

DISORDER: Experimental drug not available for women

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wheelchair.”
As Arroyo ages, her condition gradually worsens. Waiting for the U.S. Food and Drug Administration to approve the medication is excruciating.
“Every day, there’s damage that can’t be undone,” she said.
Arroyo, a 2012 Blue Mountain Community College graduate, carries on despite her condition. She expects to graduate from Eastern Oregon University with a teaching degree in spring 2016.
A special pump implanted in her chest in 2013 gives her some relief. The left ventricular assist device “does 90 percent of the heart’s job.”
Afterward the surgery “I was a completely different person,” she said. “For once, my extremities were warm. My fingernails had been gray from lack of oxygen. Now they are pink. I have more energy.”
Still, so much depends on the approval of Eteplirsen. The process, she said, moves at a glacial pace while people with Duchenne get sicker. Arroyo

wrote a letter to the FDA to remind them that there are females with Duchenne and encourage them to expedite approval of the drug.
“Congress has given the FDA the tools it needs to expedite the approval of drugs like Eteplirsen for patients just like me with rare deadly disorders that have no current treatment options,” Arroyo said. “The Catch-22 for the manufacturer of the drug, from my perspective, is that while the FDA has been slow to start using the accelerated approval pathways, there are hundreds if not thousands of Duchenne patients like me hoping and praying to wake up one day and read that this drug has been approved.”
Arroyo communicates with other Duchenne patients via social media. She knows three other females in Oregon who have the disorder.
Last summer she met Scott Griffin, who testified in his home state of Alabama to allow terminally ill patients access to medicines that pass phase one of the FDA approval process. His 10-year-old son Gabe has

Duchenne. Griffin was on a team supporting two cyclists riding across America to put a spotlight on the disorder. One of the cyclists, Michael Staley, is a former congressional chief of staff who heard Griffin speak. The other, Wes Bates, a freshman at Indiana State University, lost a close friend to the disorder.
“It touched their hearts,” Arroyo said. “They took the summer off from work to ride their bikes across the country and raise awareness.”
Griffin and two other volunteers met Arroyo at Pendleton City Hall when the team reached Pendleton.
“They had never met a girl with Duchenne,” she said.
She became friends with Staley through social media, though she hasn’t met him personally. Staley encourages people to tell the FDA what they think about drug development by sending comments to www.regulations.gov.
“The general public can help Susie by writing to the FDA before Aug. 10 and simply stating why they believe a patient like Susie

Arroyo should be given access to drugs like Eteplirsen,” he said.
In the meantime, the muscle wasting continues.
“After becoming wheelchair bound and eventually losing arm function, most Duchenne patients end up bedridden with breathing tubes and loss of control of virtually all bodily functions,” Staley said.
The FDA does have a process to allow people to gain access to experimental drugs called “Compassionate Use.” Arroyo’s doctor has initiated the process, but it is long and challenging.
If Arroyo does get access to the medication, she’s not worried about side effects.
“There’s a lot of fear that this is risky, that the drug will cause adverse health problems,” Arroyo said. “Honestly, Duchenne is worse than any side effect could be. I feel I should be able to choose something that is potentially good even though it could make me sick.”

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Contributed photo
Susie Arroyo, a Pendleton woman who has Duchenne Muscular Dystrophy, met up with Scott Griffin as he traveled through the country supporting the Ride-4Gabe bicycle tour named for his son, who has Duchenne. The pair poses last summer with Pendleton Mayor Phil Houk (right) in front of the Hope for Gabe motorhome in the city hall parking lot.

SUMMER: Free books handed out

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“We have different ways that we fund different kids, but the key thing is that any kid can come,” Sipe said. “They’re covering reading. They’re covering writing. They’re covering math. But they try to do it in a way that is pretty hands-on and very engaging.”
On Tuesday, students who will be entering the third grade this fall were performing experiments on gummy bears to see how the different substances affected the candy.
Jayden Vela said he thought summer classes would be boring, but after attending, he enjoyed them. Pedro Figueroa said he is bored when he is not at summer school.
The teachers try to make learning a fun experience, but Taylor said the education they impart is very beneficial.
“The kids are having a good time, but they are definitely getting reading and math intervention, which is what they need so you don’t see a huge drop in their fluency,” she said. “One thing that people don’t realize about



Staff photo by Kathy Aney
Kids check out the new books they received Wednesday at McNary Heights Elementary School in Umatilla. The Children’s Reading Foundation READ Up literacy program provides free books each week paid for with Ready 2 Learn grant dollars.

reading benchmarks is that they are actually expected to gain (proficiency) over the summer with no instruction whatsoever, and that’s just almost impossible.”
Students are expected to read 60 words per minute at the end of their first-grade year, she said, but 80 words per minute by the beginning of second grade.
Sipe said the district has also been giving away free

students participating in the science, technology, engineering and math academy, however, the educational opportunities continued into the afternoon.
Sipe said for the first time the district has been offering its STEM academy during the summer. For \$10 per day, she said the students have the opportunity to further their technical education by studying topics such as the moon and volcanoes.
McNary Heights attendance secretary Natasha Ugarte said the fee scares many people away, but it costs less than a babysitter.
“They pay a minimum of \$20 per day (for childcare),” she said. “We’re a lot cheaper, and they get educated.”
Sipe said students can still register and participate in the remainder of the STEM academy. For more information, call McNary Heights, 541-922-6650.

TAX CREDITS: Cost state \$986.1M in revenue

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pricing rules going back to mid-2012, so deals that violated the rules in place at the time will be legitimate.
Business energy tax credits issued from 2006 to 2014 could cost the state up to \$968.1 million in tax revenue, according to the Department of Energy. A majority of that cost — \$703.6 million — comes from tax credits that were sold to investors.
Although an auditor is conducting the investigation, it is not an actual audit, according to energy agency spokeswoman Rachel Wray.
“Those forms were pulled because the Secretary of State’s office has some questions about our processes,” Wray said Tuesday. “It is not an audit.”

Wray referred other questions about the inquiry to the Secretary of State’s office.
Tony Green, a spokesman for the Secretary of State’s office, declined to comment on any aspect of the auditor’s work, including the timing of the investigation and what prompted it.
“As you know, the Audits Division has some investigatory responsibilities that are confidential in nature until resolution is reached,” Green wrote in an email Tuesday.
The Secretary of State’s office operates the state’s government waste, fraud and abuse hotline. Under state law, those complaints and the investigation findings are confidential until the agency completes the inquiry.

MEALS: Small fee for adults to eat

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continues to grow. As word spreads, more and more people attend.”
Sipe said an average of 185 people eat breakfast, 250 eat lunch and 30 eat dinner at the various sites. Adults can also partake in the meals for \$1 for breakfast and \$2 for lunch or dinner, she said.
“For the adults, that fee simply recoups our cost, so that we’re not misusing the funds,” she said. “We have to make sure that we’re only feeding children for free, so we are very careful about that. It’s still a great way for families to get out, go for a walk, do an activity.”
Sipe said the meals also provide a social opportunity for families. McNary Heights attendance secretary Natasha

Ugarte said many families are joining in.
“My kids have dinner during dinner time, and it’s pretty successful,” she said. “Full families come and eat, and I’ve noticed them intermingling with other families and talking about school. It’s actually pretty cool.”
The meals are served at different times and locations

Mondays through Fridays. Breakfast is served from 8-9 a.m. at McNary Heights and from 8:30-9:30 a.m. at Umatilla High School. Lunch is served from 11:30 a.m. to 12:30 p.m. at McNary Heights, the high school and Kiwanis Park near McNary Market. Dinner is served from 4-5 p.m. at McNary Heights.

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First Foods Festival and Race

— Formerly known as Salmon Walk

Saturday, August 1, 2015 • July Grounds
(73310 July Grounds Lane, Pendleton, OR 97801)

Race Events & Times

(Jackets and medals for 1st – 3rd place for hike, 10 K & 5 K race events)

7:10 am Kanine Ridge Hike Departs July Grounds

9:00 am 10 K Spawn Run

9:30 am 5 K Smolt Run

10:30 am Family Fun Walk & Cycle (noncompetitive)

1st Annual Chumash Lacrosse Tournament

Team Categories Grades 1st - 3rd, 4th - 6th, 7th - 8th, 9th - 12th & Adult (Medals for Winning Team in Each Category)

8:00 am - 10:15 am Chumach Tournament Begins

10:15 am - 12:00 pm Break for Family Fun Walk/ Race

12:00 pm - 2:30 pm Chumash Tournament Continues

1-888-809-8027 ext. 7219 or firstfoodsfestival@ctuir.org

Event Agenda

6:45 am	Race Registration Opens
7:10 am	Hikers Depart for Kanine Ridge Hike
8:00 am	LaCrosse Tournament Begins (Game Times 8 - 10 am & 12:00 - 2:30 pm)
8:15 - 9:40 am	Yoga Stretch & Breath
9:00 am	10 K Spawn Run
9:30 am	5 K Smolt Run
10:00 am	First Foods Info Booths Open
10:30 am	Family Fun Walk & Cycle (Noncompetitive)
11:30 am	BBQ Fundraiser Lunch
12:00 pm	Awards Ceremonies for Race Events
1:00 pm	First Foods Contest
2:30 pm	Festival and LaCrosse Tournament Ends

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