

## Things to celebrate

**Emboldened as the newly elected president of the Williams Syndrome Family Support Group (after being elected in my own absence, and unanimously, against such a hot field of contenders), I decided to take a risk and go out on a limb.**

I wanted to suggest that our group consider having a year where instead of focusing largely on 'supporting' families with kids with Williams syndrome, we focus on 'celebrating' the richness that these children bring to our lives and our families. This would coincide with the 20th year of the group—which in itself is an event to celebrate.

By way of example, let me share some of my experience of our daughter Mairead. It's true that we had three very ordinary first years of her life, with lots of health issues and lots of cleaning up vomiting, worrying about major intra-thoracic surgery and grieving over the 'able' child that we didn't get and feeling sorry for ourselves. But I won't bore you with more of that.

The other side of the story that I wish to emphasise here goes a bit like this ...

I just spent two fantastic days over last weekend with my two girls, while my wife Grainne went horse-riding. When she got back and we were lying in bed on Sunday night, Grainne asked me, "What was the best part of the weekend for you?"

Without having to think, I spontaneously replied, "The two hours from 5.30 to 7.30am on both mornings when Mairead crawled into my bed. She laughed and giggled and tried to wake me up. She poked me in the eyes, crawled all over me, sat on me and pestered me with melodic commands of, "Time to get up Dad!" and questions about what we were going to do today."

Every time I have Mairead to myself for a whole weekend I spend the rest of the week buzzing around on a high and you can't wipe the smile off my face. She makes our holidays together as a family sparkle with warmth.

The joy and delight on Mairead's face when she achieves something that most of the population takes for granted is just so infectious and so incredibly inspiring.

Nobody inspires and moves the three of us like she can. No-one, and I mean no-one, in our entire extended family or friends has the



Mairead

ability to lift the mood of myself, Grainne, and sister Miranda like Mairead does. She can bring a smile to our faces when there is nothing but tears and pain on our faces. She can do it to all of us.

Mairead lights up the life of my parents. She gives a massive amount of meaning to the life of my sister Tanya. She warms and blesses with richness the life of her adopted grandmother 'Kat'. Her teachers write comments in her communication book such as, "Mairead, you give me laughter everyday I come to work." She is adored by her interchange family who has a daughter Olivia who can't get enough of her.

Her sister Miranda is constantly smothered with love by her and Miranda finds it really difficult to understand her friends who have problems with their siblings. Miranda feels genuinely lucky to have the sister she does and many (though not all) of her friends feel she is lucky too.

She rains affection on us all and we love it. Sometimes I try to imagine a life if she had not been born and it was just Grainne, Miranda and I in the family and the thought of it just makes my eyes go all wet. It is hard to imagine how much poorer that life might have been.

Mairead is adored and enriches the lives of everyone she comes into more than passing contact with. This is not something that she does 'almost as well' as an able child. She dramatically changes the lives of people where no-one else could. I celebrate that.

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Then there is a whole other conversation to have about the personal growth that we get out of facing the challenges she throws up for us.

I know from my contact with the Williams Syndrome Family Support Group that Mairead isn't alone. And I don't want to pretend there is some exclusivity about Williams syndrome that can't apply to all other children with disabilities. I believe our kids deeply enrich our lives and the lives around us—but I suspect sometimes we all forget to be open to seeing that as clearly as we could.

The very name 'support group' and the use of language around children with disabilities implies a sense of neediness and taking, of negatives and disadvantage. While I don't want to pretend that there are no difficulties or hardships, I also want to recognise that sometimes the conversations and contexts can become a bit lopsided.

I am not talking about marvelling at their music abilities or at their abilities with language compared to their peers. I am talking about the genuine enrichment of our lives, and their siblings' lives, compared with not having had them at all or even compared with having had a perfectly able child in their place. This is not a conversation that you often see in the world of disability and yet I think it is a blind spot of our culture and one we are all the poorer for having.

One thought I had was to propose changing the name of the group to the William Syndrome Family Friendship Group (WSFFG). I think this more accurately reflects what the group is and how it behaves while at the same time removing the potentially negative implication in the name of having a child with Williams syndrome. I think the vast majority of us get together for the friendship—not out of a need for any great support.

If we want to expand our membership, if we want to keep the group vibrant, alive and growing I think that some time spent on celebrating our kids can only be helpful to this purpose.

After a year spent focusing on letting each other know how wonderfully our WS kids have touched and enriched our lives we might just become a group that everyone wants to become a part of and is extremely proud to be a part of.

**Des Darrer**  
(Exceptionally proud father of Mairead)

This is an edited version of a piece Des wrote for the Williams Syndrome Family Support Group newsletter.

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## About Williams syndrome / disability specific support groups