

Global Congenital Diaphragmatic Hernia



# THE CDH AWARENESS TOOLKIT

YOUR GUIDE TO RAISING CONGENITAL DIAPHRAGMATIC HERNIA AWARENESS



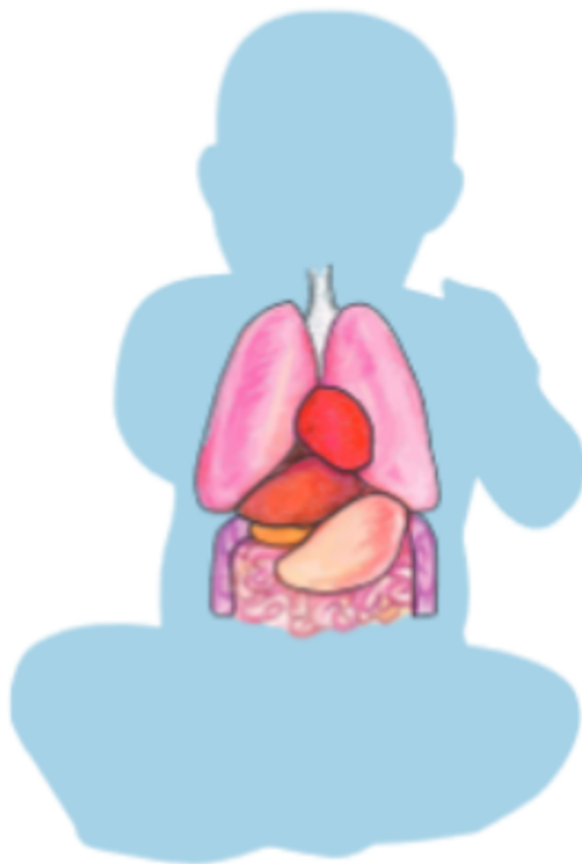
# CDH AWARENESS

- April 19th is the Official Congenital Diaphragmatic Hernia Awareness Day
- The Official CDH Awareness Ribbon is blue, pink and yellow with clouds.
- No one owns the day or the official ribbon
- Congenital Diaphragmatic Hernia Awareness is imperative to supporting patients and funding research

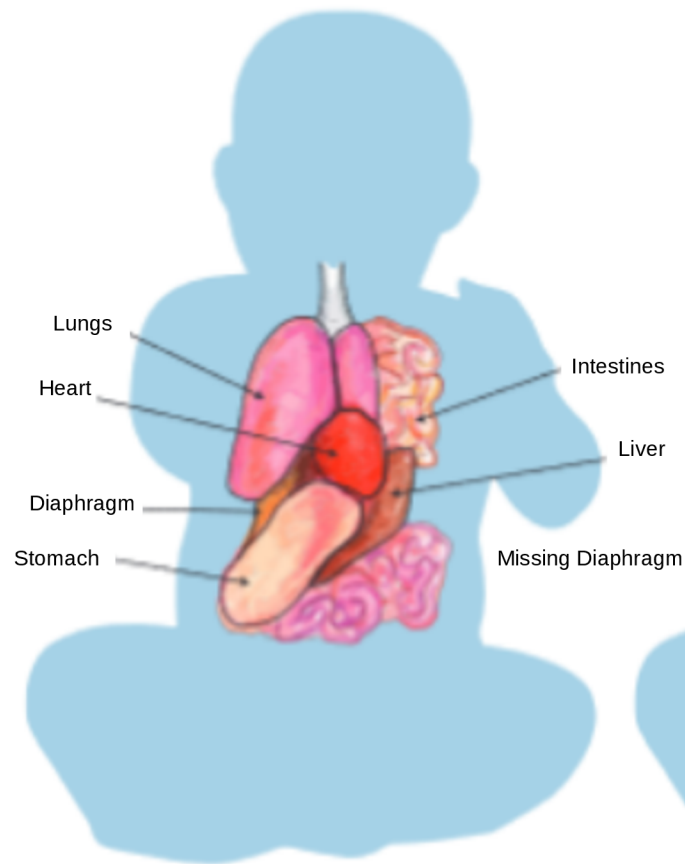
**GET INVOLVED!**

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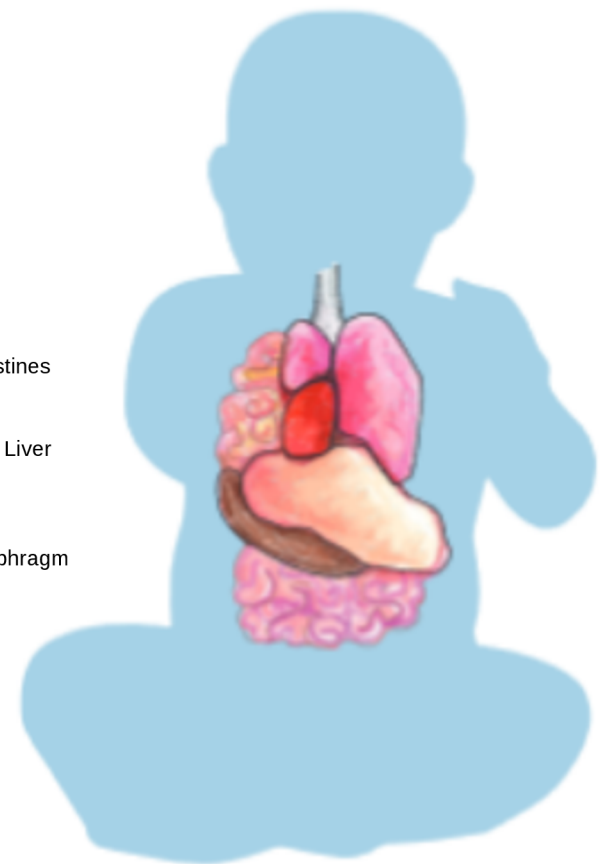
**Congenital Diaphragmatic Hernia (CDH)** is a birth defect that occurs when a baby's diaphragm (a thin sheet of muscle that separates the abdomen from the chest) fails to fully form, allowing abdominal organs to enter the chest cavity and preventing lung growth. Treatment requires surgery and intensive hospital care.



Healthy Infant



Left-Sided CDH



Right-Sided CDH

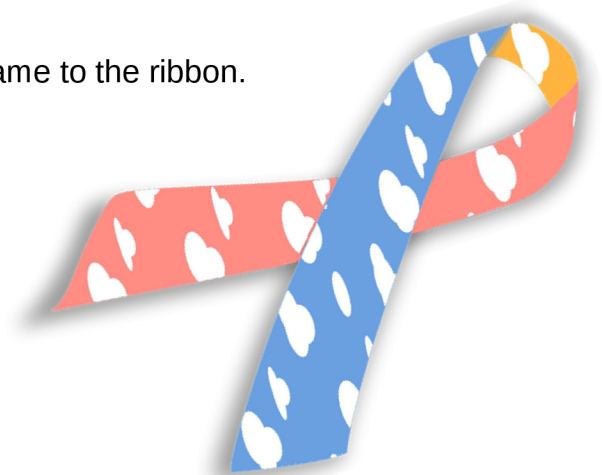
# The CDH Awareness Ribbon

The official CDH Awareness Ribbon is recognized in 74 countries and all 50 states and by many non-profit organizations, groups and hospitals. It was voted on by CDH parents, is trademark and copyright free and is not used by any other cause.

The Congenital Diaphragmatic Hernia Awareness Ribbon is as unique as the babies born with CDH. The awareness colors for birth defects are pink and baby blue, so they were incorporated into our ribbon. The official Congenital Diaphragmatic Hernia Awareness Ribbon is pink, baby blue and light yellow, with white clouds to represent the 50% of babies born with CDH who do not survive. It is original, not used by and doesn't infringe upon any other cause – yet, it also signifies that CDH is a birth defect. The baby colors truly keep the meaning of the cause – helping CDH babies – close to heart.

This is the Congenital Diaphragmatic Hernia Awareness Ribbon recognized by the members of the Alliance of Congenital Diaphragmatic Hernia Organizations. Is it recognized by CHERUBS, the world's oldest and largest CDH organization with over 7000 members in 84 countries. It is the ribbon associated with the Congenital Diaphragmatic Hernia Research Study and the CDH Research Congressional Bill. Wikipedia recognizes this ribbon. There is even a postage stamp with this ribbon, created February 12, 2008. Not to mention 1000's of items with this ribbon available on our stores and various other sites.

If you have a child born with CDH, feel free to add your child's name to the ribbon.





# Congenital Diaphragmatic Hernia Awareness Day

## Why April 19th?

On April 1, 2008, a woman filed a trademark on “Congenital Diaphragmatic Hernia Awareness” and “Congenital Diaphragmatic Hernia Awareness Day” for March 31, which was based on the day she started her own (now defunct) non-profit.

If another group or any patient family wanted to say the phrase “Congenital Diaphragmatic Hernia Awareness” or participate in “Congenital Diaphragmatic Hernia Awareness Day” without her permission, there were threats of lawsuits. Thus, awareness was no longer about the cause but ownership.

CDH Research International (then CHERUBS) was threatened several times with lawsuits and with the help of pro bono attorneys and the support of many other non-profits and patient families filed to remove the trademark on “Congenital Diaphragmatic Hernia Awareness”.

After 2 long years of legal actions and much division caused in the CDH community, the trademark was removed on April 19, 2010. Congenital Diaphragmatic Hernia Awareness was now free again for all patients, hospitals and organizations.

To celebrate this, and the fact that both trademarks were now gone, the members of ACDHO voted to make April 19th international “Congenital Diaphragmatic Hernia Awareness Day”. This is a day for everyone to raise CDH Awareness freely, to fundraise for whatever hospital or charity that you want and to celebrate the lives of the patients while working together globally on one day to have a larger voice. Most patients and charities recognize April 19th. Families and hospitals in over 70 countries have participated.

As part of the ACDHO charter, never again will one person or entity try to own CDH Awareness or any part of the cause.

# CDH Awareness Month Proclamations

We work hard every year to gather proclamations from Governors and Mayors. We have received proclamations from all 50 states but never in the same year. This is our goal! Make a copy of this map and color in each state as we receive proclamations.



View the updated list at <http://www.cdhawarenessday.org>

## How to request a Proclamation from your Governor or Mayor:

1. **Make sure that it's not been already requested by emailing [awareness@cdhi.org](mailto:awareness@cdhi.org)**
2. **If not, use this template to write / email to make the request. <https://cdhi.org/proclamations/> (Between January 1 and March 15th is best)**
3. **Keep us updated!**



## CDH Awareness Light Ups

Every year, our volunteers work really hard to get landmarks and historic sites light up to raise CDH Awareness. Our goal is to get a landmark lit in every state and all 84 countries that we work in!

### Some Landmarks That We Have Lit Up:

- Niagara Falls
- Pyramids in Cairo
- Eiffel Tower
- CN Tower
- Superdome
- Dublin Town Hall
- BC Parliament
- BC Place
- WoodmenLife Tower
- Bank of America
- Calgary Tower
- Retirement Systems of Alabama
- Brant Street Pier
- Sails of Light
- Science World
- PECO Crown Building

### Landmarks That We Are Still Trying For:

- White House
- Empire State Building
- Space Needle in Seattle
- Brooklyn Bridge
- Old Parliament Building – Australia
- La Basilica de la Sagrada Familia – Barcelona
- Osaka Castle – Japan
- Nelson Mandela Bridge – South Africa
- Princes Palace – Monaco
- Cristo Redentor – Rio de Janeiro, Brazil
- Taipei 101 Tower – Taipei City, Taiwan
- Sydney Opera House
- Parthenon - Athens

View the updated list at <http://www.cdhawarenesday.org>

### How to request a light up:

1. **Make sure that it's not been already requested by emailing [awareness@cdhi.org](mailto:awareness@cdhi.org)**
2. **If not, use this template to write / email the landmark to request a light up.** *(Please make sure to request April 19<sup>th</sup> for ALL patients born with CDH)* <https://cdhi.org/lightups/>
3. **Keep us updated!**

# Annual CDH Telethon

Every year, we hold a telethon. Some years it's on April 19<sup>th</sup>. Some years it's on April 30<sup>th</sup>. Some years it's 12 straight hours live. Some year's it's videos posted all month long. The telethon schedule is dictated by research projects and conferences and how many volunteers we have on hand to help.

Check out this year's telethon info at <https://www.facebook.com/cdhsupport/events>

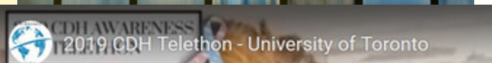
The CDH Telethon Includes:

- Doctor / Researcher Interviews
- Patient / Family Interviews
- Volunteer / Staff Interviews
- Research Updates
- Celebrity Videos
- Live Coverage
- Total Updates
- Full Social Media Push

**Want to Share Your Story?**

Submit your information at <http://www.cdhi.org/shareyourstory>

Submitted stories are used on the Telethon, books, social media and interviews on the CDH Radio Show.



# Fundraising for CDH Research

Congenital Diaphragmatic Hernia is the most underfunded birth defect per patient for research and who else is going to fight as hard as we, the CDH families and friends, to help save these kids? "Fundraising" sounds complicated and hard but it doesn't have to be!

## Easy Fundraising Ideas:

- Facebook / Instagram Fundraisers
- Collecting Change for CDH
- Bake Sale
- Yard Sale
- Jeans Day at Work
- Raffle
- T-Shirt Sale
- Restaurant Night
- CDH Bracelet Sale
- Lemonade Stand
- Facepainting

## More Fundraising Ideas:

- Walk / Run for CDH
- Car Show
- Bike Run
- Motorcycle Poker Run
- Basket Auction
- Phoneraising Fundraising
- Car Wash
- Bingo Night
- CDH Wings Mural
- Club Night
- Fundraising Lunch

## Big Fundraising Ideas:

- Golf Tournament
- Formal Gala
- Baseball Tournament
- Bowling Tournament
- Dance-a-Thon
- Bake-a-Thon
- Art Show
- Fashion Show
- Carnival / Circus
- Cook Off

Name the event in honor or memory of a CDH patient. You can donate directly to the CDH Research Fund or raise \$10,000 to create a CDH Research Grant. Make it a family or neighborhood annual event!

Make sure to follow local and state laws and be safe. Take lots of photos! Reach out to us at [fundraising@cdhi.org](mailto:fundraising@cdhi.org) to learn more and to submit your story and photos. Please mail funds to CDH Research International, 3650 Rogers Rd #290, Wake Forest, NC 27587. Please do not mail cash.



Brody Stolz

Ella Rose Stone

Jon Lee Storevik

Laura K. Stratton

Liam Francis Streeter

Cody Travis Streetman

Wyatt Strelow

Cooper Strevel

Nicholas Alexander Strickland

Thomas Cooper Strickland

Allisyn Grace Strickler

Cheryl Lynn Strieby

Ellington McLaine Stringer

Christopher Strobe

Oskar Ström

# Virtual CDH Ribbons

Every year we post the names of 1000's of CDH patients (survivors, non-survivors, and those in utero still) on our web site. Beside each name, we place 1 virtual ribbon.

Family and friends donate \$5 to add additional ribbons by each name. Many families fundraise in April by asking others to add ribbons next to their child's name. All money raise through ribbon sales goes to CDH research and is tax-deductible.

We all share the link to the list on social media and encourage everyone to go see just how many children are affected by Congenital Diaphragmatic Hernia!

There are also contests and the patient with the most ribbons on April 30<sup>th</sup> wins a trophy for his/her family! This is a fun way to raise awareness and funds for CDH.

Is your child listed? Members of the charity are listed if they give us publishing permission.

Join for free at <http://www.cdhiboards.org>

Find the list of ribbons at <http://www.cdhawarenessday.org>

Purchase more ribbons at <https://cdhawarenessshop.org/products/virtual-ribbons-for-cdh-awareness-month>



# Social Media Engagement

CDH Research International is very active on all social media and we often schedule posts. This is especially true in April for CDH Awareness Month. You can help us to raise awareness by liking, sharing, reposting, dueting our posts and videos on the various platforms. Our main accounts are monetized so just watching the videos helps raise research funding too!

Tag us in your posts! We often share and repost videos made by CDH families and hospitals.

Duet with our videos! Watch for our "Call to Action" posts asking for specific videos and images that we use to raise global awareness for different projects.



[www.facebook.com/cdhsupport](http://www.facebook.com/cdhsupport)  
[www.facebook.com/cdhintl](http://www.facebook.com/cdhintl)  
[www.facebook.com/cdhawareness](http://www.facebook.com/cdhawareness)



[@cdhinternational](https://www.instagram.com/cdhinternational)



[@cdhawareness](https://www.tiktok.com/@cdhawareness)



[@cdhintl](https://twitter.com/cdhintl)  
[@cherubs](https://twitter.com/cherubs)



[www.linkedin.com/company/25032763/](http://www.linkedin.com/company/25032763/)



[pinterest.com/cdhawareness](https://pinterest.com/cdhawareness)

#cdhawareness #cdhawarenessday  
#congenitaldiaphragmatichernia #cdh  
#savethecherubs



## CDH Call To Action!

Many of our awareness projects call for specific images or videos:

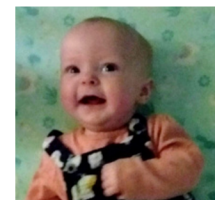
- Survivors holding NICU photos
- NICU photos at the graveside/urn for Non-Survivors



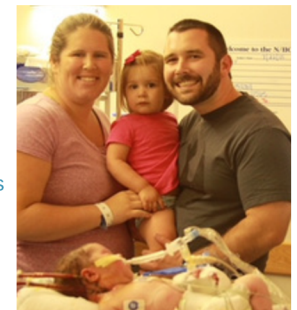
- Survivors wearing wings
- Wings at the graveside/urn of Non-Survivors
- Expectant moms holding wings
- Doctors, nurses, researchers holding wings



- 30 second videos of patients or family members stating why CDH Research is important to them
- 20 minute videos of patient families sharing their CDH stories



- Photos / updated photos of all CDH patients for our "Faces of CDH" campaign



You must be a member give publishing permission.. Join for free at [www.cdhboards.org](http://www.cdhboards.org)  
Submit photos & videos to [awareness@cdhi.org](mailto:awareness@cdhi.org) with patient's full name and your name please.

# Free Social Media Graphics

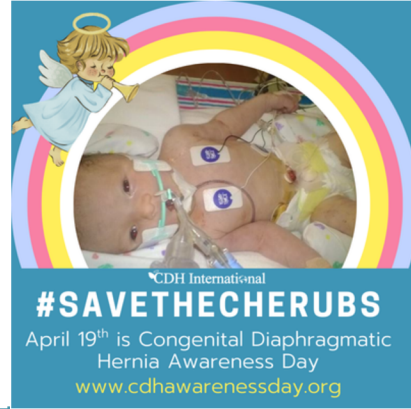
Free CDH Awareness Ribbons and other graphics!

Over 20 free personalizable Congenital Diaphragmatic Hernia Awareness images for April!

Using our Canva template and your own photos, you can create the perfect social media images to raise awareness and share your story!

All for free for personal use! More added as we have time.

Grab them at <https://cdhi.org/free-personalizable-cdh-awareness-graphics/>





## The Official CDH Awareness Shop

The easiest way to raise awareness is to wear it! The CDH Awareness Shop is the one stop shop for all CDH items. With over 1000 official items, you are bound to find the perfect gift for you or someone you love to raise Congenital Diaphragmatic Hernia Awareness. 100% of all shop profit goes to CDH Research!



Visit the shop at <http://www.cdhawarenessshop.org>

- T-Shirts
- Sweatshirts
- Tank Tops
- Bathing Suits
- Bikinis
- Shorts
- Pants
- Jogging Pants
- Pajamas
- Tennis Shoes
- High Heels
- Onesies
- Jackets
- Skirts
- Dresses
- Neckties
- Bedding
- Table Linens
- Glassware
- Canvas Prints
- Curtains
- Lamps
- Jewelry
- Christmas Stockings
- Tree Skirts
- Ornaments
- Mugs
- Tumblers
- Flags
- Bath Linens
- Pillows
- Luggage
- Scarves
- Dress Shirts
- Purses
- Totebags
- Backpacks
- Lunch Boxes
- Teddy Bears
- Baseball Hats
- Baseball Shirts
- Jackets
- Official CDH Awareness Scottish Tartans



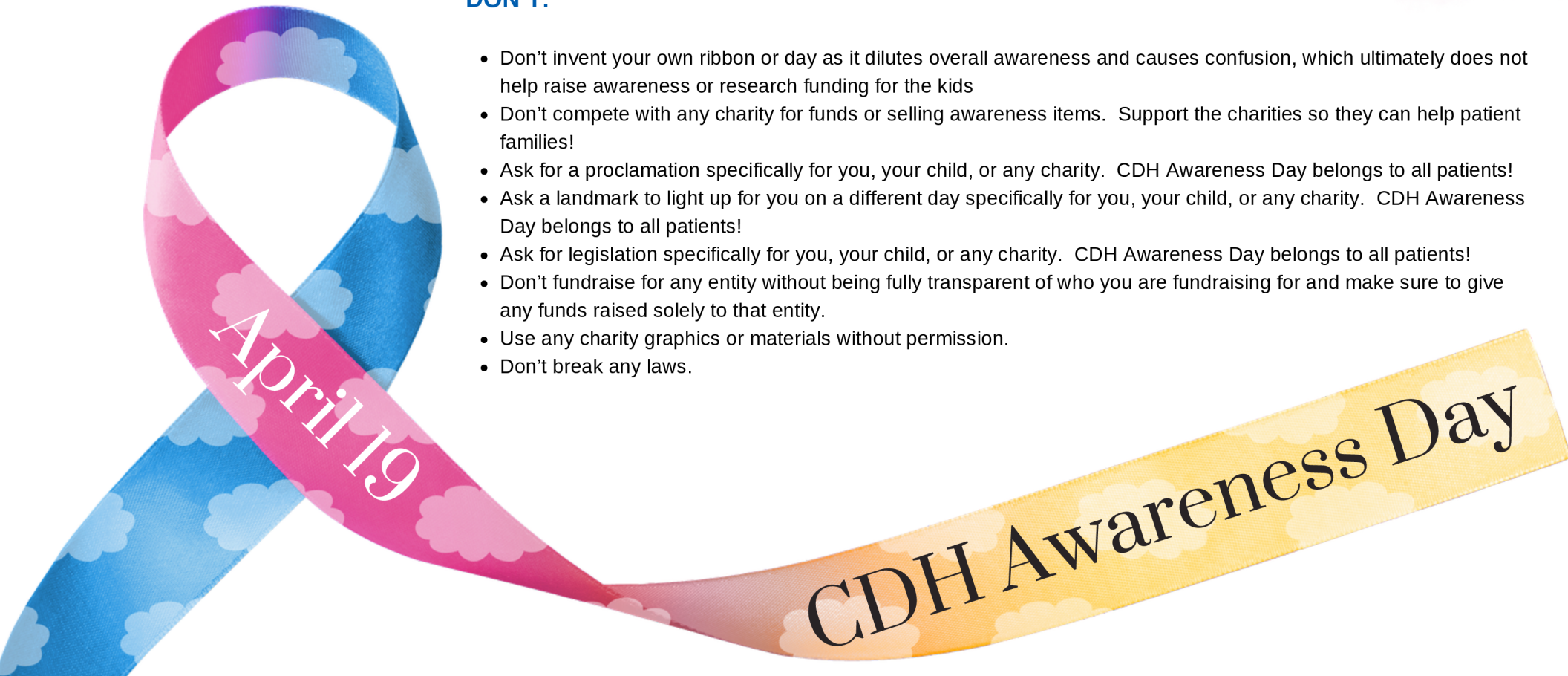
## DO:

- **Tell people about Congenital Diaphragmatic Hernia!**
- Do participate in charity and hospital events
- Do share posts on social media
- Do share your own CDH story, photos & videos
- Do use the official CDH Awareness Ribbon or create one that is like it (pink, blue, yellow with white clouds)
- Submit a request for a proclamation from your mayor
- Work with CDH Research International to get more light ups for April 19th
- Wear CDH Awareness clothing purchased from a charity or pink, blue and yellow clothing
- Support CDH Legislation
- Hold a fundraiser
- Purchase virtual CDH Awareness Ribbons
- Participate in the CDH Telethon and/or share the video

DO'S & DON'TS

## DON'T:

- Don't invent your own ribbon or day as it dilutes overall awareness and causes confusion, which ultimately does not help raise awareness or research funding for the kids
- Don't compete with any charity for funds or selling awareness items. Support the charities so they can help patient families!
- Ask for a proclamation specifically for you, your child, or any charity. CDH Awareness Day belongs to all patients!
- Ask a landmark to light up for you on a different day specifically for you, your child, or any charity. CDH Awareness Day belongs to all patients!
- Ask for legislation specifically for you, your child, or any charity. CDH Awareness Day belongs to all patients!
- Don't fundraise for any entity without being fully transparent of who you are fundraising for and make sure to give any funds raised solely to that entity.
- Use any charity graphics or materials without permission.
- Don't break any laws.





## More Ideas & Events

Below are some more ideas that CDH families have done in the past. Please let us know if you can think of any more!

- **Share your story!**
- **Hold a fundraiser for research!**
- **Wear CDH Awareness clothing**
- Attend a CDH light up
- Wear wings
- Call your local newspaper or TV station and ask to share your story
- Local angel parade (kids wearing wings, everyone holding awareness signs)
- Pink, blue and yellow lights on houses
- CDH Awareness cakes and cupcakes at work and school
- Ask us about a CDH Wings Mural
- Collect change for CDH Research (please mail a check or donate online)
- Hand out CDH Awareness fliers
- Display CDH Awareness posters
- Giving a talk about CDH at school, a club, church, or business meeting
- Handing out CDH ribbons or buttons
- Decorating your car with streamers and car chalk
- Pink, blue, and yellow corsages for grieving parents
- Take flowers to the cemetery
- Put a CDH awareness sign or flag in your yard

Check out this year's scheduled events at <https://www.facebook.com/cdhsupport/events>



[www.cdhawarenesssday.org](http://www.cdhawarenesssday.org)

[www.cdhrefsearch.org](http://www.cdhrefsearch.org)

3650 Rogers Rd #290  
Wake Forest, NC 27587  
USA

[awareness@cdhi.org](mailto:awareness@cdhi.org)