



CHD-UK© E-NEWSLETTER

*Educating and Raising Awareness of
Congenital Heart Defects*

3rd Edition, April 2009

www.congenital-heart-defects.co.uk
and
www.chd-ni.co.uk

Welcome to April's e-newsletter and I hope you all had a good Easter and that you didn't eat too many Easter Eggs, I didn't get any!! I am continuing with the theme of raising awareness due to the fact that CHD-UK had a fund-raiser and also to raise CHD Awareness. Also included in this month's e-newsletter is a personal story of a teenager from the USA.

We are including our usual CHD World Websites, CHD'ers birthdays as well as the usual What's in the News? And not forgetting that CHD-UK will be 2 years old in May :-)

CHD-UK Raising Awareness and funds.

CHD-UK had a fund-raiser in The Three Magpies, Sheffield which was organised by Tony Cox and Desiree Rebeck and was a successful night whereby awareness of CHD was raised as well as a total of £220.00. The money raised was split between two very important hospitals that are close to CHD-UK's heart.

£120.00 for the Chesterman Wing, Northern General Hospital Sheffield

£120.00 for Bristol Royal Hospital for Children

CHD-UK's skydive to raise awareness was postponed until the end of May due to the weather (yes, it actually rains in Spain). CHD-UK is hoping to raise awareness and money for two wonderful and worthy organisations (Fundación Española del Corazón in Spain and Tiny Tickers in the UK)

CHD-UK celebrates their 2nd Anniversary in May – details in the June e-newsletter

Children's Heart Week - 9-17th May 2009

Every year in the UK over 5000 parents are told that their baby has a heart condition. This May, Children's Heart Federation and member groups will be raising awareness of congenital and acquired heart disease in children and young people, under a collective campaign called **Hearts4Hearts**.



Key events include:

- BBC Radio 4 appeal, Sunday 10 May
- Parliamentary Reception, Thursday 14 May
- [Family Sports Day](#), Saturday 16 May - [find out more and reserve your place!](#)

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.

Stress Cardiomyopathy Can Occur with Routine Procedures

[Click here for the Medpage Today Article](#)

Associations update Heart Failure Guidelines

[Click here for the Medpage Today Article](#)

What is NEW on the website?

We have added more articles about different types of CHD's and related to CHD's which are:

- ♥ Atrioventricular Septal Defect (AVSD)
- ♥ DiGeorge Syndrome
- ♥ Ebstein's Anomaly
- ♥ Williams Syndrome
- ♥ Velocardiofacial Syndrome
- ♥ 22q11 Deletion

If you have a particular type of CHD, that you want more information on, please contact us, and we will post on the site, for everyone's benefit.

Other new articles are:

Fundraisers

- ♥ Skydiving Fundraiser
- ♥ Valentine's Night 2009 Fundraiser

Blog following Meghan and her family dealing with a CoHD (Tetralogy of Fallots):

- ♥ Meghan's birth - 20th July 2008
- ♥ Paediatrician appointment – Friday, August 2008
- ♥ Meghan's birth - 20th July 2008
- ♥ Paediatrician appointment - Friday, 29th August 2008
- ♥ The day our world shattered into several thousand pieces - Monday, 22nd December 2008
- ♥ Synagis Injection - Thursday, 8th January 2009
- ♥ Flu Jab and Cardiologist Appointment - Monday, 26th January 2009
- ♥ The Call
- ♥ Pre-op appointment - Thursday, 5th February 2009
- ♥ Admittance for open heart surgery, Tuesday 10th February 2009
- ♥ Day of the open heart surgery - Wednesday 11th February 2009
- ♥ Meghan Raising CHD Awareness at Tesco's – Saturday, 14th February

Meghan has now had the operation and I will update the blog as soon as I have the information emailed to me.

Personal Stories added:

- ♥ Christy and TJ (Mother and Son) living with Tetralogy of Fallot,
- ♥ Cordelia and TGA – the story so far
- ♥ Hilary with TGA and minor stenosis of the Aorta (see personal stories)
- ♥ Jeni Busta a HLHS survivor with a happy heart
- ♥ Kurtis Cunningham and Williams Syndrome
- ♥ Victor living with TGA

Personal Stories

Hilary, contacted me in regard to her personal story and I thought I would let you all read it before I put it up on the website. She is a very strong, courageous girl.

Hi my name is Hilary Molenda I was born in February 1992 in Park Ridge Illinois. I was the first child of Mike and Mary. Shortly after I was born; I turned blue and had difficulty breathing. It was at that point that my parents were informed that I was born with a “broken heart”. After much medical diagnostic testing, it was determined that I had transposition of the greater arteries of the heart. This is a condition in which the two main arteries (one carrying oxygenated blood to the body / one carrying oxygenated blood away from the body) of the heart are in the wrong spot, thus transposed. At three hours old, I underwent a cardiac angioplasty to reopen a small hole in my heart to allow oxygen to travel to / from my heart. It was the beginning of my life long battle with congenital heart defects.

3 days later I underwent open heart surgery. This procedure was an arterial switch. The surgeons switched the two main arteries of my heart, the pulmonary and aorta to the correct spots. The largest artery that the doctor switched was 3/8 inch in length. The surgery was a new procedure, only approved by the FDA in 1990. *I was the 14th person in the world to have this surgery.* I remained in the hospital for one month, recovering from open heart surgery. I was discharged to home with a large amount of cardiac medications.

On October 8, 1993, I underwent a cardiac catheterization to fully examine my heart. The doctors realized that I had a minor leak in the area where they switched the arteries. In addition, I had minor stenosis of my Aorta. The leak and stenosis were minor, so the doctors decided that I did not need any cardiac medication.

My childhood differed greatly from my typical peers. My activity level was limited and I was unable to participate in any competitive sports. When I became ill, it was a major concern. I spent many days in my childhood on a lot of medication to combat any infections from settling in my heart. I underwent many tests that children typically do not have to do. My family worked hard to give me a typical childhood. However, I was often going to the cardiologist or in the hospital when other children were playing and having fun.

As a teenager, I began to develop symptoms of congestive heart failure. These symptoms included shortness of breath, palpitations, and being constantly tired. In 2008, the cardiologist decided that I needed to wear a holter monitor to measure my atypical heart rate. I wore this monitor to school and other activities. The results of the halter monitor lead to further testing, including a new procedure, an echnographic MRI. The MRI revealed that I now have a moderate pulmonary and aortic leaks and moderate aortic stenosis. I now will be followed by my cardiologist more frequently.

There are many things that I wish I could do like skydiving, riding roller coasters and running a marathon. I cannot do these activities because of my heart condition. I am very limited in what I can do and this bothers me terribly. It is hard for my friends to understand why I cannot participate in certain activities. Congenital heart defects are not obvious, so people do not realize the disabling effect that they have. I am a survivor who will fight for my whole life. However this battle is very difficult. I struggle daily from emotionally and physically dealing with my heart defect.

I often think about being a survivor of congenital heart defects and how my life is forever changed and different from my peers. I feel strongly that I have been given a significant purpose in life. My mom says that I was chosen to endure these challenges so that I can grow, develop, and change the world one heart at a time. My situations have made me stronger. These situations have made me appreciate and respect life at all levels.

To read more stories like Hilary's which range from growing up with a CHD, having a CHD and

suddenly finding yourself pregnant! And thinking will my baby also have a CHD? How will my heart cope with being pregnant? Will I be able to carry full term? Click here to read some amazing stories of courage, in the face of the unexpected.

- ♥ [Mother and son living with Tetralogy of Fallots](#)
- ♥ [Cordelia Griffin with TGA - story so far](#)
- ♥ [Jeni Bust a HLHS survivor. Happy with half a heart](#)
- ♥ [Hilary with TGA and Minor Stenosis of the Aorta](#)
- ♥ [Kate with Dexto-TGA](#)
- ♥ [Kurtis Cunningham and Williams Syndrome](#)
- ♥ [Sienna and HRHS, TGA and VSD](#)
- ♥ [Victor living with TGA](#)

CHD World websites

Here are April's editions two websites from around the world:

- 1) **United Kingdom: Grown up Congenital Heart Patients Association (GUCH PA)**

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

This website is devoted to supporting young people and adults with congenital heart defects .



- 2) **America: American Congenital Heart Association (ACHA)**

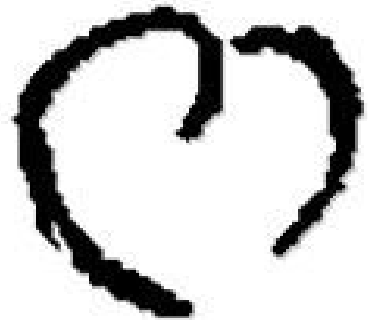
<http://www.achaheart.org/>

This website is an organisation is a non-profit organization which seeks to improve the quality of life and extend the lives of congenital heart defect survivors. Through education, outreach, advocacy and promotion of research, ACHA serves and supports the more than 1.8 million individuals with congenital heart defects, their families, and the medical community.

Designer Heart

Wrote by The Designer Heart Team:

Our journey with a congenital heart defect (CHD) began one chilly February afternoon in Toronto, Canada. We had our level two ultrasound at 19 weeks and were excited and anxiously waiting another glimpse of our baby. This was the ultrasound that confirmed the sex of the baby and we had decided a few months back that we wanted to know rather than have only yellow and green baby items once the baby shower came around. Plus we were too excited to wait the remainder of the nine months.



It so happened that given the space limitations at this health clinic my wife went in first and I was told that I would be called in after all the basic checks were done. One hour into the appointment I started to get a bit worried given the length of the wait and I also wanted in to see my baby. Just as I was going to ask for a status update I was called in by the ultrasound technician. I was thrilled and super excited as I walked the narrow hallway. As the door to the room opened I noticed my wife's face and something did not seem right. She seemed concerned, a little afraid, and tears were forming in her eyes. The mood in the room seemed off and nothing like the first ultrasound we experienced together.

I could sense a tense tone in the technician's voice and we wrapped things up with a warning that something was very wrong with our babies heart and that we were being referred to a specialist. We went home that day concerned but not too worried as the folks at the health clinic said that a second

ultrasound was rather common given that our baby would not sit still and was moving a lot. That same evening we got a call from our OB at 7:30 in the evening telling us that things looked rather grim and serious. What stands out the most about that call with the OB that evening was my wife crying and her voice looking for some form of reassurance from the doctor as she gave her the news.

The next two weeks were filled with a constant stream of specialist appointments and the final diagnosis from Sick Kids Hospital that our baby had a congenital heart defect called Hypoplastic Left Heart Syndrome (HLHS). A CHD as severe as it gets with a life expectancy as rare as the condition itself. We decided then that we were going to fight for our little girl's heart and give her a chance at life!

As we researched HLHS we found it very hard to find a social network for families who have a loved one affected by a congenital heart defect (CHD) some place to share ones stories and experiences, learn from other families who had or were going through similar situations and grow together through mutual support. The Sick Kids Hospital due to privacy issues is not able to share contact details of other parents with HLHS children for us to speak with (We understand their position and agree with their decision) . That is when we decided to take things into our own hands and start www.DesignerHeart.com a congenital heart defect network.

Presently we run the network from Toronto, Canada and are continually amazed at all the international traffic and visits the site gets from the world over. We encourage families and parents out there to join and share their stories, blogs, pictures and videos with other parents the world over looking for a ray of hope in a sometimes very dark life situation.
The Designer Heart Team

CHD Warrior's Birthdays

CHD-UK would like to wish a Happy Birthday to the following warriors whose birthday's are in February, March and April, and also belated birthday's to those who had them in January.



MAY

- ♥ 14th May 2004: Amelia Mercer, Interrupted Aortic Arch, ASD, large VSD, Sub-aortic Stenosis, and DiGeorge Syndrome (5 years old)
- ♥ 19th May 2004 :Alex Howarth, Tetralogy of Fallot (ToF) (5 years old)
- ♥ 11th May 2007 Kian Taylor, Pulmonary Stenosis, Heart Arrhythmia (low irregular HR), 2 VSD's (2 years old)
- ♥ 24th May 2005 Thomas "David" Moore, HLHS (4 years old)www.kentuckianalefthearts.com

JUNE

- ♥ 7th June: Oliver King, AVSD and PDA (repaired October 2007). Repair caused a residual VSD, mitral regurgitation, tricuspid regurgitation and Pulmonary hypertension. Other conditions include a rare form of long gap oesophageal atresia with multiple complications, completely gastrostomy fed and has an oesphagostomy stomas, sleep apnea's, significant hearing loss, downs syndrome and the most infectious smile you could imagine,
- ♥ 19th June 2004: Rhys Sobey, Sub Aortic Stenosis - awaiting surgery (Re-section of the Heart) (5 years old) <http://mystorybyrhys.blogspot.com/>

CHD Angel's Birthdays

CHD-UK has been asked to provide a birthday section for all the CHD Angel's. This is for all the CHD Angel's who sadly lost their fight with CHD:



MAY

- ♥ 18th May 2004 - 2nd January 2005: Eliza Steele, 2 Ventricular Septal Defect's, Eliza would have been 1 year old today if she had survived)

Always in our hearts and forever an angel.

This is why we have the petition for Echocardiogram, to prevent this happening. Please sign the petition and also could you sign the Media Awareness for CHD. It only takes 5 minutes, please forward on the petitions to your friends and family to sign. The UK government closed on the 7th April but we are keeping the Go Petition one open.

The link for all petitions is <http://congenital-heart-defects.co.uk/chdukspetitions.aspx>

Pulse Oximetry Clinical Trials in Birmingham

Here is the latest newsletter from Birmingham:

http://www.pulseox.bham.ac.uk/investigators/Newsletter_January_2009.pdf

Joining Forces: CHD-NI and CHD-UK

As you may have noticed CHD-UK has started working together with CHD-NI.

CHD-NI stands for Congenital Heart Defects Northern-Ireland and is founded by me, Alexandra. The name has been chosen deliberately like an off spring of CHD-UK because from the beginning we were planning to work together.

I came in contact with Hazel because she had put on Heartline that as a part of the CHD-UK e-newsletter, she will be having a section on Birthdays: CHD Warriors Birthdays and a separate section called CHD Angel Birthday's. I emailed her with Dounya's details as she had asked, and told her that if she wanted she could use Dounya's story on her site.

We kept in touch as we had a good rapport and the same aims

I shared with her my wish to get more involved in raising awareness and that I had a lot of ideas but didn't know where to start. I also felt that there was a need here in N-Ireland for more support groups, unlike England where there are several support groups/charities which are heart related and are working alongside each other, there is just one in N-Ireland. This was how the idea to start my own website was born, which is aimed at support and awareness alongside CHD-UK which is more focused on educating, raising awareness as well as all types of research.



Congenital Heart Defects N-Ireland

Although we have separate websites we link to each other with a lot of subjects, for example, personal stories are all on CHD-UK's site.

What makes our partnership strong is that the two sites have two different perspectives:

CHD-NI is founded by a parent with a child with a CHD while CHD-UK is run by an adult with CHD.

We hope to reach as many people as possible who have been affected by CHD who are looking for either support or information and to raise awareness whenever/wherever possible!

Alexandra Mouhsine
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Next Edition

The next Edition of the CHD-UK e-newsletter, will feature more exciting ideas, but we do want your input. If there something you want then please email us. This e-newsletter is yours too.

Please contact us either on:

<mailto:chduk@hotmail.co.uk>

or

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

[mailto: alexandra@chd-ni.co.uk](mailto:alexandra@chd-ni.co.uk)

And if you would like to subscribe to our e-newsletter, then please go to the Subscribe form and send <http://congenital-heart-defects.co.uk/chduksenewsletter.aspx>

Finally, we wish you a pleasant May and June.

Hazel, **CHD-UK**
Alexandra, **CHD-NI**

A Huge Thank you to our Supporters



To obtain their information or links please go to

<http://www.congenital-heart-defects.co.uk/supportedby.aspx>

Links Mentioned in the Newsletter

- ♥ http://www.chfed.org.uk/news/sports_survey/family_sports_day
- ♥ <http://www.medpagetoday.com/Cardiology/AcuteCoronarySyndrome/13429>
- ♥ <http://www.medpagetoday.com/Cardiology/CHD/13442>
- ♥ <http://www.congenital-heart-defects.co.uk/atrioventricularseptaldefect.aspx>
- ♥ <http://www.congenital-heart-defects.co.uk/22q11deletiondisordersdigeorgeandvelocardiofacialsyndromes>
- ♥ <http://www.congenital-heart-defects.co.uk/ebsteinsanomaly.aspx>
- ♥ <http://www.congenital-heart-defects.co.uk/williamssyndrome.aspx>
- ♥ <http://www.congenital-heart-defects.co.uk/fundraisingevents.aspx>
- ♥ <http://www.congenital-heart-defects.co.uk/blogonmeghanlifewithtof.aspx>
- ♥ <http://www.congenital-heart-defects.co.uk/motherandsonlivingwithtof.aspx>
- ♥ <http://www.congenital-heart-defects.co.uk/cordeliagriffinwithtgasofar.aspx>
- ♥ <http://www.congenital-heart-defects.co.uk/jenibustaahlhssurvivorhappywithhalfaheart.aspx>
- ♥ <http://www.congenital-heart-defects.co.uk/hilarywithtgaandminorstenosisoftheaorta.aspx>
- ♥ <http://www.congenital-heart-defects.co.uk/katewithdextrotga.aspx>
- ♥ <http://www.congenital-heart-defects.co.uk/kurtiscunninghamandwilliamssyndrome.aspx>
- ♥ <http://www.congenital-heart-defects.co.uk/siennaandhrhstgaandvsd.aspx>
- ♥ <http://www.congenital-heart-defects.co.uk/victorlivingwithtga.aspx>

- ♥ <http://www.guch.org.uk>
- ♥ <http://www.achaheart.org>
- ♥ <http://www.DesignerHeart.com>
- ♥ <http://www.kentuckianalefthearts.com>
- ♥ <http://mystorybyrhys.blogspot.com>
- ♥ <http://congenital-heart-defects.co.uk/chdukspetitions.aspx>
- ♥ <http://www.chd-ni.co.uk>
- ♥ <http://congenital-heart-defects.co.uk/chdukenewsletter.aspx>
- ♥ <http://congenital-heart-defects.co.uk/contactus.aspx>