

ilíocht

Celebrating Diversity in Gaelscoil Bhaile Brigín



What's On

Dyslexia Association of Ireland Seminar on Dyslexia for Adults

Wednesday, June 29th,
5 p.m. to 7 p.m.

DAI will be holding a seminar on understanding Dyslexia in adults. Topics covered will include general advice and coping strategies, the indicators of dyslexia in adults and how to get an assessment.

This seminar will take place at
**DAI's National Office
on Talbot Street, Dublin 1.**

No booking is required, just turn up on the night. These events will be free to attend, but as always we welcome any donations to help towards running costs.

Call: **01 877 6001**

Email: info@dyslexia.ie

ACHILL BACK TO BACK 2016

CF Ireland are delighted to have been chosen as charity partner for the **Achill Back to Back 2016** which takes place on **August 27th & 28th**.

Now in its fourth year, Achill Ultra is a two day, 3 race event featuring a half (21km), full (42km) and ultra (63km) marathon. The 13 mile loop, running along the 'Wild Atlantic Way' can be completed once, twice or three times.

The Atlantic provides a beautiful backdrop along with the islands of Clew Bay, Clare Island and the dramatic coastline of Achill.

Why not challenge yourself and your friends and make a running weekend out of it! For more information and to register see www.achillultra.com



Feels Like Summer

Welcome to the 6th edition of ilíocht.

It's hard to believe another school year is almost over as we hurtle towards the Summer holidays. Our article "Preparation For The New School Year" deals with making the transition into summer and back to school in September a little easier.

The poignant article on **Cystic Fibrosis** details how CF affects the life of Harry through the eyes of his mother Ruth Cahill. A huge thank you to Ruth for helping us understand how CF affects not just the person with the condition, but the whole family.

The Government launched their new **Inclusion** campaign for preschools this month and the article **Access and Inclusion Model for Preschool** details how this fantastic new initiative can help children with disabilities access the preschool curriculum.

We would sincerely like to thank everyone who contributed to ilíocht over the past year. If you would like to submit a parent piece, an article of interest or get involved in ilíocht in any way please email, celinecronan@gmail.com

As always, if there is any other topic you would like us to cover please do let us know.

Cystic Fibrosis (CF) Awareness

By Ruth Cahill, mum to a wonderful little boy, Harry (and a gorgeous little girl, Emily). She has kindly shared some of her own insights and Harry's experiences of CF, to raise awareness of cystic fibrosis.

Cystic fibrosis (CF) is an inherited chronic disease that primarily affects the lungs and digestive system of about 1200 children and adults in Ireland (70,000 worldwide).

About 50 new cases of cystic fibrosis in Ireland are diagnosed each year. A defective gene and its protein product cause the body to produce unusually thick, sticky mucus that:

- **clogs the lungs and leads to life-threatening lung infections; and**
- **obstructs the pancreas and stops natural enzymes from helping the body break down and absorb food.**

CF Awareness - Ireland has the highest instance of CF in the world and we desperately need new CF centres around the country and funding for research. In the past few months, I have seen too many bright wonderful lives cut short by this disease, one aged just 11 years old. Everyone comments to me how well Harry looks, but the inside is a very different picture to what you see in our happy go lucky, cheeky little chap! All anyone wants for their kids is the best.

Before Harry was born, I occasionally saw people wearing masks, usually at airports or hospitals. Back then I always thought to myself, "My God, I wonder what they have that's so contagious. I better stay away from them!" Now I realise this was probably not the case. Chances are they were avoiding bugs from me.... and you! Harry wears a mask anywhere we feel he is or could be in danger, hospitals, pharmacy, church(!), cinema, play zones, airport, airplanes. Harry wears a mask, not because he has something contagious, but because he has a compromised immune system and he may catch a bug from anyone. What may be a simple cold for you could land him in hospital.

"We don't know how STRONG we are, until being strong is the only CHOICE we have."

So, I would like you to be more aware of two things, a mask may not be necessarily a sign that someone is contagious, but could be for their protection, and secondly, if you are out and about and you have a cold or cough, please shield yourself using a tissue and use hand sanitiser when you see it. It's best for everyone, not just my superhero!



When you ask the average person what is CF, their general response is, "that's the disease that makes people cough a lot." Yes, this is true, BUT it is so much more. It affects the digestive system and almost every organ for that matter. Did you know people with CF can't digest their food without the help of an enzyme called Creon.

Harry takes Creon tablets with any meal containing fat. He takes approximately 9125 of these tablets a year! Without these tablets people with CF would not gain weight, they would suffer severe malnutrition and this would be fatal. Next time you take a tablet, think about what it would be like to take 25+ tablets, everyday, for life. You can see now why Harry is my hero!

Cystic Fibrosis (CF) Awareness, continued from page 3

Let's face it, kids just want to play and be kids. Same goes for our little superhero. **But every single solitary day, Harry does 3-5 nebuliser treatments (saline x 2, pulmozyme x 1 and gentamicin x 2). Harry is lucky he has a super fast nebuliser (he calls it fog!). This means that it ONLY takes 1hr 15 mins to do these treatments daily, compared to his old machine which took over 2 hours.** This means more time to have fun!

After all, that's what being a kid is all about!

Nebulisers help bring the medicine directly to the lungs, they kill the bugs and make the mucus thinner. Therefore allowing our little boy be like every other boy, out playing with a ball or having Pokemon battles! While Mummy and Daddy are busy with lots of cleaning and sterilising everyday.

I have been overwhelmed by the messages of love and support from people. "We don't know how STRONG we are, until being strong is the only CHOICE we have." We would do anything for our Harry, he deserves the world, as do all his CF friends.

CF primarily effects Harry, but it also effects our whole family. When Harry is unwell it effects us all, Emily, his little sister, included. At 4 years old, she knew the

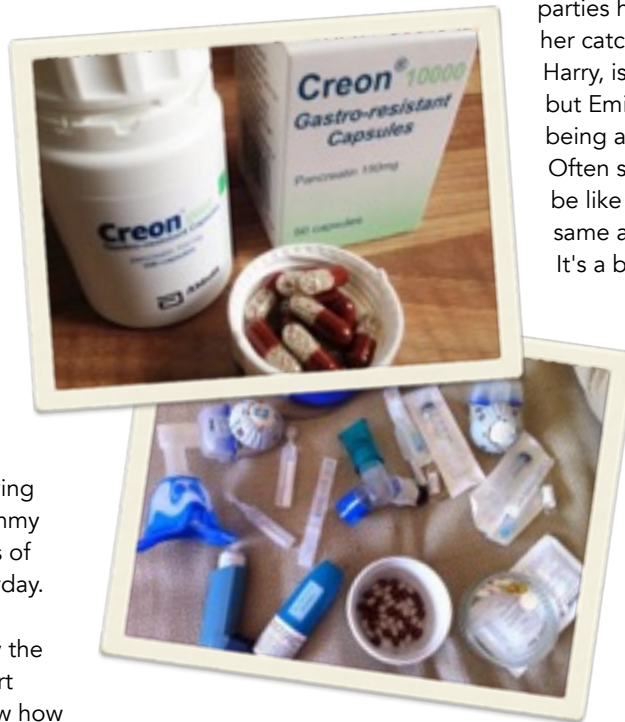
name of every medicine Harry took. At treatment time (5 times daily) even if she is watching her favourite cartoon, she changes the channel to Harry's cartoon without a question. She has missed parties, play dates and events because other kids at parties had coughs and colds, and her catching and passing germs onto Harry, is a big risk. Harry is our hero, but Emily equally so. It's not easy being a sibling of someone with CF. Often she would say, "I wish I could be like Harry." Harry would say the same about not having CF. It's a bond, an extraordinary one.

Today I urge you to think of all families with CF and how it affects a family, not just a person.

Go onto YouTube and type in '**OLI AND NUSH**' and watch a fabulous little cartoon (get your kids to watch it too) explaining CF. This is what Harry showed to his class to explain his condition. (The gorilla bit is his favourite part!)

On a final note, can I please please, ask each one of you, to talk about organ donation to your next of kin.

**The gift of life, there is nothing more precious.
Thanks everyone!**



For further information on Cystic Fibrosis, and how you can donate to help improve services and research, please check out, www.cfireland.ie

If asked, most people would say they would be happy to have their organs donated after death, but that is not enough, you must take action now. Make a commitment - it's just a few simple steps. You can either request a donor card online at www.organdonation.ie or contact the Irish Kidney Association to request a donor card in one of the following ways:

- email: donor@ika.ie
- freetext: DONOR to 50050
- lo call: 1890 543639
- by post to: Freepost, Donor House, Irish Kidney Association, Park West, Dublin 12



Preparing For The New School Year

By Celine Ronan, *ilíocht* Editor

Now that the summer holidays are fast approaching and we are looking forward to long lazy days, we have to remember that preparation is key for our children with ASD and look to preparing them for the new school year. The return to school, like any big change in routine for a child on the autism spectrum, can be very daunting. Even when the return has been eagerly awaited as an escape from younger siblings (yes, I'm speaking from personal experience here!) the transition from a familiar classroom and routine to a new one can still cause anxiety to rear it's disruptive head. When you add to that the possibility of a new teacher, it's understandable why our kids can get so upset about starting a new term.

BELOW ARE SOME TIPS YOU MAY FIND HELPFUL IN MAKING THE TRANSITION EASIER:

- Before the term ends, if at all possible arrange for your child to meet his new Teacher in his new classroom. This can make a world of difference when September comes around. Let him know where he will be sitting and that any important agreements made last year will still apply (e.g. SNA, computer time rewards etc).
- *If he has a new Teacher, make sure she is aware of anything that makes life particularly hard/easier for your child. <http://www.asiam.ie> have handbooks for children and teachers that are designed to help the teacher understand the particular child's needs.*
- Keep a loose routine throughout the summer. The tendency is to throw routines out the window once school finishes, but children with ASD need even a loose routine to feel secure. It can be as simple as Breakfast – Activity – Lunch – Techie Time – Activity – Dinner – Chores.
- *Keep school at the forefront in the couple of weeks before term starts by mentioning it briefly each day, for example "who are you looking forward to seeing again?"*
- If there are negative feelings around returning to school, try make a list with your child of all the positive things about school, for example, subjects he likes, friends or Teachers he has missed, etc.
- *Start waking your child up earlier around a week before term begins to ensure he is not exhausted facing his first morning.*

WHEN SCHOOL BEGINS:

- Establish a routine for his time outside of school, morning and evening, and try to stick to it. For the first few weeks at least, try to keep that time as quiet and stress free as possible. Mornings can be tricky when there's so much to

be done in a short amount of time – visual schedules that show the process can make a huge difference: Wake Up – Get Dressed – Breakfast – Brush Teeth, etc. For younger children use pictures and for older pictures and words work well. The same can be done for after school routines: change uniform – snack – obair bhaile – etc.

- *Communicate with Teachers. Communication is absolutely vital, especially in the settling in period and a communication notebook can work really well. In addition to letting you know how your child is doing it also is an invaluable source of information for your child's multi-disciplinary team in terms of your child's mood/sensory needs etc.*

“Communication is absolutely vital, especially in the settling in period.”

- *Make sure your child has an “out” if things are getting too overwhelming for him. It can be as simple as leaving the classroom to walk to the oifig or sensory room for a few minutes. Help Teachers, SNAs and the child himself learn to recognise when he needs some time out and a way for him to leave without causing a fuss.*

- *A Visual Timetable for school, which shows which subject is next/what time is break etc, is very useful and reassuring for a child with ASD and can play a huge part in reducing anxiety. Lots of Teachers now use them at the top of the class as all children thrive on routine and knowing what's next. Most importantly, if the Teacher is using a visual timetable it's vital that she sticks to it! She needs to highlight any changes before they happen if at all possible (however sometimes change is inevitable and unforeseen). Individual timetables which include when an SNA is arriving/leaving/taking a break work well too.*
- As I mentioned, inevitably there are times when a routine has to change without warning, for example if a teacher is sick. I've found in the past that a little “things I need my Teacher to know” envelope in his mála, which explains to a substitute Teacher/SNA etc. the things that are vitally important to the child, can go a long way towards reducing the anxiety a huge change in routine like this can throw up.

New Access & Inclusion Model (AIM) for Preschool ECCE Scheme

By Celine Ronan, *ilíocht* Editor

Every child is entitled to a free year of preschool (Early Childhood Care and Education Programme) before they start Primary School. In June 2016, the Government rolled out a new scheme to ensure that children with disabilities can access this free year from September 2016 onwards. The child **does not** need to have a diagnosis when entering preschool as the scheme recognises that many children do not receive a diagnosis until much later.

The AIMs model works with up to 7 levels of support. Levels 1 – 3 are known as “Universal Supports”. This means that the ECCE Practitioner is given a range of strategies and techniques that promote an inclusive environment for all children. If the Practitioner and the parents agree that the child requires more specific support then they can apply for one or more of the Level 4-7 supports.

LEVEL 4 - EXPERT ADVICE AND SUPPORT FROM AN EARLY YEARS SPECIALIST SERVICE

This service will involve specialists in early years care and education for children with disabilities. Depending on the needs of the child, it can involve advice and mentoring on developing a strengths/needs analysis or developing an Individual Access and Inclusion Plan for the child. They can help determine if further supports are required and if the expertise of HSE professionals is required.

LEVEL 5 - EQUIPMENT, APPLIANCES AND MINOR ALTERATIONS

Under this level, the preschool can apply for specialised equipment, appliances or a grant towards minor alterations to the building to facilitate the child's participation in preschool.


LEVEL 6 - THERAPY

Under level 6 the child can access therapies that are essential to his/her participation in the ECCE scheme. Arrangements have been made with the HSE to deliver these therapies and extra posts have already been sanctioned and funded.

LEVEL 7 - CAPITATION

Under level 7 the preschool can apply for extra capitation to fund extra support for the child or to enable them to reduce the child/practitioner ratio.

How To Apply: When you have chosen a preschool for your child, your Service Provider, in consultation with you, will decide if your child needs extra support. They can then, in partnership with you, apply for support under AIM. The application process is now open, and will remain open all year.

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