

Rare reaction puts 8-year-old on waiting list for 2d heart transplant

May 28 2015, by Jonel Aleccia, The Seattle Times

An 8-year-old Spanaway, Wash., girl has been hospitalized since December with a failing heart, waiting for a second transplant that could save her life.

Doctors at Seattle Children's say Aiyana Lucas is battling a rare reaction that has caused the arteries of her first [donor heart](#) to narrow dangerously, far sooner than expected.

"The big thing with her is we're worried that she's going to have a [heart attack](#)," said Dr. Yuk Law, medical director of the cardiac-[transplant](#)/heart-failure service at the hospital.

The thin child with the tight braids and polka-dot hair bow is classified as status 1A, the most urgent of patients on the transplant waiting list. But her odds of getting a new heart are complicated by the demands of her disease - and the scarcity of donor organs in her age group.

She's just one of two children in Washington state younger than 10 on the list for heart transplants - and the only one between the ages of 6 and 10. Only about 2 percent of the 2,655 [heart transplants](#) conducted last year in the U.S. went to children in that age group, according to figures from the United Network for Organ Sharing.

Nationwide, there are 4,202 people waiting for hearts, including 82 between the ages of 6 and 10.

The dearth of hearts for school-age kids is partly because fewer children in that age group need them; most pediatric transplants are performed in babies younger than 1 or in children in their teens, data show. Organs also have to be matched for size and for blood type.

In Aiyana's case, she requires an even closer match. Her [coronary artery disease](#) is likely caused by the effect of antibodies she developed against the donor tissue, a mismatch in the [human leukocyte antigen](#), or HLA, that regulates immune response, Law said. A team at the University of Washington Medical Center had to insert two stents into her heart to prop open the arteries while a transplant is pending, he added.

Seattle Children's doctors have issued strict instructions about the characteristics of the new heart Aiyana can accept. They want to make sure it has matching HLA so she doesn't have to endure another transplant in just a few years. That's likely why she's been waiting longer than the Seattle Children's median time until transplant of less than four months, Law said. Nationwide, the wait for pediatric hearts is more than seven months.

"It's possible she could have gotten five offers, but because of the HLA match requirements we wouldn't hear of them," he said.

Aiyana's mother, Promeese Lucas, 33, said the family relies on faith while they wait.

"It could come any minute, but we don't focus on that," she said. "It's bigger than that. We just wait until something happens."

It was eight years ago this month - May 31, 2007 - that Lucas got the call at a Charlottesville, Va., hospital that Aiyana's first donor heart was available.

The child had been born with a rare and severe heart defect.

The Lucas family had waited six months then, too, before they learned that a 6-month-old girl had drowned in nearby North Carolina and that her heart was available. It's a loss that Lucas said she has appreciated keenly.

"While we're in here praying for the doctors and praying for Aiyana, that family is losing their child," she said, eyes glistening. "They have to be strong enough to let their child go."

That thought has been constantly present this time, too, Lucas said. She and her husband, Kevin, 35, a customer-service representative for Comcast, trade off time at the hospital and time at home caring for their other daughter, Madison, 6.

But even as Lucas spends nights on the hospital's foldout couch, or plays quiet games to keep Aiyana's heart rate low, or helps her keep up with second-grade studies, she said she's thinking of that other family.

"What you need to do is be a mom and be thankful," she said. "Every time you look at her, that's a gift."

©2015 The Seattle Times

Distributed by Tribune Content Agency, LLC.

Citation: Rare reaction puts 8-year-old on waiting list for 2d heart transplant (2015, May 28)
retrieved 10 April 2024 from

<https://medicalxpress.com/news/2015-05-rare-reaction-year-old-2d-heart.html>

<p>This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.</p>
--