WSI News

Volume 25. Issue 2 Autumn 2020

Covid 19 - Challenging Times

Hello to all our members and people with Williams Syndrome. Hopefully you are all keeping safe and well in these difficult times. Sadly we have had to cancel all of our annual events for the foreseeable future. We can only hope that the public health emergency is resolved as soon as possible and we can get back to organizing events where we can meet in person again.

In small recompense for these cancellations the Committee decided to distribute some gifts to the homes of paid up members. Many thanks to Fionnuala Tynan for her inspired gift choices and we hope that everyone enjoyed their little surprise.

WSI also managed to provide some level of support online during the year.

Thanks to Linda Kane we ran a WS Awareness Month Facebook campaign in May which was wonderfully supported by our members.

In addition Fionnuala and Mary Immaculate College provided online Camp sessions for all ages and by all accounts the sessions worked very well.

On a sad note our Patron Desmond Guinness passed away recently. Desmond was very supportive in setting up the charity from very small beginnings.

As a registered Charity we are required to hold an Annual General Meeting every year. Due to the Covid 19 situation we have made arrangements for this year's AGM to be held online.

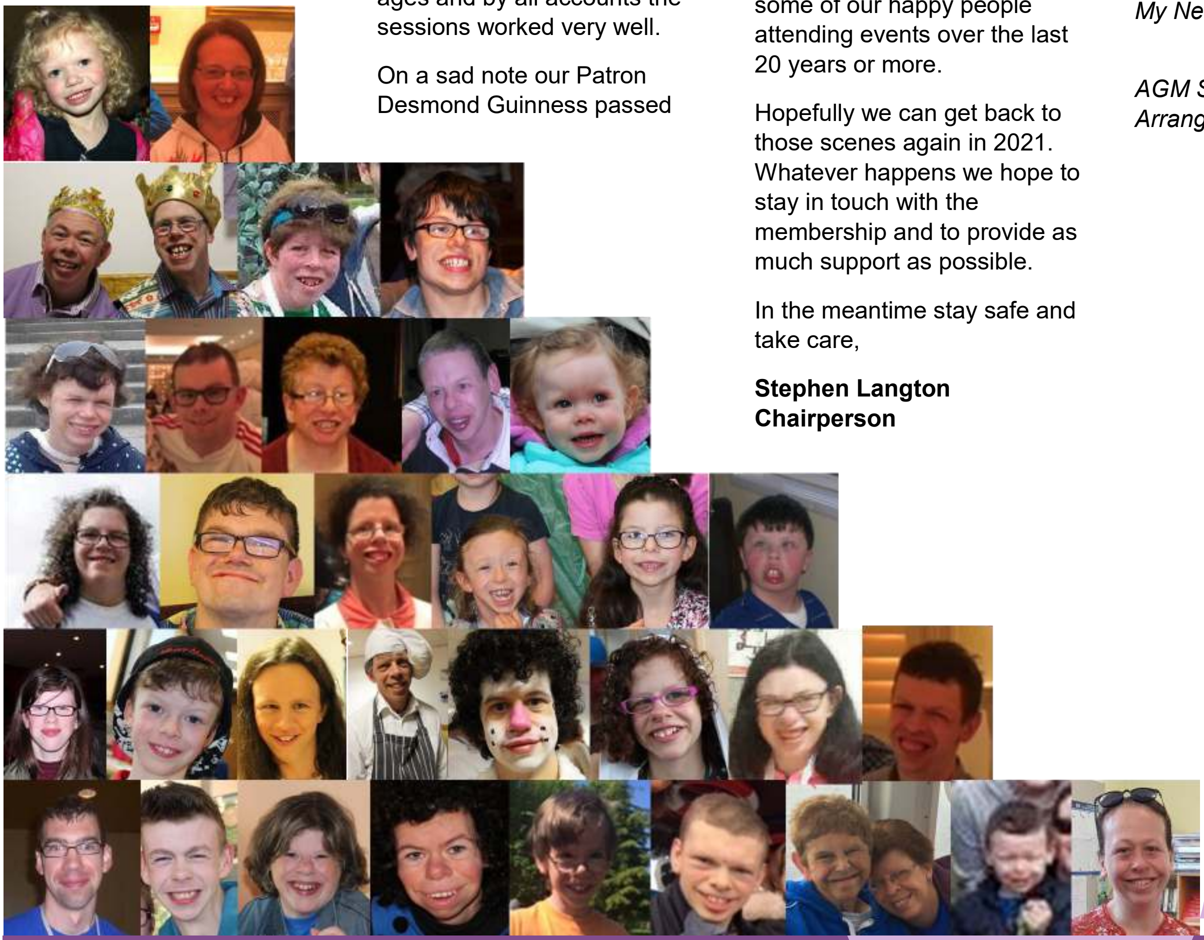
Normally our Newsletter would be filled with pictures of happy faces at many of our events over the past year

So instead we thought we would include a picture of some of our happy people attending events over the last 20 years or more.

Hopefully we can get back to those scenes again in 2021. Whatever happens we hope to stay in touch with the membership and to provide as much support as possible.

In the meantime stay safe and take care,

Stephen Langton
Chairperson



Inside this Issue

Apologies we did not have absolutely everyone's picture to hand.

If we missed you get in touch with a picture and you'll be in the next issue

WSI Summer Camps Go On-line

Fionnuala Tynan

We were delighted to provide Zoom based summer camps in view of the current restrictions. We provided three different options depending on the age of the family member with WS.

Baby Camp

This year was the first year of running a camp for the under-fives. There were on average three children that attended each day. It ran for 45 minutes each day. It was wonderful to have had three new families take part and to see parents and siblings taking part to support the young child with WS. The activities included nursery rhymes, action songs, stories, music and language development. Parents were also given advice on the purpose of the activities and how to best use them with their child. The feedback from parents was positive. Following on from this camp, a document entitled Reach for the Stars: Supporting the Early Development of Your Pre-school Child with Williams Syndrome was developed. Once feedback is received from parents whose child attended the camp, it will be made available for any parent or practitioner working with a child with WS. Please contact Fionnuala Tynan for details.

Parent Feedback

"The whole family really enjoyed participating in the Baby Camp this year. I was amazed at how well all the children kept focused on Fionnuala throughout the session! Izzy was really engaged with Fionnuala throughout and even sang a song by herself without prompting! It was really nice to also have her bigger sister in on the action too. A huge plus was being in contact with other families at the same stage of the journey as us! Over all it was a huge success and I only wish it could happen more often".

Linda Kane

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Junior Camp

It was great to welcome back all our regular attenders and to meet two new participants. As with the baby camp, the commitment and support from parents was outstanding. Many grandparents also helped out to ensure the children could join the camp each day. The camp ran for two hours each day, from 11-1pm. Attendance was very stable each day. Activities focused on talking about life during lockdown, social distancing, sneezing/coughing etiquette, maths (the time), sharing news, language games and story time (with a focus on topics such as resilience and road safety). The children were also prepared for going back to school and what they were likely to expect. It became evident that two hours was ambitious and after the second day a disco was organised for the last half hour of the session from Wednesday to Friday. The children were WILDLY excited to see one another every day and it showed the importance of keeping them connected through WSI events.

Parent Feedback

"Katie was thrilled that the junior camp went ahead via zoom as she was so bitterly disappointed that we weren't travelling to Limerick this year. She was so happy to see all her friends on line. Fionnuala showed her expert skills at engaging with the children taking part each day and keeping them interested and focused. It was a huge success, incorporating fun and learning over a two hour session for the week. Well done and thank you to Fionnuala for all her hard work. It was an ambitious undertaking but as always she pulled out all the stops and did a phenomenal job. It was of such great benefit to all the WS children who took part and Katie thoroughly enjoyed every minute".

Helena Begley

I felt I gained a lot from the chats, all we spoke about and it really cheered me up during this difficult time for everyone.

Adult Camp

The adult camp was a hugely successful session which was enjoyed very much by the participants. It ran for one week from Monday to Friday, from 3pm to 5pm. The approach to the camp was flexible to allow the participants to decide what they wanted to do each day. They chose to share their own news, talk about living in lockdown, their anxieties about Corona virus, language games, Maths games and a disco where each participant picked their favorite piece of

WSI Camps...

Continued

music each day. The participants really valued the opportunity to connect and felt this is something they would like to do more often.

Camper Feedback

"I really enjoyed seeing my William Syndrome friends again, I really enjoyed the music, the games, the chatting - just being there really to see everyone. It was great to see Fionnuala again and it meant a lot that she did this camp for the WS people because we are all at home and we miss each other.

I'd love to do it again, if it was on again, I'd definitely do it. I felt I connected with everyone even though I couldn't see them in person, just the company, to see everyone looking safe and well and Fionnuala is so much fun - I felt I gained a lot from the chats, all we spoke about and it really cheered me up during this difficult time for everyone".

Rebecca Conroy

July Provision/ Summer Provision Programme

Debbie Brannigan/Fionnuala Tynan

Deputy Paul McAuliffe

As many of you are now aware, all children with special educational needs were able to access July Provision this summer. WSI put forward a proposal to the Minister for Education and Skills about children with WS being automatically entitled to this because they have not been able to access it before. The July provision program was originally set up on foot of landmark court cases by Kathy Sinnott (for her son with Autism) and the parents of Paul O'Donoghue (who had severe/profound general learning difficulties). Parents of both individuals argued that the educational system wasn't meeting the needs of their child and that having a program over the summer would help their child's development. Interestingly, the parameters have extended to include Down syndrome. From our perspective, this is only because Down syndrome has a large lobby group. If Down syndrome is a condition that can automatically avail of July Provision, then WS should also be included.

We contacted a number of TDs about this and got it brought up as a parliamentary question by Deputy Paul McAuliffe. It was also raised by the INTO (Irish National Teachers' Organisation) with the Department of Education and Skills. They felt we had a very strong case. The bottom line is that any child deemed to have needs has been given access to July provision this summer but this will not be the case next year or in following years. As members of WSI we need to continue to put political pressure on for this support. This does not mean your child HAS to avail of it. A letter is available on the WSI website. It is written to the Minister. You can change this to the name of a public representative for your area. But please also send it to the Minister. You can sign your name to the end of it, it currently has Fionnuala's name. We ask you to please download it and send it to any local public representatives in your area, regardless of political party. Ask family and friends to do the same please. It appears the bigger the lobby group, the louder we sound and the clearer we are heard.

Debbie Brannigan and Fionnuala Tynan

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Home Schooling a Child with WS

Fionnuala Tynan

Many of you have had the experience of teaching your child while the schools were closed. No one is fully sure what will happen next term and for those of you with children with underlying health issues (which may or may not be associated with WS), you may end up doing more of this in the future. I have put together an information booklet on home-schooling your child with WS. It gives ten top tips on how to do this and gives a range of ideas and resources for developing your child's skills across different curriculum areas. The booklet is available on the WSI webpage.

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Desmond Guinness - An Appreciation

Ann Breen

I was very sorry to hear that the Patron of our association, the Honorable Desmond Guinness, passed away recently. He was a really nice, generous man who lent his name to our organisation at the very early stages of its development. I believe his association with the Williams Syndrome Association of Ireland from its infancy has lent us an air of legitimacy and gravitas over the years.

The Honorable Desmond Guiness with Nuala Keady and Ann attending WSI's 20th Anniversary Celebration in 2007

Over the years we were always delighted to welcome Desmond Guinness to many of our events and celebrations including the 20th and 25th anniversary

My daughter, Karen, was diagnosed with Williams Syndrome in February 1986. After a number of months, having come to terms with the diagnosis, I made contact with another parent of a WS child. This WS family was the Giles family from Leixlip in county Kildare. In 1987, as other families started to make contact with us, Cait Giles and I decided that we should form a parent support group. We also began to look for someone to act as patron of our group. As the Giles family lived in Leixlip, they knew of Desmond Guinness who lived in Leixlip Castle. Cait suggested that we approach him for his support. She contacted him and he expressed interest in helping us with our organisation. However, he wanted to hear about Williams Syndrome from the medical, teaching and caring professions, as well as parents, before he committed himself. Therefore, a meeting was organised with people who had worked with our WS children. This meeting was held in Leixlip Castle and was attended by a cardiologist, a pediatrician, special needs teachers and health care workers as well as Cait Giles and myself. Desmond Guinness asked many questions and listened to all we had to say about WS. At the end of the meeting he agreed to act as Patron of our Association. Needless to say, we were very grateful to him for his decision. We believed that having his name associated with our very small organisation would be of great benefit to us. I developed letter headed paper showing him as Patron and I believe it helped us in our efforts to spread awareness of WS and to raise funds to help us with our work.

Over the years we were always delighted to welcome Desmond Guinness to many of our events and celebrations including the 20th and 25th anniversary celebrations. He was always very happy to be with us. Over the years I also kept him updated, via letters, with all the work of the association. He has not been with us in recent years as his health has been in decline for some time.

Our sincere sympathies go to Desmond's wife, Penny, his daughter Marina, his son Patrick and all the extended Guinness family.

May Desmond Rest in Peace.

Ann Breen
Honorary President
Williams Syndrome Ireland

WS Awareness Month

Linda Kane

For this year's Williams Syndrome Awareness Month we encouraged our members to get involved and tell their story on Facebook! We had a new post each day for the month of May to highlight. We offered easy to understand explanations surrounding the condition. A lot of families found this helpful to share with families and friends. 18 different families offered a glimpse of their lives as they shared their likes and dislikes. We wanted to make sure our members know that even though we cannot meet up like normal we are still interested in each and every one of them. Our engagement on our Facebook page was phenomenal. On one post we reached 24.2K people. We encouraged some families who have never been active before to take a real interest in the association.

My goodness we will have a great time when we all meet up again!

In the meantime for anyone who is not on Facebook here is a few snaps of some of our newest members that posted their stories. Apologies it is not possible to include everyone in this short article.

Linda Kane

> **We encouraged some families who have never been active before to take a real interest in the association**


This is Izzy and she loves to sing, dance and blow bubbles


This is Alfie, he loves traucks especially the Scania Fire Truck


Maddie is 5 and loves to sing, dance and play hide and seek


This is Claire and she loves baking brown bread and cakes


Jay loves the trampoline and being on YouTube.


Fia from Dublin and loves swinging and jumping in the garden


This is Ian and he loves music, cooking and airplanes


Darragh from Galway loves animals and especially dogs..


Aoife is loved by so many people. Yellow is her favourite color


Oscar is from Louth, he loves the piano and listen to music


Rosannah from Waterford loves chocolate and swimming


Elizabeth works in a hairdressing salon, she has a dog called Harry

My New Adventure

Ashleigh O'Hagan

I have recently changed training centers and I cannot wait to tell you all about it!

I had been with the Daughters of Charity since I was 8 and I made some amazing friends and grew up with them all, but in the last year or more I felt as though I wanted to see what else was out there so my mom went on the hunt for a new service for me and did she deliver!

I am now in a full-time day service in Killaloe which I absolutely love!

No two days are the same, with something new or different available to me each day. I have settled in so well and have made more great friends and the staff have been so supportive and helpful to me since my very first day.

We spend our days involved in art work, outings, shopping trips, lunch dates, baking, education, life skills and so much more. They also have discos regularly and anyone who knows me will know how much I enjoy a good dance!!

I'm really content and stimulated in my new service and I'm so looking forward to finding out what the rest of the term has in store!

The person responsible for these services in the HSE is called the Occupational Guidance Advisor. This is the key contact you need to make if you need your training services improved in your area.

Ashleigh

Special Arrangements for the WSI 2020 AGM

In view of the Covid 19 emergency it will be necessary to hold our annual general meeting via video conference using the Zoom AP. All members will be notified well in advance by post and email of the arrangements for the AGM. The email invitation will contain a link to the AGM meeting online. The meeting notification will provide detailed instructions on how to use Zoom to access the AGM. In addition the Committee will issue the Chairman's Annual Report and the Annual Financial statement for 2020 to all members. Members who are not in a position to use Zoom or would prefer not to attend the online AGM will have sufficient time to submit queries regarding the reports or to raise other issues in advance of the November meeting and these will be discussed and considered at the meeting.

Members will also have the opportunity to put their names forward for the Committee for 2021. Any proposals received will be considered as part of the election of the 2021 Committee during the online meeting.

The key dates for the on-line AGM are:

October 15th: Invitation to online AGM including: Agenda for Meeting, Minutes of the 2019 AGM, Annual Reports and Instructions for using Zoom

Saturday November 14th: Online AGM at 12pm to 1pm .

Williams Syndrome Ireland

Williams Syndrome Ireland
Carmichael House
North Brunswick Street
Dublin 7

Phone: Phone: 087 2398055
E-mail: info@williamssyndrome.ie

We're on the web!
williamssyndrome.ie

facebook.com/
williamssyndromeireland/

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