

CDH International

# THE SILVER LINING

CONGENITAL DIAPHRAGMATIC HERNIA MAGAZINE

Petition For A CDH Standard of Care

Sign the new petition written by CDH families

CDH Awareness Month Recap

The light ups, proclamations, events and more!

CDH and Mother's Day

Trauma and Celebrating

Contest Winners

50/50 Raffle and Ribbon Contest

Meet The Patients

Ayla Cebelieu, Katie Edic, Harlie Raneae Gray

The Latest CDH Research News

What's new in the research world?

Volunteer Opportunities at CDH International

Make a real difference in the fight against CDH

THE VOICE OF CONGENITAL DIAPHRAGMATIC HERNIA PATIENTS

Bought to you for free by CDH International

May 2023 Issue



This issue of the CDH Magazine is dedicated to the loving memory of CDH patient, volunteer, friend

*Josh Benson*

1995 - 2023



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Cover photo of Aaron and Erin Fisher, in memory of Zoe Aris Fisher.

**CDH Survivors, Family Members, Researchers and Care-Providers are welcome to submit stories, articles and editorials to [news@cdhi.org](mailto:news@cdhi.org)**





# CDH International

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

## CDH INTERNATIONAL NGOS >

### United States:

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 Mailing Address - 3650 Rogers Rd #290, Wake Forest, NC 27587, USA  
 Office: 152 S White St, Wake Forest, NC 27587  
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### Canada

### United Kingdom:

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 Mailing Address - CDH International, 77 Victoria Street, Box 135 London SW1H 0HW, UK  
 CDH International - Registered UK Charity no. 1189819

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 Mailing Address - CDH International, c/o Chapel & York Switzerland Association, 4 Rue Charles-Bonnet, P.O. Box 399,1211, Geneva 12, Switzerland  
 CDH International c/o Chapel & York Switzerland Association is a tax-exempt not-for-profit association governed by Articles 60 et seq. of Swiss Civil Code.

### Hong Kong:

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 Mailing Address - CDH International c/o Hong Kong Foundation for Charities Limited, Unit B, 19/F, Queen's Centre, 58-64 Queen's Road East, Wanchai, Hong Kong  
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 CDH International c/o Singapore Foundation for Charities Ltd | Registration Number 65159428-000

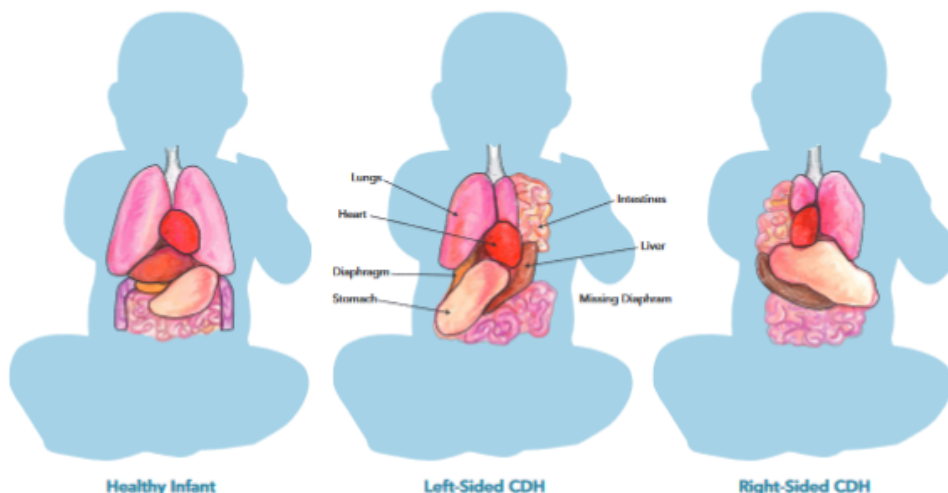


## MISSION STATEMENT >

**CDH INTERNATIONAL** is 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 >



"Mothers are like glue. Even when you can't see them, they're still holding the family together." – Susan Gale





# May 2023



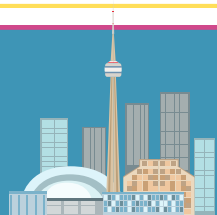
SUN	MON	TUE	WED	THU	FRI	SAT
<b>CDH Telethon</b> Photos & Recipes Due!	1 May Day	2	3	4	5 Cinco de Mayo	6
7 Bereaved Mother's Day	8	9	10	11	12 International Nurses Day	13
14 Mother's Day (US)	15	17	16	18	19	20
21	22	23	24	25	26	27
28 Emergency Medical Services Week	29 Memorial Day (US)	30	31			

30

Notes:

### 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.



### CDHi Executive Board of Directors

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





# CDH INTERNATIONAL

## MAY BIRTHDAYS & ANGELVERSARIES

- Angelversary of Achilles Joseph Ommart
- Angelversary of Aidan Jay Katz
- Angelversary of Aiden Hartley
- Angelversary of Alana Maria Steward
- Angelversary of Alannah Marie Trickett
- Angelversary of Alex Firmin Duguay
- Angelversary of Alexandria Katelyn Job
- Angelversary of Allison Ann Koettters
- Angelversary of Amir Daniel Mohd Kharizul
- Angelversary of Anastacia Hope Tryfona
- Angelversary of Andrew Christopher Kemmer
- Angelversary of Andrew Walter Jenkins
- Angelversary of Ashley Hope Footit
- Angelversary of Ashley John Davies
- Angelversary of Averie Jean Vitense
- Angelversary of Ayden Kristopher Henderson
- Angelversary of Becca Haines
- Angelversary of Billy Thomas Hampton
- Angelversary of Brayden Michael Bammerlin
- Angelversary of Brewen Ross Jilka
- Angelversary of Bridget Hope Jussaume
- Angelversary of Bryson James Melendez
- Angelversary of Caitlyn Bennett
- Angelversary of Carson Ray Elliott
- Angelversary of Caylor Rebecca Bird
- Angelversary of Christian Damon Keough
- Angelversary of Christopher Cade Cowling
- Angelversary of Clayton Mast
- Angelversary of Cole Walker Pittman
- Angelversary of Colleen Kara-Ann Hyde
- Angelversary of Dakota Mae Vosse
- Angelversary of Dallas Faith Contreras
- Angelversary of Darragh Edward Lennon
- Angelversary of Delaney Ann Williams
- Angelversary of Denali K. Korb
- Angelversary of Elizabeth Kelly Staggs
- Angelversary of Emily Nicole Clark
- Angelversary of Eric Angel Ciprez
- Angelversary of Faith Emily Marshall-Elkins
- Angelversary of Gianna Joann Gray
- Angelversary of Gracie Elizabeth Bell
- Angelversary of Hannah Alysabeth Hamby
- Angelversary of Holden Wade Graham
- Angelversary of Hope-Eliza Villarreal
- Angelversary of Isaiah Wilson McIntosh
- Angelversary of Jake Andrew Thompson
- Angelversary of James Garry Townsend
- Angelversary of Jaquelyn Bonnie Weiser
- Angelversary of John Angelo O'Donnell the fifth
- Angelversary of John Burton Messer III
- Angelversary of Jose Rupert Luis Twins Baxcajay
- Angelversary of Kaiya Marie Nuas
- Angelversary of Kamille Faith Rous Lanorio
- Angelversary of Kay Chevalier Lindell
- Angelversary of Kaylie Kathryn Marczak
- Angelversary of Keira Isabella Caudle
- Angelversary of Kirsten Jewell Foster
- Angelversary of Kullen Michael Denegri
- Angelversary of Kyle James Barbee
- Angelversary of Kylie Ann Cheek
- Angelversary of Kynnedi Annabelle Faith Collins
- Angelversary of Lars Blumenroehr
- Angelversary of Liam Duncan Shields
- Angelversary of Little Dee C Scheibly
- Angelversary of Lucas Emmet Dubray
- Angelversary of Madison Lillian Schultz
- Angelversary of Makenzee Edell Spencer
- Angelversary of Manuel Sarabia
- Angelversary of Matthew Joseph O'Donnell
- Angelversary of Max Garrett Foshe
- Angelversary of Max Matteo Logozzo
- Angelversary of McKenna Meredith G
- Angelversary of Meike Elizabeth Auerswald
- Angelversary of Mila Fate Laganis
- Angelversary of Miley Ann Hoke
- Angelversary of Miley Rae Willis
- Angelversary of Myles Steven Albin
- Angelversary of Nathan Presley Bacon
- Angelversary of Nathaniel Richard Claes
- Angelversary of Owen Jude Tomczyk
- Angelversary of Owen Reed Densmore
- Angelversary of Quincy Thomas Haynes
- Angelversary of Rachel Marie Barragan
- Angelversary of Ricky Ray Nunez Jr.
- Angelversary of Robbie Mullen
- Angelversary of Ryland Mark Mitchell
- Angelversary of Sadie Miller
- Angelversary of Samuel Zion Eddy
- Angelversary of Sara Hope Lamkin
- Angelversary of Sarah Jane Crawford
- Angelversary of Sean E. Harkins
- Angelversary of Shae Ashley Webster
- Angelversary of Skylar Anntoinette Raine Watson
- Angelversary of Suze Zwart
- Angelversary of Sylous Caige Hayes
- Angelversary of Trey R. Powell
- Angelversary of Winter Rae Webb
- Angelversary of Wyatt Walker Wagner
- Angelversary of Yasmin Reynolds
- Angelversary of Zachary Michael Blue
- Angelversary of Zack Anthony Motbey
- Angelversary of Zeyah Grace Ackerman
- Angelversary of Zoe Madelyne Gonzalez
- Birthday of Aayliah Daijah Lee
- Birthday of Abigail Grace Ammeraal
- Birthday of Abigail Leigh Wilson
- Birthday of Abigail Watermulder
- Birthday of Aden Musa Legrand Zaidi
- Birthday of Adrian Pignolo
- Birthday of Alex Firmin Duguay
- Birthday of Alexander Scott Rinehart
- Birthday of Alexander William Snowball
- Birthday of Alexandria Katelyn Job
- Birthday of Alexis Marie Hutton
- Birthday of Alexis Nicole Vigo
- Birthday of Allie Mae Williams
- Birthday of Allison Michelle Ertwine
- Birthday of Allyson Hughes
- Birthday of Allyssa Lawson
- Birthday of Alyssia Nicole Polizzi
- Birthday of Ambie Gilbert
- Birthday of Amelia Slattery
- Birthday of Amy Belmonte
- Birthday of Andrew James Sazima
- Birthday of Andrew Nicholas Phillips
- Birthday of Aneska Bothma
- Birthday of Annalia Nasia Quijada
- Birthday of Anthony Charles Thomas
- Birthday of Anthony Monaco
- Birthday of Archie Daniel Watts
- Birthday of Aria Izabel Wiley
- Birthday of Ariana Kjaersgaard
- Birthday of Aron Tamm
- Birthday of Ashley Rose Meyers
- Birthday of Aspen Adeline Welty
- Birthday of Audrey Frost
- Birthday of Austin Mangum
- Birthday of Avery Elizabeth Dondero
- Birthday of Ayden Kristopher Henderson
- Birthday of Bastiani Boots Richards
- Birthday of Becca Haines
- Birthday of Benjamin Gibson
- Birthday of Bethany Camryn Mollring
- Birthday of Billy Thomas Hampton
- Birthday of Braiden Shiloh Anthony
- Birthday of Brandi Marjorie Warren
- Birthday of Brandon Chad Motley
- Birthday of Brandon Edward Day
- Birthday of Braxton Rebando
- Birthday of Brendan Isaiah Grayson
- Birthday of Brewen Ross Jilka
- Birthday of Bridget Hope Jussaume
- Birthday of Briella Saige Hayes
- Birthday of Bryanna Lee Hope Lee
- Birthday of Brynn Hatfield
- Birthday of Bryson James Melendez
- Birthday of Caden Louis Wilchie
- Birthday of Callum Alexander Walker
- Birthday of Camden Buzzell
- Birthday of Carleigh Sharon O'Rourke
- Birthday of Carly Kufs
- Birthday of Carson James Goodmote
- Birthday of Carter Edward Hutchins
- Birthday of Carter Matthew Liedy
- Birthday of Cayden Angelo Bose Cabarubias
- Birthday of Charley Frederick Langford
- Birthday of Charli Jordan Wilson
- Birthday of Charlotte Anne Nicholls
- Birthday of Charlotte Grabitz
- Birthday of Chastity Auron White
- Birthday of Chelsalie Ann Carlson
- Birthday of Christian Damon Keough
- Birthday of Christopher Cade Cowling
- Birthday of Christopher S. Knowles
- Birthday of Ciaran Thomas Farrell
- Birthday of Colbie Judith Riblet
- Birthday of Cole Alexander Spurlin
- Birthday of Cole Benton Edwards
- Birthday of Colin Small
- Birthday of Colleen Kara-Ann Hyde
- Birthday of Colton James Hillsinger
- Birthday of Connor Joseph McKenzie
- Birthday of Cordelia Pearl Monte
- Birthday of Crystal Rose Tweeten
- Birthday of Curran Richard Plant
- Birthday of Curtis Thomas
- Birthday of Dakota Mae Vosse
- Birthday of Damian Ramin
- Birthday of Damien Brannon
- Birthday of Daniel Josef Hinojosa-Belyakovich
- Birthday of Darragh Edward Lennon
- Birthday of Declan James W
- Birthday of Delaney Ann Williams
- Birthday of Denali K. Korb
- Birthday of Dillon L. Wheeler
- Birthday of Dominic Israel Moreno
- Birthday of Drake Jeffrey Dean Clark
- Birthday of Easton James Antony Cordova
- Birthday of Elijah Borne Litzner
- Birthday of Elle Susane Margaret Phillips
- Birthday of Ellison B Hermillier
- Birthday of Emalee Lillian Charity Coker
- Birthday of Emma Doreen Gabites
- Birthday of Eric Angel Ciprez
- Birthday of Erica Olivia Davis
- Birthday of Eryn Griffen
- Birthday of Euri Felicity Simblante Manlapaz
- Birthday of Evan Alan Malaer
- Birthday of Evan Joseph Downs
- Birthday of Fabricio Jadier Estrada Noboa
- Birthday of Faith Emily Marshall-Elkins
- Birthday of Fiona Heather Suzanne Daniels-Brown
- Birthday of Flynn Simons





# CDH INTERNATIONAL MAY BIRTHDAYS & ANGELVERSARIES

- Birthday of Gabriel Brissette
- Birthday of Gabriel Francis Kelosky
- Birthday of Gabriel James lee Garnick
- Birthday of Gabriela Monteiro
- Birthday of Gavin Meyer
- Birthday of Gianna Joann Gray
- Birthday of Gianna Monroe King
- Birthday of Gianni Josue Schuller-Acosta
- Birthday of Gilbert Baca III
- Birthday of Granville Morgan Whitener
- Birthday of Grayton Karleigh Creekbaum
- Birthday of Gregory Allen Mueller Jr.
- Birthday of Hailey Elizabeth Steiner
- Birthday of Hannah Alysabeth Hamby
- Birthday of Hannah Elizabeth Preiser
- Birthday of Haydn Daniel Mani
- Birthday of Hayley Chantelle Ginns
- Birthday of Henry Liam Johnson
- Birthday of Holden Wade Graham
- Birthday of Hope Analise Magenta Sunseri
- Birthday of Hunter Gabriel Moak
- Birthday of Hunter James Alexander
- Birthday of Ian Riley Robinson
- Birthday of Ian Sinclair O'Sullivan
- Birthday of Ida Elisabet Larsson
- Birthday of Imogen Elizabeth Rose Sherry
- Birthday of Ines Bahurel
- Birthday of Isabella Grace Ferrone
- Birthday of Isabella Rey Gibson
- Birthday of Jabriel Christopher Nicholson II
- Birthday of Jack Braxton
- Birthday of Jack Warren Payne
- Birthday of Jackson Alexander Ray
- Birthday of Jackson Luxem
- Birthday of Jackson Plowman
- Birthday of Jacob Matthew Jalique
- Birthday of Jacob Ray Hall
- Birthday of James Bradley Foster
- Birthday of James Garry Townsend
- Birthday of James Matthew Hanron
- Birthday of Jan Pawel Janicki
- Birthday of Jane Olivia Lignana
- Birthday of Jaquelyn Bonnie Weiser
- Birthday of Jared James Buchamer
- Birthday of Jarod Levi Wagner
- Birthday of Jaron Noah Hege
- Birthday of Javier Arturo Pellerano
- Birthday of Jaxson Isaac Mayer
- Birthday of Jennifer Marie Poole
- Birthday of Jesse Wright Lamkey
- Birthday of Jessica Reck/Thomas
- Birthday of Jessica Tustin
- Birthday of John (Keoni) Nicholas Gonzalez-Rivera
- Birthday of John Angelo O'Donnell the fifth
- Birthday of John Burton Messer III
- Birthday of John Daniel Friedlander
- Birthday of John Lee Thompson
- Birthday of Jordan James Knight
- Birthday of Jorge Luis Pedraza
- Birthday of Jose Rupert Luis Twins Baxcajay
- Birthday of Julia Sophie Salazar
- Birthday of Kaitlyn Eleanor De Luca
- Birthday of Kaiya Marie Nuas
- Birthday of Kaleigh Knight
- Birthday of Kaleigh Shayne Hamilton
- Birthday of Kamden Grayson Babin
- Birthday of Kamille Faith Rous Lanorio
- Birthday of Kamryn Kay Edwrads
- Birthday of Kayden Michael Keith
- Birthday of Kayla N. Byrd
- Birthday of Kaylie Kathryn Marczak
- Birthday of Kaylyn Marie Stiner
- Birthday of Keira Isabella Caudle
- Birthday of Kellan Michael Morehouse
- Birthday of Kendra Randolph
- Birthday of Kieran Gabrielson
- Birthday of Kinza Ymeen Muneeb
- Birthday of Kirsten Jewell Foster
- Birthday of Krosby Nay
- Birthday of Kynnedi Annabelle Faith Collins
- Birthday of Kytara Isabella Tovar
- Birthday of Lakin Marie Spoonhower
- Birthday of Lars Blumenroehr
- Birthday of Laura Darlene Kennedy
- Birthday of Laura K. Stratton
- Birthday of Levy Chance Pelouquin
- Birthday of Liam Anthony Hunt
- Birthday of Liam Augustin Lavelle
- Birthday of Liam Duncan Shields
- Birthday of Lincoln Daniel Olds
- Birthday of Lindsey Janet Williams
- Birthday of Lindy Cherry
- Birthday of Logan Gregory Scarlavai
- Birthday of Logan Lee Wagner
- Birthday of Lorenzo Armando Croce
- Birthday of Lucas Emmet Dubray
- Birthday of Luke Everett Ellis
- Birthday of Luke John Ditchfield
- Birthday of Lyla Kayden Werner
- Birthday of Maddox Malakai White
- Birthday of Madison Lillian Schultz
- Birthday of Mahalah Theresa Arnold
- Birthday of Manuel Sarabia
- Birthday of Margaret Kathleen Downtin
- Birthday of Marshall Cord Hendley
- Birthday of Mary Ann Greenwood
- Birthday of Mason Theodore Mitchell
- Birthday of Matthew John McNaught
- Birthday of Matthew Ryan Johnson
- Birthday of Matthew Tyler Beach
- Birthday of Mattson Edward Houghton
- Birthday of Maxwell Anderson Martin
- Birthday of McKenna Meredith G
- Birthday of Meagan Downing
- Birthday of Meike Elizabeth Auerswald
- Birthday of Melissa Heyme
- Birthday of Michael Joseph Carroll
- Birthday of Michael Nelson Bradshaw
- Birthday of Michael William Micallef
- Birthday of Miley Ann Hoke
- Birthday of Miley Rae Willis
- Birthday of Myles Steven Albin
- Birthday of Nadia Marilyn Larson
- Birthday of Nathan Leroy Cranston
- Birthday of Nathan Presley Bacon
- Birthday of Nathaniel Richard Claes
- Birthday of Nellie Frescas
- Birthday of Nicola Katherine Lewis
- Birthday of Noah Blake Adkins
- Birthday of Noah Eugene Uhl
- Birthday of Noah Robert Sullinger
- Birthday of Noelle Lorraine Copsey
- Birthday of Ole Jakob Serkland
- Birthday of Oliver Thelonious Liddic
- Birthday of Olivia Catherine Case
- Birthday of Olivia Joan Therese Fitzpatrick
- Birthday of Olivia Maylyn Nelson
- Birthday of Owen Jude Tomczyk
- Birthday of Penelope Lane Spencer
- Birthday of Quincy Thomas Haynes
- Birthday of Rachel Marie Barragan
- Birthday of Ralph Matthew Gillen
- Birthday of Reese Thomas Lauer
- Birthday of Ricky Hull
- Birthday of Riley Bell Brady
- Birthday of Riley Dawn Stevens-Goebel
- Birthday of Riley Nicole Soria
- Birthday of Robbie Mullen
- Birthday of Rowan James Keating
- Birthday of Ryan Hilarion Crasto
- Birthday of Ryan Michael Kilgore
- Birthday of Ryan Michael Peterson
- Birthday of Ryan Robert Dominguez
- Birthday of Ryland Braxton
- Birthday of Ryland Mark Mitchell
- Birthday of Salaly Sanchez
- Birthday of Samantha Justeen Rodell
- Birthday of Samar Caballero
- Birthday of Samuel Bailey
- Birthday of Samuel Kincade
- Birthday of Sara Hope Lamkin
- Birthday of Sarah Brianne Howerton
- Birthday of Sarah Jane Crawford
- Birthday of Sasha Maxine Coker
- Birthday of Savannah Grace Patterson
- Birthday of Sean Anthony Feaster
- Birthday of Sean E. Harkins
- Birthday of Sebastian Alexander McErlean
- Birthday of Seth Derek Anderson
- Birthday of Shae Ashley Webster
- Birthday of Shane Allen Ohlemeyer
- Birthday of Skylar Anntoinette Raine Watson
- Birthday of Sofia Louise Fiorillo
- Birthday of Sono Darshan Lal
- Birthday of Sophia Gehrka
- Birthday of Sophie Wakelin
- Birthday of Stacey Jayne Smith
- Birthday of Stephen Matthew Duncan Jr.
- Birthday of Steven Micheal Pakula
- Birthday of Sullivan Cushing
- Birthday of Sydney Claire Tucker
- Birthday of Taylor Greene
- Birthday of Teagan Renee Green
- Birthday of Tobias Julian Lieshoff
- Birthday of Tommy Jr. Terrebonne
- Birthday of Tony Austin Thomas
- Birthday of Trent Ryan Jones
- Birthday of Trey Lamont Vance
- Birthday of Trislyn Annabelle Gregory
- Birthday of Tristan Dean
- Birthday of Tristan MacDonald
- Birthday of Tucker Lee Von Hatten
- Birthday of Tyler Anthony Finley
- Birthday of Tyler Michael Wilson
- Birthday of Tysen Rick Fausett
- Birthday of Valek Hendrickson
- Birthday of Victoria Lee Snoddy
- Birthday of Vincent Michael Vogan
- Birthday of Vivian Westenhofer
- Birthday of Whitney Caroline Williford
- Birthday of William Erik Anderson
- Birthday of William Russeth
- Birthday of Wyatt Walker Wagner
- Birthday of Xyana Romero
- Birthday of Yasmin Reynolds
- Birthday of Zachary Max Schultz
- Birthday of Zachary Michael Blue
- Birthday of Zack Anthony Motbey
- Birthday of Zane Lee Warner
- Birthday of Zeyah Grace Ackerman
- Birthday of Zoe Madelyne Gonzalez



# Editor's Note

## Mother's Day



Mother's Day for the parents of children born with a life-threatening birth defect can be a bundle of emotions.

Those who spend their first Mother's Day in the NICU are happy and frustrated. Grateful to have their child, jealous of those celebrating at home, angry that their journey isn't "fair," and all the dreams of this day have to be put aside and replaced with a new "normal."

For those mothers who spend the day at home with CDH survivors, it's a beautiful occasion feeling with love, breakfast in bed, flowers, homemade cards with little fingerprints, and massive amounts of gratitude to be able to celebrate with their child.

For those mothers who lost their children to CDH, or any illness or incident, the day is painful in many ways and soft in a few ways as memories flood back. It is filled with "what if" and "should be." It is especially painful for those mothers who lose their only children.

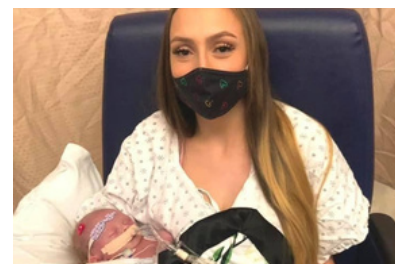
And for a whole new generation of CDH children on the way with mothers who are still expecting them, the day is filled with hope, fear, anxiety, and prayer that next year they will be able to hold their child on Mother's Day.

So how do we celebrate together when our journeys are on the same path but so very different?

We just do. We celebrate every mother. We remove the labels of "grieving mother," "expectant mother," and "mother of a survivor," and we celebrate every mother equally, together. All the trauma, all the fear, all the love. We celebrate for each other that we had the chance to be mothers to cherubs... a job chosen for the strong, no doubt. But what brings us together is a bond far more substantial than our differences.

On this Mother's Day, we wish love and peace to all the mothers and those who mother our children.

DAWN M. TORRENCE IRELAND  
**President & Founder**



## CDH International Patient Advocacy Board

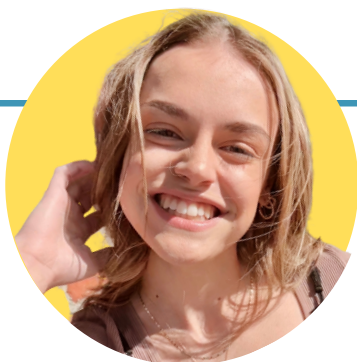
- Nicole Colvin
- Robyn Fletcher
- Melissa Johnstone
- Morgan Nuchols
- Sean Forney
- Taylor Steffensmeier
- Danae Perkins
- Lauren Dietz
- Renci Scurlock
- Tina Ingham





## CDH INTERNATIONAL

## MEET OUR VOLUNTEERS



**Maddy Sortino**  
Volunteer

My name is Maddy Sortino and I was born in 2004. I am a bilateral CDH survivor. Only 16% of my diaphragm had formed by the time I was born, and I have had multiple patch repairs throughout my life. I am from Omaha, Nebraska and I have had my amazing thoracic surgery team care for me at the Omaha Children's Hospital. Despite all the CDH obstacles, I was a dancer for 10 years, I ran sprints on my highschool track team, and played instruments in both orchestra and band. I graduated highschool in May of 2022 and I am now at the University of South Dakota majoring in nursing. My goal is to be a pediatric med-surg nurse to help kids like me. I am very excited to be a part of the CDH International marketing team. Ultimately, I hope I can give new CDH families the peace of mind that they are not alone and that every CDH challenge is beatable.



**Katie Carman**  
Volunteer

I am a proud resident of Claremont, North Carolina. I am married with a teenage daughter who is a CDH Survivor. I also have two adult stepchildren and two grandsons.

My proudest accomplishments include raising my daughter and co-leading a Girl Scout troop. These experiences have taught me the importance of nurturing young minds and instilling strong values in them. As a parent and mentor, I take great pride in guiding the next generation towards becoming responsible, compassionate individuals. I believe in staying true to myself and am always striving to be a better person for those around me. This has led me to become a reliable friend and confidant to many.

Living life with integrity and compassion is at the core of my belief system. I firmly believe that when we treat others with kindness and respect, we can create a more harmonious world. In this fast-paced society, it's crucial to remember that our actions impact not only ourselves but also those around us.

I wish people understood that working together can make the world a much better place. It's easy to get caught up in our individual lives and forget about the bigger picture. But when we come together as a community, we can achieve so much more than we ever could alone.

In my free time, I enjoy indulging in my creative side by reading, writing fan fiction, and creating short stories while my dogs and cats are sleeping near my feet. I find solace in escaping into the worlds I create and exploring the depths of my imagination. Additionally, I love challenging myself by learning new things - whether it's a skill, hobby, or simply gaining knowledge on various subjects.

If given the opportunity to travel to the future and impart wisdom upon future generations, I would advise them to use resources wisely and take the time to learn about history from their parents, grandparents, and other elders. Understanding our past is essential for shaping a better future, and we must be mindful of how our actions today will impact those who come after us.

In conclusion, I am a person who values integrity, compassion, and resourcefulness in all aspects of life. My experiences as a parent, mentor, and friend have shaped me into the person I am today - someone who strives to make a positive difference in the world. By working together, treating others with kindness, and learning from our past, we can create a brighter future for generations to come.



# CDH INTERNATIONAL MAKE A REAL DIFFERENCE!

If interested in any of the following opportunities, please reach out to us at [volunteer@cdhi.org](mailto:volunteer@cdhi.org)

Board Positions	Duties
Executive Board of Directors	Fundraising, networking, licensing, Overseeing and ensuring legal, financial and operating responsibilities of the entire charity.
Admin & Marketing Positions	Duties
Web Site	Web site updates and fixes
SEO	Web site updates and fixes
Videography	Create videos for telethon, documentary, PSAs and more
Graphics	Use our software to help create product graphic, social media graphics (approx. 3 hours a week)
CDH Shop	Create items (approx. 5 hours a week), maintain shop, programming, customer support (approx. 2 hours a week)
Press Releases	Help to write and send out press releases as needed (approx. 2 hours a week)
CDH Magazine	Help to gather stories of patients born with CDH, edit magazine (approx. 3 a week) Due 1st of each month.
Facebook Ambassadors	Engage CDH families, answer messages (approx. 2 hours a day)
Instagram Ambassadors	Engage CDH families, answer messages (approx. 2 hours a day)
TikTok Ambassadors	Engage CDH families, answer messages (approx. 2 hours a day)
Twitter Ambassadors - CDHi	Engage CDH doctors, answer messages (approx. 2 hours a day)
CDHi UK Social Media	Engage CDH families on FB, Twitter and Instagram, answer messages (approx. 2 hours a week)
CDHi Canada Social Media	Engage CDH families on FB, Twitter and Instagram, answer messages (approx. 2 hours a week)
CDHi Switzerland Social Media	Engage CDH families on FB, Twitter and Instagram, answer messages in French and/or German (approx. 2 hours a week)
CDHi Netherland Social Media	Engage CDH families on FB, Twitter and Instagram, answer messages in Dutch (approx. 2 hours a week)
CDHi Hong Kong Social Media	Engage CDH families on FB, Twitter and Instagram, answer messages in Chinese (approx. 2 hours a week)
CDHi Singapore Social Media	Engage CDH families on FB, Twitter and Instagram, answer messages (approx. 2 hours a week)
Research Committee	Duties
Patient Recruiting	Helping patient families to be a part of research through the CDH Patient Registry and University research studies.
Research Library	Finding new research publications, adding them to the virtual library, graphic, blog post, social media posts
Translators	Translate the CDH Parent Reference Guide, Brochures, and Registry Fields
Research Grants	Fundraise for research at CDHi and grants to hospitals
Fundraising Committees	Duties
Facebook Fundraisers	Recruit people to hold FB fundraisers, help set them up, blog posts, social media posts, graphics (approx. 3 hours a week)
Birthday Fundraisers	Recruit people to hold FB birthday fundraisers, help set them up, blog posts, social media posts, graphics (approx. 3 hours a week)
CDH Cookbook	Collect recipes, put them in book template (approx. 10 hours a week for 1 month) Project due May 31, 2023.
Family Fundraising Events	Recruit people to hold fundraising events, set up FB event blog posts, social media posts, graphics (approx. 5 hours a week)
Save The Cherubs Book	Collect photos and put them in book template (approx. 10 hours a week for 1 month) Project due May 31, 2023.
Golf Tournament	Find sponsors, action items, sell tickets for April 2024 event in Raleigh, NC (approx. 5 hours a week) April 2024 in Raleigh, NC.
Angel Club	Recruit Angel Club Members (approx. 3 hours a week)
CFC Grants	Promote Combined Federal Campaign, organize State Reps to attend events (approx. 5 hours a week, September - December)
Masquerade Ball	Find sponsors, action items, sell tickets for February 2024 event in Raleigh, NC (approx. 5 hours a week) February 2024 in Raleigh, NC.
Sponsorships	Find potential corporate sponsors and introduce them to David Holt, Board Member (approx. 3 hours a week)
Awareness Committees	Duties
Light Ups	Email / call landmarks to request light ups, follow up, graphics, video, blog post, social media posts
Proclamations	Email / call governors to request proclamations, follow up, graphics, video, blog post, social media posts (approx. 3 hours a week January-February, 5 hours a week March- April)
Radio Show	Video interview CDH families about their stories, recruit guests, graphics, blog post, social media posts (approx. 3 hours a week)
Telethon	Use our software to help create product graphic, social media graphics (approx. 3 hours a week)
Faces of CDH	Create graphics and social media posts for our 1 cherub a day campaign (approx. 3 hours a month)
Awareness Events	Help families organize events for April to raise awareness (approx. 2 hours a week, 10 hours a week March-April)
Support Committees	Duties
Welcoming Committee	Send new members welcome emails
Prayers & Celebrations	Collect requests, make graphics, post on social media (approx. 2 hours a week)
Special Days	Create and schedule daily post of birthdays and angel days (approx. 2 hours a month)
Facebook Groups (merging with Forums)	Moderate groups, engage members (approx. 2 hours a day)
Forums	Moderate forums, engage members (approx. 2 hours a day)
On-Call for Survivors (merging with Expectant)	On-Call for families who need to talk (approx. 1 hour per month)
On-Call for Grieving	On-Call for families who need to talk (approx. 1 hour per month)
International Representatives	Actively engage families, plan events, ask for proclamations, light ups, translate if needed (approximately 10 hours per week)
State Representatives	Actively engage families, plan events, ask for proclamation, light ups, represent CDHi at CFC events (approximately 10 hours per week)
Totebags	Fundraise for totebags (anywhere) or put them together (local) (currently closed unless help and resources return)
Financial Assistance	Fundraise and then vote by committee to award grants (currently closed unless help and resources return)
Funeral Assistance	Fundraise and then vote by committee to award grants (currently closed unless help and resources return)
Scholarships	Fundraise and then vote by committee to award grants (currently closed unless help and resources return)





# CDH RESEARCH UPDATES

JASON MILLER, CDHI RESEARCH DEPARTMENT

For those born with CDH, treatment is often lengthy and intensive, requiring multiple surgeries and sometimes extended hospital stays. It is an emotionally taxing experience for both patients and their families as they navigate medical care for their child. The CDH International organization has been working to improve the care of CDH patients and their families by developing a comprehensive global natural history registry of CDH patients.

The CDH International registry was first presented in poster form at the International Congress of the International Confederation of Midwives in 2015, which reported the general data in the CDH Patient Registry. Since then, the organization has been collecting valuable information from adult survivors of CDH as well as parents of those currently living with or who have lost their battle against this condition. The questionnaires contain multiple-choice, yes/no queries accompanied by grid-based questions so that participants can more thoroughly fill out their responses when applicable. Participants are sent periodic reminders yearly so that any changes or updates regarding their experience can be tracked properly.

Thanks to advancements made in modern technology, such as the REDCap web application hosted by WOFAPS, these datasets are far more flexible than ever before, now being easily accessible by clinical researchers without compromising participant confidentiality or control over individual data ownership. They retain full control over what details they choose to share. Over 15,000 unique data points have been gathered thus far across 765 questions, making it easier than ever before for researchers both globally and locally to access information on prenatal diagnosis, extracorporeal life support (ECLS), reherniation, transitional care, quality of life assessments post-surgery, and more.

The registry also allows organizations like the Association of Congenital Diaphragmatic Hernia Organizations (ACDHO) and the Scientific and Advisory Council for Congenital Diaphragmatic Hernia (SARA) to access its instrumentation free of charge. They can develop natural history studies allowing them greater insight into respective patient populations while simultaneously contributing towards deidentified combined databases, thereby providing scope further research endeavors.

To gain a better understanding of the patient and family experience, CDH International conducted a survey of 4,513 members who had voluntarily signed up for participation in the registry. The survey asked basic subjective questions surrounding communication between patients and medical professionals regarding diagnosis and treatment options. The results revealed that the majority (88%) thought communication between them and medical professionals was adequate, while 7% reported negative experiences, and 4% were undecided or unwilling to respond.

The survey also covered general research pertaining to congenital diaphragmatic hernia, asking where funds and efforts should be concentrated upon arguably pressing topics such as standards of measurements, mortality, morbidity, and supporting the claim that there exists a disconnect between the CDH patient community and research communities despite constant updates provided by various organizations. Many individuals surveyed complained of pressure to travel outside their state or region due to the inability to determine survival rates at particular hospitals, contributing even further to the financial burden of an already emotionally taxing period of time.

The CDH International registry has shed light on the need to improve patient care and research efforts for CDH patients. The registry provides valuable insights into the experiences of patients and families and allows for a more comprehensive understanding of the condition. The survey revealed the importance of communication between patients and medical professionals and highlighted areas for improvement.

One of the major findings of the CDH International registry is the importance of communication between healthcare professionals and CDH patients and their families. The survey conducted by CDH International revealed that the majority of respondents felt that communication with medical professionals was adequate. However, a significant proportion of respondents reported negative experiences, suggesting that there is still room for improvement in this area.

It is important to note that the registry also includes data on prenatal diagnosis, ECLS, reherniation, transitional care, and quality of life assessments post-surgery. These data points are valuable for researchers who are interested in improving the care and outcomes of CDH patients. In addition, the registry allows organizations like ACDHO and SARA to access instrumentation free of charge, which can help them develop natural history studies and contribute to deidentified combined databases.

Despite the many benefits of the CDH International registry, there are still challenges to overcome. For example, some participants reported feeling pressured to travel outside of their state or region to receive care, which can be a significant financial burden. CDH International needs to ensure that respondents feel comfortable enough to come forward and provide accurate, unbiased information to better inform everyone's decisions going forward.

CDH International's Natural History Registry is an innovative way of collecting valuable information about Congenital Diaphragmatic Hernia patients. The registry not only serves current needs but offers scope for improvement not just in local institutions but ones around the world. By gathering data from adult survivors, parents of those currently living with or who have lost their battle against this condition, we now have a better understanding of the financial and emotional impact of the condition on a patient's family. Moreover, thanks to surveys conducted to discover the opinions of family members regarding communication between themselves and medical staff, alongside much-needed feedback being used to create standards to measure mortality and morbidity, we can help make informed decisions going forward.

## CDH INTERNATIONAL AT WORK

As of April 25th, CDH International has so far this year:

### PRESENTATIONS

- 2023 CDH Telethon

### RESEARCH POSTERS

- **BDRP 2023** (Charleston, SC)
  - "Congenital Diaphragmatic Hernia: Patient Parents As Partners"
- **ICBD 2023** (Santiago, Chile)
  - "Introducing the CDH Patient Registry; A Global Natural History Registry"
  - "27 Year Retrospective on Congenital Diaphragmatic Hernia"
  - "Congenital Diaphragmatic Hernia: Patient Parents As Partners"
- 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
- CDH International Signs Letter of Support for March of Dime's ECHO program funding request
- 4 ongoing CDH Research Registry collaborations with various labs and universities



# CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

## DARLENE SILVERMAN, CDH RESEARCH LIBRARY

Morgagni's hernia in adult  
<https://pubmed.ncbi.nlm.nih.gov/37013215/>

"Heart of the Matter": Cardiac Dysfunction in Congenital Diaphragmatic Hernia  
<https://pubmed.ncbi.nlm.nih.gov/37011900/>

Congenital diaphragmatic hernia increases the sensitivity of pulmonary arteries to nitric oxide  
<https://pubmed.ncbi.nlm.nih.gov/37004830/>

Fetal Tracheal Occlusion for Congenital Diaphragmatic Hernia  
<https://pubmed.ncbi.nlm.nih.gov/37002399/>

PBPK-based dose finding for sildenafil in pregnant women for antenatal treatment of congenital diaphragmatic hernia  
<https://pubmed.ncbi.nlm.nih.gov/36998614/>

Robotic Morgagni's hernia repair in adults - A single centre experience  
<https://pubmed.ncbi.nlm.nih.gov/36827305/>

Outcomes of congenital diaphragmatic hernia among preterm infants: inverse probability of treatment weighting analysis  
<https://pubmed.ncbi.nlm.nih.gov/37055479/>

Successful on-ECLS Repair of CDH and Omphalocele in a Newborn  
<https://pubmed.ncbi.nlm.nih.gov/37051184/>

Role of microRNAs in Congenital Diaphragmatic Hernia-Associated Pulmonary Hypertension  
<https://pubmed.ncbi.nlm.nih.gov/37047629/>

Correction To: Early nitric oxide is not associated with improved outcomes in congenital diaphragmatic hernia  
<https://pubmed.ncbi.nlm.nih.gov/37045947/>

Characterization of suboptimal responses to fetoscopic endoluminal tracheal occlusion in congenital diaphragmatic hernia  
<https://pubmed.ncbi.nlm.nih.gov/37040717/>

Inhaled Nitric Oxide Utilization in Congenital Diaphragmatic Hernia Treated With Extracorporeal Life Support: A Propensity Score Analysis  
<https://pubmed.ncbi.nlm.nih.gov/37040072/>

Association Between Early Prostacyclin Therapy and Extracorporeal Life Support Use in Patients With Congenital Diaphragmatic Hernia  
<https://pubmed.ncbi.nlm.nih.gov/37036717/>

Editorial: Unsolved problems in congenital diaphragmatic hernia  
<https://pubmed.ncbi.nlm.nih.gov/37033179/>

Intraoperative Transpyloric Tube Insertion for Congenital Diaphragmatic Hernia: Analysis of Japanese Study Group Data  
<https://pubmed.ncbi.nlm.nih.gov/37032194/>

The combination of Chilaiditi syndrome and Bochdalek hernia in an adult: successful management with a robot assisted approach  
<https://pubmed.ncbi.nlm.nih.gov/36151746/>

Intra-amniotic sildenafil administration in rabbits: Safety, pharmacokinetics, organ distribution and histologic evaluation  
<https://pubmed.ncbi.nlm.nih.gov/37080362/>

Survival in very preterm infants with congenital diaphragmatic hernia and association with prenatal imaging markers: A retrospective cohort study  
<https://pubmed.ncbi.nlm.nih.gov/37069727/>

Early vasopressin infusion improves oxygenation in infants with congenital diaphragmatic hernia  
<https://pubmed.ncbi.nlm.nih.gov/37063685/>

Treprostinil in neonates with congenital diaphragmatic hernia-related pulmonary hypertension  
<https://pubmed.ncbi.nlm.nih.gov/37059388/>

Core outcome set for perinatal interventions for congenital diaphragmatic hernia  
<https://pubmed.ncbi.nlm.nih.gov/37099763/>

Long-Term Functional Outcomes at 1-Year After Hospital Discharge in Critically Ill Neonates With Congenital Diaphragmatic Hernia  
<https://pubmed.ncbi.nlm.nih.gov/37098788/>

Giant Morgagni hernia with transthoracic herniation of the left liver lobe and transverse colon: a case report  
<https://pubmed.ncbi.nlm.nih.gov/37088823/>

Right-side diaphragmatic eventration with atrial septa defect and cleft palate in an infant: a case report  
<https://pubmed.ncbi.nlm.nih.gov/37081543/>

### 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
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- 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





# AYLA CEBELIEU

CDH SURVIVOR, UNITED KINGDOM



"I'm having trouble seeing the heart". Those words were where it began. I'd gone to my 20 week scan by myself and my 2yr old. All I was concerned with was finding out the gender; I never even knew it was known as 'the anomaly scan'. The scan was taking forever, but I was too preoccupied with my 2yr old to notice. Before we left, the midwife mentioned something about a Diaphragmatic Hernia, but we were running late for our bus, so I left without really speaking to anyone about it. I'd never heard of it and I honestly wasn't that worried at that point. I googled it on the way home and I very quickly understood the seriousness. I was pregnant with a little girl and she was very very poorly. The rest of my appointments and check ups were very bleak. I was offered termination at nearly every one and was told that my baby was "not viable". Not viable? How could anyone say my baby wasn't "viable"? I'd seen her, I'd heard her heart beat, I felt her kicking! I was angry, but mostly I was petrified. I was booked in for an induction at 39 weeks. I'd spent the last 19 weeks trying to mentally prepare myself for what was to come, which is impossible by the way. The delivery went well and I saw her briefly before she was whisked away by a team of doctors and specialists. It would be the only time for 3 months I'd see her without any tubes or wires attached to her, and the only time in her life her body would be unmarked by scars. I wanted to look at her forever but I remember shouting at the doctor to take her, to help her.

Those first few weeks were truly terrifying. I don't think it's something you're able to understand unless you've been through it, and I hope to god you never do. We were told to expect the worst so many times. We were living minute to minute and a minute in a PICU is like an hour.

She wasn't responding to any treatment, she maxed out every drug, but she was deteriorating. At one week old she was put onto ECMO. We were told to expect the worst for the procedure, but she pulled through. They were hoping she'd start to improve on ECMO, but she didn't. After a week of no improvement, and some deterioration, they decided to perform her diaphragm surgery whilst she was on ECMO. This was a ridiculously risky surgery, but she was out of options. Again, we were pulled into a side room, signed papers saying we understood everything that could go wrong and told to expect the worse. She made it through. The next few weeks were touch and go. It honestly felt like I didn't take a full breath the whole time. My whole body was coiled in anticipation of the bad news everyone was telling me was coming. But slowly, SO slowly, she showed us she was improving. This girl, this baby, fought for her life. She is a warrior. She has the many scars to prove it.

It is simply not possible to convey the despair of CDH, I struggle to find the words. Part of that is the brain's disposition for self-preservation; we don't like to contemplate such suffering, let alone confront it.

My baby girl, Ayla, is 3 now. She's re-herniated twice since her initial surgery, but she is strong and active and a gorgeous little weirdo. I just love her.

I hate CDH, but I want everyone to know what it is. Ayla's story isn't unique and, even though she went through so much suffering, hers is considered a success.

Written by Ayla's mother, Lindsey Cebelieu





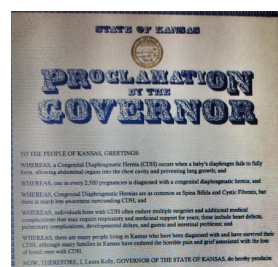
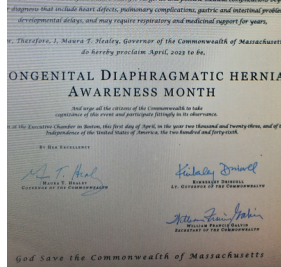
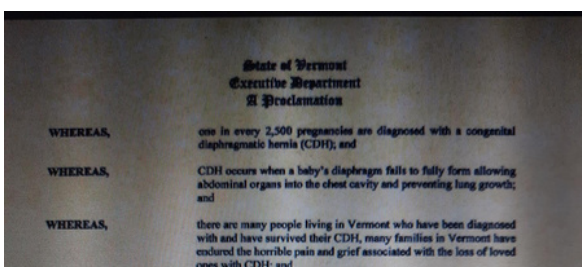
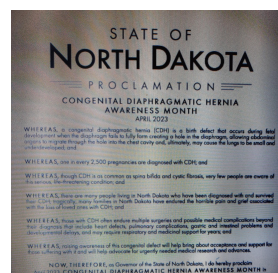
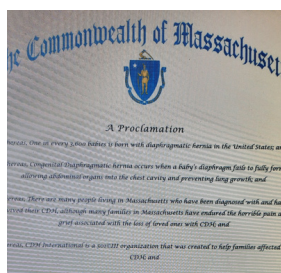
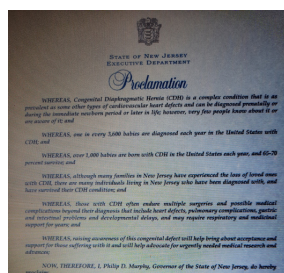
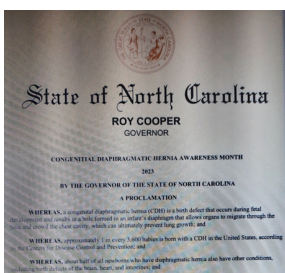
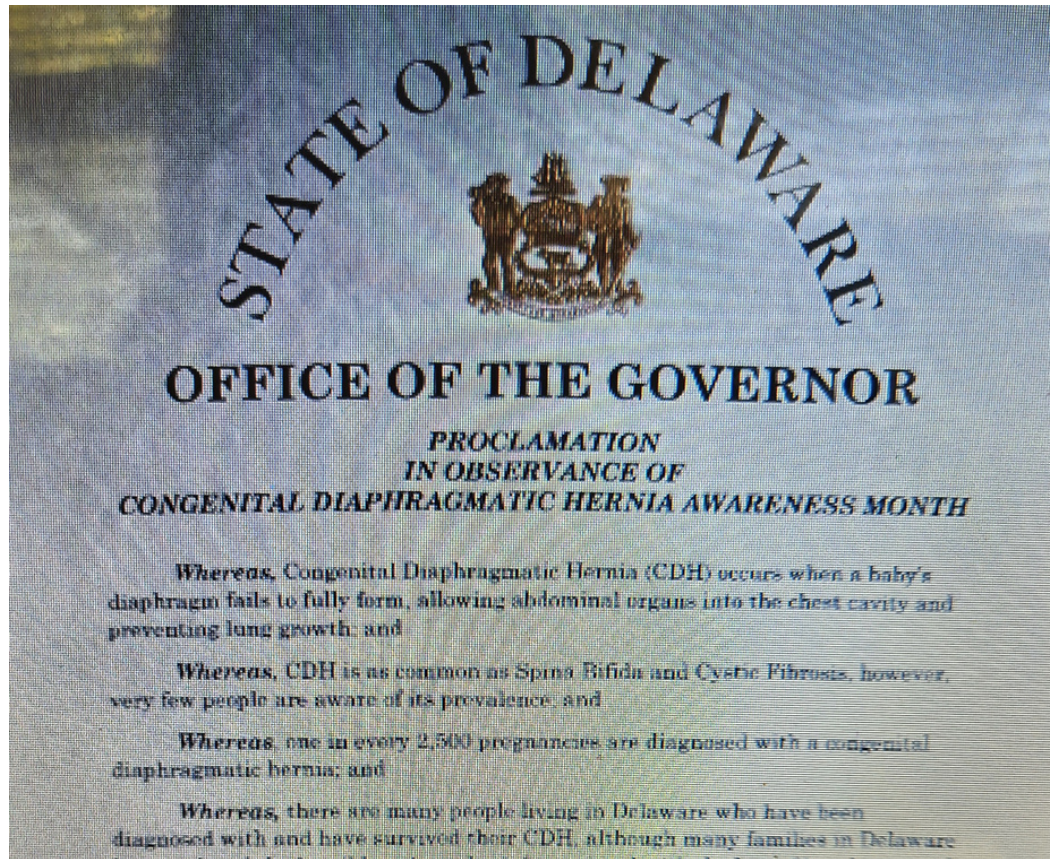
CDH AWARENESS MONTH

2023 CDH PROCLAMATIONS

Mellissa Reaves, Director of Congenital Diaphragmatic Hernia Awareness

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

- Delaware
- Georgia
- Hawaii
- Idaho
- Illinois
- Kansas
- Louisiana
- Massachusetts
- Nebraska
- New Jersey
- New Mexico
- North Dakota
- North Carolina
- Oklahoma
- South Carolina
- Tennessee
- Texas
- Vermont
- Virginia
- West Virginia
- Wisconsin
- Wyoming

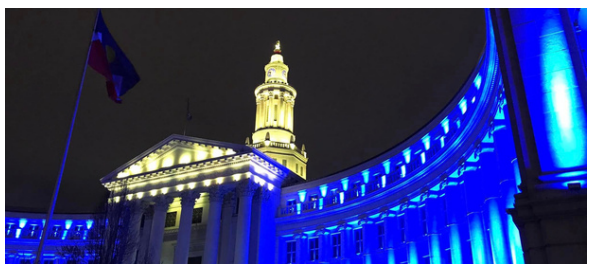
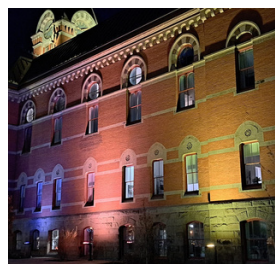
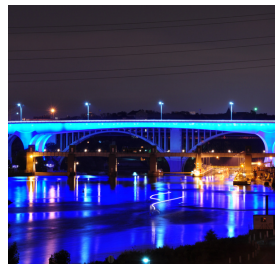
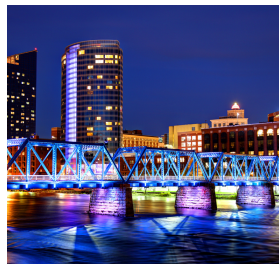
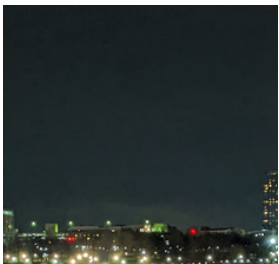
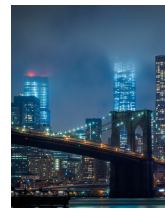
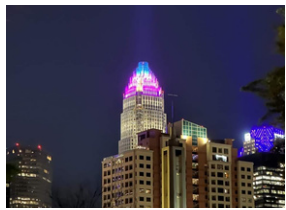
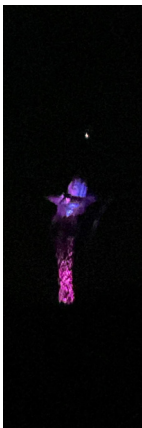
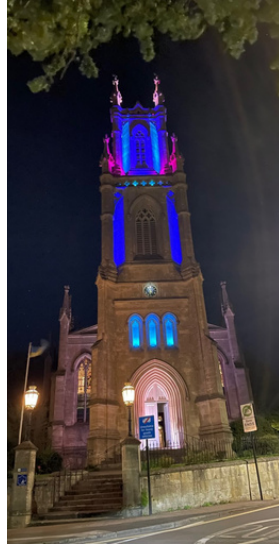




# cdh awareness light-ups

JENNIFER DOOLAN, GLOBAL DIRECTOR OF CDH AWARENESS LIGHT UPS

THESE FOLLOWING LANDMARKS LIGHT UP IN HONOR OF CDH AWARENESS DAY, APRIL 19, 2023.



# KATIE EDIC

## CDH SURVIVOR, UNITED STATES



Hi, my name is Katie Edic and I am a 36-year-old right-side CDH survivor.

Born in March of 1983, I was given 9-1 odds against survival past a few days. I was undiagnosed before birth and ECMO wasn't a common method yet. Therefore, I was life-flighted from my small community hospital to Omaha Medical Center where I underwent multiple correction surgeries. During the first surgery, it was discovered that there was enough lung tissue on the right side of the chest to allow a tiny lung to begin growing and made a patch using my own tissue for the diaphragm repair. I remained in critical condition for 2 ½ weeks after the operations and my parents were allowed to hold me for the first time after three weeks post-delivery. I left Omaha Medical Center 8 weeks later without feeding tubes or oxygen.

At the age of 4, I re-herniated and underwent my second repair surgery using Dacron for the diaphragm patch and also underwent a pectus excavatum to repair my sunken chest cavity. As a child living with CDH, my childhood and adolescent was heavily saturated with specialists, doctor's appointments, tests and x-rays. I developed asthma and scoliosis, but opted out of surgical repair. But this medical community became like family and I realized that everyone wanted to see me thrive, not just survive.

So, I played sports in junior high and high school. I ran track, played soccer, danced and tried out for most athletic style events. I have two older brothers that I loved keeping up with and they never treated me any different. I attended college, where I met and fell in love with my husband Shane. We are BLESSED to have one biological daughter, Addison, who is 11 years old and born without CDH related complications and two HEALTHY lungs!

At the age of 30, I was diagnosed with a horrible re-herniation. I had my third repair surgery using Gore-Tex for the diaphragm repair at Phoenix Children's Hospital by the best CDH team I could have ever hoped for. After a very long surgery, and 11 days in recovery at PCH, I was released with no restrictions and now maintain annual appointments with my surgeon.

My faith has been my rock through the continuation of my story. I feel blessed to live a life full of adventure and happiness. And although the threat of re-herniation and future complications is real, I have never let this disease hold me back. I am honored to be a part of this community!

Written by Katie Edic, CDH survivor (United States)

*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>





# MAY 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.  
[www.cdhrace.org](http://www.cdhrace.org)



# MAY MURDER MYSTERIES



### Hold an EASY Murder Mystery Night Fundraiser!

Dubious Mysteries, Inc has generously donated all game costs and a discounted price to CDH International. You can choose from 3 different murder mystery themes:

- The Roaring 1920's
- The Old West
- The 1980's

Each game can have between 5 and 20 players with an unlimited number of spectators.

Each player has a role, suggested clothing, and no one knows who the murderer is until the night of the event.

You can hold the event at home, at a venue, and even at dinner. The photos below are at a potluck dinner held at a venue owned by a former Board Member, and there were 15 players.

[FIND THE GAMES HERE.](#)

For \$10, you receive a downloadable zip file that includes:

- Game Instructions
- 20 Player Sheets
- Questions
- Murder Evidence Files
- Invitations
- Certificates (Best Dressed, Best Ad Lib, Best Accent, Murderer)
- It's easy, simple and FUN! And all for a great cause!





# CDH RAFFLE FOR RESEARCH WINNER

CONGRATULATIONS, TINA INGHAM!

TINA HAS WON OUR 50/50 RAFFLE FOR RESEARCH WITH A PRIZE OF \$1,570.50!



## LINDSEY'S FUNDRAISER



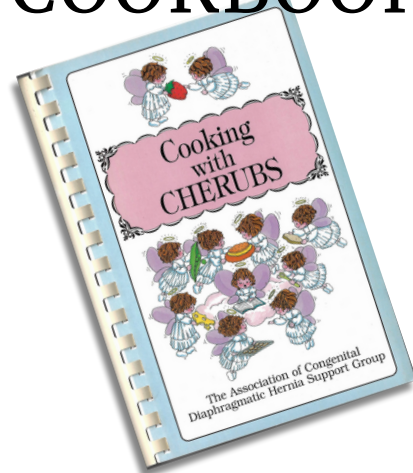
Shout out to CDH survivor, Lindsey Green, for raising almost \$300 with her snow cone stand!

Lindsey has raised money and awareness for CDH many times and even lobbied in Washington DC with CDH International.

Way to go, Lindsey!



# "COOKING WITH CHERUBS VOL. III" COOKBOOK



It's been almost 20 years since our last cookbook so we are doing it again. Thank you to everyone who submitted recipes!

The cookbook will be published by September, 2023.

Last-minute submissions are accepted on contingency if there is room in the book.

[Submit your recipes here](#)





2023

# CDH Telethon

*\$10,000 raised despite Facebook platform crash*

Just hours into April 19th, Facebook's fundraising platform crashed for every charity, and the cost of our fundraising efforts for April went crashing. While CDH International usually raises about \$75,000 around April each year, this year, our best efforts could not compete with software issues and a lousy economy.

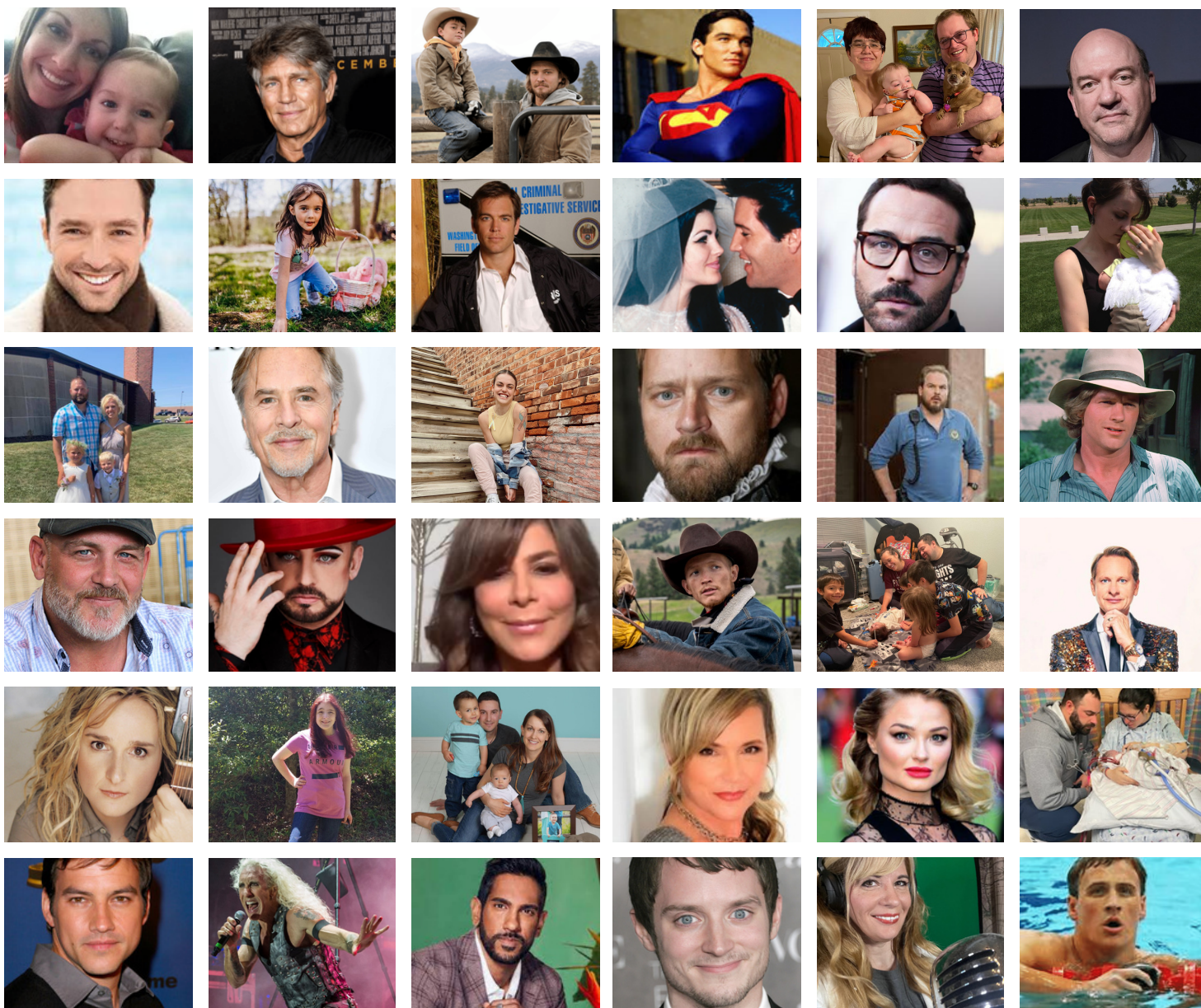
But we march on! And we invite you all to help us to continue to help these children by donating and fundraising at [www.cdhi.org](http://www.cdhi.org)

A huge thank you to every CDHi family and friend who fundraised, donated, purchased raffle tickets and ribbons, and participated in this year's April CDH Race for Research. We are incredibly grateful to the families and celebrities who participated in this year's end. Here are a few:



## 2023 CDH AWARENESS RIBBON FUNDRAISER CONTEST

It was a very close contest, but the most money raised and ribbons earned were purchased in memory of **Juniper Alanna Doolan-Hamilton!**





# HARLIE RANEE GRAY

CDH ANGEL, UNITED STATES



Hello, my name is Megan Gray. My daughter is a CDH angel, and this is our story. My daughter, Harlie Ranee Gray is a twin and has a surviving sister, Lilian Ruth Gray, who we call Lillie. At my 19-week anatomy scan I was already considered high-risk due to the twin pregnancy. At the appointment with my mother and friend by my side we learned that baby B had a hole in the left side of her diaphragm and her stomach was into her chest making her heart go to the right. Two days later I returned to Akron Children's Hospital in Boardman, Ohio for a fetal MRI and a fetal echo to confirm the diagnosis. The results were the same, left-sided Congenital Diaphragmatic Hernia. Over the next few weeks, I looked up information on it even after being told not to. It was like a world of emotions come crashing down. Here I am 28 years old going thru my pregnancy without a partner and now learning that one of my babies is sick. There were so many emotions but looking back on it now the worst was the fear. The fear of not knowing what was going to happen to one of my babies, the fear of how I was going to care for a sick child and fear because as a mother I am supposed to protect my children and here I was not being able to keep something bad from happening to Harlie. When we met our team at Akron Children's main campus in Akron we learned that Harlie's chances were less than we had hoped. She only has 25% lung volume. Only ¼ of her lungs were what they should be. Her heart was good (just not where it should have been) and the vessels to the lungs were intact but one was compromised. We also learned that miraculously her liver was not in her chest like it was originally thought. Harlie was always the dramatic twin. She had to be full of fire after all she was going to have the fight of her life when she would be born. During sonograms, she would have her hand on her head or be resting her feet on her sister's head since they laid opposite. One time even during a sonogram that my dad got to see, when looking at Lillie's head you could see Harlie's feet kicking her sister. I thought to myself, "man I am going to have my hands full with these girls!" The following weeks went by fast but also slow. Doctors' appointments, planning for babies and a baby shower. The beginning of October 2018 I believed I had a UTI. Fast forward to October 20, 2018 I had my baby shower celebrating my girls at almost 28 weeks pregnant. On Tuesday the 23rd I had my 28 week check-up with my local OBGYN and my care was being transferred to Akron the following Monday. I was having cramping that was believed to be Braxton Hicks. A hospital visit that evening due to severe contraction cramping all day I was told it was Braxton Hicks and was dehydrated and sent home. Between 11 and 11:30 the morning of October 24, 2018, I was rushed by ambulance to the birthing unit at our local hospital. At the time I did not know which of my daughter's limb had broken thru my cervix but I felt ridges after a severe contraction. Upon arrival to the hospital we learned that baby B, which was Harlie, foot had broken thru my un-dilated cervix! Pittsburgh Children's Hospital life flight was called in and I was put under for emergency surgery. Harlie became Baby A born first with her sister a minute later. One thing about my girls is my entire pregnancy Lillie was vertex while Harlie was breech. In the last few minutes before they were born Lillie flipped and I truly believe that was because they knew what was happening. Harlie was born alive and fighting and fought thru 3 intubations, 10 rounds of epinephrin, and CPR. She also had a collapsed left lung and her right lung developed a pneumothorax. Unfortunately, after 2 hours and 17 minutes she passed away with her final heartbeat while I held her. I believe that my daughter was meant to save me. I had developed chorioamnionitis and Harlie took the impact of the infection. If it were not for her giving me those signs of something being wrong something worse could have happened. While my girls are both miracles, Harlie is our savior. She saved her sister's life, and she saved mine. We may not be here to tell her story if it were not for her. CDH may have stolen my baby but it didn't steal her story and her sister and I are here to tell about it. Tell about her, our perfect angel who fought as hard and as much as her little 2lb 4oz body could. Harlie Ranee Gray lives forever in my families lives!

Written by Harlie's mother, Megan Gray (United States)





CDH INTERNATIONAL FUNDRAISERS

FACEBOOK FUNDRAISERS

- In Memory of My Sylous, Fundraiser for CDHi
- Ian's Birthday Fundraiser for CDHi
- Melissa's Birthday Fundraiser for CDHi in Honor of Kieran
- 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
- Tricia and Cadenne's Fundraiser for CDHi in Honor of Cadenne
- Danae's Fundraiser in Memory of Jade Skye Perkins
- Jill and Ben's April Fundraiser for CDHi
- Cassie's Fundraiser for CDHi in Honor of Graham
- Mellissa's Fundraiser for CDHi in Honor of Allison
- Cristal's Fundraiser for CDHi in Honor of Christopher
- Gloria's Birthday Fundraiser for CDHi
- Kelsey's Fundraiser for CDHi in Memory of Thomas
- AnneMarie's Birthday Fundraiser for CDHi in Memory of Milo
- Karen's Birthday Fundraiser for CDHi
- Milinda's Fundraiser for CDHi in Honor of Bryer
- Janice's Birthday Fundraiser for CDHi in Honor of Aiden
- Olympia's Birthday Fundraiser for CDHi
- Kelly's Birthday Fundraiser for CDHi in Memory of Grandson Kayden
- Tristan's Birthday Fundraiser for CDHi
- Curt's Fundraiser for CDHi

FACEBOOK FUNDRAISERS

- Austin's Birthday Fundraiser for CDHi
- Anesha's Birthday Fundraiser for CDHi
- Terri's Birthday Fundraiser for CDHi in Honor of Abigail
- Tammy's Birthday Fundraiser for CDHi
- Cherie's Fundraiser for CDHi in Memory of Lily
- Donette's Fundraiser for CDHi in Honor of Kimmy and Nevaeh
- Sharon's Birthday Fundraiser for CDHi in Honor of Oona
- Jena's Birthday Fundraiser for CDHi in Honor of Carter
- In Loving Memory of Randen Steklasa, Fundraiser for CDHi
- Wanda's Birthday Fundraiser for CDHi in Honor of Courtney
- Tasha's Birthday Fundraiser for CDHi in Memory of Luna
- Kay's Birthday Fundraiser for CDHi in Honor of Kaylani
- Danielle L.'s Birthday Fundraiser for CDHi in Honor of Vera
- Beth's Birthday Fundraiser for CDHi
- Don's Fundraiser for CDHi in Memory of Makenzee
- Misty's Birthday Fundraiser for CDHi in Memory of Dylan
- Amanda's Birthday Fundraiser for CDHi in Memory of Hunter
- Adam's Birthday Fundraiser for CDHi
- Joycelen's Birthday Fundraiser for CDHi for Baby Girl Due in July



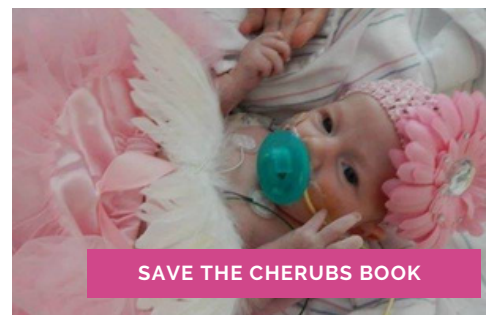
CDH COOKBOOK



MURDER MYSTERY MAY



CDH AWARENESS SHOP



SAVE THE CHERUBS BOOK



GET YOUR SHINE ON GOLF TOURNAMENT



RACE FOR RESEARCH





# Congenital Diaphragmatic Hernia Standard of Care

Every year 52,000 babies are born with Congenital Diaphragmatic Hernia (CDH). In addition, 100,000's survivors struggle with medical problems. Too often, these patients do not have access to experienced medical care.

Rather than focusing on a few hospitals that can provide adequate care, we implore the medical world to give all these patients access to care regardless of where they are born, where they can afford to travel to, and what age they are.

Because every child deserves a chance to grow up and grow old.

Please consider signing this petition to support the best possible medical care for all of these patients, along with the over 2500 people who have supported this effort in the first month.

<https://www.change.org/CDH-Standard-of-Care>

Congenital Diaphragmatic Hernia (CDH) is a congenital anomaly that occurs when a baby's diaphragm fails to form fully, allowing abdominal organs to enter the chest cavity and prevent lung growth.

1 in every 2500 babies is born with CDH. The cause is unknown.

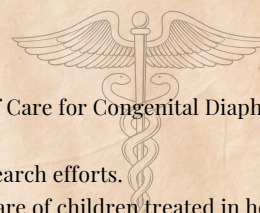
Babies born with CDH undergo complicated surgeries and extended hospital stays. In Higher-Income-Countries, the survival rate is approximately 50 to 80%. In Lower-to-Middle-Income-Countries, the survival rate is less than 1%.

Though a few countries have a Standard of Care for Congenital Diaphragmatic Hernia, most do not, including the United States.

When patients reach adulthood, they are often turned out of appropriate medical care by experienced care providers and left to create their own patchwork care plan.

Congenital Diaphragmatic Hernia treatment has become a \$1 billion annual industry\* with a massive disparity in the amount of research funding (roughly \$5 million) compared to the cost of care.

## The Petition



We hereby petition that all stakeholders\*\* collaborate for a minimum global Standard of Care for Congenital Diaphragmatic Hernia with goals to:

1. Create Standard Measurements of Mortality and Morbidity to aid and accelerate research efforts.
2. Outline care of Congenital Diaphragmatic Hernia as a guideline for the emergency care of children treated in hospitals and/or by physicians without CDH experience, with an emphasis on helping those not diagnosed until birth and those born in Lower to Middle-Income Countries.
3. Raise the level of care in all hospitals that can treat patients with Congenital Diaphragmatic Hernia to make it accessible so that patient families can stay closer to their homes, jobs, other children and support systems.
4. Set standards for patient Individual Education Plans (IEPs) so that patients will have better access to therapies and medications.
5. Set standards for insurance coverage for all medical care involving Congenital Diaphragmatic Hernia patients during their entire lifetimes so that these patients do not lose access to experienced care when they age out of pediatrics or access to needed medications when they pass age markers set for healthy children.

We hereby declare that said Standard of Care for Congenital Diaphragmatic Hernia should not:

1. Overrule any Standards already established in specific countries or continents.
2. Inhibit any research efforts or collaborations.
3. Hinder medical care in any way.

For the acceleration of research, we also highly encourage global collaboration of all stakeholders in that:

1. All hospitals that treat Congenital Diaphragmatic Hernia participate in the CDH Research Study database.
2. All patients participate in the CDH Patient Registry.
3. All patients and hospitals participate in the DHREAMS/CARES for Kids genetic registry.

Signed,

The survivors, family members, friends, medical care providers, and all those who wish to participate in stopping the monster, Congenital Diaphragmatic Hernia, as soon as possible.

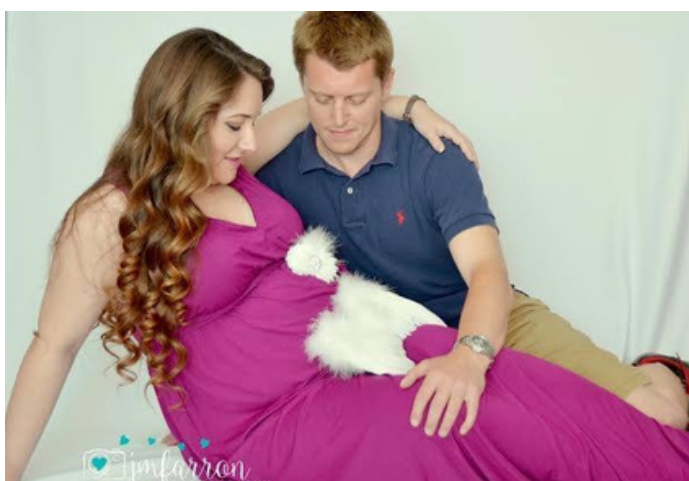
\*\*\*\*\*

\*\*The mean cost per patient ranged from \$86,742 to \$331,893, depending on the severity of the CDH, with an estimated total annual cost of \$1.1 BILLION in the United States." - Basta, M. N., Harrison, W., Schulert, G. S., & Wagner, A. J. (2020). Economic burden of hospitalizations for congenital diaphragmatic hernia in the United States. *Journal of Pediatric Surgery*, 55(7), 1268-1274

\*\* Stakeholders are those who have a vested interest in the care of these children; patients, families, caregivers, pediatric surgeons, nurses, hospitals, other physicians, organizations, etc

\*\*\* This petition created for the better medical care of all patients born with Congenital Diaphragmatic Hernia and in the memory of Josh Benson and all those lost to CDH.





# THE QUEST TO SAVE THE CHERUBS

Photographs by Members of CDHi

CDH International was founded in 1995 under the name "CHERUBS - The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support," and soon CDH patients were lovingly called "cherubs" for the next 20 years.

To raise awareness, members of CDH International have for years worn wings to bring attention to the birth defect.

Now, we are collecting these photos and publishing a coffee table book of photographs of CDH patients in wings, or memorials of those lost.

We expect the book to be available for purchase on Amazon by October 1st.

Are your photos included?

View photos in our Facebook album at <https://www.facebook.com/media/set?vanity=cdhsupport&set=a.584538370367874>

Last minute submissions accepted if room is available, Photos not accepted will be held for a second book in 2025..

[Submit photos here.](#)

Additionally, our President, Dawn Ireland, is publishing a book of her travels with 100's of photos of wings around the world, taken in memory of her son, Shane Torrence.

Proceeds from both books will go to Congenital Diaphragmatic Hernia Research at CDH International.



NEW CDH AWARENESS SHOP ITEMS



**"I WEAR CLOUDS FOR MY BABY" WOMEN'S HOODIE**

Various sizes and colours  
50% cotton/50% polyester  
Soft, plush inside

**\$35.06**



**"I WEAR CLOUDS FOR MY BABY" UNISEX T-SHIRT**

Various sizes and colours  
50% polyester, 25% cotton, 25% rayon  
Light, super smooth fabrics 3.8 oz

**\$27.21**



**RIBBON KID'S FINE JERSEY TEE**

Various sizes and colours  
100% combed, ring-spun cotton  
Light fabric

**\$23.54**



**AROUND THE WORLD TO SAVE THE CHERUBS JIGSAW PUZZLE**

252 precise interlocking pieces  
Pre-diecut chipboard with a satin finish  
White tin with finished image on cover

**\$24.43**



**CDH AWARENESS DAY YARD SIGN**

22" x 15" yard sign  
Metal H-shaped stake for mounting included  
Fluted polypropylene, one sided print

**\$14.37**



**IT'S NOT JUST A HOLE CDH AWARENESS LUMBAR PILLOW**

20" x 14" lumbar pillow  
Double sided print  
100% Polyester cover

**\$20.38**



**CDH SURVIVOR SOFTSTYLE TEE**

Dark chocolate in color  
100% ringspun cotton  
Light Fabric/Classic Fit

**\$19.26**



**CDH WINGS KIDS FINE JERSEY TEE**

Colbalt in color  
100% combed ringspun cotton  
Light Fabric/Classic Fit

**\$26.88**



**CDH BUTTERFLY CDH AWARENESS TODDLER T-SHIRT**

Heliconia in color  
100% Ringspun cotton  
Light Fabric/Classic Fit

**\$24.44**





IT'S ALWAYS A STRUGGLE.  
IT'S AN UPHILL BATTLE THE  
WHOLE TIME. BUT YOU  
KNOW WHAT? THE  
REWARDS ARE SO GREAT, I  
WOULDN'T TRADE IT FOR  
THE WORLD.

JENNIFER LOPEZ



# CDH AWARENESS DAY ON SOCIAL MEDIA

