



BARABOO
NEWS REPUBLIC



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weather



High: 70°F
Low: 55°F
Slight Chance Rain

poll

What is your opinion on the Obama administration's plans for national health-care reform?

- A — It's a good idea, especially with so many people who do not have health insurance.
- B — It's a bad idea, because the plan is too costly and is a step toward socialized medicine.
- C — I don't know enough about it to have an opinion.

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LOCAL

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Her wish to make would be to ski again

By Christie Taylor / News Republic

Sixteen-year-old Sarah Holm has banned her parents from describing her as "handicapped." She has a wheelchair that she almost never uses, and swims with her arms as well as most people swim with all four limbs. Until about two years ago, she could move on crutches faster than her mother could walk.



CHRISTIE TAYLOR / NEWS REPUBLIC
Sarah Holm, 16, doesn't let problems with her spinal cord keep her from going where she wants to go and doing what she wants to do. Recently accepted by the Make-A-Wish Foundation, she hopes to learn adaptive, sit-down skiing in Breckenridge, Colo.

So it's only natural that, when she was accepted by the Make-A-Wish Foundation in June to have one wish granted, she would want to learn how to ski again.

Sarah has "tethered cord syndrome," in which the spinal cord becomes attached to the inside of the sac which covers the cord and also contains the spinal fluid. Sarah's mother Chris Holm, a medical technologist at St. Clare Hospital, said that because of the attachment, a benign but invasive tumor formed on the spinal cord and began causing nerve damage that increasingly limited her mobility starting about when she was 10. Surgeries to free her nerves culminated in a cordectomy, or removal of part of her spinal cord, and removal of most of the tumor in early May. Now Sarah has no feeling below her mid-thigh, but continues to have control of her knees.

Sarah began downhill skiing when she was five under the tutelage of her father, Dave Holm, who coaches Cascade Mountain's ski team. Thanks to supportive ski boots, she could stay on the slopes even when weakness in her feet required her to adapt or completely forego other activities. She was an avid skier until her legs began to fail her and back surgery became necessary two years ago.

With help from Make-A-Wish, she hopes to go to an adaptive skiing school in Breckenridge, Colo., where she would receive private instruction in sit-down skiing techniques that she would be able to use for the rest of her life.

"This could help her have a better life," Chris said.

"(Skiing) is actually something I can do," Sarah said.

Since she stopped skiing, she said she continued to cheer for her friends at races, going up and down Cascade Mountain on the crutches that have become her constant companions.

Meanwhile, Sarah's family and friends remain staunch cheerleaders of her own life, which has included nearly a dozen surgeries since Chris and Dave adopted her in India — the first when she was two days old. When she was about two, she began requiring surgery approximately every other year just to allow her feet to form properly, because her

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muscles were not stretching to accommodate bone growth. And after the cordectomy, she has had to learn a completely new way to walk, now that she can no longer feel her still-functioning knees.

The Holms also adopted a son, Matthew Holm, who is autistic. Now 21, Matthew lives on his own.

Chris and Dave, who teaches third grade at East School and also runs a carpentry business, say it's Sarah's positive attitude that keeps them going through long surgeries and the medical appointments that take the family to Madison nearly once per week.

"Every time we spend a week at UW hospital we just come home feeling blessed," Dave said.

He said the family felt lucky after seeing patients with malignant tumors and other terminal problems.

"Sarah is smiling and crutching around," he said. "We know Sarah will be alive next Christmas."

While the family can no longer hike together, Sarah's upper body strength makes her a strong paddler and swimmer, and they enjoy kayaking, sailing, fishing and other "sit-down" activities.

"We keep finding ways to catch up," Chris said. "We're always there for each other."

Sarah said her friends have found new ways for them to still hang out since she began to lose function in her legs. They'll jump on the trampoline while Sarah sits in the middle and bounces along, or give her piggyback rides, or bicycle in circles in front of her stoop.

And this summer she's learning to drive, using an adaptive technology that allows her to accelerate and brake with a lever in her left hand.

"Sometimes I say 'Oh, I wish I could do that,'" Sarah said. "I still have fun."

Sarah said the worst part, for her, is that her prognosis is still uncertain. Doctors have told the family that because the tumor is of a unique and, so far, unknown composition, they are not sure how the small remaining segment will behave and whether her mobility will worsen.

"It will not get better," Chris said. "It's just part of our life."

But for the most part, Sarah remains upbeat.

"I just don't let that bother me," she said.

Meanwhile, as an upcoming junior at Baraboo High School, she works hard, particularly in choir and art classes. She said she is even "starting to like" English, especially when it comes to writing stories or journals about her life.

"I never have nothing to write about," she said.