

THE SILVER LINING

CONGENITAL DIAPHRAGMATIC HERNIA MAGAZINE

**When Families Are Struck by
Congenital Diaphragmatic
Hernia More Than Once**

Trauma and Research

Lobbying for CDH Research

Post-Pandemic Efforts on The Hill

**Global Research Alliance
for Congenital Anomalies
(GRACA)**

Groundbreaking Research For
Millions of Children

CDH Research Task Force

Helping Adult CDH Survivors

The Latest CDH Research News

What's new in the research world?

THE VOICE OF CONGENITAL DIAPHRAGMATIC HERNIA PATIENTS



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Share Your Story

Is your cherub a twin, triplet, or other multiple? Our August issue will feature CDH in multiples. Please submit your story by July 20th.

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

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

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

CDH INTERNATIONAL NGOS >

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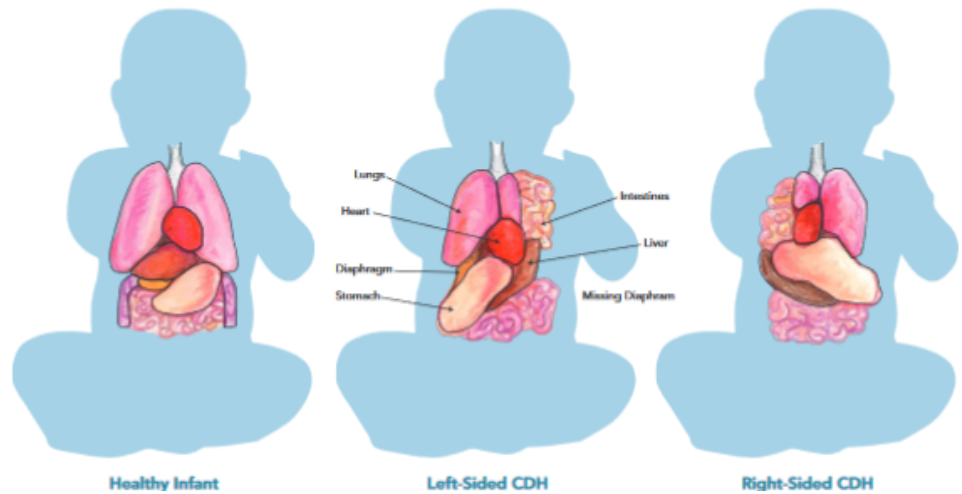


MISSION STATEMENT >

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 >



"Do not judge me by my success, judge me by how many times I fell down and got back up again." - Nelson Mandela



July 2023

SUN	MON	TUE	WED	THU	FRI	SAT
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30						

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CDHi Executive Board of Directors

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



CDH INTERNATIONAL

JULY BIRTHDAYS & ANGELVERSARIES

- Birthday of Zoie Katrina Abel
- Birthday of Zakaree Ugene Needham
- Birthday of Zachary Lane Pittman
- Birthday of Zachary Elias Chapman
- Birthday of Wyatt Xavier Brockman
- Birthday of Wyatt Joseph Forte
- Birthday of Wyatt James Davis
- Birthday of William Wenceslaus Gillis
- Birthday of William Joseph Kibler
- Birthday of William Gerald Bock
- Birthday of Whitney Haynie
- Birthday of Weston Nicholas Rogers
- Birthday of Vivian Michelle Glennie
- Birthday of Vincent Valentine Strother
- Birthday of Victoria Renee Ware
- Birthday of Valerie O. Funk
- Birthday of Tucker Cross Hinson
- Birthday of Trey Christopher Gill
- Birthday of Thalia Elizabeth Marvin
- Birthday of Teressa Gianna Faustina Diprimio
- Birthday of Taylor Wyckoff
- Birthday of Taylor Louise Hopkins
- Birthday of Suzanne Dani'L Simone
- Birthday of Stratton Clark
- Birthday of Stephen Andrew Tomes
- Birthday of Stella Alaine Berger
- Birthday of Starlite Sky Courchesne
- Birthday of Spencer James Bean
- Birthday of Sophia Anne McFarland Moore
- Birthday of Skylar Lee Maddox
- Birthday of Sheree Helen Beth Pettit
- Birthday of Shelby Lee Smith
- Birthday of Shelbi Sue Ray
- Birthday of Shana Kay Hagood
- Birthday of Scott William Spudich
- Birthday of Scarlett Ray Benitez
- Birthday of Scarlett Grace Engrem
- Birthday of Scarlett Elizabeth McKenzie
- Birthday of Savanna Saige Davidson
- Birthday of Sandra Charlotte Bishop
- Birthday of Samuel Edward Ashby
- Birthday of Samantha Lynn Stewart
- Birthday of Sade Hemmekam
- Birthday of Rosie Mae Denham-Newton
- Birthday of Riley Violet Redman
- Birthday of Riley Joseph Marzolf
- Birthday of Rhys Robert James McMahon
- Birthday of Rhian Tiffany Mclee
- Birthday of Reid Hensley
- Birthday of Rebecca Ann Tharp
- Birthday of Rayline Oli'i
- Birthday of Raylee Ann Cochran
- Birthday of Rannva Fjallstein Dam
- Birthday of Quinn Michael Verdin
- Birthday of Pysmon James Laviola
- Birthday of Poppy Davis
- Birthday of Pietra Agnelli Martinelli
- Birthday of Phoebe Louise Archer
- Birthday of Peter Hernan Montes
- Birthday of Payton Nicole Brenner
- Birthday of Payton Alan Parks
- Birthday of Payden Janelle Black
- Birthday of Patrick R Marshall
- Birthday of Patrick E George
- Birthday of Parker Jason Pierce
- Birthday of Pamela Montzerra Gonzalez-Jimenez
- Birthday of Paizlee Grace Testerman
- Birthday of Osmund Wyatt Kidd-Ward
- Birthday of Oskar Ström
- Birthday of Oscar Steven Wood
- Birthday of Oona Rose Shink
- Birthday of Oliver Wesson
- Birthday of Oliver Oakley McLellan
- Birthday of Oliver Lee Farrugia
- Birthday of Odyn Kade Sexton
- Birthday of Norah Celina Reynolds
- Birthday of Noah Nathaniel Horton
- Birthday of Noah Karev Esparza
- Birthday of Niklas Isaac Egli
- Birthday of Nicolas Raul Custodio
- Birthday of Nicholas G. Nelson
- Birthday of Nia Sherin
- Birthday of Neah Perkins
- Birthday of Naomi Irene Hiishch'I Nagurski
- Birthday of Myles Mututo
- Birthday of Moriah Grace Blackburn
- Birthday of Morgah Margaret Nuchols
- Birthday of Molly Axtell
- Birthday of Milo Hale Mahoney
- Birthday of Miles Whalen Lloyd Chamberlain
- Birthday of Milas James Covington
- Birthday of Mila Violet Puraci (Cosa)
- Birthday of Mila Shick
- Birthday of Mieke Louise Bekker
- Birthday of Michael Patrick Lee
- Birthday of Michael Glenn Haase
- Birthday of Melissa Marie Beck
- Birthday of Melanie Hope Nuthals
- Birthday of Megan Noble
- Birthday of Mayzie Kendaleyah Marie Blevins
- Birthday of Maxwell Airington Gonzales
- Birthday of Matthew Joseph Swartout
- Birthday of Matthew Angel Guzman
- Birthday of Mason Robert Young
- Birthday of Marlene Ann Claman
- Birthday of Mariah Hope Haveman
- Birthday of Maria Lynn Mascary
- Birthday of Maria Jean Dahl
- Birthday of Maria Elizabeth Redfoot
- Birthday of Margret Faith McSwain
- Birthday of Marco Ariell Cantu
- Birthday of Maliyah Lee Gomes
- Birthday of Malani Turner
- Birthday of Malaiya Annabelle Galeas
- Birthday of Makenzie Magallanes
- Birthday of Maisie Odele Lawson
- Birthday of Maia Christine McCabe
- Birthday of Magdalena Emilia Wassner
- Birthday of Madison Lynne Rhees
- Birthday of Lucie Rose Henderson
- Birthday of Lucas Gabriel Sweet
- Birthday of Lucas Adrian Blitger
- Birthday of Louise Kay Savage
- Birthday of Loghan Angelica Mark
- Birthday of Logan Jason Gilleland
- Birthday of Logan James Campbell
- Birthday of Lily Helena Golding
- Birthday of Liam Carl Pohlman
- Birthday of Liam Allen George Walker
- Birthday of Lexi Wheatley
- Birthday of Levi John
- Birthday of Leonidas Eddy
- Birthday of Leo Emmanuel Hernandez
- Birthday of Leilani Marie Nisperos
- Birthday of Layla Mae Zoltek
- Birthday of Lauryn Sofia White
- Birthday of Laura Grace Salesky
- Birthday of Larisa Anique Apodaca
- Birthday of Landon Free
- Birthday of Kyzer Lane Kent
- Birthday of Kynlee Bree Bowlin
- Birthday of Kyler Matthew Hart Testerman
- Birthday of Kristen Brooke Wilson
- Birthday of Klaus Michael Dickson
- Birthday of Kiyari Juliet Manriquez
- Birthday of Keyva Marie Roper
- Birthday of Kevan Benjamin Mahendran
- Birthday of Keone Zachary McEachern
- Birthday of Kendra Christine Meyer
- Birthday of Kelsie Madison Haymore
- Birthday of Kelly Marie Daley
- Birthday of Kaylee Naomi Van Ede
- Birthday of Kaylee Dawn Harbison
- Birthday of Kayden Ostrousky
- Birthday of Canyon Cooper
- Birthday of Kanarra Faith Franklin
- Birthday of Kaleigh Marie Myers
- Birthday of Kaden Michael Brown
- Birthday of Justin M. Stromberg
- Birthday of Justin Dwythe Howard
- Birthday of Justin Cernobyl
- Birthday of Justin Brodie Labudda
- Birthday of Junior Rowe
- Birthday of Juliana Isabella Marin
- Birthday of Julian Matthew Burby
- Birthday of Jude Harper Daff
- Birthday of Judah Daniel Shirah
- Birthday of Josiah Damir McDile
- Birthday of Jordan Amodeo
- Birthday of Jonathan Michael O'Malley
- Birthday of Johnny Eugene Ashley
- Birthday of John Richard Welsh IV
- Birthday of John Blocker
- Birthday of Joe (Joseph) Mathieu Noel
- Birthday of Jeremy Lason Harer
- Birthday of Jennifer Knight
- Birthday of Jaythan B Whitt
- Birthday of Jaydee Aspen Griffith
- Birthday of Jaxon Thomas Rogers
- Birthday of Jasper Eugene Secoy
- Birthday of Jason Hunter Hartman
- Birthday of Jansen Hezekiah Wong Thean Yin
- Birthday of Janessa Opal Margaret Young
- Birthday of James T. III Stauffer
- Birthday of James Ryan Weber
- Birthday of Jalen Griffiths Di-Maio
- Birthday of Jake Lee O'Connor
- Birthday of Jak Thomas Roy Parsons-Forshaw
- Birthday of Jaiden Nunez-Glasgow
- Birthday of Jade Riley Wolfarth
- Birthday of Jacob Thomas Zimmerman
- Birthday of Jacob Andrew Pagliarulo
- Birthday of Jackson Dean Dandurand
- Birthday of Jack Ryan Gillham
- Birthday of Jack Denis Ryan Charles
- Birthday of Jace Bowman
- Birthday of Isaiah Luis Rivera
- Birthday of Isabella Rose B.
- Birthday of Isabella Johnson
- Birthday of Isaac Kenyon Dean
- Birthday of Hunter Scott McClain
- Birthday of Hope Natasha Scott
- Birthday of Honey Evans
- Birthday of Henry Jackson
- Birthday of Henry Christopher Blum
- Birthday of Hayley Caitlin Mills
- Birthday of Hayley C Jarrett
- Birthday of Hayden Michael Zimmerman
- Birthday of Hannah Rae Holland
- Birthday of Gunner Cade Shobe
- Birthday of Graydon Tibbles
- Birthday of Grady Michael Vogel
- Birthday of Gracelyn Danielle Pace
- Birthday of Gracel Erich Della Cruz
- Birthday of Grace Lisa Barry
- Birthday of Giulia Collatuzzo
- Birthday of Gioia Cavazza
- Birthday of Gage Richard Ollerenshaw
- Birthday of Gabriel Reza Kia
- Birthday of Fredrick Vleugels
- Birthday of Frank Zion Sanchez Bulaong
- Birthday of Faith Ellen Wesner
- Birthday of Evie Kornegay
- Birthday of Evelyn Sophia Wallis
- Birthday of Evelyn Layne D'Onofrio
- Birthday of Eva Mariana Rincon Garcia
- Birthday of Ethan Michael Millet
- Birthday of Ethan Donnelly Schmol



CDH INTERNATIONAL

JULY BIRTHDAYS & ANGELVERSARIES

- Birthday of Erik Benson Weber
- Birthday of Emma Rae Williams
- Birthday of Emma Louise Van Cant
- Birthday of Emma Gallagher
- Birthday of Emma Ballard
- Birthday of Emily Flowers
- Birthday of Emily Clarissa Hayes
- Birthday of Emil Knudsen
- Birthday of Emerson Harleigh Horne
- Birthday of Emerson Edwyn James Meek
- Birthday of Emeli Holmberg
- Birthday of Elli Mills-Mair
- Birthday of Ella Renae West
- Birthday of Ella Jerlid
- Birthday of Eline Ianke-Ulriksen
- Birthday of Elijah James VanDeventer
- Birthday of Eli Emmanuel Hsu
- Birthday of Eleanor Grace Weldy
- Birthday of Dylan Richard Forsythe
- Birthday of Dylan Reed Jasmin
- Birthday of Dylan Dean Hoffman
- Birthday of Drew Benjamin Moscona
- Birthday of Dominic Joseph Reitz
- Birthday of Devon Dean Stevenson
- Birthday of Dennis Van Der Mark
- Birthday of Demetri Manuel Silva
- Birthday of David Hunter
- Birthday of Darren A. W. Honsinger
- Birthday of Darci Mae Mountain
- Birthday of Danielle Nicole Swank
- Birthday of Danielle Fastert
- Birthday of Daniel Ben Frankli
- Birthday of Dane Michael Christensen
- Birthday of Dallas Aiden Kislow
- Birthday of Daisy Stevenson
- Birthday of D. Vishva Balaji
- Birthday of Cylas August Hominger
- Birthday of Crystal Geren
- Birthday of Courtney Grace Wallace
- Birthday of Courtney Marie Young
- Birthday of Colton Wayne Milligan
- Birthday of Colten Saylor
- Birthday of Colten Regier
- Birthday of Collin Scott-Patrick Hendricks
- Birthday of Cohen Matthew D'Elia
- Birthday of Claire Elise Stenlund
- Birthday of Christopher Michael Boren
- Birthday of Christopher David Hall
- Birthday of Christian Paulsen
- Birthday of Christian John Thompson
- Birthday of Chloe Olivia Mitchell-Greenfield
- Birthday of Cheyanne Marie Parker
- Birthday of Chelsea Scott Leeds
- Birthday of Charley Incerto
- Birthday of Charis Ivey Schemm
- Birthday of Chaia D'Lynn Boyett
- Birthday of Cayden Fletcher
- Birthday of Catalaya Mimi-Reign Caceres
- Birthday of Cason Micah Williams
- Birthday of Carys Amber Lamb
- Birthday of Carter Patrick Alexander Calhoun
- Birthday of Caroline McGill
- Birthday of Carly Elizabeth Stark
- Birthday of Cameron Paul Goldbach
- Birthday of Callan James Redding
- Birthday of Cali Summer Lizarraga
- Birthday of Caleb Sims
- Birthday of Caleb Joshua Sanchez Tenorio
- Birthday of Cailynn Nicole Gdowski
- Birthday of Cade Michael Thompson
- Birthday of C. Douglas Bernstein
- Birthday of Bryson William Woodruff
- Birthday of Brycen Noah Spivey
- Birthday of Brooke Robin Sroka
- Birthday of Brooke Beecham
- Birthday of Brody Eugene Williams
- Birthday of Brittany Cathleen Shiits
- Birthday of Brayden Bull
- Birthday of Brandon O. Toledo
- Birthday of Brandon Lee Sharp Jr
- Birthday of Brandon James Hall
- Birthday of Brandon Blaine Bjella
- Birthday of Brady Wedge
- Birthday of Brady Joseph Campbell
- Birthday of Bradley Wilson
- Birthday of Blake Asher Wyatt
- Birthday of Bethney Reed
- Birthday of Bentley Alexander Lawry
- Birthday of Benjamin Joseph Broom
- Birthday of Benjamin Azariah Smith
- Birthday of Beckett Logan Goll
- Birthday of Azalie Crain
- Birthday of Avery Mae Keirseay
- Birthday of Averi Rose Wilkins
- Birthday of Autumn Brianna Climer
- Birthday of Austin Bradley Johnson
- Birthday of Athena Heap
- Birthday of Ashley M McGee
- Birthday of Ashley Lauren Siegfried
- Birthday of Asher Joel Carlson
- Birthday of Asher James Youde
- Birthday of Asher James Switzer-McCoy
- Birthday of Arabella Kogut
- Birthday of Anya Katherine Lock
- Birthday of Anthony Moschilla
- Birthday of Annelise Nicole Hallinan
- Birthday of Andrew Daniel Castle-Hudson
- Birthday of Amelia Coroy
- Birthday of Amanda L. Kubus
- Birthday of Alyssa Nicole Bradshaw
- Birthday of Alondra Martinez
- Birthday of Allyson Keolani Reynolds
- Birthday of Alfonso Guarilar
- Birthday of Alexis S. Lawson
- Birthday of Alexandra Goggins
- Birthday of Alannah Marie Trickett
- Birthday of Al Anthony Guarisco
- Birthday of Aiden James Reed
- Birthday of Aiden Derrick Plaisted
- Birthday of Aidan Christopher Hepworth
- Birthday of Adrian Alex Ryzak
- Birthday of Adeline Acerno
- Birthday of Abrianna Roxanne Zajac
- Birthday of Abigail Marie Kaczrouse
- Birthday of Abigail Elizabeth Garza
- Birthday of Abel Edward William Helmer
- Birthday of Aaron G. Younce
- Birthday of Aaden Zinedine Zagaris
- Angelversary of Zedekiah Christopher Bagwell
- Angelversary of Zachary Lane Pittman
- Angelversary of Zachary Elias Chapman
- Angelversary of William Wenceslaus Gillis
- Angelversary of Tucker Cross Hinson
- Angelversary of Travis Lee Fenn
- Angelversary of Thalia Elizabeth Marvin
- Angelversary of Shelby Marie Nunes
- Angelversary of Shelby Lee Smith
- Angelversary of Shelbi Sue Ray
- Angelversary of Seth Keaton Van Dyke
- Angelversary of Serena Grace Brent
- Angelversary of Scarlett Emilie Bailey
- Angelversary of Sarah Ann McMerriman
- Angelversary of Samantha D. Johnson
- Angelversary of Rhys Robert James McMahon
- Angelversary of Remy Brian Mossman
- Angelversary of Rachel Elizabeth Murphy
- Angelversary of Quinn Michael Verdini
- Angelversary of Pietra Agnelli Martinelli
- Angelversary of Payton Rose Shoemaker
- Angelversary of Paizlee Grayce Pittman
- Angelversary of Paige LeighAnn Davis
- Angelversary of Osmund Wyatt Kidd-Ward
- Angelversary of Oscar Steven Wood
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- Angelversary of Masingita Nyiko Mabasa
- Angelversary of Margret Faith McSwain
- Angelversary of Magdalena Emilia Wassner
- Angelversary of Luke Joseph Thomas
- Angelversary of Luca Belo Narvaez
- Angelversary of Logan James Campbell
- Angelversary of Logan Gavin Miranda
- Angelversary of Lexi Wheatley
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- Angelversary of Joshua T. Portner
- Angelversary of Jorge Samuel Sales Rodriguez
- Angelversary of Jesse Wright Lamkey
- Angelversary of Janessa Opal Margaret Young
- Angelversary of Jade Riley Wolfarth
- Angelversary of Jack Denis Ryan Charles
- Angelversary of Isaiah Cain Prater
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- Angelversary of Gage Richard Ollerenshaw
- Angelversary of Gage Jonathan Manes
- Angelversary of Eunice Emily Banda
- Angelversary of Ethan Michael Huizenga
- Angelversary of Emma Ballard
- Angelversary of Emil Knudsen
- Angelversary of Emarosa Concepcion Lomas-Diaz
- Angelversary of Elli Mills-Mair
- Angelversary of Eli Michael Krejci
- Angelversary of Dylan Dean Hoffman
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- Angelversary of Daniel Josef Hinojosa-Belyakovich
- Angelversary of Daisy Stevenson
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- Angelversary of Chloe Olivia Mitchell-Greenfield
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- Angelversary of Carys Amber Lamb
- Angelversary of Carson James Goodmote
- Angelversary of Callan James Redding
- Angelversary of Caleb Sims
- Angelversary of Brody Eugene Williams
- Angelversary of Brendon John Hart
- Angelversary of Brendan Isaiah Grayson
- Angelversary of Brady Joseph Campbell
- Angelversary of Benjamin Joseph Broom
- Angelversary of Austin Bradley Johnson
- Angelversary of Ashley Lauren Siegfried
- Angelversary of Asher James Switzer-McCoy
- Angelversary of Anthony Michael Pompeo
- Angelversary of Andrew Lee Whitten
- Angelversary of Andrew Daniel Castle-Hudson
- Angelversary of Amanda L. Kubus
- Angelversary of Aiden Robert Grant
- Angelversary of Aiden Derrick Plaisted
- Angelversary of Adam Salas
- Angelversary of Abel Edward William Helmer
- Angelversary of Aaden Zinedine Zagaris



Editor's Note

CDH Research Opportunities Grow



Dear Members and Friends,

The summer has been very busy so far, especially in our CDH Research Department.

We are extremely proud and excited about our recent publications, accepted abstracts, and the growth of GRACA, as you will read about in this issue of the CDH Magazine.

We have welcomed new volunteers that you will meet over the next few months, hope to bring back some patient support services, and continue to raise awareness around the world.

Our team is still small and we are in need of more volunteers and funding. This summer, we welcome you to join the group of people actively fighting Congenital Diaphragmatic Hernia on a global level for all the children by volunteering, donating, or holding a fundraiser for CDH International.

CDH International continues our many research projects with universities, labs, other patient communities, and government agencies, we have to be able fund the work.

What better way for you to get involved and to fight the CDH monster than to support such a massive undertaking as the GRACA collaboration? We have waited 30 years for the opportunity to DO something to help these children directly and not wait on others to do it for them. I am personally so determined and happy to be able to do something so tangible in memory of my own son lost to CDH - I invite you to do so as well in honor or in memory of someone you love born with CDH.

As you read through this issue, please pause for a moment and remember where we came from - nothing. CDH International is a truly grassroots organization founded by and run by moms, dads, grandparents and patients. Who would've guessed that we could have done all of this together? It makes me so proud. It should make you proud as well.

As always, thank you for your support of these children and CDH International; the world's oldest, largest, and leading Congenital Diaphragmatic Hernia charity.

Very Sincerely,
DAWN M. TORRENCE IRELAND
President & Founder



CDH International Patient Advocacy Board

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



KIMBERLY PASS

CDH SURVIVOR, UNITED STATES

MOTHER



My name is Kimmy Pass and I am 24.

I was born February 2nd 1999 at the University of Utah Hospital.

My mom found out about my CDH two weeks before I was born. I spent about 5 weeks in the NICU at Primary Children's Hospital before going home.

I went into heart failure at 6 months old due to my pulmonary hypertension. When I was 5 I had my atrial septal defect closed.

I have been on oxygen my entire life, except for during the day in high school and a couple of years after graduation.

About a year after being off of my oxygen all of the time I started having syncopal episodes and chest pain, with increased work of breathing. I was misdiagnosed with COPD, then eventually I was diagnosed again with pulmonary hypertension.

Fast forward to getting married and having my daughter.

I was married in 2019 and I found out I was expecting my first baby in the end of May 2020.

At first we were really worried about how my body would handle pregnancy. Would I reherniate? Would I struggle even more to breathe? Would it be too much stress on my heart?

Those worries soon felt like nothing when I heard the words, "what do you think, left or right?" on an early anatomy scan.

I instantly knew what that meant and my heart dropped.

It was at the peak of the COVID-19 pandemic so I was alone in that room when I heard those words. Suddenly, I knew how my mom had felt.

She was alone in that as well as a single mom. My grandma raised me as my mom was young when she had me and I was so sick. Both have always been in my life but I always thought they were dramatic when they would tell my story. CDH was my normal but to them it was their nightmare.

My husband sat in the car outside as no visitors were allowed. I didn't know how to tell him, so first I called my mom. I said, "mom, my baby has CDH." I remember her just crying.

Going through CDH as a patient was one thing. It was all I knew. Going through it as a parent has been much more difficult, and now I understand my moms constant worry.

MOTHER



NEVAEH PASS

CDH SURVIVOR, UNITED STATES

DAUGHTER



Now this brings us to my daughter's story. Her name is Nevaeh Pass and she is now 2 and a half years old. Nevaeh was born on January 5th, 2021.

Her diagnosis was severe LCDH with coarctation of the aorta and possible Hypoplastic Left Heart Syndrome. If she did have HLHS and Coarc of the aorta along with her extreme case of CDH, her survival rate was 1% and they would offer no interventions.

Luckily when she was born they found that it was just CDH, with a slightly hypoplastic aorta and of course tiny lungs. She was also born premature and weighed only 3 pounds. Nevaeh was so tiny. She was perfect nonetheless.

I had a placental abruption and had to be put under general anesthesia because my epidural failed due to my spinal fusion.

I just knew I would wake up with the news that she didn't make it.

When I woke up the first thing I said was, "is she alive?" then the next was "is she ugly?" with tears just flowing followed by laughter.

I for sure had lost my mind by that point.

Growing up with CDH I never knew the importance of sharing my story, now because of Nevaeh I do. Because of her I share our story every chance I get.

Nevaeh almost died many, many times. The first really scary moment was when she was about a month old. She developed a chylothorax in each lung because her lymphatic system was injured in surgery. She was drowning in her own bodily fluids.

She was so swollen that it was just leaking out of every part of her. She was a 3 pound baby who was 8 pounds because of how swollen she was. She was unrecognizable, gray, and cold. They were going to put her on ECMO but ultimately decided not to because "whatever is going on with her is irreversible and she is just not compatible with life."

She had some amazing nurses looking out for her and advocating for her.

The medical team (most of them) fought hard for her.

She also had a Priesthood Blessing. He blessed her with peace and comfort, no matter what happened. She was blessed with strength and to know that she was loved. The next day, on my birthday. She woke up. She was responsive, pink and warm. To this day, nobody knows how she lived.

I thought that would be the last time I would hear end of life discussion with her but it was not. We had that talk probably on a monthly basis during her time in the NICU. She was so sick, and really it is miraculous that she made it through. She came home at 14 months old for the first time.

She was on a ventilator with a tracheostomy, g-tube, continuous infusion of a medication and meds around the clock. I'm not sure how but we made it through all of that. Nevaeh is the strongest and bravest person I have ever had the pleasure of meeting and I'm proud that she is my daughter.

She is now sprinting off of the ventilator and will be off of it all day in two months. She only gets medications twice a day now. She has come so far. We were told she would never sit unassisted, never breathe on her own and live in a vegetative state her entire life because she spent so long sedated and in bed. She is talking, singing, running and playing with other kids. She loves to ride boats and horses and is always smiling.

The hard times are hard, but the good times are so worth the wait.

DAUGHTER



CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH CDH INTERNATIONAL AT WORK

2023 RESEARCH WORK

It is halfway through the year and we are excited about our momentum. Later this month, we will be presenting our poster "Congenital Diaphragmatic Hernia: Patient Parents As Partners" at this year's Birth Defects Research and Prevention meeting.

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"



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
- 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

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



CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

CDH RESEARCH UPDATES

JASON MILLER, CDHI RESEARCH DEPARTMENT

The Congenital Diaphragmatic Hernia (CDH) Natural History questionnaire aims to explore the prevalence and patterns of CDH, as well as related medical conditions, within patients' family histories. CDH is a congenital condition characterized by the incomplete formation of the diaphragm, leading to abdominal organs protruding into the chest cavity. This questionnaire gathers crucial information regarding the presence of CDH, heart defects, chromosomal anomalies, and other birth defects in various family members. By examining the data collected from this comprehensive questionnaire, researchers and healthcare professionals can gain valuable insights into the potential genetic and environmental factors associated with CDH, contributing to a better understanding of its natural history and potential risk factors.

Congenital Diaphragmatic Hernia (CDH) Family History:

Yes: 250 respondents (58.7%)

No: 162 respondents (38.0%)

Unknown: 14 respondents (3.3%)

Among the respondents with a family history of CDH:

Maternal 1st Cousin: 9 respondents (37.5%)

Maternal Uncle: 5 respondents (20.8%)

Paternal Aunt: 2 respondents (8.3%)

Father, Mother, Paternal Grandfather, Paternal

Grandmother, Maternal Grandfather, Maternal

Grandmother, Maternal Aunt, and Maternal 1st Cousin: 1

respondent each (ranging from 4.2% to 20.8%)

Brother, Sister, Son, Daughter, Paternal Uncle, Paternal

1st Cousin, and Unknown: No reported cases

Chromosomal Anomalies Family History:

Yes: 24 respondents (10.7%)

No: 184 respondents (81.8%)

Unknown: 17 respondents (7.6%)

Among the respondents with a family history of chromosomal anomalies:

Maternal 1st Cousin: 16 respondents (30.8%)

Maternal Aunt: 9 respondents (17.3%)

Maternal Uncle: 6 respondents (11.5%)

Brother: 4 respondents (7.7%)

Paternal Aunt: 4 respondents (7.7%)

Father and Mother: 5 respondents each (9.6%)

Sister: 3 respondents (5.8%)

Paternal Uncle, Paternal 1st Cousin, Maternal Grandfather, and Maternal Grandmother: 2 respondents each (ranging from 3.8% to 7.7%)

Paternal Grandfather and Paternal Grandmother: 1 respondent each (1.9%)

Daughter, Son, and Unknown: No reported cases

Heart Defects Family History:

Yes: 39 respondents (17.3%)

No: 175 respondents (77.8%)

Unknown: 11 respondents (4.9%)

Among the respondents with a family history of heart defects:

Maternal Grandmother: 22 respondents (21.0%)

Maternal Grandfather: 18 respondents (17.1%)

Father: 12 respondents (11.4%)

Mother: 20 respondents (19.0%)

Paternal Grandfather: 13 respondents (12.4%)

Maternal Uncle: 14 respondents (13.3%)

Paternal Uncle: 8 respondents (7.6%)

Maternal Aunt: 10 respondents (9.5%)

Paternal 1st Cousin and Maternal 1st Cousin: 5 respondents each (4.8%)

Brother: 7 respondents (6.7%)

Sister: 5 respondents (4.8%)

Son: 1 respondent (1.0%)

Daughter: No reported cases

Other Birth Defects Family History:

Yes: 40 respondents (17.9%)

No: 169 respondents (75.4%)

Unknown: 15 respondents (6.7%)

Among the respondents with a family history of other birth defects:

Maternal 1st Cousin: 18 respondents (20.9%)

Brother: 13 respondents (15.1%)

Sister: 12 respondents (14.0%)

Paternal 1st Cousin: 12 respondents (14.0%)

Maternal Aunt: 8 respondents (9.3%)

Maternal Uncle and Maternal Grandmother: 6 respondents each (7.0%)

Father and Paternal Aunt: 9 respondents each (10.5% and 7.0% respectively)

Mother: 8 respondents (9.3%)

Paternal Uncle: 3 respondents (3.5%)

Paternal Grandfather, Paternal Grandmother, Maternal Grandfather,

Maternal Grandmother, and Unknown: 1 respondent each (ranging from 1.2% to 4.7%)

Daughter, Son, and None: No reported cases



CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

CONT.

The prevalence of a family history of Congenital Diaphragmatic Hernia (CDH) among the respondents is significant, with 58.7% reporting a positive history. However, the majority (38.0%) does not have a family history of CDH, indicating a possible non-genetic component to the condition.

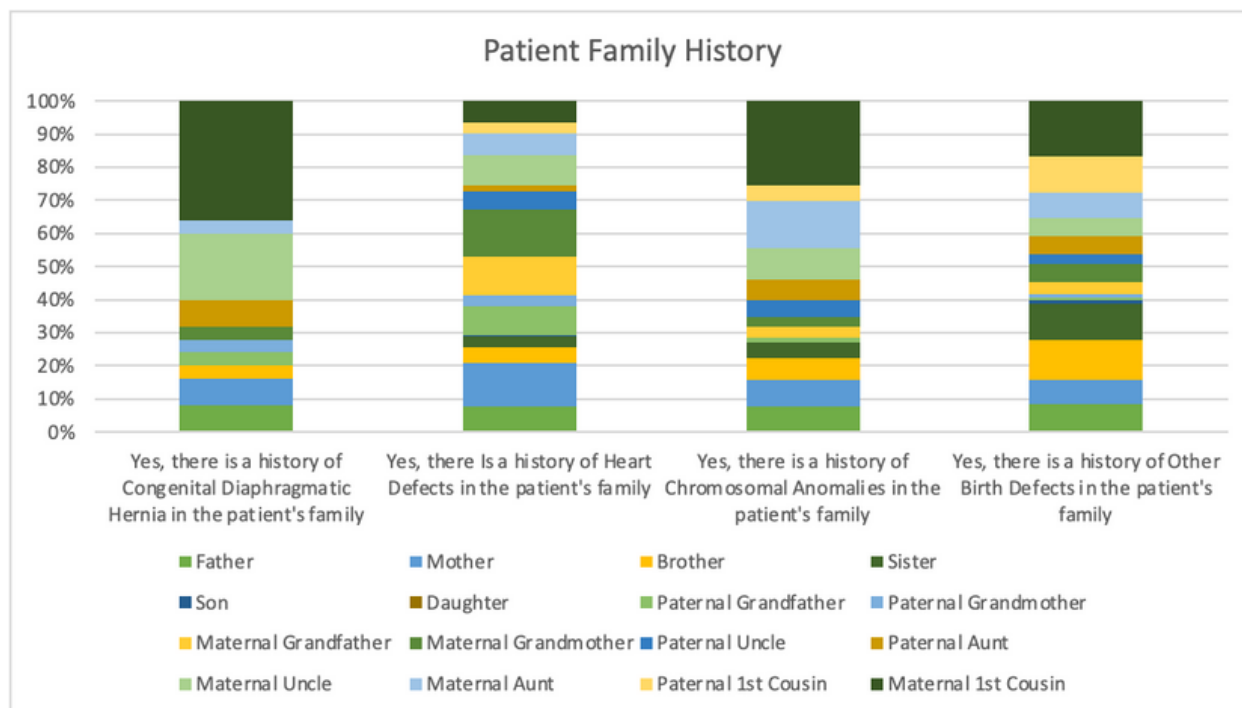
The maternal 1st cousins and maternal uncles have the highest reported cases of CDH in the family, suggesting a potential genetic link or shared environmental factors.

The majority of respondents (77.8%) do not have a family history of heart defects, indicating that heart defects may not be strongly associated with CDH in the family.

The maternal grandparents and parents have higher reported cases of heart defects, suggesting a possible genetic predisposition or familial clustering of heart defects.

Chromosomal anomalies show a relatively low prevalence (10.7%) among the respondents, with the maternal 1st cousins and maternal aunts having the highest reported cases, indicating a potential genetic component to these anomalies.

Other birth defects have a moderate prevalence (17.9%) in the family history, with siblings and maternal 1st cousins being the most commonly reported affected relatives, suggesting a potential familial influence on these defects. The presence of unknown responses in each category suggests limited knowledge or incomplete family medical history, which may impact the accuracy and interpretation of the findings.



Participating in the CDH Natural History study is of utmost importance for families affected by Congenital Diaphragmatic Hernia (CDH). By sharing your family's medical history through this questionnaire, you have the opportunity to contribute to groundbreaking research that aims to unravel the underlying causes and risk factors associated with CDH. Your participation can help identify patterns, genetic links, and potential environmental influences that may be associated with the development of CDH and related conditions. By joining this study, you become an integral part of a collective effort to advance medical knowledge, improve diagnostic strategies, and ultimately enhance the care and outcomes for CDH patients and their families. Your valuable contribution can pave the way for early detection, preventive measures, and personalized treatments, providing hope and support for future generations of CDH-affected individuals. Your participation truly matters and can make a significant difference in the understanding and management of this complex condition.



DONATE AT
WWW.CDHI.ORG/DONATE

GRACA

GLOBAL RESEARCH ALLIANCE FOR CONGENITAL ANOMALIES

The Global Research Alliance for Congenital Anomalies (GRACA) was founded on the advice of the World Health Organization to bring together like Congenital Anomalies to create global Standards of Care and Standards of Measurements and Mortality for millions of patients with similar medical issues.

Lead by CDH International, GRACA was created with co-founding organization, the Global Gastroschisis Foundation in 2020. The pandemic put plans on hold but now alliance is moving full-steam ahead.

CDH International is the Fiscal Sponsor of GRACA, supplying patient registries and training to other patient communities and working as liaison to medical associations and government entities.

At this time, the following are confirmed members of GRACA:

- CDH Community (CDH International and all ACDHO charities)
- Gastroschisis Community
- Omphalocele Community
- World Health Organization
- March of Dimes
- Kid's First Registry (NICHD)
- Center for Disease Control (CDC)
- The World Federation of Associations of Pediatric Surgeons (WOFAPS)
- Global Initiative for Children's Surgery
- G-4 Alliance
- DHREAMS / Columbia University
- Zani Lab / University of Toronto
- Univ of Manitoba

Many more communities, government organizations, surgical associations and foundations are coming on board and will be announced shortly.

Current Goals:

1. Transform the old CDH Forums to add the other patient communities.
 - a. Giving other patient families a non-social media platform to communicate
 - b. Used as a springboard to onboard patients onto registries
 - c. Each patient community will have it's own set of admins & moderators. CDH International is just the hosting entity.
2. Use the skeleton of the CDH Patient Registry (patient data removed) to create Natural History Registries for each of the other patient groups, none of which currently have patient registries.
 - a. Registries are free to the other communities, with 10 training hours after set up
 - b. WOFAPS is hosting the data, CDH International is building the registries
 - c. Each patient community will have 1 organization that will admin their Patient Registry.
 - d. All data is owned by individual patients. Not GRACA, CDH International, or any organization.
 - e. All patient data is de-identified.
 - f. All registries are HIPAA & GDPR Compliant
3. Collect data to work all of the other GRACA members and researchers to create a minimal Standard of Care for Congenital Anomalies
4. Use the registries to work with other registries to advance research as quickly as possible.
 - a. Communities will be able to use their registries to collaborate on research projects with universities, labs and other registries
 - b. Registries will be compatible with NIH, NHS and ERN governmental registries

There are several other large goals that are not public yet.

As you can imagine, this is a massive undertaking but one that will undoubtedly help to save the lives of millions of children. At this time, we are looking for corporate and government sponsors to help cover the costs these registries for all the patient communities; to build them, secure them, train teams and recruit patients to participate.



CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

CURRENT GENETIC STUDIES

The following hospitals and organizations are currently conducting CDH research studies.

Each has their own set of guidelines. Some studies include blood work on all family members, some include oral swabs. Some studies also include grieving families. There is no cost to families to participate in research studies. We encourage members to participate in as much research as possible so that we can help save babies of the future and their families from suffering from Congenital Diaphragmatic Hernia.

Genetic Molecular Basis of CDH
DHREAMS Study
Columbia University Medical Center
info@cdhgenetics.com
<https://careforkidsgenetics.org/dhreams/>

RESPIRE program
Stem cell therapy for CDH lungs
The Hospital for Sick Children
Zani laboratories – Developmental & Stem Cell Biology (DSCB)
Peter Gilgan Centre for Research and Learning
686 Bay Street, Toronto, ON M5G 0A4, Canada

Identifying Genes Which Cause CDH
Massachusetts General Hospital
Boston, Massachusetts
Patricia K. Donahoe, MD, Program Project Director
Frances High, MD, PhD, Principal Investigator
617-355-8780
CDHResearchStudy@childrens.harvard.edu

University of Utah
Diaphragm: Development, CDH, and Evolution
Department of Human Genetics
University of Utah
Contact: Gabrielle Kardon
801-585-6184 office
801-585-7365 lab
gkardon@genetics.utah.edu



CDH INTERNATIONAL

NEW CDH RESEARCH TASK FORCE

We are excited to work with Dr. Alexandra Benachi at the University of Paris on a new research project, as well as extending our work with Dr. Augusto Zani at the Zani Lab at the University of Toronto, by looking into the medical complications and quality of life for Congenital Diaphragmatic Hernia survivors over the age of 18 years old. To help accelerate this research, we have created a task force of 5 adult CDH survivors who will help recruit the adult members of the patient community to participate in this very important research. We implore every to support and participate for the sake of all current and future CDH patients. If you would like to participate in this new survey, please email research@cdhi.org



Morgan Nuchols
Adult CDH Survivor



Jason Miller
CDH Registry Manager



Taylor Steffensmeier
Adult CDH Survivor

MEET THE NEW CDH SURVIVORS RESEARCH TASK FORCE



Caroline King
Adult CDH Survivor



Taylor Hannah
Adult CDH Survivor



Maddy Sortino
Adult CDH Survivor





CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

CDH RESEARCH UPDATES

CDH International UK Signs Support Letter to Prime Minister on Behalf of Small Charities in the United Kingdom

As part of the Civil Society Wider Group, the UK NGO of CDH International has officially signed our support of funding for smaller charities in the United Kingdom by co-signing the following letter:

Dear Prime Minister,

We are representatives from small charities and the voluntary sector in the UK.

In the spring budget your government committed £100 million to voluntary organisations working at the front line of the cost of living crisis. While the money is yet to get out to organisations, we welcome this boost to the sector. But there is much more to do.

During this Small Charity Week, we want to highlight the critical role which small charities are playing in communities and encourage you to further demonstrate your support for these vital organisations.

In recent years we have encountered crisis after crisis - from Covid-19, to supporting refugees fleeing conflict, to now helping with cost-of-living pressures. We have stepped up and stepped in, filling gaps in public services or using our specialist local knowledge, to ensure that communities are safe, supported and reassured. Small, local charities are deeply embedded in their communities and form lasting relationships which have far-reaching positive outcomes.

We are keen to work with government at all levels to meet our shared goals of driving down inequalities and strengthening local communities. But if small charities aren't supported through these difficult times, we risk losing a crucial national asset. Every day, small charities are closing or reducing services. We are exhausted, burnt out and the mental health of our staff and volunteers is suffering.

Unlike businesses, charities cannot increase prices to cover financial challenges. The tide of demand threatens to overwhelm small charities which make up 96% of voluntary organisations in the UK.

We truly hope that one day many of us will not be needed. And that we will proudly close our doors for the right reasons, knowing we have achieved our visions.

In the meantime, we do not want platitudes, we want to be heard, especially as your government continues to make important spending decisions. We invite you, as Prime Minister, to visit small charities so you can fully understand the critical role these organisations play. We also call on you to agree to meet with the Small Charities Advisory Panel so we can discuss sustainable solutions to ensure we can continue offering lifesaving and life-enhancing support to the people your government serves.

Yours faithfully,
The undersigned



CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

CDH RESEARCH UPDATES

CDH International Signs Support of the Congressional PREEMIE Reauthorization Act of 2023

CDH International is proud to support the PREEMIE Reauthorization Act of 2023 to expand research, education and intervention activities related to preterm birth, but that will benefit babies born with congenital anomalies, like Congenital Diaphragmatic Hernia, as well.

Spearheaded by the March of Dimes and the Friends of NICHD committee (of which CDH International has been a part of for many years), we are one of 79 well-respected organizations that signed our approval and encouraged the United States Senate and House of Representatives to support and pass for the benefit of all of our children.

June 9, 2023

Dear Representative:

On behalf of the undersigned 79 organizations, we write express our strong support for the PREEMIE Reauthorization Act of 2023 (S.1573/H.R.3226), vital legislation to reauthorize and expand research, education and intervention activities related to preterm birth. It was introduced on May 11, 2023 by Sen. Michael Bennet (D-CO), Sen. John Boozman (R-AR), Rep. Michael Burgess (R-TX), Rep. Anna Eshoo (D-CA), Rep. Marianne Miller-Meeks (R-IA), Rep. Robin Kelly (D-IL), Rep. Lisa Blunt Rochester (D-DE) and Rep. Jen Kiggans (R-VA).

U.S. preterm birth rate has steadily increased since 2014 to 10.5% in 2021, with a significant 4% increase in just one year and the highest recorded rate since 2007. This represents an increase to 383,082 preterm births. Black and Native American women are 62% more likely to have a preterm birth and their babies are twice as likely to die as compared to White women. Preterm birth also accounts for 35.8% of infant deaths in the U.S. and the annual societal economic cost (medical, education, and lost productivity) is an estimated \$25.2 billion.

Although there are some clinical predictors of preterm birth, all pregnant individuals are at risk for preterm birth. Infants born prematurely have increased risks of morbidity and death throughout childhood, especially during the first year of life. Long-term health impacts include intellectual and developmental delays, behavioral problems, neurological disorders, visual and hearing impairments, cerebral palsy, and respiratory insufficiency or intestinal insufficiency.¹

While many risk factors associated with preterm birth have been identified, the "biological basis for many of these risk factors and the underlying mechanisms remain poorly understood."² This is particularly true for social and structural disparities. The PREEMIE Act will help reduce preterm birth, prevent newborn death and disability caused by preterm birth, expand research into the causes of preterm birth, and promote the development, availability, and uses of evidence-based standards of care for pregnant women.

Among the programs authorized by the PREEMIE Act is CDC's highly successful Pregnancy Risk Assessment Monitoring System (PRAMS). PRAMS collects site-specific, population-based data tracking maternal attitudes and experiences before, during, and shortly after pregnancy on 81% of births and is used by researchers and state, territory, and local governments to plan and review programs and policies aimed at reducing health problems among mothers and infants. This legislation will also provide for a new study on the costs, impact of non-medical factors, gaps in public health programs that lead to prematurity, and calls for recommendations to prevent preterm birth.

We look forward to working with you this year to advance this critical legislation. For more information, please contact Andrew Fullerton, Deputy Director of Federal Affairs, at afullerton@marchofdimes.org.

¹ Prediction and prevention of spontaneous preterm birth. ACOG Practice Bulletin No. 234. American College of Obstetricians and Gynecologists. *Obstet Gynecol* 2021;138:e65-90.

² Rubens C, Sadovsky Y, LMuglia L, et al. Prevention of preterm birth: Harnessing science to address the global epidemic. *Science Translational Medicine*. 2014; 6(262):262sr5. doi: 10.1126/scitranslmed.3009871.

AIDS Action Baltimore
 AIDS Foundation Chicago
 American Academy of Ophthalmology
 American Academy of Pediatrics
 American Association for Pediatric Ophthalmology & Strabismus
 American Association of Colleges of Pharmacy
 American Association on Health and Disability
 American College of Nurse-Midwives
 American College of Obstetricians and Gynecologists
 American Public Health Association
 American Society for Reproductive Medicine
 Arnold Solutions 53, Incorporated
 Association of Black Cardiologists
 Association of Maternal & Child Health Programs
 Blue Cross Blue Shield Association
 Blue Skies Consultation
 Calming Nature Doula Service & Center
 CARES Foundation Inc.
 CDH International
 Cerebral Palsy Foundation
 Child Neurology Foundation
 Children's Hospital Association
 dsm firmenich North America
 Educare Learning Network
 Endocrine Society
 Erie Niagara Area Health Education Center
 Etana Tax and Accounting LLC
 Families USA
 Family Voices
 Family Voices NJ
 First Focus Campaign for Children
 Futures Without Violence
 Galactosemia Foundation
 Genetic Alliance
 Global Down Syndrome Foundation
 Hadassah, The Women's Zionist Organization of America
 Health Equity Solutions
 Healthy Birth Day, Inc.
 Impetus - Let's Get Started LLC
 Ipsas
 Jericho Road Community Health Center
 John Burton Advocates for Youth
 Kaleida Health Family Planning
 Lakeshore Foundation
 March for Moms
 March of Dimes
 Michigan Council for Maternal and Child Health
 MTS Sickle Cell Foundation, Inc.
 National Association of Pediatric Nurse Practitioners
 National CMV Foundation
 National Health Law Program
 National League for Nursing
 National Partnership for Women & Families
 National WIC Association
 National Women's Health Network
 Necrotizing Enterocolitis (NEC) Society
 Nemours Children's Health
 North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
 Preeclampsia Foundation
 Prevent Blindness
 Public Advocacy for Kids (PAK)
 PUSH for Empowered Pregnancy
 RESOLVE: The National Infertility Association
 Rhia Ventures
 Sigma Gamma Rho Sorority Inc.
 Sigma Gamma Rho Sorority, Inc.- Lambda Epsilon Chapter
 Sigma Gamma Rho, Alpha Phi Sigma Chapter Pretty Poodles
 Society for Birth Defects Research and Prevention
 Society for Maternal-Fetal Medicine
 SPAN Parent Advocacy Network
 Spina Bifida Association
 STHealth
 SWCyril Holdings Inc
 Tennessee Health Care Campaign
 The Collaborative
 The Fibroid Foundation
 U.S. Breastfeeding Committee
 Unite for Reproductive & Gender Equity (URGE)
 United Way of Buffalo & Erie County



CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

CDH RESEARCH UPDATES

CDH International Attends the 27th International Conference on Prenatal Diagnosis & Therapy

We were honored to attend the 2023 International Conference on Prenatal Diagnosis & Therapy Congress in Edinburgh, Scotland, and to represent not only Congenital Diaphragmatic Hernia patients but all Congenital Anomaly patients as the Patient Advocacy organization at the event. CDH International is a proud member of the International Society for Prenatal Diagnosis (ISPD).

By attending this event, we were able to share the patient perspective and experience of being diagnosed prenatally with a fatal diagnosis and what parents need at the time of diagnosis.

Several research connections were made and we look forward to working with new institutions to better serve CDH families, as well as other patient families.



CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

CDH RESEARCH UPDATES

[CDH International Signs Letter Of Support for the Accelerating Kids' Access to Care Act](#)

We are proud to sign on our support of the very important Accelerating Kids' Access to Care Act to help push research for cancer patients, rare disease patients and congenital anomalies patients as a member of the National Organization for Rare Diseases.

The Honorable Chuck Grassley
U.S. Senate
135 Hart Senate Office
Washington, DC 20510

The Honorable Lori Trahan
U.S. House Of Representatives
2439 Rayburn House Office Building
Washington, DC 20515

The Honorable Michael Bennet
U.S. Senate
261 Russell Senate Office Building
Washington, DC 20510

The Honorable Mariannette Miller-Meeks
U.S. House Of Representatives
1034 Longworth House Office Building
Washington, DC 20515

Dear Senator Grassley, Senator Bennet, Representative Trahan, and Representative Miller-Meeks:

Our xxx organizations are dedicated to improving the health and well-being of children – including children impacted by pediatric cancers, rare diseases, and complex medical conditions. We are pleased to offer our strong support of your legislation, the Accelerating Kids' Access to Care Act (HR XXXX / S XXXX) (AKACA). Once enacted into law, this legislation will help reduce the time it currently takes children covered by Medicaid or the Children's Health Insurance Program (CHIP) to access specialized care when providers in their home state cannot address their care needs.

Both Medicaid and the CHIP are core sources of health insurance coverage for children, with children accounting for roughly 50% of total Medicaid enrollment and more than one-third of all children with special health needs enrolled in Medicaid. Families with children who live with complex medical needs such as cancer, pediatric brain tumors, sickle cell disease, congenital heart disease, and other rare diseases often struggle to access and coordinate the specialized care needed to treat their child's condition. Many times, the best treatment for these children requires out-of-state travel coupled with substantial coordination between the child's family and their care team. Particularly for patients with rare conditions and for novel gene therapy treatments, it is not uncommon for there to be only one or two clinical centers in the country with specialists who have the requisite expertise to treat their condition. A 2019 study of rare disease patients and caregivers across the US found that 39% of respondents traveled more than 60 miles to receive medical care, and 17% had moved (or considered relocating) to be closer to care. For children with cancer, an initial diagnosis or relapse can require immediate and intensive treatment or clinical trials that may not be available in the child's home state.

When a child's medical needs cannot be met by providers in their home state, the State Medicaid Agency and/or Medicaid Managed Care Organization authorizes such care with an out-of-state provider. The out-of-state provider must then be screened and enrolled by the home state's Medicaid program. While current laws and regulations allow for the child's state to rely on provider screenings done by other state Medicaid programs or by Medicare, unfortunately, there is no single federal pathway. This means providers are often required to be screened and enrolled every time they are called upon to treat a child from out-of-state. This process can delay time-sensitive care by weeks or months. During this time, a child's condition can worsen, resulting in worse health outcomes and higher health care costs.

Your legislation would address this problem by establishing a voluntary pathway for qualified providers caring for children to enroll in other states' Medicaid or CHIP programs quickly. This limited pathway, only available to providers in good standing within their home state program or Medicare, would enable them to bypass subsequent screenings, expeditiously enroll in another state Medicaid program, and step in to provide essential time-sensitive care to children when necessary.

This legislation only pertains to provider screening and enrollment and does not change the authority states have to authorize out-of-state care and negotiate payment with accepting providers. It is a common-sense solution that will reduce burdens on health care providers, facilitate access to critical, time-sensitive treatment, and reduce the risk of care disruption and subsequent negative outcomes.

Thank you again for your leadership on behalf of all children with cancer, rare diseases, and other complex health conditions. We look forward to working with you to advance the AKACA. If you have any questions, please contact Matt Marks, Senior Manager of Federal Government Affairs with The Leukemia & Lymphoma Society, Aimee Ossman, Vice President, Policy Analysis with the Children's Hospital Association, or Mason Barrett, Policy Analyst with the National Organization for Rare Disorders. Thank you for your consideration.

Sincerely,
The Undersigned

[1] [Medicaid & CHIP Enrollment Data Highlights, CMS, May 2021](#)

[2] ["Medicaid Access in Brief: Children and Youth with Special Health Care Needs." MACPAC, March 2023](#)

[3] ["Barriers and Facilitators to Rare Disease Diagnosis, Care and Treatment: 30-year Follow-up." National Organization for Rare Disorders, 2020](#)



CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

CDH International Presents Research at 2023 BDRP

CDH International was proud to present a research poster at the 2023 Society for Birth Defects Research and Prevention Conference in Charleston, South Carolina. We were able to sit in on epidemiology and toxicology lectures on the causes of congenital anomalies, as well as to network with members of the CDC, NIH, March of Dimes and many universities.



CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

CDH RESEARCH UPDATES

CDH International Signs On To Letter To Congress To Protect the Orphan Drug Act and pass the RARE Act

CDHi is proud to sign our support of the protection of the Orphan Drug Act and in support of the RARE Act, both headed by the National Organization for Rare Disorders.

May 1, 2023

The Honorable Bernie Sanders
Chairman
Committee on Health, Education, Labor & Pensions
United States Senate
Washington, D.C. 20510

The Honorable Bill Cassidy, M.D.
Ranking Member
Committee on Health, Education, Labor & Pensions
United States Senate
Washington, D.C. 20510

Dear Chairman Sanders and Ranking Member Cassidy,

do not have an FDA-approved treatment indicated for the specific rare disease. If the RARE Act is not enacted, there is likely to be fewer orphan drugs approved for special patient populations, an outcome that runs counter to the goal of the ODA and is not in the best interest of the rare disease community.

We urge members of the HELP Committee to support the RARE Act and vote to advance this legislation out of Committee to preserve the intent of this critical ODA incentive that has benefited millions of Americans and their families facing rare disease diagnoses. For more information, please contact Heidi Ross, Vice President of Policy and Regulatory Affairs for the National Organization for Rare Disorders, at hross@rarediseases.org or Karin Hoelzer, Director of Policy and Regulatory Affairs, at Hoelzer@rarediseases.org.

Thank you for your consideration,

National Organization for Rare Disorders
Adrenal Insufficiency United
Adult Polycystic Kidney Disease Research Foundation (APBRF)
Alport Syndrome Foundation
ALS Association
Alternating Hemiplegia of Childhood Foundation
American Behcet's Disease Association (ABDA)
American Cancer Society Cancer Action Network
APS Foundation of America, Inc
Avery's Hope
Born a Hero, Research Foundation
CancerCare
CDH International
Children's Cancer Cause
Children's PKU Network
Cholangiocarcinoma Foundation
Chondrosarcoma CS Foundation
Coalition to Cure Calpain 3
Congenital Hyperinsulinism International
Cure CMD
Cure HHT
CURED (Campaign Urging Research for Eosinophilic Disease)
cutaneous lymphoma foundation
Cystic Fibrosis Research Institute
Dup15q Alliance
Epilepsy Foundation
FACES: The National Craniofacial Association

FOD Family Support Group
Foundation for Sarcoidosis Research
FONG1 Research Foundation
Friedrich's Ataxia Research Alliance (FARA)
Gaucher Community Alliance
Glut1 Deficiency Foundation
Gorlin Syndrome Alliance
GRIN2B Foundation
HCU Network America
Hepatitis B Foundation
Hypertrophic Olivary Degeneration Association
International Foundation for Gastrointestinal Disorders
International Pemphigus Pemphigoid Foundation
International Waldenström's Macroglobulinemia Foundation
Juju and Friends CLN2 Warrior Foundation
KrabbeConnect
Lemmon-Gastaut Syndrome (LGS) Foundation
Mississippi Metabolics Foundation
MLD Foundation
MSUD Family Support Group
Muscular Dystrophy Association
National Ataxia Foundation
National Health Council
National MAALS Foundation
National Niemann-Pick Disease Foundation
National PKU News
NBA Disorders Association
Necrotizing Enterocolitis (NEC) Society

NR2F1 Foundation
NTM INFO & RESEARCH
Oral Cancer Foundation
Organic Acidemia Association
Phelan-McDermid Syndrome Foundation
Pulmonary Fibrosis Foundation
Pulmonary Hypertension Association
Smith-Kingmore Syndrome Foundation
STXB1 Foundation
Superior Mesenteric Artery Syndrome Research
Awareness and Support
Team Telomere

The Foundation for Casey's Cure, Inc
The Leukemia & Lymphoma Society
The Life Raft Group
The Mast Cell Disease Society (TMS)
The RYR-1 Foundation
The Sudden Arrhythmic Death Syndromes (SADS) Foundation
TSC Alliance
United MSD Foundation
United Porphyrias Association
Vasculitis Foundation
Yellow Brick Road Project- HNRNPH2 NDD

CC: Members of the Senate Committee on Health, Education, Labor & Pensions

CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

CDH RESEARCH UPDATES

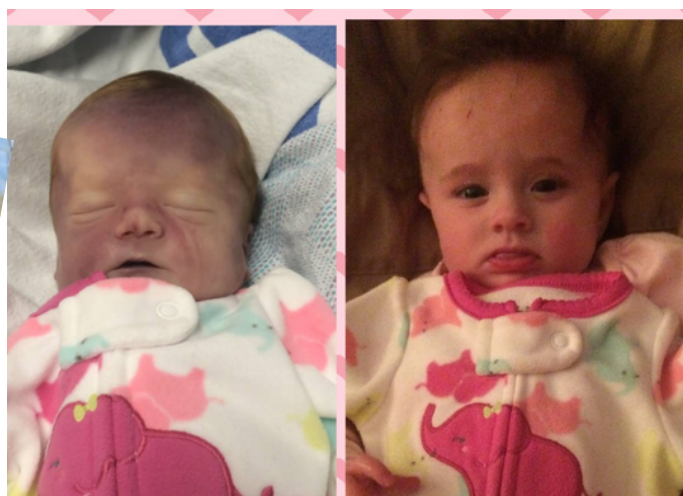
- [Congenital diaphragmatic hernia: exploring the intersection of personal experience and research](#)
- [Comparing Intubation Rates in the Delivery Room by Interface](#)
- [Post-natal prognostic factors in CDH: experience of 11 years in a referral center in Brazil](#)
- [Birth Defects Associated with Prenatal Alcohol Exposure-A Review](#)
- [Persistent Tachypnoea in Early Infancy: A Clinical Perspective](#)
- [Does prediction of neonatal mortality by the observed / expected lung-to-head ratio change during pregnancy in fetuses with left congenital diaphragmatic hernia?](#)
- [Thoracoscopic repair for late-presenting congenital diaphragmatic hernia with thoracic kidney in a child](#)
- [Sedation Prior to Intubation at Birth in Infants with Congenital Diaphragmatic Hernia: An International Survey on Current Practices](#)
- [Congenital Heart Disease With Congenital Diaphragmatic Hernia: Surgical Decision Making and Outcomes](#)
- [Congenital Diaphragmatic Hernia With Intra Thoracic Gastric Volvulus: A Rare, Life-Threatening Combination](#)
- [Successful treatment of spontaneous diaphragmatic hernia with gastric necrosis: A case report](#)
- [Longitudinal Trajectory of Ventricular Function and Pulmonary Hypertension in Congenital Diaphragmatic Hernia](#)
- [Percutaneous, ultrasound-guided single- and multisite cannulation for veno-venous extracorporeal membrane oxygenation in neonates](#)
- [Congenital diaphragmatic hernia](#)
- [Diagnostics and surgical treatment of Bochdalek hernia in adults](#)
- [Early Postnatal Ventricular Disproportion Predicts Outcome in Congenital Diaphragmatic Hernia](#)
- [Case reports: a variety of clinical presentations and long-term evolution of Bochdalek hernias](#)
- [Population-based prevalence study of common congenital malformations of the alimentary tract and abdominal wall in Thailand: a study using data from the National Health Security Office](#)
- [Late diagnosis of congenital diaphragmatic hernia: a case report](#)
- [Prenatal Diagnosis of an Intrathoracic Left Kidney Associated with Congenital Diaphragmatic Hernia: Case Report and Systematic Review](#)
- [Laparoscopic double mesh repair of a large Morgagni hernia: a video vignette](#)
- [Center Volume and Survival Relationship for Neonates With Congenital Diaphragmatic Hernia Treated With Extracorporeal Life Support](#)
- [Dynamics of pulmonary hypertension severity in the first 48 h in neonates with prenatally diagnosed congenital diaphragmatic hernia](#)
- [En bloc resection of gastrobronchial fistula associated with mesh infection](#)
- [Single-cell transcriptomic profiling of microvascular endothelial cell heterogeneity in congenital diaphragmatic hernia](#)
- [Quantitative Measures of Right Ventricular Size and Function by Echocardiogram Correlate with Cardiac Catheterization Hemodynamics in Congenital Diaphragmatic Hernia](#)
- [Pathological findings in congenital diaphragmatic hernia on necropsy studies: A single-center case series](#)
- [MIF Increases sFLT1 Expression in Early Uncomplicated Pregnancy and Preeclampsia](#)
- [Low-pressure endoscopy using the gel immersion method facilitates endoscopic reduction of a Morgagni hernia](#)
- [Lung ultrasound and postoperative follow-up of congenital diaphragmatic hernia](#)
- [Have the results of the TOTAL-trials changed the attitude and practice of maternal-fetal medicine specialists?](#)

CHERUBS Helps Families of CDH Babies



My mother found CHERUBS when I was pregnant with my 1st son Claude, he passed away at 10 days old. They were a great support system during this time. Little did I know that almost 5 years later I would need them again when my 3rd child Celie was born with CDH. Celie is 5 now and I am so lucky to have such a awesome group of moms and dads to share this journey with. All the good CHERUBS does to bring awareness to this little known birth defect as well as advocating for research leaves me with hope that my children will never have to go through what we did as parents when they decide to have children. Pictured above is Lil Claude and then Celie now at 5 yrs old" - DeAnn McGilberry (2012)

www.savethecherubs.org



"I HAVE 2 CDH LITTLE GIRLS. AN ANGEL AND SURVIVOR. CHERUBS GAVE ME HOPE WHEN NO ONE ELSE DID. THEY GAVE ME COMFORT IN A DARK PLACE. THEY CONNECTED WITH SOME OF THE BEST FRIENDS I'LL EVER BE "SAD" TO KNOW. FOREVER GRATEFUL! BRIELLA GRACE, AND LILLY ANN."

Roxanne Warnick

CHERUBS CDH International

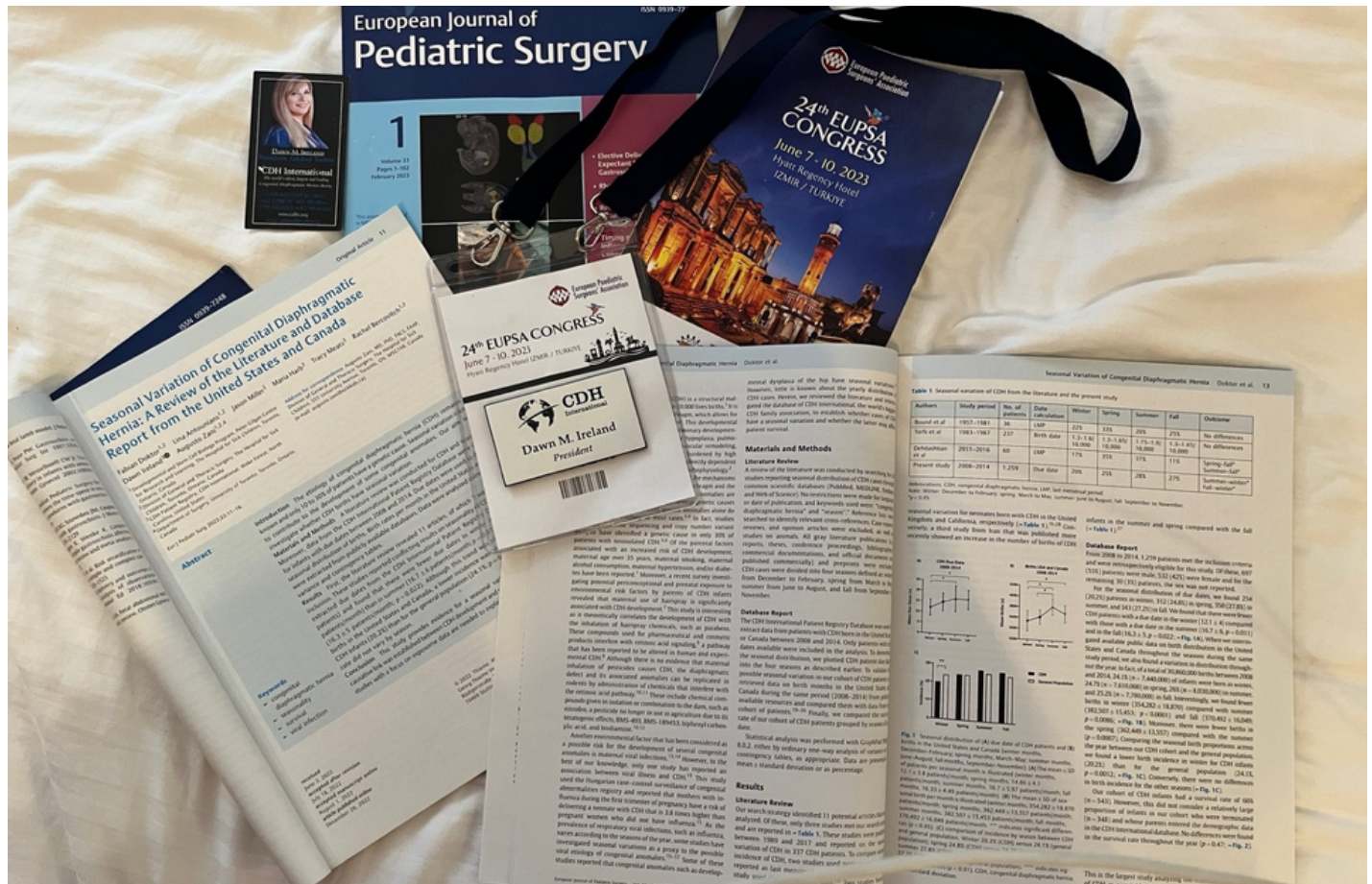


CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH CDH RESEARCH UPDATES

CDH International Attends the 2023 European Pediatric Surgical Association Congress

CDH International was proud to attend this year's EUPSA conference in Izmir, Turkey, where our joint research with the Zani Lab (University of Toronto, SickKids) was presented! We learned much new CDH research and made plans for new collaborations that we cannot wait to share in the future.

We also were able to see our publication in the European Journal of Pediatric Surgery.



ELIJAH HURLEY

CDH NON-SURVIVOR, UNITED STATES

BROTHER



At 21 years old I found out I was pregnant with an unplanned pregnancy. I was in school and on birth control and very surprised.

At 17 weeks pregnant I found out some levels were off with blood work, could be a false positive but needed to see a specialist. That man was by far the worst experience of my life. He told me my baby had CDH, and these babies do not live. In his country they do not help them, and I should terminate. I had never heard of it, didn't have enough information and the room was spinning. I agreed to an amniocentesis that went wrong and I left, headed down the rabbit hole of google to try to understand what was happening. I found CHERUBS, which was the best source of information and gave me hope and armed me with some knowledge before I headed into a long two days of ultrasounds echos MRIs and all kinds of appointments at a better hospital who had way better medical staff and we had a plan and some hope.

Toward the end of the pregnancy we figured out that the way the LHR was taken, the spleen was being counted as lung. This brought his expected lung volume under 20% and completely changed our prognosis. At this point I still was hopefully but understood to the best my naive then 22 year old self could.

The C-section was rough, out Elijah was 9 lbs 8 oz and 21 inches at only 28 weeks. The tossed around the possibility of genetic disorders but couldn't figure out anything concrete. He was immediately intubated and taken away. I don't think I even got to see him as they were still working on me. Pediatric surgeon was in and out a few times and his Dad kept trying to relay information but was confused himself. He was put on ECMO within a few hours.

He remained on ECMO for his entire four weeks of life. His repair was done after a few days but the parts didn't quite fit back in and he kept bleeding at his surgery site. Almost every other day they were doing "washouts" and about a few times emergency procedures for bowel perforation. By weeks three he needed dialysis. He was sedated almost constantly. I spent my days sitting at his bedside. Just trying to soak up as much time as possible and to scared to leave for to long. It felt like every day was torture. Not knowing how things would be, trials off of the ECMO weren't encouraging, he kept bleeding and they kept turning down his blood thinners, but that would cause the machine to clot and a part need to be changed then he would swell up and we kept up with that cycle over and over. March 29 we decided we weren't going to do it anymore, he had fought hard and was tired. We wanted him to have peace. We called all of our close family to come and give him a kiss and say good bye. Our favorite nurse came in just to help. We finally got to hold him. We held him and cried and said good bye at 27 days old to our little monkey, our angel baby.

BROTHER



LUKA HURLEY

CDH SURVIVOR, UNITED STATES

BROTHER



In April 2021 I found out I was expecting my youngest, while a surprise we were so excited!

Due to my first CDH pregnancy, I was automatically High risk. I delivered a perfectly healthy baby boy in 2016 and the doctors assumed it was an isolated abnormality.

Unfortunately we started noticing some abnormality from the very beginning. From the first ultrasound around 12 weeks proportionally things were off and we were having difficulty figuring out how far along I was for awhile. After a few suggestions of wrong diagnosis, some issues bleeding and several ultrasounds later, at 16 weeks the MFM department confirmed the CDH diagnosis.

I had sworn I was not going to do this again, that I wouldn't go through it or out another baby through it, but it felt different. We agreed to the amniocentesis, scheduled an MRI and went home with only the information that it seemed to be a mild to moderate case. I was at a different hospital this time and everyone we saw seemed so much more confident. The MRI a few weeks later confirmed he was in the mild category and we decided we would continue the pregnancy.

3 MRIs 2 fetal ECHOS, multiple abnormalities noted in regards to baby's size with no diagnosis and a 2nd & 3rd trimester of polyhydramnios and we got a call. At nearly 35 weeks, one of the research projects we were a part of confirmed a genetic diagnosis from the amniocentesis, Simpson Golabi Behmel syndrome. This gave us an answer and a lot of questions and lots of new possible issues. We scheduled a delivery date with all the extra people on standby. Baby our little Luka was born and intubated and immediately intubated and stabilized. He fought the vent and the sedatives for a few days, there was talk of ECMO which almost crushed us. He pulled through and fought hard. The repair was done on day three and the surgeon was excited to report she could visualize quite bit of lung. He was extubated at 2 weeks, CPAP for about a week and a half and graduated the NICU at 6 weeks! He came home in an NG tube but was done with that by 5 months old.

Now he is 18 months, and a huge force of nature. We have managed to only have a handful of bumps in the road but other than his scar you'd never know what this kid went through. Good luck telling him he can't do something or was supposed to have all these issues or speech delays. We still struggle with some reflux and it takes him a bit longer to get rid of a cough sometimes but there is no stopping him. He is our little ball of sunshine (and crazy).

BROTHER



CDH INTERNATIONAL FUNDRAISERS

FACEBOOK FUNDRAISERS

- Candie's Birthday Fundraiser for CDHi in Honor of Jasmine
- Liz and Lincolns' Walk for CDHi
- Milinda's Birthday Fundraiser for CDHi in Honor of Bryer
- LeAnn's Birthday Fundraiser for CDHi in Memory of Ashley
- Kristy's Birthday Fundraiser for CDHi in Honor of Granddaughter Lyric
- Ada's Birthday Fundraiser for CDHi
- Clara's Birthday Fundraiser for CDHi
- Amanda's Birthday Fundraiser for CDHi
- Lynne's Birthday Fundraiser for CDHi in Honor of Daniel
- Amber's Birthday Fundraiser for CDHi
- Krysta's Birthday Fundraiser for CDHi in Memory of Evander
- Tanya's Birthday Fundraiser for CDHi in Memory of Hunter



AAGJE, BABETTE, & SUZE ZWART

CDH NON-SURVIVORS, THE NETHERLANDS

SISTERS



As an introduction of myself.. well where to start... Let me start at the present. I'm a bit like Dawn, busy up to my eyebrows :) keeping the Dutch support group going and growing, trying to reach as many people as I can involved with CDH. In the mean time I have a job too, to keep my family supported. Married, two healthy children, a boy, 4 1/2 and a girl, 1 1/2. At first sight a very happy family.

Hmm, happy story, I should stop at this stage... No, have to tell more, because there is more to tell. I have not committed myself to this support group just because. (though I wish I could have). Our first encounter with CHD (as we call it- and looks better in typing also) was in 1990. While in the hospital to make a routine echo to establish the duration of the pregnancy, the dr. did not trust what she saw and sent us to a university-hospital for a second opinion. Yes, you guessed right. Both hospitals advised to end the pregnancy (at about 25 weeks). At that time we were completely blank and we let ourselves be lead by the advice from both hospitals. We had a beautiful little girl and named her Aagje. We never saw her eyes, too shy to ask if we could look, or too reserved to take a look at everything. Having your first baby is one thing, having your first stillborn is yet another. Doctors said, after some genetic counseling, that something like this was so unlikely to happen, that it was never to happen to us again.

So after unbelief, grief, sorrow, anger, we started to find out more about CHD. To our astonishment we found a medical studybook which contained a chapter on hernia repair... our mouths fell open. So there would have been another option for our little girl and they never told us. But there was no way of turning back the clock. No way of knowing what would or could have happened. A year went by and about the time our daughter was born a new life was starting to grow. Yet again we were not sure when this little life started, and the whole history repeated.

And the WHOLE history repeated, but this time we were determined to keep this baby, to let it show the world CHD could be defeated. We went to another university hospital, where a -at that time- new technique in Holland, ECMO, had started... Who knew, maybe we would need that. Our second daughter came, doctors fought for her life, but Babette was no more than 15 minutes with us. We learned a lot, we have had her home and many friends and family members came to see her. Frightened, not knowing what to expect, and then, after visiting Babette, astonished, happy almost, for so much beauty and peace they saw.

One can call it stupid, one can call it brave, but we wanted to have children of our own. so after a year and a half we had our first son. By that time we had started the support group and we became very well informed about CHD. When our son was born we had to fight the prejudice that 'it would be inherited by girls only'.

Having a healthy baby tends to keep you busy... sometimes drifting on pinkish clouds, sometimes worrying, little sleep... In a way our two girls got their place in the family and we tried to live on, getting the support group on the track, which by then had some 40 couples. So a year and a half later CHD was not the first thing we thought about when my wife was pregnant. Of course we went to the hospital, at 13 weeks gestation. An ultrasound did not exclude CHD!!! The dr. would be sure at 16 weeks... Three more weeks... Hell... Three long weeks in which we could not do a thing but wait. After that time we went back to the hospital to be certain of what it was... The world collapsed. We almost wrecked the machines. Again... Why we, why, why, why, what now, what to do? End the pregnancy? Carry on? We had done both, none of them with a result we were satisfied with. And there was no other alternative. After long talks with a psy we came to the conclusion that the only thing you have to live with your whole life is your feelings, not your ratio. And our feelings told us we wanted the child to show us -with medical assistance- what it was worth.

Weeks crept by, at 37 weeks we went to hospital and a large team was ready, even the professor, who wanted to see this one for himself. (he became one of our closest 'battle-companions') April 28 1995 Suze was born. And she was taken care of by almost everybody in hospital (seemed like that anyway). After fifteen minutes she survived her sister, after half an hour she was taken from the delivery-room to intensive care. In the evening, when she almost had died of a bloodpressure-drop, she was put on ECMO. For us, that looked like a success. Up and down she went, and our emotions with her. She was on ECMO for a long time. Nurses started to ignore us... like they were already giving up.

After almost three weeks the system became blocked by colonies of bacteria, so the membrane was exchanged. A few days later the whole system failed and a complete new machine replaced the old one. After that it went better, surgery was scheduled and hernia repair was done. Two days later she was off ECMO, on the ventilator. On may 28 suddenly her lungs went back to the stage they were in at the start of the ECMO. She could no longer take the oxygen from the machine, that was puffing like a steam-engine on high speed. There was no way back. Suze was at her end. In the evening we were taking out all the IV's and getting her ready to hold her in our arms for the first time and for the last.

It was special. All the children on the ICU were silent at that time. Where normally one could hear all kind of alarms there was a complete silence. As if the other children felt this was time to say goodbye to Suze.

She too stayed at our home for a few days. For the first time we had a funeral with more than us two attending. A few people, good friends and some relatives visited the hospital, they were invited to say goodbye and to be with us sending Suze on her long voyage.

Telling all this still brings tears to my eyes. I hope I am doing the right thing telling all this right away and not holding back a lot. While writing I thought about it a lot: Push the send button or not... Well, when you've read this I guess I did.

When people are asked what they would prefer, a baby boy or a girl, most of them would say I don't care as long as it is healthy. Maybe you can understand by now that I wanted a baby girl more than anything. In September 1996 we were blessed with our pride and joy Rozefien. A non-existing name, containing both a rose and the name of the academic childrens hospital, Sophia. For she flowered from the same hospital where our other girls died. Believe me, she has the spirit of all her sisters combined in one. A better monument for them is unthinkable.

Written by Onno Swart in 1998, father of



CDH AWARENESS UPDATES

July means summer is officially here! We have some great ways to raise awareness for our CHERUBS!

A fun family activity is painting rocks and hiding them around your home town or even when you're out on adventures! CHERUB Allie has painted rocks to raise awareness and have taken them to her appointments at various children's hospitals and left them for other children to find and keep or hide. She has been able to raise awareness in her home town and even in other cities!

A new fun idea is a car show! Rev them up and roll them out to raise awareness for CDH International and all of our CHERUBS! You can contact your local car dealerships or other local business's that will let you use their space for a CHERUB cruise. Most car fanatic's are eager to show off their cool looking rides. You can charge a certain price for each vehicle who is entering the show and even offer prizes to the best looking car if you wish to do so. It's fun for the whole community.



NEW CDH AWARENESS SHOP ITEMS



CDH LUNGS DAISIES UNISEX HEAVY SWEATSHIRT

Various sizes and colours
50% cotton, 50% polyester
Loose Fit

\$25.30



"CERTIFIED CDH MOM" UNISEX HEAVY COTTON TEE

Various sizes and colours
100% cotton
Classic Fit

\$15.42



"IT'S OKAY IF ALL YOU DO TODAY IS SURVIVE" INFANT TEE

Black in color
100% cotton
Medium fabric, regular fit

\$18.16



IT'S NOT JUST A HOLE CDH AWARENESS HOLIDAY CARDS

One size: 6.9" x 4.9" blank card
Each card comes with a white envelope
Use as portrait or landscape card

\$0.47



CDH AWARENESS RIBBON MUG

Black ceramic mug
C handle, rounded corners
15 ounces

\$12.00



CDH AWARENESS RIBBON BEACH TOWEL

30" x 60" or 36" x 72" in size
Soft and absorbent
50% Polyester 50% Cotton

\$22.01/\$30.65



"NOT GOING DOWN WITHOUT A FIGHT" CDH AWARENESS KIDS TEE

Black in color
100% cotton
Midweight Fabric/Classic Fit

\$23.06



"YOU AUTOMATTICALLY LOSE THE CHANCES YOU DON'T TAKE" INFANT TEE

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

\$14.72

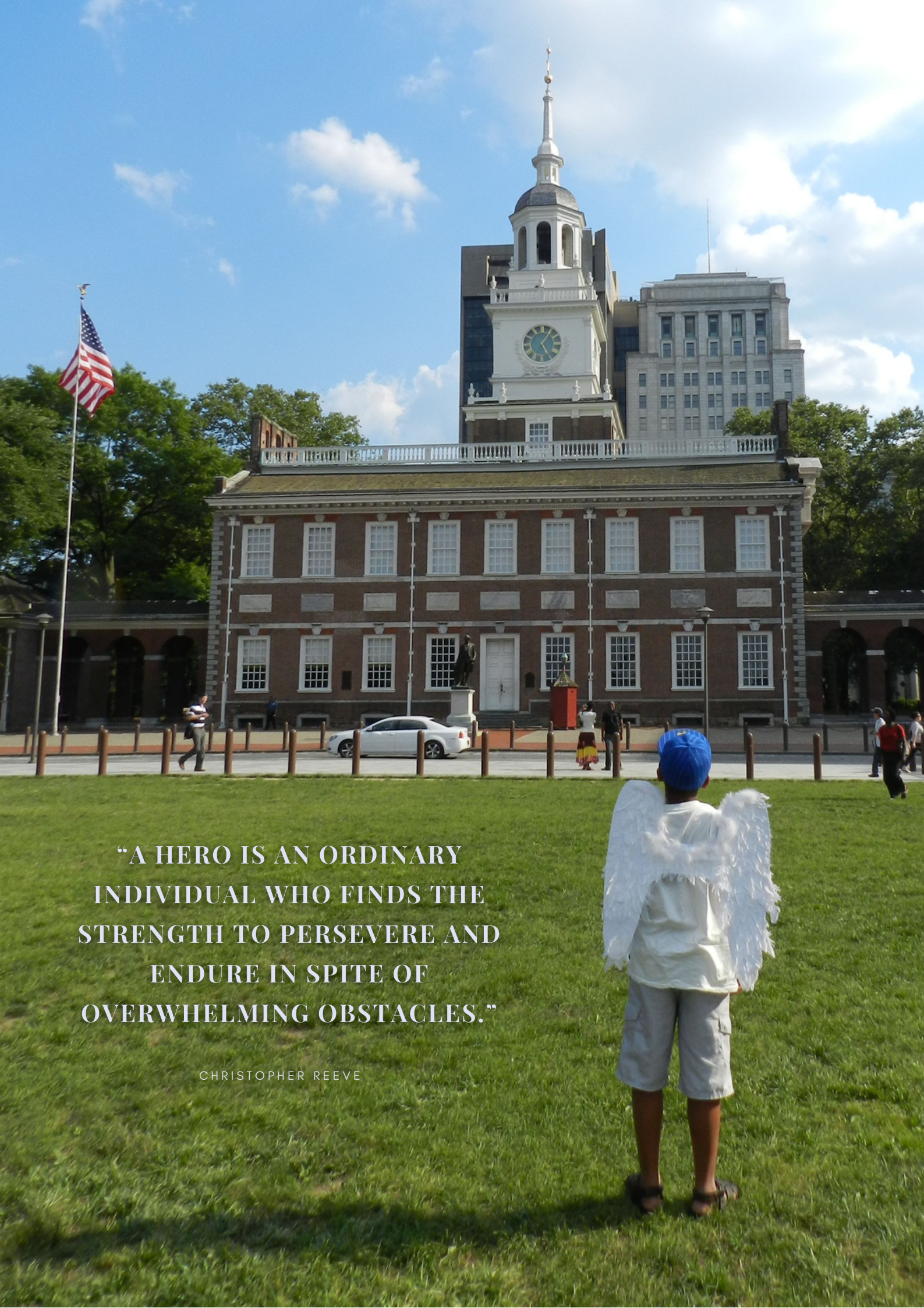


"DREAM BIG AND CREATE YOUR OWN STORY" INFANT TEE

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

\$14.72





“A HERO IS AN ORDINARY
INDIVIDUAL WHO FINDS THE
STRENGTH TO PERSEVERE AND
ENDURE IN SPITE OF
OVERWHELMING OBSTACLES.”

CHRISTOPHER REEVE