WSAI News

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Stars in Tadhg's Eyes

Kelsey Brannigan

The Tadhg Fainín Foundation was set up in 2011 by Kariann & Eoin Fainín in honour of their beloved son Tadhg, who died tragically in 2011. The Foundation works tirelessly fundraising for children and their families that need help, In 2016 the Foundation selected WSAI for their fund raising activities for the year.

WSAI would like to thank Eoin and Kariann and our own Debbie Brannigan for all the hard work during the year supporting the Association and raising awareness of Williams Syndrome. We would also like to thank Erin's Isle GAA Club for all their support in 2016.

Kelsey Brannigan was also a key player in the years events and was a smash hit at the Stars in Tadhg's Eyes event at the Helix in November. Here she explains how the year and the big show went.

Last year the Tadhg Fainin Foundation picked WSAI as their chosen charity. My mam went on their committee for the year to help with fundraising. Hundreds of people got on board by having coffee mornings, parachute jumps, hell & back, raffles, the mothers & others in Erins Isle ran a blitz held on 10th September in Erins Isle where myself and Cian helped out raising awareness for Williams Syndrome. The day was a blast. .

The main event for the year was when I represented WSAI in "Stars in Tadhg's Eyes". Lots of families from the association sponsored me and bought tickets for the show. Thank you all so much for the support. On the night I had my own dressing room with my name on the door. I got to sing an Edel song. There was 750 people in attendance and I got a big round of applause. We had great fun! We raised lots of money for the association a total €23,714.

I would like to give a big thankyou to Kariann, Eoin, the Foundation & Erins Isle for all the support and work they done in fundraising and raising awareness for Williams Syndrome last year. I will always have Tadhg in my heart and I often read his book, he will always be my hero!

Kelsey your friend....

Kelsey Backstage Getting Ready

Kelsey with her Proud Parents

Kelsey On Stage

Kelsey's Fans & Supporters

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Robbie’s High Life
Michael McMahon

I never knew that a quick ten minutes could ever bring so much joy to someone so special. I also didn't know about the knock on effects it would have. Everything happened so fast.


Robbie and Michael High in the Sky

I landed after my test flight and pulled up beside the family on the intersection of the runway. We put Robbie's booster seat into the right seat. I then put a very excited Robbie into it and secured his 4 point harness. I was quite nervous about this one. Robbie was a VVIP on this flight. I got a quick flight brief from dad and Peter who was the instructor of the day. I closed up and started the engine. Robbie was good so far. My plan was to take him down the end of the runway first and see how he did. He asked if we were going to the sky. I giggled at the thought and said, “Well we'll see how this goes and then we'll go flying”. I turned at the end of the runway and applied full power to see how he'd react to the noise and feel of it. “Weeeee” is what I heard. I had a good feeling that Robbs would enjoy this. I gave the family thumbs up to say we're going. I turned at the other end of the runway and did my final checks. I asked Robbie if he was ready to go. We high fived and I applied full power. The wheels left and we shot skyward. As we got to 100 feet he said “Mikey, We're flying!!” we then whooped and continued the climb upwards. I tried to talk to him as much as I could but I soon found out I didn't need to. He was already relaxed. I levelled out at 2,000 feet. We had a sing and laughed. I was really happy with how Robbie was taking it all in. He was glued to the window and watched as the world went by below. He spotted a train and said “choo choo”. As I brought us on the down wind leg Steve on the ground radioed us. “Captain Robbie, Is Robbie on Frequency? ”His face lit up with both excitement and confusion as to who was talking to him. I looked at Robbie and for the first time I could see how happy he was. I grinned and I couldn't stop it. It broke out into the biggest smile I ever had. I set us up on finals and Robbie went quiet for a second. Just before I could ask him if he was ok he said “Mikey, Are we getting dinner?” I had to try my best not to laugh. “Yes buddy, We're getting dinner”. He then announced he loved me. I'm still to this day trying to figure out if he meant it or was it just because he had dinner. We touched down and the feeling of pride overwhelmed me. We gathered the family and got a group picture with the plane. Both of us went home happy as could be. I stayed up till 4 that morning editing the video. I loved it. Robbie's reactions were just fantastic. The next morning I put it on Facebook. I did the half hour drive to work and by the time I got there the video had over 2,500 views. What would happen next was unbelievable. Both myself and Robbie were catapulted into the lime light, Becoming Irelands number one VLOG for 2 weeks running. Getting interviews on the Tubridy show and TV3. What was most fantastic was getting William Syndrome out there. Showing the world what Fantastic people they are. The video finally topped out at 6.5 million views. A few weeks later we got Robbie a flight in a Helicopter. He loves Helicopters and was so excited. We loaded him in and started up. He wasn't sure about the engine starting as he looked through the glass panels in the roof at the rotors starting to turn. He then burst into a massive smile as the skids lifted. He was glued to the window the whole time. It was hard to talk to him because of all the other air traffic around talking over the headsets. He had a smile from start to finish. Near the end he was pointing stuff out to me. It was amazing. I loved it. We had the GoPro camera on board too. After editing the video and putting it online it settled at 2.5 million views. I have lots more stuff planned for Robbie as he gets older. I now work for British Airways and live in London but I plan on bringing Robs around the world with me for more adventure and fun.

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Robbie Celebrating his First Flight with Family & Friends

Music Camp 2017

Carmel Daly

Brian Ahern giving a Music Lesson to Cian

The dates for this year's camp are 6th to 11th August . The camp will be held, as usual in Share Holiday Village, Lisnaskea, Fermanagh. It would be lovely to see some new faces there so if you are over 16 please think about joining us for a week of fun, friendship and music. If you think that the week might be a bit much for you we could arrange for you to attend for a few days or to visit us briefly to check it out. Please talk to me. If your WS child is under 16 we would love for you to visit us while at camp so that you can see the camp in progress and consider sending him/her in the future.

Unless you have seen it first hand, it is difficult to understand just how worthwhile the annual music camp is in terms of improving confidence, positive image, self respect, friendships as well as developing music ability. Even those that are not particularly musical gain such fun and confidence from the experience that at the end of the week, they get up on stage and give as much as any professional entertainer. Looking around at the faces of parents, watching their offspring on stage and realising, maybe even for the first time, that their child is a happy, whole, beautiful individual, capable of so much.

Our camp has dedicated musicians and teachers who volunteer their services for 1 week. In addition to the many musical offerings e.g. music lessons in piano, singing, violin, percussion etc we also have music therapy, relaxation, performances, sing-songs, drama, etc. In addition we have other activities e.g. art, circus skills, games, treasure hunt, cinema night, disco, picnic and many more. It really is a fun-filled and very enjoyable and rewarding experience for all.

We have a fantastic bunch of dedicated volunteers, all of whom are Garda vetted and sign up to a strict Code of Practice.

I will be writing out to all families over the next couple of months with full details and application forms.

If you, or anyone you know, would like to work at this camp as a volunteer teacher/helper, please complete the application from which is available on the website www.williamssyndrome.ie/. If you are accepted as a teacher/helper, your accommodation and meals for the week will be provided. You will find that it is a very worthwhile and rewarding experience to work with Williams Syndrome people many of whom are musically gifted despite the fact that they have a mild or moderate learning disability. Please give me a call if you want to discuss without committing yourself or I can get one of our previous volunteers to talk to you for a first hand account.

Carmel

086 2074608

WSAI Junior Camp

Fionnuala Tynan

The WSAI has, this year, decided to offer a music and activity camp to our younger people with WS. The camp will run for four days, 1-4 August this summer in Mary Immaculate College, Limerick. It is open to any individual with WS from the age of 4-17. The camp will start at 11.00 and finish at 3.00 each day. It will be organised by Fionnuala Tynan and Deirdre Graham and will be run with the help of student teachers from Mary Immaculate College. Your child is very welcome to come any day, you do not have to sign up for all four days. There will be a cost of €10 per day which must be paid in advance when booking.

Activities will include singing, music making, drama, story-telling, dance, physical activity and art. There will be a focus on development of self-help skills, language skills, social skills and academic skills through these activities.

This will be run like a 'summer camp' but because we have the advantage of student teachers as our volunteers, we would also like to offer the following 'services':

A mini IEP where we can work on a priority of your selection for your child

An end of camp report to let you know the activities your child enjoyed and the strategies that worked for your child

A 'parent-teacher meeting' at the end of the day/week where you can ask questions or get additional support.

The WSAI is indebted to Mary Immaculate College for the use of its facilities for the camp. As you can imagine this saves our organisation a significant amount of money.

Mary Immaculate College Limerick

The Transition to Secondary School

Ruth Brabazon

Nick Brabazon

Mainstream primary school certainly has been a good experience for our family, with a local primary school that has been very active in integrating Nick into every aspect of school life.

Socially, he has made local friends who call round to the house and hang out; he can walk to school, and to visit classmates' homes; and we have local contact and friendships with other parents too.

Now he is 12; he is in 5th class in a boys-only school; and the time has come to decide on his second-level education.

Some thoughts from our experience, in no particular order!

1. There is no single secondary school in the area that the boys can all feed into. The boys splinter off into as many as 6 (Dublin) schools. So we are conscious he won't have his primary 'posse' looking out for him in 1st year and onwards. His mainstream classmates are beginning to outgrow him anyway. It's important he feels safe and secure in his new surroundings. This means small classes, and familiar faces where possible.
2. Academically, he would be suited to the new adapted Junior Cert School Programme (Level 2), and possibly later, the Leaving Cert Applied Programme (although we wonder if he has the literacy required for that). These focus on continuous assessment as well as exams. This narrowed our search to schools offering one or both of these exams.
3. Practical subjects like woodwork were also on our wishlist. FETAC courses would suit his interests.
4. In preparation, I'd say don't rush yourself - start early. I've been going to local Open Evenings for years (since 2nd class! They must think I have a load of children) even just to get a feel for what each school is like.
5. Don't be afraid to call the principal/s and introduce yourself, even if it's years ahead! You get a feel for the welcome.
6. Our aims for Nick: that he spend his days in an environment where he can achieve at a level relevant to his ability; that he be accepted socially; and that he forge links for adult life (eg adult training programmes, activities like Arch clubs, sport etc).
7. At the moment we are leaning towards special schools for students with a mild intellectual disability. There can be a certain amount of well-meaning pressure from a primary school to 'keep it mainstream': understandable when they have put huge effort and high expectations into him over the ears. But we feel there's a risk of him falling between 2 stools later on if we do that. His teens is the time to make social and academic links for later life (see point 6!)
8. Many of the students who choose special education seem to make the move from mainstream at the start of 6th class. At that stage, the programme in their mainstream primary has moved on to such an extent that it would be very difficult to keep up. And due to pressure of numbers, you might miss out on a place in a special school if you left it any longer (This may not be the case countrywide!) You may have to apply in 5th class, or even as early as 4th class. Check application deadlines, as there can be a lot of paperwork, reports from teachers etc, to organise.
9. The schools will look for a report from the educational psychologist . This has to be less than 2 years old, and students can only be tested every 2 years or so. So keep that in mind when spacing out any assessments to be done earlier in your primary schooling. It's good to have a report done in early 5th class, as that will still be valid early in 1st year (when applying for resource teaching etc), but it's also valid if you decide to apply to a special school during 5th class.
10. And finally - keep an eye on the calendar: application dates can be up to one year in advance of admission!

Those are our experiences so far. The main tip I have got from those who have been through this process is 'go with your gut feeling'. That will be the right school for your child.

I'd welcome any input from those more experienced than us, and will keep you posted on how it all goes for Nick!

Ruth Brabazon

The Ongoing Battle with Behaviours in Williams Syndrome

Deirdre Graham

I sat down to write this with the intention of explaining how to help the child with Williams Syndrome conquer their tics or habits, but frankly I don't have the answers, I don't know if anyone has! The tics are individual and unique to each Williams syndrome sufferer. We have witnessed other members within the Williams Syndrome community displaying all sorts of Tic like behaviours, Tics such as nail biting, clearing the throat, smelling everything and everyone, noisy swallowing, mouth noises – the list goes on. As a family, we can be despairing of these nuances and often wonder will they ever go away. Ed, our 6-year-old, is somewhat of an expert in creating new and better tics each time!

Ed and his Favourite Windmills

The first real one we encountered was nail biting, not just fingernails but his toenails also. He often caused his nailbeds to bleed and sometimes become infected, but he was relentless in his mission to bite and chew. We tried everything including distraction and reminders. Eventually I banned him from removing his socks in bed. The ferocity in which he attacked his nails did start to wane only to be replaced with another tic, throat clearing. Again, we started distraction techniques and reminders to stop. One evening he tearfully explained to his Daddy that he "couldn't" stop. That very statement led us to deliberate and understand that these tics are necessary for something, relief perhaps, from the pressure of what Ed must do daily. It must be difficult to concentrate in a classroom for long periods when you have a very short attention span. Imagine if your brain was wired in a complicated way and you were expected to learn in the same way as your counterparts? We look at the tics as an indicator of Ed's stress levels. They work like the steam that comes off a pressure valve. We became detectives and closely monitored Ed's behaviours. Now we started to realise what created the behaviours so we kept an eye on what increased and improved them. We noticed an increase when he was anxious about something. For example, we had a family bereavement recently which had a big impact on all the children. Ed developed a spectacular noisy gulping/ breathing / swallowing tic because in true Williams Syndrome style, he soaked up everyone's sorrow and grief. We concentrated on helping him through this time by employing a variety of techniques. We monitored when it happened and when it increased. We always acknowledged it once and asked him once to try to stop. Then we would distract him. The biggest part of this process is the most frustrating one, and that is to ignore the behaviour. This is not easy to do, and it was not unusual to hear our 4-year-old shouting at Ed to "STOP". Sometimes siblings are the best monitors!

Another trick that we employed proved very effective. The goal is to make the behaviour socially acceptable. We were inspired by a technique employed by an older member of the WS group who when he feels anxious he grabs his sleeve. Another member taps a solid surface. Ed loves the Mickey Mouse Clubhouse, and particularly the Mouseketool that Mickey uses when he is solving problems. We asked Ed to imagine that he had a Mouseketool bell on his wrist. We asked him to "ring" the bell every time that he wanted to make the noise. It did help and slowly he started to "ring" the imaginary bell instead of the noises.

Eventually the behaviour started to reduce and become less frequent. This is just an example of the ongoing battle with these anxiety driven behaviours that Ed displays. As his parents, we need to continue our detective work and establish the reason why they start and accelerate, as well as what helps them reduce. Ed is learning to read in school and he is making satisfactory progress. However, we know that he finds it difficult because at school he reads with very little issue, but when he reads at home with us the words are accompanied by whistles, noises, smells and sniffs!

We don't worry too much about these behaviours when he is alone with us as we realise that he needs to blow off steam so to speak. He feels relaxed and safe at home and it is appropriate that he only displays these behaviours in his place of safety. We are by no means experts in these behaviours and we don't have the magic answer on how to make them go away. We are however Ed's parents, and therefore are detectives, who examine his behaviour daily, constantly monitoring for potential triggers and new behaviours. It is frustrating, tiring and thankless. However, when the behaviour disappears, we always feel victorious and better prepared for the inevitable arrival of the next one! Our advice? Be a detective, explore possible causes and acceleration points. Put another technique or more socially accepted behaviour in its place. It certainly is a roller coaster ongoing marathon and battle, but it is not a lost cause.

WSAI Annual Picnic

Carmel Daly

As usual, we will be holding our annual picnic again this year. This event has proved very successful in the past and I'm sure it will be a big success again this year. This is a fun day out for all the family and we hope that as many of you as possible will come along and support it.

It is open to everyone and anyone so bring along all your family and friends. Entrance is free and there will be lots of fun and games and we will do everything we can to make it as much fun as possible.

Because it is the 30th year of the Association we are planning to make this year's picnic something special so **WATCH THIS SPACE!**

I will be writing to all families with full details nearer the date.

Carmel

Alan's Graduation Ceremony

Alan Keady

Alan Receiving his Award

I have completed a three year training programme in Performing Arts with The Blue Teapot Theatre Company. I graduated on November 26th 2016.

There were seven of us training together and we all graduated together. The graduation ceremony took place in The G Hotel in Galway City.

The room was set up like a Theatre with stage and red velvet curtains. I wore a suit and dickie bow and also wore a Cap &Gown.

My family and some friends were there as well as the Mayor and invited guests of sponsors, board members, Galway Arts Council and staff from GRETB(Galway Roscommon Educational Training Board).

Everyone was seated and then we were invited to our seats in the front row.

The Director of Blue Teapot-Petal Piley- and other staff spoke of what a special day it was to have the Teacups graduating and how we had learned so much over the three years. This is the only Performing Arts School for People with disabilities in Ireland.

I was invited up on stage to be presented with my QQI Level 3 Awards in Art& Design, Craft & Puppetry, Drama, Drawing, Event Participation, Music Appreciation, Communication and General Learning. I was so excited and had lots of photos taken. Then we had a Cocktail Reception and more Photos.

We returned for a surprise. Each Tutor choose an actor/ess to present a Golden Envelope to based on their personalities. Paul one of the Tutors presented me with Mr. Bubbly as he said I was always happy, in good form and had a great laugh.. After all presentations were complete we spent time chatting.

I couldn't believe it when i was interviewed by RTE crew and I was so excited when i saw us on the Six One and Nine o'clock news that evening. I got lots of congrats messages from people and also people I met in town.

There was a photo of me in The Irish Times next day and all local papers.

It was a very special day as my 1st nephew/godchild Aaron was there with his Dad Jason and Mom Sheila and my Mom Nuala.

We had a lovely meal after and I had a brilliant day.

The Blue Teapot staff and the G Hotel treated me so special that day and it was perfect.

I am now in a new place called Arts Alive where I am very busy and happy. I still continue with some of the same things but I am doing Tai Chi which I love. I will be in the St. Patrick's Day Parade in Galway City on a float playing The Gamelan. I have started doing Music Mechanics for a street performance as part of Galway 2020 Capital of Culture in May.

Alan Keady.

Williams Syndrome Highlighted in New Early-Years Course

Fionnuala Tynan

LINC (Leadership for INClusion in the Early Years) is a new national programme designed to help with the inclusion of children with additional needs in early childhood care and education settings. LINC has been developed with reference to best practice in leading the inclusion of children with additional needs in early years settings and aims to prepare early childhood personnel to adopt a leadership role so they can support other staff to plan for, implement and review inclusive practice. The programme is fully funded by the Department of Children and Youth Affairs and is operated by a consortium led by Mary Immaculate College and including Early Childhood Ireland and Maynooth University- Froebel Department of Primary and Early Childhood Education.

The course is run over an academic year, it commenced for the first time last September. There is funding to run this course for 900 early years practitioners each year for four years. There are six modules offered. Dr. Fionnuala Tynan, from the WSAI, who lectures in Mary Immaculate College was involved in writing one of the modules. The module entitled 'Inclusion in Early Years Settings: Concepts & Strategies' introduces practitioners to different learning needs and strategies for including children with those learning needs.

The practitioners get one week's input on Williams syndrome as a complex need. This is very exciting as it will expose up to 3600 early years practitioners to the condition over the next four years. Participants are asked to interact with the website of the WSAI as part of the course content. Hopefully this will impact on greater awareness of WS and give better support to parents of young children with WS.

Linc
LEADERSHIP FOR INCLUSION
IN THE EARLY YEARS
CEANNAIREACHT DO CHUIMSIÚ
SNA LUATHBHLIANTA

Review of TV show 'The Undateables'

Ruth Brabazon

Monday nights at 9pm on Channel 4 brings a programme called "The Undateables", which deals with the experiences of adults in the UK with various physical or intellectual disabilities as they seek a partner.

To be honest, I had always avoided watching this show before, as the title is just awful, very negative, and I wondered if the show just made fun of people. However, when I read that the show was to feature a young woman with WS, I decided I had to give it a try. And it was a pleasant surprise!

Overall it was quite moving. It illustrates the challenges that people with different abilities face when mixing with others. Very striking was the heartache of wanting a relationship but finding it difficult to start or maintain one. One musical young man with autism was very shy and could only stammer, but when he sang and played an instrument, his personality shone out.

The young lady with WS, Lucy, was from England and was 18 years old. She was filmed chatting in the garden with her mum and sister about the upcoming date. Her family were supportive, and her excitement was obvious.

The Love4Life organisation, which seems to be a charity based in Hampshire, matches applicant couples (not just for the purposes of this show). Its aim is to help people find relationships in a safe way, without relying on chance meetings, or online dating services used by the wider public. When they called Lucy , she reacted with delight.

The Cast of The Undateables

Her partner was a charming if shy young man who may have had a level of autism. Lucy's big interest was haunted houses, so they had a tour of a spooky location, and as Lucy reacted with shock and glee to a mysterious knock on the table in the cellar, her date valiantly struggled with his nerves.

As they swapped numbers afterwards, you could see the familiar beaming smile and open nature in Lucy's face. She chatted easily and seemed to have enjoyed her day. More episodes can be viewed on www.channel4.com

PS Another series on a similar theme is 'Born This Way' (also Mondays) , an Emmy-award-winning US series following some adult friends, most of whom have Down Syndrome, as they negotiate adult life, love and growing independence. There is lots from their parents' point of view, which is quite an interesting insight.

Are these programmes an invasion of privacy? I don't know. The overall vibe is positive, but it is a debate that deserves to be had. They definitely throw up issues that we will all meet in the present or future.

Forthcoming Publication on WS

Fionnuala Tynan

I am delighted to announce that the Curriculum Development Unit of Mary Immaculate College is interested in publishing a book on Williams syndrome. The book will be based on the Irish context, on our people with WS, with information from the various research projects I have undertaken in the past few years. It will focus on the many strengths of people with WS and how to support their learning needs, from the cradle to later life. It is geared to families and to any professional involved in supporting an individual with WS. It will also be geared to people with WS themselves and each chapter will have specific WS-friendly information by our own wonderful people with WS. It will not be health based. It will address such topics as early learning, choosing a school, talking to your child about WS, developing literacy and numeracy skills, supporting your child's concentration, fine-motor skills and anxiety, internet safety and relationships. If there is anything you would specifically like included in this publication please feel free to contact me at fionnuala_tynan@eircom.net

Thanks to all the WSAI members who support the research I do and especially to the individuals with WS who are now telling me what research they want done and keep asking me when I'm going to interview them again! You make my work so worthwhile!

Spreading the News

A special thank you to the Williams people who have provided such excellent contributions to this edition of the Newsletter.

The WSAI Newsletter is one of our key ways of communicating with our members and news from our WS Members is an encouragement and inspiration for all concerned.

We welcome news items from all our members and we look forward to many great articles in future additions. If you have an idea for an article just get in touch with any member of the WSAI Committee or contact WSAI at the address below:

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