

WSAI News



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New Piano for Williams Syndrome Association

Ann Marie Leahy



Ann Marie with Jarlath and Fionnuala Tynan

On Friday the 27th July 2018, my mum and I travelled to Mary Immaculate College in Limerick

to deliver a piano for the Williams Syndrome Association. The day started with me going to

participate in a show at the summer camp I was going to for the month of July. My day started off with singing and dancing and from there my mum and I left to head to Limerick to meet up with Fionnuala and Ja. The piano was donated to us by a neighbour. We travelled with the piano in the back of the car and set off for Limerick. We arrived and I helped to get the piano out of the car to present to Fionnuala and Ja. After we dropped off the piano we went for lunch with Fionnuala and Ja and had a catch up. I had an amazing day and was delighted to deliver the piano to Limerick.

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Picnic in the Tayto Park

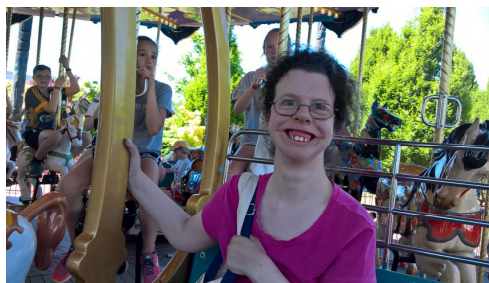
Ruth Brabazon

The WSAI Annual Picnic took place in Tayto Park, Ashbourne, Co Meath on Sunday 24th June 2018.

There was great turnout of 54 people including family, friends and helpers. We were pleased to welcome a few new faces too this year.

Many were happy to have a look around the zoo and theme park, while some had a go on the theme park rides like the Viking Voyage (where you could get

splashed and cool off), the giant Climbing Wall, and of course the highlight being the noisy rattle of the Cu Chulainn wooden rollercoaster.



Patricia Enjoying the Merry Go Round at Tayto Park

There was also the playground for the smaller ones, as well as the zoo with all sorts of creatures including meerkats, monkeys and even bison.

This event took place in glorious sunshine, and marked the start of the best summer weather we have had in years!

-Ruth Brabazon

WSAI Contact Details

Williams Syndrome Association of Ireland
Carmichael House,
North Brunswick Street,
D07 RHA8
Dublin 7

Phone: 087 6190213
E-mail: info@williamsSyndrome.ie

WSAI Music and Activity Camp

Carmel Daly

Camp 2018 definitely was a huge success. This was obvious from the happy faces of campers as they left filled with renewed confidence, satisfaction, and looking forward to future camps.

On a personal level, I can't pretend that the preparations for camp is not hard work. There is a huge volume of preparation in the months leading up to it this year I even had to take time off work to accomplish it. But, it is one of the most satisfying things I have ever done in my life and I have been privileged to be able to do this work over the last number of years. In particular, I have been blessed to meet some wonderful people along the way, campers, volunteers and parents. You will always have a place in my heart.

Camp 2018 was held from, 5th to 11th August. We arrived on the Sunday afternoon to a hive of activity as each camper and volunteer was met and introduced during the course of the afternoon. We busied ourselves making up beds, unpacking and getting everyone settled into their chalets. It was challenging to get much done with the intermittent arrival of another "old" friend not seen since last year. But so lovely to see everyone, especially seasoned campers back in the fold. After dinner we got to meet everyone properly and to introduce new volunteers and campers.

This year we had 13 WS campers in attendance, 3 of which were international, Bernardo, Tobias and Rosie. Our international campers always bring something new, different and special to the camp. It was lovely to meet and befriend them, learn a little of their languages and culture, and make life long friends with them.

Each day began with breakfast at 8.15am. This year, it was decided to change the format a little to make it more interesting for our campers. As well as individual music classes we offered group classes and workshops and this proved to be a great success and was loved by all the campers.

We had classes in drums, percussion, piano, voice, guitar, cello and drama with 3 such classes in the mornings up to break time.

After lunch there was a variety of outdoor activities, or indoors if weather required it with foosball, circus skills, t shirt painting, and a



Music and Activity Camp 2018

shopping trip for the obligatory gifts for family and friends left behind.

As a special surprise for our campers we ventured offsite on a bus tour to Omagh on Tuesday. There we visited the Ulster American Fold Park. All agreed that it was a most interesting and enjoyable day.

Evening entertainment included a disco, band-night, sing-songs, pizza party and cinema night. During the week we also fitted in other activities such as relaxation, mindfulness and circle time, facilitated by Fionnuala for which I would like to give a huge Thank You!

This year at Camp we had 2 radio producers with Whistledown Productions - an independent audio production company in London who want to produce a documentary about Williams Syndrome and the Music/Activity Camp for BBC Radio 4. We saw this as a great opportunity to raise awareness of Williams Syndrome, as well as to educate listeners and discuss how society can be better prepared to support those affected by WS and to talk more generally about why music is such a powerful tool, too. During the week Katie and Yolanda interviewed the campers, talked to the volunteers and organisers and often took part in our activities. They were a joy to work with. We will keep you informed as to when the programme is released.

Saturday came too quickly. All day there was a flurry of activity as everyone prepared for the show and looked forward to the arrival of family and friends. This year we held the show at the earlier time of 3pm and all agreed

that this was a good idea as it made it easier for those travelling long distances afterwards. The show consisted of individual performance by each camper as well as a group choir performance. We also had a girl band and a boy band. One Direction eat your heart out. The talent was amazing as usual and it was a resounding success.

Thanks in particular to Emer Lacey, our Musical Director extraordinaire and to Sean Walsh for the all his technical know-how. They both did trojan work to facilitate all the classes and evening events as well as putting together a brilliant end of week show. I hope they know how much we appreciate them both.

I want to say a huge Thank You to our wonderful volunteers. Indeed all our volunteers outdid themselves this year and made us proud. I especially want to thank all the campers who attended this year. They are such a fun-loving, friendly, bunch and are a pleasure to spend time with. In particular they are very supportive of each other, a real WS family.

I can't not mention Debbie who unfortunately could only help for a couple of days but that help was invaluable. And last but definitely not least, a humongous Thank You to Andrea Hegarty. You were a huge help and support to me personally as well as a friend, mentor and leader for all at camp.

Finally, all I can say is a Huge THANK YOU to each and everyone of you!

Carmel Daly

Williams Syndrome Junior Camp

Fionnuala Tynan

Limerick was delighted to welcome back six fabulous young campers for the WSAI junior camp this summer. It was an action-packed week that was hugely successful. Each day our campers came into Mary Immaculate College and followed a structured timetable of activities, where learning skills were developed through music and drama. Parents had filled out an information form about their child in advance of the camp and had selected areas to be developed during the week. On foot of this an education plan was devised for each child. Each day started with bundles of energy running through the door to play with their friends! When everyone was in we did circle time to ensure everyone was relaxed and settled. This was followed by the development of fine-motor skills. Here we had a programme of work laid out for each child matched to his/her ability and interests. We tried out various approaches to help them to focus on their tasks. Each child was able to work for a whopping 30 minutes on a range of fine-motor tasks. We were so proud of them because this was really difficult. The best strategies to keep them focused were to avoid eye contact and to refuse to get drawn into a conversation! We could only do this when we were fully sure that each child had no anxiety about the tasks they had to complete. We also gave them a lot of praise for staying focused and this worked very effectively. It was during this time too that we also did one-to-one work with children



Ed the Music Man

whose parents had asked us to work on speech and language skills, phonics or reading.

After this we did handwriting skills which was copying different writing patterns that were modelled on

the board but to their favourite songs. They had to change the colour of their marker, chalk or pencil when the music changed to reinforce a good pencil grip. Again, they would work very happily for up to 30 minutes doing



Three Cheers for the Junior Camp!

handwriting! Unbelievable!! We found that they were highly motivated by the music and by the changes in writing to the music. They also liked to do 'social writing'. Here they liked to draw a picture or make a card for a friend at camp.

Next up was gross-motor skills. We had a room set up with brand new equipment specifically to develop these skills. Here the children did obstacle courses, activity stations and dance. Boy did we see some great moves to the Cha Cha Slide!!

After lunch everyone had to clean their face and hands and brush their teeth! This was followed by choir practice and music class which led to a beautiful concert on the last day for the parents. They sang a range of songs and played songs on the hand bells. It was incredible to see their capacity for learning during the week.

In the afternoon the children also had a choice of talking about WS or doing additional music activities. This was decided by parents. Three of the six children took part in the discussions. This led to the development of a story by one of our little campers which she might share in the next newsletter! The day ended with time with relaxation. We had turned one of the rooms into the college into a sensory room by putting black-out on the windows and decking the room with fairy lights, tents, cushions, mats and soft toys. We tried out meditation and mindfulness which worked very well for most of the campers. They also just liked being in the room with reduced stimulation to

play with the soft toys. Each day finished with circle time to discuss what they liked about the day and what they didn't like about the day. We also did some additional activities like making pancakes and playing board games with siblings.

For me as a teacher and researcher this week is my favourite week of the whole year. By having all these highly motivated and adorable children who are happy to share their thoughts and feelings about everything, I am seeing new ways of working with them all the time. It is a heart-warming experience. The wonderful outcome from the camp is that teachers of the campers are getting in contact and seeking additional support. I've already done three school visits this year and have another two to do before Christmas. Rather than giving generic advice about what is likely to work with a child with WS I can now give tailored, individualised advice because I know the children so well. The week couldn't have run so well without the support of the parents.

Thank you to Deirdre Graham who once again co-ordinated the parents room and facilitated discussions there each day. The camp is likely to run at the end of July again in 2019, please don't hesitate to contact me if you have any questions about it.

Fionnuala

(fionnuala_tynan@eircom.net)

Details of the associated Sibling Camp are on the Pages 4&5.

WSAI Sibling Camp

Fionnuala Tynan

This year we ran a sibling summer camp alongside the junior camp in Limerick. This was for children aged 4-12. There was a wide range of activities organised for these campers including football, drama, orienteering, obstacle courses, puppet making, pancake making, art, music and games.

The siblings also had a chance to take part in research on being a sibling. We met for four of the five days for half an hour to talk about our experiences of being a sibling. The children were free to come and go as they wanted during this time, they didn't have to participate if they didn't want to. This was a huge success. There were great friendships made and the older siblings have expressed an interest in coming back to help out with the camp next year. There are some really incredibly kind, sensitive and compassionate brothers and sisters in our association. It was a pleasure to have spent a week in their company! .



The Fabulous Happy Campers at Mary I

See Next Page for more photos!

FEWS Camp Report

Fionnuala Tynan



Butlin's Holiday Centre in Skegness

FEWS (the European Federation of Williams Syndrome) supports the organisation of a camp in a member country each year. In 2018 it was organised by the United Kingdom. The two Irish campers that went were Kelsey Brannigan and Jarlath Tynan. While the FEWS camp is normally held for a week, this year's camp was shorter and was held over a long weekend.

The camp took place in the seaside resort of Skegness on the East Coast. It was a Butlin's centre so there was any amount of entertainment available. The camp coincided with the bi-annual conference of the Williams Syn-

drome Foundation in the UK. We were thrilled to meet with our friends Dr. Mary Hanley and Dr. Debbie Riby who were presenting at the conference. We met the oldest man in Britain who has WS. He is an ambassador for the UK association. We also met identical twins with WS who were the best dancers on the dance floor every night!

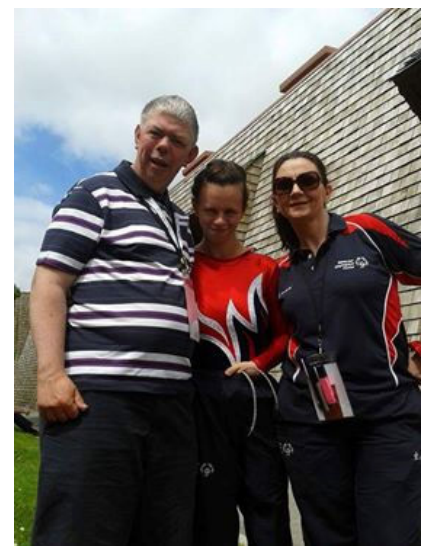
It was incredible to see so many people with WS of all ages.

The pace was easy for the weekend. We had very enjoyable day trips and evening activities. The weather was fabulous which also helped! We went to an aquarium and to the sea-side. We met Mr. Grumpy and Mr. Tickle, we saw shows, had discos and live entertainment. There was any amount of food!! It was a wonderful weekend and a great opportunity for our campers to meet other people with WS from all over Europe.

News Flash!

Late to Press—Carmel Daly

Huge congratulations to Padraig Reilly who has been chosen to represent Ireland in the Special Olympic Word games in Abu Dabi. Go Padraig!!



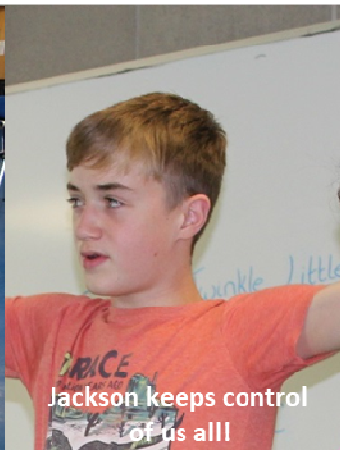
Padraig with Ann Marie and Pauline

WSAI Siblings at Junior Camp

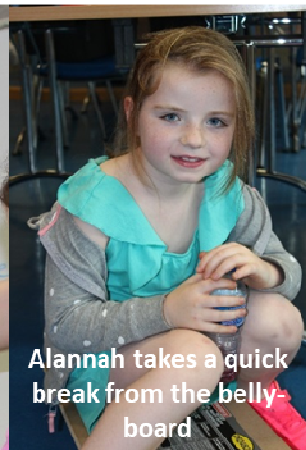
Mary Immaculate College - Limerick - In Pictures



Abbey was a natural chef ... look at that for concentration!



Jackson keeps control of us all



Alannah takes a quick break from the belly-board



Rian follows in the footsteps of his big sisters and brother



Julie REALLY enjoyed chocolate spread on her pancake!



Cathy leading the Cha Cha Slide for everyone!



The tunnel was no challenge for Charlie!



Belle gave us all a fright, popping out of nowhere!



Chloe was a big sister to everyone at camp



James snatches a few quiet minutes to refuel!



JJ made his pancake as big as he possibly could

WSAI AGM in Limerick

Debbie Brannigan

This year our Annual General Meeting will be held in Mary Immaculate College, Limerick on 24th November 2018.

On Saturday 24th we will also be holding a National Symposium on Supporting Individuals with WS in Mary Immaculate College, with guest speakers who will discuss topics of particular interest to our members and also to professionals who work with them. It will start at 10.30am. This meeting is open to all with an interest in WS; you might also like to invite teachers/professionals or anyone who works with your family member with WS.

While the presentations are in process, we will be holding workshops for our people with WS and their siblings. Further information and a

precise timetable will be available nearer to the date. Also on that day Dr Fionnuala Tynan will launch her book *WiSHES* (Williams Syndrome Holistic Educational Strategies) in Mary Immaculate College Limerick and you are invited to attend with your family.

The AGM of the WSAI will then start at 4pm in the same venue. The nearby Clayton Hotel are offering us a special overnight rate if anybody wishes to stay on either the Friday or the Saturday night. Please contact the hotel directly to book accommodation using the booking code number, 11531196.

We look forward to seeing you and your family on the 24th November.

GDPR

Carmel Daly



A new European Data Protection law, the General Data Protection Regulation ("GDPR") was introduced on 25th May 2018. This new

law applies to any organisation, including the Williams Syndrome Association of Ireland, that manages and processes people's personal information.

The WSAI Committee is working on ways of ensuring that what we do with your information is compliant with this new law. It is a work in progress and over the next few months we will keep you informed through the newsletter as policies are put in place.

In the meantime, we will continue to communicate with WSAI members and all on our contact list with news about WSAI including our activities and events. I recently wrote to all our members informing you of this development and am happy to say that no one asked to be removed from our contact list so far.

Please be assured that we will not be sharing your data at any time with individuals or organisations. A full copy of our privacy procedures will be available in the coming months. To access more information on GDPR please visit: <http://gdprandyou.ie/wp-content/uploads/2017/05/The-GDPR-and-You-2.pdf>

Carmel Daly

Get the Kettle On WSAI Committee

We the WS committee are trying to raise Williams Syndrome Awareness within our communities and also raise some much-needed funds for the association to continue working to improve supports for our WS families.



Would you, your families or friends like to host a tea party in Aid of Williams Syndrome. It can be done at home, at work, at school, at your local club or at work.

During the week of 7th November 2018 our members will be hosting Tea Parties all across Ireland with all proceeds going to the WSAI.

We have written to all members about this event and circulated a poster to share with your families and friends. All support would be greatly appreciated.

Let's get the kettles on and raise WS awareness

Ann O'Rourke

An Appreciation

It is with great sadness that we recently learned of the death of our dear friend and fellow member Ann O'Rourke. Ann was an active and vibrant member of WSAI and attended many of



our events over recent years. Ann discovered she was affected by Williams Syndrome when she was 48 years old and she really embraced this discovery and became a central member of the Williams family. She was particularly fond of our music camp where she discovered her love for drumming and got involved in all aspects of camp activity with enthusiasm.

Anyone who met Ann will remember her wonderful smile, warm personality and great sense of humour. She developed a wide circle of friends in the Williams family and we will all miss her greatly.

Our thoughts and prayers are with Una, her sister and the rest of her family.

Articles for Newsletters 2018 WSAI Committee

We would very much welcome contributions from more WS people and member families and are sure that there are lots more fantastic stories out there about how people are coping with WS on a daily basis.

All we need is an email or letter with some photos if possible and we will do the editing and presentation from there. If you would like to contribute then just get in touch with any member of the committee or just send your material to our email or postal address.

**Williams Syndrome Association of Ireland,
Carmichael House,
North Brunswick Street,
Dublin 7, D07 RHA8**

Phone No: 087 6190213

Email: info@williamsSyndrome.ie