



CDH International

THE SILVER LINING

CONGENITAL DIAPHRAGMATIC HERNIA MAGAZINE

June 2023 Issue

Dad's Corner

Our Father's Day Issue

BIG NEWS!

CDH Research Collaborations

In Memorium

We Have Lost Another Volunteer

Flashback to 2009

Texas CDH Conference

New CDH Song

"The Incredible Ones"

Estate Planning

Saving Children From CDH

CDH Parent Refence Guides

Now in 10 Languages

New! Magazine Ads

Celebrate Your Special Moments

THE VOICE OF CONGENITAL DIAPHRAGMATIC HERNIA PATIENTS

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This issue of the CDH Magazine is dedicated to all the fathers, with special acknowledgement to one in particular.

In Loving Memory of David Finger

Dave and his beautiful, wife, Allison, are the parents of CDH Survivor, Vivian. Dave volunteered for CDH International for many years and was key in our lobbying efforts in Washington DC. His smile, gentle kindness, and dedication to help all of our children is surely missed. Thank you, Dave. Fly high, dear friend.



CDH International

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

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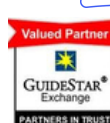
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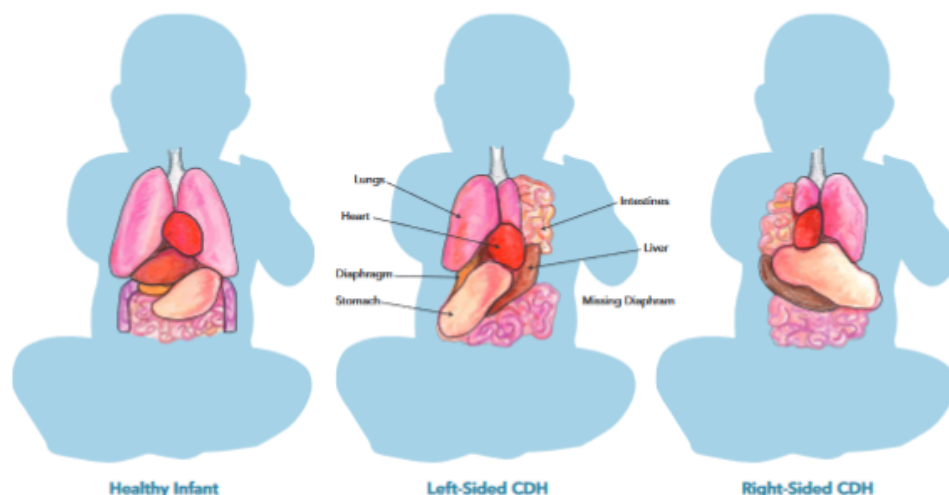


MISSION STATEMENT >

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 >



June 2023



SUN	MON	TUE	WED	THU	FRI	SAT
				1	2	3
4	5	6	7	8	9	10
11 Flag Day (USA)	12	13	14	15	16	17
18 Father's Day	19 Juneteenth	20	21	22	23	24
25	26	27	28	29	30	

30

Notes:

DISCLAIMER: The information on all pages of this newsletter are for education only. It is not meant to be used in place of proper medical care and advice. CDH International does not encourage or discourage any medical treatments or procedures or promote any specific hospitals or doctors. Our purpose is to educate families and medical care providers so that they may make the most informed decisions for the patients' best interests. You can not compare your child to other children born with CDH, they are all different. The opinions aired by members are not necessarily the views of all members, staff, or of CDH International.

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Tracy Meats, Vice-President
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David Holt



CDH INTERNATIONAL

JUNE BIRTHDAYS & ANGELVERSARIES

- Angelversary of Aagje Zwart
- Angelversary of Aayliah Daijah Lee
- Angelversary of Aidan Michael Williams
- Angelversary of Alekzander Aaron Aguirre-Carranza
- Angelversary of Alexander James Sievers
- Angelversary of Alexis Marie Hutton
- Angelversary of Alexis Nicole Vigo
- Angelversary of Ali A. Boner
- Angelversary of Allyson Belle Hensley
- Angelversary of Andrew Christian Riley
- Angelversary of Angel Sutton-McClean
- Angelversary of Angela Faith Zdravac
- Angelversary of Anthony Malachi Temons
- Angelversary of Arthur IV (A.J.) Carrington
- Angelversary of Ashton Lee Williams
- Angelversary of Austin Mangum
- Angelversary of Autumn Nicole Turner
- Angelversary of Berkley Lynn Roper
- Angelversary of Blake Donald Hanlon
- Angelversary of Braiden Shiloh Anthony
- Angelversary of Brandon Miller
- Angelversary of Braxton Ramsay Bice
- Angelversary of Brielle Theresa Santo
- Angelversary of Brody Center
- Angelversary of Cameron Lamond Hill
- Angelversary of Carleigh Sharon O'Rourke
- Angelversary of Chloe Elise Robertson
- Angelversary of Darrian Earl Adams
- Angelversary of Eden Olivia Coker
- Angelversary of Emily Grace Funkhouser
- Angelversary of Eryn Griffin
- Angelversary of Evan Joseph Downs
- Angelversary of Evie Nanette Hensley
- Angelversary of Gabe Edward Slager
- Angelversary of Gabriel Robert Kyes
- Angelversary of Gavin Michael Miller
- Angelversary of Gloria Joyce Meza
- Angelversary of Grayton Karleigh Creekbaum
- Angelversary of Hailey Elizabeth Steiner
- Angelversary of Hannah Sophia Gerhard
- Angelversary of Henry Liam Johnson
- Angelversary of Hunter Alan Casto
- Angelversary of Hunter Gabriel Moak
- Angelversary of Ian Riley Robinson
- Angelversary of Isabella Rose Endres
- Angelversary of Isabelle Yap
- Angelversary of Isaiah M. McQueen
- Angelversary of Jack Warren Payne
- Angelversary of Jackson Levi Durst
- Angelversary of Jacob Vincent Esparza
- Angelversary of Jak W. P. Foster
- Angelversary of James Thomas Naifeh
- Angelversary of Jane Olivia Lignana
- Angelversary of Jessica Hope Saunders
- Angelversary of John Daniel Friedlander
- Angelversary of Johnathan Michael McCormick
- Angelversary of Johnathan Robert Martin
- Angelversary of Johnna Hinklin
- Angelversary of Jordan James Knight
- Angelversary of Joseph Morgan Ashton
- Angelversary of Joshua Kelly
- Angelversary of Joshua Lee Stauring
- Angelversary of Kamden Grayson Babin
- Angelversary of Karter Kash Lusardi
- Angelversary of Katherine Ann DeGroot
- Angelversary of Kaydon Cullingworth
- Angelversary of Kegan Joseph Wright
- Angelversary of Laila Alana Carrero
- Angelversary of Laila Elizabeth Youssef
- Angelversary of Levy Chance Peloquin
- Angelversary of Liam Anthony Hunt
- Angelversary of Logan Edward Sanchez
- Angelversary of Logan James Samples
- Angelversary of Louis William Santamore
- Angelversary of Lydia Wilhelm
- Angelversary of Madeline Sentner
- Angelversary of Mahalah Theresa Arnold
- Angelversary of Mallory Ann Snively
- Angelversary of Marshall Cord Hendley
- Angelversary of Matthew William Neeley
- Angelversary of Megan Jane Allinson
- Angelversary of Michael Joseph Lovejoy
- Angelversary of Milo Jonathan Horner
- Angelversary of Nataly Rodriguez
- Angelversary of Nathan Daniel Scelfo
- Angelversary of Niall Martin Curry
- Angelversary of Nicolai Tikjob
- Angelversary of Noa James Thomas
- Angelversary of Oliver Thelonious Liddic
- Angelversary of Olivia May Halstead
- Angelversary of Patrick Samuel Murray
- Angelversary of Penelope Lane Spencer
- Angelversary of Piper Grace Jarvis
- Angelversary of Prince Mae'El Harris
- Angelversary of Reece Channing Kolke
- Angelversary of Reese Thomas Lauer
- Angelversary of Riley Nicole Soria
- Angelversary of Roslyn Renae Bailey
- Angelversary of Rowan James Keating
- Angelversary of Ryan Charles
- Angelversary of Ryan Matthew Mudderman
- Angelversary of Ryan Mitchell Toms
- Angelversary of Samantha McKennon
- Angelversary of Sean Anthony Feaster
- Angelversary of Selene Syne
- Angelversary of Skyla Manawa Te Maipi
- Angelversary of Sophia Lynn Collins
- Angelversary of Taylor Austin Runion-Hintzman
- Angelversary of Trislyn Annabelle Gregory
- Angelversary of Valek Hendrickson
- Angelversary of VinaBelle Maria Soliel Bifferato
- Angelversary of Vincent Steven D'Ulisse
- Angelversary of Willow Grace Burg
- Angelversary of Wyatt James Mullins
- Birthday of Aagje Zwart
- Birthday of Abbey Murphy
- Birthday of Abbey Von Gohren
- Birthday of Abdullah Habib
- Birthday of Abigail Hibbs Smith
- Birthday of Abraham Leo Lopez
- Birthday of Adam Joseph Donald McLaughlin
- Birthday of Adam Salas
- Birthday of Adeline Rae Hoffmann
- Birthday of Adrian Deylan Rivera
- Birthday of Aidan Michael Williams
- Birthday of Aiden Laine Griffith
- Birthday of Aiden Robert Grant
- Birthday of Aiden Schmitt
- Birthday of Aleah Lily Grant
- Birthday of Alexander James Sievers
- Birthday of Alexander LeStat Bardwell
- Birthday of Alexander T Bloom
- Birthday of Ali A. Boner
- Birthday of Alijah Penelope Fortiz
- Birthday of Allie Kathryn Wilson
- Birthday of Allison B. Wine
- Birthday of Allison Elizabeth Patton
- Birthday of Alvin Bjuvigord-Onnevall
- Birthday of Amanda Pauline Pagano
- Birthday of Amber Jade Jones
- Birthday of Anastasios Glykos
- Birthday of Andrew Christopher Ryan
- Birthday of Andrew Dean Jimerson
- Birthday of Andrew Joseph Pacan
- Birthday of Andrew Robert Snyder
- Birthday of Andrew Walter Jenkins
- Birthday of Angel Sutton-McClean
- Birthday of Angela Faith Zdravac
- Birthday of Angela Kirstin Reedell
- Birthday of Anthony Michael Pompeo
- Birthday of Arnold Todd Chleboun
- Birthday of Arthur IV (A.J.) Carrington
- Birthday of Arwyn Kathleen Doris Johnstone
- Birthday of Ashley John Davies
- Birthday of Ashton Lee Williams
- Birthday of Austin James Tanner
- Birthday of Autumn Nicole Turner
- Birthday of Ava Marie Medina
- Birthday of Ava Roberts
- Birthday of Axel Gabriel Booth
- Birthday of Azrielle Walker
- Birthday of Berkley Lynn Roper
- Birthday of Blake Donald Hanlon
- Birthday of Bob Marie King
- Birthday of Bradley Dean Bakos
- Birthday of Brandon Miller
- Birthday of Braxton Ramsay Bice
- Birthday of Braxton Tranell McLeod
- Birthday of Brendan Jeffrey Beck
- Birthday of Brennen M Loftus
- Birthday of Brian Daniel Jude Koerner
- Birthday of Brian Motyka
- Birthday of Brianna Teigen
- Birthday of Brianna Elizabeth Orr
- Birthday of Brielle Theresa Santo
- Birthday of Brock Richard Jones
- Birthday of Brody Alexander Daniel Scaggs
- Birthday of Brody Center
- Birthday of Brooke E. Weiss
- Birthday of Brooke Lynn Huson
- Birthday of Caden Andrew Parker
- Birthday of Caitlin L. Blair
- Birthday of Caleb Michael Russell
- Birthday of Cameron Lamond Hill
- Birthday of Camilla Niece Mazier
- Birthday of Caoimhe Aine Beare
- Birthday of Carley Blair
- Birthday of Carly Anne Cribben
- Birthday of Caroline Harpur Cassese
- Birthday of Caroline Mae Benson
- Birthday of Carter Brandt Kitchens
- Birthday of Cary Anne Smith
- Birthday of Case William Bourdeau
- Birthday of Castiel Daley
- Birthday of Chance McKenna Talamantez
- Birthday of Chase Owen Mosier
- Birthday of Cheer Ainsley Solove
- Birthday of Chelsea Elizabeth Smith
- Birthday of Chloe Elise Robertson
- Birthday of Christain Matthew Andrus II
- Birthday of Christiana Renee Wierschem
- Birthday of Claire Catlett
- Birthday of Cody Gene Washam
- Birthday of Cole Matthew Pamula
- Birthday of Connor John Boyle
- Birthday of Corey Dean Woodring
- Birthday of Cullen Lank Anderson
- Birthday of Dallas Cox
- Birthday of Daniel Vinicius Hisi Link
- Birthday of Danielle Marie Ranta
- Birthday of Darrian Earl Adams
- Birthday of Delancey Tannia Bailes-Hastings
- Birthday of Desirae M A
- Birthday of Drake Andrew Neeley
- Birthday of Dylan Galler
- Birthday of Eden Olivia Coker
- Birthday of Elijah Miffin
- Birthday of Elsa Monroe Lebby
- Birthday of Elyse Solange Maas
- Birthday of Emarosa Concepcion Lomas-Diaz
- Birthday of Emerson Anne Lough
- Birthday of Emily Grace Funkhouser
- Birthday of Emma Jayne Pecori
- Birthday of Emma Mackenzie Ava Newell
- Birthday of Emma McClary
- Birthday of Erin Leigh Chapman
- Birthday of Ethan Alexander Wiseman
- Birthday of Ethan Carney Moore
- Birthday of Ethan Michael Huizenga
- Birthday of Ethan William James Marchand
- Birthday of Eva Lucy Lizardi
- Birthday of Evan Andrew Tessmer
- Birthday of Evan Michael Brannon
- Birthday of Evander Fitzgerald Gunther



CDH INTERNATIONAL

JUNE BIRTHDAYS & ANGELVERSARIES

- Birthday of Eve Fabio
- Birthday of Evelyn Marie Godsey
- Birthday of Evie Nanette Hensley
- Birthday of Faith Adley Nolen
- Birthday of Faith Bennethum
- Birthday of Federico Antonio Michele Contu
- Birthday of Finn Heaney
- Birthday of Francesco Adattini
- Birthday of Freddie Jack Brown
- Birthday of Gabe Edward Slager
- Birthday of Gabriel Robert Kyes
- Birthday of Gage Inan Hoskins
- Birthday of Gage Jonathan Manes
- Birthday of Gavin A.N. Werner
- Birthday of Gavin Haynes
- Birthday of Gavin Lee Park
- Birthday of Gavin Michael Miller
- Birthday of Genesis Dyann Ortiz
- Birthday of Giannah Marie James
- Birthday of Gideon Pete Rericha
- Birthday of Gloria Joyce Meza
- Birthday of Godswill Munachi Anthony-Orji
- Birthday of Hannah Sophia Gerhard
- Birthday of Harper Elaine Yucka
- Birthday of Hayden Michael Reiling
- Birthday of Haze Anthony Godwin
- Birthday of Heather Patrick Weisenfels
- Birthday of Hillary Jayne Leipold
- Birthday of Hunter Alan Casto
- Birthday of Ian Robert Haynes
- Birthday of Ignatius Matthew Cartwright
- Birthday of Isaac Alias Ramos
- Birthday of Isaac Ervin Peterson
- Birthday of Isabel Howard
- Birthday of Isabel Nicole Smith
- Birthday of Isabella Rose Endres
- Birthday of Isabelle Yap
- Birthday of Isaiah Flores
- Birthday of Ivania Pivalica Freres
- Birthday of Jackson Keely McKay
- Birthday of Jackson Levi Durst
- Birthday of Jacob Bryan Allingham
- Birthday of Jacob Edward Sedgwick
- Birthday of Jacob Owen Richardson
- Birthday of Jak W. P. Foster
- Birthday of Jake Max Knoll
- Birthday of James Lawrence Randazza
- Birthday of James Martin Mackay Lane
- Birthday of Jamie Michael Clarke
- Birthday of Janessa Hope Vargas
- Birthday of Jared James Balow
- Birthday of Jaret Paul Spelich
- Birthday of Jase Richard Whitesel
- Birthday of Jaxtyn, Jacob and Chance Smith-Green
- Birthday of Jay Ashleigh Ogburn
- Birthday of Jessica Frances Margaret Tophen
- Birthday of Jessica Hope Saunders
- Birthday of Joel Archie Jacobs
- Birthday of John Mark Bennett
- Birthday of John Thomas Schwerdtfeger
- Birthday of Johnathan Michael McCormick
- Birthday of Johnathon Marshall Stanley Coleman
- Birthday of Johnna Hinklin
- Birthday of Jonah Alexander Carrier
- Birthday of Jonathan Nicholas Panetta
- Birthday of Jonathan Ross Markram
- Birthday of Jordan Xavier Bertolozzi
- Birthday of Joseph Morgan Ashton
- Birthday of Joseph Ray Hidalgo
- Birthday of Joshua Kelly
- Birthday of Joshua Lee Stauring
- Birthday of Josiah Sebastian Johnson
- Birthday of Juan Pablo Lopez Arce
- Birthday of Julian Deckard
- Birthday of Justin Michael Hildebrandt
- Birthday of Justin Robert DeMars
- Birthday of Justin Timothy Nelson
- Birthday of Kaden Lee Kruciak
- Birthday of Kaitlyn Romano
- Birthday of Kamryn Hope Studdard
- Birthday of Karter Kash Lusardi
- Birthday of Kaycie-Anna Brogan Maye Heneghan
- Birthday of Kaydon Cullingworth
- Birthday of Kayla Nicole Rubio
- Birthday of Kaylee Lyne Bentz
- Birthday of Keegan McCrea
- Birthday of Kegan Joseph Wright
- Birthday of Kelsey Sha Holiday
- Birthday of Kenna Ranae Howell
- Birthday of Kennedy Mann
- Birthday of Kevin Daniel Knight
- Birthday of Kevin Ison
- Birthday of Kimberly Chow
- Birthday of Kinzie Raye Wertz
- Birthday of Kirsten Leona Smith Leona Smith
- Birthday of Koleka Julia Casimir
- Birthday of Kyra Haley Landau
- Birthday of Laila Jaber
- Birthday of Landon Matthew Kelly
- Birthday of Landon Tyler Boothe
- Birthday of Laney Kate Daniels
- Birthday of Laura Allison Sumner
- Birthday of Laura Long
- Birthday of Laycee Marlatt
- Birthday of Lillianna Crystal Rose Gifford
- Birthday of Lillian-Sophia Meyer
- Birthday of Lindy Rose Spence
- Birthday of Logan Edward Sanchez
- Birthday of Logan Gavin Miranda
- Birthday of Logan James Samples
- Birthday of Logan Thorin Shouse
- Birthday of Logan Wehmeyer
- Birthday of Lorenzo Santos Valles
- Birthday of Lorraine (Raini) Whimsy Sublett
- Birthday of Louis William Santamore
- Birthday of Luca Belo Narvaez
- Birthday of Lydia Lavonne Faust
- Birthday of Lydia Wilhelm
- Birthday of Lyla Marie Dekoekkoek
- Birthday of Mackenzie Renee Aldridge
- Birthday of Maddison Allyn Ramsey
- Birthday of Madeline Sentner
- Birthday of Madelyn Rae Flannery
- Birthday of Malachi Reed Unrau
- Birthday of Malcolm Henry Wilson
- Birthday of Mallory Ann Snavelly
- Birthday of Mariah Grace Evans
- Birthday of Masingita Nyiko Mabasa
- Birthday of Mason Romeo Kroon
- Birthday of Matthew Ryan Peterson
- Birthday of Matthew Schroeder
- Birthday of McKenna Lynne Varen
- Birthday of Megan Jane Allinson
- Birthday of Melissa K Snapp
- Birthday of Michael Joseph Lovejoy
- Birthday of Mikaela Rozalia Wjutowicz
- Birthday of Milo Jonathan Horner
- Birthday of Mohammed Yaqeen Siers
- Birthday of Muhammad Abdul-Hakim
- Birthday of Myla Goss
- Birthday of Natalie Deitz
- Birthday of Natalie E. Banks
- Birthday of Nathan George Low
- Birthday of Noa James Thomas
- Birthday of Oliver James Ammons
- Birthday of Olivia Annette Gates
- Birthday of Olivia May Halstead
- Birthday of Owen W. J. Mulak - MacPhee
- Birthday of Paige LeighAnn Davis
- Birthday of Patricia Gutierrez
- Birthday of Patrick Allen O'Brien
- Birthday of Patrick Samuel Murray
- Birthday of Payton Rose Shoemaker
- Birthday of Phoebe Kleensang
- Birthday of Prince Mae'El Harris
- Birthday of Rachel Elizabeth Murphy
- Birthday of Rafael Armando Gomes
- Birthday of Reagan Stiles
- Birthday of Rebecca Lynn Sanche
- Birthday of Reece Channing Kolbe
- Birthday of Rex Piner- III
- Birthday of Rhett Talon Townsend
- Birthday of Ricky James Brock
- Birthday of Riley Francis Ortiz
- Birthday of Roberta Lynn Pawlowski
- Birthday of Rocco Edward Rymer
- Birthday of Roger Matthew Gentile
- Birthday of Roman Oropeza
- Birthday of Roslyn Renae Bailey
- Birthday of Ryan Alton
- Birthday of Ryan Charles
- Birthday of Ryan J. Richard
- Birthday of Ryan Matthew Mudderman
- Birthday of Ryan Matzuka
- Birthday of Ryan Mitchell Toms
- Birthday of Ryan Tindall
- Birthday of Ryder Douglas Gregory Moorehead
- Birthday of Sam Gibson
- Birthday of Samantha Chavez
- Birthday of Samantha Faith Cronquist
- Birthday of Samantha L. Burchart
- Birthday of Samantha McKennon
- Birthday of Sara Mondello
- Birthday of Sarah Ann McMerriman
- Birthday of Savanna Rai Payne
- Birthday of Savannah A. P. Bendik
- Birthday of Scarlett Ann Hesse
- Birthday of Scarlett Hanna Bowler
- Birthday of Sebastian Benoit Skelton
- Birthday of Sebastian Lawson Archer
- Birthday of Sebastian Walker Mclain
- Birthday of Selene Syne
- Birthday of Serena Grace Brent
- Birthday of Seth Keaton Van Dyke
- Birthday of Shannon Scharrer
- Birthday of Shelby Marie Nunes
- Birthday of Sherman Soh
- Birthday of Sherrie Lynn Roberts (Talley)
- Birthday of Shiann Rose Reedy
- Birthday of Sophia Hope Mesa
- Birthday of Sophia Lynn Collins
- Birthday of Sophie Davies
- Birthday of Stephanie Ann Thompson
- Birthday of Stephanie Tolley
- Birthday of Surabhi Akshay Mulki
- Birthday of Talon Kresh
- Birthday of Taylor Austin Runion-Hintzman
- Birthday of Taylor Marie Hallenback
- Birthday of Taylor Sindoni
- Birthday of Taylor Theresa Marie Murphy
- Birthday of Taylor Zoitos
- Birthday of Theo Jeremiah Haselman
- Birthday of Thomas John Hartigan
- Birthday of Thomas Mike Nash
- Birthday of Thomas Robert Jurkowski
- Birthday of Tiffany Sharon Bediner
- Birthday of Tom Eric de Groot
- Birthday of Travis Lee Fenn
- Birthday of Trenton Michael Lewis
- Birthday of Tristan Christopher Garbutt
- Birthday of Tyler John Kordus
- Birthday of Tyrell James Campbell
- Birthday of Valentina Mai Tran
- Birthday of Vincent Steven D'Ullisse
- Birthday of Walker Levi Woods
- Birthday of Weston Keith Manwill
- Birthday of William Andrew Monday
- Birthday of William Larry Lord-Gillihan
- Birthday of Willow Grace Burg
- Birthday of Wyatt Andrew Gill
- Birthday of Wyatt Thomas Allen
- Birthday of Zachary Moran
- Birthday of Zoe Aris Fisher



Editor's Note

The Father's Edition



Very often, dads are overlooked during a family's CDH journey. Mothers carry the pregnancy in most cases, in other cases, surrogacy, adoption and other alternative ways to become a parent offer different stresses. There are baby showers that focus on the mother-to-be, people ask how the pregnancy is going and the mother is the center of attention during labor, delivery and a major focus postnatally. In the cases where we lose children, people tend to check on the mother more often than the father.

Father's (and / or other partners and care-providers) are also invaluable in the life of a child. When you have a sick child with a life-threatening birth defect who may spend weeks or months in the hospital and may, or may not, come home... the stress is enormous on both parents.

Often, it is the fathers who must leave the NICU to go back to work, who must figure out how to cover the economic burden of CDH and sometimes relocating the family. They are looked at as a source of security and stability in a harsh storm, even though they are blowing in the storm as well.

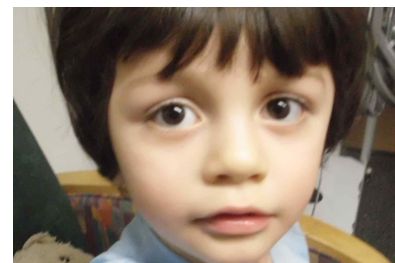
We dedicate this issue of the CDH Magazine, "The Silver Lining" to all the fathers, grandfather, stepfathers, adoptive fathers, foster fathers, single moms playing dual roles and all those who stepped up to be father figures to children born with CDH, with our hearts going out to the those grieving especially.

The stories in this issue are written from the perspective of some of the dads and we invite more dads to participate in the charity.

This issue is also dedicated to our dear friend, volunteer and CDH dad, David Finger. For those of who knew him, worked with him and called him a friend... our hearts are broken for his wonderful family and for this great loss to the whole CDH community.

We wish you all a wonderful Father's Day and appreciate all that you do on behalf of your children and all children born with Congenital Diaphragmatic Hernia.

DAWN M. TORRENCE IRELAND
President & Founder



CDH International Patient Advocacy Board

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



CDH INTERNATIONAL

MEET OUR VOLUNTEERS



Ben and Mary Lundeen
Volunteers

Ben and Mary Lundeen are sharing the Minnesota State position. Ben was born in 1989 with an undiagnosed CDH, had surgery and was placed on ECMO. Ben has learned to deal with his lung disease as he lives a happy and productive life. Ben is a licensed early childhood teacher, married with his first child on the way. Ben enjoys gardening, all sports, and fantasy leagues. Mary, a Child Psychologist, is scaling back her practice to have time for volunteering. Mary is in a Writer's studio, is published, and enjoys reading. She is also an activist for children's rights. Ben and Mary hope to make a difference for families.

I'm Heather Kerbow originally born and raised in Dallas, Texas but met the love of my life and secured my first teaching position in a little town called Uvalde and moved down in 2014 to start my teaching career and be with the love of my life Paul. I have a BA in Theater from the University of North Texas as well as a teaching certificate in ESL Ec-6. I am currently in school to completely change career fields and become an Occupational Therapy Assistant. As well as a stay at home mom to my CDH star Robert. I have a strong desire to help those who are facing challenges and be a source of support and comfort whether newly diagnosed or facing a set back. You have everything correct on the PDF. And as I said in teams the other night if you need someone to take over support/prayers for you I have no problem doing that.



Heather Kerbow
Volunteer



Tracy Meyer
Volunteer

Tracy Meyer is the proud mother of Lillian Sophia Meyer, born on June 7, 2011 at North Shore Long Island Jewish Hospital (Stephen & Alexandra Cohen's Children's Medical Center). Tracy found out unexpectedly that Lillian was diagnosed with left-sided CDH during her 36-week sonogram. With the love and support that was given to her from friends and family near and far, Lillian proved the world that she is a fighter. After a successful surgery 3 days after she was born (which was performed laparoscopically), Lillian was in the hospital for almost 2 weeks and came home on Father's Day. Known as the "miracle angel," Lillian still amazes everyone to this day how strong of a fighter she is.

Tracy currently resides on Long Island, New York alongside with her beautiful daughter and son. In order to spread awareness and provide moral support, Tracy has been a CHERUBS volunteer for New York since June 2012. Tracy has been working in the accounting profession since 2003, and she loves spending time with friends and family.



"THE INCREDIBLE ONES"

NEW CDH SONG



We are very grateful to Amber Sweeney for lending her talent to our charity to help raise awareness of Congenital Diaphragmatic Hernia.



Artist Bio

Amber Sweeney is a highly sought-after performer and songwriter who sings from the depths of her soul and uses the power of her voice to unlock curiosity and compassion in those who hear it. Amber's voice, musical talent, and songwriting have been featured in two CW television series: *One Tree Hill* and *Life Unexpected* while one half of the duo *Everly*. Another original song and performance by Amber was featured on television show *Queen Sugar* in collaboration with Italian artist Michael Prado. Her voice has also been featured in Stephen King's film adaptation of *Riding The Bullet*, while bass player and backup singer for the rock band *Enation*, and also had a song reach #1 on the indie soul charts in the U.S. and U.K. Most recently Amber can be seen playing songwriter rounds in Nashville, was a semi-finalist for the 2021 Independent songwriter competition, and was a runner up for Tennessee's Songwriter week in 2022.

LYRICS

Your dad and I were just nineteen
Excited for our little baby
We had so many dreams
Of all the things you would be
There was sudden confusion
As the doctors whisked you away
Nothing could have prepared us
For what happened that day
We held our breath
As you were fighting for yours
Not knowing how much time we'd get
Would it be days, months, or more

We'll be your champions
We'll fight for you everyday
We'll be the advocates
Making sure everyone knows your name
You won't be invisible
You won't have to go this alone
We'll do the impossible
And we'll do it all for you
The incredible ones

There's so many of us
Who keep fighting for care and answers
Survivors and families
Relentlessly helping each other
For every angel
That flies away we remember
We'll keep marching on
For the ones that we hold dear

We'll be your champions
We'll fight for you everyday
We'll be the advocates
Making sure everyone knows your name
You won't be invisible
You won't have to go this alone
We'll do the impossible
And we'll do it all for you
The incredible ones

The incredible ones
The incredible ones
We'll be your champions
For you, the incredible ones



CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH CDH RESEARCH UPDATES

JASON MILLER, CDHI RESEARCH DEPARTMENT

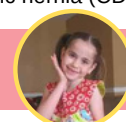
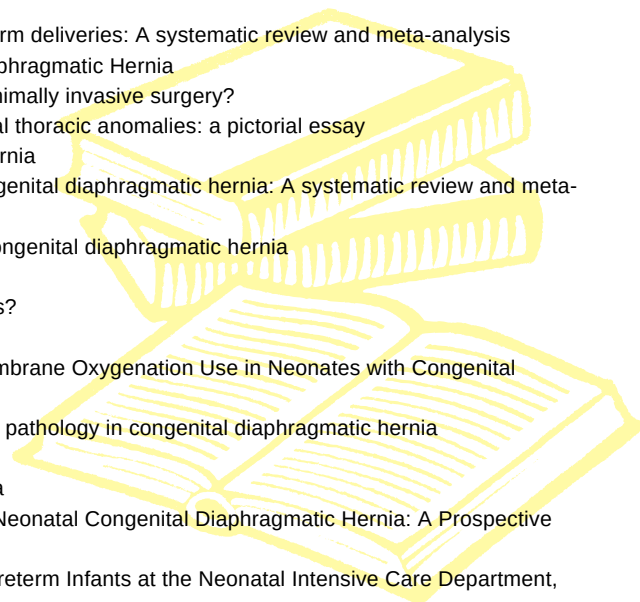
CDH International will be presenting a research poster titled "Congenital Diaphragmatic Hernia: Patient Parents As Partners" at BDRP 2023 in Charleston, SC. The study evaluated the patient-family experience in CDH care, focusing on the financial and emotional toll on families who relocated for medical care. They surveyed over 4,500 CDH families and identified gaps in collaboration between Patient Parents and Medical Care Providers. The study also addressed the need for standardized care and measurements, as well as research priorities in CDH. The findings highlighted frustration among families regarding insurance approvals, school IEPs, and the lack of accurate information. There is a desire for more research and collaboration to improve long-term quality of care and enable informed decision-making.

In addition to assessing the patient-family experience and collaboration gaps, the study explored the opinions of CDH families on research priorities and global standards. The survey revealed a strong desire for more focused research that directly benefits ongoing CDH care. Families also emphasized the need for standardized care guidelines and measurements of mortality and morbidity. Many families reported feeling pressured to seek medical care outside their local region due to a lack of reliable hospital-specific data. The study highlighted a disconnect between the CDH Research Community and the CDH Patient Community, underscoring the importance of increased collaboration among research institutions. By establishing standards of care and measurements, the overall quality of CDH care can be improved, empowering patients and families to make informed decisions regarding their treatment.

DARLENE SILVERMAN, CDH RESEARCH LIBRARY

This month's additions to the Congenital Diaphragmatic Hernia Research Library:

- Congenital diaphragmatic hernia survival in an English regional ECMO center
- Extracorporeal Membrane Oxygenation for Neonates With Congenital Diaphragmatic Hernia: Prevalence of Seizures and Outcomes
- Prognostic value of echocardiographic parameters in congenital diaphragmatic hernia: a systematic review and meta-analysis
- Differences in prenatal diagnosis rate of congenital anomalies associated with singletons and multiple births: An observational study of more than 1.9 million births in Zhejiang Province, eastern China, during 2012-2018
- Neonatal outcomes of congenital diaphragmatic hernia in full term versus early term deliveries: A systematic review and meta-analysis
- Racial and Ethnic Disparities in Outcomes Among Newborns with Congenital Diaphragmatic Hernia
- Para-conduit diaphragmatic hernia following esophagectomy-the new price of minimally invasive surgery?
- Prenatal ultrasound, magnetic resonance imaging and therapeutic options for fetal thoracic anomalies: a pictorial essay
- Brain cortical assessment by MRI in fetuses with left congenital diaphragmatic hernia
- The grading of stomach position for postnatal outcomes in isolated left-sided congenital diaphragmatic hernia: A systematic review and meta-analysis
- Beyond the diaphragm and the lung: a multisystem approach to understanding congenital diaphragmatic hernia
- Inhaled nitric oxide use in newborns
- Do FETO CDH survivors need the same follow-up program as non-FETO patients?
- Laparoscopic Repair of a Right-Sided Diaphragmatic Hernia: A Technical Report
- Failure to Normalize Biventricular Function is Associated with Extracorporeal Membrane Oxygenation Use in Neonates with Congenital Diaphragmatic Hernia
- In utero delivery of miRNA induces epigenetic alterations and corrects pulmonary pathology in congenital diaphragmatic hernia
- Treatment of Esophageal Perforation: Endoscopic Vacuum-Assisted Closure
- Longitudinal Health Status and Quality of Life in Congenital Diaphragmatic Hernia
- Assessment of Antenatal and Postnatal Prognostic Indicators in the Outcome of Neonatal Congenital Diaphragmatic Hernia: A Prospective Observational Study
- Factors Associated With Emergency Department Visits or Readmission of Late Preterm Infants at the Neonatal Intensive Care Department, National Guard Health Affairs, Riyadh
- Sex-specific Differences in Congenital Diaphragmatic Hernia Mortality
- Role of MAGI2-AS3 in malignant and non-malignant disorders
- The myocardial capillary network is altered in congenital diaphragmatic hernia in the fetal rabbit model
- Maternal-fetal surgery as part of pediatric palliative care
- Synthetic versus Biological Patches for CDH: A Comparison of Recurrence Rates and Adverse Events, Systematic Review, and Meta-Analysis
- The upper airway parameters: the potential diagnostic clues for congenital intrathoracic lesions
- Morgagni hernia presenting in a 68-year-old patient treated for pneumonia
- Difficult airway management and low Bispectral Index (BIS) in a patient with left Bochdalek congenital diaphragmatic hernia (CDH)



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



ELIZIA CHICOINE

CDH Angel, Canada



At the 30th week of pregnancy, we found out our little daughter had an important deficiency in her thorax called Congenital Diaphragmatic Hernia (CDH) – (1 in 2500). The doctor's prognosis gave us only a 20% chance that our daughter would survive. Even after that news we decided to follow through with the uphill battle and having to be at the hospital on a daily basis for meticulous follow ups on our baby's development.

The bad news just kept coming, and we found out that Elizia was also having problems with her heart. The last two months of pregnancy where plagued with unbelievable ups and downs and the burden of the unknown. However, we were very well informed as to the nature of the problem and what type of treatment Elizia would need at birth. The most important thing we needed to understand was that the hole in her diaphragm was causing her vital organs (stomach, intestines, liver) to push against her rib cage and was preventing the normal development of the lungs. However, it was impossible to determine, until Elizia would be breathing on her own, what type of pulmonary tissue was in place to allow a real chance of survival.

On December 14 we were admitted to the hospital to induce labour. At 3 p.m. my extra-super, beautiful little girl was born, and her vital statistics were quite good considering her condition. Her chances of survival were then upgraded to 50%. The first treatments went so well that when they were ready to transfer her to CHEO, they gave us a 70% chance that Elizia would survive.

CHEO (Children's Hospital of Eastern Ontario) - During the transfer from the General hospital to CHEO many complications where beginning to arise. Elizia's pulmonary pressure began to rise and her prognosis was reverted back to the same as before the delivery. The goal in the first 8 to 10 days was to stabilize her pulmonary pressure while keeping a good blood pressure. Since only one lung was present in the echogram, we had to hope that it would be enough to allow future development after the operation. Many medications were administered to her through intravenous to help her get through the critical first few days. She needed to be hooked up to a special ventilator to help her breathe and supply enough air to maintain her vital statistics. One of the essential medications used to prevent her from fighting the ventilator was Pavulon. It would paralyze her and prevent her from suffering too much because she couldn't breathe normally.

YOYO (ups and downs) - During her 9 days of life, Elizia was a living yoyo as many different levels were attained. The first was at her birth when she showed signs of improvement. Then the first down was when she was transferred to CHEO and was put on a special ventilator. On the second and third day her vitals improved greatly, but on the fourth and fifth things turned worse again. So much so that when an echogram was done on the Monday after her birth (the fifth day), the neonatologist noticed a deterioration of the pulmonary mass which diminished all hope. It was at that time that we realized our daughter would not win this fight. We were then told that if there were no improvements by Friday we would need to make a decision. After the terrible news, we needed to gently prepare our daughter for her journey towards the light. While we were preparing, our little Elizia had a week of great improvement to which point the doctors told us she would make it to the surgery. The surgery consisted of lowering all the organs stored in the thorax and repairing the hole in the diaphragm. The Thursday before the fateful day was the best Elizia had, we could definitely see some major progress.

The last day and the last moments - Around midnight, the doctors on hand were trying a maneuver in the hopes of lowering the O₂ levels for the operation. This maneuver turned out to be Elizia's final rites since her reaction to it considerably increased the pressure of her lungs. The doctors announced to us that that night would be critical and to be prepared for anything. Around 4 a.m. they informed us that Elizia had continued a downward spiral and they were trying to stabilize her but that it wasn't working. All we could notice was the dwindling numbers of O₂ and NO₂. I will always remember the multiple critical moments and the decision that we had to inevitably make. The main neonatologist was called and upon arrival I cracked. I understood the end had come.

Everyone who was asked to assist in the final moments was called: family, friends and missionaries. The Elders had graciously blessed us and Elizia the day before not knowing that that she was in her final moments. The time had come to make sure the day would pass in peace, harmony and serenity to accompany our little Angel towards the light. We were told that Elizia would be brought into a private room where we could spend our last moments with her. She was placed on a special respirator that was used to keep her alive. The intensity was at its maximum in this room where Elizia would spend her last moments. Everyone was saying their goodbyes, and I was feeling great enlightenment mixed with great sadness. I felt I had the chance to help this little soul find enlightenment but at the same time my daughter was leaving me. I will never forget those magical moments.

Many minutes later it was time to finally disconnect our little girl and to let her rest in peace. We were informed that when she was disconnected that she would only live a few minutes. And that is exactly what happened. We had just enough time for a final prayer and to sing her a song to accompany her through the passage of her soul. The four hours that followed were precious hours were Mommy held her daughter with love. The first steps of her grieving process.

Today the mourning continues its path, and I am filled with gratitude towards this Angel that was sent from heaven to help me grow and give me strength to realize my new potential. I will never regret anything. Having our Angel for 9 precious days has made me the happiest man in the world.

Written by Elizia's dad, Gabriel Chicoine (Canada) in 2006



CDH AWARENESS UPDATES

MELLISSA REAVES, CDHI AWARENESS DEPARTMENT

Raising awareness for Congenital Diaphragmatic Hernia can be done all year long. There are several ways that you, your CHERUB, and family and friends can help raise awareness for our CDH community. Coin jars are a great way to help raise awareness and funds. You can get creative and place a picture and summary of your cherub in the jar and ask places such as: gas stations, local business, restaurants, etc.. if they would be willing to let you place the jar at their establishment and this too gives you an opportunity to raise CDH awareness by sharing your story with various people. Other ways to raise awareness are hosting bake sales, making crafts to sell and placing information about CDH and your CHERUBS story with your event. In most places, farmers markets are happening and you can always set up a space to sell your goodies or to just simply share your story and educate others about CDH. You can also contact your local news stations and news papers and share your CHERUBS story and how they are raising awareness.

As summer time approaches, the weather is warming up and summer fun activities are being planned. This is a great time to set up lemonade stands or even a snow cone stand like the one CHERUB Lindsey recently ran to help raise awareness and funds for CDH International that was mentioned in last month's magazine issue! Not only is this a great way to raise awareness, it's also a very fun way to do so. This is also a good learning experience for children, teenagers and even adults. This would give the younger age groups a chance to run their own "business", learn how to exchange money and disperse change to customers, they get to learn how to speak with others and share their journey and having their voices be heard! Family members can get involved by doing the same and helping their CHERUBS or angels story be heard and shared within your community.



CDH Survivor, Alie, and her little brother, Ryder.

JOIN THE ANGEL CLUB



Have you ever wanted to help CDH babies but aren't sure what to do?

Have you ever wanted to be a philanthropist?

Did you know that you can help fund the fight against Congenital Diaphragmatic Hernia for as little as 3 cents a day? Or if you skip Star-bucks coffee for just 2 days a month, you can donate over \$200 a year in honor or in memory of someone you love!

You CAN make a difference! Simply by making an automated, monthly tax-deductible donation, you are helping our charity to help babies born with CDH and their families. And you can even do so in honor or in memory of your own cherub.

Sign up now at <http://www.cdhi.org/angelclub>



Dad's Corner

BY JEREMY TORRENCE
REPRINT 2001

Well, it's been a few years since I wrote a Dad's Corner column so I figured I would write another. In case you don't remember what I wrote or you weren't a member then, I'm going to recap on what I had said.

When Shane was born and in the hospital I guess you could say I was kind of the silent partner in our marriage. When it came to making decisions about Shane and his care I didn't know what to say. I was scared of making the wrong decisions. Here was this fragile child who needed his parents to speak out and be his voice, but mommy was the only one speaking. When we had care conferences, bedside meetings or any dealings with the doctors, Dawn was the voice of the family. Here I am the man of the family and I'm scared to death to voice my opinion about the care my son should be getting. I am very, very grateful for a wife like Dawn. She wasn't intimidated by anything, especially doctors. She told them what she thought was the best care for Shane, and she was always right. If she didn't know a solution, she researched enough to make the doctors weigh all the options before they did anything. Why I didn't have the nerve to tell the doctors this I still don't know. I wish I would've been there for Shane and Dawn more while he was in the hospital. I had to go back to work and only saw them on Wednesday nights and on weekends, so I missed a lot.

When Shane finally came home I still relied on Dawn for making decisions about his therapies and doctors appointments. I was like the gopher, if they needed something I made sure they got it. Then I realized that I wasn't being the dad I wanted to be. I started voicing my opinion, doing things I should have been doing all along. When Shane started school, I took him everyday and was learning sign language too. He became my little shadow, everywhere I went, he went. I only wish I would have done all this earlier in his life. He went riding with me, fishing with me, basically everywhere with me except work. You could see a big difference in him and me. I was starting to act like the dad I was supposed to be, the dad I wanted to be. I can't believe I missed out on doing things with him the first 2 years. I don't know why I acted that way, but I'm glad I changed, for my sake and his.

Now I look back and wish I could turn back time to fix what I didn't do, but everyone knows you can't. I'm glad I saw the light and straightened up myself and became an influence on his life and care before it was too late. After losing a child it really makes you look back on his/her life and see all the things you've done whether it be good or bad. Losing a child is hard on both the mom and dad. Being the dad, people always think that you are supposed to be the strong one. Boy, are they wrong. When I'm by myself I think a lot and that's when the emotions normally hit me. When I'm riding home from work, going to the store, or going anywhere by myself. I guess this is because Shane went with me everywhere, the passenger seat in my truck was his. Sometimes I look over and think I see him sitting there, I want to see him there. Dads go through emotional stages too but it seems like everybody consoles the mom. I know that some cases are different but most I've seen this happens too. We are hurting too.

So Dads, if your acting anything like I did the first few years, its time to change, for you and your child. Spend time with them, be involved in there care, voice your opinion. If your child is sick or healthy, please don't take the time you have with them for granted. You may never know how much time you have with them. And if you've lost your cherub, know that it's OK to grieve too and not be afraid to show how much you loved your child.

Jeremy Torrence, father of Shane Torrence (1993-1999)

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>





ZOE FISHER

CDH ANGEL, UNITED STATES

It was June 03, 2009. My daughter, Zoe Aris, had just been born. What should have been my first chapter in parenting, turned out to be, my first chapter on a whole new life. Zoe suffered from a condition known as CDH (Congenital Diaphragmatic Hernia). Going through the ups and downs with her, threw my world into a blender and hit frappe. What came out has been a change of career and a softer, more caring heart.

It was warm that evening, mild compared to normal North Carolina summer temperatures. Even the mild temperatures didn't keep my body from pouring sweat. I was on edge, wanted to scream, wanted to be anywhere else but there. I hated hospitals and the people in them. I walked through the darkening parking deck, toward the entrance to Brenner Children's Hospital.

I had a deep seeded belief, that hospitals were a place to die, a place to escape from life and be free. As I would hear people talk about children being sick and close to death, I would want to tell their parents or family to be happy, not sad. That if their child did not make it, they could smile knowing that they would not have to grow up in this world. All life ends, better sooner rather than later. Now, it was my child in the hospital and I didn't know how to handle it.

Walking into the hospital was a blur and suddenly I was on the sixth floor, walking down a long hall. The walls were lined with pictures of smiling children. All of them with captions, thanking various people and hospital departments for saving their lives. I imagined that one day my own child would be gracing the hall with her own smiling face and words of thanks. The reception desk was at the end of the hall, in the corner of a large open waiting room. I did my best to hide any shakiness in my voice as I approached the chest high wall around the desk.

"Aaron Fisher, to see Zoe Fisher."

Due to my blurring reality, it was a faceless and bodiless entity that answered me. "Mr. Fisher, she has just arrived. Give me just a moment to make sure you can go in." stepped back from the desk to lean against the nearest wall, while I waited. I swallowed hard in a vain effort to push my heart down my throat, where it had lodged itself, back to where it belonged.

"Mr. Fisher, she's ready. When you hear the buzz, just push the door open." I nodded my understanding and stepped toward the door.

Buzz. Click. I pushed open the surprisingly heavy door. Nothing had prepared me for what greeted me. The air smelled clean, not the freshly washed clothes clean, but the absence of smell clean. Darkness from lights turned low. My eyes were slow to adjust. Like turning the dial on a microscope, the room came slowly into focus. Babies in Plexiglas boxes, some so small they could not fill a grown man's hand. Countless tubes filled with various fluids, attached to arms, feet, and chests of every small child. The sound of clicks, pings, beeps and bells surrounded and assaulted me. I stood still; my feet dug deep roots to support me as they would a mighty oak. Not sure what to do or where to go, my mind told me to run and hide; however, my feet and my heart could not leave my little girl.

A woman in light blue scrubs walked up to me then asked if I was Zoe's father. All I could manage was a slight nod of my head. She guided me to a wide, open room. There were at least two other babies in the room. Both in their Plexiglas boxes and being attended to by other nurses. My eyes drifted slowly around the room, seeing everything but keeping information as a box with no bottom holds water. Then I saw her, my little Zoe, in her own Plexiglas box. Two nurses were at her side moving lights around, adjusting sensors, and watching monitors that had been placed prior to my arrival.

One of the nurses, feeling my presence, turned to me. She was smiling but the smile felt faked, as if she was just about to pretend to be joyful.

"You must be dad." Her voice was soft with a strange air of peace within it.

My voice was lost, hiding in the depths of some dark part of me, not wanting to be found. So I just nodded, not allowing my eyes to be drawn away from my daughter.

She told me who she was but all I heard was Zoe's nurse. She continued to speak; the shock of where I was, as well as, why I was there drowned out all her talking. I do not even know if I spoke to her or just stood, silent and unresponsive.

The nurse turned, spoke to whom she was working with, then walked off. Maybe it was minutes or perhaps hours. I'm not sure but it felt like time stood still while it raced past at the same moment. The nurse returned with a small folding chair under her arm. She set it down telling me to take a seat. I tried to comply but my body stood frozen, not wanting to work. She helped me sit down informing me that Zoe's doctor would be around shortly to check on Zoe and to speak with me.

As I sat waiting for the doctor, my eyes never left Zoe. I stopped just seeing her and actually saw her. She lay very still, no movement other than her chest moving up and down in rhythm with a pfft, pfft, pfft sound I could hear. White tape, on her chest, holding down wires that ran to a monitor where three lines bounced up and down, while numbers constantly fluctuated. A clear tube had been inserted into the side of her chest. Her arms and legs were blue, from toes and fingertips up to where they joined her body. A tunnel closed around my line of sight so all I could see was her face. No tubes or anything had been attached to it. Zoe's eyes were closed; she appeared to be sleeping peacefully, unaware of anything going on around her. My heart started to pound; ready to burst out of my chest. I began to cry silently. Trying to be strong, I fought them back allowing only a couple tears to escape my eyes and run down my cheeks. I began to pray.

When Zoe's doctor, Dr. Petty arrived, he had an entourage of doctors in training with him. They walked past me and straight to Zoe's side. I couldn't hear what he was saying, but he was speaking to the group, I assumed about Zoe and her condition. After his apparent lecture was over, he stepped towards where I sat. I wanted to stand but I knew I wouldn't have the strength to hold myself up.

"Hi Aaron. How are you holding up?" He asked in the friendly, yet serious way he always was. He extended his hand in greeting and compassion. Dr. Petty always carried himself in a caring, serious way. A calm would fall onto any room he walked into, no matter how chaotic or stressful the situation. I used what little energy I had to shake his hand.

"Hey, Dr. Petty. I'm hanging in there I guess." My voice had a little shake to it. "How does she look?" I readied myself for the worst of news.

"She is a very beautiful little girl. If you remember when we spoke a few months back, I had told you Zoe was very sick. This remains true but we will do every thing we can for her. First, we need to get her stabilized. You probably noticed the blue color of her upper and lower extremities." I nodded. My body had gone numb while I listened to him speak but the urge to run had abated for the moment.

"She isn't getting enough oxygen into her blood, to be carried to her arms and legs. That isn't a surprise, since we already knew she would most likely have just one functional lung. The problem is that that one lung has collapsed two times. We have had to refill it and the ventilator she is on will, I am hopeful, start to deliver the oxygen her body needs.

"She is also having trouble maintaining her body temperature. So, if you look just above her, we have a heater. This should help her stay warm. We also have her getting the basic nutrients she needs through an IV, we don't want to start any kind of milk or formula till after she has her surgery. Are there any questions or concerns I can answer or address for you?"

I took a deep breath; trying desperately to take in and understand everything he had just told me. I knew there had to be more information, more going on with Zoe, but I was grateful he didn't overwhelm my already troubled mind with everything. After a few seconds I asked the only question I could think of. "Is she feeling any pain?"

In his soft-spoken way he said, "No Aaron. Zoe feels no pain at the moment. We have her on medication to keep her comfortable, so she can focus on resting and getting stronger each day."

A small relief washed over me knowing that at least she couldn't feel the pain from the tube in her side or from the IVs that were in her. "Thank you. So what comes next?" I couldn't seem to remember everything we talked about before.

Dr. Petty looked over his shoulder at Zoe then turned back to look at me. I saw both confidence and concern in his eyes. "Before we start looking down the road, to our next step, she has to stabilize. Zoe needs to get stronger and be able to get oxygen throughout her body. If she can't we will have to look at giving her a helping hand, by putting her on ECMO. We have a long road ahead of us, there will be ups and downs. What we need is to have more ups than downs. Then we can start looking ahead to the surgery. But, what Zoe needs the most, is for her mom and dad to stay healthy. So you can be with her. You both need sleep."

"Thank you again Dr. Petty. I'll try to go take a nap at least. I'll be back in a few hours." I felt a sudden fatigue wash over me. I knew she was in good hands. I knew that Dr. Petty would do everything he could to help my baby girl.

"You just go get some real sleep Aaron. I'll call you if we need anything or just to update you."



"Okay. I'll try." I looked over at Zoe. "Bye my sweet Zoe, Daddy will be back soon and mommy can't wait to meet you." With that, I blew her a kiss and headed back to my wife and maybe get a little sleep.

I walked into my wife's hospital room. Erin was passed out from the pain medication she was on. I sat down onto what had to be the hardest cot known to man, sleeping on a concrete slab would have been softer. I lay there for several minutes, unable to sleep, my mind playing over and over, everything I had just seen. I allowed myself to half cry once again as I slowly drifted off to sleep.

I sat up quickly. Disoriented, groggy and my right hip was playing music very loud. I took my phone and looked at the caller ID, it was Brenner's. My heart sank; my first thought was she wasn't doing well and that my baby girl was not going to make it. I didn't want to answer the phone but I did anyway. —Hello? —Hello. Is this Aaron?!

"Yes, this is Aaron."

"This is Dr. Petty." He sounded different on the phone, still soft-spoken, still serious, but now there was a caution to his voice.

I started to panic. "Is everything alright? How's Zoe?" I felt my pulse quicken as my heart went from 0 to 60 in 3.1 seconds.

"We are still having difficulty keeping Zoe's oxygen level up. I feel that for Zoe, the best option will be to put her on ECMO, which should stabilize her oxygen level enough for her to start getting stronger. I need your authorization to do the operation."

I tried to be strong, but I did not think I could ever be strong enough. "Okay, what does this mean for Zoe? What should I expect?" I fought back my tears, keeping the floods of Noah from breaking free.

"This is one of those obstacles that we knew was a possibility and had spoken about. I am very confident that ECMO is the right step to take, to give Zoe her best chance to live. I have to tell you, that with this operation, there is a risk of infection or even that Zoe will not survive."

I understood the legalities of having to hit me with the rocks of possibility but it was still tough to hear. I had to know just one thing, so I asked it. —If we do not put her on ECMO, what are her chances? I needed to know, even if I would not like the answer.

"In truth, I feel that without ECMO, Zoe may be able to live another few days at the most. Her body is working so hard to try and deliver the oxygen she needs, but like you and Erin, Zoe needs to rest. She needs to get stronger and I feel that ECMO can give her the best chance for long-term survival." I could feel the truth and conviction behind his words.

Knowing this was Zoe's best Chance; I gave my consent. Dr. Petty gave the phone to a nurse, who for legal reasons, had to verify my consent. I was told that Dr. Petty would call me as soon as the operation was complete to give me an update.

I sat at my wife's side, holding her hand and watching the clock, as time slowly clicked by. I prayed, I cried, and I lied about the seriousness of things to my wife. Three grueling and gut wrenching hours passed, before my phone rang again.

I jumped and fumbled with my phone, trying to answer it. "Hello, How is she?" the words came out so fast I was sure it was just one word.

"Zoe is doing well. She is starting to stabilize and her color should be much better when you come see her. Her oxygen levels are up because the ECMO machine is putting the extra oxygen she needs into her blood for her. Also, when you come to see Zoe, we had to move her to the PICU. She has her own room and will be under supervision and care twenty-four hours a day." Relief washed over me. I told Dr. Petty thank you and that I would be there soon.

The next ten days passed without major incident. Zoe was recovering from the ECMO operation; she was gaining strength and becoming even more stable. I spent every waking moment with her, reading The Hobbit to her, listening to music with her, holding her hand and talking to her. As her strength grew Zoe would grab hold trying to squeeze my finger; I allowed myself to hope. She was now strong enough for the surgery that, could very well, decide the outcome of her life.

The day before her operation Dr. Petty spoke with us. "Zoe has made it through so much already and is ready to take the next big step, to correct the hole in her diaphragm. The procedure on Zoe will be very long. I know we have talked in the past about it, but I want to go over it again now. What we are going to do is move all the organs that moved up into her chest through the hole in her diaphragm, and put them back where they belong. Then we will be using a mesh-like patch to close the hole."

I nodded understanding as he spoke. All this we had already talked about, but then he hit me with the proverbial two-by-four.

"There is a chance that her abdomen will not have room for us to place all the organs back where they belong and still be able to close her belly around them. If this is the case, we will have to leave some of her intestines on the outside of her, in a protective sack, until her skin has grown enough for us to finish the process. In that situation her risk of infection would increase greatly. My hope is that we won't have to worry about that and we will be able to just focus on her progression of healing and growing after the surgery."

I spent the remainder of the time before her surgery, holding her hand and just silently praying over her. That time passed by very quickly and before I was fully ready, it was time for her surgery. As they were finishing preparations to take Zoe to the operating room, I kissed her forehead and told her, "I love you Zoe. I'll see you soon." I held back my tears making sure I didn't sob, at least not in front of Zoe. My inner fear was that I had just said good-bye to my daughter and that I just looked into her eyes for the last time.

I took my wife's hand and together we walked to the waiting room where our parents were waiting. We told them that Zoe was being taken to the operating room and that we didn't want to wait here but down the hall in the "Ronald McDonald House" room.

The Ronald McDonald House was a quiet place, similar to how I imagined old libraries would be. We had to sign in and say whom we were visiting in the children's hospital. When we entered, I noticed no one other than the receptionist was in the room. I was relieved to have the whole large room empty and to ourselves for the moment. The six of us found a secluded corner to sit and wait.

I sat in silence, next to my wife, holding her hand. I didn't know what to do or say. My mother led us in prayer, for Zoe and for the doctors operating on her. After several minutes passed by I stood up. The uncertainty and fear of never seeing Zoe alive again was eating away at me. I felt bits of myself fall off into an abyss of despair. I walked over to one of the windows and looked out at nothingness. I could no longer see what was in front of me; I was dazed and lost, floating in my own sea of confusion. Even being in the large open room, I could feel the walls closing in around me. I felt the crushing weight of my fear surrounding me, pressing me and trying to squeeze every ounce of hope out of me. I had to run and hide. I needed air. I needed Zoe. One of our parents approached me putting their hand on my shoulder. I told them I had to go get some air then left the room. I took the closest elevator to the top floor.

The top floor had a way to go outside onto the roof of the hospital. There was a small empty playground with several benches. I found the furthest corner and sat down against it.

I began to talk out loud to myself. "Why is this happening? No child or parent should have to feel this. Why me and why Zoe? Why did Zoe have to be born with CDH?" What really scared me was when I started to answer myself out loud. "Because you don't care about others. Because you wished others pain, that they didn't deserve. Because you stopped trusting in God." I'm sure if anyone saw me or heard me, they would have had me locked away in an asylum.

I pulled my knees close to my chest, rested my head on them letting the tears flow freely. I cried, I prayed, and I cried some more. I don't know how long I sat there, but eventually I stood up. I felt a peace and a freedom I had not felt since everything with Zoe began. Refreshed and somehow full of the knowledge that I would see Zoe again, that she would survive the surgery; I went back inside to finish the long wait with my wife and family.

I walked back into the McDonalds House room and back to the secluded corner we had all taken up. Erin asked me if I was okay. I told her I would be fine and gave her a hug. While I held her I told her that Zoe was going to be fine. We both started to cry. My tears were no longer of anything other than relief.

An hour or so later my phone rang. I answered it. The nurse on the other end told me that everything with the surgery went well and that Dr. Petty would be calling me after Zoe was brought back to her room. I told her thank you hanging up the phone.

I looked up and everyone was looking at me, waiting on me for word on how Zoe's operation had gone. I smiled telling them everything went according to plan and that now we just had to wait for the doctor to call so we could see our precious little Zoe again. We hugged and cried. I even allowed myself to laugh and relax. I felt a renewed sense of hope and allowed myself to look forward to a future with my daughter.

As I have been remembering and writing this, Zoe would have been celebrating her second birthday. Due to the efforts of the children's hospital, I was able to spend four and a half months with Zoe, when the most likely outcome would have given me a week or less with her. After looking back on her life and asking myself, what could have been? I decided I wanted to be a part of a surgical team. I want to be able to help give parents and loved ones of other sick or hurting children the chance to spend more time with those who are most precious in their lives.

This is not the complete story of my time with Zoe. Just what I wrote for my Narrative Essay. A lot of events have been left out of the period I wrote about. If I had included everything in this time period my paper would have been over 40 pages. The whole story of my time with Zoe would have been closer to 200 pages.

Thank you for reading.

Written by Zoe's father, Aaron Fisher (NC, USA)

(photo of Aaron and his son, Cole, with Zoe's photo for our Save the Cherubs Campaign by Martha Cate photography)



HAPPY BIRTHDAY



WYATT

CDH MAGAZINE ADS

As a way to help CDH families celebrate and remember the big milestones, we are now offering ad space in each issue.

Full Page - \$1000
Half Page - \$500
Quarter Page - \$250
1/8 Page - \$150

To purchase ad space, email news@cdhi.org

CDH International must approve each ad.



*Remembering
Rowan James Keating*



Brandon Sandoval, Terry Sanford Rodd Baxley/The Fayetteville Observer

After logging a 50% save percentage in his first two seasons, Sandoval has a 62% save percentage as Fayetteville's top goaltender in his senior year. He has a career-best 159 saves and is allowing an average of 7.9 goals per game.

CONGRATULATIONS CDH SURVIVOR, BRANDON SANDOVAL!

BRANDON FINISHED HIS
HIGH SCHOOL SENIOR
LACROSSE SEASON WITH 300
CAREER SAVES, MAKING THE
MONTREAL COLLEGE TEAM

The Fayetteville Observer

Sports | 910Preps

PHOTOS: Cape Fear, Terry Sanford boys lacrosse

HIGH-SCHOOL 2:06 p.m. ET May 2



A look at six of Fayetteville's top lacrosse players. Cape Fear and Terry Sanford are set for a game in the NCHSAA playoffs.

CLASS OF 2027



BRANDON SANDOVAL

TERRY SANFORD HIGH SCHOOL



5-9 256 G

HEIGHT WEIGHT POS



Estate Planning & Charitable Giving to CDH International

"WAYS OF CHARITABLE GIVING" by GiveDirectly

*Guide to planned and legacy giving
Updated September 2022*

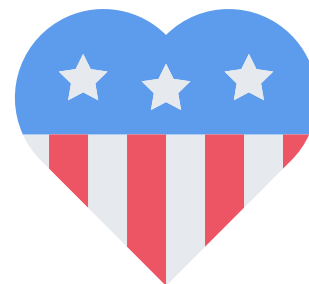
Planned or legacy gifts can be a tax-efficient and impactful way to support the charitable cause of your choice. Here's a basic definition for each type of gift:

- Planned gifts: any charitable contribution planned now to be made later.
- Legacy gifts: donations granted after the donor has passed away.

Legacy gifts are often included in a planned giving strategy to ensure that the donor's charitable objectives are met without the delay and cost of the probate process.

Here's an overview of several planned or legacy giving vehicles, including:

1. Bequests
 - What types of bequests are available
 - What are the advantages of making a bequest
 - How to set up a charitable bequest
2. Charitable trusts
3. Charitable gift annuities
4. Life insurance donations
5. Retirement asset donations
6. Retained life estate donations
7. Frequently asked questions about planned and legacy giving.



This content is specific to U.S. tax law – refer to IRS Publication 526 for more information and official guidance. You should consult with a financial advisor or tax professional for advice on your individual situation before making any investment decisions.

What is a bequest?

Bequests or bequeathments to charity are gifts made as part of a will or trust during the estate planning process. Just as you're able to leave cash and non-cash assets to heirs and loved ones, you can choose to bequest any amount to the nonprofit organization of your choice to ensure that your legacy includes a commitment to charitable impact and advancement of social good.

There are multiple types of bequests to consider when estate planning, and charitable bequests can fall into any of these categories:

1. General bequests: Gifts of a specific dollar amount.
2. Specific bequests: Gifts of a non-monetary asset.
3. Demonstrative bequests: Bequests that include instructions for how the gift should be distributed or where it should be drawn from.
4. Percentage bequests: Gifts that designate a portion of your overall estate or asset portfolio, rather than a specific dollar amount or by asset. This is most commonly used to divide assets among a pool of heirs or beneficiaries and may require the executor of your estate to liquidate assets to facilitate distribution.
5. Residuary bequests: Gifts that designate where to send any remaining assets after all other bequests have been made.
6. Contingent bequests: Bequests that include specific conditions that must be met in order to proceed with the distribution of the gift.

Here are example scenarios to help you understand the basic differences between these bequests:

Advantages of charitable bequests

Charitable bequests can allow you to make a lasting impact on the organizations and causes you support while potentially unlocking significant tax benefits.

According to the latest IRS guidance issued in 2022, any estate exceeding \$12.06 million will owe an estate tax, also known as a death tax. The current federal estate tax rates are on a sliding scale from 18% to 40%, with several states imposing additional estate taxes and/or inheritance taxes, which are imposed on the heirs to an estate.

There are currently 17 states that impose an additional estate and/or inheritance tax.

Setting up a charitable bequest of financial or other assets in your estate will typically reduce the overall value of your estate. This is one way to consider reducing or avoiding estate taxes.

How to make a charitable bequest

In order to make a bequest to charity, you can prepare a new will with the support of a lawyer or online service like FreeWill or make an amendment to your existing will with a subsequent will or through a codicil. A codicil is a legal supplement that allows you to make relatively minor changes or additions to your will. You should consult with a lawyer in your jurisdiction on how to validly draft or amend your will based on your specific state laws and individual circumstances.



If you intend to make a charitable bequest, you should reach out to the charity or charities of your choice to ensure they are able to accept and use your gift as intended. If you'd like to make a bequest or bequeathment to CDH International, you should consult with your lawyer, but here is an example of phrasing including the information typically required for designation:

I hereby give, devise and bequeath _____ to CDH International, a 501(c)3 nonprofit corporation, of 3650 Rogers Rd #290, Wake Forest, NC 27587, federal tax ID number 56-1916661 for CDH International's general use and purpose.

You can reach out to us at donations@cdhi.org for additional information on making bequests to CDH International.

What is a charitable trust?

Charitable trusts are financial vehicles that allow donors to transfer gifts to charities at multiple points over time.

What are charitable gift annuities?

A charitable gift annuity, or CGA, operates similarly to other financial annuities that offer a guaranteed income stream. In the case of charitable annuities, donors set up an annuity agreement with the charity of their choice, make an irrevocable, lump sum contribution to the annuity, and then receive regular payments. Upon the donor's death, the charity receives any assets remaining in the annuity.

Note that charitable gift annuities are regulated at the state level and tax implications may vary based on the structure of the annuity. The amount of annuity payments can also vary based on actuarial considerations like the initial contribution level and age of the annuitant.

You can use this [charitable gift annuity calculator](#) to estimate your tax deduction, annuity payments and total charitable contribution based on your target gift amount.

What is a life insurance donation?

Making charitable donations through life insurance is a popular form of planned giving that can carry advantages in the form of reduced estate taxes or more immediate tax benefits. Life insurance giving can fall into the following categories:

1. Charitable benefit riders

An insurance policy rider is any policy provision that amends the coverage terms in order to customize your policy. Under a charitable benefit rider, or charitable giving rider, you can designate a specific amount or percentage of your policy's value to be donated to the IRS-qualified charity of your choice after death.

2. Policy donations

Gifting your insurance policy involves transferring ownership of the policy directly to the charity of your choice to ensure they receive the entire payout amount, or death benefit, of the policy after your death. If the policy has cash value, the charity would also have the option of surrendering the policy in order to access the present cash value. Once you transfer ownership, you may be entitled to take tax deductions on any policy premium payments made after the gift. There could also be significant estate tax benefits, as donating the policy will reduce your taxable estate value.

3. Naming a charity as your life insurance beneficiary

Much like you can name an individual the beneficiary of your life insurance policy, you can also designate a charity as your beneficiary to donate the policy's death benefit. Unlike donating the policy, this option won't offer the same short-term tax benefits on any premium payments but will reduce your taxable estate value once the death benefit donation is made. Note that you also have the option of naming a charity as a revocable beneficiary, which creates flexibility in case you may want to change beneficiaries in the future.

4. Gifting life insurance dividends

If you receive dividends from your life insurance policy, you may be able to donate current dividends and any pooled prior dividends to charity. While taking dividends can reduce the death benefit associated with a policy, you would be eligible to take tax deductions for donating any dividends to charity.

What is a retirement asset donation?

A retirement asset donation is any contribution made directly from an Individual Retirement Arrangement (IRA), 401(k), and 403(b) to a qualified charity. One of the most common forms of retirement asset donation include qualified charitable distributions (QCDs), or charitable IRA rollovers, under which you can begin donating to the charity of your choice during your lifetime. Additionally, you are able to designate a qualified charity as the beneficiary on most retirement accounts through the plan administrator. Retirement asset donations made through this beneficiary designation will likely also help reduce your estate tax liability.

What is a retained life estate donation?

Under a retained life estate donation, a donor will transfer a property deed to a charity but preserves the legal right to live on the property for the rest of their life or a spouse or beneficiary's life. You are eligible to make a retained life estate donation using a primary residence, vacation home, farm, commercial property, or undeveloped land. Tax benefits may include receiving an immediate income tax deduction, avoiding capital gains tax on appreciated real estate assets, and reducing your estate tax burden.

You can use this [retained life estate calculator](#) to estimate your potential income tax deduction based on your age and property value.

This content is for informational purposes only and should not be construed as legal, tax, investment, financial, or other advice. Nor does this information constitute an endorsement or recommendation of any financial institution or an offer to buy or sell any securities or other financial instruments. The investments or other strategies mentioned herein do not take into consideration your particular investment objectives, financial situation or needs and may not be suitable for you. You must make an independent decision regarding any financial or investment strategies mentioned herein and should consult a legal, financial or investment advisor before making any financial decisions.



CDH INTERNATIONAL FUNDRAISERS

FACEBOOK FUNDRAISERS

- Lyndsay and Janice's Birthday Fundraiser for CDHi in Honor of Shayne
- Kathryn's Birthday Fundraiser for CDHi in Honor of Kayla
- Ann's Birthday Fundraiser for CDHi in Honor of Grandson Mason
- Michael's Birthday Fundraiser for CDHi in Memory of George
- Rick's Birthday Fundraiser for CDHi in Honor of Hannah
- Joyce's Birthday Fundraiser for CDHi in Honor of Grandson Legacy
- Janal's Birthday Fundraiser for CDHi in Honor of Elle
- Michelle's Birthday Fundraiser for CDHi in Honor of Alexis
- Deirde's Birthday Fundraiser for CDHi in Memory of Elliott

FACEBOOK FUNDRAISERS

- Monyque's Birthday Fundraiser for CDHi
- Donna's Birthday Fundraiser for CDHi
- Shawn's Birthday Fundraiser for CDHi
- Mary's Birthday Fundraiser for CDHi
- Brianna's Birthday Fundraiser for CDHi in Honor of Her Daughter
- Amanda's Birthday Fundraiser for CDHi in Memory of Amelia
- Jami's Birthday Fundraiser for CDHi in Honor of Jerheat Jr.
- Leah's Birthday Fundraiser for CDHi in Memory of Blaise
- Diane's Birthday Fundraiser for CDHi



TREKKING FOR CDH

2023

TREKKING FOR CDH

BBQ COMPETITION AND FUN/RUN
SEPT 16TH - 11AM - 10PM & SEPT 17TH - 8AM-6PM
P.I.C PARK - PIERRON, IL

*LIVE MUSIC *CAN BEER *FOOD TRUCKS
*PRO AND BACK YARD BBQ COMPETITION
* KIDS ENTERTAINMENT AREA W/ BOUNCE HOUSES



9th NORTHEAST MUSTANG MEET & MUSCLE CAR SHOW

SUNDAY SEPTEMBER 17, 2023

9AM - 3PM @ DANA FORD

NORTHEAST MUSTANG MEET

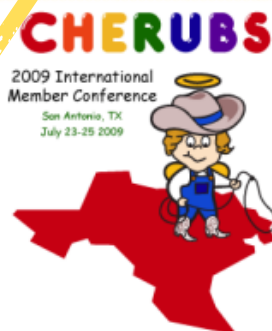
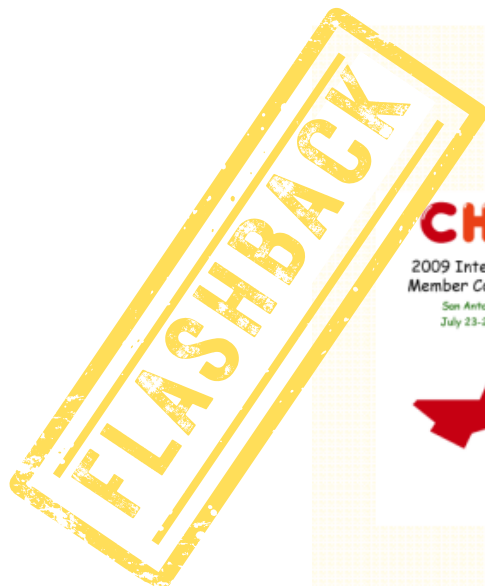
20 spots available \$125 for 5 Pairs
Top 4 Performers will receive a trophy

Save the Date!

July 22nd 2023!

GET YOUR SHINE ON GOLF TOURNAMENT





CHERUBS 2009 International CDH Conference

San Antonio, TX



Our 2009 International Member Conference for families affected by CDH was a wonderful success!

We had 17 families and 8 organizations represented from 4 countries. It was truly an international CDH conference. One person called it a "CDH Summit" but we hate to use the word "summit" as that is a meeting of peace of countries / organizations who can't get along - and we most definitely all get along! :) It was a "CDH Conference" - for and about Congenital Diaphragmatic Hernia. It included CDH Research, Awareness and Support.

It began on Wednesday with our Pizza Party and Introductions. We presented Danielle Kessner of CHERUBS Australia with a cherub statue. In 2000, CHERUBS members presented Dawn with a crystal statue. Now that CHERUBS Australia and CHERUBS UK have their own non-profit status and president, it is fitting that all 3 have the statue. Brenda Lane of CHERUBS UK received hers on Thursday as they missed the Pizza Party. Also at the Pizza Party, the new CDH song "I'll Never Let You Go" by The Jammies was unveiled. We will post that video in a few days.

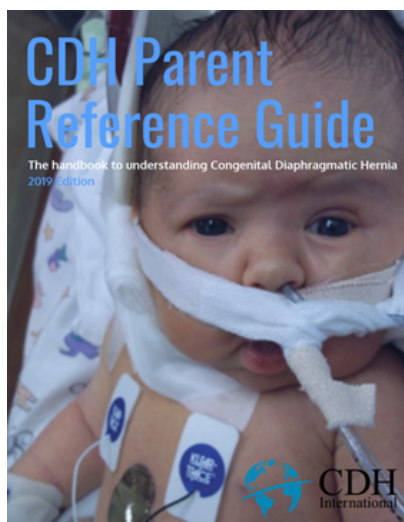
On Thursday, we were blessed with incredible guest speakers!!! Daryl Scott MD and David Pearson from Baylor's CDH Research Team were wonderful! Their presentation was very informative and the parents were able to ask lots of questions. We all learned quite a bit about genetics and CDH! Then Dr. Kevin Lally presented from the CDH Study Group and we learned about the history of CDH, the future of CDH and all the research that the group is doing. And Pam Lally was so sweet to provide us with the latest (unpublished) survey tabulations. The parents were able to ask more questions about ECMO, CDH repair and survival rates. It was extremely informative. On Friday, Drs. Meaghan Russell and Mauro Longoni from Boston Children's spoke on their CDH Research Study. We learned even more about CDH and genetics and how they use mice to create diaphragmatic hernias. The parents got to ask more genetic questions. They bought us copies of CDH News, their newsletter, as well and it featured a photo of last year's conference! :)

On Saturday and also on Friday we had round-table discussions and parents had the opportunity to talk to each other about their stories and various topics dealing with CDH. We all learned a lot from each other and we laughed, cried and shared so much. The doctors sat in on the discussions and learned from parents just as we learned from them. It was such a blessing to have the opportunity to do this. And on Saturday, the kids learned a little song about CDH and performed it for us.

This conference was also a milestone for CHERUBS - it was the first time the Presidents of all 3 CHERUBS have met in person. Dawn Williamson of CHERUBS (USA), Danielle Kessner of CHERUBS Australia and Brenda Lane of CHERUBS UK came together for the first time this year. We also welcomed Kim Richards of The Olivia Raine Foundation and Michelle Brown of Little Lambs. Not to mention doctors from 3 more CDH studies - Kevin and Pam Lally of the CDH Study Group, Meaghan Russell and Mauro Longoni of Mass General / Boston Children's CDH Study and Daryl Scott and David Pearson from Baylor College's CDH Study. All 8 organizations are members of ACDHO, The Alliance of Congenital Diaphragmatic Hernia Organizations - a group of CDH organizations and research centers dedicated to working together to help support, protect and advance the CDH community. 8 CDH organizations all together at once to help each other and CDH families!!!

We want to say thank you to our guest speakers and to Karen Myers, a member who went above and beyond to make this conference possible. We'd also like to thank Barbara Wagner, who showed what a CHERUBS volunteer is all about with all she's done to help us. And all of our wonderful volunteers and sponsors!





CDH International

CONGENITAL DIAPHRAGMATIC HERNIA PARENT REFERENCE GUIDE



CDHi created the first parent guide for Congenital Diaphragmatic Hernia in 1995 and it has been updated several times.

The latest edition (2021) was due to the labor of love of the CDHi Parent Advisory Board, the many CDH experts on our Medical Advisory Board and input from the 1000's of patient families who are members of the charity.

The first project of it's kind to utilize the expertise and experience of such a vast number of stakeholders in the CDH community, the CDH Parent Reference Guide is the go to source of easy to understand information for newly diagnosed patients.

You can download all versions of the Parent Reference at <http://www.cdhi.org/prg/>

The CDH Parent Reference Guide is free to use to any patient family, hospital or charity. Please give credit to CDH International. More translations are being worked on and hope to be published by the end of the year.

Our enormous gratitude goes out to all who made this possible, especially to all the people who volunteered for many, many hours tediously translating each page in order to offer support to many more families.



NEW CDH AWARENESS SHOP ITEMS



CDH SUPERHERO AWARENESS FAMILY YOUTH MIDWEIGHT TEE

Denim in Color

100% Combed Ringspun Cotton
Classic Fit

\$27.98



SAVE THE CDH CHERUBS KID'S JERSEY TANK TOP

White in Color

100% airlume combed and ringspun cotton
Light fabric

\$21.94



CDH AWARENESS WING YOUTH SHORT SLEEVE TEE

Gold in Color

100% airlume combed and ring-spun cotton
Extra light fabric

\$23.88



CDH AWARENESS DRESS TARTAN WOMEN'S INDOOR SLIPPERS

Black soled slippers

100% polyester outer-layer and lining
Black rubber sole

\$15.33



CDH AWARENESS DAY PENNANT BANNER

24 " x 36" vinyl pennant banner

Two brass grommets on each top corner
Two white ropes for hanging

\$19.22



IT'S NOT JUST A HOLE CDH AWARENESS FELT STORAGE BOX

14.5" x 13" black felt box

100% polyester felt
lightweight, easy to fold

\$34.48



KIDS CDH AWARENESS REGULAR FIT TEE

White in color

100% soft cotton
Light fabric, runs small

\$18.40



VIOLET LUNGS CDH TODDLER TEE

Pink in color

100% airlume combed and ringspun cotton
Extra light fabric

\$24.78



FORGET-ME-NOT CHERUB TODDLER SHORT SLEEVE TEE

White in color

100% airlume and ringspun cotton
Extra light fabric

\$24.56





THE GLOBAL
GASTROSCHISIS FOUNDATION

CDH International



CONGENITAL ANOMALIES COLLABORATION

CDH International is excited to share with you that we are collaborating with several other CDH organizations and The Global Gastroschisis Foundation to escalate research for 10,000's of patients.

- CDH International is collaborating with Congenital Diaphragmatic Hernia charities, volunteers and hospitals to translate the CDH Patient Registry into French, German, Spanish and Italian to include 1000's more CDH patient families in research efforts.
- Using the backbone of the CDH Patient Registry, CDH International is giving the Gastroschisis community a chance to create their own registry for free, helping 100,000 of Gastroschisis patients.
- More patient communities will be added to GRACA (the Global Research Alliance for Congenital Anomalies) and will benefit from their own registries and international research collaborations. Because these defects are similar, it is imperative to be able to compare data easily and proficiently.

By working together to help like congenital anomalies and in collaboration with WOFAPS (World Federation of Associations of Pediatric Surgery), the NICHD, DHREAMS, the Zani Lab and CDH Study Group, this will bring extensively more data and accelerate research for all of our children by providing a platform that is free and compatible with NIH, ERNS, and retains patient ownership of all data.

[DONATE ON-LINE AT WWW.CDHI.ORG/DONATE](http://WWW.CDHI.ORG/DONATE)

JENNIFER LOPEZ

CDH International subsists off of donations. CDH International does not charge membership fees. Currently less than 1% of our over 7000 member families are able to donate annually. It costs over \$250,000 per year to run our organization, before CDH Research Grants. Please help us to cover these costs by donating or fundraising to help us stop Congenital Diaphragmatic Hernia.

Make a Tax-Deductible Donation

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E-mail _____

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Method of Payment

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☐ Check

☐ Visa

☐ MasterCard

☐ American Express

☐ In Honor Of ☐ In Memory Of

☐ Newsletter Donation (\$5 covers this U.S. newsletter mailing)

☐ Donation to CDH Family Support Fund

☐ Donation to CDH Research Fund

☐ Donation to CDH Family Assistance Fund

☐ Donation to CDH Awareness Fund

☐ Donation to CDH Scholarship Fund

Donation:

\$ _____

\$ _____

\$ _____

\$ _____

\$ _____

\$ _____

Total: _____

Credit Card # _____

Exp. date _____

Signature _____