

WSAI News

August 2014

Music/Activity Camp 2014

For some of our WS people, the annual Music/Activity Camp is the highlight of their year and this year was no exception. This year's camp was held from 3rd to 10th August 2014 and we had a record attendance. All agreed that it was the best camp ever. New friends were made, lots of music played, fun and games and, of course dancing til our feet hurt. We're all exhausted after it but will remember it fondly.

In addition to our own 17 Irish WS campers, we had 8 international attendees this year. Five travelled from Italy, one from France, one from Holland and, of course our Rosie from UK. 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. I know that they will all keep in touch, at least on facebook. "Au Revoir", "Ciao" and "Tot Ziens", we hope to see each of you again soon.

The camp began on Sunday 3rd August. We arrived to a hive of activity, as each camper and volunteer arrived 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. Of course, as is the usual with WS people, after a very short time there were no strangers, only the best of friends. We soon got to know everyone even better with the traditional first night sing song.

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, 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, archery, wall climbing, nature trail, a cruise on the lake and a shopping trip – hard to believe we fitted so much in.

Evening entertainment included a disco, band-night and cinema night. We were also entertained with a very funny helpers show, their take on the 'Late Late Toy Show'. The campers performed for us on the Thursday night 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, courtesy of Nuala and Helen, a cocktail (or mock-tail) evening, pyjama party, beauty salon, tattoo parlour, and of course lots of tea and chats and laughs in chalet 13. 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 barbeque and, of course, the show. It was a resounding success. With its usual individuality and flair and a touch of poetic licence Toy Story was brought to life, literally. It was brilliant. Each camper got to perform center stage and the talent was amazing.

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.

What can I say about the 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, all our volunteers outdid themselves. They were hardworking, generous, inclusive, committed, talented, helpful... the list goes on. 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 2nd to 9th August 2015.

Roll on Camp 2015!!!



Social Events	2
Fundraising	3
Education	4
Medical	5
Points of Interest	6



Family Weekend

Our annual weekend away was held at Newpark Hotel in Kilkenny on the 4th-6th April, this is a great opportunity for younger families to meet each other. This fabulous hotel sat on acres of beautiful woodland, has a petting farm and was a perfect location for our weekend. We had our usual bowling with medals. Thanks to Gerard Leahy a wonderful dinner on the Saturday night and a fabulous time was had by all. Thanks to Debbie Brammigam for organising this.



Picnic in the Park

The annual WS Picnic in the Park was organised for Sunday 29 June. It took place in Tayto Park. There was a record number of people there, including many of our new families who we were delighted to see. There were also relations of different WS individuals who added to the craic on the day. Tayto Park had something for everyone. The weather was glorious which meant we could all eat at the picnic benches and take time to catch up with one another. There was a pet farm, a magic show, rides, walks, the crisp factory, the gardens and the activities for the seriously adventurous!! Thank you to everyone who came, particularly those who travelled long distances to be there. A special word of thanks to Debbie Brannigan who, once again, organised this event flawlessly.



Ireland Games

The day has come for the Athletes to travel from all over Ireland to Limerick to take part in the Special Olympics Ireland Games. Everyone got ready for the opening ceremony, the athletes marched through the streets of Limerick to the Peoples Park everybody was cheering the Athletes on as they passed by. The excitement on the athletes faces when family and friends were calling out to them, they were so happy to be part of the games. The opening ceremony was -



electric the excitement and joy on everyone's faces when they saw the street performers , singers and dancers put on their show. There was 2 Hrs of dancing and singing where the athletes were doing most of it, they were sad when the show came to an end, but couldn't wait for the games to start on the Friday Padraig, Donal, Ashleigh and Annmarie enjoyed the opening ceremony they were so happy to see each other and wished each other the best . Padraig was participated in pitch & put . Donal was taken part in the athletics. Annmarie & Ashleigh were taken part in the gymnastics Ashleigh in Rhythmic , Annmarie in Artistic Competition. I was head coach for Rhythmic I was with Ashleigh for the competition but I could only get to see a few of Annmarie's routines. All of our Williams athletes met most days at dinner then it was on to the disco to catch up with everybody else dancing and singing but most of all to see how everyone was getting on and if they were enjoying themselves . This was the scene every night

The time was drawing closer to an end when you heard the announcement for The Awards Event. Everyone was waiting with excitement , when they heard their name been called it was made their day, was it going to be a Ribbon or a Medal. looking to see what number they were going to be placed by the joy the excitement its number ONE screams of joy I got gold . After the awards the Closing Ceremonies took place at each event.

Everybody was dancing to the music with balloons falling down around them tears in their eyes, It made them sad to say goodbye to all their friends old and new friends that they made over the weekend. The four days went by so fast and everyone was sad to go home but they had a great time and enjoyed themselves at the games in Limerick

Pauline Leahy

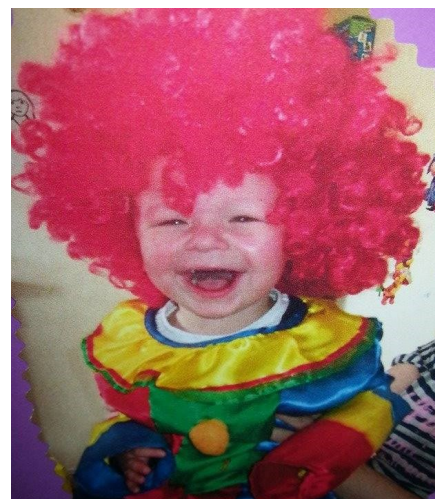
Fundraising

50 Mile Run

Kieran Savage from Dublin (Fiona's Brother) is supporting WSAI by taking part in the Dingle Ultra Marathon on 6th September To sponsor Kieran go to www.sponsor.ie

Hell & Back

Mikey McMahon (Robbie's brother) is taking part in Hell & Back (Ireland's toughest challenge) which is a 12 k assault course. You might remember Mikey gave a presentation on this at last year AGM. Sponsor Mikey on www.sponsor.ie



Robbie McMahon

Parachute jump

Thank you to our two teams who took to the skies for a charity skydive we had a team in Ireland and another team in England via Ms Kirsty Grainy Together they managed to raise a £3,500 Well done!!!!



Midsummer Melodies Concert

Massive well done to Jarlaith for his performance in his fourth annual Midsummer Melodies concert in aid of WSAI. He sang a song and conducted the Radetsky March played by the Mayo concert Orchestra. The concert raised 520euros. This event should definitely be put in your diary for next year folks it is an magical experience in the most beautiful venue. Jarlaith's singing is not too bad either!!!! lol



If you are thinking of raising money on behalf of the WSAI have you thought about setting up your own fundraising page on www.sponsor.ie. Its simple, fast and totally secure. Once you donate they send the money directly to the charity and make sure any Gift Aid is reclaimed on eligible donations.

Education

Teacher Support Group Meeting

On Saturday 17 May there was a first support-group meeting for teachers of children with WS who are in primary school or special schools. It was a great afternoon, attended by both teachers and SNAs. The feedback was very positive and this will now be an annual event. The participants really enjoyed hearing the stories of other children with WS from one another and sorting out aspects of the child's profile that were specifically Williams-related and those that were just part of the child's personality. I made a number of specific presentations on the day:

- Accommodating the WS educational profile in the classroom
- Dealing with distractibility and other behavioural issues in WS
- Dealing with motor-skill challenges
- Developing literacy in learners with WS

These presentations and a number of academic articles and teaching resources were also made available to the participants and put on memory keys.

These included:





Anxiety and mood problems in people with WS

Drawing the line: Drawing and construction strategies for simple and complex figures in Williams syndrome and typical development

Honing in on the social phenotype in Williams syndrome: Using multiple measures and multiple raters

Language and literacy development of children with WS

Learning to read in WS: Looking beneath the surface of atypical reading development

A longitudinal study of cognitive abilities in WS

Music and Minds: Using a talent development approach for young adults with WS

The neurocognitive profile of WS: A complex pattern of strengths and weaknesses

Psychopathological and behaviour impairments in Williams-Beuren syndrome: the influence of gender, chronological age and cognition

Developing a balanced reading programme for teaching a child with WS

Research review: Williams syndrome: a critical review of the cognitive, behavioural and neuroanatomical phenotype

Attention Deficit/Hyperactivity Disorder and WS: shared behavioural and neuropsychological profiles

Anxiety and repetitive behaviours in Autism spectrum disorders and WS: A cross-syndrome comparison

Teaching creative dramatics to young adults with WS

WSA information for teachers (from the American association)

If any of you are interested in these articles or if your child's teacher wants copies let me know and I can email them on. You should be aware that they are of an academic nature and the vast majority don't give a lot of practical advice. I hope in the coming few months to produce our own teacher guidelines which are relevant for the Irish educational system based on the research done with Irish children with WS, their parents, teachers and SNAs.

If you have any queries about your child's education (from age 0-18) or if your child's teacher is seeking support or advice, please contact me: 086-2063773 or fionnuala_tynan@eircom.net

NCSE

NEW NCSE Information Booklet on Post School Options for Adults and School Leavers with Disabilities in Education and Training. NCSE has now published on our web-site an Information Booklet on Post School Options for Adults and School Leavers with Disabilities in Education and Training.

<http://www.ncse.ie/uploads/1/NCSE-Post-School-Education--Training.pdf>

This information is based on families in Southern Ireland, but some information could be helpful to families in the North

Medical

Medical Card Submission

Fionnuala Tynan has done a submission for a medical card consultation on behalf of people with Williams Syndrome. It outlines all the different aspects of what can be a problem for some or all of our Williams Syndrome people. If you would like to see this submission please don't hesitate to contact the association.

International Professional WS Conference

the International Professional WS Conference that is being organised by FEWS will go ahead on weekend of the 21st to 23rd November 2014. It will be held in Budapest in Hungary. The idea of the conference is to bring information on WS to the countries that do not have the research facilities, etc. that are available in the other parts of the world. Therefore, the concentration for this conference is on educating the professionals in Hungary, Romania, Slovakia, Czech Republic and Poland. We are also hoping for participation from Bulgaria, Serbia, Russia, Ukraine. Experts on WS will be brought from other countries e.g. France, UK, Germany, etc to give presentations to professional participants at the conference. Areas to be covered will include Paediatrics, Genetics, Education, Cardiology, Psychology, etc. Ann Breen & Fionnuala Tynan will be attending the conference and will keep us informed on international matters.



Points of Interest/Interesting Links

This is the most wonderful clip of a child with WS. It's the singer Taylor Swift who calls into a hospital in Boston to see a little six-year old boy called Jordan who has WS and has recently been diagnosed with leukemia. I cry every-time I watch this. Little Jordan is just so like our people with WS at that age, he's full of the joys, his social skills are fantastic and he just can't help himself moving to the music! The link to this clip is <http://www.breakingnews.ie/showbiz/watch-taylor-swift-serenades-little-boy-fighting-cancer-638283.html#.U-Dc8B3diQo.mailto>

If the link doesn't work just google Taylor Swift and Williams Syndrome. Enjoy



This might be of interest!

https://www.youtube.com/watch?v=R_Go2HYotO0

It's a trailer for a French-Canadian movie called Gabrielle. It's about a young woman with Williams Syndrome who joins a choir and falls in love.

Mary Hanley Shared this link on Facebook.

The Interplay between anxiety & Social Functioning in Williams Syndrome

https://www.facebook.com/n/?mimhanley/posts/10152107583587690&medium=email&mid=9aad375G5af33abb9117G0G109G3986643e&bcode=1.1396758087.Abl5e2ojM_kjz8Cr&n_m=fionnuala_tynan%40eircom.net

If you have any news, any celebrations please send a letter or Email to me. Also, Feel free to phone and I can write the article from what you say.

Contact Details

Angela Davis

319 Ballysillan Road Belfast, BT14 6RD

Tel: +44 (28) 90504173

Mob: 07871904726

Email: justangela2007@hotmail.co.uk

