I am number 17
Chloe and Ronnie's experience

Ronnie has MPS II, which is also known as Hunter's Syndrome. We found out whilst he was getting diagnosed for autism through blood and urine tests which kept coming back inconclusive, but it wasn't, it was just that it was so rare that they couldn't match it. He doesn't look like he has MPS II, which can lead people to have a characteristic look, like some of the other children do and so they thought it couldn't be. How I describe it is that he doesn't have a bin ban, so he has been born without an enzyme in his body that filters out toxins and waste. If we didn't have a bin bag our rubbish would just pile up and pile up until it was overflowing into the garden, it would take over your house. He doesn't have a bin ban, so he doesn't have anything to filter out the waste in his cells. His treatment helps clear out some of the waste products, helps clear the storage, and stops his bin bags piling up. Rebecca came into his nursery and described it that way!

Before he started his treatment, he stopped walking because his hips were so sore, his knees were sore, he had hearing aids because he couldn't hear, he couldn't speak at all. He was tired and he was going to bed all the time, but for a three-year-old he should be running around all the time, he shouldn't be like that. If he didn't have the treatment he has now, he would be a lot worse than he is, so we're thankful, and grateful that he does have it.

The process from diagnosis to access to getting proper support from the MPS society was amazing. I remember phoning the hospital crying when we received his autism diagnosis. I said, 'he's not walking' 'this isn't autism, you don't not walk because you're autistic' 'It's like he is dying'. The doctor said, 'we have some results will you come in on the 22nd August', and I said I was not going to wait that long. So, she said come in today at 6 o'clock. At that point we knew that something was wrong, and straight from then they put us through to the children's hospital. From there it was quick; he started his treatment a few weeks after and he was there until Christmas. I cried when we started having to have the access from home because we had become so close to the nurses there; we had to come into the hospital a couple of times a week for the treatments, which took all day, and so they were just like our little family and it was amazing. Then they started accessing him at home which turned out great. So, everything went smoothly. The MPS Society came into his nursery and spoke to the workers and anyone else who wanted to listen, and they talked about what it was and how it would affect him. The MPS II nurse at the children's hospital even put me in touch with another mum so I could speak to her about things, because I had no idea what it was beforehand. I honestly couldn't not have asked for better. We didn't have to wait; the longest wait was diagnosis, which was about a year, which for this is quick.

Ronnie does also have an autistic diagnosis as well as an MPS II. We had the MPS II diagnosis on the 16th July 2016 and the autism diagnosis on 6th September 2016. We were actually moving to Australia before we got the diagnosis of his condition, so we had been over for three weeks to look at all the schools, my partner had passed all his tests to be a carpenter over there, we had spent a hell of a lot of money and we were going the November of 2016, but then we got Ronnie's diagnosis in the July so we couldn't go because they wouldn't treat him over here because it is a pre-existing condition. We had moved out of our house as well, so ended up living at my dad's. Mike has fallen out with Australia massively as a result, but I absolutely love it and if I could go, I would go, but obviously his health is more important. But overall it was really smooth, they were really helpful, and I couldn't be more grateful for that.

There is such a large spectrum with his condition, because there are children much more severe than Ronnie and children that are much less severe, and we are really lucky that there is a treatment available because for some rare conditions there aren't. We were unlucky that someone in my family knew that their son had it and didn't tell us so I wasn't tested as a child so I had no idea that when I was going to have children they could be born with MPS II. So, if there is anyone in your family that does have anything like that you do really need to make other people aware, so you don't end up in the situation we've been in. I think that's really important.

There are 9 children in his class, and you have to put all this paperwork together to fight for his place, to prove to the panel that mainstream school is not for him. He was one of the children that was on the border so I wasn't even sure if he would get a place. He would be very unhappy in mainstream school and I would be unhappy. He loves school now. There are other people in his class with similar conditions. They do baking, re-bound therapy, there is loads of stuff he does that he wouldn't have access to at a mainstream school.

We spend a lot of time in the hospital. Our doctors won't see us, and walk-in doctors won't see us because they have no idea about the condition. They often have to google Ronnie's condition whilst we are with them. We just get sent to hospital. We were in hospital two weeks ago because he had a chest infection and the walk-in centres sent us to the hospital. It's really just to cover themselves because they just don't know, because it's easier and that's where the specialists are.

We have had continuity in our care from the beginning. We also have a load of tests every 6 months, and I see the same consultant every time, the treatment at home every Tuesday is the same. His MPS II nurses and consultants are amazing. I know that is I ever needed any help or support they would be there.

There are many challenging aspects of Ronnie's condition. The first challenge was diagnosis. I knew there was something wrong, but the test results just kept coming back normal. Other issues included difficulty accessing things that you're entitled to benefit wise; they make you go into so much detail which you don't really want to have to go into because you're entitled to it. That's another battle. Getting into the school that Ronnie's in now was a challenge. Having to prove that I deserve my place there is not something I feel like I should have to do. Another is access on a Tuesday. I have to have treatment every week which is probably the worst part because he hates it. A nurse comes every week and he has his treatment. He can't access it at school, so he has to come home and have it and then get back in. Day-to-day things are a struggle, for example we couldn't find the lift this morning, so we had to put his pram on the escalators. There are so many things that you don't actually think. He speaks his mind for example, and sometimes you think 'he should not have said that', sometimes people will look at him funny. I have gotten over that, but he doesn't like it. For example, if he screams of says something out of turn. I'm used to it because I am with him all the time, but, when you look at him it doesn't look like he has a rare condition, it doesn't look like he has much wrong with him, and so people just think he is just being naughty. So, these are just a few of the things we have to face. People shouldn't judge somebody just by looking at them. We get filthy looks off so many people, and before we had Ronnie, I would have been one of those people. People just think he's naughty or rude. I wish I could take that away from him. Luckily, he doesn't know any different, he doesn't see people looking at him. People need to think before they judge.

I would like to raise more awareness of the different conditions really and to make it easier for people to get diagnosed really, so you don't have to wait so long and push so hard and fight for everything.

-END-