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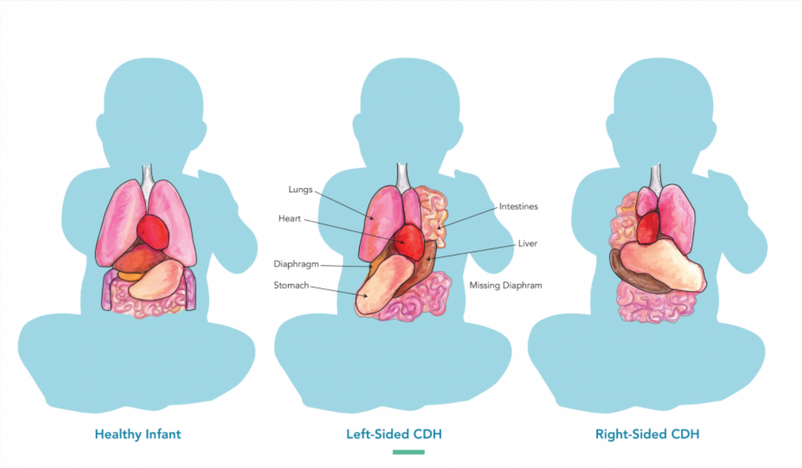
Grieving Moms Take on the World to Save Other Peoples’ Children

They lost their sons 25 years ago but they teamed up with others and continue to fight to save the lives of 1000's of children born with deadly birth defect.



Congenital Diaphragmatic Hernia (CDH) is a birth defect that strikes over 52,000 babies each year.

WAKE FOREST, NC, UNITED STATES, January 4, 2021 /EINPresswire.com/ -- CDH International was created 25 years ago on the kitchen table of a 22 year old mom, seeking help for families like hers affected by Congenital Diaphragmatic Hernia.

CDH is a birth defect that affects over 52,000 children worldwide every year. During gestation, the diaphragm fails to fully form often allowing abdominal organs to reach the chest cavity and restrict lung growth. There is a 50 percent chance of survival with CDH and the cause is still unknown.

> Shane was flown out of state to the closest children’s hospital that could take him. We had no information, no internet, no support group, nothing.”
>
> *Dawn Ireland*

Dawn Ireland gave birth to her son, Shane Torrence, in 1993. He wasn’t diagnosed until birth and there were no resources for families.

“Shane was flown out of state to the closest children’s hospital that could take him. We had no information, no internet, no support group, nothing” says Ireland.

Shortly after Shane was admitted to Duke University Medical Center, she met another mom of another little boy born with CDH. Rhonda Montague became a fast friend and together, they founded CHERUBS – The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support. It was named “CHERUBS” (baby angels) after Rhonda’s son, Preston, who never made it home and Andrea Jones, who was also a CDH patient at Duke at the time who passed away a few days after birth.

"We have no idea what happened to Andrea's mom, also named Andrea" says Ireland "We'd love to tell her that her little girl's memory lives on at the charity along with our sons'".

Ireland's son, Shane, passed away at 6 years old from complication of Congenital Diaphragmatic Hernia. The charity was renamed and restricted in 2017 as "CDH International".

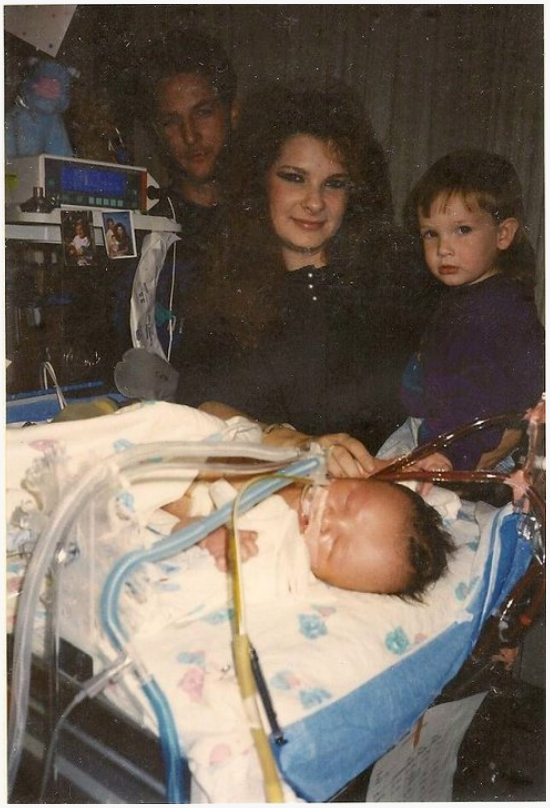
"The past 25 years have flown by. Especially the past 4 years. We have grown so much at lightening speed that it's exhausting and dizzying but the babies need us so we go through every door that opens" says Ireland.

Congenital Diaphragmatic Hernia is as common as Cystic Fibrosis and Spina Bifida but has little awareness and very little funding.

"CDH is classified as a rare disease but it's a fairly common birth defect. The March of Dimes no longer funds birth defect research so our kids have lost over half of the little research funding that they had. NIH funds less than $5,000,000 a year for CDH. My son's medical bills alone in 1999 were over $4,000,000. The economical cost of CDH on families and governments is astronomical. They need funding. Now, Covid-19 has taken much of that funding too. Our kids feel invisible because the world doesn't see them but we will keep screaming until they do!" says Ireland.

Despite the pandemic and many other obstacles this year, they opened 5 new NGO's overseas, held an on-line telethon, asked governors to sign proclamations, got over 50 landmarks to light up around the world including the Superdome, Eiffel Tower, Niagara Falls, Blarney Castle and many more.
CDH International is headquartered in North Carolina and is now a registered non-profit in the United States, United Kingdom, Hong Kong, Singapore, Netherlands and Switzerland. They have helped over 6500 CDH families in all 50 states and 74 countries, through patient services, raising awareness and funding and participating in global research. Their

Dawn Ireland with her son, Shane Torrence, in 1993



The Montague Family in 1993

mission is to support affected families, facilitate research, and raise awareness for Congenital Diaphragmatic Hernia.

“Because of the pandemic and lack of grants, the charity’s income is down over 50% this year from 2 years ago. If we had more funding, we could rule the world in the fight against CDH with as creative and hard working as our teams of moms, dads, grandparents, survivors and researchers are. We opened 5 new NGO’s during a global pandemic on a total budget of less than $250,000! That’s an incredible accomplishment! I am so proud of our team”.

Also, in 2020, Ms. Ireland spoke in front of 2 international research conferences, traveled to 6 countries, gave a national television interview on CBS on the struggle of non-profits during the pandemic and she herself is a Covid-19 long hauler. Her co-worker, Tracy Meats, survived a heart attack in 2020. CDH International only has 2 full-time employees, 1 part-time employee and a handful of active volunteers worldwide. The charity was 15 years old before it hired it’s first employee.

Dawn Ireland and Rhonda Montague at a memorial service for Shane Torrence in 1999

Dawn Ireland and Rhonda and Joe Montague at a charity event for CDH International in 2017

“This year has been a real struggle with volunteers as so many have quit or disappeared because they couldn’t juggle volunteering, life and the pandemic. This has put a real strain on the remaining team members who have had to pick up a lot of extra work but we pulled it off. We have an amazing team of people who really love these children and want to see all of them grow up”.

In their spare time this year, they learned how to build an elaborate phone app to help both patients and medical care providers that was received with much praise

Along with managing the Congenital Diaphragmatic Hernia Patient Registry for research, CDH

International continues all of their other work in educating the public on CDH, supporting families with information, care packages, on-line groups, conferences, scholarships and financial assistance. Ms. Ireland also works with committees at the National Institutes of Health, the Global Initiative for Children's Surgery, the World Health Organization and is a founding member of the Rare Advocacy Movement.

Their dedication to saving these children is incredible.

Did we mention that they do all of this on less than $250,000 a year? The charity's overhead has never been above 10%. Someone get these ladies to Congress to help with the national budget.

If you'd like to donate to this extraordinary charity, please visit them at http://www.cdhi.org

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