Welcome to the CHD Symposium 2017!

We are delighted to have you join us for this important conference that will provide you with information about what is new, cutting edge, and innovative that will help your child, a loved one or yourself live longer, healthier, and happier lives.

We understand that 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.

This CHD Symposium provides answers and solutions. You will learn about innovations available right now or in the near future. You will also be given new tools to help you and your family have a better quality of life—to be both healthier and happier—not only during childhood, but during the transition to adult CHD care.

Experts from top children’s hospitals around the nation have come to speak at this CHD Symposium to bring their unique experiences and ideas to you. Thank you for joining us for this vital conference to improve the quality of life for the littlest heart patients of all and their families.

Heartfully,
Mended Little Hearts
Panel sponsored by:

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, Misty Sharpe, Membership and Volunteer Coordinator, Adult Congenital Heart Association
- Dr. Jeffrey Heinle, Surgeon, Texas Children’s Hospital
- Dr. Keila Lopez, Pediatric Cardiologist, Texas Children’s Hospital
- Dr. Wilson Lam, Adult Congenital Cardiologist, Texas Children’s Hospital
- Renee Bays, social worker, Texas Children’s Hospital
- Scott Leezer, dad with CHD, The Federal Group
- Annaleci Lamantia, CHD Teen/Young Adult
- Cassie Lamantia, Mother of Young Adult with CHD

6:30—9:00  Out of This World Reception  Houston Marriott Medical Center
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.

Speaker: Maria Paula Riofrio
Award Ceremony
Bravery Bag Service Project for Houston
Saturday, September 23

8:00—8:45  Texas Children’s Hospital Heart Center Tour
CHD Symposium host, Texas Children’s Hospital, has generously offered a tour of their heart center 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
- Through the Looking Glass: New Ideas and Old Concepts in Mechanical Circulatory Support and Total Artificial Heart, Dr. Tara Karamlou, Phoenix Children’s Hospital
- Regenerative Medicine Approaches for Congenital Heart Disease, 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, Kathryn Dodds, RN, MSN, CRNP, Children’s Hospital of Philadelphia
- How Quality Metrics in Nursing Can Improve Outcomes, CNMP4, Jean Connor PhD, RN, C4-MNP, FAAN, Boston Children’s Hospital
• Collaborating with Parents and Providers to Improve Family-Based Psychosocial Care: the CHD Family Support Crowdsourcing Study, Dr. Erica Sood, Nemours/Alfred 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.

 Steppin’ it Up: A Novel Approach to Pediatric Cardiac Rehabilitation, Michael Danduran & Andrea Moker, Children’s Hospital of Wisconsin
 How Do We Create Resilient Children in the Face of Adversity? Cynthia Mulder, Menninger Clinic and The Daring Way
 Families as Part of the Care Team, Michelle Lawson, Texas Children’s Hospital

1:30—4:30 Bereavement Breakout Workshop

This is a private breakout workshop for parents and family members who have experienced the loss of a child or loved one living with CHD.

 Speakers:
  o Leigh Peregoy

3:00–4:30 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. Many parents want to know what issues adults with CHD face when they need surgery or other interventions and how these procedures are different as a child gets older. 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
 Surgical Issues for the Adult with CHD, Dr. Tom Macgillivray, Chief, Cardiac Surgery, Houston Methodist DeBakey Heart & Vascular Center
 Nutrition for the CHD Child
 CHD Care for the CHD Adolescent—Unique Issues and Challenges, DK Lovick, BSN, RN & Nicole Goodly, LMSWS

4:30-4:40 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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