

# Teen survives rare amoeba infection that kills most people

August 23 2016, by Mike Schneider

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Dr. Humberto Liraino, left, makes comments during a news conference as Dr. Rajan Wadhawan listens, at Florida Hospital, Tuesday, Aug. 23, 2016, in Orlando, Fla. The doctor spoke about the treatment of Sebastian DeLeon, a patient that has survived a brain-eating amoeba that kills most people who contract it. (AP Photo/John Raoux)

A South Florida boy has survived a rare brain-eating amoeba that kills most people, aided in part because a hard-to-get drug to fight the

infection is made by a company in Orlando where he was hospitalized, doctors said Tuesday.

Sebastian DeLeon came to the [hospital](#) two weeks ago with sensitivity to light and a headache so severe the 16-year-old couldn't tolerate anyone touching him, [doctors](#) at Florida Hospital for Children said at a news conference.

Hospital staffers had been trained to look for the [amoeba](#), which often is contracted through the nose when swimming in freshwater lakes or rivers. The infection has a fatality rate of 97 percent and another boy died from it at the same hospital two years ago.

The Centers for Disease Control and Prevention says only four out of 138 people have survived being infected with the amoeba in the past 50 years, including DeLeon, according to the hospital's doctors.

"It is so rare that a lot of times we don't think of it and that's where a delay occurs in starting a treatment," said Dr. Dennis Hernandez, head of the hospital's emergency department. "It wasn't very clear-cut and I'm still shaking about the whole case."

DeLeon, who had worked as a camp counselor in Broward County, was infected in South Florida. He began having a severe headache two weeks ago on the same day his family traveled to Orlando for a vacation. His parents took him to the emergency room at Florida Hospital almost a day and a half later when his headache worsened.



The parents of Sebastian DeLeon, mother Brunilda Gonzalez, left, and father Rafael DeLeon attend a news conference at Florida Hospital, Tuesday, Aug. 23, 2016, in Orlando, Fla. Their son Sebastian has survived a brain-eating amoeba that kills most people who contract it after he was treated at the hospital. (AP Photo/John Raoux)

Acting on a hunch, [emergency room](#) doctors ordered a spinal tap to test for meningitis, and lab scientist Sheila Black found the amoeba moving in the spinal fluid. Doctors lowered the teen's body temperature to 33 degrees, induced a coma, inserted a breathing tube and gave him a cocktail of drugs that help kill the amoeba.

One of the drugs, miltefosine, isn't readily available at most hospitals.

"When the family came to me, I had to tell them to say their goodbyes,"

said Dr. Humberto Liriano, who choked up as he described the case. "I had to tell them, 'Tell him everything you would want to tell your child because I don't know if he will wake up.'"

Luck was on DeLeon's side since the manufacturer of miltefosine is based in Orlando, and a shipment got to the hospital quickly.

"This infection can be rapidly fatal. Minutes count and having the drug rapidly at hand ... is crucial," said Dr. Federico Laham, a hospital pediatrician specializing in infectious diseases.



The mother of Sebastian DeLeon, Brunilda Gonzalez, speaks at a news conference at Florida Hospital, Tuesday, Aug. 23, 2016, in Orlando, Fla. Gonzalez's son Sebastian has survived a brain-eating amoeba that kills most people who contract it after he was treated at the hospital. (AP Photo/John Raoux)

Because the amoeba infection is so rare, the Centers for Disease Control and Prevention typically flies the drug miltefosine to the patient. But in DeLeon's case, a hospital pharmacist called the chief executive of the Orlando-based company that manufactures the drug and the CEO's son dropped it off at the hospital within minutes.

The drug, which originally was used to treat breast cancer, isn't readily available. But the manufacturer, Profounda Inc., and the family of the 12-year-old boy who died from an amoeba infection at Florida Hospital two years ago, are pushing for the drug to be in hospitals, especially in the South where the amoeba thrives in warm weather.

DeLeon is expected to recover with therapy. He is still at the hospital and needs a walker to get around, doctors said.

"We are so thankful that God has given us this miracle through this medical team ... to have our son back and having him full of life," said Brunilda Gonzalez's DeLeon's mother. "He's a very energetic, adventurous, wonderful teen. We are so thankful for the gift of life."





Dr. Humberto Liraino answers questions during a news conference at Florida Hospital, Tuesday, Aug. 23, 2016, in Orlando, Fla. The doctor spoke about the treatment of Sebastian DeLeon, a patient that has survived a brain-eating amoeba that kills most people who contract it. (AP Photo/John Raoux)

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