

**Title: National Collaborative to Improve Care of Children with Complex Congenital Heart Disease: A Project of the Joint Council of Congenital Heart Disease (JCCHD)**

**IRB# 2010-027**

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**Synopsis:**

The CHRCO Department of Cardiology is participating in the JCCHD National Collaboration to Improve Care of Children with Complex Congenital Heart Disease.

The purpose of this initiative is to improve care and outcomes for infants with univentricular heart by:

- developing a National Registry to gather clinical process and outcome data on the care of infants with a univentricular heart during the interstage period between the initial surgical procedure (the Norwood surgery) and the second surgery (Glenn shunt); and
- learning how to most effectively implement consensus standards into everyday practice across pediatric cardiology centers.

The effort will utilize a quality improvement methodology, known as the learning collaborative model, that facilitates the implementation of tools and strategies that facilitate systematic care coordination, interstage cardiovascular monitoring, and nutritional monitoring into every day practice. The Collaborative will utilize the National Registry to document the impact of these changes on various care processes and outcomes (e.g., mortality rate; severe adverse event rate; weight gain).