

# **Best Practice: Psychosocial Support for Cardiac Patients and Families - Meeting Emotional, Social, Developmental, and Educational Needs**

### Purpose

• To enhance psychosocial support for patients and their families through these programs and to share best practice examples of ways pediatric healthcare systems can replicate these programs in their centers

### Programs

#### • Kids at Heart

- Flagship program which has over 3,000 families enrolled and offers social, educational and emotional support programs for children with congenital heart disease and their families. All offerings are free.
- Educational Offerings: Parenting Conference, Teen Retreat, Family Support Dinners
- Fellowship and Support: Sibling Support Day, Monthly Support Group, Mom's and Dad's Day Out, Parent's Night Out, Cardiac Family Advisory Council, Facebook Group, Fetal Cardiology Support
- Social Events: Camp Braveheart, Teen Events, Holiday, Fall and Summer Celebrations, CHD Awareness /Heart Month Festivities



### Feed the Heart

- For our patients and families, the wait time for treatment and/or a transplant can be days, weeks or even months creating periods of stress, financial worry and concern for the entire family.
- Feed the Heartwas created and is designed to provide meals, snacks and drinks to meet the needs of our patients and families
- Food pantry and kitchen on unit, snack cart available all day, hot meals served once a week
- Many rely on our pantry for 1-2 meals a day and look forward to our weekly meals to feed their entire family. Since its inception in 2015, Feed the Heart has served meals to more than 8,000 people

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### Programs cont.

#### Feed the Mind

- Upon admission, infants will receive a bag containing two age-appropriate books and an ageappropriate, developmental toy so caregivers can start reading to our littlest patients
- Patients can start playing with developmentally appropriate toys to promote neurodevelopment
- Patient Teaching Coordinators continue to encourage bonding and parental involvement

### Feed the Mom

- Feed the Mom supports postpartum mothers in the CICU as their babies are often admitted directly from the birth hospital, which can delay bonding between a mother and her baby.
- Feed the Mom helps mothers and infants by providing emotional support groups, mental health resources, breastfeeding support and donor-funded care packages that include an encouraging note from a heart mom who has been through a similar experience.



## **Program Sustainability**

- Collaboration with foundation and donors
- Daily communication with patient family community and clinical team about needs
- Families, community groups, outside organizations and patients organize inkind donation drives and/or charitable giving
- Families organize donations in honor of birthdays, heart surgery anniversaries (heartiversaries) milestones or in honor and memory of loved ones
- Support the Heart Center webpage that details wish lists and donation guidelines
- Social media recognition for each donation







## Patient Testimonials

- US.







### How To Implement a Program at your Center

- Seek support from family advisory council, leadership teams, clinical staff organizations and foundations
- Seek funding from grant writing team, hospital foundation and/or outside charitable
- Start small, part-time position
- Identify a key person to manage programming • Create a registration form and begin database
- Seek permission from Marketing/Public Relations to begin a private social media group for patients and families
- Utilize Children's Healthcare of Atlanta support programs teams, resources and framework as a starting point – we would love to help!

• "In May my daughter had a sudden cardiac arrest while running at field day. She was at Egleston for over a week which meant I was with her with her while her dad commuted back and forth to stay with our other kids an hour and a half away. After nearly losing our daughter, the last thing we wanted to do was leave her for a long time to get food and thankfully we didn't have to. The cart with breakfast items, snacks, and meals ensured that we could quickly return to her. I cannot say how much that helped us and the positive impact cannot be measured. Being in the hospital is stressful enough, but thankfully getting food was not part of it for

• "Our second week here with my son, two days after his first open heart surgery he had a very rough day. I had planned to go to the Feed the Mom support group, but I was feeling down so I just didn't think I should leave my child. My nurse gave me a push of encouragement to go... so I did. I am so grateful I went. I met some great moms I've really connected with. We talk and spend time together most days while our kiddos are inpatient. It's so nice to have a safe place to go to talk out your struggles, frustrations, or even happy things. It's even better that you can make these friendships and know you're not alone on this journey." • "We have been involved with Kids At Heart for over 18 years! It has been a true blessing for our family! The support we have received over the many times our

warrior has been hospitalized has been a true treasure! The friends we have made over the years at all the different events have become family! We could not have made it this far without the never-ending support and love from everyone!"



