

# A pocket of warmth



KEIZERTIMES/Andrew Jackson  
Cows huddled together near the intersection of Chemawa Road Northeast and Verda Lane Northeast for warmth and grub on a snowy morning Tuesday, Jan. 11.

## MDA, continued from Page 1

"I had problems throughout my pregnancy and Allison was born six weeks premature — she weighed three pounds 14 ounces. She had to have a high-calorie formula to gain weight and she started missing development markers," Elizabeth said.

Even after finding a doctor willing to take the developing issues more seriously, it took another nine months to settle on a diagnosis.

Mitochondrial myopathy is a rare genetic disease, but one covered in the research performed by the MDA. Mitochondria are specialized compartments in cells that create 90 percent of the energy needed by the body. When they don't perform their job correctly, it can lead to a host of symptoms ranging from blindness to coma to developmental regression.

In Allison's case, one of the primary symptoms is general weakness. After years of specialized care — Elizabeth estimates Allison has been the subject of more than 300 tests in her short life and she's been taken to the emergency room at least two dozen times — the pain walking caused her became too much to bear.

"I had a back brace, but I would get too hot because I can't regulate my body temperature. I just wanted to try something else than keep trying to correct it on its own," Allison said.

A lengthy MRI revealed

that Allison's spine had become tethered by other tissue, and it was causing more than just pain. The arc of her back was preventing her lungs from growing and they already operate at a reduced capacity.

She underwent one surgery to release the connective tissue, then another to install a "halo" brace to help straight-



en her spine was followed by a lengthy stay at Doernbecher Children's Hospital in Portland.

The last surgery was the most worrisome, to the point that Elizabeth, Allison and her brother David all took a Make-a-Wish trip to Disney World. Allison's ability to maintain basic life supporting functions like breathing while undergoing the operation to install rods and pins supporting her spine was a concern, but she made it.

"There must have been lots of prayers because she sailed through," Elizabeth said.

In the two years since, Allison has grown four inches and walking doesn't hurt as much. She's even started taking some classes at McNary

High School after being homeschooled for much of her life. She started with a creative writing class last fall and will take physical science and a wellness class next term.

The operations revealed other issues that still make daily tasks more of a chore than a fully able teenager would encounter — the latest need in her life is actually a new wheelchair-accessible van — but Allison is as vibrant a teenager as one could hope for.

Her next big service project is making cookies for local first responders as an American Heritage Girl, a Christian-based scouting organization.

She is a voracious reader with an interest in photography and the great outdoors, but she had made attempts to fundraise for "mito" research even before facing down some of her own challenges.

Now that she holds the title of MDA ambassador, it feels a bit like the fulfillment of a dream.

"I like it because I get to meet a lot of new people and I get to be part of raising money for research, even some for kids that are dealing with mito," she said.

While she has a big year ahead, Allison shows no signs of slowing down.

"Whenever we go shopping, we look for stuff on clearance and we buy art supplies, cake supplies and party supplies so that kids going through halo surgeries at Doernbecher get to have parties," Allison said.

## Salem Library launches reading project

Salem Reads: One Book, One Community — a community reads project that invites the public to read the same book, take part in discussions and enjoy related programs throughout the month of February, has selected *Spare Parts* by Joshua Davis as this year's community book.

*Spare Parts* tells of four Latino teenagers and their journey as they are encouraged by two inspiring science teachers to build an underwater robot and

enter the Marine Advanced Technology Education Robotics Competition.

The following upcoming events will revolve around *Spare Parts*:

- Friday, Jan. 13, 7 p.m. in Loucks Auditorium. A screening of the film based on the book.

- Saturday, Jan. 14, 2:30 p.m. in Loucks Auditorium *Underwater Dreams*, a documentary based on *Spare Parts* will be screened.

- Sunday, Jan. 22, 2:30 p.m., the Salem Library Foundation will give away 500 free copies of *Spare Parts*.

- Saturday, Jan. 28, noon to 3 p.m. Salem Reads robot expo, which will feature the Cheme-keta Community College Robotics Program Chair and his team demonstrating all sizes of working robots.

- Tuesday, Feb. 21, lecture by the author at 7 p.m.

For a full listing of all related events, visit [salemlibrary.org](http://salemlibrary.org).

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