

WSAI News



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WISHES Book Launch Fionnuala Tynan

As some of you may know I am a Lecturer in the Department of Reflective Pedagogy and Early Childhood Studies at Mary Immaculate College (MIC) Limerick.

Recently I launched a new book, in conjunction with MIC, that has been described as “a must-have guide” for all parents and professionals working with people with Williams Syndrome.

The book is called *WISHES* – Williams Syndrome Holistic Educational Strategies. This is first book in Europe to be published on promoting inclusive learning in children with Williams Syndrome (WS). The book outlines a way forward for supporting learners with WS and moves away from a medical model of disability to a more holistic profile that acknowledges the biological, social and psychological aspects of learners with Williams Syndrome.

While primarily focused on learners of primary and post-primary school age, much of the book is relevant for younger learners and for those who have left school. The book’s underlying belief is that individuals with WS have a wide range of talents and learning abilities which need to be developed to enable high quality and lifelong learning to take place.

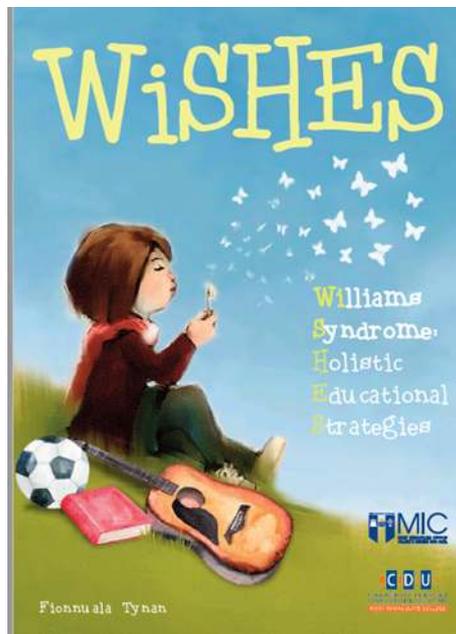
Williams Syndrome is currently under-diagnosed in Ireland – its rarity means that parents and

professionals often struggle to know how best to support the individual.

WISHES is full of strategies for promoting learning in all aspects of the child’s life. I have the privileged experience of having a brother with WS and the book is based on my personal as well as professional experiences.

WISHES is published by the Curriculum Development Unit (CDU) at MIC. I would especially like to thank my colleagues in MIC for a fantastic work environment that supports my work on behalf of individuals with WS.

This book was prepared over a nine-year period. At the outset I was working with parents, teachers and children with WS in 2009 and saying that the outcome of the research may not benefit them but that we were preparing for our next generation of children with WS, preparing a world to welcome them. The most moving thing of all was seeing all these beautiful, bright, energetic, talented children sitting in front of me, who I know so well and knowing that we know a little bit more about WS



Front Cover of *Wishes*

for THEM. That made me so proud. To all my friends in the WSAI, the parents, siblings, teachers, support staff, friends and staff of MIC who attended the launch, thank you so much for sharing this most special day in my life. All the children and siblings were given a medal which was engraved with ‘*I am inspiration*’. They inspired the book and will continue to inspire me I have no doubt. If you were unable to attend please contact me and I will send on a medal for your child. Thank you so much to all the members who sent on cards, notes and emails with their views on the book. I really appreciate your support.

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WISHES Book Launch In Pictures **A few snaps from a very busy day**



Picnic in the Park 2019

Ruth Hegarty

We will be holding our annual picnic in Newbridge Farm in Donabate on the 16th of June. This event has always been very successful and its sure to be well attended again this year. This is a fun day out for all the family and we hope that as many of you as possible will come along and support it. This year we are returning to Newbridge Farm as its very suitable for our younger members who will no doubt be seeing all the different animals that live on the Farm.

The Picnic will be held on June 16 and fingers crossed the weather will be good on the day to make it extra special. Entrance is free and the Picnic is open to everyone and anyone so bring along all your family and friends.



A Sample of Images from Newbridge House and Farm

WSAI Committee for 2019

Tommy Moylan

The 2018 Annual General Meeting was held in Mary Immaculate College, Limerick on the 24th of November 2018. The AGM was timed to coincide with the other WS related events held in MIC on that date. Many thanks to MIC for providing the venue for the AGM which facilitated a very busy schedule for WSAI on the day.

On the day, our outgoing Chairperson, Carmel Daly outlined that she was taking a break from the WSAI Committee for a while and we take this opportunity to express our sincere thanks for the fantastic work that Carmel undertook on behalf of WSAI our the last decade or so.

We would particularly like to express our appreciation to Carmel for her wonderful commitment and dedication to the Music and Activity Camp. She is of course a great loss to the committee, but not the association as she will continue to support the Association from time to time.

The AGM elected Mr. Stephen Langton as the new Chairperson. Stephen has had a long association with the organization having previously served on Committee for many years.

The full WSAI Committee for 2019 is as follows:

Stephen Langton (Chairperson), Pauline Leahy, Fionnuala Tynan, Debbie Brannigan (Secretary), Joyce Boggans, Philomena O’Hagan (Treasurer), Ruth Hegarty, Tommy Moylan.

Over the last few years we have also appointed Associate Committee members. This arrangement enables members take part in Committee work without being on the formal WSAI committee and without attending Committee meetings. For 2019 we are happy to say that Deirdre Graham and Helena Begley will continue as an Associate Committee Members.

New Venue for WSAI Music and Activity Camp

Debbie Brannigan

As most of you will be aware we have provided an annual Music and Activity Camp for WS adults for many years. This Camp provides a great social outlet for WS people over 16 years of age. The Camp has been held in the Share Centre in Lisnaskea Co. Fermanagh from the outset and this venue has proved very successful over the years. At this point the Committee has decided to seek a new venue and to freshen up the approach for 2019. The WSAI Music Camp 2019 will be held in Mary Immaculate College Limerick from **Monday the 5th until Friday 9th**

August. Campers will arrive Monday to settle into the apartments with classes starting Tuesday. This year will be a pilot run camp. It will be residential focusing on Music, Drama, Life Skills & Independence. As this will be a new venue and structure to our camp we appreciate your patience in our transition. As soon as the details are set in stone we will be contacting families.



Book Review—'You My Friend' Ruth Hegarty

This novel is written from the point of view of Grace, a young woman who, like the author's sister Cara in real life, has Williams Syndrome.

It is also a novel about growing up and becoming independent of your parents, both for a person with WS and for their siblings.

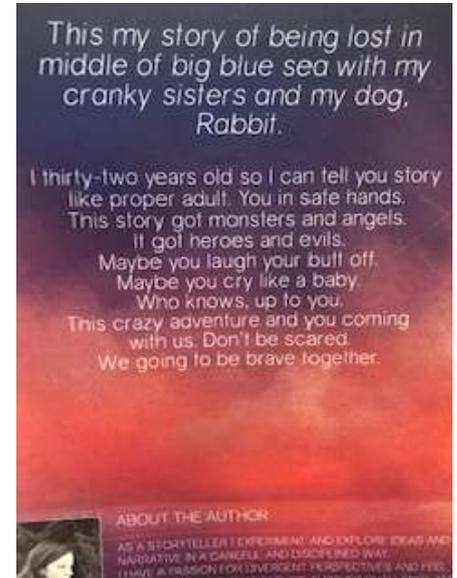
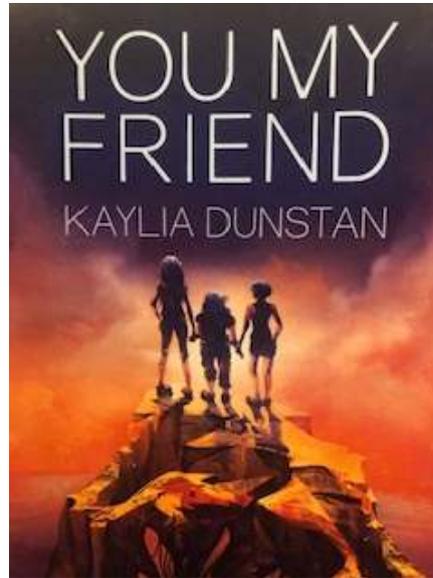
The story opens off the coast of Australia on a family sailing holiday that goes terribly wrong. When their parents go ashore to camp overnight on a deserted island, their three daughters, all in their thirties, remain overnight on board their sailboat, anchored offshore. They wake in the morning to find their anchor has slipped, and they have drifted far out to sea. They are lost at sea, and their parents are also marooned onshore.

Flashbacks to their earlier lives growing up show how their mother has struggled to cope with the responsibility for Grace, who has WS, as well as her sister Mya, who has emotional problems, all without much support from her husband.

The story is narrated by Grace. While their boat drifts, she is frantic that the 'Scarywary', a creepy monster figure that for years has embodied all her fears, will emerge from the sea to finish them all off. Her only comfort is her little dog, Rabbit. After weathering a storm, they hit a reef and are shipwrecked on a mountainous island.

The main part of the story deals with how Anna, her younger sister, takes on the role of parent, grimly coping with the practicalities of finding shelter and food for them all. They find a mysterious cabin with some food in it, which seems to have been abandoned only recently.

A rift soon develops between Anna and the



'You My Friend' Front and Back Covers

eldest sister, Mya, who has long struggled with depression after the breakdown of her career and marriage, and refuses to help build a signal fire, or to take on responsibility for Grace's safety.

Over the days, Mya emerges stronger, especially after an injury puts Anna out of action. She is forced to step up, and learns to cook and to catch fish.

All along, Grace is dealing with the situation in her own way. She befriends some wild deer, falls in love with a scarecrow figure, and even makes another secret friendship of her own.

Mya helps her to deal with her fear of the Scarywary, and Grace in turn helps Mya with her fear of swimming, meaning they can now catch fish to survive. They rely on each other.

It is a gripping read, if a bit overlong, and the flashbacks to home life provide relief from the tension on the island. Grace's simplified language takes a bit of getting used to, but her sisters' speech is represented clearly so we can keep track of what's going on.

The author is originally from Australia, where the story is set, but now lives in Scotland. In the foreword she says that her aim in writing this book was to explore the need for friendship, love and connection felt by all of us, but particularly by people with WS. It's also a book about growing up and away from our parents.

It's interesting to see WS represented on the wider stage. If anyone would like to read it, it's by Inquiry Press, or I can send on my copy to you if you email ruthhegarty@yahoo.com

Weekend Break 2019 Pauline Leahy

This years weekend break will be returning to the Galway an always popular destination for Spring weekends. This years get together will be held on the weekend of **26th April 2019 at the Connacht Hotel, Dublin Road, Renmore, Galway City.** This is our oldest and most popular event and is a great way to meet other families affected by Williams Syndrome who are more that happy to share their experience of living WS on a day to day basis. The weekend will begin on the Friday

evening with an informal get together for families to sit, relax and have a cup of tea or coffee. On Saturday we hope to organize some events during the day for families who can opt to attend these events or do their thing if they prefer. In a city like Galway there will be no shortages of attractions for all tastes. On Saturday evening we will hold dinner for all WS families attending which will again provide lots of opportunities for sharing experiences. We hope to see you there!



First National Symposium on Williams Syndrome Tommy Moylan

The First National Symposium on Supporting Individuals with Williams Syndrome was held in Mary Immaculate College, Limerick (MIC) on Saturday 24 November 2019. The Symposium was organised by Fionnuala Tynan with the fantastic support of MIC and was attended by families with an individual with WS and also teachers and education support staff from around the country. The Symposium consisted of a series of talks provided by:

1. Fionnuala Tynan
2. Orla Murphy
3. Anne O'Byrne
4. Jean Reale
5. Orla Murphy and Fionnuala Tynan

These presentations were delivered in two streams one aimed at parents of children with WS and the other stream focussing on the needs to education professionals who work with children affected by WS.

Adults with WS had a day of activities to themselves and greatly helped with the preparation of the book launch. They developed beautiful 'WiSHES' of their own for parents and teachers which adorned the entrance to the room where the book WiSHES was launched.

FEWS Update Fionnuala Tynan

The WSAI is a member of the European Federation of Williams Syndrome. The representative of the WSAI is Fionnuala Tynan who took over from Ann Breen. There are a number of updates on this front. FEWS is currently working with new associations in Eastern Europe to ensure individuals with WS can get high quality supports in line with their needs. To this end, FEWS members will meet in Serbia next October for the AGM. Dr. Fionnuala Tynan will present to parents and professionals on educational support while Dr. Debbie Riby (Durham University) will give a workshop of anxiety in WS. Last October FEWS members met in Norway and visited the Frambau Centre for Rare Diseases (see <http://www.frambu.no/>). This centre is a model for what we would all want in terms of support for a whole family when there is a diagnosis of a condition such as WS. The centre takes a family for a week and the child meets

Younger children with WS and their siblings (U-16) were provided with a range of activities including art, music, drama, dance and time in the sensory room.

A team of student teachers looked after the children while other student teachers co-ordinated the programme for the adults with WS.

Some of the Key Topics Covered Included:

'Is Williams syndrome a disability?': How people with WS perceive the condition

Supporting Positive Behaviour in Children and Adults with WS through Collaborative Proactive Solutions

Developing Dynamic Parent-Professional Partnerships to support Individuals with WS

Harnessing the Power of Everyday Technology for Learning



Parallel Session at the Symposium for U16 WS Children and their Siblings

Understanding WS: Meeting the needs of professionals to meet the needs of clients

A big thanks you to Fionnuala and all the team at MIC and to all the WS families who attended. A special vote of thanks to Adapt-Pharma and PRISEM (Mary Immaculate College) for funding the National Symposium on WS.

If you would like more information about any of the topics discussed at the Symposium just get in contact with Fionnuala or WSAI. .



Research Fionnuala Tynan

I am currently looking to work with parents of children with WS under the age of 5 so that we can look at producing a book, like WiSHES that can support younger children. As parents of newly diagnosed children tend to make contact with the association but don't usually come to WSAI events at first I would be very happy to meet with parents in their homes to talk about their needs and to provide support for their child.

Please contact me if you feel you can support this research (086-2063773) or fionnuala_tynan@eircom.net

psychologists, specialised teachers and other therapists while the parents are given information and support. Siblings are also catered for, as are grandparents! It is hoped that the centre in Frambu will be the venue for the 2020 FEWS Summer Camp. FEWS is looking for a permanent holiday destination for adults with WS. This is being actively pursued.

FEWS is also organising a photo contest. The theme this year is HAPPINESS. Please send on your entries to Fionnuala Tynan who will forward them on your behalf. We'd love to see you supporting this competition (and we all know you have photos of your family member with WS on the theme of happiness!!!).

If you are interested in seeing more on the work of FEWS please see <https://eurowilliams.org/>

Junior Camp and SCAMPS (Summer Camp for Siblings) 2019

Fionnuala Tynan

MIC is again home to our Junior Camp for children with WS and their siblings. The Camp will run from **29 July to the 2 Aug.** MIC student teachers volunteer at this camp and can use it in tandem with the summer camp for adults with WS as their alternative education experience. The junior camp is used to build on the children's skills and develop individualised approaches to support their learning. The day is highly structured with a focus on developing age-appropriate fine-motor skill development, handwriting to music, gross-motor skills, singing and music, relaxation, social skills, emotional regulation and life-skill development. We use a variety of approaches including TEACCH, social stories, visual scheduling and music therapy. Each child has an individual education plan for the week and a follow up report which parents can share with their child's teacher. Last summer some children took part in research on self-perception of WS and this summer we hope to build on this research with any children who are interested (with permission from parents!). If parents have specific issues they would like support with, we are happy to try to address it at camp. IN previous years this has included anxiety management, tolerance of certain sounds and anger management. As many families go to Limerick for the week for their child to avail of this camp a small subsidy will be offered to families this year towards accommodation/travel costs.

The Summer Camp for Siblings (SCAMPS) will also run at the same time. This is run in a very different way to that of the juniors as it is not skill focused. This allows the siblings to



Some of the Children at Last Years Junior Camp

forge links with one another in a very natural way, to share interests and to get to know one another better. They engage in sports, art, crafts, music and dancing. The siblings are also invited to take part in research to talk about their experiences of having a sibling with WS, with permission from parents. Many of the siblings, particularly the older ones, really enjoy this experience as they can articulate their feelings in confidence and share the emotions that go with being a sibling. This year we have a student who volunteered last year and who will be a qualified teacher by summer, who will be in charge of this camp. Emma has huge

experience of summer camps and will know the siblings from last year and organise a greater variety of activities that we had last year.

We'd love to welcome back our junior camps and our SCAMPS! this year. We'd also love to welcome some new campers. Please make contact to let us know if you are interested to ensure we can recruit an appropriate number of volunteers.

A big thanks you to MIC for once again hosting these camps. It saves us a huge amount of money as an association to have the support of MIC.

Summer Camp for Teenagers 2019

When the first summer camp for juniors was introduced there was some interest by teenagers but very few signed up and those who came, came on different days and ended up doing the same activities as the juniors. To acknowledge our young adults I would be delighted to run a parallel camp for teenagers this summer if there is enough interest. It will be open to teenagers from the ages of 13-19 and will be developed in line with the interests of the teenagers as well as having some focus on skill development. Please text me on 086-2063773 if you are interested at this point.

Thank you!, **Fionnuala**

Literacy School for Williams Syndrome

Fionnuala Tynan

Following on from research with parents and individuals with WS, it has emerged that literacy is sometimes an area that is underdeveloped in WS. The learning profile in WS does not indicate an inherent inability to read so I believe that all people with WS should be able to read to at least some degree in line with their cognitive ability. To this end, I am establishing a literacy school for individuals with WS. This will once a month on Saturdays. It will involve individual assessments and teaching approaches to start with. In time, it is envisaged that some individuals may be able to work in pairs or small groups where their abil-

ities and needs are similar and complementary. I will be able to work with 7 individuals for one hour once a month. All expressions of interest will be considered but priority will be given to adults with WS who WANT to be able to read better themselves. This will feed into a research project on literacy development in WS. The first two sessions will be on Saturday 6th April, Saturday 11 May, Saturday 8 June. If you are interested, please contact me and I will send on an application form (086-2063773) or

fionnuala_tynan@eircom.net