ireland. Pictured on the front cover is John Niland, one of over 500 cyclists who took part in the third Saddle Up For Epilepsy in County Mayo. A selection of photos from the day are featured on page 14.

Last year Epilepsy Ireland reflected on 50 years of service but we are now looking ahead with our Strategic Plan (2017-2021). Ireland Rugby Head Coach Joe Schmidt again showed his support for EI at the recent launch of the document and stressed the "importance of having a plan". You can read some of our aims for the next five years on pages 4 and 5 as well as some photographs from the launch in the Royal College of Physicians of Ireland.

This time last year we started our #iseebeyond campaign and we are

delighted to unveil its second phase which encourages employees to reward their employer for being supportive of hidden disabilities. Full details are on page 6 and Barrister, Lorraine Lally reveals her challenges of working with a hidden disability on the next page.

Epilepsy Ireland is always striving for ways to improve treatments of the condition and you can read details of the exciting new SENS E and Model of Care programmes on pages 8 and 9.

Epilepsy News frequently publishes human interest stories that people can relate to and on page 10 we have an extract from Colin Grant's award winning book: "A Smell Of Burning" which reveals the history of the condition relating to his brother's diagnosis. On the following page we have the penultimate part of Kate Maher's journey with epilepsy, as she seeks a second opinion.

Finally, I'd like to wish the best of luck to all our readers for the year ahead and hope you enjoy this spring issue of Epilepsy News.

TRAINING FOR SUCCESS 2017

NOW ENROLLING



Even though the course is only available in Sligo, we've had students from all 26 counties across Ireland. Indeed, TFS is the only course of its kind anywhere in Europe!

Students participate in a wide variety of activities including lectures, tutorials, presentations, assignments, portfolio development, project work, discussion groups, one to one supported training, goal-setting, peer learning, outdoor pursuits and much more.

Pictured is Michaela Murphy, one of TFS's most recent graduates. "Training for Success is something I will look back on very fondly and with a lot of warmth and happiness. With the team at Training for Success I never felt alone or that I wasn't being heard because there is always someone there to listen to you", she said.

Epilepsy Ireland's award-winning Training for Success course is currently recruiting for the new one-year course starting in August 2017.

Based on campus at the Institute of Technology Sligo, the course has had over 250 young people with epilepsy attend since its' inception in 1998.

For more information please contact Honor or Maire on 071 9155303.



249 Crumlin Road,
Dublin 12.

Tel: 01 4557500

Fax: 01 4557013

Email: info@epilepsy.ie

Web: www.epilepsy.ie

Registered Charity Number:
20010553

CHY Number: 20010553



Design and layout by
PlipSpace.com

Printed by Doggett Print & Design



International Epilepsy Day increases awareness

International Epilepsy Day took place on February 13th and Epilepsy Ireland used the day to focus on awareness of the condition in the workplace. Epilepsy awareness was spread across all communications platforms on the day. Some of the highlights included:

- Patron Rick O'Shea talking about the condition on RTE's Today programme
- Epilepsy News contributor Kate Maher told her story to the Irish Independent
- The hashtag #EpilepsyDay was a number one Irish Twitter trend throughout the day
- Over 14,000 people have viewed Karen Lee's personal story video on Epilepsy Ireland's Facebook page (pictured above)

International Epilepsy Day is a global event which aims to promote awareness of the condition right around the world in more than 120 countries. It aims to increase visibility of epilepsy and encourage discussion about it worldwide with educational activities.

GO goo.gl/8Quku7

Epilepsy Ireland release results of new Valproate Survey

Epilepsy Ireland conducted our third online survey on valproate awareness between November and December 2016.

The aim of the survey was to determine the levels of awareness around the restrictions on valproate use; the risks involved for women of child-bearing potential and the level of communication taking place between patients and their medical teams on the issue.

The survey revealed that over half of those surveyed have had face to face discussions with their medical team on the issue in the past two years, while almost 8 in 10 people are now aware of the risks associated with the drug. Both

findings represent a major improvement from our 2015 studies.

The latest survey relies on a smaller sample size than previous surveys. However, the available information clearly shows that there are improvements in both awareness of the risks of valproate and in communication between patients and professionals on the issue. While this is to be welcomed, we believe that more can be done to improve awareness and communication further. Every woman or parent of a girl on valproate should know the risks and have had the issue raised by their prescriber in the past two years.

The HSE 'toolkit' is available to download via the link below.

- GO** 1. More info: goo.gl/IGWrGk
2. Toolkit: goo.gl/nWDOKd

Apple Watch tracks causes of seizures

Research using an Apple Watch app to monitor seizures in people with epilepsy has found that stress and missed sleep are frequent triggers. These findings are according to a recent study at the American Academy of Neurology's 69th Annual Meeting in Boston.

For 10 months, 598 people signed up to track their seizures with an app called EpiWatch built using ResearchKit, a software framework designed by Apple to make it more convenient for researchers to collect data more regularly and more accurately from participants using iPhone and Apple Watch. Over 1,500 seizures were recorded.

When participants felt a seizure aura starting, they opened the app and using the Apple Watch's sensors, EpiWatch recorded participants' heart rate and movements for 10 minutes. The app asked them to perform tasks to test responsiveness. After the seizure ended, participants were given a brief survey about seizure type, aura, loss of awareness and possible seizure triggers.

Stress was linked to 37% of the seizure activity, with sleep deprivation accounting for 18%, menstruation for 12%, and over-exertion for 11%. Other notable triggers included diet, missed medications and fever or infection. Interestingly, seizure triggers did not seem to depend on the type of seizure the participants reported.

GO goo.gl/4WZUTk



Epilepsy Ireland's new North East CRO

We are delighted to announce Mary Baker as the new Community Resource Officer for the North East. Mary replaces Noreen O'Donnell who retired in late 2016 after 14 years as our CRO covering counties Louth, Meath, Cavan and Monaghan.

Mary is originally from Cork but has lived in Dublin and Meath for many years. She is a graduate of Social Science from UCD and then went on to complete her Masters in Regional and Local Development at DIT. Mary has 16 years community sector experience, which included working with Dublin based partnership companies where she gained a broad range of experience.

You can contact Mary in our Dundalk office on 042 9337585 or email her on mbaker@epilepsy.ie

GO goo.gl/Ss5Cit

Dublin Chamber raises €33k for Epilepsy Ireland & Father Peter McVerry Trust

Dublin Chamber of Commerce, the organisation which represents businesses in the Dublin region, recently announced that it raised over €33,000 in 2016 for its two chosen charities - the Peter McVerry Trust, and Epilepsy Ireland.

Mary Rose Burke, CEO of Dublin Chamber said: "Epilepsy Ireland provide a fantastic support for the 37,000 people in Ireland who suffer with epilepsy. We hope that the money we have raised will go some way to allowing them to continue the essential services they provide throughout the country."

A huge thank you to Dublin Chamber and Epilepsy Ireland will continue to be a partner charity in 2017.

GO goo.gl/r2Hk6g

EPILEPSY IRELAND'S NEW STRATEGIC PLAN 2017-2021

Epilepsy Ireland's new Strategic Plan for the next five years has been published.

Officially launched in December by Ireland Rugby Head Coach Joe Schmidt in the Royal College Of Physicians of Ireland, the Plan has been developed over an 18-month period with input from a wide range of stakeholders, including Epilepsy Ireland members, service users, volunteers, health professionals and staff.

Over the next five years, Epilepsy Ireland aims to protect and maintain existing services and activities, while also developing in new directions to ensure we continue to meet the needs of people with epilepsy and their families in Ireland.

Built into the six Strategic Aims are 21 Strategic Objectives (see page 9) that we will endeavour to meet during the five year period of the plan, subject to suitable funding streams becoming available and being maintained.

The Plan is ambitious and many challenges lie ahead, particularly in resourcing our objectives but with the support of existing and potential funders; our members, volunteers and fundraisers; the wider epilepsy community and the general public, we believe that Epilepsy Ireland can continue to work towards a society in which no person's life is limited by epilepsy.

To download a copy of the new Epilepsy Ireland Strategic Plan 2017-21 log onto:

goo.gl/TRdxXi.

You can also watch an excerpt of Joe Schmidt's speech via this link:

goo.gl/zwvuAn.



Epilepsy Ireland CEO, Peter Murphy, Ireland Rugby Head Coach, Joe Schmidt, Epilepsy Ireland Chairman, Mark Dowdall and Patron, Rick O'Shea



Joe Schmidt discussed the importance of 'having a plan'



Epilepsy Ireland board member Carol Saarsteiner and Dr Amre Shahwan, Temple Street Children's University Hospital



Joe Schmidt speaking in Dun's Library, RCPI

Strategic Aim #1 : To provide quality and relevant support, information & advice, meeting the needs of people with epilepsy, their families and carers, professionals and the wider community

Strategic Outcome #1: People with epilepsy, their parents and families, and those with an interest in epilepsy are supported with, and are well informed about, the condition of epilepsy.

Objective #1. Providing a high quality support and advice service for people with epilepsy, their families and carers

Objective #2. Developing service user participation, involvement and peer-to-peer opportunities

Objective #3: Supporting service user needs for aids & appliances

Objective #4: Supporting children and young people with Epilepsy

Objective #5: Reaching particular groups with specific needs

Objective #6: Building relationships with professionals and shared working

Objective #7. Supporting Adult and Transitional Nursing Services

Strategic Aim #2: To communicate effectively with stakeholders; to raise awareness and to improve public understanding of epilepsy; and to advocate for the rights of those with epilepsy, their families and carers.

Strategic Outcome #2: Broader groups in society and the general public have a strong understanding of epilepsy – how it affects people and what it is, and how to respond to the condition appropriately.

Objective #8: Ensuring active and ongoing communication and awareness about epilepsy to key target audiences

Objective #9: Prioritising issues of risk, safety and SUDEP in our communications and across all areas of the organisation

Objective #10: Representing and advocating for the rights of those with epilepsy

Strategic Aim #3: To provide relevant training and education services to people with epilepsy, their families, and healthcare and other professionals

Strategic Outcome #3: Groups and individuals with an interest in epilepsy improve their knowledge and skills through engaging with relevant training activities provided by the organisation

Objective #11: Providing quality training, education and self-management programmes to people with epilepsy & parents of children with epilepsy.

Objective #12: Providing Epilepsy Awareness & Buccal Midazolam training and information

Objective #13. Providing educational seminars, conferences and events

Objective #14. Developing website and online educational resources

Strategic Aim #4: To undertake, encourage, fund and communicate research into the causes of, cures for and management of epilepsy and into the social and psychological effects of the condition

Strategic Outcome #4: Epilepsy Ireland contributes to the body of research relating to epilepsy causes, cures and management and this research is effectively communicated to stakeholders.

Objective #15. Providing research funding and supports to encourage and support Irish research

Objective #16. Communicating research findings & volunteering opportunities and advocating for research

Strategic Aim #5: To support people with epilepsy by raising the funds necessary to ensure the short-term funding requirements and long term sustainability of the organisation

Strategic Outcome #5: The organisation is sustainable and continues to develop and deliver its services over the long term

Objective #17. Providing and developing the financial resources required to operate the organisation to its full potential

Objective #18. Managing and building relationships with key funders

Strategic Aim #6: To operate a stable progressive organisation meeting all regulatory requirements and striving to implement best-practice standards in the areas of governance, organisational quality, human resources and financial management

Strategic Outcome #6: The organisation demonstrates best practice in the areas of governance, quality, human resources and financial management.

Objective #19: Operating good governance, financial management and managing organisational resources

Objective #20: Supporting people who are working or volunteering in the organisation

Objective #21: Operating the organisation in line with recognised operating standards and ensuring that we provide a service which is informed by wider national and international models of working

EPILEPSY IRELAND AND HEADWAY EXPANDS

#ISEEBEYOND CAMPAIGN



Caroline Earley, Community Reintegration Officer at Headway Ireland, Cathal McCoy (Headway Client) Rick O'Shea, Epilepsy Ireland Patron, Rebecca Cunningham (Headway Client) and Kieran McCullagh, Community Re-Integration Officer at Headway Ireland

Epilepsy Ireland and Headway have issued a call for those in the workplace living with a hidden disability to nominate their employer in the 'National Hidden Disability Awards 2017'.

There are 37,000 living with epilepsy and an estimated 30,000 people in Ireland living with an acquired brain injury.

A national survey conducted by Amárach shows that 7 in 10 people would not feel comfortable telling their employer they had a disability and 9 in 10 employees in Ireland show that workplaces lack awareness of hidden disabilities.

CEO of Headway, Kieran Loughran commented:

"A hidden disability can be easily overlooked. It is important that people without a disability take a moment and think before pre-empting any situation. We hope to create a national conversation that helps illuminate any stigma that is aligned with a hidden disability and of course celebrate the companies that have made a positive impact with their employees".

CEO of Epilepsy Ireland, Peter Murphy said:

"Epilepsy Ireland's vision is to achieve a society where no person's life is limited by the condition. This campaign wants to honour and recognise companies that have played a huge part in believing in their employees.

Well-known radio presenter Rick O'Shea has worked with Epilepsy Ireland for over ten years and was diagnosed with epilepsy at aged 16, also commented: "I am thrilled to be here today to show my support for the #iseebeyond campaign".

"Living with any disability can be difficult, but when the disability is not visible unfortunately stigma can be attached.

"As a society we need to stop and think for a minute before assuming anyone's circumstance. Epilepsy Ireland and Headway are doing a fantastic job of highlighting hidden disabilities and today are encouraging employees to nominate their company in the 'National Hidden Disability Awards 2017'.

"I would urge people to start talking about this important topic. And always remember never judge a book by its cover".



Rebecca Cunningham (Headway Client), Epilepsy Ireland Patron, Rick O'Shea and Karen Lee, a person with epilepsy

#iseebeyond is supported by six videos which tell a short story of people that live and work with a hidden disability. The videos promote a positive message towards people living with a hidden disability in the workplace.

If your employer is hidden disability friendly, log onto www.iseebeyond.ie to nominate. Examples of good practice in supporting employees with hidden disabilities include:

- Fully understanding the disability
- Discussing the full implications of the disability
- Investigating the supports that may be needed
- Implementing necessary changes to ensure safety
- Arranging for co-workers to be trained/ informed to support the employee
- Making allowances for medical appointments
- Providing accessible technologies at work
- Ensuring that company policies are inclusive and accessible

You can also find #iseebeyond on Facebook, Twitter and Instagram.



Epilepsy Ireland CEO, Peter Murphy and Headway CEO, Kieran Loughran



Galway native Lorraine Lally works as a Barrister in Dublin. Like many people with epilepsy across the country she faces numerous challenges in the workplace but does not feel burdened by her condition. Here she writes about hidden disability, the theme of the Epilepsy Ireland/ Headway #iseebeyond awareness campaign.

As an employer would you employ me? That is the question. I have two degrees and a masters. I have been practicing as a Barrister for six years. I am currently learning Spanish as part of a wonderful class of adult learners. This is partly as a result of a dream of working in another part of the world, someday.

The question is still the same though - would you hire me? Would I be a suitable employee? If you do up a job description and I tick all the boxes. Then will you offer me a contract? Will I join the payroll of your company?

Once you googled me and see that I have epilepsy - this is the issue for talented and bright people who have a hidden disability which is why there may be repercussions for disclosing their condition.

I have news for anyone with a hidden disability: you cannot control how another person will react but you can communicate the news of your condition in an educational and informative way and invite questions. I do not believe that I should have to apologise for my epilepsy. Like the birthmark in my left eye, it is part of me.

A fellow lawyer recently contacted me to say he had been diagnosed with epilepsy and asked that I not tell anyone at work. There is a right to privacy for employees but when you are in the workplace you are there to work, therefore your condition may be relevant.

I can function at a high level and a person with epilepsy needs to know what they can handle in relation to appropriate work and suitable hours possibly. There are ways employers can assist an employee with epilepsy such as flexitime and organised scheduling.

As a woman with epilepsy there is another issue that is relevant - the possibilities of pregnancy impacting on your condition. I once met a woman who when she was pregnant kept having absence seizures linked with the morning sickness. Once that stage of the pregnancy passed she was fine. The absence seizures can involve a person losing time, dropping objects, or carrying out the same task repeatedly for no reason, it is a sight to be seen in reality because people do not see it as a seizure. The same woman only noticed the seizure when she was pregnant. Her husband would joke it was the baby taking over.

I know that for an employer there are issues around insurance and health and safety. I really do understand the insurance underwriters are ruthless individuals who assess liability and aim to make a profit. There must be a place in society for support and equality of opportunity. I mention this for a reason because insurance is important but it should not be an acceptable justification for social exclusion.

We are a nation of great people. In Professor Gerard Quinn, we have one of the leading voices and advocates on the rights of a person with a disability. He presents at the United Nations and has been fighting in Ireland for decades to see real practical change to have rights implemented. We need employers to be encouraged to embrace a person's talents without perceived legal restrictions in the hiring process.

"We need employers to be encouraged to embrace a person's talents without perceived legal restrictions in the hiring process."

So back to the original question which is as an employer would you employ me? Would a condition make me unworthy of being a part of your organisation? Can you afford to hire a person with a disability? Do you need to check with the company solicitor? Do you need to revise the health and safety statement? Will your employee indemnity insurance go up next year on renewal?

What if I have the potential to innovate and revitalize your business. What if I increase profits by 63% this quarter?

And my favorite question to ask is what if you as a manager drop and have a seizure tomorrow and hit your head? Then you are confirmed as being a person with epilepsy. Your life changes with medication and routine not to mention the conversations with friends and family.

I wish at times that others got to know what it is to have epilepsy and still want all the same things. The truth is that a condition can only kill your dreams if you let it. A person can only make you feel inferior if you let them. Do not let any prospective employer make you feel less of a deserving candidate and keep applying for positions.

NURSE MODEL IMPROVES CARE



SENSE Author, Prof. Agnes Higgins (TCD), Minister of State for Health Promotion, Marcella Corcoran Kennedy and Epilepsy Ireland CEO, Peter Murphy

A new study launched in February at Trinity College Dublin by Minister of State at the Department of Health Marcella Corcoran Kennedy has found that an innovative model of care involving Epilepsy Specialist Nurses (ESNs) has had a very positive impact on the health of people with epilepsy. The study also found that ESN posts are a cost-effective way of delivering quality care to thousands of epilepsy patients and their families while reducing attendance at emergency departments.

Epilepsy Ireland estimates that there are approximately 12,000-15,000 people with uncontrolled seizures who require regular contact with secondary and tertiary hospital services.

In the last decade, 16 ESNs were recruited by the HSE's National Clinical Programme for Epilepsy (NCPE). Specialist epilepsy nurses provide a range of services to people with epilepsy including nurse-led clinics, rapid access clinics, telephone advisory services and outreach services.

In the early-mid 2000s Epilepsy Ireland advocated for new ESN roles, including the 2008 Epilepsy Manifesto "The Case for Investment" and since the establishment of the NCPE, 16 ESNs were recruited. The SENSE Report, funded by Epilepsy Ireland and the Health Research Board, found that as a result of ESNs:

- There was improved co-ordination and continuity of care, more prompt identification of problems and improved satisfaction with care;
- There was reduced attendance at emergency departments;

- People with epilepsy in the study who received care from an ESN had the same costs as those treated in a non-ESN site but experienced better outcomes in the management and treatment of their epilepsy
- People with epilepsy had increased access to specialist epilepsy care and more services available to them

People with epilepsy reported:

- improved psychological well-being
- improved sense of involvement in their care
- that they were more prepared for tests and investigations
- that they had an enhanced knowledge of epilepsy and related issues and had more confidence to self-manage their condition

Multi-disciplinary teams reported:

- Informed decision-making on diagnosis and treatment and the promotion of evidence-based practice
- Improved communication between healthcare practitioners across disciplines and services

Speaking at the launch, Prof Agnes Higgins, lead author of the report and Professor in Mental Health at the School of Nursing and Midwifery, Trinity, said: "This report is testimony to the value of nurse specialists within the health care environment. The findings provide clear evidence of the positive impact epilepsy nurse specialists have on the health and well-being of people with epilepsy and their family members. Not only did they improve people's knowledge and confidence to

self-manage, but they enhanced availability, accessibility, co-ordination and continuity of care."

Dr Colin Doherty, senior lecturer in Neurology, Trinity, and Consultant Neurologist, St James's Hospital, Dublin, said: "The SENSE study proves that specialist roles for nurses can provide added value to the management of chronic disease. But more importantly, during this time when the whole medical model of emergency care is under constant pressure, they provide the best hope for both urgent and emergency care in patients who have exacerbations of chronic disease."

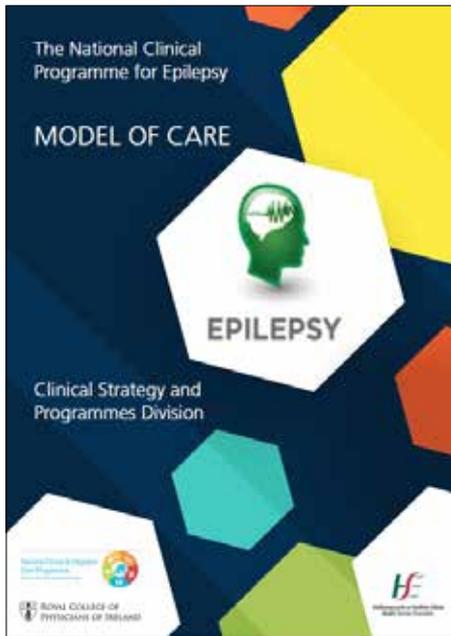
Professor Higgins concluded: "People with epilepsy and family members who were surveyed and interviewed as part of the research were overwhelmingly positive about the practical and emotional support the epilepsy nurses offered. In particular they spoke about the reassurance it gave them in dealing with their epilepsy, knowing that the ESN was only a phone call away. They were also very positive about the manner in which the ESN helped reduce their attendance at ED, reduced waiting times for services and ensured that they did not fall through the 'cracks' of a busy and stretched service."

Epilepsy Ireland CEO, Peter Murphy said: "The Irish healthcare system is frequently maligned but this study highlights the positive and innovative work that is happening in the field of epilepsy to improve the quality of care for people living with the condition."

"The research has shown that the ESN model is highly beneficial, yet cost neutral. We would therefore call on the Minister for Health, Simon Harris TD to implement the key recommendations of the study and in particular to ensure that the ESN service is expanded nationally and with a focus on groups with specific needs such as women with epilepsy, adolescents, and people with an intellectual disability."

Epilepsy Ireland would like to thank all the people with epilepsy, family members, nurses and others who took part in the SENSE study. Massive thanks in particular to Prof Higgins and her team at TCD for all their work over the past four years on the SENSE study. To read the full report log onto:

goo.gl/M291TZ



The HSE National Clinical Programme for Epilepsy (NCPE) recently launched its Model of Care document with Minister for Health Simon Harris TD.

The Model of Care sets out a vision for the transformation of epilepsy care in Ireland to provide the best patient-centred care for all people with epilepsy in the right place, at the right time, sharing the best available information.

The launch of the document is a landmark moment for people with epilepsy in Ireland and its vision of developing and improving services nationally is warmly welcomed by Epilepsy Ireland. Great credit must go to the NCPE Clinical Lead Dr Colin Doherty, Nurse Leads Maire White and Cora Flynn and the wider network of healthcare professionals who have not only developed the Model of Care, but also implemented numerous service innovations in recent years.

Speaking at the launch, Minister Harris, said, "The model of care launched today takes an integrated approach to epilepsy healthcare. It spans primary and acute settings and reflects the varying needs of people with chronic disease. It will be a blueprint for epilepsy services and will ensure that the best value and most appropriate care is provided for all."

The National Clinical Programme for Epilepsy has three core aims:

- To improve **access** to expert care and information
- To improve the **quality of care** across the healthcare spectrum from prevention, through to managed

primary care to complex surgical care for difficult epilepsy

- To improve **value** conscious care by shifting care where possible from expensive hospital based care to the community.

The key innovations of the National Clinical Programme for Epilepsy to date include;

- The creation of a cohort of registered advanced nurse practitioners (RANPs) to complement the current medical expertise to help in the management of epilepsy and to integrate it with care in the community. This will provide timely access, intelligent support to general practitioners, and outreach clinics in the community. It is anticipated that these services will reduce admissions and length of stay in acute hospitals, both of which are key performance indicators for the National Clinical Programme for Epilepsy. The SENSE report, also launched recently (see page 8) has already shown the impact that this model is having and how its expansion can continue to improve epilepsy services in Ireland.
- The development of the Epilepsy Electronic Patient Record (EPR). More than 6,500 patients are now registered on the Epilepsy EPR. It has also been identified as a demonstrator project for the Individual Health Identifier through the Office of the HSE's Chief Information Officer and is leading out on the development of precision medicine and personalised care through a patient portal within the EPR.
- The expansion of pre-surgical evaluation beds to serve the 15% of patients with highly complex epilepsy



NCPE Clinical Lead, Dr Colin Doherty

- The development and implementation in two hospitals of the Acute Seizure Integrated Care Pathway (ICP). The ICP means that anyone presenting to the Emergency Department with a first or breakthrough seizure will be treated under a standardised, evidence-based system and only admitted to hospital when necessary. The preference is not to admit but to provide fast follow up as an outpatient. The ICP has already reduced admission rates from 46% when it wasn't used, to 29% where it was used.

In addition to these changes, the Model of Care includes innovative new services like telephone/email access and outreach programmes to intellectual disability centres, regional hospitals, maternity services etc. Considerations are also given to special groups such as children and adolescents (including recommendations on Transition care), older people and those experiencing non-epileptic seizures.

It also highlights a greater role for appropriate care in the community including a bigger role for GPs and crucially also recognises the key role of Epilepsy Ireland in supporting people with epilepsy and their families. There is a strong inbuilt emphasis on self-management and patient centred care.

Full implementation will see significant changes in the way epilepsy care is delivered across the country, and while there are many challenges ahead, we hope that it will ultimately deliver more efficient, appropriate, consistent and integrated care to all people with epilepsy regardless of geographic location.

To read the full report log onto:
goo.gl/VMNxhW





'A Smell of Burning,' a Sunday Times Book of the Year, tells the story of a condition which is still widely misunderstood today. Author Colin Grant reflects on his own experiences in the book, where he details his brother's diagnosis and reveals the complex history of the condition. Below is an extract from Chapter 2: "Best Kept Secret" when it is revealed that Colin's brother Christopher has epilepsy.

Even though we were in the kitchen, at the back of the house, the drone from the M1 motorway, perhaps half a mile away, was immense.

'Is it always this noisy?' I asked my mother.

'You hear something?'

'No, it doesn't matter. I was just saying.'

I'd left home four years earlier and it was strange to think that throughout my childhood in Farley Hill that background hum of speeding cars on asphalt, fenced off from the estate, had always been there but that I'd never noticed until now.

My mum returned to the theme of the night; to the reason why I'd been summoned from medical school in London to our home in Luton, to the kitchen where we'd sat from the early evening till now close to midnight (so absorbed that as dusk had fallen we had forgotten to switch on the overhead ceiling light) with my mother drawing up an inventory of her problems. Christopher, at fifteen her youngest child,

had had two more collapses since the first a month ago.

'I grow to hate that sound, you see,' she said of the awful thud of his body hitting the ground.

We talked through the night, with the moonlight throwing shadows across the walls and kitchen table; there was really only one subject. I liked the intimacy of the dark. It made it easier to talk.

'How can he be all right one minute, and then this?'

'Christopher?'

'Yes. You never see anything?'

For as long as I could remember I'd been charged with watching over my baby brother. Christopher occupied a unique position in our family. He was the youngest, the most exuberant and happy. He seemed a blessed being who gladdened the heart of even the most miserable. It was as if, miraculously, his card had not been marked. At home, our tyrannical father Bageye threatened always to explode, but in the presence of Christopher he was disarmed.

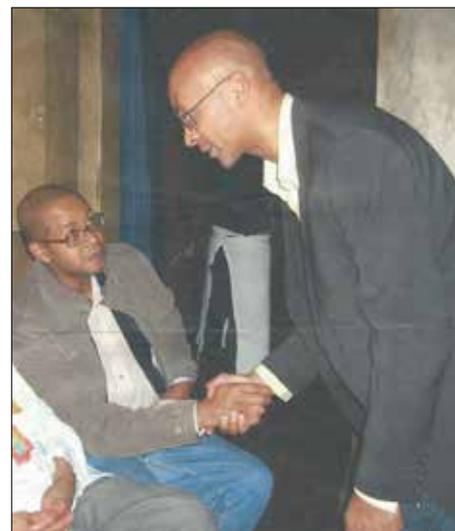
After separating from Bageye, our mother had brought up seven children on her own. She'd been constantly on the move: rushing to the town hall to pay the rent; taking on overtime at Vauxhall Motors; popping over to the neighbours to borrow just enough to ward off the bailiffs. Throughout the 1970s, 'soon come' was our mother's watchword. She would soon come from whatever emergency she'd have to fix before it was succeeded by the next one; and in the meantime, could I keep an eye on my baby brother?

It wasn't too much to ask, surely. But lately it was a role I hadn't been able to sustain as a student at the London Hospital; and Christopher's recent fainting episodes had taken her back to that decades-old daily anxiety. It had alarmed her so much, she'd sent for me for reassurance.

'Something is wrong.' Her heavy words barely supported a horrible truth that was going to come crashing down.

'Evil must have come into the house.' She meant the evil that had befallen Christopher.

'I don't think it's the devil's work. Come on now, Mum, it's not the devil. You don't really believe that. It's something else.'



Colin Grant (right) with his brother Christopher

'Tell me, then. I must know. You can tell me, you know.' I hesitated. 'I'm not sure.'

'You just there humouring me,' she said gravely. 'I carry you for nine months. I must know when my child is bluffing.'

'Well, it's, you know, it's epilepsy, isn't it? Don't you think?'

'I don't think it's the devil's work. Come on now, Mum, it's not the devil. You don't really believe that. It's something else.'

'Yes, Lord,' she cried out immediately.

'Anybody see my cross? Anybody see my cross?' She had suspected it all along but now I'd said it, the great flood of emotion burst through her chest.

She heaved. She breathed heavily, howling and wailing, 'Yes, Lord, Yes, Lord.' I could find no words to console her. I sat in silence, cowardly, averting my gaze. After some time the sobbing subsided and was driven out and replaced by the unremitting drone of the f**king motorway.

'Oh, I hear it now,' she whispered, drying her eyes. I placed a hand on her arm and slowly, snivelling, she composed herself.

'Don't tell him a thing.' 'Who? Christopher?' 'Don't tell him a thing. Promise me. I beg you.'

Extracted from *A Smell of Burning: The Story of Epilepsy* by Colin Grant (Jonathan Cape, £16.99) which can be purchased on [Amazon.com](https://www.amazon.com).

THE DISCOVERY OF MY CORRECT DIAGNOSIS



In the third part of her series of articles charting her personal journey with epilepsy, Kate Maher spoke about her worsening seizures and a need for answers. In this piece she reveals how a trip to London answered many questions about her epilepsy.

In my mid-twenties I was beginning to reach boiling point. I invariably remained the sole witness to each of my seizures. My 2009 MRI scan had been reported on as clear. So what could be causing these daily seizures I would wonder? As I shared great memories with wonderful close friends, I continued to remain in denial of my epilepsy however clinging onto the stigma and fear of admitting it to work colleagues. In the years following this scan the seizures increased in frequency and length. I was having 4 to 5 complex seizures alone; along with 3 to 4 simple partial seizures per day. The simple partial seizures were much easier to hide. I began to see my consultant every six months, giving him copies of my seizure diary. Little changed however occasionally my medication would be slightly altered. I was on Tegretol Slow-Release 400mg and Lyrica 150mg twice daily at this time.

What was changing at this point however, was my body, my mood and my psychology. Each time I now attended my doctor I would begin to cry. Seriously what was causing these seizures? There must be an answer, surely? So in early 2012 there came a point where I cracked. I went into the doctor's room once again but this time

I was angry. Angry that so little had been done. I now wanted and needed a second opinion, no longer could I put my trust in this particular neurologist. So I asked him, who is the best Neurologist in either the UK or Europe. I wanted and needed another opinion. He gave me the name of Professor John Duncan who works in the National Hospital for Neurology and Neurosurgery based in London. That July I travelled to London with my father filled with nervousness and hope.

Sitting in the waiting area I was armed with various reports and my 2009 scan films. Professor Duncan then appeared and called me in. He welcomed us both, before obtaining an extensive medical history from me. After our conversation he looked at my scan films. He placed the films up against the window and for a minute studied them closely. A minute that to me felt like a year. His head then began to shake. Inviting me over to the window, he pointed out an area of the brain known as the hippocampus. The hippocampus lies on either side of the brain and is primarily responsible for memory and language. He pointed out and explained how my left sided hippocampus appeared to be whiter and more swollen than my right. He believed most likely that my convulsion at 7 months of age had caused this scarring. Sitting me back down

“Each time I now attended my doctor I would begin to cry. Seriously what was causing these seizures?”

he said “from this scan it looks like you have left sided hippocampal sclerosis, Kate”.

Shock would be too mild a word to explain how I felt hearing this. I had always had a slightly poorer memory than everyone else. Something I just thought was down to pot luck. Now however, perhaps not. Perhaps this scar was causing my memory weakness. Upon leaving, my father and I sat down in the first “Greasy Spoon” café that caught our eye. Sipping our tea we stared at the two words he had written down for us, “hippocampal sclerosis”. From a 2009 scan that in Ireland supposedly had “No Abnormalities Detected”, in London imperfections were spotted. Perhaps now an answer was beginning to come into view. A vision of my epilepsy was beginning to become clearer, as my fog surrounding it was starting to lift.

In the summer issue of Epilepsy News, Kate will reveal the huge decision to opt for brain surgery.



Kate sought a second opinion in the National Hospital for Neurology and Neurosurgery, London

FLUFFY AND FRIENDS: PUPPET WORKSHOPS

WITH EPILEPSY IRELAND



Epilepsy Ireland's Director of Services, Wendy Crampton explains the return of the puppet workshop classes.

Epilepsy Ireland in partnership with Helium Arts hosted a series of puppet-making workshops for children with epilepsy and children whose parents

have epilepsy in Galway, Cork and Dublin in spring of 2016. The workshops provided a space for the children to come together and meet other children with epilepsy and to explore epilepsy in a fun and non-threatening environment. Parents had the opportunity to share and learn from each other as the children interacted.

Led by puppeteer Niamh Lawlor, the children explored story-making, characterisation and puppet play and put on a short performance for parents.

The world of Fluffy and friends

In the workshop for the younger children (4-7 years), they are introduced to a puppet character called Fluffy who is feeling shy and not very well as she had a seizure that morning. To make her feel better the children are encouraged to make her some sock puppet friends. So the creativity began with parents and children using a variety of art materials to make their own sock puppet characters. The workshops ended with their puppets meeting Fluffy and telling her it's okay as they know how she feels.

Talking about epilepsy in a fun, relaxed way through puppet characters removed the fear factor that might otherwise inhibit the children. When Fluffy told them about taking her medication, they nodded and offered advice. Parents remarked on the importance of seeing their children express what they understood about epilepsy and how they felt about it.

Puppet TV

The older children (8-11 years) had an opportunity for their puppets to be on Puppet TV and to tell the audience anything they wanted to say about epilepsy. The puppets let it be known that they had lots of hobbies and epilepsy wasn't going to stop them doing all the things they wanted ... they'd even learned to sew that very day!



The interactive nature of the workshops – bonding through puppet-making, performing on Puppet TV – was a highlight for many parents. Being able to talk with other parents about their experiences with GPs, schools and general attitudes to children with epilepsy was also considered very beneficial.

Epilepsy Ireland and Helium are delighted to announce another series of puppet workshop over the next three months in Dublin, Cork and Galway. We all look forward to the classes and I would encourage you to spread the word among your friends and family.

'She came home telling stories about fluffy (the puppet) having epilepsy like her...she was nearly excited to have epilepsy all evening because the puppet had it...I came away with a light heart and a happy head and it was lovely to be able to sit down and relax and know that no matter what happened that day, nobody would bat an eyelid because we were all in the same boat...' – Parent

For bookings please contact the Epilepsy Ireland Head Office on (01) 4557500 or contact your nearest Regional Office. Please see www.epilepsy.ie for further details.

CORK

Saturday 7th May 2016
4 – 7yrs 11am – 1.15pm
8 – 11 yrs 1.30pm – 4pm

DUBLIN

Saturday 23rd April 2016
4 – 7 yrs 11am – 1.15pm
8 – 11yrs 1.30pm – 4pm

Children must be accompanied by an adult.

Epilepsy Ireland and Helium Arts present

Spring Film Workshops

For young people aged 16-21 living with epilepsy

CORK [Nano Nagle Place, Evergreen Street]
Saturday 25th March | 11am – 4pm

Hands on introduction to

Filmmaking and Plot Generating

- Workshops with lunch provided
- All workshops are FREE
- Workshops led by professional artists from Helium Arts

To REGISTER for a workshop contact your regional office –

Cork (021) 4274774 Niamh/Loretta

Your Story, Your Way. These workshops offer a taster of what's to come during a film camp in Summer 2017 and some of the creations will feature in the final film! Contact Epilepsy Ireland for further details about the Summer Film Camp 2017

www.epilepsy.ie
www.helium.ie

Tel +353 (0) 1 455 7500 Email info@epilepsy.ie
249 Crumlin Road, Dublin 12, D12RW92, Ireland



Saddle Up For Epilepsy 2017



A massive thank you to everyone who took part and supported the 2017 Saddle Up For Epilepsy. Over 500 cyclists of all abilities and from across the country took part with over €20,000 raised so far. An Taoiseach Enda Kenny again showed his support by officially starting the cycle.

Everyone at Epilepsy Ireland would like to thank Event Organiser

Brenda Quigg, the organising committee and all the sponsors who supported the 3rd Saddle Up For Epilepsy. For the third year in succession numbers have increased and we are already looking forward to the 2018 event.

To see more photos from the day and a special video of the event, check out the Saddle Up For Epilepsy Facebook page.



Rose Week Appeal

Thanks to all our Rose week volunteers who bought and sold roses for us and to all the colleges and schools who also supported our Rose Appeal as well as everyone who made a donation to our text line. Pictured left is Rob Cullen from Dublin Chamber who was one of the many who sold Roses last February.

Penneys raises hundreds!

Thank you to Rachel McCormack and the staff of Penney's Kilkenny (right) who raised a fantastic €500 for our charity. Well done all.



Thank you

- Sincere thanks to all who donated funds of €1,427 in memory of Sorcha Daly who passed away recently
- Thanks to everyone who bought and sold our Christmas cards and Calendars in our 2016 Christmas appeal
- Charlie Ruxton, Cork, who raised €300 from the Recent Movember event
- Thanks to Ann McGlynn and Clare from Roscommon who made a donation to us of €1,628
- West Cork Bar Association, McCarthy & Co Solicitors who donated €1,000 to Epilepsy Ireland

REGIONAL EVENTS

SOUTH EAST

(Co's Kilkenny, Carlow, Waterford, Wexford and South Tipperary)

Contact: Joan Ryan, Community Resource Officer, Epilepsy Ireland, c/o HSE, St. Joseph's, Waterford Rd, Kilkenny. Tel: 0567789904. Email: jryan@epilepsy.ie. Office Hours: Mon, Tue, Wed 10am - 5.30pm; Thur 10am - 2pm

Upcoming Events

Kilkenny: New Diagnosis Group Toolkit

Epilepsy Ireland Office, Kilkenny
Thursday 30 March
Time: 10.30am - 1.00pm

Waterford: National Epilepsy Week Information Stand

Waterford University Hospital
Tuesday 16 May
10.30am - 4.00pm

CORK

Address: Epilepsy Ireland, 35 Washington Street, Cork. Tel: 021 4274774

South Lee & West Cork: Niamh Jones, Community Resource Officer. Email: njones@epilepsy.ie. Office Hours: Mon & Tue 8am - 4.30pm; Wed & Thur 8am - 1pm

North Lee & North Cork: Loretta Kennedy, Community Resource Officer. Email: lkennedy@epilepsy.ie. Office Hours: Tue, Wed, Fri 9.30am - 5.30pm; Thur 1.30pm - 5.30pm.

Upcoming Events

Cork: STEPS for PARENTS of Children with Epilepsy

Bru Columbanus, Wilton
Starting Tuesday night 14th March for 4 weeks
7.00pm - 10.00pm

EAST

(Co's Dublin, Kildare, Wicklow)
Contact: Carina Fitzpatrick, Community Resource Officer, Epilepsy Ireland, 249 Crumlin Road, Dublin 12. Tel: 01 4557500. Email: imurphy@epilepsy.ie. Office Hours: Mon, Tue & Wed, 10am - 6pm; Thur 1.30pm - 6pm

Upcoming Events

Dublin: Support & Information and Toolkit Group for People recently diagnosed with Epilepsy

Carmelite Community Centre, 56 Aungier St. Dublin 2
Wednesday March 22nd
6.00pm - 9.00pm

Tuesday March 28th
6.00pm - 9.00pm

Commencing Thursday April 27th for 6 Thursday afternoons
2.00pm - 5.00pm

Tuesday May 2nd
6.00pm - 9.00pm

Commencing Monday May 8th for 4 Mondays
6.30pm - 9.30pm

Bray: Outreach Service

Bray Health Centre
Wednesday May 10th
10.00am - 4.00pm

Leixlip: Seminar for Women Living with Epilepsy

Springfield Hotel, Leixlip Road, Leixlip, Co. Kildare
Monday May 15th
6.30-8.30pm

Guest Speaker: Sinead Murphy
Epilepsy Nurse Specialist,

Dublin: Seminar for Women Living with Epilepsy

Talbot Hotel Stillorgan Road, Dublin
Wednesday June 15th
6.30-8.30pm

Guest speaker: Sinead Murphy
Epilepsy Nurse Specialist

Dublin: Film Summer Camp for Young People Living with Epilepsy 16-21 years

IMMA - Irish Museum for Modern Art, Royal Hospital, Kilmainham, Dublin 8
July 3rd to July 7th

NORTH WEST

(Co's Donegal, Sligo & Leitrim)

Contact: Agnes Mooney, Community Resource Officer, Epilepsy Ireland, Grand Central Complex, Floor 2B, Canal Road, Letterkenny, Co Donegal. Tel: 074 9168725. Sligo Office: Epilepsy Ireland, 2C Castle House, Castle Street, Sligo. Tel: 071 9141858. Email: amooney@epilepsy.ie. Office Hours: Mon, Tue, Wed 9am - 5pm; Thur 9am - 1pm.

Upcoming Events

Donegal: Support Group Meeting for Parents of Children with Epilepsy

Spraoi agus Sport, Carndonagh, Co. Donegal
Thursday March 23rd
11.00 - 12.30pm.

Sligo: Outreach Service

Epilepsy Ireland Sligo Office
Tuesday 11th April - 10.00am to 12.00pm
Monday 15th May - 2.00pm to 3.30pm
Tuesday 30th May - 10.00am to 1.00pm

Donegal: Neurology Out patients Clinic

Out Patients, Scally House, Letterkenny
Date 5th April 2017
Date 31st May 2017
Agnes will be available to meet with you at Dr Murphy's Clinic. Please to confirm dates.

Donegal: Women & Epilepsy Seminar

Station House Hotel, Letterkenny, Co. Donegal
Saturday 8th April
10.00am - 12.00pm

Health & Well-being for women workshop with Epilepsy Specialist Nurse

Sinead Murphy, Clinical Nurse Specialist in Community Services

Donegal: STEPS programme for parents of children with epilepsy

Station House Hotel, Letterkenny, Co. Donegal
Monday 27th March & Monday 3rd / 10th & 24th April
6.00pm to 9.00pm.

MID-WEST

(Co's Limerick, Clare & North Tipperary)

Contact: Anna Kelly, Community Resource Officer, Epilepsy Ireland, Social Service Centre. Henry St. Limerick. Tel: 061 - 313773. Email: akelly@epilepsy.ie. Office Hours: Mon 9.30am - 5pm; Wed 9.30am - 5.30pm; Thur 12.30pm - 5pm; Fri 11.30am - 4pm.

Upcoming Events

Limerick: Innerwise workshop
Kilmurry Lodge Hotel, Limerick
Saturday 25th March
9.30am - 4.30pm

Limerick: Group toolkit morning

Limerick Education Centre, Dooradoyle,
Monday 3rd April
10.15am - 12.30/12.45p

Limerick: Group toolkit morning

Limerick Education Centre, Dooradoyle,
Monday 8th May
10.15am - 12.30/12.45pm

Limerick: Epilepsy Awareness Presentation

for teachers and SNAs
Kilmurry Lodge Hotel,
Monday 10th May
7.00pm - 8.15pm

Ennis: Epilepsy Awareness Presentation

for teachers and SNAs
Ennis Education Centre, Government Buildings, Kilrush Road
Monday 8th May
4.15pm - 5.30pm

MIDLANDS

(Co's Offaly, Laois, Westmeath & Longford)

Contact: Cliona Molloy, Community Resource Officer, Epilepsy Ireland, c/o Carers Association, Market Square, Tullamore, Co. Offaly. Tel: 057 9346790. Email: cmolloy@epilepsy.ie. Office Hours: Mon, Tue, Wed & Fri 10am - 2.30pm; Thur 9am - 5pm.

Upcoming Events

Epilepsy Nurse Specialist Talk

Date: May 18th
Time: 7pm
Venue: The Charleville Centre, Tullamore

NORTH EAST

(Co's Louth, Meath, Cavan, Monaghan)
Contact: Mary Baker, Community Resource Officer, Epilepsy Ireland, Unit 1a Partnership Court, Park Street, Dundalk, Co Louth. Tel: 042 - 9337585
Email: mbaker@epilepsy.ie. Office Hours: Mon, Tue & Wed 9am - 6pm.

Upcoming Events

One day Innerwise workshop

The Crowne plaza Hotel, Dundalk.
May 20th

BM training

Hotel Kilmore, Dublin Road, Cavan
April 11th

KERRY

Contact: Kathryn Foley, Community Resource Officer, Epilepsy Ireland, Glenwood, Park Road, Killarney, Co. Kerry. Tel: 064 6630301. Email: kfoley@epilepsy.ie. Office Hours: Mon- Fri 9am - 2.30pm.

Upcoming Events

Support group for people with epilepsy

22nd March, 26th April 10.30-12.30pm
Epilepsy Ireland Killarney Office

Support groups for parents of children with epilepsy-

28th March- 10am
Epilepsy Ireland office Killarney

Parents STEPS course commencing 14th March for 4 Tuesday mornings
Epilepsy Ireland office Killarney

Family morning at the Playdium

Tralee-
12th April- 9.30am
Hospital outreach available at Kerry University Hospital.

WEST

(Co's Galway, Mayo, Roscommon)
Contact: Edel Killarney, Epilepsy Ireland, Westside Resource Centre, Seamus Quirke Rd, Westside, Galway, Tel: 091-587640. Email: ekillarney@epilepsy.ie. Office Hours: Mon-Wed 8.30am - 4.00pm; Friday 8.30am - 4pm.

Upcoming Events

Roscommon Support Group Meeting

Monday 20th March
6-8 pm
Cuan Aire Family Centre, Castlereagh.

Galway Support Group Meeting

Wednesday 22nd March
11 am - 1 pm
Imperial Hotel, Eyre Square, Galway.

Innerwise Galway Innerwise

Tuesday, 4th April, 10 AM - 4 PM
Maldron Hotel, Oranmore

Mayo Innerwise

Wed, 5th April, 10 AM - 4 PM
Mayo Education Centre



IRELAND'S ANCIENT EAST PEAKS CHALLENGE

13th - 14th MAY 2017

Featured Mountains:

**Lugalla 595m, Lugnaquilla 925m, Blackstairs 732m
and Ridge of Capard 509m.**

**Followed by a medieval banquet,
story-telling and much more.**



**To receive an information pack, please contact our fundraising
team on 01 4557500 or email mcarty@epilepsy.ie**

To register, please go to www.epilepsy.ie