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.
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 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.
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.
**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

**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
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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 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

**Parent Advisory Board**
Tracy Meats, CHERUBS President
Darlene Silverman, Research
Nicolle Colvin, Fundraising
Mary Kate Brenner, Awareness

**Office Staff**
Laura Tomczyk, Bookkeeping
Kamal Saleh, Programming
The roles of CDH International

Research
- CDH Research Database
- Hospital Accreditation
- CDH Standard of Care

Awareness
- National Legislation
- April 19th Proclamations & Light Ups
- Media and Social Media

Patient Advocacy

Support
- Accurate and easy to understand information
- Patient and family support
- Charity peer-to-peer support

Representing CDH
Representing Patients
Representing the Cause

CDH International
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 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 20 more

**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.

**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 Jackson
- Kim Alexis
- Paul Amos
- Sean Astin
- Lance Bass
- Jaron Brown
- ‘Downtown’ Julie Brown
- Dean Cain
- Michael Campion
- Justin Coleman
- Randy Couture
- Chase d’Arnaud
- Luanne de Lesseps
- Chris Daughtry
- David DeLuise
- Dr. Drew
- Colin Eglesfield
- Peter Faccinelli
- Brett Favre
- Jeff Foxworthy
- 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.

85% ARE DIAGNOSED IN UTERO
During return pre-natal ultrasounds, usually at 20 weeks gestation. 15% are still not diagnosed until birth.

1600 a year in the US

Every 10 minutes, a baby is born with CDH

An Entire Elementary School
In population of CDH kids (800) disappears every year in the US
Congenital Diaphragmatic Hernia has the exact same occurrence rate (1:2500) as:

- CDHi / CHERUBS | 409,406
- Turner Syndrome Society of the US | 700,105
- Spina Bifida Association of America | 1,937,657
- Children's Craniofacial Association | 1,002,887
- Charcot-Marie-Tooth Disease | 3,300,962
- Cystic Fibrosis Foundation | $1,393,954,611 ---->

$1,393,954,611 ---->

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 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. My son will be able to talk to other peers when he’s older. I’m blessed about his and their experience is also a blessing.

Kasey Leidy

Cherubs has helped us raise awareness and educate others. The birth defect is rare and needs to be raised awareness. We don’t want our children to feel isolated by other people who do not understand.

Christine Daly

When my Camden passed, I felt the love and I knew I was not alone. Other Cherubs welcomed us into the community of families who have travelled the same road.

Corey and Robbie Fletcher

Thank you Cherubs! For your continued efforts to spread awareness, and for always being there for us. Your work is appreciated and it helps our hearts ache for those who have received their wings. It is our dream 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 18 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.

Molanne 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 others off the list. We would have been lost without the support we received.

Emily Green

We found Cherubs right after our son’s diagnosis. We were so deep in our grief, and we were terrified. Cherubs gave us strength and love. We are eternally grateful that there was hope and support during the early days. We are so grateful to everyone who supported our journey through surgery and beyond.

Emily Taylor

Cherubs gave my husband and I the hope and strength to be brave when all experts said our daughter probably would not see her first birthday.

Ammiee 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, 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

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 complement 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 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
1570 - 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.
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.

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.

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.


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.

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

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

1995 - The first CDH newsletter was published.


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.

2000 - FETENDO balloon first used on a CDH patient.

2000 - The first international conference for families affected by CDH was held in Orlando.
2005 - Baylor genetic CDH study started.

2001 - CHERUBS reaches 1000 families.
2004 - CHERUBS UK becomes a non-profit.

2005 - DHREAMS CDH genetic and postnatal care study was created.

2007 - The Association of Congenital Diaphragmatic Hernia Organizations (ACDHO) was formed.
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 - 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 - CHERUBS introduces legislation in both the US House and US Senate

2012 - CHERUBS presents to the CDH Study Group in Rotterdam, Netherlands.

2013 - First International ACDHO Conference in Europe held in Dublin, Ireland

2014 - $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 - Joint research abstract with Toronto Sick Children’s to the American Academy of Pediatrics.
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 - CDH Study Groups begin the path to establish a Standard of Care for CDH in the United States
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

- CDH International Turns 25 Years Old
- CDHi represents structural birth defects at Global Initiative for Children’s Surgery in Johannesburgh, South Africa
- CDH Patient Registry converts to new platform and grows to over 6500 patients
- CDH International becomes a registered charity in the United Kingdom
- CDH International creates the first phone App for patient families

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 - New CDHi NGO Status started in Ireland
2019 - New CDHi NGO Status started in Canada
2019 - CDHi participates / speaks at over 40 medical conferences in 9 countries

2020 - CDH Study Groups meets in Houston
2020 - First Draft of Global Standard of Care for Congenital Diaphragmatic Hernia
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
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.

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.

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.

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.

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.
25 Years By The Numbers

- 6500+ Registered Patients
- 280 Newborn Care Packages
- 1500+ Registered Patients
- 100+ Medical Conferences
- 220+ Videos
- 40,000+ Followers
- 77,000+ Forum Posts
- $2,000,000+ raised
- 9% overhead
- 1,000,000+ monthly reach
- Over 20 years of service
- CDH Awareness Month proclamations in all 50 states
- 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.

Noteworthy

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.

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

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

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

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

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

“The smallest act of kindness is worth more than the grandest intention” - Oscar Wilde
Financial Highlights

Growing Investments in the fight against CDH (in thousands):

<table>
<thead>
<tr>
<th>Year</th>
<th>Investment (in thousands)</th>
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<tbody>
<tr>
<td>2008</td>
<td>$29</td>
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<tr>
<td>2009</td>
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<td>$381</td>
</tr>
<tr>
<td>2018</td>
<td>$363</td>
</tr>
<tr>
<td>2019</td>
<td>$240</td>
</tr>
</tbody>
</table>

Financial Efficiency 2018:

- Fundraising: 15015.78%
- Awareness: 46862%
- Support: 52129.24%
- Operations: 8372.22%
- Family Assistance: 17695.29%
- Scholarships: 0%
- Research: 122357.35%
- Lobbying: 0%
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.

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.

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.

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

91¢
of every dollar
goes directly to the cause

56-1916661
501(c)III Charity

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
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 (ACDHO), 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.
Philippines

Amira Kate Engleb, parent of CDH survivor Zoe Kristin.

Scotland

Donna Warden, parent of CDH non-survivor Myle.

Singapore

Lyn Laiiste, parent of CDH survivor Sherrie.

South Africa

Amanda Dean, parent of CDH survivor Tellem.

Spain

La Vida Con Herida Diaphragmática Congenita.

Sweden

CDH Sverige

United Arab Emirates

Gemma van Rijswij, parent of CDH survivor Ellis.

United Kingdom

Matthew Keck, parent of CDH survivor Hugo.

United Kingdom

Jen Keck, parent of CDH survivor Hugo.

United Kingdom

SMILE - The Chloe Tate Foundation

Fundraising for Leeds Hospital Charitable Foundation.

CDH Fact

Over 2,000 babies are born with congenital diaphragmatic hernia every year.

Over half of these children will not survive.

Survival rates vary from 5% to 0% depending on which country a child is born in.

CDH Fact

Congenital diaphragmatic hernia awareness day, April 15th, is recognized by patient families and researchers in over 70 countries.

Patricia House

SAY IT OUT LOUD, WE ARE CDH HEROES!

Ashley McAlpine

“CHERUBS HELPED ME TO NOT FEEL SO ALONE DURING THE HARDEST DAYS OF MY LIFE.”

Gemma van Rijswij

“SINCE EUGENIE WAS DIAGNOSED 3 YEARS AGO, IT’S CHERUBS THAT HAVE GIVEN ME THE STRENGTH TO FIGHT, THE COURAGE TO FUNDRAISE AND THE WILL TO HELP OTHERS.”

United Kingdom

SMILE - The Chloe Tate Foundation

Maria Tomas Evans

“CDH DIAGNOSIS WAS A HUGE BLOW FOR US. BUT CHERUBS HELPED ME AND MY FAMILY LEARN SO MUCH ABOUT CDH AND OUR CHILDREN. OUR FAMILY IS STRONGER AND OUR TRAVELS ALIKE OUR FAMILY.”

Jessica Young

“CHERUBS HAS HELPED ME SAFETY PREGNANT BY SHOWING ME HOW TO FIGHT AND BE STRONG. I NOW PLAN TO HELP OTHERS FIGHT AND HELP CDH BABIES.”

Ashley McAlpine

“CHERUBS HELPED ME FIND MY VOICE AND HAS BEEN THERE FOR ME DURING EVERYTHING. I KNOW THAT WITH THE SUPPORT OF OTHER FAMILIES I CAN FIGHT CDH.”

“CHERUBS HAS HELPED ME SAFETY PREGNANT WITH THE HELP OF CDH FAMILIES.”

35
CDH Fact
CONGENITAL DIAPHRAGMATIC HERNIA OFTEN OCCURS WITH OTHER BIRTH DEFECTS AND SYNDROMES.

Utah
Hope Clyde, parent of CDH survivor Tyler

Utah
Melanie Spencer, parent of CDH non-survivor Makenna

Utah
Monica Warren, parent of CDH survivor Fenix

Utah
Brenda Marie Anderson, parent of CDH survivor Valentino

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

Virginia
Claudia Staggs, parent of CDH non-survivor Elizabeth

Virginia
Lisa Baxter, parent of CDH survivor Lindsay

Virginia
Kim Arbs, parent of CDH survivor Samuel

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

Washington
Hope Dirier, parent of CDH survivor Henry

Wisconsin
Janelt Linder, parent of CDH survivor Elijah

Wyoming
Tracy Mote, parent of CDH survivor Ian

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

CDH Fact
CONNECTED AND WEANCED TO TAKE IT IN MY STEPS TO HELP OTHERS THROUGH THE SAME THING THAT I WENT THROUGH. SCARLETT HELPED ME STRENGTHEN MY MENTAL HEALTH AND OTHER MUMMIES AND DADS THAT ARE ON THE JOURNEY. SHE ALSO HELPED ME BECOME ENGAGED IN ACTIVITIES TO HELP OTHERS AND SUPPORT OTHERS THROUGHOUT THEIR JOURNEY. I WANT TO BE ABLE TO HELP OTHERS AND LEARN FROM OTHERS, AND I'M LUCKY TO HAVE BEEN A PART OF SUCH A COMMUNITY TO LEARN ON.

Libby Maatstra

Brenna Seelbach

Jennifer Eystad

Amanda and Grant Dean

THIS DON'T BECOME OUR OBSESSION ON FINDING A WAY TO OVERCOME IT. THIS IS A TRAGEDY BUT WE CAN HELP HELP EACH OTHER THROUGH IT. YOU CAN FIND THE STRENGTH WITHIN YOURSELF AND OTHERS TO HELP EACH OTHER. KNOWING THAT YOUR DAUGHTER IS NOT THE ONLY ONE IS A RELIEF. KNOWING THAT YOUR DAUGHTER HAS NOT HEARD THE SAME THINGS THAT YOU HAVE HEARD. KNOWING THAT YOU ARE NOT ALONE IS A RELIEF.
Contact Us

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

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152 S White St (Office)
Wake Forest, NC 27587
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www.cdhi.org
info@cdhi.org
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77 Victoria Street, Box 135
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uk@cdhi.org
+44 20 3966 5346
Registered UK Charity no. 1189819

Italy
To be finalized in 2021
+39 347 3020001

Canada
To be announced in 2021

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

http://www.facebook.com/cdhintl
http://www.facebook.com/cdhsupport
http://www.facebook.com/cdhiuk

https://www.linkedin.com/company/cdhi/
@cdhintl
@cherubs
@cdhiuk

https://www.pinterest.com/cdhawareness/
@cdhintl
@savethecherubs
@cdhiuk
WE DO NOT TAKE QUOTAS UNTIL OUR FUNCTION AND OUR ACTIVITY ARE INTERESTING.

AS WE COME ALONG THE ROAD TO THE FUTURE, THE ROAD IS NOT EASY.

WE FACE MANY DIFFICULTIES AND OBSTACLES, BUT WE ARE NOT ALONE.

OUR COMMUNITY SUPPORTS US AND OUR FAMILIES, AND TOGETHER WE CAN FIGHT FOR A BETTER FUTURE.

OUR COMMUNITY PROVIDES A SAFE HAVEN FOR EVERYONE, REGARDLESS OF BACKGROUND OR CIRCUMSTANCES.

WE ARE STRONGER TOGETHER, AND OUR COMMUNITY IS OUR GREATEST STRENGTH.

PRIMARY IMAGE: "We were told by the doctor that my daughter was born with a heart condition. We were scared and didn’t know what to do. But we were not alone.

As we walked through the hospital, we connected with other families who were experiencing the same thing. We shared our stories, our fears, and our hopes. We found strength in each other.

We all know that life is not always easy, but with the support of our community, we can face any challenge.

Thank you for being there for us."

Amanda Knight

"WE TOOK OUR DAUGHTER TO THE HOSPITAL WITH THE HOPE THAT SHE WOULD BE FINE... BUT WE WERE TOLD THAT SHE HAD A CONGENITAL HEART CONDITION..."

Evelyn

"WE REMEMBRED THE DAY WHEN WE HAD TO SAY GOODBYE TO OUR DAUGHTER... BUT WE KNOW THAT SHE IS STILL WITH US IN OUR HEARTS..."

Annie

"WE WERE TERRIFIED BUT HOPEFUL WHEN WE MET OUR DAUGHTER... BUT WE KNEW THAT WE WOULD DO EVERYTHING TO HELP HER..."

Stephanie Stephens

"WE WERE OVERWHELMED BY THE SUPPORT THAT WE RECEIVED... BUT WE KNEW THAT WE WERE NOT ALONE..."

Nick Young

"WE WERE BLESSED TO HAVE OUR COMMUNITY SUPPORT US... BUT WE KNOW THAT WE NEED TO KEEP FIGHTING TO MAKE SURE THAT EVERYONE HAS ACCESS TO THE BEST CARE..."

Erikke Hammer

"WE WERE NOT YOUR USUAL FAMILY... BUT WE KNOW THAT WE CAN BE STRONG TOGETHER..."

Mandy Alcock