

'Together, people can make a difference'

By Susan Bromley
Staff Writer

Ortonville- Devin Kalisz was a single working mother and full-time student two years ago when the accident happened.

The legal assistant was at a stop when she was rear-ended by a driver who was doing 50 mph. Kalisz hit her head on the steering wheel and dashboard, giving her an instant headache and neck pain.

The hospital diagnosed her with whiplash, but what they didn't know, and what Kalisz would not discover until suffering a year with fatigue and almost constant migraines, was that the accident had awakened a congenital disorder in her—Chiari Malformation.

Life has not been the same since and Kalisz, 26, is on a mission. "I want people to be aware of this condition," she says. "Together, people can make a difference."

Kalisz was diagnosed with Chiari in February 2006 through an MRI, the only way to find the disorder. She says it is missed with X-rays and people who have the malformation are misdiagnosed 50 percent of the time.

In April 2006, she had decompression surgery, in which a piece of her skull was removed in order to relieve pressure. The surgery alleviated her headaches and dizziness, but she has had a long recovery from the operation itself, and has required a great deal of aid from her now 7-year-old twins, Paige and Micah, and new husband, Christopher. "I need help with normal care," says Kalisz, sitting at her kitchen table, wearing a neck brace and a shirt emblazoned with her website, www.devinsdiary.com. "I can't hold my neck up and can't drive. I have to build the muscles in my neck again." An artificial shunt was put in to cover the area taken out and while her headaches improved, her balance has worsened. She compares her head to a weeble-wobble and used a walker to help with balance. People ask her what is wrong with her and her children's classmates at H.T. Burt Elementary stare. The family has struggled financially since she is now unable to work. Kalisz recalls being very active previous to the accident, which jolted the malformation and caused her to be symptomatic. She ran track and played with her kids—soccer, bike-riding, rollerblading and just throwing a ball around.

Now, she says, they help parent her—cleaning, cooking, helping her wash her hair. They bring laundry downstairs so their mother doesn't fall. They wash the dishes that would fall from her hands. They carry the groceries inside because she uses her walker.

"They had to learn about Chiari and what happened to mommy," she says. "They had one type of mom and I did it all as a single mom. Now, I can't... They're



Devin Kalisz with her 7-year-old twins Paige and Micah in their Ortonville home. Photo by Susan Bromley.

awesome. I don't know what I would do without them."

Kalisz would like to go back to work. The most difficult thing, she says, is not being able to support her family, physically or financially. But she is unsure what the future holds. She is afraid to be alone for fear of getting hurt. Her leg is constantly numb, as are her fingers. She fears she may end up in a wheelchair. But she has a goal. "I want to get awareness out there," she says. "I want people to understand and donate to Chiari research. If there was a cure, I could be that person I used to be."

Kalisz is writing two books—one on life with Chiari, and the other on surviving pre- and post-decompression surgery. They will be published through Lulu, an online free publishing company and will be available on her website. The profits will be used for Chiari research. She also plans to speak to the PTA at school and at the local Curves fitness center. "The sky's the limit," Kalisz says. "There's not a lot of things I can say I did at 26, but if I can say I wrote a book and raised awareness, that's important."

Chiari malformations

According to www.conquerchiari.org, Chiari malformations are a set of neurological conditions which afflict approximately 1 in 1,000 people (300,000 in the United States), causing debilitating headaches, neck pain, weakness and numbness in the limbs, balance problems, visual disturbances, and a host of other symptoms. The malformation itself is located at the base of the skull, with the cerebellum descending out of the skull into the spinal area, resulting in compression of parts of the brain and spinal cord and disrupting the normal flow of cerebrospinal fluid (a clear fluid which bathes the brain and spinal cord).