## Best Doctors MEMBER STORY



NAME: Freddy AGE: 7

**Reason for consulting Best Doctors:** chiari malformation and syrinx

## **BEST DOCTORS EXPERT**

Specialty: paedriatric neurological surgery

Freddy was due to have invasive neurosurgery. He had no symptoms and his parents were confused.

When seven year old Freddy went in for a routine check-up for his amblyopia (lazy eye), exams revealed thickening of his left optic disc. Yet despite numerous specialist consultations, the cause remained a mystery. When Freddy was eventually referred for an MRI, it showed a chiari malformation, an abnormality which occurs when brain tissue pushes into the spinal cord. In addition to this, the test indicated a syrinx, or cyst in Freddy's spinal cord as well as another cyst in his brain and abnormal fusion of his skull bones.

Although Freddy had absolutely no symptoms to speak of, his parents, Alison and Brendan, were advised to proceed with surgery on both the chiari malformation and the syrinx. They were also informed that he would most likely require surgery on his skull in the future.

Alison and Brendan were in shock. Their little boy was behaving and apparently feeling just like his normal self yet he was suddenly facing not one, but possibly two invasive surgeries. As the day of the operation drew near, they felt increasingly anxious, and wondered

if they were doing the right thing. It was then that they were encouraged to contact Best Doctors.

Speaking to Freddy's parents about his diagnosis and medical history, the Best Doctors nurse assigned to the case got things going right away. Freddy's complete medical records and imaging were sent to one of the world's foremost experts in paediatric neurological surgery based at Harvard Medical School.

The expert findings were dramatically different to what Alison and Brendan had been told. While he confirmed that Freddy did have a chiari malformation, he was not at all convinced he had a syrinx but rather mild dilatation of the central canal of his spinal cord, which was absolutely nothing to worry about. Moreover, the expert felt that just because Freddy had a chiari malformation did not mean he needed any treatment, and he himself had never operated on patients with this condition unless they actually had symptoms that warranted it. The expert went on to caution Alison and Brendan that the proposed operation was not only incredibly risky but would likely need to be repeated anyway when Freddy got older. In fact, there was a strong possibility that the chiari malformation might even improve over time.

Turning to the other findings, the expert was of the opinion that the brain cyst that had been detected was very

minor and would likely never require any medical action, and found no strong evidence for any abnormal fusion of Freddy's skull bones. For both these and the chiari formation, the only thing Freddy needed were annual MRIs and neurological assessments.

Alison and Brendan shared the Best Doctors final expert report with the surgeon who was to perform the operation, who was impressed with the findings and promptly cancelled surgery. The family is thrilled to be back to life as usual, relieved that Freddy has been spared the pain and emotional stress of a complicated and unnecessary operation.

"It was such a stressful time for us and I actually almost didn't go ahead with the service. But I'm so glad I did." – Alison

"There are no words to express the relief that comes with knowing that, rather than being in hospital, your son will be going to birthday parties and playing soccer" - Alison

"I googled the expert who wrote our report. He obviously knows what he is talking about as he has set up a research centre in the USA on this very condition." - Alison

Freddy has avoided unnecessary surgery and only needs annual testing.

This is a real Best Doctors case. Where necessary, personal details have been modified and photographs have been used for illustrative purposes in order to respect and maintain patient privacy. Best Doctors services are being provided solely for the purpose of providing medical information for use in the treatment provided by your treating doctor(s). The outcome of this case does not represent or guarantee that anyone will obtain a similar result, as the case will vary depending, among other circumstances, on the information provided to Best Doctors. It is prohibited to copy, use or publish the content or parts of the content of this case story without the express permission of Best Doctors. Best Doctors. Best Doctors and the star-in-cross logo are trademarks of Best Doctors, Inc. Used with permission. All rights reserved © 2014 Best Doctors.

