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Rettsyndrome Ireland

newsletter - winter 2010



Tipperary Hurler Conor O'Mahony brings the Liam McCarthy cup to visit the families at the Family Day in Roscrea, October 9th.

Family Day 2010 News

We had a very successful family day in Roscrea on October 9th. In all, 20 families were there for the event.

They heard presentations from Deirdre Carroll about the Inclusion Ireland organisation, John Costello (Beauchamps Solicitors) who talked about Wills and provision for our dependents after we're gone and after lunch there was a presentation on CPR from Civil Defence.

We were visited during the afternoon session by Tipperary Hurler Conor O'Mahony who brought along the Liam McCarthy Cup to show off to the girls. Every one got their photo taken with it.

Face Painting and story telling went on in the Break Out room so there was something for siblings, the girls themselves and anyone who needed a break.

The AGM had a good open Discussion and there were calls to return to a having two events per year and also consider other locations for the Events, to facilitate those traveling long distances. Other speakers suggested we should find ways to use the experience already in the group, as well as aim to raise more awareness of the condition. The Committee will consider these in planning next year's activities.

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.

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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.

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*

NEW FACES ON ASSOCIATION COMMITTEE

The AGM of the Association saw some changes to the Committee. Kevin Barry, Joe Lawlor and Angie Fitzsimons resigned from the Committee during the year. Joe and Angie have both been involved since the foundation of the Association and have made a huge contribution to its growth and development. Kevin made a huge contribution to the Family Days and reorganised how they are run. A huge vote of thanks to them for their efforts on behalf of the Association and people with Rett Syndrome.

New members joined the Committee. Declan McPhilips is from Monaghan, and Dad to Shauna. Emmet Harten is from Wicklow and Dad to Kayla. The current line up of the Committee is as follows: Andrew Kehoe (Chair), Cathy Cleary (Secretary) Deirdre Horan, (Treasurer) and ordinary members Noreen Harrington, Alan Connolly, Declan McPhilips and Emmet Harten.

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!

WILLS AND ESTATE PLANNING

We were delighted to have John Costello, a Consultant with Beauchamps Solicitors to talk to us at the Family Day. John gave an entertaining and informative chat on the subject of Wills, and planning for the long term for our disabled children. John emphasised that it's very important to make a Will, and also gave us some pointers on some of the key issues. For instance, if you leave money or property to a disabled person, that person will have *means*, and could then be *Means-tested*, and so lose out of benefits and services. So he suggested a way to leave resources for a Disabled Relative, while not affecting their means.

He introduced us to the Concept of **Discretionary Trusts**. Under this system you would will your estate to Trust, run by a couple of relatives or friends. They would then disburse the funds to the Disabled Person as needed for any matters that might arise. The advantage to this system is that the Trust does not affect the disabled person's means, and

therefore their entitlement to services and support from the State.

John also pointed out that the requirements for a person in full-time care can be quite small, so that was another thing to take into account when making your decisions. Finally, John again stressed the importance of making a Will. He also said we

should never be afraid to ask our solicitors if they have experience with Discretionary Trusts, and to take the time to find one who has.

He also said, especially in these times, not to be afraid to seek the best prices from your Solicitor!

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

MUSIC THERAPY IRELAND

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



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.



Shauna McPhillips with her Dad, Declan and Tipperary Hurler Conor O'Mahony at the Family Day in Roscrea



Who's Who at the Rett Syndrome Family Day in Roscrea

1. Megan Cleary and her Nan
2. Rachel Horan with her Mum, Dad and Tipp Hurler Conor O'Mahony
3. Jessica O'Flynn, with her sister, Mom and Dad
4. Kate Devlin and her brother Ben
5. Sarah Kehoe with her Mum and Dad
6. Olga Geoghan with her Mum and Dad
7. Grace Gilliland and her Mum
8. Laura Rankin with her Mum and Dad
9. Robyn Scully with her Dad and Sisters
10. Theresa Davoren and her Mum and Dad





Sisters Doing it for Retts!

Pictured before the Mini-Marathin are Deirdre Horan, Rosaleen McCarthy, Katherine Horan and Catherine Horan with Deirdre's daughter Rachel.

The ladies are all wearing t-shirts made by Niall Rankin, Niamh's Dad, so a big thank you to Niall!

WHERE THERE'S 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!"

Regards Deirdre Horan

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 the Rett Syndrome Ireland 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. In some ways it's still very much the same, and anybody can access the articles that were there as before. However, there is now an 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.

All of this requires a log-in, so the information, photos and anything else you put on the site is protected and can only be accessed by you and the other members of the association.

Registration is easy and quick.

Click on the Register link and it will open the form. Fill it out - it asks for things like your Name, Address, it allows you to pick your own UserName and Password. All of these things are simply to verify that you are a member of the Rett Association or have a valid interest in the site.

Terms and Conditions

Take a moment to read the terms and conditions and if you agree then proceed.

When you fill in the form it will be added to the approval list, and that won't take long - a couple of minutes usually, because each application is reviewed by the Association - again, to make sure that anyone applying to join the site has a valid reason to do so.

Once your membership is approved you'll get an email and you can then log into the site using your Username and Password

When you log in you'll see two new Menu Items. One is the Member List. There you can see links to the profiles of other members, and photos if they have uploaded some.

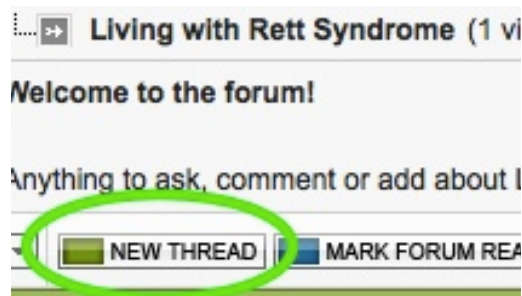
You can email another member from their profile.



The other new Menu item is the Forum. Here you can create a New Thread to ask a question, or respond to someone else's question. If you do ask a question when someone responds you will get an email to let you know that there is a response.

The forum is there to be used for any query that you might have about any aspect of Rett Syndrome or living and working with your girls.

Like any forum, it's as good as its Users, so the more you contribute to it, the better it will be.



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THE APPLE IPAD

Terry Devlin

There's been a lot of buzz and fuss recently about Apple's new iPad device which was launched earlier this year. About the size and weight of a hardback book (but a lot slimmer) this device is a small but very powerful computer. Of special note is the interface, or how you use it. There is no mouse or keyboard like a traditional computer. It responds entirely to touch. So, tap something on the screen and it opens. Swipe your finger and the material on the screen moves in that direction and so on.

Because of its marvellous interface the iPad has attracted attention in the world of Special Needs. It really is simple to use and even people with limited dexterity can achieve quite a lot on it.

We purchased one for Kate in September and have been using it since. It's a very attractive device and very easy to use. But it's not cheap. We bought the base model at €499 and there are more expensive versions that include things like 3G connectivity. However, every iPad comes with Wireless networking as standard.

Like any computer you can do the basics: email, web surfing and so on. It's a lovely device to look at photos on, you can play music and movies too.

The iPad is like a big brother to the iPhone and iPod Touch. Like those, you can download apps (or programmes) from iTunes to the device and use them. The iTunes apps store has about 200,000 apps to choose from, and that's growing all the time. There are free apps, inexpensive apps (less than €5) and apps that cost a whole lot more than that.

Our Kate has limited hand function. She can tap and with a little help she can also swipe. We downloaded several games for her and she enjoys them a lot. One, SoundTouch is a simple game with lots of options. There are different categories - musical instruments, animals, and so on. Select a category - musical instruments, say - and you'll get a screen with 12 pictures. Tap the cello and it will show a full screen photo of the cello and play a clip of cello music. Tap again to return to the screen of 12. Tap another instrument and get a photo and clip and so on.

From a parents point of view I certainly appreciate that there is more than one photo for each instrument and more than one piece of music. So, when the same instrument gets tapped over and over again I don't get same 5 seconds of 'Twinkle Twinkle Little Star' over and over again.



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!

There are - literally - hundreds of apps that might be useful to someone with Rett, from basic games to ones that might help with communication and decision making. If you go to www.rettysndrome.ie and click on the 'Links of Interest' menu, you'll see some pointers to sites that will tell you more.

When you add in the fact that you can include favourite movies and even books on an iPad, it's certainly a device worth considering.

Pros: It's really easy to use, a huge range of apps and very flexible. Battery life very good - 10 hours or more

Cons: You need a computer (Windows or Mac), expensive.