Well-run support groups leave people feeling empowered, positive, connected to others and to resources, and better able to cope. However, as the national program director of 71 congenital heart defect support groups around the nation, I often hear objections.

More than a few parents and caregivers, medical professionals and others have told me, “Support groups are where people sit around and complain about their child’s condition, and I don’t want any part of that,” or “Support groups are all about the disease. I don’t want my child to be faced with his illness each time we go to a meeting or event.”

But properly run support groups are greatly beneficial and improve the lives of children and the
Mended Little Hearts recently hosted the first two webinars in a new series “Raising My CHD Child: Questions Parents Ask” designed to help answer questions to help families care for their child with congenital heart defects (CHD).

Neurodevelopmental Issues and CHD
Dr. Brad Marino of Cincinnati Children’s Hospital and lead author of the American Heart Association’s Scientific Statement on the issue, presented “Neurodevelopmental Issues and CHD” Some children with CHD have certain risk factors and are likely to have neurodevelopmental issues that prevent them from performing at the same level as other children their age, according to Marino. They should be evaluated early by a developmental pediatrician or a specialty center that is familiar with these issues, if possible, so that they can work with parents or caregivers and educators to develop a plan to help the child be as successful as possible.

There were more than 230 registrants for the webinar. Comments included, “Outstanding,” “This webinar was like water to a parched soul,” and “I was so relieved I cried. I knew something was different about my child, but no one wanted to acknowledge it. This was excellent information.”

Trans-Catheter Valve Replacement in Children
Dr. Dennis Kim of Children’s Healthcare of Atlanta presented on this important issue that many parents have questions about. This webinar was graciously co-hosted by The Society for Cardiovascular Angiography and Interventions on Nov. 12. Again, there was a wealth of information including information about the procedure itself, who is eligible, risks and benefits, and expectations for the future. Comments included, “I found the webinar to be very informative. It was the perfect amount of time and the doctor was a fantastic speaker. I look forward to the next one. Thank you for your work with heart families. It is appreciated more than you realize.”

Both webinars are available for viewing on the Mended Little Hearts website (www.mendedlittlehearts.org)