

# The Rett Syndrome Handbook

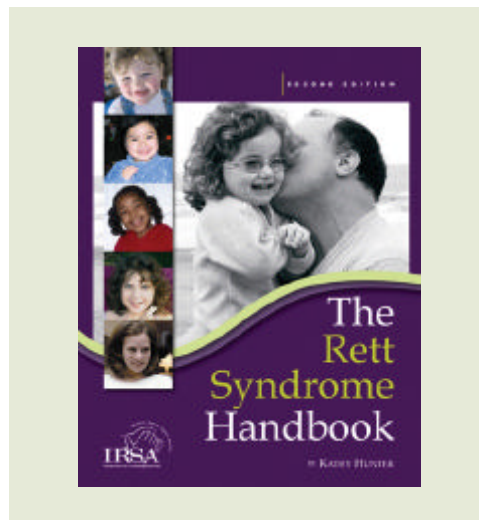
The long awaited second edition of the Rett Syndrome Handbook has been published and is now available.

The Handbook is edited by Kathy Hunter, parent and chairperson 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 really is a must have volume for anyone who parents or cares for someone with Rett.

The Association has imported 100 copies of this vital text, and over the next while we'll be distributing it to members. The Handbooks will be available at the next family day. If you or your child's school is interested in obtaining a copy of the book then please contact the Association - we're on the web at [www.rettsyndrome.ie](http://www.rettsyndrome.ie) or c/o The Bishop's Palace, Church St., Limerick.

The books are large format and heavy, so we prefer not to post them, but we will try and work out a way of collection or delivery that works for everyone.



The books were shipped to Ireland from the US by the Eastway Logistics of Loughmore Road, Raheen Business Park, Limerick. They arranged shipping for a fraction of the cost other shippers quoted, and didn't charge The Association for their services. We are extremely grateful to Eastway Logistics and especially Frank Mc Namara and Don Cusack and for their generous assistance and support of the Association.

## 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

Contact Us;

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# Physiotherapy in Rett Syndrome

*regular and intensive physiotherapy is vital to people with Rett*  
writes Noreen Harrington

**Meir Lotan is an international expert** in physiotherapy with a special interest in Rett. Based in Israel, he has given presentations at the International Rett Syndrome Association's conference in the USA and also at the UK Association's conference. He has also written articles on the importance of physiotherapy in person with Rett Syndrome. He has co-authored papers with Susan Hanks, physiotherapy consultant to the IRSA.

According to Lotan regular physiotherapy is essential for people with Rett. Typical problems in Rett include functional limitations, low cardiovascular capacity, hypotonia, ataxia, apraxia, loss of transitional movements, spasticity, scoliosis and/or kyphosis, loss of ability to walk, loss of hand function, foot deformities and spatial disorientation. Coping with such difficulties and overcoming the associated limitations is difficult for people with Rett Syndrome and their families. 'An informed and intensely applied physical therapy regime can help the child and her family cope and even overcome the above mentioned limitations' (Lotan and Hanks 2006). Unless it is delivered in a regular and consistent manner it can result in deterioration in physical function. He also points out that people with Rett are prone to sudden and severe deterioration and this may be irreversible if it occurs in a period without intervention. (Lotan 2007).

He asserts that there is a growing body of research recommending an intensive and sustained approach to therapies in RS. He claims that sustained continuous intervention is preferable to 'episodic' therapeutic intervention and also recommends that therapies should be continued through the summer period as it has been found that children with this degree of developmental delay regress in

the absence of appropriate services. Physiotherapy can help the girl's physical fitness and function thus reducing the secondary dangers of immobility.

**In the management of scoliosis**, a common and disabling problem in Rett Syndrome, Lotan uses a combination of



Families at the recent meeting in Tullamore

'over-correction' exercises and positioning with appropriate equipment to maintain spinal mobility. Daily standing for at least 30 minutes is also seen as essential. Lotan has even succeeded in reversing scoliosis severity in one case study. This is contrary to the general belief among experts that it is not possible to reverse scoliosis.

The aims of any physiotherapy programme for a person with Rett Syndrome are:

- To maintain or increase motor skills
- Develop or maintain transitional skills
- Prevent or reduce deformities
- Alleviate discomfort and irritability and
- Improve independence.

It is important in any physiotherapy programme that the therapist recognise that these girls are age appropriate emotionally and that their understanding of what goes on around them is recognised as far greater than clinicians believe.

**Routine is helpful and a running commentary** of what is happening and verbal prompting relating to movement exercises is important, so that person can anticipate the movement and work with the therapist where possible. As the majority of people with Rett find it difficult to cope with physical manipulations, it is vital that they are prepared at the start of a session for what they are about to do. Where possible the person should be given the opportunity to indicate which activities s/he likes and music and other things that s/he enjoys be incorporated into the programme.

Lindberg (1991) found that exercise helps people with Rett concentrate so it is useful to plan other educational interventions to happen after physiotherapy sessions. People with Rett Syndrome are known to tire very easily so any physical interventions should be timed with this in mind, morning being better for physiotherapy activities. Programs should be sensitive to what the child can cope with

It is important for those working with girls with Rett Syndrome to understand that the research has found that improvements can be achieved in both childhood and adulthood as a result of therapeutic interventions. We also know as parents that it is important to be realistic in our goals and that improvements can be small. However, any improvement is significant in the life of a person with Rett Syndrome and their families.



**Rett Syndrome Association Christmas Cards**

This year for the first time, the Association is selling its' own charity Christmas cards.

Each card contains the logo of the Irish Rett Syndrome Association with a brief explanation of Rett Syndrome.

The cards are selling at €6 plus postage to you, for a pack of 12. The cards come in 6 different designs and there is a pair of each design in a pack. Boxes of 30 packs are available.

We're delighted to say that the first order of cards has already sold out but more are now available. Contact Andrew in Dublin (087 6152335) or Noreen in Limerick (087 6152183).

**Neuroscope assessments**

To date reports have been received for two of the girls assessed by Dr Julu at the Neuroscope Demonstration in Dublin last February. The Association is continuing in correspondence with Dr. Julu to arrange to have the remainder of the reports provided to families.

A number of other families have indicated that they would be interested in having their daughters undergo the

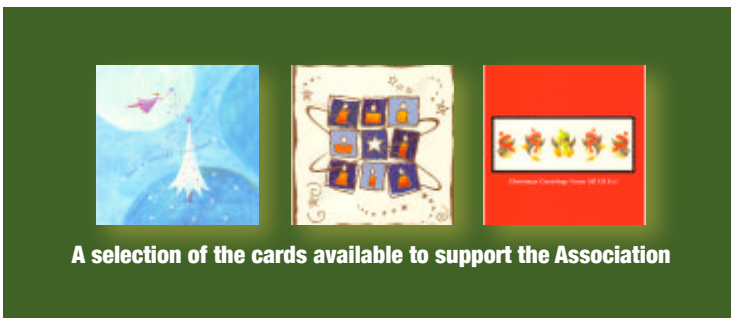
Neuroscope assessment. Dr. Webb, Consultant Paediatric Neurologist at Our Lady's Hospital in Crumlin has suggested that he might arrange further neuroscope assessments if there is interest from families at some time in the future if funding can be made available through the hospital. Anyone interested should contact him directly by letter at the Childrens' Hospital in Crumlin.

**Research into Rare Disorders**

Research is currently being carried out by Rehabcare into consumers experiences of access to and quality of service provision to families of people with rare disorders. It is proposed that this research will be used in order to plan and lobby for more appropriate services for our children.

Researchers can travel to meet family members for discussion at a place that is suitable to the family. Anyone interested in participating in the research may contact Bernadette McGarvey at 01 2057224 or email at [bernadetteemcgarvey@rehabcare.ie](mailto:bernadetteemcgarvey@rehabcare.ie).

Any opportunity for families to have a say on their experiences of access to services for their children with Rett Syndrome and the quality of same is very important.





Emma O'Donoghue at the recent Family Day in Tullamore

## Family Meeting September 07

The most recent family meeting took place on the September 2007 in Tullamore. This was also the Association's AGM.

We are very pleased to welcome 2 new committee members:

Deirdre Horan, mother of Rachel (11) from Tralee and

Susan Boland, mother of Anna (12) from Kilkenny.

Angie Fitzsimons will continue as Treasurer  
Andrew Kehoe as Secretary

Noreen Harrington as Chairperson.

## Support for new families

Do you think that you would be able to talk to parents of younger or newly diagnosed children who are looking for information?

The Association regularly receives calls from new families enquiring about services in particular areas of the country, or looking for information on epilepsy or scoliosis management and feeding problems.

Parents who have had experience of surgeries, anti-convulsant medications or peg feeding would be very useful to these families. If you think you can help, get in contact with Andrew (087 6152335) or Noreen (087 6152183).

## Programme for Government

Following the May 2007 General Election and the formation of a new Government a new programme for Government was agreed.

Included in this were measures relating to disabled people and service provision.

- Advocacy officials will be recruited (as regulated in Citizens Information Act 2006) to work with the Citizens' Information Board (formerly Comhairle)

- The rolling out of the Education for Persons with Special Educational Needs Act (EPSEN 2005) will be completed. This refers to the fact that all children up to age 5 are entitled to an assessment of need with a view to service planning.

- Improvements in support for carers (but does not specify the abolishment of means test for Carers' Allowance) and 'examine a needs assessment protocol for family carers, incorporating health and social issues, and see how the shortfall in places for people with an intellectual disability in need of respite and day-care services can be addressed'

- Implement appropriate standards in service delivery to people with disabilities.

## Subscriptions

Membership of the association is due for renewal in January 2008 and costs €30 per family. For those families who cannot afford the subscription, membership is still welcome. Subscriptions may be forwarded to the Association address. The application form is now available to download and print off from the Association website.

## Newsletter

We would also welcome any features and photos families might like to add to the newsletter, particularly about their girls. Also anyone with any information or tips that you think might be useful to other families would be very welcome.

Experiences and information regarding house alterations, car adaptations, social welfare entitlements, toys and other tips are all useful.

## Website

The website has been updated with a new design by Terry Devlin (father of Katie, 8). Back issues of the Association newsletter can now be downloaded from the website.

We would welcome any contributions families might like to make to the website. This can be a story about your daughter that you would like to share or a piece of information that you think other families might find useful.

We would also like to create a section on the site where families are welcome to submit pictures and some biographical information about their Rett children and their achievements. Contact Terry at [terrydev@gmail.com](mailto:terrydev@gmail.com).

## CHRISTMAS IS COMING...

*www.thinkingtoys.ie is the name of an Irish-Owned website that specialises in toys for Children with Special Needs.*

*First and foremost the shop is a Toy Shop and carries a range of popular brands that kids and parents would hope to see in a Toy Shop. However, it is Toy Shop with a difference. The majority of the toys stocked, carry an emphasis on adding value to the user. In most cases, the child has to construct, design, problem solve or use imagination while playing with the toy and therefore create stimulation for the child through play in an enjoyable environment. In addition to the above, the shop carries a range of toys which bring specific benefit to kids who have very special needs.*

*www.mimitoys.ie is another option: What does Mimitoys offer...Mimitoys is the 1st Irish mail order catalogue and website for toys. Their selection for boys and girls allows parents choose traditional and unique quality toys from home. The toys are each selected to be fun, entertaining and educational for the child. 'Whilst the range of toys covers the full age spectrum from birth to 5 years of age, we avoid heavily branded or advertised toys, weapon-look-alikes and have strict anti child-labour ethics in place'.*

## Thank you

A big thanks to Tim and John and all the staff at Stamark for their continued support in printing our newsletter