



# WSI News

Volume 27, Issue 2 Autumn 2022

## The Show Must Go On



**Ciaran, Aoife and Fia attending our Annual Picnic in May**

Williams Syndrome Ireland is delighted to continue expanding our programme of events following the difficult lockdowns and restrictions of the last few years. As outlined at our AGM last February we are now organizing many of our events around different age groups as we realise that families and people affected by WS have very different experiences and challenges at the different stages of their lives. With that in mind we have started organizing focus groups to engage with families of very young children affected by WS and also to cater for the interests of adults and their families and carers affected by WS. We also

hope to establish a focus group for parents of teenagers affected by WS moving forward.

This was the first time for WSI to undertake this initiative and so far the response from parents and children and adults affected by WS has been very encouraging from our initial small steps.

In August we kicked off the first of what we hope will be a series of social events for adults affected by WS at a musical show in the Bord Gas Energy Theatre which was very well attended and enjoyed by all. Next up for our adults will be a Christmas party in Limerick in December.

Our very young people with WS and their families attended a day out in Malahide Castle also in August and while the weather did not cooperate on the day everyone who attended enjoyed the day and hopefully we can build on this good start going forward.

If you would like to participate in the focus groups for the 2023 then do please get in touch. We will also be discussing this issue at our Annual General Meeting in the New Year.

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## Weekend Break/AGM

WSI's Annual Weekend Away is taking place Friday 24th February until Sunday 26th February.

During this weekend we will also hold our AGM.

The weekend away will be held in the Amber Springs Hotel, Gorey, Co Wexford.

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## Summer Camps Are Back

### Fionnuala Tynan

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**“Each activity is specifically selected for each individual child to include activities they find motivating but also pitched at the right level so they do not experience any frustration”**

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It was wonderful to be back to our face-to-face camp again this year. We had a fantastic week. It saw the return of old friends Katie, Alice, Katie and Ed who could run the camp at this stage! We were delighted to welcome new friends Amy, Darragh, Aoife, Oscar, Izzy and Fia. As always, we were delighted to have the brothers and sisters with us to make the week more special. We had wonderful volunteers without whom we could not have held the camp.

Every day we followed our routine of circle time where we checked in emotionally and rated our emotions on a scale of 1-5. The children would say ‘I’m a five today because I’m very happy to be at camp’ or ‘I’m a four today because I’m happy to see my friends but I’m a bit tired’. This was followed by our gross motor circuit. This included throwing and catching activities, crawling and rolling, throwing at a target, balancing and other hand-eye co-ordination activities. After this we worked at our individual ‘stations’ to



do fine-motor and academic skills. During this time, we get the children to focus for prolonged periods of time, building them up to work for 30 minutes on a variety of activities. The children have a selection of fine-motor activities arranged on trays and they work on each tray in order. Each activity is specifically selected for each individual child to include activities they find motivating but also pitched at the right level so they do not experience any frustration. After all this hard work we had break time. The favourite drink was a cocktail which was a mix of Mi-Wadi orange and blackcurrant!

After break we had an academic lesson each day. We focused on Australia and it gave us valuable insights into how children with WS engage and participate in these activities in an educational setting. We learned all about Australia. They all got to play the didgeridoo! They also loved singing our two Australian songs ‘I’m a Koala, not a Bear’ and ‘The Super Marsupial’. You can play these songs back on YouTube if you search for

Don Spencer!

The afternoons were more unstructured and included singing, dancing, drama, sing-songs or concerts where the volunteers played music, life skills and sensory room. We were particularly proud of the work the children did on their life skills. We did this on an individual basis with the older children. It included making toast, a cup of tea, making rice krispie buns and marshmallow-krispie delights. The children made an instructional video for each of these activities. They were amazing at working in front of a camera. It showed us that this is a strong motivator. It also means that they use language as they are doing the activity which reinforces each step of the process. As part of life skills, the children were also supported in their toileting. This included supporting one of the children with toilet training! The older children were thrilled to provide the clapping and cheering every time a wee wee was announced! In addition, the children brushed their teeth after their lunch.

The children always love the sensory room. We have a

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## Summer Camps (cont'd)

Fionnuala Tynan

darkened room with tents, cushions, fleece blankets, soft toys, a projector and fairy lights. It's very interesting to see the different sensory needs of the group. There is not a common profile! Some like to lie on the floor with just a cushion. Others like to be in a tent, with a soft toy and fleece blanket. Some like to sleep, some like to just look at the projections. We have noticed also that some children need half an hour and actually sleep in that time. Others like the quietness and low sensory demands.

The sibling camp was much more flexible. The children did a range of sporting, artistic and creative activities. They took part in the singing and dancing and sensory room activities too. We always work separately with the siblings to help them to understand WS better. Without exception, each of the siblings was kind and caring and shows an understanding beyond their years of the needs of their brother or sister with WS. We love that we can give them the opportunity to meet other children in the same boat. They are future leaders,



without a doubt, and will be much more sensitive to the world around them because they have a sibling with WS. I know this because they already are. This year we had the age limit of the siblings at 13 as we always had. It was very surprising to see that older siblings wanted to come back and be part of helping out. This is something we will revise for future camps. We are delighted to facilitate these wonderful young people who are eager to help and learn more about WS.

The highlight of the week was the show the children put on for their parents on the Friday afternoon. They performed songs, dances and a drama 'The Very Lazy Ladybird'. It was the first time we tried a drama. It will definitely be on the agenda for all future camps! We also showed video clips of the different activities from the week and the instructional videos of our wonderful children making some cuisinery delight!

A big thank you to all the parents who are so supportive of our summer school. Every time your child attends we get to learn more about WS and this allows us to help other children with WS. Thanks also

to Mary Immaculate College for their continuing support for WS.

### A Parent's View Helena Begley

It was a real joy to be back at WS junior camp in person this year and it was really wonderful to meet up with parents and families in Mary Immaculate College in Limerick. The children and siblings taking part in the camp had a ball every day and thoroughly enjoyed their time with Fionnuala and her incredible volunteer helpers. Parents met daily for tea, coffee and chats in the parents room. As always, it was wonderful to converse with parents all going through the same struggles. Parents were delighted to get the opportunity to discuss common difficulties faced by WS children and offer any pearls of wisdom or advice to others. The end of week performance by the camp participants was a highlight and brought a smile to everyone's face. Well done to Fionnuala and to all involved on a super successful junior camp. We can't wait for next year already!

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**"We love that we can give them the opportunity to meet other children in the same boat. They are future leaders without a doubt."**

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## Lessons from the WS Summer School

Fionnuala Tynan

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**“Some of our children could not express themselves in writing. When we got them to talk through their learning and have it written for them by an adult, the children showed a much better outcome.”**

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Academic lessons need to have a wide range of activities to facilitate the engagement of learners with WS. This includes giving them opportunities to work collaboratively to process the information being taught.

Songs are a particularly engaging way for children with WS to learn. While this can be challenging for teachers, the learning outcomes are much stronger. Our children remember the content of the songs very well and they are likely to continue singing it long after the lesson has been taught.

We already know that writing is a difficult skill for children with WS. We found that when children were asked to write about their learning, many could do this but it was slow and did not yield much information. Some of our children could not express themselves in writing. When we got them to talk through their learning and have it written for them by an adult, the children showed a much better outcome. Some dictated up to half a page of information where when writing themselves they only

had four or five lines. This is very important for how we support children with WS. At school, there should be opportunities for the children to develop their handwriting, it's an important life skill. However, we must consider the objective of the writing activity: is it to practice handwriting or is it to document learning? If it is to document learning then the child should have the choice of writing themselves or dictating to an adult. This will typically be the SNA in the classroom. It is also about parents scribing for their child when doing homework. But parents, please write exactly what your child says, don't manipulate it in any way so that it reflects their learning.

We noticed children went to the toilet when they got bored during our academic lessons. This meant they didn't actually need to go to the toilet, they simply wanted a break! If the child is going to the toilet to get a break, they are leaving the classroom. If we can get them to indicate they need a break, they can stay in the classroom but they will still hear what is going on. This is

preferable to leaving the classroom. The children were given red circles to indicate if they needed a break. They could sit in a tent for a few minutes and they came back when they were ready (usually after two or three minutes).

Many children with WS have difficulty transitioning from one activity to another, particularly if they have to move from one room to another.

Practicing a skill to have it recorded on a phone/tablet is hugely motivating for children with WS. This means that being able to write a letter of the alphabet, or add two numbers, recite a poem or give a number of facts about a country can be recorded. It makes the practice of the skill very worthwhile because they get to 'perform' and show this video to many people. They get a lot of positive feedback and this enhances their self-esteem but also their future motivation to learn.

The use of the sensory room needs to be managed to find out what is the best time frame for each child. For some, half an hour in the afternoon works magic. They

recharge completely. For others, they are cranky and disorientated after this timeframe and need less time.

Siblings like to be involved in learning about WS and learning about learning. We need to develop this aspect of the camp to support these wonderful young people to learn what they want during the summer camp.





## A Day Out at the Castle

Linda Kane

Our younger members enjoyed meeting up recently in Malahide Castle. Our members came from far and wide to brave the weather! The rainy weather didn't dampen anyone's spirits on the day. Our members

loved exploring the butterfly house to see how many different kinds of butterflies they could see. We took some respite in the Avoca cafe to dry off and when we finished our well needed cocoa and coffee the rain had

finally stopped so we could go on a fairy hunt! There certainly was some magic in the air



## Notice of Weekend Away and AGM

Linda Kane

**SAVE THE DATE!!!!** WSI's Annual Weekend Away is taking place Friday 24th February until Sunday 26th February.

During this weekend we will also hold our AGM.

We are delighted to announce our weekend away will be held in the beautiful Amber Springs Hotel, Gorey, Co Wexford.

This hotel holds a whole range of facilities and amenities which we are delighted to be able to offer our members! Go Karting, Archery or Mini Golf anyone? They also have an extensive kids club with play zone AND THEIR OWN CINEMA!!!!

I will be updating with further details regarding room prices and events a little closer to the

time but if you would like to register your interest to book your place please let me know via email  
[info@williamssyndrome.ie](mailto:info@williamssyndrome.ie)

## Over 18s Go to Town

Phil O'Hagan

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**"The show was fantastic with almost continuous song and dance numbers which naturally kept our audience very happy indeed"**

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We were delighted to get our events programme for adults with WS underway in early August of this year. Our inaugural event was held in Dublin where a group of us attended the musical show Joseph and His Amazing Technicolour Dreamcoat at the Bord Gas Energy Theatre. The show was fantastic with almost continuous song and dance numbers which naturally kept our audience very happy indeed.

After the show we walked a

short distance to the MV Cill Airne which is a shio on the river Liffey which now operates as a bar and restaurant. The forward section of the restaurant was reserved for our party which meant it was very easy for us to move around and circulate and enjoy the craic with their friends.

We were delighted to welcome Molly Gillespie and her mother Loraine who were attending a WSI event for the first time. Molly is a fantastic addition to the gang and we look forward to meeting up with her and her family soon again.

We were delighted to be able to arrange what will be the first many days for our WS adults and their families. The feedback from the event was very positive and many of the attendees will really appreciate

meeting up with their friends on a regular basis into 2023.

Our next outing for the gang is our first WS Adults Christmas Party which will be held on the 10th of December in the Greenhills Hotel and Leisure Centre, Limerick. If you are over 18 we do hope that you have booked your place for the party. The event will feature dinner in the hotel followed by plenty of song and dance into the early hours. So get your dancing shoes ready!

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**"Our next outing for the gang is our first WS Adults Christmas Party which will be held in the xxxx Hotel in Limerick on December. "**

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## Picnic in Clonfert Pet Farm

Linda Kane

Once again WSI was delighted to be able to put on our Annual Picnic in Clonfert Pet Farm in Kildare which was held in May of this year. This is always a very popular event and 2022 was no exception with many families attending where everyone young and old had a very

enjoyable day. Once again we were fortunate with the weather with the sun shining throughout the day.

Having our own dedicated space within the pet farm provided plenty of opportunity for families and the young and not so young to mingle,

exchange experiences and enjoy the fun. We were also delighted to welcome little Leon and his parents from Ukraine who had recently joined WSI having relocated from Kiev.



## WSI Survey—Understanding Your Needs

Stephen Langton

To coincide with Williams Syndrome Awareness Day we were very pleased to announce that the consultancy company Seven Psychology at Work would carry out a member survey on behalf of the WSI Committee.

Williams Syndrome Ireland is a charity and a community dear to SEVEN's hearts. In 2021, the company agreed a partnership to support the work of WSI going forward. The initial step on this partnership was to develop a survey to support the gathering and analysis of members requirements. This survey was titled "WSI Understanding Your Needs".

On behalf of the Committee I would like to thank everyone who took the time to contribute their feedback. The completion rate was almost 50% and we received feedback from all parts of the country which was excellent. The results provide us with a very clear picture of your

views and requirements and we hope to input this feedback into our planning going forward. As a starting point we hope to present the detailed findings of the Survey at our next AGM. I would like to sincerely thank Johanna Fullerton and the team at Seven for the tremendous

support.

We very much appreciate your input to improve our support going forward and we hope that the results of this survey provide a good start to planning the next stage of WSI.

I would also like to encourage anyone who may have additional feedback or comments to get in touch with us. If you have any fundraising ideas or if you would consider getting involved with the committee or focus groups then please contact the association

### SUMMARY: SURVEY RESPONDENTS-DEMOGRAPHICS



#### SOCIAL SUPPORT

- VALUED MOST OVERALL.
- INCREASED FREQUENCY OF EVENTS.
- SUPPORT SHOULD EXTEND TO PARENTS/ GUARDIANS AND SIBLINGS.
- EVENTS SHOULD BE AGE APPROPRIATE E.G., CONCERTS AND DISCOS FOR ADULTS.
- MORE LOCALISED EVENTS/ DIVERSE LOCATION OF EVENTS.

#### ESSENTIAL SKILLS TRAINING

- GUIDANCE ON TRANSITION TO SECONDARY SCHOOL.
- CONFIDENCE BUILDING.
- SUPPORT FOR INDEPENDENT LIVING.
- VOCATIONAL SKILLS TRAINING.
- EMOTIONAL SUPPORTS E.G., HOW TO COPE WITH ANXIETY.

#### HEALTHCARE SUPPORT

- INCREASED HEALTHCARE NEEDED SUPPORT ACROSS ALL DISCIPLINES E.G., PHYSICAL & PSYCHOLOGICAL.

#### INCREASED COMMUNICATION

- REGULAR UPDATES ON FACEBOOK PAGE.
- SET UP A WHATSAPP GROUP FOR WSI MEMBERS.

### Summary of the Seven WSI Survey 2022



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*Williams Syndrome Ireland ( WSI ) was founded in 1987. Its mission is to promote the general welfare of individuals with Williams Syndrome, to provide practical help and support to them and their families and to enable them to reach their full potential through their strengths and interests*

*WSI provides support and advice on Williams Syndrome to individuals and families affected by WS. We enable individuals, families and professionals to make contact with other people affected by WS and who have already experienced the many challenges posed by WS. Annually WSI organizes a range of events for our members and they can use these events to tap into the knowledge and experience for every stage of a person's development*

**Together we can make a massive difference!**