

It's Back!

CDH International

THE SILVER LINING

CONGENITAL DIAPHRAGMATIC HERNIA MAGAZINE

CDH International Becomes Research Organization

Learn how this affects the Congenital Diaphragmatic Hernia community.

April is Congenital Diaphragmatic Hernia Awareness Month

25 Ways to get involved to raise awareness and funds.

CDH Light Ups & Proclamations

Is your country or state participating?

The Latest CDH Research News

What's new in the research world?

Virtual CDH Race for April

Walk, run or bike with us to raise money!

Get Involved At No Cost

10 ways to donate without money

CDH Research Registry

Why it's the key to stopping CDH.

CDH Awareness Shop

Everything is on sale for April!

**CALL
TO ACTION:**
GET INVOLVED TO
HELP STOP
CONGENITAL
DIAPHRAGMATIC
HERNIA

Watch the
2023 CDH
Telethon
Live on
April 30th!

**CONGENITAL
DIAPHRAGMATIC
HERNIA IS NOT
JUST A HOLE!**

Join the CDH
Awareness
Campaign!



APRIL 19TH IS GLOBAL CDH AWARENESS DAY

Light Ups, Proclamations, Contests, Fundraisers, Events, and more all month long

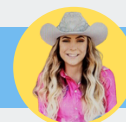


April 2023

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It's back! After a 10-year hiatus, the CDH Magazine "The Silver Lining" is back! and will be delivered digitally monthly.



CDH International

The world's Oldest, Largest, and Leading Congenital Diaphragmatic Hernia Charity

CDH INTERNATIONAL NGOS >

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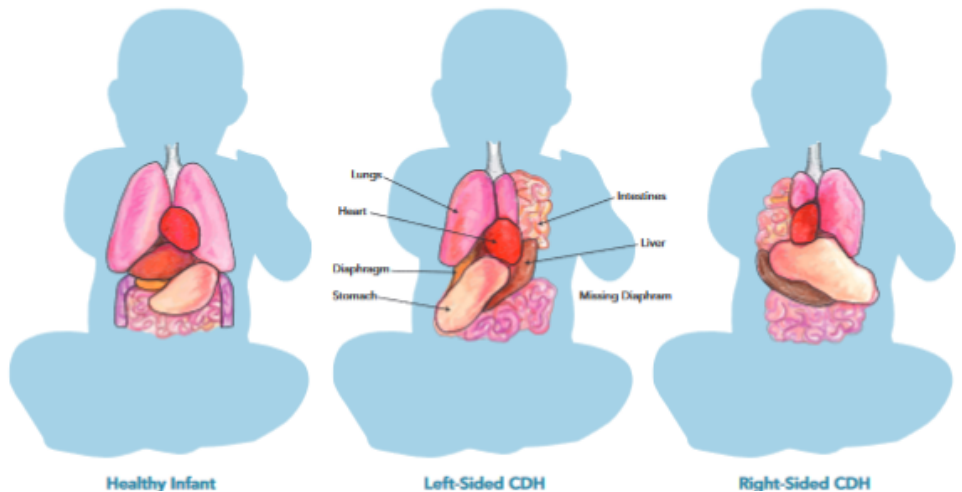
MISSION STATEMENT >

CDH INTERNATIONAL

A grassroots charity founded in 1995 to help families of babies born with Congenital Diaphragmatic Hernia by providing support services, promoting research, and raising awareness.



CONGENITAL DIAPHRAGMATIC HERNIA >



PARTNERSHIPS & MEMBERSHIPS COMMITTEE WORK >



"Thank you so much CDH International for being our solid rock. Without you and the wonderful members we've met, I wouldn't know where to turn when issues arise with Sofia." - Katie Carman



April 2023

SUN	MON	TUE	WED	THU	FRI	SAT
Virtual CDH Ribbons Are Now Up!	It's Time To Start Your April Fundraiser!	Get Your CDH Awareness Gear Ready!			CDH Race for Research starts tomorrow!	1 CDH Awareness Month Begins
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18 Light Ups Are Tomorrow Night!	19 GLOBAL CDH AWARENESS DAY	20	21	22
23	24	25	26	27	28 Cookbook Recipe Submissions Due Sunday!	29 Wings Photo Book Submissions Due Tomorrow!
30 2023 CDH Telethon						

Notes:

CDHi Executive Board of Directors

Dawn Ireland, President
 Tracy Meats, Vice-President
 Rhonda Montague
 David Holt



WAYS TO RAISE CDH AWARENESS

<p style="text-align: center;">SOCIAL MEDIA</p>	<p style="text-align: center;">FOR CDH FAMILIES</p>	<p style="text-align: center;">AWARENESS MONTH</p>
<ul style="list-style-type: none"> <input type="radio"/> Like CDHi FB Posts <input type="radio"/> Share Facebook Posts <input type="radio"/> Like CDHi Twitter Tweets <input type="radio"/> Retweet Tweets <input type="radio"/> Like Instagram Posts <input type="radio"/> Share Instagram Posts <input type="radio"/> Like TikTok Videos <input type="radio"/> Duet TikTok Videos <input type="radio"/> Like LinkedIn Posts <input type="radio"/> Share LinkedIn Posts <input type="radio"/> Join In the CDH Awareness Month Challenge <input type="radio"/> Share CDH Trivia 	<ul style="list-style-type: none"> <input type="radio"/> Share Your Story <input type="radio"/> Share Photos <input type="radio"/> Share Videos <input type="radio"/> Take Wings Photos <input type="radio"/> Use the Free CDH Awareness Graphics & Encourage Others To Use Them Too <input type="radio"/> Participate in Research <input type="radio"/> Share 'Before & After' Photos <input type="radio"/> <input type="radio"/> <input type="radio"/> 	<ul style="list-style-type: none"> <input type="radio"/> Request A Proclamation From Your Mayor <input type="radio"/> Request A Light Up <input type="radio"/> Attend a CDH Light Up and Take Photos & Video <input type="radio"/> Wear CDH Awareness Clothing <input type="radio"/> Use Our Free CDH Awareness Graphics & Encourage Others To Use Them Too <input type="radio"/> Click "Attend" on CDH Light Up Events on FB <input type="radio"/> <input type="radio"/>
<p style="text-align: center;">FUNDRAISE</p>	<p style="text-align: center;">JOIN A FUNDRAISER</p>	<p style="text-align: center;">DONATE</p>
<ul style="list-style-type: none"> <input type="radio"/> Create a Facebook Fundraiser <input type="radio"/> Hold A Dress Down Day at work or school <input type="radio"/> Ask your company to donate or sponsor CDHi <input type="radio"/> Hold a Fundraising Event <input type="radio"/> Collect Change with CDH Coin Jars <input type="radio"/> Become A Fundraising Executive 	<ul style="list-style-type: none"> <input type="radio"/> Join the CDH Race for Research <input type="radio"/> Purchase a Virtual CDH Ribbon <input type="radio"/> Purchase Items from the CDH Awareness Shop <input type="radio"/> Purchase 50/50 Tickets In the CDH Research Raffle <input type="radio"/> Donate to Someone Else's Facebook Fundraiser <input type="radio"/> Use the Bing Search Engine Give App 	<ul style="list-style-type: none"> <input type="radio"/> Make A Donation <input type="radio"/> Join the Angel Club <input type="radio"/> Choose CDH International in the Combined Federal Campaign (#31232) <input type="radio"/> Donate Your Birthday to CDH International <input type="radio"/> Sponsor A Wings Mural <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
<p style="text-align: center;">VOLUNTEER</p>		
<ul style="list-style-type: none"> <input type="radio"/> Executive Board Member <input type="radio"/> Grant Writer <input type="radio"/> Fundraiser <input type="radio"/> Magazine Editor 	<ul style="list-style-type: none"> <input type="radio"/> Social Media Ambassador <input type="radio"/> Representative <input type="radio"/> Videographer <input type="radio"/> SEO <input type="radio"/> Graphic Design <input type="radio"/> Web Design 	<ul style="list-style-type: none"> <input type="radio"/> Awareness Committee <input type="radio"/> Research Recruiter <input type="radio"/> Welcome Committee <input type="radio"/> Prayer Committee <input type="radio"/> Copyright <input type="radio"/> Data Entry

"Through CDHi, we have found a great support group and have connected with so many families going through the same struggles as us. The overwhelming support from so many CDH families of past, present, and future, has helped to give us a lot of knowledge and peace about what we could expect as our daughter progresses." - Zach and Shelly Callegos



CDH INTERNATIONAL UPDATE

DAWN IRELAND, PRESIDENT

As the world has changed in the past few years, so has volunteerism and philanthropy, as well as the shift from support groups to social media. In the 28 years since CDH International started on my kitchen table as a family support group, we have seen and adjusted to many changes. We have watched children grow up, said too many goodbyes, welcomed many incredible volunteers and staff, formed productive global partnerships, and celebrated each accomplishment as the community went from 2 families to 10,000's families.

The charity has grown past our wildest expectations, and as we navigate this new post-pandemic world, we have to adjust for growth so that we can continue to serve children and families affected by Congenital Diaphragmatic Hernia to the best of our abilities.

Where CDH International was once the only charity providing help to families, there are now many CDH charities offering support groups, Facebook groups, care packages, financial grants, and scholarships. As our Executive Board of Directors took a look at the services provided across the community, we realized that there is such a profound waste of resources in redundant, and often competing, services and still such a huge gap in research funding and patient advocacy in the research world. The pandemic and economy have hit all charities and made this even more apparent in the past few years as volunteers burned out and donations have been halved. The world has changed, and so many charities.

While we are incredibly proud of the projects and services that we have provided for years to 1000's families, the inspiration and assistance we have given to many other charities and groups, and the right to call CDH International "the world's oldest, largest and leading Congenital Diaphragmatic Hernia charity," we have a responsibility to be good stewards and always to do what is best for these children. It is our sincere devotion to this responsibility that has led us to decide to step aside from Support and let other charities continue their work while we shift our focus to save resources, foster collaborations, and hopefully stop Congenital Diaphragmatic Hernia quicker, saving more lives.

As of April, 2023 CDH International will focus on what we now do best - Congenital Diaphragmatic Hernia research. We will continue to raise awareness, share patient stories and our team will always personally be there for families. But the majority of our time and efforts as an organization will go towards where efforts are most needed - saving the lives of these children - and we will continue to engage with families as we work together to make that happen.



Awareness

- CDH Magazine
- CDH Radio
- CDH Awareness Day Light Ups
- CDH Proclamations
- CDH Telethon
- Public Education



Research

- CDH Research Registry
- Research Publications
- Research Grants
- Research Collaborations
- CDH Study Group & DHREAMS Collaboration
- Standards of CDH Care
- Standards Measurements of Mortality & Morbidity
- WHO, NIH, NICHD, and Govt Collaborations
- Global Surgery Collaborations
- Rare Disease Collaborations
- March of Dime & Birth Defects Collaborations
- Hospitalize Accreditation



Support

- CDH Forums
- Educational Materials
- CDH Phone App
- CDH Conference
- Other services as provided by volunteers.



CDH RESEARCH UPDATES

- Radiographic, MRI, and CT findings in a young dog with Becker-like muscular dystrophy
- Early Pre- and Postoperative Enteral Nutrition and Growth in Infants with Symptomatic Congenital Diaphragmatic Hernia
- Case report: High-dose epoprostenol therapy in pediatric patients with pulmonary hypertension and developmental lung disease
- Ethical Considerations in Critically Ill Neonatal and Pediatric Patients
- Acute kidney injury in infants diagnosed with congenital diaphragmatic hernia
- Lung Ultrasound Score in Neonates with Congenital Diaphragmatic Hernia (CDH-LUS): A Cross-Sectional Study
- Fetoscopic endoluminal tracheal occlusion with Smart-TO balloon: Study protocol to evaluate effectiveness and safety of non-invasive removal
- Risk-stratified results among congenital diaphragmatic hernia patients in two large extracorporeal membrane oxygenation centers in South America
- Ductus arteriosus flow predicts outcome in neonates with congenital diaphragmatic hernia
- Congenital pleuropulmonary blastoma in a newborn with a variant of uncertain significance in DICER1 evaluated by RNA-sequencing
- Distinct roles for SOX2 and SOX21 in differentiation, distribution and maturation of pulmonary neuroendocrine cells
- Systemic opioids versus other analgesics and sedatives for postoperative pain in neonates
- State of the Science on the Benefits of Human Milk for Hospitalized, Vulnerable Neonates
- Diaphragmatic hernia in a term newborn with congenital myotonic dystrophy: case report
- Effects of 1.5-T versus 3-T magnetic resonance imaging in fetuses: is there a difference in postnatal neurodevelopmental outcome? Evaluation in a fetal population with left-sided congenital diaphragmatic hernia
- NFκB Keeps Basal Cells Undifferentiated in Congenital Diaphragmatic Hernia
- Congenital Diaphragmatic Hernia: Perinatal Prognostic Factors and Short-Term Outcomes in a Single-Center Series
- Fetal Lung Volume Appears to Predict Respiratory Morbidity in Congenital Diaphragmatic Hernia
- [Acute gastric volvulus complicating congenital diaphragmatic hernia in a 3-month-old infant: a case report]
- Continuous Erector Spinae Plane Block in Paediatric VATS: A Case Series
- Management of infants with congenital diaphragmatic hernia and pulmonary hypertension-one size does not fit all
- Bochdalek hernia masquerading as pleural effusion in a young adult
- Minimal access surgery for congenital diaphragmatic hernia: surgical tricks to facilitate anchoring the patches to the ribs
- The metabolic and lipidomic profiling of the effects of tracheal occlusion in a rabbit model of congenital diaphragmatic hernia
- Respiratory physiology during NAVA ventilation in neonates born with a congenital diaphragmatic hernia: the "NAVA-diaph" pilot study
- Brain growth in fetuses with congenital diaphragmatic hernia
- <https://cdhi.org/research-brain-growth-in-fetuses-with-congenital-diaphragmatic-hernia/>
- Case report: Emergency treatment of late-presenting congenital diaphragmatic hernia with tension gastrothorax in three Chinese children
- Laparoscopic Repair of a Congenital Diaphragmatic Hernia Presenting with a Small Bowel Obstruction
- Congenital diaphragmatic hernia in a middle-income country: Persistent high lethality during a 12-year period
- Crossing birth and mortality data as a clue for prevalence of congenital diaphragmatic hernia in Sao Paulo State: A cross sectional study
- Association Between Mortality and Ventilator Parameters in Children With Respiratory Failure on ECMO
- High frequency jet ventilation for congenital diaphragmatic hernia



CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

CDH INTERNATIONAL PUBLICATIONS

THE CDH RESEARCH REGISTRY AT WORK

Though CDH International consistently presents research and speaks at medical conferences, not every report and poster is published in medical journals.

Our organization is proud to have co-authored or assisted in the following publications:

Seasonal Variation of Congenital Diaphragmatic Hernia: A Review of the Literature and Database Report from the United States and Canada

European Journal of Pediatric Surgery

2023-02 | Journal article

DOI: [10.1055/a-1905-4808](https://doi.org/10.1055/a-1905-4808)

CONTRIBUTORS: Fabian Doktor; Lina Antounians; Jason Miller; Maria Harb; Tracy Meats; Rachel Bercovitch; Dawn Ireland; Augusto Zani

Social media communities for patients and families affected by congenital pediatric surgical conditions.

Pediatric Surgery International

2022-05 | Journal article

DOI: [10.1007/s00383-022-05139-6](https://doi.org/10.1007/s00383-022-05139-6)

PMID: [35588326](https://pubmed.ncbi.nlm.nih.gov/35588326/)

PMC: [PMC9117832](https://pubmed.ncbi.nlm.nih.gov/35588326/)

CONTRIBUTORS: Reppucci ML; De La Torre L; Pickett K; Wehrli L; Nolan MM; Ketzner J; Bischoff A

Paediatric surgical outcomes in sub-Saharan Africa: a multicentre, international, prospective cohort study.

BMJ global health

2021-09 | Journal article

DOI: [10.1136/bmjgh-2020-004406](https://doi.org/10.1136/bmjgh-2020-004406)

PMID: [34475022](https://pubmed.ncbi.nlm.nih.gov/34475022/)

PMC: [PMC8413881](https://pubmed.ncbi.nlm.nih.gov/34475022/)

CONTRIBUTORS: PaedSurg Africa Research Collaboration

Mortality from gastrointestinal congenital anomalies at 264 hospitals in 74 low-income, middle-income, and high-income countries: a multicentre, international, prospective cohort study.

Lancet (London, England)

2021-07 | Journal article

DOI: [10.1016/s0140-6736\(21\)00767-4](https://doi.org/10.1016/s0140-6736(21)00767-4)

PMID: [34270932](https://pubmed.ncbi.nlm.nih.gov/34270932/)

PMC: [PMC8314066](https://pubmed.ncbi.nlm.nih.gov/34270932/)

CONTRIBUTORS: Global PaedSurg Research Collaboration

Global Initiative for Children's Surgery: A Model of Global Collaboration to Advance the Surgical Care of Children.

World journal of surgery

2019-06 | Journal article

DOI: [10.1007/s00268-018-04887-8](https://doi.org/10.1007/s00268-018-04887-8)

PMID: [30623232](https://pubmed.ncbi.nlm.nih.gov/30623232/)

PMC: [PMC7019676](https://pubmed.ncbi.nlm.nih.gov/30623232/)

CONTRIBUTORS: Global Initiative for Children's Surgery

Mortality from gastrointestinal congenital anomalies at 264 hospitals in 74 low-income, middle-income, and high-income countries: a multicentre, international, prospective cohort study.

BMJ open

2020-03 | Journal article

DOI: [10.1136/bmjopen-2019-034253](https://doi.org/10.1136/bmjopen-2019-034253)

PMID: [32209626](https://pubmed.ncbi.nlm.nih.gov/32209626/)

PMC: [PMC7202732](https://pubmed.ncbi.nlm.nih.gov/32209626/)

CONTRIBUTORS: Rocha TAH; Vissoci J; Rocha N; Poenaru D; Shrimme M; Smith ER; Rice HE; Global Initiative for Children's Surgery

Optimal Resources for Children's Surgical Care: Executive Summary.

World journal of surgery

2019-04 | Journal article

DOI: [10.1007/s00268-018-04888-7](https://doi.org/10.1007/s00268-018-04888-7)

PMID: [30725368](https://pubmed.ncbi.nlm.nih.gov/30725368/)

CONTRIBUTORS: Global Initiative for Children's Surgery

20 Year Demographics and Preliminary Surgury Results From CDH International

Surgery: Current Research

2018 | Journal article

DOI: [10.4172/2161-1076-c5-046](https://doi.org/10.4172/2161-1076-c5-046)

Part of ISSN: [2161-1076](https://doi.org/10.4172/2161-1076)

CONTRIBUTORS: Jason Miller, Josh Hensley, Darlene Silverman, Dawn M Ireland

Parent Opinion in Medical Care for Congenital Diaphragmatic Hernia

Journal of Pediatric Care

2018 | Journal article

DOI: [10.21767/2471-805x-c3-010](https://doi.org/10.21767/2471-805x-c3-010)

Part of ISSN: [2471-805X](https://doi.org/10.21767/2471-805x)

CONTRIBUTORS: Jason Miller, Josh Hensley, Darlene Silverman, Dawn M Ireland



CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH CDH INTERNATIONAL AT WORK

2023 RESEARCH WORK

As of March 15th, CDH International has so far this year:

PRESENTATIONS

- 24 Hours of Rare
- Wake Forest Rotary Club

RESEARCH POSTERS

- 3 Research Posters presented at International Conference on Birth Defects and Disabilities in the Developing World in Santiago, Chile
- 1 Research Poster accepted for the Society for Birth Defects Research and Prevention Annual Meeting
- CDH International Signs On To Support the World Health Assembly Food Fortification Resolution

COLLABORATIONS

- CDH International Signs Letter of Support for National Institutes of Children's Health and Diseases Fiscal (NICHD) Year Appropriations.
- CDH International Signs On To Support the World Health Assembly Food Fortification Resolution
- CDH International Signs Letter of Support for DHREAMS research project
- CDH International Signs Letter of Support for ZANI Lab research project
- 4 ongoing CDH Research Registry collaborations with various labs and universities



CDH International Medical Advisory Board

- N. Scott Adzick, MD – Children's Hospital of Philadelphia
- Kristin Aigner, RN – OSF, Peoria. MAB member and CDHi UK Board
- Badr Chaban, MD - Royal College of Paediatrics and Child Health, London, UK
- Priscilla Chui, MD – Toronto Sick Kids Hospital
- Wendy Chung, MD – Columbia University
- Jan Deprest, MD, PhD - University Hospital Gasthuisberg, Leuven, Belgium
- Patricia Donahue, MD – Massachusetts General Hospital
- Mahmud El Fiky, MD – Faculty of Medicine, Cairo University, Egypt
- Florian Friedmacher, MD – NHS, Oxford, UK
- Matthew Harting, MD, MS - University of Texas Medical School at Houston
- Michael R. Harrison, MD – University of California, San Francisco Fetal Treatment Center
- Tim Jancelewicz, MD MA MS FAAP FACS - Le Bonheur Children's Hospital at Memphis
- Gabriel Kardon, MS - University of Utah
- Richard Keijzer, MD, PhD, MSc - University of Manitoba and Children's Research Institute of Manitoba
- Steadman McPeters, RN – Huntsville Alabama, Pediatric Surgery Nurse Clinician, CDH Survivor
- Doug Miniati, MD – University of California, San Francisco
- Giovanna Ricciperitoni, MD - Vittorio Buzzi Hospital, Milan, Italy
- Henry Rice, MD – Duke University Medical Center
- Dick Tibboel, MD, PhD - Erasmus University MC, Sophia Children's Hospital, Netherlands
- Jay Wilson, MD - University of Texas Medical Children at Houston, CDH Study Group
- Naomi, Wright, MD – Global Initiative in Pediatric Surgery, Oxford, UK
- Edmund Yang, MD – Peace Health, Springfield, OR
- August Zani, MD - Toronto Sick Kids Hospital, Zani Lab



CDH INTERNATIONAL RESEARCH GRANTS

CDH International has given out a number of Congenital Diaphragmatic Hernia Research Grants to hospitals over the years.

Grant application information will be posted on our web site as funds are available.

CDH International / CHERUBS has given grants to the following medical facilities to study Congenital Diaphragmatic Hernia:

- All Children’s Hospital
- Boston Children’s Hospital
- CDH Study Group
- Children’s Hospital of Philadelphia
- DHREAMS / Columbia University
- Lurie Children’s Hospital
- Massachusetts General Hospital
- Seattle Children’s Hospital
- University of Florida, Shands
- University of Philadelphia
- University of Toronto, SickKids
- University of Utah



CREATE A LEGACY OF SUPPORTING CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH >

Whether your child is a CDH survivor or angel, whether you want to create something in their name, your name or your family is blessed to be able to give generously and you want to grow your family legacy, CDH International can help you.

By creating a CDH Research Grant, a scholarship or other project at our charity, we take away all the worry and work of starting a nonprofit and allow you to focus on helping the cause. You can give directly or hold a fundraiser in the name of a loved one and honor these children who fight so bravely.

With 5 Funds at CDH International, you can choose to donate solely to Research, Patient Support, Awareness, Financial Support, your own Scholarship Fund or the CDHI General Fund. Email us to learn more at david.holt@cdhi.org



LEONIDAS DEMETRIOS PEGASIOU

CDH SURVIVOR, GREECE



On Leonidas 20 week scan we found out he had CDH. Initially we didn't know what it was or what to do. The consultant who diagnosed him wasn't very optimistic and gave us all sorts of negative outcomes.

Leonidas was under the care of professor kipros nicolaides and his team at Harris birth right centre. We returned on the 26th week to see the true extent of his issue. We had a meeting with professor who told us about his new feto trial with moderate to severe cdh baby's. For us we knew this was the right thing to do and we went ahead there and then. The way we saw it was we wanted to give our baby the best chance at survival, and do what ever it took. We opted for the feto as our thought process was when they survived their lungs would be bigger than if we didn't do the feto. The initial process went great and we was out of there within an hour! We were scheduled for fortnightly scans to see how things progressed.

At his first scan we was amazed his lung had grown from around 32% lhr to above 50! We were estatic. On his second scan his lhr had dropped down to near enough where we started, so we were scheduled for a scan a week later with professor. This is where we discovered the feto balloon had deflated and we were back to square one. So we opted to go again and remove the old balloon and put a new one. After a couple painstaking hours this was complete.

On 33 weeks his mums waters broke and was rushed to kings college hospital. This was a major issue and the feto balloon was in his throat meaning he couldn't breathe if he was born. Kings maternity unit wouldn't discharge her incase she went into labour, and the professor couldn't do his removal surgery without being in his centre. It took around 12 hours but once the logistics were figured out she went to the professor for removal surgery. This in itself was an issue as the waters had broken and took much longer than usual.

Back in the maternity unit pregnancy slowed down so by day 4 they were willing to discharge mum home, however she and the baby both took a turn and they opted for an emergency c-section. Leonidas was born naturally (without c section) on a theatre table at 15.30 on 28/04/22 weighing 5lbs 6. He was ventilated within 1 minute and was allowed a brief moment of skin to skin with his mum. This is where his Nicu journey began.

He was ventilated and put on sleeping drugs and anti Biotic from birth. On day 5 he had his surgery, which took around 4-5 hours. He had a very large hole and minimal diaphragm so they stitched together what they could, and stitched a animal skin patch to his rib cage. He was then taken back to Nicu until he was 10 days old. Whilst he was in NICU we was allowed to stay in the hospital as his mum had an infection so we spent every moment with him singing and talking to him trying to give him strength.

On day 10 he was transferred to hdu where we finally got to hold him! He was off his ventilator and graduated to a different breathing machine. He kept going from strength to strength and lowering oxygen and pressure. This change of room was such a big deal for us as you look for any small win in these horrible times.

On day 20 he was transferred to Scibu at kings college being on only minimal oxygen through a canula. We were then transferred to our local hospital to establish feeding. On day 35 after 2 sleep tests we were finally discharged home!

We went home on 2 different reflux meds and vitamins. He came off all of these by 4/5 months old and is now establishing eating food. We have regular check ups with our surgeon and consultants but Leonidas is doing great! He is now 11 months old and crawling every where, eating everything in sight and playing as any baby would.

He has been on holiday (after doing a oxygen depravation test), he goes swimming every week and sensory. Looking at him nobody would ever tell. He is a Spartan!

- George and Karina Pegasiou



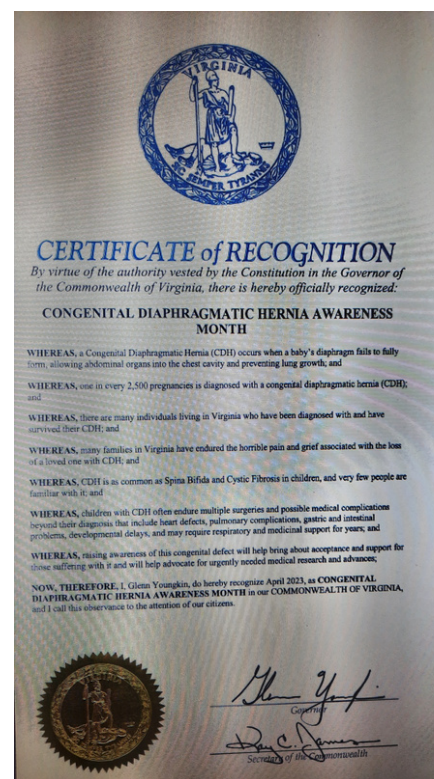
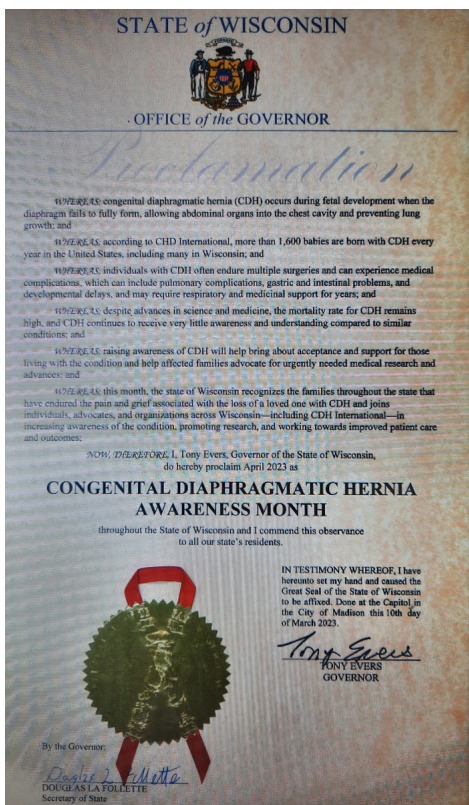
CDH AWARENESS MONTH

2023 CDH PROCLAMATIONS

Melissa Reaves, Director of Congenital Diaphragmatic Hernia Awareness

The following states have declared April 2023 "Congenital Diaphragmatic Hernia Awareness Month" as of March 29th:

- Georgia
- Hawaii
- Idaho
- Illinois
- Louisiana
- New Mexico
- Oklahoma
- South Carolina
- Tennessee
- Texas
- Virginia
- West Virginia
- Wisconsin
- Wyoming



For an updated list, please visit www.cdhawarenessday.org.

CDH International Patient Advocacy Board

- Nicole Colvin
- Robyn Fletcher
- Melissa Johnstone
- Morgan Nuchols
- Sean Forney
- Taylor Steffensmeier
- Danae Perkins
- Lauren Dietz
- Renci Scurlock
- Tina Ingham

2023 CDH Conference Postponed

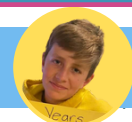
CDH International regretfully had to make the decision to postpone the annual CDH Conference once again due to a lack of funding for the event.

It is our hope to hold the event in 2024 in Toronto. We look forward to seeing you next year!

Our deepest thanks and appreciation to the team at the Zani Lab for all their support.



"When my son was born 14 years ago with an undiagnosed RCDH, I felt scared and alone. Discovering CDH shortly after we brought him home was the answer to my prayers! I was immediately welcomed and connected to other families that have walked in my shoes, answered any questions I had, or simply offered a listening ear. I have a life-long family in CDH." - Karla and Dave Holt



cdh awareness light-ups

JENNIFER DOOLAN, GLOBAL DIRECTOR OF CDH AWARENESS LIGHT UPS



United States

- The Retirement System of Alabama - Mobile, Alabama
- RSA Tower - Montgomery, Alabama
- Gilbert Water Tower - Gilbert, Arizona
- Union Plaza Building - Little Rock, Arkansas
- McNichols Civic Center Building - Denver, Colorado
- Ocean Center - Daytona Beach, Florida
- Martin Luther King, Jr. Memorial Bridge - Fort Wayne, Indiana
- AES Indiana at Monument Circle - Indianapolis, Indiana
- Flint Hills Discovery Center - Manhattan, Kansas
- Baltimore City Hall Dome - Baltimore, Maryland
- TD Garden - Boston, Massachusetts
- Longfellow Bridge - Boston, Massachusetts
- Leonard P. Zakim Bunker Hill Memorial Bridge - Boston, Massachusetts
- Fore River Bridge - Quincy/Weymouth, Massachusetts
- Kenneth F. Burns Memorial Bridge - Worcester, Massachusetts
- Kalamazoo City Hall - Kalamazoo, Michigan
- I35W St. Anthony Falls Bridge - Minneapolis, Minnesota
- MEET - Las Vegas, Nevada
- Peace Bridge - Buffalo, New York
- Niagara Falls Illumination Board - Niagara Falls, New York
- Thaddeus Kosciuszko Bridge - New York, New York
- Mid Hudson Bridge - Poughkeepsie, New York
- Rundel Memorial Library Building - Rochester, New York
- Lights on ROC - Rochester, New York
- Romare Bearden Park Fountain - Charlotte, North Carolina
- Skydance Bridge - Oklahoma City, Oklahoma
- Philtower - Tulsa, Oklahoma
- PHL Tower at the Philadelphia Airport - Philadelphia, Pennsylvania
- Gulf Beacon at Gulf Tower - Pittsburgh, Pennsylvania
- Koppers Building - Pittsburgh, Pennsylvania
- Sakonnet River Bridge - Tiverton, Rhode Island
- State Capitol Cupola - Nashville, Tennessee
- Virginia Aquarium & Marine Science Center - Virginia Beach, Virginia
- Capitol Theatre - Wheeling, West Virginia
- Pfister Hotel Tower - Milwaukee, Wisconsin
- Mitchell Park Horticultural Conservatory Domes - Milwaukee, Wisconsin



Ireland

- Dublin Convention Centre - Dublin, Ireland
- Dublin City Hall - Dublin, Ireland
- Dublin City University - Dublin, Ireland
- Swords Castle Co - Dublin, Ireland
- Askeaton Tourist Office - Dublin, Ireland
- Limerick City and County Hall - Dublin, Ireland
- County Buildings Tralee - Tralee Co Kerry, Ireland
- Prince's Quay, Tralee - Tralee Co Kerry, Ireland
- Ashe Memorial Town Hall - Tralee Co Kerry, Ireland
- Killarney Town Hall - Killarney Co Kerry, Ireland
- Civic Offices, Clonmel - Clonmel, Ireland
- Town Hall, Clonmel - Clonmel, Ireland
- Fire Station, Clonmel - Clonmel, Ireland
- Town Hall - Carrick on Suir, Ireland
- Laois County Hall - Portlaoise Co Laois, Ireland
- Tipperary Town Council Offices - Tipperary, Ireland

Australia

- Kurilpa Bridge - Brisbane, Australia
- Suncorp Stadium - Brisbane, Australia
- Telstra Tower - Canberra, Australia
- Bolte Bridge - Melbourne, Australia
- Federation Square - Melbourne, Australia
- Matagarup Bridge - Perth, Australia
- Mount Street Bridge - Perth, Australia
- Joondalup Drive Bridge - Perth, Australia
- Northbridge (GFF) Tunnel - Perth, Australia
- Sky Ribbon Bridge - Perth, Australia
- Bell Tower - Perth, Australia
- Optus Stadium - Perth, Australia
- Yagan Square - Perth, Australia
- Toowoomba City Hall Annex - Toowoomba, Australia
- Victoria Street Bridge - Toowoomba, Australia



United Kingdom

- St Stephen's Church - Bath, England
- Bradford City Hall - Bradford, England
- Margaret McMillan Tower - Bradford, England
- Riverside Leisure Centre - Chelmsford, England
- Evesham Abby Bell Tower - Evesham, England
- Ashton Memorial - Lancaster, England
- Alive Corn Exchange Theatre and Cinema - Norfolk, England
- Nottingham Council House - Nottingham, England
- Rochester Cathedral - Rochester, England
- The Guildhall - Swansea, England
- Hoad Monument - Ulverston, England
- Weymouth Pavilion - Weymouth, England
- Burnavon Theatre - Cookstown, Northern Ireland
- Down Leisure Centre - Downpatrick, Northern Ireland
- Ranfurly House - Dungannon, Northern Ireland
- Dungannon Council Building - Dungannon, Northern Ireland
- Lagan Valley Island Building - Lisburn, Northern Ireland
- The Bridewell Building - Magherafelt, Northern Ireland
- Newry Town Hall - Newry, Northern Ireland
- Camera Obscura - Edinburgh, Scotland
- St Andrew's House - Edinburgh, Scotland
- Victoria Quay - Edinburgh, Scotland
- Arria the Mermaid - Glasgow, Scotland

More Countries

China

- Macau Tower Convention and Entertainment Center - Macau, China

Croatia

- Vukovar Water Tower - Vukovar, Croatia

Isle of Man

- Ramsey Swing Bridge - Ramsey, Isle of Man

Jersey

- Fort Regent Leisure Centre - St. Helier, Jersey

Norway

- Rockheim - Trondheim, Norway



get involved

Photos are needed of these landmarks! Lit up or not, we need photos. Please visit, take photos and videos and send to us at awareness@cdhi.org



Canada

- Lafarge Lake Fountain - Coquitlam, BC
- Skytrain Guideway Pillars - Coquitlam, BC
- Pinetree Way Light Column - Coquitlam, BC
- Maple Ridge City Hall - Maple Ridge, BC
- The Bastion - Nanaimo, BC - April 18th
- Quesnel City Hall - Quesnel, BC
- Fraser River Foot Bridge - Quesnel, BC
- Surrey Civic Plaza - Surrey, BC
- Vancouver City Hall and Burrard Street Bridge - Vancouver, BC
- BC Place Stadium - Vancouver, BC - April 13th
- Vancouver Convention Centre - Vancouver, BC - April 13th
- Bloedel Conservatory - Vancouver, BC
- Vancouver Lookout - Vancouver, BC
- BC Parliament Building and the Front Fountain - Victoria, BC
- Fitzsimmons Creek Bridge - Whistler, BC
- Reconciliation Bridge - Calgary, AB
- McMahon Stadium - Calgary, AB
- Calgary Tower - Calgary, AB
- Telus Spark Science Centre - Calgary, AB
- High Level Bridge - Edmonton, AB
- Saline Creek Pedestrian Bridge - Fort McMurray, AB
- Shell Place Canopy - Fort McMurray, AB
- Lethbridge City Hall - Lethbridge, AB - April 18th
- Medicine Hat Public Library - Medicine Hat, AB
- Red Deer City Hall - Red Deer, AB
- Regina City Hall - Regina, Saskatchewan
- Canada Life Building - Winnipeg, Manitoba
- IG Fields - Winnipeg, Manitoba
- Canada Life Building - Winnipeg, Manitoba
- IG Fields - Winnipeg, Manitoba
- Burlington Beacon and Brant Street Pier - Burlington, ON
- Niagara Falls Illumination Board - Fort Erie/Niagara Falls, ON
- Peace Bridge - Fort Erie/Niagara Falls, ON
- City Hall HAMILTON Sign - Hamilton, ON
- Kingston City Hall and Springer Market Square - Kingston, ON
- RBC Place London - London, ON
- JA Taylor Building at Wellington and Dundas - London, ON
- City Hall of London - London, ON
- Canada Life Building - London, ON
- Civic Centre Clock Tower - Mississauga, ON
- Port Credit Lighthouse - Mississauga, ON
- Oakville Town Hall - Oakville, ON
- Shaw Centre - Ottawa, ON
- Peterborough City Hall - Peterborough, ON
- The 3D TORONTO Sign - Toronto, ON
- CN Tower - Toronto, ON
- Ripley's Aquarium of Canada - Toronto, ON
- Canada Life Building - Toronto, ON
- Vaughan City Hall - Vaughan, ON
- La Grande Roue de Montréal - Montréal QC
- The Montréal Tower - Montréal, QC
- International Civil Aviation Organization - Montréal, QC
- St. John's City Hall - St. John's, NL
- Fredericton City Hall - Fredericton, New Brunswick
- Downing Street and Downing Place Plaza - Moncton, New Brunswick - April 17th
- Halifax City Hall - Halifax, NS
- Holman Grand Hotel - Charlottetown, PE
- Charlottetown City Hall - Charlottetown, PE



TAYLOR MILES

CDH SURVIVOR, UNITED STATES



To start, my name is Taylor Miles, and I am from Tuscaloosa, Alabama. I was born at 36 weeks, on September 21, 1995. My mother went into natural labor, she had a very uncomplicated pregnancy. My CDH was never detected via ultrasound...the ONLY indication that something may be off was some extra fluid in her/around me, but her doctors didn't think much of it.

So, my mother went into labor, & I was born around 1 am. My mother says that I came out looking completely blue, from head to toe, & not making a sound. She states that the nurses & doctors immediately start to "beat" me to get me to make some kind of a peep, & when I do make sound, she said it sounded like a cat screaming. It was not your typical "good" baby cry.

I was immediately rushed to my hospital's NICU, for further testing, & at some point I was diagnosed with right sided congenital diaphragmatic hernia. But, my case was different, I had NO right diaphragm, & everything was in my chest cavity.

Plans were made to rush me to Children's Hospital of Birmingham, AL, which is only about an hour away from Tuscaloosa. I was taken by ambulance, & Children's NICU was waiting for me.

On September 26, 1995 I was placed on ECMO venous-arterial route & stayed on ECMO for two weeks. During those two weeks the doctors were allowing my body to rest, but also trying to come up with a game plan. Close to the end of those two weeks, the physicians proposed a plan to my parents: take me off of ECMO & see "what happens", or attempt surgery & hope for the best. I was then taken off of ECMO & it was time for surgery. I had my first surgery sometime in October. I had a diagram made for me out of the Gortex patch & had all of my organs placed in their correct spots. My first patch failed & busted, so the surgeons had to go back in & fix it - and it has been stable ever since! At the end of everything, I don't have my right lung, and only a partial left lung developed.

I lived at Children's of B'ham NICU for 3 months, & was discharged right before my first Christmas! What a special Christmas gift for my family. I was discharged home on supplemental oxygen & a feeding tube (I was also considered failure to thrive). I had this feeding tube through my nose until I was 6 months old & had supplemental oxygen until I was 2 years old.

I started daycare like any "normal" kid at 5 months old & attended The RISE Program of the University of Alabama, also known as The Stallings Center, until I was 5 years old.

When I was two years old I was diagnosed with scoliosis, & my family & I started a new health journey. From two years old to eight years old I was seen by multiple specialist & physical therapists, wore different back braces & nothing seemed to stop my curvature. The summer that I was eight years old, I had my first spinal fusion, back at Children's Hospital of Birmingham. My curvature went from 68 degrees to 8 degrees. I ended up having a second spinal fusion five years later to replace the size of the rods. But I have had no issues since!

I grew up living a pretty "normal" childhood! I participated in various sports, played hard, & also participated in choir. But to say it's not easy, is an understatement. Physical activity can be harder for me, but this is my normal.

Fast forward to when I'm 18 years old, and I'm seeing my pulmonologist at Children's for the very last time. We had a long, hard discussion regarding family planning & that I didn't need to consider having my own baby - the baby could die, or we could both die, no matter what, it didn't "need to happen".

Today, I follow up with an adult pulmonologist every 6 months, and have pulmonary function tests (PFTs) performed. They're not the greatest - but that's to be expected with my chronic damage.

I'm now 27 years old, with a perfectly healthy 7 month old baby girl. I was followed very heavily by UAB's Maternal Fetal Medicine Clinic and had a scheduled c-section planned for when I turned 37 weeks of gestation, but my baby girl had other plans and she came on her own at 35 weeks. Marlee is her name, and she also required 10 days in the NICU, but she is perfectly healthy today!

I now work as a Pediatric RN, and am married to a Flight Nurse RN. I will always be an advocate for this terrible defect. Prayers for all families & angel babies, & current babies & adult survivors, that live with this defect. It's not an easy journey - but we're all in this together.





APRIL 2023

Race for Research

JOIN US FROM WHEREVER YOU ARE!



Virtual Switzerland

Walk, run, or cycle from Zurich to Geneva! Along the way you will receive virtual postcards of over 40 landmarks with great trivia information.



Participate

No matter where you are, you can participate! Everyone who finishes receives a medal. Join now at www.cdhrace.org.



Research

100% of money raised goes to Congenital Diaphragmatic Hernia Research.



JONAH PARNHAM

CDH SURVIVOR, UNITED KINGDOM



I was pregnant with my third child and went for my 12 week scan, excited like every mother to see their baby for the first time. As I lay there the staff member said there is something wrong, that the baby's stomach was next to the heart. We were taken to another room and explained that I would have to come back in 4 weeks for another scan. I wasn't told anything further other than there might be a hernia. I was devastated and we spent the next 4 weeks imaging the worst, not even understanding what it might be. At 16 weeks we went to fetal medicine and then we were diagnosed with left sided CDH, I had never heard of it or understood what it meant. The Dr and nurse said that we would be referred for heart scans, MRI and genetic testing and we could consider medical termination. Over the following weeks I did research, went for tests and scan across the country and got results for genetic testing. Everything was all clear (genetically) and we were given around 43% Head to lung ratio and a 50-50 chance of survival. We also found out we were having a boy. Over the coming months we continued to be monitored, meet the surgeons and staff who would be looking after him and started to mentally prepare ourselves and our children for the birth.

Jonah was born on the 19th of October and was put straight on to ventilator and moved to NICU. Within the first night he was struggling and had to be moved into oscillation ventilation. He was so still and small, I didn't realise I wouldn't see his eyes and I would just stroke his head. Over the next few days there was countless heart-stopping moments where they had to do suctioning as he was struggling to breathe at all and just feeling helpless to do anything to help your own child. On day 6 he was finally strong enough to go to for his operation. After 3 hours we were rung and told that it wasn't looking good and to prepare ourselves for the worst. We have 45 mins of thinking that we had lost him, I remember thinking about how I would tell his siblings that I'd never seen his eyes or held him. But after the longest 45 mins of my life the surgeon came in and told us they had stabilised him. Over the next week it was recovery time and trying to start him on feeds, which they struggled with and he was on a NJ feed for a while, but after another week he'd started to reduce oxygen and pressure, go onto NG feeds and had awake time. At 12 days old I got to hold him for the first time! (Picture) he went from strength to strength, going onto c-pac then finally air and breastfeeding. After just over a month we were discharged. He's still got a lots of outpatient appointment but is currently 15 months and meeting all his milestones! CDH has been the biggest rollercoaster of my life, I'm so grateful for the great support networks we have and wish there was more understanding and support for parents throughout this journey.

Beth Parnham, mother

Share Your Story

Raise Congenital Diaphragmatic Hernia and advocate for better care by sharing your family's journey.

One 20-minute video can be seen on our Telethon, YouTube, website and social media. That video is turned into a podcast for the CDH Radio Show, a press release and more!

<https://www.cdhi.org/shareyourstory>



CDH INTERNATIONAL FUNDRAISERS

FACEBOOK FUNDRAISERS

- Sierra's Birthday Fundraiser for CDHi in Honor of Hazel
- Tricia's Wedding Fundraiser for CDHi in Memory of Juniper
- In Memory of My Sylous, Fundraiser for CDHi
- Kendra's Birthday Fundraiser for CDHi in Memory of Nephew Macklin
- Dakota's Birthday Fundraiser for CDHi
- Peggy's Birthday Fundraiser for CDHi in Memory of Amy
- Zach's Fundraiser for CDH Awareness Day in Honor of Reagan
- Pat's Birthday Fundraiser for CDHi
- Shelly's Birthday Fundraiser for CDHi in Memory of Shelton
- Toni's Birthday Fundraiser for CDHi in Memory of Atlas
- Ian's Birthday Fundraiser for CDHi
- Melissa's Birthday Fundraiser for CDHi in Honor of Kieran
- Serena's Birthday Fundraiser for CDHi
- Donna's Birthday Fundraiser for CDHi
- Breanna's Birthday Fundraiser for CDHi in Memory of Mallory
- Jen and Doug's Fundraiser for CDHi in Memory of Juniper
- Heidi and Sean's Fundraiser for CDHi in Honor of Sean
- Morgan's Fundraiser for CDHi



FREE CDH AWARENESS GRAPHICS



Free social media graphics that you can personalize to raise CDH Awareness! <https://cdhi.org/freegraphics2023/>



SCARLETT GRACE ROBERSON

CDH ANGEL, UNITED STATES



On June 27, 2013, we found out we were pregnant, due March 2, 2014. We had just moved, via military orders, to Germany and decided we wanted another baby. Scarlett's older sister was only 11 months old when we found out we were expecting again. Although we were trying to conceive, we didn't expect it to happen so quickly. None the less, we were ready to start our journey with two under two, once baby number two arrived. We were excited, nervous, and anxious to meet our new baby. The pregnancy was a breeze. On October 15th, we found out we would be having another girl. Just like her older sister, she looked just like their dad. I could tell she would be much different than her big sister. While I was pregnant, she was over the top energetic most of the day, and even a bit feisty when daddy would try to feel her kick and move. The pregnancy progressed well, with a thought that I had too much fluid, which at thirty-two weeks got us another ultrasound. Everything turned out just fine, and baby was so beautiful. After long consideration, we decided Scarlett Grace would be her name, and when we met for the first time, we knew it was the perfect choice. We were to decorate her room in turquoise and pink. We had everything we needed, ready for her arrival.

At 1:30 a.m. on Monday, February 24, 2014, I was lying in bed awake, as I couldn't sleep with a feeling that it was just about time. Suddenly, my water broke. Excited, nervous, anxious, tired and many other emotions were running through us as we got ready to head to the hospital to meet our baby girl. Labor was quick. At 4:58 a.m. Scarlett Grace Roberson made her entrance to the world. They laid her on my chest and she stared into mommy's eyes. They suctioned her, she tried so hard to cry, but couldn't. That's when we knew something wasn't right.

Near the end of my pregnancy, I was haunted by the thought of death. Not towards Scarlett specifically, but I couldn't shake the bad feeling I had, and just chocked it up to hormones and anxiety over having a new baby in the house. During labor, when I got my epidural, the name of the anesthesiologist was the same as a person at one time in our lives, who was pretty horrible. When he walked into the room, my heart sank, and I knew something was wrong. Never in my wildest dreams would I have imagined what was about to happen.

Scarlett was taken from my arms and intubated in the delivery room. She was then rushed off to have an x-ray to see what was going on; why she wasn't able to breathe on her own. When they knew what was wrong, they came back to tell us she had a right-sided congenital diaphragmatic hernia. I had never heard about this condition. My husband, who is an LPN had only briefly heard of it, but didn't know much. They went on to tell us that she was critical, had a decent chance of surviving, but that she would have to be transferred to another hospital that was equipped to deal with her situation. Our friend who worked in the NICU, put calls out for prayers. People from every inhabited continent were praying for our baby girl.

After what seemed like forever, traffic was horrible, the transport team arrived to take baby Scarlett to the new hospital. We were told we weren't allowed to go with her in the ambulance. The hospital discharged me immediately so that my husband and I were able to go be with her. The hospital was an hour away, and the drive, again, seemed like forever.

When we got to the hospital, we found where Scarlett was and got to see her finally. She was hooked up to many tubes and machines, and after our first daughter spent her first eleven days in the NICU, we weren't too overwhelmed or intimidated by what we saw. The doctors then came in to tell us they were about to start the hour and a half long process of the ECMO surgery to get her strong enough for her repair surgery.

After the surgery, the doctors called us back to her room. They told us that the ECMO surgery was successful. They also told us at that point, that her chance of survival was 70%. Since both of her ultrasounds, including the one at 32 weeks were completely normal looking, they said there was a good chance that her lung tissue was probably developed up to at least 32 weeks, which meant that if she made it through the surgery, she'd have a relatively short NICU stay and would get to go home with us after that. They added though, that the next hours were critical, so be prepared.

After hearing that the surgery was successful, and the odds were in her favor, we started feeling hopeful that we would make it through this. However, shortly after, they found a bleed in her belly. When she was getting the chest tubes inserted when she couldn't breathe on her own at birth, her liver was punctured, and was bleeding badly due to the Heparin used to thin her blood for the ECMO process. They had to add clotting factors back to her blood to try and stop the bleeding. They told us it would be a little while to get it stopped, but they were managing it. Adding clotting factors back in to her blood came with its own set of risks, though. We were now having to be cautious of brain bleeds, which is a common problem seen with the ECMO therapy.



It had been a long day, we were hungry, tired, and anxious. We went to get a hotel room on the hospital grounds so we could stay close. Some friends came to visit us to show their support and help us in any way they could. We went back Scarlett's room to see her one more time before we would head to bed for the night. The doctor's told us they would call if anything went wrong during the night.

After getting settled into our room, we went to sleep. We slept through the entire night, with not a single phone call. When we woke up and realized this, we were ecstatic. There were no problems through the night. We hastily got dressed and ready to go see Scarlett. When we arrived at her room, the doctors were performing an ultrasound on Scarlett, which we were told was just a normal check that they do, and changing shift so we waited outside.

When we went in, they told us everything went well through the night, but that the ultrasound they were just performing, may have shown a spot in her head. They couldn't really tell what it was if it was anything. They said they would have to do a more detailed scan. We were told that we could stay in the room as long as we wanted. We hung out in the room with Scarlett for a while, then went to get some breakfast. When we returned, we got horrible news. Scarlett had bleeding between her brain and skull, and with the clotting factors they were adding to stop the belly bleed, the blood around her brain was now clotting as well. The doctor told us that the team of doctors would have to discuss what our next move was. The team wasn't all there so we had to wait a couple of hours.

We called our friends to tell them the news and they were there shortly after, so we went to find lunch while we were waiting on the doctors. While having lunch, we got a phone call from the doctor, telling us that they were ready to discuss with us what was going on as far as progress, and what we were to expect at this point. When we showed up they took us to a conference room to tell us what was going on. The doctors looked solemn; were quiet, and we knew what they were going to tell us.

The doctors explained that, had we known about her condition before her birth, Scarlett would have probably had a different outcome. They were hopeful that she would make it, but the belly and head bleeds were not problems they expected to face. Ultimately, because of the brain bleed, the ECMO had to be stopped. They informed us that they had tried lowering the amount of support she was getting by a very small amount, but she couldn't handle it. They told us she would die once we took her off of the machine. They would be doing the surgery to remove the ECMO shortly after, once the surgeon arrived.

When the procedure was done, we got to go in to the room and hold her for a little while before they would turn off the oxygen she was receiving. Once we were ready, they turned off the oxygen, and we watched her pass, so peacefully at 3:45 p.m. on February 25, 2014. The doctors had a leave briefly to clean her up and remove the rest of the tubes she was connected to. When they called us back, we got to bathe and dress her to get her ready to go to the mortuary. Then we got to stay in the hospital chapel with her for a few hours until it was time to leave.


The following week we held a viewing for our friends, and a memorial at the church we attend. The next weekend we flew home to the states to have a funeral and bury her next to her grandmother. Our friends, family, and church family helped us so much during this time, by watching our older daughter and helping us in any way they could, really making this stressful time, much less stressful.

We are moving forward, and hope to be able to raise awareness to others by sharing Scarlett Grace's story. Her life was short, but had so much meaning. We believe in Christ with all of our hearts, and that's all her life was about. She brought a world to their knees in Jesus' name. We love and miss her more than we can say, but we know her short life was for a beautiful purpose, and we couldn't be more proud of what she accomplished.

- Cary Roberson, mother


CDHi is very proud to announce our partnership with MyRareID.

Congenital Diaphragmatic Hernia is not a well known medical condition and not one that is easily visible. In a medical emergency, every second is crucial and these patients have complicated medical histories. My Rare ID put their information in the hands of emergency responders and treating physicians within seconds.



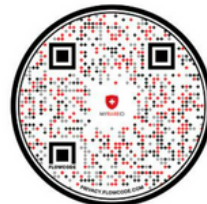
Personal Digital Health Record

24/7 Emergency Medical Support



John D. Palmer
 DOB: 06/07/89
 ID: 9999999 | PIN: 9999

- *Adrenal Insufficient
- *Cortisol Dependent
- *Blood Type: O-
- *Emergency Solu-Cortef Injection in Backpack



SCAN FOR MEDICAL DETAILS

With a medical ID on your person, your child's carseat, stroller, medical equipment or anywhere near by, their medical information is always on hand. No longer do you have to carry around a 3-ring-binder or worry when they off at school or staying over with a friend or grandparent – if there's an emergency, all YOUR knowledge about your child's care, along with medical documents, goes with them wherever they go. Not only does this bring help faster, but it brings peace of mind as well.

You can also save time filling out information on the CDH Patient Registry by opting to give permission to share the information that you input at MyRareID. Sign up at <https://myrareid.co/cdh-subscriber-details/>

10 NON-MONETARY WAYS TO GIVE TO CDH INTERNATIONAL

by Dawn Ireland



20-year-old Marianne Teigen recently published her first young adult novel, and in only a month, it has reached the New York Times Bestsellers list.

The world has gone a bit crazy and unstable in this post-pandemic economy and as we all struggle, charities are drastically impacted. CDH International's donations are down by 50% this year and our volunteers are burning out trying to juggle stress and volunteering. We know that many of you want to help but cannot afford to or don't know how to.

Here are 10 ways people can help our charity for free:

1. Spread the word: Share information about CDH International on social media, with friends and family, and in your community. This will help raise awareness and encourage others to support the cause.

2. Volunteer: Many charities rely on volunteers to help with events, fundraising, and other activities. By giving your time, you can make a real difference in the lives of those our charity serves.

3. Donate goods: Items such as postage stamps, printer ink, paper, flights and hotel costs to research conferences and meetings can really add up. By donating items, you can free up resources toward research grants and to families in need.

4. Participate in online fundraising campaigns: CDH International hosts online fundraising campaigns that allow you to donate money without spending any extra.

5. Use charity shopping portals: Some online shopping portals like Giving Assistant allow you to shop while donating a portion of the purchase price to a charity of your choice.

6. Attend charity events: Attending charity events can help raise awareness and funds for the organization.

7. Share your skills: CDH International can benefit from your skills, such as marketing, accounting, or web design. Consider volunteering your skills to help the organization.

8. Offer your services: If you are a professional such as a lawyer, graphic designer, or writer, you can offer your services to a charity pro bono.

9. Host a fundraiser: You can organize a fundraiser with your friends and family, like a bake sale or a charity run, to support the charity.

10. Become an advocate: CDH International often needs trusted and knowledgeable advocates who can speak on the charity's behalf to elected officials or media outlets. You can help by becoming an advocate for the charity and raising awareness about our mission.

WARRIOR



BROOKE HUSON

CDH SURVIVOR, UNITED STATES



A 50% chance of survival is what they told my family. If my mom continued her pregnancy that I would most likely have a failure to thrive. Some context, I was diagnosed in utero at 30 weeks with a Congenital Diaphragmatic Hernia (CDH), a very rare birth defect that only 1,600 babies are born with each year & out of that, only 50% survive. CDH happens when the fetus does not have a diaphragm, or there is a hole in the diaphragm. Because of this hole, or lack of a diaphragm, the contents of the abdomen, including the stomach, intestines, liver and spleen, can go into the chest preventing the normal development of the lungs. After birth I could have difficulty breathing if the lungs were not developed enough. My mom has always had the mentality that God doesn't give us more than she can handle and at 39 weeks, I was born. Doctors began to work on me to make sure I could breathe and rest easily, and so they could do the necessary tests to assess my condition. After about two hours I was transferred to the SSM Health Cardinal Glennon Children's Hospital NICU (neonatal intensive care unit).

When I was only four days old, the pediatric surgeons at SSM Health Cardinal Glennon performed my CDH repair surgery. Using a telescopic instrument that allows for a faster recovery, and less scarring, surgeons made three, quarter-inch incisions to enter my abdomen. During the surgery they were able to place my organs in the correct position and repair the hole that was in my diaphragm. Over the next few days, my condition continued to improve. And I was slowly coming off the ventilators, drinking a bottle and gaining weight. I was becoming a normal infant and was born, transferred, had surgery and was home in eight days, it was truly a miracle!"

Now that I am older and understand that I am supposed to be on this planet for a reason, I am doing whatever it takes to give back to the hospital that gave me a second chance of life while bringing a smile to each patient's face at Cardinal Glennon. I started competing in scholarship beauty pageants in late 2020 and they are very community service driven and allows me to not only tell my story, but help out people in my community along the way. One way I have done this is by creating my own non-profit Cardinal Crew (est 2022) – Giving children across the world the ability to SOAR through life saving care, community, and creativity.

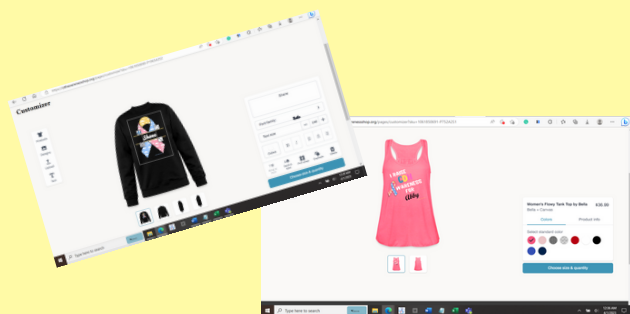
My goal last year was to create 100 fun DIY craft kits each season (Winter, Spring, Summer & Fall) & well as donate as many arts & craft supplies I could get my hands on. Some of the kits that I created were, make your own Cardinal, friendship bracelet kit, design your sunglasses & others. One thing that makes my donations extra special is that I include a fake mustache in each kit and always have step #1 read "Apply your mustache, laugh and have fun while creating your masterpiece", these kids need to be able to laugh and still be kids regardless of their environment.

- Brooke Huson, CDH survivor

Personalizable CDH Shirts!

Add photos and text to make your own Congenital Diaphragmatic Hernia shirts with our personalizable shirts and sweatshirts!

<https://www.cdhawarenessshop.org>



CDH Awareness
Month SALE!

CDH Awareness SHOP

Over 1000 Congenital Diaphragmatic Hernia
Awareness Items.

COUPON CODE: 4-19-23

Clothing | Shoes | Jewelry | Hats |
Housewares | Canvas Prints | Books |
Exclusive CDH Awareness Tartan Items



COUPON CODE: 4-19-23

100'S OF ITEMS



WWW.CDHAWARENESSSHOP.ORG

CDH International supports diversity and inclusion and serves all CDH patients.

CDH International
www.cdhi.org



Congenital Diaphragmatic Hernia

1 IN EVERY 2500 BABIES



Approximately
85%

of CDH babies are diagnosed in utero during routine ultrasound

14% are diagnosed at birth, 1% later.



Congenital Diaphragmatic Hernia (CDH) is a birth defect that occurs when a baby's diaphragm (a thin sheet of muscle that separates the abdomen from the chest) fails to fully form, allowing abdominal organs to enter the chest cavity and preventing lung growth. Treatment requires surgery and intensive hospital care.



Congenital Diaphragmatic Hernia Awareness Day Around the World

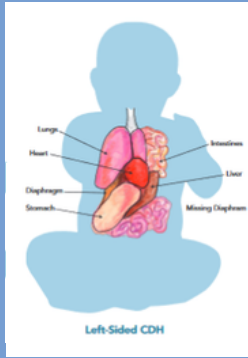
April 19



50% Survival

In Higher Income Countries, CDH has a 50% overall survival rate. In Lower to Middle-Income Countries, the survival rate is less than 1%.

CONGENITAL DIAPHRAGMATIC HERNIA



Every 10 minutes, a baby is born with CDH.

Every hour, at least 3 children lose their battle.

CDH does not discriminate against gender, race, nationality, religious beliefs, or socioeconomic status.

The cause is unknown.

7 The number of countries that CDH International is registered in so far.

CDHi is the world's oldest, largest and leading CDH charity.

CHERUBS was founded in 1995 and renamed in 2017 as CDH International.



The official CDH Awareness Ribbon was voted on by several charities and is owned by no one.

April 19th is the day the CDH Community defeated the trademark on "Congenital Diaphragmatic Hernia Awareness"



All 50 states have proclaimed April 19th Congenital Diaphragmatic Hernia Awareness Day and Legislation has been repeatedly introduced in the US House and Senate since 2014.

11¢

of every dollar goes to overhead at our award winning charity

- 40% support
- 29% research
- 22% awareness
- 1% fundraising
- 8% operations

We do all of this on a \$250,000 annual budget



Our charity has given over

1500

CDH HOPE Totebags to families

CDH RESEARCH

- CDH Patient Registry
- Research Grants
- CDH Research Publications with Universities
- Partnerships with the CDH Study Group, NIH, the WHO, GICS, WOFAPS, EURORDIS, NORD, Rare Disease International, Global Genes, DHREAMS/CARES for Kids, Universities, and more
- Unbiased, global CDH Measurements of Mortality and Morbidity while creating a Standard of Care for CDH and other like anomalies
- Accrediting CDH hospitals
- Fighting for every CDH baby, in every country



FUNDRAISE



The costs of CDH are draining and families need much support, as well as information and research.



- \$5 - 3 CDH Bracelets
- \$10 - 1 CDH Parent Guide
- \$200 - 1 Totebag
- \$250 - 1 Financial Grant
- \$500 - 1 Hospital Kit
- \$1000 - 1 Funeral Grant
- \$1000 - 1 Scholarship
- \$10,000 - 1 Research Grant
- \$15,000 - 1 Family Conference

VOLUNTEER



Volunteers are the heart of our charity.

What is your skill set and how can you help these families by volunteering?

Contact us at info@cdhi.org

\$2 Million Dollars Raised by CDH International

CDH INTERNATIONAL HAS HELPED OVER

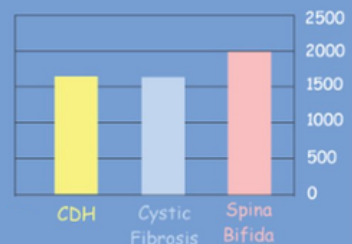
7000

FAMILIES AFFECTED BY CONGENITAL DIAPHRAGMATIC HERNIA

CDH is as common as Spina Bifida and Cystic Fibrosis,

but it receives only a fraction of research funding.

New Cases Each Year in the US



The number of countries that CDH International works in.

84

"I already had a lot of knowledge (I thought) about CDH, but because of CDHi I now have not only the support from everyone who 'gets it' I have educated myself with their help. I have learned more than I ever thought I could." - Kimmy Pass

