## Zoe by Angela

When Zoe was born in April 2016, like many people, we had never heard of Prader-Willi Syndrome. After a ‘normal’ pregnancy and a ‘normal’ birth we were sent to the ward with our quiet and sleepy baby. After about 12 hours when Zoe still would not feed, hadn’t cried and had only opened her eyes a couple of times, the maternity staff began to share our concerns and Zoe was admitted onto NICU.

We spent 18 days in NICU whilst tests were run and we desperately tried to coax Zoe to suck from her bottles, celebrating every extra millilitre she would drink. Results started to come in negative and each was a relief, however, we were still in limbo and looking for answers.  After a confusion with her test results which meant they had to be repeated, we were sent home when Zoe was 19 days old. For another few days we lived in our bubble at home with Zoe and her big sister. Then we got the call to say the results were in and the hospital wanted to see us. The hospital would not tell us what they had found but in our hearts we knew what they were going to say.

The diagnosis meeting went by in a blur. We were handed a leaflet and told we would get follow up appointments from a variety of other professionals. At that point all we felt we had was internet searches and the ‘list’ of potential symptoms and problems that came with PWS seemed to get longer with every search. Looking back now this was one of the worst things we could have done. The majority of information online was outdated, insensitive and unhelpful for new parents looking for support. However, the internet isn’t a bad thing when it comes to PWS research, we were just looking in the wrong places!

We then stumbled upon another PWS parent’s blog and suddenly PWS seemed to be something that could fit into the real world and the future started to look different from the brick wall we felt was put up at diagnosis. Over the next few months we reached out to PWSA and joined social media groups. These steps were a game changer to us and it felt like we were no longer the only family dealing with this ‘new world’. Other people were dealing with PWS, jumping it’s hurdles, celebrating achievements and supporting each other when necessary. We didn’t do this until Zoe was around 8 months old and I wish we had done this sooner as it opened up another world to us and a realisation that others were doing this and so could we.

Zoe is totally amazing. She is funny, bright, chatty, determined and so caring (she gives the most amazing cuddles and high fives). She has had issues with her mobility and getting her on her feet has been a big challenge but her courage and persistence is so inspiring and we couldn’t be more proud of her. Zoe can charm a room of strangers and even at age 3 has an

awesome sense of humour. She adores her big sister and the feeling is mutual. We have worries that a lot of parents might when it comes to how having a sibling with PWS will affect other children. However the bond they have and the love they share is beautiful.

The world of Additional Needs is a new one to navigate and sometimes it can seem stormy, however it's important to remember that you aren't alone. Whether it be reaching out to other families, professionals for their advice or PWSA for their support, there are lots of people and places who are on your side. We've recently been working on ensuring Zoe gets the correct support for school and we've had amazing support from PWSA and after a quick ask amongst other parents we had lots of examples of support other children had in place to guide us.

So for any newly diagnosed families, always remember you are not alone. It may feel now like your world has changed, and it has- but in an amazing way. No two people with PWS are the same. The symptoms of the condition all fall on a spectrum and affect people in different ways but also your child's own dazzling and individual personality will melt you, inspire you and make you so proud. You've just met a real life superhero!