October is Baby Loss Awareness Month

Join us for the Wave of Light on October 15th

Sign the Petition for Standard of Care for CDH

Support Standard Measurements of Mortality and Morbidity for CDH to Help Save Lives

CDH Awareness Ideas for Halloween

Trick-or-Treating for a Cause

Calling All Adult Female CDH Survivors

New Research Collaboration

Research Opportunities

Adult Survivors, Covid and More

Get Involved

Easy ways to help stop CDH

The NEW CDH Angel Club

The Coolest Club You Can Join!
"When you are looking at your mother, you are looking at the purest love you will ever know." — Charley Benetto
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.

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"Mothers are like glue. Even when you can’t see them, they’re still holding the family together." — Susan Gale
### October 2023

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**Notes:**

**VOLUNTEERS NEEDED!**

If you are interested in helping families affected with CDH, please reach out to volunteer@cdhi.org

The following positions are essential and volunteers are needed:
- Prayer & Positive Thoughts Team
- Fundraisers
- Grant Writers
- Social Media Admins
- Event Planners
- Graphic Artists

**CDHi Executive Board of Directors**

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

“It is strange how a memory will grow into a wax figure, how the cherub grows suspiciously prettier as its frame darkens with age—strange, strange are the mishaps of memory” — Vladimir Nabokov
Him that you soars on golden wings, guiding the fiery-wheeled throne, the Cherub Contemplation. — John Milton
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*“O innocence, with laughing eyes! Thou art a cherub from the skies. A wanderer from heaven.” - Harvey Rice*
Dear CDH International Families, Friends, and Supporters,

Autumn is once again upon us and the end of the year is arriving soon.

We have been very busy the past few months at CDHi and the CDH Magazine has gotten a few issues behind. We are kicking the Magazine Committee into high gear and hopefully, you will have new Editor for the November issue.

We have lots of ways to get involved at the charity and help support the fight against Congenital Diaphragmatic Hernia. We hope that as you read through this issue, you will be inspired to help.

October is solemn month for our grieving families and for all of us who remember the 1000’s of babies lost as we raise awareness for Baby Loss Month. Virtual candles are lit on our web site for our babies lost to CDH and real candles will be light at 7:00 pm in every time zone around the world for the Wave of Light.

This issue, we are sharing the stories of 3 angels to remind us what we are all here to do - save the lives of the children still here and the children yet to come.

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

DAWN M. TORRENCE IRELAND
President & Founder
CDH Awareness Shop Affiliate Program

Attention Social Media Influencers & CDH Models! - Earn 10% commission as a CDH Awareness Shop Affiliate!
Make money and help raise CDH Awareness while supporting the world’s oldest, largest and leading Congenital Diaphragmatic Hernia charity!

Sign up at https://af.uppromote.com/cdh-international/register

CDH International Fundraising Executive Program

CDH International Is Hiring Remote Workers!

Are you good at sales? Or even just “ok” at it? Do you like to share your family’s story in dealing with CDH? Do you have side gigs selling MLM items to make ends meet? Do you set your mind to something, roll your sleeves and make it happen? You can be a professional fundraiser fighting CDH!

Stuck at home because of the pandemic or frequent medical appointments or hospitalizations and an outside job just isn’t an option for your family right now? Stay at home parent who wants to earn money?
Want to make a difference in the world while making money to support your family?
Why work for a job when you can work for a cause? Work on your own schedule!

Learn more at https://cdhi.org/work/
CALLING ALL ADULT, FEMALE CDH SURVIVORS

We hope this finds you in good health and high spirits. As valued members of CDH International, we are excited to announce a significant research initiative in collaboration with Dr. Benachi aimed at enhancing the understanding of childbearing CDH patients' experiences during pregnancy and providing valuable insights to their OBGYN doctors.

You are cordially invited to participate in the "Adult Patient Pregnancy Questionnaire," a crucial survey designed to gather essential information about women who are CDH patients and of childbearing age. We want to clarify that participation is open to all eligible CDH patients, regardless of whether they have had children or are planning to have children in the future. By participating in this survey, you will be making a meaningful contribution to improving the care and support for CDH patients during their pregnancy journey.

Before you can partake in the "Adult Patient Pregnancy Questionnaire," it is mandatory to have completed CDH International's Natural History Questionnaire. This questionnaire serves as a foundational study that lays the groundwork for a comprehensive understanding of CDH and its implications for patients.

If you have already completed the Natural History Questionnaire, we extend our sincere gratitude for your contribution to our research. If you haven't done so yet, we kindly request you to take a moment to fill it out by visiting [Insert link to the Natural History Questionnaire] before proceeding with the Adult Patient Pregnancy Questionnaire.

The Adult Patient Pregnancy Questionnaire delves into various aspects of your experiences as a child-bearing CDH patient. Your responses will be entirely confidential, and the collective data will assist Dr. Benachi and our research team in developing crucial insights that will:

1. Help child-bearing CDH patients understand what to expect during pregnancy.
2. Provide OBGYN doctors with valuable guidelines on how to best handle CDH patients during pregnancy and childbirth.

We want to emphasize that whether you have already had children, are planning to have children in the future, or have no plans for childbirth, your experiences and perspectives are highly valuable to us.

We genuinely value the opinions and experiences of each participant, as it is the collective voice of the CDH community that drives us toward better outcomes and improved care. Your input can make a significant difference in the lives of countless CDH patients and their families.

We understand the value of your time, and as a token of our appreciation, all participants will be entered into a drawing to win a [Insert prize details] as a gesture of our gratitude for your support.

Should you have any questions or encounter any issues during the questionnaire process, please do not hesitate to reach out to us at [Insert contact email/phone number]. We are here to assist you in any way we can.

Thank you for being an essential part of our CDH community and for your commitment to advancing research that betters the lives of CDH patients and their families. Together, we can make a real impact!
Advancing Congenital Diaphragmatic Hernia (CDH) Research: Current Status and Future Directions

Introduction
Congenital Diaphragmatic Hernia (CDH) is a rare but serious congenital birth defect that occurs when a baby's diaphragm does not fully develop, allowing abdominal organs to enter the chest cavity. Despite significant strides in research and medical care, CDH continues to pose challenges to both healthcare professionals and affected families. This article explores the current state of CDH research, the inconsistencies in reported numbers by various organizations, and the role of the CDH International Natural History database in advancing our understanding of this condition.

The Current Landscape
CDH research has made remarkable progress over the years, leading to improved diagnostics and treatment options. However, the precise epidemiological data regarding CDH remains a matter of concern. Discrepancies in the numbers presented by organizations like the CDC, NIH (National Institutes of Health), and NHS (National Health Service) have raised questions about the prevalence and outcomes of this condition.

One of the primary challenges is the lack of a unified data collection system. CDH cases are often reported through various healthcare networks, making it difficult to maintain consistency in data. Additionally, CDH can vary in severity, which further complicates data collection and analysis.

The Role of the CDH International Natural History Database
To address these challenges and further CDH research, CDH International has established the Natural History database, a groundbreaking initiative designed to compile comprehensive data on CDH cases. This database collects and stores information from various sources, including medical records, patient surveys, and clinical studies.

The CDH International Natural History database aims to:
1. Improve Data Accuracy: By centralizing CDH data, the database helps reduce inconsistencies in reporting, enabling researchers to obtain more accurate and reliable information about the prevalence and outcomes of CDH.
2. Enhance Research Opportunities: Researchers can access this rich dataset to conduct in-depth studies on CDH. This, in turn, can lead to better understanding of the condition's causes, risk factors, and potential treatment options.
3. Facilitate Collaboration: The database promotes collaboration among healthcare professionals, researchers, and affected families, fostering a more comprehensive approach to CDH research.
4. Support Clinical Trials: As CDH research progresses, the database becomes a valuable resource for clinical trials and studies, helping identify potential therapies and interventions.

Challenges and Future Directions
While the CDH International Natural History database is a significant step forward, CDH research still faces several challenges:

1. Standardization of Data Collection: Achieving uniformity in data collection across different healthcare institutions and regions remains a challenge.
2. Long-Term Outcomes: Understanding the long-term outcomes of CDH survivors is essential. Research must extend beyond infancy and childhood to assess the lifelong impact of the condition.
3. Genetic Research: Investigating the genetic factors contributing to CDH is an area that requires further exploration. Identifying genetic markers may lead to early diagnosis and personalized treatments.
4. Prevention and Prenatal Diagnosis: Efforts to prevent CDH and enhance prenatal diagnosis are critical. Research should focus on identifying risk factors and developing advanced diagnostic techniques.

How You Can Help
We encourage all CDH International members and individuals touched by CDH to actively participate in advancing CDH research. By contributing your data and experiences to the CDH International Natural History database, you can play a vital role in furthering our understanding of this condition and improving the lives of those affected.

To update your records in the CDH International Natural History Database, please send an email to research@cdhi.org with your relevant information and experiences. Your involvement can make a significant difference in our efforts to combat CDH.

Conclusion
CDH research has come a long way, but there is still much to be done to improve our understanding of this complex condition. The inconsistencies in reported numbers by various organizations highlight the need for a unified approach to data collection and analysis.

The CDH International Natural History database offers a promising solution to these challenges by centralizing data, facilitating collaboration, and supporting research initiatives. However, researchers, healthcare professionals, and organizations must continue to work together to address the remaining gaps in CDH research.

By investing in comprehensive research, standardizing data collection, and exploring genetic factors and prevention strategies, we can make significant strides towards better diagnosing, treating, and ultimately preventing Congenital Diaphragmatic Hernia. CDH International's database is a vital tool in this ongoing effort to improve the lives of those affected by this condition and their families. Your active participation can help drive these efforts forward.
CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

CDH RESEARCH UPDATES

DARLENE SILVERMAN, CDH RESEARCH LIBRARY

- Pneumonia-Induced Thyroid Crisis With Thyrotoxicosis Exacerbation: De Novo Graves' Disease Presentation on a Cornelia de Lange Syndrome (CdLS) - https://pubmed.ncbi.nlm.nih.gov/37519569/

SPECIAL CDH RESEARCH PROJECTS

IF YOU HAVE NOT COMPLETED THE CDH RESEARCH SURVEY, PLEASE DO SO. IF YOU NEED HELP SIGNING IN, PLEASE REACH OUT TO JASON MILLER AT RESEARCH@CDH.ORG

CURRENTLY, WE ARE KEENLY INTERESTED IN DOING RESEARCH ON:

- FAMILIES WITH MORE THAN 1 CDH PATIENT
- CDH PATIENTS BORN IN MULTIPLES (TWIN, TRIPLET, ETC)
- CDH SURVIVORS OVER 18 YEARS OLD
- FEMALE CDH SURVIVORS WHO HAVE BECOME PREGNANT
- FAMILIES THAT RELOCATED FOR HOSPITAL CARE
- CDH PATIENTS WHO REHERNIATED
- CDH PATIENTS DIAGNOSED WITH RSV
- CDH PATIENTS DIAGNOSED WITH COVID-19
- FAMILIES WHO LIVE IN THE MIDDLE EAST, AFRICA AND ASIA
- FAMILIES WHO CHOSE TO TERMINATE THEIR CDH PREGNANCY
- THE HOSPITAL CARE EXPERIENCE OF ALL CDH FAMILIES

“In three words I can sum up everything I’ve learned about life: it goes on”. - Robert Frost
CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH

CDH INTERNATIONAL AT WORK

2023 RESEARCH WORK
It is three quarters through the year and we are excited about our momentum. We are currently working on abstract submissions for GICS 2024 and CDH 2024 International Symposium.

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 Insitute of Manitoba
- Steadman McPeters, RN – Huntsville Alabama, Pediatric Surgery Nurse Clinician, CDH Survivor
- Doug Miniati, MD – University of California, San Francisco
- Giovanna Riccipertoni, MD - Vittorio Buzzi Hospital, Milan, Italy
- Henry Rice, MD – Duke University Medical Center
- Dick Tibboel, MD, PhD - Erasmus University MC, Sophia Children's Hospitall, 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

“No matter how much falls on us, we keep plowing ahead. That's the only way to keep the roads clear.” – Greg Kincaid
CDH RESEARCH UPDATES

CDH International Attends Research Meetings

We were honored to sit on committees with multiple prestigious entities, representing Congenital Diaphragmatic Hernia patients and often, also Congenital Anomaly and/or Rare Disease patients.

Since July, we have attending the following meetings and events:

- Rare Fair 2023
  Durham, NC
  CDHi President, Dawn Ireland, represented our charity at this annual event for Rare Disease.

- Kids First Pediatric Research at NICHD (Virtual)
  CDH International has been a member of the Congenital Anomalies committee of the Kids First project since 2017.

- Friends of NICHD (Virtual)
  CDH International has been a member of the Friends of the NICHD since 2018, pushing for funding at NIH and on Capitol Hill.

- United Nations World Health Meeting (Virtual)
  CDH International attends world health events as a member organization of Rare Diseases International and the European Organisation for Rare Diseases.

- Global Initiative for Children’s Surgery (Virtual)
  CDH International has been a member of the Global initiative for Children’s Surgery (GiCIS) and sits on two committees.

“Friendship improves happiness and abates misery, by the doubling of our joy and the dividing of our grief.” - Marcus Tullius Cicero
The Silver Lining CDH Magazine  
October 2023 Issue

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.

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.

The Patient Communities

10 Congenital Anomalies were chosen based on the fact that they are formed around the same time of gestation, are all mid-line defects and are all surgically correctable. The first 6 Patient Registries will include the following Congenital Anomalies:

- Cleft Palate
- Hirschsprung's Disease
- Congenital Hiatal Hernia
- Intestinal Atresia

The remaining 4 will be added as soon as funding and time allows:

- Cleft Palate
- Hirschsprung's Disease
- Congenital Hiatal Hernia
- Intestinal Atresia

"I still miss those I loved who are no longer with me but I find I am grateful for having loved them. The gratitude has finally conquered the loss". - Rita Mae Brown
My name is Catherine Taylor and I’m a mum. It seems funny to say that when I’ve never changed a nappy or had to get up in the middle of the night to that all familiar cry, but six months ago I did become a mother for the first time. My baby is a little girl and her name is Mersayd.

We discovered our precious angel had CDH at six months in utero. To say my husband and I were shocked at this diagnosis is an understatement. To be told that your baby has an abnormality is just not something you expect to hear! That happens to other people not us!! My first reaction was guilt – “what have I done?” but we were reassured that it was “just one of those things.” With this diagnoses I was immediately referred to a specialist in Tauranga and then an Obstetrician in Hamilton. The next few months were a blur of more scans and check-ups. We were told that our baby had a 50/50 chance of survival but I was determined to be positive and I did not want Mersayd to feel any bad vibes. I think back now to that time and wonder if I may have been a bit naive but I truly and honestly did not expect Mersayd to die. I bought everything. The nursery was complete. The drawers were full. The crib was ready.

The obstetrician gave us the option of induction or c-section at 38 weeks but Craig and I decided that the less stress on Mersayd the better, so we chose the c-section.

The big day arrived and I was scared. After a sleepless night we arrived at the hospital but were told due to unexpected complications with another newborn, Mersayd’s arrival was to be postponed. I felt so relieved.

Craig and I wondered, with this turn of events, what to do next! We decided to have a bit of fun, so the three of us had a trip to the Hamilton Zoo. We had a great day. I have always believed things happen for a reason and I truly believe we were given that extra day to spend with Mersayd. It is a special day I will never forget and I hope we can visit the zoo again on Mersayd’s anniversary.

The next morning I was feeling allot more relaxed as I lay on the operating table (maybe it was the drugs!). There were so many doctors and nurses in theatre - some to assist me but most waiting for the big arrival of Mersayd. As soon as she was born I remember her sailing past me and onto the OHIO table. She was immediately intubated and whisked away to the NICU accompanied by her Dad.

I was stitched up and taken back to the recovery room. Craig joined me with Polaroid’s of Mersayd. He informed me things weren’t good. I refused to believe it.

A couple of hours passed. The Paediatrician came to see me with the bad news. The hernia was far worse than predicted. Mersayd’s lungs were tiny nodules and one had ruptured.

Numb with shock I was pumped full of morphine and wheeled up to see my wee fighter for the first time. I know all parents think their babies are beautiful but mine truly was. Except for all the lines and tubes attached to her; Mersayd looked like any other healthy, bonny bundle. She looked peaceful. It was hard to believe she had only moments to live. One of the nurses asked me if I would like to hold Mersayd and I said yes. She was placed gently in my arms. I have never been one for babies but I felt so confident holding her. It felt right.

I didn’t cry when Mersayd died. I feel guilty about that but I think I must have been in shock. The reality of the situation didn’t really hit me till a few days later.

If someone had told me a year ago I would be planning my baby’s funeral I wouldn’t have believed it. But here we were sorting out readings and music to be played. We chose ‘The Power of Love’ by Celine Dion, ‘Angel Song’ (my favourite) by Sarah MacLaughlan and ‘Whenever God Shines His Light’ by Van Morrison. We decided to not only have a service to say farewell but to also celebrate a life that although short; touched so many. We also let everyone there release a pink or silver balloon at the cemetery as a final goodbye. It was such a terribly sad day.

So now six months on not a day goes by when I don’t think about Mersayd. I wonder does she know how much we all love her and how truly wanted she was? I feel envious when I see other mothers with their babies. I hope they know how lucky they are.

To lose a child, especially one that has not had a chance to experience life is hard. There is no one to tell you why this has happened or when the grief will pass. I have since joined SANDS and that has helped. I have found talking about Mersayd is the best therapy. Craig and I have also had lots of support from our family and close friends. Even strangers have shown genuine concern and great kindness.

But still, I wake up every morning missing my baby and wondering ‘what if?’ and ‘why us?’. But still, tears come to my eyes at the mention of her name. But still, most of all, I can’t forget I am a Mother.

Written by Mersayd’s mom, Catherine Taylor
CDH Angel Club

Join a prestigious group of philanthropists by becoming a member of the Angel Club in honor or memory of a cherub. The Angel Club is a recurring monthly or yearly donation that makes it easy to provide continued support to CDH International. The Angel Club provides our charity with a stable income to provide research, awareness and support services to patients and their families. Join at https://cdhi.org/cdh-angel-club/.

BENEFACTOR ANGEL CLUB MEMBERS

Benefactor Level Club Members donate over $600 per year ($50 a month) and/or have been Angel Club Members for 10 years or more.

“When you are sorrowful look again in your heart, and you shall see that in truth you are weeping for that which has been your delight”. - Khalil Gibran
PATRON ANGEL CLUB MEMBERS
Patron Level Club Members donate between $120 and $599 per year ($20 to $49 a month) and/or have been Angel Club Members for 5 years or more.
CDH Angel Club

SUSTAINER ANGEL CLUB MEMBERS
Sustainer Level Club Members donate up to $119 per year (up to $9.99 a month) to help fight CDH.

Angel Club Member Benefits
- Shop discounts (based on donation amounts)
- Event recognition
- CDH Magazine recognition
- Personalized social media graphics
- And more!

Weekly, Monthly, or Annual Donations
To join, make weekly, monthly or annual donations of any amount in honor or in memory of someone born with Congenital Diaphragmatic Hernia.

Your Membership Saves Lives
Every tax-deductible donation goes towards CDH Research projects, grants and the CDH Patient Registry, as well as funding awareness projects and supporting patient families financially and emotionally.

“Grief. The pain now is part of the happiness then. That's the deal”. - C. S. Lewis
We found out we were expecting our 6th baby in September 2005. It was a very welcome surprise. The early days were difficult with nausea and tiredness. October when the nucal scan was done and the results looked fine. The sonographer couldn’t see the baby’s stomach on that scan but said at that stage it wasn’t a problem as it was probably just empty, in hind site it was probably already in his chest. We decided not to have amnio as although I was 44 we wouldn’t have taken any action anyway whatever the results showed. The pregnancy continued nicely and we were curious to find out if we were expecting a little boy or girl.

Our life changed forever on 23rd December when we went for the routine 21 week scan. At first the sonographer seemed to be struggling to get a good picture. She told us we were expecting another little boy which was great news. After about 20 minutes she told us she couldn’t get a good picture of his heart due to his position and asked me to go for a walk to see if the baby would change position. At this stage we were both oblivious to anything being wrong. After 5 minutes we came back and she tried again. The scan was stopped and she said to us that our baby’s heart and stomach were in the wrong position. I had read about someone having a congenital diaphragmatic hernia in the paper just 3 days before this and I immediately knew what she was talking about. We were devastated.

We went to see the consultant who told us more about the condition and said that sometimes it can be related to other genetic abnormalities but in our case he did feel it was an isolated defect as nothing else on the scan appeared to indicate any other problems. He said our baby had a 60-70% chance of survival. He did offer us amnio but we declined. He said we would be regularly monitored and arranged a whole series of meetings with the neonatal consultant, pediatric surgeon and many more scan appointments. We were then sent home with a follow up appointment.

On the way home we sent a message to all our friends so they all knew and then had to face our children who were wondering if they were having a brother or sister. It was so hard telling them this news but we wanted to be honest. One of them asked if the baby would die and we said to them it was a possibility but we were going to hope and pray that he would survive. Christmas was very hard. We just went through it like zombies trying to be happy for the children but devastated. I found CHERUBS on the internet and was very well supported throughout by CHERUBS-UK and CHERUBS members all over the world via the CHERUBS listserv. We decided to name our baby son Joel (strong willed) Archie (brave) Jed (beloved by the lord) and Abel as Abel means breath and we knew this would be Joel’s problem. I set about eating anything that helped lung development including lots of dark organic chocolate that contains lots of nitric oxide.

We attended all the various appointments waiting to hear someone say it would be alright which no one could say. They all said that CDH can be very unpredictable and you cannot predict how the lungs are developing. We had an echo cardiology which showed Joel’s heart was severely squashed over to the right of his chest but appeared normal in its development. Our friends and families all rallied around trying to be positive and many of my work colleagues who are in the medical professional talked to me about their experiences with this cruel defect. The scans indicated Joel was growing well and he grew a healthy head of hair. I gave up work a little earlier than planned and suffered badly with my pelvis. At about 28 weeks I developed polyhydramnios which I knew was a bad prognostic sign. I was offered an amnio reduction which I refused as I was scared it would start labour off and I had been told that the longer Joel stayed in me the better for him. I was also told a good birth weight would help. I did start getting tightenings and at 34 weeks had 2 steroid injections to help mature his lungs if he came early. The decision was made for induction at 38 and half weeks so everyone could be ready for our precious baby’s entry into our world.

The induction went very well. My waters were broken and there was lots and lots of amniotic fluid. I wasn’t allowed an epidural because of a clotting disorder I have and had decided I didn’t want anything like pethidine that could affect his respirations although the doctors said it really wouldn’t make a difference as Joel would be intubated straight away. So I decided to do it with just gas and air and Robbie Williams blasting down my walkman!!!!!!!For me this was a challenge as I have a very low pain threshold. The syntocinon infusion was started after 2 hours and about an hour later Joel’s heartbeat took a dip from which it didn’t recover very quickly. I was put on the bed, told not to drink anything else, all jewellry etc removed in case the doctors decided to do a caesararean. The doctor examined me and put a fetal scalp clip on Joel’s head to monitor him more accurately. Joel’s heart beat recovered and the doctors decided he was fine and had probably just grabbed his cord!!! After this scare my labour continued without anymore drama. I was looked after throughout by my friend Sarah who I trained as a midwife with. She is a wonderful person and was fantastic throughout. Joel finally made his entrance into our world at 20.12 hours weighing 8lbs 8oz and pink with an initial apgar score of 7 @ 1 minute. He was intubated immediately by the neonatal team. Joel was then briefly shown to me before being whisked off to the neonatal intensive care unit. He had one eye open and looked at me. To me he looked frightened and I gently stroked his cheek and told him not to worry it would all be okay. That moment sticks in my mind so vividly now, it was the only time I saw his eyes open.

David and Sarah went around to NICU about 15 minutes later and came back saying Joel was on the oscillator and was ok. By the time I got round there 30 minutes later the consultant said he was now also on nitric oxide and maximum ventilation and if we wanted to get him baptised we needed to do so now. He was very poorly. It was such devastating news. The chaplain came and with David and I at Joel’s side along with the nurses Joel Archie Jed Abel was baptised. We were told they were taking it hour by hour and that they were in contact with great Ormond Street Children’s Hospital with a view to transferring Joel there to go on ECMO. This is a special heart lung bypass machine that can sometimes help these babies. He had a brain scan which was normal and we were waiting for an echocardiogram too. We went to see the consultant who told us more about the condition and said that sometimes it can be related to other genetic abnormalities but in our case he did feel it was an isolated defect as nothing else on the scan appeared to indicate any other problems. He said our baby had a 60-70% chance of survival. He did offer us amnio but we declined. He said we would be regularly monitored and arranged a whole series of meetings with the neonatal consultant, pediatric surgeon and many more scan appointments. We were then sent home with a follow up appointment.

We attended all the various appointments waiting to hear someone say it would be alright which no one could say. They all said that CDH can be very unpredictable and you cannot predict how the lungs are developing. We had an echo cardiology which showed Joel’s heart was severely squashed over to the right of his chest but appeared normal in its development. Our friends and families all rallied around trying to be positive and many of my work colleagues who are in the medical professional talked to me about their experiences with this cruel defect. The scans indicated Joel was growing well and he grew a healthy head of hair. I gave up work a little earlier than planned and suffered badly with my pelvis. At about 28 weeks I developed polyhydramnios which I knew was a bad prognostic sign. I was offered an amnio reduction which I refused as I was scared it would start labour off and I had been told that the longer Joel stayed in me the better for him. I was also told a good birth weight would help. I did start getting tightenings and at 34 weeks had 2 steroid injections to help mature his lungs if he came early. The decision was made for induction at 38 and half weeks so everyone could be ready for our precious baby’s entry into our world.

The induction went very well. My waters were broken and there was lots and lots of amniotic fluid. I wasn’t allowed an epidural because of a clotting disorder I have and had decided I didn’t want anything like pethidine that could affect his respirations although the doctors said it really wouldn’t make a difference as Joel would be intubated straight away. So I decided to do it with just gas and air and Robbie Williams blasting down my walkman!!!!!!!For me this was a challenge as I have a very low pain threshold. The syntocinon infusion was started after 2 hours and about an hour later Joel’s heartbeat took a dip from which it didn’t recover very quickly. I was put on the bed, told not to drink anything else, all jewellry etc removed in case the doctors decided to do a caesararean. The doctor examined me and put a fetal scalp clip on Joel’s head to monitor him more accurately. Joel’s heart beat recovered and the doctors decided he was fine and had probably just grabbed his cord!!! After this scare my labour continued without anymore drama. I was looked after throughout by my friend Sarah who I trained as a midwife with. She is a wonderful person and was fantastic throughout. Joel finally made his entrance into our world at 20.12 hours weighing 8lbs 8oz and pink with an initial apgar score of 7 @ 1 minute. He was intubated immediately by the neonatal team. Joel was then briefly shown to me before being whisked off to the neonatal intensive care unit. He had one eye open and looked at me. To me he looked frightened and I gently stroked his cheek and told him not to worry it would all be okay. That moment sticks in my mind so vividly now, it was the only time I saw his eyes open.

David and Sarah went around to NICU about 15 minutes later and came back saying Joel was on the oscillator and was ok. By the time I got round there 30 minutes later the consultant said he was now also on nitric oxide and maximum ventilation and if we wanted to get him baptised we needed to do so now. He was very poorly. It was such devastating news. The chaplain came and with David and I at Joel’s side along with the nurses Joel Archie Jed Abel was baptised. We were told they were taking it hour by hour and that they were in contact with great Ormond Street Children’s Hospital with a view to transferring Joel there to go on ECMO. This is a special heart lung bypass machine that can sometimes help these babies. He had a brain scan which was normal and we were waiting for an echocardiogram too. We were asked to go back to our room as they had a new baby being admitted and parents are asked to leave the unit when this happens. The consultant also felt we needed the rest. She promised to come and get us if Joel’s condition changed. We didn’t sleep every time we heard footsteps we thought they were coming to us. I held Joel’s photo all night. By 06.00hrs we could wait no longer and went round to the neonatal unit. Joel was the same but had suffered a right pneumothorax overnight and had a chest drain inserted. We were told they were going to try Joel on a conventional ventilator instead of the oscillator because he could not be transferred for ECMO on the oscillator. We were also told if he was transferred we would not be able to travel in the ambulance with him and they were very concerned he would die in the ambulance. Joel however could not maintain his oxygen levels on the conventional ventilator and became very blue so he was put back on the oscillator.

We called our family and they brought our children Sam, Jessica, Joshua, Jacob and Ben up to see their baby brother it was very, very sad. As our families left they lifted Joel out of the incubator and for the first time I got to hold my precious son. He was so beautiful. He laid on our laps for about 2 hours still attached to the ventilator. We cuddled and kissed him, we told him we loved him so much and we also told him that we understood if he couldn’t fight anymore. We wanted him so much to stay with us but we told him that we understood if he couldn’t stay. It was the hardest thing we have ever done. Joel’s heart was slowing down all the time.

"You care so much you feel as though you will bleed to death with the pain of it" - J. K. Rowling
Although they were still trying to save him nothing they did was making any difference. Joel’s nurse went for a very quick break and left another nurse with us. When she came back, Joel suddenly started having ectopic heartbeats and his nurse said this was very significant and removed his ventilator tube so we could hug our beautiful little boy close as he died. At 14:00 hours our precious little boy left us. It was the worst moment of my life. Just 17 hours, 48 minutes after our beautiful baby entered this world he left us again. We sat with Joel in the neonatal unit for a while then we went to a bedroom and waited while all Joel’s tubes etc were removed. He was brought to us very quickly and we spent a very special 1½ hours with our son. We were able to bath him, dress him, and take hair cuttings, hand and foot prints and lots and lots of photos. It was very, very special. It was so hard to leave him there. Just 36 hours after we had left home we arrived back empty after having given birth too and lost our beautiful son. The following days passed in a blur. Friends and family took over the cooking and looked after us.

Joel came home to us the night before his funeral. It was lovely having him home here surrounded by his family. We had all put things in his coffin such as photos, letters, little trinkets and a bible. His coffin was tiny, white with coloured balloons over it. Joel’s funeral was lovely. Many people came and we had a lovely service at our Methodist Church. David carried Joel in to Tears in Heaven and we both read poems. David read “I’ll be there” and I read “In a baby castle”. We had music by Keane Bend and Break and you’ll be in my heart by Phil Collins. All the words were so relevant. Judith read a Childs angel and Sarah read Gods Loan. We left the church to Robbie Williams Better Man, the same song that was playing when Joel entered this world.

We choose a beautiful cemetery near where we live for Joel to be buried. It is like a big garden and has many beautiful trees and flowers. The birds are always singing there. As he was laid to rest the minister said a very special verse from the bible that had given me lots if hope when I was pregnant.

For I know the plans I have for you declared the Lord. Plans not to harm you but to prosper you, plans for hope and for a future. Jeremiah 29.11

It was very special

We had chosen not to have a post mortem but recently went back to meet the consultant. Joel’s blood gases had never been normal and she felt he had lung hypoplasia along with the effects of the CDH. This is a devastating defect.

We miss our special little boy so, so much. Our lives will never be the same and this little boy although with us for such a short time had made a huge impact on our lives.

Written by Joel’s mom, Debbie Blakley (Great Britain)

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**JOURNAL OF SURGICAL RESEARCH**

**VOLUME 273, MAY 2022, PAGES 71–78**

**Pediatric Surgery**

**Center Volume and Cost-Effectiveness in the Treatment of Congenital Diaphragmatic Hernia**

Ruth Lewit MD, MPH, Tim Jancelewicz MD, MA, MS

**Abstract**

**Background**

The care of patients with congenital diaphragmatic hernia (CDH) is expensive, yet little is known about variability in cost-of-care for these patients. The purpose of this study was to examine the cost-effectiveness of CDH treatment, comparing high- versus low-volume centers.

**Methods**

This is a retrospective study of neonatal patients with CDH at U.S. hospitals using data from the Pediatric Health Information System database (2015-2018). Centers were considered high-volume if they had ≥10 patients with CDH for ≥ 2 y. Cost-effectiveness analysis was performed with cost per survivor as the outcome measure, and probabilistic sensitivity analysis was performed.

**Results**

A total of 1687 patients were included in the study. Overall mortality was 24.4%. Patients at high-volume centers had a longer mean length of stay (164 d versus 48 d for low-volume centers, P = 0.0001) and higher extracorporeal life support (ECLS) rates (32% versus 24%, P = 0.002). Risk-adjusted mortality did not differ between high- and low-volume centers (23.9% versus 25.9%, P = 0.39), except when ECLS was involved (42% versus 56%, P = 0.01). Costs were significantly higher at high-volume centers ($395,291 ± 508,351 versus $255,074 ± 308,802, P < 0.0001). Survival status, ECLS use, operative repair, length of stay, high-volume status, and gestational age were identified as independent drivers of cost. On cost-effectiveness analysis, low-volume hospitals were more cost-effective in 95% of simulations.

**Conclusions**

High-volume centers have substantially higher costs without an associated survival benefit and are less cost-effective than low-volume centers. Standardization of care is necessary to minimize the delivery of low-value care.

**Introduction**

Congenital diaphragmatic hernia (CDH) is a common neonatal surgical condition seen in approximately 1 in 3000 live births. Overall mortality is approximately 30%, and CDH is universally fatal without surgical correction. Those who survive often have long hospital stays, and some require extracorporeal life support (ECLS). Very few studies have investigated the costs associated with the care of patients with CDH. A recent study by Cameron et al. showed that CDH had the highest cost burden among surgical procedures in pediatrics, with an adjusted median hospital cost per patient of $158,113. An earlier study from 1994 reported the mean cost per patient, including hospital costs plus professional fees, was reported as $137,000 in 1993 dollars, which would be equivalent to $245,251 now adjusted for inflation.

Studies further elucidating the trends behind these high costs are limited. Poley et al. found that treating CDH was cost-effective compared with no treatment. Studies have demonstrated that ECLS is the largest contributor to these high costs and that higher costs are seen in patients with more severe disease. Furthermore, there is conflicting evidence regarding the relationship between center volume and outcomes in CDH.

With increasing health care costs nationally, cost-effective care and avoidance of low-value care remain vitally important components of health care delivery. Risk-adjusted mortality and cost-effectiveness comparing high- and low-volume centers would provide valuable data that could inform the construction of clinical practice guidelines for CDH. The purpose of this study was to expand on prior work to better define the relationship between center volume, outcomes, and cost in CDH care and to perform a full cost-effectiveness analysis comparing high- and low-volume centers to determine if greater expenditure is associated with any survival advantage in the care of CDH. A secondary objective of this study was to explore the significant drivers influencing expenses. It is hypothesized that high-volume centers will have equivalent risk-adjusted mortality to low-volume centers and will be less cost-effective.

*Read the full publication at [https://www.sciencedirect.com/science/article/pii/S0022480220007460]*

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“Grief can't be shared. Everyone carries it alone. His own burden in his own way.” - Anne Morrow Lindbergh
Petition for a Congenital Diaphragmatic Hernia Standard of Care

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

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

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

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

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

Babies born with CDH undergo complicated surgeries and extended hospital stays. In Higher-Income-Countries, the survival rate is approximately 50 to 80%. In Lower-to-Middle-Income Countries, the survival rate is less than 1%. Though a few countries have a Standard of Care for Congenital Diaphragmatic Hernia, most do not, including the United States.

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

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

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

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

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

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

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

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

Signed,

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

Sign the CDH Petition at https://www.change.org/CDH-Standard-of-Care

** Stakeholders are those who have a vested interest in the care of these children: patients, families, caregivers, pediatric surgeons, nurses, hospitals, other physicians, organizations, etc
*** This petition created for the better medical care of all patients born with Congenital Diaphragmatic Hernia and in the memory of Josh Benson and all those lost to CDH.

“Suppressed grief suffocates, it rages within the breast, and is forced to multiply its strength”. - Ovid
My name is Lisa Coleman. I’m 26 years old, a mother of 3 children, one of which was born with a left-sided CDH. My daughter’s name was Trinity A. Coleman. She is a non-survivor. She was born 9/29/99 and passed away 10/15/99. She lived a hard 16 days. It’s taken almost 2 years to write this letter. Also, I want to spend a moment to send a special thanks to one of your On-Call Volunteers. She stayed in touch with me during my pregnancy. I was one that found out in utero. She also spent time in Columbus, OH with me and my family. She was there for support every step of the way. She was there the day Trinity passed away, also the day of her funeral. Her name is Dawn Halley. Something happened in her life that I haven’t heard from her again. Her daughter, Ashley, is a survivor of CDH. But I send her my love and thanks everyday in my prayers.

I want to write you in reference to your Spring 2001 newsletter and your story. I don’t look down on you for even trying to file a malpractice suit. I tried the same thing. The doctor went and gave Trinity her first surgery after taking her off of ECMO. It was my 25th birthday, October 4, 1999. I was so happy; it was the greatest birthday present a mother could ask for. I thought for sure she was going to make it through all of this OK. But after hours of her surgery and waiting, the doctor came out and told us everything was moved back OK, but he ran into something he had never seen before. Her small intestines were buckled and rotted, so he had to remove that piece of intestine. After they brought her back to the NICU, I saw a sight I was not prepared to see-- her intestines in a cone-shaped bag, suspended and tied to the top of her bed. Her intestines were lying outside of her, resting on her stomach. I couldn’t believe the sight I saw. I was told that they were too swollen to put back, so we would have to wait for a few days before they could try to put them back. I was so devastated. They were able to put them back, but she had to have a colostomy bag on her. I wasn’t sure for how long. Well, as days went on, she started to get worse. Then I was told that she had a form of e-co-li, that when the doctor cut her intestines, he let a form of the e-co-li out into her bloodstream, and that the doctor didn’t wait on her blood test to come back. I was upset at this time, but I quickly turned my attention to Trinity and put this in the back of my head.

On the 15th of October, I went to Children’s to see my daughter. Before I could step off of the elevator, my dad was at the doors waiting for me, telling me that the doctors want me to pull the plug. We went into a private room. The doctor told us Trinity’s oxygen level was low, that she was in a coma, and she wouldn’t survive the night. If by some miracle she would survive, Trinity would have brain damage from lack of oxygen. So the doctor stepped out of the room so my husband and I could come to a decision. Of course it didn’t take long. We decided it wasn’t up to us to choose when she should pass away. It would be hers and God’s, of course. The doctors and nurses were almost disgusted with our decision, but I didn’t care, this wasn’t their daughter; she was mine. So that night was very hard. Time went so slowly. When I was finally alone with my baby girl, I put my hand on her head and sung “Jesus Loves You.” Then I said something that was so hard for a mother to say. I held her sweet little hand and told her that if she couldn’t fight anymore and she had to go, that it was OK and Mommy will always love her. I kissed her on the head and walked out. An hour later. I decided it was time to hold her, so they did what they could do so that I could hold my daughter. That was the first and last time I held her warm body in my arms. She passed away 2 minutes after I held her. Two days before that, I knew it was coming. It’s like she let me prepare myself for it. Not every parent is the parent of an angel. That is what I tell myself everyday I wake up.

When I had found out about her defect when I was 5 months pregnant, on the way home from the doctor during my crying, I looked at my husband and said that her name would be Trinity. He asked why. I said, “The Son! The Father! The Holy Ghost! is what that beautiful names stands for.” But after Trinity passed, I told my husband that I blame the doctor for letting the e-co-li virus through her blood stream. We talked to a lawyer, but he won’t touch the case because of CDH. I was going to send all money for CDH research, also buy my daughter a headstone, which she still doesn’t have. I feel so guilty about that. I’m having a hard time affording one, but I will one of these days. I learned not to take James, 7, and Dacia, 3, my son and daughter for granted anymore. Every day of their life is precious to me. I also learned not ever to say “never.” I thought something like this would never happen to me. So I tell everybody I know to don’t ever, ever say “never.”

Written by Trinity’s Mom, Lisa Coleman
Hernia. This year, we decided to honor these patients for 2 months, beginning in October for the 2022 Wave of
Every winter, we honor the memories of those children (and a few adults) lost to Congenital Diaphragmatic

- Zoie Katrina Abel
- Caleb Joseph Acker
- Zeyah Grace Ackerman
- Virginia Addison Acord
- Aileen Iris Adams
- Brianna Nicole Adams
- Cadyn Carter Adams
- Darrian Earl Adams
- Gabrielle Marie Faye Adamson
- Taquinn Mikhail Adcock
- Alfonso Aguilar
- Ruben Luis Aguierre IV
- Alexander Jan Aguierre-Carranza
- Myles Steven Albin
- Lynlee Albrecht
- Dakota Rooney Aldred
- Leo Alexander
- Logan Andrew Alexander
- Sean Michael Alexander
- Guage Michael Allen
- Landen Allen
- Edyn Grace Allinson
- Megan Jane Allinson
- Brianna Samanta Almeida Hidalgo
- Prince Carl Zimmerman Mac
- Jordan Amodeo
- Cloudy Rae Anders
- Holly Christine Anderson
- Maverick Gabriel Anderson
- Sela Anderson
- Zander Kaige Anderson
- Addison Andreaozzi
- Jakob Nelson Andriacchi
- Olivia Grace Andrise
- Marley Mikka Anema-Blake
- Alexandra Teroshenko Angel
- Braiden Shiloh Anthony
- Dale Linden Appleyard
- Sergio Salvador Morena Arana
- Hunter Arlidge
- Mahalah Theresa Arnold
- Laney Marie Arriaga
- Savanna Arthur
- Aiden Matthew Ashman
- Bryson Timothy Maurice Atkins
- Meike Elizabeth Auerwald
- Philip Meade Austin
- Rielly Caleb Ayers
- Victoria Marie Ayscue
- Jerry B
- Isabella Rose B.
- Kamden Grayson Babin
- Nathan Presley Bacon
- Daxton Keith Brown
- Madeline Brooks
- Riley Owen Brewer
- Kayla Rae Brewer
- Riley Owen Brewer
- Travis II Brindley
- Ian Brocklebank
- Madison Brooks
- Benjamin Joseph Broom
- Daxton Keith Brown
- Robert Barrett
- Connor Blake Bass
- Skyline Paige Bass
- Amyla Fatima Bassa
- Brady Edwin Sundt Baumann
- Meghan M. Baxter
- Noah J. Beaumont
- Seth Christopher BelBus
- Cooper Lynn Beeler
- Mieke Louise Bekker
- Evalon Zoe Bell
- Gracie Elizabeth Bell
- John Brody Bell
- Luca Belo Narvaez
- Isabella Beltran
- Garrett Reid Benedict
- Jude Walter Benham
- Brodie McBickin Bennett
- Caitlyn Bennett
- Joshua Allen Benson
- Stella Alaine Berger
- Anthony Joseph Bergman
- Jaila Berrios
- Cooper Hawk Betram
- Nathan Levis Bevan
- Braxton Ramsay Bice
- Vinailbelle Maria Soliel Biffenato
- Paxton William Aaron Billings
- Caylor Rebecca Bird
- Emily Anne Birdwisa
- Alfie John Black
- Sean Peter Blakley
- Joel Archie Jed Abel Blackley
- Cagle William Blalock
- Miabella Lis Blanchard
- Keeno Rafael Blanco
- Josiah Stephen Blay
- Mayzie Kendaleah Marie Blevins
- John Blocker
- Rachel Natalie Bloomfield
- Zachary Michael Blue
- Henry Christopher Blum
- Lars Blummenroe
- Ali A. Bomer
- Evan Bonistall
- Alec Bonser
- Gabrielle Marie Booker
- Landon Tyler Booth
- Aubrey Anne Borgen
- Lily Borowski
- Kennedy Alyssse Bourgeois
- Lauren Marie Bowen
- Hannah Kate Bowring
- Aria Kane Bowen
- Chiara D’Yann Boyley
- Mitchell Robert Boyles
- Madeline Hope Bozart
- Kasey Hines Boyles
- Kinsley Grace Boyles
- Kylah Jo Boyles
- Koi Boyles
- Kasey Payton Boyles
Courage is being afraid but going on anyhow. - Dan Rather

Rebecca Ewing
Baby Boy Ewen
Shelton Earl Evans
Jay William Leroy Evans
Connie Katherine Evans
Jacob Vincent Esparza
Richard Charles Englehardt III
Isabella Rose Endres
Callie Ann Embleton
Jamison Lee Ellis
Carson Ray Elliott
Oliver Eliuk
Nora Rae El-Gamel
Daniel Jens Ekelund
Reese Gabrielle Eisele-Elizondo
Beau Eric Corey Edwards
Taylor Elizabeth Edmond
Joshua Angel Echelbarger
Emily Elizabeth Templar Earl
Mikayla Marie Duscher
Vincent Steven D'Ulisse
Mela Ciann Dulier
Alex Firmin Duguay
Lucas Emmet Dubray
Floyd Edward DuBois
Farah Djukic
Karim Dizdarevic
Braice Menno Geoffrey
Jade Alexandra Genys
Noah Samuel Geisler
Caleb James Bradley Geaghan
Dominique Nellige Angelique Gaye
Avery Hope Gaynor
Caleb James Bradley Geaghan
Noah Samuel Geisler
Kidnapped Marjorie Gaynor
William Wenclosaus Gillis
Alexander Jacob Clancy
Gwendolyn Leigh Glover

Anastasios Glykos
Aurora Patricia Goddard
Emily Rae Godwin
Serra Meghan Golden
Beckett Logan Coll
Annabelle Marie Gomez
Graciela Milagros Gonzalez
Juan Pablo Gonzalez
Zoe Madeleine Gonzales
Carson James Goodmote
Donovan Gabriel Gorter
Callie Grace Gould
Bruce Richard Goudie
Avery Lynn Graham
Holden Wade Graham
Aiden Robertson
Elin Elizabeth Grant
Harper Rae Graveman
CeCe Graves
Gianna Joann Gray
Harlee Ranee Gray
Brandon Isaiah Grayson
Kylee Freedom Green
Lydia Rose Green
Maximus Paul Green
Brylie Gregory
Faith Gregory
Tristyn Annabelle Gregory
Andrew Jeremy Cresser
Eryn Griffin
William Griffin
Jonathan Cordell Griffin II
Reece H. Griffith
Kaleb Matthew Groce
Grover Charles Grubbs
dgren

Abel Edward William Helmer
Reese Vivian Heim
Bryton Daniel Heaton
Amelia Head-Gorton
Rylyn James Haywood
Skyler Hawkins
Rebecca Faith Havar
Luke McCoy Hastings
Aiden Hartley
Ada Lynn Harris Haluszczak
Prince MaeÆEl Harris
Ellianna Nevaeh Harris
Matthew Michael Harper
Cameron Lee Malik France
Vivianne Darby Frankel
Kanarra Faith Franklin
Teresa Glenn Fontaine
Lea Luna Fontana
Ashley Hope Footit
Morgynn Sydney Ford
Kaitynn Renee Foret
Candis Nakole Forman
Callum Fossett
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Callum Fossett
Kennedy Ren Forsythe
Candis Nakole Forman
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"Service to others is the rent you pay for your room here on earth." Mohammed Ali
FACEBOOK FUNDRAISERS

- In Loving Memory of Christian Casey Copley Fundraiser for CDHi
- Dan's Birthday Fundraiser for CDHi
- Sherry's Birthday Fundraiser for CDHi in Honor of Jacob
- Elizabeth's Fundraiser for CHERUBS in Memory of Sawyer
- Marrah's Birthday Fundraiser for CDHi in Honor of Remstar
- Ellen's Birthday Fundraiser for CDHi in Honor of Grandson Oscar
- Beck's Birthday Fundraiser for CDHi
- Lisa's Birthday Fundraiser for CDHi in Memory of Trinity
- Amy's Fundraiser for CHERUBS in Memory of Alex
- Kathryn's Birthday Fundraiser for CDHi in Honor of Anna
- Dawn's Birthday Fundraiser for CDHi in Memory of Jade
- David Holt's Birthday Fundraiser for CDHi in Honor of Braden
- Ximena's Birthday Fundraiser for CDHi in Honor of Rosalie
- Fynn's Birthday Fundraiser for CDHi (he is the cherub)
- LL's Birthday Fundraiser for CDHi
- Donate Just $6 in Memory of Shane to Fight CDH
- Krystal's Birthday Fundraiser for CDHi
- Tarah's Birthday Fundraiser for CDHi
- Mindy's Birthday Fundraiser for CDHi in Memory of Matthew
- Jessica's Birthday Fundraiser for CDHi in Memory of Stefan
- Brittany's Birthday Fundraiser for CDHi
- Geraldine's Fundraiser for CHERUBS

FACEBOOK FUNDRAISERS

THANK YOU TO THE FOLLOWING FUNDRAISING EVENTS! YOU ARE VITAL IN OUR FIGHT AGAINST CDH.

Get Your Shine On Golf Tournament in Memory of Rae Ann Davis

Liz and Lincoln's Walk in Memory of Lincoln McAngus and in Honor of Elizabeth Plakholm

Trekking for CDH in Honor of Tucker Lee Von Hatten and Barrett David Korte

Northeast Mustang Meet in Memory of Skylar Milagros Fonseca

"Grief can be a burden, but also an anchor. You get used to the weight, how it holds you in place". - Sarah Dessen
October is a month full of fall activities. This time of year at CDH International we are starting to request landmarks and buildings to light up for CDH Awareness Day on April 19, 2024. You can personally request a building or landmark yourself, if you would like to.

During all the trunk or treats this year, instead of collecting candy you can ask for donations instead even if it’s just change and use it as a fundraiser for CDH International. Call it Change for Cherubs.

Everyone loves pumpkin patches and the cute photo opportunities, why not add a CDH spin off to it? Painting pumpkins in the colors blue, pink and yellow or adding clouds and wings would help raise awareness.

Don’t forget those sweet fall goodies. You can add a little color to your ghoulish treats using blue, pink and yellow as well.

Halloween costumes come in all shapes and sizes too. You could dress you or your Cherub up as an angel and trick or treat to collect candy or change for Cherubs.

More Easy Ways to Get Involved:

- **Light a Virtual CDH Candle**
  - In memory of your child or someone else’s - [www.cdhi.org/ncmd2023](http://www.cdhi.org/ncmd2023)

- **Share your Story in the CDH Magazine**
  - E-mail one page of text and 3 photos to dawn.ireland@cdhi.org

- **Share your Story on CDH Radio**
  - E-mail fundraising@cdhi.org to schedule an interview

- **Hold an Event in Your Child’s Name**
  - E-mail volunteer@cdhi.org to get started

- **Support CDH Research in the CFC Campaign**
  - 2023 CFC Charity #31232

- **Support CDHI on Giving Tuesday**
  - Hold a fundraiser or donate online at [www.cdhi.org/donate](http://www.cdhi.org/donate)

- **Volunteer at CDHI**
  - E-mail volunteer@cdhi.org to get started

- **Write a Review on GuideStar for CDHI**
  - Write a review at [https://greatnonprofits.org/org/cdhi-international](https://greatnonprofits.org/org/cdhi-international)
Do you happen to know a kid with a surgical scar (or two or three, etc) who might be embarrassed by it? Not feeling especially proud of it? After all, that kid survived something, right? Or perhaps you know of a kid who is proud of their scar(s), and shows them off and points them out to educate? Ahh, then please, please, introduce those kids to Aggie. Poor guy’s been hiding his ever since a not-too-happy experience at the beach in kindergarten.

Aggie and Ryan: finding out that scars can just maybe, be magical.

Now available on Amazon.com
# New CDH Awareness Shop Items

<table>
<thead>
<tr>
<th>Item Description</th>
<th>Color/Size/Features</th>
<th>Price</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>UNISEX OFFICIAL CDH AWARENESS TEE</strong></td>
<td>Navy and Black in Color 100% cotton Classic Fit</td>
<td>$19.58</td>
</tr>
<tr>
<td><strong>UNISEX SHORT SLEEVE OFFICIAL CDH AWARENESS TEE</strong></td>
<td>Various sizes and colors 100% Airlume combed and ringspun cotton Light fabric</td>
<td>$18.68</td>
</tr>
<tr>
<td><strong>UNISEX OFFICIAL CDH AWARENESS CREWNECK SWEATSHIRT</strong></td>
<td>Various sizes and colors 50% cotton, 50% polyester Loose fit</td>
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<tr>
<td><strong>UNISEX OFFICIAL CDH AWARENESS CREWNECK SWEATSHIRT</strong></td>
<td>Various sizes and colors 80% ring-spun cotton, 20% polyester Relaxed fit</td>
<td>$27.65</td>
</tr>
<tr>
<td><strong>DESK MAT OFFICIAL CDH AWARENESS</strong></td>
<td>Dark chocolate in color, 12&quot; x 18&quot; in size 14 mm thick neoprene Anti-slip backing</td>
<td>$13.42</td>
</tr>
<tr>
<td><strong>VELVETEEN CDH AWARENESS BLANKET</strong></td>
<td>Grey and white in color, 50&quot; x 60&quot; in size 100% Polyester One sided print</td>
<td>$32.57</td>
</tr>
<tr>
<td><strong>CDH AWARENESS TOTE BAG</strong></td>
<td>Blue in color, 18&quot; x 3.46&quot; x 17&quot; in size 100% Polyester Black Cotton Handles</td>
<td>$18.67</td>
</tr>
</tbody>
</table>

*“Tears are the silent language of grief.” - Voltaire*
“WE ARE EACH OF US ANGELS WITH ONLY ONE WING, AND WE CAN ONLY FLY BY EMBRACING ONE ANOTHER”.

- LUCIANO DE CRESCENZO