

A sibling's perspective

By Hannah Smith

I've thought so much about what I'd like to say in this piece. I've sat and tried to imagine who would be reading it and where they would be reading it.

Is it another sibling reading this in the newsletter? A new parent looking on the website? A friend? A stranger? It's been hard to know how to write this without knowing whom I'm addressing. In the end, I've decided that I'm just going to start writing and see what happens!

One thing I want to be quite clear about is that I don't want to be representing anyone. I am Erin's sister and will talk from my perspective, but I'm not writing on behalf of all siblings because I really believe that we all have our own story and our own feelings about Williams Syndrome.

As I get older and go into new stages of my life, I feel like I'm always changing my mind about what Williams Syndrome means to me. And I really mean - what Williams Syndrome means to me. I'm not going to describe what it's like to have a sister with Williams Syndrome because as a 21 year old, that is not the biggest issue anymore. I'd like to describe what Williams Syndrome means to me. What my life is like because of the existence of the Williams Syndrome Family / Friendship Group. (I really like the suggested new name and totally support the encompassing meanings!)

When I was in my young primary years, I didn't really understand why every so often the family would jump in the car and head to a park or a big place with trampolines and bikes. I just knew I was in for a great day! I knew I'd see those friends that I didn't see too often.

The friends that, without ever having to talk about it, just connected with me. I don't know how old I was, but at some point I became a lot more conscious about why we were all meeting. Of course, I always heard the words Williams Syndrome, and could see clearly that there were other kids 'like Erin', but there was a vague point where I became aware that this didn't happen to every family. Not every family spent weekends away with indoor pools and cave exploring. We got to do this for a reason! With this newfound understanding, my relationships with my old friends changed. We started talking about what

our brothers or sisters 'did'! We shared embarrassing stories and had some laughs, but most of all we were just aware of each other in different ways.

The Williams Syndrome Family Support Group has given me the chance to be different. A place where I'm Hannah, I believe with my whole heart that I wouldn't be the same person if I did not have this opportunity. The opportunity to meet with amazing people and the chance to know what it feels like to truly belong to something special. This feeling has been so significant in my life. Like everyone, I've had difficulties at school, or work, or other aspects of my life. I've also met some really diverse people with very different opinions, including opinions on disabilities. I can be confident when I speak and when I act in so many situations because of the self-confidence that has grown in me. I truly believe that this self-confidence and esteem has been nurtured by the WSFFG.

I'm currently on a break from my Bachelor of Applied Science (Health Promotion) degree at Deakin University. When I graduate, I will have a major in Disability Studies. University has been a great forum to really start to identify how I feel about Williams syndrome and what 'disability' means to me and to our world. I feel confident that I have so much to offer!

Even though I made the point that I'm not speaking on behalf of other siblings, I'd like to take this opportunity to just say - I am very proud to be a sibling. When I think about who else is a sibling, I just smile because the name 'sibling' means that in some way, we are categorised together. Not in a negative way that can often be associated with naming or categorising with disability, but in the most positive way. Like being on the same team. In some way, I can stand up next to them. I am proud when I think about the brothers and sisters that grew up with me, and inspired by the new ones I meet and see at the meetings now.

I really feel a responsibility to the WSFFG. I believe that when I go to a Picnic Day or a camp now, I have the chance to create a positive experience with someone younger than me. A gift that I really treasure.

"Thank you" to my parents and the generation of parents who created the Williams Syndrome Support Group.
"Thank you" to the new parents, who are leading "our" group into the future, - it is exciting to be a part of this!
.....Hannah