

Registered nurses Sally Bishop and Lisa Ward set an IV port in a vein in Susie Arroyo's left hand on Friday at St. Anthony Hospital in Pendleton. Staff photo by E.J. Harris



## ARROYO: Eteplirsen runs between \$300,000 to \$750,000 for a year-long course of treatment

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in her heart's left ventricle to help pump blood to the rest of her body. The surgery came just as Arroyo's heart was on the verge of failing.

"They were thinking I had only a few days," she said. "My heart was giving out."

The device in her chest gave her more time, but provided only a stopgap.

Eteplirsen offered hope, though it was stuck in deep in the Food and Drug Administration drug trial process. In the winter of 2016, she flew to Washington, D.C., to testify to an FDA panel that the agency should give accelerated approval to the drug since people with Duchenne have no other option. The meeting, canceled after a snowstorm descended on the Capitol city, had to be rescheduled for April. Arroyo flew home. In April, the FDA heard testimony, then denied the request.

One morning last September, however, Arroyo awoke to a flurry of phone calls. The FDA had changed course and decided to approve the drug on a conditional basis.

"I guess they were listening," Arroyo said. "Something finally clicked in their hearts."

Just because a medication is approved doesn't necessarily mean insurance companies will cover it, though. Eteplirsen is expensive. The price, based on a person's weight,

runs annually from \$300,000 to around \$750,000. Skeptics argue that the drug's effectiveness hasn't yet been determined. Arroyo, covered by the Oregon Health Plan, would have to wait to learn if she would get the drug.

Earlier this month, she traveled to Salem to testify in front of the Oregon Drug Utilization Review Board's Pharmacy and Therapeutics Committee. Also speaking were Jamie Ambuehl (the mother of a toddler with Duchenne), three clinicians and a biologist.

"They gave us three minutes each," she said. "I had to make every second count."

She focused on making eye contact with each of the 20 panel members. She beseeched them to cover the drug and lift a proposed restriction that would bar Duchenne patients who can't walk for at least six minutes from receiving the drug.

"I got a little emotional," Arroyo said. "They were listening."

At the end of the session, the committee lifted the walking requirement, pending approval by the state Health Evidence Review Commission. Arroyo later learned she would have access to the drug at least until the end of the year.

"Susie is a fighter," said Pat Furlong, founder and CEO of Parent Project Muscular Dystrophy, an organization that advocates for Duchenne patients and their families. "She's trailblazing for all

of us."

Furlong knows the pain of Duchenne. In 1984, doctors diagnosed her two sons, Christopher and Patrick, with the deadly disorder. Not much was known about cause or treatment then.

"My sons died at 15 and 17," Furlong said. "They never had a good standard of care. Their physician said, 'Go home and love them.'"

Furlong said her organization works to understand the genetic disorder and raise funds for research. The approval of eteplirsen brought excitement to the Duchenne community.

"Before this approval, there were no approved drugs especially for Duchenne. This is our first approval," she said. "It's hope."

Arroyo certainly has hope. She personally knows some of the boys in the initial trials and has followed their progress.

"This is a progressive disease," she said. "They haven't gotten worse in five or six years - that's huge."

If the state decides not to pay for the drug next year, she plans to push on.

"If they decide not to approve me, I'll fight," she said. "That's what I know how to do."

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## EOTEC: VenuWorks suggested developing RV park on the site

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"This week, we had a management company on site to do a facility assessment walk-through," he said. "We did a two-hour tour. They saw potential at the entire site."

Rivera said the company, VenuWorks (which also operates the Three Rivers Convention Center in Kennewick), told him the first objective for management should be revenue creation.

"They said we need to get something at this facility that makes money every day," Rivera said.

The most likely way to do that, they suggested, is by developing the RV park on the EOTEC site.

But Rivera also told the board that they need to solidify their own objectives before bringing in a general manager.

"As we transition from a

construction board to an operations board, we have to set vision and expectations," he said. "Until we answer some of those questions, it's going to be difficult for someone to take this journey with us."

Rivera requested direction from the board on several operations issues. He suggested hiring a team from MLD Services for maintenance and janitorial services, and that the board enter a contract with them from now until the end of October. He also asked for approval on booking an event — a horse sale — at the facility using existing pricing structures from the fair, and requested that the board approve planting trees in the swells at the north end of the fairgrounds parking lot so they don't have to be hand-watered. The board unanimously approved Rivera's requests.

The next EOTEC meeting is 7 a.m. on Friday, Sept. 29.

## DRY CLEANER: 'I knew I was taking a risk with my business ... with my safety'

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to clashes between self-described alt-right white nationalist, white supremacist and neo-Nazi protesters and counter protesters in Charlottesville, Virginia, on Aug. 12. One of the protesters allegedly drove his car into a crowd, killing a 32-year-old woman and injuring several others.

In the days following the event, Trump gave conflicting statements, sometimes blaming "many sides" and other times more directly condemning white supremacists.

"There is no moral ambiguity in this situation — white supremacy is wrong and I'm not going to be quiet about it," Van Schoonhoven said in an interview with the *East Oregonian* Friday.

The sign has been ripped off the store twice since she taped it to the window, but she has replaced it each time and made corresponding donations to the American Civil Liberties Union.

Van Schoonhoven acknowledged the wide range of support and criticism her Facebook page has received. Most of the authors who have reviewed La Grande

Dry Cleaning hail from outside Oregon — including people from Alabama, South Dakota, New York and Missouri.

"I knew I was taking a risk," she said about posting the sign. "I knew I was taking a risk with my business. I knew I was taking a risk with my safety."

While she has received a few personal threats, Van Schoonhoven said the online criticism has mostly involved calling her a racist and saying her business is going to fail.

In contrast to the comments on social media, she said most of her in-person interactions about the signs have been positive and her business has actually grown, although that wasn't her original intention.

Even the in-person criticism has been more civil than the online discourse, Van Schoonhoven said.

Van Schoonhoven ran for state House District 58 in 2012 and 2014 as the Democratic candidate. The district spans Union County, Wallowa County and parts of Umatilla County, including Pendleton.

Van Schoonhoven said she has no plans to take the sign down.

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