A6 THE ASTORIAN • TUESDAY, FEBRUARY 23, 2021



Hailey Hoffman/The Astorian

From left, Trudy, Alina and Djordje Citovic have lobbied for legislation to screen for spinal muscular atrophy. Alina, 8, was diagnosed with the medical condition several years ago.

## Bill: About 1 in 40 people carry the gene for spinal muscular atrophy

Continued from Page A1

didn't already include the screening. "It could just be a weird COVID thing where a bunch of stuff kind of got lost in the shuffle," the Portland Democrat said. "Or it could be that, frankly, they thought, 'Well, we just can't afford this.""

Over the past several years, several treatments have become available for the condition. The Food and Drug Administration in 2019 approved Zolgensma, a one-time intravenous gene therapy targeting the root of the disease. But the medication needs to be administered before children turn 2 years old.

"Like any disease, it's pretty crappy to get," Nosse said. "But if you can test for it soon, you can mitigate it and prolong the person's life, and not have that child's life be as difficult as it might otherwise be."

Alina Citovic, an 8-yearold from Astoria, was diagnosed with a milder form of the condition allowing her to still walk. She became the first patient at Doernbecher Children's Hospital at Oregon Health & Science University to take a new at-home oral treatment for the condition.

Citovic and Wren Grabham, a 15-year-old Portland girl who lost the ability to walk from the condition and uses a wheelchair, thanked Nosse in a YouTube video for introducing the bill.

"It's very good to have SMA on the newborn screening," Citovic said. "It saves lives, and it's very, very important to do it within two years."

About 1 in 40 people carry the gene for spinal muscular atrophy.

"There are over 80,000 Oregon residents who don't know that they're carriers of this genetic disease," said Cheryl Grabham, Wren's mother.

"They don't know that they're carriers," she said. "And for the first time, there's something we can really do about it, but it relies on early testing." Alina's parents, Trudy

and Djordje Citovic, have reached out to state Sen. Betsy Johnson, who has supported the effort and plans to sign on to the bill when it reaches the Senate.

Along with saving the lives of children afflicted with the condition, Johnson and Nosse have pointed to the long-term savings that would come from early diagnoses and treatment.

"There are significant costs associated with caring for people who have persistent diagnoses," Johnson, D-Scappoose, said. "It isn't going to get better."

# **Hurd:** 'I think I find most of my inspiration from people and humanity'

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Autumn Hurd | artist

Continued from Page A1

Hurd's day job is delivering coffee for Columbia River Coffee Roaster, but she devotes the rest of her free time to making and selling her art.

"I had tried so many different avenues and nothing ever spoke to me the way that creating did," she said. "And it's been never about money for me. It's always been about having an outlet for myself, and then also just creating something that other people also relate to and can see and take inspiration from."

H u r d started with d r a w i n g graphite portraits at Asto-

ria High School and then moved to painting with acrylics. Last year, she started using Procreate, a digital illustration app.

"It's just a lot more convenient, and it's kind of the way the art world is going," she said. "I feel like the horizon has broadened so much just from turning to digital art because I can go anywhere with it. There's so many more options.

"I do want to get back into acrylic paints this year and that's what Foragers will kind of give me is a studio space to be able to do that and have that available. So, I can have my canvases set up and my easel just waiting for whenever I have that instinct to paint."

A lot of her work features portraits of people, female figures and messages around inclusivity. One of her favorite drawings this year is of the Asto-Bridge ria and a rainbow-colored

River. think I find most of my inspiration from people and humanity, Hurd "And way that people come together, and just the representation of

Columbia

all different kinds of people in all forms, and the beauty that everyone has in their own ways.

"And I think my main goal is to kind of have a support system for people that may not find that in a small town," she said. "To have something that people will see and be like, 'Yeah, that's me. Finally.'

"I'm not trying to be a voice for everyone, but just to have that little something for the people here that aren't like the majority."

#### US tops 500,000 coronavirus deaths

By HEATHER HOLLINGSWORTH and TAMMY WEBBER Associated Press

The COVID-19 death toll in the U.S. topped 500,000 Monday, a staggering number that all but matches the number of Americans killed in World War II, Korea and Vietnam combined.

The lives lost, as recorded by Johns Hopkins University, are about equal to the population of Kansas City, Missouri, and greater than that of Miami; Raleigh, North Carolina; or Omaha, Nebraska. The U.S. recorded an estimated 405,000 deaths in World War II, 58,000 in the Vietnam War and 36,000 in the Korean War.

President Joe Biden will hold a moment of silence and a candle-lighting ceremony at the White House, and will order U.S. flags lowered at federal buildings for the next five days.

Monday's grim milestone comes as states redouble efforts to get the coronavirus vaccine into arms after last week's winter weather closed clinics, slowed vaccine deliveries and forced tens of thousands of people to miss their shots.

Despite the rollout of vaccines since mid-December, a closely watched model from the University of Washington projects more than 589,000 dead by June 1.

The U.S. toll is by far the highest reported in the world, accounting for 20% of the nearly 2.5 million coronavirus deaths globally, though the true numbers are thought to be sig-



David Goldman/AP Photo

Gravediggers lower the casket of someone who died of coronavirus at the Hebrew Free Burial Association's cemetery in the Staten Island borough of New York in April.

nificantly greater, in part because many cases were overlooked, especially early in the outbreak.

The first known deaths from the virus in the U.S. were in early February 2020. It took four months to reach the first 100,000 deaths. The toll hit 200,000 in September and 300,000 in December, then took just over a month to go from 300,000 to 400,000 and another month to climb from 400,000 to 500,000.

Average daily deaths and cases have plummeted in the past few weeks. Virus deaths have fallen from more than 4,000 reported on some days in January to an average of fewer than 1,900 per day.

But experts warn that dangerous variants could cause the trend to reverse itself. And some experts say not enough Americans have been inoculated yet for the vaccine to be making much of a difference.

Instead, the drop-off in

deaths and cases has been attributed to the passing of the holidays; the cold and bleak days of midwinter, when many people stay home; and better adherence to mask rules and social

distancing.

Dr. Ryan Stanton, an emergency room physician in Lexington, Kentucky, who has treated scores of COVID-19 patients, said he never thought the U.S. deaths would be so high.

"I was one of those early ones that thought this may be something that may hit us for a couple months ... I definitely thought we would be done with it before we got into the fall. And I definitely didn't see it heading off into 2021," Stanton said.

Kristy Sourk, an intensive-care nurse at Hutchinson Regional Medical Center in Hutchinson, Kansas, said she is encouraged by the declining caseload and progress in vaccinating people, but "I know we are so far from over."

People "are still dying, and families are still isolated from their loved ones who are unable to be with them so that is still pretty heart-wrenching," she said.

Snow, ice and weather-related power outages closed some vaccination sites and held up shipments across a large swath of the nation, including in the Deep South.

As a result, the seven-day rolling average of administered first doses fell by 20% between Feb. 14 and Feb. 21, according to data from the Centers for Disease Control and Prevention.

The White House said that about a third of the roughly 6 million vaccine doses delayed by bad weather were delivered over the weekend, with the rest expected to be delivered by mid-week, several days earlier than originally expected. White House coronavirus response coordinator Andy Slavitt on Monday attributed the improved timeline to an "all-out, round-the-clock" effort over the weekend that included employees at one vaccine distributor working night shifts to pack vaccines.

### Fish deaths: Homeowners association plans to build a new spillway, fish ladder

Continued from Page A1

In addition to the penalty, the state directed the homeowners association to create a water quality management plan and a 10-year schedule for becoming compliant with standards for temperature and dissolved oxygen within the lake and creek.

The state Department of Fish and Wildlife is seeking a separate claim against the homeowners association for the fish kill, but did not disclose the amount.

The homeowners association has argued that the state mandated the drain repair and was kept informed through the process. It also denied being responsible for a fish kill.

"DEQ has not substantiated their allegations that the mandated repair work resulted in the death of salmon and trout," the association said in a statement. Fishhawk Lake "community members observed the lake draining and did not observe dead fish or scavengers that would substantiate the fish kill DEQ asserts."

Fishhawk Lake "implemented specific measures to prevent fish mortality,

including following the direction of Oregon Department of Fish and Wildlife to conduct the work during the in-water work window."

After floodwaters nearly topped the dam in 2007, the homeowners association was tasked by the state with building a new emergency spillway, along with improving fish passage.

The association is planning a \$3.5 million project to build a new spillway over one side of the dam and tunnel a fish ladder through the other. It contends the project will prevent failure of the dam in a major flood and open 13 miles of salmon habitat upstream of the lake.

County and state leaders and agencies, including the Department of Fish and Wildlife, have backed the project. The homeowners association is applying for state and federal grants based on safety and the project.

ect's benefits to fish passage. "DEQ's enforcement action puts that project at risk by seeking to divert community funding that could be used to continue efforts to implement this environmental project," the association said.



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