RETT SYNDROME MEETING – February 2003 Limerick

February meeting

The first Rett Syndrome meeting (in recent times) of Irish families was held at Enable Ireland in Limerick on Feb. 1st this year. It was attended by 16 families, most of whom were able to bring their daughters with them. It was a much greater turnout than expected, given the difficulty families have travelling with their disabled daughters, and the distance people travelled. Families attended from all over ireland. There were families from Waterford, Kerry, Clare, Galway, Mayo, Dublin, Kildare and Limerick. The girls ranged in age from 21 down to 2. For most of the families it was their first time meeting with other families living with Rett Syndrome. Other families, who were unable to attend the meeting, got in contact with us asking to be kept informed of any happenings, and many said that they looked forward to attending any further meetings that might take place. In total, we now have a list of 30 families.

Aim of meeting

As it was a first meeting, the focus of the meeting was to decide what families wanted from getting together as a group. Parents said that they want to get together for support, to share information, to lobby for services and to raise awareness. It was decided that the group should meet 3 times a year, as that would be most practical and reasonable from the point of view of travelling. A decision was made to alternate the meetings between the west and east coast to facilitate people who might have difficulty travelling long distances. The centre of the country, Athlone or Tullamore, was suggested as possibly the most convenient, but at present there is no one in either of these locations in a position to organise such a meeting.

Items discussed at the meeting included:

- The difficulty in getting a **diagnosis** currently, particularly the fact that it is taking months for test results to be be returned.
- **Poor support following diagnosis:** Most people attending the meeting referred to the fact that there is very little information available to those who are newly diagnosed and much of this is misleading. Once diagnosed, people are usually left to their own devices with little support. A suggestion was made that an information pack, with practical information and advice, could be put together for those who are newly diagnosed, and that this could be made available at the children's hospitals.
- The **Rett Syndrome conference** in December 2002, jointly organised by the Departments of Health and Education. It was felt that this was not advertised widely enough and concentrated largely on the medical and genetic issues. It was suggested that the Departments could be approached and a suggestion made that a follow-up conference might take place. This would be particularly useful for care staff working with our children, throughout the country and a follow up conference could focus more on the functional and practical aspects of caring for girls with Rett Syndrome.

- Formalising the **Rett Syndrome Group** in Ireland. It was decided that this would be discussed further at the next meeting. In order for the meetings to take place on a regular basis and suggestions made by the group to be followed through, a committee will need to be put in place.

Rett Syndrome Survey
A suggestion was made at the meeting in Dublin in December 2002 that it would be useful to look at the service needs and services available to girls with Rett Syndrome and their families. There appears to be much variation across the country in what is available to girls and their families. It was felt that by obtaining an accurate picture of what is available, some families who are having problems accessing services and entitlements might be helped.
A survey was passed around to the families who attended the Limerick meeting. Thank you to all those who have returned these, and to those who haven't yet, I would appreciate, if possible, if you could send them on. To those who were not at the meeting, I am enclosing a copy of the survey and would appreciate if these could be returned before May the 10th so that I can attempt to summarise the findings for the meeting.

Music Therapy
A brief presentation on the benefits of music therapy for girls with Rett Syndrome was given by music therapist, Andrea Intveen. Some useful suggestions were given for parents who don't have direct access to a music therapist. Andrea also included some recommended reading for parents.

Next meeting

It was decided that the next meeting would be held in Dublin and Joe Lawlor has been in contact with Cheeverstown House to arrange this. Please find map and directions attached.

Next meeting: Cheeverstown House, Rathfarnham, Dublin
Saturday, the 10th of May 2003