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## Boy's heart repaired in pioneer procedure

BY ERIKA BERAS

By age 9, Charlie Anderson had undergone open-heart surgery six times, with doctors attaching mechanical and pig valves to his young heart to ensure the flow of oxygen and blood.

Each time, the valves leaked. Then came a stroke. Death seemed imminent.

Only a heart transplant would save Charlie, doctors told the boy's parents, who spent months searching for a medical miracle. It came in the form of Dr. Evan Zahn, chief of cardiology at Miami Children's Hospital.

Where dozens of doctors refused to operate on Charlie, fearing that the Central Florida boy could not possibly have more heart surgery, Zahn suggested replacing the valve in Charlie's heart -- not by open-heart surgery but by a catheter through the neck.

But Zahn explained that the minimally invasive procedure had never been done before.

On Thursday, Zahn told the story of how he saved little Charlie with the experimental procedure. Sitting next to him: a smiling boy, twirling a Gators cap in his hands, with only a small bandage and some bruising on his neck.

### A RARE DEFECT

Charlie was born with Ebstein's Anomaly, a rare congenital heart defect characterized by displacement of the tricuspid valve. Because the valve is not in its usual location, it is displaced downward in the right ventricle toward the heart muscle, causing the deformed valve to leak backwards.

Simply put, the heart valve is in the wrong place, causing blood not to flow properly to the heart.

In Charlie's case, the signs of the disease emerged when he was a newborn. His first surgery was at 4 weeks of age.

"Doctors were amazed that even the first surgery worked," said the boy's mother, Tina Anderson.

It didn't last. Charlie would have five more surgeries. All proved unsuccessful. Each time, Charlie grew lethargic and struggled with his schoolwork.

In 2006, less than three years after his last surgery, Charlie suffered a stroke. The family was not sure which way to turn.

They called and sent letters to doctors around the country. None was interested. But at Miami Children's Hospital, Dr. Zahn learned of the Anderson case and got in touch with family members to

tell them about the experimental procedure. His plan: Insert a catheter through Charlie's neck to replace a heart valve.

The boy's father, Charles Anderson, wasn't convinced but came around after talking with his son and wife.

Charlie's only request: Knowing the risks, he wanted it done after the holidays to be sure they all had one last Christmas together.

Doctors at Miami Children's Hospital said that Tuesday's procedure, which took four hours, marked the culmination of years of medical advances in catheter valve implantation.

Of the heart's valves -- the tricuspid, pulmonary, aortic and mitral -- the tricuspid valve is the most complicated to treat because of its location.

Miami Children's is one of only three hospitals nationwide doing federally approved procedures with the Melody Transcatheter Pulmonary Valve and Ensemble Transcatheter. The others are Boston Children's Hospital and Morgan Stanley Children's Hospital in New York.

The new valve in Charlie's neck is now a stent -- from a cow's jugular vein -- wrapped around a valve.

Zahn obtained approval from the hospital's Institutional Review Board and the U.S. Food and Drug Administration. He also requested "compassionate use" from Medtronic, the company that makes the valve and transcatheter.

## **FRENCH INVENTION**

The valve and procedure used in Charlie's heart were invented by a French cardiologist, Phillip Bonhoeffer, who performed the world's first human heart-valve implantation without surgery on a 12-year-old boy in France in 2000.

It's unclear what complications Charlie will face, said Zahn, who is optimistic. "Charlie's disease -- it's not common," he said. "We don't have a good solution for it surgically. If he were to remain with his valve the way it was, it was as bad as it could get."

Charlie's parents are optimistic, too.

"You don't want to be the first one," said Tina Anderson, Charlie's mother. "I'm very happy. We've been through heart surgeries. It's taken him months to recover. But this time, he's energetic and as close to normal as we ever saw him."

On Thursday morning, Charlie, a third-grader, spoke via conference call to his classmates in Central Florida. He chatted with his siblings at the hospital. And he talked about the 15 spicy chicken wings he had eaten the night before.

By the afternoon, Charlie was no longer a patient at Miami Children's. Instead, he and his family were on their way to Walt Disney World for a short vacation before returning home to Macclenny, near Gainesville.

Said Charles Anderson, the boy's father: ``We've always looked to get from day to day. It's taken a lot out of us. We don't have to worry just about tomorrow. We have time now."

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