

RETT SYNDROME ASSOCIATION IRELAND

NEWS UPDATE

September meeting

We had our third meeting of families on 20th of September last in Riada House , Tullamore. Nine families were represented on the day including seven of the girls , who of course stole the show as usual.

As always it was an informal get together giving parents an opportunity to meet each other and exchange information and share their experiences on a broad range of issues which may be common to all of us at some time. When we first met in February of this year, those attending felt that it would be good to meet twice a year. As it turned out we ended up meeting three times in 2003 which is an indication of the need and desire to meet with other families living with Rett Syndrome.

Before we forget, a big thanks to Brenda who organised the venue, including food and refreshments.

Specific issues discussed on the day were as follows ;

1) Committee – There was a slight re-shuffle of the existing committee members and also three new members were nominated and accepted.

Noreen Harrington – Chairperson

Brenda Duff - Treasurer

Andrew Kehoe - Secretary

Joe Lawlor

Neil O'Donoghue

Vincent Prendergast

It was suggested and agreed that the committee should meet again before Christmas in order to progress some of the work of the association. The meeting will take place in Dublin on the 29th of November.

Funding

Methods of fundraising and the use of collected funds were discussed briefly. The Association will obviously have some administration costs, which will be met from collected funds including membership fees.

At every meeting so far, families have suggested that they would like to have a national workshop or conference if enough funds were available. We hope that we will be able to finance Rett Syndrome workshops here in Ireland and invite experts from the U.K. such as Dr. Alison Kerr and Lynn Weeks , but this is obviously not going to happen overnight.

Membership and Subscription

We would like to invite all the families to become members of the Rett Syndrome Association of Ireland. Subscription for membership is €30 per family. Anyone not able to afford this is still welcome to join as a member, but we would ask that you would complete and return the subscription form in any case so that you will be added to the members list. Membership subscriptions will help towards funding the running costs of the association, such as postage, photocopying, meetings, information leaflets etc. Please complete and return the enclosed membership form with your subscription fee.

Registration

We are currently looking into registering as an official charity, as this will assist in managing any incoming funds. The cost of this is in the region of €1000.

NAMHI membership

Also, Noreen has applied, on behalf of the Association, to join NAMHI (National Association of Mentally Handicapped in Ireland) which is an umbrella organisation of various associations with common issues and goals , to act as one voice / lobby.

Membership would keep us informed of important issues that affect our daughters and will also give us a voice on such issues.

RSAUK and IRSA

The International Rett Syndrome Association in America , and the Rett Syndrome Association U.K are now aware of our newly formed Association and have wished us well and offered their support.

We will need to discuss the nature of the relationship we will have with both of these associations, particularly the U.K. association which has been and continues to be a great help to parents of children with Rett Syndrome in this country. Due to the fact that they have been in existence for a number of years and the large size of the membership in the UK, they are and will continue to be better resourced and better able to offer certain services to Irish families, which we cannot, at least for the foreseeable future.

Association logo and letterhead

Noreen and Terry have designed an association letterhead / logo for printed stationery, a copy of which was shown on the day and was very well received. We have decided to stay with the theme of a child's hand in keeping with other Rett Syndrome associations. We hope to have them printed and in general circulation within weeks.

Committee meeting

As we said earlier in the newsletter, the committee hopes to meet before Christmas to progress some of the issues above and we would very much welcome any comments , suggestions or advice on any of these issues or any others which you might want to raise.

You can write, phone or e-mail as follows ;

Address : Rett Syndrome Association Ireland
C/o Bishops Palace
Kings Island
Limerick

Website : HYPERLINK <http://www.rettsyndromeireland.com> www.rettsyndromeireland.com

EMail : HYPERLINK <mailto:rettsyndromeireland@eircom.net>

rettsyndromeireland@eircom.net

Phone : 087 6152335 / 087 6152183

Thankfully we are, and will always be a small association so everybody's input is not only welcome but essential if we are to survive.