

Tullamore Family Day on April 24

The most recent meeting of the Rett Syndrome Association took place at Riada House in Tullamore on Saturday, April 24th. Eight families attended and most were able to bring their girls. Because of the postal strike it was necessary to phone everybody to let them know about the meeting. This was a great opportunity to catch up with many people who haven't been able to attend meetings. Some families find it difficult to travel for reasons of illness or because the location was too far away. While unable to attend meetings, families wanted to maintain contact with the Association and be kept up-to-date with news and events.

At the meeting there was a lot of discussion about Medical Cards and Long Term Illness Cards. There was confusion about whether or not a girl with RS is entitled to both or just one type of card. The various benefits and disadvantages of each type of card were discussed at length. There seems to be considerable variation from Health Board to Health Board with regard to what medications are covered by medical cards and which are not. For instance, in one area a family is receiving melatonin on the long term illness card and in another area a family with a medical card was paying up to €200 a month for



Olga Geoghegan at the Association Family Day in Tullamore on April 24

the same medication. Yet you can buy a year's supply over the counter in the US for approximately \$15.

There also continues to be a lot of variation in service delivery depending on the area of the country in which a family live. Some families having access to day care 5 days a week while others struggle to get any service at all.

Another issue causing concern was the fact that some families are being refused a primary medical cert, which entitles them to apply for tax relief on transport. Even for those families whose girls are able to walk, there is still considerable difficulty when it comes to lifting into and out of cars. This has been particular evident for two families we are in contact with: one has been waiting years for a stairlift for their adult daughter who does not walk and another has waited 8 years for a wheelchair for their adult daughter, who although she can walk, cannot walk distances and suffers from epilepsy. It would seem that those with responsibility for awarding Primary Medical Certs have little understanding of Rett Syndrome as a disability. This, in turn, suggests that as an Association we have an important role to play in educating those who make these decisions about our daughters about Rett Syndrome and what the disability actually means for them and their families.



Mums and Daughters: gathered together for the family day in Tullamore.