

2013 Issue

CHERUBS

The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support



Calls To Action

**Senate Bill for Congenital Diaphragmatic
Hernia Awareness Month April 2013
Passed Unanimously**

Cherubs Descend on Capital Hill

April 19th Parades in 14 Cities

2013 CDH Conference in Boston, MA

2014 CDH Conference in Dublin

2014 Conference in Washington DC

Dublin Town Hall Lights for CDH

CN Tower & Miami Tower Light for CDH

\$50,000 in CDH Research Grants

Masquerading Angels Ball

Stories of Cherubs

Local CDH Events & Fundraisers

CDH on Social Media

CHERUBS 2012 Financials

Participate in CDH Awareness

New CDH Awareness Shop Items

CDH in the CFC Campaign

**The Silver Lining
CDH Magazine**





The Association of Congenital Diaphragmatic Hernia Research, Awareness & Support

www.cdhsupport.org

Letter from CHERUBS President

Dear Members,

It's been almost 2 years since we printed a newsletter. With over 4700 families to support and so many wonderful events and projects going on, we simply haven't had time. And as in recent newsletters past, we are unable to afford to print and mail newsletters but they are available to freely download on our web site. Printed copies are also available to purchase in our on-line store.

So much has been going on here at our office in Wake Forest and so much around the globe for Congenital Diaphragmatic Hernia Awareness! Since April, 2012, we have marched on Capitol Hill again and had a Senate Resolution unanimously passed to make April "Congenital Diaphragmatic Hernia Awareness Month"! We held parades in 14 large cities, buildings lit up in 3 countries and governors from 31 states proclaimed April 19th a Day of Congenital Diaphragmatic Hernia Awareness. We have had fundraisers around the world from marathons in NYC, San Francisco, Baltimore and more to volunteers jumping out of planes in the UK. We have granted tens of thousands of dollars for CDH research, have new Boards, held 2 CDH conferences and went to Holland to represent CDH families internationally at a medical conference. We have supported 1200 new CDH families and shipped over 500 CDH HOPE Totebags. We have been on television, in newspapers and now have a mascot, "Hope", that was named by vote of our members on-line. This is just the tip of the iceberg of all we accomplished in 2012 and 2013!



2014 will be even bigger with the first ever European CDH Conference for families hosted by the Alliance of Congenital Diaphragmatic Hernia Organizations in August in Dublin. In June we are holding another joint Family & Medical CDH Conference but this year we are going to Washington DC where we march to the Capitol, speak with Senators and Representatives, learn more about CDH and get more research for our children. Our State & International Representatives are busy planning Parades of Cherubs for April 19th and other events and get-togethers on a local level. We hope you can join us!

We have a new logo, new web site, new office. We joined the Combined Federal Campaign. We welcomed many new volunteers and interns. We are working with ACDHO, as well as many research centers to better help families. We gave 2 \$1000 scholarships this year and our second \$10,000 CDH Research Contest grant along with over \$30,000 more in research funds. We now reach over 100,000 people weekly through our web site, blog and social media.

None of this would be possible without the hard work of all of our incredible donors, our CHERUBS Parent Advisory Board, our Board of Directors, Representatives, all of our Committee Members and the families who have fundraised for our charity. Thanks to all of you, CHERUBS is continuing to grow and further our work in Congenital Diaphragmatic Hernia Research, Awareness and Support services.

Sincerely,

Dawn M. Torrence Williamson, President and Founder



CHERUBS was founded in 1995 to help families of babies born with Congenital Diaphragmatic Hernia by providing accurate and easy to understand medical information and support services, promoting research and raising awareness of CDH. CHERUBS has helped over 4500 families in 60 countries as of 2013.

Telephone: 919-610-0129
Toll Free Telephone: 855- CDH Baby
Facsimile: 815-425-9155

Questions, Comments and Complaint:
cpab@cherubs-cdh.org

Mailing: 3650 Rogers Rd #290, Wake Forest, NC 27587
Office: 152 S White St, Upstairs, Wake Forest, NC 27587



PEOPLE LOVE US ON GREATNONPROFITS.ORG

"For there is nothing heavier than compassion. Not even one's own pain weighs so heavy as the pain one feels with someone, for someone, a pain intensified by the imagination and prolonged by a hundred echoes" — Milan Kundera



2013 European CDH Conference

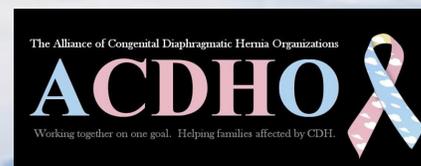
CHERUBS is proud to work with ACDHO on the first ever planned European CDH Conference for families.

August 11—15, 2014
Bewley's Hotel
Dublin, Ireland

Contact our UK CHERUBS Representatives Clair Maher, Melanie Parsons and Zoe Burcell at uk@cherubs-cdh.org for more information or visit <http://cdhuk.eventbrite.com>

Stichting Hernia Diafragmatica

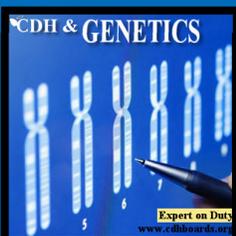
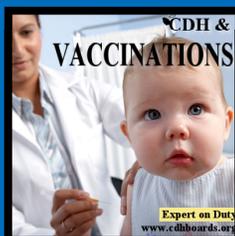
Our sincerest appreciation to the Dutch CDH charity for their incredible hospitality to us during our visit and speech at the CDH conference in Rotterdam. We are honored to work together with this amazing organization for 15 years!



Meet the fellow members of the Alliance of Congenital Diaphragmatic Organizations:

- ◆ The Alice Hiley Memorial Trust (United Kingdom)
- ◆ Baylor College of Medicine CDH Genetic Study*
- ◆ CDH-New Zealand
- ◆ CHERUBS - The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support
- ◆ Chloe Tate Foundation (United Kingdom)
- ◆ Congenital Diaphragmatic Hernia Study Group*
- ◆ DHREAMS Research Study*
- ◆ Denmark CHERUBS (Denmark)
- ◆ HDC Hérnia Diafragmática Congenita Brasil (Brazil)
- ◆ Hernie Diafragmatique - groupe de soutien (France)
- ◆ Incredible Teddy Foundation
- ◆ Mass General Congenital Diaphragmatic Hernia Genetic Research Study*
- ◆ Max Richard Thornsby Foundation
- ◆ Olivia Faith Foundation
- ◆ Olivia Raine Foundation
- ◆ Peyton's Promise
- ◆ Stichting Hernia Diafragmatica (Netherlands)
- ◆ UK CHERUBS (United Kingdom)

Learn more at www.acdho.org



Join us on the CDH Family Forums to talk with monthly guest speakers, meet other CDH families and learn more about Congenital Diaphragmatic Hernia.



**S. Res. 85
Sponsors**

Jeff Sessions
[R-AL]

Benjamin
Cardin [D-MD]

**H. Res. 133
Sponsors**

Martha Roby
[R-AL2]

George Holding
[R-NC13]

Leonard Lance
[R-NJ7]

Walter Jones
[R-NC3]

Jim Matheson
[D-UT4]

Louise Slaughter
[D-NY25]

Our sincerest appreciation to all of these distinguished men and women for their support of our children, to their aides for all their assistance and to all of our members who visited Capitol Hill, their offices and who wrote and called in for support of these resolutions.

Now let's get this passed by the White House in 2014!

**S.Res. 85: A resolution designating April 2013 as
“National Congenital Diaphragmatic Hernia Awareness Month”**

113th CONGRESS

1st Session

S. RES. 85

IN THE SENATE OF THE UNITED STATES

March 20, 2013

Mr. Sessions (for himself and Mr. Cardin) submitted the following resolution; which was considered and agreed to

RESOLUTION

Designating April 2013 as National Congenital Diaphragmatic Hernia Awareness Month.

Whereas congenital diaphragmatic hernia occurs when the diaphragm fails to fully form, allowing abdominal organs to migrate into the chest cavity and prevent lung growth;

Whereas the Centers for Disease Control and Prevention defines congenital diaphragmatic hernia as a birth defect;

Whereas congenital diaphragmatic hernia occurs in 1 of every 2,500 births;

Whereas congenital diaphragmatic hernia affects approximately 1,600 babies each year in the United States;

Whereas the majority of congenital diaphragmatic hernia patients have underdeveloped lungs or poor pulmonary function;

Whereas congenital diaphragmatic hernia patients often endure long-term complications, including pulmonary hypertension, pulmonary hypoplasia, asthma, gastrointestinal reflex, feeding disorders, and developmental delays;

Whereas congenital diaphragmatic hernia survivors sometimes endure long-term mechanical ventilation dependency, skeletal malformations, supplemental oxygen dependency, enteral and parenteral nutrition, and hypoxic brain injury;

Whereas congenital diaphragmatic hernia patients have a survival rate ranging from 62 percent to 90 percent depending on the severity of the defect, the treatment available at delivery, and whether extracorporeal membrane oxygenation must be used;

Whereas congenital diaphragmatic hernia has affected more than 600,000 babies throughout the world since 2000;

Whereas babies born with congenital diaphragmatic hernia endure extended hospital stays in intensive care with multiple surgeries;

Whereas congenital diaphragmatic hernia is as common a birth defect as spina bifida and cystic fibrosis;

Whereas congenital diaphragmatic hernia is diagnosed in utero in only 75 percent of cases;

Whereas congenital diaphragmatic hernia is treated through mechanical ventilation, extracorporeal membrane oxygenation machines (commonly known as heart and lung bypass machines) and surgical repair;

Whereas patients often outgrow congenital diaphragmatic hernia surgical repair, leading to reherniation and requiring additional surgery;

Whereas the occurrence of congenital diaphragmatic hernia does not discriminate based on race, gender, or socioeconomic status;

Whereas the cause of congenital diaphragmatic hernia is unknown;

Whereas the average hospital bill for a congenital diaphragmatic hernia patient is \$500,000; and

Whereas the total annual cost of medical care for children with congenital diaphragmatic hernia in the United States is more than \$800,000,000: Now, therefore be it

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That the Senate—

(1) designates April 2013 as National Congenital Diaphragmatic Hernia Awareness Month;

(2) declares that steps should be taken to—

(A) raise awareness of and increase public knowledge about congenital diaphragmatic hernia;

(B) inform minority populations in the United States about congenital diaphragmatic hernia;

(C) disseminate information on the importance of good neonatal care for congenital diaphragmatic hernia patients;

(D) promote good prenatal care and the use of ultrasounds to detect congenital diaphragmatic hernia in utero; and

(E) encourage research on congenital diaphragmatic hernia in order to discover its causes, develop treatments, and find a cure; and

(3) calls on the people of the United States, interest groups, and affected persons to—

(A) promote awareness of congenital diaphragmatic hernia;

(B) take an active role in the fight against this devastating birth defect; and

On March 20, 2013 Senator Jeff Sessions (R-AL), along with Co-Sponsor Senator Ben Cardin (D-MD) introduced S.Res. 85: A resolution designating April 2013 as “National Congenital Diaphragmatic Hernia Awareness Month”. **On March 20, 2013 it was passed unanimously.**

2014 CDH Conference in Washington DC

June 24 - 29, 2014

Join us for the annual Congenital Diaphragmatic Hernia Conference in Washington DC.

Joint Family & Medical Conference

March on Capitol Hill

Meet Senators and Representatives

Learn about and participate in CDH Research

Meet other CDH families

Visit the Smithsonian, Monuments and more during afternoons

www.cdhconference.org



New Arrivals

Broderick A.	Clemencia Castillo	Audrey Frost	Phoebe Kleensang
Gabrielle Grace Ackerman	Hunter Alan Casto	Ashlee Kate Funkhouser	Live Agusta Kleivstul
Zeyah Grace Ackerman	Ava Josephine Caulfield	Cesar Armando Gamez	Kaleigh Knight
Mariah Franchesca Acosta	Rylan Cavallo	Dominique Gayle	Parker Knoll
Jaecy "JC" Mae Acosta Sedlis	Avarey Grace Champagne	John Gibbons	Baby Girl Knudsen
Javin Mathew Afre	Lindy Cherry	Kadence Gibson	Emil Knudsen
Baby Boy A Ajit	Gavin Cheves	Aiden Gill	Baby Knudsen
Divaj Ajmani	Brynlee Tuska Christian-Mays	Wyatt Andrew Gill	Arabella Kogut
Bryson Akingbemi	Gavyn Cilino	Samuel Giraldo	Carly Kufs
Audrey Alaniz	Elise Coffey	Maliyah Gomes	Kyle Joseph Kurras
Aubrianna Mae Albin	Kynnedi Collins	Maxwell Airington Gonzales	Jack L
Lynlee Albrecht	Brighton Cook	Aiden Robert Grant	Baby Girl L.
Mohammed Algehilani	Kanyon Cooper	Ava Graziano	Mila Fate Laganis
Zain Ali	Amairani Vianney Corea-Galvez	Eben Greeff	Allyson Lamb
Jordan Amodeo	Nash Cormack	Dexter Green	Killian Kayne Lambert
Kyle Anderson	Amelia Coroy	Rivers Green	Nora Grace Lange
Toven Anderson	Trenton Wayne Cox	Joshua Greene	Nadia Marilyn Larson
Olivia Grace Andridge	Josephine Craft	Brylie Gregory	Birger David Lawall
Baby Boy Anon	Jordan Croce	Baby Grenier	Bentley Lawry
Twain Arevalo	Baby Boy Cruz	Macy Griffin	Bentley Alexander Lawry
Kamden Grayson Babin	Lucy Curry	Averee Gruber	Allyssa Lawson
Deniz Bahsi	Nova D	Sophia Rose Guerrero	Kalleigh Lay
Asjiah-Fate Bailey	Jude Harper Daff	Hailey Lynn GuzowskiRaelyn H	Angel Lee
Amariana Bain	Tatum Avery Rose Dains	Landon Hadermann	Walter Levin
Baby Girl Baker	Christian Davis	Madison Jo Hager	Jessie Angelique Limas
Rayanne Dawn Ball	Poppy Davis	Ari Hall	Devon Linden
Brayden Michael Bammerlin	Skylar Alycia Davis	Jacoby James Hall	Levi Lingenfelter
Adeline Barker	Thomas Davis	Harper Hallmark	Baby Lloyd
Timoteo Beck	Wyatt James Davis	Milton Hammer	Pere Loaiza
Jenna Beda	Rhea Francine De Belen	Levi Hansen	Parker Locklear
Noah Beech	Agustin De La Fuente Pino	Gabriel Harrington	Jenna Lopez
Cooper Lynn Beeler	Wyatt Lynn Deal	Brynn Hatfield	Sophia Leigh Lovett
Evalon Zoë Bell	Bay Girl Del	Baby Girl Havican	Arianna Lugo
Jacob Bensusan Lasry	Gracel Erich Dela Cruz	William Hawkins	Jackson Luxem
Phoenix Keoni Alec Bentley	Kalleigh Delaporte	Gavin Haynes	Motheo Camila Mafike
Arabella Beston	Logan Dendler	Baby Heal	Maximus Maltby
Paxton William Aaron Billings	Kullen Michael Denegri	Reed Wyatt Heaton	Lucas Marro
Anastasia Rose Blackwell	Baby Girl Deprez	Harper Heide	Daniel Marshall
Anya Blackwell	Toby Jr Derrevere	Joseph Michael Heimke	Hunter Wilson Matteson
Carley Blair	Luna Diaz	Kevin Hemming	Katelyn Mayes
Miabella Lis Blanchard	James Todd (JT) Dickerson	Lucie Henderson	Emma McClary
Keeno Rafael Blanco	Addison Dinero	AJ Hensley	Emmalyn Dawcyn McCoy
Landyn Boltz	Olive Dionne	Jayden Hill	Tucker McCoy
Baby Bonack	Lillyaunna Marie Ryan Dittmar	Tucker Cross Hinson	Liam Mccue
Baby Girl Bonds	Alexis Dorsey	Devorah Hollander	Hunter McDonald
Evan Bonistalli	Brooklyn Douglas	Liam And Owen Holley	Jacquael McHerron
Gabriella Marie Booker	Joshua Drapeau	Esther Holtrop	Isaiah McIntosh
Aubrey Borgen	Baby Girl Drayton	Baby Boy Honnert	Baby Girl McKittrick
Jayden Wesley Bowcutt	Jordan Dunn	Baby Girl Hornstein	Brandon McMahon
Baby Boy Boyd	Baby Boy E	Baby Boy Houchin	Baby Boy McPheeters
Fátima Sofia BR	Dvij E	Savannah Houselog	Baby Boy Meher
Alice Caroline Bradley	Anya Mae Eaton	Sienna Marie Howard	Katherine Nina Menes
Damien Brannon	Gabriel Ebaugh	Walker Peyton Huddleston	Gavin Meyer
Ian Brocklebank	Bailey Ellison	Walker Huddleston	Wyatt Mighton
Elliot Brough	Will Erazmus	Blayne Hughes	Hunter Miller
Brayden Bull	Jacob Esparza	Brayden Jay Hulsizer	Alphonso Mims
Olivia Bunich	Baby Girl Estacio	Charley Incerto	Julissa Miramontes
Baby Boy Burba	Mariah Evans	Kevin Ison	Tripp Mitchell
Brantley Burton	Julia F	Baby Jackson	Caleb Matthew Mohmand
Isabella Bustillos	Eve Fabio	Baby Boy Jackson	Jayson Mooney
Kimberlea Buxman	Maria Athena Faith Mitchell	Shannon Jelly	Callie Moore
Baby Byrd	Casey James Fassold	Emsley Jenkins	Liam Morales
Baby Boy Calhoun	Jordan Ferris	Faith Jenkins	Baby Boy Morgan
Jacklynn Campbell	Melanie Flores	Aleah Lily Jones	Colin Myer
Kenlie Capen	Skylar Milagros Fonseca	Baby Girl (Aleah) Jones	Baby Girl Nawarski
Baby Carlson-Jones	Vivianne Darby Frankel	Jackson Grey Joseph	Daniel Nordman
Lila Kate Carpenter	Allie Freeman	Baby Boy Kealy	Baby Girl B Norman
Gavin Cartaya	Lila French	Baby Keehner	Mya Norman
Jesse Casias	Mateo Frias	Sophia Kersh	Shelby Marie Nunes
Makenna Cason	Noah Fries	Lia Khalil	Ridley Ellis Nunn

2012-2013 CDH Angel Club Members

Aaron McClary
 Aaron Parson
 Andrea Zimmerman
 Ann Whiteside
 Anthony Pyland
 Cameron Silva
 Carla Grover
 Catherine Tryfona
 Christie Erickson
 Cynthia Linden
 Danielle Hallinan
 Dawn Williamson
 Dayron Feliz
 Deborah Parker
 Devon Roell
 Freedom Green
 Heather Crockett
 Helene Berchtold
 Jackie Tune
 Jade Hunt
 Jaime Blakley
 Jason Yahaya
 Joanna Daughtry
 Jocelyn Lacey
 Jody Larrison
 Judith Nazareth
 Julie Svoboda
 Karen Myers
 Kathryn Laganis
 Kendrah Kidd
 Layna Lambert
 Lisa Carter
 Lori Czerwien
 Maria Paciona
 Mary Sierra Hales
 Melissa Burney
 Michael G Seabooks
 Michele Snyder
 Patricia Kubus
 Rebecca Thurmond
 Roxanne Reynonds
 Sandra Rivera
 Shannon Thomas Passieu
 Shelly Evans
 Sheri De Feo
 Summer Carlson
 Tara Hall
 Teresa Meherg
 Tony Nix
 Tony Sandoval
 Vanessa Lanza
 Vicki Collins

John Angelo O'Donnell, V
 Lillian Olsen
 Grace Opie
 Brayden Osborne
 Kayden Ostrousky
 Eleanor P
 Eden Palm
 Leo Partsafas
 Zoey Pavilanis
 Harper Peck
 Jaime Manuel Pedroza
 Olivia Pelham
 Ricky Leonardo Perez
 Dylan Perkins
 Olcigi Perkins
 Oakley Petcher
 Claire Phinney
 Avacyn Pichay
 Faith Platt
 Lilliana Polk
 Alex Porricelli

Waylon Porteous
 Isabella Preston
 Grayson Price
 James Christopher Price
 William Prudhomme
 Mavrik Austin Pruitt Jackson
 Purvis
 Annalia Quijada
 Baby Qur
 Damian Ramin
 Alan Ramón
 Gavin Wilson Ream
 Braxton Rebando
 Mason Vincent Redman
 Kassidy Jahzara Reed-Pratt
 Sunni Reeves
 Caitlin Regit-Enyingi
 Baby Girl Reid
 Leah Reid
 Lily Reid
 Stella Kairos Resurreccion
 Lylah Reynolds
 Baby Boy Rhoda
 Baby Boy Riddle
 Christopher Riker
 Alexander Scott Rinehart
 Patrick Charles Roark
 Andrew Roberson
 Ava Roberts
 Elijah Rodriguez
 Junior Rodriguez
 Kane Rogers
 Baby Boy Rogowski
 Baby Boy Rooyackers
 Baby Roper
 Berkley Lynn Roper
 Declan Roskey
 Kian Roux
 Luke Roy
 Brody Asher Rubenstein
 Vivienne S
 Kendall S.
 Emilia "Mia" Salamanca
 Adam Salas
 Baby Boy Salazar
 Jagger Cayden Ray Salazar
 Rylan Salazar
 Baby Girl Sanchez
 Stormy A Sandefur
 Nathan Scelfo
 Jacob Anthony Schaal
 Waylon Dean Schaefer
 Aiden Schmitt
 Baby Girl Schneider
 Matthew Schroeder
 Avery Schulz
 Hlolo Sehlapelo
 Einya Elizabeth Sengsourya
 Oscar Senior
 Skylar Sherman
 Liam Duncan Shields
 Anna Shuman
 Mohammed Yaqeen Siers
 Jacob Scott Silbernagel
 David Keith Siler
 Kai Sisay
 Bas Sleuwenhoek
 Baby Boy Slivnik
 Colin Small
 Baby Boy Smith
 Hudson Smith
 Sarah Smith
 Radhika Soni
 Carter Sorensen
 Sydney Ophelia Sorrells

Jacob Spelman
 Brinklee Marie Spinazzola
 Harper Stanfield
 Alden Gregory Strozzyk
 Eeva Sujith
 Lucas Sweet
 Ellery Rose Tait
 Ayaan Tak
 Aron Tamm
 Liam Miguel Tapia
 Parker Taylor
 David Michael Tewksbury Jr.
 Baby Girl Theodore
 Baby Girl Thompson
 Shiloh Tiedt
 Caroline Tillery
 Fiona Timoney
 Patrick Allen Tinker
 Samuel Tortorelli
 Emilie Toth
 Baby Boy Trojand
 Madeline Truscott
 Malani Turner
 Brooke Allyson Tyler
 Barrett Uncapher
 Lizay Van Zyl
 Oscar Venn
 Baby Girl Verage
 Sarah W
 Surprise Baby! W
 Charlie Waayers
 Michael Thomas Waldron
 Baby Boy Walker
 Damon Alexander Walker
 Joshua Wall
 Evelyn Wallis
 Victoria Ware
 Baby Girl Webb
 Liam Weeks
 Baby Boy Weick
 Eva Weigand
 Oliver Wesson
 Lexi Wheatley
 Owen Wheelan
 Ellie White
 Micaiah White
 Alaina Grace Wieringa
 Adrian Wikstrom
 Baby Girl Wiles
 Ava Faith Wilkerson
 Alis Williams
 Bryson Williams
 Delaney Ann Williams
 Henry Davis Williams
 Imogen Williams
 Ja'kayla Willis
 Baby Boy Winders
 Jaxson Winders
 Baby Girl Winthers
 Blaire Alexandria Wise
 Jade Aurora Wogsland
 Baby Boy Wolf
 CJ Wood
 Bryson William Woodruff
 London Elizabeth Woodward
 Evelyn Elizabeth Yardley
 Anderson Young
 Tamara Young
 Wyatt Young
 Angela Faith Zadravec
 Legacy Zanders-Jones
 Baby Zdeb
 Andy Zhang
 Dominic Zimmerman
 Chaya Zyskind

CDH Raffle for Research

In 2012 we sold 900 50/50 raffle tickets at \$20.00 each to raise \$18,000. The drawing was held at the 2012 Masquerading Angels Ball and \$9000 was awarded to the raffle winner, Mark Stamper of North Carolina.



The remaining \$9000 went towards a \$10,000 CDH Research Grant Contest that was held on our Facebook page in December. Families voted for their favorite CDH Research Center and \$10,000 was awarded the Fetal Treatment Center at the Children's Hospital of Philadelphia after a VERY close competition!



The family of Tatum Ashley Larson fundraised in her memory and we were also able to award a surprise \$10,000 grant to DHREAMS!



In 2013 we repeated this very successful event and sold 600 tickets for a \$6000 prize to Jane Hull of Utah. Families also raised an additional \$4000 on-line through Firstgiving.com

Our \$10,000 CDH Research Grant Contest was won by a landslide by Shands for Children at the University of Florida in Gainesville to help the research of Dr. David Kays.

We would like to award \$25,000 in Research Grants in 2014. Please contact us if you'd like to help!

"Never underestimate the power of dreams and the influence of the human spirit." - Wilma Ru-

2012 Congenital Diaphragmatic Hernia Conference

Our 2012 CDH Conference was held San Francisco, California on July 26th through the 29th. Families came together to meet, learn about CDH, walk in a Parade of Cherubs and participate in Research. Special thanks to our guest speakers; Dr. Doug Miniati from the University of California, San Francisco Fetal Treatment Center, Meaghan Russell from the Congenital Diaphragmatic Hernia Genetic Research Study in Boston and Julia Wynn from DHREAMS at Columbia University.



2012 Milestones

- New Executive Board of Directors
- New Parent Advisory Board
- New Medical Advisory Board
- New Vice-President, Ashley Barry
- New Secretary, Lauren Campbell
- New Treasurer, Kelly Green-Krist
- Senate Bill S.3396 Introduced
- Parade of Cherubs on April 19th in Washington DC to Capitol Hill
- Members met with the offices of over 25 Senators
- April 19th CDH Parades of Cherubs in Chicago, Seattle, Portland, Denver, St. Louis, Peoria
- UK Light up The Night on April 19th
- First ever Virtual CDH Awareness Parade on April 19th
- 2012 CDH Conference in San Francisco
- New CHERUBS Web Site
- New Facebook Forums Application created
- \$10,000 CDH Research Grant contest
- \$10,000 CDH Research Grant awarded to CHOP on December 30th
- Another \$10,000 CDH Research Grant awarded to DHREAMS on December 30th
- Over 300 care packages sent to families through our CDH HOPE Totebag project
- CDH families represented at the American Pediatric Surgical Association conference
- Our 2012 National Children's Memorial Day tribute honored over 1000 cherubs
- Texas Get-Together
- Ohio Picnic
- UK Get-Together in Scotland
- Chicago CDH Carnival
- Pennsylvania / NJ / Delaware Picnic
- Denver Picnic
- Indiana Get-Together
- Washington Zoo Trip
- Oregon members met with Senators
- Oregon members represent CDH families at the opening of Randall Children's Hospital
- Over 900 raffle tickets sold for the 50/50 CDH Research Raffle
- Over 10,000 Facebook Fans reached
- Over 10,000 signatures reached on CDH Research Bill petition
- Participated in televised Raleigh Christmas Parade
- It's a Knock-Out UK Fundraiser
- Masquerading Angels Ball
- UK Formal Ball
- CDH Awareness Calendar featuring over 1300 CDH patients
- Save the Cherubs CDH Awareness Calendar
- First CDH Awareness Calendar in the United Kingdom
- Won Shane Co. charity contest
- Won the JuJuBelle Facebook contest
- CDH Awareness Ribbon included in St. Louis Cardinals Game to raise money for St. Louis hospital
- Washington Mud Run Fundraiser
- Enter Stage Left Fundraiser
- UK Fishing Competition Fundraiser
- CHERUBS joins Google+, Chirpify, Pinterest, Instagram,
- CDH Fundraising Kits created
- Participated in the San Francisco Marathon, the Great Human Race in Durham, NC
- Save The Cherubs in the Silicon Valley
- New Holiday Facebook Covers project started
- Dozens of free CDH Awareness graphics made
- New yellow CDH Awareness Bracelets created
- 47 members of the Angel Club
- Over 100 new Save the Cherubs posters created
- Membership reaches over 4200 families in 54 countries
- CHERUBS moves to new office
- 5 television interviews
- Over 2 dozen newspaper articles
- 1 magazine article

CDH Get-Togethers, Fundraisers and Awareness



"All parts of the universe are interwoven with one another, and the bond is sacred. Nothing is unconnected with some other thing."
- Marcus Aurelius



"The trouble with organizing a thing is that pretty soon folks get to paying more attention to the organization than to what they're organized for" - Laura Ingalls Wilder



"Life's under no obligation to give us what we expect." - Margaret Mitchell

CHERUBS International & State Representatives

*It is our goal to have 2 Representatives for each state and country; a (S) Parent s of a Survivor, (G) Grieving Parent and/or (A) Adult Survivor.
We also are in the process of assigning Hospital Angels to every Children's Hospital.*

Country / State	Representative	Telephone	E-Mail
Canada	Tara Howie	902-431-8334	canada@cherubs-cdh.org
Denmark	Rikke Hammer	+45 302299115	denmark@cherubs-cdh.org
India	Shankari Murali	80-25283423	india@cherubs-cdh.org
Ireland (S)	Tina McGrath	003531-4578526	ireland@cherubs-cdh.org
United Arab Emirates (S)	Gemma Van Rilliar		unitedarabemirates@cherubs-cdh.org
United Kingdom (G)	Zoe Burchell	7843387878	uk@cherubs-cdh.org
United Kingdom (G)	Melanie Parsons		uk@cherubs-cdh.org
United Kingdom (S)	Clair Maher	798-336-5233	uk@cherubs-cdh.org
Alabama (G)	Teresa Meherg	205-270-1386	alabama@cherubs-cdh.org
Alabama (S&G)	deAnn McGilberry	334-875-6402	alabama@cherubs-cdh.org
Arizona (A)	Stephanie Tolley	480-251-0988	arizona@cherubs-cdh.org
Arizona (S)	Somer Ball	602-299-8636	arizona@cherubs-cdh.org
Arizona Hospital Angel - Phoenix area	Nicki Young	602-680-0411	nyoung@cherubs-cdh.org
California (A)	Amy Schlueter	559-313-8329	california@cherubs-cdh.org
California (S)	Mikkel Kyle	707-463-2774	california@cherubs-cdh.org
California Hospital Angel	Amy Schlueter	559-313-8329	aschlueter@cherubs-cdh.org
California Hospital Angel	Mikkel Kyle	707-463-2774	california@cherubs-cdh.org
Colorado (G)	Nicolle Colvin	720-870-2518	colorado@cherubs-cdh.org
Connecticut (G)	Jennifer Dickinson	860-877-0900	connecticut@cherubs-cdh.org
Illinois (S)	Neil Rubenstein	847-537-9170	illinois@cherubs-cdh.org
Illinois Hospital Angel - OSF ST Francis CHOI	Kristin Aigner	309-371-8566	illinois@cherubs-cdh.org
Indiana (S)	Karol Napers	317-858-5073	indiana@cherubs-cdh.org
Indiana (S)	Michelle Rogers		indiana@cherubs-cdh.org
Louisiana (G)	Alexis Prudhomme	337-275-9404	louisiana@cherubs-cdh.org
Louisiana (S)	Lisa and Dana Thibeau	504-452-5193	louisiana@cherubs-cdh.org
Massachusetts (S)	Tracy Landers	508-840-5743	massachusetts@cherubs-cdh.org
Massachusetts (S)	Marie Marchesseault	978-664-2358	massachusetts@cherubs-cdh.org
Michigan (S)	Megan Weedon	269-816-0857	michigan@cherubs-cdh.org
Mississippi (S)	Shereen Kostmayer	228-243-8500	mississippi@cherubs-cdh.org
Missouri Hospital Angel - Cardinal Glennon	Laura Henderson	636-373-3312	missouri@cherubs-cdh.org
Nevada (S)	Jill Gibson	702-267-7441	nevada@cherubs-cdh.org
Nevada (S)	Patricia Houle	702-508-8544	nevada@cherubs-cdh.org
New York (S)	Tara Zoitos	516-622-3324	newyork@cherubs-cdh.org
New York Hospital Angel	Jennifer Cuomo	845-987-7826	newyork@cherubs-cdh.org
New York Hospital Angel - North Shore LIJ Hosp	Tracy Meyer	214-748-3647	newyork@cherubs-cdh.org
North Carolina (G)	Matt Willis	910-538-2002	northcarolina@cherubs-cdh.org
North Carolina (S)	Lauren Ward	704-298-5442	northcarolina@cherubs-cdh.org
North Carolina (S)	Karla Holt	276-362-5114	northcarolina@cherubs-cdh.org
North Dakota (S)	Donna Stolz	612-709-1238	southdakota@cherubs-cdh.org
Ohio (S)	Julie Tunnell	614-519-2292	ohio@cherubs-cdh.org
Oklahoma Hospital Angel	Kacy Hurley	405-613-0788	oklahoma@cherubs-cdh.org
Oregon (G)	Shelly Moore	503-430-7568	oregon@cherubs-cdh.org
Oregon (S)	Andrea Martin	253-863-9566	oregon@cherubs-cdh.org
OR Hospital Angel - Randall Children's, OHSU	Alicia Gilbert	503-820-8986	oregon@cherubs-cdh.org
Oregon Hospital Angel - Randall Children's Hosp	Jamie Rowan	971-259-9001	oregon@cherubs-cdh.org
Pennsylvania (S)	Felecia Woodruff	610-241-6581	pennsylvania@cherubs-cdh.org
Pennsylvania (S)	Dana McCue	570-685-4884	pennsylvania@cherubs-cdh.org
Pennsylvania (S)	Matt Small	856-381-5114	pennsylvania@cherubs-cdh.org
Pennsylvania Hospital Angel - Western PA	Jessica Cummings	724-316-0725	pennsylvania@cherubs-cdh.org
Rhode Island (S)	Tracy Landers	508-840-5743	rhodeisland@cherubs-cdh.org
South Carolina Hospital Angel - MUSC	Elizabeth Burton		southcarolina@cherubs-cdh.org
South Dakota (S)	Donna Stolz	612-709-1238	southdakota@cherubs-cdh.org
Texas (A)	Cassandra Carter	817-690-0562	texas@cherubs-cdh.org
Texas Hospital Angel - Texas Children's	Ashley McCafferty	281-785-2320	texas@cherubs-cdh.org
Utah (G)	Josh Hensley	801-953-5622	utah@cherubs-cdh.org
Vermont (G)	Jade Hunt	802-922-3666	vermont@cherubs-cdh.org
Virginia (G)	Melissa Larrison	757-673-2567	virginia@cherubs-cdh.org
Washington (S)	Christina Stembler	425-922-2828	washington@cherubs-cdh.org
Wisconsin (S)	Neil Rubenstein	847-537-9170	wisconsin@cherubs-cdh.org
Wyoming (S)	Tracy Meats	307-362-9630	wyoming@cherubs-cdh.org

Cherubs On-Call Volunteers

Need someone to talk to? These volunteers are here to lend a shoulder or an ear. Our CDH Forums are also available 24/7 at www.cdhboards.org

Volunteer	On-Call For	Telephone	E-Mail
Elizabeth Lopez	Older Survivors	919-360-1728	elopez@cherubs-cdh.org
Jill Gibson	Expectant / Parents of Survivors	702-267-7441	jgibson@cherubs-cdh.org
Lauren Ward	Expectant / Parents of Survivors	704-298-5442	northcarolina@cherubs-cdh.org
Christina Stembler	Expectant / Parents of Survivors	425-749-7226	washington@cherubs-cdh.org
Freedom Green	Grieving Parents	410-363-7465	fgreen@cherubs-cdh.org
Karen and Will Myers	Grieving Parents	210-355-6801	kmyers@cherubs-cdh.org

CDH HOPE Totebag Project

CHERUBS currently mails out 30 to 40 CDH HOPE (Helping Other Parents Expecting) Totebags to new and expectant parents every month. Our charity covers the costs of the totebags, CDH Baby Books, folders, shipping and items we are out of. All other items are donated by our wonderful members in honor of or in memory of your cherubs!



Totebag Item Wish List

CDH Baby Books
Baby Blankets
Baby Hats
Baby Booties
Pacifiers
Handprint Kits
Disposable Cameras
Chapsticks
Baby Pillows
Soft Picture Frames
Eye Masks
Hand Sanitizers
Journals
Onesies
Children's Books
Teddy Bears
Lotion
Game Books (for parents)
Gas and Restaurant Gift Cards



CHERUBS invites you to donate or fundraise for a great cause! Please support our 5 CDH Funds:

CDH Family Support Fund – to fund the dozens of services and projects that we provide to families affected by Congenital Diaphragmatic Hernia

CDH Research Fund – to fund our CDH Research Survey hosting and to contribute to CDH research facilities.

CDH Family Assistance Fund – to help families of the financial hardships of dealing with CDH.

CDH Awareness Fund – to bring more awareness to Congenital Diaphragmatic Hernia through various projects

CDH Scholarship Fund – to help with the education of survivors and family members of those affected by Congenital Diaphragmatic Hernia so they can go out into the world and bring about more CDH research and awareness

Your tax-deductible donation can be made on-line via our web site at <http://www.cherubs-cdh.org> or by check or money order to:

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

April 19, 2013 Events & Celebrations



April 19, 2012 Parades and large events were held in:

- New York City
- Chicago
- Dallas
- Salt Lake City
- Portland
- Seattle
- Denver
- Phoenix
- Peoria
- Las Vegas
- Gainesville
- St Louis
- Philadelphia
- United Kingdom

Senator Jeff Sessions & Family
Olivia Faith Foundation
Dr David Kays
Alicia Gilbert
Andrea Martin

Ashley Barry
Ashley Moore
Cara Stevenson
Cassandra Carter
Christina Stember
Christina Stember

Clair Maher
Dana McCue
Jamie Rowan
Janna Caravia
Jennifer Rodi
Jill Gibson

Josh & Melaie Hensley
Joy Perkins
Julia Wynn, MS
Karla Holt
Katie Francis
Kristin Aigner

Leslie Peck
Lisa Carter
Marie Marchessault
Meaghan Russell
Melanie Parsons
Melissa Larrison

Neeran Lang
Neil Rubenstein
Nicolle Colvin
Noel Williams
Patricia Houle
Shannen Bailey

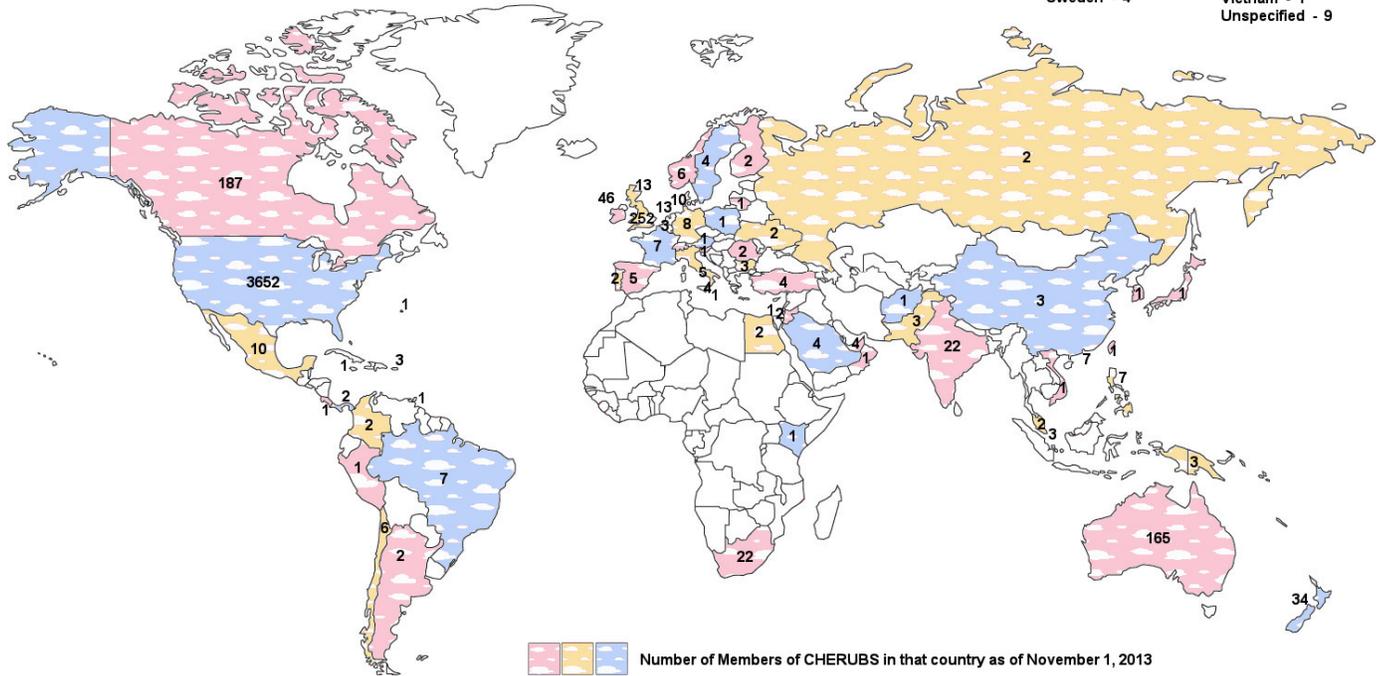
Shelly Moore
Sommer Ball
Stephanie Tolley
Tara Zoitos
Tracy Meats
Tracy Landers



"The things you do for yourself are gone when you are gone, but the things you do for others remain as your legacy." - Kalu Ndukwé Kalu

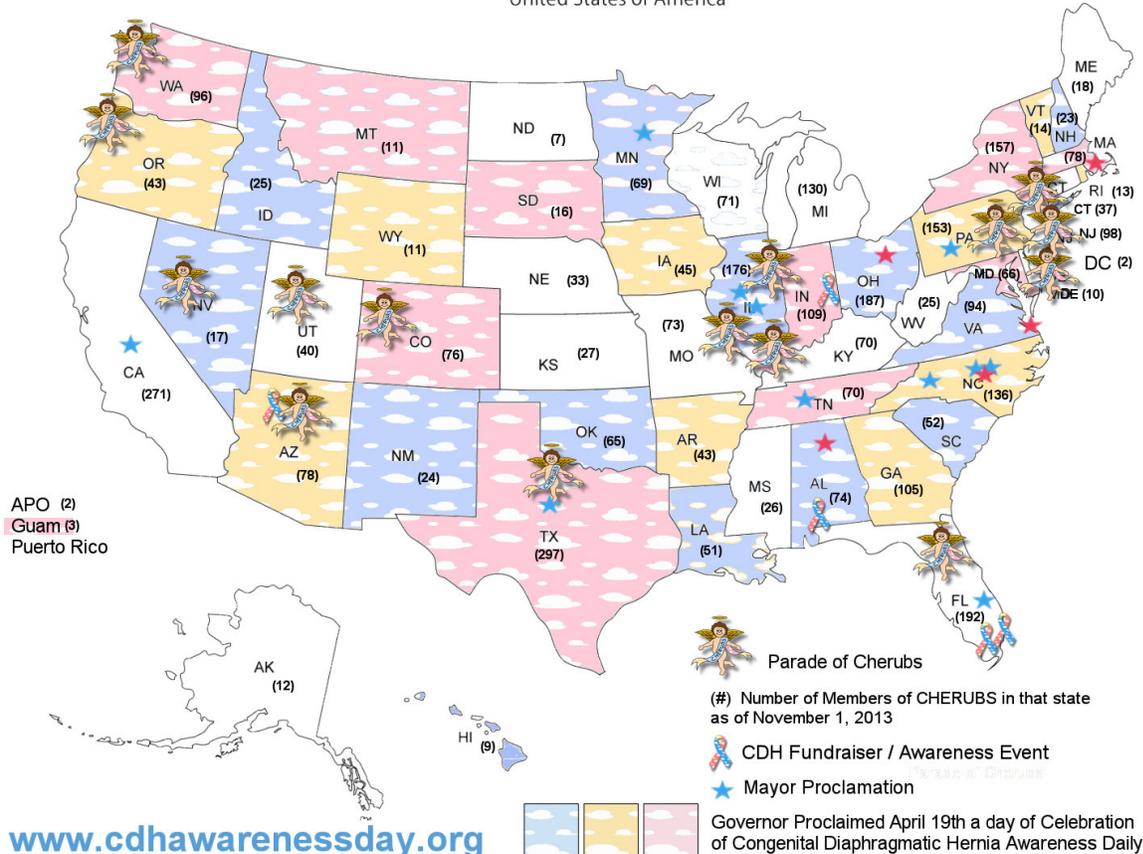
2013 CHERUBS Membership

Afghanistan - 1	Canada - 187	Egypt - 2	Ireland - 46	Lithuania - 1	Pakistan - 3	Romania - 2	Switzerland - 1
Argentina - 2	Cayman Islands - 1	Finland - 2	Israel - 2	Malaysia - 2	Panama - 2	Russia - 2	Taiwan R.O.C - 1
Australia - 165	Chile - 6	France - 7	Italy - 5	Malta - 1	Papua New Guinea - 3	Saudi Arabia - 4	Trinidad and Tobago - 1
Belgium - 3	China - 3	Germany - 8	Japan - 1	Mexico - 10	Peru - 1	Scotland - 13	Turkey - 4
Bermuda - 1	Colombia - 2	Greece - 4	Kenya - 1	Netherlands - 13	Philippines - 7	Singapore - 3	Ukraine - 2
Brazil - 7	Costa Rica - 1	Hong Kong - 7	Korea, South - 1	New Zealand - 34	Poland - 1	Slovenia - 1	UAE - 4
Bulgaria - 3	Denmark - 10	India - 22	Lebanon - 1	Norway - 6	Portugal - 2	South Africa - 22	UK - 252
				Oman - 1		Spain - 5	USA - 3652
						Sweden - 4	Vietnam - 1
							Unspecified - 9



April 19th is the International Day of Congenital Diaphragmatic Hernia Awareness 2013 Proclamations, Parades of Cherubs & Events

United States of America



Welcome to the Following New Members:

- Broderick A
- Zeyah Grace Ackerman
- Mariah Franchesca Acosta
- Jaecy "JC" Mae Acosta Sedlis
- Joshua Adamigo
- Francesco Adattini
- Javin Mathew Afre
- Aira Aganan
- A Ajit
- Divaj Ajmani
- Bryson Akingbemi
- Aubrianna Mae Albin
- Lynlee Albrecht
- Mohammed Alghelani
- Zain Ali
- Beatriz Almeida
- Alejandro Alva
- Jordan Amodeo
- Kyle Anderson
- Toven Anderson
- Olivia Grace Andridge
- Twain Arevalo
- Savanna Arthur
- Nicolas Ascencio
- Johnny Ashley
- Mikaele Aualiitia
- Molly Axtell
- Ryan B
- Kamden Grayson Babin
- Baby Boy Baby Boy
- Tauryn Bachicha
- Deniz Bahsi
- Asjiah-Fate Fate Bailey
- Amariana Bain
- Baby Girl Baker
- Rayanne Dawn Ball
- Brayden Michael Bammerlin
- Adeline Barker
- Alexander Barnes
- Izabella Beck
- Timoteo Beck
- Jenna Beda
- Tiffany Sharon Bediner
- Noah Beech
- Cooper Lynn Beeler
- Evalon Zoë Bell
- Dale Benjamin
- Jacob Bensusan Lasry
- Phoenix Keoni Alec Bentley
- Arabella Beston
- Cayden Betts
- Cayden Betts
- Paxton William Aaron Billings
- Amanda Black
- Anastasia Rose Blackwell
- Anya Blackwell
- Carley Blair
- Miabella Lis Blanchard
- Keeno Rafael Blanco
- Lucas Adrian Blitger
- Samuel Boddie
- Landyn Boltz
- Baby Bonack
- Baby Girl Bonds
- Evan Bonistalli
- Jaimee-Rose Hope Bonner
- Gabriella Marie Booker
- Aubrey Borgen
- Lily Borowski
- Katelynn Botell
- Jayden Wesley Bowcutt
- Baby Boy Boy
- Fátima Sofia BR
- Amanda Bracher
- Alice Caroline Bradley
- Brennen Bradshaw
- Damien Brannon
- Mark Breed
- Frankie Brigance
- Ian Brocklebank
- Elliot Brough
- Baby Boy Brown
- Derek Brown
- Hank Brown
- Samuel Brown
- Danielle Brumfield
- Brayden Bull
- Olivia Bunich
- Baby Boy Burba
- Julian Matthew Burby
- Brantley Burton
- Isabella Bustillos
- Kimberlea Buxman
- Emalee-Faith Callen
- Jacklynn Campbell
- Chasity Canham
- Hailey Cantrell
- Kenlie Capen
- Baby Carlson-Jones
- Lila Kate Carpenter
- Elana Carrol
- Michael Carroll
- Gavin Cartaya
- Shannon Carter
- Magnolia Carty
- Olivia Catherine Case
- Jesse Casias
- Makenna Cason
- Clemencia Castillo
- Abigail Castle
- Hunter Alan Casto
- Diogo Castro Pires
- Ava Josephine Caulfield
- Rylan Cavallo
- Justin Cernobyl
- Samantha Chavez
- Gabriella Checotah
- Jayden Chen
- Lindy Cherry
- Gavin Cheves
- Brynlee Tuska Christian-Mays
- Gavyn Cilino
- Daniella Ciollo
- Cassi Clark
- Johnathan Clark
- Kennedy Clark
- Stratton Clark
- Matthew Clemens
- Catherine Elizabeth Clements
- Elise Coffey
- Kynnedi Collins
- Oliver Commons-Wilds
- Madalynne Contreras
- Brighton Cook
- Li Cooke
- Riley Coombs
- Canyon Cooper
- Nash Cormack
- Emma Cornish
- Amelia Coroy
- Ignacio Cortes
- Donyae Cotton
- Kennidee Cotton
- Joseph Cox
- Trenton Wayne Cox
- Josephine Craft
- Azalie Crain
- Jordan Croce
- Baby Boy Cruz
- Tallulah Blue Cudlip
- Shay Cuomo
- Lucy Curry
- Nova D
- Anthony D.
- Jude Harper Daff
- Tatum Avery Rose Dains
- Kelly Daley
- Alyx Nicole Dalton
- Zachariah "Zac" Daniels
- Ashley John Davies
- Sophie Davies
- Alexandar Davis
- Baby Girl Davis
- Christian Davis
- Poppy Davis
- Skylar Alycia Davis
- Thomas Davis
- Wyatt James Davis
- Rhea Francine De Belen
- Reegan De Bruin
- Wyatt Weston Deal
- Baby Degretto
- Bay Girl Del
- Gracel Erich Dela Cruz
- Kalleigh Delaporte
- Logan Dendler
- Kullen Denegri
- Kullen Michael Denegri
- Baby Girl Deprez
- James Todd (JT) Dickerson
- Addison Dinaro
- Olive Dionne
- Lillyaunna Marie Ryan Dittmar
- Melissa Docker
- Matthew Doesrscheln
- Karoline Faith Domaoan
- Alexis Dorsey
- Brooklyn Douglas
- Meagan Downing
- Joshua Drapeau
- Baby Girl Drayton
- Anderson Chase Duffin
- Jordan Dunn
- Julianna Dusch
- Dvij E
- Anya Mae Eaton
- Clay Eaton
- Jameson Eaton
- Baby Boy Ebaugh
- Gabriel Ebaugh
- Katie Edic
- Kenli Edwards
- Ashtyn Ellis
- Bailey Ellison
- Colton Embrey
- Anders Engelby
- Abra Engler
- Jacob Esparza
- Baby Girl Estacio
- Trenton Estes
- Mariah Evans
- Julia F
- Tristan F
- Eve Fabio
- Maria Athena Faith Mitchell
- Noah Falardeau
- Ethan Farmer
- Casey James Fassold
- Rin Fem
- Jordan Fern Amodeo
- Jordan Ferris
- Kristian Feutrell
- Warren Fink
- Julian Finnegan
- Owen Fisher
- Carol Flood
- Melanie Flores
- Vivian Flores
- Abbie Flowers
- Emily Flowers
- Olivia Fomby
- Skylar Milagros Fonseca
- Amia Forbes
- Morgynn Ford
- Sean Forney

- Callum Fossett
- Cameron Lee Maliki France
- Vivianne Darby Frankel
- Candy Freed
- Allie Freeman
- Lila French
- Mateo Frias
- Noah Fries
- Gabrielle Froio
- Audrey Frost
- Emma Gallagher
- Cesar Armando Gamez
- Emmi Garcia
- Liani Garcia
- Dominique Gayle
- Jeffrey Georges
- Ben Germanio
- John Gibbons
- Kadence Gibson
- Aiden Gill
- Wyatt Andrew Gill
- Logan Jason Gilleland
- Samuel Giraldo
- Alexandra Goggins
- Maliyah Gomes
- Maxwell Airington Gonzales
- Desireé Gonzalez
- Julia Ann Grafe
- Aiden Robert Grant
- Erin Elizabeth Grant
- Ava Graziano
- Eben Greeff
- Dexter Green
- Rivers Green
- Joshua Greene
- Brylie Gregory
- Baby Grenier
- Ryan Grieci
- Eryn Griffin
- Macy Griffin
- William Griffin
- Breanna Grooms
- Avereë Gruber
- Sophia Rose Guerrero
- Hailey Lynn Guzowski
- Raelyn H
- Taylor Lee Hacker
- Landon Hadermann
- Madison Jo Hager
- Brooklyn Hales
- Ari Hall
- Harper Hallmark
- Milton Hammer
- Milton Hammer
- Jamesia Hammonds
- Levi Hansen
- Gabriel Harrington
- Gabriel Harrington
- Brendon John Hart
- Brynn Hatfield
- Baby Girl Havican
- William Hawkins
- Gavin Haynes
- Whitney Haynie
- Ira Hays
- Luna Hays
- Baby Heal
- Reed Wyatt Heaton
- Kayla Hedman
- Harper Heide
- Joseph Michael Heimke
- Kevin Hemming
- Lucie Henderson
- Madison Henning
- AJ Hensley
- Baby Herman
- Robert “Bentley” Hernandez
- Grant Herod
- Baby Girl Herold
- Logan Hesselbrock
- Bryan Hewitt
- Arabella Hightshoe
- Elizabeth Hope Hill
- Jayden Hill
- Baby Girl Hilsinger
- Baby R Hilsinger
- Johnna Hinklin
- Tucker Cross Hinson
- Baby Boy Hoffmann
- Tierney Hohman
- Alexandra Holladay
- Devorah Hollander
- Liam And Owen Holley
- Esther Holtrop
- Baby Boy Honnert
- Baby Girl Hornstein
- Lucy Jane Horton
- Baby Girl Houselog
- Sienna Marie Howard
- Abigail Howell
- Sarah Howerton
- Walker Peyton Huddleston
- Jackson Hufford
- Blayne Hughes
- Sarah Hughes
- Brayden Jay Hulsizer
- Liam Hunt
- Jaiden Husted
- Abrianna Iezza
- Charley Incerto
- Kevin Ison
- Connor J
- Baby Jaber
- Baby Jackson
- Baby Boy Jackson
- Esteban Jasso
- John (Trey) Jay
- Shannon Jelly
- Emsley Jenkins
- Faith Jenkins
- Cooper Payne Leo Jensen
- Lucy Jensen
- Reese Sophia Jimenez
- David John
- Henry Liam Johnson
- Justin Johnson
- Miles Johnson
- Nevaeh Johnson
- Aleah Lily Jones
- Cayden Jones
- Kadin Jones
- Sedrick Jordan Jr.
- Jackson Grey Joseph
- Baby Girl K
- Baby Boy Kealy
- Baby Keehner
- Sophia Kersh
- Julianna Key
- Lia Khalil
- Bryson King
- Phoebe Kleensang
- Live Agusta Kleivstul
- Carson Klink
- Kaleigh Knight
- Jake Knoll
- Parker Knoll
- Emil Knudsen
- Baby Girl Knudson
- Arabella Kogut
- Nikhil Kohar
- Ben Kolb
- Micaela KostmayerCarly Kufs
- Kyle Joseph Kurras
- Caden Kurz
- Jack L
- Jordan Lafond
- Mila Fate Laganis
- Allyson Lamb
- Killian Lambert
- Ericka Landers
- Nora Grace Lange
- Bryce Laplante
- Sandi Larocque
- Nadia Marilyn Larson
- Birger David Lawall
- Bentley Alexander Lawry
- Allyssa Lawson
- Kalleigh Lay
- Angel Lee
- Flynn Leigh-Baker
- Bradley Leuchte
- Walter Levin
- Baby Lewis
- Devon Linden
- Levi Lingenfelter
- Baby Lloyd
- Pere Loaiza
- Parker Locklear
- Jenna Lopez
- William Lord-Gillihan
- Sophia Leigh Lovett
- Jack Joseph Lowe
- Simon Lowe
- Arianna Lugo
- Rylee Luther
- Jackson Luxem
- Deacon Lynch
- Zoe Lythgoe
- Jesse M
- Lynneah M
- Tristan Macdonald
- Jodie Mack
- Sierra Madsen
- Motheo Camila Mafike
- Maximus Maltby
- Kennedy Mann
- Austin Maple
- Makaila Marohn
- Natasha Marrison
- Lucas Marro
- Daniel Marshall
- Joe Martino
- Ryan Mason
- Hunter Wilson Matteson
- Katelyn Mayes
- Joseph McAfee
- Emma McClary
- Ethan McClelland
- Emmalyn Dawcyn McCoy
- Tucker McCoy
- Liam McCue
- Christy McDaniel Dews
- Cadenne McDaris
- Hunter McDonald
- Jacquael McHerron
- Isaiiah McIntosh
- Jessica McIntyre
- Samantha McKennon
- Baby Girl McKittrick
- Conner McLaughlin
- Baby McMahan
- Beren McMahan
- Brandon McMahan
- Matthew McOwen
- Baby Meadows
- Ava Marie Medina
- Baby Boy Meher
- Baby Boy Mejia
- Karen Mendez
- Katherine Nina Menes
- Gavin MeyerLuca Michleb
- Wyatt Mighton
- Anthony Miller
- Brandon Dwayne Miller
- Hunter Miller
- Alphonso Mims
- Abigail Minczer
- Julissa Miramontes
- Tripp Mitchell
- Erinou Momo
- Jasmyne Montez
- Mason Moon
- Jayson Mooney
- Molly Moore
- Maquinzy Moore Atwell
- Liam Morales
- Baby Boy Morgan
- Cecilia Mottin Molinari
- Michael Mueller
- Kenadi Muffler
- Abbey Murphy
- Colin Myer
- Jake Myers
- Baby Girl Nawarski
- Krosby Nay

- Timothy James Nelson
- Andrew Neptune
- Elliott Nicholls
- Carson Niles
- Daniel Nordman
- Live Nordstrøm
- Baby Girl B Norman
- Mya Norman
- Shelby Marie Nunes
- Jaiden Nunez-Glasgow
- John Angelo O'Donnell, V
- Damion Edward O'Guin
- Lincoln Daniel Olds
- Lillian Olsen
- Grace Opie
- Brayden Osborne
- Kayden Ostrousky
- Alexis Ostrum
- Eleanor P
- Pierce Paitsell
- Eden Palm
- Nicole Palmisciano
- Harmony Park
- Andy Matthew Parker
- Jackson Parker
- Leo Partsafas
- Tineal Pasese
- Muaaz Patel
- Sarah Paul
- Zoey Pavilanis
- Dakota James 'DJ' Payne
- Harper Peck
- Jaime Manuel Pedroza
- Katarah Peick
- Olivia Pelham
- April Perez
- Ricky Leonardo Perez
- Dylan Perkins
- Olcigi Perkins
- Oakley Petcher
- Josiah Peterman
- Elle Phillips
- Claire Phinney
- Avacyn Pichay
- Elizabeth Lynda-Anne Plakholm
- Faith Platt
- Lilliana Polk
- Baby Boy Poon
- Taylor Poquette
- Alex Porricelli
- Waylon Porteous
- Grayson Price
- James Christopher Price
- Kaylleb Pritchard
- William Prudhomme
- Mavrik Austin Pruitt
- Mavrik Pruitt
- Eileen Purves
- Jackson Purvis
- Everett Pyland
- Annalia Quijada
- Baby Qur
- Jacqsuen R
- Nathan Ragland
- Ashu Rai
- Damian Ramin
- Alan Ramón
- Gavin Wilson Ream
- Braxton Rebando
- Jessica Reck/Thomas
- Abigail Redding
- Mason Vincent Redman
- Bethney Reed
- Kassidy Jahzara Reed-Pratt
- Sunni Reeves
- Caitlin Regit-Enyingi
- Leah Reid
- Lily Reid
- Samuel Reis
- Stella Kairos Resurreccion
- Lylah Reynolds
- Bianca Reynoso
- Baby Boy Rhoda
- Tabatha Rice
- Olivia Faith Richardson
- Sara Rick
- Baby Boy Riddle
- Bentlee Rider
- Chelsea Noel Riegel
- Christopher Riker
- Kinley Riley
- Alexander Scott Rinehart
- Patrick Charles Roark
- Patrick Roark
- Skiyla Robbins- Shilling
- Andrew Roberson
- Ava Roberts
- Braden Roberts
- Sherrie Roberts Talley
- Louise Rodden
- Dante Samuel Rodriguez
- Elijah Rodriguez
- Ellieanna Grace Rodriguez
- Junior Rodriguez
- Kane Rogers
- Baby Boy Rogowski
- Kaitlyn Romano
- Stepan Romanov
- Xyana Romero
- Luka Rommeck-Kornbluth
- Baby Boy Rooyakkers
- Baby Roper
- Berkley Lynn Roper
- Levi Rosbury
- Declan Roskey
- Kian Roux
- Jacob Rowan
- Luke Roy
- Brody Asher Rubenstein
- Mason Rudder
- Vivienne S
- Logan Saienni
- Emilia "Mia" Salamanca
- Adam Salas
- Jagger Cayden Ray Salazar
- Rylan Salazar
- Baby Girl Sanchez
- Rebecca Rae Sanders
- Paola Santillana
- Mikey Sapio
- Nathan Scelfo
- Jacob Anthony Schaal
- Waylon Dean Schaefer
- Amy Schlueter
- Aiden Schmitt
- Noah Schneider
- Renee Schoonmaker
- Matthew Schroeder
- Faith Schultz
- Avery Schulz
- Lainey Seelbaugh
- Hlolo Sehlapelo
- Kyson Seidel
- Einya Elizabeth Sengsourya
- Oscar Senior
- Baby Girl Shea
- Natasha Shellans
- Skylar Sherman
- Liam Duncan Shields
- Anna Shuman
- Mohammed Yaqeen Siers
- Jacob Scott Silbernagel
- David Keith Siler
- Scotlynn Silfies
- Caleb Sims
- Jeremy Sims
- Taylor Sindoni
- Kai Sisay
- Marionna Slaney
- Bas Sleeuwenhoek
- Baby Boy Slivnik
- Colin Small
- Baby Boy Smallman
- Baby Boy Smith
- Hudson Smith
- Lakyn Smith
- Sarah Smith
- Jadon Snider
- Carson Somerset
- Radhika Soni
- Carter Sorensen
- Sydney Ophelia Sorrells
- Daniel Sousa
- Pedro Souto
- Hayden Spangler
- Jacob Spelman
- Baby Boy Stambaugh
- George Rafael Stamos
- Harper Stanfield
- Charley Stanfield Maher
- Pheonix Stanley
- Tristan Stell
- Ava Madison Sternfield
- Luke Stevens
- Sara Louise Stevens
- Brody Stolz
- Cooper Strevel
- Alden Gregory Strozzyk
- Eeva Sujith
- Rhys Swanson
- Lucas Sweet
- Ayaan Tak
- Aron Tamm
- Liam Miguel Tapia
- Bradley Tarr
- Parker Taylor
- Truman Taylor
- Heather Terpening
- David Michael Tewsbury Jr.
- Ada Thakkar
- Baby Girl Theodore
- Anthony Thomas
- Atticus Thomas
- Ziyah Thomas
- Ayden Thompson
- Baby Girl Thompson
- Levi Thorson
- Shiloh Tiedt
- Caroline Faye Tillery
- Fiona Timoney
- Ryan Tindall
- Patrick Tinker
- Stephanie Tolley
- Jessica Tophen
- Aliyah Jenee Torres
- Daniel Torres
- Samuel Tortorelli
- Emilie Toth
- Carmello Towns
- Benjamin Townsend
- Jeremy Tribble
- Baby Boy Trojand
- Madeline Truscott
- Malani Turner
- Brooke Allyson Tyler
- Barrett Uncapher
- Madison V
- Dennis Van Der Mark
- Lizay Van Zyl
- Dave Vander Woude
- Oscar Venn
- Baby Girl Verage
- Hope-Eliza Villarreal
- Abbey Von Gohren
- J.R. Vranes
- Deb W
- Sarah W
- Charlie Waayers
- River Waddell
- Michael Thomas Waldron
- Baby Boy Walker
- Damon Alexander Walker
- Joshua Wall
- Evelyn Wallis
- Victoria Ware
- Fenyx Warren
- Bailey Grace Watson-Smith
- Baby Boy Webb
- Baby Girl Webb
- Liam Weeks

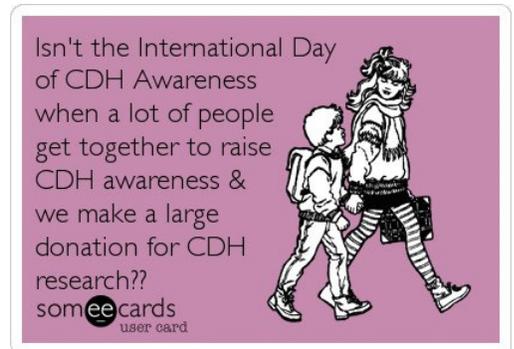
- Logan Wehmeyer
- Baby Boy Weick
- Eva Weigand
- Landon Wescoe
- Oliver Wesson
- Vivian Westenhofer
- Arik Wetzel
- Lexi Wheatley
- Owen Wheelan
- Ellie White
- Joslyn White

- Micaiah White
- Andrew Whitten
- Alaina Grace Wieringa
- Adrian Wikstrom
- Baby Girl Wiles
- Ava Faith Wilkerson
- Alis Williams
- Brittany Williams Williams
- Bryson Williams
- Delaney Ann Williams
- Henry Davis Williams

- Imogen Williams
- Lorenz Williams
- Ja'kayla Willis
- Baby Wilson
- Bradley Wilson
- Baby Boy Winders
- Jaxson Winders
- Zevin Winegar
- Baby Girl Winthers
- Blaire Alexandria Wise
- Jade Aurora Wogsland

- Baby Boy Wolf
- CJ Wood
- Bryson William Woodruff
- London Elizabeth Woodward
- Riley Kimball Worthen
- TJ Wright
- Evelyn Elizabeth Yardley
- Savannah Yelton
- Anderson Young
- Tamara Young
- Wyatt Young

- Angela Faith Zdravec
- Legacy Zanders-Jones
- Baby Zdeb
- Andy Zhang
- Dominic Zimmerman
- Johnathan Zuniga
- Chaya Zyskind



Every December our web site homepage goes black and virtual candles are lit for every child in our membership lost to CDH for National Children's Memorial Day. In 2013, in mid-December snowflakes were also added in honor of CDH



Meet our new mascot, Hope! Hope's name was chosen by CDH families through a vote on Facebook. She will participate in events, parades and conferences to help us raise CDH awareness.



CHERUBS AT MEDICAL CONFERENCES

CHERUBS has had the distinct honor of being able to participate, and even speak at several medical conferences:

- CDH Workshop in Rotterdam, Netherlands
- “Dialogues in Neonatal-Perinatal Medicine” at Duke University
- “Meet our CHOP Fetal Medicine Experts” at the Children’s Hospital of Philadelphia
- 2012 American Pediatric Surgical Association meeting in San Antonio, Texas
- 2013 American Pediatric Surgical Association meeting in San Marco, Florida
- CHERUBS CDH Medical Conference in Boston



CHERUBS team Felecia Woodruff, Dana McCue, Matt Small and Dawn Williamson tour the operating room at the Children’s Hospital of Philadelphia



CHERUBS President, Dawn Williamson, and Onno Zwart, President of Stichting Hernia Diafragmatic in the Netherlands.



CHERUBS is a CFC Charity and eligible for donations through payroll deductions by government employees.

CFC #31232



“Strange as it may seem, I still hope for the best, even though the best, like an interesting piece of mail, so rarely arrives, and even when it does it can be lost so easily.” - Lemony Snicket

How You Can Help Babies Affected By CDH



CDH Research

- ◆ Write your Congressmen and ask for their support of the CDH Research Bill
- ◆ Donate to the CDH Research Fund
- ◆ Volunteer to be on our Research Committee
- ◆ Submit links to our CDH Research Library
- ◆ Post only accurate CDH data on your site or blog
- ◆ Help raise CDH Awareness
- ◆ Make sure your CHERUBS membership form / profile is accurate and up-to-date
- ◆ Join the following research studies:

Identifying Genes Which Cause CDH

Massachusetts General Hospital Contact: Meaghan Russell, Clinical Coordinator, at (617) 726-0828 mrussell@partners.org

Identifying Genes Which Cause CDH

Baylor College of Medicine Daryl Scott, M.D., Ph.D. Phone: 713-203-7242 E-mail: dscott@bcm.edu

Genetic Molecular Basis of CDH

DHREAMS Study Columbia University Medical Center ph: (212) 305-6987 info@cdhgenetics.com

Fryn's Syndrome

University of California San Francisco, California Anne Slavotinek, (415) 514-1783

Identifying Genes Which Cause CDH Emergen Labs, Salt Lake City, Utah Contact: Mary Meade, MMeade@emergen.com

Early childhood follow-up of congenital diaphragmatic hernia survivors.

Duke Children's Hospital
Jennifer Benjamin, MD, 919-668-4000

Identifying Causes and Long-Term Survivors of CDH

CHERUBS
Wake Forest, North Carolina

CDH Support

- ◆ Join the CDH Angel Club
- ◆ Participate in the CDH forums and support other families also dealing with CDH
- ◆ Adopt a Hospital and supply CDH info to newly diagnosed families
- ◆ Never give medical advice to other CDH families
- ◆ Donate to the CDH HOPE Totebag Project
- ◆ Hold a Baby Cherubs Shower and gather tote-bag donations
- ◆ Donate to the CDH Family Support Fund and help fund our services
- ◆ Donate to the CDH Family Assistance Fund and help families with expenses
- ◆ Donate to the CDH Scholarship Fund
- ◆ Hold a fundraiser
- ◆ Visit member blogs on our site and give encouragement and support
- ◆ Share your cherub's story to inspire others
- ◆ Share your cherub's photo to inspire others
- ◆ Submit your story to our newsletter and books
- ◆ Volunteer to be a State or International Representative
- ◆ Volunteer to be an On-Call parent
- ◆ Volunteer to be a Hospital Angel
- ◆ Help put together items for the CDH HOPE tote-bag project such as handprint and footprint kits
- ◆ Attend conferences and meet other families
- ◆ Attend local get-togethers meet other families
- ◆ Pray for cherubs and their families
- ◆ Offer condolences to the families of those cherubs lost
- ◆ Lend a shoulder or an ear to other CDH parents



CDH Awareness

- ◆ Participate in a Parade of Cherubs, April 19th events for the International Day of CDH Awareness
- ◆ Wear a CDH Awareness Ribbon, Bracelet or clothing
- ◆ Participate in the Save the Cherubs campaign
- ◆ Write your Governor and Mayor to Proclaim April 19th the International Day of CDH Awareness
- ◆ Put a CDH Awareness magnet or bumper sticker on your vehicle
- ◆ Post information about CDH on the internet
- ◆ Tell people about CDH
- ◆ Include information about CDH in your church bulleting, club newsletter or other materials
- ◆ Give a presentation about CDH at your local school, club or church
- ◆ Contact your local media about your story
- ◆ Have a blood drive and give out information about CDH
- ◆ Hold a fundraiser and give out info about CDH
- ◆ Hold a balloon release and give out info on CDH
- ◆ Have a birthday or memorial party and give out information about CDH
- ◆ Post flyers or posters about CDH
- ◆ Participate in CHERUBS events and fundraisers
- ◆ Give CDH Awareness items as gifts for birthdays and holidays
- ◆ Order CDH Awareness Kits for family and friends
- ◆ Participate in virtual events
- ◆ Donate to the CDH Awareness Fund
- ◆ Participate in a local Christmas parade dressed as cherubs and handing out CDH info
- ◆ Participate in our Trick-or-Treat -Change for Cherubs! campaign

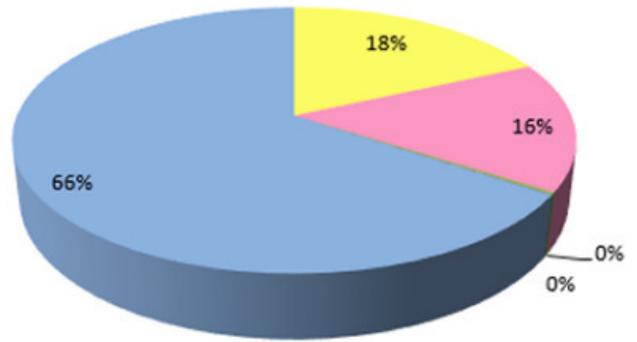


Your Donation Dollar

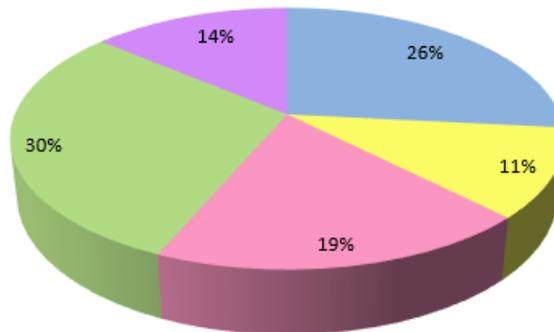
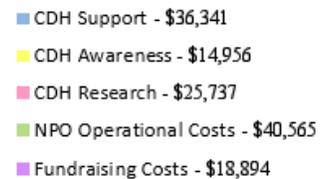
- \$1 will cover 1 copy of our Parent Reference Guide
- \$2 will cover 1 2-pocket folder
- \$7 will cover 1 newsletter printing and US postage
- \$10 will cover 1 New Member Packet
- \$15 will cover 1 CDH Baby Book for a new or expectant family
- \$20 will cover shipping of 1 CDH HOPE Totebag
- \$50 will cover our annual non-profit state registration fee
- \$50 will cover our volunteer software subscription for 1 month
- \$100 will cover staples, paper clips and glue for 1 year
- \$125 will cover web site hosting fees for 1 month
- \$150 will sponsor 1 hospital with CDH info for 1 year
- \$150 will cover 1 local get-together
- \$200 will help cover parking fees or food for 1 CDH family in the hospital
- \$350 will cover envelope costs for 1 year
- \$400 will cover printing 5000 brochures
- \$500 will cover outside programming fees
- \$1000 will cover office assistance for 2 months
- \$1000 will create a college scholarship for 1 CDH survivor or sibling
- \$1200 will cover non-newsletter postage fees for 1 month \$5000 will cover 1 international member conference
- \$8000 will cover 1 newsletter printing and mailing

CHERUBS 2012 Financial Statement

CHERUBS 2012 Income



CHERUBS 2012 Expenses



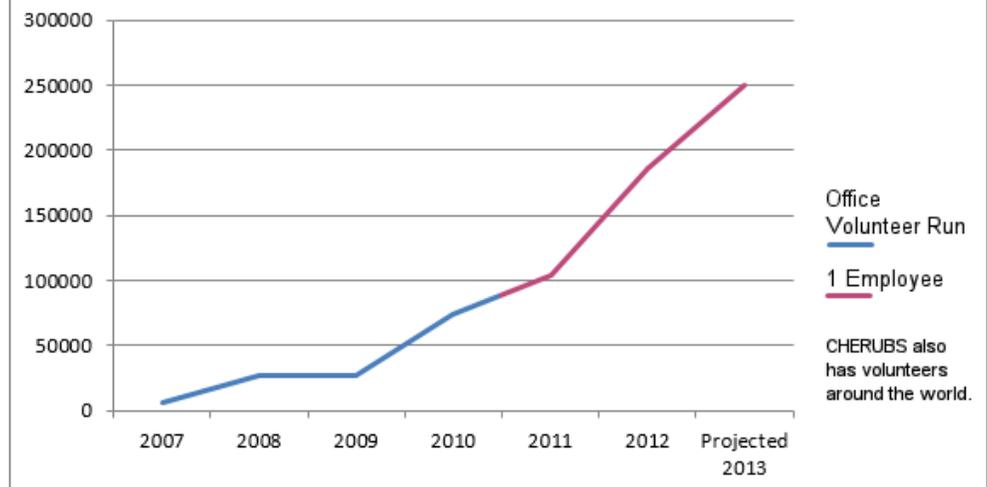
Thanks to the hard work of our fundraisers, the generous support of our donors and the installment of our first full-time employee and office, CHERUBS has increased our income dramatically in the last 5 years.

As funds have increased, so have our services. We now are able to offer CDH Hope Totebags, Financial Assistance, Scholarships, CDH Awareness Parades, Conferences and more. In 2013 alone, we have been able to grant over \$50,000 for Congenital Diaphragmatic Hernia Research.

Our goal for the near future is to hire an office assistant to help with the overload of work now that we now have serving over 4700 families, to fund much more CDH research, to provide Funeral Assistance to those in need, fund more local events for families, conference scholarships to attendees and to once again print and mail out newsletters

It is our hope that with your continued support, we will be able to offer more services, fund more research and raise more CDH awareness than ever before in the next few years.

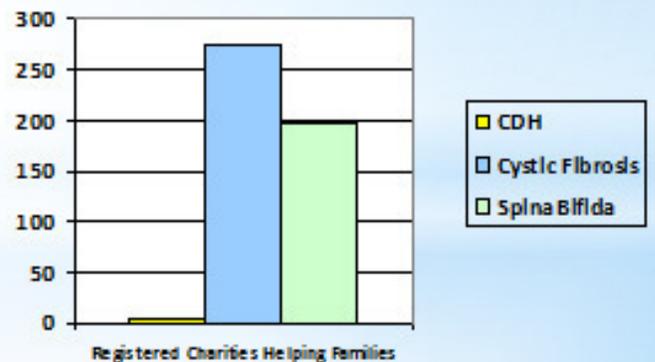
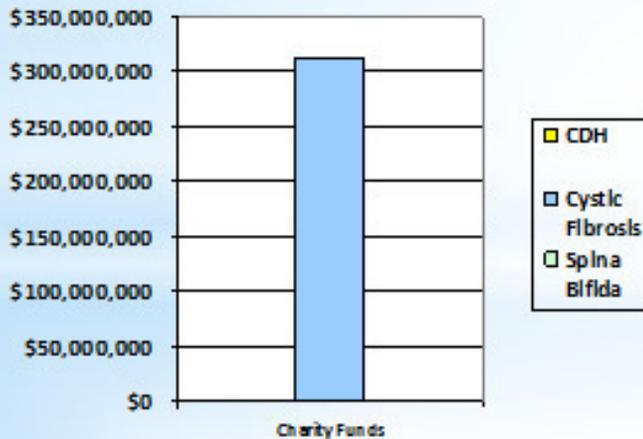
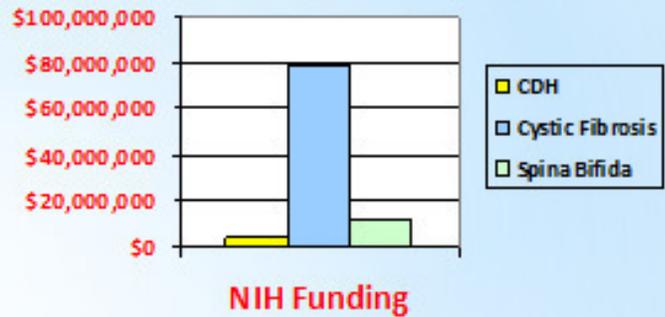
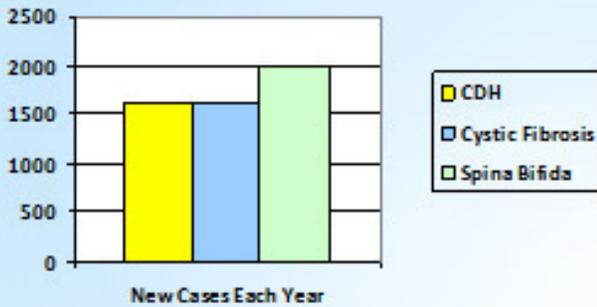
CHERUBS Growth Chart



Funding Statistics on 3 Similar Birth Defects

	Congenital Diaphragmatic Hernia	Cystic Fibrosis	Spina Bifida
Occurrence Rate	1 in 2500	1 in 2500	1 in 2000
Approximate number of new cases in the U.S. annually	1600	1600	2000
Survival Rate	50%	Average life span 30 yrs	75%
Cause	Unknown	Genetic	Unknown, Probable Folic Acid Deficiency
NIH Funding	\$4 Million	\$79 Million	\$11 Million
2010 Charity Revenue (from largest charity for this cause)	\$59,280 CHERUBS	\$313,308,873 Cystic Fibrosis Foundation	\$517,001 1 chapter of the Spina Bifida Association
Number of Guidestar Registered charities for each cause	4	275	197

- <http://cherubs.org> -The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support
- <http://www.cfdp.org>
- <http://www.spina-bifida.org>
- <http://www.cysticfibrosis.org>
- <http://www.nih.gov>
- <http://www.guidestar.org>



2013 Charity Milestones

- New Logo
- New Parent Advisory Board
- New Medical Advisory Board Members
- Worked with other CDH organizations and research groups to re-establish the Alliance of Congenital Diaphragmatic Hernia Organizations
- Senate Resolution S. Res. 85 Introduced and passed unanimously to make April Congenital Diaphragmatic Hernia Awareness month
- House Resolution H. Res. 133 introduced
- Our meetings with many Senators and Representatives instigated a Congressional Inquiry into NIH funding of CDH thanks to the support and dedication of Sen. Jeff Sessions
- Joined the Combined Federal Campaign
- Parade of Cherubs on April 19th in Washington DC to Capitol Hill
- Members met with the offices of over 25 Senators
- April 19th CDH Parades of Cherubs in New York City, Dallas, Chicago, Philadelphia, Phoenix, Seattle, Portland, Denver, St. Louis, Peoria, Salt Lake City
- UK Plane Jump Fundraiser
- CDH Baseball Night at the Las Vegas 51's
- Virtual CDH Awareness Parade on April 19th
- 31 Governors proclaimed April 19th a Day of CDH Awareness
- 12 Mayors proclaimed April 19th a Day of CDH Awareness
- CN Tower in Toronto lit for April 19th
- Miami Tower lit for April 19th (thanks to the Olivia Faith Foundation)
- Dublin City Hall lit for April 19th
- New CDH Mascot "Hope"
- 2013 CDH Conference in Boston
- Mass General CDH Genetic Lab Tour
- New CHERUBS Web Site
- \$10,000 CDH Research Grant contest held in December
- \$10,000 CDH Research Grant awarded to Shands for Kids
- \$10,000 CDH Research Grant awarded to Texas Children's Hospital Fetal Research Center
- \$5000 CDH Research Grant awarded to Mass General CDH Genetic Research Center
- Additional CDH Research Grants awarded to DHREAMS, Shands, Legacy Emanuel, Lurie Children's and Seattle Children's Hospitals
- A total of over \$50,000 in grants from Congenital Diaphragmatic Hernia Research granted by CHERUBS in 2013
- Over 250 care packages sent to families through our CDH HOPE Totebag project
- 2013 CDH Magazine
- 10 new videos made
- 2 College Scholarships awarded at \$1000 each
- Financial Assistance to a dozen families
- CDH families represented at the American Pediatric Surgical Association conference in San Marco, Florida
- Participated in a meeting of DHREAMS participating research centers
- Participated in Meet the Experts at the Fetal Research Center at CHOP
- CDH families represented and speech given at Euro CDH Conference in Holland
- Our 2012 National Children's Memorial Day tribute honored over 1000 cherubs
- Texas Get-Together
- California Get-Together
- Ohio Picnic
- UK Get-Together
- Pennsylvania / NJ / Delaware Picnic
- Denver Picnic
- Indiana Get-Together
- Utah Get-Together
- Nevada Get-Together
- Over 600 raffle tickets sold for the 50/50 CDH Research Raffle
- Over 25,000 Facebook Fans reached
- Average social media reach of 100,000 people weekly
- Participated in televised Raleigh Christmas Parade
- 5th Masquerading Angels Ball
- UK Formal Charley's Masquerade Ball
- CDH Awareness Calendar featuring over 1600 CDH patients
- Save the Cherubs CDH Awareness Calendar
- Won the Emericon contest on Facebook
- Groupon Totebag Fundraiser
- One a WEGO Health Award
- Participated in marathons in NYC, Baltimore, Blue Ridge of Virginia, Atlantic City, Pittsburg
- Runs held in Canada, Ohio and North Carolina
- Participated in a Color Me Rad Run
- New Holiday Facebook Covers project started
- Dozens of free CDH Awareness graphics made
- Over 100 new Save the Cherubs posters created
- Membership reaches over 4700 families in 60 countries
- National Children's Memorial Day memorial to over 1200 lost cherubs
- Monthly medical expert speakers on the forums
- Became an official #GivingTuesday charity
- Given a Gold Seal by guidestar.com
- Given a 5-star rating on greatnonprofits.com
- Participated in Courture for a Cause fashion show
- 4 television interviews
- 1 short film
- Over 2 dozen newspaper articles
- 100's of newspaper reprints of our press releases
- Justcoz.org reach of over 50,000
- Created first CDH Trolley Tokens
- First charity to plan a Euro CDH Conference
- First CDH Window display
- T-fund T-shirt fundraiser
- "A Fighter's Lullaby" song fundraiser
- CDH Jewelry Fundraiser
- Indiana Car Show
- Wine and Design Fundraiser
- Members hold dozens of fundraisers in honor and in memory of cherubs

CHERUBS Boards of Directors

2012 - 2013 Executive Board of Directors

* currently serving

- Dawn M. Williamson - President & Founder, CDH Mom *
- Ashley Barry - Vice-President, CDH Mom *
- Lauren Campbell – Secretary *
- Kelly Green-Krist, CPA – Treasurer *
- David Baldwin
- Greg Havenstein
- Kenneth Cain
- Darlene Silverman

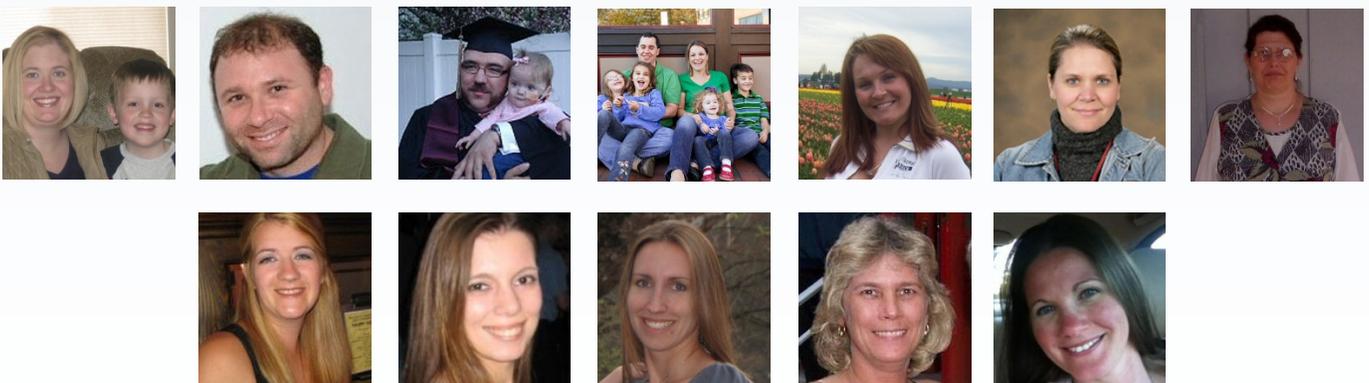


CHERUBS Parent Advisory Board

2012 - 2013 CPAB Members

* currently serving

- | | | |
|------------------------------|--------------------|--------------------|
| • Tracy Meats, Co-Chair* | • Shelly Moore* | • Christine Weaver |
| • Neil Rubenstein, Co-Chair* | • John Hensley* | • Nicolle Colvin |
| • Christina Stembler* | • Karla Holt* | • Karen Myers |
| • Freedom Green* | • Melissa Larrison | • Noel Williams |



Our Amazing Volunteers

2012 Volunteers of the Year



Ashley Barry



Neil Rubenstein



Melissa Larrison

2013 Volunteers of the Year



Christina Stembler



Freedom Green



Clair Maher

We also have some amazing office volunteers that pop in from time to time to help



Medical Advisory Board

The following medical professionals assist our charity by reviewing publications, speaking at events and supporting our awareness efforts:

- ◇ David Kays, MD – University of Florida at Gainesville
- ◇ Henry Rice, MD – Duke University Medical Center
- ◇ Patricia Donahue, MD – Massachusetts General Hospital
- ◇ Edmund Yang, MD – Fetal Treatment Center of St. Louis
- ◇ N. Scott Adzick, MD – Children’s Hospital of Philadelphia
- ◇ Kevin Lally, MD, MS - University of Texas Medical School at Houston
- ◇ Doug Miniati, MD – University of California, San Francisco
- ◇ Jan Deprest, MD, PhD - University Hospital Gasthuisberg, Leuven, Belgium
- ◇ Paul Losty, MD FRCSI FRCS(Eng) FRCS(Ed) FRCS(Paed) – Liverpool University, UK
- ◇ Steadman McPeters, RN – Huntsville Alabama, Pediatric Surgery Nurse Clinician, CDH



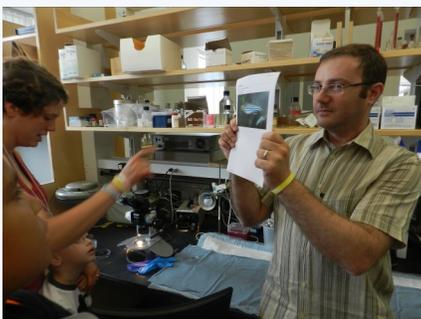
2013 Congenital Diaphragmatic Hernia Conference



The first joint CDH Family & Medical Conference took place in Boston on July 10 - 14, 2013. With over 100 attendees representing 5 countries, it was the largest CDH Conference ever held.

During the first day, round table discussions were held for medical professionals and then families arrived for the Family CDH Conference for the remaining days with a Parade of Cherubs in Boston, more round tables, guest speakers and more.

Special thanks to guest speakers: Dr. David Kays & Joy Perkins from Shands, Dr. Jay Wilson from Boston Children's, Julia Wynn from DHREAMS / Columbia Presbyterian, Meaghan Russell, Dr. Mauro Longani and team from the Mass General CDH Study Clinic (who also gave our families a tour of the lab), Prof. Wakhlu Ashish from India, Ashley Barry, Josh Hensley, Clair Maher and Karen Myers from CHERUBS. And thanks also to the kid's room team; Dakota Jones, Ciarra Joyner, Nikki Jones and Jaden Jones as well as our Massachusetts State Representatives Tracy Landers and Marie Marchesseault



Stories of Cherubs

(unedited)

Charley Stanfield-Maher

It had been a struggle for years but with the help of fertility drugs we had 2 sons Niall & Joshua. Samuel, Joshua's twin had passed away at 20 weeks gestation and years later we had an early miscarriage, so we had decided enough was enough and given up on any more children. I had seen a clairvoyant who had told me she saw no more babies for us and that she saw 2 x2 in our children? She told me she saw 2 here on earth and 2 in heaven but that 1 in heaven had a strong bond with one on earth, had I lost a twin? It was strange listening to this but nice to know. So no more babies for us.

So we started saving to take a holiday. After dieting for a couple of months we left for my dad's apartment in Spain for 2 weeks relaxation. It was July 2009. On the second day there I was ill. So I'll I couldn't keep water down and didn't have any energy to get out of bed, or when they did get me out of the apartment I lay on the sun lounger weak. Locals told Rodney my husband to take me to the medical centre maybe I had Spanish Belly. So off we went. At the medical centre I was seen by a Dr and asked to do a water sample, I was severely dehydrated I spent ages trying. Back in the Drs room I heard them words "congratulations you are pregnant" ! I was shocked How ? For years we had struggled and needed help yet now with no planning or I shamelessly say " wanting" I was pregnant. At 36 I considered myself too old to be having another child.

Rodney and the boys were over the moon, and when we arrived home so was family. Because of previous pregnancy problems I had scans at 8 & 12 weeks and we talked about finding out the sex of our baby.

Our 20 weeks scan was here. We dreaded it because this was the scan that we found out Samuel had passed away, but we pulled through excited to know our babies sex.

In the scan room, scan started I immediately scan the image for a heart beat. Phew there it is! "Can you tell the sex " we ask. I'm as sure as I can be your expecting a little girl. Tears roll down my cheeks as they are now writing this. Rodney squeezes my hand x Our little girl how exciting.

It was then onto checks. I don't know how, but you just know when something is not right. We were asked to take a walk and drink some more water and come back. Once back in the room the lady had been joined by another lady. They wanted to check something with the scan. I can't remember now what the exact word were but " not right " and can we take a seat in a room where a Dr will come and explain. In this bare unwelcoming room a box of tissues sat on the table & we were offered a cup of tea! I thought it must be bad. I cried, Rodney tried to console me and a lady in with us tried her best to calm me as I didn't know what was wrong yet.

That day our CDH journey began.

The Dr explained (not very well) that our baby had CDH and that she would have a 13% chance of survival. They wanted to do an amino as it was linked to lots of syndromes some of which would mean no hope at all. We didn't want too but agreed to the amino, looking back now we were upset and confused. We didn't understand. 13% Our baby girl was going to die. That's all I could think of. Another Dr tried to do the amino but she was moving around so much they couldn't do it. We were advised that termination would be best ! To this day I hate the Dr who told us that! Baby wouldn't keep still so we were told to go back the next morning and have the night to think about it. Once home I hit the Internet. Google CDH. I found a mum on Net mums who is still a good friend to this day x thanks Kelly x She pointed me in the direction of Cherubs & told me about her son who was 6 now. I read stories of CDH survivors and non survivors well into the early hours & my fight kicked in!

The next day at the hospital she still wouldn't keep still for the amino so I asked for them to stop trying. I felt it was a sign, she was telling us she didn't need it ! Into another room the Dr explained our options again. Now anyone who knows me knows I am a little bit stubborn. I wasn't feeling that they totally knew what they were talking about and the Dr said if we continued with the pregnancy the likelihood was our baby would die and we would have to transfer to a Specialist hospital to continue care through the pregnancy if we decided to proceed. To be honest we had already decided 13% !!! This was our baby girl & someone had to be in the 13% so off to Manchester we went.

We attended the fetal medical unit and was under the same Dr who delivered the twins. At 1st I was relieved but to be honest no one ever told us anything. No lung to heart ratio nothing. Yes we had a few extra scans but I was learning so much from Cherubs and the other CDH parents that I was frustrated with our care. We had to ask could we meet the surgeon or visit NICU and too be honest back then I felt like they gave her no hope at all. I know now that they probably did me a favour by telling us nothing. The truth is no one knows just how a baby will do once they are born.

I said I wanted to have a c section. The consultant told me if I was determined to have a c section then I should prepare myself that my baby could die before I ever got to see her! I said Thank you for your honesty ! Now my reason for wanting a section was that I just couldn't comprehend that a natural birth could be good for a baby with lung problems ? All that stress. I wanted her out and helped as soon as possible and I had delivered the twins by section and felt I recovered quicker. She was gonna need her mummy. So c section booked .

March 4th 2010 Charley Brooke Zoya Mae entered the world. A little cry and a peep over my shield I saw our baby girl before she was whisked away. Once incubated Daddy went for a quick peek and took her picture. My dad was pacing back in my room and I was very sick so spent hours in recovery before being transferred back to my room. Dad & Rodney went to visit Charley, she was table but of course only time would tell.

The 1 st time I saw Charley I remember thinking how fat she was. She wasn't it was the meds and vent .

Charley did well and we had no major hiccups on day 4 a surgeon came to speak to us to say they were hoping to do her CDH repair the next day. She was on prostin as her aorta was having a little trouble but they hoped this was because of the congestion in her chest and should settle after her repair. Day 5 and 5 hours in surgery. Her stomach, bowels, spleen, intestines and tip of liver all up. Large gortex patch inserted, but all had gone back well and she was settled and stable back in NICU.

Charley was transferred to Alder Hey for open heart surgery to correct a coarctation of her aorta. On day 15 this was repaired and a band placed on her pulmonary artery. It was hard as she fought pressure on her lungs, her heart and the gap where her little left lung sat kept filling with fluid, but she did really well and was eventually transferred back to Manchester 3 weeks later .

Charley was home a week later feeding bottle and ng as she tired easily but 2 weeks later we were onto bottle only and the ng tube was out..

Life was wonderful & never had we allowed ourselves to imagine this day would come. We had bought her nothing. When we heard she was coming home family & friends rushed around to buy cot, pram, clothes.

It was a difficult 1st year as Charley got chest infection after chest infection and was in and out of hospital. She didn't gain weight and suffered badly with reflux, but she threw up like a professional and it never bothered her. She went to nursery and was very sociable. We held our 1st Charity Ball to give back something to those who had supported Charley and us all.

We had noticed Charley has a curve to her spine for months now and she didn't appear to have the strength of other toddlers. I knew scoliosis was something that is associated to CDH so we asked the Dr at her next appointment. Sure enough it was confirmed and a body cast made for Charley to wear to help straighten



her spine. Normally a plaster jacket would be fitted but due to her heart condition it was a no go.

Reoccurring chest infections, reflux, little weight gain, asthma & scoliosis. Daily meds and a body cast, but we were so blessed with our beautiful little girl. She lit up the room .

Almost 2, her favourite song was Bruno Mars Marry You. She would sing it constantly sitting in her pink bucket & point to you " marry you" .

The band placed on Charleys pulmonary artery at 15 days was now tight so 2 weeks after her 2nd birthday we travelled to Alder Hey to have it removed. Surgery should of been on the Tue but we received a cancellation so It was brought forward ,to the Friday 16th March. As Rodney booked us into RMDH the staff member commented that we were almost to the minute checking in as we had done 2 years earlier.

Charley was in theatre for 8 hours. The longest 8 hours of my life. Dad had come over and our friend Elaine. We sat in RMDH awaiting news. Now as strange as this may sound after 5 hours in theatre I had a terrible sinking feeling. I'm not saying I thought something terrible had happened but I got the feeling that I wasn't going to get the same little girl out that went in. I know that must sound strange and I can't explain it any better. I was anxious but that turned to relief when we got the call she was back in ICU and we could go over to see her. Sedated and still our baby girl was back. They explained about when she started to come round and how she would be hungry etc etc. She was extubated a few hours later and her says we're good, but she wasn't really waking up. She said grandad when my dad kissed her but wasn't really with it. It can take some people 24 hours to come round they said so we were told to go to bed as we too needed sleep and they would call us if we were needed. We had only just got into bed when the phone in our room rang. Nothing to worry about said the lady, Charley has woken up and is a little unsettled we think she would benefit from mummy & daddy being here. We dressed and went over to ICU. What we saw when we got to Charley will stay with me for the rest of my life. Charley was bouncing off the bed. Every part of her shaking. " do you think she is in pain" the Dr asked us. Minutes later she settled from me stroking her head and then again followed by lots of dark bloody vomit. No one seemed as concerned as we were. An hour later she was settled again and we went back to bed reassured by Dr she was ok. We were back hours later worried we didn't want to be away from her. A nurse said they would probably keep her in ICU for another 24 hrs because of her " funny episode" but that afternoon she was transferred to the ward still not awake. When she did wake & I'm not talking like you and I are now she didn't move anything but her right arm which pointed at you as she made frustrated growling noises. I sand Bruno Mars trying to get her to respond to us. There was a time that she did and she drank from her bottle. Then she started shaking, later her head bobbed, her eyes fixed left, she tried to bite my finger and eventually couldn't drink from her bottle. She just bit down on the teat. We had shown the nurses and they asked us to log her movements. When the consultant came we explained to him about her movements and lack of waking, eyes fixed etc. he said he would try and get a ct scan organised.

The consultant who did her pre op was now on the ward and she was shocked to see us there. Charley hadn't been due surgery till Tuesday. She greeted me with a big smile and the what are you doing here. I burst into tears and pointed to Charley lying eyes fixed. She could tell immediately this wasn't the little girl who sang to her and typed a shopping list on her computer 2 days earlier.

Charley had a ct scan on the Sunday but nothing shown up. A nurse said to me that they thought Charley has had a stroke ! I was livid. No one had said anything of the sort to us but we knew something had happened. A neurologist visited Charley and an MRI scan was booked. For 2 days she was she wasn't having one. All because of metal clips. A lack of communication ! These clips were 2 years old not from her recent surgery so on the Tuesday she went for her MRI. Our worst fears were confirmed Charley had suffered global brain damage. " an acquired brain injury" what recovery she would make only time would tell ,no one had a crystal ball. Life can be very cruel sometimes, how could her journey take another twist.

Another 5 weeks in hospital and Charley came home

It's been 10 mths since her brain damage. They told us the 1st 6mths are crucial, what she gets back during this time will be the foundations for the next 2 years, then that's pretty much where you stand. She can no longer walk, sit on her own, stand, or use her left arm. She is back in nappies and is now fed via a g tube, but she is the strongest most remarkable young lady I have ever met. Beautiful, intelligent, funny. She continues to light up a room. Never say never. They say she will never walk again. Didn't they say she wouldn't survive at birth? What I do know is how different life would be if we didn't have the love an support of our CDH family.

I became a Volunteer Rep here in the UK for Cherubs in 2011. The support, information and dedication of Cherubs Volunteers and the friends we have from all over the world get us through each day. No 2 CDH journeys are the same. Awareness and Fundraising are part of our lives now.

It's for the babies we never give up Hope x

CDH is a cruel condition and so as all Cherubs do we must continue to fight .

Clair Maher, United Kingdom (2013)

Gerald Ross Vosburg

Gerald Ross Vosburg was born March 11,1988 in a small hospital in NC. He looked perfect and scored well at his first Apgar. But he was showing signs of distress before the second. The pediatrician let us hold him for just a minute then whisked him away. Shortly she brought in x-rays of his chest showing quite clearly the presence of misplaced abdominal organs. When we were allowed into the nursery to see him, he was being hand bagged by the respiratory therapist with tubes out of his navel, tubes pumping air out of his stomach and intestines and his little abdomen looked as if there was nothing in it. There was very little.

Our hospital had just approved and marked off the space for a helicopter pad. It was used that night with the help of the local fire department and their trucks provided the landing lights. Ross was airlifted to what is now called Brenner's Children's Hospital - Wake Forest Baptist Medical Center in Winston Salem, NC. We were told that he had a 20% chance of survival and a 5% chance of living a "normal" life. Miraculously he survived 2 major surgeries and was home with us with no special instructions 30 days later.

I often think that in our ignorance we didn't know enough of what we were facing to be terrified. Ross had just enough of a diaphragm that his surgeon was able to stretch it without using any type of patch. He did not have any other accompanying defects or issues but did require the second operation to re-manipulate his intestines. Several years later we realized he had issues when exposed to latex. He has acid re-flux and tends to have some nagging respiratory issues but other than those issues he has been normal as any child.

We are sending this and a donation to CHERUBS in honor of his 25th birthday. At 6'3" he is a strapping - good looking young man. He bears his scars with pride and has made up many great stories about them to tell his friends and the young campers when working the water front at a local BSA camp.

We know we have truly been blessed when compared to so many dealing with the impacts of a Congenital Diaphragmatic Hernia. Our hearts and prayers go out to all CHERUBS and their families.

Bob and Barbara Vosburg, Victor and Laura Vosburg, G. Ross Vosburg, North Carolina (2013)



Poppy Davis

When i eventually calmed down after hearing our diagnosis of CDH I started reading the stories on this site to give me hope (i think i read every story!). I said to myself that when we get through this i will be writing my own daughter's story to share with other people, so here it is.

I am so thankful to write that at nearly 4 months old my daughter Poppy is a beautiful and content baby on the 50th centile for weight and 91st for height. She is healthy, fully breastfed, and is hitting all her milestones.

I had a very easy pregnancy, physically anyway, I felt fantastic. Our 12 week scan was normal, our 20 week scan confirmed we were to have a girl! The sonographer also noted that she had a two vessel cord (a normal umbilical cord has two arteries and a vein; in our case there was one artery and one vein), but described this as a 'normal variant' and not to be concerned by this. Of course i googled this and found that this *could* be linked to poor growth later on in the pregnancy and so i called my midwife who arranged for us to have a growth scan at 32 weeks.

Thank goodness she did! We had the scan at a local hospital and the growth was normal. However they thought her stomach looked dilated and so referred us to a more specialised department later that week for a further scan. They agreed with the initial diagnosis and we were referred up to St Thomas hospital in London.

At 34 weeks we had our appointment at St Thomas - i will never forget this day. After an extensive scan the sonographer held my hand and drew us a picture of what she was seeing - suspected diaphragmatic hernia with our baby's heart pushed to the right, bowel tissue in the chest cavity and the abdominal organs displaced. She disagreed with the local hospital's diagnosis of stomach dilation and explained that with a diaphragmatic hernia it is very difficult to distinguish organs on ultrasound because nothing is in its usual place. They arranged a detailed heart scan for later on that day with the heart specialists. In the meantime we had blood tests and i took a course of steroids to help lung maturation in case we opted to have an amniocentesis (we later decided not to have this).

We had our first good news of the day with the heart scan, which confirmed that although pushed to the right, it was structurally normal. They agreed with the diagnosis of CDH and explained to us that the problem isn't so much the hernia itself, but that organs in the chest cavity can hinder the development of the lung tissue. Since baby doesn't have to breath until she is born we won't know until birth whether they are big enough to keep her alive.

This was such a lot to take in one day - although we had prepared ourselves for bad news it wasn't on this scale. I made it back to my family home (which is close to london) before i broke down in tears trying to explain what was wrong to them. Fortunately i had a very understanding boss who gave me the rest of the week off so i could stay with my family who fed me, kept me healthy and did their best to cheer me up. In that week i read a lot about CDH, although scary i thought it better to be prepared. It was the stories of the survivors on this site that really kept me going.

Two days later we had a further ultrasound, with a surgeon also present. The initial view was better than previously - up until i started to feel faint (as was becoming common when lying on my back late into the pregnancy) and rested on my left hand side for a few minutes to come round. When they started rescanning there was more tissue in the chest cavity than previously. After i heard this i made sure that i slept on my right hand side every night, just in case it made a difference (she was head down at this point) !

We also met the "high risk" pregnancy midwives who confirmed that i would be induced at around 39 weeks to ensure that a cot and bed were available, and who also recommended that at 37 weeks i start to try and express colostrum and freeze this in syringes, so that there is a bank of this precious food for baby when the time comes that she is able to take this (they say not to try before 37 weeks because nipple stimulation might cause contractions to begin). There are YouTube videos that demonstrate this technique and I would strongly recommend anyone talking to their midwife about doing this because when my milk did come in, there was loads for me to express and save.

We were called in at 39 weeks and were both terrified! After a 3 and a half hour labour she was born, at 3am. I was in shock because of how quickly everything had progressed but i heard her cry (what a great sound that was) and she was immediately intubated and taken to NICU, along with her father Lawrence. I am not entirely sure what happened, but in the rush the umbilical cord detached from the placenta, and so i was then whisked to theatre to have a spinal block so that they could investigate properly and make sure none of the membranes were left inside me (they tried putting their hands inside and with no pain relief just after giving birth i was having none of it!!!)

So i didn't get to see my baby girl until much later on that day, but Lawrence had spent time with her, and in the meantime my mum and brother had come to the hospital to see her (and me!) and they reassured me of how she was. Looking back now i was very scared of how i would take seeing her. I just had the Athlete song "wires" going through my head the whole time. I need not have worried because she was beautiful, and much bigger than i expected, but my heart hurts every time i think of her in the cot sedated with all the wires and the breathing tube and the monitors and not being able to hold her. She required ventilation and because she was a reasonably large baby at 8 and a half pounds the surgeons said if she remained stable they would perform the operation to repair her hernia in 2 day's time.

Those 2 days were a bit of a blur, i spent a night in hospital and then was discharged the next day so stayed the night at my parents but got up very early so we could be back at the hospital to see Poppy (we finally decided on a name in those 2 days!) off for her surgery and waited for the phone call to say she had returned. In the meantime we had been given a room in the Ronald McDonald house close by so we were only a short journey from the hospital. Every time my phone made a noise i panicked! But 4 hours later we had a call saying she was back in NICU and the operation had been successful. We went to see her and talk to the surgeon who we bumped into in the reception area. He explained the operation had gone well, small and large bowel tissue were moved back into their correct place and they managed to seal the hole by stitching the diaphragm only. I wanted to pick this man up and hug him! But i gave him a more sensible handshake instead.

We went straight into NICU and saw her, they had taken her off sedation so she was moving a bit more, although the morphine was still limiting this. Her ventilation was being stepped down and she started to poo some meconium! Her bowels were working i never thought i would celebrate a dirty nappy! The drs predicted that she might try to pull out her breathing tube, and the day after her operation she did just that. They left it out to see how she got on and gave her additional oxygen. At this point i was allowed my first cuddle. It was the best feeling ever, I didn't want to put her down. Over the course of a couple of hours they stepped down her oxygen until by the end of the day she was breathing independently!

Over the next 2 days she was monitored to make sure her breathing was good, and they slowly reduced all her medication until she was just on TPN (an intravenous feed replacement fluid). They asked if we would be happy to give her a dummy which we did and i also would express small amounts of milk onto cotton wool to clean her mouth etc, i wanted to do everything we could to associate things in the mouth with pleasurable experiences. The nurse mentioned that she might be moved down soon to HDU but i didn't let myself believe this could be true after only a few days in NICU. The next morning we went to her usual spot and she wasn't there, she had been promoted overnight!

The next step was to start reducing the TPN and giving her the breast milk that i had been storing. They inserted a nose tube to do this so they could measure exactly what she was getting and make sure she was tolerating this ok. She hated the nose tube going in, but her face after the first tiny amount of milk was a picture, she just looked drunk! She had no problems with reflux or absorption of the milk and every time the drs did their rounds they accelerated the amount of milk she was getting. At this point the nurse asked if i would like to try breastfeeding her, i was a bit nervous after so long but it was something i really wanted to do so we went for it. I was so proud of her when she just latched straight on and immediately started sucking... and then fell asleep after a few minutes i think it was so comforting- for both of us, i could have done the same!



The next morning we had our next promotion - to SCBU - I couldn't believe it, she was only 8 days old. By 10 days she was onto full feeds and to my surprise during the ward round the consultant discussed us moving to a local hospital for rooming in with her! We were nearly home!

I had an overnight stay at East Surrey hospital with Poppy where it was up to the two of us to feed - no top ups through her nose tube. They weighed her before and after and she had lost 15g in weight - i had a long wait to see if the dr would allow us to be discharged but - thank goodness - she did! So less than 2 weeks after she was born we were home ... it was more than i ever could have hoped for.

We had a follow up x ray 12 weeks after discharge and her left lung has inflated to fill the cavity, we will be going back in another 6 months but her surgeon said all being well the checkups will be annual from then on. She is now a perfect, smiley and chatty 4 month old baby who is such a pleasure to be around, and her scar has healed so well you can barely see it. We've had no problems with weight gain or illness; I have to check myself to remember the rough start we had.

I am incredibly grateful and thankful to all of the people who have supported us throughout this. I can't speak highly enough of the sonographer who diagnosed her, the surgeons who mended her, the consultants and drs who guided her back to full health and the amazing nurses who looked after and comforted her when we weren't at the hospital (we came back one morning to find the overnight nurse had drawn poppies all over her hat, it was such a nice thought). Anyone who speaks poorly of the NHS needs to hear our story, we are so lucky in this country. We were only able to stay in London and be close to her because of the amazing support of the Ronald McDonald house, the staff there are fantastic and we met some wonderful people, all going through their own tough times. My family and especially my mum helped me through the early stages of this, i don't know how i would have coped without them and everyone who sent a message saying they were thinking and praying for us. I remain overwhelmed by the support we received.

To anyone going through the same experience then my thoughts are with you, please try and stay positive and look after yourself. We met a lot of poorly babies in the hospital and wow, what amazing little fighters they are! The medical expertise we have available to us now is incredible, and the babies heal so well there really is lots to be hopeful for.

Written by Emma Davis, United Kingdom (2013)

Ridley Ellis Nunn

Ridley was a surprise. We found out that we were expecting at the ER, for what was believed to be an extreme stomach bug, turned out it was an extreme case of morning sickness. The shock factor left us speechless, and scared. Our baby was 4 months old, and we were taking every precaution to prevent another pregnancy...His surprise conception would later give me the hope I needed to not give up. You see I felt he was just meant to be. I shouldn't have gotten pregnant, I even had a consult scheduled to have a tubal ligation. We thought our family was complete. When he was diagnosed I held on to that, why would this happen if we could lose him? He WAS meant to be, just not the way I believed.

All went great; it was a normal healthy pregnancy from weeks 5 to 20. Then our son was diagnosed at our anatomy ultrasound. We had no idea this could even happen, yet it did. Three words took away that special time that mom and baby develop and share a sacred bond, and replaced it with fear and anxiety.

At first the outcome seemed good; they said his was a small defect. Everyone was fairly optimistic. As the pregnancy progressed though, his prognosis grew bleaker. We would have one small piece of good news then at least 2 negative facts handed to us. After a fetal MRI revealed his lung volume was about 12 when it should have been 60 for his gestational age, they even asked if we wanted to deliver at our local hospital...she said the family support would help get us through, as she had never seen a baby with such small lungs survive.

We opted to give him a chance. On February 6th, 2012 at 10:28 am Ridley Ellis Nunn was born silently into the world...they worked so hard to stabilize him for transport to Arkansas Children's Hospital, just a few miles away. They did all they could possibly do. He wasn't responding to their efforts. They said his only hope was to go on ECMO, a heart lung bypass. We had to chance him passing on the way or hold him and tell him bye. We couldn't give up. They brought him by to see me, I touched his face, and said my I love you's but refused to say goodbye. I got a call a few hours later. He made it, and was doing better than they expected....I know it was foolish, but at that point, I banished any thoughts I had about not bringing my son home. I began pumping milk around the clock. I was determined that he would eventually be able to nurse.

Ridley surprised them for 15 days. He began having significant lung sounds on his left side on day 4 and they had previously said there was nothing there. They believed he had endured a significant amount of brain damage, the head ultrasounds were always NORMAL, and when he finally awoke on day 3(he was sedated) they were impressed with how aware he was. Seeing his eyes or the first time was so amazing. The little things you take for granted when your children are healthy are astounding.

He was doing so well. He continued surprising them till day 15. It too was a surprise but not a good one. Seizures began. On day 16 they found a brain bleed...one of the side effects from the ECMO...On day 17 they found that not only was the first one ongoing, active, and large, there were more. At that point it was so bad that there was no chance that he would ever wake up, or even breathe on his own. We chose comfort care for our son...We chose to be there for him in a way only we could, in the ONLY way we could.

River and Raylen finally got to meet their brother, and Travis and I finally got to hold our son. His grandparents were also there, as they had been every step of the way...It should have been a joyous moment in our lives, but CDH stole that from us. Instead all I could think was how this would be the last time I would feel the warmth of his skin on mine, the last time that I could cuddle him, as I did countless times with his sissy and bubba. For those few hours though I was complete. My heart was whole even as it shattered into a million pieces. My family was together for the first and last time on this earth.

Sometimes I still question the choice we made. I know that we made the right one for him, but grief can make you ask yourself if the sky is blue, if the grass is green, and it will make you wonder what if? The hardest thing I have ever done was to tell him it was okay that I knew he fought his hardest and that it was time to rest. I held him, and his daddy held us as he left this world. I can only hope he could feel how much we loved him that day, and I hope he can see how much we still do.

As I write this it has been 21 months and 2 days since he was born and I still feel like I am stuck in Little Rock, Arkansas. Every day I wake up thinking of my son, and every time I close my eyes I see his face. All I have left of the miracle that CDH took from me are his ashes, keepsakes from the hospital, and memories that I hold in my heart from when he was mine in this world. All of the hopes and dreams we had for him were stolen by that awful defect that is CDH...We love you all the way to Heaven and back again Sweet Boy and I miss you every second of everyday!!!

Teri Nunn, Arizona (2013)



Emma Scarlet Javorek

My husband and I went in for a routine appointment at 29 weeks concerned that I might still have placenta previa. That was when we learned our daughter had a congenital diaphragmatic hernia. We were confused and devastated. After a phone call to my mom I laws reminded that my 18 year old cousin, Rebecca, had also been diagnosed with a congenital diaphragmatic hernia and she has lived a fantastic life. That gave me strength to face this obstacle that faced us. I dove into researching CDH and wanted to find the best care for our daughter.

After learning on Emma's condition, my husband and I knew that our daughter needed a strong and powerful name if she was going to be a fighter. We decided on Emma Scarlet Baker. Emma means "God's chosen one" and Scarlet means 'vivacious'.

Emma was born on September 23 at Riverside Methodist Hospital and transported to the NICU at Nationwide Children's Hospital. Emma was immediately intubated and put on the oscillating ventilator. The first few days of Emma's life were full of ups and downs. Emma's team of doctors worked non stop to provide Emma with the best care. They constantly monitored her stats and made adjustments to her medicine as needed. ECMO was a constant possibility for the first 72 hours. Each time the doctors prepared us for the possibility that Emma would need to be put on ECMO Emma showed us her strength and fought back.

On day 8 of Emma's life she had her repair surgery. The team finally felt Emma had stabilized enough to be able to handle surgery. The doctors prepared us that all of the strides Emma had made may be lost after the surgery. We were ready to go through all of the ups and downs after surgery. To everyone's surprise Emma came back from surgery and just kept fighting. She maintained her pre-surgery medicine levels and quickly weened off of the most of them. Four days after her repair surgery on day 12 Emma was moved from the oscillating ventilator to the conventional ventilator. Over the next 48 hours the team moved Emma from the conventional ventilator to CPAP then to nasal cannulas. It was amazing to watch this little girl fight so hard for her life. Without even knowing it Emma had hundreds of supporters that were inspired by her strength and courage.

Eventually Emma was moved to a step down room when she began learning how to feed. After everything Emma had been through with her team of doctors watching her struggle to feed was very hard for me because it was something I had control over and it wasn't going well. We spent a week working on feeding which was the only thing keeping her in the NICU. On Monday, October 28 the team decided to remove her NG tube and give Emma a chance to show she could feed on her own. Once again Emma showed everyone how strong she was and finally mastered feeding on her own. At rounds the following day Emma's nurses informed us that Emma would be discharged the next day. I can't describe how excited and nervous I was to finally get to bring Emma home after 37 days in the NICU. I am so proud of how strong Emma has been. Her fighting personality is an inspiration to myself and all of supporters.

I love this quote from Yvonne Pierre, "Use what you've been through as fuel, believe in yourself, and be unstoppable." That is what I have learned from my two month old daughter. I can't wait to see what else she teaches me!

Katelyn Javorek, Ohio (2013)



Rebecca Rae

We became aware of CDH when I was diagnosed at 15 weeks of my pregnancy. The hernia was severe, with all of my baby's organs up in her chest cavity. The Doctors said there was a zero (0) chance for my baby to survive and they wanted me to abort at that time. We decided to continue the pregnancy and deliver our baby, and let God decide our baby's outcome.

Rebecca Rae, our Miracle Baby, was born on November 30, 2013. She weighed 8lbs 6oz, which I believe really helped her with her fight. It was touch and go for several days, but she just kept fighting back. She was so determined to stay with us. They had the ECHMO Machine ready for her five times.

The NICU Nurses were our life support. Our nurse, Margie, talked the Doctors into seeing if the High Velocity Ventilator was available to try on Rebecca. So they hooked her up and we waited and watched. They said they would check one more blood gas and if it had not improved, they would have to put her on ECHMO, which at that time, did not have good outcomes for CDH Babies.

Another Miracle happened. Rebecca started to stabilize. This ventilator saved her life. Her blood gases started to improve. Rebecca stabilized and on December 5, 1994, when she was 5 days old, had her surgery. Before her surgery, her surgeon told us that we would not know if she would survive for several weeks and that it would be touch and go. After surgery, her surgeon came out and said he had never seen anything like it, during surgery, as he was moving all of her organs back down, her lung that they did not think existed, just popped open and her vital signs greatly improved during surgery. Another MIRACLE!!! From that time on, she just showed us what a fighter she is.

They expected her to be in the hospital for months after birth, but she defied all the odds and we left the hospital with our MIRACLE Baby Girl in 3-1/2 weeks, just in time for our Christmas Miracle. Rebecca was discharged with no equipment or medicine.

The only after affects, if you will, is that Rebecca was diagnosed with a high-pitched hearing loss in 1st grade, and scoliosis, directly related to her birth defect, both of which she has learned to live with.

I have always celebrated two birthdays for Rebecca, the day she was born, but also the day she had surgery, because I feel that was the day she was re-born.

We always have felt that the scar she shows is to show everyone what a fighter and miracle she is and to be proud of what she has accomplished in her little life from the start. She wears her two-piece bikini with pride!!!

Rebecca Rae has been a joy in our lives for the past 18 years. I have ALWAYS known she was brought to us for a special purpose and one day we might know why. I know that Rebecca has been an inspiration to her 2nd cousin, Emma and family, who was born this year with CDH. I believe that the two girls will ALWAYS share this special bond, as only, THEY, will be able to understand. I feel that because of Rebecca's Miracle, we were able to provide the hope, guidance, courage and understanding to Emma's Family that was needed to help them get through this life changing ordeal.

Thank you for all you are doing for all the families that are faced with this diagnosis, whether it be a good outcome and they stay here on earth or they earn their wings and fly home.

Lori Sanders, Ohio (2013)



Liam Tapia

During our ultrasound at age 20 weeks, Baby Liam was diagnosed with a severe Congenital Diaphragmatic Hernia. CDH occurs in about 1 in 5,000 live births. It occurs when the diaphragm does not form properly and as a result, some parts of the abdominal organs moves into the chest that affects the lungs to develop and grow. As to what causes CDH? our doctors said it was an accident by nature. Our baby boy was given less than 10% chance of survival. We were given an option to terminate the pregnancy but we chose not to. With our strong faith in God and our faith in our son Liam, we continued with our pregnancy. And as parents, we just felt like it's so wrong to just give up on our baby without giving him a chance to fight for his own life. Since then, we had doctors' appointment twice a week. And as our due date got closer, Liam's situation worsened. He was too small for his age, his heart was too weak, he didn't have enough lung tissues to basically breath when he gets out, and that he might not even make it out from the resuscitation room after birth. We were heartbroken but our faith remained unshaken. Doctors decided to induce labor at 38 weeks, we were in labor for 3 days until baby boy Liam came out August 6, 2013 through normal delivery. Liam was so strong, everybody predicted I was going to have a c-section because his heart was too weak, but our baby boy made sure he came out through normal delivery. He was taken away from us immediately. We never got the chance to hold him, he tried to cry but his lungs were underdeveloped we never heard him cry. We waited for an hour after delivery and it was one of the best news we had, he made it out from the resuscitation room when everybody doubted he will. He was then sent to the NICU, and for 24 hrs he tried to fight for his life. August 7, 2013, we were faced with the biggest decision of our life, doctors said his stats were going down and he wont make it for one more night. He was just too weak already. We decided to just hold him in our arms until he passed. We know Liam wanted to get to know his Papa and Mama before he reunites with the Lord. It was the most painful, but we know Liam were able to feel our love and warmth. Liam was a warrior, he knew since he was inside that we were fighting for him, that's why he really fought so hard when he came out. We wanted to see him, we were so excited to be with him and so was he. Liam is now an angel but he will forever be in our hearts. Liam has taught us the value of life. And we will forever be grateful to God that we were chosen as Liam's parents.



Charlotte Pajatin, California (2013)

Christian Peter Kime

Our journey with Congenital Diaphragmatic Hernia began at our 20 week ultrasound. The ultrasound tech was steadily talking to us and describing our baby's body parts. It was a boy! Then she became silent as she moved the wand over my belly and kept checking the chest area of our little boy. Our joy over news of having a little boy was very brief. Quickly, we became panicked by watching her face. She concluded the ultrasound and said that she needed to speak with the doctor and to wait just a moment before leaving the room because she wanted to get his opinion on something. After she left the room, my husband and I looked at one another puzzled. I am not an ultrasound tech, but I am somewhat familiar with the inside anatomy of a person and couldn't help but notice how she took extra notice of the area around his heart. After the doctor returned and took a look he confirmed her suspicions of an abnormality in the chest. We were then referred to a high risk doctor and had another ultrasound scheduled within the week.

After meeting with the high risk doctor and receiving our second ultrasound, we were told that our baby boy had one of two things going on. He either had a cyst growing on his lungs or a rare condition called Congenital Diaphragmatic Hernia. If it were just a cyst, then we would be better delivering in Birmingham, AL, but if it were CDH then Gainesville, FL would be the way to go. Either way, our child would require surgery. Due to his size at 20 weeks they could not tell for sure, but as he grew we would be able to confirm which diagnosis and go from there. We were then asked if we wanted an amniocentesis to check for other abnormalities. I opted to have the amnio and the results came back fine.

My son was our first child. I am sad to admit that I never got excited about my new baby's arrival. I cried a lot during my pregnancy. I didn't decorate a nursery for him. I didn't even want to buy him a crib for fear that I would have to come home to a baby crib, yet no baby with me to put to sleep. As with most CDH pregnancies, I had polyhydramnios (extra amniotic fluid) and had to have an amniotic fluid reduction done just to be comfortable enough to breath during my 8th month of pregnancy.

Two weeks before my due date, my husband and I relocated to Gainesville, FL. My son was delivered via C-section on the evening of January 31, 2006. We heard 2 small cries before he was whisked away with a team of doctors and nurses to be intubated. It all happened so fast. I was then wheeled into a recovery room as my husband went out to talk to family members. Alone in recovery, I tried to recall my son's face. "Would I know him if I saw him in the NICU with all the other babies?" I thought to myself. About 30 minutes after delivery, my husband came in to check on me. He had decided on a name for him as well, Christian Peter, which means strong rock. He then handed me a picture of our son that was taken by a very nice volunteer with the March of Dimes. I clung on to this picture for the next 24 hours as I lay in my bed, unable to visit my sick baby boy.

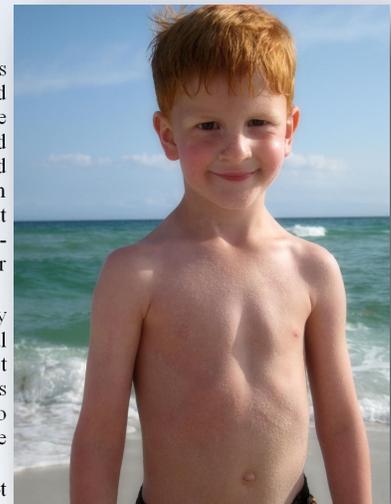
The next few weeks were a busy blur. I do remember finally getting permission to walk to the NICU III to see my baby boy after 24 hours away from him. Nothing prepares you for seeing your newborn with tubes and wires everywhere. I wanted so badly to hold him. All I could do was place my hand on his head or hand, but had to be careful not to stimulate him. We had to talk in a whisper and camera use was limited due to the stimulation from the flash.

We were told Christian had a mild left congenital diaphragmatic hernia with only intestines and spleen located in the chest. He had some respiratory failure, which they tried to help with a high frequency oscillator and nitric oxide, but that wasn't enough. At just 2 days old, due to worsening respiratory failure, he was placed on venoarterial ECMO. He stayed on ECMO for 10 days. He also had PPHN, which stands for persistent pulmonary hypertension in a newborn.

Let me just say that witnessing a baby on ECMO is not a pleasant thing. His whole body was really puffy and lumpy. Whenever he did open his eyes, they just rolled around in his head as if he was really dizzy. We were afraid he might have brain damage since he didn't seem to be able to focus his eyes on anything, but in hindsight I know that was only because of all the medications they were using to keep him sedated so as not to pull at his ECMO tubes (which he did try to do a few times!).

His surgery took place when he was 16 days old. Dr. Kays and his team did his repair with a Gortex patch. When they wheeled Christian to the NICU III, we noticed he looked sort of gray. After a few hours of close observation by the doctor, he noticed our son's abdomen began to swell. They confirmed there was internal bleeding and they rushed him back to surgery to find and control the bleed. Our whole family was a wreck waiting for word from the doctor. We paced by the elevator doors waiting on his return. Thankfully, Dr. Kays found the bleed and was able to stop it.

In the days following surgery, our son had to have chest tubes placed on both sides of the chest due to pleural effusions. He had a barrage of tests and scans during his stay. He was weaned off the ventilator at 26 days old and then placed briefly on CPAP for about a week. After CPAP, he was placed on a nasal cannula. Up until this time, I had not gotten to see my baby's face free of tubes and tape. It also wasn't until he was on the nasal cannula, that I was able to hold him



for the first time. He was 6 weeks old when I first held him. It brought me such joy!

Time seemed to slow down once we moved from the NICU III to NICU II. Our biggest goals were to get him to tolerate his feeds, gain weight, and keep his oxygen saturation levels up. In the NICU II, I was able to be more hands on. I could feed him, change him, and dress him (unlike in the level 3 NICU). Finally, after a very long 57 day stay in the hospital, we were discharged with supplemental oxygen and medications for fluid retention and reflux.

Things went rather well once we got home though I was constantly checking to make sure he was still breathing and wasn't strangling himself with the nasal cannula. He only used the supplemental oxygen for the first month when we got home. We did have issues with finding an understanding pediatrician that would listen to the request of our pediatric surgeon, Dr. Kays, to keep our son on supplemental oxygen to help his lungs.

I was hyper-vigilant about keeping germs away from him. I refused to take him out in public until he was almost 6 months old. I remember having to fight with the doctor and insurance about getting him an RSV immunization shot when winter rolled around. Nobody seemed to understand how sick he was and could get with just a cold. Due to his medical issues, I was afraid to put him in daycare for fear of him getting sick and having to go back in the hospital. I ended up quitting my job to stay home and take care of him.

We continued traveling to meet with our pediatric surgeon yearly for the first 5 years of Christian's life. That was how we were able to spot the reherniation when he was only 3 years old. We went back to have Dr. Kays and his team repair the reherniation. It turned out that the gortex patch that they had used, had come away from the back wall of his chest and it was an easy fix. Dr. Kays noted that the muscle tissue of the existing diaphragm had fused together with the patch rather well on the other 3 sides of the repair.

We are finally down to visits every 2 years, with an upcoming visit in the spring of 2013. Christian has not had any big issues other than the reherniation. He doesn't have to take any medications anymore. His only issues are getting winded easily, he can't eat large amounts of food at a time (he grazes when it comes to eating in order to prevent puking), he has to immediately use the restroom after eating, weight gain, and seasonal allergies. We will always be worried about possible reherniation as he grows. We also worry about long term side effects that he may have from ECMO, but it all is an unknown path.

Christian will be in 1st grade this year and is doing well. He is in the accelerated reading program at school and just started taking tumbling classes this year. Our hope is to let him live a normal life. We always encourage him to follow his passions.

Carrie Kime, Alabama (2012)

Riley Nicole Soria

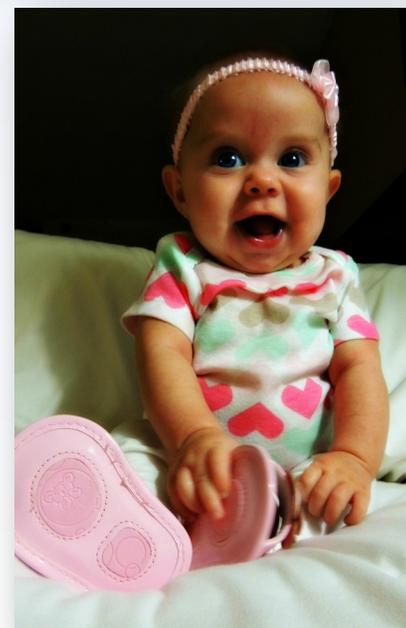
I found out I was pregnant towards the end of 2007 shortly after finishing school. The beginning of my pregnancy seemed normal, like any other normal pregnancy would. When I was 20 weeks along I had my first ultrasound, where we were so anxious to find out the sex. Instead we found out that our baby had something wrong. I was referred to high risk specialist in Virginia and continued my care there for the remainder of the pregnancy. They informed me that our baby had CDH. We had no idea what that was and spent the next several months researching and learning everything we could about it. There was, of course, no way of knowing what was going to happen. I had many ultrasounds and stress tests done, nothing seemed to worsen, but nothing was getting better either. I was told I would have to give birth at another hospital in case we needed the ECMO machine. While her father and I were at home putting her crib together in anticipation to bring our sweet girl home, we got the call that the doctors wanted us to travel to Duke to be induced there. I was only 37 weeks, but they did not want to risk me going into labor on my own and not being able to get her the help she might need on time. We got to the hospital on May 14th 2008 around 6pm where they started the induction. I stayed in labor for an entire day before I was dilated enough to start pushing. I was wheeled into the OR to deliver, and after only 30 minutes of pushing this beautiful 5 lb 15 oz little girl was born. She was immediately taken to another room, and we later found out she had to be placed on the ECMO machine, or she would not have made it through the night. She fought for two weeks and did very well until she was able to be weaned off. For the following two weeks she remained on a jet ventilator where she continued to fight. On June 13th, after a month of holding our breaths, we realized that Riley would never be strong enough to endure the surgery that she needed. She was removed from all machines where she peacefully slipped away in her mothers arms around 1:00 AM on June 14th 2008.



Alex Bundy, North Carolina (2013)

Emmalyn McCoy

Emmalyn was born on April 12th, 2013 after a long 16 hour birth. Upon arriving into the world, Emmalyn was blue, lethargic, and not breathing. The nurses quickly rushed her to the care station, and began to give her oxygen. Originally, we thought that her lungs were punctured, because she wasn't able to hold air in her left lung. They whisked her away to the NICU to continue to figure out what was wrong with our sweet little one. After an hour, the nurses came back into my delivery room and broke the news to us that our beautiful baby girl had a Left-sided Congenital Diaphragmatic Hernia (CDH). The nurses and doctors then handed us a huge stack of papers involving CDH. They had explained to us what exactly was wrong with her, but as soon as they told me she only had a 50% survival rate, my mind raced and I didn't hear anything else they were saying. The very next thing we had to do was make a decision on which hospital we wanted her to fly to that night. We chose Levine's Children's Hospital in Charlotte, North Carolina. Within 2 hours of her birth they had her sedated, stabilized, and on a midnight flight to a better hospital. When we made it to Levine's the next morning, Emmalyn's nurse had told us that she was on morphine, to keep her sedated. She was hooked to a ton of machine and had a repleg tube; she was intubated, and had 3 IVs. Her doctors and future surgeons talked to me the same afternoon and told me that she would be having a repair surgery within a few days, depending on how stable she remained. They reassured us that they had seen a lot of worse cases, continued to keep us thinking positively. Emmalyn was born on a Friday night, the following Wednesday was when she had her repair. Her repair was performed laparoscopically and took 2 ½ hours to complete. After her surgery was complete, the surgeon came out and told us that Emmalyn had her small intestines, colon, and spleen in her chest cavity. He was able to fix her diaphragm with several stitches. He was positive that she would progress smoothly and be home within 2 weeks! The day after her surgery, Emmalyn was taken off of the morphine and was no longer sedated! Within three days, Emmalyn was breathing on her own, above the settings on the machine- so the nurses decided to extubate her. Emmalyn did perfect, on the first try, with being extubated. She never needed to be put back on the



machine. However, the nurses did give her a nose canula for a few days; the canula was set to "room air". After 11 days of being in the NICU, Emmalyn's doctors decided it was time for her to try feedings. She was given bottles of breastmilk, 5 mL's at a time. After two days, Emmalyn was up to drinking 2 ounces at a time without refluxing any of her feedings. This was amazing progress, and we were so proud of our sweet girl! Finally, after tons of videos, a car seat test, removal of IV's and PC lines- Emmalyn was all set to come home! On Sunday April 28th, we were able to bring Emmalyn home. She had been in the NICU for 16 days. She didn't need to come home with any machines, tubes, or any medical interventions. The only medical intervention she has needed, are regular doctor appointments. Emmalyn has been regularly seeing a Cardiologist for her 7 heart murmurs, her surgeons every few months for check-ups and x-rays, and a Gastro-Intestinal doctor for her reflux problems. Having a daughter diagnosed with CDH after birth was extremely scary. We didn't have any time to make decisions, to research, or to talk to anyone. We found CHERUBS after we had already been discharged from the hospital. Although it would have been nice to have had information and support during the stay in the NICU, we didn't have that luxury. We are so blessed to have found CHERUBS and the wonderful support that comes along with being a CHERUB family!

Lauren Ward, North Carolina (2013)

Amia Genesis Forbes

My Daughter Amia Genesis Forbes CDH was found at our 20 week ultra sound, it was an exciting morning for my other half and I, we were getting ready to learn the sex of our baby and then the day went south. It wasn't clear to us, what was going on but it's a day we both will never forget. Despite what we were told, we wanted nothing more than to see our daughter. We had to take measures in our own hands and found a doctor who was able to perform in utero surgery to help our daughter survive. Fast forward, Amia Genesis Forbes was born on September 25th, 2012 weighing 5 lbs 4 oz and 17 inches, born at 35 weeks cesarean procedure due to the device (stint) which was placed in her trachea at the utero surgery. She was born at Jackson Memorial Holtz Children hospital, she did not need the ECMO machine, she was intubated at birth and was breathing fairly well on her own. The doctors felt she was doing so great her repair surgery of the hernia was done on September 26th, 2012, they were unable to close the area the same day and went back in 2 days later to close op her stomach area. She was released from the NICU on November 16, 2012. Amia is 3 months now and is doing great, she continues to show progress, being release from her cardiologist last thursday 01-10-13. As of today she weights 10lbs adn 24 inches. We are very happy with her progress. I pray for all the families of CDH.



Gertrude Evelyn, Coral Springs Florida

Caroline Tillery

My husband and I found out on August 5, 2012 our little girl had been diagnosed with CDH. The only reason this caught was because I had an ultrasound at 28 weeks for placenta previa otherwise our little girl would have been undiagnosed. We were blessed the ultrasound tech and our OB caught there was something not quite right on the ultras ground. We were referred that day for a more detailed ultrasound. At the time they thought it was fluid around her lungs. We had a MRI the next week and the results were in it was CDH. I went into immediate research mode since there only three months left in my pregnancy. I found all the material I could so I could be prepared. During the whole process from diagnosis, birth, surgery, and the NICU my husband and I remained positive. We truly knew our little girl would be okay. She was on various prayer lists before birth and we were as prepared as we could be.

Caroline Faye Tillery was born October 5, 2012 via a csection after 52 hours in the hospital. 16 of those hours in active labor. She was born at Forysth Medical Center with a immediate transfer to Brenner's Children Hosptial at Wake Forest Baptist. We was immediately ventilated through a jet vent. My husband went with her on the transport since I had to recover in the hospital. He met with the surgeon Dr.Petty and was given the best and worse case scenarios. We had already prepared ourselves do as much as possible. I had sent him with five pages of questions to be answered in their initial meeting. Dr.Petty even thought I had a medical background which is not the case but I found amusing!

Caroline did well on the jet but they wanted to transfer her to a conventional on day four to see if she could stand it for surgery. She was able to and on day 5 had the repair. Her bowels, colon, spleen, and a portion of her stomach were herniated. The amazing part was Dr.Petty was able to do the repairs muscle to muscle! She went through surgery amazingly. She came off ventilation on day 10 and was able to start eating on day 12. It was truly amazing! To our surprise she came home on day 17! We are pretty sure she broke the record for a baby with CDH at Brenner's getting out so quickly! She is our living miracle! She was strong throughout the entire process and was not going to let CDH have the best of her. We are truly blessed with our experience and only hope one day there is some way to detect why this terrible condition occurs.



Shawna and Jim Tillery, North Carolina (2012)

This Issue Is Dedicated to the Memories of:

(as of December 31, 2013, of those who have updated their membership profiles)

Zeyah Grace Ackerman
Jaecy "JC" Mae Acosta Sedlis
Javin Mathew Afre
Lynlee Albrecht
Olivia Grace Andridge
Savanna Arthur
Kamden Grayson Babin
Deniz Bahsi
Asjiah-Fate Bailey
Brayden Michael Bammerlin
Izabella Beck
Cooper Lynn Beeler
Evalon Zoe Bell
Paxton William Aaron Billings
Miabella Lis Blanchard
Keeno Rafael Blanco
Evan Bonistalli
Jaimee-Rose Hope Bonner
Gabriella Marie Booker
Baby Boy Boy
Fátima Sofia BR
Brennen Bradshaw
Damien Brannon
Ian Brocklebank
Hank Brown
Samuel Brown
Jacklynn Campbell
Lila Kate Carpenter
Magnolia Carty
Hunter Alan Casto
Justin Cernobyl
Brynlee Tuska Christian-Mays
Stratton Clark
Matthew Clemens
Catherine Elizabeth Clements
Brighton Cook
Amelia Coroy
Trenton Wayne Cox
Tallulah Blue Cudlip
Ashley John Davies
Christian Davis
Baby Degretto
Gracel Erich Dela Cruz
Kullen Michael Denegri
James Todd (JT) Dickerson
Matthew Doesrscheln
Joshua Drapeau
Anderson Chase Duffin
Gabriel Ebaugh

Kenli Edwards
Bailey Ellison
Maria Athena Faith Mitchell
Rin Fem
Jordan Fern Amodeo
Jordan Ferris
Warren Fink
Julian Finnegan
Abbie Flowers
Skylar Milagros Fonseca
Morgynn Ford
Callum Fossett
Cameron Lee Maliki France
Vivianne Darby Frankel
Mateo Frias
Gabrielle Froio
Cesar Armando Gamez
Emmi Garcia
Dominique Gayle
Aiden Robert Grant
Erin Elizabeth Grant
Brylie Gregory
Ryan Grieci
Eryn Griffin
William Griffin
Hailey Lynn Guzowski
Ari Hall
Brendon John Hart
Reed Wyatt Heaton
Joseph Michael Heimke
Kevin Hemming
Allyson Hensley
Baby Herman
Robert "Bently" Hernandez
Logan Hesselbrock
Bryan Hewitt
Arabella Hightshoe
Elizabeth Hope Hill
Johnna Hinklin
Tucker Cross Hinson
Savannah Houselog
Sienna Marie Howard
Liam Hunt
Faith Jenkins
Reese Sophia Jimenez
Henry Liam Johnson
Miles Johnson
Jackson Grey Joseph
Jackson Grey Joseph

Bryson King
Carson Klink
Emil Knudsen
Nikhil Kohar
Kyle Joseph Kurras
Jack L
Jordan Lafond
Mila Fate Laganis
Nora Grace Lange
Sophia Leigh Lovett
Deacon Lynch
Zoe LythgoeBaby Boy M
Makaila Marohn
Lucas Marro
Ryan Mason
Hunter McDonald
Samantha McKennon
Conner McLaughlin
Matthew McOwen
Brandon Dwayne Miller
Hunter Miller
Jasmyne Montez
Liam Morales
Timothy James Nelson
Elliott Nicholls
Mya Norman
Shelby Marie Nunes
John Angelo O'Donnell The Fifth
Grace Opie
Brayden Osborne
Kayden Ostrousky
Alexis Ostrum
Harmony Park
Dakota James 'DJ' Payne
Jaime Manuel Pedroza
Avacyn Pichay
Micah Poston
James Christopher Price
Liviana Price
William Prudhomme
Mavrik Austin Pruitt
Ashu Rai
Damian Ramin
Alan Ramón
Gavin Wilson Ream
Kassidy Jahzara Reed-Pratt
Lily Reid
Olivia Faith Richardson
Kinley Riley

Skiyla Robbins- Shilling
Dante Samuel Rodriguez
Ellieanna Grace Rodriguez
Gavin Rogowski
Berkley Lynn Roper
Jacob Rowan
Adam Salas
Nathan Scelfo
Jacob Anthony Schaal
Waylon Dean Schaefer
Lainey Seelbaugh
Holo Sehlapelo
Einya Elizabeth Sengsourya
Liam Duncan Shields
Jacob Scott Silbernagel
David Keith Siler
Caleb SimsSarah Smith
Jadon Snider
Radhika Soni
Daniel Sousa
Baby Boy Stambaugh
Liam Miguel Tapia
Ziyah Thomas
Daniel Torres
Brooke Allyson Tyler
Lizay Van Zyl
Hope-Eliza Villarreal
Charlie Waayers
River Waddell
Michael Thomas Waldron
Damon Alexander Walker
Evelynn Wallis
Victoria WareBailey Grace Watson-
Smith
Liam Weeks
Lexi Wheatley
Ellie White
Andrew Whitten
Alis Williams
Delaney Ann Williams
Henry Davis Williams
Jaxson Winders
Amelia Phoenix Winthers
Blaire Alexandria Wise
CJ Wood
Riley Kimball Worthen
Evelyn Elizabeth Yardley
Angela Faith Zadravec

Would you like to support CDH families hands on? CHERUBS is always on the look out for great volunteers! You can volunteer in our office, at your local hospital or on-line for as many hours as you'd like.

Contact Tracy and Josh for more information at volunteer@cherubs-cdh.org



"Fairy tales do not tell children the dragons exist. Children already know that dragons exist. Fairy tales tell children the dragons can be killed." - Sabina Dosani

Latest CDH Research

Did you know that CHERUBS visited Capitol Hill last year? And that meeting with many Senators and Representatives instigated a Congressional Inquiry into NIH funding of CDH thanks to the support and dedication of Sen. Jeff Sessions?

Will you be with us this June on Capitol Hill?

<http://nichd.nih.gov/news/resources/spotlight/Pages/071713-CDH.aspx>

UF Health surgeons release record survival rates for infants with congenital diaphragmatic hernia

David Kays, MD, University of Florida Health

Postdischarge Follow-up of Infants With Congenital Diaphragmatic Hernia

American Pediatrics Association, <http://pediatrics.aappublications.org/content/121/3/627.full.pdf>

GATA6: A new genetic cause of CDH

DHREAMS - <http://www.cdhgenetics.com/results.cfm>

Developmental outcomes in two-year-old children with CDH

DHREAMS - <http://www.cdhgenetics.com/results.cfm>

Fetal tracheal occlusion for pulmonary hypoplasia in severe congenital diaphragmatic hernia: A systematic review and meta-analysis of survival outcome

Jamila Al-Maary, K. Milbrandt, Rasheda Rabhani, R.Keijzer, Pediatric surgery Department, Winnipeg Children Hospital, MB, Canada

Congenital diaphragmatic hernia with(out) ECMO: impaired development at 8 years

Marlous J Madderom¹, Leontien Toussaint², Monique H M van der Cammen-van Zijp^{1,2}, Saskia J Gischler¹, René M H Wijnen¹, Dick Tibboel¹, Hanneke IJsselstijn¹

¹Intensive Care and Department of Pediatric Surgery, Erasmus Medical Center-Sophia Children's Hospital, Rotterdam, The Netherlands

²Department of Rehabilitation Medicine and Physical Therapy, Erasmus Medical Center-Sophia Children's Hospital, Rotterdam, The Netherlands

Exome Sequencing Identifies Inherited Pathogenic Variants For Congenital Diaphragmatic Hernia

Paul D. Brady¹, Hilde Van Esch¹, Koen Devriendt¹, Joris Vermeesch¹, Jan Deprest².

¹ Centre for Human Genetics, KU Leuven, University Hospital Leuven, Belgium.

² Department of Development and Regeneration, Unit Pregnancy, Foetus & Newborn, KU Leuven & Obstetrics and Gynaecology, University Hospital Leuven, Leuven, Belgium.

Benefits Of The Intravenous Phosphodiesterase Inhibitors Sildenafil And Milrinone In Infants With Congenital Diaphragmatic Hernia

Anja Bialkowski, Florian Moenkemeyer, Neil Patel, Newborn Intensive Care Unit, Royal Children's Hospital, Melbourne

CDH Mortality Score: A validated clinical prediction rule to stratify patients with Congenital Diaphragmatic Hernia (CDH) based on their risk of mortality

M Brindle, E F Cook, P Lally, K Lally, CDH Study Group

Sildenafil Weaning Post-Discharge In Congenital Diaphragmatic Hernia

Joanne Behrsin¹, Michael Cheung², Neil Patel¹

¹ Newborn Intensive Care, Royal Children's Hospital, Melbourne, Australia, ² Paediatric Cardiology, Royal Children's Hospital, Melbourne, Australia

Intensive Care Of Newborns With Congenital Diaphragmatic Hernia In The Perinatal Center. Russian Experience

Burov AA, Podurovskaya YL, Zaretskaya NV, Nikifirov DV, Dorofeeva EI, Baibarina EN
Research Center for Obstetrics, Gynecology and Perinatology
Ministry of Healthcare of the Russian Federation

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The way to shorten the postoperative intubation period in neonates with congenital diaphragmatic hernia.

Osamu Kimura, Taizo Furukawa, Koji Higuchi, Yuuki Takeuchi, Shigehisa Fumino, Shigeyoshi Aoi, Tatsuro Tajiri
Department of Pediatric Surgery, Graduate School of Medical Science, Kyoto Prefectural University of Medicine, Kyoto, Japan

A Nationwide Survey Of Prosthetic Patch Utilisation In Newborns With Congenital Diaphragmatic Hernia

PD Losty¹, D Wilkinson¹, PRV Johnson², J Rankin³, S Marven⁴, L Draper⁵, D Howe⁶, M Knight⁷, J Kurinczuk⁷

¹ Alder Hey Children's Hospital University of Liverpool, ² University of Oxford, ³ University of Newcastle, ⁴ Sheffield Children's Hospital, ⁵ University of Leicester, ⁶ Southampton General Hospital, ⁷ National Perinatal Epidemiology Unit (NPEU) University of Oxford.

Low recurrence rate after Gore-Tex/Marlex composite patch repair for posterolateral congenital diaphragmatic hernia

Riehele KJ, Magnuson DK, Waldhausen JH
Department of Surgery, Children's Hospital and Regional Medical Center, University of Washington School of Medicine, Seattle, WA 98105, USA.

Family Bilateral Congenital Diaphragmatic Hernia

Burov AA, Podurovskaya YL, Zaretskaya NV, Ekimov AN, Trofimov DY, Lyapin VM, Schegolev AI, Baibarina EN
Research Center for Obstetrics, Gynecology and Perinatology
Ministry of Healthcare of the Russian Federation

Lung To Head Ratio In Infants With Congenital Diaphragmatic Hernias Does Not Predict Long Term Pulmonary Hypertension

Alejandro Garcia, MD, Abbey Fingeret, MD, Eunice Hahn, MD, Matthew Leskowitz, Gudrun Aspelund, MD, MS, Usha Krishnan, MD, Charles JH Stolar, MD, Columbia University, New York, NY, USA.

Recurrence After Thoracoscopic Congenital Diaphragmatic Repair In Neonates And Infants

Henry Chang, MD, Thomas T. Sato, MD, David M. Gourlay, MD, Casey M. Calkins, MD, Dave R. Lal, MD, John J. Aiken, MD, Keith T. Oldham, MD, Jessica Enters, BSN, Marjorie J. Arca, MD, Children's Hospital of Wisconsin, Milwaukee, WI, USA.

Pulmonary Radial Alveolar Count And Vascular Morphometry After Prenatal Temporary Gel Plug Occlusion Of The Fetal Trachea In A Rabbit Model Of Congenital Diaphragmatic Hernia

Ramy Elattal, BS, Barrie S. Rich, MD, Oliver J. Muensterer, MD, PhD.—Weill Cornell Medical College, New York, NY, USA.

Impaired Angiogenesis And Decreased Highly Proliferative Endothelial Cells In An Ovine Model Of Congenital Diaphragmatic Hernia

Shannon Acker, MD, Gregory Seedorf, Jason Gien, MD, David Partrick, MD, Steve Abman, MD, University of Colorado, Aurora, CO, USA.

Ex Utero Intrapartum Treatment To Extracorporeal Membrane Oxygenation (EXIT-to-ECMO) Strategy For Severe Congenital Diaphragmatic Hernia (CDH)

Naira Baregamian, Foong-Yen Lim, Sundeep G. Keswani, Jason S. Frischer, Beth Haberman, Paul Kingma, Mounira Habli, Ronald Jaekle, James Van Hook, William J. Polzin, Timothy M. Crombleholme.

Cincinnati Childrens Hospital Medical Center, Cincinnati, OH, USA.

Congenital Diaphragmatic Hernia Patients Treated With ECMO Are At Risk For Chronic Malnutrition Into Childhood

Daphne S Mous MD¹, Marjolein Spoel MD PhD¹, Laura Andriessen MD¹, Joanne Olieman PhD¹, Saskia J Gischler MD PhD¹, Rene MH Wijnen MD PhD¹, Dick Tibboel MD PhD¹, Hanneke IJsselstijn MD PhD¹

¹: Intensive Care and Department of Pediatric Surgery
Erasmus Medical Center – Sophia Children's Hospital, Rotterdam, The Netherlands

Prenatal Maternally-Administered PDE5 Inhibitors Increase Relative Expression Of Cyclic Gmp Pathway Proteins In Lungs Of Fetal Lambs With Diaphragmatic Hernia

Eveline H. Shue, MD, Samuel C. Schechter, MBBS, Muzziyar Etemadi, MS, Jianfeng Wu, Peter Oishi, MD, Jeffrey Fineman, MD, Jeffrey Fineman, MD, Doug Miniati, MD, University of California, San Francisco, San Francisco, CA, USA.

Pulmonary Support On Hospital Day-30 As A Predictor Of Long-Term Morbidity In Congenital Diaphragmatic Hernia Survivors

Ryan P. Cauley, MD, Nora M. Fullington, MD, Kristina Potanos, MD, Jonathan Finkelstein, MD, MPH, Dionne Graham, PhD, Ronald Becker, MD, Catherine Sheils, MD, Virginia Kharasch, MD, Charles J. Smithers, MD, MPH, Thomas Jaksic, MD, PhD, Terry Buchmiller, MD, Jay M. Wilson, MD, Boston Children's Hospital, Boston, MA, USA.

Maternal Medical And Behavioral Risk Factors For Congenital Diaphragmatic Hernia

Jarod P. McAteer, MD¹, Avram Hecht, MD, MPH², Anneclaire J. De Roos, PhD, MPH³, Adam B. Goldin, MD, MPH¹, ¹Seattle Children's Hospital, Seattle, WA, USA, ²University of California, San Diego, San Diego, CA, USA, ³University of Washington, Seattle, WA, USA.

Higher Costs, Charges And Resource Utilization Do Not Affect Survival In Congenital Diaphragmatic Hernia

Ryan P. Cauley, Kristina Potanos, MD, Nora Fullington, MD, Jonathan Finkelstein, MD MPH, Dionne Graham, PhD, Jay M. Wilson, MD, Boston Children's Hospital, Boston, MA, USA.

Single centre results and patient selection criteria for thoracoscopic repair of congenital diaphragmatic hernia in neonates

K. Zahn, T. Schaible, L.M. Wessel
UMM Mannheim, Germany

MicroRNA miR-200b rescues abnormal branching morphogenesis of nitrofen-induced hypoplastic lung explants.

Patricia Pereira Terra^{1,2,4,5}, Anouk Chantal Deden^{1,2,7}, Fuqin Zhu^{1,2}, Barb Iwasowi^{1,2}, Jorge Correia Pinto^{4,5,6}, Richard Keijzer^{1,2,3}

¹ Manitoba Institute of Child Health, ² Department of Surgery, ³ Department of Physiology, University of Manitoba, Winnipeg, Canada, ⁴Life and Health Sciences Research Institute (ICVS), School of Health Sciences, University of Minho, Braga, Portugal, ⁵ICVS/3B's - PT Government Associate Laboratory, Braga/Guimarães, Portugal; ⁶Department of Pediatric Surgery, Hospital de Braga, Braga, Portugal, ⁷ErasmusMC, Rotterdam, The Netherlands

Energy intake in infants with congenital diaphragmatic hernia (CDH).

B. Haliburton¹, M. Mouzaki², M. Chiang¹, A. Zweekin³, M. Marcon², T. Moraes³, P. Chiu¹.

¹ Division of Pediatric Surgery, ² Department of Pediatrics, Division of Gastroenterology, Hepatology and Nutrition, ³ Department of Pediatrics, Division of Respiratory Medicine, The Hospital for Sick Children, Toronto, ON, Canada.

What CDH Families Are Saying About CHERUBS



"CHERUBS - Congenital Diaphragmatic Hernia Research, Awareness and Support just sent me a goody box full of all kinds of baby stuff. Luna got socks, a hand print kit, hercherub wings, a precious moments book, some awareness bracelets and pins, a stuffed pink piggy, a tote bag and books for me, some onesies, pacis, tissues, a disposable camera, a John Deere pink blanket and some tummy cream & other things. I can't tell you what this means to us & how much we appreciate having an army of people supporting us. These are the happiest tears I've cried in sometime. Thanks so much guys!" - Tasha Hays

"After losing our precious grandson, Liam Anthony Hunt after 33 days to right-sided CDH, our family found CHERUBS. What a wonderful, compassionate organization filled with fabulous people who are knowledgeable, know what your going through, and are always always there for you. There are not enough words to describe this organization or express my sincerest gratitude. When my grief even 2 years later gets too much, I know I can always blog on CHERUBS and I know that I will always get responses that comfort me". Maria Farnsworth



"CHERUBS is such an amazing support group. Our lives have been blessed by CHERUBS more than I can put into words. They are at the head of supporting families, a supporter in CRH research and overall, just a wonderful charity. I'm so grateful for this wonderful organization in my life" - Hope Clyde

"It's almost 3 years to the day that I first found Cherubs, these members are like family to us. Amazing support and great friendships have formed all over the world. Our journey would be so much harder without this amazing Charity. Very grateful!" - Zoe Burcell



"Cherubs is such an amazing place for support, information, help for families and friends who have been touched by CDH. Today, my CDH survivor turned 30 years old. He is blessed with a healthy son. Cherubs us a place to turn for hope... its a place to share concerns, grief, information. Its a place to go when you feel as though you are alone with your concerns about anything related to CDH. I wish it were around when Michael was born. I have made amazing friends and have been able to direct people here to gather information as well as support. So grateful for Cherubs" - Gail Hyziak

"I have NEVER been involved with a more compassionate group of caring individuals as Cherubs. I have found many times that when I am in need of support or answers - Cherubs has been there for us -ALWAYS!" - Dawn Trodglen



"When my daughter was born 26 years ago there was no CHERUBS. You only had your family and friends who were very supportive and loving but it would have been so much better if CHERUBS had been around then. I did not find them until several years ago while doing a search on CDH and its affects on adult survivors. Very little is known about the affect on adult survivors or doctors that know much about the affects on them. We have met so many wonderful families and adult survivors. We have learned more from them than any adult doctor has ever been able to share.

My daughter, Casey and I have been involved with CHERUBS ever since. She is become the Texas State Rep for CHERUBS after a family get together in San Antonio a couple of years ago. Casey would not have become involved had CHERUBS not been the wonderful charity it is." - Lisa Carter



"CHERUBS is an extension of my family! When I thought there was nowhere to turn, just days before delivery, I was given love and support... by people who I didn't know, but knew what I was feeling and going through" - Nicki Young

"Where else could I go to find this kind of love, support, information and care? Thank you!" - Rikke Hammer



"CHERUBS helped me understand what my baby was up against!! It gave me hope when nothing else could!! Thank you from the bottom of my heart!!!" - Crystal Benitez

"I found out my daughter had LCDH at 24 weeks. The next day I found CHERUBS. They gave us hope. We saw survivors and knew we weren't going through this alone. They understood the jargon and I didn't have to explain the severity. They just knew" - Laura Henderson



"When we found out about CDH we were clueless and Cherubs sent us a care package which included a book which means the worlds to us. Its what helped us get through. We met another family in the same hospital whom also had a CDH baby, we lent them the book because they were like us clueless. Cherubs is amazing and work incredibly hard and nonstop to get the word out and support. Thank you Cherubs and all the amazing volunteers" - Norma Banda

"I first learned about CHERUBS 3 years ago when my grand daughter was diagnosed with CDH. I had never heard of CDH before this. I called and spoke with Dawn and she was awesome at listening to all my concerns and fears. It was nice to have someone to talk to who had already embarked on this horrifying journey. Two days after Maddie was born my daughter received a tote bag of hope in the mail it was great and very generous. I decided to become the Nevada State Representative volunteer in January 2012. CHERUBS website is the most comprehensive site with information on CDH!" - Patricia Houle

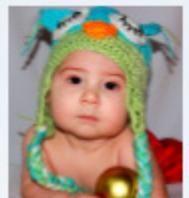
"Cherubs has been amazing over the last 14 years. My son was diagnosed before he was born and I had no clue what to expect. They were there for me, giving me information I couldn't find anywhere else. My son has been through many surgeries over the years and Dawn and other parents were there with me or just a phone call away" - Julie Younce



"As the director of the Pediatric Surgical Research Laboratories at Massachusetts General Hospital (MGH) (Boston, MA) and the Principal Investigator of a research study entitled, Gene Mutations and Rescue in Human Diaphragmatic Hernia (based at MGH and Boston Children's Hospital) that aims to understand better the genetic causes of congenital diaphragmatic hernia and pulmonary hypoplasia, our group has been honored to work with the CHERUBS association for over 6 years. CHERUBS has provided enormous support to many of our local New England families, as well as to those we have recruited both nationally and internationally. We look forward to presenting our research and interacting with new and returning families at the annual CHERUBS conferences. Dawn Williamson's professionalism in initiating and shepherding this dedicated group and their support of our genetic research has made an enormous impact on our efforts towards devising novel treatments for CDH and associated abnormalities of lung development" - Patricia Donahoe, MD



"Best organization I've ever seen everyone welcomes you with open arms & full of support, without CHERUBS I would be lost! Best of the Best!" - Eli Corea



Join the CDH Angel Club

Have you ever wanted to help CDH babies but aren't sure what to do?

Have you ever wanted to be a philanthropist?

Did you know that you can help fund CDH research, awareness and support for as little as 3 cents a day? Or if you skip Starbucks coffee for just 2 days a month for \$10, you can fund a CDH HOPE Totebag for a critically ill newborn baby? For \$100 a month you can fund materials for 5 hospitals to help 100's of newly diagnosed families understand what CDH is.



You CAN make a difference! Simply by making an automated, monthly tax-deductible donation, you are helping our charity to help babies born with CDH and their families. And you can even do so in honor or in memory of your own cherub.

Sign up now and as a thank you to you for your support, our charity will mail you a free 2014 Save the Cherubs desktop calendar (to the first 50 new CDH Angel Club members). You can view the calendar every day and be reminded that YOU are making a difference!

It's very easy and secure to sign up through PayPal on our web site .

Grab a pair of wings and help us raise Congenital Diaphragmatic Hernia awareness by participating in the Save the Cherubs campaign! We are especially in need of maternity and NICU photos, as well as candid photos of children in front of landmarks. Siblings welcome to participate. Visit www.savethecherubs.org for more information.



"Babies are such a nice way to start people." - Don Herold

Estate Planning & Charitable Giving to CHERUBS

Leave a legacy of helping children born with Congenital Diaphragmatic Hernia

When developing your estate plan, you can do well by doing good. Leaving money to charity rewards you in many ways. It gives you a sense of personal satisfaction, and it can save you money in estate taxes.

A few words about transfer taxes

The federal government taxes transfers of wealth you make to others, both during your life and at your death. In 2013, generally, the federal gift and estate tax is imposed on transfers in excess of \$5,250,000 and at a top rate of 40 percent. There is also a separate generation-skipping transfer (GST) tax that is imposed on transfers made to grandchildren and lower generations. For 2013, there is a \$5,250,000 exemption and the top rate is 40 percent.

You may also be subject to state transfer taxes.

Careful planning is needed to minimize transfer taxes, and charitable giving can play an important role in your estate plan. By leaving money to charity the full amount of your charitable gift may be deducted from the value of your gift or taxable estate.

This article is from Ameriprise.com and is for informational purposes only.

If you are interested in setting up a trust for our charity and need assistance, we are happy to refer you to a financial planner or an attorney who is familiar with our organization.

Make an outright bequest in your will

The easiest and most direct way to make a charitable gift is by an outright bequest of cash in your will. Making an outright bequest requires only a short paragraph in your will that names the charitable beneficiary and states the amount of your gift. The outright bequest is especially appropriate when the amount of your gift is relatively small, or when you want the funds to go to the charity without strings attached.

Make a charity the beneficiary of an IRA or retirement plan

If you have funds in an IRA or employer-sponsored retirement plan, you can name your favorite charity as a beneficiary. Naming a charity as beneficiary can provide double tax sav-

ings. First, the charitable gift will be deductible for estate tax purposes. Second, the charity will not have to pay any income tax on the funds it receives. This double benefit can save combined taxes that otherwise could eat up a substantial portion of your retirement account.

Use a charitable trust

Another way for you to make charitable gifts is to create a charitable trust. There are many types of charitable trusts, the most common of which include the charitable lead trust and the charitable remainder trust.

A charitable lead trust pays income to your chosen charity for a certain period of years after your death. Once that period is up, the trust principal passes to your family members or other heirs. The trust is known as a charitable lead trust because the charity gets the first, or lead, interest.

A charitable remainder trust is the mirror image of the charitable lead trust. Trust income is payable to your family members or other heirs for a period of years after your death or for the lifetime of one or more beneficiaries. Then, the principal goes to your favorite charity. The trust is known as a charitable remainder trust because the charity gets the remainder interest. Depending on which type of trust you use, the dollar value of the lead (income) interest or the remainder interest produces the estate tax charitable deduction.

Why use a charitable lead trust?

The charitable lead trust is an excellent estate planning vehicle if you are optimistic about the future performance of the investments in the trust. If created properly, a charitable lead trust allows you to keep an asset in the family while being an effective tax-minimization device.

For example, you create a \$1 million charitable lead trust. The trust provides for fixed annual payments of \$80,000 (or 8 percent of the initial \$1 million value of the trust) to ABC Charity for 25 years. At the end of the 25-year period, the entire trust principal goes outright to your beneficiaries. To figure the amount of the charitable deduction, you have to value the 25-year income interest going to ABC Charity. To do this, you use IRS tables. Based on these tables, the value of the income interest can be high—for example, \$900,000. This means that your estate gets a \$900,000 charitable deduction when you die, and only \$100,000 of the \$1 million gift is subject to estate tax.

Why use a charitable remainder trust?

A charitable remainder trust takes advantage of the fact that lifetime charitable giving generally results in tax savings when compared to testamentary charitable giving. A donation to a charitable remainder trust has the same estate tax effect as a bequest because, at your death, the donated asset has been removed from your estate. Be aware, however, that a portion of the donation is brought back into your estate through the charitable income tax deduction.

Also, a charitable remainder trust can be beneficial because it provides your family members with a stream of current income—a desirable feature if your family members won't have enough income from other sources.

For example, you create a \$1 million charitable remainder trust. The trust provides that a fixed annual payment be paid to your beneficiaries for a period not to exceed 20 years. At the end of that period, the entire trust principal goes outright to ABC Charity. To figure the amount of the charitable deduction, you have to value the remainder interest going to ABC Charity, using IRS tables. This is a complicated numbers game. Trial computations are needed to see what combination of the annual payment amount and the duration of annual payments will produce the desired charitable deduction and income stream to the family.



Fundraiser Awards

Every year at our annual conferences we acknowledge those families who go above and beyond to raise money for our charity. While we appreciate every single penny donated for our cause, we feel that the time and energy these families have put into fundraising deserves acknowledgement and gratitude. Awards are granted on a July - June schedule.

Would you like to hold a fundraiser in honor or in memory of your cherub? Contact our Fundraising Coordinators Karla and Lauren at fundraisers@cherubs-cdh.org with your ideas or if you need some suggestions on what type of fundraiser to hold. They will also make sure that you follow all laws and send you materials.



2012—2013 Award Winners

In honor and in memory of the following cherubs:

Jamie Abbott
Braiden Athony
Bryson Dobbs
Benjamin Gibson
Sierra Golden
Ally Hensley
Evie Hensley
Miles Johnson
Kaden Kruciak
Lillian Emma Olsen
Elizabeth Plakhholm
Tatum Ashley Larsen
Jak Parson Forshaw
Aidan Rubenstein
Penelope Lane Spencer
Charley Stanfield-Maher
Aidan Williams
Eli Willis
Blaire Alexandria Wise
Evelyn Yardley



Fundraising Kits are available in our store for nominal, refundable fees at

www.cherubs-cdh.org



CDH Scholarships Awarded

Congratulations to the recipients of the first 2 Oz-Kidd Ward Scholarships! Jessica Tunnel (cherub, pictured) and Melissa Young (sibling) both received \$1000 towards their college educations.



2014 CDH Calendars are now available!

Our CDH Awareness calendar features over 1600 cherubs - that is exactly how many CDH babies are born each year in the United States! Our Save the Cherubs calendars are available as well.

www.cafepress.com/cherubs



CHERUBS

3650 Rogers Rd #290
Wake Forest, NC 27687
USA



CHERUBS



Congenital Diaphragmatic Hernia has harmed over 700,000 children since 2000, taking the lives of over 300,000. Cause unknown.
www.SaveTheCherubs.org

CDH cherub Ethan Wiseman