

WSI News

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New Look Williams Syndrome Ireland



WSI Families Attending DePuy's Family Day in Cork

We are pleased to announce that our charity has a brand new look for 2020. Last year saw the approval of our new constitution which is the legal foundation for our charity. The new constitution has revised our objectives to better reflect our understanding of Williams Syndrome (WS) and focuses on the individual with WS as well as parents and guardians, In addition, our constitution is now fully aligned with the standards set down by the Charities Regulator which will ensure appropriate governance into the future. Our new constitution is available on our new website

at: www.williamssyndrome.ie

These changes also include a new name for our charity Williams Syndrome Ireland, (WSI). This simpler name is more in line with charity names which have now been adopted in the sector and provides a simpler name for use on social media and other online platforms.

As Pauline Leahy explains, on the next page, WSI was selected by her employer DePuy as their chosen charity for 2019. DePuy set up a support team to work on creating a new image for WSI including a new logo and a range of promotional material such as posters and other promotional material. This support has also enabled us to re-design our WSI website and Facebook pages.

We hope that all of these changes will assist WSI to continue to develop into the future and provide even greater support to all people in Ireland who are affected by Williams Syndrome.

Our thanks to Pauline and the DePuy team for their support on these developments and for making a tremendous contribution to WSI for the future.

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DePuy Sponsorship for Williams Syndrome Ireland Pauline Leahy

"In November
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Each year in DePuy where I work employees can propose a charity for the company to support during the year. In November 2018 I nominated Williams Syndrome Ireland once again and third time lucky I was successful!.

Fionnuala Tynan, Annmarie and myself went to meet James and Denis who were members of the CSR Charity Team in DePuy, This team would decide which charity to support for the year ahead. James came back to me following a committee meeting to say they picked our charity. I cried tears of joy and fear at same time knowing that I had to talk about Williams Syndrome at a plant communications meeting. I felt very nervous because only a few co-workers knew about Annmarie having Williams Syndrome.

I joined the CRS team for the coming year as point of contact. We brainstormed different ideas that we could put into action for the year having explained to everyone what we needed help with. Limelight Media came on board to design a new logo for WSI and a range of publicity material such as new WSI leaflets, posters and pop ups, all of which will be fantastic for fundraising events. One Vision Media was hired to develop a video to promote our WSI Camps, Limelight Media redesigned our Facebook page and Evans from the DePuy team worked hard to develop a new WSI website.

We also put a plan together to run various fundraising events during a very busy year.

Our first event was the Easter



Pauline and DeDuy Team Presenting a Cheque to WSI

Raffle in April where plenty of Easter eggs and spot prizes were donated to us. In May we had a cake sale.

In June the Ironman competition took place in Youghal and a 3 man team from DePuy entered this event. A great amount of training was done for the event which raised €3,000. In July we held a Quiz night where we filled the bar that hosted it with 30 teams of 4 people each.

In August the WSI Adult Camp took place in Limerick. The entertainment was supplied by the staff from DePuy who gave their time to entertain our Campers during the week. Monday Night was Fun Bingo and James Roche (the CSR team leader) and I hosted this event. Ashleigh O'Hagan called the numbers with me and James was on the floor all evening chatting and helping where needed,. Everyone had a great night and James loved meeting everyone. For the rest of the week our Campers led the events with our support.

Tuesday was karaoke night featuring Adrian. Wednesday night was a sing along with Meghan & Co, and on Thursday night we finished up

with a Disco with Dean . Everyone really enjoyed the weeks entertainment.

DePuy also have a family day every year at end of August and we organized for a few families from WSI attend and they had a fantastic time.

In September we had a Road Race which took place in Ringaskiddy. Our celebrities at this event was our very own Alice Daly & Katie Leahy who had photo shoots on the night. When the race started both Alice & Katie were cheering for DePuy.

In October we held a Thon-athon which involved 24hours of exercise which took place in out facilities at work. Everyone that took part paid for their slot to exercise for 30mins.

Quality week also took place in October and the team held a Quality Bake Off where they sold the Cakes to raise awareness for WS.

In addition our Facilities team held a Golf Classic & Cake sale during the year which raised over €5,000.

A big thank you to James Roche, the CSR team and everyone at DePuy for all their support during the year.

"In August the WSI Adult Camp took place in Limerick. The entertainment was supplied by the staff from DePuy who gave their time to entertain our Campers during the week."

My Own Gaff Alex Davis

On 16th Jan I moved into my new house in Belfast. It's in a quiet cul-de-sac near a park and has shops and a bus stop round the corner. I was verv nervous and verv excited at the same time. I worried that I would get burgled, how to pay my bills, working the oven all these kind of things were in my head.

Four weeks on I'm
very happy and content
in my house with the
help of my mum and
my carer Caroline. Caroline
comes to me 3 times a week
for 2 hours she helps me with
food shopping, cleaning,
checking I'm taking meds and
we go to the shop every week
to top up my gas and electric.
We also do a few social
things. She's really nice.

I love my independent life. I love the peace and quiet (no brothers annoying me lol) TV



Alex Relaxing in his new Apartment

and sports channels all to myself. I have a job cleaning in a cafe on a Friday afternoon and I'm hopefully starting a job 2 mornings a week in a blinds shop next week.

I am also volunteering in an urban farm called Kilcraggan. It has a cafe called dancing goat IoI, I will be helping with the animals so I'm very excited. I also play football for a disability team on a Wednesday afternoon so my life is quite busy and I can visit my family whenever I like. I have a wonderful life.

Alex D

"I love my independent life. I love the peace and quiet, (no brothers annoying me lol) TV and sports channels all to myself."

Picnic In The Park Stephen Langton

This year we are planning to hold our Picnic in the Park on Saturday the 21st of March in Clonfert Pet Farm, Maynooth, Co. Kildare. Clonfert Pet Farm is an open farm containing over 60 types of wonderful and exotic animals. In addition the farm contains a large array of facilities including a coffee shop, walk ways, picnic areas and outdoor play areas. 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. Entrance for WS families and friends is free and there will be lots of fun and games on the day.

See You There!!



WSI Weekend Break—In Cork! Debbie Brannigan

"Rochestown
Park Hotel Cork:
150 spacious
rooms, award
winning leisure
centre,
complementary
wi-fi and 350
parking"

This years WSI annual weekend break will be held in Cork from Friday the 24th of April until Sunday the 26th of April. The venue for this weekend is the Rochestown Park Hotel, Douglas, Cork. WSI will subsidize the cost of the weekend by 250€ per family or 125€ for a single person provided that they are fully paid up members of the association.

The annual weekend provides a great opportunity for individuals and families affected by WS to get



Down Town Cork City

together, socialize and share experiences. We would particularly welcome new members as this is a great way to get to know some of the WS community in Ireland. Hopefully we will see you all there!

WiSHES for your Local Library Stephen Langton

Rosanna and i attended the Library in Stewarts Hospital grounds in Palmerstown which is the local South County Dublin Library. Also known as the John Jennings Library, Stewarts Care Ltd.



Presentation at South County
Dublin Library

Rosanna presented the book 'WiSHES' to the Senior Librarian, Siobhan Mc Crystal. Siobhan was delighted to receive the donation of the book and expressed interest in having a second one. We duly obliged.

The book was registered on the Library website and was requested from another library within a week.

Following that Rosanna presented another copy to Angelina, her Supervisor in the Coach House café, where she works. This copy was for the use of the staff 'upstairs' who look after the clients registered with Stewarts Care.

The Coach House is a brilliant environment, bright, spacious, and very friendly. Staff are brilliant and always smiling and delighted to see all who



Presentation at Stewarts
Care

come through the door. They also have a well stocked gift shop adjoining the café.

Rosanna has worked here for many years and loves it.

"The book was registered on the Library website and was requested from another library within a week"

Peace Proms Dublin February 2020 Ciarán Mullan

My name is Ciarán and I'm 11. I'm in 4th class in Our Lady of Good Counsel Boys N.S. in Johnstown, Co. Dublin.

I am in the School Choir with boys from 3rd to 6th Class. Our choir was entered into the Peace Proms which was taking place in the RDS in Dublin on Sunday 2 February 2020.

We had to do LOTS of practice every week and coming up to the event even every DAY during school and also before school. We had to learn lots of songs and dances.

On the day of the Peace Proms, my Dad dropped me to the bus at school at 4 o'clock and we all went to the RDS with our teachers, Mr. Clancy and Ms. Browne, and some helpers, Louise and Suzanne. We all had to wear white tops and black trousers. We had a dress rehearsal and then we had to wait for the show to start. I was a bit nervous but excited too.

We could see all the families arriving to watch us. Then the main show started at 7 o'clock. There were 2,400



Me Doing the Peace Sign at Peace Proms!!!

children singing. There was an Orchestra called the Cross Border Orchestra of Ireland. And in charge of us all was the Conductor called Greg Beardsell. It was his job to tell us when and what to sing and make sure we were singing in time with the Orchestra. He was very good fun and really nice.

Our songs included: Disney Medley, Pop Chart Medley, Queen Medley, Brothers in Arms, Power of One and A Million dreams - from The Greatest Showman

The Conductor told all the audience to turn the torches on their phones on - it looked

really cool. You can see it on this video https:// www.facebook.com/ peaceproms/ videos/185015215919341/

My mum asked me what my favorite song was but I can't decide!! I think that they are all great. The show finished at 9.30. There was lots of cheering (which sometimes was a tiny bit TOO loud!!!) and clapping and dancing.

I am very proud that I got to sing at the RDS with all my friends and get to be part of the Peace Proms.

Ciarán Mullan

Fundraising for 2020 Debbie Brannigan

We the WS committee are trying to raise Williams
Syndrome Awareness within our communities and also raise some much-needed funds for the association to continue working to improve supports for our WS families.
Would you, your families or friends like to host a tea party in Aid of Williams Syndrome. It can be done at home, at work,

at school or at your local club. All support would be greatly appreciated.

If you would like to give your tea party the official look A3 size copies of the WSI Tea Party poster can be obtained by contacting WSI



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My Ceramics Patricia Moylan

I have been studying Ceramics for the last three years..

I attend Stillorgan College of Further Education in Dublin on Fridays and I spend most of the day doing Ceramics.

The first year I worked on making beads and pendants and house ornaments. The second year I worked on decorative bowls and large plates. This year I have just finished a tea set, It is made up of a tea pot four cups and saucers and four plates. They are all colored blue and white.

My teachers name is Carol and I really like working with her.

First I think of what the product is going to be. Then I make the shape of the



Patricia at the REHAB Art Exhibition with a Selection of her Work

ceramic using wet clay. I like to get my hands dirty working with the clay. Then you leave it to dry which takes a few days. Once it is dry you put it in the kiln to make what is called bisque fire. This hardens the clay. Once that is done I take it out of the kiln and decide on the color pattern. I start the painting which is called glazing. Then I have to wait until it dries to a powder. After all of that the I

put the ceramics back in the kiln which makes the colors turn all shiny and glazy. Then the ceramics are finished. At the end of the year all our art work goes to an exhibition in Bray. People come to view our work and so far I sold many of my pieces.

I really love ceramics because I get to create and be arty/ crafty. Its really a lot of fun and I would really recommend it to everyone. "At the end of the year our art work goes to exhibition in Bray. People come to view our work and so far I sold many of my pieces"

Advance Notice of Mary I Camps Fionnuala Tynan

I am delighted to tell you that once again we will be running our Junior, Sibling and Adult Camps in Mary Immaculate College, Limerick in August this year. The format will be similar to last years camps but as always we will be looking to improve things this year again.

The Junior Camp will run from the 10th of August until the 14th. An international Junior Camp will run from the 4th to the 7th of August for children from outside Ireland and there may be an opportunity for children from Ireland to attend that week also depending on the numbers.

The Adult Camp will be held from the 3rd to the 7th of August.

If you would like to attend any of these camps please get in touch with me as soon as possible as demand for places is high and of course places will be allocated on a first come first served basis.

This year we hope to organize an Anxiety Workshop and we will provide information on the venue and dates as soon as the program is finalized.



Rose and Chloe at a Camp 2018

Calling All WS Stories WSI Committee

As we said previously our members are always interested in stories about the WS experiences of other people and we love to include WS Stories in each addition of our Newsletter where possible. So the WSI Committee would like to invite all WS members to write a short article about any subject of their choice.

Your story can be on any subject you like such as your day at work, school or leisure, a sporting event you attended, your holidays or even your favorite TV program, to name but a few topics. You can of course also write about any of your days or weekends away with the WS 'gang', Feel free to seek help from any of your family or friends in writing your story and don't worry about



grammar or spelling as we can polish off the story if necessary. Each entry submitted will receive a 25€ cheque provided it can published in the Newsletter.

Plus we will publish each letter in the next issue of the Newsletter subject to each person's permission.

WSI 2020 Committee

The 2019 Annual General Meeting was held in the Lucan Spa Hotel, Dublin on the 24th of November 2019.

The AGM re-elected Mr. Stephen Langton as Chairperson.

The following Committee members were re-elected for 2019 as follows; Stephen Langton (Chairperson), Pauline Leahy, Fionnuala Tynan, Debbie Brannigan (Secretary), Philomena O'Hagan (Treasurer), and Tommy Moylan.

Ruth Heggarty and Joyce Boggans have decided to step down from the Committee and we would like to extend our thanks to Ruth and Joyce for their time on Committee. We are delighted to welcome two new members to the Committee this year, namely; Maeve Tynan and Linda Kane

Over the last few years we have also appointed Associate Committee members. This arrangement enables members take part in Committee work without the commitment of being on the formal WSI committee. For 2020 we are happy to say that Helena Begley will continue as an Associate Committee Member and we welcome Dearbhail Mullan to that role as well.



Williams Syndrome Ireland

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We're on the web! williamssyndrome.ie

The 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