

Rett Syndrome newsletter No. 5

The last family meeting of the Rett Syndrome Association of Ireland was held on xxxxx in Limerick. We are grateful to Anne Long and Enable Ireland for making their premises and facilities available to the Association once again. It was attended by families from Dublin, Galway, Kildare and Limerick. Rose Anslow and yyy, community welfare officers 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 practices of the Health Service and Corporations and County Councils in processing and managing these benefits and grants.

Many thanks to John Doyle, uncle to Laura Finucane (age xx) 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 xxxx from the Atlantic Philanthropic Association (check name and date of donation, date of last newsletter). Thanks also to Marie and Don Harrington who made a donation of €200.

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.

Rett Syndrome Association launch.

We are hoping to have a formal launch of the Association later in 2005. We are hoping to hold it in Dublin on a weekday in order to attract the attention of the national media and politicians. We also hope to have some guest speakers so that families will receive some added value from travelling on the day and so that we can take the opportunity to invite along service providers and professionals. We would also hope that families will be able to bring their girls along so that we can also celebrate it as a family day. After all the girls are the reason we have come together. At this time, we would like to know who would like to attend a launch. Please find a form attached giving examples of the people you believe should be invited or those who you would like to invite. Please include contact details so that we can forward invitations or in the case of extended family we can send them to your home address. Having some indication of those who should be invited would greatly help in organising the launch.

Disability Bill

Namhi news

Namhi conference

The 2005 Namhi conference was held at the Radisson Hotel in Sligo on Friday the 22nd and Saturday the 23rd of April. The main theme of the conference was

Committee meeting

International news

Research news

Website

Joe Lawlor and Terry Devlin have been working on developing a website for the Association. It can be found at xxxxxx. Any ideas for the website should be forwarded to the Association email or postal address. 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.