



Anxiety Workshop Debbie Brannigan

On Saturday 27th February an Anxiety Workshop was held in the Spa Hotel, Lucan.

Dr. Mary Hanley, Dr. Debbie Riby & Dr. Jacqui Rodgers from Durham & Newcastle University came and gave the workshop on their research and findings on Anxiety in WS. They covered areas that included identifying anxiety, developing a toolbox to deal with it and measures to help avoid it.

Our very own Dr. Fionnuala Tynan talked about anxiety within the WS educational profile, expressions and interventions.

A total of 68 people were in attendance, which included parents, teachers and key workers.

Jarlath Tynan and Brian Aherne, who you all know, gave talks on their experience with anxiety,



Jarlath Tynan Presenting with Dr Mary Hanley

how they cope with anxiety on a daily basis and little measures they have put in place to help with their anxiety.

Our committee member Deirdre Graham gave a very refreshing talk on her experience dealing with her young son Ed's anxiety levels and what coping mechanisms they have put in place.

The day was broken up into presentations and group discussions. The overall feedback was very good and everybody felt it was beneficial.

It is vital for research purposes that all questionnaires be returned to Durham. If you have not done so can you do a.s.a.p.

Booklets have since been sent to all families on our mailing list with children of school going age. With the booklets there is a

cover letter and on the cover letter there is an online address. Can you please fill in the questionnaire for parents. Also when you give the booklet to you child's teacher can you remind them to fill in the questionnaire also.

If you have not received your Booklet contact Debbie Brannigan on 0851652641.

If anyone has had difficulty access the survey please try the following web address:

<https://durham.onlinesurveys.ac.uk/newquestionnaire>

This questionnaire is essential so that the research team can continue their work and hopefully we will all benefit from this research into the future.

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Brian Aherne Speaking at the Workshop

My Easter Holidays Annmarie Leahy



Annmarie and Sarah

My Holidays started on Wed 24 March but my Adventures started on Monday 28 March. My Mam dropped me at my college where I met up with my fellow workers and the staff we were going on our trip with. We packed the bus with our bags and then we went shopping for food for our trip to Allihies in West Cork. It took us two hours to get to West Cork we stayed in the Beara Holiday Homes. I got a room to myself whereas the other girls had to share a room. The first day we walked along the Ballydonegan Strand where we saw the surf from the sea hit off the rocks. We went to look at the Haunted Moor too. On the second day we walked towards the Garnish sandy beach on our way to the Cable Car. We had to climb over rocks where I slipped and fell on my bum a few times, we had to walk through muddy grass and small streams of water before we got to the cable cars which took us to Dursey Island. The cable car was scary because we had to go up first before we crossed over the sea to get to the Island. When we got to the Island we sat down for a bite to eat and a little rest before we explored the Island.

On Wednesday the 30th of March my Mam and I got the train to Dublin. We checked into our hotel and then went for lunch. After lunch we went back to the hotel to



Annmarie at the Little Mix Concert

WSAI Annual Picnic Carmel Daly

get ready for the concert.

Wednesday evening we went to see Little Mix. I was super excited that the concert was finally here. The Concert was absolutely fantastic, I had so much fun. I was in awe by the crowd that was there, the concert was amazing I was singing along with

all the songs. I LOVE Little Mix soooooooooooooo much. There was two supporting acts before little mix came on they were good but when little mix came on stage the crowd lifted the roof off the 3 arena. They put on a fantastic show and I wished it was longer than two and a half hours. On Thursday my Mam and I went to the wax museum. I enjoyed it so much they had all different characters from TV shows and movies and also many famous pop stars. We also met up with Sarah Binchy on Thursday night it was so much fun to meet up and have a catch up with her. We got the train home Friday morning and on Saturday I had a singing lesson and was singing little mix songs. Over all I had a fantastic week. And to top it all off when I went back to work I received my first aid cert.

I can now announce details of this year's Annual Picnic.

It will be held on 19th June 2016 in Newbridge House and Farm, Donabate, Co Dublin, website:

<http://www.newbridgehouseandfarm.com/>

This is a fun day out for the all the family and we hope that as many of you as possible will come along and support it.

It is open to everyone and anyone so bring



New Arrivals @ Newbridge Farm!

along all your family, friends neighbours ...anybody. Entrance is free and there will be lots of fun and games and we will do everything we can to make it as much fun as possible.

I will be writing to all families with full details nearer the date.

Carmel

2016 Music Camp Carmel Daly

The dates for this years camp are 31st July to 6th August . The camp will be held, as usual in Share Holiday Village, Lisnaskea, Fermanagh. It would be lovely to see some new faces there so if you are over 16 please think about joining us for a week of fun, friendship and music. If you think that the week might be a bit much for you we could arrange for you to attend for a few days or to visit us briefly to check it out. Please talk to me. If your WS child is under 16 we would love for you to visit us while at camp so that you can see the camp in progress and consider sending him/her in the future.

Unless you have seen it first hand, it is difficult to understand just how worthwhile the annual music camp is in terms of improving confidence, positive image, self respect, friendships as well as developing music ability. Even those that are not particularly musical gain such fun and confidence from the experience that at the end of the week, they get up on stage and give as much as any professional entertainer. Looking around at the faces of parents, watching their offspring on stage and realising, maybe even for the first time, that their child is a happy, whole, beautiful individual, capable of so much.

Our camp has dedicated musicians and teachers who volunteer their services for 1 week. In addition to the many musical offerings e.g. music lessons in piano, singing,

violin, percussion etc. we also have music therapy, relaxation, performances, sing-songs, drama, etc. In addition we have other activities e.g. art, circus skills, games, treasure hunt, cinema night, disco, picnic and many more. It really is a fun-filled and very enjoyable and rewarding experience for all.

I will be writing out to all families very soon with full details and application forms.

We have a fantastic bunch of dedicated volunteers, all of whom are Garda vetted and sign up to a strict Code of Practice.

If you, or anyone you know, would like to work at this camp as a volunteer teacher/helper, please complete the application form which is available on the website www.williamssyndrome.ie/. If you are accepted as a teacher/helper, your accommodation and meals for the week will be provided. You will find that it is a very worthwhile and rewarding experience to work with Williams Syndrome people many of whom are musically gifted despite the fact that they have a mild or moderate learning disability. Please give me a call if you want to discuss without committing yourself or I can get one of our previous volunteers to talk to you for a first hand account.

FEWS Camp Update Ann Breen

WSAI plan to host the FEWS camp in Ireland this year. Most of you will know that, over the years, some of our Williams Syndrome people have availed of the opportunity to attend summer camps in various countries within the FEWS member group. We offered to host the camp this year!

The camp (subject to EU funding, of course!) will be held in the University of Limerick from 3rd to 10th July next. It will be organised and run by Nuala Keady and Ann Breen.

11 countries from all around Europe have applied to take part. Each country will send 4 Williams people with 2 leaders. Including Ireland, this gives a total of 12 countries participating with a total group of 80 – 90 people. Plans for the camp are well advanced at this stage. The 4 participants plus two leaders from Ireland have been selected. Provisional bookings have been made and a preliminary schedule for the week in Limerick has been prepared.

We have also made provisional arrangements for an Advance Planning Visit to be held in UL in Limerick at the end of May. This will involve 1 leader from each participating country meeting in Limerick to finalise the activity programme for the week in July.

The most difficult part of the process so far was preparing the application for the funding. There were many visits to possible venues before UL was chosen. We made a number of follow-up trips to UL as well. The finished application was 64 pages long! This was submitted to the Irish National Agency – Leargas – at the end of January. We are now waiting to hear if that application for funding is approved. We hope to have a decision in the next couple of weeks.



2015 Camp Photo

SIBN St. Patrick's Day Ball a Huge Success

Ann Breen



cheque to Ann Breen of the WSAI and Rosa Perez of the ASWE.

In addition to ticket sales, the guests dug deep and contributed an astounding €7,700 to participate in the raffle, bringing our fundraising total to €30,000! The money raised will be divided equally between the Irish and Spanish Williams organizations. The aim is to fund a European Summer Camp in Ireland in 2016, enabling members from both Ireland and Spain to participate and foster as much autonomy as possible for individuals with Williams Syndrome and further deepen the ties between the two countries.

Six people in total travelled to Madrid (at their own expense) to represent WSAI at the ball. This number included Angela Davis, Andy Neill, Nuala Keady and myself.

We all had a wonderful time and were very proud to represent WSAI on such a great occasion.

On behalf of WSAI, I would like to thank the members of the SIBN organising committee for selecting us as one of their chosen charities this year and for the tremendous amount of hard work they put into organising and running the ball

Irish Ambassador to Spain, David Cooney, Minister Pascal Donohoe with representatives from SIBN, ASWE and WSAI at the ball

and Spain together.

The Spanish-Irish Business Network (SIBN) was launched in January 2008 with the primary purpose is of serving as a network of companies and individuals to promote business links between Spain and Ireland.

The third SIBN St. Patrick's Day Ball took place in the Westin Palace Hotel in Madrid on Friday 18th March and managed to raise an incredible €30,000 for The Williams Syndrome Association Ireland (WSAI) and Asociación de Síndrome Williams España (ASWE).

ASWE is already linked to WSAI within the FEWS organization. The European Federation of Williams Syndrome (FEWS) groups the different organizations within Europe which are actively involved in supporting people with Williams Syndrome.

An unforgettable night was had by all 300 guests who were treated to a magnificent four course dinner, copious Spanish wine, an open bar, live music & dance and a DJ who kept many of us dancing into the small hours. All in all, it was a fantastic way to celebrate St. Patrick's Day and further strengthen the many cultural and commercial ties that bind Ireland

With the Irish Minister for Transport, Tourism and Sport Paschal Donohoe, Irish Ambassador to Spain David Cooney and representatives from our many generous sponsors looking on, the highlight of the evening was undoubtedly the emotional presentation of a €30,000



Rosa Perez from SIBN and Ann Breen from WSAI accepting the cheque

FEWS Photo Competition

Ann Breen

As part of the celebration of Williams Syndrome across Europe, the Federation of European Williams Syndrome associations (FEWS) ran a photographic competition in the build up to May 20th which is European Williams Syndrome Awareness Day.

Under 14 Photographer



Alexia Colmorgen, Germany

The theme of the competition was music and participants were asked to enter photographs that have something to do a music theme. Various photos were submitted of loved ones or

friends playing music or pictures of people dancing or singing.

Final winners were selected by a vote of FEWS delegates along with the vote of a professional photographer from Germany at a recent FEWS conference call.

A big thank you to members from WSAI who submitted photos for this competition.

The winner of the competition are shown here.

These photos will be used by all Williams associations across Europe to promote Williams Syndrome awareness on Friday May 20th.

Over 14 Photographer



Rosa Aznar Gomez, Spain

WSAI Weekend Away

Carmel Daly

This year's annual weekend family get-together has been arranged for the weekend of 29th April to 2nd May. Details are as follows:

Venue: The Tower Hotel and Leisure Centre, Waterford www.towerhotelwaterford.com

Date: Friday 29th April to Monday 2nd May 2016 (long weekend)

The hotel has many facilities including an indoor heated swimming pool, and full leisure facilities. Over the course of the weekend we will organise activities/outing of some nature (yet to be decided; if you have any ideas let me know).

The annual weekend outing provides a great opportunity for individuals and families of WS people to get together, socialise and swap experiences. We

would particularly welcome new members. In the past it has proved to be a great success and a very enjoyable event.

If you have any further questions you may contact me at 086 2074608 or e-mail carmel.daly@dcenr.gov.ie.

Carmel



3 Amigos @ a WSAI Weekend: Billy, Cian and Padraig

Junior Music Camp

Dr Fionnuala Tynan

The WSAI is currently preparing a one day music 'camp' for children with WS. A number of high-quality practitioners have been sourced.

If you have any particular requests or suggestions for this day please contact fionnuala_tynan@eircom.net as there is still scope to include other ideas. A letter will be issued to families in the coming weeks about this.

Rehearsals with Band for Club Tropicana

Ann Breen

In a previous newsletter, I wrote an article about Karen's involvement in a show called "Trickster" that was showcased in Galway in October 2014. This show was a collaborative effort between the Brothers of Charity (BOC) group in Galway and a group from Bradford in England called "Mind the Gap". The show was presented to sell-out audiences for two nights in the Black Box theatre in Galway.

Karen was part of a 7 piece band for that show, 5 of whom were from BOC, Galway. The show was such a hit that, early the following year, the 5 members of the band from Galway decided to come together and produce some music for the "Club Tropicana" night in the Black Box theatre in June 2015.

Rehearsal began in the studio in the BOC's Woodland's Centre in Galway on Wednesday 11th Feb 2015 from 10.30am to 3.30pm. These rehearsal days continued on most Wednesdays right up to the night of "Club Tropicana" on 24th June 2015. By this time the band had become known as "Electric Dreams" and had composed the music and lyrics for three new songs – "Ready To Go", "Consciousness" and "Positive". They performed these three songs on the night to great acclaim. Everyone was very impressed with the work they had done. They also performed some of the music from the "Trickster" show with members of the "Mind the Gap" group who had travelled from Bradford to take part in "Club Tropicana".



Karen playing her keyboard synthesizer at Club Tropicana



Electric Dreams with "Mind the Gap" group performing Trickster songs

In October and November 2015, the "Electric Dreams" band got together again every Wednesday to do some further work on their three new songs. The result of the two month's work was professionally mixed versions of the three songs on a CD produced in January 2016! It is really very good!

The band had another performance on the night of 27th Jan 2016 in the Black Box theatre. This was a "Club Tropicana" style event organised as part of the Arts and Disability

Ireland annual conference (titled "Creative Connections") which was held in Galway. Once again, the "Mind the Gap" group travelled from Bradford to perform with "Electric Dreams" on the night. Once again, the performance was very well received by everyone present.

The "Electric Dreams" band continues to meet once a week and is now in the process of writing some more new songs. They hope to continue to work and perform for a long time to come.

Michael and Robbie Go Viral!

Tom Moylan

Warm congratulations to Michael and Robbie McMahon for making their wonderful video which has gone viral and in the process does a lot to promote Williams Syndrome.

This video shows an Irish pilot making his younger brother's day by taking him for a surprise trip on a plane.

Michael McMahon took five-year-old Robbie, who has Williams Syndrome, with him for a

spin and the video says it all from there.

You can see the video at <http://www.irishmirror.ie/news/irish-news/watch-offaly-pilot-make-younger-7785438> or just search for Robbie and Michael and Williams Syndrome.



Robbie and Michael Sky High over Offaly

WS Research Update

Dr. Fionnuala Tynan

Individual Education Planning

Exploring the Individual Education Planning Process for Students with WS of Post-Primary-School Age.

This piece of research has been ongoing for the past year and is just completed. It was undertaken with four students with WS. It involved interviewing the student, his/her parents and his/her teacher. I was interested in answering the two following questions:

What are the experiences of students with WS, their parents and teachers of the IEP process?

What aspects of the WS educational profile are most commonly targeted through the IEP process?

The findings show an overall positive

experience of the IEP process for parents and teachers. However, students are rarely included in the process despite having the capacity to express aspects of school they like, aspects they don't like, areas they feel they are good at, areas they find challenging, areas they would like to work on, their favourite way of working and their favoured person to support them.

I also found that academic targets are most frequently chosen for students with WS even though when we look at the components necessary for inclusive learning, 'academics' only form one aspect.

The families involved will be contacted in the

coming weeks with more detailed findings. In the next newsletter I will also supply more detailed findings and outline some guidelines for parents. I hope to work on guidelines to guide the IEP process for parents and teachers in the coming months and these will be put on the website. If anyone would like to contact me at any stage about IEP planning for their child (primary or post-primary), I am always available (fionnuala_tynan@eircom.net).

A very big thank you to the parents, teachers and students who worked with me on this. It was a great privilege for me to work with you, thank you for your ongoing support of my work.

Experience of Pre School WS Parents

Current research project: Children with WS of pre-school age: experiences of parents, children and pre-school teachers.

In the coming weeks I will be making contact with parents of children of pre-school age to conduct some research.

I have to date carried out research on children with WS of primary-school age and those of post-primary age. There is currently no information on children with WS of pre-school age in Ireland. We don't know about the experiences of parents, pre-school practitioners or the children themselves, therefore, there are no guidelines of best practice for supporting the child in pre-school contexts. It is unclear how the complex learning profile associated with WS is perceived by parents and pre-school practitioners in young children with WS, and consequently, how they support the child. Due to the rarity of the condition, pre-school practitioners are unlikely to have worked with a child with WS before and parents are expected to be fully knowledgeable on the condition for professionals, a role which they can find stressful. The children's views will be invited to establish aspects of preschool that they like, do not like, those they can access and those they find challenging. In the past

two years I have had many parents of children of pre-school age contacting me about their child. I am always delighted to help in any way I can but I've noticed some of the same issues coming up. If we work together to find out what the main issues are we can provide some solutions.

The purpose of the study is to find answers to the following questions:

What are the experiences of parenting/educating/caring for a child with Williams syndrome (WS) of pre-school age,

What are the aspects of the WS profile that help and hinder the child's inclusion in pre-school settings

How do families and pre-school practitioners manage transition for the child (starting pre-school and/or going from pre-school to primary school)

What practical strategies can promote inclusive pre-school practices for children with WS?

Benefits: This research will provide baseline data on how the child with WS is likely to present in Irish pre-school settings and will lead to the production of guidelines on how to support the child both in the home and the pre-

school setting, while acknowledging that all children with WS are unique.

If you are willing to be involved it would require:

An interview with you before the end of June

An interview with your child's pre-school practitioners (to include pre-school teachers, SNAs, child minders) before the end of June

Structured interviews with children with WS using objects of reference, visual aids, puppets and play items

Documentary evidence to include individual education plans, home-school communication books, specialist reports (psychologist, physiotherapist, speech and language therapist, occupational therapist)

Observation of the child: once in the pre-school setting and once in the home setting

The completion of behaviour checklists

In reality this would mean me spending a maximum of two mornings or afternoons with you. You can decide when, that will all be arranged to suit you if you decide to participate. The more families that get involved in the research the stronger the results so I'd be very grateful if you'd consider this!

WS Research Update contd.

Dr. Fionnuala Tynan

Research with Adults with WS

Over the past few years I have worked with adults with WS at the music camp and I have been extremely interested in their views about WS. I am hoping to conduct research this summer at the camp on self-perception in WS.

Over the past two years I have worked with adults with WS at weekends away and at camp on anxiety and I am very keen to have them participate in research to tell their own story. Most researchers only get the views of parents, I think it is vital we give the opportunity to our people with WS to voice their opinions.

The development of this research is at an early stage but I will make contact with the parents of all those who are enrolled for the music camp this summer. The research would involve an interview with the person with WS

asking them questions about themselves, about living with WS, their strengths, things they find difficult, experience of the music camp, dealing with challenges, friendships, future dreams, worries etc. There will be an individual interview and also group interviews as part of circle time. The aim of this would be to provide future support for individuals with WS and to advise the association on workshops for parents or for the individuals themselves. Even if parents give consent for their child to participate in this research, I would not interview the individual unless they had been fully informed of the process and gave their own consent. The research will be guided by the very strict ethical guidelines of Mary Immaculate College, Limerick with whom I am affiliated.

Research on Adults with WS

The last piece of research I want to share with you is research on adults with WS from parents/carers' perspectives. We have such a young population of people with WS in Ireland it would be good to know what are the experiences of parents so far for their family member once they leave school. Again this research is at an early stage but I hope to send out a questionnaire to families before or during the summer. This will give us data on which we can plan supports for our people

with WS and their families. If we know about issues we can deal with them. I will have more details on this in the next newsletter. Again, I thank you in advance for your support of my work. We all want a better world for our people with WS and sometimes you need facts and figures to have leverage to access supports and resources



Fionnuala Presenting at the Anxiety Workshop

Education Update

As most of you know I took up a post with Mary Immaculate College, Limerick in September, working as a lecturer in Special Education. It has given me wonderful opportunities to do research and to present at conferences. My main aim in life is to spread word about WS, to make it known to education professionals. This is an update of the presentations I have done over the past few months:

9 December: Presentation to the Special Education Support Service about the WS educational profile and how best to support learners with WS.

29 January: TacPac training: this is a programme on sensory integration based on the principles of music therapy.

2 February: Presentation to teachers doing a Masters in Education in Mary Immaculate College

10 February: Presentation to teachers doing a post-graduate diploma in special education on WS (in Mary Immaculate College)

20 February: Presentation at a college conference called 1916: Memory and Vision about changes in attitudes to disability in the past hundred years with a focus on WS.

26 February: Presentation to teachers doing a post-graduate diploma in special education in St. Patrick's College, Drumcondra on 'the magic of music in special education' and also a presentation on 'WS: A hypermusical species'.

22 March: Presentation to trainee educational psychologist about WS

1 April: Presentation at the conference of the Education Studies Association of Ireland on 'Choosing school placements for learners with complex learning profiles: the conflicts and the contradictions' (this was based on WS).

In the past few months I have also worked with individual schools to support children with WS. If your child's teacher is looking for support or advice please pass on my contact details. Fionnuala Tynan