

RETT SYNDROME ASSOCIATION IRELAND NEWSLETTER – AUGUST 2003

February Rett Syndrome Meeting

The second meeting of families with Rett Syndrome took place at Cheeverstown House, Dublin on Saturday the 10th of May. Eight families from various parts of the country attended, including some families who hadn't attended the previous meeting.

After some discussion a name for the group was decided on. The group will be known as the **Rett Syndrome Association of Ireland**. A core committee was elected, consisting of:

Brenda Duff, Treasurer,
Joe Lawlor, Secretary
Noreen Harrington, Chairperson

A membership fee of €30 was agreed per family. However, for those who cannot afford the fee, membership is still welcome.

Noreen and Brenda have agreed to contact Anne Kemmy in relation to the work that was done in setting up the previous association.

Next get together

A decision was made to set up the next get together in Tullamore in an attempt to be as accessible to as many families as possible. The purpose of families getting together is to try and share information and support each other in any way we can. We would particularly like to welcome any new families and also families of older girls with Rett Syndrome, as they are the best source of information for new families.

NEXT GET TOGETHER OF IRISH FAMILIES LIVING WITH RETT SYNDROME WILL TAKE PLACE AT 2PM, SATURDAY, SEPTEMBER 20TH AT RIADA HOUSE, ARDEN RD., TULLAMORE.

Other news

ELIVE, a Limerick based computer company have donated web space to the association, and although there is little as yet on the site, we can be found at HYPERLINK "http://www.rettsyndromeireland.com" www.rettsyndromeireland.com.

We can be reached by email at HYPERLINK "mailto:rettsyndromeireland@eircom.net" rettsyndromeireland@eircom.net.

Our postal address is:

Rett Syndrome Association Ireland,
c/o Bishop's Palace,
King's Island,
Limerick

Andrew Kehoe has succeeded in negotiating the sponsorship of a couple of mobile phones from Vodafone for the association. This will allow a couple of phone numbers to be put on the website and on any other literature that will be circulated to the Children's Hospitals etc. and enable parents of newly diagnosed children to get in contact. Andrew is also checking out the cost of printing information leaflets for the association.

At the moment the phone holders are:

087 6152335 Andrew
087 6152183 Noreen

At the moment we are sending updates and information about our group to all those on the list provided by the RSAUK at the December conference in Dublin. If you do not wish to receive mailings from the group, please let us know, otherwise we will continue to send newsletters to all those on the list.

For those who are not able to attend our next meeting, we welcome any comments, suggestions etc. Please contact Noreen or Andrew at the above numbers.

Looking forward to seeing you,

Best wishes,

Noreen Harrington,
Chairperson and parent.