



CHD-UK© NEWSLETTER

Educating and Raising Awareness of Congenital Heart Defects

1st Edition, December 2008

www.congenital-heart-defects.co.uk

Welcome to our first ever newsletter, I hope that you like what we have done and if you would like us to publish your story, for example, growing up with CHD, from a parents point of view or what we would love to have is stories from a siblings point of view. We would love to hear from you especially if you have any ideas.

What are we doing?

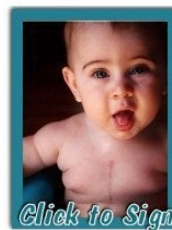
We are educating, informing and raising awareness of CHD. In the 60's and 70's there was no awareness of CHD and with medical advancement you would think that there would be a lot of awareness but no there is still no awareness. The first time a parent/parent-to-be hears about the condition is when their son or daughter is diagnosed with one of the 35+ types of CHD's. So, please help us raise awareness, take a look at the website to see what we have done and will be doing to raise awareness.

The website has come about due to great feedback from the two pages that we have been running since May 2007 and we thought we would put it all into one but also keep the two pages going.

The two other pages are (1) [Myspace – CHD-UK](#), and for the CHD-UK Group on Facebook the link is here: (2) [CHD-UK Group on Facebook](#)

What are our aims for 2009?

Some of you may be aware that since January 2007 there has been a petition going around to raise Media Awareness of CHD, this is due to close on the 31st December, so please if you have not already signed it, then please sign - it only takes a minute of your time compared to a lifetime of living with CHD. Click on the link below to sign.



*Please care for us and sign for
CHD Awareness in the Media*

[\(3\) Media Awareness for CHD](#)



The second petition which will close in April 2009 is the Every Baby needs an Echocardiogram, this also takes a minute to sign the petition, so please sign if you have not done so already. For more information please go to (4) [Ways you can help](#) and if you want to sign the petition you can either (5) [click here for UK](#) or (6) [click here for the World](#) or sign via the Ways you can help.

Once these petitions have been completed and sent to the various places, we will start on finding out more information on Pulse Oximetry, which tests the oxygen in the blood by putting a clip onto your finger.

As well as the 20 week scan, I will be contacting Tiny Tickers: a better start for babies born with heart disease to find out what I can do to help them raise this vital scan that is needed. Tiny Tickers believe in detecting CHD before birth and they are working locally and nationally to improve early detection, diagnosis and care and give these babies a better start in life.

Anything that can be done to detect CHD whether before birth or after is better than nothing at all.

Publicity

We have had some good publicity in November, so much so that people are now emailing to say that they found the sites via Newcastle Chronicle or from someone else's pages.

The best news is that I had a local Gloucestershire paper called 'The Citizen' write an article about Hazel, yes a GROWN-UP CHD'er not a baby. We need to get the papers to take more notice of the grown-ups because if it wasn't for us, then the next generation would not have had as much of a chance. Every new generation that survives helps the next generation but we still need to get the word out there about CHD. Not only do we need the grown-up chd'ers in the papers but also babies/children to raise awareness.

What is in the News

Here are some links that will take you to articles which have been published in the news the last month.

[\(7\) Cord Blood Stem Cells May Help Repair Babies' Hearts Defects](#)

New Guidelines for congenital heart disease in America, the UK does have a NHS guideline which came out around 2000. (8) [Click here for the American New Guidelines](#).

What is new on the website?

A personal story about Ezekiel Timothy Bruce, who survived for 1 month, this is why we need to raise awareness. (More personal stories will be added during the coming months).

Publications: A newspaper article about the petition for Every Baby Needs an Echocardiogram.

Inherited CHD's

What is inherited CHD's? Are CHD's inherited? Is it only a few that are inherited or none at all? To find out, view the website in 1 month for the article.

CHD World websites

I am going to list a couple of websites from around the world in each newsletter and this month the two world websites are:

1) **New Zealand: Heart Children NZ**

<http://www.heartchildren.org.nz>

This website is dedicated to raising awareness of CHD in New Zealand and helping all heart children and their families. They do several charity events a year.



2) **United Kingdom: Heartline**

<http://www.heartline.org.uk>

This website provides support and help for children with congenital heart conditions and their families.

Don't FORGET that FEBRUARY 8th to 14th 2009 is CHD AWARENESS WEEK.

What have you got planned to raise awareness during this week? Do you want to raise awareness this week? Send me your ideas and I will let you all know what everyone is planning or has planned to do in the next newsletter.

CHD Awareness Day is on the 14th February (every year). It is already been recognised as the day to raise awareness in some states of America but here in the UK it is not recognised yet. We are hoping that this day will also become the day of CHD Awareness as well as Valentine's Day... A day of hearts for everyone.



Next Edition

At the moment of release, we do not know what we will put in the next edition of the newsletter (probably updates of what we have added onto the website) but if you have any ideas or would like to have your story shared on our website, then please contact us either on:

<mailto:chduk@hotmail.co.uk>

or

[mailto: desiree.chd-uk@hotmail.com](mailto:desiree.chd-uk@hotmail.com)

And if you would like to subscribe to our newsletter, then please go to the Contact Us form and send
(9) [CHD-UK's Contact Us Form](#)

Finally, we would like to wish you all a very Happy Christmas and a Happy New Year



Hazel, **CHD-UK**

Links Mentioned in the Newsletter

- 1) <http://www.myspace.com/chduk>
- 2) <http://www.facebook.com/groups.php?id=872000343#/group.php?gid=2361087995>
- 3) <http://www.gopetition.com/petitions/media-awareness-for-chd.html>
- 4) <http://congenital-heart-defects.co.uk/waysyoucanhelp.aspx>
- 5) <http://petitions.number10.gov.uk/babyecho/>
- 6) <http://www.gopetition.com/petitions/every-baby-needs-an-echocardiogram.html>
- 7) <http://www.bloomberg.com/apps/news?pid=20601124&sid=aWRs4Rf8yvJY&refer=home>
- 8) <http://www.news-medical.net/?id=42591>
- 9) <http://congenital-heart-defects.co.uk/contactus.aspx>