



Hosted by:



What do parents and families of children born with a heart defect/heart disease want to know? They want to know what is new, cutting edge, and innovative that will help their child live longer, healthier, and happier lives.

Many families of children with complex heart problems feel like they are racing against time—they need solutions and wonder if they will be there in time for their child. They want answers, and they want them **now**. Congenital heart defects/disease (CHD) also takes an enormous emotional toll on families, and they want tools and resources to help them in their everyday lives.

Mended *Little* Hearts' CHD Symposium provides answers and solutions and is open to the 2 to 4 million patients, parents, and families impacted by congenital heart defects/disease (CHD) and the health care professionals who care for them. Families will learn about innovations available right now or in the near future. They will also be given new tools to help them have a better quality of life—to be both healthier and happier—not only during childhood, but as they transition to adult CHD care.

Experts from **top children's hospitals around the nation** come to speak at the CHD Symposium to bring their unique experiences and ideas to parents and families. Participants come from the U.S. as well as from Mexico and Canada. Last year, the Symposium had over 150 participants, and the live streaming had more than 12,000 views which highlights the incredible demand for the information provided.

Mended *Little* Hearts works to keep the CHD Symposium cost as low as possible for families by seeking sponsorships and support from organizations and foundations. Join us for this vital conference to improve the quality of life for the littlest heart patients of all and their families.

## AGENDA

Transition Panel in Partnership with the:

Adult  
Congenital  
Heart   
Association

Panel sponsored by:



### Friday, September 22

#### **3:30—5:15     Panel: Supporting the Teen and Family During Transition to Adult CHD Care**

Based on last year's popular [CHD According to Me](#) panel, in this panel, healthcare professionals, parents, patients, and teens will talk about how parents and families can support teens as they transition to specialized adult CHD care *from their unique perspectives*. It can be difficult enough to prepare a teen, and for a teen to prepare himself or herself for adulthood without the added complication of CHD. This panel helps teens and parents understand the steps for making the transition easier along with providing some tools and resources available to them so they can make this transition more confidently.

- Facilitator, Adult Congenital Heart Association
- Dr. Keila Lopez, Pediatric Cardiologist, Texas Children's Hospital
- Dr. Tom Macgillivray, Chief, Cardiac Surgery, Houston Methodist DeBakey Heart & Vascular Center
- Scott Leezer, dad with CHD, The Federal Group
- CHD Teen
- ACHD patient
- Social Worker

#### **6:30—9:00     Out of This World Reception**



The **Out of This World Reception** is *open to ALL CHD Symposium participants and their families*. This year, you will be able to learn from some inspiring speakers who will give us information about how they embrace their CHD and make a difference in the lives of others. We will also be giving out some special awards to leaders in the MLH communities and pioneers in CHD care. Finally, wear your space costumes and bring your dancing shoes because we will have out-of-this-world music and fun for all ages.

## **Saturday, September 23**

### **8:00—8:45 Texas Children's Hospital Cardiac Unit Tour**

CHD Symposium host, Texas Children's Hospital, has generously offered a tour of their cardiac unit open to all CHD Symposium participants.

### **9:00—9:30 Keynote Michael Montgomery, former Green Bay Packer and Founder of The Heartbeat Away Foundation**

Mr. Montgomery will speak about what inspires him and how he uses his experience with a rare rhythm disorder to help others.

### **9:35—11:25 Panel: Innovations in CHD Care—The Operating Room and Beyond**

This panel will introduce some exciting innovations in the medical treatment of congenital heart disease. Parents, patients and families are often looking for the best and less invasive procedures for their child, and there are many things being done today in CHD surgery and cardiac catheterization that improve outcomes and quality of life. In addition, in the event mechanical support is needed, parents need a plan and to know what is available. Finally, many parents, patients and families believe that stem cell therapies may be the answer they are looking for and want to know more. This panel will address all of these innovations.

- **Innovations in CHD Surgery, Dr. Charles Fraser, Jr., Texas Children's Hospital**
- **The Evolution of Cardiac Catheterization for Congenital Heart Disease, Dr. John P. Breinholt III, UT/Children's Memorial Hermann (confirmed)**
- **Innovations in Mechanical Support and Total Artificial Heart, Dr. Tara Karamlou, Phoenix Children's Hospital**
- **Stem Cell Therapies—What Is on the Horizon? Dr. Ming Si, C.S. Mott Children's Hospital**

### **11:35—12:50 Panel: Collaborative Innovations that Improve Lives**

Parents and families are often looking for hospitals and medical professionals working together, sharing information, and looking at their child as a whole person rather than just a cardiac issue. In this panel, participants will learn about an innovative multidisciplinary approach to treating a complex set of patients. Also, nurses are the main point of contact for families in the hospital, and nursing care greatly impacts the health of the child. Find out how nurses have come together to create quality metrics to improve the care of CHD children in the hospital. Finally, most parents of children with CHD report considerable stress, and a new crowdsourcing study is looking at the issue from a variety of perspectives, including the parents'. They will share information about the collaboration and key learnings.

- **A Multidisciplinary Approach to Treating CHD—Lessons from the Fontan Survivorship Clinic, Children's Hospital of Philadelphia**
- **How Quality Metrics in Nursing Can Improve Outcomes, CNMP4, Jean Connor PhD, RN, CPNP, FAAN, Boston Children's Hospital**
- **Parent Stress and Trauma—An Innovative Approach to Bringing Stakeholders Together, Dr. Erica Sood, Nemours/Alfred E. I. duPont Hospital for Children**

### **1:00—1:30 Lunch**

**1:30–2:45**

**Panel: Caring for the Needs of the Child and Family**

CHD can take toll on the whole family, and the impact on the family including the mental health issues that result from the journey with CHD are often overlooked. When they are addressed, they are typically addressed for the patient himself or herself, yet the entire family is impacted. In this panel, participants will learn about a new approach to Cardiac Rehab for children with CHD. In addition, children with CHD often face more adversity than the average child, and in this panel, parents and families will learn about resilience and how to help their child have more of it. Finally, we hear a lot now about Family-Centered Care, and in this panel, you will learn how families can truly be a vital part of the Care Team.

- **Cardiac Rehab—An Innovative Approach for Children with CHD, Michael Danduran, Marquette University, Wisconsin**
- **How Do We Create Resilient Children in the Face of Adversity?**
- **Families as Part of the Care Team**

**1:30–4:30**

**Bereavement Breakout--Marriott**

New this year, we are having a special afternoon for parents and family members who have experienced the loss of a child or loved one living with CHD. This afternoon session will have speakers and be facilitated by Mended *Little* Hearts National Bereavement Chair.

**3:00–4:15**

**Panel: The CHD Journey**

Many parents have heard about new discoveries of genes that have a causal link with certain CHDs, but they want to know what that means for their child and their family. Our first panelist will talk about the role genes play in CHD and what is being done with that information. When a child is born with CHD, most parents worry about how this will affect their growth and development. In fact, in many complex forms of CHD, growth and development may be impacted. However, there are things parents and families can do to help the child have the greatest chance of success, and these will be presented in this panel. Finally, the CHD adolescent faces unique issues and challenges, such as the fear of surgery and cardiac procedures and exposure to risky behaviors, that will be discussed in this panel.

- **How New Genetic Discoveries Impact Our Families and Our Future, Dr. Yuri Zarate, Arkansas Children's Hospital**
- **Growth & Development of the CHD Child**
- **CHD Care for the CHD Adolescent—Unique Issues and Challenges**

**4:15–4:30**

**Closing**

**6:30**

**Astros Game**

Every CHD Symposium participant and their families are invited to the Astros game Saturday night for a night of fun for all.

## About Us

### About the CHD Symposium

Mended *Little* Hearts had its first CHD Symposium in 2014 to solve an unmet need—the need for a ***national*** educational conference about innovations in treatment and care of congenital heart defects/disease (CHD) both in the hospital and at home. By creating a conference for families to learn from cardiologists, surgeons, health care professionals, patients, parents and other experts from around the nation, families are able to discover different perspectives in treating CHD and receive the most up-to-date information to help them make decisions about their child's care. Presenters from top children's hospitals share information and give parents and families tools to help them in their CHD journey. They take this information back to their local Mended *Little* Hearts chapters, hospitals and communities to help create better programs and services for families there.

The past three years, between 150-200 participants attended the CHD Symposium from the U.S., Mexico and Canada. CHD Symposium sessions are shared on the Mended *Little* Hearts website and social media venues for a wider reach to Mended *Little* Hearts' 10,000+ members and almost 50,000 social media followers. The CHD Symposium has been highly successful each year leaving participants asking for more.

### About Mended *Little* Hearts

Mended *Little* Hearts is a program of the Mended Hearts, Inc. a non-profit, volunteer-based organization with over 65 years of service to heart patients and their families. Mended Hearts is the ***largest heart patient support network in the world***, making more than 215,000 patient visits annually through its 300+ chapters. The Mended *Little* Hearts program works nationally and in communities to support and inspire hope in families of children born with congenital heart defects/disease, the nation's most common birth defects, affecting almost every 1 in 110 babies (40,000 annually). There are 2-4 million children and adults living with CHD in America today. Mended *Little* Hearts' mission is to empower families affected by CHD through peer-to-peer support, education, hospital programs, CHD awareness activities and advocacy. Mended *Little* Hearts provides hope and support to “the littlest heart patients of all” and their families.

For more information, please contact

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