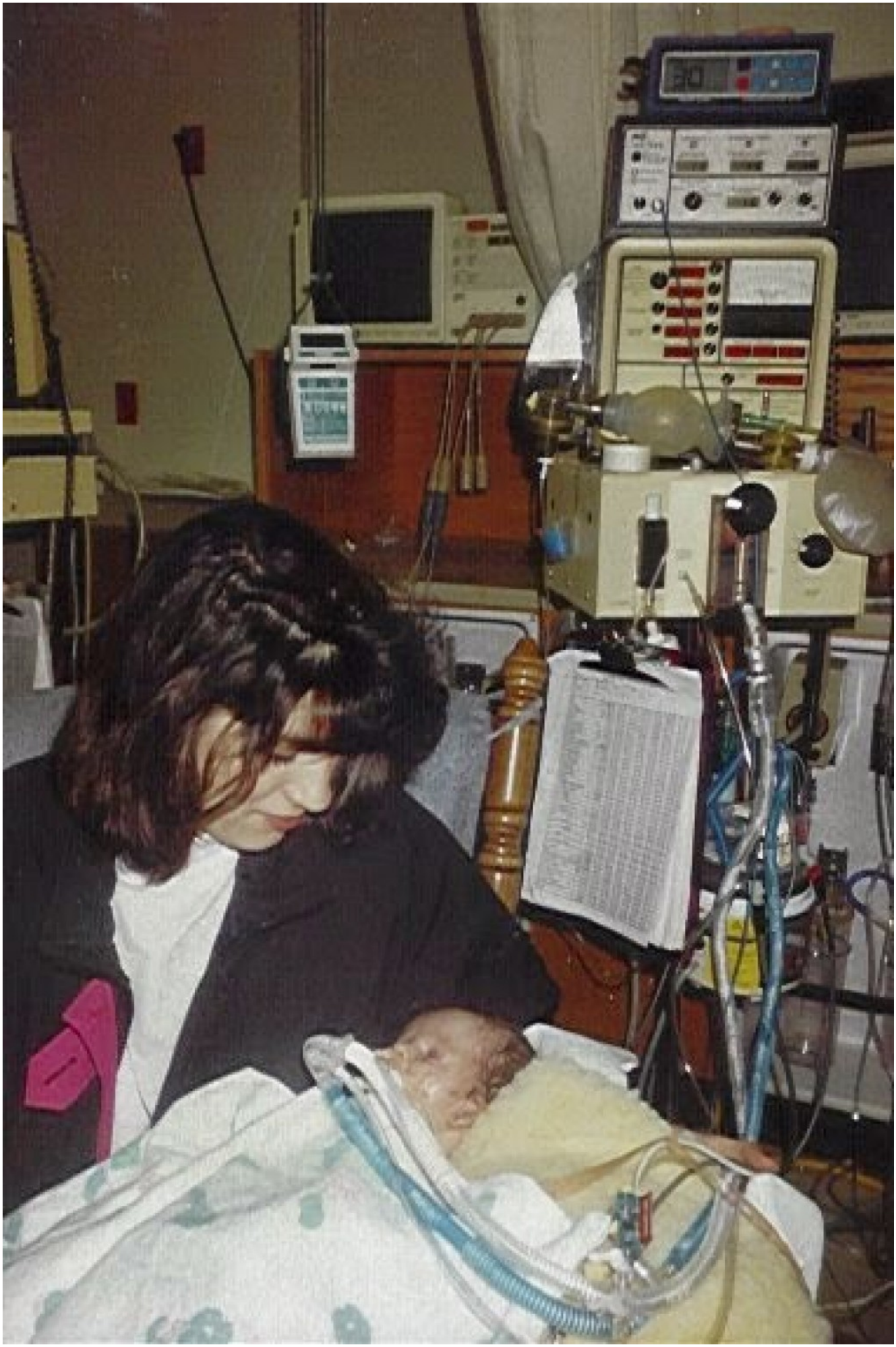
Grieving Moms Take on the World to Save Other Peoples' Children

They lost their sons two decades ago but they continue to fight to save the lives of 1000's of children also born with a little known but common deadly birth defect.



Raleigh, Jan 1, 2021 (Issuewire.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.

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 complications of Congenital Diaphragmatic Hernia. The charity was renamed and restructured in 2017 as "CDH International" to focus more on the research of the birth defect and to work on a global standard of care for the children so that the babies born with CDH in lower and middle-income countries also have a chance of survival and families worldwide have better access to accurate statistics to make more informed choices in care.

"The past 25 years have flown by. Especially for the past 4 years. We have grown so much at lightning 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 economic 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 NGOs 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 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 insane! 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 its first employee.

“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

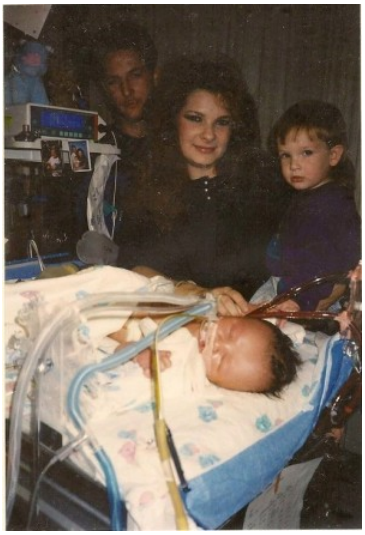
Along with managing the Congenital Diaphragmatic Hernia Patient Registry for research, CDH International continues all of their other work in educating the public on CDH, supporting families with information, care packages, on-line groups, conferences, scholarships, and financial assistance. Ms. Ireland 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





Media Contact

CDH International

dawn.ireland@cdhi.org

19196102972

3650 ROGERS RD 290

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