

Major Event for next November

Conference on Music Therapy and Physio in Rett

Following on the success of the Neuroscope Assessments in Dublin, we are organising a day-long conference in conjunction with the Music Therapy Dept. of the University of Limerick. The event will focus on both Music Therapy and Physiotherapy in Rett Syndrome.

Cochavit Elefant, is a Music Therapist who has worked extensively with girls with Rett Syndrome and has completed her Ph.d. on music therapy and Rett Syndrome. She will cover issues in Music Therapy and Rett. On Physiotherapy, **Meir Lotan** is an international expert. He is a consultant to the International Rett Syndrome Association. In 2000 Meir was given an award by the International Rett Syndrome Association for his service to individuals with Rett Syndrome. Both Meir and Cochavit are well experienced in matters relating to Rett Syndrome and their work demonstrates the value and importance of working and giving appropriate therapies to people with the condition.

We hope to see as many families as possible at the event, and we will also be inviting teachers, carers and therapists to the event. The Association will pay the accommodation costs for member families traveling to the conference. We will be in contact with firm details closer to the date. The event is currently scheduled for early November.



Sarah Kehoe pictured at the recent Family Day in Tullamore. There are two Family days each year where members can meet and chat with each other about anything and everything. All are welcome, especially the Rett girls.

THE RETT SYNDROME ASSOCIATION OF IRELAND

We are an association of parents and families of people with Rett Syndrome.

We came together to provide support and information:

to each other

to parents and families who have received a new diagnosis

to raise awareness among medical professionals and others who work with people who have Rett Syndrome

to raise public awareness of the condition and it's effects on those affected by it.

The Irish Rett Syndrome Association is a registered Charity: Chy 16340

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Good news for Mallow girl

Many of you will have been aware of the story of 12 year old Anne Marie Kelliher from Mallow in Co. Cork. Along with her Rett Syndrome she developed Scoliosis. She was assessed in June 2007 as having a 64% curvature to her spine. The curvature in Anne Marie's spine increased so severely that it was causing her pain and putting pressure on her chest and stomach. At an assessment in London in January this year, the Kelliher's were told that the curvature had progressed to 100%. Surgery was planned to take place in Crumlin but was cancelled a number of times. The Kelliher's then applied to the Treatment Purchase Fund so that the surgery could be carried out in the UK. However, they were refused the funding of £100,000 on the grounds that the surgery was available in Ireland.

The family were extremely distressed at this, particularly as Ann-Marie had been absent from school since the previous Spring and she was unable to sleep at night. Bernie, Ann-Marie's mother, decided to approach the national media. She achieved coverage in national newspapers, Television and the Liveline on Radio 1 with Joe Duffy. An anonymous donor offered to fund the surgery because of his outrage at the HSE's response to Ann-Marie's situation. The HSE eventually relented agreed to fund the surgery.

The good news is that Anne Marie has now successfully undergone two surgeries to correct her Scoliosis and is recovering well at the Royal National Orthopedic Hospital in Stanmore, Middlesex. It is expected that as a result of the surgery, the curvature in Ann-Marie's spine will reduce to 30% and she will be able to walk again.



Emma O'Donoghue at the recent family day in Tullamore

Guidelines for informing families of a child's disability

The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability has published a welcome booklet to advise those delivering a diagnosis of disability how they might do this in a sensitive and appropriate way.

Many of the families who have had contact with our Association have reported that the manner in which they were told of their child's disability was as distressing as the diagnosis itself. We have heard many stories of inaccurate, misleading and insensitive communication of a diagnosis. The guidelines are the result of a consultation process as a result of feedback from many families concerning the inappropriate way in which they received their diagnosis.

The aim of the booklet is to give guiding principles and best practice guidelines. The Guiding Principles include concepts such as family centred disclosure;

respect for child and family, sensitive and empathic communication; appropriate, accurate information; positive realistic messages and hope; team approach and planning to support the family; family focused and supported implementation of best practice.

The Recommendations focus on attention to the setting/location and people present at disclosure communication so that it is sensitive and easily understood, information and support, culture and language so that the diagnosis is fully understood by the family, training, education and support for professionals, Organisation and planning so that those working with the family are communicating with each other, Referral to the appropriate services and supports and dissemination of the guidelines to those involved in giving diagnoses. The Federation deserves credit for its work on this very necessary and welcome publication.



Angela Dolan

It's with great sadness that we note the passing of Angela Dolan who died after a brief hospitalisation with pneumonia on the 24th of September last. Angela was aged 24 and lived in Longford with her mother Junette. Angela had many illnesses and complications since early childhood but repeatedly fought these off. From the time Angela was a small girl Junette brought her to the UK in search of the best treatments and therapies. Junette campaigned endlessly for the best care for Angela. Thanks to Junette's efforts on behalf of Angela and the Association, we invited Dr. Julu to Ireland last year, and a number of the girls in the Association were assessed using the Neuroscope. We wish Junette and her family all the best. Our thoughts are with them at this difficult time.

Govt. not delivering on commitments - poll

More than 60% of people canvassed in a recent opinion poll for Inclusion Ireland believe that the State is not

delivering on its commitment to Disabled people. The people surveyed also believe that the Disability Act 2005 does not go far enough in supporting people with Disabilities. Under the 2005 Act, disabled people are entitled to an independent assessment of their needs, but have no automatic right to have the services and supports that are recommended by that assessment. However, in the recent survey, 97% of respondents said that Disabled people have a right to all health and education services that are recommended by an independent assessment.

According to Inclusion Ireland CEO, Deirdre Carroll the results of the poll "highlight the public's support for people with an intellectual disability.

The Government now needs to show their support by ensuring that people with an intellectual disability have the opportunity to contribute to society and have the right to live and participate in their community with equal rights as citizens to live the life of their choice to their fullest potential."

Almost two thirds of respondents believe that people with intellectual

disability are treated worse than others, whereas almost all believe that the intellectually disabled can contribute to society, should have the opportunity to work and live as normal a life as possible. You can read more here:

<http://www.inclusionireland.ie/attitudessurveyresultunveiledatagm2008.asp>

Fundraising

We would like to thank the Smith family from Waterford who raised €1000 for the Association through a sponsored walk. We would also like to thank Mrs Ann Kehoe from Dublin who very kindly donated €500 to the Association. Andrew Kehoe organised a raffle at Ascon and raised €805 at Christmas. And Signlab made a donation of €800 via Niall Rankin. The sale of the Association Christmas cards was a great success and raised €1,886. We will be ordering the cards again for next Christmas.



Laura Dowling with Brenda O'Donoghue pictured at the recent Family Day in Tullamore

Dept. of Education Discrimination

The Department of Education policy is that students in Special Schools should leave school at the end of the Academic year in which they turn 18. There is no account taken of the student's abilities, track record, the extra challenges they face as disabled people. The only assessment is their birth date.

This is discriminatory because this policy is applied only in Special Schools and does not apply to mainstream schools in a way.

Heretofore, a student (or a parent or guardian on his/her behalf) and the school together could apply to retain the student past the academic year in which they turned 18. If allowed, the student could come to school, however, this was a concession, and the terms of this concession were discriminatory also: the student did not count on the Roll, and as such, did not count in calculating class sizes, or in the assessment of support requirements such as Needs Assistants or capitation.

Because these students were not allowed count on the Roll, it means that other students in the school were required to share their support and teaching resources.

On the other hand, students in mainstream schools - even disabled students - count on the Roll and count for the calculation of support resources, regardless of their age.

However, from the end of this academic year, even this meagre concession is to be finished and retaining students even on a concession basis will not be allowed.

It's a very clear and simple case of discrimination. There is one rule for disabled students in Special Schools and another one for students - regardless of their abilities - in other



Top: Rachel Horan with her Mum

and bottom: Emma O'Donoghue holds baby Cassie Lawlor at the recent Family Day in Tullamore

schools. It is astonishing that a Government Department routinely tells disabled young people that - literally - they do not count. It's truly shameful.

Students in Special Schools should be treated the very same as students in Mainstream schools - that is, the point at which they leave school is decided by the Student him/herself (where possible) in association with Parent/Guardian and the School Principal.

Wheelchair Access Vehicles

Andrew Kehoe and Terry Devlin compare their experience with Wheelchair Accessible Vehicles.

Andrew recently purchased a Fiat Doblo 1.3 Multijet Diesel, that costs €25,410 - though €4,410 was reclaimed under the scheme. The adaptations to the vehicle included

- Lowering the floor
- A full-width manual ramp
- Seat belts and strapping for the wheelchair passenger

For Andrew the principle advantages of the Fiat with this conversion are price, ease-of-use and trade-in value. The Fiat is the keenest priced vehicle on the market, and as a diesel is very fuel efficient - though recent price increases for diesel are a cause for concern. Andrew also stresses that it is very easy to load and unload the wheelchair passenger. As the Fiat is very popular in the Wheelchair Access Vehicle market, it holds its trade-in value very well.

The adapted vehicle holds the wheelchair passenger plus 4.

On the downside, Andrew cites the narrow back seats as "not very comfortable" for the larger passenger - especially on longer journeys. It's a basic vehicle, with no frills. And, worth noting, as loading the passenger requires a good push up the ramp, an electric lift may be required for some.

The modifications to Andrew's Fiat were done by Parfit (www.parfit.ie)

Lowering the floor of the vehicle is a big job and it's a permanent change to the vehicle so when you do this you are limiting the after-market for the vehicle. This is one of the reasons that Terry Devlin went for a bigger vehicle. He drives a Renault Grande Espace 1.9 diesel.

This is a 7 seater People Carrier that's priced in the €44,550 - €59,900 range. Terry reclaimed the maximum €15,870 on the vehicle. For Terry the principle attractions were that he could have wheelchair access without lowering the floor - hence a wider trade-in market. Also, as Kate, his daughter travels sometime in her Chair, and sometimes in her car seat, he wanted a big rear door for easy lifting in and out.

The adaptations involved



You may be entitled to significant tax reliefs if you qualify under the Disabled Drivers and Disabled Passengers Scheme. At its most simple, if you have a Primary medical Certificate then you can purchase a new vehicle for a disabled passenger and claim back the Vehicle Registration Tax and VAT on the price of the vehicle up to a limit of €15,870, plus you can also reclaim excise duty on fuel. (For full details of the scheme check out <http://www.citizensinformation.ie/categories/travel-and-recreation/transport-and-disability/>)

- removing 3 of the seven seats
- inserting a rotating rear passenger seat
- adding two "lift-into-place" aluminium ramps
- seatbelts and strappings as above.

The adapted vehicle holds the wheelchair passenger plus 4.

For Terry this is an expensive vehicle but with excellent trade-in value. It's very comfortable to drive, Kate has a great viewing position, and the car has all the mod cons you'd expect from a vehicle in that price range.

On the downside, like Andrew, Terry points out that pushing Kate up the ramp may present challenges, also the recent increase in diesel prices are a negative, but the van is very fuel efficient. The rear passenger doors, though large, are still not large enough to allow for Kate's seat to be rotated out fully. "Next time I'm looking for a sliding rear door" says Terry.

As always, the best advice is to take your time before buying. Shop around. It's always a good idea to chat with others for their experience both with the vehicle and adaptations.



Travel Insurance

Remember: Anyone traveling abroad should take care to ensure that they have sufficient insurance cover. As many travel insurance policies do not cover illnesses or incidents related to pre-existing conditions, it is vital to read the fine print or check with your Insurance Broker or Insurance Company to make sure that you and your family are fully covered should anything arise while you are on holiday. If you're traveling in the EU Irish citizens have access to health care and should carry an E111 card for each member of the family. However, if you're journeying to the United States where hospital care is extremely expensive you really need to ensure that you have your insurance in order.

Top: Laura Dowling, Tralee

Middle: Loren Rankin, Lucan Co. Dublin

Lower: Anna Boland, Kilkenny
at the recent Family Day



Have Your Say In Rett Syndrome Chatroom Online Survey For Action On Disability

Enable Ireland Disability Services are asking children and adults with disabilities, their parents and carers to have their say on a range of accessibility issues.

Their 'Access All Areas' online survey aims to uncover the reality of people's experiences around all types of access, from physical to recreational, social to educational.

The findings of the survey will be released during Enable Ireland's annual Action Week on Disability, taking place this year from 15-20 September.

During the week Enable Ireland will focus on raising awareness of the access issues experienced by people with disabilities and fundraising for enhanced services.

You can see and fill in the survey at <http://www.enableireland.ie/newsitem.php?NewsID=99>

Recently the two large American associations - The IRSA and the RSRF - merged to create the International Rett Syndrome Foundation. They have a re-launched their website. It's easy to register there and they have added a busy and broad-ranging Chatroom to their facilities. A Chatroom is easy to use and here are plenty of regulars there who are happy to advise you on any thing that might be on your mind when dealing with Rett or the many issues that it brings with it. The Website of the IRSF can be found at www.rettsyndrome.org and the chatroom is an easy link from the top of the front page.



above: Cassie Lawlor came to visit us.



left: Kate Devlin with her Mom at the recent Family Day in Tullamore

Please support Our Association

When you become a member of the association you can access the resources of the association, and these include: A **free copy of the Rett Syndrome Handbook for your family** and if required we can supply a free copy of the handbook for your child's Service Provider or School

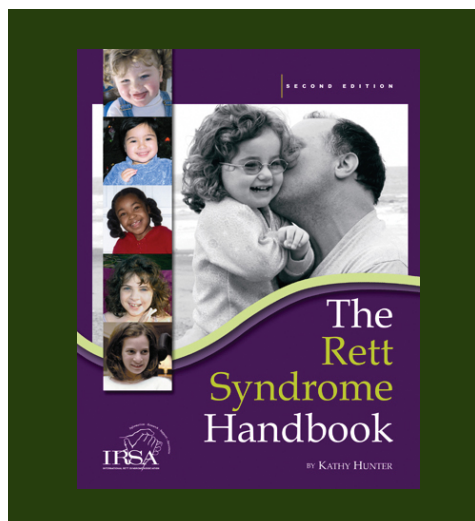
The Handbook is edited by Kathy Hunter, parent and founder of the IRSA. Much of the book is written by parents of children with Rett Syndrome and by professionals, both therapeutic and educational. Covering topics such as background medical and genetic information, family issues, common problems and issues as well as the care and management of people with Rett Syndrome, the Handbook is a **must have volume for anyone who parents or cares for someone with Rett.**

Membership costs €30, just fill in the form below and return it, along with your cheque to

The Irish Rett Syndrome Association
% the Bishop's Palace
Church St.,
King's Island, Limerick

If you cannot afford to pay, your membership is still very welcome, just fill out the form and send it in.

You can contact Andrew on 087 6152183 or
Noreen on 087 6152335



Application For Membership / Renewal of Membership

Name _____ Address _____

Contact No. _____ Email _____

Name of Child With Rett Syndrome _____

D.O.B _____ Your Relationship to the Child _____

If your relationship with the child is Professional, please tell us your occupation and where you're employed: _____

Subscription fee is €30. However, if you're unable to afford this, your membership is still welcome