

# WSAI News



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## Special Olympics, LA Games 2015

Ashleigh O'Hagan

Los Angeles or the City of Angels as it's commonly known is a city full of movie stars, fashion and sports stars but come July this year it will be full of Special Olympics stars who will be taking centre stage when they compete at the 2015 Special Olympics World Summer Games. From all corners of the earth and all walks of life, over 7,000 athletes will descend on the iconic Californian city to fulfil their dreams of contending for an Olympic medal.

The 88 Irish athletes that make up Team Ireland will fly out from Dublin Airport on the 21<sup>st</sup> of July with high hopes of a strong team performance. As some of you may be aware our very own Ashleigh O'Hagan is a member of that team and this Newsletter is tracking her involvement with keen interest.

In this Newsletter Ashleigh updates us on the build up for the games.

### Hi Everybody,

The count down for the Special Olympics 2015 world games has begun!!!! The Olympic torch has left Greece and is heading for L.A. The training is getting a little easier or maybe I am getting better at it I am still on track anyway, I'm still meeting up with all the other athletes from all over the country it's great craic. The Irish team are competing in 12 different sports. I will be competing in Rhythmic gymnastics. The Irish team are also competing in equestrian, football, bowling, golf, table tennis, kayaking so on. We will be training for two more

weekends in Dublin. On the last weekend after we have finished our training, we have all been invited to the US Embassy in the Phoenix Park to have lunch with the US Ambassador at his residence, I am very excited about that. Then we will be flying to Los Angeles on the July 22<sup>th</sup>. We are going to have a few days rest when we get there and then the opening ceremony is on the 25<sup>th</sup>. So fingers crossed I will do well !!!

### Love Ashleigh

### News just in !!

The Irish team are invited on to Miriam O'Callaghan's Saturday night show on RTE1 on the 18th July

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7,000 athletes from 170 countries will gather in Los Angeles for the World Games

## WSAI Contact Details

Williams Syndrome Association of Ireland  
13 Kilgarve Park,  
Ballinasloe, Co. Galway

Phone: 090 964 3247

E-mail: [wsai@eircom.net](mailto:wsai@eircom.net)

Launch of Team Ireland for 2015 Special Olympics World Summer Games

## My Experience of the Summer Music Camp

### Ann O'Rourke

My name is Ann O'Rourke, I started going to the summer camp 4 years ago. It was my first time getting involved with The Williams Syndrome Association.

My sister brought me to the camp on the first day. I did feel nervous as I was worried. I was unsure what was going to happen. I should not have been worried; I was made feel very welcome and I became part of a big family.

I have made loads of new friends over the years at the camp and have taken part in as many activities as I can.... like drumming, walking, dancing, shopping, day trips, singing. I have even tried football and archery which I still laugh about, I won't be winning any medals yet. We partied almost every night and still found time to relax.

The highlight for me was getting up on stage and talking part in the show on the last night of camp. I especially loved drumming on stage.

I would highly recommend the camp, it is good fun and I have made lots of friends. I am already planning for the next camp in August this year and I cannot wait to return

I look forward to seeing you all there.



Ann on Drums at the Camp

## National Sports Inclusion Disability Programme

### Niamh Daffy CARA Centre

Throughout Ireland there are a number of organisations who provide support and advice to people with disabilities, their families and carers on how to increase their participation opportunities within sport, physical activity and physical education settings. Over the next few editions of this Newsletter the CARA National Adapted Physical Activity Centre will provide an insight into the vast array of organisations, events and activities throughout the country who provide opportunities, support and guidance for adults and children with disabilities to be active within their local community.

This edition provides a brief introduction to the National Sports Inclusion Disability Programme which was established in 2007. The Sports Inclusion Disability Programme is an Irish Sports Council initiative delivered through the network of Local Sports Partnerships throughout the country. The aim of the National Sports Inclusion Disability Programme is to increase opportunities for individuals with disabilities to participate in sport and physical activity at a local level. The programme is coordinated and supported by the CARA National Adapted Physical Activity Centre which is a national organisation responsible for coordinating, advocating and facilitating for the inclusion of people with disabilities in sport and physical activity.

As part of programme there are 17 Sports Inclusion Disability Officers (SIDOs) employed by the Local Sports Partnerships. These SIDOs work at local level to support people with disabilities to be active and participate regularly in sport and physical activity. If you have an interest in sport and physical activity or want to try new activities then this is the chance for you, contact your local sports partnership and they will be able to assist you in locating suitable activities within your locality.

On the WSAI website you will find a list of partnerships and the relevant contact person.

For further information please contact your Local Sports Partnership or the CARA Centre at 0667145646.

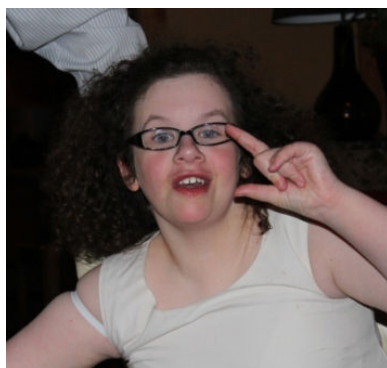
## 'London Calling'

### Kelsey Brannigan

This is Kelsey reporting on my first trip away from home on my own to London. I went to London with my youth club on the 18th April. We met together in the airport and got the 8am plane to London. On Saturday we went to many places on a bus. I got to see the Harry Potter experience at Kings Cross. I bought some jelly slugs in the shop they were yuck flavour. We went to Madame Tusauds and I went on a roller coaster. Scary!!! That night we went to see Charlie and the Chocolate factory in the west end. It was awesome.

Sunday we went to see the changing of the guard it was great, but I didn't see the Queen. We went on an open bus around London and then we went on a boat cruise. London was very busy. I got home

at 10pm and Shauna had a welcome home sign for me, I was sooo tired. London was fantastic and everybody was so proud of me for going on my own. Over and out **Kelsey xx.**



Kelsey Brannigan

## Bells, Ears, Fears - Our Experience of Anxiety and Williams Syndrome

Deirdre Graham

Before Ed's Diagnosis, during that turbulent first year of crying and very little sleep, his Dad and I would joke that he could hear a teabag hitting a teacup! Ed would always wake crying when we put on the kettle in the evening. Unknown to us the slow boil of the kettle held a resonance that we didn't notice but was nightly torture to our WS child. Hyperacusis meant the noise of the boiling kettle caused Ed pain, inevitably restarting another crying session. At the time in our exhausted state we thought he was being obstinate! How could he start crying again just when got a chance to have a cuppa! Now of course we understand how much hyperacusis affects him. After diagnosis we started to notice how different noises affected him. The hand blender and vacuum were particular enemies of his. We began to experiment with different techniques to normalise this concern and noticed that if Ed had a warning before the hand blender was used then he could tolerate the sound. So began the "1...2...3...now!" approach. By counting in the use of the machine we discovered Ed could tolerate the noise well enough; success!! We began to



Ed experiencing Hyperacusis

realise that each time a problem presented itself, we would have to address it in accordance to Eds needs. We observed his reactions to different things and tried to figure out how to help him cope with his own emotional reactions. Going to visit his Grandad and Nanny threw up more issues as his fascination with tractors grew. Ed loves tractors, he loves their wheels, colour and size but their noise used to terrify him. We sourced a pair of ear defenders on the internet and popped them on his ears. When he wore them he realised he could go outside nearer to the tractor and not be worried about the noise. Another great advantage to the ear defenders was their use in loud places. Ed would self-regulate their use, once he discovered that he could cope around the noise then he would remove them himself! Initially he wore them in every new situation but within six months his reliance on them started to wane. Now at 5 years old, he knows where they are but barely requests them anymore, and recently he laughed and said no when we offered them to him!

Eds condition has taught us to be more observant of our environment. Noises we never noticed before are more apparent to us now. For example, when we listen to the radio, a change in tempo or volume can lead to total meltdown and tears. We decided that we could not allow Ed to be controlled and held captive by often uncontrollable noises. The challenge is to teach Ed coping techniques or strategies to control the anxiety he has around certain sounds. Another positive example of teaching coping techniques to Ed involves a helicopter! A new initiative started in our local hospital involving the transfer of patients frequently 24 hours a day by helicopter, with our house lying smack bang in the middle of the flight pathway! Our little boy with hyperacusis and anticipatory anxiety could hear the helicopter approach at least 15 – 20 seconds before the rest of us. So began 3 weeks of interrupted sleep and a lot of snotty tears and meltdowns. One particular day when the 3<sup>rd</sup> helicopter passed over the house in as many hours I had



Ed enjoying a Helicopter

had enough. I grabbed my terrified bundle of tears, shoved on his ear protectors and drove to the landing pad. When the time was appropriate I approached the helicopter and spoke with the pilots. I explained the situation and could not believe what happened next. The pilots took Ed by the hand, introduced themselves and walked him around the helicopter, showing him the blades, controls and engines. Little did those 2 lovely men know that they have a fan for life, now each

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time a helicopter passes overhead, Ed simply says, "Oh that's Niall and Stuart", and he no longer holds any anxiety about it!

Unfortunately not all anxieties are as easily solved. The Bell in his sisters' school is a prime example. The anticipatory anxiety surrounding this bell continues to be a big issue for Ed. Despite the use of ear defenders, music, a computer for distraction and

## Bells, Ears, Fears—Contd.

breathing techniques, this anxiety fluctuates. He can be fine one day and rooted to the ground in fear the next. I feel this fear still requires a lot of reasoning that I don't think he has the cognitive ability to figure out yet.



**Ed with his Ear Defenders**

Hopefully we will address this as his cognitive ability increases. However techniques such as deep breathing really help Ed. We were lucky enough to take part in a specific yoga group organised by his early intervention team. I can't speak enough as to how beneficial yoga has been to Ed. The focus on deep breathing and relaxation techniques have proved very useful and effective in assisting Ed to self sooth. We have always been determined that Ed self sooth from an early age as he will have to perfect this for life.

On occasion we use a puppet technique to help distract Ed from a meltdown. When he was younger he used to cry uncontrollably some nights for often undeterminable reasons. We were frustrated and deflated as we tried everything to soothe him with little success. Then one night in sheer desperation his Dad grabbed his night time teddy and began to use it like a puppet. Another revelation, it worked! We noticed that Ed began to interact more freely with the puppet then he did with us. He would ask the puppet questions, tell him about his day and generally have a conversation with the puppet. This would lead to him forgetting about whatever had upset him, peace reigned again! This technique continues to work

particularly on the nights when Ed ruminates on any distressful event that occurred over the day. As people with Williams Syndrome are so in tuned with peoples facial expressions, focusing on an expressionless puppet allows Ed to disentangle himself from others emotions and helps him control his own. Fionnuala Tynan is currently carrying out more research around this technique.

Lately another anxiety lies with a child in his class. He has become obsessed about this child, talking about him and mimicking this child's behaviours. A new technique we have

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taken to tackle this new issue is based on a mindfulness approach. We remind Ed that he is Ed and not this child. We make him state it out loud and bring him back to the present as he often states "..... was crying,.....was cross". It distracts him and jolts his change in behaviour back to his own. We have just started this method but already it is looking positive.

Ed has just turned 5 years old. We realise that these are early days, but there appears to be a growing understanding of the huge impact that anxiety has on the lives of people with Williams Syndrome. In fact thanks to this recognition it may mean that even though Ed has been classified on the mild intellectual category, his anxiety issues may gain him the valuable resource hours he requires in school. There is always going to be a new challenge for Ed to tackle, another "bell" or similar trigger. Some sounds can be managed but the majority cant. We believe that it is the surprise element that can't be heralded that causes the most anticipatory anxiety for Ed. To reduce this anxiety Ed continues to need to learn how to manage his feelings. As his parents we have comfort in knowing that it will be the techniques that we show him that will

ultimately help him conquer his fears, control his anxiety and hopefully prevent him from being swallowed up by the burden of fear. It is the greatest challenge of WS as well as the challenge of raising a confident child. We hope to rise to it, with the help of many cuppas along the way!!

## Picnic in the Park 2015

**Debbie Brannigan**

This years Picnic in the Park was held in Tayto Park on Sunday the 14th of June. The sun shone down in Ashbourne making a lovely day for a picnic. Families from North, South East and West attended this event which is going from strength to strength and caters most especially for our younger WS people and families. In all about 65 people attended the picnic which must be a record. It was a great day for the younger WS families and successful outing for all who attended.



**Big Turnout in Tayto Park**

Don't miss out on next years event which will be advertised well in advance in this Newsletter.

# Trickster

Ann Breen

Last year my daughter, Karen, got involved with a musical production called Trickster. This production took place in the Black Box Theatre in Galway on 10<sup>th</sup> and 11<sup>th</sup> October and was a huge success.

The show was a collaborative effort between two groups - That's Life which is an award-winning Arts Programme of the Brothers of Charity Services in Galway and Mind the Gap which is England's largest intellectual disability theatre company. Mind the Gap is based in Bradford and creates work for the UK and international audiences.

The show was commissioned by Galway City and County Councils as part of Ignite. Ignite is managed by a unique partnership involving the Arts Council, Arts & Disability Ireland, Cork City Council, Galway City & County Councils and Mayo County Council. Ignite is a new platform designed to generate Ireland's most ambitious showcasing of talent from people with disabilities, led by international and Irish artists and performers with disabilities. Projects took place in Cork, Galway and Mayo in 2014.

An interesting aspect of the production in Galway was the fact that the show was spearheaded by Jez Colborne from Mind the Gap who has Williams Syndrome! Jez is described as "a professional musician, actor and all-round performer. He has previously had great success with other shows, such as "Irresistible", which were performed in UK and further afield.

Jez composed all the music and co-wrote the lyrics for Trickster. He is quoted as saying – "My inspiration for Trickster came from a visit to Galway and Inis Oirr in January 2014. It felt like a deserted island and the weather was so wild that we got stuck there for a few days. The experience sparked my imagination. The lighthouse inspired me and made me think of a Cyclops character. Galway City, the industry, the weather and being stranded all had a big influence on the development of the music".

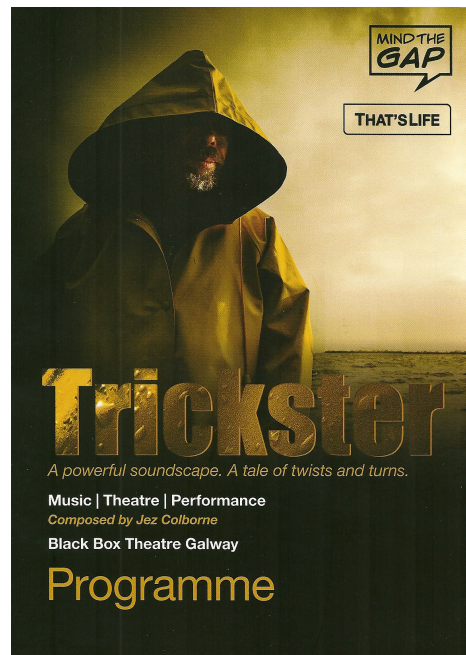
Work on the show began with the visit to Galway by members of the Mind the Gap group in Jan 2014. The premise for the show

was developed. Music was written, lyrics were written. Then began the hours of practice that continued for many weeks and months. Mind the Gap rehearsed in Bradford, That's Life rehearsed in Galway. Both groups travelled to the other's location on a couple of occasions so they could all practice together. Many hours of work were put in to get the final one-hour version of the show. And what a show it turned out to be!! It played to sell-out audiences for its two-night run in Galway. Props used as part of the show

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Karen played her heart out as a member of the 7-piece band for the show, five of whom were professional musicians. She played keyboard and a keyboard synthesiser. She absolutely loved every minute of it all – the rehearsals, the trips to Bradford in UK, the performances on the two nights! There was a light in her eyes that I have not seen there for quite a number of years! She was buzzing!

For me, the whole project reminded me very clearly once again just what our WS people are capable of. We need to continue to encourage and support them in whatever their area of interest is. They never cease to amaze!!



## Midsummer Melodies

Jarlath Tynan

I'm famous. I've ten year's worth of experience conducting. I was asked by George Lee the musical director of Mayo Concert Orchestra to conduct the Radetsky March at their annual concert ten years ago. It was a huge honour and I was so glad Fionnuala was in the orchestra. I accepted his offer and no one could believe both of us were part of an orchestra that was expanding.



**Jarlath singing "Pure Imagination"**

Five years ago Fionnuala and myself decided to do a summer concert for the summer solstice because it was the longest day of the year. The concert was to raise money for the music camp of the WSAI to make sure it could run for five years so this was our fifth year.

To prepare for the concert I had to come into the boys school in Castlebar for practice each Wednesday at 7.30 pm with the orchestra. I

liked going to the practices but it was tough because I also had to practice singing with the pianist and the violinist. Everyone said I was spot on. They were saying bravo, well done and stuff like that.

Before the concert I felt nervous but then I got used to it. I had to wear a shirt, black pants, dicky bow and a jacket to look like a true mini conductor. When I arrived at Ballintubber Abbey there were guests coming. I felt alright, I felt a bit nervous but then I felt better having the people and the orchestra around me. The abbey was full. The orchestra played the Thunder and Lightning Polka, Te Deum, Panis Angelicus, Hymn to Joy and the Hallelujah chorus. I sang Pure Imagination from the film Willy Wonka with Mary Reilly on piano and Anne Moriarty on the violin. I thought I was excellent. The audience clapped and I took a bow then. It felt marvellous. It was great to have all my sisters around for the concert. At the very end I conducted the Radetsky March by Johann Strauss. I raised my two hands up so I could start conducting, I just said one two and they played. They played very well. I conducted the audience too to get them going, they clapped and clapped and clapped. Just before the end I raised my finger so the orchestra knew it was nearly the end of the piece for this year's midsummer concert. It felt ex-

cellent. I got a standing ovation, they were smiling and saying Ah he has done it! After the concert I met and greeted people. They were all coming up and gave me hugs and kisses and they told me I did brilliant. I then went upstairs in the abbey for a cuppa with my friends. My friends came from Castlebar, Roscommon and Limerick. More friends came from Galway, Dublin, Carrick-on-Shannon and New York. I wasn't expecting it. Some people couldn't make it but they still gave



**Jarlath & friends after the show**

money to our charity.

You can see me on Facebook and YouTube. I think I'm more famous than Michael Jackson or Matt LeBlanc. I now need the paparazzi and security to really feel the part!

## Weekend Break

Debbie Brannigan

The annual WS weekend away 2015 was held in the Ardilaun Hotel in Galway. We had 15 families taking part this year. On Friday we had a meet and greet and Fionnuala Tynan did an anxiety workshop with our WS people.

On Saturday the group got the bus into town with the exception of Brian, Ja, Stan and Tommy "the fit team" who walked into town. We went on the Princess Corrib cruise. It was very relaxing and all the families enjoyed the experience. On Saturday night we all dined together in

the restaurant. A presentation was made to Ashleigh for her up and coming Special Olympics trip. Everyone wished Ashleigh the best and she made a lovely speech. Well done Ashleigh! Brian Ahearne entertained the whole hotel on Saturday night with his beautiful piano playing. This man's talent is amazing. He definitely has the WOW factor. Everybody said their goodbyes on the Sunday morning and went on their musical ways looking forward to the next event or get together.

## Music Camp Update 2015

Carmel Daly

The build up to the 2015 Music/Activity Camp is now in full swing. This year's camp will be held from the 2nd to the 9th of August in the Share Holiday Village, Lisnakea Co. Fermanagh. Booking for this year's Camp is now closed but other members of the Association are invited to visit the Camp during the week. If you would like to visit the Camp then please contact Carmel Daly or Debbie Brannigan our camp organisers. If you know of anyone who would like to volunteer as a helper or a teacher please contact Carmel for details or visit [www.williamssyndrome.ie](http://www.williamssyndrome.ie)

## How Happiness and Sociability Mask High Anxiety in Williams Syndrome

### Fionnuala Tynan

On the 12<sup>th</sup> of June I did a presentation on this title to the Irish Association of Teachers in Special Education. It was received very well and I was delighted at the interest shown by teachers who had never heard of the condition before. It also gave me the chance to talk to teachers who are currently teaching a child with WS. I put a note up on Facebook about the conference and several teachers have made contact looking for more information. Perhaps most significantly I met a teacher whose aunt was diagnosed recently with WS aged 70!

Anxiety is very often reported by parents but not by teachers and this poses a problem for our children. At home, they can display anticipatory anxiety, fears and phobias and this can be difficult to manage. However, when they are in out-of-home settings, such as school they are so friendly and happy that teachers usually do not see anxiety in these beautiful students. Sometimes compliments by a student with WS is their way of preventing a teacher's bad mood. In a classroom the student with WS works hard trying to keep a positive atmosphere in the class but at a heavy price ... their own anxiety is high all the time but no one sees it. Some of you know this because your child has outbursts at school. This is usually the result of keeping it all in and then something small can be the straw that breaks the camel's back. It's very important that as part of your discussion with your child's teacher or employer (this doesn't go away unfortunately) that you emphasise that your child is likely to be highly anxious and to watch for when your child uses compliments, picks skin, paces, has a jumpy leg or is highly distracted ... these can be signs of anxiety. The most basic strategies for the teacher/ employer to use are to smile regularly at your child, to use a calm tone of voice at all times and to give reassurances (either verbal or by signs such as thumbs up).

In the WSAI we are continuing to research this area and to work on strategies for different types of anxiety.

### Anxiety Workshop

On the wonderful weekend away organised by

Debbie Brannigan I ran a short workshop (45 mins) with all the WS individuals over 5 on anxiety. It was very productive and yielded interesting information. The workshop was based on the needs of this group, so only a rough outline was prepared in advance.

The workshop started by finding out what anxiety means and in what situations they feel anxious. Did you know some of your children worry about you? They worry about your health and some are worried that you'll die. Some worry about fights with siblings or people shouting at them or being angry with them. I decided to focus on this aspect. We discussed what makes someone angry and explained that anger is not a bad thing (if anger is suppressed it leads to depression), the difficulty is in how anger is expressed. It emerged that sometimes some individuals with WS find it difficult to distinguish between someone being angry and someone raising their voice.

We used the story of Goldilocks and the Three Bears as a basis for how anger can be expressed: who's been eating my porridge became who's been eating my maltesers!! We used puppets to do this.



**When you get angry!**

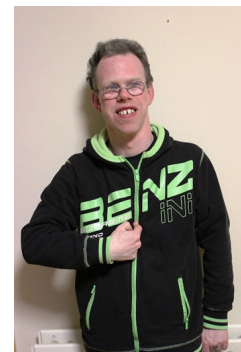
Puppets serve three purposes: they have a sensory function (they feel nice and can be relaxing to touch), they focus the attention of the person and they allow the individual with WS respite from reading emotion on a face. We then moved from the fun aspect to applying this to everyday situations. We identified situations in which people may use an angry or loud voice: finish your dinner, take out your homework, go to bed, hurry up, did you do that, what are you doing, etc. The



**STOP!**

strategy we developed is what is called a script with a total body response. A script is where you learn something by heart which you can use in a particular situation without having to think so your energy does not go into reacting in other ways. It is used a lot with students with Autism, predominantly to help their socialisation. A total body response is where you do an action and the energy goes into the action rather than into the emotion. So here is the strategy ... the group was taught to say the following (with actions in brackets) when someone gets angry: "stop" (two hands up in front of chest), "when you" (point to person) "get angry, I" (point to self) feel anxious". This will buy them time to not react emotionally, it will also diffuse some of the anxiety for them by being 'active'. It also puts them in control and is likely to boost their self-esteem as a result.

It would be very useful for you to try this at home ... we need to see how effective it is. However, you should expect some complications!! Your child is likely to overuse this strategy to get out of doing tasks etc. Your



**I feel nervous!**

reaction to your child using the strategy should be to take a deep breath, take a step back from them and apologise (I'm sorry I didn't mean to sound angry ... rather than getting into an argument of you not being angry in the first place! So this is scripting for you!), then to repeat the request or the information in a calm, unemotional voice. This was explained to the individuals with WS, that just because they use this strategy doesn't mean their parents won't make the same request of them, so don't let them away with it! I hope this explains the strategy, please feel free to ring me if you need any clarification (086-2063773)