

## Otto's story

When I took Otto for his first inoculations, at the age of two months, I dreaded it like any other mother does. But I wasn't prepared for the reaction that he had.

The first injection was fine - only a bit of screaming - but the second made Otto cry out in so much pain that he held his breath, went floppy, rolled back his eyes and turned an alarming shade of grey.

In a state of panic, the nurse took Otto from my arms and rushed out of the room. I sat there, in floods of tears, not knowing what was happening. A few minutes later the nurse came back and calmed me down, saying that Otto was okay - he was a bit dozy but gurgling happily - and was being looked over by a doctor. I was told that it was a breath-holding episode, that it was very common in babies and young children and that he would grow out of it. But I was left unconvinced.

Following that incident, Otto had numerous 'breath-holding' attacks as a baby, often when he was overtired or shocked by a loud noise (such as a plane overhead or even someone sneezing). In the early stages of Otto walking, these episodes came about after a fall, a bump to the head or being pushed by other little ones. They would vary in frequency but at their worst they were happening up to five times a day. This made me become fearlessly protective and unable to leave him with anyone. Fortunately, Otto's attacks only happened during the day, when I was there to watch out for him. But sleep time was often restless and disturbed with night terrors.

On my many visits to the GP, I kept being told that it was breath-holding and not to worry - easier said than done. And, thankfully, epilepsy was ruled out because his attacks never occurred without a cause and Otto would always cry beforehand.

I spent hours scouring the internet, looking for comments from parents in a similar situation, to no avail. Then I came across some videos of a little boy with reflex anoxic seizures (RAS). They were horrible to watch, but seeing them convinced me that Otto had the same condition, because their attacks were so alike. I also found the STARS website and read up on the information and case studies, all of which were so reassuring. The next day I went to my GP and insisted that Otto have further checks.



Otto has since been diagnosed with RAS. He has had a number of cardiovascular examinations - all fine - and is booked to have a brain scan later this year, as a precautionary measure. I have also taken him to see a cranial osteopath who has been working to tone down Otto's central nervous system, as he could feel it was 'startled and out of balance'. In my opinion, this has made a significant difference to the frequency of seizures and has lessened their intensity. It has helped Otto to sleep better too and his night terrors have almost gone.

As Otto reaches two, he seems to be growing out of RAS - he hasn't had a seizure for three months - so my husband and I are hoping that the worst is over. And although we still can't stop feeling terrified each time he passes out, at least now we know what is wrong - and that we're not the only ones going through it.

And I hope, by recounting Otto's story, I can lessen the anxiety of another mother or father who has a child with RAS. Because, no matter how bad it gets, we're all in it together.

**Fiona**