



TRUMP PARDONS FORMER SHERIFF JOE ARPAIO 6A



WEEKEND EDITION  
GRAND COLORS OF THE SOUTHWEST LIFESTYLES/1C

Adults look but never leap

OPINION/5A



# EAST OREGONIAN

AUGUST 26-27, 2017

141st Year, No. 225

WINNER OF THE 2017 ONPA GENERAL EXCELLENCE AWARD

\$1.50



Susie Arroyo of Pendleton sits in a patient room in the day surgery unit of St. Anthony Hospital receiving her second dose of newly approved drug, Exondys 51, to help treat a rare muscle weakening disorder called Duchenne muscular dystrophy.

Staff photo by E.J. Harris

## Susie's battle

Woman with rare disease lobbies for drug approval, gets chance at life

By KATHY ANEY  
East Oregonian

Susie Arroyo savored the moment. The 27-year-old sat in her wheelchair with a rubber tourniquet around her forearm, looking calm as St. Anthony Hospital registered nurse Sally Bishop installed an IV port. Soon a drug called Exondys 51 sluiced into her veins. Arroyo's green eyes conveyed a mixture of elation and victory. She had waited for years to try this drug, known generically

as eteplirsen. The Pendleton woman has a rare, muscle weakening disorder called Duchenne muscular dystrophy. Children with Duchenne are usually in wheelchairs by the time they're teenagers and often die in their 20s and 30s. The disorder strikes one out of every 3,500 boys. Arroyo estimates she is one of only 20-or-so females in the U.S. with Duchenne. Girls usually serve only as carriers, but Arroyo is what's known as a manifesting carrier and she exhibits the same symptoms as her male counterparts.

As a young girl, her muscles progressively weakened, then she seemed to rally in her teenage years, warding off stiff muscles with exercise. Then in 2009, things changed when Arroyo fell, broke her back and was encased in a full-torso cast for six months. Her heart deteriorated rapidly during her time of inactivity. Suddenly wheelchair-bound, the Blue Mountain Community College student was terrified. In 2013, a surgeon implanted a device

See ARROYO/12A

"Susie is a fighter. She's trailblazing for all of us."

—Pat Furlong, mother of two boys who died of Duchenne muscular dystrophy

### HERMISTON

## EOTEC looks ahead

By JAYATI RAMAKRISHNAN  
East Oregonian

The first fair and rodeo at the new Eastern Oregon Trade and Event Center grounds has come and gone, and board members are now turning their attention to operating and maintaining the facility. Board members of both the Umatilla County Fair and Farm-City Pro Rodeo spoke at Friday's first EOTEC board meeting since those events ended. Both said that overall, their events went well. "The board didn't meet ... because they were worried about getting it completed, not having an event," said Dennis Barnett of the rodeo board. "After months of working on the facility, the event went off without a hitch."

Dan Dorrان, an outgoing fair board member and a member of the EOTEC board, said seeing the facility in operation was a dream come true. "I have thousands of new friends I never would have had before, and probably as many enemies," he said. "Dreams don't come this big very often." Despite their overall satisfaction with the first event at the new location, EOTEC board members quickly shifted focus. Their next major job will be to find a permanent manager to run the facility. Nate Rivera, the superintendent of Hermiston Energy Services, agreed earlier this month to serve as interim manager of EOTEC for up to six months — but one of his main goals will be finding a candidate to replace him full-time. Rivera updated the board on some tasks he's been working on since the fair and rodeo ended.

See EOTEC/12A

### LA GRANDE

## Anti-Trump sign in business draws criticism, support

By ANTONIO SIERRA  
East Oregonian

La Grande Dry Cleaning's Facebook page is home to nearly 1,000 reviews, most of which deal less with the company's ability to eliminate stains and more to do with President Donald Trump. The business became a hotbed of political attention when owner Heidi Van Schoonhoven posted a new sign in the downtown storefront's window Aug. 16. "White supremacy is wrong," the sign states. "Trump condones white supremacy. If you still support Trump, your business is NOT welcome here." Van Schoonhoven decided to post the sign following Trump's response

See DRY CLEANER/12A



Heidi Van Schoonhoven, owner of La Grande Dry Cleaning and a former Democratic candidate for state representative, has placed a sign in her shop window that reads, in part, "If you still support Trump, your business is not welcome here."

### PENDLETON



Staff photo by E.J. Harris

Tomatoes of a different color  
Yellow pineapple tomatoes sit in a bin in the Way of Life Farms booth on Friday at the Pendleton Farmers Market.

|              |              |              |               |
|--------------|--------------|--------------|---------------|
| Sat<br>90/58 | Sun<br>97/64 | Mon<br>98/66 | Tues<br>99/65 |
|--------------|--------------|--------------|---------------|



7 29467 10002 2