

In Conversation With Francesca and Pearl.



PANS PANDAS UK
awareness support education



PANS PANDAS UK had the privilege of interviewing Francesca Gallagher to learn more about her daughter, Pearl age 10, and their journey with PANDAS. We spoke with Francesca about Pearl's diagnosis, the impacts on their family, and to hear more about some of the amazing fundraising Pearl has recently done for PANS PANDAS UK.

**Can you share with me the journey of how Pearl was diagnosed with PANDAS?
How did you first notice something might be wrong?**

Pearl was 8 at the time. She went to bed one night completely fine. She came back down the stairs an hour later saying she just didn't feel right. She said, "Mum I feel scared, and I don't know why". I reassured her and cuddled her to sleep which I had never had to do before. I thought nothing of it and then she woke up the next morning like a completely different child.

She was having full panic attacks, hyperventilating, hallucinating, and screaming crying and didn't know why. This went on all day long every day for the next couple of weeks and she was completely exhausted with it.



Written by Ceridwen Clark.

Ceridwen is a recent Sociology graduate from the University of Birmingham, currently undertaking an internship with PANS PANDAS UK.

What were some of the initial symptoms or changes you observed in Pearl that led you to seek medical attention?

She had never been anxious before; she didn't even know what anxiety was. She was such a happy, bubbly, confident child so straight away I knew something wasn't right. It was like someone switching personalities with her.

She said she felt sad and not like herself but she was so frustrated that she didn't know why she was feeling like this. She couldn't face going to school and didn't want to talk to any of her friends or even go out of the house so I knew I had to get help.



“ It was extremely difficult trying to be there for Pearl and to console her but still try to be a mum to my other two children. ”

How did you and your family feel when you received the diagnosis for Pearl? How did you navigate through those initial stages of understanding the condition?

I felt a sense of relief getting the diagnosis because then at least I knew I wasn't going mad. The more I read about PANDAS, the more she ticked every box and every symptom, but I was still worried in case she didn't have it, and we would be back to square one. I sat up until 2 to 3am every night researching it, learning everything I could and finding out what I could do to help her. When she got the diagnosis, I just read back over other people's success stories constantly and prayed that we could get her the treatment that would help her get back to normal.



Could you describe some of the specific symptoms Pearl experienced as a result of PANDAS? How did these symptoms impact her daily life and overall well-being?

The main symptoms Pearl had was she was so irritable she would just cry all day for me to help her. She couldn't sit still. Terrible panic attacks where she couldn't catch her breath for sometimes over an hour at a time and afterwards she wouldn't remember anything that she had done or said. Hallucinations, food restriction, rage.

The separation anxiety was so bad I couldn't even go into another room to talk on the phone without her following me, she couldn't be left in a room alone. She couldn't think straight or concentrate on

anything at all, she said she felt like her brain wasn't working properly. The thought of going to school used to terrify her. Even speaking the word 'school' in front of her would send her into a huge panic attack. We later realised that school was a massive trigger for her and once we stopped pushing her to go to school things got slightly easier because there wasn't as much pressure on her.

In what ways has PANDAS affected your Pearl's education? How did you work with the school to accommodate her needs?

Pearl missed around 9 months of school due to her illness. School have been brilliant and I sent them all of the information from the PANS PANDAS UK website so that they could learn for themselves and understand it better. I always felt like they might have thought I was making a lot of it up because Pearl masked it so well if she ever did make it into school, but then her headteacher came to visit us at home and he witnessed first-hand how bad things were.

Once he saw it for himself, he was so understanding and we worked together to support her once she was eventually back at school. She is still slightly behind in her school work but she is doing a great job catching up and after what she has been through, she has done amazing.

“ She said, 'Mum I feel scared, and I don't know why'... she woke up the next morning like a completely different child. ”

Can you share some of the challenges your family has faced as a result of your Pearl's condition? How has it affected your family dynamics and daily routines?

Pearl has younger twin siblings who were only 3 at the time and witnessed everything. They used to cry a lot because they were scared seeing Pearl in such a state. It was extremely difficult trying to be there for Pearl and to console her but still try to be a mum to my other two children whilst reassuring all three of them that everything was going to be ok (even though I didn't know if it ever would be ok again). I had to leave my job of 13 years to look after Pearl because she wouldn't stay with anyone else and I couldn't keep staying off work all the time.

We didn't really have a daily routine at one point we just had to take each day as it came and just see how Pearl was that day. If she had a bad day we would all stay in, if she was feeling ok sometimes we could get out but then had to come home because she would have a panic attack just as we were walking around the shops. Sometimes Pearl would ask me to just drive her around in the car because she said it made her feel calm, so we would drive for an hour and she would feel much better.

How have you sought support or resources for Pearl's condition?

I joined the PANS PANDAS UK Facebook support group and fell down a PANDAS rabbit hole! I learnt so much and found all of the best private doctors to go to and what to test for etc. I did my research and we decided to go to a private immunologist in London who has been brilliant.



Have there been any particular moments or experiences that have been especially difficult or challenging for Pearl and your family?

There was one time when Pearl was in such a state of rage, I called an ambulance just to see if they could try and calm her down because I was worried she was going to hurt herself. There were no ambulances in the area so they sent two police officers instead to check on us. Pearl saw the police and thought we had called them to take her away, and she was absolutely terrified. She was traumatised, and even to this day the thought of it makes her so upset.

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**Looking towards the future, what are your hopes and aspirations for Pearl?
How do you envision her journey with PANDAS evolving as she grows older?**

I would say Pearl is around 80% back to her normal self now, she does still struggle with certain things but when I look back at how ill she actually was she has done so well. I just want her to be happy and healthy as does any parent and I hope we can keep the flare-ups under control.

As she has gotten older and learnt more about PANDAS herself, I think if she was to have another flare now, she would be able to mentally deal with it a lot better as she is that little bit older now and more understanding of the condition. I can actually see Pearl being a PANS/PANDAS advocate when she is older as she is so passionate about it and wants to do as much as she can to help others and ensure children don't have to suffer as long as she did before being diagnosed and treated.

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As a parent, what advice or insights would you give to other families who may be facing a similar diagnosis or navigating the complexities of PANDAS?

The main thing I would suggest is just research into it as much as you can. Learn everything you possibly can. Unfortunately, at the moment the majority of treatment is private and expensive! It is so unfair that some families simply can't afford it but one thing I would say is to find the money that you do have because nothing hurts more than seeing your child suffer like that.

We were very lucky, and our GP agreed to run some of the blood tests and prescribed an initial course of treatment so it is always worth trying your GP first. There are some leaflets on the PANS PANDAS UK website that you can print out and take to your GP detailing the tests and treatments which might help.

How has your perspective on life, parenting, and health been shaped by your experiences with PANDAS? Are there any valuable lessons or personal growth that you've gained along the way

The main thing I have learnt from our journey is not to settle for what professionals say just because they say so. I was turned away from A&E about 5 times with Pearl. They told me she needed psychiatric help and sent me off with a load of CAMHS leaflets. They didn't do any tests or scans to check for neurological conditions. If you feel something is not right then fight for it. We had to go private in the end because no one would even suggest it could be anything triggered by an infection but it was worth every penny as I dread to think where Pearl would be now if we hadn't.

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What are some of the positive moments or achievements Pearl has had despite their condition? How do you celebrate and acknowledge their progress?

Pearl has been fundraising recently for PANS PANDAS UK. This is something she has always wanted to do to help other children and families. She has raised over £5000 so far and we are so proud of her. After all she has been through it is amazing to see how much joy she is getting from helping others.



Also, whilst she was ill Pearl took an interest in crystals. She used to say that when she was better she wanted to start up a business making crystal bracelets and that's exactly what she did. She now has a successful little crystal jewellery business with her best friend and they are doing so well. We are so proud of her.

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We would like to extend our heartfelt gratitude to Francesca and Pearl for sharing their story. Their efforts in fundraising for PANS PANDAS UK reflect their resilience and commitment to making a difference in the lives of others. It's thanks to brave people like Francesca and Pearl that progress can be made. Families are at the heart of the fight for raising awareness for PANS and PANDAS. If you have felt inspired by their story, you can learn more by visiting www.panspandasuk.org or by starting your own fundraiser or making a donation so that children like Pearl can get the support they need.

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