

Marissa's Story

Now age 20 and a professional model, Marissa Irwin was 12 years old when she developed a stomach ache. When the stomach pain recurred along with headaches and sore throats, her mother, Gayle, took the girl to the family doctor. From here, mother and daughter began a frightening five-year journey from specialist to specialist as Marissa's condition deteriorated; in constant pain by her 15th birthday, she could no longer attend school and spent most days so weak and dizzy she could barely walk.



Gayle Irwin was alarmed. "While other moms were driving their kids to soccer practice and ballet classes, we were spending our days with doctors who were all baffled by what was causing Marissa's growing list of symptoms. I watched my normally social daughter become increasingly isolated, depressed and eventually wheelchair bound." Determined to find relief, Gayle searched the Internet and stumbled on a description of Chiari I malformation (CM1). She remembered a casual remark by a radiologist two years earlier about an odd bulge at the base of Marissa's skull. In a CM1 chat room, Gayle read about the successful work going on at the Chiari Institute. Within a week, the Irwins traveled from Ohio to meet with Thomas H. Milhorat, M.D., Paolo Bolognese, M.D., and other members of the multidisciplinary team at the Chiari Institute.

"Over two days, Marissa was examined and tested from top to bottom," Dr. Bolognese recalls. "She had many of the typical markers of CM1, but others didn't fit. Her joints were very wobbly, a sign of Ehlers-Danlos syndrome, a disorder of the connective tissues frequently associated with CM1. She was also found to have a retroflexive odontoid. This together with the weakness brought on by Ehlers-Danlos made Marissa's neck unable to support her head sufficiently, so the odontoid bone was pressing into her brain."

To confirm that surgery would improve Marissa's condition, she was sent home with a cervical collar and a traction unit to see if the therapy would ease her pain. "I could hardly believe what a difference the gear made," says Marissa. "Within 10 minutes of going into traction, the pain in my head would go away."

With pain relief through surgery now a viable option, Drs. Milhorat and Bolognese made it clear to Gayle and her daughter that the proposed surgery – actually two operations in one – was both rare and dramatic. It would require repositioning Marissa's skull so that her odontoid bone no longer pressed on her brain stem. The vertebrae would then be fused and the spine locked in place permanently with surgical screws. In addition, the portion of the cerebellum being squeezed down into Marissa's spine would need to be decompressed to create more space for cerebrospinal fluid flow.

Although both mother and daughter were apprehensive, Marissa underwent the recommended surgery just after her eighteenth birthday. "Having come as far as we had," Gayle explains, "we really had no choice but to go ahead, scared as we were. The surgery took six hours – an agonizing wait – but when Dr. Bolognese came out, he was smiling. All had gone well. It was a truly wonderful moment."