



2009 –2010 CDH Events, Fundraisers & Get-Togethers

<u>Date</u>	<u>Event</u>	<u>Location</u>	<u>For More Information:</u>
May 16, 2009	March for Babies	San Antonio, TX	www.marchofdimes.org
May 16, 2009	Peyton's Promise for CHOP	Sea Isle City, NJ	peytonlaricks.blogspot.com
May 17, 2009	CDH Day of Prayer & Education	EVERYWHERE	Dawn - 919-610-0129
May 17, 2009	Michigan Member Bowl-a-Thon	Flint, MI	Barb - 810-845-8480
May 17, 2009	North Carolina Get-Together	Raleigh, NC	Dawn - 919-610-0129
May 17, 2009	North Carolina Balloon Release	Raleigh, NC	Dawn - 919-610-0129
June, 2009	2009 UK Conference	Great Britain	Brenda - 0800 731 6991
June 6, 2009	Pennsylvania Get-Together	Elizabeth, PA	Kate - 412-414-7073
July 11, 2009	Shelby's Summertime Celebration	Indianapolis, IN	Stephanie - 574-224-2223
July 22-25, 2009	2009 International Member Conference	San Antonio, TX	Dawn - 919-610-0129
August, 2009	Ohio Get-Together	Columbus, OH	Tara - 614-275-0858
September, 2009	Jeremiah's Car Show	Columbus, OH	Sarah - 419-512-3446
September, 2009	CHERUBS Ebay Auctions	EVERYWHERE	Dawn - 919-610-0129
October, 2009	2008 Australia Conference	Australia	Danielle - 03 5135 6999
October 29, 2009	CHERUBS Masquerade Angel Ball	Durham, NC	Dawn - 919-610-0129
November 7, 2009	New England Get-Together	Salem, MA	Corin - 401-524-9182
November 8, 2009	Gabe's Bowl-a-Thon	Cranston, RI	Corin - 401-524-9182
December, 2009	New England Truffle Sale	New England, USA	Corin - 401-524-9182
December 13, 2009	National Children's Memorial Day	EVERYWHERE	Dawn - 919-610-0129
January 16, 2010	Shannon Crawford CDH Spaghetti Dinner	Elizabeth, PA	Kate - 412-414-7073
January 28, 2010	Blood Drive in memory of Shane Torrence	Raleigh, NC	Dawn - 919-610-0129
February, 2010	Valentine's Day Fundraiser	EVERYWHERE	Dawn - 919-610-0129
March, 2010	Friends of Faith Book Drive	EVERYWHERE	Amy - 989-621-1471
April 10, 2010	CHERUBS Golf Tournament	Wake Forest, NC	Dawn - 919-610-0129
July, 2010	2010 International Member Conference	San Francisco, CA	Dawn - 919-610-0129
October 29, 2010	CHERUBS Masquerade Angel Ball	Durham, NC	Dawn - 919-610-0129

Congenital Diaphragmatic Hernia Day of Prayer & Education

May 17th is almost here! This day is set aside to say a prayer (or make a wish) for the end of Congenital Diaphragmatic Hernia. CDH is a devastating birth defect that has struck more than half a million babies since 2000. That's a baby every 6 minutes diagnosed with CDH! 50% of these babies do not survive and the cause is not known. More awareness and research is desperately needed!!!!

On May 17th please take a moment to say a prayer (or make a wish) that the cause and prevention of CDH is found. There is power in prayer (and wishes)! And please tell at least 1 person about CDH to educate them about this birth defect. Just 1 person (or more!).

How else can you help?

Ask your church or other group to include info about CDH in their programs for that day. Attend an event. Wear a CDH ribbon, wear a shirt or other logo item. Hand out buttons. Release balloons. Send info to your family and friends. Post on your blogs and web sites. Post on your Facebook or Myspace account. Get more friends to join this event!

CHERUBS

3650 Rogers Rd, #290
Wake Forest, NC 27587

919.610.0129 Phone
815.425.9155 Fax

www.cdhsupport.org

DISCLAIMER

The information on all pages of this newsletter are for education only. It is not meant to be used in place of proper medical care and advice. CHERUBS does not encourage or discourage any medical treatments or procedures. Our purpose is to educate families and medical care providers so that they may make the best decisions for the patients' interests. You cannot compare your child to other children born with CDH, they are all different. The opinions aired here by members are not necessarily the views or opinions of all members, staff or of CHERUBS.



Letter From Dawn

Dear Members,

2009 has brought a lot of wonderful things to CHERUBS and a lot of projects and events underway! We have 3 new Celebrity Spokespeople with more to be revealed soon. Our Angel Ball, local events, a partnership with Kohl's Department Store, a grant for research software, our new Adopt A Hospital program and much, much more.

May 17 has been set aside as an international day to take a moment and pray (or make a wish) for the end of CDH and also to educate the public and raise awareness. Please join us and CDH families around the world for this momentous event.

In July, we'll be hosting our annual International Member Conference. We are so pleased that attendance will break records and, once again, we have phenomenal guest-speakers! Also this year, we will have the leaders of several CDH organizations present and members coming in from around the world. This is just one of the many events that we have going on around the world and hope that you will participate when able.

We are so proud to announce many new services and funds to help families affected by Congenital Diaphragmatic Hernia, including funds for more CDH Research, Family Assistance Funds and Scholarships for CDH survivors and siblings. CHERUBS has worked hard for 14 years to help CDH families and we will continue to add resources to try to help. We desperately need donations to help fund these services. I know times are tough right now for everyone but if you can afford to give, even just a few dollars - please do so. All of our services are free and we depend on donations to continue our work.. Please also consider volunteering as we have a lot of empty positions that need to be filled.

CHERUBS Research Database is up and will be live by the end of May! We are so thrilled to be working on this database that will benefit CDH families and CDH Researchers. This database is the world's largest long-term study of CDH, with over 2500 patients. CHERUBS is working with The CDH Study group to come up with ways that we can help further research.

CHERUBS is still working hard to stop the trademark on "Congenital Diaphragmatic Hernia Awareness". Another false allegation by the leader of the organization behind the trademark even put us through an IRS audit in March, which we of course passed. As most of you know, we've been dealing with these antics for the past 5 years. We would like to thank 2 law firms who have joined our cause and to stop any further drama or harm to the CDH community by those whose priorities and ethics are a little off-base. Parker Poe Adams & Berstein LLP and Kilpatrick Stockton LLP are working pro bono to keep the CDH community safe, productive and focused on helping CDH families. Now, we have put all that in their capable hands so that we can focus solely on the positive goals of helping CDH families - which is what all CDH organizations should be doing.

More great things are in store at CHERUBS that will be revealed soon! In the meantime, browse through this newsletter issue and see the many incredible things we already have going on! I hope you all have a wonderful summer and I hope to see you at the conference!

Dawn M. (Torrence) Williamson Founder, President & CDH Mom



CHERUBS 2009 Angel Ball

Our 2009 Angel Ball is planned for October 30, 2009 at Duke Gardens in Durham, NC. The theme this year is "Masquerading Angels" and of that means that this is going to be a formal masquerade ball this year! We are also extremely excited to announce that this year CHERUBS will be co-hosting the event with the Durham Ronald McDonald House, which helps families of children at Duke University Medical Center. This a wonderful charity that helps CDH families across the country and we are so proud to be working with them! For more information on this year's event visit our



Conference Sponsors Needed



We still need sponsors for this year's conference!

\$100.00 sponsors a guest-speaker for 1 night - 9 sponsors needed!

\$250.00 sponsors the pizza pity

\$300.00 sponsors kid's entertainment

\$750.00 sponsors the conference hall fees and miscellaneous items (lecture equipment rentals, name badges, tissues, etc)

Sponsors will be listed in the conference program, on our sites and in our newsletter. Sponsorship can be made in honor or in memory of your cherub! Visit our site at www.cdhconference.org for more information

2009 International Member Conference

We will be posting more information (driving directions, etc) soon on our conference site at www.cdhconference.org

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

<http://www.hisairport.com>

CHERUBS Room Rate is \$89.00
CHERUBS Room Rate + Breakfast for 2 adults is \$97.00

Breakfast is not free with your room! I'm sorry, we tried, but this is the best we can do! Feel free to bring milk, cereal, etc if you want to save money! I think kid's do eat free in the dining room (per their site).

Rooms come with coffee makers, microwaves and mini fridges. There is a pool, restaurant, bar and fitness center. Free internet.

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!!! :)

We worked really hard to find a nice, safe hotel that was inexpensive and we hope we did ok. We didn't want our members paying \$150 a night to stay on the Riverwalk. This hotel is near the airport and includes an airport shuttle and will also go anywhere in a 2 mile radius of the hotel (that's not including the Riverwalk or Sea World, but does include the malls).

They have been very generous to us and are allowing us a FREE suite for the kids during the conference and are only charging us a cleaning for the Meeting Room... that's saving us \$1000's!!! So a huge thank you to the Holiday Inn Select!!!

We're working on the conference web site and brochure. Tentatively, here's our schedule:

July 22, 2009 - Check In
July 22, 2009 6:00 pm to 9:00 pm - Pizza Party and Introductions
July 23, 2009 8:00 am to 12:00 noon - Conference
July 24, 2009 8:00 am to 12:00 noon - Conference
July 25, 2009 8:00 am to 12:00 noon - Conference
July 25, 2009 - Check Out

That gives everyone the afternoons & evenings to go play.

Our guest speakers will speak on CDH Research, Genetics and Repair - including the head of the CDH Study Group, Dr. Kevin Lally. And from Boston Children's we welcome again Meaghan Russell and Mauro Longoni. Round table discussions will be held for both parents of survivors and grieving parents.

There will be free babysitting during conference hours for the kids (volunteers needed!) and entertainment for them too (clown, magician, etc).

There is no conference fee, you just have to be a member of CHERUBS to attend!

You are responsible for your own lodging, food and other travel costs.

We are working on discount tickets for the local attractions. I have to say that the San Antonio Tourist Bureau has been AMAZING! They will be sending all of our member info on the conference and San Antonio at no cost to CHERUBS!.

So far it looks like there will be about 150 in attendance!!! We have members coming in from Australia, Mexico, Great Britain, Canada and Italy as well - including leaders from at least 6 CDH organizations! This is truly a CHERUBS INTERNATIONAL Conference!!! We hope to see you all there!!!

Visit www.cdhconference.org to keep up with the latest info and news!

CHERUBS

2009 International
Member Conference

San Antonio, TX
July 23-25 2009



New Funds to Help Families

CHERUBS is extremely excited to announce 5 new funds to help the CDH community!

CDH Family Support Fund – this fund covers all support services, including our web sites, newsletters, conferences, New Member Packets, get-togethers and other general operating costs. CHERUBS does a lot for CDH families and the CDH community and we incur quite a few costs during so. Just 1 newsletter mailing is now over \$3000 for printing and posting with so many members. Our conferences are also expensive. Our monthly expenses are several hundred dollars for ink, postage, web site hosting fees, fax number, etc. It takes a lot to fund an organization with almost 3000 members. Remember, no one at CHERUBS gets paid and we have no office so every penny directly helps CDH families. And all of our services are FREE so we do charge membership fees. Only 2% of our members donate annually so we depend on public donations quite a bit. And the occasional grant as well.

CDH Research Fund – to pay for the \$1000 a year cost of research database hosting and to raise money for research organizations such as the International CDH Study Group – unless a request is made to go a specific hospital. The CDH Study Group is a collective group of over 30 hospitals around the world specializing in CDH research. We chose to support groups like this one because we know that every cent will go directly to research on Congenital Diaphragmatic Hernia and research will be broader and more advanced when collaborating with dozens of hospitals and researchers together.

CDH Family Assistance Fund – A majority of this fund will go to help families with travel expenses such as airline tickets and gas. It will not go to lodging because CHERUBS highly recommends the free lodging available at Ronald McDonald Houses. Families will submit confidential applications to assistance and a committee will consider each request. Our goal is to make sure that all CDH families can afford to get to their cherub's medical center and have a place to stay so that they can concentrate on their children instead of travel worries. We hope to assist a family through this fund by this fall. The remaining small percentage of this fund will go to Gabe's Gifts, a new program that helps new and expectant families by supplying them with items needed. This project will start this summer!

CDH Awareness Fund – this fund will help raise awareness of Congenital Diaphragmatic Hernia through balloon releases, giving away free CDH ribbon buttons and brochures and other items. It will also cover advertising costs, billboards, video production and much more.

CDH Scholarship Fund – for CDH survivors and siblings. Families can raise money to give scholarships in honor / memory of their cherubs. We hope to award our first scholarship in 2010.

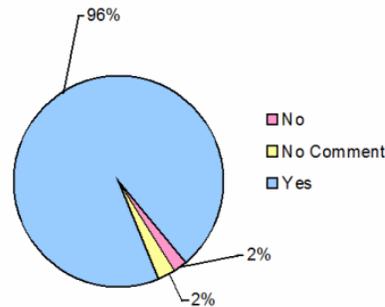
This will all be funded through donations, grants and fundraisers.



Member and the general public will be able to donate directly to a particular fund of their choosing. Donations not allocated to a specific fund will be deposited into the CDH Family Support Fund. We are very excited about all 5 of these new funds!

Customer Service Survey

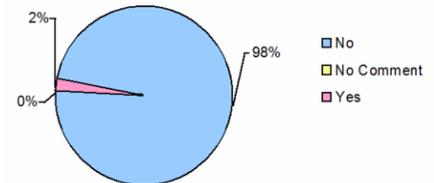
On February 15th, Kohl's Department Store volunteers conducted a phone survey of CHERUBS members. They called over 250 random members located in the United States. The results are as follows:



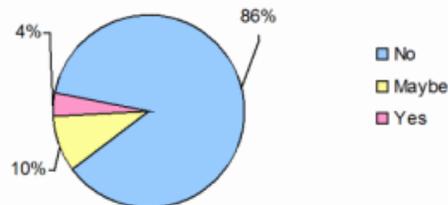
Question #1. Are you happy with CHERUBS services?

We had requests for more local events and more newsletters.

Question #2. What other services would you like to see?

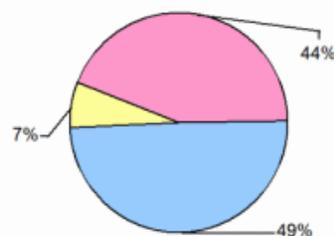
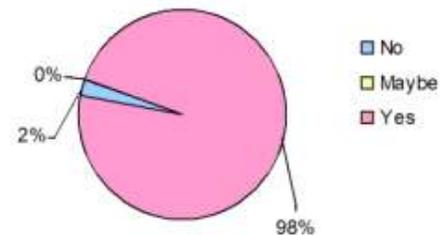


Again, we had requests for more local events and more newsletters.



Question #3. Do you plan on attending the 2009 Conference in Texas?

Question #4. Would you be interested in participating in a CDH Research Survey this year?



Question #5. Would you be interested in donating \$20.00 a year to help our charity?

We hope to use this data to help target funding for our 5 Funds to help CDH families!

New Celebrity Spokespeople for CDH!

CHERUBS Welcomes New Celebrity Spokeswoman, Patsy Pease!!



Patsy Pease is best known for playing the character of Kimberly Brady Donovan on "Days of Our Lives" from 1990 to 2008. She is one half of the soap's supercouple of Kim and Shane (played by Charles Shaunnessy). She has also appeared in "Two Shades of Blue" (1999), "Total Reality" (1997), "The Young and the Restless" (1996), "Hardball" (1994), "Silk Stalkings" (1992), "Space Raisers" (1983), "Remington Steele" (1983), "Trapper John, M.D." (1983), "Search for Tomorrow" (1979-1982). Ms. Pease has won several Soap Opera Digest Awards. She is a strong advocate for raising awareness of child abuse, giving lectures and speeches on her own personal experiences. She has semi-retired to raise her children and to continue her charity work. CHERUBS is thrilled to have Patsy on board to help with our cause!

Patsy's son was born with Eventration of the Diaphragm, a form of CDH and part of Arthrogyposis. Ms. Pease is well aware of the struggles CDH families face. "My son Russell was born with Arthrogyposis in 1990. He has had 11 surgeries before the age of 15. His first was to correct an eventrated diaphragm at 11 hours old. He was given a 10% chance for survival. Part of his multiple contracture and diaphragm problems resulted in Restrictive Lung Disease (He breathes at 40 % capacity) Despite Russell's condition he earned a



Black Belt in Tae Kwon Do at the age of 12. I was given invaluable advice by one of his surgeons long ago...."Don't treat him like anything is wrong with him and never do anything for him that he can do for himself". I watched with tears as he struggled to find his strengths and weaknesses and in turn discovered my own. I thank God for trusting and believing in me to care for my teacher, my inspiration.....my son."

Eventration of the Diaphragm is a form of CDH that occurs when the weakened muscle of the diaphragm allows organs from the abdominal cavity to move into the chest cavity; but unlike more common types of CDH, the diaphragm remains intact. Arthrogyposis is a rare congenital disorder that is characterized by multiple joint contractures and sometimes includes muscle weakness and fibrosis.

Meet Wendy Petty!

Wendy is a celebrity local to the Raleigh - Durham, NC area. I personally met Wendy a few years ago at Duke Gardens and subsequently helped to photograph her wedding (I was a photography assistant at the time). Last year we were looking for volunteers for our Angel Ball and Wendy responded to our ad. She not only volunteered for our Angel Ball but our Golf Tournament as well and is now a celebrity spokesperson for CHERUBS! And if that wasn't wonderful enough, Wendy, who is also Mrs. Durham County, NC is now using CDH as her pageant platform! We can say we met Wendy at the very beginning of our celebrity career on her way to the top - and on the way to the top Wendy is definitely going!



Dawn & Wendy at the 2008 Angel Ball

Some of Wendy's career achievements so far; Film appearances in "Racing Dreams"; "Absence With Pictures" and "April Fools Day". She was in Chris Daughtry's music video "Home". She has appeared on television on the shows "One Tree Hill", "Paris Hilton's BFF" and "Whittaker Bay". She's also done quite a bit of local commercials and promotions including playing Diamond Barbie. She is currently on the Nascar circuit as an Ask.com spokesperson. She is Mrs. Capitol City 2008 and Mrs. Durham County 2008 and has represented North Carolina and local towns in the Mrs. NC America 2007, Mrs. North Carolina America 2007, Mrs. Granville County 2007 pageants and was a Miss Hawaiian Tropic Final.. With a huge heart, Wendy is very active with many local charities, including Duke's Children's Classic.. Wendy will be at our 2009 Angel Ball!

Meet Rene Couret

Rene Couret is a plus-size model, actress, entrepreneur and student, currently residing in Southern California. She is studying Musical Theatre and American Sign Language. In her spare time, Rene runs several websites including a CDH birthing options activism site. She also loves giving advice on vegetarian healing diets, whole food nutrition, and self-image issues. Rene has appeared in the movie "Phat Girlz", appeared in many stage productions and is very involved in Hollywood's "Love Your Body Day".



Rene's son, Gregory Zion Couret, was born August 3, 2004 with a Morgagni (or right-sided) Congenital Diaphragmatic Hernia. When Gregory died at six months of age, it was a bittersweet experience. Rene felt it was her greatest source of pain but he was also her greatest source of inspiration.

When Gregory was born he was rushed right away to the NICU. He had a right-sided hernia, which causes more trouble due to the liver piercing into the right lung and pushing over the heart. He was only breathing about 30% on his own and he needed the assistance of a Ventilator in order to keep him alive. He was placed on ECMO for one week and had emergency surgery to fix his diaphragm after a small brain bleed. He had six surgeries and was taken off and on breathing support more than ten times. In the end his lungs just could not handle anymore and his heart gave up on him. My son was supposed to come home right around Thanksgiving in 2004, but he got an infection and had to heal all over again. My family and I prayed hard, stayed

up nights visiting him, and had as much faith as we possibly could. He went through ups and downs and fought his best, but by the time he was six months old he passed away. After my Gregory passed away, I felt as if something was wrong with me and I thought I did something wrong. Maybe I could have done more, or maybe it was karma sneaking up to bite me. I went through many ups and downs in my mind before I could just accept what happened and move on. It is still a process and two years later I have days when the thoughts cripple me and there are times where I feel that it never even happened.

In our next issue we will feature 4 more celebrity spokespeople!

This Newsletter Is Dedicated to the memories of:

Virginia "Addison" Acord
Layla Mae Burket
Caleb Ray Cox
Grayton Karleigh Creekbaum
Hannah Alysabeth D.
Ava Rose Daher
Nicholas Robert Doades
Jack Arthur Dowling
Connie Katherine Evans
Kaden Michael Ferguson

Kaitlynn Rene Foret
Brandon Christian Frush
Gwendolynn Leigh Glover
Callie Grace Gould
Anika Faith Guertin
Celeste M Hall
Jessica Howell
Ryan Heustess Inman
Kaden Alex Kuehl
Kaylie Kathryn Marczak

Jacob Travis Meyerson
Maxwell Christopher Mocaabee
Audrey Aileen Monreal
Jacob Alexander Morrison
Jack Joseph Nelson
Emadeane Rose Owen
Corben Hudson Blake Paone
Jady Ryanne Paxton
Vito Robert Pensavecchia
Devin Scott Person

Brandon Daniel Peterson
Bryan Taylor Piazza
Kayla Nicole Rubio
Isaac James Santimaw
Anthony Bryce Smith
Dylan Joel Smith
Marley Jane Steingass
Nicholas Walter Treska

Submitting Stories and Photos for Our Newsletter

If you would like to make a newsletter submission please e-mail your story or photo to membership@cherubs-cdh.org. You can also send your story by postal mail but we prefer e-mail that so we don't have to retype. You must be a member of CHERUBS who has given publishing permission on your membership form to have your story or photo published.

Volunteering at CHERUBS

Volunteering at CHERUBS is fun and helps CDH families! Some volunteer positions take as little time as 1 hr per month. CHERUBS runs solely by volunteers and we can use all the help that we can get!

If you would like to volunteer, please contact us at volunteer@cherubs-cdh.org

New Arrivals

*siblings

Virginia "Addison" Acord
Layla Mae Burket
Phillip Roland Butterfield
Ashley Grace Cain
Caleb Ray Cox
Grace Crawford*
Lily Crawford*
Ava Rose Daher
Cohen Matthew D'Elia
Connie Katherine Evans
Kaden Michael Ferguson
Basile Gibeaux

Gwendolynn Leigh Glover
Ruby Goldblum-Klebe
Callie Grace Gould
Anika Faith Guertin
Ethan Michael Howard
Jessica Howell
Ryan Heustess Inman
Kaden Alex Kuehl
Kiernan Thomas Leonard
Nicolas Lesende
Lexi Rose Lindsey
Kiyari Juliet Manriquez

Ericka Elizabeth Mcgettigan
Joshua Samuel Moran Lopez
Evelyn Elizabeth Morris
Colin Patrick Murphy
Jayden James Nicholas
Corben Hudson Blake Paone
Christopher David Payams
Andrew Perry
Devin Scott Person
Camden James Roell
Joel Clark Roycik
Jon Lee S.

Conner Gage Shaw
Ruby Hope Starling
Wilson Alexander Tuten
Gabriel Bryson W
Piper Brooklyn Waddell
Bennett Gary Wallace
Lorcan Warrior
Andrew Lee Whitten
Averi Rose Wilkins
Jesse Michael Wood

CHERUBS "Adopt A Hospital Program"

We have a new educational project going on at CHERUBS! We are asking members to "Adopt A CDH Hospital". When a member "adopts" a hospital, he/she will deliver Parent Reference Guides and CHERUBS brochures. CDH parents can also donate a CDH Awareness Poster or "Stories of Cherubs" books available in our on-line store.

Would you like to help families affected by Congenital Diaphragmatic Hernia? Would you like to do something in honor or in memory of a cherub? CHERUBS has created a new program that will soon be helping CDH families across the country.

There are 2 options to our Adopt A Hospital program:

Adoption Plan #1 - You order / print out the list of items below and take them to the hospital. You also become a CHERUBS Hospital Ambassador for new CDH families at that hospital and you periodically refurbish the materials.

Adoption Plan #2 - You make a \$100 donation to CHERUBS and we order and put together the materials and send them to the hospital in honor / memory of your cherub.

CHERUBS Adopt A Hospital Care Package Includes:

- 1 copy of "Stories of Cherubs" Volume I
- 1 copy of "Stories of Cherubs" Volume II
- 1 CDH awareness poster
- 20 Parent Reference Guides
- 50 CHERUBS CDH Info Brochures
- 50 CDH Awareness Ribbon Pins
- 10 copies of our latest newsletter

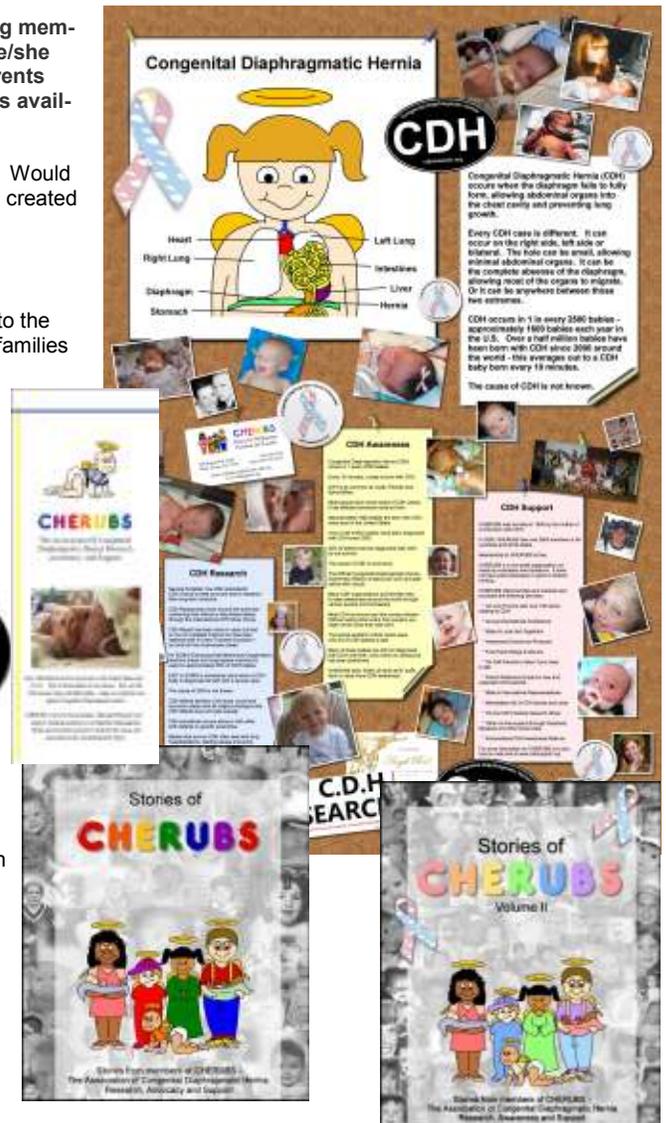


Each item (except the CDH ribbon pins) is labeled with a sticker that says "Donated in honor of _____" or "Donated in memory of _____"

These items are then available to all CDH parents admitted into these hospitals. Upon joining CHERUBS, new parents will soon receive more information and support through our Gabe's Gifts program.

These items are an invaluable source of support and information for families affected by Congenital Diaphragmatic Hernia. Because there are so many hospitals, CHERUBS cannot possibly afford to donate to all hospitals and we are inviting our members and the general public to help us to help CDH families.

If you would like to Adopt A Hospital, please contact us at volunteer@cherubs-cdh.org



CHERUBS & "The Jammies" working together on kid's CDH song and book!!!

CHERUBS is proud to work with the children's music group, "The Jammies" to collaborate on a children's song and book about Congenital Diaphragmatic Hernia!!!



<http://thejammiesmusic.com/>

We are tickled beyond belief to be able to work with 2 great guys - one of which has a cherub of his own! A book about CDH on a child's level to help explain things to young siblings and survivors has been needed for so long! We are so excited that there will be a song as well!!!

We hope to also have them perform at our 2009 CHERUBS CDH Conference in San Antonio, Texas in July!

We're currently looking for sponsors to cover these projects - please let us know if you are interested in helping us! donations@cherubs-cdh.org



Congenital Diaphragmatic Hernia Awareness Tattoos



Stephanie Olivarez, in honor of her daughter, Shelby Olivarez

Just look at what some of our members will do to raise Congenital Diaphragmatic Hernia Awareness!!

We have some members at CHERUBS who raise Congenital Diaphragmatic Hernia Awareness ALL the time! These brave moms and amazing moms and dads have gotten tattoos of our Congenital Diaphragmatic Hernia Ribbon and other logos!



Barbara Wagner, in honor of her son, Logan Wagner



Dave Holt, in honor of his son, Braden Holt



Megan Bradshaw, in honor of her daughter, Alyssa Bradshaw



Danielle Boyle, in honor of her son, Connor Boyle



We Would Like To Thank The Following For Their Gracious Help & Sponsorships

Dr. Kevin P. Lally
 Dr. Mauro Longoni
 Dr. Meaghan Russell
 Dr. Michael Harrison
 Dr. Pam Lally
 Dr. Patricia Donahoe
 Ana Elisa Pena
 Andrea More
 Anna Beltran
 Art DeBaugh
 Barbara Wagner
 Bethany Gillham
 Bob "The Blade"
 Brendan Jones
 CafePress
 Carole Olson

Chris Thomas
 Chris Wilkinson
 Corin Nava
 Craig Williamson
 Danielle Kessner
 Darlene Silverman
 Durham Visitors Bureau
 Elaine Moats
 Evan Fultz
 Heidi Cadwell
 Heidi Carlson
 Hope Musgrove-Timmons
 Jana Lewallen
 Jason Kerley
 Jean Nava
 Jean Williamson

Jeanie Toney
 John Moyer
 John Welch
 Jennifer Brighton
 Kara Hess
 Karen Myers
 Kate Crawford
 Kilpatrick Stockton LLP
 Kimberly Switzer
 Kohl's Department Store
 Laura Miller
 Lise Dill
 Many Sroka
 Melissa Kelly
 Nikki Haye
 Paige Cos

Parker Poe Adams & Berstein LLP
 Patsy Pease
 Rene Couret
 San Antonio Visitors Bureau
 Sebastian Villalobos Moltedo
 Shane Perry
 Shana Kelly
 Signature Events
 Stephanie and Shane Olivarez
 Steve and Amy Miles
 Tamara Klein
 Teri Prochaska
 Victoria Jensen
 Wendy Petty
 William Cannon
 Womble Carlyle Sandridge & Rice, PLLC

Welcome to the Following New Members:

(+ 36 more new members who did not want their cherub's name published)

- Virginia "Addison" Acord
- Baby Adler
- Madison Eve Anderson
- Ireland Rose B
- Joshua F. Baker
- Casen James Barrilleaux
- Amanda Mary Bracher
- Melissa Breitweiser
- Baby Brogden
- Layla Mae Burket
- Ashley Grace Cain
- Tony Callejas
- Cassandra Carter
- Caden James Churcher
- Sophia M Clark
- Baby Clarketimmins
- Madelyn Faith Colletti
- Caleb Ray Cox
- Angelia Crawford-Shelton
- Grayton Karleigh Creekbaum
- Katie Curley-Hannaway
- Seth Lee Curtis
- Alex D
- Hannah Alysabeth D.
- Ava Rose Daher
- Cohen Matthew D'Elia
- Giavanna Digregorio
- Nicholas Robert Doades
- Jack Arthur Dowling
- Connie Katherine Evans
- Phyllis Anne Faust
- Kaden Michael Ferguson
- Kaitlynn Rene Foret
- Charlie W Freed
- Brandon Christian Frush
- Tyler Micheal Gary
- Basile Gibeaux
- James Edward Gillrie
- Gwendolynn Leigh Glover
- Baby Gorman
- Callie Grace Gould
- Gabriella Morgan Groenewald
- Anika Faith Guertin
- W. Guip
- Cooper Weston Gulycz
- Christopher David Hall
- Eli Camden Harvey
- Ian Haynes
- Rebecca Breana Higgins
- Ethan Michael Howard
- Jessica Howell
- Ryan Heustess Inman
- Joshua Grayson Inverarity
- Elijah Scott Jaburg
- Makayla Jackson
- Taylor Nicole Jarecki
- Lauren Michelle Kaleleiki
- Renee Kebodoux
- Avery Mae Keirsej
- Landon Matthew Kelly
- Arpan Khurana
- Allie Kinniburgh
- Rees Jordan Knudsen
- Brian Daniel Jude Koerner
- Emily Grace Kozik
- Gabriela Lima Lapa E Silva
- Kiernan Thomas Leonard
- Nicolas Lesende
- Tracey Lynn Lesner
- Jesse Aaron Maddox
- Kiyari Juliet Manriquez
- Kaylie Kathryn Marczak
- Tyler Dwayne Mason
- Parker Isaiah Matlock
- Zechariah Mattocks
- Ericka Elizabeth Mcgettigan
- Ciaran Andrew Mcrobbie
- Amy Marie Meyers
- Jacob Travis Meyerson
- Max B Mills
- Maxwell Christopher Mocaabee
- Jonathan Louis Moehl
- Audrey Aileen Monreal
- Gabriela Monteiro
- Joshua Samuel Moran Lopez
- Evelyn Elizabeth Morris
- Jacob Alexander Morrison
- Chase Owen Mosier
- John Ries Murphy
- Colin Patrick Murphy
- Jack Joseph Nelson
- Jayden James Nicholas
- Caleb Mason Novak
- Brianne Elizabeth Orr
- Emadeane Rose Owen
- Addison Bea Owens
- Corben Hudson Blake Paone
- Jadyn RYanne Paxton
- Christopher David Payams
- Vito Robert Pensavecchia
- Devin Scott Person
- Brandon Daniel Peterson
- Bryan Taylor Piazza
- Marcella M Polfer
- Baby Price
- Kellan Floyd R.
- Cameron Zane Redmon
- James Reeve
- Christian Matthew X.
- Bastiann Boots Richards
- Thomas Robert-Blaine Rodgers
- Camden James Roell
- Sam Rossiter
- James Paul Rowe
- Joel Clark Roycik
- Kayla Nicole Rubio
- Jon Lee S.
- Isaac James Santimaw
- Eli Kevin Satterfeal
- Sienna Mackenzie Scott
- Ella Rose Sealock
- Conner Gage Shaw
- Amber Nichole Shelton
- Unknown Slager
- Chelsea Elizabeth Smith
- Anthony Bryce Smith
- Dylan Joel Smith
- Sara Jessica Soltis
- Stacy Spain
- Ruby Hope Starling
- Marley Jane Steingass
- Kamryn Hope Studdard
- Noah R Sullinger
- Nicholas "Baby Nicky" Walter Treska
- Jaime Albert Trost
- Wilson Alexander Tuten
- Piper Brooklyn Waddell
- Darrian Walker
- Sam Marc Walshaw
- Lorcan Warrior
- Dillon L. Wheeler
- Zach White
- Andrew Lee Whitten
- Megan Elizabeth Wilkes
- Averil Rose Wilkins
- Jesse Michael Wood
- Jacob Thomas Zimmerman

State & International Representatives

More State & International Representatives needed! We try to have 2 Reps for each state and country - 1 parent of a survivor, 1 grieving parent. As you can see, we have a lot of states and countries with only 1 Rep or not represented at all. If you would like to volunteer, please let us know!

<u>Country / State</u>	<u>Name</u>	<u>Phone</u>	<u>CHERUBS E-Mail</u>	<u>Web Site / Blog</u>
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Great Britain	Kevin Lane	01553 762 884	klane@cherubs-cdh.org	http://www.uk-cherubs.org.uk/
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Vermont	Jeanne Nava	401-578-8279	jnava@cherubs-cdh.org	http://newenglandcherubs.wordpress.com/
Vermont	Corin Nava	401-524-9182	cnava@cherubs-cdh.org	http://newenglandcherubs.wordpress.com/
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Washington DC	Brenda Slavin	443-624-2187	bslavin@cherubs-cdh.org	

CHERUBS Brochure Now Available In Different Languages

We now have the English version of our CDH Information Brochures and 3 additional languages! You can download them from our site. Thank you to Ana Elisa Pena for translating it into Portuguese, Sebastian Villalobos Moltedo for translating it into Spanish and Nikki Haye for translating it into Dutch.

If you would like to volunteer to translate our brochure, Parent Reference Guide and newsletters, please let us know!

We Would Like To Thank The Following For Their Donations:

In Honor of:

Baby Huntress - Peter and Virginia Huntress
Braden Holt - Abington Senior High School
Braden Holt - Dave and Karla Holt
Callie Abell - Angela Abell
Courtney Young - Wanda Young
Dominick Christiano - Tammy Marques
Dr. J.A.N. German - Barbara Vosburg
Gus Ginder - Lisa Schoenherr
Jason Collins - Cythia Collins
John Murphy - Barbara Murphy
Logan Lee Wagner - Barbara Wagner
Logan Wagner - Barbara Wagner – Valentines' Day Fundraiser
Mason C. Flax - Howard Clark
Mason C. Flax - Ryan and Nikole Flax
Mattson Houghton - Golden Girls, LLC
Michael Kelly - Melissa Kelly
Ray Wilkinson's grand daughter - Elizabeth Morse
Shelby Grace Olivarez - Shane and Stephanie Olivarez
Sophia Clark - Debbie and Bill Jefferson
Sophia Clark - Miki Mathioudakis
Soraya Haye - Nikki Haye

In Memory of:

Abigail Taylor Long - Douglas Taylor
Abigail Taylor Long - Mary Jo Taylor
Bridget Hope Jussaume - Anne Callahan
Caleb Ray Cox - Paige Cox
Caleb Ray Cox - Shandi Cox
Caleb Ray Cox - Sharronda and Doyce Waldrop
Christopher Faraldi - Albert and Claudia Faraldi
Cody Travis Streetman - Clarissa Streetman
Cooper Weston Gulycz - Valerie Gulycz
Elizabeth (Bean) McGrath - Adam Hathaway
Ethan James Moloney - Keith and Lynette Moloney
Ethan William James Marchand - Melanie Morningstar
Faith Grace Miles - Mary Feazell
Faith Grace Miles - Shawn Boris
Gabriel Kolacia - Amy Kolacia
Gabriel Nava - Big Y Foods, Inc.
Grayton Creekbaum - Eliza McKewen
Grayton Creekbaum - James Doyle
Grayton Creekbaum - Leigh Creekbaum
Hanna Larrison - Richard Baldwin
Hanna Larrison - Robbie Evans
Jack Payne - Elissa and Jason Shoaf
Jack Payne - Elizabeth Payne
Jenna Rose Dayton - Beverly and Hugh Dayton
Johnathan Luke Rademaker - Pete & Amy Rademaker
Kiera Uliano McKenny - Kathryn McKenny
Kyra Maxime Keller - Robin and Klaus Keller
Lucy Sofia Vaz - Anthony Vas
Madison Brooks - Christie Brooks
Maxton Standifer - Carmel Lakhani
Maxton Standifer - Ellen Clements
Maxton Standifer - Rick Langreck
Maxton Standifer - Rita Todd
McKenna Varen, Shane Torrence and all other cherubs - Alyssa Hagen
Megan Rene Miller - Libbie Miller
Megan Rene Miller - Libbie Miller
Michael Wolfe - Brian and Ann Wolfe
Shane Torrence - Darlene Silverman
Shane Torrence - Dawn Williamson
Shane Torrence - Josh and Paige Cox
Shannon Crawford - Kyle McWhinney
Shelton Earl Evans - Shelly Evans
William Glennon - Anne Callahan & Joanne Foley

Non-Specified Donations:

Kylee McWhinney
Lisa Bortolotti
Melissa Griffin

Patricia D'Angelo
Rachel Lee

Corporate Donations / Sales / Events / Fundraisers:

Abbott Laborities Employee Giving Campaign
Abington Senior High School
America's Charities
Cafepress
Capitol One Associates Political Fund Match Program
Firstgiving
GoodSearch
Kohl's Department Store

Several Families are raising oney through Firstgiving.com, an on-line service that allows you to set a free page to raise money for charity. The following are donations taken up in the past year through pages set up for CHERUBS:

Adam Hess - Monica
Ashner Switzer-McCoy - Kim Switzer
Ashner Switzer-McCoy - Onella Rossi
Ashner Switzer-McCoy - Shauna
Caleb Ray Cox - Brandon & Rachel Stanfield
Caleb Ray Cox - Josh & Paige Cox
Caleb Ray Cox - Sharronda Waldrop
Emily Lapaige Spencer - Bessie Batton
Faith Grace Miles - Allison Mitchell
Faith Grace Miles - Amy 'Reid' Starnes
Faith Grace Miles - Angela Hessler
Faith Grace Miles - Barbara Lindley
Faith Grace Miles - Bill & Marsha Grace
Faith Grace Miles - Brandon, Kathy, Jacob & Elizabeth
Faith Grace Miles - Brent & Kristy Taylor
Faith Grace Miles - Dan Grace
Faith Grace Miles - Danielle Golding
Faith Grace Miles - Diane and Richard Fleming
Faith Grace Miles - Eva Cabral
Faith Grace Miles - Federico Cabral JR.
Faith Grace Miles - Friends at Michigan Spine & Pain
Faith Grace Miles - jennifer and taylor
Faith Grace Miles - Jim and Pat Hathaway
Faith Grace Miles - Joe "Swede" Ortquist
Faith Grace Miles - Joyce Rhodes
Faith Grace Miles - Kurt, Doug, Ramez, Nate, Tanner & families
Faith Grace Miles - Kyle and Laura (Lessin) Edwards
Faith Grace Miles - Mary and Glenn
Faith Grace Miles - Mary Knapp
Faith Grace Miles - Matthew Grace
Faith Grace Miles - Meghan & Jason Hathaway
Faith Grace Miles - Micheigan Spine and Pain "Friday's for Giving" fundraiser
Faith Grace Miles - Norman White
Faith Grace Miles - Oakland Academy Staff
Faith Grace Miles - Oakland Academy Star Wars photo booth fundraiser
Faith Grace Miles - Patty Machuta
Faith Grace Miles - Robert and Carolina Grace
Faith Grace Miles - Robert Grace
Faith Grace Miles - Robin Mower
Faith Grace Miles - SaPrice
Faith Grace Miles - Sarah Price
Faith Grace Miles - Scott and Jeimi Diedrich
Faith Grace Miles - Sean & Katie Carey
Faith Grace Miles - sherry & jason robinson
Faith Grace Miles - Sidney and Mary Graham
Faith Grace Miles - Stephanie Olivarez
Faith Grace Miles - Steve and Amy Miles
Faith Grace Miles - The Shaf Family
Faith Grace Miles - The Vavala Family
Jayden Valasek - Judith A. West
Jayden Valasek - Katie and Michael Valasek
Jayden Valasek - Shelley
Logan Lee Wagner - Barbara Wagner
Shane Torrence - Craig & Dawn Williamson
Shane Torrence - Vanessa Gilley

CHERUBS & Kohl's Department Store

On February 16th, we were blessed with 10 volunteers from Kohl's Department Store! For 3 hours we talked about Congenital Diaphragmatic Hernia, folded brochures and held our CHERUBS Phone Survey. Our volunteers called 100's of CHERUBS members in those 3 hours, asking them about our services and what more we can do to help CDH families. We learned a ton.

Our local district stores at Kohl's, and especially our new Wake Forest, NC store, have adopted CHERUBS and we will be working together about once a month on many different projects and events through the year. We are so very, very appreciative for all they are doing for CHERUBS and for CDH families. They are such an incredibly kind and wonderful group of people and we are proud to work with each of them!



CDH Baby Blankets—Volunteers Needed!

From our New England Representative, Corin Nava:

We started the Gabriel's Gift Bags project to provide new and expecting CDH parents with a gift bag filled with comfort items for their baby's NICU stay. We would really like to include a handmade blanket which can be knit, crochet, or quilted in each of these bags. These blankets take a lot of time to make and we cannot do it by ourselves! There are too many parents out there who need these for us to keep up with, so we are looking for volunteers. If you are interested, in making 1 or 100, please let me know! You can email me at cnava@cherubs-cdh.org.

If you can, please consider doing this, it can really make a difference for those families in need of a little comfort. Our goal is to start providing these by the end of this summer. We help on average 100 new and expectant families each year at CHERUBS so we really need a lot of help!

(The blanket pictured was made by cherub Logan's mom, Barb Wagner.)



CHERUBS Texas Bake Sale

From our Texas State Rep, Melissa Kelly. WTG Texas members!!!!

What a day! We opened a little early and stayed a little late. We raffled off three delicious cakes and held a silent auction for an amazing cake shaped like a Leprechaun's Hat.

We sold cookies, cupcakes, candy, bread, and candied apples, we mingled with cherubs and their families, and we raised a lot of awareness. Oh, and we made a little money for two very good causes, too. \$1200 total!!

On behalf of our CHERUBS members, I would like to thank Dee, Jo Ann, Monica, Tara, and all the members of the Driscoll Children's Hospital team for making this event possible. We had an absolute blast and can't wait to do it again next year!



CDH Moms reporting for duty! Rosaena, Rachel, Laura (a CDH survivor!) and Mel





Congenital Diaphragmatic Hernia Awareness

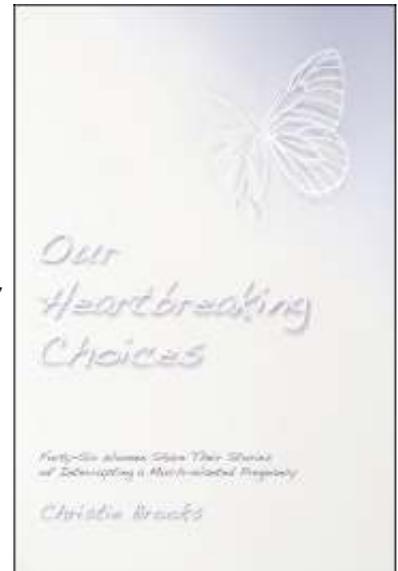
"Congenital Diaphragmatic Hernia Awareness" belongs to everyone. Over 6000 people have signed an on-line petition to help stop this trademark. Over 300 photos of cherubs are featured on a video on our YouTube site standing up against this trademark, including many families who submitted videos.

CHERUBS and CDH families and researchers around the world are standing together so that it is known and fought for that "Congenital Diaphragmatic Hernia Awareness" belongs to everyone.

"Our Heartbreaking Choices"

Pregnancies aren't always perfect. Prenatal testing can reveal life-threatening issues with the baby's health, which can leave a parent contemplating the unthinkable- ending the pregnancy. Christie Brooks, a CHERUBS member, made the heartbreaking decision to interrupt her pregnancy in 2003 when her baby was diagnosed in utero with a left-sided diaphragmatic hernia. Through online support networks she was able to connect with other mothers who made the same agonizing decision, but for a variety of different anomalies. Together they put their stories in a book and self-published it last October. The book, "Our Heartbreaking Choices," contains the personal stories of 46 women who interrupted their much-wanted pregnancies for medical reasons. The purpose of the book was to share their stories in the hopes of helping other parents who have undergone a similar loss to feel less alone, less isolated, and less stigmatized.

This book is available on Amazon.com



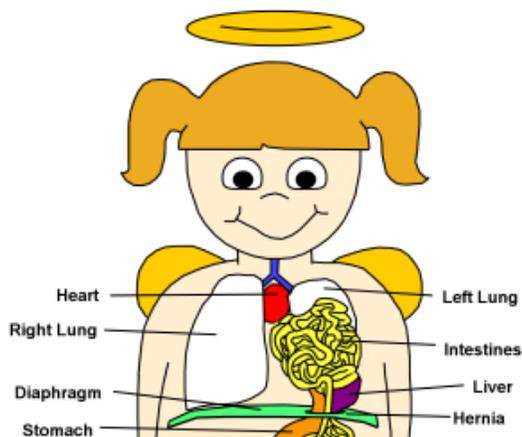
CHERUBS Wish List

We are looking for donations of the following for our various projects:

- | | |
|--------------------------------|----------------------------------|
| Monetary Donations | Baby Blankets / Quilts |
| Printing Sponsors | Journals / Notepads |
| Event Sponsors | White / Natural Cotton Tote Bags |
| Adopt A Hospital Sponsors | Chapsticks |
| Volunteers | Small bottles of lotion |
| 2-pocket folders | Small bottles of hand sanitizer |
| Postage Stamps | Travel Kleenex |
| Printing Paper | Disposable Cameras |
| CDH Awareness Ribbon Pins | Pens |
| Copies of "Stories of Cherubs" | Newborn Button up T-Shirts |
| CDH Education Posters | Restaurant Vouchers |
| CDH Awareness Bracelets | Gas Cards |

Congenital Diaphragmatic Hernia Research

Congenital Diaphragmatic Hernia



www.cdhrefsearch.org

CHERUBS is thrilled to announce that the CDH Research Survey Software Company has granted our charity a discount to help our cause! Instead of the \$6000 a year that we expected to pay, QuestionPro.com is allowing us to use their software for just \$1000 a year - saving our non-profit organization \$5000!!! We are so grateful for the assistance! QuestionPro is the top Research Software On-Line - the one we have been comparing all other software to. We didn't dare dream that we'd be able to do this research so soon, saving so much money!

Thank you QuestioPro for your generosity and for helping CDH families around the world!

Our CDH Research Site programming has begun and it will be live by May 31st!



We Love It When CDH Families Get Together!

Here at CHERUBS we are strong advocates for CDH families meeting in person and getting to know each other and sharing experiences and support! We have many get-togethers around the world and our annual Congenital Diaphragmatic Hernia International Conference as well. But families often get-together on their own informally and

below are photos of 2 such get-togethers.



CDH families meeting in Atlanta:

Pictured to the left: Carla (Joseph's mom), Lynne (Baer's mom), Marion and Jason (Virginia's parents) and Amy and Steve (Faith's parents)



Pictured to the right: Our South Carolina Representative, Lynne Brogdon (Baer's mom), rubbing Amy Miles' (Faith's mom) tummy.



Indiana Get-Together:

Pictured to the right: Kate making cookies with the Olivarez girls

Pictured to the left: Stephanie and Kate surrounded by gorgeous little girls (Lexi, Lily, Grace and Makayla)

Pictured to the right: Barb, Corin, Kate and Stephanie



Pictured to the left Barb Wagner (Logan's mom), Corin Nava (Nate's mom), Amy Miles (Faith's mom), Kate Crawford Shannon's mom) and Stephanie Olivarez (Shelby's mom)



Denver Children's Hospital:

Pictured to the right: Cherub Kristen Moats meets baby cherub, John Michael Larson



If you would like us to post photos of your get-together, please e-mail them to us at membership@cherubs-cdh.org

History of the CDH Awareness Ribbon

The first awareness ribbon or bracelet for CDH was discussed on CHERUBS old listservs in 2004. Because all the colors are taken, we didn't want to impede on any other cause's ribbon or their awareness efforts. Besides, we widely used the "cherub" as our awareness symbol for CDH. We tossed the idea around and talked about it with CHERUBS members but there was no real desire to join in on the awareness ribbon bandwagon.



The very first awareness ribbon for Congenital Diaphragmatic Hernia was a turquoise ribbon created in memory of Drew Lewallen in May, 2006 and posted on Rainbow of Hope. Because of awareness issues now associated with another organization's co-opting of Drew's ribbon and trying to copyright it (twice) as they filed to trademark "Congenital Diaphragmatic Hernia Awareness" and "Congenital Diaphragmatic Hernia Awareness Day", most families view wearing a turquoise ribbon as *endorsing the trademark*.

The Congenital Diaphragmatic Hernia community needed an awareness symbol that was owned by no one and chosen by CDH families. We also wanted something that belonged to just the CDH community and not several other causes. The turquoise ribbon happens to also be used by many organizations and the public for Addiction Recovery, Lymphedema, Native American Reparations, Sexual Assault, Ovarian Cancer, Anxiety Disorders and more.

We came up with several ideas for an original awareness ribbon. Members of several organizations voted for many days and a decision was made. The *official* congenital diaphragmatic hernia awareness ribbon, as voted on by CDH parents and survivors, is baby blue, pink and pale yellow with clouds.

This is the Congenital Diaphragmatic Hernia Awareness Ribbon recognized by the members of the Alliance of Congenital Diaphragmatic Diaphragmatic Hernia Organizations. Is it recognized by CHERUBS, the world's first and largest CDH organization with over 2800 members in 38 countries. It is the ribbon associated with the Congenital Diaphragmatic Hernia Research Study. Wikipedia recognizes this ribbon. There is even a postage stamp with this ribbon, created February 12, 2008. Not to mention 1000's of items with this ribbon available on our stores and various other sites.

And now, there are personalized Congenital Diaphragmatic Hernia Awareness Ribbons. If you would like one, please e-mail your child's photo, name and date(s) to ribbons@cherubs-cdh.org and Fer, Barb or Shana will make your ribbon as soon as possible.

ACDHO - The Alliance of Congenital Diaphragmatic Hernia Organizations

<http://health.groups.yahoo.com/group/acdho/>

Alliance of many CDH Organizations supporting families and research of Congenital Diaphragmatic Hernia. The listserv is for organization founders, presidents and CEO's to keep each other abreast of research studies, new procedures, and organization problems. By working together as a team we can support each other, and the babies and families, in the fight against CDH.

These are the CDH organizations that truly support these babies and work together. We are a large international CDH community working to increase research, make sure that all families have information and support and protect CDH awareness so that it belongs to all.

Each organization in ACDHO is equal, there are no leaders. Organizations / groups / sites invited into ACHO have shown high integrity in helping CDH families, offer research or support for CDH and a clear desire to work with the entire CDH community. Invitations are by a majority vote to secure that ACDHO goals remain positive, that the group works well together and that ACDHO is a safe environment to work together to help CDH families. This listserv / alliance is *not* for individual CDH parents, survivors, etc.

Organizations / sites / groups that are members or who have been invited and that show a high degree of integrity in helping the CDH community and that we support are:

CHERUBS
CHERUBS Australia
CHERUBS UK
CHERUBS Mexico
A Rainbow of Hope / CDH Rainbow
Jack Ryan Gillham Foundation
Olivia Raine Foundation
Cody's Foundation
Kays Kids / Real Hope For CDH
Johns Hopkins As Yet Unnamed CDH Group

Little Lambs
The J.C. Nicholson II Research Foundation
Connor's Books
En Stitching Hernia Diafragmatica (The Netherlands)
Ernia Diaframmatica Congenita gruppo di supporto (Italy)
Association Hernie Daphragmatique (France)
International CDH Study Group
Every hospital participating in the CDH Study Group

Support
Congenital Diaphragmatic Hernia
Public Awareness



Stories of Cherubs

Baer Kellam Brogdon

12/4/07

This is the story of my son Baer Brogdon, CDH survivor. He is our 4th child. My husband and I were so excited to find out at 21 weeks that we were having a boy. The pregnancy progressed great. I worked up until the day I went into labor. This was to be my 4th c-section. Baer had plans to arrive 3 days before his scheduled date, on December 4th, 2008. I had several ultrasounds with no abnormalities for a woman of 35 years old. The last one was 2 weeks before the baby was born. Upon delivery Baer was slow to cry. They suctioned and bagged him for a while. Finally a weak cry! We were told he just needed some oxygen. Being a nurse and my husband being a paramedic, we knew something else was wrong. Nonetheless, the NICU nurse stated they would take our son to the newborn nursery and may move him to NICU if need be. BIG MISTAKE! By the time he arrived at the nursery my husband noticed that his color was bad, he was turning blue. The nurses there were use to healthy babies and just stood around. So my husband the NICU nurse carried him in my husband arms down the hall in a sprint to the NICU for a rapid intubation. He had no left sided breath sounds. They were thinking a collapsed lung. Good thing they did not treat it with the usual needle decompression, they would have punctured his intestines! After a chest x-ray it was discovered that he had a Congenital Diaphragmatic Hernia? A Congenital Diaphragmatic what? I had never heard of this. The pediatric surgeon explained to us that he had only been at this NICU (a level 3) for 3 months, but CDH was his specialty. He had written papers on this birth defect. My baby had a birth defect? The neonatologist explained that they would probably have to fly him to another state for ECMO. I told them this was not going to happen, that he would be fine and able to remain in this hospital. I was told it would depend on his arterial blood gases. I knew all to well what those were and what that meant. I wanted to not have the answers already, for someone to give them to me along with hope. They kept asking how could we have not know before he was born? Like we would have wanted to deliver in a place where none of the nursing staff had ever taken care of a CDH baby before and neither had most of the doctors. Talk about a wing and a prayer. They told us that they separate "these" babies in to thirds. One third die, one third live with a lot of problems, and one third are just fine after surgery. Baer was in the first one third. A thirty percent chance to live. I never felt that he would be anything but perfect. Call it ignorance, call whatever you like, but I call it God's grace. He gave me a sense that all would be fine no matter what the outcome, that he was in control, not me. For the first time ever, I bargained with HIM with all that I had for 28 days. Now came the hard part. We had to tell our family. The other kids took it rough at first but we have a great church family who stepped in. A couple of best friends took them out that night to try to take their minds off of things. They got see their new baby brother when he was 2 days old. They could not believe how "buff" he looked. Baer had two echocardiograms which were both perfect. They told us they think the herniation must have occurred within the last couple of weeks. They would not know the extent of the herniation until the actual surgery. The surgeon called us on day 2 to tell us that he could not believe it but Baer's labs were perfect and he would not have to be transported and would have his surgery on day 3. Our minister and my husband's sister came to stay with us during the surgery. The minister told us how he opened his bible to a scripture that very morning fitting for us. It has become Baer's scripture in our home. "Those who hope in the Lord will renew their strength. They will soar on wings like eagles; they will run and not grow weary, they will walk and not grow faint." After surgery we were told that Baer had small bowel and spleen only herniation. His right lung was fully developed but they could not say about the left because it was collapsed and would need to reinflate. Only time would tell. He did not need a patch. He was repaired with sutures only. His labs were only of range once, and that was after surgery. A little sodium bicarbonate and he was back in line. He did have some fluid around his left lung, which resolved on its own in a couple of days. As with a lot of CDH babies, Baer had a small oral aversion. He would not accept anything in his mouth but a breast. Smart boy. I was thrilled. After 28 days of pumping every 2 hours I was determined to nurse this child! He was determined to nurse! We finally got to try on day 20 after his respirations came down below 60 per minute. The only holding us back from going home was eating and gaining weight. He had an NG tube and hospital policy was not to let parents take babies home with NG tubes. I showed them I could put it in as fast as he could take it out and he took it out every chance he got to get his tiny little fingers around that tube. I did get to spend Christmas night at the hospital in a private room in the NICU with him. Don't ask me how that happened. Up until 7 days before he came home, Baer was still in the "sickest" part of the NICU. He just was so skinny. We brought him home on day 28, New Years Eve. I had to take him to the pediatrician's office every other day to be weighed. He was still so small. In his first year of life Baer had pneumonia. That had been his only big illness so far. As I write this Baer is 11 months old, happy and healthy. He got a clean bill of health and released from the pediatric surgeon when he was 6 months old. The doc asked me to look at Baer's latest chest x-ray. He said to look at it would never know he had CDH. I told him he did good work. The doc told me No God does good work and Baer grew a lung. Thanks to modern medicine and GOD, my sweet boy Baer has renewed his strength.



Written in 2008 by Baer's mom, Lynne Brogdon (SC, USA)

Jessica Kate Murphy

9/9/08-9/9/08

Jessica was our fourth child and we were so looking forward to this fourth and final addition to our family. After having three beautiful children, Sam 8, Hannah 6 and Zac 4, I was still unable to dispose of old baby clothes and accessories and we decided that we would try for our fourth. Following a positive pregnancy test at the end of April we were over the moon.

However, our excitement was to be short lived. On August 21st, we were 2 days short of 19 weeks, we went for our routine ultrasound. Everything seemed to be going along just fine until the end. Finally my sonographer made a comment that he felt that the stomach was higher than it should be and he would like a doctor to come in and have a look at it for him. We waited a short moment and the doctor arrived. They went over the ultrasound together, pointing to the screen and nodding to each other. After what seemed like forever, they turned to me and said that they believed our baby had what was called a congenital diaphragmatic hernia. What this meant was that there was a small hole in the left hand side of the diaphragm that had allowed the stomach to move from the abdominal cavity up into the chest. We were told that we would need to go to see a specialist in Brisbane. And that was it. No further explanation as to what this meant, how life threatening the condition was or anything. The sonographer asked us if we had any questions, which at this stage we didn't, and then said he was so sorry and we left.

His leaving comment did make me wonder. Why was he sorry? What did this mean? As we drove home the only words that stuck in my head were hernia. Plenty of kids have hernias and they are repaired after birth and everything is good. Was he just sorry that we were going to have to put our new baby into surgery? Pete and I didn't talk much on the way home; I think we were both a bit stunned.



It was once we arrived home that our lives turned upside down in a moment. Of course, as any person of the computer era does, we googled “congenital diaphragmatic hernia”. We were devastated. Nobody mentioned that this condition was life threatening, that our baby only had a 50% chance of survival and could have several life long complications. This was too much for us to bear. I didn't even cry I think I was just so gob smacked that something like this could be happening to me. I had had three perfect pregnancies before this and three incredible beautiful, natural deliveries, no stitches, no intervention and no drugs. This was just something so out of left field.

And so began our CDH journey. We saw our GP the next day, I cried in her office as I explained to her what the ultrasound had showed. Whilst she was familiar with the condition she had had no experience directly with it so, as suggested by the sonographers, referred us to the specialist in Brisbane, Frank Carmody. Unfortunately we could not get an appointment with Frank until the following Friday, 29th August. It was the longest week of my life. I spent endless hours on the computer reading stories and articles about CDH and finding out as much as I could. I wanted this ride to end, I wanted to get off, but I knew that I couldn't. I was stuck on this path whether I liked it or not and all I could do was hang on.

That's when I found Cherubs. On the 24th August I emailed Danielle Kessner, the Australian President of Cherubs and asked for help. She was amazing. She reminded me to be wary of what I read on the internet and gave me a lot of good information to read. She also pointed me towards the main Cherubs website and suggested that I use this to post any questions or concerns that I had. So from there I joined the Cherubs forum, emailed Danielle and Joanne (our Queensland Volunteer) regularly and waited for my appointment in Brisbane on the 29th.

After what felt like the longest week of my life, Friday 29th finally rolled around and we headed to Brisbane, a 2-hour drive north, for our specialist appointment. We saw Frank Carmody at about 5.30pm and didn't leave until about 7.30pm. One of his other sonographers did another complete ultrasound and confirmed the CDH and looked closely at all the other bits of the baby. We then got to meet Frank who was just brilliant. He really made me feel relaxed, if that was at all possible. We chatted for quite a while. He explained that basically we have a baby with a left sided CDH and at the moment the stomach and part of the bowel are located in the chest cavity. We talked a lot he said that nobody can tell until that baby is born how well they are going to do and as such they can only give them a 50/50 chance of survival. He did say that generally if they did survive, they survived well. He also explained that about 20-30% of CDH cases can be related to chromosome disorders and suggested that we do an amniocentesis to check for chromosomal abnormalities, which we agreed to. Frank explained the main problems they would be looking for and also the mortality rates attached to them. Pending the outcome of that then we would have to decide where we go from there. We would get back the short-term results of the amnio on Monday so again, we would have to wait until then.

We left there feeling much more positive and we both agreed that if the amnio came back clear, then we would give our baby the 50/50 chance at birth, and carry to term. We also agreed that if there were chromosome problems, then we would end the pregnancy. So we waited. On Monday evening, 1st September, at around 5:30pm, Frank called us. He informed us that our baby had Trisomy 18, or Edward's Syndrome. Trisomy 18 is a triplication of the 18th chromosome, and coupled with the CDH, the chances of survival were virtually zero. Pete could tell by the look on my face that it wasn't good news. I hung up from Frank, held my husband and we cried. We knew what we were going to have to do and I had no idea how we were going to do it. The following day I rang Frank back. I had forgotten to ask the sex of the baby. He told me she was a girl and I just cried. I made an appointment with my GP again, to get a referral to an obstetrician to get the process started. This was also the beginning of my journey on the Cherubs website. I posted my story thus far, and asked these women for help with any keepsakes that they had taken when their babies had passed away, and also anything that they had regretted not getting etc. There response was overwhelming. Such an incredible bunch of women with so many supporting and helpful responses. I thank them all from the bottom of my heart.

On Wednesday 3rd September we saw the obstetrician. He explained that due to the fact that I was just short of 21 weeks, that the baby would have to be delivered naturally via a gel induction. We arranged to go to hospital on Monday 8th September.

The next few days were crazy. I spent endless hours on Cherubs, getting support and answers to many of my questions. We purchased two blankets to take to the hospital, one which we would wrap her in while I was there and then take home, and the other we would wrap her in when we left. I purchased a plaster mould kit for her footprints and a beautiful pink candle. I also followed up on a suggestion from one of the Cherub Mum's regarding a volunteer photography association called “Now I Lay Me Down To Sleep” who will come and take photographs of your baby and you. I got in contact with their Australian co-coordinator and she was incredibly helpful. She had no one in my area that did this but she emailed a number of professional photographers around and explained firstly what NILMDTS does and then explained my situation to them. Within a couple of hours I had a response from an amazing guy, Neil, who offered to help.

We then had to tackle the subject of telling the other children. How do you explain to them that this baby that they are all so excited to meet, is not going to live. It was heart wrenching. On the Sunday morning we asked all the kids to come and sit down and that we had something very sad that we had to tell them. They straight away knew that it was about the baby, as we had had a miscarriage earlier in the year in January, and so they were across the fact that things can go wrong with the baby. We said that yes there was a big problem with the baby and she was very sick. We tossed up whether or not we should tell them that she had died inside my tummy or not. In the end we decided that this was probably not the best way and that we would just say that she was very sick and was not going to be able to breathe properly and that she wasn't going to be able to live. We then explained that I would be going to hospital the next day to have her and that that is when she would die. We didn't want to delve into terminations or inductions, as they were just too young. My eldest, Sam, exclaimed that we were going to hospital to kill her and stormed off. We called him back and explained to him that that wasn't the case. Jessica had a lot of problems and that no matter when she was born, she would not live. It didn't matter whether that was tomorrow, the next day, the next month, or at 9 months. She had too many problems and the doctors thought it would be best if we had her tomorrow. Hannah, my daughter, got angry and told me that this is now two babies that I haven't been able to make. My youngest, Zac, asked if he could go back and play with his power rangers. We took some time as a family and I tried to explain a little more about what was wrong with Jessica. I also told them that in the afternoon a lovely man called Neil would be coming to take some photographs of our family while Jess was still alive in my tummy.

Neil came to our house that afternoon and took some family portrait shots around our yard. He would also come after she was born and photograph her then. These are the most incredible memories that I have of my precious little girl. He gave us both a CD of the shots along with a DVD slideshow of them. I cannot thank him enough for this special tribute to my little girl.

On Sunday evening we stayed in town with my parents as they live a block from the hospital and I needed to be there by 6am. Mum would then also be able to look after my other three children for the day. That night I took time separately with each of the kids. We hugged and they cuddled up next to my tummy and talked to their little sister. They each told her how much they loved her and that they were so sad that she couldn't stay to be part of our family. When they were ready they kissed her and said goodbye before heading off to bed.

We woke early on Monday and made our way to the hospital. We went straight to the delivery wards where the midwife met us and set us up in a delivery room. After about 30 minutes she came back to give me the first dose of the gel. I cried as she inserted it. This was it! There was no waking up from this

terrible nightmare. It was real, it was happening to me, and there was nothing I could do about it. Shortly after we were moved to a normal room (non-delivery room) around in the maternity section. This is where we stayed until Jessica was born the following day. I received 5 doses of the gel on the Monday and whilst there was some twinges, my labour did not start until about 11pm that night. I tried to rest but awoke at about 12pm when the contractions were getting stronger. At 2pm my waters broke and that is where it stopped. My labour virtually stopped within a few minutes. They were unable to give me any more gel until the 7am the following morning, so I settled for a couple of panadol and a sleeping tablet.

At 10am the next morning I woke and we started the whole process again. I began to labour shortly after and at 1pm I was given another dose of the gel to ensure we kept progressing. It was tough. I was offered pethadeine which I refused. I wanted to be mentally aware when she was born. I wanted to be able to greet my little girl with a clear head and I was worried the pethadeine would knock me out too much. I had never had any drugs with my others so was unaware exactly how my body would react. At around 2pm I relinquished and agreed to have the pethadeine. It was fine. It literally took the edge off the contraction but I was still 100% in control of everything that was going on. At 2:52pm, on the 9th September 2008, Jessica Kate Murphy arrived. She was born sleeping. The obstetrician had explained to me that she would most likely die before she was born, as the stress of induction is too much for their little bodies. She was tiny. She weighed only 315 grams and was just beautiful. My husband cut the cord and then the midwife wrapped her and handed her to me. We both hugged her and cried.

The staff at the hospital were amazing and they gave us all the time we needed with Jessica. We bathed her and dressed her in some clothes that were donated to the hospital for occasions such as this. A couple of hours later my Mum arrived to meet her granddaughter, shortly followed by Neil, our photographer. He spent the next hour or so capturing my only memories of my gorgeous little girl. Pete then headed home around 8pm to let our kids know that she was here and that they could come up and see her in the morning.

In the mean time I was moved to a different room, which is set aside for grieving parents. It was a gorgeous space, with a lounge, table, double bed and a crib. We were able to spend the night with her and hold her, talk to her and just love her. My husband returned around 10pm and we were able to spend the night together and slept beside our little girl for the one and only night we could be together.

The next morning the kids came up with my Mum and met their little sister. Their reactions were mixed, but at the end of the day I am so glad that they got to spend time with her. Both the boys, Sam and Zac held her and cuddled her. Hannah was happy just to look from a distance. We took a couple of full family photos and the kids had done drawings for her that they brought with them. The rest of the day was spent just sitting with her, holding her and filling out oodles of paperwork. We met with an amazing woman called Nici who was our funeral director. After long conversations we decided to do a proper funeral service for Jessica and she convinced me to ask two of my girlfriends, who were celebrants, to write and give the service for me. They agreed without hesitation and began making plans straight away.

That afternoon, at around 4pm, we left the hospital, myself, Pete, my eldest son Sam and Jessica. I was allowed to take her to the funeral home, rather than leave her in the hospital. This was very special and I am so glad that I had the opportunity to do this. We drove directly to the funeral home. Getting out of that car was so hard. I sobbed uncontrollably in the front seat of the car for a good couple of minutes. Then as the tears slowed, I got out of the car and handed Jess to Sam. He had asked if he could carry her into the funeral home. We entered the front doors and were greeted by Nici. She led us out the back where she had set up a baby's basket lined with sheets. There were candles lit and it looked beautiful. Sam placed her in the basket and we took some more time with her before leaving. I found it so hard to leave but was comforted by Nici who said something to me that has stuck with me through all of this. She said that I wasn't really leaving her. Jessica was now part of who I am as a person, part of my spirit, my aura, an no matter where I go I will carry that with me, even if I don't have her physical body. I believe that this is true and with that knowledge I was able to leave the funeral home and return home to the rest of my family.

The next week was spent planning the funeral service. I spent hours on the computer searching for the right songs and seeking support from Cherubs. I was also very grateful to Nici for letting me know that I didn't need to have a white casket for her. As she was to be cremated she just needed to be enclosed in something. We chose to buy a small white cane basket with an arched handle to place her in. I lined it with sheepskin and we draped a sheer pink sarong over it. It looked beautiful!

The service was amazing. It was held in the gardens of the crematorium, which were picturesque. My girlfriends wrote the most touching service and I could not have asked for more. We opened with my son singing on his own. He sang "I Have A Dream" by Abba. This was directly followed by "You'll Be In My Heart" by Phil Collins. The girls spoke for a while and then they played "Smallest Wingless" during which we our family placed 5 pink rose buds in her basket. After more amazing words from the girls, we played "Fix You" by Cold Play and released 5 pink helium balloons into the sky. I then picked up the basket, and surrounded by my family and lead by Nici, who was sprinkling rose petals on the ground in front, carried Jess to the Crematorium Chappell where we laid her to rest. We said goodbye and returned to the garden to our family and friends.

I will never forget my little girl. Why she had to suffer such a horrible fate I will never understand. I do know that we loved her and we all miss her very much.

Written in 2007 by Jessica's mom, Kathryn Murphy (Australia)

Justin Wright Anderson

9/17/06

Our story with our amazing child began long before he was born. My (now) ex-husband and I had tried to have a baby for a long time. We were initially successful in getting pregnant within six months of trying, but I miscarried before 10 weeks. After that horrible experience, I decided to try and find out what might have caused the miscarriage. We had already seen a heartbeat and development was on track (as much as anyone could tell that early on), so I just knew that something had gone wrong with me, not the baby. I went to an infertility specialist and through much testing, she determined that I had consistently very low progesterone levels. Armed with this knowledge, we set out to get pregnant again. It was 18 months before we were successful. This time, I went back to the infertility doctor and she put me on oral synthetic progesterone to help me keep the baby. In 1996, synthetic progesterone was used frequently, but did not carry its current side-effect warning that abdominal wall defects could occur with usage. I've had 2 more children, but I always use natural progesterone now. I don't know for sure that was the cause for Justin's problems, but I refuse to take that kind of chance ever again.



I went in for a routine ultrasound at 20 weeks on the Friday before Memorial Day, thinking that the biggest news I would be hearing that day would be the

sex of my baby. The ultra-sound technician told me we were having a boy and, not to worry, but that the baby's stomach looked a little "high up" to him. He said he'd send the report to my doctor and she would call me if she thought that further exams were necessary. I left that day very worried, but my husband seemed unconcerned so I tried not to dwell on the fact that I had a long weekend ahead waiting for news from my ob/gyn. Tuesday, May 28, 1996, the phone rang at 8:02am. It was my doctor, not the secretary or nurse, but the doctor asking me to come in at 11am and then she asked to speak to my husband. She told him not to let me come alone. Panic set in. I knew what she was going to tell us. I had just learned what CDH was the night before on a rerun of a "Chicago Hope" episode. What a terrible way to find out what's wrong with your child. The baby on the show died.

My heart broke when we got the news. We were sent immediately to University Medical Center (connected with the Texas Tech Health Sciences Center) for a very high-tech ultra sound with a wonderful doctor I will never forget. Dr. Welt was very upfront and clear about what was going on with our son. He said Justin had a left-sided congenital diaphragmatic hernia and that parts of intestines, his stomach, and his appendix were up instead his chest cavity. He assured us that Dr. Goldthorne and Dr. Lacey were excellent pediatric surgeons and would take good care of us. (I didn't take his word for it. I checked them both out thoroughly and was more than happy with what I learned about them.) Then the waiting began.

There is nothing like waiting for your child to be born when you have been told that the likelihood of their survival is less than 40 percent. I am a Christian and therefore, a person of deep faith. I leaned on God, my family, and my friends like I never had in my life. I found a sense of peace about Justin that is beyond my understanding. I simply knew that God had everything under control and felt an overwhelming assurance that he was a survivor. We scheduled his delivery for September 17, three days after his due date. I've always said he knew what was going to happen after his birth because he did not want to be born! After more than 20 hours of hard labor, Justin was born at 1:13pm unable to breath and completely blue. It was the most frightening moment of my life. His first Apgar score was zero. The second Apgar score was two because by that point he was intubated.

Justin was put on ECMO at 2:44pm, an hour and a half after he was born, and stayed on that machine until 4:36pm on September 21, 1996, over 4 days (97 hours and 52 minutes). He went into surgery the next morning at 8:35am. An hour later, Dr. Lacey came into the waiting room with a big smile on his face! He told us that there was enough muscle to close the hernia with no patch and that Dr. Goldthorne was resectioning Justin's intestines. She had also removed the appendix, which had been in his chest, as well. After the surgery, Justin flew through recovery fast than anyone's wildest expectations. He removed his own chest tube and ventilator when he was good and ready and was home after just 37 days in the hospital. It truly was a miracle to watch him get better!

I remember all of this like it was yesterday. Yet it happened almost 12 years ago. Justin has continued to amaze me. Life hasn't been perfect for him, but you'd never know it to talk to him. Justin is now profoundly deaf as a by-product of everything done to save his life. He started to lose his hearing gradually when he was 6 months old and now has cochlear implants by his own choice. After hearing with aids for so many years, he didn't want to lose that ability. He is such a hard worker and that can be seen in his incredible speech. Most people don't even realize that his speech has been affected at all. Justin was also diagnosed with ADHD when he was 4 years old and Type 1 Diabetes when he was 6. Add to that 2 corrective eye surgeries and you get a long medical chart, I can promise you that!

I know how blessed we are to have him in our lives. I will never, ever forget it! I thank God every day that I still have my Cherub.

Written in 2008 by Justin's mom, Laurie Williams (TX, USA)

Jacob Ogilvie

10/18/05—10/26/05

Jacob was born at Christchurch women's hospital 18th October 2005, he was born with CDH ("Congenital Diaphragmatic Hernia". Congenital means "born with" and a hernia is a problem where something goes through a hole it is not supposed to. The hole is in the diaphragm. The diaphragm is a muscle that helps us to breathe and keeps the organs in the abdomen from going into the chest cavity.

When Jacob was very small (early in the pregnancy), there was a hole in the diaphragm. This is normal, but the hole usually closes by the end of the third month of pregnancy. In Jacob's case, the hole stayed open. This allowed some of the intestines to go into the chest cavity. Since the intestines were in the chest cavity and not where they were supposed to be, the lungs could not grow in the normal space that they need (they had to share the space with the intestines). This means that the lungs are smaller than they should be. The intestines can also push on the other lung and keep it from growing fully and can sometimes keep the heart from growing normally (Jacob had a left-sided hernia).

At 19 weeks gestation my partner and I went for what we thought was a routine scan, we had taken our daughter Hannah with us so she could see the growing baby inside mum's tummy. Hoping to see two arms, two legs, head etc etc all in the correct places and find out the sex of our baby, we were shocked to find a hole in his diaphragm. Not knowing how bad his condition was or what his outcome would be, we were sent away and told our midwife would contact us soon. Within 10 minutes our midwife Prue contacted us and informed us that we need to meet at Queen Mary at Dunedin hospital. Two hours later we were sitting with Prue waiting to see a doctor, when the specialist arrived she started to explain Jacob's condition and he was given a 50/50 chance of survival.

It was also explained that we would have to travel to another hospital when the time came for Jacob to enter our world if that is he survived the pregnancy.

At first we went for a scan monthly to check on his condition and the development of his lungs and then the scans were to become fortnightly.

At 30 weeks gestation we decided it was time I gave up working and by the middle of my first week off work I was flown to Wellington women's hospital with what the doctors thought was a premature labour. After five nights in Wellington the doctors decided there was no longer a threat of early labour and I was sent home.

At 35 weeks gestation my mother, daughter and I moved to Christchurch and we all stayed at Ronald McDonald House, with my partner and dad visiting each and every weekend. Going to Christchurch without Darryl was one of the hardest things I've ever done, knowing that Jacob could decide to arrive early and Darryl not be there.

After the fourth weekend visit we said our goodbye's and once again I reminded them to keep the cell phones handy (just incase). The following day I went in for yet another scan and it was noted that Jacob was low on fluid. The decision was made that an induced labour would follow the next day.



After leaving the hospital I was straight on the phone to Darryl and dad asking them to get back in the car and come back to Christchurch. The night that followed was one a very mixed emotions unsure whether to be happy or sad that the birth would take place the following day. We all knew that Jacob may not survive the birth and if so would the doctors be able to stabilise him in time? What would it be like to see our son in the neonatal unit with tubes feeding him and breathing for him?

Jacob survived the birth and was stabilised within 7 minutes and then rushed off to neonatal. I had a fleeting glance at Jacob as they wheeled him away but longed to hold him in my arms. It would be another 3 hours before I got to see him and Darryl was allowed to visit with him within an hour. When Darryl arrived back from his visit he brought photos that the neonatal staff had taken for me. Those photos were my lifeline, he was so perfect & it was hard to believe that there was anything wrong with him.

After being admitted to neonatal Jacob was transferred to overhead radiant warmers and connected to Sensor Medics High Frequency oscillating ventilates, he was given a paralysing agent and sedatives. After numerous tests and medical assistance it was decided to operate on the 20th October. Jacob handled surgery without event, the surgeons repaired the Diaphragmatic hernia with a gortex patch via a rooftop incision and post-op was very stable, settled boy. Day four arrived and Jacob was still heavily sedated but still doing well, by day five 3mls of breast milk was introduced 3 hourly. Day six arrived and so did Jacob's deterioration, oxygen saturations decreased to 88-90% in 100% oxygen. Breast milk decreased to 1ml 3 hourly. Day seven oxygen saturations still decreasing down to low 80's now everything possible being done to assist Jacob now.

Day eight: Marked deterioration overnight, decreased oxygenation and poor blood pressure. We were told that there was no further therapies available for Jacob. Darryl and I then had to break the news to other family members and get ours daughters to come and say goodbye to Jacob before he passed away. Those there to say goodbye were: Nana & Grandad Smythe (Colin & Margaret), Nana & Grandad Ogilvie (Barry & Glenys), Big sisters Jasmine & Hannah, and also a visit from Nigel & Vicky and Edie & Derek.

At 12noon Jacob was finally placed in my arms and it was so good to give him a cuddle all of his tubes had been removed and Darryl also got his first cuddle. At 12.11pm on the 26th October 2005 Jacob was gone.

Roughly an hour later I took Jacob into the family room for the rest of the family that was present to have a cuddle also, we all spent time with Jacob and said our goodbye's.

I want to thank all the staff at Ronald McDonald house (Christchurch) and all the staff at Christchurch women's hospital for all the help and care provided for Jacob and our families.

Also a huge thank you to my mum & dad who without I could not have coped those weeks in Christchurch & a huge thank you to Darryl's dad and wife Glenys who also made a huge contribution of support to us at our time of need.

To all the rest of our family and friends thank you for your support also, without your support I don't know how we would have coped.

Written in 2008 by Jacob's parents, Tania Smythe and Darrell Ogilvie (New Zealand)

Claire Jackson

12/10/07

I found I was pregnant again on Earth day 2007. I was Happy yet nervous about what it might mean to my older daughter Kirsten. I scheduled a doctor's appt and waited for that day to come. 2 weeks later I was bending down to give Kirsten a bite of oatmeal all of a sudden I felt a gush and ran to the bathroom and realized I had started to hemorrhage. I rushed to the emergency room. Several hours and tests later they determined I had a tear in my placenta I was only 7 weeks along, my due date was Christmas Eve. I was put on strict bed rest for 4 weeks. After that things were going smoothly, We went to have our first major ultrasound at 18 weeks. I was so excited to find out if we were going to have a prince or princess join the family. We learned we were having another girl. However, they were concerned because she was tucking her chin to her chest that she could possibly have a hernia. September 26th is a day that I will remember for the rest of my life. I was sitting there in maternal fetal medicine talking with Dr. Henkel when he said very frank "Your baby has a Congenital Diaphragmatic Hernia she has a 50% chance of survival. My world stopped. Before I knew it I was having an amino to check for down syndrome. There is a 35% chance of Downs for a baby with CDH. I went home that night and researched everything I could find on this defect. I found a wonderful and supportive group CHERUBS they helped more than anyone. Months past I continued going to maternal fetal medicine (I was considered very high risk) I found out so much.

I was so scared. We learned each month that another part of the anatomy was herniated before I knew it the Liver, bowels, small intestine, kidney and stomach were in the chest cavity.

In October we went to have a consultation with the surgeon Dr. Upp. He sat down and the first thing he said was Claire's hernia was moderate to severe and that she had a 45% chance of survival. We knew what the odds were. He told us to go visit the NICU and get a feel for what we were going to be in for. On the day I went for my 2nd round of tests for gestational diabetes, I went. I met with a nurse she explained to me that a team would be notified and assembled as soon as I went in to labor and would be ready to take the baby as soon as she was born. She explained the different ventilators and showed me each wing and even the operating room, all except pod 10 it was restricted.

Months past and December was here. On December 10th I had an overwhelming energy I was changing a diaper when I felt a familiar twinge. I knew right then I was in labor. I arrived at the hospital and I was already 4 cms!! I was excited to meet my new bundle yet scared of what was to come. 6 hours later. Claire Noel Jackson 7lbs, 2 ounces and 19 ¼ inches long with the prettiest head hair you have ever seen came into the world. I knew from my research she wouldn't cry yet, A part of me wanted her to. I saw her for just a second then she was whisked away to the team of 25 NICU Nurses and Neonatologists. Were waiting. I saw her as they put the ventilator in and took her prints. I held her little finger before they rushed her to NICU and me to see my anxious family. I passed a mother on a gurney with a beautiful baby and I cried for mine who was fighting for her life on the floor below me. After a spent 2 hours in recovery (I had a heart complication) I went back to my room and saw my husband who was then allowed to see Claire. I couldn't see her until I could walk on my own. 9:00 that night I was wheeled down to the NICU I went through the double doors and went to POD 10 Isolation. There in the back corner was my baby. Covered in tubes and on the ventilator. A large sign said NO STIMULATION. For the next few days her lung pressure would increase and surgery couldn't be done to fix the hernia until that went down. I was discharged On Wednesday and Left the hospital empty handed. I slept with her picture that



night. I went everyday and spent hours just looking at her and when we were allowed lighting touching her tiny foot she was on so many medications that for weeks we never saw her eyes. Andy would come after work and for the next 22 days we spent every hour we could in pod 10. On December 18th at 11: am Claire went into surgery I remember giving her a kiss and the nurses were so nice they let me give her very gentle half hug. Then she was gone. DR. Lopo came out an hour and a half later and said it was a success she did wonderfully and they were able to put it back muscle to muscle! I jumped for joy and hugged everyone I saw. Dr. Smith came out after that and gave us the news . Claire's left lung was the size of a lima bean . She had a Bochdalek hernia involves an opening on the left side of the diaphragm. The stomach and intestines usually move up into the chest cavity.. Claire spent 18 days on the vent., blood gases being drawn every 4 hours and when they were bad she went to every 2 hours. She had to have a blood transfusion 2 days after surgery shortly after that she was doing so much better. On December 27th she got off the vent . She spent a total of 53 days in the NICU .

Since then we have hit some bumps along the way she has been in the hospital twice one for a bronclioitis and a week for a bowel obstruction. I deal with the fact that she has a 6% lifetime risk of reherniating and obstructing. Never the less , she is proving everyone that she has beaten the odds and is working her way to crawling. So many people I have met that have babies with her defect either haven't survived or are suffering from some debilitating chronic problems. Claire is a true miracle and I thank God and the Staff at Womans Hospital everyday for that cause without them she would have never stood a chance.

Written in 2008by Claire's mom, Ashley Jackson (LA, USA)

Logan James Campbell

7/17/07 - 7/17/07

Hello my name is Lynn Tidy, I am 18 years old. I had my baby boy Logan on the 17th July 2007. He weighed 6lb 10oz.

When me and my partner David went for our 21week scan the doctor said to me that I was having a little boy but there is a problem. They reckon that my baby had a hernia but was sending me to specialist in Glasgow to confirm it. I waited the two days and me David and his mum went up to Queen Mother Hospital in Glasgow and I got my Scan then the doctor sent us into a side room and told us Logan had CDH I was shocked but I continued my pregnancy without the tests and just went for all the scans. Logan also had heart problem his left side was smaller than the right side.

I went up to Glasgow every two weeks for scans and at 34weeks I got steroid injections to mature his lungs I was feeling quite positive that everything would be ok.

I got taken into hospital on the 16th of July to be induced. And I had Logan on at 04.18hrs on the 17th July. I never heard him cry or saw him move as the medical team took him away. I had an emergency C- section as Logan was in distress. I was in the recovery room when Logan's pediatrician came and told me and David that Logan was stable but they had to paralyse him as his lungs are not strong enough. David was then told he could go home.

Two hours later the doctor came back and told me to get the family up to the hospital soon as Logan is getting worse. So when the family arrived we went to see Logan and it was the first time I saw him he looked the perfect baby we got him baptised and got a hold of him but I couldn't understand why my baby. We had to turn the machine of as he was just getting worse.

When the family went away me and David got to bath him and dress him and we got to take pictures of him with us together as a family and that was so special as I felt we got to give him his final goodbyes as a family.

Written by Logan's mom, Lynn Tidy (Scotland)

Griffin Winn Vaughn

11/20/07

"There is something wrong with the baby." Those are words no parent wants to hear. Unfortunately, this is what we heard at our 18-week ultrasound. Weeks of testing led to the diagnosis of a left sided congenital diaphragmatic hernia. We knew our baby was strong. My husband, Damon, is a cancer survivor and we were told having children would be very difficult after his chemotherapy. We were surprised and thrilled to be having our first baby. Griffin had already beat the odds!

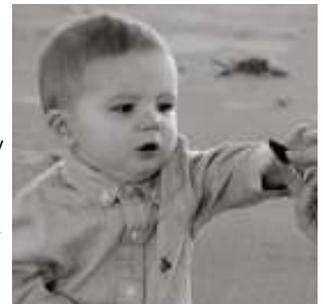
We researched for the best physicians for CDH. I am a nurse practitioner, so was able to use my medical connections for this referral. When we met the team in the Advanced Fetal Care team at Children's Hospital in Boston, we felt very comfortable. After that, we just waited for our baby- we did not know if it was a boy or girl. The pregnancy went well. The only complication was pregnancy-induced hypertension, leading to induction at 38 weeks. During labor, the baby's heart rate dropped so a c-section was performed.

We were told that the baby may be too sick to cry after birth. We were so happy to hear our baby crying right away! After a quick hello, Griffin Winn Vaughn was brought to the NICU. Damon went with him and took a lot of videos and pictures for me. I was able to go to the NICU after a few hours. Despite the all of tubes and monitors, Griffin was beautiful! He had surgery the day after he was born, which went well. He did not need ECMO, and was off the ventilator in 7 days. He was out of intensive care in 2 weeks. He slowly came off tube feedings and oxygen and left the hospital at the age of 5 weeks. He came home on Christmas Eve. It was the best Christmas we have ever had.

Griffin has stayed out of the hospital! He had pneumonia once, and has had many ear infections. He is very active. He loves going for walks in his carriage. He is a huge fan of the Boston Red Sox, Boston Celtics and New England Patriots.

We are very thankful to our friends and families for their support and love. We know that Griffin is a miracle, and we owe that to his team at Children's Hospital, Boston.

Written in 2008 by Griffin's mom, Jeanne Vaughn (MA, USA)



Cody A.J. Maerten

9/2/99

On Sept. 2 1999 my husband and I brought our first child into the world. He was full term but weighed only 4lbs 13oz and had left sided CDH that was surgically repaired when he was 5 days old. He was born by c-section and was quickly taken to the NICU as they knew before his birth that he had a hole in his diaphragm. The days leading up to his surgery were very rocky (filled with a ECMO machine and lots of questions, hopes and prayers.) After the surgery Cody improved quickly and we brought him home on Sept. 25/99. Today Cody is 9 but has many struggles especially with his health. He has asthma, ADHD and a heart condition (bicuspid aortic valve). Cody has had three additional surgeries as well, one to bring down an undescended testicle, one to remove his tonsils and adenoids and the last one to put in a pharyngeal flap (to reduce nasal air flow). He also has some learning disabilities and is seen monthly at school by speech, physio and occupational therapists. He plays hockey and swims and has a great love for monster trucks, hockey and tornadoes. He is very compassionate and loving. Cody has a younger sister who was born perfectly healthy.



Written in 2008 by Cody's parents, Stephanie and Marty Maarten (Canada)

Dain Terence Kingston

4/4/02

I went to have my 20-week scan, when it was discovered that Dain had CDH. I was traumatised. We had tried for so long to have children and finally we conceived naturally and then our world fell apart. We were given a 50% chance of Dain surviving at birth. The first week after we were told was the worst week of my entire life. I couldn't speak to anyone, not even my mother or sister. I was in shock. The Saturday morning after we were told (we were told on the Monday) I woke up and I had a complete feeling of calm and I just knew that everything was going to be okay. I had only positive thoughts and feelings from that day on. We flew to Melbourne about a month before Dain was due. We had so many doctors appointments and tests. Finally the day arrived and I had a planned Caesar. Dain gave us one squawk and we knew that that was our sign. We knew he was going to be okay. I finally got to see Dain very briefly about three hours after he was born. He was hooked onto life support and ready to be transported to the Royal Children's Hospital. All my fears returned. Seeing our helpless baby with so many tubes. It took three days for Dain to stabilize before the doctors could operate on him. It was 21 days before I actually got to hold Dain in my arms for the very first time. Dain spent a month at the children's hospital in Melbourne and then another week in the nursery at the Royal Hobart Hospital. We thank God every single day for our miracle baby. We are so incredibly blessed to have Dain in our lives. Dain is now a very healthy and active six year old. My message to other parents of CDH babies – please, please don't give up hope. The power of positive thinking is amazing. Stay positive, think positive, be positive. Our CDH baby survived and we are grateful. We pray for all the CHERUBS and their families. God Bless.



Written in 2008 by Dain's parents, Lindsay and Sabine Kingston (Australia)

Photos of Cherubs



Jaxson Mayer



John Michael Larson



Amaiya Thomp-



Lauren Kaleleiki



Josephine Quick



Marley Jane Steingass



Cadenne McDaris



Jesse Draper Byington



Charles Freed, II



Camden Gage Seay



Sade Hemmekam



Caleb Ray Cox

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