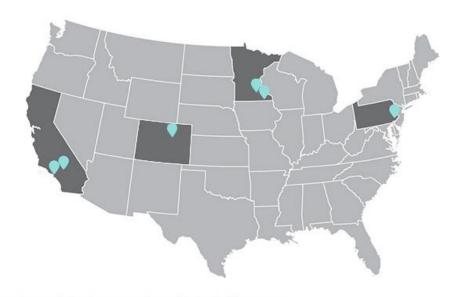
# TODD AND KAREN WANEK FAMILY PROGRAM FOR HYPOPLASTIC LEFT HEART SYNDROME (HLHS)

# **HLHS CONSORTIUM**



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The Todd and Karen Wanek Family Program for HLHS at Mayo Clinic, Children's Hospital of Philadelphia, Children's Minnesota, Sisters by Heart, Children's Hospital Colorado and Children's Hospital of Los Angeles have joined forces in a nationwide collaboration to develop an HLHS consortium.

The HLHS Consortium was developed to give patients more options when it comes to participating in groundbreaking clinical trials and other HLHS research, no matter their location.

The consortium's national network aligns regional centers to accelerate the pace of completing Phase 1 and Phase 2 clinical trials and develop a financial model to sustain a continuous pace of HLHS research and innovation.

The HLHS Consortium drives innovation, discovery science and clinical expertise by investing local resources back into research. The consortium is designed to have five to seven regional centers across the U.S. to fund the development of cell-based, innovative research opportunities that can transform the lives of people living with HLHS.

This collaboration improves important access to clinical trials and allows HLHS researchers to pool scientific knowledge with other top cardiovascular programs around the country. The consortium helps decrease the amount of time from research and discovery to the clinical application of innovative cell-based therapies.

Visit this link to view video that discussing The HLHS Consortium in more detail"

http://www.mayo.edu/research/centers-programs/todd-karen-wanek-family-program-hypoplastic-left-heart-syndrome/hlhs-research-patient-care/hlhs-consortium

### Novel Stem Cell Treatment Means New Lease on Life

 $By \ Sharing MayoClinic$ 



Halloween is an especially meaningful day for Jared Ausnehmer and his family. On Oct. 31, 2011, Jared's family saw a news story about a man who had had stem cells injected into his heart to reverse damage from a <a href="heart attack">heart attack</a>. Jared's mom, Patty Ausnehmer, wondered if this type of treatment could help her son, who was born with <a href="hypoplastic left heart syndrome">hypoplastic left heart syndrome</a> — a birth defect in which the left side of the heart is underdeveloped or nonexistent.

The news story kicked off a search for answers that led Jared and Patty to <u>Mayo Clinic's</u> <u>Rochester campus</u>, where he participated in an innovative <u>clinical trial</u>. The trial paved the way for Jared to have successful heart surgery. As a result, Jared is no longer weighed down by his heart condition, and he's returned to the athletic activities he enjoys.

"Mayo Clinic is an amazing place. They care, and they know what they're doing," Jared says. "I'm most grateful that I'm not sick anymore and everything went well. You can't take that for granted."

### New strength

On Dec. 16, 2015, in the **first clinical trial of its kind**, Jared had 94 million stem cells from his own bone marrow injected into his right ventricle through a heart catheterization. The results were significant. Within a month, Jared's ejection fraction increased to 40 percent.

"Jared had a very remarkable response to this stem cell therapy," says <u>Yasir Qureshi, M.B.B.S.</u>, lead investigator for the clinical trial. "While we predicted increased heart function, Jared has surpassed all expectations."

"He had this second wind he hadn't had in a long time," Patty says. "He seemed like he was so much better in every way."

By August 2016, Jared's heart was strong enough to undergo open heart surgery to replace his leaky valve. Cardiothoracic surgeon <u>Joseph Dearani</u>, <u>M.D.</u>, did the valve replacement on Aug. 24 and placed a <u>pacemaker</u> in Jared's abdomen.

"It's common for patients that have a <u>Fontan circulation</u> like Jared to have a slow heart rate," Dr. Dearani says. "We put a pacemaker in to ensure the heart has the ability to slow down and speed up depending on his activity level."

"With the new mechanical valve, his endurance was way up. It was like a new lease on life," Patty says.

After eight days in the hospital, Jared headed home to get back to normal life. Two months after his surgery, he was cleared to play basketball.

## Winning ways

Jared has follow-up appointments every six months, but he hasn't experienced any significant problems, and he's back to athletic competition. Six months after the valve replacement, Jared won first place in the running long jump and got third place in the 100-yard dash at the Special Olympics.

"Short of contact sports, he can do anything he wants to do and move toward achieving his goals and aspirations," Dr. Dearani says. "It's a great feeling to know I was able to make a difference in what his quality of life could be."

"For him to do what he wants to do is amazing," Patty says. "He can now get married and have kids and make a life for himself without this hanging over him anymore."

The clinical trial is slated to be completed by the end of 2017. Dr. Nelson and his entire team are grateful for the trust everyone who is part of the study has placed in them.