

rett syndrome newsletter



Nathalia Lawlor and Sarah Kehoe at the recent RSAI Family Day in Tullamore

DISABILITY BILL DISAPPOINTS

The recent Disability Bill will “do nothing to improve the lives of people with disabilities or their families” according to NAMHI. Further, they state “it will not meet the widespread demand for basic rights; and it will force people with disabilities into a bureaucratic nightmare in the search for essential services”. They go on to call for an “un-

equivocal right to an independent assessment of need for every person with a disability. That assessment must be translated in law into a statement of entitlement to services, together with an agreed plan to secure access to those services within a reasonable time frame if the services are not immediately available.” Along with a call for a

RETT SYNDROME ASSOCIATION OF IRELAND

We are a group of families who get together for the purpose of sharing information and offering support to each other. We are a small group, mostly parents, who aim to meet approximately three times a year. For those unable to attend meetings we keep in touch by circulating our newsletter.

genuine complaints and appeals procedure, they also demand “meaningful progress and targets in relation to issues of employment and access to buildings and services.”

RETT ASSOCIATION LAUNCH

We are planning to have a formal launch of the Association early in 2006. We have been offered the PR support of Limerick-based Alice Kennelly (Island Theatre Company, formerly PR with Sadler's Wells). We will have some guest speakers so that families will receive some added value from traveling on the day and will also help attract service providers and professionals. We hope that families will be able to bring their girls along as it is their day and they should be at the centre of

everything. Do YOU have any ideas about who should attend the launch? Please drop us a line or an email with your suggestions. Please include contact details so that we can forward invitations. Having some indication of those who should be invited would greatly help in organising the launch.

The contact addresses for the Association are rettsyndromeireland@eircom.net or Rett Syndrome Association of Ireland, c/o The Bishop's Palace, Church St., Limerick.

RECENT FAMILY DAY MEETINGS

Since the last newsletter last family meetings of the Rett Syndrome Association of Ireland have been held, one on 2nd October 2004 in Limerick and the others in Tullamore on 7th May and 24th September 2005. We are very grateful to Anne Long and Enable Ireland for making their premises and facilities available to the Association once again for the Limerick meeting. This meeting was attended by families from Dublin, Galway, Kildare and Limerick. Rose Anslow, community welfare officer with the Health Service Executive Mid-Western area came along to answer questions families had in relation to applications for benefits and other issues such as grants for adapting housing for disabled relatives. There appears to be much disparity across the country with regard to access to entitlements, equipment and supports across the different Health Service areas. There is also considerable variation across Corporations and

County Councils in processing and managing benefits and grants.



Anna Boland at the RSAI Family Day in Tullamore



Aoibhinn Cassin from Co. Kilkenny

The April and September meetings were held in Days Inn Hotel in Tullamore. The venue was found to be very suitable for our families and was well equipped for the benefit of people with disabilities. The

surroundings were very comfortable and even included a large flat screen tv with dvd, which allowed the girls to watch Bear in the Big Blue House while families had a chance to talk. There was good access to disabled bathroom facilities. Our thanks to Brian and Anne at Days Inn who made our visit very comfortable and offered a much reduced rate for the rent of the room for our group. We were also offered the parking facilities at the nearby multi-storey car park free of charge. However, in view of the difficulty some families might have managing wheelchairs

in a multi-storey car park, LIDL supermarket, across from Days was approached in order to ask for access to parking for the day. Again the staff here were most helpful in making this available and also donated a large box of sweets for the girls coming to the meeting. As families have indicated that they find a central venue most suitable, and our recent Tullamore experience went so well, we would expect to be meeting at Days Inn again for all meetings in the foreseeable future.

RECENT CONTACTS

In the last while we have received contact from three new families, one from the south-east with a little girl aged 6 and another from a family in the same area with two boys just diagnosed with Rett Syndrome. There was also contact from a family in the Midlands area with an adult daughter with Rett Syndrome.

ASSOCIATION LEAFLETS

We now have our very own leaflets which have been sent out to the main children's hospitals for the benefit of new families and health care staff dealing with Rett Syndrome. We hope to circulate the leaflets to hospitals, paediatricians and services around the country in the near future. Many thanks to Stamark Printers in Naas for donating their printing services to the Association and to Neil O'Donoghue (Dad to Emma, age 9) for his work on the leaflet.

Shaw. Thanks also to Marie and Don Harrington who made a donation of €200.



Joe and Nathalia Lawlor

RECENT DONATIONS

Many thanks to John Doyle, uncle to Laura Finucane (age 15) from Limerick who produced a CD of Christmas songs and donated the proceeds of €1200 to the Association. We were also extremely pleased and surprised to receive the unsolicited donation of €28000 from the Atlantic Philanthropic Association. Thanks to Nathalie

LONG STAY CHARGES

Long stay charges were discontinued in December 2004. New charges for in-patient services came into effect in July 2005. For those who receive nursing care on a 24 hour basis, the maximum weekly charge is €120 or their weekly income less €35. For those inpatients where nursing care is not provided 24 hours a day, the charge is €90 or weekly income less €55 or 60% of the person's weekly income. Charges may be waived in the case of hardship.

There is concern about the amount of income that will be left after charges are deducted. NAMHI feel that this amount does not allow a person to live with dignity and is not conducive to a model of supported or independent living. There is also an issue of inequity as more independent intellectually disabled people can access funded social housing and have legal rights as tenants and entitled to a rent supplement.

People living in residential services should now receive an

account of how much they will be charged and how these charges are arrived at. There will be an appeals mechanism.

If you think that a member of your family has been illegally charged for residential care in the past, you may be entitled to claim some of this from the HSE. Please contact at National Repayments Scheme, HSE Midland Area, Arden Rd., Tullamore, Co. Offaly.

CHARITABLE STATUS

The Association has finally achieved charitable status as of April 2005. This should assist greatly in our work in supporting families living with Rett Syndrome.

NAMHI PARENTS SEMINAR

NAMHI are holding the 10th Parents' Seminar 'Supporting Families- Innovative Approaches to Respite Services' in the Killarney Plaza Hotel, Co. Kerry on Saturday the 12th of November. The fee for the day is €30. Queries may be directed to NAMHI at 01 6766035.

TAX RELIEF AND HEALTH EXPENSES

Advice from the Office of the Revenue Commissioner states that tax relief may be claimed in the case of children with permanent disabilities in respect of the following:

Where a child is treated at home, a flat rate of €260 to include telephone rental and calls directly related to the treatment of the child.

Payments for overnight accommodation made by a parent/guardian when a child is a hospital patient and an overnight stay by the parent is necessary for the treatment of the child.

The cost incurred in travelling to and from any hospital in respect of the patient or parents/guardians where such trips are shown to be essential to

the child. If a private car is used €0.35 per mile is allowed.

Cost to a maximum of €500 per year for the purchase of hygiene products and special clothing.

Revenue's explanatory leaflet on health expenses is available at www.revenue.ie or by post from the Office of the Revenue Commissioners.

CHRISTMAS CARDS

If you would like to support Rett Syndrome Association UK this Christmas, Rett syndrome Christmas cards are available from the UK Rett Syndrome Association at www.rettsyndrome.org.uk. Alternatively, you can contact the Association at Rett Syndrome Association UK, Sue Morse, 92 Abercrombie Gardens, Lordshill, Southampton, SO16 8FR, phone 0044 23 80737890. (This address is for ordering Christmas cards only).

HIRSTWOOD MULTI SENSORY TRAINING COURSE

A day course aimed at those working with children and adults with special needs will be run in Limerick, 7th and 8th of November and in Dublin on the 10th and 11th of November. For more details phone 0044 1524 426395 or email Richard@hirstwood.edi.co.uk

INTERRETT IRSA RETT PHENOTYPE DATABASE

InterRett is an international online database which will examine the clinical features (how our children present) and genetic characteristics of Rett Syndrome. Information is gathered from families and professionals around the world from internet questionnaires. The purpose of the InterRett is to collect enough information about children with Rett Syndrome so that comparisons may be made between the genetic information and physical characteristics of those with Rett Syndrome. It also aims to educate and increase understanding about the disorder. It is hoped that it will be possible to link certain common genetic profiles and eg. the ability to walk or the tendency to develop scoliosis.

Anyone wishing to participate in the study can contact the InterRett team by email at rett@icmr.uwa.edu.au. If you would like to explore the existing database go to www.icmr.uwa.edu.au/rett/irsa. Professionals with an involvement or interest in Rett Syndrome can also take part, so feel free to pass on the details to your paediatrician.

DISCLAIMER

While every effort is made to ensure accuracy, the Rett Syndrome Association of Ireland cannot accept any responsibility for the content of any of the notices herein

IRSA RETT SYNDROME HANDBOOK

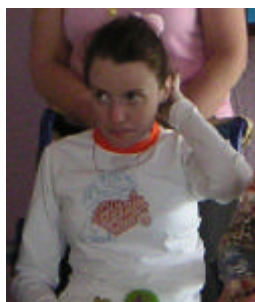
The revised edition of the handbook by Kathy Hunter, parent and president of the International Rett Syndrome Association will soon be available. For anyone who has not yet seen this book, it is highly recommended. It is written in language that is easy for all to understand and has many contributions by parents and carers of people with Rett Syndrome. The revised handbook will have new chapters covering issues such as 'atypical Rett Syndrome', the parent-doctor relationship and medical research. There will be expanded chapters on communication, education, genetics and day to day care. There will be new information on challenging behaviours, sensory integration therapy, grandparents, single parents, literacy, seating and positioning, friendships and preparing for the future.

We hope to be able to provide copies of the book to Irish families at cost, once they become available.



THE SHARE A DREAM FOUNDATION

The Share a Dream Foundation is an organisation based in Limerick, specialising in organising holidays, outings and special events for disabled children and their families. Founded in 1991 by Shay Kinsella, they operate in various parts of the country and their aim is to establish one in every town in Ireland. Their purpose is to provide something fun and special for the children and families who are living with sickness and disability all year round. The Gotts in Cashel had a



wonderful holiday in EuroDisney with their four children (Darren 12 and Oisin 9, both RS). It was all provided courtesy of Share a Dream. Everything was paid for except meals. They had travel

and accommodation catered for and a carer to assist them during the day in EuroDisney.

Families of children with special needs can receive special passes in EuroDisney and Disney US. The passes allow them to access rides and events without queuing and they get special attention from Mickey Mouse and other characters at Disney.

To contact Share a Dream, telephone 061 343434 or email at dreams@iol.ie. The organisation also has a website at www.share-a-dream.com

AIDS AND APPLIANCES

Julie and Andrew Kehoe have just installed a lift in their home to help them get Sarah upstairs to her new bedroom. Sarah is able to walk but like most children with Rett Syndrome needs to be lifted frequently and cannot climb the stairs. The Kehoes had their garage converted and a bedroom built overhead. The lift runs from the garage conversion up to the new bedroom. After much waiting and hard work managing the building work and grant application process the Kehoes are delighted with their new lift. Andrew says that anyone interested in seeing the lift is welcome to get in contact at 01 4933452



WHAT IS RETT SYNDROME NEWSLETTER

Rett Syndrome is a complex neurological disorder affecting mainly girls. It is almost always the result of a spontaneous genetic mutation and in the majority of cases not hereditary, that is, will not affect other brothers and sisters. According to the Rett Syndrome Research Foundation (RSRF) Rett Syndrome is the leading genetic cause of severe impairment in girls. It is the only autistic spectrum disorders with a known genetic cause.

Contrary to general belief among health professionals, it is not a degenerative disorder and many of those affected have been shown to demonstrate a capability of life long learning. With improved medical care people with Rett Syndrome are living longer and it is not unusual to hear of people in their 40s and 50s with Rett Syndrome.

It is commonly found among families of people with Rett Syndrome that these children and adults have a high level of understanding but an inability to carry out the actions to indicate understanding. There is usually a delay in responding in Rett Syndrome which can be as long as 2 minutes and this can give the impression that the person with Rett Syndrome has not understood. Among the greatest impairments are absence or loss of any acquired speech and hand function. Body movements are generally affected at a gross level e.g. walking, and fine movements such as ability to pick up small objects. As a result those affected by Rett Syndrome remain unable to care for themselves independently, in most cases are not able to indicate basic needs or carry out basic activities.

We include any information we think might be useful to families and welcome any contributions from families around the country, whether it's a piece of equipment that has been found to be useful, a course or information about entitlements. We would also welcome stories about your children that you would like to share with other families. Families are also welcome to submit ideas about professionals or organisations that they would like to see invited to the family meetings to give presentations or answer questions. We would also welcome any ideas about items they would like to see in the newsletter.

RETT DISORDER AND THE DEVELOPING BRAIN

Edited by Alison Kerr is now available in paperback for £29.25 and is available directly from the author at Academic Centre, Department of Psychological Medicine, Gartnavel Royal Hospital, Great Western Road, Glasgow G12 0XH, UK.

However, this is an academic work, for those who are interested in delving into the genetic and neurochemical aspects of the condition.

THE JACK AND JILL FOUNDATION

The Jack and Jill Foundation, set up by Jonathan Irwin, helps families who have children with special needs under the age of four. The foundation will pay a relative or friend to help parents

WEBSITE

Joe Lawlor has developed a website for the Association.

[www.
rettsyndromeireland.ie](http://www.rettsyndromeireland.ie)

is the address. Any ideas for the website should be forwarded to the Association by email or post. We would like to include a webpage about our girls on the site. Nathalia Lawlor's story and photographs are already on the site for people to see. We would love to receive more pictures and stories about the other girls

for up to 10 hours a week. They also advise on benefits, entitlements and provide other useful services for families of disabled children.

NEXT ASSOCIATION FAMILY DAY:

**Days Inn, Tullamore,
November 26th, 2pm**

As always we will have an opportunity to chat and allow the Rett girls to meet and mingle. We will also hold the AGM of the Association. If you have any motions you would like on the agenda of the meeting, please get in touch.

We hope to see you there.