

Rettsyndrome Ireland

newsletter - summer 2010



Alex Connolly and Dad, Alan, Shauna McPhillips with Dad, Declan, Ciara Barry and Dad, Kevin, Rachel Duff her Dad, John are joined by Paraic Duffy, GAA and Tommy Bowe, Irish Rugby Star.

Family Day 2010 Announced

The next Rett Family Day will take place on **Saturday, October 9th**, next.

After last year's great success the Family Day will be again be held at the **Rackett Hall Country House Hotel, Roscrea, Co. Tipperary**.

We're still finalising the details but the topics we will cover this year include issues like Accessing Services for our Children, Wills, and CPR.

There will be entertainment for the girls, a breakout room so that the girls can take a break from the excitement too. Lunch will be provided on the day, and, as in

previous years the Association will pay for up to two night's accommodation (for one room) at the Hotel for families travelling to the event.

Of course, everyone is invited to come to the Family Day. It's a great opportunity to meet other families with a Rett Girl, to learn and maybe share some of your experience with others.

Full details will be mailed out later in the summer and will be on the web site too.

Hope to see you there!

THE RETT SYNDROME ASSOCIATION OF IRELAND

PATRONS:

Paraic Duffy, Director General, GAA

Miriam O'Callaghan, Broadcaster

Dr. David Webb, Consultant
Paediatric Neurologist

We are an association of parents and families of people with Rett Syndrome. We came together to provide support and information:

to each other

to parents and families who have received a new diagnosis

to raise awareness among medical professionals and others who work with people who have Rett Syndrome

to raise public awareness of the condition and it's effects on those affected by it.

Contact Us:

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The Irish Rett Syndrome Association
is a registered Charity: Chy 16340



Miriam O'Callaghan, who along with Paraic Duffy and Dr. David Webb is now a Patron of the RSAI

PATRONS FOR RETT ASSOCIATION

We're delighted to announce that three very special people have agreed to become Patrons of the Rett Syndrome Association.

Miriam O'Callaghan needs no introduction. She has presented flagship Current Affairs programmes on Television and Radio as well as her own Talk Show. **Paraic Duffy** is the Director General of the GAA and many of us already know **Dr. David Webb** as a Consultant Paediatric Neurologist at Our Lady's Hospital, Crumlin, where he is doctor to many of our girls.

Having such respected patrons will add to the profile of the Association and help us to reach out to other families affected by the condition.

THE FIGHT FOR SERVICES

I recently attended a Conference in Dublin hosted by Beauchamps Solicitors, the subject of which was "The laws and legal issues affecting persons with disabilities". There were a number of guest speakers discussing various topics including the importance of making a will and the intricacies of doing so where there is a disabled or dependant relative involved.

We hope to have a presentation on this very important topic at our next family day in October.

While all of the speakers and topics were interesting and informative, one in particular stood out as a "wake up call" to every parent or relative and service provider in attendance. It was a presentation by the CEO of St. Michaels House (one of the largest service providers to persons with intellectual disability in the greater Dublin area). The presentation was titled "The challenges facing disability organisations in 2010".

In it he outlined the stark reality now facing all service providers due to the unprecedented downturn in our economy, such as

- Cutbacks in funding at a time when the demand for services is increasing
- Moratorium on recruiting staff until 2014 – i.e. not only are

they unable to recruit additional staff to match demand but they cannot even replace staff who leave or retire.

- Review of allocation of special needs assistants with the intention to reduce numbers .
- Low staff morale due to wage cuts coupled with increased workload.

As parents we know only too well that even when the country was awash with money during the "boom time", we still had to fight tooth and nail to get even basic services for our girls and unfortunately given the current situation outlined above we will have to continue the fight with even more vigour .

We will need to take every opportunity both individually and collectively to voice our concerns and frustrations to politicians from every party to put pressure on them to legislate for the "rights" of the most vulnerable in our society.

Our Government signed up to the "UN Convention of the Rights of Persons with Disabilities " in May 2008 but to date they have not ratified it. This Convention provides a critical step in the journey from a "Welfare" based approach to a "Rights" based approach towards disability so we all need to put pressure on our politicians to ratify it as soon as possible.

*Andrew Kehoe
Chairperson RSAI and Parent*



Sisters Doing it for Retts!

Pictured before the Mini-Marathon are

Deirdre Horan, Rosaleen McCarthy, Katherine Horan and Catherine Horan with Deirdre's daughter Rachel.

WITH A WILL!

Hello all in Rettland! Deirdre Horan here, Rachel's Mom. I have been on the committee for a few years now and I now find as Rachel is getting older I can do a little bit more to help out. Hence my attendance at the conference by Inclusion Ireland in Killarney on sat 24th April 2010.

Inclusion Ireland are a national organisation (and we in the Retts Association are members). They work tirelessly for people with disabilities in Ireland. They represent little or large groups, and they will make noise. For instance, if any parent has an issue they can write a resolution and we can put it forward to Inclusion Ireland to present in Government debates about issues facing people with disabilities. At the conference different groups big and small had put issues forward from all over the country to be taken to national level by Inclusion Ireland. There were 4 workshops on the day.

I looked carefully at each one and decided I would attend the workshop on Wills, Trust Funds and Capacity: Essential Information. I was a little apprehensive at first but said what the heck we all have to make a will some day. Was I glad I did! It was an inspiring workshop and a lesson I learned is that we do need to prepare a will and when doing so we need plenty of know-how from people that work in the area of Persons with Disabilities especially our girls.

It would take me another few hours to write down what I learned so I discussed with committee about having a speaker on the upcoming Family Day to share all this knowledge with all of you and let you all decide what you want to take from it. While I know it is a personal thing for each family but really there are some things you would want to know about what to do - and what not to do.

For example: we all want what's best for our girls so we may say we will leave her the house and money. However, then when she

reaches 16 and becomes entitled to disability allowance, travel allowances etc., it's easy to forget that all these are Means Tested and it is possible that she might not qualify because of the Will, and be left without her allowances!

The solicitor at the workshop had many different suggestions of ways to avoid this as well as many other thoughts on the different situations that arise when people making wills. A lot of parents at the conference asked general questions and found it to be enlightening and there was plenty food for thought.

The day went quickly and as I left Kilarney my thoughts were "Every parent in Rettland should know this stuff!"

We'll must sign off now have a great summer and hopefully see you all on family day on October 9th.

Regards Deirdre Horan

Mini-Marathon

A very special thanks to all those who ran, walked or otherwise took part in the recent Mini-Marathon in Dublin. Lots of people took part, with a group from Kerry with Deirdre Horan, Kildare with Bridget Scully and more with Cathy Cleary from Dublin. Marey Devlin from Galway was there too. All that marching on the rain was well worth the effort, the combined total raised for the Association was more than €3,000. Well Done Walkers!

Music Therapy Ireland

New Music Therapy Service in Limerick.

Families in and around the MidWest might be interested to hear of a new Music Therapy Service based in Limerick. They offer a range of services for all ages. All of the therapists have completed the Masters in Music Therapy from the University of Limerick. You can find out more on their web site:

www.musictherapyireland.com

Láidir le Chéile

New Support group for families in Co. Kildare

Láidir le Chéile is a support group for families with Special Needs in County Kildare. Created by parents its aims are to inform people on the education, health and social services available in the area. They are forging links between organisations and people who live and work there. They have a Facebook page or they can be emailed at laidirlecheile@gmail.com

Rett Syndrome Research Trust UK

New organisation to promote research in the UK

RSRT UK is a partner organisation for the Rett Syndrome Research Trust in the U.S. They aim to raise funds and focus on high quality research focussed on curing Rett Syndrome. Their web site is <http://www.reverserett.org.uk/>. The American Trust is at <http://www.rsrt.org>

Updating our Website

New Features at www.rettsyndrome.ie

We've updated the Web site recently and included some features which we hope will add value to it for all our members. There is now an



Declan and Marie McPhillips and their daughter Shauna with Tommy Bowe, Irish Rugby Star and Paraic Duffy of the GAA and Patron of the Association. A Very Special Thanks to Declan McPhillips for his tremendous efforts raising funds for the Association. Declan has raised more than €13,000 from companies and individuals in the County Monaghan area. Well Done and Thank You Declan!

opportunity to Register at the site. If you do and log in you will see the extra features:

- You can search for other members and email them from within the site
- You can upload photos now
- There's a forum on the site, where you can ask - and answer - questions about anything to do with managing and living with Rett.

Privacy is very much to the forefront in our thinking, and everything you add to the site is protected by your password. Registration is quick and easy and only takes a couple of moments. Check it out!