

CHERUBS

2009 International
Member Conference

San Antonio, TX
July 23-25 2009



brought to you by

CHERUBS
**The Association of Congenital Diaphragmatic Hernia Research,
Awareness, and Support**

www.cdhconference.org

CHERUBS
3650 Rogers Rd #290
Wake Forest, NC 27587
USA



The Holiday Inn Select San Antonio Airport
77 NE Loop 410
San Antonio, TX 78216
210-349-9900

<http://www.holidayinn.com>

Hotel reservations: 210-349-9900

We would like the following for their generous donations:

Chuck and Kara Hess, in honor of Adam Hess
Jennifer Brown, in honor of Adrian Rivera
Karen Myers, in memory of Kaleigh Myers
Kevin and Barbara Wagner, in honor of Logan Wagner
Kimberly Richards, in memory of Olivia Raine Richards

Conference Volunteers

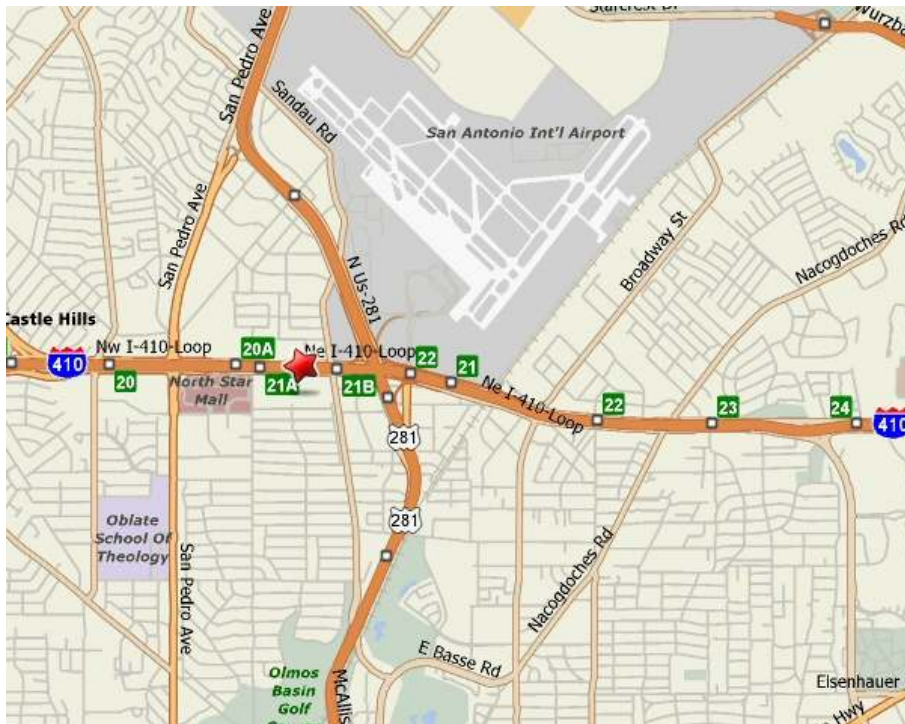
A very, very special thank you goes to the following individuals:

Alec Myers – in memory of Kaleigh Myers
Barbara Wagner – in honor of Logan Wagner
Chad Knudsen
Charles Hess – in honor of Adam Hess
Chris Arango
Craig Williamson – in memory of Shane Torrence
Dave Lipsit
Dawn Williamson – in memory of Shane Torrence
Fernanda Arce – in honor of Juan Pablo Arce
Jean Williamson – in memory of Shane Torrence
Jennifer Brown – in honor of Adrian Brown
Kara Hess – in honor of Adam Hess
Karla Holt – in honor of Braden Holt
Karen Myers - in memory of Kaleigh Myers
Kevin Lally, MD
Kimberly Richards – in memory of Olivia Raine Richards
Kimberly Switzer – in memory of Asher Switzer-McCoy
Lynne Brogdon – in honor of Baer Brogdon
Pam Lally, MD
Penny Campsey – in honor of Cole Campsey
Primerica
The Jammies

Conference Schedule

Hotel Directions

From I-410 West via EXIT 166 toward TX-368-LOOP S. Take the US-281 exit, EXIT 21, toward I-37/SAN ANTONIO/JOHNSON CITY. Take the exit on the left toward Airport Blvd/S.A. International Airport / Jones – Maltsberger Rd. Stay Straight to go onto NE I-410-LOOP. End at 77 NE LOOP 410.



WEDNESDAY, JULY 22nd

3:00 pm - Check in

7:00 pm - CHERUBS Pizza Party Meet & Greet - Join us for introductions!

THURSDAY, JULY 23rd

8:00 am - Welcome Speech by Dawn

8:30 am - 10:00 am – Guest Speaker Daryl Scott, MD (Baylor College of Medicine, Houston, TX) will discuss "Genes for CDH: Arrays, Mice and Humans"

10:30 am -12:00 pm - Guest Speakers Pamela Lally, MD and Kevin Lally, MD (The University of Texas, Houston, TX) will discuss the International CDH Study Group

FRIDAY, JULY 24th

8:00 am - 9:00 am - (Choice of) Round Table Discussions

“Grieving A Lost Dream & Life” (Grieving Parents)
or “Grieving A Lost Dream” (Parents of Survivors)

9:00 am - 10:00 am - (Choice of) Round Table Discussions

“IEPs and School for Cherubs”
or “Dealing With Family and Friends”

10:00 am – 12:00 noon – Guest Speakers Meaghan Russell and Dr. Mauro Longoni (MassGeneral CDH Clinic, Boston, MA) will discuss Genetic Research Into CDH

SATURDAY, JULY 25th

8:00 am - 9:00 am - (Choice of) Round Table Discussions

"Feeding Issues and Other Therapies"
or "Ways To Remember Our Cherubs"
or "Being A CDH Survivor / Sibling" (for kids over age 7)

9:00 am - 10:00 am - (Choice of) Round Table Discussions

"How We Have Changed Who We Are" (Parents of Survivors)
or "How We Have Changed Who We Are" (Grieving Parents)

10:00 am - 11:00 am - (Choice of) Round Table Discussions

"Dealing With Relationship Issues With A Sick Child"
or "Dealing With Siblings"

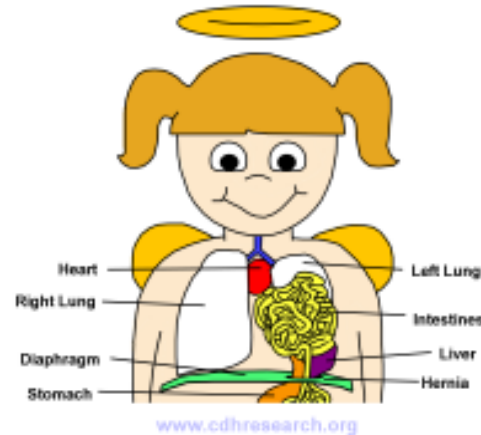
11:00 am – 12:00 noon – Good-byes

*topics and presenters are subject to change

Local Attractions:

Buckhorn Saloon & Museum
Downtown San Antonio River Walk
Japanese Tea Gardens
La Villita
Mission San Jose
Mission Trail
Natural Bridge Caverns
Rio San Antonio Cruises
Ripley's Believe It Or Not Museum
Ripley's Haunted Adventure
Rivercenter Comedy Club
San Antonio Children's Museum
San Antonio Missions National Historical Park
Sea World
Spanish Governor's Palace
The Alameda National Center of Latino Arts and Culture
The Alamo
The Alamo Ghost Hunt Tour

Congenital Diaphragmatic Hernia



What Is Congenital Diaphragmatic Hernia?

Congenital Diaphragmatic Hernia (CDH) is a birth defect that occurs when the diaphragm does not fully form, allowing organs to enter the chest cavity preventing lung growth. CDH strikes 1 in every 2500 babies, of all races, religious backgrounds, and financial status - no matter how well the prenatal care.

Nearly 4 million babies are born in the United States each year. This means that approximately **1600 babies are born with CDH each year** - in the U.S. alone! There are more babies born with CDH than with Cystic Fibrosis (1 in 3900) and it's almost as common as Spina Bifida (7 in 10,000) - yet, *unless you've been personally affected by CDH, you probably have never heard of it.* CHERUBS is working hard to

raise CDH Awareness!

The cause of Congenital Diaphragmatic Hernia is not yet known.

50% of babies born with CDH do not survive and sometimes the remaining 50% have to overcome very difficult medical complications. Many CDH babies have minor lasting health problems such as feeding aversions, asthma, scoliosis, or short-term oxygen dependency. A small number have major lasting health problems such as ventilator dependency, brain damage, or hearing problems. Many patients have no long-lasting medical problems at all other than a scar from the CDH repair. CDH can occur alone or with other birth defects, and rarely, it occurs as part of a syndrome.

Every CDH baby is different, there is no way to predict the outcome of any patient. Some babies with no diaphragm and little lung growth have survived, while some babies with full lungs do not. These children are very different, requiring different treatments, and varying amounts of medical support.

Why CHERUBS Was Founded

To help parents understand what's happening to their child by cutting through all the medical jargon that so many doctors use.

To let parents know that they are not alone and that there are other people who know exactly what they are going through and how they fell.

To advocate for pre-natal diagnosis of CDH and National Birth Defects Monitoring.

To provide support in a time of need, through our many services or just by lending an ear.

To help prevent complications by informing parents of potential problems and side-effects

To help doctors better communicate with the parents of their patients.

To encourage awareness for a disease that receives little research funding and virtually no media attention.

CHERUBS was founded in 1995 by Dawn Torrence, mother of Shane Torrence. Shane was born in 1993 with left-sided CDH and multiple other birth defects. "When my son was born, I was ignorant of the medical world and the terms that his doctors used. I wished someone had explained things to me and emotionally supported me the way that only a parent with experience and hindsight can do. Though I met many parents of children born with CDH and other problems, and made quite a few dear friends- none of us understood everything or could offer each other advice on what to expect. I vowed that if and when our lives reached some degree of normalcy, I would help other parents. That's what CHERUBS is all about".

Conference Rules

What Do You Need To Bring?

- Cool clothing and swimming clothes (optional). Conference attire is casual (no bare feet, bare chests, or swimsuits during meetings). The average temperature in NC in July is 95 degrees.
- Medical records (an outlined brief history is fine) in case of emergency.
- All medications, insurance cards, prescriptions, medical equipment, medical supplies, etc. Prescribed nutrition (formula, TPN, etc).
- Personal items such as hygiene and health items (diapers, wipes, toothbrushes, etc.), sunglasses, hats, and sunscreen. Cameras, film, batteries.
- Your child's favorite toys, strollers, baby carriers, etc.
- What not to bring? Anything illegal (unprescribed drugs, alcohol, weapons, etc) - anyone caught with illegal goods will be reported, no exceptions!
- Good walking shoes if you want to hit Downtown San Antonio or any of the tourist attractions or parks

Breakfast can be provided by the hotel at additional costs. Make sure to take advantage of our breakfast discount when you book your room!

Pizza will be provided on Wednesday, July 22nd.

Families are responsible for all other meals.

- ❖ You must be a member of CHERUBS to attend any conference activities.
- ❖ All attendance to any discussions and meetings are optional.
- ❖ Each family is responsible for their own hotel, travel, and other costs.
- ❖ Each family is also responsible for reimbursing the hotel for any damages caused by a member of the family.
- ❖ Every parent is responsible for the behavior and of their child/children.
- ❖ Every parent is responsible for knowing where his/her child/children is at all times. Please do not assume that another parent is watching your child. We don't want anyone lost or injured!
- ❖ Playing in the blow up toys, swimming in the pool, etc – all activities are done at your own risk. CHERUBS will take no responsibility for accidents, incidents, injuries or damages.
- ❖ No children under 18 years of age will be allowed to swim in the hotel pool unattended.
- ❖ Families are responsible for bringing all needed medications, equipment, records, nutrition (formula, TPN, etc), insurance cards, and other medical needs for their cherub.
- ❖ All personal information given by members during discussions is confidential!
- ❖ No one will be judged for their decisions or opinions and we all be supportive and behave like adults at all times.
- ❖ CHERUBS does not assume responsibility for cancellization of this conference due to natural disasters, national security, or any other emergency that is out of our control.
- ❖ CHERUBS does not assume responsibility or liability for any injuries, illnesses, or lost or stolen property suffered by any members during the duration of this conference and travel to and from the conference locations.
- ❖ Baby-sitting will be provided by volunteers. If you would like to volunteer, please let us know. We will not prohibit children from attending lectures and discussions, but we strongly advise against it as the meetings may become very emotional and the topics are oriented for adults.
- ❖ Sitters are NOT allowed to perform any medical procedures on any children other than their own. That includes feedings, administering medications or using medical equipment.
- ❖ All toys, personal items (bottles, pacifiers, baby bags, etc), and medical equipment or supplies taken into the conference or babysitting areas must be CLEARLY marked and all children in the babysitting area must be wearing their name tags (we don't want any formula or food mix-ups). A large suite has been obtained for the children to play in and nap in during the conference on Friday. A magician and clown will be entertaining the kids for a few hours.

About the Hotel

- **Hotel reservations: 210-349-9900**
- **CHERUBS Room Rate is \$89.00**
- **CHERUBS Room Rate + Breakfast for 2 adults is \$97.00**
- **To receive the CHERUBS discount you *MUST* tell them you are CHERUBS members when you book the room and you must book it for July 22-25th or longer. We have to book 25 rooms to get our discounts and freebies so please, please, PLEASE stay at this hotel!!! It's definitely the best value around anyway!!! :)**
- **Breakfast is not free with your room!**
- **Rooms come with coffee makers, microwaves and mini fridges. There is a pool, restaurant, bar and fitness center. Free internet.**
- **Check-In Time: 4:00 PM**
- **Check-Out Time: 11:00 AM**
- **Pets are allowed with a deposit.**
- **2 restaurants are located in the hotel.**
- **A shopping mall is next door.**
- **Airport transportation is free.**
- **The River Walk is 7 miles away, transportation is not provided.**



Please fill this out at the end of our conference

Your Name (optional): _____

Did you enjoy your stay at Comfort Suites Hotel? Would you recommend them for future conferences?

Did you find the speeches of interest and easy to understand?

Did you find lectures that pertained to your family?

Did you find the information here helpful?

Did the children have fun?

Do you think you will be attending future CHERUBS conferences?

Suggestions for locations of future conferences:

Comments, suggestions, criticisms, or compliments on this conference:
