WSAI News

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Special Olympics, LA Games 2015

Ashleigh O'Hagan

Congratulations to our one and only Ashleigh O'Hagan who recently competed in the Special Olympics in LA and won 2 bronze and three placements medals for Rhythmic Gymnastics in the World Olympic Games . She's been mixing with the stars, has become a media star herself and a great ambassador for Williams Syndrome and the Special Olympics.

As you may know we have been tracking Ashleigh's wonderful adventure in the Special Olympics and in this issue Ashleigh reports on her wonderful experience in LA the home of the stars.

Ashleigh, right with her two bronze medals at the John Wooden Centre, UCLA with Kirsty Devlin from Belfast, who won two gold and two silver medals, in gymnastics

Hi Everybody,

I am just about recovered from my trip to the world games in Los Angeles with Team Ireland, it only took me 12 days of sleep to get over the jet lag!!

We left Ireland on the 22nd of July and hit for New York where we had a stop over and had to get our connecting flight to L.A. The buzz leaving the airport was fantastic what with all the media and reporters interviewing us and wishing us all the best of luck.

We had 4 days rest and fun in the host town of Downey in Los Angeles where we partied and got used to the heat, it was lovely and warm every day. The American host town really went all out to welcome us all. There were bands out on the streets playing music and lots of the residents were out applauding us and singing and dancing and they even treated us to barbecues each night, it was great fun. Then after those few days we were all ready for the week ahead.

I competed in 4 events during the games, Ribbon, Ball, Hoop and Rope. There were so many brilliant gymnasts from all around the world taking part in the competition. The standard was really high. I competed against Estonia, Peru,, Russia Poland, the U.K. Portugal and of course the USA but I kept my cool and gave it my all.

I am delighted to report that I also met a girl who was competing in the artistic gymnastics who is American and who also has William Syndrome. She had a young man there supporting her who is also gifted with Williams Syndrome, Two more new friends joined up now (Thanks Facebook).

Team Ireland competed in 12 events and brought home 123 medals in total 26 gold 28 silver 28 bronze and 41 world game placements medals which is quite a victory, I think

When the day came for the awarding of the medals I was so excited I thought my heart was going to burst, I couldn't believe it when I won 2 Bronze and three placements medals in the World Olympics Games The entire experience is still like a dream to me.

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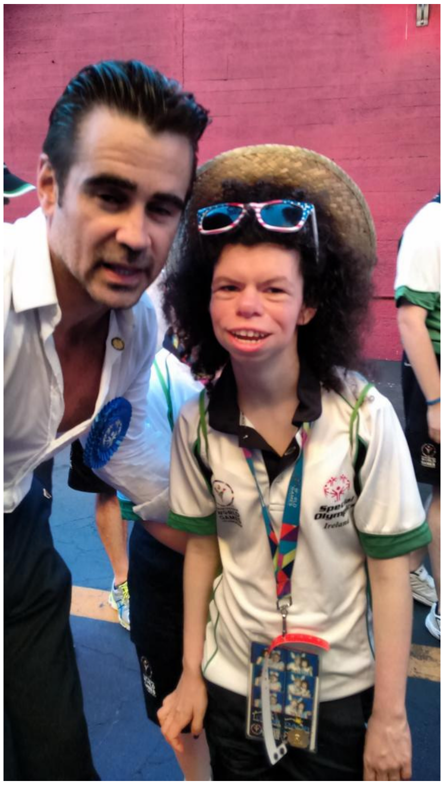
Special Olympics, LA Games 2015 (Contd)

Ashleigh O'Hagan



Ashleigh, posed with Hollywood A-lister Colin Farrell for a photograph at the opening ceremony of the Games.

After I won the medals I remained on campus to watch and support all my teammates who were taking part in their events, we all really supported each other all week, volunteers, coaches, families and the crew that travelled all the way from Cork to wave the Irish flags for us every day in L.A. really topped off the entire experience.

There were a few other famous people that wanted to have selfies with me to name but a few Nicole Scherzinger, Colin Farrell and my mom!!

We received a great welcome in Dublin airport on the 3rd of August when we returned home, I couldn't believe the amount of people who knew my name from seeing me on the Miriam O'Callaghan show and on RTE news.

Going to America was definitely a great achievement for me and although I was with the whole team I was also an adult that had my own independence and it was wonderful to taste the sweetness of the success!

I now hope that people will begin to recognize that we are people that have a different ability rather than people with a disability.

I must also pass on my apologies for not attending the music camp this year I was hoping to make the show on Saturday night but I seen from the pictures a good time was had by all. Any of ye that know me will know I went straight to bed when I got home from the airport and slept for quite a few days!!

Thank you all so much for all your continued support. There are no words to describe the whole experience, it was all so so amazing.

All the best and I hope to see ye all soon and remember what I said, "Keep going, think of the big dream and just let it happen, Anything is possible if we keep trying.

Lots of love,

Ashleigh

Lotto Funding

Carmel Daly

WSAI have now submitted an application for Lotto Funding. We were successful in our application for funding two years ago and it is this funding which has allowed us to continue to run our Music Camp and increase the number of campers attending.

If you would like to support this application we invite you to lobby your local TDs or alternatively the Minister who will be making the decision: Mr Leo Varadker, Minister for Health. If you like more information on this application please contact Carmel Daly or Ann Breen.

Annual General Meeting 2015

Carmel Daly

This year's AGM will be held, as usual, in the Spa Hotel, Lucan on Saturday 7th November 2015.

I hope that you can all come. We will try to make it as interesting and informative as possible for you. I'll be writing to you all with full details.

It's a great opportunity to meet other families, to catch up on how other WS people are getting on, to discuss issues etc. but most of all just to have a friendly chat.

This year we hope to have some guest speakers. Subjects that we have considered as being of interest are "Making a Will" and "WS medical issues – what should be checked regularly" but I would very much welcome your own suggestions and we will see if we can arrange it.

Suggestions by email, writing or text:-

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The School Marathon

Deirdre Graham

The first question I had asked that beautiful summer afternoon in the paediatrician's office was "will he be able to go to school?" Up until then this had been a given, naturally our children would go to school, experience the same innocent joy as we had done, similar battles with English, Maths and the dreaded "mo coneelach" (still can't spell it, never mind apply it!). But these expectations had apparently been snapped away by a diagnosis of WS. However the dream lingered and when he reached the appropriate age we began searching for the right pre-school for Ed. I had researched a little, and hoped a lot, looking for the right place. The pre-school needed to cater to his unique needs, with a curriculum separate to his peers but yet somehow following along with what the rest of the children were doing. We had treated pre-school as a socialisation preparation for our oldest child, but we realised Ed needed something more. He required a greater emphasis on the development of basic social skills and independence, as well as focusing on the academic side of pre-school. The Montessori approach appeared to fulfil all of these criteria. The Early Intervention (EI) team were on hand from the beginning, offering advice and guidance; however they did not influence our choice of pre-school, but supported us unfailingly. Once we had made the decision the support team kicked into action. And so began our journey with Little Flower Montessori.

Our first task was to secure funding for a Pre-School Assistant (PSA). We applied through our EI team and received three hours funding a week. We personally financed 2 more hours leading to one hour a day of PSA. This was adequate to Ed's needs. Although the role of the SNA in the primary school setting is one of supervision and safety, in the pre-school setting our PSA provided one on one teaching as well as toileting assistance. This role can vary from school to school and needs negotiation. We were lucky enough to find a PSA who took a gentle approach with Ed in his first year and helped him settle into the classroom setting. Our objectives were simple, Ed was to learn to sit still for periods of time, He should develop increasing attention spans, and he should participate in circle time. After his first year we realised how much he was benefitting from the Montessori, however he had used up the free pre-school year and we were facing a large monthly bill to keep him there. So we decided to take out a college loan for Ed, albeit 18 years too early! But as far as we were concerned this was his continuing education because the early years are the most important years for childhood development. For the second year, we stepped up a gear and found a PSA with a firm and fair approach to his learning. If Ed had progressed in his first year then he excelled in his second as he met more and more complex objectives. I look back at the initial objectives we had and still can't quite believe how far we have come.

Ed's Graduation from Montessori

The EI pre-school liaison teacher entered our lives at this time. Ed had graduated within the EI team from his "baby" nurse to his pre-school liaison teacher. She was fantastic. Where we needed reassurance and advice from our initial nurse, now the focus fell solely on Ed and his needs. She would come into our house every 2 – 3 weeks and sit with Ed for an hour and do his "work" with him, focusing on his pincer grip, simple sequencing, simple numbers, shapes and colours. She was firm but kind and fair. At the time I was continually wary of her feedback. I was completely fixated on the fact that Ed would probably never count, recognise numbers, and as for writing, that was so far off the agenda that I didn't dare hope. But after each session, she would come out of the sitting room, where we had a desk and chairs set up, and sit at my kitchen table and reinforce what he could actually do. Usually I would look at what he had achieved during a session and I would question her "did you hold his hand / direct/ lead him?" We talk about my disbelief now, and I recognise that it was a coping mechanism that I used to shield myself from anticipated disappointment that never came. Ed excelled in areas that I couldn't have imagined. He holds his pencil with a loose pincer grip now, he can write 1,2,3 and ED. He sight reads some words. More importantly he sits still for long periods in the classroom setting. His ability to concentrate and focus on a topic has also improved dramatically over the two years of his pre-school life.

> *"The Montessori approach appeared to fulfil all of these criteria. The Early Intervention (EI) team were on hand from the beginning, offering advice and guidance; however they did not influence our choice of pre-school, but supported us unfailingly.."*

A huge factor in his progression was the dedication of the exceptional teachers he met in his pre-school. They took him on whole heartedly and immediately began catering to his needs. The Montessori approach worked really well for him. The holistic individual approach in his curriculum development is the ethos of this style of education. Ed was able to follow the class curriculum but at his own pace leading to great inclusion, acceptance and integration with his peers. At the end of the day his achievements are amazing to us, however we realise that to everyday parents who don't have a child with special needs

The School Marathon (Contd)

Deirdre Graham

these huge achievements are a given for them. More often than not I would walk away from the school door with eyes filled with tears of pride where his teacher had told how he had sat still in circle time, or had climbed up the slide steps. I think other parents thought I was an emotional wreak! But that's what it was like, a roller coaster of emotions as it began to dawn on us, actually Ed might just be, maybe, able for main stream school!

Ed in his School Uniform

We slowly allowed to possibility to sink in. Up until now we kept saying "whatever suits him", but it looked like it was main stream that suited! Unfortunately he continues to hold huge anxiety around the bell in his sister's school. Despite huge effort in helping him through that anxiety, he is only partially able for the bell. Her school is large, with a huge playground and a lot of pupils. I wasn't able to visualise him in that setting, bearing in mind that he is a measly 14.5kgs at 5 years old! I could however, visualise him being knocked over while wailing snotty tears after the bell rang! So began the hunt for a suitable school. The EI team allowed a lot of discussion around this topic. I named a few schools and they suggested I call in. They also gave me the number for a school catering specifically to children with mild to moderate learning difficulties. However I did not need to contact them as I found a school that appears ideal for his needs. A small, carpeted school, with a small playground and a curriculum with a huge emphasis on music; perfect for my tiny WS child! I approached the principal and was immediately impressed by her interest and enthusiasm at having Ed join her school. I have always trusted my instincts, and like my feelings for Little Flower Montessori I immediately knew that this was the school for Ed. Once the decision was made the EI team again kicked into action.

And so began a succession of meetings and form filling. The first priority was to ensure Ed would receive a Special Needs Assistant (SNA). We assumed this was a given considering our son has special needs. But the realisation that we have a continuing fight on our hands is frustrating. The application document was arduous to fill out, however the school principal was generous with her time and we completed it together. We focused on Ed's safety needs including the risk of him running out of the school if he potentially spots an irresistible bicycle or tractor! We also highlighted the risk of him injuring himself due to his poor spatial awareness and his inability to negotiate stairs without minimal help. He also continues to require toileting assistance. The next task was to gain him those valuable resource hours. Although Ed has a recognised syndrome, again what we thought would be a given, requires a fight.

The irony of Ed being diagnosed with mild intellectual disability immediately rules out his right to full resource support hours in our education system. So began the battle for the resource hours. After a lot of reading and research, as well as a helpful discussion with Fionnuala Tynan (WS committee member with a passionate interest in WS education needs), we realised that although Ed's intellectual disability is mild, because of his anxiety, his emotional needs certainly are not. So armed with a psychologists report outlining his moderate emotional needs, we applied for the maximum resource hours that we could receive for him. A Special Education Needs Officer (SENO) was assigned to us by the Department of Education. This individual makes the decision as to how many hours Ed will ultimately receive. A meeting was called, and once again I marvelled at the number of people gathered in one room all discussing my little man. A total of 12 adults including his pre-school teachers, his potential new teachers, speech therapist, pre-school liaison teacher, and us, his weary parents all battling to impress this SENO with the need for the maximum distribution of precious resource hours. The conversation had to centre on what Ed could not do rather than his ability; it was a difficult meeting for us as his parents considering how much we focus on his ability on a daily basis. I often muse on the fact that if we just invested more for our special needs children in their formative years we could save a lot of money for the state in the future in the development of independent adults who strive to reach their potential. But for now we continue to battle the bureaucracy. As of yet we have not formally received feedback as to the exact number of hours he will receive.

> *"The irony of Ed being diagnosed with mild intellectual disability immediately rules out his right to full resource support hours in our education system. So began the battle for the resource hours. "*

The school have held a number of meetings with us to help prepare Ed for the transition. They have diligently put together a photo album for Ed with images such as the front door, hallway, classroom, his teachers, the toilet and even the fish tank! This will develop a familiarity that will help dissipate any extra anxiety around his new environment. We are currently working on a booklet titled "all about me" to arm Ed with the necessary vocabulary to ensure that he is able to participate in the curriculum. The EI team have also had a programme to help the transitioning into school. This 4 session programme held over 4 weeks focussed on school readiness skills, such as group interaction, hand and finger skills, self-care skills and playground skills. This programme proved invaluable as it highlighted areas that Ed continues to need help with. This information has been compiled on a report for the new school and aims to help with his transition.

The School Marathon (Contd)

Deirdre Graham

The first day of school is fast approaching. The uniform is hanging upstairs. The new schoolbag and books are in his wardrobe. It is an exciting time in the life of any family, but for our little family, the immense pride, joy, anxiety and fears are all too obvious. We hope that the new team of teachers he meets will be as dedicated as his previous teachers; we hope the children are as caring. We are a long way from that beautiful summer afternoon. Against my wildest dreams, he has done it. He is starting school. Although it seems to be all over, it most definitely is all about to begin! Here's to a new set of parents imagining me to be an emotional wreak, and to me not really caring as I know I will be so proud!

Post script : The first day 1st Sept

Well he did it, he had the dreaded "first" day. Ironically nearly 4 years to the day of his diagnosis he has gone to school. Thanks to a well prepared and receptive school and staff the day passed uneventfully, thank goodness. He ran into the classroom and started greeting the other students like an old pro! Even when one child started the inevitable tears, distraction and deep breaths prevented what could have been a disastrous meltdown. Of course I bawled as soon as the coast was clear, but what a lot I had to cry about, scared, happy, sad, proud and heartbroken tears. I realise that for other parents this is an emotional day; this is the first step towards independence. For us it's the first step towards a sort of independence only experienced by people with Ed's particular needs. He has happily secured 40 minutes of resource hours a day, I feel this will be about as much as he can handle. So time will tell how this next chapter plays out. It seemed like a marathon to get to this point but the reality is, this race is over, the marathon is just beginning! .

Ed's First Day

Backstage at The Gaiety

Patricia Moylan

Last April my Dad and I went to a show in the Gaiety theatre called the Gondoliers by Gilbert and Sullivan. This is a light opera show with lots of singing and dancing. At the start I was really enjoying the show until a man interrupted me and told me that I was moving my head too much and that I was blocking his view. The man was very rude and I got really very upset and started crying and I could not really enjoy the show at all.

However at the interval a very nice lady came over and asked me if I wanted to move seats to her box where she was sitting. Her name was Marina Kealey and she was the choreographer of the show, in charge of all the dancing. We moved to her box and for the rest of the show we sat in the box which we had all to ourselves. I had best view in the whole theatre and we were very close to the stage. I was really delighted and I enjoyed the rest of show a huge amount.

Afterwards Marina's assistant came and invited me backstage to the Green Room to meet the cast and have my picture taken with the stars of the show. One of the girls presented me with a beautiful rose which I brought home and put on display for ages.

When the rose was finished my Dad sowed a cutting from it and its now growing so hopefully I will have lots of roses next year.

I would like to thank Marina and the cast for being so nice to me. It made all the difference because it cheered me up and made me happy again.

Lots of Love, Patricia

Patricia Backstage with the Cast

WILLIAMS SYNDROME ANNUAL MUSIC/ACTIVITY CAMP 2015

Carmel Daly

"Music is a world within itself, with a language we all understand". So said Stevie Wonder and this is never more obvious than at WS annual music camp. Within minutes of meeting each other on day one of camp we are all friends, language barriers don't exist and everyone is equal. As usual new friends were made, lots of music played, fun and games and, of course dancing till our feet hurt. We're all exhausted after it but will remember it fondly.

This year's camp was held from 2nd to 9th August 2015. All agreed that it was the best camp ever – OK, we say that every year, but it really does seem to get better and getter!

Camp 2015 was a smaller group than last year. In addition to twelve of our own Irish WS campers, we had four international attendees this year; two travelled from Italy, "Caoi Bernardo e Elisa!", one from France, "Ca va Nicolas!" and one from Holland "hallo Harm!" and, of course our Oscar from Poland who is now living in Ireland so we'll see a whole lot more of him.

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 friends with them, and I don't just mean Facebook friends.

The camp began on Sunday 2nd 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 Meet and Greet followed by a 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.


WSAI Camp 2015

After lunch there was a variety of outdoor activities, or indoors if weather required it. We had foosball, circus skills, wall climbing, arts and crafts, scrapbooks, 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. The highlight, for me anyway, was the Thursday Night show when the campers performed for us providing 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 courtesy of Fionnuala Tynan, 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. This year they brought us "Circue do WSAI" and it was a resounding success. The costumes and sets were brilliantly colourful, imaginative and unique.. all made by our group. The choreography was spot on. And of course the singing and dancing were so entertaining and high standard. Each camper got to perform centre stage and the talent was amazing. I'd like to offer a huge thank you to Sarah Corcoran, Sean Walsh and Aoife Gibney who wrote, choreographed and set music to this wonderful show. Their work started well in advance of camp so that the week of rehearsals could run fairly smoothly.

I want in particular 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.

And of course all 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 31st July to 6th August 2016.

Roll on Camp 2016!!!