

Response to 2019 US News and World Report Pediatric Congenital Cardiac Center Rankings:

Families deserve transparent information that is meaningful to them.

The US News and World Report (USNWR) provides information to patients and families through the annual publication of the Pediatric Congenital Cardiac Center Rankings. However, at the Pediatric Congenital Heart Association, (<http://www.conqueringchd.org>), the largest congenital heart patient advocacy organization in the U.S., we find that these rankings can be misleading for patients and families. We are encouraging patients and families to use caution in utilizing this tool when making important treatment decisions.

In 2015, the Pediatric Congenital Heart Association published the Tenets of Transparency (<https://bit.ly/2lXbW2e>). In years following we have had the opportunity to engage with USNWR Hospital Ranking editors as they strived to improve the accessibility of their rankings for patients and families. Yet, as new rankings are published each year, they deviate further from these tenets and the guidance of the congenital heart disease community.

Due to lack of transparency and context we are concerned that the rankings are misleading, which may result in families seeking care at a center that is not suited for the type of treatment their child/patient requires. Providing a rank order number implies a significant amount of information about a very nuanced system that is subject to wide variability of interpretation by patients and families of different health literacy. The rankings fail to include the definitions of which data points are being collected. The methodology for how the data is analyzed to create the ranking process is also not transparent. Lastly, there is not enough context to support consumer understanding beyond the oversimplified rank number.

As a result, these rankings appear to inflate centers that perform fewer complex procedures, ranking them higher than centers who frequently take on the riskier, more complex patients. At face value, these rankings do not allow families to consider such relevance to their child, particularly failing those families of children with complex congenital heart disease, who, one could argue, need this information the most. Should these rankings provide inappropriate reassurance, misleading a family to believe their child can receive necessary complex care at a high-ranking center, this could have serious consequences.

While we appreciate the USNWR's desire to hear from parents and families on this issue, they are certainly not responding to our input and cannot report that they are doing "what the families want." On the contrary, we are concerned that they are setting themselves up to misinform patients and families.

We strongly encourage everyone to stay informed and be an advocate. We must continue to increase transparency and open and honest communication. For more information about this and other transparency and public reporting activities at the Pediatric Congenital Heart Association, such as our Public Reporting Portal or our upcoming 6th Summit on Transparency and Public Reporting, please contact Amy Basken at advocacy@conqueringchd.org.



Pediatric Congenital
Heart Association

email. advocacy@conqueringchd.org

visit. www.conqueringchd.org