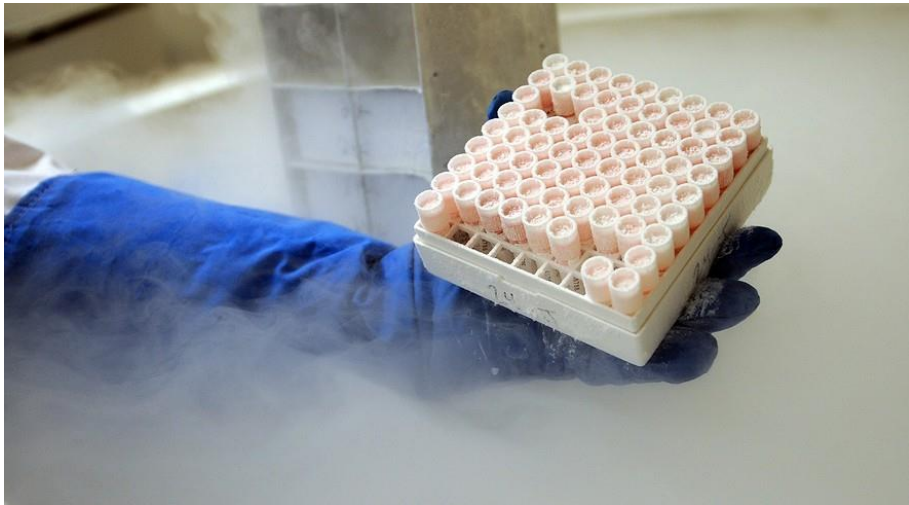


# Mayo to conduct stem cell study for babies born with rare heart defect

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Darcie Radel removes a tray of cryovials of umbilical cord blood mononuclear cells at the Mayo Clinic in Rochester, Minnesota. The cells will be used in the first clinical trial in the United States of using stem cells to treat congenital heart disease in newborns. Photo: Richard Sennott/Minneapolis Star Tribune/MCT

ROCHESTER, Minn. — Every year, about 1,000 babies are born in the United States with half a heart. The rare defect requires a series of risky surgeries and, even then, leaves the infants with the likelihood that their hearts will wear out prematurely.

Now, the Mayo Clinic has been approved to conduct a study to see if stem cells from the babies' own umbilical cords can strengthen their underdeveloped hearts and extend their lives. Stem cells can grow into different types of organs.

If it works, the new technique could buy these children time as scientists scramble for a cure for the birth defect called hypoplastic left heart syndrome (HLHS).

The Mayo study will begin as soon as 10 eligible candidates can be enrolled. It could also pave the way for additional breakthroughs in stem cell treatments that would help the 19,000 children born each year with other heart defects. But for the time being, the doctors at Mayo are keeping their focus on those babies who need the most help now.

## "To Make A Difference"

"We are not here to build an academic career out of science and technology," said Dr. Timothy Nelson, director of Mayo's HLHS research program. "We're really here to make a difference in children's lives who are living today with unmet needs."

Christina DeShaw of Clive, Iowa, was pregnant with twins when she learned that the left side of her daughter's heart was not developing properly.

"The world just started spinning," DeShaw said. "Our lives were forever changed from that moment on."

DeShaw and her husband, Brad Weitzl, sought help from the Mayo Clinic for the baby they named Ava Grace.

They learned that children born with defects on the left side of the heart must undergo a series of three complex surgeries. Within a few days of birth, surgeons reconstruct the heart so that the right ventricle can do both its own work and the work of the defective left ventricle.

## Rising Success Rate

Dr. Harold Burkhart, who is overseeing surgeries in Mayo's new study, said that when the procedure was developed in 1983, only about 30 percent of the patients survived. About 70 percent survive now, he said. About nine of 10 at the Mayo live.

The second and third surgeries are much safer. They involve rerouting blood from the body directly to the lungs, bypassing the heart entirely to reduce the workload of the right ventricle.

Ava Grace Weitzl was born on May 8, 2012, then whisked away for her first surgery. “Her heart was the size of a walnut,” DeShaw said. “She had less than a 40 percent chance of making it.”

Ava remained under intensive care until Labor Day. DeShaw, who works at ING Financial Partners in Des Moines, spent months living in a Rochester hotel; her husband, a construction estimator, drove up on weekends. But their trauma didn’t stop when they finally took their daughter home. Ava has suffered numerous complications and once had to be flown back to Mayo in a helicopter.

Unfortunately, Ava won’t be eligible for the stem cell trial: The design calls for stem cells to be injected into the right ventricle during the second surgery, and Ava has already had hers.

Still, Ava’s parents remain dedicated to helping with Mayo’s research. “We wanted to participate, not only because we thought that at some point Ava might benefit, but we also wanted to help all the other babies ... and to try to give them the best shot,” DeShaw said.

### **Stem Cell Treatments**

Cardiac stem cell treatments were pioneered in adult patients. Worldwide, 5,000 to 6,000 people have received stem cell treatments for heart conditions, but those procedures relied on cells taken from the patients’ bone marrow, said Dr. Atta Behfar, one of Mayo’s leading researchers in the field.

Doctors at Mayo found that stem cells typically weaken as they age and apparently become “sick” along with the patient. Mayo just finished a trial in Europe showing that they could kick-start those cells in a way that significantly improves the patient’s health, cuts treatment costs and improves quality of life.

Nelson said he thinks stem cells taken from umbilical cord blood and placed into a growing heart will work even better.

Also, Nelson said, stem cells from the umbilical cord seem to know when to stop producing heart cells. That means using them does not create the same cancer concerns as using other types of cells.

Nelson dedicated himself to finding a cure for HLHS when he was studying to become a heart surgeon for children. He said it tore him up to know that babies who endured three surgeries would often return as young children with heart damage that could not be fixed and little chance of finding a donor heart in time to save them.

Some research suggested that half the children with HLHS don’t make it to their fifth birthday, Nelson said. But there are also children living into their early 20s.

### **An Optimistic Outlook**

Joshua and Sandra Hughes said they learned about Mayo’s children heart research from a friend. Their 5-year-old daughter, Jaclyn, also has HLHS, and although she gets treated in Washington, D.C., they volunteered to participate in Mayo’s program.

Jaclyn underwent an MRI last week, and she and her parents each contributed skin tissue for genetic testing and other research. The body’s internal structures are visualized through the magnetic resonance imaging, or MRI, technique. A Mayo doctor said Jaclyn’s heart is performing quite well after her third surgery.

“The stuff they’re working on now may not be available for Jackie,” Sandra

Hughes said. “But it may be available for the next generation.”

The doctor interrupted her, voicing his optimism for the Mayo research.

“It may be available for her, too,” he said.