

## **PANDAS – a parental perspective**

### **Lecture in Stockholm and Lund, March 2013, Gunilla Gerland**

Some of you know may me from the autism field. I was as a young adult diagnosed with Asperger's syndrome, a diagnosis which at that point meant a lot for me as it offered an explanation of why I had been so different growing up. I wrote an autobiography about my childhood, and with time I started working in the autism field as a professional. Years went by and I outgrew my diagnosis, that is I did no longer in my mid-thirties meet the criteria for a diagnosis. How that happened, or why I could not explain.

Some more years went by and I became a mother. Knowing that autism can be hereditary of course I watched my son closely. I was not particularly worried as I did not feel that Asperger's syndrome is the end of the world. But still, as a mother, of course I hoped for him to have a normal development. Well, he met all the milestones as he should, he was a lot like me as a child but without the problems, you could say.

By this I mean he is quite intelligent (actually more intelligent than I am, I suspect), he was very early in language-development, learned everything very easy, and could read at four and write at 5.

He has always had friends and has functioned very well socially both with children and adults. He was an easy-going happy kid, and I was a happy mother. There was absolutely nothing about him that signalled autism, or any other psychiatric problem for that matter. So eventually I stopped looking for autistic traits, of course.

As a single mother I also put an effort in making him quite independent, I mean although we of course are very close, he had no problem with speaking up for himself, sleeping over at friend's, waiting for me while I went for groceries or similar things.

So last year in March, he was 8,5 years old, and we went for a vacation to the Canary Islands for a week. At the beginning of the week he was more in the pool than out of it, and after a day or two he complained about discomfort when urinating and he also had frequent urges to go. I felt he might have an infection, but since we were abroad, I decided to just buy some cranberry juice and see if it would disappear. He wet the bed two nights in a row.

On Friday March second, we were at the beach, and were done snorkelling. While waiting to be driven back to our hotel, we went to look for beautiful rocks and shells on the beach. Suddenly he started crying with an intense anxiety. When I asked him why he was crying it was because he wanted to take *all* the beautiful rocks from the

beach with him and he couldn't carry them. "They are on my brain" he said. "I can't let go of them, I have to have them all".

I found this odd, since both the crying, the anxiety and the unreasonableness were so out of character. I finally got him off of the beach and we went for an icecream. Now he had to save all the garbage, like the icecream paper, the straw from the soda, and during the following night and day it just escalated. I recognised this was OCD, after all I see OCD on a regular basis in my work, and I began to talk to him about that the only way of handling this is to try to resist what your brain tells you you have to do. I used cognitive-behavioral strategies, and got it somewhat under control.

But the situation felt absurd, I mean you don't just get OCD from from nothing like that at two a clock an afternoon.

Unfortunately he hadn't *just* got OCD, it was about to get worse.

Two days after this he developed a separation anxiety, if he couldn't see me he thought I had abandoned him.

Then we went back home, and now four days after the first OCD-sign he told me he was hearing voices, a male voice telling him he must die. He also had visual hallucinations. He saw arrows pointing him in directions where he should go.

At that point I called child psychiatry, BUP in Sweden, which offered me an appointment with a psychologist within four weeks. That would have seem like joke, if the situation hadn't been that serious. I felt my son had to see a neurologist very fast, something was obviously going on with his brain.

He deteriorated quickly. He now developed paranoia, thinking I was trying to kill him, and that his cousin was a secret agent. He spotted and reacted to cameras when we were out in the city. He called this his "suspicions".

His personality changed so that I did not recognise him anymore. I mean he looked like himself, but when I looked in his eyes it was as if there was someone else there.

I was terrified. It was the worst nightmare I have ever been through.

His OCD grew from hoarding to intrusive thoughts and anxiety that things might break. He wouldn't touch any of his toys, games or computer because they might break. If something broke – it could be just that I tore open an envelope while opening the mail – he would fall into tears.

He started chewing his clothes. He had his sleeves in his mouth constantly. He became motorically restless, and got insomnia, from he would go to sleep normally in 10-15 minutes from turning off the lights, it would now take everything from half an hour to two hours, always with intrusive thoughts about things that might break. He burped constantly for some days, and when I told him to stop he said he couldn't control it.

His hoarding started to grow to hoarding things from his own body, he wanted to hoard his finger nail clippings, the skin he picked off his fingers etc. I had to become an authoritarian cognitive behavioral "police" which is far from my normal parenting style, because I saw a future where he would soon enough want to hoard his feces and urine. This was tough. And without my own cognitive behavioral training I don't think I could have pulled it through.

Some nights he would twitch in his sleep in a strange way. The symptoms were constantly changing and as I said I didn't recognise him. What was the most heartbreaking part is that you always feel your love for your children is unconditional, right?

But I realised it is conditioned to "who they are". That is, the absolute automatic emotional love I have always felt for my son wasn't really there anymore, because this was suddenly another child, it is not that he was a sick child – or yes, of course he was, but it was as if he was replaced. I know, now it sounds like I was the one with delusions, and this is difficult to describe, but I would imagine that it is similar to having a loved one who suddenly develops severe dementia. So I had to love him "intellectually", that is to use my will power to love him during this period. And that was truly one of the most awful experiences I have ever had.

What did others see of this? Well, I did sent him to school most days because he seemed to be distracted in school showing less symptoms there. His teachers did however noticed his sudden difficulties with handwriting, with concentration and he had some severe meltdowns in school which were totally out of character. But they would in the beginning more think of this as behaviour problems, as him being difficult on purpose.

He was quite good at hiding his severe symptoms from others. I remember a weekend, I call it the weekend from hell. His OCD was so severe and when I used cognitive behavioral strategies his anxiety just peaked and he would go from hitting me, screaming at me to threatening to kill me, and then to threaten to kill himself. But this weekend we had some relatives over for lunch and at the moment they entered our house his OCD-related behaviours just stopped, and he was just as usual, and then the moment they left it was like he switched it on again. It was bizarre and surreal to watch. But this also meant that other people did not see all the symptoms I saw.

He would behave childish in a strange way, like a two-year old, you know when you call their name and they just set off in another direction, laughing. I suddenly found myself chasing him around as if he was a toddler again. He just wouldn't listen. I couldn't make contact as I normally do.

He would feel dizzy, have feelings that things were unreal. He for example asked me many times while watching tv "Mom, is this happening in reality or not?", something that had never occurred before PANDAS. He had joint and muscle pains coming and going.

He did also have manic episodes, and that is usually not considered a symptom of PANDAS, I know. But he would have huge pupils, he was chatting and laughing as if he had been drugged with something, and strange enough while these episodes lasted (before he would just crash in despair and tears over something) he actually wrote and drew, and performed physically and motorically, better than he normally does. I am telling you, this is a weird disease!

So, I did what most parents in this situation do. I googled. And googled, and googled. And finally I found out what it was. I found the NIMH page with dr. Swedos research, and there it was! He had PANDAS. There was absolutely no doubt in my mind.

By then I had gotten an appointment with a pediatrician, and I asked her to check him for strep. She had never heard of PANDAS, but took a throat swab. And yes he was positive. We were started on Penicillin. This was on March 17, 15 days after his onset. A week later we saw a neurologist, who confirmed the diagnosis of PANDAS and prescribed more antibiotics. He improved somewhat, but still had psychotic symptoms and the personality change was still there. I felt he must have an immunoglobulin treatment but the referral to the hospital that the neurologist had written was not accepted by the hospital.

"This was the strangest referral we have ever seen", the nurse said, and told me they would not admit him. I was desperate. I felt that my son was dying from me. This may seem overly dramatic, but that is how I felt. He wasn't dying physically, but he was dying as the person I knew. I also felt I had his whole future on my shoulders. This was my son who had, already at three years old explained to me how nuclear power stations work, who read Stephen Hawkings at six, and has decided to go to technical university, to become an inventor and then get the Nobel prize. Now he couldn't concentrate, had difficulties writing and was anxious about everything. The voice was there everyday in his head telling, him he was worthless and that he should die. He was aware that there was nobody there, and we talked about that his brain is playing tricks on him. But, as he said, "the voice is so loud so it is difficult not to

listen to it". And there I was, trying to not show my son that I myself was falling apart over his sudden illness. I couldn't work. I cried when he was asleep and I cried when he was in school, and in between crying I called every contact I had, every doctor I knew. I couldn't eat, I couldn't sleep, and I ended up, I think in a state of extreme stress which drained me of the energy I needed to help my son.

Of course, him becoming an ingeneer, or an inventor is not important to me, all that matters is that he is happy. But at this point I could only see a miserable his future as one of a chronic psychiatric patient. I just felt he HAD to have an immunoglobulin treatment. And I faught like a lion, and finally we got the right hospital and doctor, a doctor who listened to us, and beleived in us. At March 30 he was admitted for an immunoglobulin treatment.

It is given during two consecutive days, at hospital.

When he opened his eyes in the morning the first day after the immunoglobulin treatment, he was back! It was like magic. I looked him in the eyes and he was himself again! I can't really express the relief in this.

Then gradually after the immunoglobulin treatment he got better and better. He remained on full treatment dose penicillin though, since I noticed that if we just forgot one dose he would have these peculiar twitches at night again.

By July he had been symtom free for quite a while, and that time when he was so ill started to feel more and more like just a bad dream.

Without telling him or giving it much thought I decided we probably could go for a profylactic dose of penicillin, a couple of times per week, so I just didn't give it to him. After 24 hours without antibiotics he started to complain that his legs hurt and a couple of hours later he couldn't walk.

We ended up in the ER where – of course – there was nothing detectable wrong with him. He just couldn't walk normally. And as a parent it is quite stressful to both deal with the extreme worry you feel about your child, and all the raised eyebrows from health care professionals when they seem to think you or your child are simulating. I don't have time to tell you all my experiences here but just for short, another doctor, who did not even see him while he couldn't walk suggested it was "growth pains". Sure, I am the mom who rushes my kid to the Emergency Room for growth pains! I must say that the parental stress from dealing with this disorder is really truly *much worsened* by the ignorance from health care profesisonals.

Well, to make a long story short, back on penicillin and with ibuprofen it took five days and then he could walk again.

Now it has been a year. He is mainly symptom free but remains on penicillin full dose. He does get what I would call “mini-exacerbations” when something, like a virus for example, activate his immune system. We use ibuprofen for a couple of days and it goes away. I am not clear how long he will stay on antibiotics, I can only say that if it saves his life as we know it, and his future as we expect it, if it keeps him stable, and being able to do well in school and play with friends, then I feel a long term antibiotic treatment is a small price to pay. And would he ever – god forbid – get seriously ill again, I will not hesitate to fight for another IVIG.

Finally, back to me and my diagnosis. Going back I see all my own symptoms interpreted as autistic rituals might have been OCD. I had a severe scarlet fever (which is strep) at 2 years old. I was later apart from Aspergers syndrome, also diagnosed with dyscalculia (that is, specific math difficulties a known effect of PANDAS), and with Fowlers disease, a rare disorder of unknown origin which causes urinary urges.

So what do you think? Did I really have Aspergers and outgrew it, and my sons PANDAS is totally unrelated. Or did I actually have PANDAS too? I think the latter is true.

I am in contact with about 60 families in Sweden with children with PANDAS or suspected PANDAS, and about half of them have received diagnosis such as Asperger’s syndrome, Tourettes syndrome, ADHD etc. although they did not have these symptoms prior to the PANDAS-onset, so yes, I do think there are quite a few hidden cases in our country.

And PANDAS is treatable, and the earlier you start treatment, the greater the chance of full remission it seems. So the medical community has to take a step forward now. If you feel there is too little research, than now is the time for you to initiate research. Our children are here now. They can’t be expected to lose their future while we wait for a handful of dedicated researchers to study and then publish. And although not conclusive, there is quite an amount of clinical experience with this disorder, indicating that longterm antibiotics and immunoglobulin treatment is helping. Can you imagine the frustration parents feel when they are convinced there is a treatment, their children have all the symptoms of PANS or PANDAS, many times including confirmed strep infection at onset, and yet their doctors are unwilling to prescribe the treatment – but at the same time, these same doctors are more than willing to prescribe medications with more potential side effects for children whose brains are still in development, such as SSRI’s, anti-psychotics and other drugs.

So again, we are here, our children are here, and I think many of us parents feel we will let you use our children for research, because we know what hell parents go through, and if we can prevent that from happening to other families many of us are

happy to help!