

# Meningitis victims face long, uncertain recovery

October 20 2012, by Tamara Lush

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In this photo made available, Oct. 9, 2012, by the Minnesota Department of Health shows vials of the injectable steroid product made by New England Compounding Center implicated in a fungal meningitis outbreak that were being shipped to the CDC from Minneapolis. On Thursday, Oct. 18, 2012, the U.S. Food and Drug Administration said the fungus was in one lot of vials made in August, 2012 by the New England Compounding Center of Framingham, Mass. The specialty pharmacy has been at the center of a national investigation into more than 250 fungal meningitis cases, including at least 20 deaths. (AP Photo/Minnesota Department of Health, File)

(AP)—Vilinda York lies in her Florida hospital bed, facing a dry-erase board that lists in green marker her name, her four doctors and a smiley face.

Also on the board is this: "Anticipated date of discharge: NOT YET

DETERMINED."

The 64-year-old contracted [fungal meningitis](#) after receiving three tainted steroid shots in her back. She's one of 271 people nationwide who are victims of an outbreak that began when a Massachusetts compounding pharmacy shipped contaminated medication. Twenty-one people have died.

Like many trying to recover, York, who has been hospitalized since Sept. 27, faces a long and uncertain road. Many people have died days or even weeks after being hospitalized. Fungal meningitis—which is not contagious—is a tenacious disease that can be treated only with powerful drugs.

"I'm determined I'm going to fight this thing," she said. "The devil is not going to win."

Dr. William Schaffner, an infectious disease specialist who chairs Vanderbilt University's Department of [Preventive Medicine](#), said the treatment includes intravenous anti-fungal medicines that are tricky to use.

"These are powerful drugs. They're toxic," he said. "You're walking a tightrope because you want to get enough into a patient to have the [therapeutic effect](#) while at the same time you're trying not to affect, or to minimize the effect on the liver and kidneys."

Even after leaving the hospital, he said, patients will continue [antifungal drugs](#) for weeks or months.

The infectious disease doctor handling York's case did not immediately respond to a phone message.

When York talks about the last six weeks, tears run down her cheeks. She knows the disease is deadly. And if she needed a reminder, it's right there in the headline from a local newspaper on her hospital bed: "Third death reported in Marion County from fungal meningitis."

For York, 2012 started well. The retired clothing shop clerk and widow from Illinois was doing water aerobics three times a week, tending to her flower garden and spending time with church friends. They'd get together at Olive Garden and Red Lobster restaurants a couple of times a week and go to church every Sunday.

On Jan. 21, she was on her way to a wedding when she got into a car crash. It wasn't enough to put her in the hospital, but she did suffer back problems.

The pain was strong enough for her to visit a doctor at Marion Pain Clinic, where she received two steroid shots on Aug. 16. A week later, the pain was still there and she began feeling headachy, nauseous and dizzy. She chalked it up to her back and got a third shot Aug. 28.



In this Oct. 12, 2012 file photo, shows a closeup view of a microscope taking a look at a slide with meningitis causing fungus *Exserohilum rostratum* at the Mycotic lab at the Centers for Disease Control and Prevention in Atlanta. (AP Photo/Pouya Dianat, File)

In the weeks that followed, her health deteriorated. She couldn't lie down without extreme back pain. A friend gave her a recliner to sleep in. The headaches grew severe, sharp pains shooting from all directions into her skull.

"I couldn't walk well, I couldn't see good and I could wipe the sweat off my arms," she said.

On Sept. 27, her legs and arms grew numb. The numbness flowed upwards to her waist. That's when she called the emergency dispatcher.

"I didn't know whether I was getting ready for a stroke," she said.

When she arrived at the hospital, doctors took a spinal tap and discovered she had meningitis.

Health officials have noticed that the sickest patients with meningitis are those who either did not catch the symptoms early or who didn't receive appropriate treatment early because doctors didn't know what they were dealing with. The fungi become harder to kill once they have established themselves in a person's body.

"If treatment is given early, it is very effective," said Dr. David Reagan, medical officer for Tennessee, where the outbreak was first detected. "If it is given late, it is not very effective."

Most of the positively identified cases are caused by *Exserohilum rostratum* (ex-sir-oh-HY-lum ross-TRAH-tum). The fungus is commonly found in the environment, but it has never before been observed as a cause of meningitis.



This undated file image made available by The Centers for Disease Control and Prevention shows the *Exserohilum rostratum* fungus. *Exserohilum*, a kind of black mold, is the primary cause of a number of fungal meningitis cases afflicting people who got steroid back injections for pain. There are numerous ways a fungus might contaminate medications being made in a lab. (AP Photo/The Centers for Disease Control, File)

Because of that, Reagan said, officials have been unable to firmly establish the incubation period and give those who received the tainted injections a date for when they will no longer need to worry about developing meningitis.

"We're saying at least six weeks, or 42 days, but we probably will extend that," he said. "This is new territory. There's no literature to tell us how long."

In York's case, doctors initially thought she had bacterial meningitis, but when she told them about the steroid shots, doctors began to assemble a theory. On Sept. 25, the New England Compounding Center had voluntarily recalled three lots of the steroid methylprednisolone acetate.

York's three shots were that steroid—and the Marion Pain Clinic had gotten some of the tainted medicine, health officials said.

York said a doctor from Marion Pain Clinic visited her in the hospital and told her about the contaminated shots. The doctor was crying as she spoke, York added.

York passes her days by talking on the phone to two children and three grandchildren who live out of state, receiving visitors from her church and reading the Bible.

She's lost more than 10 pounds (4.5 kilograms) in the past month. She realizes she's not the woman she once was; now she's pale and weak whereas before, she liked to put on a little makeup, fix up her short brown hair and go for a walk. The only time she has walked since Sept. 27 was to shuffle to the shower on Oct. 17.

"I got to shampoo my hair and the whole nine yards," she smiled. "I enjoyed it tremendously."

York is worried about whether the meningitis will have lasting effects on her body, and she's concerned about the powerful anti-fungal medication she's taking. Doctors have had to pause the treatment because they were concerned about her liver and kidney.

York has filed a lawsuit against NECC claiming negligence, and her lawyer is getting calls from others who were sickened.

She says she's "blessed, not lucky," to be alive at this point.

"I want to get out of here," she said. "I want to go home, I want to live a normal life again. God still has a plan for me, and I'm looking forward to it."

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