Joint Epilepsy Council Meet in Dublin

The Joint Epilepsy Council (JEC) held the first Executive Committee Meeting of 2003 in Brainwave's Head Office, Crumlin Road. This is the first time the committee has met in Ireland. Details of the Council are available in the Links section of the site.

Equality Authority Publications

Two new publications are now available.

Reasonable Accommodation of People with Disabilities in the Provision of Goods and Services

This new booklet is directed at those who provide goods or services and who are therefore liable under the Equal Status Act 2000. The aim of the booklet is to demonstrate that 'reasonable accommodation is a simple, easily achievable part of quality customer service and ordinary common courtesy'. It provides guidelines to the act, and for the implementation of provisions for reasonable accommodation for people with disabilities.

Employer's Resource Pack

This resource pack, launched on December 3rd has been developed as part of a joint initiative between the Equality Authority and the Department of Justice, Equality and Law Reform to support the employment of people with disabilities in the public service.

Publications are available from the Equality Authority Tel: 01-6670344, Email: info@equality.ie

UCD Students Union Disability Awareness Week - 2003

Brainwave had an information stand in UCD as part of the Disability Awareness Week, which commenced on January 28th.

The L&H Debate on Wednesday 29th. had as its motion "This House feels that a segregated university would be best for the disabled". Mr. Donal Toolin and Caroline Casey who spoke strongly against the motion were pitted against the cream of the L&H in what proved to be a most lively debate.

The showcase of the week - the UCD Student's Forum on Disability 2003 was held in the Astra Hall with guests from a wide range of Specialities: Caroline Casey, The Aisling Foundation; Dr. Mike Timms, Senior lecturer in Disability Studies, UCD; Anne Helan, AHEAD; Claire O'Conner (Director), National Disability Authority; John Bennett (Disability Officer), UCD; Moss Garde (Student Advisor) UCD Special Olympics Ireland; Martin Naughton, DFI
**St. Valentine Roses**

In Dublin prior to the release of ITV's adaptation of Marion Keyes' novel, watermelon, star of the Production Anna Friel was delighted to help Brainwave launch its new campaign. Focussing on the connection between the romantic red rose and St. Valentine (patron saint of epilepsy), Brainwave introduced its new fundraising drive - Valentine's Day Roses - on the 13th. and 14th. of February. The inaugural event proved very popular throughout the country and plans are already afoot for a much bigger campaign in 2004. Our thanks to all who contributed both time and money.

**Pictured:** Anna Friel, Ava Battles Brainwave Director of Services, Sinead Murphy, Community Epilepsy Specialist Nurse and Carol Mullan, Brainwave Resource and Events Co-ordinator

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**Epilepsy - A Patient's Perspective - February 17th.**

Audrey Muddiman of Brainwave's Executive Committee gave a presentation on a patient's perspective of living with epilepsy and what it can be like to deal with the health system to a group of final year medical students. The presentation was organised by Dr. Marion Dyer and took place in the Trinity Centre of St. James Hospital, Dublin. It is hoped that it will achieve a better understanding on the part of doctors as to the real implications of living with epilepsy and as a result a more personal approach from our medics. Our thanks to Dr. Dyer for the invitation.

**Pictured:** Audrey Muddiman and Dr. Marion Dyer

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**Brainwave Chairman Retires**

Colonel Jim Dowdall joined Brainwave The Irish Epilepsy Association in its early days because of his child's epilepsy. He has Chaired the Association through some years of excellent growth but has also seen Brainwave through some difficult times. Jim, although retiring from the chair, will continue to support Brainwave as a member of the executive committee.
and the Finance sub committee. At the Brainwave AGM held in Thurles, Co. Tipperary on the 9th. of November last, Brainwave President, Dr. John Kirker thanked Colonel Dowdall on behalf of the Executive Committee, the members and the staff of Brainwave both for the quality and the quantity of time he continues to devote to the association.

**Awareness Evening Held in Navan**

A very successful awareness evening was held in the Ardboyne Hotel, Navan, Co. Meath on the 10th of March. Congratulations to all involved in organising the event. A follow up Outreach Service Day will be held in the same venue on April 14th.

**19/03/03 - For People Who Are Taking SABRIL (VIGABATRIN)**

For quite some time now, people with epilepsy who take the anti-epileptic medication SABRIL (VIGABATRIN) have been advised to have regular eye examinations. This is because of possible links between the use of the drug and peripheral vision side effects.

These eye examinations can be quite expensive but in certain circumstances Brainwave has been advised that the Department of Social and Family Affairs will pay some or all of the cost involved. In order to benefit you must have the qualifying number of PRSI contributions and you must apply and have your benefit form processed before you take the eye-test. You should receive a letter from the Department of Social and Family Affairs, which you bring to your optician. The reason you must give for requiring the eye examination is that of 'CLINICAL NECCESSITY'. You should contact the Department of Social and family Affairs directly for further details. The Department operates an Application and Leaflet Information Request Line 24 hours 7 days a week the Lo Call number is - 1890 20 23 25.

**Fair Play for Epilepsy demanded from RTE by Brainwave 28/03/03**

Many people with epilepsy and their families will have been dismayed by last night's episode of 'Fair City'. A would-be First-Aider in the RTE soap opera said he would 'stick something in a person's mouth as a treatment for a seizure'.

In response to representations by Brainwaves Director of Services, Ava Battles, RTE have promised to cut the offending part of the episode from Sunday's omnibus edition. However, RTE would not agree to include a part where a person with epilepsy could be portrayed in a proper way which would allow the viewing public to receive correct information about what to do in the event of a seizure.

Brainwave urges all members and www.epilepsy.ie visitors to write, phone, text or email RTE to support decent treatment for all people living with epilepsy.
The Situation in the Mid West - 28/04/03

For many years now people with epilepsy and other neurological conditions in the mid west have been campaigning for a proper Neurological service for the region to be based at Limerick.

A twice monthly neurologist clinic has been operated in the Mid West by the Southern Health Board for more than twenty years, in Limerick. This clinic was set up to relieve the chronic situation in Limerick, Clare and North Tipperary. This clinic could never have hoped to properly address the needs of the growing population of the Mid West.

At the same time the population of the Southern Health Board area was also increasing rapidly. This has led to huge waiting lists of people who need to see a Neurologist in Limerick and very often people must wait for 2 years and more in order to get an appointment.

Overall, the population of Munster has grown by more than 8% in the past twenty years. In the same period no additional Neurologists have been recruited to the public service for the region. There are still just 3 clinical neurologists in the area, based in Cork.

Although the situation is still very poor in other areas of the country, the number of adult neurologists in Dublin has increased from 4 to 9 in the same period with 7 seven of these neurologists working in the public service. At the same time, paediatric neurologist numbers have grown from 1 to 4 in Dublin.

Even in Galway, last year saw a long overdue increase from 1 to 2 neurologists. Despite these statistics, it now seems that the mid west region is to lose even the small, inadequate (due to lack of Health Board funding) service they have had for the past twenty five years or so.

Apparently, the Southern H.B. gave the Mid Western H.B. notice last year that they would have to re-deploy the resources back to their own clinics in Cork, to help to deal with their own chronic lack of resources, and that they would not be able to continue the clinics after 31st March 2003.

The situation now is that the Limerick clinics are no more but even though the Mid West Health Board received more than adequate notice (4 months) they appear to have done nothing, to date. Comhairle na nOspideal is due to report on Neurological and Neurosurgical services in Ireland very soon. They are expected to recommend the appointment of several new Neurologists along with other specialists and backup services.

Minister Micheal Martin has promised the Neurological Alliance of Ireland (NAI) that he will set up a neurological implementation group to oversee the putting in place of these new appointments. Brainwave was a founder member of the NAI and remains very actively involved in it. Logically, Comhairle must be expected to make some recommendations for a service based on Limerick.

Although it needs to be stressed that the appointment of a Neurologist alone will not solve the problems, in the long term. It is a Neurological service that is required with a proper team built around the Neurologist.
In the meantime, all Brainwave members should continue to demand access to Neurological services through their Health Board, their local politicians, TDs and Senators.

Towards the end of last year a Mid Western Health Board spokesperson said, on local radio, that he believed there was no problem with Neurology services in the Mid West. This was in response to the Southern Health Board’s notice that they would not be able to continue the service due to the need for services in their own region.

This surely indicated an "if I put my hands over my eyes, the problem will go away" approach. Unfortunately, in the months since then absolutely nothing seems to have been done by the Health Board to resolve this situation which they, and they alone, have created.

**Neurology to be included in new private hospital planned for the North East. 29.04.2003**

Neurology is to be one of the disciplines for which consultancy services will be provided when the new private hospital is set up in Dundalk. Local Dundalk GP, Dr Mary Grehan is believed to be heading up the group of investors who plan to build the 50 million euro private hospital in Louth.

The Hospital will have 50 beds and will have a theatre block, which will include one general theatre as well as a specialist theatre where orthopaedic procedures can be carried out. There will also be 20 consulting rooms for both private patients and patients referred by the North Eastern Health Board for consultant services.

It seems that the project may be managed and financed in a broadly similar way to the very successful Blackrock Clinic in Dublin and other successful private hospitals. Typically this involves many of the consultants to the hospital investing in the project at the outset and the management of the hospital being contracted out to a specialist medical management group.

**Neurological Alliance of Ireland to be represented on Neurological Implementation Group 01052003**

A spokesperson for Comhairle na nOspideal has told Brainwave that its Neurological and Neurophysiology committee has completed its report and that they expect it to be published by the middle of May. Comhairle na nOspideal is the expert medical group appointed by the Government to oversee and plan the delivery of our public health services. All consultant appointments in the public service are made on the basis of Comhairle’s decisions.

The Neurological Alliance of Ireland (NAI) has been awaiting this report ever since it completed the third and final part of its Standards of Care (SOC) documents (for people with Neurological conditions) early last year. The Minister for Health and Children, Micheal Martin, has promised the NAI representation on the Neurological Implementation Group which he has said will be set up to implement the recommendations of the Comhairle committee. It is expected that the committee will have looked at Neurological and Neurophysiology services all over the country and compared them to best practice in Europe and other western countries. Brainwave was one of the founder members of the NAI, which represents 23 of the leading national Neurological charities in Ireland, and continues to be very actively involved with CEO, Mike Glynn the elected Treasurer of NAI. As
Brainwave members will be aware, the 2nd SOC covered epilepsy in a major way. Recently, the NAI became a registered charity and a company limited by guarantee. Minister Martin formally launched the new body at his Hawkins House office (see photo). The NAI has plans to set up Regional groups throughout Ireland and is presently seeking funds in order to do this it also hopes to recruit a part time staff member to run its office.

**Brainwave warns against the use of Ephedra for people with epilepsy.**

Brainwave The Irish Epilepsy Association is warning people with epilepsy and anyone who has ever had a seizure of any sort against the use of the herbal product Ephedra. Ephedra is a naturally occurring substance derived from the Chinese herbal plant Ma Huang. Its principal active ingredient is ephedrine, which when chemically synthesized is regulated as a drug. While products containing natural ephedrine alkaloids have long been used to treat certain respiratory symptoms in traditional Chinese medicine, in recent years they been extensively promoted in many weight loss, dietary, performance enhancing sports training products (even though it contains pseudoephedrine, a banned substance in sports) and as energy boosters.

As long ago as 1994, the Federal Drug Agency (FDA) in the USA issued warnings against the use of Ephedra. The FDA has extensive powers to police pharmaceutical drug products but it has far less power when it comes to herbal products. However, it has now proposed a warning label for all ephedra-containing dietary supplements. The proposed label warns about the risks of serious adverse events, including heart attack, seizure, stroke, and death; cautions that the risk can increase with the dose, with strenuous exercise, and with other stimulants such as caffeine; specifies certain groups (such as women who are pregnant or breast feeding).

This warning comes as a result of a recent major study (the RAND study) has concluded that ephedra is associated with higher risks of mild to moderate side effects such as heart palpitations, psychiatric and upper gastrointestinal effects, and symptoms of autonomic hyperactivity such as tremor and insomnia, especially when it is taken with other stimulants. Moreover, its review of some 16,000 adverse event reports revealed two deaths, four heart attacks, nine strokes, one seizure, and five psychiatric cases involving ephedra in which the records appeared thorough and no other contributing factors were identified. RAND called such cases "sentinel events," because they may indicate a safety problem but do not prove that ephedra caused the adverse event.

Patricia Osborne-Shafer, Chair of the professional Advisory Board of the The Epilepsy Foundation (the national epilepsy association for the US) said -

"The best policy is simply to avoid those (products) that list ephedra or ephedrine among their ingredients. Products that list both caffeine and ephedra should especially be avoided".

Dr Gregory Barkley, also a member of The Epilepsy Foundation Professional Advisory Board, said that -

"People taking Diamox (Acetazolamide), Topamax (Topiramate) or Zonegran (Zonisamide)* are at increased risk of toxicity because those medications decrease renal (kidney) clearance and lead to higher ephedra levels in the body".
* Zonegran is not yet on the Irish market
Sites where you will find more information about Ephedra:
Epilepsy Foundation (www.efa.org)
Journal of the American Medical Association (www.jama.org)Neurology (www.neurology.org) FDA (www.dfa.gov)

**Tom Smith admits seizure stopped play. 8.05.2003**

Tom Smith, the star prop forward for Scotland and the British and Irish Lions has been very honest in admitting that his ankle injury happened as the result of a seizure at home. The injury has kept him out of his club, Northampton's recent games.
Tom said that he receives lots of letters from youngsters with epilepsy who are interested in sport and, especially, rugby union. He felt it was important that he shows honest in these matters to give a good example.

Tom Smith is patron of JEC member, Enlighten Action for Epilepsy in Scotland. His rugby career was going through a bad patch some years ago but then he publicly let it be known that he had epilepsy. It may have been just a coincidence but ever since his disclosure Tom Smith has been playing the best rugby of his life. He re-established himself as one of the very best loose head props in the world with a series of stunning performances for Scotland which led to his selection for the Lions tour to Australia and his establishment as a test player there. That was Tom's second Lion's tour and he has maintained his form since for Scotland and for his club Northampton who he helped beat Munster in the Heineken European cup final.

Hopefully, Tom Smith's continued success, after his public disclosure of his epilepsy, will lead to many other famous sportspeople and celebrities from all walks of life taking courage to do likewise. Their reward would include the eternal gratitude of all people living with epilepsy to whom it will give great hope.

**National Epilepsy Week 2003 - How Would You React?**

The Picture reproduced by kind permission of the BBC is taken from the two-part drama series The Lost Prince.

Written by Stephen Poliakoff, the story follows the life and times of Prince John, the forgotten youngest son of King George V and Queen Mary, who was born in 1905.

Although remembered as a charming boy, he was diagnosed as having epilepsy and also had learning difficulties similar to autism, he was shut away at the age of twelve in Wood Farm near Sandringham to prevent the family from public embarrassment. He died there when he was just thirteen.

In summing up the difficulties of Living with Epilepsy, a founder member of Brainwave, Joe Doyle former Lord Mayor of Dublin (1998-99) once said - "**For a person living with epilepsy having seizures is not the major issue, rather, it is how other people react - too often negatively - when you have a seizure**".
Your attitude can and does make a difference. So for National Epilepsy Week and beyond - **How Will You React?**

**Brainwave Launch Outreach Service For Kerry**

The Emerald Elvis was on hand to launch Brainwave's new outreach service in Kerry at the start of National Epilepsy Week 2003. Community Resource Officer Una Barry, who also aims to deliver epilepsy awareness programmes to schools, childcare workers, employers and other health professionals, hopes the new service will provide support and information to Kerry people with epilepsy who would normally find it difficult to access such services.

**Long Awaited Comhairle na nOspidea Report**

**REPORT OF THE COMMITTEE TO REVIEW NEUROLOGY AND NEUROPHYSIOLOGY SERVICES**

Some of the key recommendations of the report include :-

- The setting up of 3 new regional Neurology units in Limerick, Sligo and Waterford (with provision for outpatient clinic & inpatient consultations to other hospitals in their Health Board areas)
- These 3 units to have 2 Neurologists each
- A long term target of 39 Neurologists for the country i.e. 1 Neurologist per 100,000 of population
- An interim target of 29 Neurologists for the country i.e. 1 Neurologist per 135,000 of population
- The interim target specifically includes the 2 new Neurologists each for Limerick, Sligo and Waterford
- The long term target for Cork to be 13 neurologists, Interim 9 (from only 3 at present)
- A target of 6 Paediatric Neurologists to include 2 posts for Cork
- Cavan, Drogheda and Tullamore to have outpatient clinics & inpatient consultations provided by Beaumont
- A massive increase in Neurophysiology posts from 3 to 9. Two of these posts to be in Cork, 1 in Galway the remainder in Dublin

Brainwave is delighted to note that the report makes reference to each of the three Standards of Care produced by the Neurological Alliance of Ireland (NAI) and their recommendations. The Comhairle report also refers to the CSAG (Clinical Standards Advisory Group) "Services for Patients with Epilepsy; Neurology Service and Epilepsy Care", the UK report produced in 1999 which included JEC input.

One disquieting aspect of the report is that it quotes the current number of Consultant (adult) Neurologists in Ireland as 14 but there are currently only 12 in post. Dr. Niall Tubridy is due to take up a post in St. Vincent's University Hospital next January and a Neurologist post appears to have been allocated to Tallaght Hospital but there is no sign of it being filled.

Likewise, the number of Paediatric Neurologists is listed as 5 currently but only 4 posts are filled with Dr. Olivia O'Mahony due to take up her post in Cork next November.

As Brainwave members and website readers will be aware, Health Minister Micheal Martin has
promised the NAI that an Implementation Group would be set up immediately the report was published with representation for NAI. This body can then ensure that Comhairle's report is translated into real action for people with Epilepsy and all other Neurological conditions.

**Ladies Mini-Marathon - 2003**

Brainwave would like to thank all who participated on behalf of the Association.

**Neurologist Numbers Update - 6/6/03**

Brainwave members and other people living with epilepsy will be pleased to learn that Dr. Peter Kelly has been appointed to the Mater Hospital as a Consultant neurologist. This brings to 13 the number of adult neurologists working in the public sector in Ireland.

When Dr. Niall Tubridy takes up his post at St. Vincent's Hospital next January the number will be up to the level (at 14) claimed to be the current number by the recent Comhairle Na nOispideal report.

**Epilepsy Programme Golf Classic**

The First Annual Epilepsy Programme Golf Classic - in aid of the Epilepsy Programme Beaumont Hospital - was held at the malahide Golf Club on Monday June 16th.

**Brainwave at the Special Olympics Festival Village**

Brainwave's information stand at the Special Olympic Festival Village in the RDS proved a great success with visitors. We would like to thank all for their kind comments and expression of support for the work of the organisation.

**Pictured:** Carol Mullan Brainwave Co-ordinator and Eunice Kennedy Shriver founder of the Special Olympics

**Gardai, Prison Service will no longer be allowed to discriminate against people with epilepsy. 18.07.2003.**

The European Commission's Directive on employment law is due to come into force all over the European Union on December 2nd 2003. Under Directive 2000/78EC the security services (other than the armed forces) will no longer be able to refuse to employ people with epilepsy and a number of other conditions. Likewise, they will no longer be able to use an employee's condition to fire somebody who develops epilepsy whilst working in the services. This has been a particular problem, which Brainwave has come across many times over the years.

Brainwave is aware of the attitudes of many employers who, when they hear a person has epilepsy, immediately think risk. Brainwave also knows there are many people with epilepsy in employment who have avoided the issue of disclosure for fear of discrimination. We therefore welcome any
legislation, which will further protect the right of people with epilepsy to a fair, individual and specific case assessment. We await the development and implementation of this new Directive with interest.

"Garda entry procedures will require amendment to reflect these improved employment opportunities for people with disabilities. The message the Directive sends out is that you have to ignore disability, and you must employ someone if they are capable of doing the job". - Shivaun Quinlivan, an expert in European disability law and law lecturer at the National University of Ireland in Galway.

The Irish Government could, in theory, defer the implementation of this Directive for up to three years. By doing this they could merely be putting off the inevitable and Brainwave and the other disability agencies intend to ensure that they honour their commitment to people with disabilities immediately.

**MYSOLINE (primidone) 11.08.2003**

Brainwave has learnt that the anti-epileptic drug Mysoline (primidone) is to be withdrawn by its manufacturers from 1 December 2003. AstraZeneca have announced a global discontinuation from that date, adding that there may be enough stock after withdrawal for the month of December only. Pharmacists and doctors have been informed.

Brainwave strongly urges people taking primidone to speak to their specialist for transfer to another medication.

**Kirker Prize 2003 - 19.08.2003**

The 2003 Kirker Prize was awarded recently to the team led by Dr G. B. Boylan, from the Department of Paediatrics and Child Health Clinical Investigations Unit, Cork University Hospital, the team included J.M. Rennie MD, G. Chorley, R.M. Pressler MD, G.F. Fox MB, K. Farrer MB, M. Morton MB and C.D. Binnie MD from the Departments of Child Health and Neurophysiology, Guy's King's St Thomas School of Medicine, London.

This prize is presented for the best work in epilepsy research. It was created by the Irish Epilepsy League (IEL) in honour of Dr. John (Joe) Kirker who was a founder member of the IEL and also of course a founder member of Brainwave and is still its president.

The winning paper - "Second Line Anticonvulsant Treatment of Neonatal Seizures: A video-EEG Monitoring Study", was an international project involving some of the leading epilepsy specialists in the UK and as Dr. Kirker has a special interest in Neurophysiology the subject matter of the winning paper is particularly appropriate.

The award was presented during the Irish Institute of Clinical Neurosciences (IICN) meeting, which was held recently. The paper has also been accepted for publication in the prestigious international publication Neurology.
Abstract
We conducted a randomised trial of second line anticonvulsant treatments for babies. The response to treatment was assessed using continuous video-EEG because the clinical diagnosis of seizure in babies is known to be unreliable. Of 27 babies with EEG confirmed seizures 5 had to be excluded because of protocol violations, and 11 responded to phenobarbitone in a dose of 40 mg/kg as first line. Three of 5 babies treated with lignocaine responded. Six babies were treated with benzodiazepines as second line: none responded, and their neurodevelopmental outcome was poor.

Employers Pack Launch 25/09/2003
Brainwave launched its new pack for Employers at a major conference about work for all, for Employers. Tanaiste, Mary Harney launched the -Access & Diversity - a new vision of work -conference in Croke Park on the 25th Sept.

Pictured: Mike Glynn & Padraic White at the Brainwave Stand.

National Conference 2003. EPILEPSY - WANT TO KNOW MORE?

Good news for the Neurological Alliance of Ireland (NAI) 30/09/2003

There are two pieces of very good news for NAI. Firstly, it was recently confirmed that the NAI has been successful in its application for a Dept. of Community, Rural & Gaeltacht Affairs grant which will enable it to take on a staff member and set up its own office. The grant is awarded under the "Scheme of grants for Federations, Networks & Umbrella Bodies in the Community & Voluntary Sector". This will allow the NAI to work on its ambitious plans, especially in relation to what it wants to achieve in the different regions outside Dublin. To date, the Alliance has been totally held back in this by lack of resources.

The other significant happening for the Neurological Alliance is that three speakers are to represent the NAI at an oral hearing of the Oirechta committee on Health. Audrey Craven, the Chair of the NAI and Dr Orla Hardiman its Medical Director will be joined by Dr Tim Counihan, the Galway based Neurologist who will speak about Neurology services in the regions.

The hearing will take place in Leinster House on Thursday, the 3rd October 2003.

Kilkenny Office Launched 8/10/2003

The official launch of Brainwave's new Community Resource Office took place on October 8th. we wish the new Community Resource Officer Deirdre Commins every success in her new post.
OUT OF THE SHADOWS"

SEMINAR FOR HEALTH PROFESSIONALS

Brainwave in association with the Midland Health Board held a seminar for Health Professionals on Wednesday October 8th in the Offaly Exhibition and Research Centre, Bury Quay, Tullamore, Co. Offaly.

The picture shows Margaret Bassett Brainwave CRO welcoming the audience who attended the health seminar.

Mysoline supplies update 20/10/2003

Brainwave members and other people with epilepsy who take Mysoline tablets in the 250mg form will be pleased to learn that supplies are no longer under threat for the immediate future. AsrtaZeneca Pharm (Ireland) have confirmed to Brainwave (in writing) that they will be able to supply the Irish market until the end of 2006. They further confirmed that they are seeking an alternative manufacturer to enable continued supply from 2007 onwards.

Elan switch production of Zonegran to its Athlone plant 6/11/2003

Elan Pharmaceuticals, the Irish based multinational drug company, has moved production of its key epilepsy brand Zonegran (generic name Zonisamide) to Elan’s original home in the Irish midlands at Athlone, Co. Westmeath.

This information was supplied by Paul Breen, Executive Vice President of the Elan Group prior to its recent AGM in Dublin. Mr. Breen was responding to concerns that the company was about to dispose of its site at Monksland in Athlone. Paul Breen told the Athlone Voice newspaper that Elan had invested 178m euro in its new 20,000 sq.mtrs. plant there.

Ironically, Zonegran cannot be prescribed for any Irish (or any other EU citizen) person with epilepsy even though the AED has been around for some 14 years in Asia and, more recently, the USA having been prescribed for somewhere between 3/4 million and 1 million people. Zonegran is mainly prescribed as an add-on treatment for partial seizures in adults but it has been associated with a number of side effects. However, Dr. Norman Delanty, a leading Irish epileptologist, has said he would welcome Zonegran as an additional weapon in the fight against seizures.

Elan has applied for an EU wide licence and this unusual step is probably what has held things up. However, an Elan representative told Brainwave recently that they hope to get a Europe-wide (EU) licence in the next few months.

Mirena IUS

The following is the text of a statement by Dr. Ray O’Connor which has been published on the Irish College of General Practitioners website www.igcp.ie by Dr. Ray O’Connor. Dr. O’Connor, who is based in Limerick, is the author of the ICGP Publication "The Diagnosis and Management of Epilepsy
in General Practice" and has long been to the forefront of epilepsy matters within the IGCP.

"Mirena" IUS as a contraceptive in women with epilepsy who are taking enzyme inducing anticonvulsants.

I wish to clarify the position of the "Mirena" IUS as a contraceptive in women with epilepsy who are taking enzyme inducing anticonvulsants.

Medical Director of NAI honoured by American Academy of Neurology 4/12/2003

Dr. Orla Hardiman, the Medical Director of the Neurological Alliance of Ireland, has been awarded the first Palatucci Advocacy Leader of the Year Award by the American Academy of Neurology. Dr. Hardiman has been a huge driving force in the campaign to improve services for all people with neurological disorders in Ireland. She was active in the creation of the Irish Institute of Clinical Neurosciences (IICN) when it was founded in 1998 at much the same time as the NAI came into being. The citation by the selection committee of the AAN praised her for her "tireless advocacy efforts on behalf of the neurology profession and patients" in Ireland. Orla strongly supports the value of partnership between medics and their patients, as represented by the lay organisations, and this has been characterised by her huge commitment to the work of the Neurological Alliance of Ireland. Dr. Hardiman has also been very actively involved in the IICN. Some years ago, she established the Diaspora Meetings. These seminars take place every two years and Irish neurolomedics working in the US, the UK and other countries present their work and research findings to their colleagues working in the field in Ireland. Drs. Michael Hennessy and Tim Counihan both presented at these meetings before returning to work in Ireland. Dr. Yvonne Langan, who many Brainwave members will be aware of, is another who contributed to the Diaspora meetings. Dr. Orla Hardiman is due to receive her award in January 2004.

KEPRA may provide a better add-on drug alternative for older people 10/12/2003

A new study on a large group of patients has indicated that Kepra (Levetiracetam) is well tolerated by older people. Doctor Joyce Cramer of Yale Medical School who lead the study is quoted as saying "Kepra treatment not only had good tolerability for younger epilepsy patients but was also well tolerated by elderly patients". The study also found that side-effects were reasonably low.