

Sam (ML3) was 12 when we attended the ISMRD conference in St Louis.

There were approximately 20 people present who are affected by ML2/3 and ML3 from USA, Canada, Australia, New Zealand, Norway, Ireland and England. It was lovely to meet Sarah Burgess from Luton who has ML3 and Aoibhe O'Connor (ML2/3) and her family from Ireland. We didn't feel as much alone from a tiny island in the North sea.

The trip and conference were a success to both Sam and myself as it gave us chance to speak to others who are affected by Mucopolidosis, share our life experiences and generally just let Sam and the others be themselves. The age ranges were between 4 to 40 years of age. Sam made friends with mainly the lads/men and boys of course. They compared wheelchairs, who's was the fastest? Whether they could make a fist, or put their knees together? Who had had the most operations and who had recovered in the quickest time! They also just talked about sports, sweets and music like most people do.

The lads I expected Sam to 'hang out' with, were, when I thought about it, young men in their 20's, (Matt, Joey and Lonnie) and what would they have in common with Sam. They just still looked youthful, but they were lovely guys who were setting a positive example to Sam in that they were doing their best to remain mobile, still studying at college, and wanting the same things in life as their friends and siblings. I suppose it was like a sneak peek at the future for Sam. In the main, Sam played with kids his age, (Tyler, Robert- Mary's brother) generally causing havoc playing indoor tennis and squashing balloons.

I gained a lot from speaking with the families of those affected. Many of them had met previously and were very supportive and friendly towards the new comers. At times I felt rude asking lots of questions, but I suppose they knew I needed answers and they could tell me from their experiences.

The speakers at the seminars were also very down to earth and approachable. I don't confess to understanding everything they were discussing, but it was all relevant to ML and in some cases supported my sketchy previous knowledge.

After the first meeting, I asked Sam what was on his mind? How did he feel about meeting people who had the same condition as him? He thought about it, then said- 'You said I couldn't have piercings and tattoos! Some of those have!' I suppose you can never tell what people really are thinking about unless you ask them.

Sam enjoyed the whole experience and enjoyed making new friends who I'm sure he'll meet up/contact again in years to come. There was only one little blip where he asked me if he was going to end up in a wheelchair all the time. I said there may be a possibility, but if he let us help him make the right decisions, we would help him to stay mobile for as long as we could. His little face creased up and tears came rolling down, but within 30 seconds, he pulled himself together and carried on eating as if it didn't apply to him.

You could tell 'The Board' had put in a great deal of care, work and attention to detail in to bringing the conference together, which I guess isn't an easy task when you're nearly all in different continents. Thank you!

To conclude, the ISMRD conference was a success for us both in giving us a bit more confidence and knowledge about the condition. We had a lovely time getting to know each other a bit more and realising that we both have a dry sense of humour which we probably don't appreciate at home when all the other chores that get in the way.

Thank you to the 'Penguin family' for being there and helping us share.

Shirley and Sam Jamil