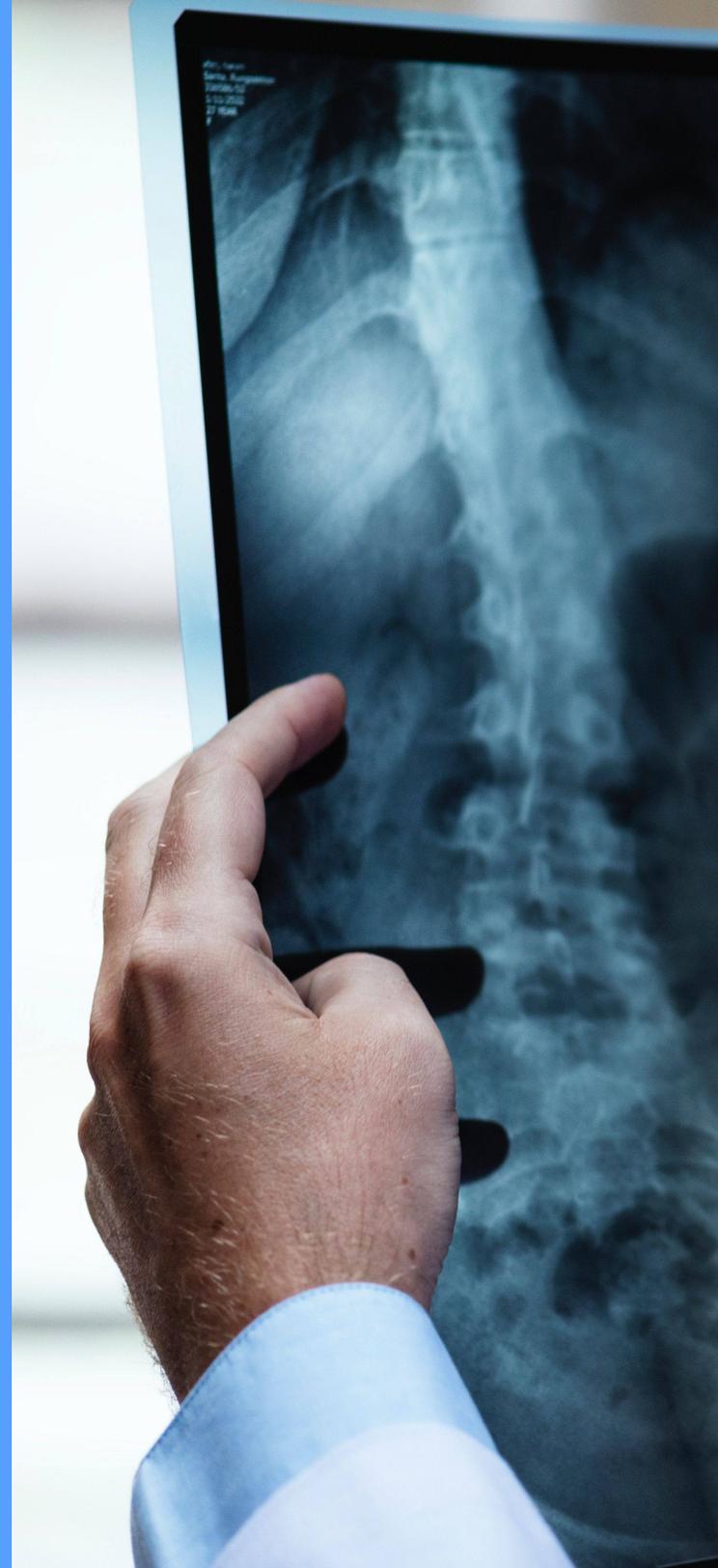




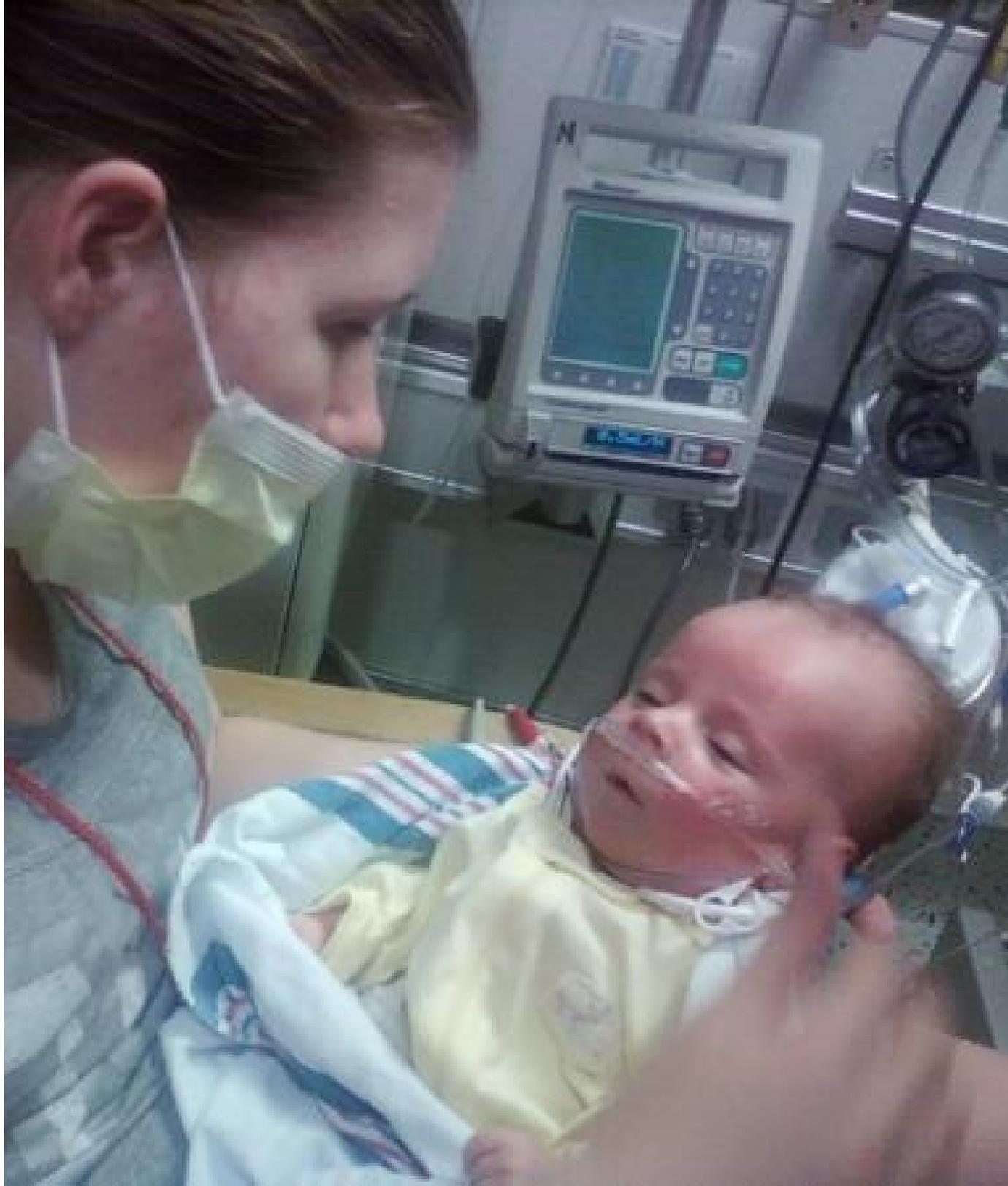
# CDH INTERNATIONAL

A global initiative to stop  
Congenital Diaphragmatic Hernia



## CDH International

CDH International is dedicated to finding the cause, prevention, and best treatments for Congenital Diaphragmatic Hernia while also supporting affected patients and families.





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# Letter from the President of CDHi

Dawn M. Torrence Ireland

*Dawn Ireland founded CHERUBS in 1995 after the 1993 birth of her son, Shane Torrence. Shane was born with undiagnosed left-sided Congenital Diaphragmatic Hernia (CDH) and spent his first 10 months in intensive care and came home on full-life support. At the time there were no support groups, no printed materials, and no internet. "CHERUBS - The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support" was started on Ms. Ireland's kitchen table with another mom, Rhonda Montague.*

*In the past 20+ years, CHERUBS has developed a wide international presence, helping over 6300 patient families in over 70 countries while leading the charge for Congenital Diaphragmatic Hernia awareness. The organization was renamed and restructured in 2017 to "CDH International" to focus on research while still maintaining CHERUBS as the family support division.*

*After overcoming many odds and becoming a happy, semi-normal child, Shane lost his battle in 1999. Ms. Ireland continues to lead the organization in the fight against CDH.*

As we blaze yet another new path in the world of patient advocacy and Congenital Diaphragmatic Hernia, CDH International is proud to announce the addition of new staff, new Medical Advisors, new projects and new Non-Government Organizations (NGO's) in the United Kingdom, Canada, and Italy.

Our goal is to continue to support families affected by Congenital Diaphragmatic Hernia, but as much as we love to hold hands and take part in the lives of thousands of patients and their families - support alone does not save children. With the restructuring of our organization into "CDH International" we are now focusing more on research and treatment of this devastating birth defect.

Congenital Diaphragmatic Hernia remains one of the most underserved populations despite the enormous number of cases. The race to find the gene(s) that cause CDH and whether or not there is an environmental trigger desperately needs funding. Once we accomplish this, gene therapy will become a possibility for these children.

There is still a great need for biological material for the repair of the diaphragm; a product that will grow with these children without causing infections or scoliosis. Currently Gore-Tex is still being used in a majority of repairs, which is the same material that was being used in the 1980's.

Pulmonary hypertension, feeding issues, developmental delays, and many other comorbidities of CDH still need to be investigated and solved.

It is unacceptable that we lose children to illnesses such as RSV, influenza, and pneumonia because there is no Standard of Care for CDH.

The greatest problem for our community right now is the desperate need for a Standard of Care for CDH, which is exacerbated by lacking standard measurements for morbidity and mortality.

CDH International was created for this purpose: To lead the charge for better care, to push for the creation of standards, and to raise the survival rate of patients with Congenital Diaphragmatic Hernia.

As we fight this battle, we also fight for more widespread CDH awareness and for more support, financial assistance, and clear information for families.

With you, our donors and supporters, we can truly make a difference in the lives of hundreds of thousands of patients and their families.



# Letter from the President of CHERUBS

Tracy L. Meats

The patient support division of CDH International

As CHERUBS enters in to its 25th year, I am proud of the strides and accomplishments we've made together for the CDH our community. Without our members, volunteers, and supporters our mission would not be possible.

In early 2017, I took on the support division of CDH International. CHERUBS remains to be dedicated to supporting families through their Congenital Diaphragmatic Hernia journeys.

CHERUBS continues to support over 6,000 families in all 50 states and over 70 countries. Through our services, we make sure that no family endures CDH without support or accurate information. Several of our services include our website/forums, CDH Hope Totebags, Parent Reference Guide, CDH Baby Book, financial assistance grants, CDH scholarships, Facebook support groups, local get-togethers, and an annual CDH conference.

Since January 2019, we have grown our volunteer staff to over 100 plus volunteers in almost every state and many countries internationally. We are parents, grandparents, survivors and friends and family members working together to fight CDH and make a difference in hundreds of thousands of CDH families.

CDH families worldwide need support and information, research funding, awareness, financial help, conferences and a safe place to go when faced with a CDH diagnosis. CHERUBS is a support environment where CDH families can come for a safe, kind and compassionate environment. Having volunteers all over the world, there is support available so no CDH family has to endure their journey alone.

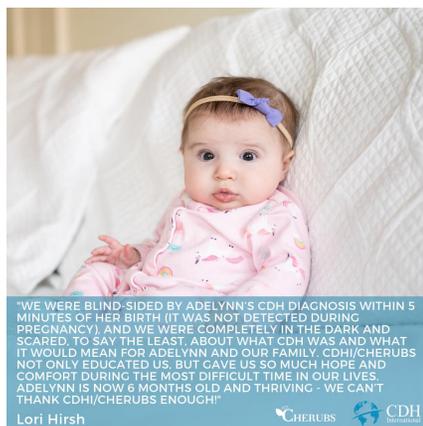
I have never been prouder to lead CHERUBS and I look forward to making a difference, together. Together, we can make a world of difference.

*Tracy L. Meats*



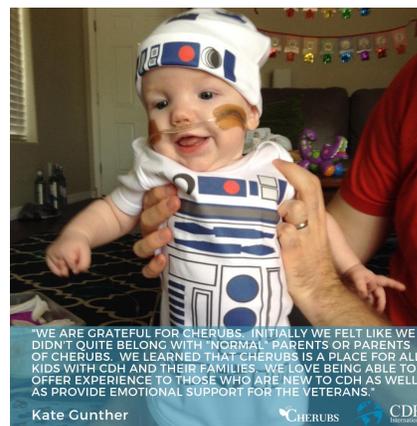
"CHERUBS HELPED US FIND A WAY TO HOLD ONTO HOPE DURING A TIME OF UNCERTAINTY."

Sarah Scribner



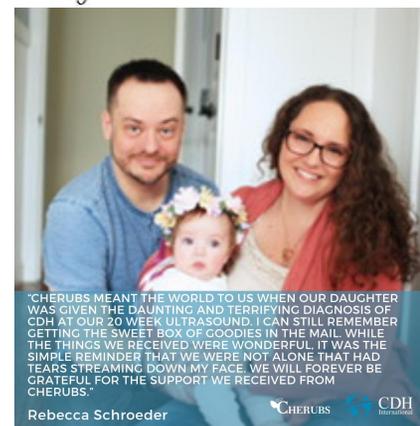
"WE WERE BLIND-SIDED BY ADELYNN'S CDH DIAGNOSIS WITHIN 5 MINUTES OF HER BIRTH (IT WAS NOT DETECTED DURING PREGNANCY) AND WE WERE COMPLETELY IN THE DARK AND SCARED. TO SAY THE LEAST, ABOUT WHAT CDH WAS AND WHAT IT WOULD MEAN FOR ADELYNN AND OUR FAMILY. CDH/CHERUBS NOT ONLY EDUCATED US, BUT GAVE US SO MUCH HOPE AND COMFORT DURING THE MOST DIFFICULT TIME IN OUR LIVES. ADELYNN IS NOW 6 MONTHS OLD AND THRIVING - WE CAN'T THANK CDH/CHERUBS ENOUGH!"

Lori Hirsh



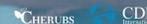
"WE ARE GRATEFUL FOR CHERUBS. INITIALLY WE FELT LIKE WE DIDN'T QUITE BELONG WITH "NORMAL" PARENTS OR PARENTS OF CHERUBS. WE LEARNED THAT CHERUBS IS A PLACE FOR ALL KIDS WITH CDH AND THEIR FAMILIES. WE LOVE BEING ABLE TO OFFER EXPERIENCE TO THOSE WHO ARE NEW TO CDH AS WELL AS PROVIDE EMOTIONAL SUPPORT FOR THE VETERANS."

Kate Gunther



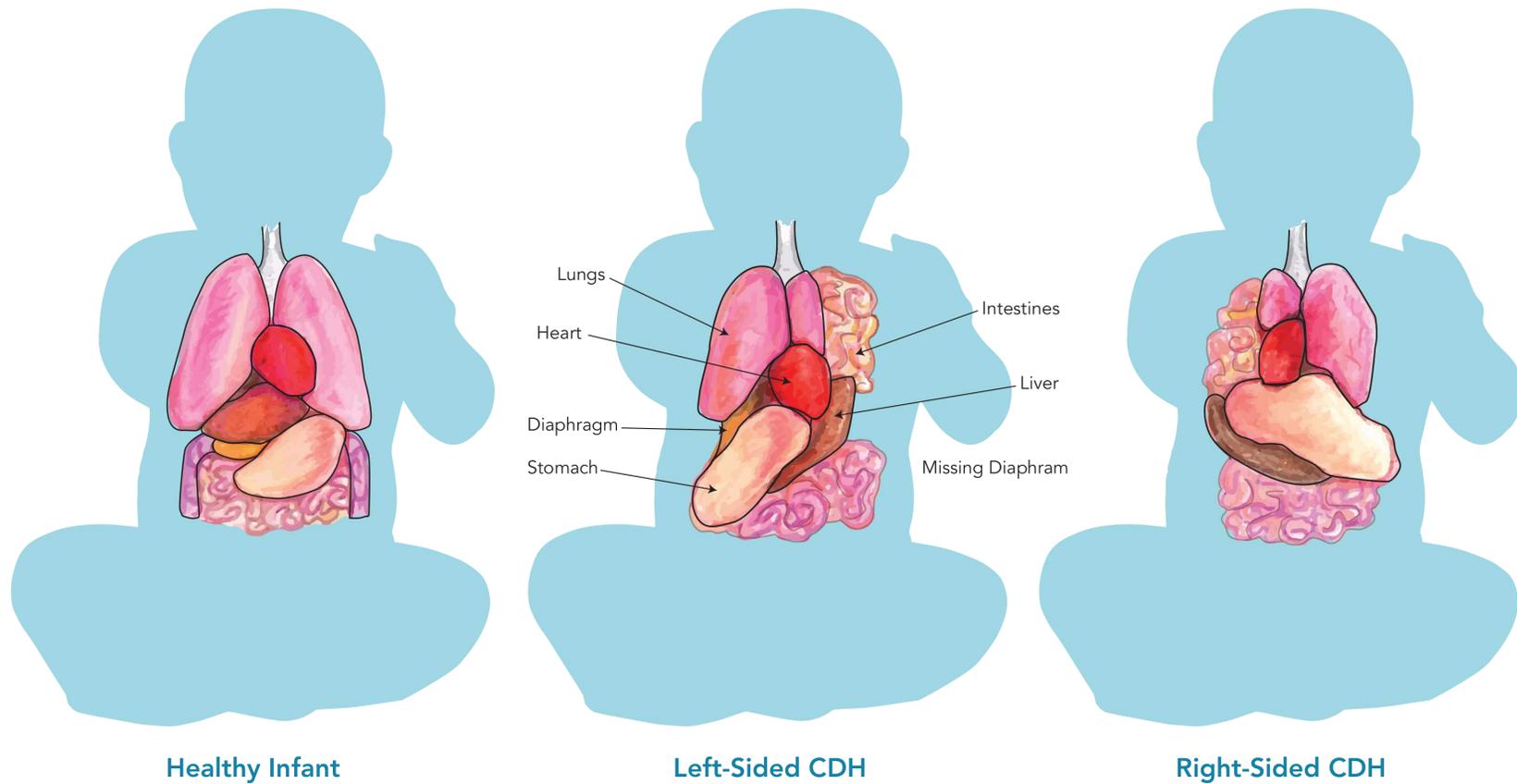
"CHERUBS MEANT THE WORLD TO US WHEN OUR DAUGHTER WAS GIVEN THE DAUNTING AND TERRIFYING DIAGNOSIS OF CDH AT OUR 20 WEEK ULTRASOUND. I CAN STILL REMEMBER GETTING THE SWEET BOX OF GOODIES IN THE MAIL. WHILE THE THINGS WE RECEIVED WERE WONDERFUL, IT WAS THE SIMPLE REMINDER THAT WE WERE NOT ALONE THAT HAD TEARS STREAMING DOWN MY FACE. WE WILL FOREVER BE GRATEFUL FOR THE SUPPORT WE RECEIVED FROM CHERUBS."

Rebecca Schroeder



## Congenital Diaphragmatic Hernia

CDH occurs when the diaphragm fails to fully form during pregnancy, allowing organs to migrate from the abdominal cavity into the chest cavity and thereby inhibiting lung growth. CDH strikes 1 in every 2500 babies, which equals 1600 babies every year in the United States. Every ten minutes, a baby is born with CDH. Fifty percent of babies diagnosed with Congenital Diaphragmatic Hernia do not survive. The cause is unknown.



# The CDHi Team

It takes a large army to fight Congenital Diaphragmatic Hernia. Our leadership team is listed below, and behind these leaders there are dozens of volunteers around the world who also work diligently to help the cause.

## Executive Board of Directors

Dawn Ireland, President

Tracy Meats, CHERUBS President

James Kornegay, Director

Warren Sumner, Director

Rhonda Montague, Director

## Parent Advisory Board

Tracy Meats, CHERUBS President

Darlene Silverman, Research

Nicolle Colvin, Fundraising

## Office Staff

Laura Tomczyk, Bookkeeping

Kamal Saleh, Programming

## Medical Advisory Board

N. Scott Adzick, MD, MMM, FACS, FAAP - Children's Hospital of Philadelphia

Kristin Aigner, RN, BSN - OSF St. Francis Medical Center

Badr Chaban, MD - Imperial College Healthcare NHS Trust

Priscilla Chiu, MD - Sick Kids, University of Toronto

Wendy Chung, MD, PhD - Columbia Presbyterian / DHREAMS

Jan Deprest, MD, PhD - University Hospital Gasthuisberg | Leuven, Belgium

Patricia Donahoe, MD - Massachusetts General Hospital

Mahmoud El Fiky, MD - Cairo University, Harvard University | Cairo, Egypt

Matthew T. Harting, MD - University of Texas Medical School at Houston, CDH Study Group

Gabrielle Kardon, MS, PhD - University of Utah CDH Lab

Richard Keitzer, MD, PhD, MS - University of Manitoba

Mauro Longoni, MD - Massachusetts General Hospital

Paul Losty, MD FRCSI FRCS(Eng) FRCS(Ed) FRCS(Paed) - Liverpool University | UK

Steadman McPeters, CPNP - Pediatric Surgery Nurse Clinician | Huntsville, Alabama

Henry Rice, MD - Duke University | Durham, NC

Giovanna Riccipetioni, MD - Ospedaledei Bambini Buzzi, Milan

Dick Tibboel, MD, PhD - Erasmus University MC, Sophia Children's Hospital | Netherlands

Jay Wilson, MD - University of Texas Medical School at Houston, CDH Study Group

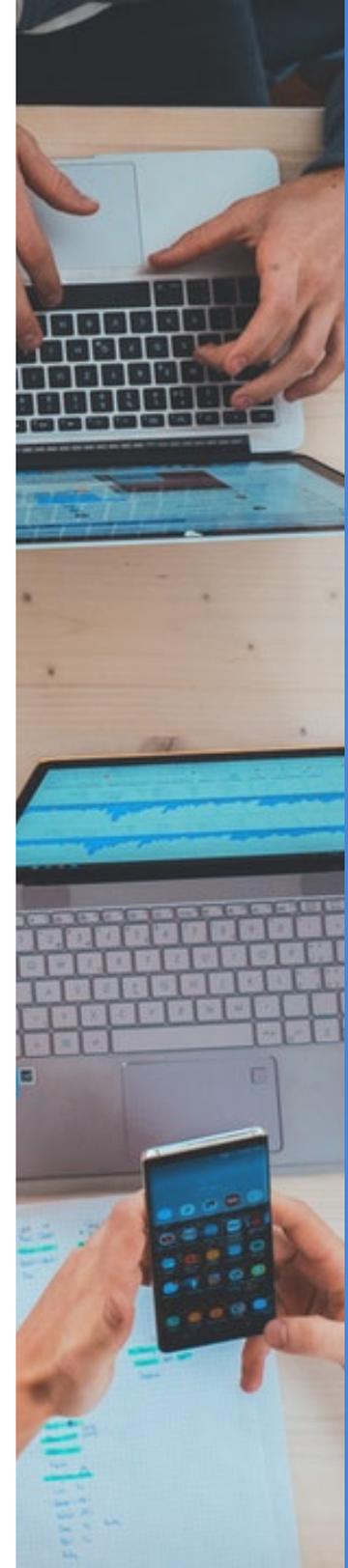
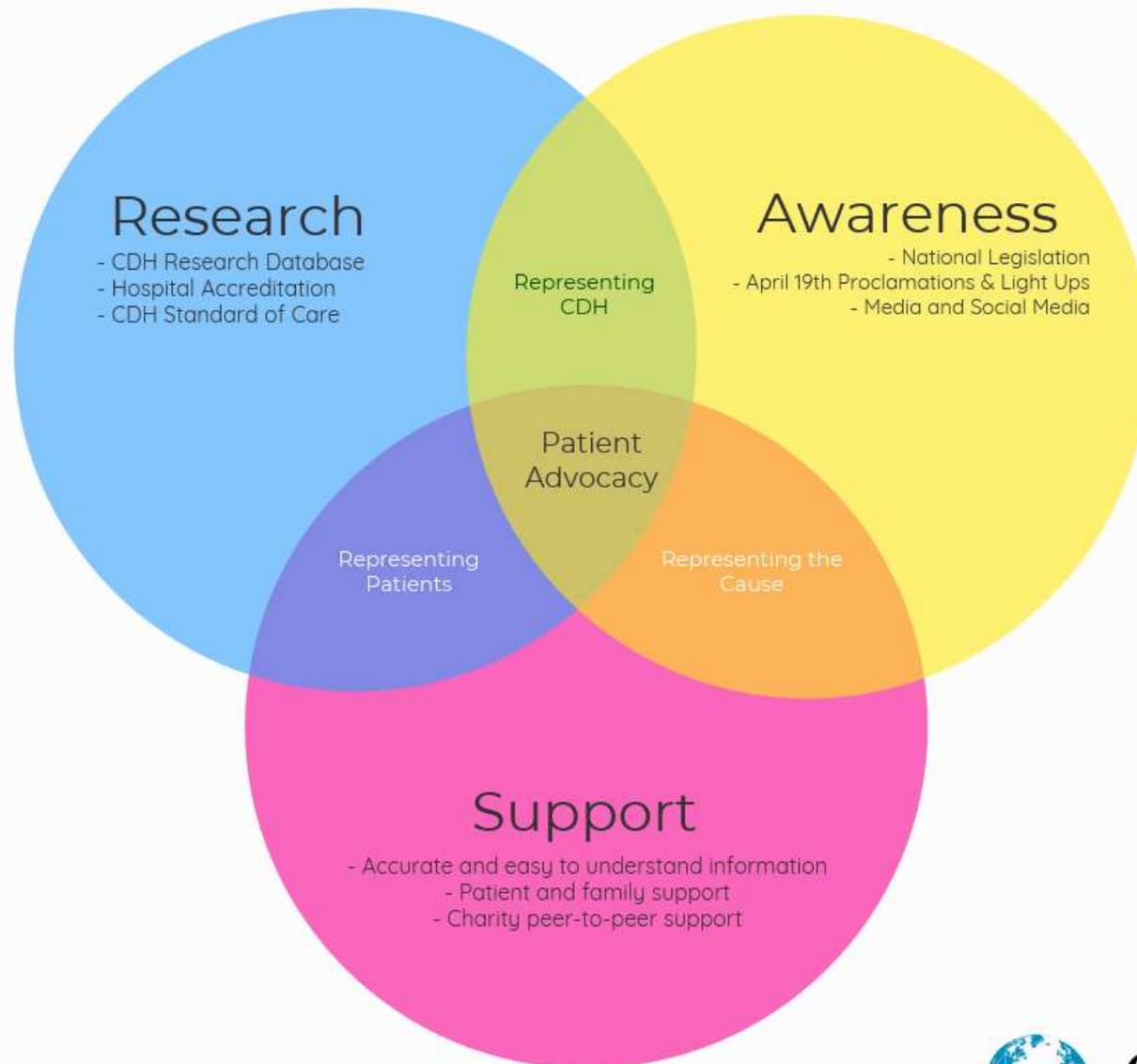
Naomi Wright, MBChB (Hons) BSc (Hons) MRCS DCH MSc - Global Initiative in Pediatric Surgery, London, UK

Edmund Yang, MD - Peace Health Sacred Heart Medical Center at River Bend

Augusto Zani, MD - Toronto Sick Kids Hospital



The roles of  
**CDH International**



# Congenital Diaphragmatic Hernia Awareness

Thanks to the hard work of our staff and volunteers, along with the collaboration of hospitals, doctors, and other non-profits, we have raised a large amount of CDH awareness thus far:

## CDH Awareness Day

April 19th is internationally observed as "Congenital Diaphragmatic Hernia Awareness Day" and is recognized with proclamations, legislation, parades, lighted landmarks, fundraisers, and other celebrations.

April 19th was chosen as CDH Awareness Day because on April 19, 2010, after two years of court proceedings, the trademark on "Congenital Diaphragmatic Hernia Awareness" was removed and CDH Awareness was once again free to be used by any person or entity without the threat or fear of legal action.

## CDH Ribbon

The official Congenital Diaphragmatic Hernia Awareness Ribbon was created in 2004 and was voted on by many families and charities. It is light blue, yellow, and pink with white clouds. It is the only officially recognized ribbon and is not owned by any one person or organization.

## CDH Legislation

Thanks to our efforts, proclamations to make April "Congenital Diaphragmatic Hernia Awareness Month" have been signed by all 50 governors and legislation has passed unanimously in the Senate and been introduced in the House since 2012.

## CDH Telethon

The first telethon for CDH took place on April 19, 2017 via Facebook and raised \$40,000. As far as we know, it was the first event of its kind for CDH on a social media platform.

We repeated this telethon every year and have raised over \$150,000 thanks to our staff, families, doctors, researchers, and celebrities we recruited to make appearances.

## Light Ups for CDH

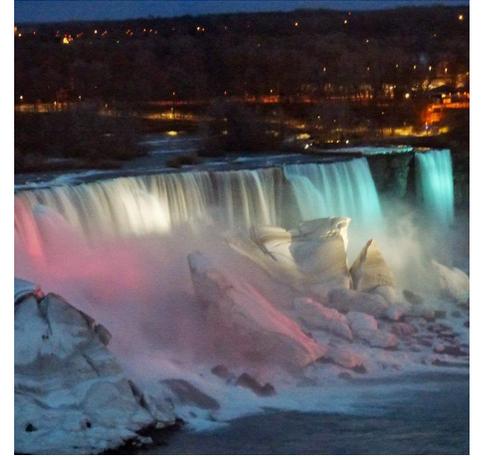
Eiffel Tower  
Niagara Falls  
Pyramids of Giza  
Blarney Castle  
CN Tower  
Mercedes-Benz Superdome  
Calgary Tower  
Bank of America  
Brant Street Pier  
Dublin City Hall  
BC Place  
Peace Bridge  
Sails of Light  
PECO Crown  
Science World  
British Columbia Parliament Building  
The Alberta Legislature Building  
Retirement Systems of Alabama  
Bank of America Plaza  
Zakim Hill Memorial Bridge  
Telus Spark in Calgary, AB  
High Level Bridge in Edmonton, AB  
WoodmenLife Tower in Omaha  
One Liberty Place Building  
Wells Fargo Duke Energy Center  
Miami Tower  
+ over 50 more

## Celebrity Support

We are grateful to the following celebrities for their guest appearances, video cameos, and social media assistance to help raise CDH awareness:

- Paula Abdul
- Rudy Abreau
- Action Jaxon
- Kim Alexis
- Paul Amos
- Sean Astin
- Lance Bass
- Kristin Bauer
- Boy George
- Billy Boyd
- Jaron Brown
- "Downtown" Julie Brown
- Dean Cain
- Michael Campion
- Justin Coleman
- Jose Conesco
- Randy Couture
- Chase d'Arnaud
- Luann de Lesseps
- Chris Daughtry
- Paula Deen
- David DeLuise
- Taye Diggs
- Dr Drew
- Colin Egglefield
- Melissa Ethridge
- Aja Evans
- Peter Facinelli
- Brett Favre
- Jeff Foxworthy
- Debbie Gibson
- Melissa Gilbert
- Bill Gilman
- Brian Austin Green
- Jared Goldberg
- Bret "the Hitman" Hart
- Melissa Joan Hart
- Larry Holmes
- Ernie Hudson
- Ice T
- Don Johnson
- Lolo Jones
- Sean Kingston
- Tawny Kitain
- David Koechner
- Lisa Lampanelli
- Joey Lawrence
- Charlie Lawson
- Kristen Ledlow
- Tommy Lee
- Rula Lenska
- Thaddeus Lewis
- Lil' Scrappy
- Kate Linder
- Ryan Lochte
- Kyle Lowder
- Clive Mantle
- Marla Maples
- Sylvester McCoy
- Ian McElhinney
- Danica McKeller
- Graham McTavish
- vic Mignogna
- Lee Montgomery
- Lance Moore
- Mandy More
- Sonja Morgan
- Matty Mullins
- Tim Murphy
- Kathy Najimy
- Vince Neil
- Oscar Nunez
- Gregg Olson
- Patsy Pease
- Jeremy Piven
- Mary Lynn Rajsku
- Chris Rankin
- Tony Ricca
- Emma Rigby
- Eric Roberts
- Bob "the Blade" Robinson
- Matt Roloff
- Milena Roucka
- Austin 'Chumlee' Russell
- John Schneider
- Drew Seeley
- Jeff Sessions
- Charles Shaunnessy
- Charlie Sheen
- Hilary Shepard
- Juliet Simms
- Kevin Smith
- Dee Snider
- Kevin Sorbo
- Tori Spelling
- Christie Swanson
- Lea Thompson
- Jack Wagner
- Andrew Walker
- Aaron Watson
- Chris Weidman
- Larry Wilcox
- William Wisher
- Elijah Wood
- Craig Robert Young
- Jacob Young





# CDH Awareness Projects

## Masquerading Angels Ball

Join us every October in Raleigh, North Carolina, for our annual fundraising and awareness gala. Formal costumes, a casino, a live band, silent auctions, and more activities provide a fun and festive backdrop for sharing the stories of struggles with CDH and encourage community engagement in our cause.

## Save the Cherubs Campaign

The majority of the 50% of patients who survive Congenital Diaphragmatic Hernia, look "normal" on the outside. This is wonderful for the survivors, but not great for awareness. Unlike patients with more visible medical conditions, our survivors look misleadingly healthy. To help raise awareness, we put wings on our survivors for photo shoots, and families of non-survivors photograph wings all around the world.

## Dear Nicholas Sparks

Every day in 2015, members of our charity wrote letters to the author Nicholas Sparks to implore him to feature Congenital Diaphragmatic Hernia in one of his world-famous books and, in turn, into a movie.

## CDH Awareness Shop

We have many great items for sale in our online shop, with all proceeds going directly to help the cause. Shop at [www.CDHAwarenessShop.org](http://www.CDHAwarenessShop.org)

## Events & Fundraisers

Our charity and supporters have held many events and fundraisers over the years, from bake sales and car washes to benefit concerts and parades on Capitol Hill. From gatherings in large metropolitan cities such as Chicago, Phoenix, Seattle, and Dallas to jumping four stories into an air mattress, we are dedicated to doing whatever it takes to save the lives of CDH children.



# Over 300,000 children have been born with Congenital Diaphragmatic Hernia Since 2000

Over 150,000 of these children did not survive.

**50 %  
SURVIVAL**

- 💡 Every race
- 💡 Every religion
- 💡 Every gender

**1** IN EVERY 2500 BABIES  
is diagnosed with Congenital Diaphragmatic Hernia.

 1600 a year in the US

**85%**

ARE DIAGNOSED IN UTERO

During return pre-natal ultrasounds, usually at 20 weeks gestation. 15% are still not diagnosed until birth.



**An Entire Elementary School**

In population of CDH kids (800) disappears every year in the US

**Every 10 minutes,  
a baby is born  
with CDH**



# Congenital Diaphragmatic Hernia has the exact same occurrence rate (1:2500) as:

Numbers based on NIH-posted funding and information from websites of individual charities.

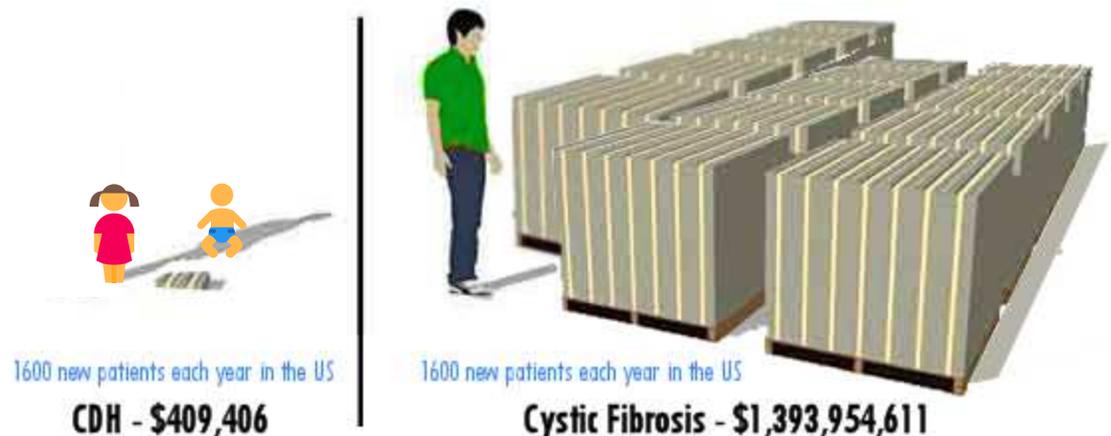


# 3406 to 1

is spent on CDH compared to every dollar spent on Cystic Fibrosis

2 great causes.

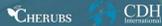
1 population invisible to the world.





"CHERUBS PROVIDED A COMMUNITY OF COMFORT, CONNECTION, KNOWLEDGE, UNDERSTANDING, AND COMPASSION FROM THE MOMENT WE WERE GIVEN OUR SON'S DIAGNOSES."

Kasey Leidy



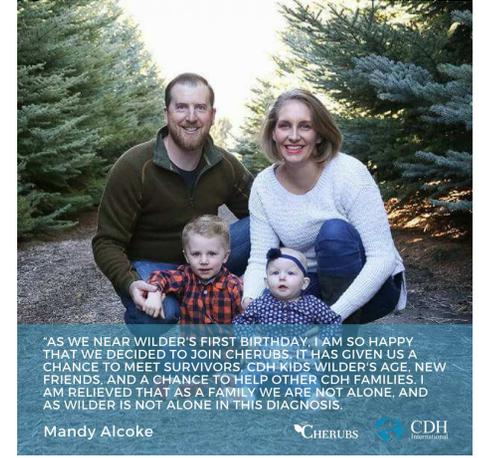
CHERUBS HAS HELPED ME IN SO MANY WAYS I CANNOT EVEN LIST THEM ALL... THEY HAVE BECOME MY SUPPORT NETWORK, MY BEST FRIENDS, AND MY FAMILY. IT'S AMAZING THE PEOPLE WHO YOU MEET DUE TO THE BIRTH DEFECT THAT STICK BY YOUR SIDE THROUGH THICK AND THIN, AND UNDERSTAND WHAT YOU'RE GOING THROUGH. KNOWING MY SON WILL BE ABLE TO TALK TO OTHER PEERS WHEN HE'S OLDER ABOUT HIS AND THEIR EXPERIENCE IS ALSO A BLESSING!

Danielle Sheffield



"WE FOUND CHERUBS SHORTLY AFTER OUR SON LIAM WAS DIAGNOSED WITH CDH. IT WAS HELPFUL TO READ OTHER PARENT'S STORIES AND KNOW WE WERE NOT ALONE. WE HAVE MADE LIFELONG FRIENDSHIPS WITH PEOPLE THROUGH CHERUBS."

Patric and Katie Shields



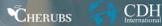
"AS WE NEAR WILDER'S FIRST BIRTHDAY, I AM SO HAPPY THAT WE DECIDED TO JOIN CHERUBS. IT HAS GIVEN US A CHANCE TO MEET SURVIVORS, CDH KIDS WILDER'S AGE, NEW FRIENDS, AND A CHANCE TO HELP OTHER CDH FAMILIES. I AM RELIEVED THAT AS A FAMILY WE ARE NOT ALONE, AND AS WILDER IS NOT ALONE IN THIS DIAGNOSIS."

Mandy Alcoke



"CHERUBS HAS HELPED US RAISE AWARENESS AND EDUCATE OTHERS THIS BIRTH DEFECT EXISTS AND NEEDS SUPPORT! THEY WERE THERE WHEN WE NEEDED THEM SO WE HAVE A FUNDRAISER EVERY YEAR "DANCING WITH REESE" TO RAISE MONEY FOR THEM!"

Christine Daly



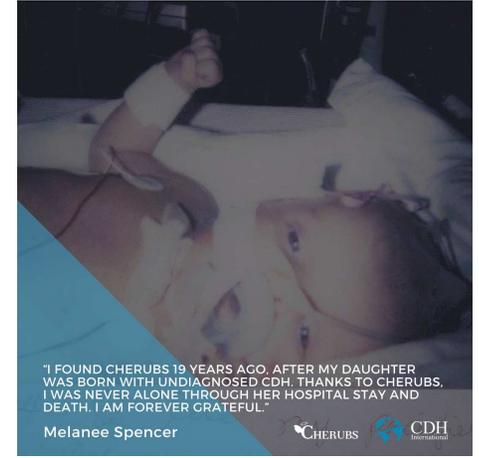
"WHEN MY CAMDEN PASSED, I FELT THE LOVE AND I KNEW I WAS NOT HURTING ALONE, BECAUSE CHERUBS WELCOMED US INTO THE COMMUNITY OF FAMILIES WHO HAVE TRAVELED THE SAME ROAD."

Corey and Robbie Fletcher



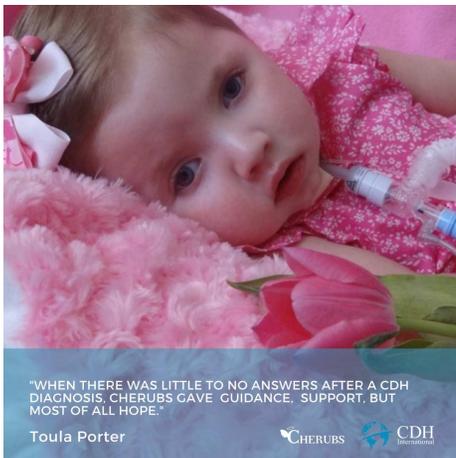
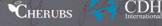
"THANK YOU [CHERUBS] FOR YOUR CONTINUED EFFORTS TO RAISE AWARENESS FOR CDH. ALTHOUGH WE ARE DEEPLY HUMBLD AND THANKFUL FOR REBEL'S PROGRESS, OUR MINDS BOGGLE FOR THOSE WHO ARE STILL FIGHTING AND OUR HEARTS ACHE FOR THOSE WHO HAVE RECEIVED THEIR WINGS. IT IS OUR PRAYER THAT ALL BABIES CAN SURVIVE. WE VOW TO JOIN THE FIGHT FOR ALL CHERUBS, BECAUSE THEY ALL DESERVE TO COME HOME!"

Savana and Jamar Williams



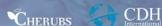
"I FOUND CHERUBS 19 YEARS AGO, AFTER MY DAUGHTER WAS BORN WITH UNDIAGNOSED CDH. THANKS TO CHERUBS, I WAS NEVER ALONE THROUGH HER HOSPITAL STAY AND DEATH. I AM FOREVER GRATEFUL."

Melanee Spencer



"WHEN THERE WAS LITTLE TO NO ANSWERS AFTER A CDH DIAGNOSIS, CHERUBS GAVE GUIDANCE, SUPPORT, BUT MOST OF ALL HOPE."

Toula Porter



"IT WAS SO NICE TO HAVE THE SUPPORT OF OTHERS WHO HAVE BEEN THROUGH IT. WE ALSO BECAME FRIENDS WITH OTHER LOCAL CHERUBS FAMILIES, AND WERE ABLE TO CONNECT WITH OTHER MEMBERS AT THE HOSPITAL BEFORE AND AFTER OUR SON WAS BORN. WE WOULD HAVE BEEN LOST WITHOUT THE SUPPORT WE RECEIVED!"

Emily Green



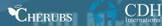
"WE FOUND CHERUBS RIGHT AFTER OUR SON'S DIAGNOSIS OF CDH AT OUR 21 WEEK ULTRASOUND. WE WERE TERRIFIED AND FELT ALONE. THE CHERUBS COMMUNITY SHOWED US THAT THERE WAS HOPE AND WRAPPED US IN LOVE. THE COMMUNITY CONTINUES TO EDUCATE AND HELP US BEYOND ROWAN'S CDH REPAIR SURGERY, AND FOR THAT, WE ARE ETERNALLY GRATEFUL."

Emily Taylor



"CHERUBS GAVE MY HUSBAND AND I THE HOPE AND STRENGTH TO BE BRAVE WHEN ALL EXPERTS SAID OUR DAUGHTER PROBABLY WOULDN'T SEE HER FIRST BIRTHDAY"

Ammie Gray



# CDH Internationally

As of 2020, CDH international works with families in over 74 countries by providing support and information.

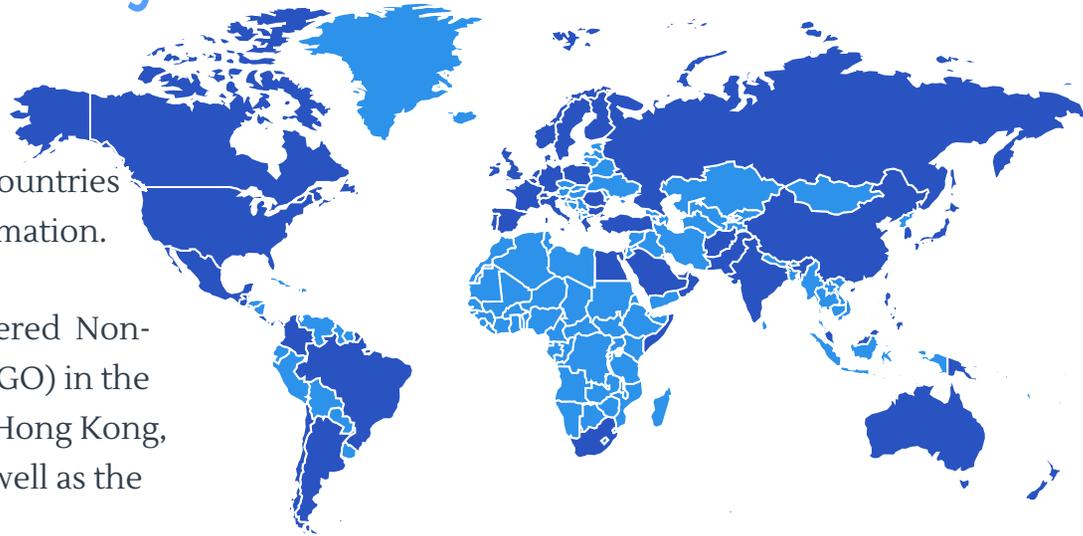
As of 2020, CDH is now a registered Non-Governmental Organization (NGO) in the United Kingdom, Switzerland, Hong Kong, the Netherlands, Singapore as well as the US.

CDH International collaborates with many hospitals, labs, and other charities across the globe on various projects and has become the voice of the CDH community, representing the patient population, pushing research initiatives and leading fellow organizations.

Our greatest collaboration in the patient advocacy community is the co-founding of the Alliance of Congenital Diaphragmatic Hernia Organizations (ACDHO). ACDHO is a group of like-minded, registered, professional, peer supportive non-profits who seek help the CDH community as a whole. For a full list of organizations in the alliance, visit [www.acdho.org](http://www.acdho.org)

CDH International is proud to mentor several organizations in ACDHO as well as leaders of other medical non-profit organizations and is an active advocate in the international rare disease community, working towards helping all patients across the globe diagnosed with rare or little-known diseases, genetic anomalies and birth defects.

*"The people who are crazy enough to think they can change the world are the ones who do." – Steve Jobs*



# CDH Research

For over 25 years, CDH International has been the world's largest supporter for research into Congenital Diaphragmatic Hernia. Our goal is to raise over \$1,000,000 for research in the next five years to find the cause, prevention, and best treatments for this debilitating defect.

## CDH Patient Registry

In 1997, CDH International (then CHERUBS) created the first Natural History Study of Congenital Diaphragmatic Hernia.

Now, over 6500 patients are registered in this database. Information from this database has been presented at multiple medical conferences and is 1 of 3 global CDH databases that compliment each other to provide a better overview of the birth defect.

You can view the de-identified results at [www.cdhresearch.org](http://www.cdhresearch.org)

## NIH, EU, and WHO

CDH International is proud to work with the National Institutes of Health on the Kids First Database Project, the Friends of NICHD committee, the European Union ERN initiative, and the World Health Organization.

## Publications

In 2021, CDH International will be published in several research journals publishing joint studies with universities.

## Collaborations

CDH International works with many universities and hospitals to co-author research abstracts and/or represent the Congenital Diaphragmatic Hernia community. We are also working towards a joint database effort between CDHi, Columbia University / DHREAMS and the University of Texas / CDH Study Group.

- International CDH Study Group
- Alliance of Congenital Diaphragmatic Hernia Organizations (ACDHO)
- World Health Organization
- World Health Summit
- European Reference Networks at the EU
- Capitol Hill
- National Institutes of Health
- Global Initiative for Children's Surgery
- American Pediatric Surgical Association
- American Pediatric Surgical Nurses Association
- American Academy of Pediatrics
- Pacific Association of Pediatric Surgeons
- Global Rare Disease Conference
- British Pediatric Surgical Association
- ELSO
- US Orphan Drug Conference
- Rare Disease and Orphan Products Breakthrough Summit
- RARE Patient Advocacy Summit
- Scientific Symposium at the Congress of jENS
- qPharma Pricing & Market Access Conference Speaker
- World Orphan Drug Conference
- Global Genes
- National Organization of Rare Disorders
- Canadian Organization of Rare Disorders
- International Conference on Surgery and Anaesthesia
- Pediatrics and Pediatric Surgery
- ICCN
- World Congress in Fetal Medicine
- World Congress on Pediatrics
- Perinatal Medicine
- UENPS
- National and International Media



# Congenital Diaphragmatic Hernia

## The History of CDH and CHERUBS

1570

CDH Discovered

1575



**1575** - Diaphragmatic Hernia was first described by Pare' in reporting two autopsies of adults who had acquired diaphragmatic hernias by trauma.

**1672** - The first description of Congenital Diaphragmatic Hernia was reported by Lazarus Riverius during the autopsy of an adult male. Miraculously, this man lived 24 years with CDH in the 17th century.

**1701** - Holt reported the first case of CDH in a child.

**1796** - Morgagni discussed various types of diaphragmatic hernia, including the anterior CDH that bears his name.

**1827** - Cooper described the symptoms, pathology, and classification of CDH.

**1834** - Laennec was the first to suggest a laparotomy that could be used to withdraw intestine from the chest cavity.

**1847** - Bowditch presented the first collected series of patients with diaphragmatic hernia in 1847 before the Boston Society for Medical Observation.

**1848** - Bochdalek described CDH that occurs posterolateral. This condition now bears his name.

**1888** - The first recorded attempt of a laparotomy to reduce the hernia was made by Naumann.

1600

1700

1800

## Successful Repair

1902



**1902** - The first reported successful operation on an infant born with CDH.

**1946** - Robert Gross reported the first successful repair of a CDH in a baby less than 24 hours old.

1940

## Pediatric ECMO

1976



**1976** - ECMO (Extracorporeal Membrane Oxygenation) was first used successfully in the treatment of persistent pulmonary hypertension.

**1976** - Doctors first used lambs to recreate CDH to research the cause and best treatments for CDH.

1970

## Open Fetal Repair

1989



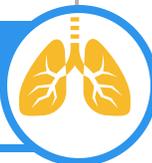
**1983** - Reversed Latissimus Dorsi Flap first used to repair CDH.

**1989** - Michael Harrison led the team at the UCSF in the first successful open fetal surgery for CDH.

1980

## Gentle Ventilation

1992



**1992** - First population-based study of CDH published by Claudine P. Torfs.

**1992** - "Gentle Ventilation" of CDH first began

**1994** - The first NIH-sponsored clinical trial for fetal surgery was done at UCSF for the open repair of Congenital Diaphragmatic Hernia.

1990

**1994** - The world's first CDH charity, Stichting Hernia Diafragmatic, was founded in the Netherlands.

**1995**



CHERUBS Founded

1995

**1995** - CHERUBS was started by two CDH moms and a typewriter on a kitchen table with a clear vision of providing CDH support, research, and awareness.

**1995** - The first CDH newsletter was published.

**1995** - First CDH Parent Reference Guide is released.

**1995** - Nitric Oxide first used in the treatment of CDH.

**1995** - The CDH Study Group was formed with medical professionals from the around the world with a vested interest in CDH.



CDHSG

1995

**1996** - CHERUBS becomes the first charity to attend APSA conference.

**1996** - First successful fetoscopic temporary tracheal occlusion for CDH was done at UCSF by Harrison and team.

**1996** - Exit to ECMO created to help newborn patients transition from womb to ECMO.

**1996** - Latisimus Dorsi flap first used to repair CDH.



CDH Web Site

1997

**1997** - First CDH listervs were created

**1997** - The first website for CDH information was created by CHERUBS.

**1997** - First successful open trachel clip used on a CDH patient in utero

**1999** - The first event for grieving CDH parents held in Washington, DC.

**1999** - FETENDO clip first used on a CDH patient.

**1999** - CHERUBS works with ABC's 20/20 for a fetal surgery story line.

**2000**



CDH Conference

2000

**2000** - The first international conference for families affected by CDH was held in Orlando.

**2000** - FETENDO balloon first used on a CDH patient.

2005

2001 - CHERUBS reaches 1000 families.

2002 - Massachusetts General genetic CDH study started

2004 - CHERUBS UK becomes a non-profit.

2005 - Baylor genetic CDH study started.

2006 - The first book about CDH, "Stories of Cherubs," is published.



ACDHO

2007

2007 - The Association of Congenital Diaphragmatic Hernia Organizations (ACDHO) was formed.



Awareness Ribbon

2007

2007 - The Official Congenital Diaphragmatic Hernia Awareness Ribbon was created by families of children born with CDH to help raise awareness and research of the birth defect.

2007 - The first online forum specifically for CDH was created.

2007 - CHERUBS Australia becomes a non-profit.

2007 - The first CDH awareness video was created.

2008

2008 - CHERUBS brings CDH awareness and support to social media via Myspace, Facebook, Blogger and Live Space.

2008 - First Financial Assistance Grant awarded to CHERUBS.

2008 - CDH HOPE Tote Bag project started as care packages to newly diagnosed families.

2010

**2008** - CHERUBS created the first website dedicated solely to free access of information for research of CDH.

**2009** - Soap Star, Patsy Pease, becomes first CDH Celebrity Spokesperson.

**2010** - CHERUBS defeats the trademark on "CDH Awareness" making the phrase free for everyone to use.



Lobbying for CDH

2012

**2012** - CHERUBS introduces legislation in both the US House and US Senate



CDH Research

2013

**2013** - CHERUBS presents to the CDH Study Group in Rotterdam, Netherlands.

**2014** - Scottish Diaphragmatic Hernia Clinical Network created.

**2014** - First International ACDHO Conference in Europe held in Dublin, Ireland

2015

Placental Pod

2015



**2015** - \$1,000,000 mark reached by CHERUBS.

**2015** - Artificial placenta created to duplicate the fetal womb environment.

**2015** - CHERUBS presents its research data to the CDH Study Group in Toronto, Canada.

2016

**2016** - Canadian Congenital Diaphragmatic Hernia Collaborative created.

**2016** - Joint research abstract with Toronto Sick Children's to the American Academy of Pediatrics.

2017



2017 - CDH Study Group meets in Liverpool, England

2017 - CDHi speaks at the CDH Study Group Conference in Liverpool, in attendance with leaders of 3 other CDH charities in ACDHO

2017 - CHERUBS was restructured into CDH International

2017 - CDH Research Database unveiled.

2017 - Multi-disciplinary committees for CDH Accreditation have begun

2018 - CDHi joins the Global Pediatric Surgery initiative, GICS, and speaks in India

2018 - ACDHO creates the first CDH Charity Charter

2018

2018 - CDH Study Groups begin the path to establish a Standard of Care for CDH in the United States

2018 - The Canadian CDH Collaborative creates a Clinical Practices Guideline for CDH Phone App



2018 - CDHi first visits the World Health Organization

2018 - CDHi represented CDH patients at the World Health Summit

2018 - CDHi moves to join ERNICA, as part of the European Research Network

2018 - CDHi begins NGO registration in the United Kingdom and Italy

2018 - CDHi participates in / speaks in medical conferences in 33 countries

2019



**2019** - CDHi raises \$2,000,000

**2019** - CDHi opens first office in Europe

**2019** - CDHi visits WHO again

**2019** - CDHi President appointed CDH Liason for NICHD Gabriella Miller Kids Fund

**2019** - Nashville CDH Family Conference

**2019** - New CDHi Web Site

**2019** - CDHi participates / speaks at over 40 medical conferences in 9 countries

2020



**2020** - CDH Study Groups meets in Houston

**2020** - First Draft of Global Standard of Care for Congenital Diaphragmatic Hernia

**2020 - CDH International Turns 25 Years Old**

**2020** - CDH Patient Registry converts to new platform with over 6500 cohorts

**2020** - CDH International becomes a registered charity in the United Kingdom

**2020** - CDH International becomes a registered charity in the Netherlands

**2020** - CDH International becomes a registered charity in Hong Kong

**2020** - CDH International becomes a registered charity in Switzerland

**2020** - CDH International becomes a registered charity in Singapore

**2020** - CDH International creates the first phone App for patient families

**2020** - CDHi participates / speaks at over 20 medical conferences, including the CDH Study Group Conference and the Global Initiative for Children's Surgery meeting in Johannesburg, South Africa

# CDH Centers of Excellence

Accreditation as a CDHi Center of Excellence signals to patients and families that a facility has committed to exceptional care and treatment of Congenital Diaphragmatic Hernia. It demonstrates to the healthcare community an assurance of high quality standards, specialized equipment, and advanced education of staff members. CDHi Centers may, in turn, use the accreditation to market themselves as distinguished leaders in CDH care, highlighting their commitment to state-of-the-art healthcare advancements.

To ensure that CDH patients continue to experience gains in quality of treatment and quality of life, CDHi helps accredited centers establish a standard of CDH care with specific guidelines that are based on the latest research, medical evidence, and consultation with experts.

## "Nothing About Us, Without Us"

It has become standard practice for large medical non-profits and associations to create Accreditation to help push and fund research, raise standards of care, provide more information to patients and to encourage the community to achieve excellence. The goal is to help medical care providers, not hinder them.

Partnership between hospitals and advocacy groups is the key to better medical care, accurate information for patients and informed decisions by patients / parents.

From the Cystic Fibrosis Foundation to the Spina Bifida Association to ELSO, accreditation is commonplace in hospitals. In 2018, patient advocacy is now in the forefront of medical care, with researchers working with subjects to progress farther, faster.



## Anticipated Outcomes of CDHi Accreditation

1. Patients are better informed about comprehensive CDH care.
2. Patients have improved access to Centers with expertise in CDH.
3. The medical community is better informed about standards of CDH care.
4. Long-term outcomes of CDH are improved through Clinical Care Guidelines.
5. Increased opportunities for collaboration between Centers, CDH researchers, and patients.

## Benefits of CDHi Centers of Excellence

1. Accountability – patients, parents, and insurance companies are ensured that quality care standards are met and statistics are accurate.
2. Ideas for improvement – host Centers and site visitors benefit from visits to other CDHi Centers of Excellence.
3. Securing resources from host institutions – when a CDHi Center of Excellence meets requirements set forth by the accreditation process, this encourages the host institution (University, hospital, etc) to support the Center in meeting these requirements.
4. Public recognition of excellent performers – CDHi Centers of Excellence can be the pride and joy for their host institutions.
5. CDHi Centers of Excellence are eligible to apply for research funding through CDH International.
6. CDHi Centers of Excellence are more attractive to research funders such as NIH and private foundations.
7. CDHi Centers of Excellence are easily identifiable and more attractive to expectant parents researching medical care for unborn patients.



# Learning From Others

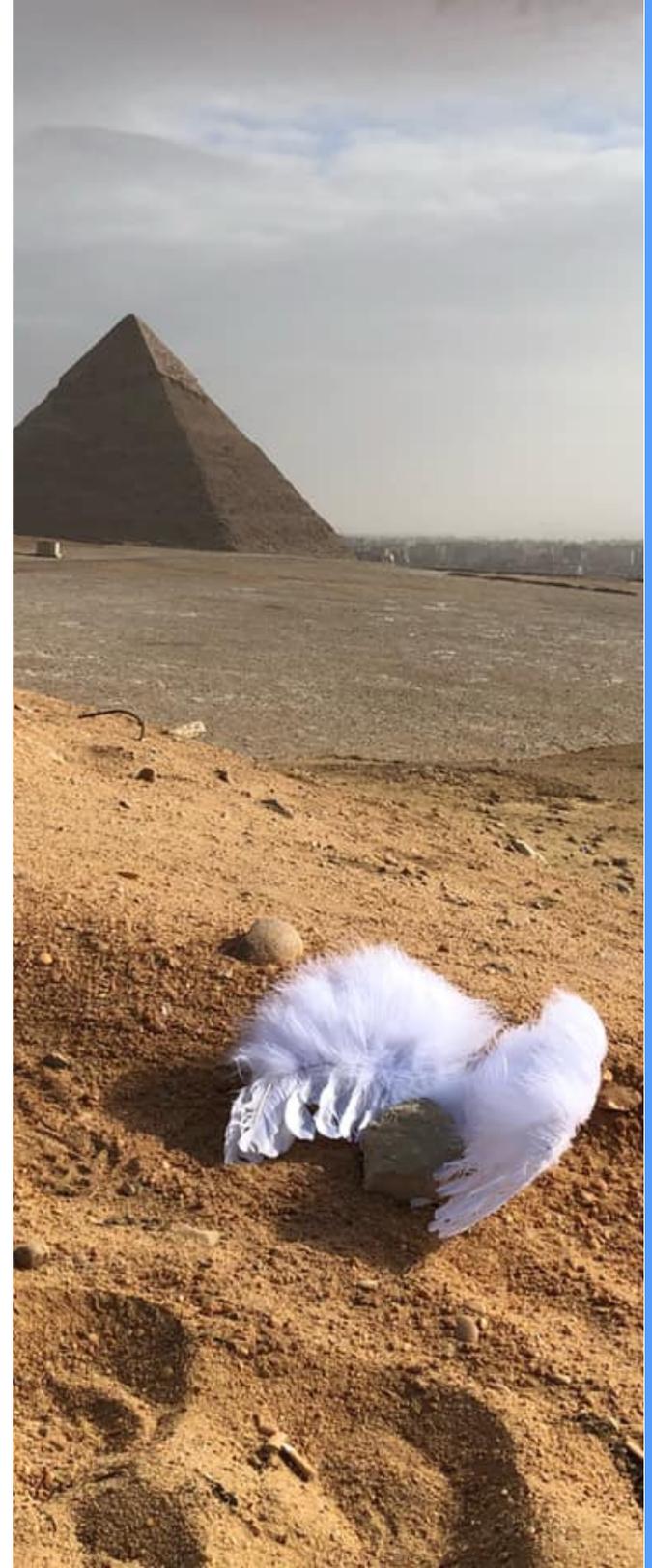
## Other Cause Leaders That Accredit Hospitals:

- Cystic Fibrosis Foundation
- ELSO (ECMO Organization)
- American Heart Association
- Muscular Dystrophy Association
- United Cerebral Palsy
- Parkinson's Foundation
- ALS Association
- Tourette Association
- American Cleft Palate-Craniofacial Association
- International Diabetes Federation
- Congenital Hyperinsulinism International
- Association for Bladder Exstrophy Community

*Hospital accreditation has been defined as “A self-assessment and external peer assessment process used by health care organizations to accurately assess their level of performance in relation to established standards and to implement ways to continuously improve.”*

## Countries With CDH Standards of Care

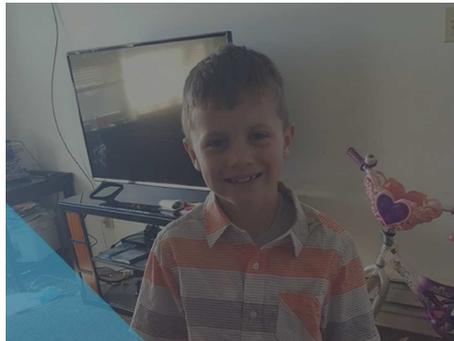
- Australia
- Canada
- Japan
- EURO CDH Consortium





"JUST AFTER DIAGNOSIS, AND AMID THE DEVASTATION, WE WERE SO RELIEVED TO FIND CHERUBS. IT GAVE US A SENSE OF PEACE, COMFORT, AND HOPE."

Stacy Wilshusen



"CHERUBS HELPED ME THROUGH MY SON'S RECOVERY WHILE I WAS JUST 17 YEARS OLD. THE ORGANIZATION SHOWED ME THAT I WASN'T ALONE. CDH HAS TAUGHT ME TO APPRECIATE ALL THE MOMENTS IN LIFE, WHETHER GOOD OR BAD."

Sarah Justice



"WE FOUND CHERUBS SHORTLY AFTER OUR SON LIAM WAS DIAGNOSED WITH CDH. IT WAS HELPFUL TO READ OTHER PARENT'S STORIES AND KNOW WE WERE NOT ALONE. WE HAVE MADE LIFELONG FRIENDSHIPS WITH PEOPLE THROUGH CHERUBS."

Patric and Katie Shields



"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



"CHERUBS WAS MY LIGHT IN A VERY DARK TIME. BROUGHT ME IN CONTACT WITH OTHERS WHO KNEW WHAT I WAS GOING THROUGH. I HAVE MADE LIFE LONG FRIENDS DUE TO CHERUBS"

Tara Hiles-Hall



"WHEN WE GOT OUR CDH DIAGNOSIS WE ALSO GOT SOMETHING MORE - AN ENTIRE EXTENDED FAMILY FULL OF ENCOURAGEMENT, LOVE AND SUPPORT. WE ARE BEYOND THANKFUL TO CHERUBS FOR THAT."

Shaun and Justine Kelly



"WE DIDN'T FIND CHERUBS UNTIL MICAELA WAS ABOUT 12 YEARS OLD. THROUGH THE CHARITY, WE BECAME CONNECTED TO OTHER CDH FAMILIES, AND THAT HAS MADE ALL THE DIFFERENCE IN THE WORLD TO US THESE LAST 8 YEARS. WE HAVEN'T FELT ALONE IN THIS FIGHT SINCE."

Shereen Kostmayer



"THE CHARITY IS A GREAT SUPPORT TO MANY FAMILIES AND I LOVE THE CLOSED FACEBOOK GROUP AS IT ALLOWS US TO SHARE FREELY AND OFFER SUPPORT."

Sandra Vance



"CHERUBS HAS HELPED ME MEET AND CONNECT WITH OTHER ADULT CDH SURVIVORS. THESE CONNECTIONS HAS HELPED ME THROUGH A FEW COMPLICATIONS THAT HAVE COME WITH MY CDH. CHERUBS HAS ALSO HELPED ME SHARE MY STORY AND GIVE HOPE TO OTHERS FACING CDH."

Taylor Steffensmeier



"CHERUBS HAS HELPED ME FIND ANSWERS TO MY VERY LONG STORY. KNOWING WHAT I WENT THROUGH ONLY ONE IN TOWN, NOW 23 YEARS LATER ANOTHER LOCAL CHERUB SAME TOWN, BUT STILL OLDEST ONE WITH CDH PH COMBO WHILE KEEPING STABLE."

Morgan Nuchols



### Cherub Hunter

"CHERUBS IS AN AMAZING CDH SUPPORT COMMUNITY, I WAS SO LOST UNTIL I FOUND THEM."

Kelley Constance



"SO HOW HAS CHERUBS HELPED US? TO REALIZE WE ARE NOT ALONE BUT MORE SO BY HELPING OTHER FAMILIES REALIZE DESPITE THE CDH DIAGNOSIS THEY WILL NEVER HAVE TO TRAVEL THIS JOURNEY ALONE."

Lisa Carter



# CDH Support

CHERUBS was founded with the sole purpose to make sure that no families have to fight Congenital Diaphragmatic Hernia alone. Since 1995, over 6500 families have become part of the CDHi family.

## Connecting Parents

CHERUBS has been tirelessly working to connect families since 1998 when with a ListServ (email mailing list) and online chat. In 2001 CHERUBS created private forums on the charity website which provided families a safe, secure, and private place to discuss any issues they may be facing.

With the advancement of social media, CHERUBS created private Facebook groups for families to have a place to openly discuss their lives with CDH. In addition to online support, we encourage local family gatherings and promotes local fundraising events families can participate in to support each other.

## Financial Assistance

CDH is financially devastating to families, requiring parents to be out of work, often relocate and yet continue to pay regular bills and now medical bills. Our organization started giving small Financial Assistance Grants of \$100 in 2012. That grew to \$500 when funding was available. We would like to offer \$5000 grants per family if they meet qualifications (note from their hospital social worker proving they are in need and in the hospital) so that they can pay bills, get to the hospital, and cover any expenses they may have without having to meet any other criteria or go to any specific hospital.

## CDH HOPE Tote Bag Project

CHERUBS H.O.P.E. (Helping Other Parents Expecting) Tote Bag Project assists families expecting babies born with CDH by providing them with much needed free information and support items through a community project in which all CDH families can participate and honor their children while helping new families affected by CDH. Donated items are collected by our members, CDH families, and friends and put together into tote bags by volunteers. Tote bags are then mailed to families who are expecting babies with CDH or who have newborns who are still hospitalized and currently battling CDH.

## Funeral Assistance

As of 2020, our non-profit has not been able to establish a Funeral Assistance Fund to assist the many families who struggle with burial costs after they have lost their child unexpectedly. Often, parents are young and not financially stable; already burdened by astronomical healthcare bills, finding the money to bury their child makes the unfathomable even harder. Our organization has helped where we can over the years to reach out to funeral homes and their local resources for assistance but a fund to help families pay last respects to their child with dignity is something that is so very needed.

## CDH Conference

Every year, the CHERUBS division of CDH International holds a family support conference. The location of the conferences alternates annually between the United States and Europe, with European conferences a joint effort between CDHi and fellow ACDHO charities.

Conferences include scientific speakers, round-table support sessions, the latest research and awareness efforts, as well as give the opportunity for patients and families to meet other patients and families. All members are encouraged to attend.

## Scholarships

Our first CDH Scholarship was established as the Oz Kidd-Ward Scholarship in memory of a child with money raised by his parents. Since then, we have awarded a dozen scholarships up to \$2500 in honor / memory of many patients and even in other family members.

It is our goal to offer \$10,000 in scholarships by 2025 to CDH survivors, siblings, or parents who are returning to school and have an interest in studying medicine to help further the fight against CDH.



# CDH International Phone APP

CDH International has created the go to App for the Congenital Diaphragmatic Hernia community! The App is free to everyone. You must have a (free) membership to log into certain sections of the App, Join at <http://www.cdhboards.org>.

Our App works with iPhones, Android phones, Tablets and your desktop computer.

We included as much as possible as we could in this ground-breaking App, including:

- CDH Parent Reference Guide
- CDH Apps for Pediatric Surgeons
- The CDH Patient Registry
- CDH Research Studies
- CDH Research Library
- CDHi Social Platform – NEW\*\*
- Patient Forums
- Patient Family Resources
- Latest CDH News
- CDH Awareness Shop
- CDH Awareness Information
- CDH Intentional Information
- Ways To Help
- In App Donations
- Event Calendar
- Social Media Links

## CDH Medical Center Map on the Phone App

- Find, contact and review Congenital Diaphragmatic Hernia Treatment Centers with our new CDH Phone App feature!
- Is your hospital not listed? Info not updated? Submit a listing on the app! Or e-mail us the info at [research@cdhi.org](mailto:research@cdhi.org).
- You may also submit one \*.png graphic (700 pixels x 350 pixels) and 1 downloadable PDF document less that 20 MB in size.



Can Be Found In The Apple And Google Play Stores

**Apple Store** – <https://apps.apple.com/app/id1525091622>

**Google Play** – <https://play.google.com/store/apps/details?id=com.app.cdhinternational>

**DISCLAIMER:** CDH International is providing this service to give parents unbiased information on the hospitals that serve Congenital Diaphragmatic Hernia patients. Any hospital listing is not a referral by CDHi and parents should do their own due diligence on finding the best hospital for their child's care. Any reviews by other parents are their own opinions and do not necessarily reflect the views of the staff and volunteers of CDH International. Any statistics or survival rates on materials or information provided by any hospital is a number created by their own measurements as there is not a universal standard of measurement for survival of Congenital Diaphragmatic Hernia.

# CDH International By the Numbers



6700+ Patient Families



\$2,000,000+ raised



Registered Charity in 6 countries



9% overhead



100+ Medical Conferences



1,000,000+ monthly reach



220+ Videos



1500+ Newborn Care Packages



50,000+ Followers



CDH Awareness Month proclamations in all 50 states



77,000+ Forum Posts



Over 250 Interviews



*"The smallest act of kindness is worth more than the grandest intention" - Oscar Wilde*

## Noteworthy

CDH International is the world's oldest and largest CDH charity, founded by 2 moms on a kitchen table with just a typewriter in 1995 under the name "CHERUBS". The organization was the first to use a model of "support, awareness and research", which has been imitated by 100's of other non-profits for various causes.

In 1997, CHERUBS was one of the first non-profits on-line and has grown to be the worldwide leader for CDH raising awareness through media, social media, and on an international level.

With an annual budget of just \$250,000 with a staff of 3 employees and approximately 100 volunteers, our organization has an overhead of just 9% and self-audits annually.

CDH International helps fight Congenital Diaphragmatic Hernia by providing information, financial grants, scholarships, care packages, connecting families, and hosting local events, international conferences, the CDH Research Survey and much more at no cost to families.

## Trail Blazing

### Congressional Bills



CHERUBS has pushed for Congressional support for CDH Awareness and NIH funding since 2012, including legislation.

### Global CDH Community



CHERUBS has served families in over 70 countries, is a founder of ACDHO and leads the international push for CDH research and awareness

### CDH Awareness



Landmarks have lit up around the world including the CN Tower, Superdome and Niagara Falls.

### Real Help for Families



Over 6500 CDH families have been served through many projects, grants, conferences and more.

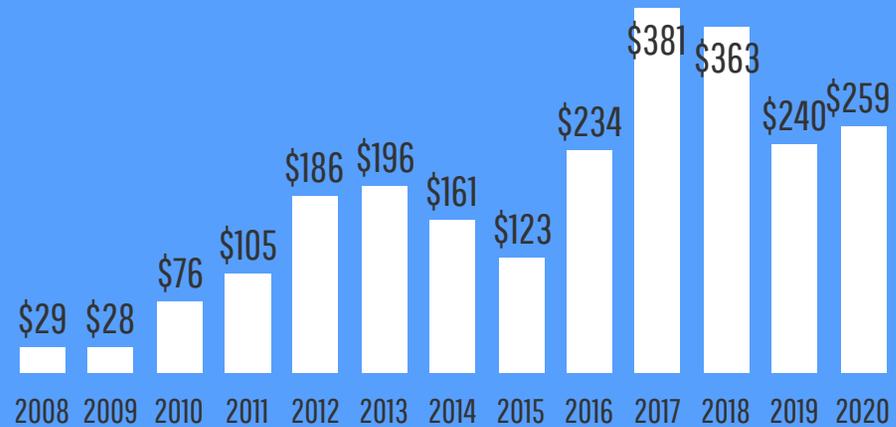
### CDH Research and Funding



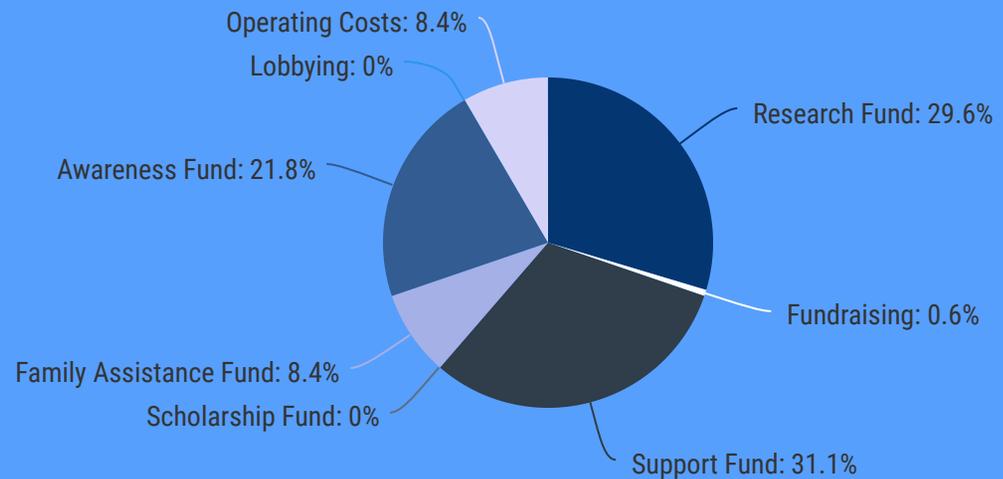
CHERUBS created the first patient driven CDH natural history database and has presented 4 studies, funds, grants and works closely with researchers.

# Financial Highlights

Growing Investments in the fight against CDH (in thousands)



Financial Efficiency 2020



# The CDH Funds

CDH International assists the community through several funds. All donations are tax-deductible. CDHi is a 501(c)III non-profit organization.

## CDH Support Fund

This fund, also known as our General Fund, covers the costs for our CDH Hope Totebag project, most publications, web site, support group forums, support projects and all the other services that the CHERUBS division of CDH International provides to patients and families.

## Financial Assistance

This fund covers grants to patient families for those who are currently expecting or hospitalized.

## Funeral Assistance

This fund will offer grants for funeral costs for those parents who do not have the means to cover the costs of burying their child.

## CDH Research

This fund covers our annual CDH parent conference, medical research conferences, CDH Research Grants and the CDH Patient Registry database.

## CDH Awareness

This fund covers ribbons, parades, balloon releases, bracelets, posters and other projects to make the world aware of Congenital Diaphragmatic Hernia.

## Scholarships

Scholarships are offered to CDH survivors, siblings and parents who are going back to school to study medicine.

*Families are encouraged to set up Research and Scholarship Grants in their child's honor or memory.*

*CDH International cannot legally fundraise for a particular patient or family.*



# Your Donation Dollar

Every dollar is stretched at CDH International, and we do our absolute best to provide as much research and services to patients and families as possible.

- \$3 - 1 CDH Bracelet
- \$5 - 1 CDH Ribbon
- \$7 - 1 Parent Reference Guide
- \$25 - 1 Info Packet
- \$30 - 1 Newsletter
- \$75 - 4 Shirts for 1 Family
- \$100 - 1 CDH HOPE Totebag
- \$150 - 1 Hospital Kit
- \$800 - 100 Parent Reference Guides
- \$1,000 - 1 Conference Scholarship
- \$5,000 - 1 Family Assistance Grant
- \$5,000 - 1 Funeral Assistance Grant
- \$10,000 - 1 College Scholarship
- \$10,000 - 1 CDH Documentary
- \$10,000 - 1 Research Grant
- \$15,000 - 1 CDH Family Conference

## Non-Profit in Every Way

- No Board Conflicts
- No paid employees for the first 15 years
- No C-Level Salaries
- No Medical Referrals
- No Competition
- Award Winning Transparency



# 91¢

of every dollar

goes directly to to the cause

## 56-1916661

501(c)(3) Charity



# Transparency

CDH International works hard to be transparent with our members, donors, and the public by:

- Voluntarily sharing our annual financial statements and 990's at [www.guidestar.org](http://www.guidestar.org)
- Undergoing annual, independent financial audits
- Accountability to 3 Boards, including a full Medical Advisory Board, Parent Advisory Board and Executive Board of Directors
- Publishing an annual End-of-Year Review of our work
- Upholding the Charter of the Alliance of Congenital Diaphragmatic Hernia Organizations



# Alliance of CDH Organizations

CDH International is a founding member of the Alliance of Congenital Diaphragmatic Hernia Organizations (ACDH), created to bring together the non-profits of the CDH community and to better support patients, families and research with a professional, collaborative, supportive environment.

## Official Purpose and Goals

- \* Work together to support and advocate for CDH patients and their families
- \* Ensure that all CDH patients are referred to an ACDHO partnered charity for support
- \* Raise CDH awareness worldwide
- \* Help set standards for new CDH nonprofits and mentor new charities/leaders

In 2017 work on a Charter was begun and it was finalized in 2019, onto which CDH International was one of the first organizations to sign.

ACDHO includes any licensed CDH charity that meets the professional guidelines as outlined in the Charter. New membership is voted on by all current members, is free and does not restrict charities in any way.

- \* ACDHO on Facebook - <https://www.facebook.com/CDHorganizations/>
- \* ACDHO Web Site - <http://acdho.blogspot.com/>

## CDHi Ambassadors

CDH International works with families in over 70 countries and to do so, we recruit the help of volunteers to translate and support patients and parents. We also work closely with our colleagues in the Alliance of Congenital Diaphragmatic Hernia Organizations and refer families to these other registered charities.

For an up-to-date list of Ambassadors, please visit our web site.



# CDH International NGO's

CDH International is the world's oldest, largest & most active charity leading the fight against Congenital Diaphragmatic Hernia. We are excited to announce our expansion into Asia and Europe with CDH International now registered in the United Kingdom, Singapore, the Netherlands, Hong Kong and Switzerland.

CDH families and supporters in these countries are invited to participate through the CDH Patient Registry, fundraising to support CDH research and participating in any US charity schemes and support services. 100% of all donations and fundraising profits will go directly to CDH research.

The NGO's are legally separate entities from the US charity and other CDH International NGO's, each with a separate Directing Board. The Medical Advisory Board will support all CDH International NGO's. CDH International's NGO's will follow all applicable regulations and are working closely with the US charity, ACDHO charities, the WHO, GICS and other research entities to make sure that every law is followed.

CDH International will continue our work in supporting and mentoring all CDH organizations in ACDHO so that families around the world can receive as much support as possible.

Patients and families can help further the research work by CDH International by participating in the CDH Research Survey at <http://www.cdhrefsearch.org>.

Patients and families are welcome to join our forums and Facebook groups. Join for free at <http://www.cdhboards.org>.



"CHERUBS HELPED TO PROVIDE INFORMATION AND SUPPORT TO US WHEN WE DIDN'T KNOW IF OUR BABY WOULD EVER TAKE A BREATH ON HER OWN. WHO KNEW THAT OUR CHERUB, SARAH, WOULD GROW TO BE A TROMBONE PLAYER WHO TAKES OUR BREATH AWAY!"

Rachel McKagan

CDH

Pequeños Guerreros Grandes Muegos

Argentina

Hernia Diafragmatica Argentina

Bermuda

Sandra Vance, parent of CDH survivor Trey

Brazil

HDC Brasil

Canada

Amanda Plakhom, parent of CDH survivor Lizzy

"I HAVE 2 CDH LITTLE GIRLS, AN ANGEL AND SURVIVOR. CHERUBS GAVE ME HOPE WHEN NO ONE ELSE DID. THEY GAVE ME COMFORT IN A DARK PLACE. THEY CONNECTED WITH SOME OF THE BEST FRIENDS I'LL EVER BE "SAD" TO KNOW. FOREVER GRATEFUL BRIELLA GRACE AND LILLY ANN."

Roxanne Warnick

CDH

Canada

Terry Buchamer, parent of CDH survivor Jared

Canada

Julie Clarey, parent of CDH survivor Jaylynn

Canada

Kate Soltys, mom of CDH survivor Jacob

Canada

Whitney Reynolds, parent of CDH survivor Norah

Denmark

Rikke Hammer, parent of CDH survivor Milton

APEHDia

Association Pour Encourager la recherche sur la Hernie Diaphragmatique

France

APEHDia

Zwercfellhernia bei Neugeborenen-CDH e.V.

Germany

Zwercfellhernia

Hong Kong

CDH International Hong Kong (NGO)

Hong Kong

Maiko S., parent of CDH survivor Chris

India

Shankari Murali, parent of CDH survivor Anugrah

Italy

Giulia Collatuzzo, CDH survivor

Mexico

Patricia Reina, parent of CDH survivor Daniel

The Netherlands

CDH International The Netherlands (NGO)

New Zealand

Lisa Harris, parent of CDH survivor Zachary

**CDH Norge**

Norway  
CDH Norge

**Philippines**

Almira Kate Eugenio, parent of CDH survivor Zen Kristalyn

**Scotland**

Donna Warchol, parent of CDH non-survivor Alfie

**Singapore**

Lim Linette, parent of CDH survivor Sherman

**Singapore**

CDH International Singapore (NGO)

**South Africa**

Amanda Dean, parent of CDH survivor Tristan

INTERNATIONAL REPRESENTATIVE

**Spain**

La Vida Con Hernia Diafragmatica Congenita

**CDH Sverige**

Föreningen för medfött diafragmabräck

**Sweden**

CDH Sverige

**Switzerland**

CDH International Switzerland (NGO)

**United Arab Emirates**

Gemma Van Rillaer, parent of CDH survivor Eilidh

**United Kingdom**

Jacqui Taylor-Jackson, CDH survivor

**United Kingdom**

Matthew Kesksek, parent of CDH survivor Hugo

**United Kingdom**

Jess Kesksek, parent of CDH survivor Hugo

Jenna Tate

**SMILE - The Chloe Tate Foundation**

Fundraising for Leeds Hospital Charitable Foundation

**United Kingdom**

SMILE - The Chloe Tate Foundation

**United Kingdom**

CDH International United Kingdom (NGO)

**Patrica Houle**

"CDH GAVE US HOPE WHEN THE DOCTORS DIDN'T. CDH IS AN EXCELLENT RESOURCE FOR INFORMATION ABOUT CDH."

Robin Deisher Lilly

"CDHERUS HELPED US TO NOT FEEL ALONE. BLESSED TO HAVE SUCH AMAZING PEOPLE WHO CARE FOR OUR EMILY AND OUR FAMILY! CDHERUS IS OUR FAMILY."

María Torres-Evans

"CDH DIAGNOSIS WAS A HARD BLOW FOR US, BUT CDHERUS WAS THERE CONNECTING US WITH OTHERS WHO HELPED PULL US FROM OUR RUBBLE. THE CARE PACKAGE WE GOT INCLUDED A BOOK THAT HAD MANY INSPIRATIONAL QUOTES THAT I BEGAN TO UTILIZE DAILY. THEY REALLY HELPED ME. OUR CDH DAUGHTER IS NOW 5 YRS OLD AND DOING AMAZING!"

Jessica Young

"CDHERUS HAS HELPED ME AND MY FAMILY LEARN SO MUCH ABOUT CDH. MY ONLY REGRET IS NOT FINDING THIS ORGANIZATION SOONER! OUR CDH SURVIVOR IS NOW 6 YEARS OLD AND THRIVING!"

Ashley Troyer

"CDHERUS HELPED ME WHEN I WAS 3 MONTHS PREGNANT BY SENDING ME A CARE PACKAGE WITH TONS OF INFORMATION ON THE BIRTH DEFECT MY SON WOULD BE BORN WITH. CDHERUS HAS ALSO BEEN AMAZING AND HAS REACHED OUT TO ME AND WAS SUPPORTIVE WHEN MY SON WASN'T DOING WELL."



**Alabama**  
DeAnn Strother McGilberry, parent of CDH survivor Gelle and non-survivor Claude



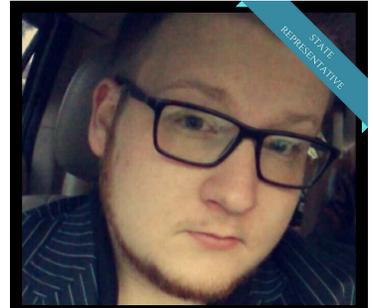
**Alabama**  
Taylor Miles, CDH survivor



**Arizona**  
Neki Young, parent of CDH survivor Anderson



**Arkansas**  
Heather Smith, CDH survivor and parent of CDH survivor Samuel



**Arkansas**  
Josh Benson, CDH survivor



**Arkansas**  
Ashley Leonard, parent of CDH survivor Greyson



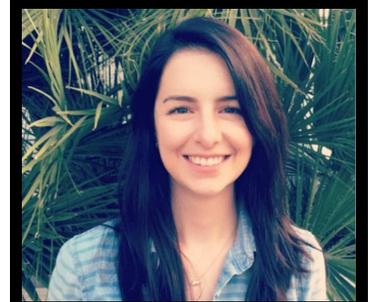
**California**  
Jake Howell, parent of CDH non-survivor Madison



**California**  
Rachel McKagan, parent of CDH survivor Sarah



**California**  
Francesca Dubroy, parent of CDH survivor Francesca



**California**  
Tessa Harrison, parent of CDH survivor Cecilia



**California**  
Jacob Aptekar, parent of CDH survivor Cecilia



**California**  
Rhonda Holsworth, parent of CDH survivor Brian



**Colorado**  
Nicole Colvin, parent of CDH non-survivor Kasey



**Colorado**  
Marissa Sanchez, parent of CDH survivor Evelyn



**Colorado**  
Debbie Stevenson, parent of CDH survivor Eli



**Connecticut**  
Sherri Ashburner, parent of CDH survivor Niall



**Connecticut**  
Reynaldo Sanchez, parent of CDH non-survivor Alexis (AJ)



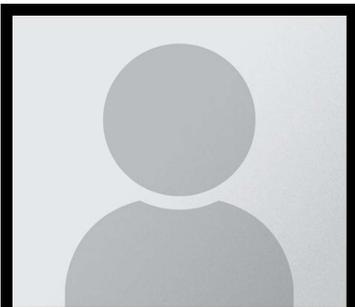
**Delaware**  
Susan Guariano, parent of CDH survivor Marissa



**Delaware**  
Roxy Warnick, parent of CDH survivor Lilly and CDH non-survivor Briella



**Florida**  
Libby Matteson, parent of CDH survivor Hunter



Florida

Allis Czerepka, parent of CDH survivor Abraham



Georgia

Christina Bray, parent of CDH survivor Connor



Georgia

Kimberly Passieu, grandparent of CDH survivor Brady



Hawaii

Denise Lin-DeShetter, parent of CDH survivor Kai



Idaho

Heidi Forney, parent of CDH survivor Sean



Idaho

Angie Kelly, parent of CDH survivor Sierra



Illinois

Rebecca Schroeder, parent of CDH survivor Lily



Illinois

Rachel Von Hatten, parent of CDH survivor Tucker



Illinois

Mindy Doelman, parent of CDH non-survivor Matthew



Indiana

Wayne Oosteroff, grandparent of CDH survivor Tyler



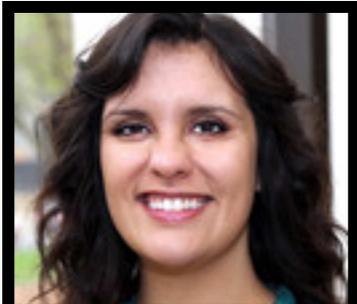
Indiana

Melanie Stephie, parent of CDH non-survivor Treyson



Iowa

Nicole Clark, parent of CDH non-survivor Christian



Iowa

Stacey Klinker, parent of CDH non-survivor Isabella



Iowa

Megan Williams, parent of CDH survivor Emma



Kansas

Mary Kate Bremner, parent of CDH non-survivor Payton



Kansas

Kerri Blair, parent of CDH non-survivor Henry



Kansas

Cassie Raney, parent of CDH non-survivor Wyatt



Kansas

Diane Punch, parent of CDH survivor Jacob



Kentucky

Brian Johnson, parent of CDH survivors Zachary and Samuel

**CDH Fact**  
 THE ALLIANCE OF CONGENITAL DIAPHRAGMATIC HERNIA ORGANIZATIONS (ACDHO) IS A GROUP OF INTERNATIONAL CHARITIES WHO WORK TOGETHER TO FIGHT CDH COLLECTIVELY.  
 WWW.ACDHO.ORG



Louisiana  
Lisa Thibeau, parent of CDH survivor Adam



Louisiana  
Kristen Cochran, parent of CDH survivor Raylee



Maine  
Carly Dudley, parent of CDH survivor Jasmine



Maryland  
Lisa Jones, parent of CDH non-survivor Khalil



Maryland  
Darlene Silverman, grandparent of CDH survivor Emily



Maryland  
Hinda Labovitz, parent of CDH non-survivor Ronen



Massachusetts  
Marie Marchesseault, parent of an adult CDH survivor



Massachusetts  
Lynn Gray, parent of CDH non-survivor Harper



Michigan  
Olivia Raine Foundation



Michigan  
Colleen Martin, parent of CDH survivor Quinn



Michigan  
Leslie Sukup, parent of CDH survivor Sage



Michigan  
Lauren Petersen, parent of CDH non-survivor Tess



Michigan  
Ellie Collman, parent of CDH non-survivor Samantha



Minnesota  
Mary and Ben Lundeen, Ben is a CDH survivor (Mary's son)



Mississippi  
Shereen Kostmayer, parent of CDH survivor Micaela



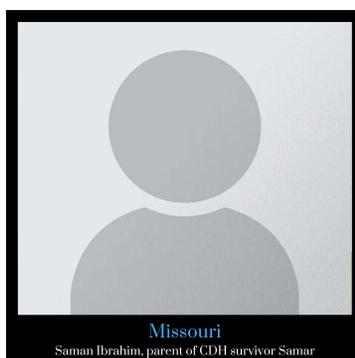
Mississippi  
Milinda Floyd, parent of CDH survivor Bryer



Mississippi  
Taylor Hacker, CDH survivor



Missouri  
Laura Henderson, parent of CDH survivor Lucie



Missouri  
Saman Ibrahim, parent of CDH survivor Samar



Montana  
Mandy Alecke, parent of CDH survivor Wilder



**Nebraska**  
Taylor Steffensmeier, CDH survivor



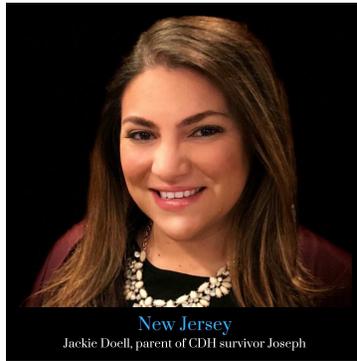
**Nebraska**  
Megan Kleensang, parent of CDH survivor Phoebe



**Nevada**  
Jill Gibson, parent of survivor Benjamin



**Nevada**  
Brandi Montenegro, parent of CDH non-survivor Sloane



**New Jersey**  
Jackie Doell, parent of CDH survivor Joseph



**New Jersey**  
Renata Casella, parent of CDH survivor Liliana



**New Jersey**  
Katy Doygala, parent of CDH survivor Nick



**New Jersey**  
Dania Diaz, parent of CDH survivor Luna



**New Jersey**  
Peyton's Promise



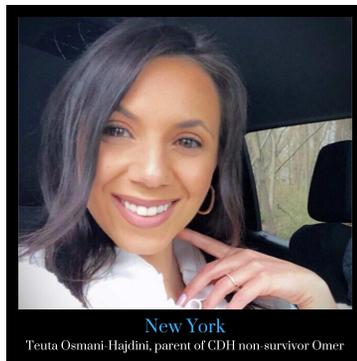
**New York**  
Tracy Meyer, parent of CDH survivor Lillian Sophia



**New York**  
Khadijah Reed, parent of CDH non-survivor Kassidy



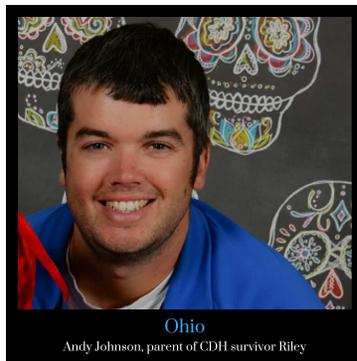
**New York**  
The Incredible Teddy Foundation



**New York**  
Teuta Osmani-Hajdini, parent of CDH non-survivor Omer



**North Carolina**  
Theresa Erazmus, parent of CDH survivor William



**Ohio**  
Andy Johnson, parent of CDH survivor Riley



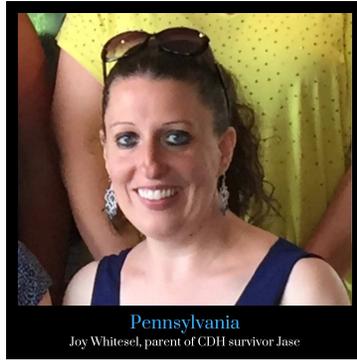
**Oklahoma**  
Kacy Hurley, parent of CDH survivor Mattilyn



**Oregon**  
Shelly Moore, grandparent of CDH non-survivor Jayden



**Oregon**  
Alicia Gilbert, parent of CDH non-survivor Jayden



**Pennsylvania**  
Joy Whitesel, parent of CDH survivor Jase



**Pennsylvania**  
Kristina Wetzel, parent of CDH survivor Arik



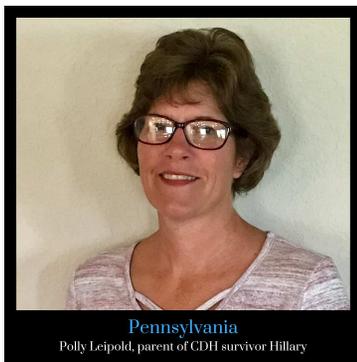
Pennsylvania

Jessica Cummings, parent of CDH non-survivor Nathaniel



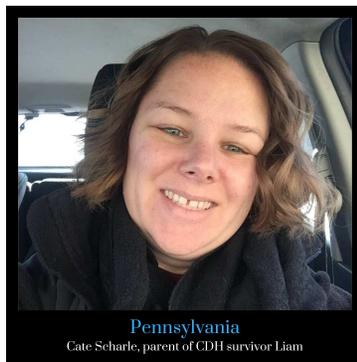
Pennsylvania

Arianna's CDH Foundation



Pennsylvania

Polly Leipold, parent of CDH survivor Hillary



Pennsylvania

Cate Scharle, parent of CDH survivor Liam



South Carolina

James Coleman, parent of CDH non-survivor Trinity



South Carolina

Lisa Coleman, parent of CDH non-survivor Trinity



South Carolina

Lynne Brogdon, parent of CDH survivor Baer



Tennessee

Sharon Weir, parent of CDH non-survivor Kaden



Tennessee

Sarah Tanner, parent of CDH survivor Austin



Texas

Sarah Cox, parent of CDH non-survivor Jasmine



Texas

Tatiana Hurley, parent of CDH non-survivor Elijah



Texas

Elsa Garza, parent of CDH survivor Kaitlyn



Texas

Christopher Cason, parent of CDH non-survivor Canyon



Texas

Erika Siggins, parent of CDH non-survivor David



Texas

Julie Lachance, parent of CDH survivor Jolene



Texas

Kaytlyn Powers, parent of CDH survivor Hudson



Texas

Christie Huff Helmke, parent of CDH survivor Felix



Texas

Jessie Alderete, parent of CDH survivor Tristan



**CDH Fact**  
CONGENITAL DIAPHRAGMATIC HERNIA OFTEN OCCURS WITH OTHER BIRTH DEFECTS AND SYNDROMES.

WWW.CDHI.ORG




**CDH Fact**  
YOUR CHILD IS MORE LIKELY TO BE AFFECTED BY CDH THAN BY LIGHTNING STRIKES, TORNADOS, HURRICANES, OR FLOODS COMBINED.

WWW.CDHI.ORG




**CDH Fact**  
THE OFFICIAL "CONGENITAL DIAPHRAGMATIC HERNIA AWARENESS" RIBBON WAS VOTED ON BY FAMILIES IN MANY CHARITIES FROM DIFFERENT COUNTRIES AND IS NOT TRADEMARKED OR OWNED BY ANY ONE PERSON OR ENTITY.

WWW.CDHI.ORG



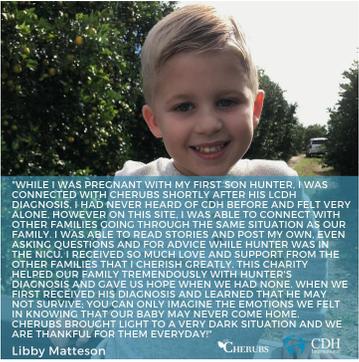
**CDH Fact**  
THE FIRST CHARITY FOR CONGENITAL DIAPHRAGMATIC HERNIA WAS FOUNDED IN 1994 IN THE NETHERLANDS BY A FAMILY WHO LOST 3 DAUGHTERS TO CDH. "STICHTING HERNIA DIAFRAGMATICA" HELPED HUNDREDS OF FAMILIES UNTIL IT CLOSED ITS DOORS IN 2017.

WWW.CDHI.ORG




**CDH Fact**  
EVERY 10 MINUTES, A BABY IS BORN WITH CDH

WWW.CDHI.ORG



# Annual International CDH Conference

Each year CDH International does their best to hold an International CDH Conference where CDH families, researchers and doctors in the CDH field come together to learn from one another and hear updates on everything happening in the CDH world. We start every conference with a pizza party, allowing families to get up and share more about their CDH journey. The next two days of conference will include speakers in the medical and research fields as well as round table discussions for families to discuss caring for survivors and the grieving process.



2021 - Virtual  
2022 - Toronto, Canada  
2023 - TBD, Europe  
2024 - TBD, United States

[www.cdhconference.org](http://www.cdhconference.org)

## CDHi Conferences:

- CDH pizza party
- Parade of Cherubs
- Research presentations by experts
- Patient and family round tables on many different topics for survivor and non-survivor families
- Meet your friendly CDH International staff and volunteers
- Lots of Q&A time
- Get your CDHi conference T-shirt and wings
- Meet fellow ACDHO member charities
- Plenty of time to spend with other CDH families to ask questions, share and make memories

# Contact Us



www.cdhi.org  
www.cdhboards.org (Patient Support)  
www.cdhrefsearch.org

Patient Support - cpab@cdhi.org  
General Questions - info@cdhi.org  
Donations - donate@cdhi.org  
Corporate Giving - giving@cdhi.org  
Fundraising - fundraising@cdhi.org

 <https://www.linkedin.com/company/cdhi/>  
 @cdhawareness  
 <https://www.pinterest.com/cdhawareness/>



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 @cdhinternational  
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<http://www.facebook.com/cdhsupport>



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Registered UK Charity no. 1189819

 @cdhiuk  
 <http://www.facebook.com/cdhiuk>



## Switzerland

c/o Chapel & York Switzerland Association, 4 Rue Charles-  
Bonnet, P.O. Box 399,1211, Geneva 12, Switzerland

www.cdhintl.ch  
switzerland@cdhi.org  
Phone - +41 22 57 54 171  
CDH International c/o Chapel & York Switzerland Association  
is a tax-exempt not-for-profit association governed by Articles  
60 et seq. of the Swiss Civil Code.

 @cdhiswitzerland  
 @cdhiswitzerland  
 <http://www.facebook.com/cdhiswitzerland>



## Netherlands

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Almere Noord Holland The Netherlands

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netherlands@cdhi.org  
+44 20 3966 5346  
Registered UK Charity no. 1189819

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 @cdhinl  
 <http://www.facebook.com/cdhintl>



## Hong Kong

CDH International, c/o Hong Kong Foundation for Charities  
Limited, Unit B, 19/F, Queen's Centre,  
58-64 Queen's Road East, Wanchai, Hong Kong

cdhi.org/hongkong  
hongkong@cdhi.org  
CDH International, c/o Hong Kong Foundation for Charities  
Limited Registration Number 65159428-000

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 @cdhihongkong  
 <http://www.facebook.com/cdhhongkong>



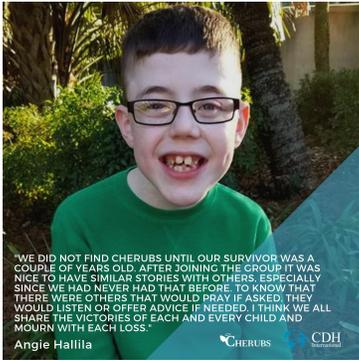
## Singapore

c/o Chapel York SG Foundation, 138 Robinson Road, 18-  
03 Oxley Towers, Singapore 068906

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singapore@cdhi.org  
+65 9223 7069  
CDH International, c/o Singapore Foundation for  
Charities Ltd | Registration Number 65159428-000

 @cdhisingapore  
 @cdhisingapore  
 <http://www.facebook.com/cdhsingapore>





"WE DID NOT FIND CHERUBS UNTIL OUR SURVIVOR WAS A COUPLE OF YEARS OLD. AFTER JOINING THE GROUP IT WAS NICE TO HAVE SIMILAR STORIES WITH OTHERS, ESPECIALLY SINCE WE HAD NEVER HAD THAT BEFORE. TO KNOW THAT THERE WERE OTHERS THAT WOULD PRAY IF ASKED, THEY WOULD LISTEN OR OFFER ADVICE IF NEEDED, I THINK WE ALL SHARE THE VICTORIES OF EACH AND EVERY CHILD AND MOURN WITH EACH LOSS."

Angie Hallilla CHERUBS CDH



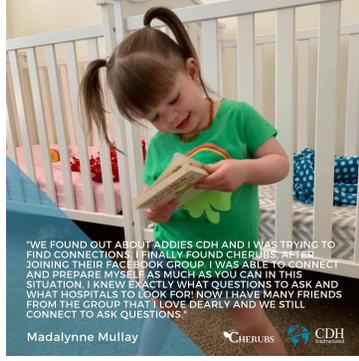
"CHERUBS PROVIDES US WITH HOPE IN OUR DARKEST HOUR. WE FOUND OTHER SURVIVOR FAMILIES THAT SUPPORTED AND GUIDED US TOWARD LIFELONG FRIENDSHIPS. CELEBRATING EACH CHERUBS MILESTONES TOGETHER IS HEARTWARMING!"

Amanda Khan CHERUBS CDH



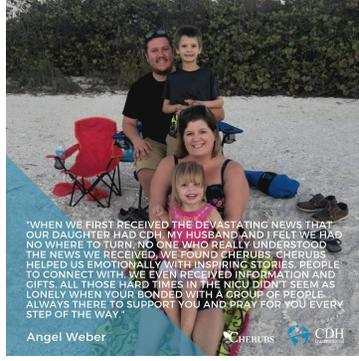
"TERRIFIED. 6/17/2003 @11:07AM WAS THE TIME MY SON WAS BORN. ABOUT AN HOUR LATER WAS THE FIRST I'D HEARD OF CDH. GOOGLE WAS THE ONLY RESOURCE I HAD AND FOUND CHERUBS, WHICH WAS THE ONLY SITE I COULD FIND WITH INFORMATION I COULD UNDERSTAND. JACOB WILL BE 16 IN JUNE AND I AM FOREVER GRATEFUL FOR THIS GROUP."

Nicole Sedgwick CHERUBS CDH



"WE FOUND OUT ABOUT ADDIE'S CDH AND I WAS TRYING TO FIND CONNECTIONS. I FINALLY FOUND CHERUBS. AFTER JOINING THEIR FACEBOOK GROUP, I WAS ABLE TO CONNECT AND PREPARE MYSELF AS MUCH AS YOU CAN IN THIS SITUATION. I KNEW EXACTLY WHAT QUESTIONS TO ASK AND WHAT HOSPITALS TO LOOK FOR! NOW I HAVE MANY FRIENDS FROM THE GROUP THAT I LOVE DEARLY AND WE STILL CONNECT TO ASK QUESTIONS."

Madalynne Mullay CHERUBS CDH



"WHEN WE FIRST RECEIVED THE DEVASTATING NEWS THAT OUR DAUGHTER HAD CDH, MY HUSBAND AND I FELT WE HAD NO WHERE TO TURN. NO ONE WHO REALLY UNDERSTOOD THE NEWS WE RECEIVED. WE FOUND CHERUBS. CHERUBS HELPED US EMOTIONALLY WITH INSPIRING STORIES, PEOPLE TO CONNECT WITH. WE EVEN RECEIVED INFORMATION AND GIFTS. ALL THOSE HARD TIMES IN THE NICU DIDN'T SEEM AS LONELY WHEN YOUR BONDED WITH A GROUP OF PEOPLE ALWAYS THERE TO SUPPORT YOU AND PRAY FOR YOU EVERY STEP OF THE WAY."

Angel Weber CHERUBS CDH



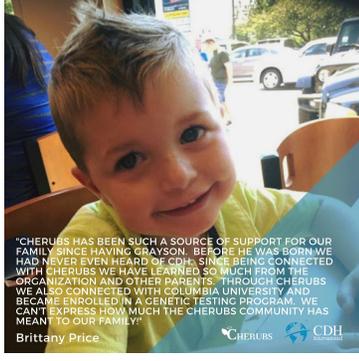
"THANKS TO CHERUBS MY DAUGHTER HAS MET OTHER CDH CHILDREN AND WE HAVE MADE MANY NEW FRIENDS. CHERUBS HAS HELPED US FIND FAMILIES WITH SIMILAR EXPERIENCES FOR SUPPORT. MOST IMPORTANTLY CHERUBS HAS GIVEN ME HOPE THAT MY DAUGHTER WILL ALWAYS HAVE A PLACE TO TURN AS SHE NAVIGATES CDH AS AN ADULT."

Amanda Plakholm CHERUBS CDH



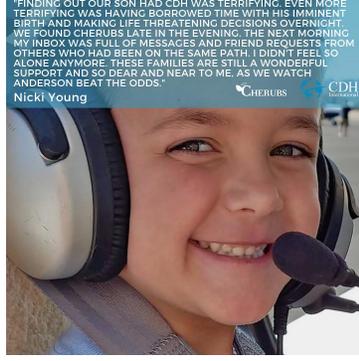
"CHERUBS COMFORTED US WHEN WE HAD AN UNEXPECTED DIAGNOSIS AT 4 WEEKS OLD. WHEN THE DOCTORS AND NURSES SAY THEY WON'T KNOW HOW BAD IT IS UNTIL THEY GET INTO SURGERY, WE FOUND HOPE AND ENCOURAGEMENT IN THE CHERUBS GROUPS."

Stephanie Stephens CHERUBS CDH



"CHERUBS HAS BEEN SUCH A SOURCE OF SUPPORT FOR OUR FAMILY SINCE HAVING GRAYSON. BEFORE HE WAS BORN WE HAD NEVER EVEN HEARD OF CDH. SINCE BEING CONNECTED WITH CHERUBS WE HAVE LEARNED SO MUCH FROM THE ORGANIZATION AND OTHER PARENTS. THROUGH CHERUBS WE ALSO CONNECTED WITH COLUMBIA UNIVERSITY AND BECAME ENROLLED IN A GENETIC TESTING PROGRAM. WE CAN'T EXPRESS HOW MUCH THE CHERUBS COMMUNITY HAS MEANT TO OUR FAMILY."

Brittany Price CHERUBS CDH



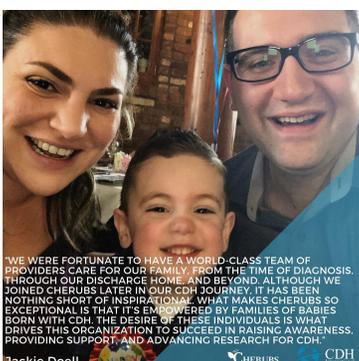
"FINDING OUT OUR SON HAD CDH WAS TERRIFYING. EVEN MORE TERRIFYING WAS HAVING BORROWED TIME WITH HIS IMMINENT BIRTH AND MAKING LIFE-THREATENING DECISIONS OVERNIGHT. WE FOUND CHERUBS LATE IN THE EVENING. THE NEXT MORNING MY INBOX WAS FULL OF MESSAGES AND FRIEND REQUESTS FROM OTHERS WHO HAD BEEN ON THE SAME PATH. I DIDN'T FEEL SO ALONE ANYMORE. THESE FAMILIES ARE STILL A WONDERFUL SUPPORT AND SO DEAR AND NEAR TO ME, AS WE WATCH ANDERSON BEAT THE ODDS."

Nicki Young CHERUBS CDH



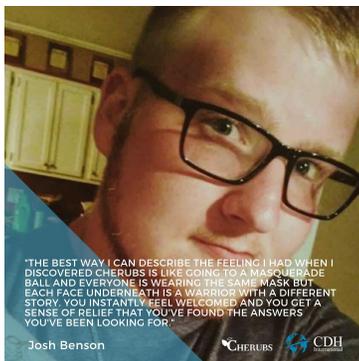
"CHERUBS WAS THE FIRST SUPPORT SYSTEM. ONLY ONE DAY AFTER WE RECEIVED THE DIAGNOSIS, THEY GAVE ME ENCOURAGEMENT, HOPE, AND INFORMATION WHICH BROUGHT ME PEACE AND STRENGTH TO CONTINUE ON OUR NEW JOURNEY."

Heidi Marie Anderson CHERUBS CDH



"WE WERE FORTUNATE TO HAVE A WORLD-CLASS TEAM OF PROVIDERS CARE FOR OUR FAMILY. FROM THE TIME OF DIAGNOSIS THROUGH OUR DISCHARGE HOME AND BEYOND. ALTHOUGH WE JOINED CHERUBS LATER IN OUR CDH JOURNEY, IT HAS BEEN NOTHING SHORT OF INSPIRATIONAL. WHAT MAKES CHERUBS SO EXCEPTIONAL IS THAT IT'S EMPOWERED BY FAMILIES OF BABIES BORN WITH CDH. THE DESIRE OF THESE INDIVIDUALS IS WHAT DRIVES THIS ORGANIZATION IN RAISING AWARENESS, PROVIDING SUPPORT, AND ADVANCING RESEARCH FOR CDH."

Jackie Doell CHERUBS CDH



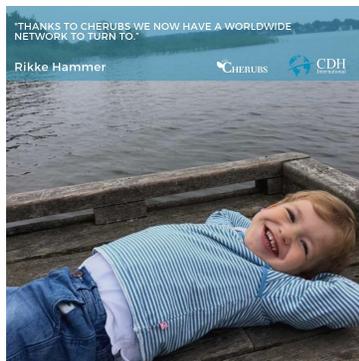
"THE BEST WAY I CAN DESCRIBE THE FEELING I HAD WHEN I DISCOVERED CHERUBS IS LIKE GOING TO A MASQUERADE BALL AND EVERYONE IS WEARING THE SAME MASK BUT EACH FACE UNDERNEATH IS A WARRIOR WITH A DIFFERENT STORY. YOU INSTANTLY FEEL WELCOMED AND YOU GET A SENSE OF RELIEF THAT YOU'VE FOUND THE ANSWERS YOU'VE BEEN LOOKING FOR."

Josh Benson CHERUBS CDH



"FOR ME CHERUBS MEANS HOPE. A COMMUNITY FOR BABIES, CHILDREN, AND FAMILIES FIGHTING OR GRIEVING AND COMING TOGETHER AS ONE TO SAVE THE LIVES OF MANY. CHERUBS HAS HELPED ME SHARE MY DAUGHTERS STORY AND HONOR HER MEMORY, ESPECIALLY THROUGH TOUGH TIMES."

Khadijah Reed CHERUBS CDH



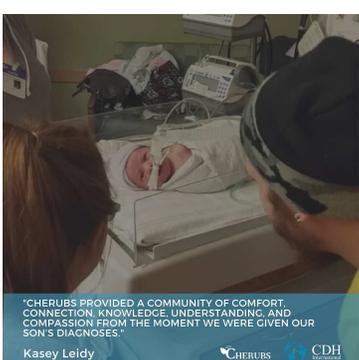
"THANKS TO CHERUBS WE NOW HAVE A WORLDWIDE NETWORK TO TURN TO."

Rikke Hammer CHERUBS CDH



"CHERUBS HAS NOT ONLY GIVEN US A FAMILY AND COMMUNITY, IT HAS ALSO GIVEN US A PLACE TO ASK QUESTIONS, GET ANSWERS, AND VOICE OUR CONCERNS. I FEEL LIKE WE ARE A TEAM CHEERING EACH OTHER ON IN OUR JOURNEY."

Mandy Alcocke CHERUBS CDH



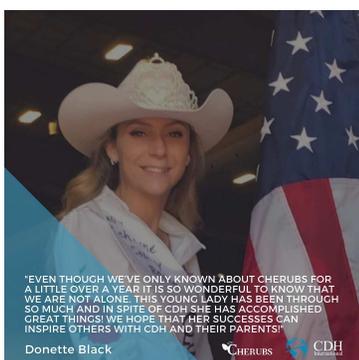
"CHERUBS PROVIDED A COMMUNITY OF COMFORT, CONNECTION, KNOWLEDGE, UNDERSTANDING, AND COMPASSION FROM THE MOMENT WE WERE GIVEN OUR SON'S DIAGNOSIS."

Kasey Leidy CHERUBS CDH



"CHERUBS HAS HELPED ME IN SO MANY WAYS I CANNOT EVEN LIST THEM ALL... THEY HAVE BECOME MY SUPPORT NETWORK, MY BEST FRIENDS, AND MY FAMILY. IT'S AMAZING THE PEOPLE WHO YOU MEET DUE TO THE BIRTH DEFECT. THAT STICK BY YOUR SIDE THROUGH THICK AND THIN, AND UNDERSTAND WHAT YOU'RE GOING THROUGH. KNOWING MY SON WILL BE ABLE TO TALK TO OTHER PEERS WHEN HE'S OLDER ABOUT HIS AND THEIR EXPERIENCE IS ALSO A BLESSING."

Danielle Sheffield CHERUBS CDH



"EVEN THOUGH WE'VE ONLY KNOWN ABOUT CHERUBS FOR A LITTLE OVER A YEAR, IT IS SO WONDERFUL TO KNOW THAT WE ARE NOT ALONE. THIS YOUNG LADY HAS BEEN THROUGH SO MUCH AND IN SPITE OF CDH SHE HAS ACCOMPLISHED GREAT THINGS WE HOPE THAT HER SUCCESSSES CAN INSPIRE OTHERS WITH CDH AND THEIR PARENTS!"

Donette Black CHERUBS CDH



"CHERUBS HAS HELPED TO GIVE OUR FAMILY THE SUPPORT WE SO DESPERATELY NEEDED AFTER KEAN WAS DIAGNOSED WITH CDH. WHAT A COMFORT IT HAS BEEN TO KNOW THERE ARE OTHER FAMILIES THAT CAN UNDERSTAND WHAT WE HAVE GONE THROUGH AND HOW IT IMPACTS US ALL EVERY SINGLE DAY. IN OUR CONTINUING DESIRE TO LEARN MORE ABOUT HOW CDH HAS AFFECTED OUR SON, WE HAVE MET A NETWORK OF EXPERTS AND FRIENDS THAT HAVE BECOME AN EXTENSION OF OUR FAMILY. KIERAN IS SURROUNDED BY SO MANY AMAZING PEOPLE AND WILL GROW UP KNOWING THAT HE IS NOT ALONE. WE KNOW THAT WE ARE NOT ALONE, AND THAT SUPPORT MEANS SO MUCH!"

Melissa Van Tassell & Justin Johnstone CHERUBS CDH



"CHERUBS HAS HELPED US TO KNOW THAT WE WERE NEVER ALONE THROUGHOUT OUR DAUGHTER'S LIFE AND WE ARE NOT ALONE NOW AFTER HER DEATH. BECAUSE OF SO MANY WE MET THROUGH CHERUBS WE KNOW THAT OUR GRACE IS NOT FORGOTTEN."

Miranda Hall CHERUBS CDH

