

Conquering CHD, Children's Hospital Colorado encourage others to provide cardiac outcomes

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Congenital Heart Disease (CHD) is the most common birth defect in the United States, occurring in approximately one in every 100 babies. However, hospital data regarding short- and long-term outcomes for patients has been limited and oftentimes difficult to access and/or interpret.

"Children's Hospital Colorado has long been committed to transparency about our outcomes," said Dunbar Ivy, MD, chief of pediatric cardiology at the Heart Institute at Children's Hospital Colorado, which is ranked #6 by US News & World Report. "We believe open, honest reporting and dialogue is key to improving outcomes for all patients."

On the heels of the 2020 Summit on Transparency and Public Reporting of Pediatric and Congenital Heart Disease Outcomes, the Heart Institute at Children's Hospital Colorado and others children's hospitals have partnered with Conquering CHD (formerly known as the Pediatric Congenital Heart Association) to develop a public, online tool using outcomes data from hospitals and centers across the country, so patients and their families can make informed decisions about where to go for cardiac surgeries or other interventions. This tool, called the Hospital Navigator, provides access to critical, reliable and understandable data.

"Of the 42,000 babies diagnosed with CHD each year in the United States, more than 13,000 will require a life-saving intervention in the

first weeks or months of life," said David Kasnic, executive director of Conquering CHD. "My daughter was one of those 13,000, and since she was born it has been my goal to improve education, awareness, research and advocacy for all those living with CHD. The Hospital Navigator will help patients and their families have the information they need to choose the right center for their child's care."

Currently, 15 hospitals with CHD programs have shared their outcomes data with Conquering CHD. The Hospital Navigator is not intended to rank surgical centers or hospitals, but instead, provide data to support an educated conversation between families and care teams.

"When Oliver was diagnosed with hypoplastic left heart syndrome, the Hospital Navigator did not yet exist. We were distraught and deeply saddened by how many doctors saw prognosis for the future," said Becca Kalivas, mother of 3-year-old Oliver. "We did a lot of research on our own and luckily, found Children's Hospital Colorado. For families looking for the right care now, the Hospital Navigator will most certainly make their search much easier. We are so grateful to our team at Children's Hospital Colorado for continuing their commitment to transparency by participating in such an important resource."

By raising awareness about the Hospital Navigator, Children's Hospital Colorado and Conquering CHD hope to encourage more hospitals to be transparent about their outcomes, including surgical volumes, survival rates overall and survival rates by surgical complexity, as well as the length of time patients stay hospitalized post-surgery. With this information, more families can make informed decisions when choosing a hospital to care for their child.

Provided by Children's Hospital Colorado

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