

RETT syndrome IRELAND

Ellie Shaw pictured at the recent Rett Family Day in Tullamore



RETT SYNDROME ASSOCIATION OF IRELAND

We are a group of families who get together to share information and offer support to each other. We are mostly parents, who meet three times a year. For those unable to attend meetings we keep in touch by circulating our newsletter.

Neuroscope Presentation In Dublin

The Rett Syndrome Association of Ireland is organising a presentation of the Neuroscope by Dr. Peter Julu for families and Neurologists and other Consultants.

Dr. Julu has devised an instrument called the Neuroscope which measures brainstem activity. The brainstem is a main site of dysfunctional activity in Rett Syndrome, responsible for many of the automatic activities in our bodies such as heart function, breathing. At the moment some Irish families are bringing their girls to the UK and Sweden in order to be assessed by Dr. Julu.

We hope that by hosting the workshop here we will interest the neurologists in the assessment and the equipment and that it will further help in the management of problems associated with Rett Syndrome.

It is hoped that the presentation should take place in Dublin early in 2007 and that some of our girls will participate in the workshop. We will keep you updated as we have more news on this event.

Information on the Neuroscope and it's relevance in Rett Syndrome can be seen at the www.medifitgroup.com.

New Families Join Association

In the past year 7 new families have made contact with the Association. Three of the families are from Waterford, the others from Dublin, Tipperary, Kilkenny and Donegal. In all cases the children affected by Rett are aged between 2 and 18. The eldest was diagnosed several years ago, while another 15 year old has only recently received a diagnosis. One family had two boys diagnosed, aged 12 and 9. From one of these new families we have learned that a new specialist has been appointed at Temple St. Hospital. Described as being very knowledgeable and sensitive to the needs of the family receiving this diagnosis, she met with the family to discuss the diagnosis and the impact it might have on the family. The family concerned reported it to be a very good experience.

www.assistireland.ie.

is a new website developed by Comhairle with information on aids and appliances available in Ireland. Families, disabled people and service providers can browse through the 4,500 products currently included. Among the 20 different categories are Personal Care, Walking and Standing Devices, Eating and Drinking etc. Information sheets are available to help people understand the different types and things to consider when choosing equipment.

Dynavox Mighty Mo

Dynavox have released a new version of the Mighty Mo, photos can be downloaded and it is touch sensitive. You can use as few as 2 picture choices. It can be used for interactive play with nursery rhymes and stories. Your speech therapist should be familiar with the Dynavox and should be able to advise you and organise the ordering of it.

Sarah Kehoe (right) and Lauren Rankin (far right) with her Dad at the Rett Family Day in Tullamore recently



Rett Syndrome Assessment Centre Our daughter's visit to Sweden

In September of this year I travelled to the Rett Syndrome Centre with Grace (11) and her Dad Neil. The centre is located in the North of Sweden at Oster-sund. It takes two flights to get there. In the centre you are met by hostess Gun-Marie, a lovely lady who looks after you during your stay. The centre has fully equipped accommodation for the family and all our meals were provided for us. The reason for the trip was for Grace to have an autonomic test done by the wonderful Dr. Peter Julu. This was recommended by our pediatrician who arranged everything. All expenses were paid by the HSE. Grace was the first Irish child to attend. It was a brilliant experience and we learnt so much about Grace and recommendations for looking after her in the future.

We were there for three days and in that time Grace was assessed by several doctors, given a complete medical by Dr. Ingegard Witt Engerstrom, and also met with the centre's music therapist. We were asked to bring Grace's music with us. The autonomic test takes about one hour and is pain free. Monitors are placed on the child's head and chest and they show every breath for a full hour. A video is taken to record the child's reactions during this time. The test assesses everything going on with the brain but focuses especially on breathing patterns. There are 13 types of abnormal breathing and Grace shows 10 of these.

On the last day Dr. Julu and the other doctors met with us to give us the test results. They could even identify Grace's music preferences and what kind of music upset her. A full and detailed report is sent to the family and the pediatrician with suggestions for treatment and follow-up.

Grace is a classic Rett Syndrome child. She was diagnosed at age three. For the next five years Grace spent many days in hospital with seizures and chest infections. Four years ago she had a peg fitted for

feeding and two years ago underwent spinal fusion surgery. These interventions have completely changed her life and now she is seizure free and the chest infections are well under control.

Our daughter should give great hope to other parents. She has gone through so much in her short life and now is so healthy and well. She travelled the whole way to Sweden with a smile and the doctors there were very impressed with her considering the early days.

I would recommend this trip as we got so much out of it. We got the best treatment from some of the best doctors in the world working with Rett Syndrome

Olga Gilliland, Bundoran

You Can Help Others

Many of the families that get in touch with the Association are isolated and find information hard to come by.

However other parents, even though they mightn't realise it, have the answers to many of the everyday challenges that living with Rett Syndrome can present. Useful information gathered through experience might include ideas for Christmas presents, practical information about equipment or house alterations, or even dealing with the aftermath of scoliosis surgery.

If you have any thoughts on these or any other areas, please send them in and we'll include them in a upcoming newsletter. After all, the real experts on Rett Syndrome are the parents!

Buccal Midazolam New Seizure Medication

from NATALIE SHAW (Dublin)
Parents of the many children who suffer with prolonged seizures or seizures which have the potential to develop into status epilepticus will be familiar with the medication Stesolid, which although very effective can be very difficult to use particularly if you are not at home when the seizure occurs, as it needs to be administered rectally. Recently, a medication related to Stesolid, Midazolam, has come available which can be given by mouth, and for this reason is called Buccal Midazolam. A few drops are given using a dropper into the inside of the cheek. The research indicates that it may be even more effective than Stesolid. As it has not yet been fully licensed in Ireland, many GPs have not heard of it. However, it is possible to obtain it with a prescription by a Consultant Pediatrician/Neurologist and I'm sure that for those families



Rebecca Smith from Waterford at the recent Family Day in Tullamore

who have difficulty meeting with their consultants, their local GP may be in a position to help. If you feel that this would benefit your child you should discuss it with your doctor. It is so effective that we were able to give it to our daughter Ellie

(4) as soon as we needed to at the last Rett Syndrome family day in Tullamore. The Epilepsy Association of Ireland has endorsed the use of Buccal Midazolam for use by their families.

Portable DVD Players

from DEIRDRE HORAN (Tralee)
For those children who find traveling by car difficult and for those who just enjoy their videos and DVDs, a portable DVD player is very useful for car journeys, particularly if it's a long journey. They can be very useful for calming a child if



Rebecca and her Cousin at the Family Day in Tullamore

she/he becomes distressed. They usually have a strap for attaching to the headrest of the seat in front so they're easy to view. They are powered in the car by plugging them into the cigarette lighter. The newer ones have a power pack that allows you to use them anywhere without having to plug them in. The charge usually lasts about 6 hours. They have come down a lot in price in the last few years and can cost as little as €100 now, in shops like Argos. They can also keep the rest of the family entertained in the car.

Early Physio

from ANGIE FITZSIMONS (Co. Kildare)
Recently Nathalia (5) needed surgery on both ankles to undo damage to her Achilles tendons which had become too short and

resulted in immobility in both ankles. Nathalia coped well with the surgery and now attends physiotherapy to keep the ankles flexible along with other exercises. In our opinion regular and appropriate physiotherapy from as early as possible is essential to avoid joint problems and surgery which could be avoided.

Vitamin D

from OLGA GILLILAND (Bundoran)
As girls with Rett Syndrome become teenagers they become more susceptible to osteoporosis. A remedy that is recommended for teenage girls is vitamin D drops which can be given daily in the form of Alphadrops.

Computer Games

from NOREEN HARRINGTON (Co. Clare)
 At the BBC's Children's Website there is a games section suitable for anyone with a switch attachment for their computer, such as the Big Red Switch from Ablenet. To find the games go to www.bbc.co.uk/cbeebies then go to grown-ups → special needs → physical development → cbeebies switch content. There you will find links to games that tie-in with Cbeebies shows, such as Teletubbies, The Tweenies and Razzle-dazzle. If your child has not used a computer before or does not have a Switch your speech therapist will be familiar with the it and other devices that can help. If you don't have access to a speech therapist speak to your school or the Disabilities department at your local HSE office.



Libby Shaw, Ellie's sister at the recent Family Day in Tullamore

Talking Photo Album

from JULIE KEHOE (Dublin)
 Our daughter Sarah (9) came home from school one day recently with a photo album. On opening the album we saw digital photos of Sarah taken in school during various activities. Then we noticed a little button on the end of each

sleeve/photo and when we pressed it a recorded message played briefly which described the photo/activity, similar to how the Big Mac switch works. The album is 6"x 4" in size and holds 24 photos. You can record your own messages (10 seconds long) for each photo and you can change the photos

for occasions, holidays, trips etc. It acts as a form of communication between home and school or just to carry around for family and friends to look at and interact with Sarah. If anyone is interested and would like more information, please make contact Andrew at 087 6152335.

Teeth Grinding (Bruxism)

from NATALIE SHAW (Dublin)
 Recently my daughter Ellie (4) needed to have all her teeth removed as a result of severe damage from tooth grinding. She had been waking at night screaming and had a temperature with red cheeks. Over a period of a year we had

brought her to the school dentist eleven times as we could see that the teeth were cracked and damaged. However, we were told that there was no cause for concern and that she would 'grow out of it' as they were baby teeth. We knew that there was something very wrong as we could see that the gums were exposed and inflamed. In the end we arranged a visit to a specialist in Crumlin Children's Hospital ourselves and finally it was recognised that that Ellie was in serious pain and the teeth needed to be removed. We were told that had the problem been picked up sooner, a lacquer could have been painted on the teeth to protect them. Parents usually know their own children best and are often the best judge of what is hurting them or causing problems. Trust your own judgement and if you are not happy don't be afraid to ask for a second opinion. Many

doctors and dentists don't have specialist skills for working with people with disabilities and our children often need to be seen by professionals specially trained in this area.

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Kate Devlin (left) and Nathalia Lawlor with their Moms.

Inclusion Ireland namhi gets a name change

As of January 2006 namhi has officially changed its name to Inclusion Ireland. Inclusion Ireland is an umbrella organisation representing disability groups throughout the country. Their role is to make submissions regarding disability services, planning and legislation and to advocate on behalf of disabled people and their families. The Rett Syndrome Association of Ireland is a member organisation of Inclusion Ireland.

A Chance to Learn

Inclusion Ireland has launched a new information booklet for parents and families of children with special educational needs called 'A Chance to Learn – Your Questions Answered'. It includes information on teaching resources and other supports and individual educational plans. The booklet is available from Inclusion Ireland, 5 Fitzwilliam Place, Dublin 2 or on their website at <http://www.inclusionireland.ie/>

Inclusion Ireland Parents' Committee

The Inclusion Ireland Parents' Committee are planning series of visits to Parent and Family groups around the country in order to provide support and advice to parents of disabled people around the country. We hope to invite the committee to one of our family days in Tullamore in 2007. If you have any issues regarding difficulty accessing services or entitlements for your child, please get in touch with us and we can raise the matter with the committee.

Website

Don't forget the Association Website can be found at www.rettsyndromeireland.com. Contact Joe Lawlor at rettsyndromeireland@eircom.net if there's anything you'd like to see up there.

'Towards 2016 - Social Partnership Agreement

A new social partnership agreement was published in June 2006. There are various commitments to people with disabilities and their families included in the agreement. These include that a people with disabilities have sufficient income for an acceptable standard of living; that they have appropriate access to care, health and education; access to appropriate housing and transport; and acknowledgment of carers and caring. The agreement states that these goals are to be reached over the next ten years.

National Disability Strategy

As part of the strategy, six government departments have been required to prepare sectoral plans for people with disabilities. The Department of Health and Children will have to provide an independent assessment of needs (IAN) for all children as part of the Disability Act 2005. For children under the age of five, this will be available from June 2007, for those between the age of 5 and 18 this will commence alongside the implementation of the Education for Persons with Special Educational Needs Act and for those over the age of 18 Independent Assessments of Needs will come into effect by the end of 2011.

Budget 2007

Increased funding has been made to disability services in the latest budget. Funding is to be provided for more supports to allow families caring for disabled people in their own homes. €75m is to be provided for additional residential, respite and day places as well as expansion in home support and personal assistance. The appointment of additional front line staff to enhance the level and range of multi-disciplinary support services to adults and children with disabilities and there priority will be given to the enhancement of assessment and support services for children with disabilities to underpin the commencement of part two of the Disability Act 2005 from the 1st of June 2007

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Recent Fundraising Contributions

Richard and Emmet Geoghegan, brothers of Olga (30) organised a fundraiser with 20 of their friends on Christmas day last. They all went for a swim in the local river at Bracknagh, Co. Offaly and raised €3,310. Thank you very much from all at the Association to Richard and Emmet and everyone else who was involved.



Mary Smith, mother of Rebecca (4) also participated in a run for Rett Syndrome with a group of friends and together they also raised €3,000. Thanks to Mary and everyone in Waterford who participated.

Thanks also to Ita O’Riordan, care worker with Ellie Shaw (4) who raised €200 for the Association with a cake sale.

Our very special thanks to all who contributed

Transport

If your child has significant mobility issues you may be able to benefit under the Disabled Drivers and Passengers Tax Relief Scheme. To qualify, you’ll need a Certificate from the Area Medical Officer, but if you do, you can reclaim up to €15,700 on the VAT and VRT on a new car, that has been suitably modified for the disabled person. It’s also possible to reclaim duty on petrol or diesel and Road Tax as well. Details from Disabled Drivers Section, Central Repayments Office, Revenue Commissioners, Coolshannagh, Co. Monaghan Lo Call 1890 606 061

You can get the Disabled Person’s Parking Card, which is valid here and overseas, from the Disabled Drivers Association of Ireland, Parking Card Section, Ballindine, Co. Mayo. 094 936 5054. It costs €25