

WSAI News



Volume 21, Issue 2, Autumn 2016

Meeting the President

Rebecca Conroy

Hi Everyone, Rebecca here!

This is my account of my day at the Aras on Sunday 18th June:

I was at a family wedding and I was talking to a friend of the family and I said that I played the bodhran for Michael D Higgins. He said he knew the President and asked me if I would you like to go to the Aras for a family day to meet him and his wife Sabina. A while later we met again and he said he was working on it but finally we got invited to go to the Aras.

On the 18th of June me and my mam got ready to go to the Aras and we dressed up and then we went to meet Don the family friend and we got our tickets for the visit. We waited outside for the bus to take us in the Aras. Everyone had dressed up for the event but it was raining. When the bus came we gave our tickets and we were driven to the Aras. When we arrived we were met by Sabina. She was so welcoming and warm to us all. So we took off our coats to go out to the garden and we got our menus for the tea. Then we met so many

people at the event. We were given poncho jackets for the rain and there were entertainers and great music and people on stilts. We walked around the garden and it was so beautiful except for the rain. There was also a green house with trees and plants. Then we went to the marquee to have our tea and we went to a table and we got tea and coffee and sandwiches and small cakes and buns. Then Michael and Sabina came in and Michael made a speech and he spoke very well. We met the McCabe family, from Co. Louth, who we had already met at the WSAI weekend in Waterford and we all sat together at the event. After the speech there was entertainment and music. Unfortunately no one was allowed to go up to the President. Then a while later we danced to the music and Sabina got up to danced with us and she's a great dancer. After that me and Eoghan McCabe were talking with Sabina. We asked could we



Rebecca and Eoghan with the President

get a picture with Michael D and she said that we could go up to the President. So Eoghan and me went up to get the picture with the President. There was strict security so we had to get the photos done quick. The host of the show was Eoghan Mc Dermott from the Voice program and we also saw Bressies band playing. Then at 5 o'clock it was all over and we clapped for Michael and Sabina as they left the marquee. At the very end Sabina and Michael got photos taken and the rain came back as they went back inside.

It was a day I will always remember. The food and music and all was great. I felt very important to the world then. It was the best day of my life.

Thanks from Rebecca

Thanks also to Linda McCabe for the great photos.

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Rebecca and Eoghan with Sabina Higgins

WSAI Contact Details

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

Phone: 090 964 3247

E-mail: wsai@eircom.net

Music/Activity Camp 2016

Carmel Daly

Camp 2016 was held from 31st July to 6th August 2016 and what a week had. All agreed that it was the best camp ever, albeit we say that every year! As usual, it was filled with fun, music, friendship, tears, laughs, yawns and emotion. We're all exhausted after it, physically and emotionally, but will remember it fondly.

This year we had 16 WS campers in attendance, 3 of which were international, Bernardo from Italy, Rosie from UK and Nicolas from France. 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.

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, packing and getting everyone settled into their chalets. It was hard to get much done with the intermittent arrival of another "old" friend not seen since last year. Hugs and kisses were in no short supply. After dinner we got to meet everyone properly and to introduce new volunteers and campers.

Each day began with breakfast at 8am. Music classes began at 9.30; each camper had 3 lessons in instruments such as piano, voice, violin, drums, guitar, concertina, tin whistle, percussion and drama. This was followed by a break for snacks and then a group session where rehearsals for the end of week show were held and this brought us up to lunch at 1pm.

After lunch there was a variety of outdoor activities, or indoors if weather required it. We had foosball, circus skills, wall climbing, art and crafts,, a cruise on the lake and a shopping trip – hard to believe we fitted so much in.

Evening entertainment included a disco, band-night, sing-songs and cinema night. On the Thursday night we had a special performance by the campers where they each provided a rendition of something that they had learned at their classes during the morning sessions. They were all amazing, such talent.

During the week we also fitted in other activities such as relaxation and mindfulness, facilitated by Fionnuala, a, pyjama party, beauty salon, tattoo parlour, and of course lots of tea and chats and laughs. During all this time there were costumes to make, sets to design and paint and practicing to be done. I'm exhausted again just thinking about it all...

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 for the pre-show barbeque. It was a resounding success. With its usual individuality and flair and a touch of poetic licence "Into the Woods" was performed WS style. It was brilliant. Each camper got to perform centre stage and the talent was amazing. Thanks in particular to Sarah Corcoran, Musical Director extraordinaire and Aoife Gibney, singing teacher and choreographer. Thanks also to the terrific band and to Sean Walsh who helped with staging and to Nicci Daly for her lead on the artwork for the sets.



Some of the Cast in Camp 2016: (Clockwise) Annmarie, Nicholas, Padhraic, Jarlath, Hannah, Corey and Ann

I 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. Can't wait to see you all again next year.

Finally, I want to say a huge Thank You to our wonderful volunteers. Each year we get a very high calibre of young people who are willing to take a week of their valuable time to come and help out at the camp. The standard is always high and, really, we cannot operate without them. This year, we had quite a few new, young volunteers and they were exceptional. Indeed all our volunteers outdid themselves this year and made us proud.

All I can say is a Huge THANK YOU to each and everyone of you!

Next year's camp has been booked for the week of 6th to 11th August 2017. I look forward to welcoming back our usual campers and would encourage any of you who have yet to take part to do so. It really is an enriching experience. We also welcome visitors during the week to come and see what we are about or if a WS person wants to stay for 1 or 2 nights only that could be arranged also.

Roll on Camp 2017!!!

Carmel Daly



Alex and Adrienne Enjoying Camp 2016

My Trip To Norway

Jarlath Tynan



Jarlath Enjoying the Magnificent Fjords

On the 12th of August me and my sister went all the way to Norway to visit my other sister Eimear. Beforehand I was a bit apprehensive because it would be two flights: Dublin to Oslo then Oslo to Tromso. I normally don't like flying but it was the only way to get from A to B.

When I got to Dublin airport I took a few sweets with me and I felt better. I had a big Irish breakfast after we had checked in. On the flight I ate more sweets and I played with my iPad. After the two flights I felt better, I was excited.

Eimear met us at the airport. I had missed her. I felt it was only yesterday when I had met her. They drive on the opposite side of the road in Norway. I saw some golden oldies cars. We had a whale of a time. We stayed in her apartment for five days. It was great to see all the views. From her apartment I could see the beach and kids playing on the beach. It was bright all day. It felt weird. We were not allowed to wear shoes in Eimear's apartment so I went around in my socks or bare feet. We went places such as taking walks into Tromso and walking along the coast, we went for a



Jarlath and Eimear

drive to see the mountains and the glaciers. My favourite part was being the co-pilot in the car! Norway felt like home.

In Norway there are lots of cruise ships because there is a big coast and lots of fjords. We decided to go on one of the cruise ships for a look. We forgot to bring our passports on the cruise ship but they let us on anyway. On the ship we had coffee, we had a look at all the different decks and myself and Eimear sat

outside and chilled out while Fionnuala made a jigsaw inside. The cruise ship was quiet at the time because the passengers had gone into Tromso.

I felt mighty going home because I had nothing to fear but fear itself. Now I feel much better about flying than I did. My plans are to go to London in October, Norway again in January and to Australia in July and we'll do a cruise in 2018. I feel much better because I am more safe than ever before and on boats. Then after the five days were up we went home.

WSA Charity Blitz

Debbie Brannigan

On the 10th of September I was so proud to be a part of a club and to be from Finglas. On this day the Erins Isle gaelic for mothers & others organised a charity Blitz in the club. This year the Tadhg Ui Fainin Foundation in partnership with the WSAI was the chosen charity. The day started off at 12 O'clock with the Finglas Marching band opening the competition. 11 teams competed from all over Dublin. While the competition was on there was a cake sale, raffle, face painting & toy sale in the club hall.

Donations came from everywhere. There was



Kelsey and Cian Pictured at the Blitz

great excitement throughout the club. Tremendous awareness was made about Williams Syndrome. Cian & Kelsey were the WSAI ambassadors on the day and great fuss was made of them in the club.

In total we raised €4350 on the day. I would like to thank The Tadhg Ui Fainin Foundation, Kariann Fannin, Lorraine Fitzgerald and all the mothers team (mothers & others), visiting teams, Erins Isle GAA club, Volunteers, all that donated prizes and all who baked and to all the club members. The Blitz was a huge success, with Erins Isle winning the Tadhg Cup.

I hope to see you all at the Stars in Tadhg's Eyes being held in the Helix (DCU) on 26th November. Tickets on sale from Debbie €20 each. Kelsey Brannigan, Niamh Keirnan, Aoife & Sarah Corcoran will be representing the WSAI. If you are unable to attend you might like to sponsor the girls. They have to raise €300 each and sell 20 tickets each.

Finally a big thankyou to the Tadhg Ui Fainin for picking WSAI as their charity for this year and helping us raise awareness for Williams Syndrome.

Keeping Ireland Alive

Alan Keady



Alan with Rebecca and Fiona at the Recent FEWS Camp in Limerick

My Name Is Alan Keady and i am a service user with Ability West. I attend respite services one or two days a month where I go to a house after work and stay overnight. Sometimes I stay for one night or I might get two together.

I enjoy this as i spend time with my friends and get to do bowling, go to the cinema or a show.

When I am in respite my Mom can go away with her friends for a relaxing time or go out and not have to worry about me being at home on my own. Its just me and Mom who live at home now.

One of the staff from the respite services of Ability West rang my Mom at the beginning of May to ask if we would take part in a documentary bout the HSE West. They are the people that give money to Ability West to part fund the Respite. I have to pay 12.50 euro from my Disability Allowance for each night I stay.

They said that a film crew would call to our house on May 31st to film me at home preparing to get ready for respite. They also spoke to Mom about what she would do when I was away. They filmed me getting on my bus to take me to Blue Teapot and also on the way home to take me to the respite house. They were two brothers who came to film and the worked for RTE. They had a lot of expensive cameras and recorders. They said if I was ever in Dublin to ring them and they would bring me into the RTE studio and show

me around. We also were filmed helping to cook dinner in the Respite house and I decided that after dinner we would go to the local hotel the Clayton to have a drink. They came with the group also. The lads were talking to my Mom at home about the services provided for people with disabilities.

I asked them if we could get tickets to The Late Late Show. They gave me the name and contact of the researcher with Ryan Turbridy. My Mom is going to ring her. I would love to be at one of the shows.

I enjoyed filming with the crew- we had to be serious during filming but had a good laugh when it was finished. I am glad I did it and I didn't mind talking on camera.

The producer of the show rang Mom in the middle of August to say the series was commencing on Monday 29th August '@ 9.35 pm.

It was titled Keeping Ireland Alive 24 Hours of the work of the HSE in Ireland.

I was so excited and texted lots of my family and friends. Mom and I watched it at home and we were delighted to see us on TV. I got lots of phone calls to say i was brilliant on TV. Some people asked me for my autograph and people stopped to say well done.

I am happy with the whole thing.

Alan

Report on WSAI Weekend Break Carmel Daly

This year's annual weekend family get-together held in Waterford on the weekend of 29th April to 2nd May. The venue for the get together was The Tower Hotel and Leisure Centre, Waterford.

The get together was very well attended with around twenty families attending and in all around sixty people attended at some stage over the long weekend.

The annual weekend outing provides a great opportunity for individuals and families of WS people to get together, socialise and swap experiences and this weekend proved no exception. It was especially nice to see some new families attending as this event provides a useful introduction to WSAI 'family'.

As usual the weekend was punctuated by our usual programme of events and our thanks to Ger Leahy organising our annual ten pin bowling 'competition', Highlight of the weekend was the beautiful river cruise on the River Barrow starting off in New Ross. We had a short bus trip to New Ross before boarding the Galley Cruiser for our trip north along the river Barrow. On board we were served afternoon tea by the ships crew who could have been more friendly.

By all accounts everyone enjoyed the weekend and if you have not already attended a weekend break we recommend that you keep an eye out for next years event which will be advertised in the Spring edition of the Newsletter



Sing Song on the Barrow Cruise

My Trip to FEWS Camp at UL Cara Harte

Hi My name is Cara Harte. I am 20 years old and come from Skibbereen in West Cork .I was a very lucky lady this year as I got to go to FEWS Camp in July at UL. (University of Limerick).

I was a bit nervous about going .It was my first time away from home for a full week. I missed my family ,but I was very busy with all my other friends from the William's association of Ireland . I met loads of new friends from the different countries . we did lots of music , singing and dance . We also played football and hurling we went on a day trip to the cliffs of Moher and Bunratty Castle. My favourite part was when the Irish team Alan Donal Rebecca , Jarlath, Karen, Niamh and Michael and myself Cara were all hanging out at our



Cara and Friends at the FEWS Camp in Limerick

apartment having the crack . Michael and Niamh were my leaders and they were very kind to me .I had the best week of my life , when I came home I said thanks to my mother for bringing me to Limerick.

Thanks to the William Syndrome Association of Ireland for holding the camp .

On Stage in JJ's Jazz and Blues Club Patricia Moylan

Hello all,

This is Patricia with a short story about singing with Honor Heffernan. . At the end of June my Dad and I were invited to visit the Dail and take part in the publicity launch for the FEWS Camp. At the launch we met the famous Jazz singer Honor Heffernan and my Dad told her that I really liked Jazz music. Honor said that she was doing a gig in JJ Smyths in July and she asked me if I would like to come along. So my Dad and I were invited to attend the JJ Smyth's Jazz and Blues Club as Honor's guests.

The gig was on a Sunday afternoon in July and featured Honor and Trevor Knight and the band. The show was called The Whistling Girl and the songs were based on the poetry of Dorothy Parker and the music was composed by Trevor.

I really enjoyed the show which was cabaret format so that we sat at a table in JJs bar and chatted to some friends of Honor's during breaks in the music.

But the best thing happened at the end of the show when Honor invited me up on stage to sing with her for the last song. At the beginning it was hard because I did not know the words but I quickly learned the chorus and joined in and had lots of fun. After we finished we got huge applause from the crowd and I really enjoyed the whole experience.

Honor and Trevor were so friendly and it was very nice of them to invite us to the show. I am looking out for their next gig.



Patricia on Stage with Hon or Heffernan

Inaugural WSAI Youth Camp Deirdre Graham

As we all know anxiety can be one of the most debilitating result of Williams Syndrome for our young children. There are techniques and tools that can help to reduce and in some instances alleviate the symptoms of anxiety.

The annual music camp run by the WSAI offers our older children an outlet to befriend and network with others, who truly understand them, in a safe and comfortable environment. But what about our younger children? Next Spring we aim to hold the first WSAI youth camp. It will be aimed at infants, toddlers, pre-school and school going children up to 14 years.

It will be a day camp, held in Athlone to allow equal access for families from all over Ireland. We aim to hold workshops on relaxation techniques and tools to reduce anxiety in our young WS children. There will also be music workshops. Most importantly it will be a chance for families to meet and network and learn from each other! It will be on a Saturday from 11am – 15.00hrs approx.

We will have more details in the new year, so watch this space! If people are interested and can help and contribute, let us know at the annual AGM in November.

Note: WSAI held the FEWS Camp in the University of Limerick in July and this involved campers from all over Europe. The Camp was a huge success and we hope to have a full report on the Camp in the next issue.

Picnic in the Park

Carmel Daly

This years Picnic in the Park was held in Newbridge House and Farm, Donabate, North Dublin. The Picnic was held on the 16th of June. If the sun shone down in Tayto Park last year unfortunately the same could not be said for this year. On the morning of the Picnic the heavens opened and it rained and rained and rained. Incredibly in spite of the weather many brave families ignored the weather and helped make the day an enjoyable day. OK, we didn't quite manage the planned barbeque but with the help of the Newbridge House staff the barbeque was delivered to us in the room provided. We all chatted and laughed while eating burgers, chicken nuggets and chips with copious amount of soft drinks and sweets for desert.

It was particularly great to see a large contingent of members from north of the border who arrived at the picnic on a bus organised by Angela Davis, Thanks Angela

The farm had a fantastic range of animals on display and it was possible to get up close to interact with the animals which was great for our younger members even the rain made it a challenge at times.

In spite of the weather everyone enjoyed the somewhat curtailed event and lets hope for better weather for Picnic 2017!!

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



Alice at the Picnic at Newbridge House

My 21st Birthday Party

Annmarie Leahy

Hi everyone,

I turned 21 on the 9th of August and had my party on the 20th of August. I had such an amazing day as a lot of my friends and family were at the party. My friends from gymnastics and swimming came also friends from the BTC came. Even more so a lot of my Williams family made the trip to Cork to attend my party and I was so happy. I had an amazing night dancing with my friends and taking pictures.

I even kept the party going until the early hours of the morning. I also want to thank all my Williams family for not only making the trip down but for the wonderful cards and presents and the amazing memories. I'm so glad everyone had a good time and want to thank my Mam for putting it altogether.



The Belle of the Ball

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:

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

Phone: 090 964 3247

E-mail: wsai@eircom.net