



Transparency in Pediatric Cardiovascular Disease

At the Pediatric Congenital Heart Association (PCHA), our mission is to “Conquer Congenital Heart Disease.” We believe that patient and family empowerment is essential to achieving this mission.

We support informed decision-making that will allow patients and families to obtain the best medical care possible. Health information that is patient-centered, accurate, accessible, and effectively communicated is a necessary component of patient and family empowerment, resulting in informed decision-making and improved outcomes in both patient health and family experience.

Congenital heart disease (CHD) is common, critical and costly. CHD is the most common birth defect, occurring in nearly 1 out of 100 births.¹ CHD is the most common cause of death related to birth defects during the neonatal and infant periods. CHD accounts for 28% of deaths due to birth defects in the first month of life and 50% of the deaths due to birth defects during infancy (2 to 12 months of age).² According to a report from the Society of Thoracic Surgeons, survival after surgery for CHD has improved over the last 17 years with hospital discharge mortality decreasing from 6.4% to 3%. While there have been dramatic improvements in survival in this high-risk population, hospital costs remain exceedingly high for pediatric patients with CHD in excess of \$5.6 billion in 2009; 15% of the total cost for all hospitalizations for children and adolescents aged 0-20 years.³

Many pediatric cardiac programs have excellent outcomes. However, there is also significant variation in outcomes across programs. Without timely and equitable access to program specific information presented in a manner that is effective for parents, it is difficult for parents to clearly evaluate the performance of a program. Simply put, without transparency, it is nearly impossible for families to make individual decisions in an informed way, and as a result, patients may experience unnecessary risk, harm or even death.

Transparency Policy Recommendations:

We believe that a thoughtful approach to transparency will make this important data accessible and relevant to parents seeking care for their child with CHD. Moreover, public reporting has been shown to catalyze quality improvement. When centers share data all participants tend to improve over time.⁴ PCHA supports the full development of the following elements:

- Transparency should occur across multiple domains:
 - Between clinicians and patients (direct, patient-centered communication about expectations and outcomes)
 - Among clinicians (peer review)
 - Between institutions (regional or national collaboratives)
 - With the public (public reporting)



- All families, upon diagnosis, should be provided with a list of questions that facilitate transparent conversations with their providers. (e.g. PCHA’s Guided Questions Tool)
- All congenital heart programs should utilize a formal review program and regularly assess performance measures and outcomes
- All congenital heart programs should participate in available national databases in order to benchmark their outcomes
- All congenital heart programs should publicly report their outcomes to a national public reporting system that adheres to the following tenets:
 - Full disclosure
 - Standardized key variables
 - Long-term outcomes data collection
 - Ability to compare institutions with risk-adjusted data (adjusting for differences in case-mix and patient factors)
 - Presented geographically
 - Include common benchmark lesions
 - Validated
 - Includes information regarding the patient experience
 - Value (cost per outcome)
 - Supportive materials for parents that enable data interpretation

Working together to improve transparency, congenital heart programs, parents and patients can improve outcomes and save lives. Congenital heart disease data may be complicated, but sharing information need not be so.

¹ Reller MD, Strickland MJ, Riehle-Colarusso T, Mahle WT, Correa A. Prevalence of congenital heart defects in metropolitan Atlanta, 1998-2005. *J Pediatr.* 2008;153(6):807-813

² Yang Q, Chen H, Correa A, Devine O, Mathews TJ, Honein MA. Racial differences in infant mortality attributable to birth defects in the United States, 1989-2002. *Birth Defects Res A Clin Mol Teratol.* 2006;76(10):706-713

³ Simeone, R. M., Oster, M. E., Cassell, C. H., Armour, B. S., Gray, D. T. and Honein, M. A. (2014), Pediatric inpatient hospital resource use for congenital heart defects. *Birth Defects Research Part A: Clinical and Molecular Teratology*, 100: 934–943. doi: 10.1002/bdra.23262

⁴ Joanne M. Hafner; Scott C. Williams; Richard G. Koss; Brette A. Tschurtz; Stephen P. Schmaltz; Jerod M. Loeb The Perceived Impact of Public Reporting Hospital Performance Data: Interviews With Hospital Staff. *Int J Qual Health Care.* 2011;23(6):697-704.

