



CHRISTOPHER'S STORY

Christopher's story started in January 2019 after having an undiagnosed strep infection. After various trips to the doctors over the coming weeks, we kept being told it was a viral infection, however we soon started seeing behavioural changes and sensory issues.

It quickly became apparent that something awful was happening to our son. Within the space of 2 weeks, he developed a body tic, verbal tics, memory issues, anxiety, OCD, he became withdrawn at school and his behaviour was awful. Our son was changing right before our eyes, and we did not know what to do to save him. It was clear some sort of neurological problem was occurring and we had to do something quickly. We immediately started researching into what it could be and came across a disorder called PANS/PANDAS on a charity site.

PANS and PANDAS are conditions causing inflammation in the brain resulting in neuro-psychiatric symptoms such as OCD, tics, eating disorders and anxiety along with many more. Our son had all the symptoms, and the guidelines stated this disorder can be brought on by a strep illness. We knew he had been unwell weeks prior to the onset of all these symptoms and that this was what had caused these problems. We immediately went back to the GP with all the charity's guidelines on what to do and the protocol that should be followed if PANS or PANDAS is suspected. We were not going to be told it was a viral infection again and was prepared to fight for our son. Luckily, the GP we saw this time knew exactly what we were talking about and had trained in paediatrics. He gave us two weeks of antibiotics and blood forms to get the necessary tests done. We were also referred to an NHS paediatrician.

Within 3 days of Nurofen and antibiotics Christopher's speech started returning to normal, his behaviour became more rational, the anxiety was better, and his

body tic was not as frequent. We knew this was only just the start of our journey and we had a long road ahead to get him back in recovery. When researching it became apparent that the sooner, we got help the better the outcome would be. The soonest NHS paediatrician appointment was 8 months away, so we arranged to see a private specialist who could help us. This was the best thing we ever did. We came away with answers to what was happening and a care plan, which our GP follows. At present we are still waiting for our first NHS paediatrician appointment.

Our PANS/PANDAS journey is now over one year in and far from over, we experience flares with any sort of illness or allergy. These flares can last for weeks or months and as parents we are still learning. As soon as something stimulates Christopher's immune system the various symptoms creep back. Generally, the first thing we notice are the tics, which are different each time and then the other symptoms start. As parents we are on constant red alert and this disorder has been hard on the whole family. We have sought help from craniologists, therapists, and nutritionists. We have done constant research into what else we could or need to be doing to get him back to baseline.

We do have setbacks, which just knock us down, but we get back up and fight. I admit we have been lucky, thanks to the charity guidelines Christopher was diagnosed quickly. He received the necessary help almost immediately mainly due to us going privately to see specialists in this area. Many children have not been so lucky and are left undiagnosed for years, causing the symptoms and brain inflammation to be much worse. By the time they are seen or diagnosed appropriately it can be too late to pull them back to the way they were before PANS/PANDAS.

Christopher, who is only 8 years old, has found the whole disorder very hard to deal with. His anxiety can take over and he sometimes finds life very difficult. He has had countless blood tests and trips to the GP surgery. He has travelled to London and Birmingham to see specialists. He doesn't know when it will end, or if it will. He just wants to feel normal. He hates and worries about trying to hide tics from his friends, as he doesn't want to be seen as different. Seeing your child having to go through this is unbearable and heart breaking. You want nothing but the best for them and you will move heaven and earth if you need to.

What we have learnt from all of this is take each day as it comes as you never know what's coming.

PANS and PANDAS is still not a well know disorder and there are only a handful of specialists in the UK who understand the gravity of how serious it is. There aren't many doctors within the NHS who know what is and what to do. This needs to change!

Matt and Lisa Blyth