

Congenital heart disease: Family-based psychosocial interventions

Translational Science Benefits Model IMPACT PROFILE

Dr. Erica Sood's research focuses on promoting positive neurodevelopmental and psychosocial outcomes for patients with congenital heart disease and their families.

The Challenge

Congenital heart defects (CHD) are widely recognized as the most common birth defect in the United States, occurring in about 1 in every 100 births. **Up to 30–50% of individuals with CHD experience some form of neurodevelopmental or psychological difficulty**, such as learning challenges, attention deficits, or anxiety. In addition, **a similar percentage of caregivers experience significant psychological or emotional difficulties** after an infant's CHD diagnosis.

The Approach

Dr. Sood's research includes:

- Developing and testing psychosocial interventions for families of infants diagnosed with congenital heart disease.
- Engaging with patient and family stakeholders as partners in the research process, research-related activities, and reciprocal learning.
- Fostering collaborations with multi-disciplinary research teams to evaluate and support the development, learning, and social-emotional functioning of children with heart disease.

The Impact

Dr. Sood's research has resulted in clinical, community, and policy benefits through:

- **HEARTPrep, a digital health psychosocial intervention** that aims to improve parental well-being (prenatal and postnatal), parent-infant interactions, and infant neurodevelopment.
- **Normalize-Ask-Pause-Connect (N-A-P-C), an intervention designed for pediatric healthcare professionals in the community** to build confidence and capability to address the emotional health and wellness of pediatric patients with chronic conditions and their families.
- **Accelerating clinical practice, community awareness, and best practice policies** by serving in leadership positions across community, non-government, governmental, and professional organizations.

The investigator:

Dr. Sood is a senior research scientist and pediatric psychologist in the Nemours Cardiac Center at Nemours Children's Hospital in Wilmington, Delaware, and holds an appointment as an Associate Professor of Pediatrics at the Sidney Kimmel Medical College of Thomas Jefferson University. Dr. Sood is the Director of the Nemours Cardiac Learning and Early Development (LEAD) Program. In addition to her research, Dr. Sood trains psychology fellows in the specialty area of cardiac neurodevelopment.

Find out more: <https://explore.de-ctr.org/profiles/erica-sood-phd>

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RESEARCH HIGHLIGHTS

Sood's research has resulted in:

- Increased awareness by practitioners and caregivers across the country of the need to identify and address psychosocial and neurodevelopmental difficulties in children with congenital heart disease.
- Disseminating best practice recommendations for neurodevelopmental care of children with congenital heart disease, including neuroprotection, risk stratification, evaluation, and management over time.
- Empowering families and practitioners to understand and secure the necessary types of support and care in the home, the community, and schools for children and their families.

Key Benefits



Development and expansion of the Nemours Cardiac Learning and Early Development Program at Nemours Children's Hospital.



Established feasibility and acceptability of HEARTPrep in collaboration with English and Spanish-speaking parents who received a prenatal diagnosis of congenital heart disease.



Dissemination of research findings to the community using lay summaries, blog posts, and social media platforms.



Lead author of a scientific statement from the American Heart Association (AHA) to inform healthcare professionals about advances in how to identify, evaluate, and manage neurodevelopmental delays and disorders for individuals with congenital heart disease.



Scientific advisor to national patient and family advocacy organizations, including Conquering CHD (Congenital Heart Disease).



Associate Editor of the Journal of Developmental and Behavioral Pediatrics and member of the Editorial Boards of the Journal of Pediatric Psychology and Clinical Practice in Pediatric Psychology.