



Complex Child E-Magazine

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Congenital Heart Defect Awareness

by Kristiana Pena

What is a congenital heart defect or CHD? I had no idea until my youngest son, Christopher, was born with a rare CHD, dilated left ventricular non-compacted cardiomyopathy. Now almost two, we have been on a rollercoaster ride since Christopher's birth. During our journey, I have personally watched many children go through the unimaginable, and have cried and mourned the deaths of children who I have never met in person. I have bonded with the parents of these children, in person and through social networking communities such as Facebook, Twitter, blogs, CaringBridge pages, and CarePages, which have provided us ways to communicate, get to know each other and share journeys.



Along with Christopher, these other children are the reason I advocate so passionately for the least known, yet most common epidemic: congenital heart defects. A CHD or congenital heart defect is a defect you are born with and have for your whole life. Open-heart surgery and even a heart transplant are options for some with the condition. All children have many doctor's appointments and therapies, and many, including

Christopher, maintain a complicated medicine regimen needed on a daily basis for survival.

The Congenital Heart Information Network (C.H.I.N.) reports that congenital heart defects are the most frequently occurring birth defect and the leading cause of birth defect related deaths worldwide. According to C.H.I.N., over a million families across America are facing the challenges and hardships of raising children with Congenital Heart Defects, since 40,000 babies are born every year in the United States with CHDs. Some congenital heart defects are not diagnosed until months or years after birth, while undiagnosed congenital heart conditions cause many cases of sudden cardiac death in young athletes. C.H.I.N. also reports that despite these statistics, newborns and young athletes are not routinely screened for congenital heart defects. Most worrisome, a disproportionately small amount of funding is available for Congenital Heart Defect research and support.

Congenital Heart Defect Awareness Week (February 7-14, 2010) was established as a national opportunity for families whose lives have been affected by CHDs to celebrate life and to remember loved ones lost. It is also intended to honor dedicated health professionals and to meet others so families know they are not alone. Congenital Heart Defect Awareness Week also provides opportunities to share experiences and information with the public and the media, to help raise public awareness about congenital heart defects.

Many CHDs can be caught in newborns through a simple test called a pulse oximetry screening. Routine pulse oximetry screening of newborns is available but not mandatory or widely used. It is hoped that in the near future hospitals will make pulse oximetry screenings mandatory on all newborns before leaving the hospital. This screening is a simple, fast, painless and inexpensive test to measure the oxygen level in the blood that can also help detect a large percentage of Congenital Heart Defects in newborns.

Another step in helping raise awareness and funds for research is the *Congenital Heart Futures Act*, which aims to help prevent premature death and disability and increase the quality of life for almost two million people in the United States with a CHD. The Congenital Heart Futures Act was introduced in March 2009, in both houses of Congress. Senator Dick Durbin of Illinois, joined by Senator Thad Cochran of Mississippi, introduced the bill in the Senate. In the House of Representatives, the bill's lead co-sponsors were Representative Zach Space of Ohio and Representative Gus Bilirakis of Florida. This act calls for more funding for research and a comprehensive national registry of CHDs to help provide more accurate information on cases, as well as to hopefully one day provide a cure. I urge you to contact your senators and representatives and encourage them to support this legislation.

Congenital Heart Defects are something every parent needs to be aware of, as any child at any time can be diagnosed with one. According to the Adult Congenital Heart Association, every fifteen minutes a baby is born with a CHD and 1 in 100 children will be diagnosed with a CHD during their lifetimes.

Help spread awareness by supporting the Congenital Heart Futures Act, and demanding your newborn have a pulse oximetry screening before leaving the hospital.

Resources:

- Brochure on Pulse Oximetry and CHD:
<http://www.articles.complexchild.com/feb2010/pob.pdf>
 - Mended Little Hearts: <http://www.mendedhearts.org/mlh/frame-mlh.htm>
 - It's My Heart: <http://www.itsmyheart.org/>
 - C. H. I. N. (Congenital Heart Information Network): <http://tchin.org/>
 - Children's Cardiomyopathy Foundation:
<http://www.childrenscardiomyopathy.org/>
 - 1in100: <http://1in100.org/>
 - International Children's Heart Foundation: <http://www.babyheart.org/>
 - CHD-UK: <http://congenital-heart-defects.co.uk/default.aspx>
 - CHD Babies: <http://chdbabies.blogspot.com/>
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- Position Statement of the American Academy of Pediatrics and the American Heart Association on Pulse Oximetry for detecting CHDs:
<http://pediatrics.aappublications.org/cgi/content/full/124/2/823>



Kristiana Pena lives in Mississippi with her husband and two sons, Justin, 12 and Christopher, 2. She is a stay at home mom and passionate CHD advocate. She volunteers with Mended Little Hearts of Mississippi and Children's Cardiomyopathy Foundation. You can read more about her fight against CHD at Christopher's CaringBridge page: <http://www.caringbridge.org/visit/cj08>. In addition to CHD awareness, she heads the Endangered Breeds Association of Mississippi, works on her church music team, enjoys traveling with her family and photography. Above all, Kristiana wants to help make a difference and provide hope for all CHD Warriors and their families.

More on Christopher:

- http://www.youtube.com/watch?v=z_3zPRZoQuI
- <http://www.ibelieveinsickkids.com/video/Christophers-Story>
- <http://www.rankinledger.com/apps/pbcs.dll/gallery?Site=D8&Date=20090916&Category=NEWS&ArtNo=909160802&Ref=PH&Params=Itemnr=10&template=WAPgallery>