



# Cardiac Newborn Neuroprotective Network

## *Special Interest Group of CNOG*

### Meet our Leadership and Founders



**Chair:** Jennifer Fogel MS CCC-SLP/L is currently working as a speech language pathologist at Advocate Children's Hospital in Oak Lawn, Illinois. She provides services in the Pediatric Cardiac Intensive Care Unit, High Risk Single Ventricle Clinic and Neurodevelopmental Follow-Up Clinic. During her more than 20 years in the field, she has specialized in pediatric feeding disorders. Her career focus has been working with infants born with complex congenital heart disease and their families in the pediatric intensive care unit before and after surgery. She has a special interest in feeding and swallowing challenges, neuroprotection interventions and neurodevelopmental support for this specialized population. Jennifer enjoys collaborating with families and medical teams to improve long-term outcomes for these infants. Jennifer has

lectured across the nation and contributed to publications providing education to others on the importance of early intervention, family involvement and clinical pathways to improve oral feeding experiences for newborns with CHD. She has been involved in the Nutrition & Growth Committee Initiatives through NPCQIC and Co-Chair for the CNOG Education and Training Committee.



**Vice Chair:** Samantha Butler PhD is a developmental and clinical psychologist at Boston Children's Hospital and Assistant Professor in the Department of Psychiatry at Harvard Medical School. She is Director of Inpatient Infant Neurodevelopment in the Cardiac Neurodevelopmental Program where she provides clinical care for infants and children with congenital heart disease (CHD), along with their families, while investigating developmental interventions to enhance long-term outcomes. She is co-chair of the NIDCAP Federation International Family Advisory Counsel and Co-Chair of the Quality Improvement Committee of the Cardiac Neurodevelopmental Outcome Collaborative (CNOG). She is the mother of school-aged twin boys, who mean the world to her, and she enjoys camping, snowboarding and biking with her family.



**Secretary:** Karli Negrin MS CCC-SLP is a speech-language pathologist with over a decade of experience working with children with congenital heart defects at the Nemours/Alfred I. duPont Hospital for Children. Ms. Negrin specializes in the evaluation and treatment of pediatric dysphagia and is committed to supporting early parental engagement in feeding experiences while preserving both breast-feeding and developmental feeding outcomes in children with congenital heart defects. Karli has lectured nationally regarding feeding and developmental challenges specific to medically fragile infants with congenital heart defects.



Courtney E. Jones MS CCC-SLP is the lead inpatient feeding therapist in the CICU and Cardiac Care Unit at Primary Children's Hospital in Salt Lake City, Utah. She developed the outpatient cardiac feeding clinic to support infants with congenital heart disease discharged with a feeding tube. She participates in the Heart Center Neurodevelopmental Program and presents annually regarding QI projects related to oral feeding advancement. Courtney continues to enjoy presenting nationally at cardiac conferences. She is committed to supporting infants with congenital heart disease and their families achieve the highest level of feeding and development.



Jodi Smith is currently the National Program Director for the Mended Hearts, Inc. (MHI), the nation's largest cardiovascular disease peer-to-peer support program for heart patients of all ages and their families. In this position, Jodi develops and implements programs and services MHI's 39,000 members, 753 volunteer leaders and 251 chapters throughout the nation. Programs include online and print educational resources, hospital programs, training programs, educational conferences, awareness campaigns and advocacy programs designed to empower patients, caregivers and families with information and resources that improve their quality of life.

Jodi has a background in corporate leadership training, teaching and law. Before joining the Mended Hearts team, she worked as a leadership training consultant creating and conducting leadership training programs for a variety of companies, including Fortune 500 companies. Subsequently, she worked at a mid-sized law firm as a litigation attorney. Jodi was also an adjunct professor teaching leadership and law classes for University of Richmond's School of Professional and Continuing Studies and the School of Law. She is currently

Vice Chair of the Advocacy Committee for American Heart Association's Mid-Atlantic Affiliate and a Steering Committee Members of the Congenital Heart Public Health Consortium and American Academy of Pediatrics' Family Partnership Network.

Jodi received her Bachelor of Arts from Randolph Macon College in Ashland, Virginia and her Juris Doctorate from T. C. Williams School of Law. She practiced law until finding out that her youngest of three sons had severe heart defects and would need multiple open-heart surgeries. After that experience, Jodi knew she needed to use her experience to help others and thus became a non-profit leader.



**Subcommittee Chair:** Hema Desai MS CCC-SLP BCS-S CLEC is an inpatient speech pathologist at Children's Hospital Orange County, treating children with feeding/swallowing disorders in an acute care setting and in the Multidisciplinary Intensive Feeding Program since 2006. Her credentials include Board Certificate Specialty in Swallowing and Swallowing Disorders as well as Clinical Lactation Educator Counselor. She provides education to hospital staff regarding feeding/swallowing concerns in children and mentors graduate students and new staff. Hema also provides guest lectures regarding pediatric feeding/swallowing at local universities in Speech Pathology graduate courses, has presented lectures about pediatric feeding/swallowing disorders at state and national conventions and has published in peer-reviewed journals.



**Subcommittee Chair:** Lauren Malik is a physical therapist at Primary Children's Hospital in Salt Lake City, Utah. She is the lead physical therapist in the rehabilitation department for the treatment of infants and children with CHD. Lauren is part of the Heart Center's Cardiac Neurodevelopmental Program both inpatient and outpatient in the Cardiac Feeding and Development Clinic. She is currently participating in several local and national quality improvement projects. She is also a co-lead for the NPC-QIC Neurodevelopmental Learning Lab Gross Motor Improvement Project focusing on improving gross motor outcomes for the single ventricle population.