

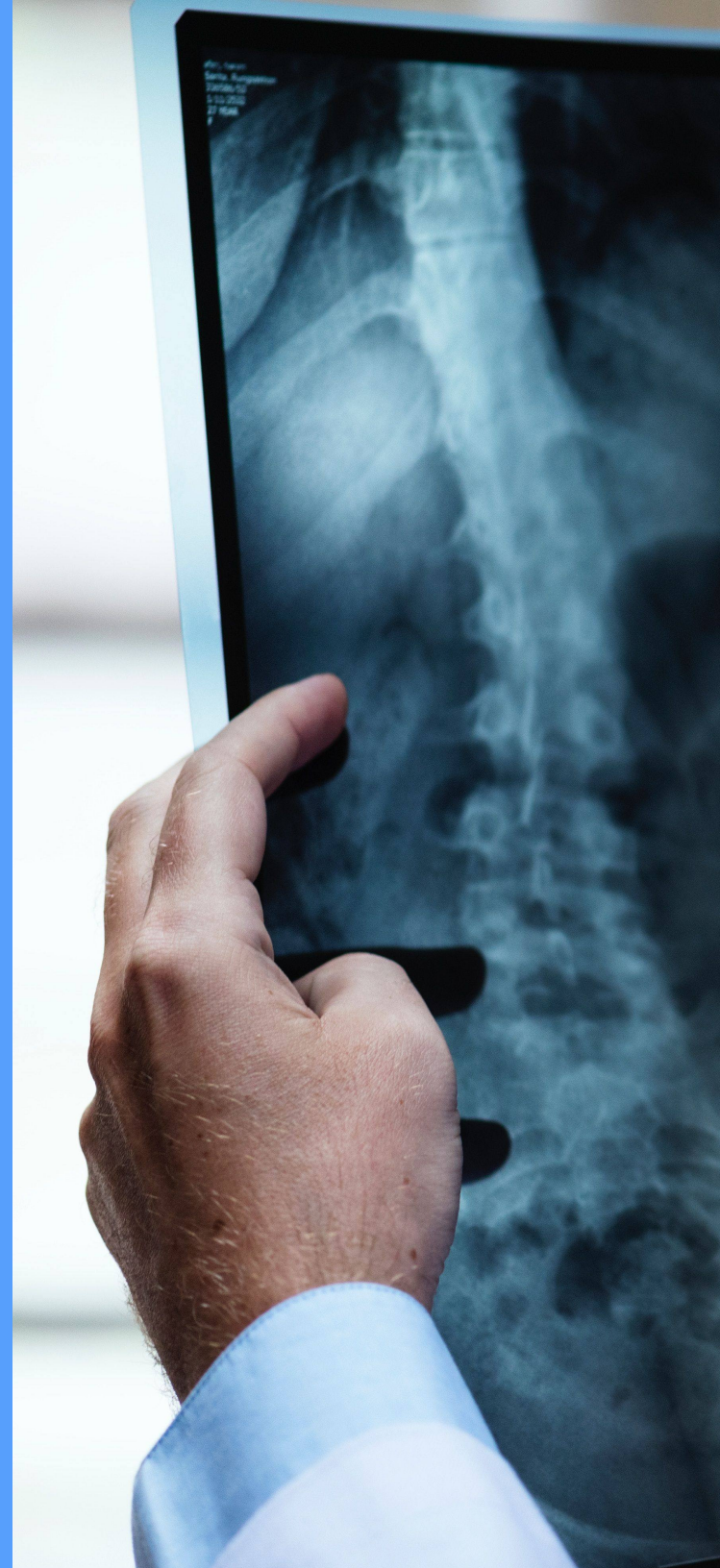


CDH INTERNATIONAL

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 there 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 co-morbidities 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 24th 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.

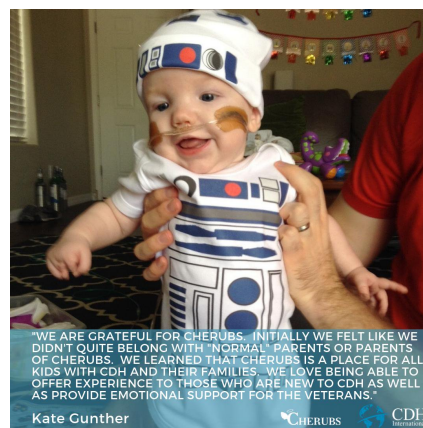
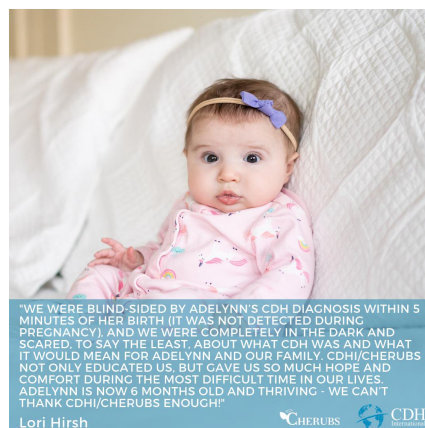
CHERUBS continues to support over 6,000 families in all 50 states and over 70 countries. Through our services, we make sure that no family endures CDH without support or accurate information. Several of our services include our website/forums, CDH Hope Totebags, Parent Reference Guide, CDH Baby Book, 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



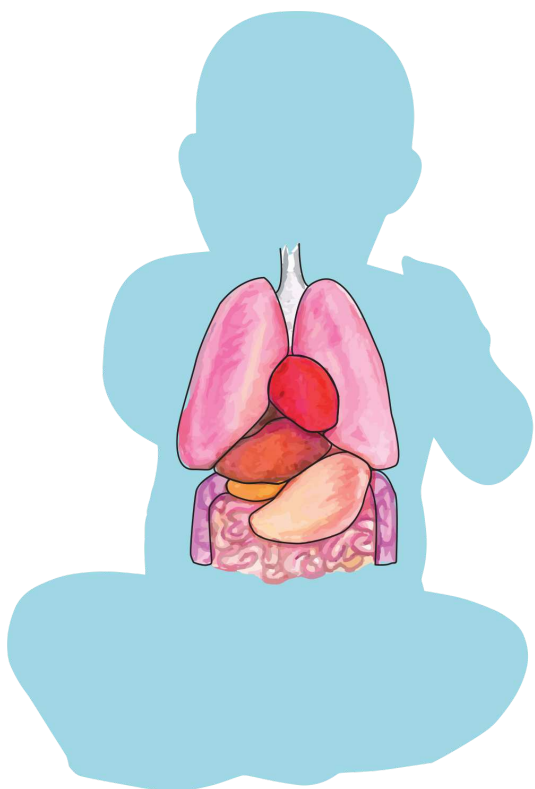


CDH
International

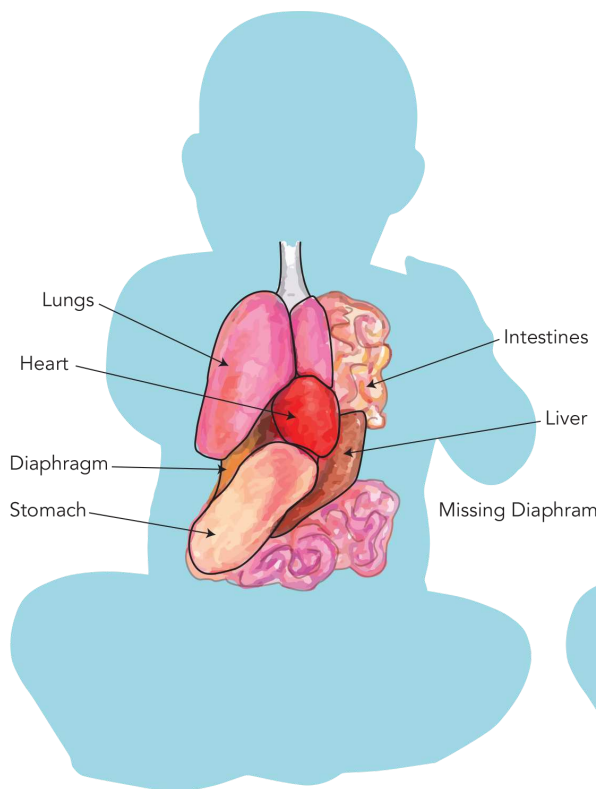
www.cdhi.org

Congenital Diaphragmatic Hernia

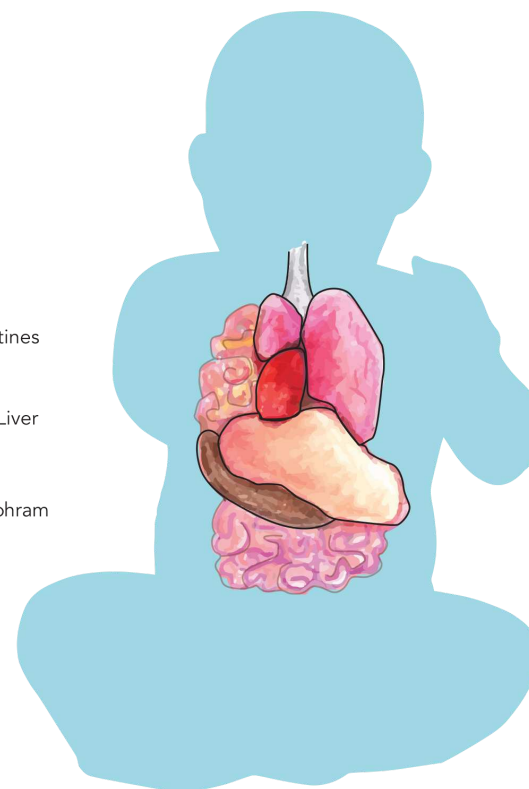
CDH occurs when the diaphragm fails to fully form during pregnancy, allowing organs to migrate from the abdominal cavity into the chest cavity and thereby inhibiting lung growth. CDH strikes 1 in every 2500 babies, which equals 1600 babies every year in the United States. Every ten minutes, a baby is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



Healthy Infant



Left-Sided CDH



Right-Sided CDH

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
Katherine Haney, Vice-President
M. Shane Perry, Esq., Secretary
Tracy Meats, CHERUBS President
Tara Henderson, Director
Warren Sumner, Director

Parent Advisory Board

Tracy Meats, CHERUBS President
Josh Hensley, Research
Darlene Silverman, Research
Nicolle Colvin, Fundraising
Amanda Plakholm, Fundraising
Hope Clyde, Parent Support

Office Staff

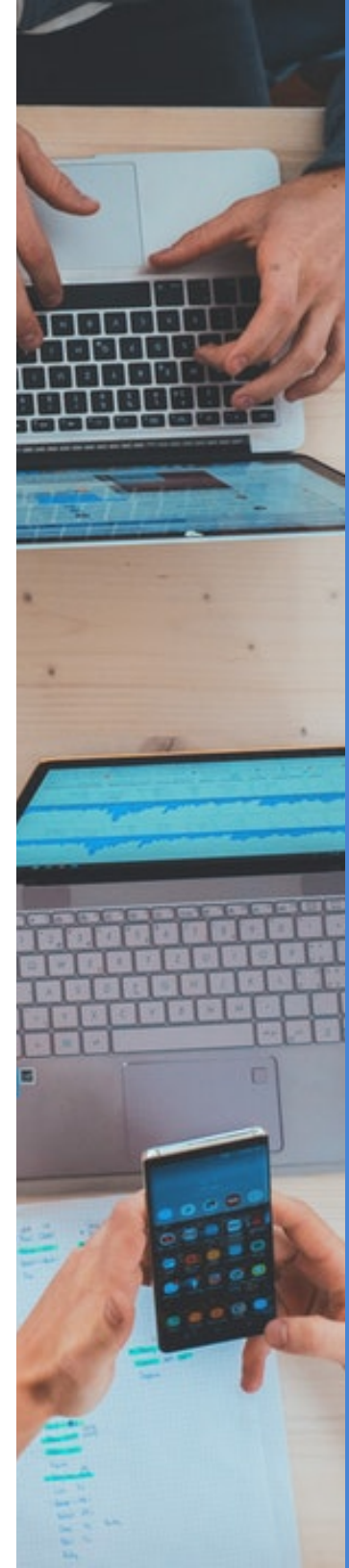
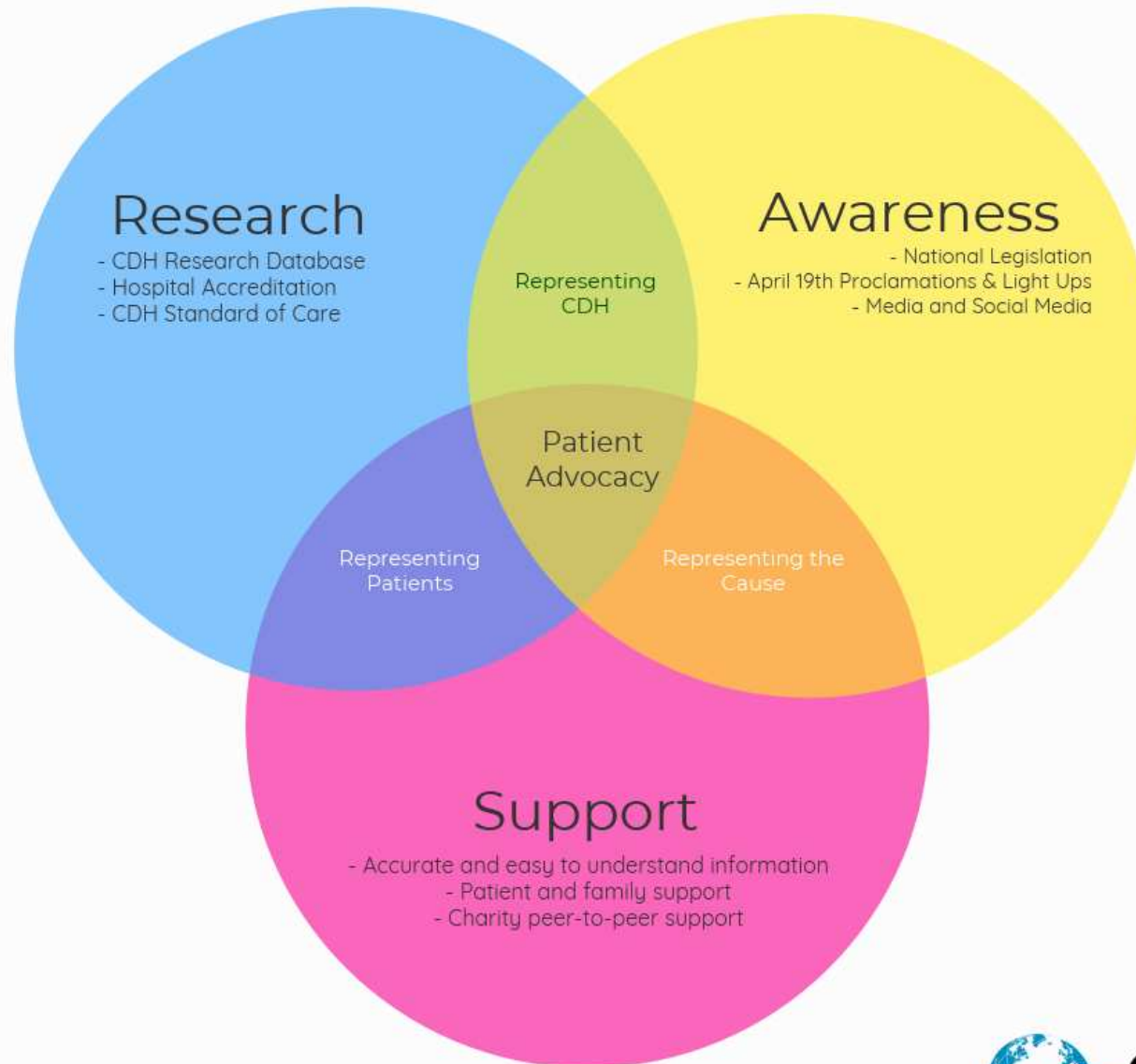
Rachael Eller, Office Manager
Kamal Saleh, Programming

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
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
Giovanna Riccipetitoni, 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 in 2018 and raised \$60,000 thanks to our staff and the dozens of families, doctors, researchers, and celebrities we recruited to make appearances.

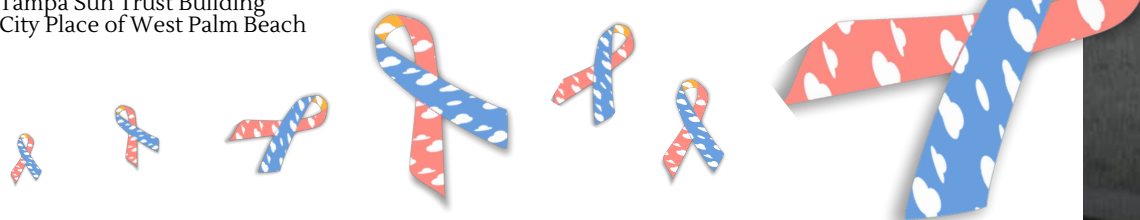
Light Ups for CDH

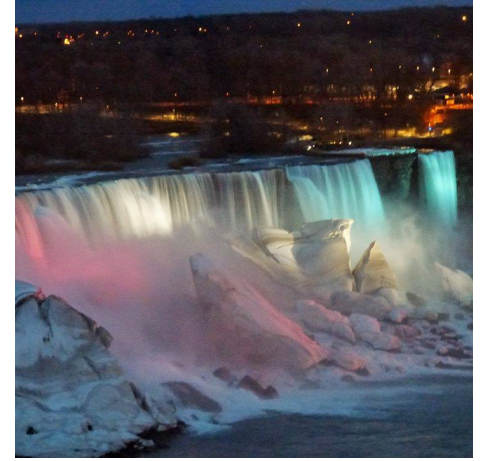
Niagara Falls
CN Tower
Mercedes-Benz Superdome
Calgary Tower
Bank of America
Brant Street Pier
Dublin City Hall
BC Place
Peace Bridge
Sails of Light
PECO Crown
Science World
British Columbia Parliament Building
The Alberta Legislature Building
Retirement Systems of Alabama
Bank of America Plaza
Zakim 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
Cleveland Terminal Tower
Tampa Sun Trust Building
City Place of West Palm Beach

Celebrity Support

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

- Rudy Abreau
- Action Jaxon
- Kim Alexis
- Paul Amos
- Sean Astin
- Lance Bass
- Jaron Brown
- "Downtown" Julie Brown
- Dean Cain
- Michael Campion
- Justin Coleman
- Randy Couture
- Chase d'Arnaud
- Luann de Lesseps
- Chris Daughtry
- David DeLuise
- Dr Drew
- Colin Egglesfield
- Peter Facinelli
- Brett Favre
- Jeff Foxworthy
- Debbie Gibson
- Brian Austin Green
- Bret "the Hitman" Hart
- Melissa Joan Hart
- Larry Holmes
- Sean Kingston
- Tawny Kitain
- Joey Lawrence
- Kristen Ledlow
- Tommy Lee
- Thaddeus Lewis
- Kate Linder
- Ryan Lochte
- Kyle Lowder
- Marla Maples
- Ian McElhinney
- Danica McKeller
- Lee Montgomery
- Lance Moore
- Lil' Scrappy
- Sonja Morgan
- Matty Mullins
- Tim Murphy
- Vince Neil
- Patsy Pease
- Chris Rankin
- Eric Roberts
- Bob "the Blade" Robinson
- Matt Roloff
- Milena Roucka
- Austin 'Chumlee' Russell
- John Schneider
- Drew Seeley
- Jeff Sessions
- Charles Shaunessy
- Charlie Sheen
- Hilary Shepard
- Juliet Simms
- Kevin Sorbo
- Tori Spelling
- Christie Swanson
- Aaron Watson
- Chris Weidman
- Larry Wilcox
- William Wisher
- 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

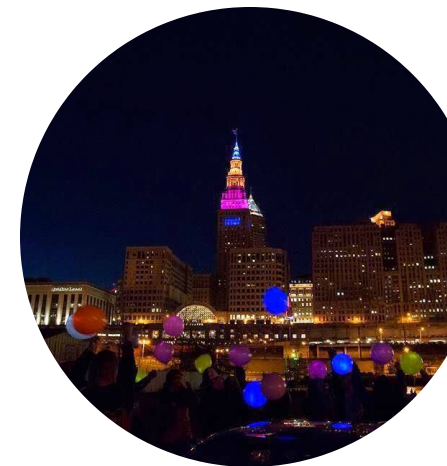
Every day in 2015, members of our charity wrote letters to the author Nicholas Sparks to implore him to feature Congenital Diaphragmatic Hernia in one of his world-famous books and, in turn, into a movie.

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

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

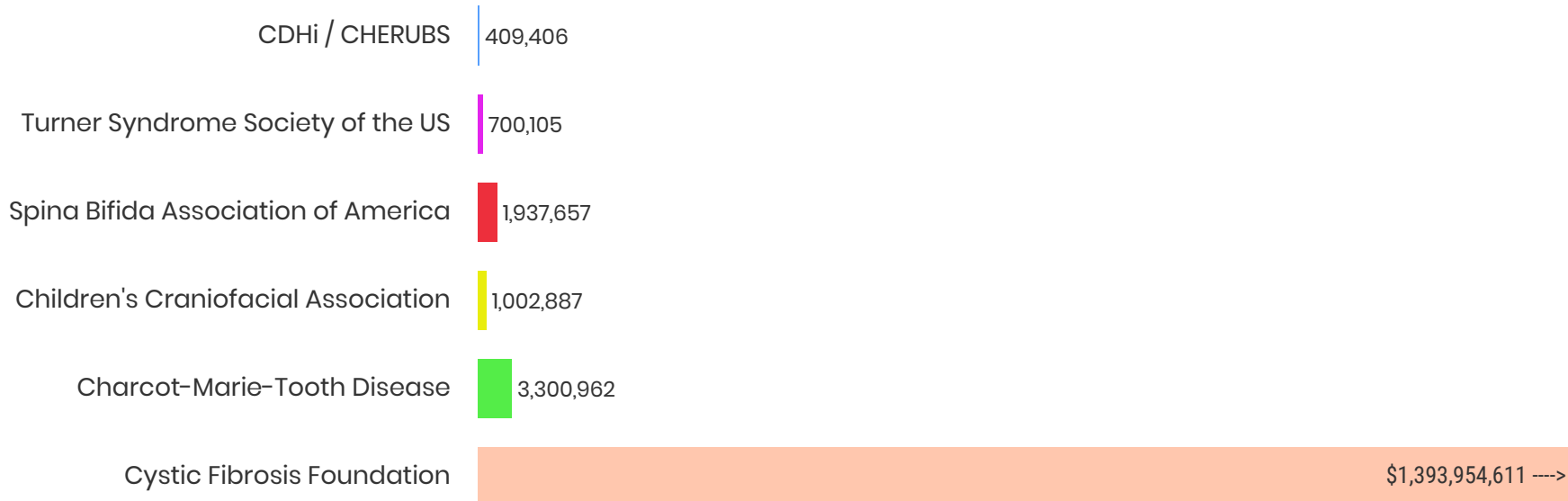
In population of CDH kids (800)
disappears every year in the US

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.

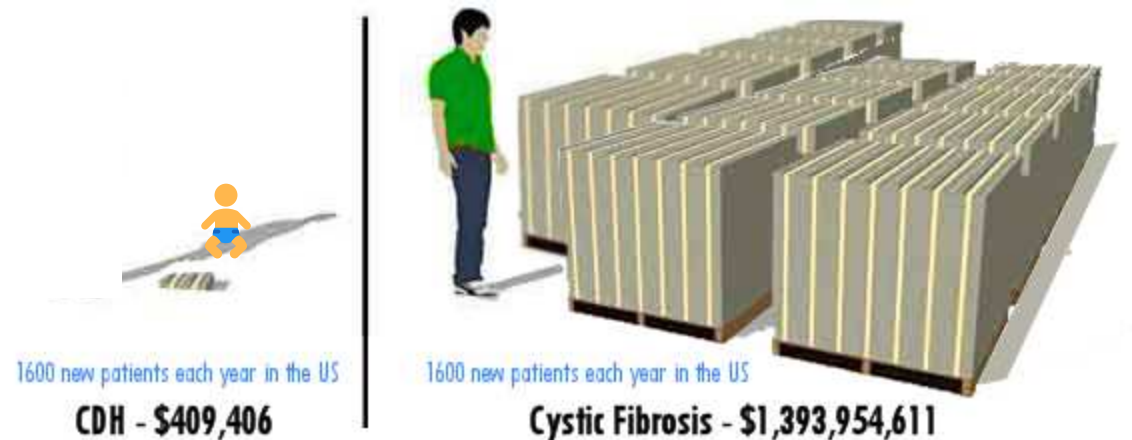


3406 to 1

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 DIAGNOSIS."

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



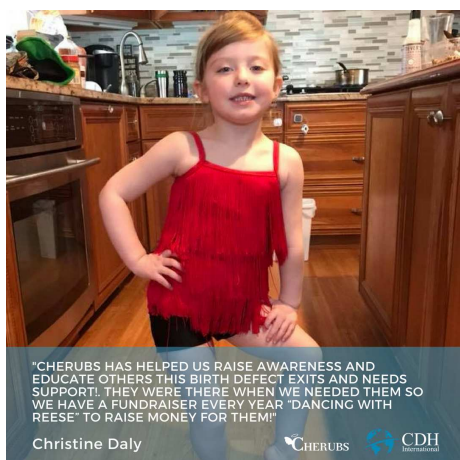
"WE FOUND CHERUBS SHORTLY AFTER OUR SON LIAM WAS DIAGNOSED WITH CDH. IT WAS HELPFUL TO READ OTHER PARENT'S STORIES AND KNOW WE WERE NOT ALONE. WE HAVE MADE LIFELONG FRIENDSHIPS WITH PEOPLE THROUGH CHERUBS."

Patric and Katie Shields



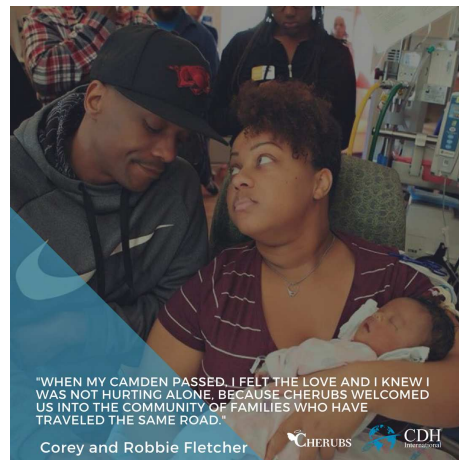
"AS WE NEAR WILDER'S FIRST BIRTHDAY, I AM SO HAPPY THAT WE DECIDED TO JOIN CHERUBS. IT HAS GIVEN US A CHANCE TO MEET SURVIVORS, CDH KIDS WILDER'S AGE, NEW FRIENDS, AND A CHANCE TO HELP OTHER CDH FAMILIES. I AM RELIEVED THAT AS A FAMILY WE ARE NOT ALONE, AND AS WILDER IS NOT ALONE IN THIS DIAGNOSIS."

Mandy Alcock



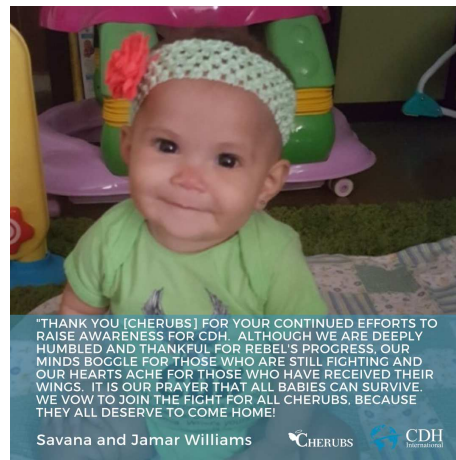
"CHERUBS HAS HELPED US RAISE AWARENESS AND EDUCATE OTHERS THIS BIRTH DEFECT EXISTS AND NEEDS SUPPORT! THEY WERE THERE WHEN WE NEEDED THEM SO WE HAVE A FUNDRAISER EVERY YEAR "DANCING WITH REESE" TO RAISE MONEY FOR THEM!"

Christine Daly



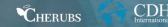
"WHEN MY CAMDEN PASSED, I FELT THE LOVE AND I KNEW I WAS NOT HURTING ALONE. BECAUSE CHERUBS WELCOMED US INTO THE COMMUNITY OF FAMILIES WHO HAVE TRAVELED THE SAME ROAD."

Corey and Robbie Fletcher



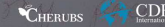
"THANK YOU [CHERUBS] FOR YOUR CONTINUED EFFORTS TO RAISE AWARENESS FOR CDH. ALTHOUGH WE ARE DEEPLY HUMBLLED AND THANKFUL FOR REBEL'S PROGRESS, OUR MINDS BOGGLE FOR THOSE WHO ARE STILL FIGHTING AND OUR HEARTS ACHE FOR THOSE WHO HAVE RECEIVED THEIR WINGS. IT IS OUR PRAYER THAT ALL BABIES CAN SURVIVE. WE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

Savana and Jamar Williams



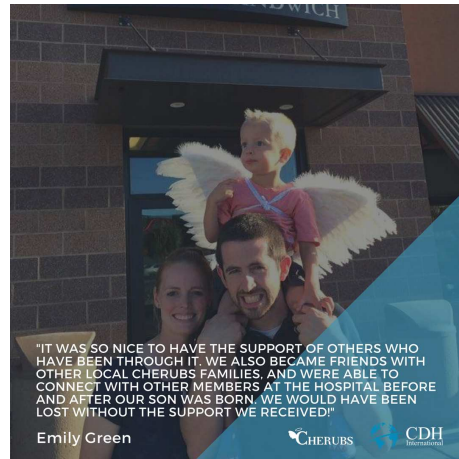
"I FOUND CHERUBS 19 YEARS AGO. AFTER MY DAUGHTER WAS BORN WITH UNDIAGNOSED CDH. THANKS TO CHERUBS, I WAS NEVER ALONE THROUGH HER HOSPITAL STAY AND DEATH. I AM FOREVER GRATEFUL."

Melanee Spencer



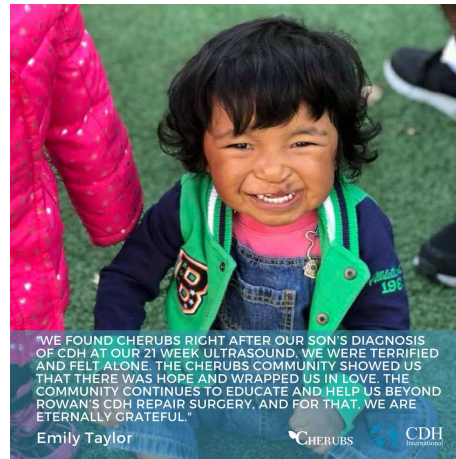
"WHEN THERE WAS LITTLE TO NO ANSWERS AFTER A CDH DIAGNOSIS, CHERUBS GAVE GUIDANCE, SUPPORT, BUT MOST OF ALL HOPE."

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."

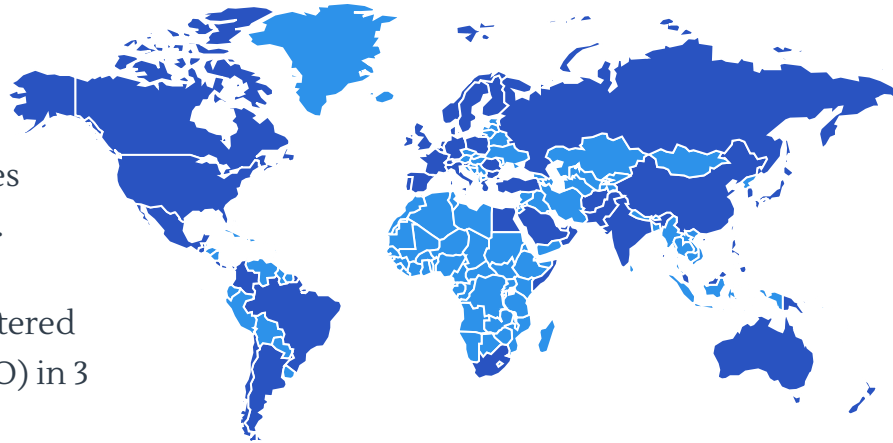
Ammie Gray



CDH Internationally

As of 2019, CDH international works with families in over 70 countries by providing support and information.

By the end of 2019, CDH will be a registered Non-Governmental Organization (NGO) in 3 more countries in addition to the U.S.



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

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 20 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 6300 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

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 2019, 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

1672



1572 - 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



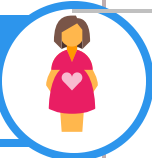
1976 - ECMO (Extracorporeal Membrane Oxygenation) was first used successfully in the treatment of persistent pulmonary hypertension.

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

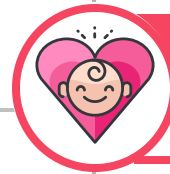
1992 - "Gentle Ventilation" of CDH first began

1990

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

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

1995



CHERUBS Founded

1995

CDHSG

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.

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

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

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

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.

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

1999 - FETENDO clip first used on a CDH patient.



CDH Web Site

1997

1997 - First CDH listervs were created

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

1998 - State & International Representative positions created for better local support of families.

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

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

2000



CDH Conference

2000

2000 - FETENDO balloon first used on a CDH patient.

2002 - Massachusetts General genetic CDH study started

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

2005

2005 - Baylor genetic CDH study started.

2001 - CHERUBS reaches 1000 families.

2004 - CHERUBS UK becomes a non-profit.

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 - DHREAMS CDH genetic and postnatal care study was created.

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.

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.

2010



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

2015

Placental Pod

2015



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

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

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

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

2017

CDH Research

2017



CDH International

2017



CDH International

2017

2017 - CDH Study Groups meets in Liverpool, England

2017 - CHERUBS was restructured into CDH International

2017 - CDH Research Database unveiled.

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

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



World Health Org

2018

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

2019 - CDHi leads a stand against CDH research restrictions

2019

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.

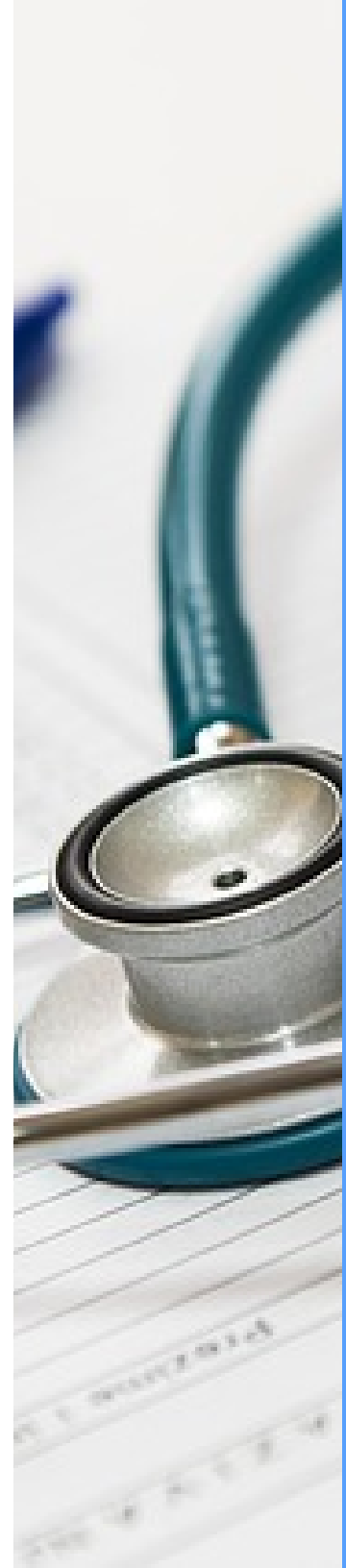
To ensure that CDH patients continue to experience gains in quality of treatment and quality of life, CDHi helps accredited centers establish a standard of CDH care with specific guidelines that are based on the latest research, medical evidence, and consultation with experts.

"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 Accredite 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

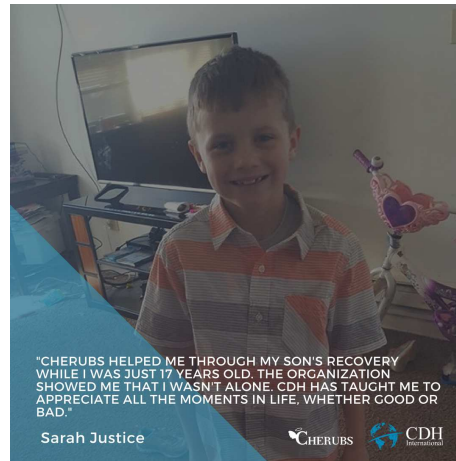
- Australia
- Canada
- Japan
- EURO CDH Consortium





"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



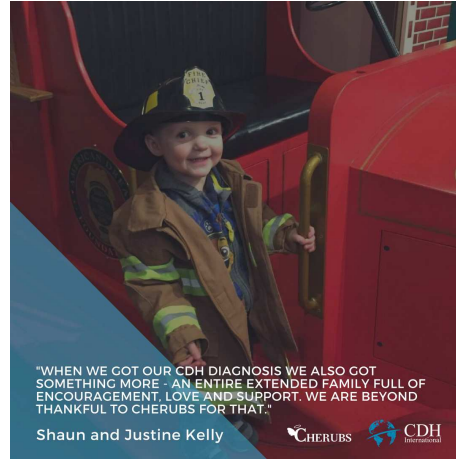
"THEY GAVE US HOPE. WE SAW SURVIVORS AND KNEW WE WEREN'T GOING THROUGH THIS ALONE. THEY UNDERSTOOD THE JARGON AND I DIDN'T HAVE TO EXPLAIN THE SEVERITY. THEY JUST KNEW."

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



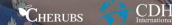
"WHEN WE GOT OUR CDH DIAGNOSIS WE ALSO GOT SOMETHING MORE - AN ENTIRE EXTENDED FAMILY FULL OF ENCOURAGEMENT, LOVE AND SUPPORT. WE ARE BEYOND THANKFUL TO CHERUBS FOR THAT."

Shaun and Justine Kelly



"WE DIDN'T FIND CHERUBS UNTIL MICHAELA 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



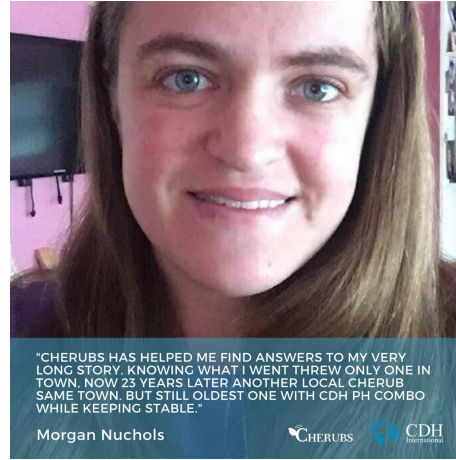
"THE CHARITY IS A GREAT SUPPORT TO MANY FAMILIES AND I LOVE THE CLOSED FACEBOOK GROUP AS IT ALLOWS US TO SHARE FREELY AND OFFER SUPPORT."

Sandra Vance



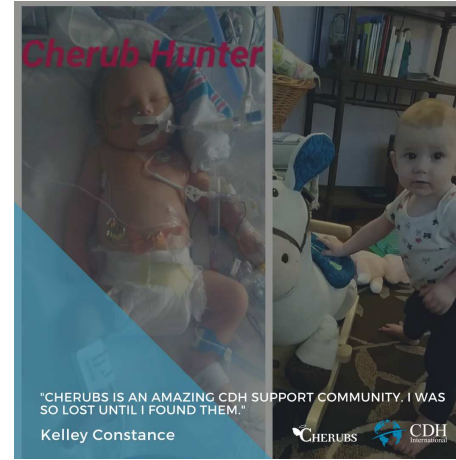
"CHERUBS HAS HELPED ME MEET AND CONNECT WITH OTHER ADULT CDH SURVIVORS. THESE CONNECTS HAS HELPED ME THROUGH A FEW COMPLICATIONS THAT HAVE COME WITH MY CDH. CHERUBS HAS ALSO HELPED ME SHARE MY STORY AND GIVE HOPE TO OTHERS FACING CDH."

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."

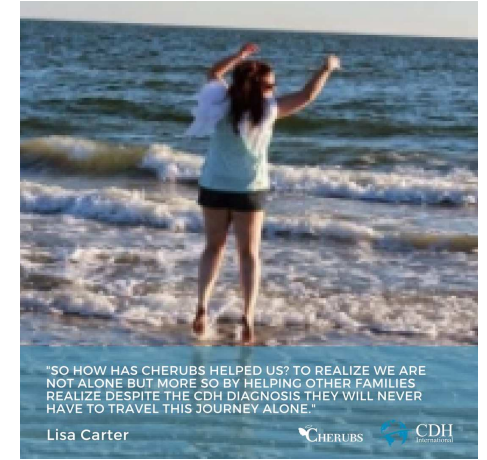
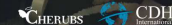
Morgan Nuchols



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 6300 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 2018, 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 2020 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.



By The Numbers



40,000+ Followers



\$1,000,000+ raised



3000+ Followers



6% overhead



8700+ Followers



1,000,000+ monthly reach



77,000+ Forum Posts



Over 20 years of service



6400+ Registered Members



CDH Awareness Month proclamations in all 50 states



220+ Videos



1200+ Newborn Care Packages

Noteworthy

CHERUBS is the world's oldest and largest CDH charity, founded by 2 moms on a kitchen table with just a typewriter in 1995. 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 6% and self-audits annually.

CHERUBS 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 6300 CDH families have been served through many projects, grants, conferences and more.

CDH Research and Funding

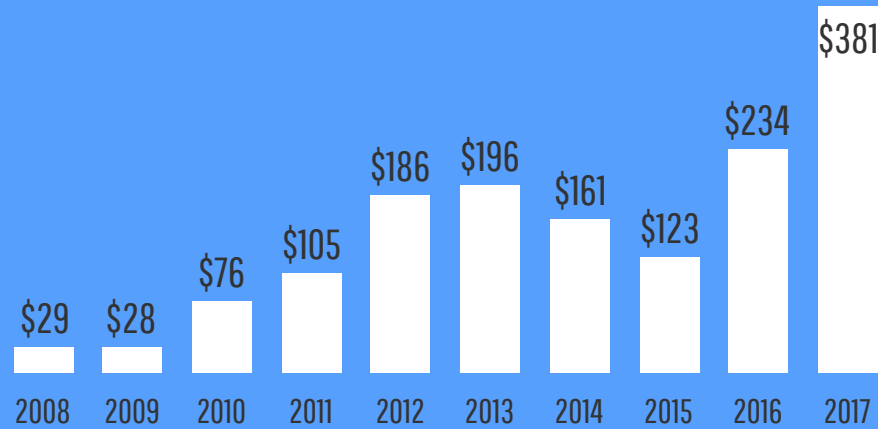


CHERUBS created the first patient driven CDH natural history database and has presented 4 studies, funds, grants and works closely with researchers.

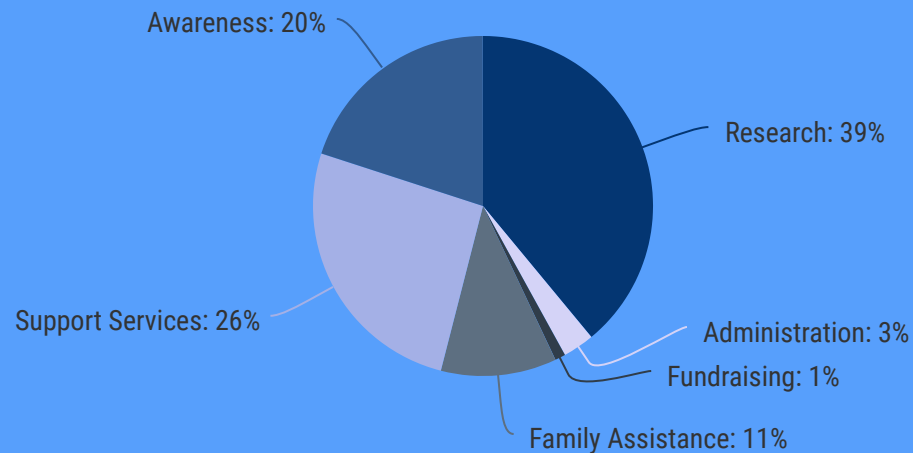


Financial Highlights

Growing Investments in the fight against CDH (in thousands)



Financial Efficiency 2017



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
- \$20 - 1 Info Packet
- \$20 - 1 Newsletter
- \$25 - 4 Shirts for 1 Family
- \$50 - 1 CDH HOPE Totebag
- \$150 - 1 Hospital Kit
- \$800 - 100 Parent Reference Guides
- \$1000 - 1 Conference Scholarship
- \$5000 - 1 Family Assistance Grant
- \$5000 - 1 Funeral Assistance Grant
- \$10000 - 1 College Scholarship
- \$10000 - 1 CDH Documentary
- \$10000 - 1 Research Grant
- \$10000 - 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



94¢ OF EVERY DOLLAR
GOES DIRECTLY 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
- 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.

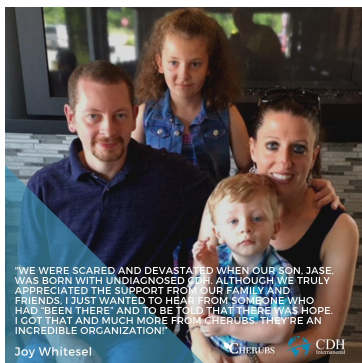
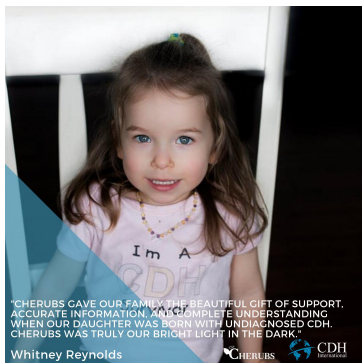
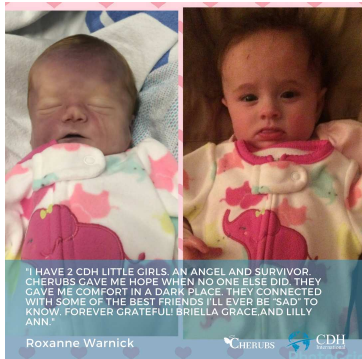
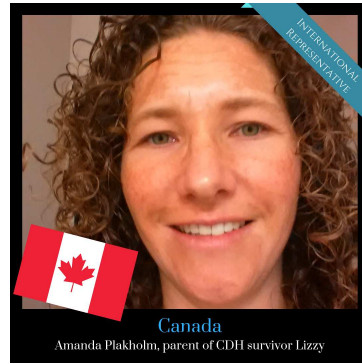
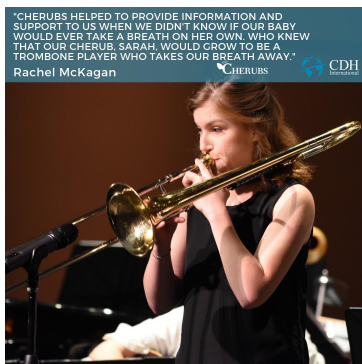
- * ACDHO on Facebook - <https://www.facebook.com/CDHorganizations/>
- * ACDHO Web Site - <http://acdho.blogspot.com/>

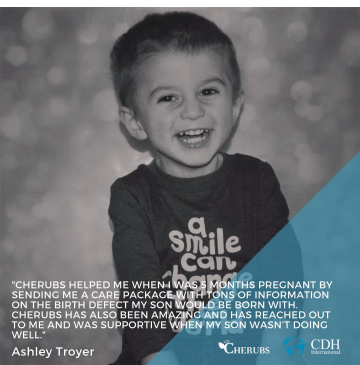
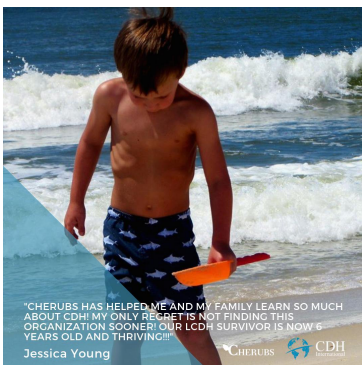
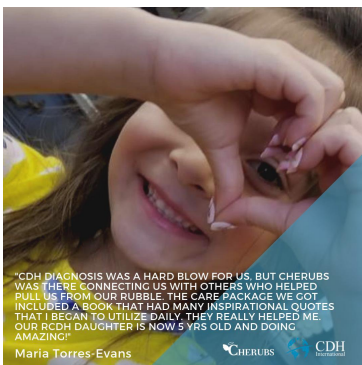
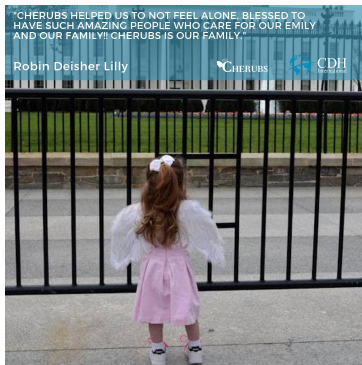
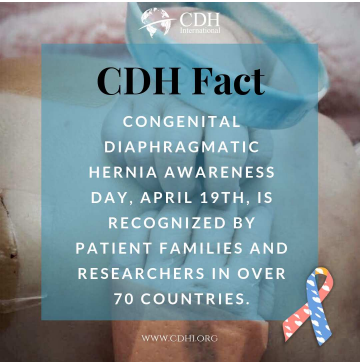
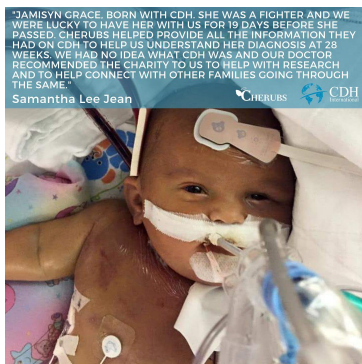
CDHi Ambassadors

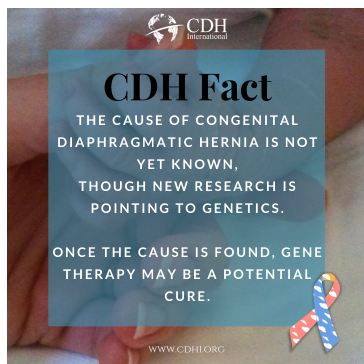
CDH International works with families in over 70 countries and to do so, we recruit the help of volunteers to translate and support patients and parents. We also work closely with our colleagues in the Alliance of Congenital Diaphragmatic Hernia Organizations and refer families to these other registered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

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









CDH Fact

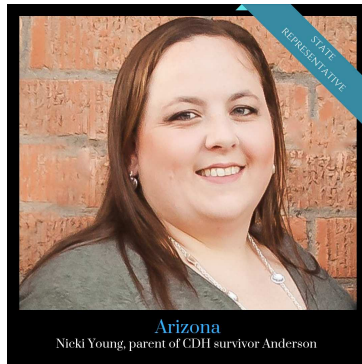
THE CAUSE OF CONGENITAL DIAPHRAGMATIC HERNIA IS NOT YET KNOWN, THOUGH NEW RESEARCH IS POINTING TO GENETICS.

ONCE THE CAUSE IS FOUND, GENE THERAPY MAY BE A POTENTIAL CURE.

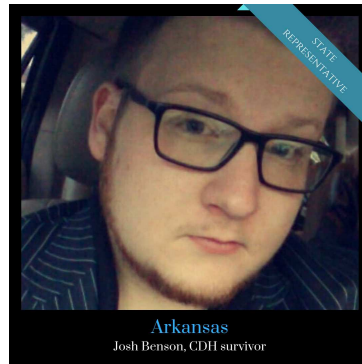
WWW.CDH.ORG



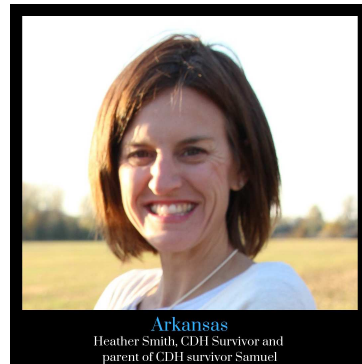
Alabama
DeAnn Strother McGilberry, parent of CDH survivor Celia and non survivor Claude



Arizona
Nicki Young, parent of CDH survivor Anderson



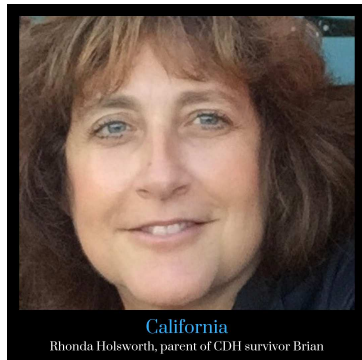
Arkansas
Josh Benson, CDH survivor



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



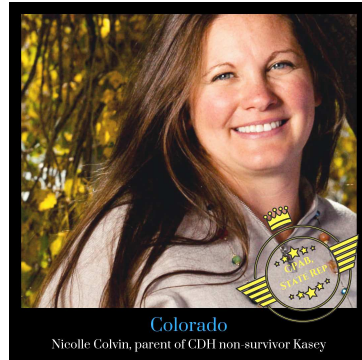
California
Jake Howell, parent of CDH non-survivor Madison



California
Rhonda Holsworth, parent of CDH survivor Brian



California
Rachel McKagan, parent of CDH survivor Sarah



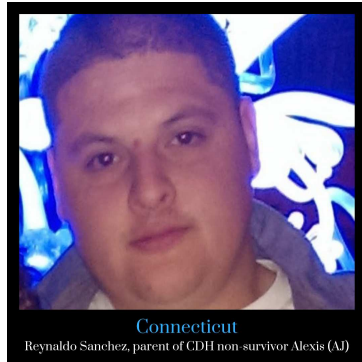
Colorado
Nicole Colvin, parent of CDH non-survivor Kasey



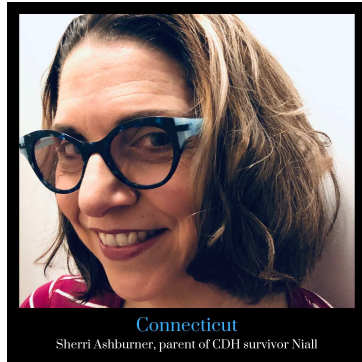
Colorado
Marissa Sanchez, parent of CDH survivor Evelyn



Colorado
Debbie Stevenson, parent of CDH survivor Eli



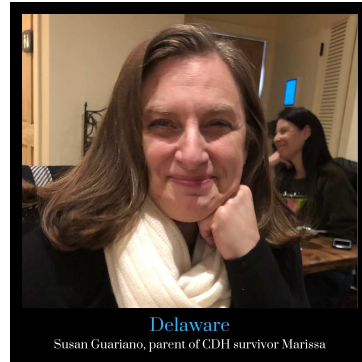
Connecticut
Reynaldo Sanchez, parent of CDH non-survivor Alexis (AJ)



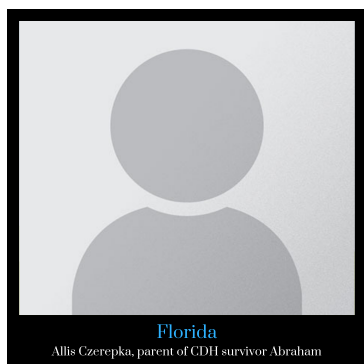
Connecticut
Sherri Ashburner, parent of CDH survivor Niall



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



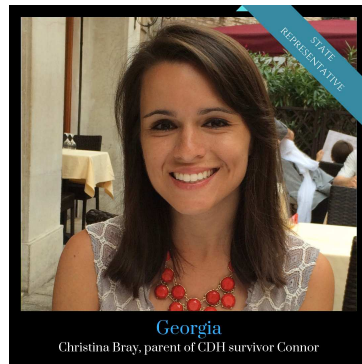
Delaware
Susan Guariano, parent of CDH survivor Marissa



Florida
Allis Czerepka, parent of CDH survivor Abraham



Florida
Libby Matteson, parent of CDH survivor Hunter



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

CDH


CDH Fact

LEFT-SIDED CONGENITAL DIAPHRAGMATIC HERNIA IS MORE COMMON THAN RIGHT-SIDED CDH.


BILATERAL CDH IS RARE.

WWW.CDH.ORG

STATE REPRESENTATIVE




Idaho
Angie Kelly, parent of CDH survivor Sierra



Idaho
Heidi Forney, parent of CDH survivor Sean



Illinois
Mindy Doelman, parent of CDH non-survivor Matthew



Illinois
Rachel Von Hatten, parent of CDH survivor Tucker

CDH

CDH Fact

CONGENITAL DIAPHRAGMATIC HERNIA IS NOT JUST A HERNIA.

IT IS A LIFE-THREATENING BIRTH DEFECT THAT AFFECTS SURVIVORS FOR THE REST OF THEIR LIVES AS THE THREAT OF COMPLICATIONS OR REHERNIATION IS A CONSTANT FEAR.

WWW.CDH.ORG




Illinois
Rebecca Schroeder, parent of CDH survivor Lily



Indiana
Wayne Oosteroff, grandparent of CDH survivor Tyler



Indiana
Melanie Stephie, parent of CDH non-survivor Treyson



Iowa
Stacey Klinker, parent of CDH non-survivor Isabella




Iowa
Megan Williams, parent of CDH survivor Emma

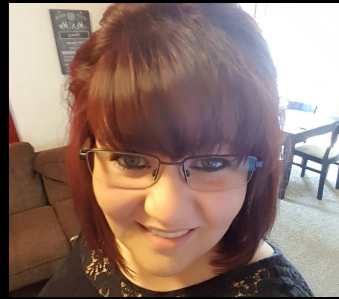


Iowa
Nicole Clark, parent of CDH non-survivor Christian

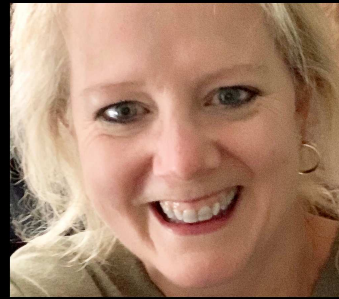
STATE REPRESENTATIVE



Kansas
Mary Kate Brenner, parent of CDH non-survivor Payton



Kansas
Cassie Rancey, parent of CDH non-survivor Wyatt




Kansas
Diane Punch, parent of CDH survivor Jacob

CDH

CDH Fact

THOUGH MANY USE HEART AND LUNG RATIOS TO PREDICT SURVIVAL IN CONGENITAL DIAPHRAGMATIC HERNIA PATIENTS, THIS METHOD IS SIMPLY A GUESS. MANY BABIES WITH LITTLE LUNG TISSUE HAVE SURVIVED WHILE MANY BABIES WITH ALMOST 2 FULL LUNGS HAVE NOT.

WWW.CDH.ORG




Kentucky
Taylor Hacker, CDH survivor

STATE REPRESENTATIVE



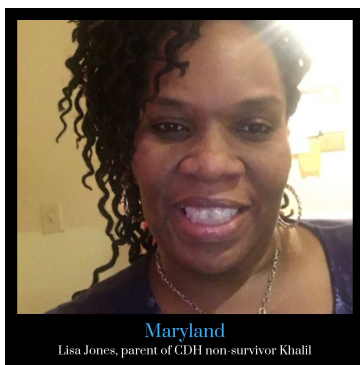
Louisiana
Lisa Thibeau, parent of CDH survivor Adam



Louisiana
Kristen Cochran, parent of CDH survivor Raylee



Maryland
Darlene Silverman, grandparent of CDH survivor Emily



Maryland

Lisa Jones, parent of CDH non-survivor Khalil



Massachusetts

Marie Marchesseault, parent of CDH survivor Anna



Massachusetts

Lynn Gray, parent of CDH non-survivor Harper



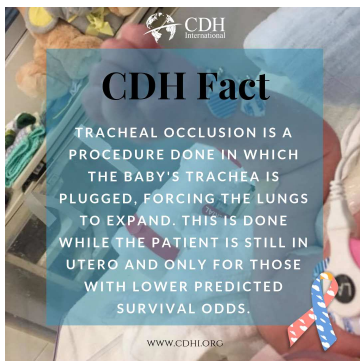
Michigan

Colleen Martin, parent of CDH survivor Quinn



Michigan

Lauren Petersen, parent of CDH non-survivor Tess



Michigan

Leslie Sukup, parent of CDH survivor Sage



Michigan

Colleen Martin, parent of CDH survivor Quinn



Michigan

Olivia Raine Foundation



Mississippi

Milinda Floyd, parent of CDH survivor Bryer



Mississippi

Shereen Kostmayer, parent of CDH survivor Micaela



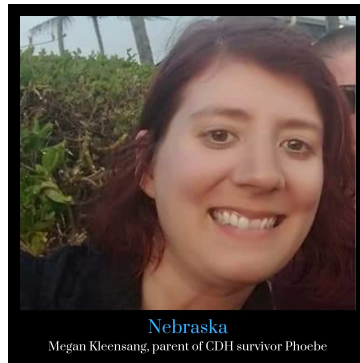
Missouri

Laura Henderson, parent of CDH survivor Lucie



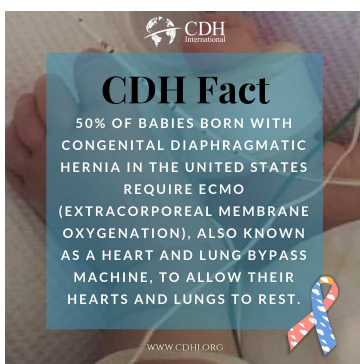
Montana

Mandy Alcoe, parent of CDH survivor Wilder



Nebraska

Megan Kleinsang, parent of CDH survivor Phoebe



Nebraska

Taylor Steffensmeier, CDH survivor



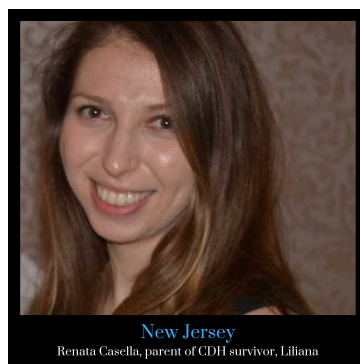
Nevada

Jill Gibson, parent of survivor Benjamin



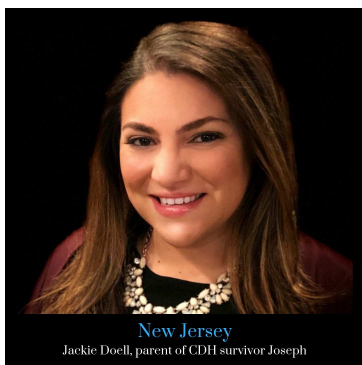
Nevada

Brandi Montenegro, parent of CDH non-survivor Sloane

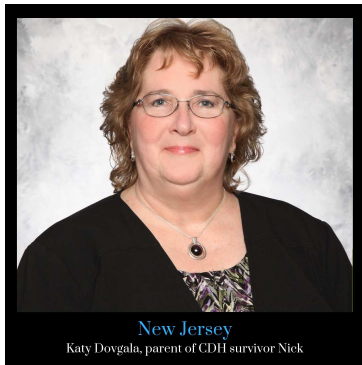


New Jersey

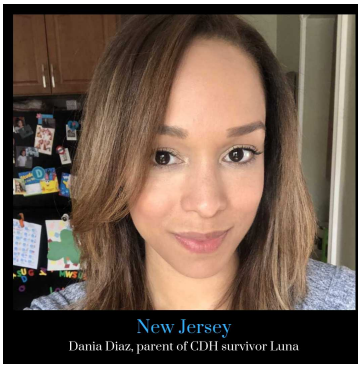
Renata Casella, parent of CDH survivor, Lilliana



New Jersey
Jackie Doell, parent of CDH survivor Joseph



New Jersey
Katy Doygala, parent of CDH survivor Nick



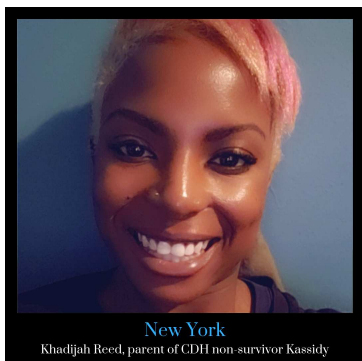
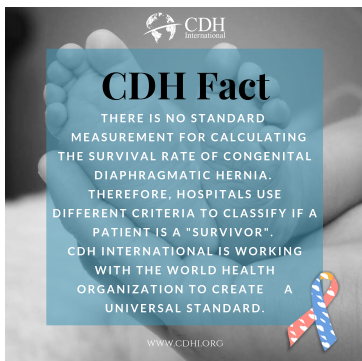
New Jersey
Dania Diaz, parent of CDH survivor Luna



New Jersey
Peyton's Promise



New York
Tracy Meyer, parent of CDH survivor Lillian Sophia



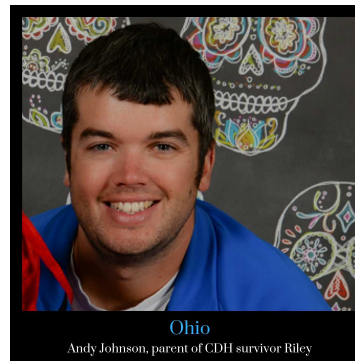
New York
Khadijah Reed, parent of CDH non-survivor Kassidy



New York
The Incredible Teddy Foundation



North Carolina
Theresa Erazmus, parent of CDH survivor William



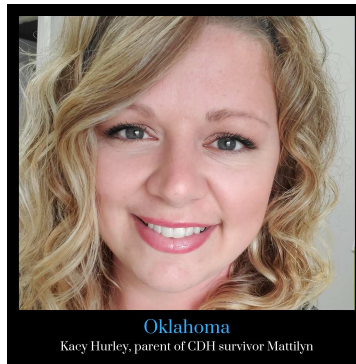
Ohio
Andy Johnson, parent of CDH survivor Riley



Ohio
Lisa Coleman, parent of CDH non-survivor Trinity



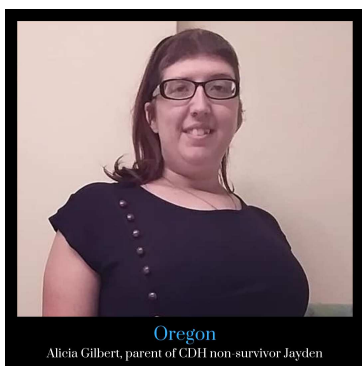
Ohio
James Coleman, parent of CDH non-survivor Trinity



Oklahoma
Kacy Hurley, parent of CDH survivor Mattilyn



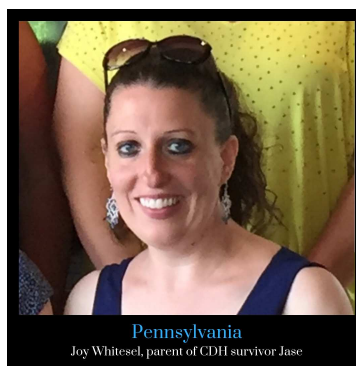
Oregon
Shelly Moore, grandparent of CDH non-survivor Jayden



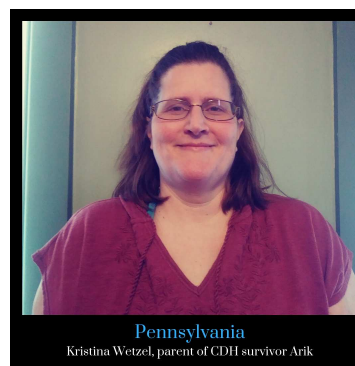
Oregon
Alicia Gilbert, parent of CDH non-survivor Jayden



Pennsylvania
Jessica Cummings, parent of CDH non-survivor Nathaniel



Pennsylvania
Joy Whitesel, parent of CDH survivor Jase



Pennsylvania
Kristina Wetzel, parent of CDH survivor Arik

CDH Fact
85% OF BABIES WITH
CONGENITAL
DIAPHRAGMATIC
HERNIA ARE
DIAGNOSED IN UTERO
VIA ROUTINE
ULTRASOUND.

WWW.CDH.ORG

Pennsylvania
Cate Scharle, parent of CDH survivor Liam

Pennsylvania
Polly Leipold, parent of CDH survivor Hillary

Pennsylvania
Arianna's CDH Foundation

South Carolina
Lynne Brogdon, parent of CDH survivor Baer

CDH Fact
CDH IS AS
COMMON AS
SPINA BIFIDA
AND CYSTIC
FIBROSIS

WWW.CDH.ORG

Tennessee
Sharon Weir, parent of CDH non-survivor Kaden

Texas
Tatiana Hurley, parent of CDH non-survivor Elijah

Texas
Sarah Cox, parent of CDH non-survivor Jasmin

Texas
Kaytlyn Powers, parent of CDH survivor Hudson

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

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

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

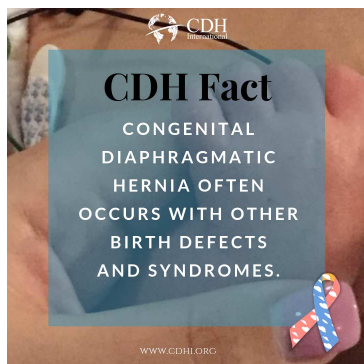
WWW.CDH.ORG

Texas
Ashley Leonard, parent of CDH survivor Greyson

Texas
Christie Huff Helmke, parent of CDH survivor Felix

Texas
Jessie Alderete, parent of CDH survivor Tristan

Utah
Josh Hensley, parent of CDH non-survivors Ally and Evie



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

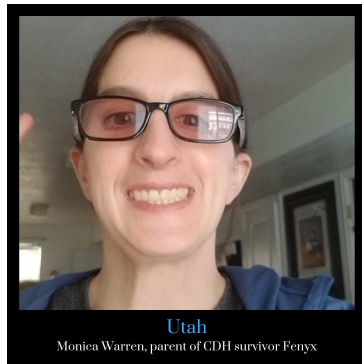
www.cdhl.org



Utah
Hope Clyde, parent of CDH survivor Tyler



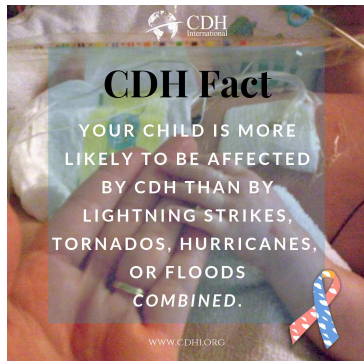
Utah
Melanee Spencer, parent of CDH non-survivor Makenzee



Utah
Monica Warren, parent of CDH survivor Fenyx

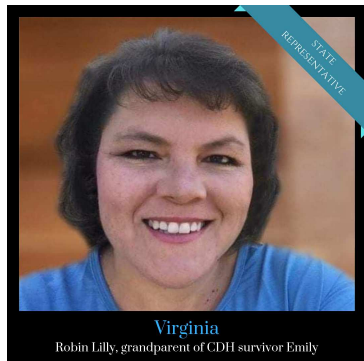


Utah
Heidi Marie Anderson, parent of CDH survivor Valancy

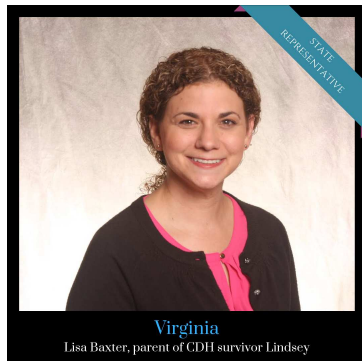


CDH Fact
YOUR CHILD IS MORE
LIKELY TO BE AFFECTED
BY CDH THAN BY
LIGHTNING STRIKES,
TORNADOS, HURRICANES,
OR FLOODS
COMBINED.

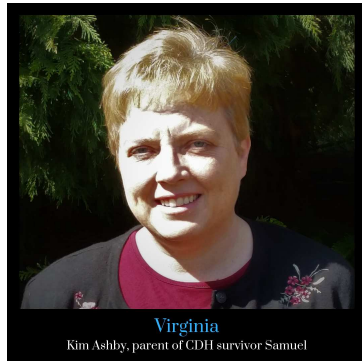
www.cdhl.org



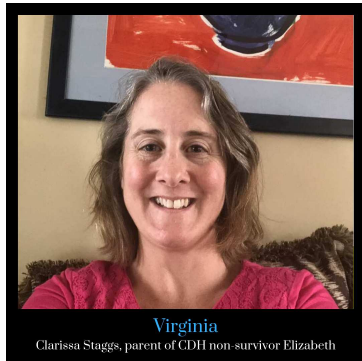
Virginia
Robin Lilly, grandparent of CDH survivor Emily



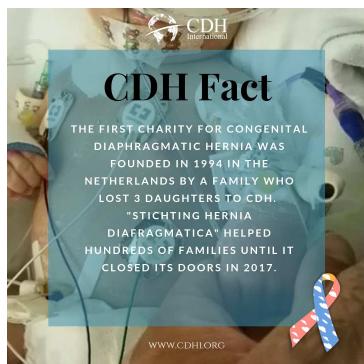
Virginia
Lisa Baxter, parent of CDH survivor Lindsey



Virginia
Kim Ashby, parent of CDH survivor Samuel

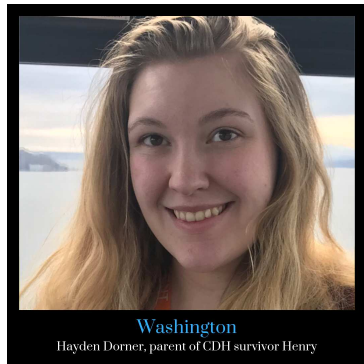


Virginia
Clarissa Staggs, parent of CDH non-survivor Elizabeth



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.cdhl.org



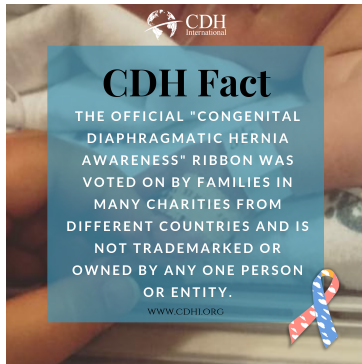
Washington
Hayden Dornier, parent of CDH survivor Henry



Wisconsin
Janel Litzner, parent of CDH survivor Elijah

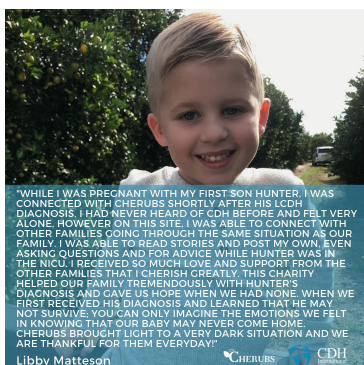


Wyoming
Tracy Meats, parent of CDH survivor Ian



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.cdhl.org



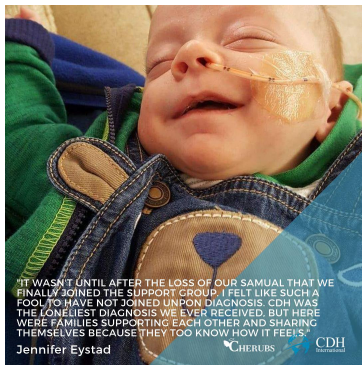
"WHILE I WAS PREGNANT WITH MY FIRST SON HUNTER, I WAS CONNECTED WITH CHERUBS SHORTLY AFTER HIS LCHD DIAGNOSIS. I HAD NEVER HEARD OF CDH BEFORE AND FELT VERY ALONE HOWEVER ON THIS SITE I WAS ABLE TO CONNECT WITH OTHER FAMILIES GOING THROUGH THE SAME SITUATION AS OUR FAMILY. I WAS ABLE TO READ STORIES AND POST MY OWN, EVEN ASKING QUESTIONS AND FOR ADVICE WHILE HUNTER WAS IN THE NICU. I RECEIVED SO MUCH LOVE AND SUPPORT FROM THE OTHER FAMILIES THAT I CHERISH GREATLY. THIS CHARITY HELPED OUR FAMILY TREMENDOUSLY WITH HUNTER'S DIAGNOSIS AND GAVE US HOPE WHEN WE HAD NONE. WHEN WE FIRST RECEIVED HIS DIAGNOSIS, WE LEARNED THAT HE MAY NOT SURVIVE. YOU CAN ONLY IMAGINE THE EMOTIONS WE FELT IN KNOWING THAT OUR BABY MAY NEVER COME HOME. CHERUBS BROUGHT LIGHT TO A VERY DARK SITUATION AND WE ARE THANKFUL FOR THEM EVERYDAY."

Libby Matteson



"MY LCHD BABY GIRL LYRIC REIGN WILL BE 3 YEARS OLD IN NOV. SHE SPENT 5 MONTHS IN THE NICU, A YEAR AND A HALF ON OXYGEN SUPPORT, EVEN AT HOME, AND GOING FROM 10 SPECIALIST DOWN TO MAYBE 10 SHE IS TRULY A MIRACLE AND IF IT WASN'T FOR CHERUBS I KNOW I WOULD NEVER BEEN EDUCATED ON CDH AND RECEIVING THEIR SUPPORT HELPED ME FIGHT THIS JOURNEY WITH MY BABY GIRL."

Renci Scurlock



"IT WASN'T UNTIL AFTER THE LOSS OF OUR SAMUEL THAT WE FINALLY JOINED THE SUPPORT GROUP. I FELT LIKE SUCH A FOOL TO HAVE NOT JOINED UPON DIAGNOSIS. CDH WAS THE LONELIEST DIAGNOSIS WE EVER RECEIVED, BUT HERE WERE FAMILIES SUPPORTING EACH OTHER AND SHARING THEMSELVES BECAUSE THEY TOO KNOW HOW IT FEELS."

Jennifer Eystad



"CHERUBS CONNECTED ME WITH OTHER FAMILIES IN MY COMMUNITY THAT WERE GOING THROUGH THE SAME THING. THEIR HOSPITAL VISITS WERE INTEGRAL FOR MY MENTAL HEALTH. HAVING SOMEONE TO TALK TO THAT HAS GONE THROUGH THE SAME THING AND A COMMUNITY TO LEAN ON IS VALUABLE BEYOND MEASURE."

Amber D'Onofrio



"WE DIDN'T FIND OUT ABOUT CHERUBS FOR QUITE A WHILE AFTER OUR EXPERIENCE. TRISTAN WAS BORN WITH UNDIAGNOSED CDH 17 YEARS AGO, AND THOSE DAYS NOT HAVING SOCIAL MEDIA, MADE IT A VERY LONELY ROAD. A COUPLE OF MONTHS LATER, I DISCOVERED CHERUBS AND IMMEDIATELY THEY FELT LIKE FAMILY. WE WERE NOT SO ALONE ANYMORE! GETTING SUPPORT FROM THEM, INFORMATION ABOUT CDH AND KNOWING WE WEREN'T ALONE MEANT THE WORLD TO US. 17 YEARS LATER AND I STILL VOLUNTEER AND LOVE CHERUBS! THANK YOU TO ALL THE OTHER VOLUNTEERS WHO HELP SO SELFLESSLY!"

Amanda and Grant Dean

Contact Us



www.cdhi.org

www.cherubs.org (Patient Support)

www.cdhresearch.org

Patient Support - cpab@cherubs.org

General Questions - info@cdhi.org

Donations - donate@cdhi.org

Corporate Giving - giving@cdhi.org

Fundraising - fundraising@cdhi.org

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To be finalized in 2019

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Canada

To be announced in 2019



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

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

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



<https://www.linkedin.com/company/cdhi/>



<https://www.pinterest.com/cdhawareness/>



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@cherubs

@cdhiuk

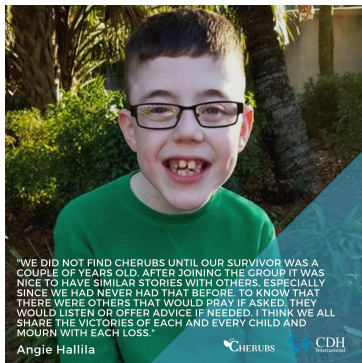


@cdhintl

@savethecherubs

@cdhiuk





"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



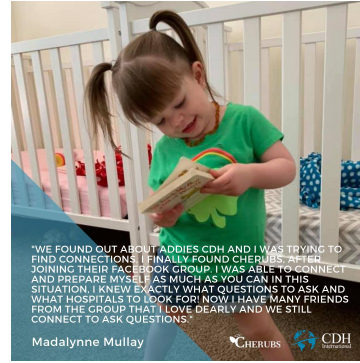
"CHERUBS PROVIDES US WITH HOPE IN OUR DARKEST HOUR. WE FOUND OTHER SURVIVOR FAMILIES THAT SUPPORTED AND GUIDED US TOWARD LIFELONG FRIENDSHIPS. CELEBRATING EACH CHERUBS MILESTONES TOGETHER IS HEARTWARMING."

Amanda Khan



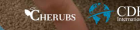
"TERRIFIED. 6/17/2003 @11:07AM WAS THE TIME MY SON WAS BORN. ABOUT AN HOUR LATER WAS THE FIRST I'D HEARD OF CDH. GOOGLE WAS THE ONLY RESOURCE I HAD AND FOUND CHERUBS, WHICH WAS THE ONLY SITE I COULD FIND WITH INFORMATION I COULD UNDERSTAND. JACOB WILL BE 16 IN JUNE AND I AM FOREVER GRATEFUL FOR THIS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

Nicole Sedgwick



"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 Mulla



"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



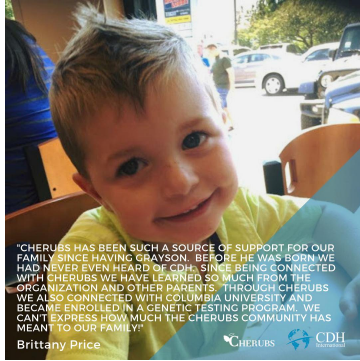
"THANKS TO CHERUBS MY DAUGHTER HAS MET OTHER CDH CHILDREN AND WE HAVE MADE MANY NEW FRIENDS. CHERUBS HAS HELPED US FIND FAMILIES WITH SIMILAR EXPERIENCES FOR SUPPORT. MOST IMPORTANTLY CHERUBS HAS GIVEN ME HOPE THAT MY DAUGHTER WILL ALWAYS HAVE A PLACE TO TURN AS SHE NAVIGATES CDH AS AN ADULT."

Amanda Plakholm



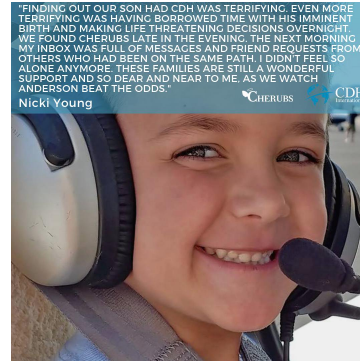
"CHERUBS COMFORTED US WHEN WE HAD AN UNEXPECTED DIAGNOSIS AT 4 WEEKS OLD. WHEN THE DOCTORS AND NURSES SAY THEY WON'T KNOW HOW BAD IT IS UNTIL THEY GET INTO SURGERY, WE FOUND HOPE AND ENCOURAGEMENT IN THE CHERUBS GROUPS."

Stephanie Stephens



"CHERUBS 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



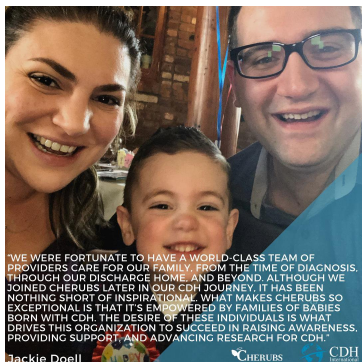
"FINDING OUT OUR SON HAD CDH WAS TERRIFYING. EVEN MORE TERRIFYING WAS HAVING BORROWED TIME WITH HIS IMMINENT BIRTH AND MAKING LIFE THREATENING DECISIONS OVERNIGHT. WE FOUND CHERUBS LATE IN THE EVENING. THE NEXT MORNING MY INBOX WAS FULL OF MESSAGES AND FRIEND REQUESTS FROM OTHERS WHO HAD BEEN ON THE 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



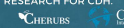
"CHERUBS WAS THE FIRST SUPPORT SYSTEM. ONLY ONE DAY AFTER WE RECEIVED THE DIAGNOSIS, THEY GAVE ME ENCOURAGEMENT, ADVICE, AND INFORMATION WHICH BROUGHT ME PEACE AND STRENGTH TO CONTINUE ON OUR NEW JOURNEY."

Heidi Marie Anderson



"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 TO SUCCEED IN RAISING AWARENESS, PROVIDING SUPPORT, AND ADVANCING RESEARCH FOR CDH."

Jackie Doell



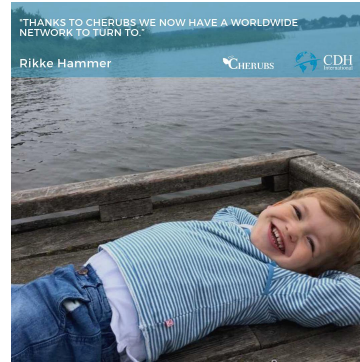
"THE BEST WAY I CAN DESCRIBE THE FEELING I HAD WHEN I DISCOVERED CHERUBS IS LIKE GOING TO A MASQUERADE BALL AND EVERYONE IS WEARING THE SAME MASK BUT EACH FACE UNDERNEATH IS A WARRIOR WITH A DIFFERENT STORY. YOU INSTANTLY FEEL WELCOMED AND YOU GET A SENSE OF RELIEF THAT YOU'VE FOUND THE ANSWERS YOU'VE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

Josh Benson



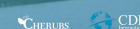
"FOR ME CHERUBS MEANS HOPE. A COMMUNITY FOR BABIES, CHILDREN, AND FAMILIES FIGHTING OR GRIEVING AND COMING TOGETHER AS ONE TO SAVE THE LIVES OF MANY. CHERUBS HAS HELPED ME SHARE MY DAUGHTER'S STORY AND HONOR HER MEMORY ESPECIALLY THROUGH TOUGH TIMES."

Khadijah Reed



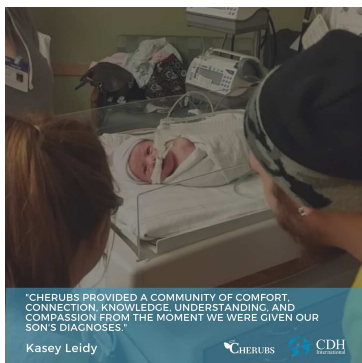
"THANKS TO CHERUBS WE NOW HAVE A WORLDWIDE NETWORK TO TURN TO."

Rikke Hammer



"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 Alcoke



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

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



"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 SPIRIT OF CDH SHE HAS ACCOMPLISHED GREAT THINGS WE HOPE THAT HER SUCCESS CAN INSPIRE OTHERS WITH CDH AND THEIR PARENTS."

Donette Black



"CHERUBS HAS HELPED TO GIVE OUR FAMILY THE SUPPORT WE SO DESPERATELY NEEDED AFTER KIERAN 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 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'VE MET THROUGH CHERUBS WE KNOW THAT OUR GRACE IS NOT FORGOTTEN."

Miranda Hall



