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Five brain surgeries? No problem

Albany senior with a rare disorder still plans to graduate later this year

By Jennifer Moody
Albany Democrat-Herald

ALBANY — Nicole Fallon could have decided to sit this one out.

A rare brain condition had already forced the 18-year-old Albany woman to miss most of her junior year and a few days of her senior year at West Albany High School. Surgery later this month will cause her to miss at least two more weeks.

Nicole won't be eligible to walk across the podium with the rest of the class of 2007 this spring. She says she needs to take a few classes this summer to fulfill all the requirements for graduation.

But Nicole is sick and tired of being sick and tired. And in spite of the pain and fatigue, she's determined to push on through the summer and graduate this year.

"I guess I really want to get it done, and it's really important to me to graduate," she said. "It'll be a big deal for me after having missed so much school."

Nicole has a condition called chiari (kee-YAR-ee), a serious neurological disorder in which the bottom part of the brain, the cerebellum, does not have room to grow. It pushes downward out of the skull and crowds the spinal cord, putting pressure on both the brain and the spine.

The condition affects about one in every 1,000 people. Evidence suggests it's hereditary. Nicole's mother, Karen, has a mild condition, and her sister, Kristina, had surgery for it. The three are now part of a genetic study at Duke University.



David Patton/Democrat-Herald
Nicole Fallon, right, and her sister, Kristina, both suffer from a rare brain condition called chiari. Nicole is facing her fifth surgery this month to correct complications from the condition.

The girls' father, Troy Fallon, a physician, studied chiari in medical school. Now he often talks about the family's experience and has diagnosed chiari in one of his own patients.

"Very few of us ever heard what it is," he said. "It's a very vague illness, and not well-known."

Chiari causes different effects in different people. In Nicole's case, it led to a secondary condition — syringomyelia — in which spinal fluid is pushed into the spinal cord and develops potentially damaging cysts.

Nicole already has had surgery four times to try to correct the problems. She is hoping this fifth one, which takes place March 26 in New York, will be her last.

Then, she said, "I'll pretty much be a normal person, a normal 18-year-old."

Nicole doesn't have much experience with normality. Neither does her sister, Kristina, whose own diagnosis ended up throwing the spotlight on Nicole.

Nicole was born with a small hole in her heart and problems with her kidneys, prompting three surgeries before her fifth birthday.

Kristina, now 15, was born with Klippel-Feil Syndrome, a rare, congenital disorder that fuses the vertebrae of the neck. Her neck straightened as she grew older, and except for occasional checkups, it wasn't an issue.

But one day Kristina, then 12, was scheduled to compete in an international swim meet in Holland.

"I dove into the pool and I couldn't feel my body for about three seconds," she remembered. "I remember trying to move my legs, and I couldn't kick."

Kristina recovered and went on to win the race, but the problems weren't over. She began feeling numbness in her limbs and an "electric shock" feeling through her whole body whenever she turned her head.

She had a checkup with her neurosurgeon, then an MRI. The diagnosis: chiari.

Kristina had decompression surgery in December 2004. Surgeons removed a piece of skull about the size of a silver dollar to decompress her brain and restore the cerebral spinal fluid.

Since then, she said, her problems have disappeared.

Nicole was another story. For years she'd complained of intense headaches and constant neck and shoulder pain. Once, she passed out.

She'd had an MRI of her own at age 11, but results were within normal limits. Doctors told her it was migraines and tension and suggested ways to relieve stress. Eventually, she just found ways to cope.

When Kristina was diagnosed, however, the Fallons began researching the symptoms and complications of chiari. It wasn't long before a picture emerged: Nicole.

Another MRI confirmed their suspicions. It showed the problem was more than three times as severe in Nicole as it had been in Kristina.

In February 2005, Nicole had her own decompression surgery, but her condition worsened. She was exhausted, nauseated and in constant pain. Surgeons found fluid leaking from her brain and scheduled her for surgery twice more. The procedures led to instability in her ability to support her neck, so she underwent a fourth surgery to fix that.

That was when doctors discovered she also had Ehlers-Danlos Syndrome. The connective-tissue disorder can keep sutures from holding correctly, and might explain why she needed so many surgeries as a child to repair her heart and kidneys, her mother said.

Nicole improved after the fourth surgery, but other complications surfaced. Her legs tingled and felt weak. She had trouble sleeping and had to urinate constantly. Doctors say she has a tethered spinal cord, which this next surgery should release.

The last several years have been "financially and emotionally devastating," Troy said, and it's only with the support from family, friends, coworkers and schools that they've held it all together.

Karen, a scientist with the state Department of Environmental Quality, said colleagues donated sick days so she would be able to be with her daughters during surgeries and recoveries without losing her employee health insurance.

All four also praised educators in Corvallis, where they lived until last year, and Albany, for sending tutors and homework packets to the Fallon home for Nicole.

"They're helping her in any way that will make her successful," Karen said.

Both Nicole and Kristina are dedicated to remaining as normal as possible.

Kristina, who has suffered no complications, plays volleyball and grouses about how the surgery means she is no longer allowed to ride horses or rollercoasters. Nicole is determined to take classes next year at Linn-Benton Community College so she can transfer to a four-year university.

She hasn't determined her course of study yet, but she knows one thing about herself: "I

really like learning.”

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