

# SUSIE: 'She was a lovely, lovely woman'

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student was someone everyone knew and who liked helping others. Beers had noticed her cruising around in her wheelchair putting up posters for Coats for Kids, a project of the Associated Student Body for which Susie was publicity coordinator.

Beers was stunned to learn of her death.

"She was definitely the most positive, strong person I've ever known," Beers said.

Her family is in shock. Susie's father, Mario Arroyo, said Susie appeared upbeat and healthy at a family dinner Thursday evening. Later that night, they found her unconscious.

Susie would never get her heart transplant. In 2013, though, she was the first woman and only the second person with Duchenne to have a heart pump called a ventricular assist device (LVAD) implanted in her chest to aid in circulation of blood.

The pump was a game changer. Her extremities warmed. Her gray fingernails turned pink.

Susie forged ahead with school, enrolling at Eastern Oregon University with hopes of teaching school. She graduated in 2016, but she would never get her own classroom.

On Monday at Burns Mortuary in Pendleton, family members gathered to plan Susie's service. They took a break for tender recollections of Susie. Sitting around a long table, her parents, grandparents, brother and pastor talked of a woman of faith who helped others and was happy, despite her condition. They will miss her activism, her spirit, her smile, her peaceful heart.

"She left a big legacy," said Pastor Hugo Villalobos, of the Pendleton Spanish Adventist Church. "She was a warrior who fought to the end."

After graduating EOU, Susie wrote letters to the FDA urging emergency approval of a promising Duchenne drug called Eteplirsen, the first drug ever for Duchenne patients. In the winter of 2016, she flew to Washington, D.C., to testify before an FDA panel that the agency should give accelerated approval for the drug since people with Duchenne have no other option. Eventually, the approval came through on a conditional basis. The Oregon Health Plan didn't automatically cover the drug, which can run from \$300,000 to \$700,000 per year, depending on the weight of the patient. So Susie traveled to Salem to testify in front of the Oregon Drug Utilization Review Board's Pharmacy and Therapeutics Committee.



Staff photo by E.J. Harris  
**Susie Arroyo laughs with registered nurse Sally Bishop as Bishop prepares an IV port last August at St. Anthony Hospital in Pendleton.**

She finally got temporary approval and started getting weekly injections. After six treatments, she noticed more strength in her neck and arms.

Pat Furlong, founder and CEO of an advocacy group called Parent Project Muscular Dystrophy, called Susie a pioneer.

"She was a lovely, lovely woman who made us realize that girls have Duchenne, too," said Furlong, who lost two sons to the disease. "She bravely went forward with the LVAD and fought for access to treatment."

Furlong, too, was shocked to learn of Susie's death.

"We all expected her to go on," she said. "You just felt like there was something that would keep enabling her to go on."

Mario Arroyo Jr. marveled at his sister's life. Plenty of people make excuses for why they can't do things, he said, but "despite the limitations she had, look how much she was able to accomplish."

Around that table at Burns Mortuary, family members switched off telling me what they will miss most about Susie.

"Her smile," said Mario, Jr. "Her service," said her pastor. "Her love for life," said her grandmother.

"Everything," said her mother. Tears built up in my eyes. I swallowed hard. So much for journalistic detachment. Some people just lodge in my heart and I can't do anything about it.

Goodbye, Susie Arroyo. We won't forget you.

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# OKTOBERFEST: Some people came from a few hours away

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"Oktoberfests traditionally just have German beers," he said. "So for us to have all these different craft beers is pretty different."

There were beers from as far away as Corvallis, Eugene and Astoria and Ellensburg, Washington.

The event also featured food from the Pendleton-based Hill Meat Company, Barhyte Mustard and Rolling Stone Bakery. Proceeds went to several local organizations, including the Pendleton Swim Association, the Lions Club and the City Club.

"The first year, we were scared because we didn't have any money," said board member Niki Naughton. "But local companies like Hill Meat were so excited when we came to them. Same with Barhyte.

The first year we had the event paid for with sponsors, and made money with the ticket sales."

Naughton estimated that in the last three years, they've averaged about \$10,000 in annual donations, but hoped they would increase that number this year.

Naughton said they were hoping to making it a "heads and beds" event, attracting visitors from out of the area.

Tony Zubiria, owner of Mario's Basque Bar B-Q, said this was only his second year at the event, but he was looking forward to a good turnout, especially with the nice weather.

"We're selling a Basque sandwich called Solomo," he said, describing the dish from northern Spain. "It's real pork loin with roasted red pepper."

Some people came from a

few hours away.

Terry and Julie Erntson enjoyed a "Benedict Cumberbatch" Gose from Buoy Beer Company in Astoria, and a dry cider from Blue Mountain Cider Company in Milton-Freewater.

"This is our first time here," Julie said. "We are from Ontario, and we were passing through and thought we'd stop."

Gary, Sharon, Brandon and Diana Hayden came from Hermiston and the Tri-Cities, and enjoyed the unique flavors of beer they found.

"I never would have thought cucumber would be good in a beer," Diana said of the Benedict Cumberbatch Gose. "It's surprisingly good."

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# FIRE: Strike team expected to be deployed for 14 to 21 days

Continued from 1A

south late Saturday along with four other Oregon strike teams deployed by the Oregon State fire marshal. The Umatilla/Union team is staged in Chino, California, to fight one of the state's wildfires. Fires further north near Sonoma have killed more than 40 people and drawn in dozens of strike teams from other states.

"We send firefighters to Washington state on a pretty regular basis, or into southern Oregon, but things have to get pretty bad in California for them to send for help," Pendleton Fire Chief Mike Ciraulo said.

A few weeks ago it was Oregon that needed the help, as the Chetco Bar fire burned almost 200,000 acres in southwestern Oregon and another blaze swept across the Columbia Gorge. Ciraulo said his department has sent personnel out to help fight nine different fires in the Northwest this summer, and Umatilla County Fire District has deployed to a number of out-of-district wildfires as well. Ciraulo is a wildfire incident commander for the state and said there were times they asked for help that other states

couldn't send because they were already dealing with too many fires of their own.

"This is probably one of the busiest seasons we've seen in recent years," he said.

Umatilla County Fire District operations chief Jim Forquer said the frequent mutual aid deployments is a "testimony to the extreme fire season" the country is having. California firefighters have already been up in Oregon fighting the Chetco Bar fire, he said, so it was only right that Oregon would be willing to turn around and help them.

One thing non-firefighters can do to help is keep the local fires to a minimum by remaining cautious and remembering that vegetation is still dry despite burn bans being lifted.

"I'd just remind folks to be safe out there," he said. "Don't leave fires unattended."

Ciraulo said that fire districts and departments are paid for sending personnel to assist in wildfire responses like the ones in California, so Pendleton, Hermiston and Stanfield taxpayers are not footing the bill for the strike team's travel to Chino — in fact, it creates "a little bit of revenue" for the

department.

Beyond the question of money, however, Ciraulo said firefighters from different states being willing to help each other out is just the morally right thing to do. And the personnel who have a chance to fight fires alongside teams from other states in different terrains come back more experienced, with new ideas.

"It's a win-win for everyone," he said.

The Oregon State Fire Marshal's office said in a statement that the department is "extremely grateful to Oregon's fire chiefs and their agencies for again stepping up to the plate to help our neighbors to the south as they continue to struggle with an unprecedented amount of fires on their landscape."

The Umatilla/Union strike team is expected to be deployed for 14 to 21 days, not including travel. Updates on their deployment are available on the Pendleton Fire & Ambulance and Umatilla County Fire District #1 Facebook pages.

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