

winter 2009

Rett Family Day

Roscrea, October 09

The Rett family day was held in The Racket Country House Hotel in Roscrea on Saturday 3 October 2009. There were lots of families there and it was great to see all the girls. The morning started off with tea and coffee and light refreshments for the girls and families. They had a clown who painted all the kids faces and this went down really well as they got to pick which one they wanted. Then the clown played party games and tricks and great fun was had by all and everyone got a prize. We played musical chairs and the music was great and all the kids were dancing to the Hokey Kokey and had great fun.

Toys for Special Needs Children

The first part of the morning was a talk on Sensory Toys by Thinking Toys. (www.thinkingtoys.ie. Phone: 061 374402, 086 8792769) All these were laid out on the tables for the parents to look at and order if they wanted. Some of the products on show were extremely good and beneficial for the girls. There was a wide range to choose from and something for every age group. The website above can be used to order the toys, books or you can phone the order in and they will be shipped to you.



Robyn Dagg from Wicklow at the Family Day

Equipment

Later in the morning Kevin Barry showed us the bike which he specially adapted for his daughter Ciara. He adapted it to suit her needs and adjusted to suit her size. She now can go out with her dad for cycle and can be quiet independent on it by herself. This was so encouraging and has given food for thought for us that nothing is impossible for our girls to do, just they are doing it a different way. Murrays Pharmacy was to be there but could not make it but left a book which anything that needed to be ordered could be done so through Kevin and he would be able to get a discounted rate. All orders need to go through him and he will be able to put the orders through.

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;

by Post:
% the Bishop's Palace
Church St.,
King's Island, Limerick

by e-mail
rettsyndromeireland@eircom.net

on the Web
www.rettsyndrome.ie



Anna Boland (Kilkenny) and Ciara Barry (Waterford) at the Family Day in Roscrea

Dental Hygiene

The hotel provided a lunch for everyone and then we went back to a talk by Dental Hygienist who works in Tralee and has experience with children with special needs.

Attention to dental hygiene is very important for the girls because of the build up of plaque and the constant drooling. The Hygienist had various different types of cleaning equipment, and she gave out samples. She demonstrated the best way to clean the girls' teeth. She said especially with all the drooling and the saliva that the girls' diet was also important. Parents should watch sugary drinks, foods, sweets etc. There is a natural sugar in most things without even realising it so it is best not to be giving sugary drinks etc. Water is the best and also good for flushing out their systems. She stressed on about brushing the teeth the correct way and each child is going to be different.

Whether it be a normal tooth brush or electric tooth brush or a cotton bud it is important that the teeth be cleaned in a circular motion. Some children will be amenable to this and think it fun and others will not like at all. The gums are also an important factor when cleaning of the teeth as there can be a build up also on the gums.

She had various types of brushes etc with her and explained the benefits of each one. She spoke about the constant drooling and how this causes problems with build up of plaque etc. There is not that much can be done with this as you can get these small tablets which are placed under the tongue to dry up the saliva but this in turn can make their mouths very dry and one of the families had used this but decided not to use it anymore. Getting the girls to drink from beakers or cups and not out of bottles was also suggested. To try and not give milk or sugary drinks last thing at night as the sugar builds up in the saliva and attacks the gums hence making them weak. In general Oral hygiene is a must with the girls and everyone for that matter. There are a lot of hygienist and dental practitioners available to work with the girls so if your child is not attending one of these a list can be got from the HSE or from your child's school etc.

Questions and Answers

In the afternoon there was a questions and answer time where everyone gave opinions etc on different topics. The subject was brought up about different cars and accessories for cars, car-seats/

lifts etc. People shared their opinions on this and families looked at different seats with regard to the girls' comfort. Also the topic of constipation which is a problem for a lot of the girls was discussed. It looked like we all had the same problem with the girls on this subject. Most of the girls do suffer with it and most are on medication Movicol/ Senokat/Liquid Paraffin etc. It is important to manage this so that the girls should not be any pain. The issue of energy/vitamin supplement drinks was raised and a supplement called Fortijuice Nutricia was recommended. It is given once a day and can be ordered from chemists and the cost should be covered under the long term illness booklet. It also helps with appetite. The girls' weight also needs to be monitored as with a lot of Rett girls it can fluctuate.



Aiobhinn Cassin (Kilkenny)

Passports

The idea of a 'passport' for the girls was also presented and a CD copy was circulated among the families so that others could create them for their own girls. Basically it goes everywhere with the girl and it tells about her family, her likes, dislikes, her good habits bad habits and so on. Kevin Barry and Dee Horan had very detailed ones for their daughters, Ciara and Rachel, which were amazing. They have folders which can be added to or changed at any time. The passport goes everywhere with the girls and if they need to leave the girls with another carer for the day all the information on their needs is in the passport. The issue of travelling abroad with the girls also came up. Some families had problems trying to getting insurance for the girls. Others had no problems. One family said that they had booked with Blue Insurance Company and they were extremely helpful and insuring of the girls was no problem. The following number can be used to contact Blue Insurance Company 0818 484484.

A.G.M.

Then the meeting was coming to a close and families started making a move so the Annual General Meeting was held. Kevin Barry has become acting Chairman, and will be getting help and support from Noreen Harrington who has worked so hard over the last many years. The Secretary is now Angie

Fitzsimon and Treasurer is Joe Lawlor. Susan Boland, Cathy Cleary and Dee Horan are also committee members. Kevin is looking for new ways for the Rett girls to be more recognised and more publicity about Rett in general. We also need funds for the other Rett girls to have the Neuroscope Test done with Dr Julu. The Christmas cards with help with funding and a lot of the mothers had done the womens' mini marathon for Rett. We are looking into new ways of fund raising.

Catherine Cleary

News from Inclusion Ireland

We have already seen cuts to special classes, therapy services and very serious problems around where school leavers will go. There is no scope for further cuts.

Last year the Minister for Finance framed his Budget in terms that Budget measures must protect the most vulnerable in our society, including people with disabilities. This year the priority must remain the same. Cuts cannot be made in the area of essential services and in some areas the challenge will be to find extra resources.

The Report of the 'Bord Snip' Group was announced in July. Many of the cuts proposed affect people with a disability, including: A cut of €50 million out of a total of €2.53 billion to state funded disability and mental health services. Proposed cuts include: The suspension of additional recruitment to the National Education Psychological Service; Abolishing the half rate carer's allowance; Introducing charges for special needs school transport; Reducing the number of special needs assistants;

Inclusion Ireland has called again for no cuts to frontline services for people with a disability, and calls on the Government to remember the following: for the last three years, schools have experienced major delays in getting assessments for children with special needs, which are key to helping a child's development; carers play a vital role in Irish society; some of the children

availing of special needs school transport are forced to travel long distances to schools as their local school will not accept them; no decision should be taken on reducing the number of special needs assistants until the review of special needs assistants and special schools is completed. No decision has been taken by Government on which recommendations will be implemented.



Shauna McPhillips (Co. Monaghan)

Christmas Cards

This year the Association is selling packs of 15 cards instead of last year's 12. And the good news is that the price stays the same. This year you also have a choice of two different kinds of card. The first type is the same as last year's cards, square in shape and the other is rectangular/portrait. The packs cost €6 each. Please contact us at the Association numbers or the email address to order and check on postage costs or to see if collection is an option for you.

Mini Marathon

We would like to congratulate and thank Natasha Kemmy, sister of Louise and Niamh Rankin, mother of Lauren. Both completed the Mini Marathon last June and raised much appreciated funds for the Association.



Top: (l to r) Alex Connolly (Bray) ; Rachel Horan (Tralee) with her Dad

Left: Teresa Davoren (Lahinch) and Ciara Barry takes a Time Out

Bottom (l to r);

Megan Cleary (Dublin); Sarah Keogh (Dublin); Talia Lawlor (Co. Kildare)

