CDH INTERNATIONAL
A global initiative to stop Congenital Diaphragmatic Hernia
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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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.

Dawn M. Torrence Ireland
As CHERUBS enters into its 24th year, I am proud of the strides and accomplishments we’ve made together for the CDH 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 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
- Katherine Haney, Vice-President
- M. Shane Perry, Esq., Secretary
- Tracy Meats, CHERUBS President
- Tara Henderson, Director
- Warren Sumner, 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
- 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 - Ospedale dei 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
- Josh Hensley, Research
- Darlene Silverman, Research
- Nicolle Colvin, Fundraising
- Amanda Plakhom, Fundraising
- Hope Clyde, Parent Support

**Office Staff**
- Rachael Eller, Office Manager
- 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

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

Representing CDH

Representing Patients

Representing the Cause
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 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
- PECO Energy Center
- Miami Tower
- Cleveland Terminal Tower
- Tampa Sun Life Tower
- City Place of West Palm Beach

**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 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 Fàcinelli
- Brett Favre
- Jeff Foxworthy
- Debbie Gibson
- Brian Austin Green
- Matthew Morrison
- Tim Murphy
- Vince Neil
- Patsy Pease
- Chris Rankin
- John Schneider
- 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
- Jeff Sessions
- Christie Swanson
- Aaron Watson
- Chris Weidman
- Larry Wilcox
- William Wiser
- 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.

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

IN EVERY 2500 BABIES
is diagnosed with Congenital Diaphragmatic Hernia.

50% SURVIVAL

Every race
Every religion
Every gender

1600 a year in the US
Congenital Diaphragmatic Hernia has the exact same occurrence rate (1:2500) as:

<table>
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<tr>
<th>Organization</th>
<th>Amount</th>
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<tr>
<td>CDHi / CHERUBS</td>
<td>409,406</td>
</tr>
<tr>
<td>Turner Syndrome Society of the US</td>
<td>700,105</td>
</tr>
<tr>
<td>Spina Bifida Association of America</td>
<td>1,937,857</td>
</tr>
<tr>
<td>Children’s Craniofacial Association</td>
<td>1,002,887</td>
</tr>
<tr>
<td>Charcot-Marie-Tooth Disease</td>
<td>3,300,962</td>
</tr>
<tr>
<td>Cystic Fibrosis Foundation</td>
<td>$1,393,954,611</td>
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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 how much the people you meet due to the birth defect that stick by your side through thick and thin, and encourage you to continue your journey to make your child the best they can be. My son will be able to talk to other kids when he's older. The people he will meet will be able to help him in his journey to be a better person.

Kasey Leidy"

"We found Cherubs shortly after our son Liam was diagnosed with CDH. It was incredible to see all the other families who have gone through this experience. Our son has made lifelong friendships with people through Cherubs. It has given us a sense of community and support, which is invaluable.

Danielle Sheffield"

"I found Cherubs 12 years ago after my daughter was born with undiagnosed CDH. Thank you Cherubs! I was never alone through her hospital stay and death. I am forever grateful.

Mandy Alcock"

"Cherubs has helped us raise awareness and educate others about birth defects. It has built a community of people who understand what we are going through and have been there before.

Christine Daly"

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

Corey and Robbie Fletcher"

"I found Cherubs 12 years ago after my daughter was born with undiagnosed CDH. Thank you Cherubs! I was never alone through her hospital stay and death. I am forever grateful.

Savana and Jamar Williams"

"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"

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Ammiee 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.

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

Publications

In 2019, CDH International will be published in several research journals publishing joint studies with universities.
**Congenital Diaphragmatic Hernia**

*The History of CDH and CHERUBS*

**1570**

- **CDH Discovered**

**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 world’s first CDH charity, Stichting Hernia Diafragmatic, was founded in the Netherlands.

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

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.


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

1996 - Latisimus Dorsi flap first used to repair CDH.

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

2000 - FETENDO balloon first used on a CDH patient.

2002 - Massachusetts General genetic CDH study started
2005 - Baylor genetic CDH study started.

2005 - 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 presents to the CDH Study Group in Rotterdam, Netherlands.

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

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

2013 - CHERUBS presents its research data to the CDH Study Group in Toronto, Canada.

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

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

"Nothing About Us, Without Us"

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

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

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

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

Benefits of CDHi Centers of Excellence

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

Other Cause Leaders That Accredit Hospitals:

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

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

Countries With CDH Standards of Care

- Australia
- Canada
- Japan
- EURO CDH Consortium
“JUST AFTER DIAGNOSIS. AND AMID THE DEVASTATION, WE WERE GOING TO FIND SOMETHING THAT CALMED US A SENSE OF PEACE, COMFORT, AND HOPE.”
Stacy Willshearsen

“CHERUBS HELPED ME THROUGH MY SON’S RECOVERY. WHEN IT WAS ASTI, IT WAS HARD TO KNOW WHAT WAS GOING ON. MAMAS SHOWED ME THAT I WASN’T ALONE. CDH HAS TAUGHT ME TO APPRECIATE ALL THE MOMENTS IN LIFE, WHETHER GOOD OR BAD.”
Sarah Justice

“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 NEVER THOUGHT WE WOULD MAKE IT TO AGE ABOUT 12 YEARS OLD. THROUGH THE CHARITY, WE BECAME CONNECTED TO OTHER CDH FAMILIES ONCE THAT HAS MADE ALL THE DIFFERENCE IN THE WORLD TO US THESE LAST 6 YEARS. WE HAVEN’T FELT ALONE IN THIS JOURNEY SINCE.”
Shereen Kostmayer

“THE CHARITY IS A GREAT SUPPORT TO MANY FAMILIES AND I LOVE THIS CLOSED FACEBOOK GROUP AS IT ALLOWS US TO SHARE FREELY AND OFFER SUPPORT.”
Sandra Vance

“CHERUBS HAS HELPED ME HEAL AND CONNECT WITH OTHER CDH CDH PARENTS. THESE CONNEXIES 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 PARENTING CDH.”
Taylor Staffenmeier

“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 IN COMBO WHILE KEEPING STRONG.”
Morgan Nuchols

“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 MOST TO BE HELPING OTHER FAMILIES REALIZE CDH AND THE CDH DIAGNOSES FBE 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.

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 new 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 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.

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):

- 2008: $29
- 2009: $28
- 2010: $76
- 2011: $105
- 2012: $186
- 2013: $196
- 2014: $161
- 2015: $123
- 2016: $234
- 2017: $381

Financial Efficiency 2017:

- Research: 39%
- Support Services: 26%
- Awareness: 20%
- Family Assistance: 11%
- Fundraising: 1%
- Administration: 3%
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.

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

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

**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

94¢ of Every Dollar Goes Directly to the Cause

56-1916661  
501(c)(3) Charity

Non-Profit in Every Way

• No Board Conflicts  
• No paid employees for the first 15 years  
• No C-Level salaries  
• No Medical Referrals
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 (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 in the United States, please visit our web site.
CDH Fact

There is no standard measurement for calculating the survival rate of congenital diaphragmatic hernia. Therefore, hospitals use different criteria to classify if a patient is a "survivor." CDH International is working with the World Health Organization to create a universal standard.

CDH Fact

In the worst cases of congenital diaphragmatic hernia, in utero procedures are sometimes performed as a last ditch effort to save the patient’s life.

CDH Fact

Only a handful of countries have a standard of care for congenital diaphragmatic hernia, including Canada, the United Kingdom, the Netherlands, Belgium and Japan. The United States does not, which is how many insurance companies can deny treatments and vaccines.
Contact Us

www.cdhi.org
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www.cdhresearch.org

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To be announced in 2019

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