



CHD-UK© E-NEWSLETTER

*Educating and Raising Awareness of
Congenital Heart Defects*

10th Edition, June 2010

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

Welcome to June's e-newsletter. This is our 10th edition and we'll be focusing on organ donation, especially as the first week of July is Transplant Week. Also we'll be focusing on CHD parents on how they deal with life, how things that are thrown at them, how they are affected by others with our new regular feature called 'Life as a CHD Mum' wrote by Amanda Prentice, whose child has a CHD and we would like to welcome her. We also have an article from our regular writer Sarah.

We would also like to send our condolences to Katie William's family, who sadly lost her fight for life. Unfortunately a new heart was not found in time. As we have already mentioned 4th to 11th July is Transplant Week, so please if you have not already signed the Donor Registration in your country, then please do.

We are including our usual CHD'ers birthdays CHD Angels, What's in the News? and CHD World Websites

Transplant Week

Catriona Hamilton has spent the week of 4th July - 11th July campaigning to get more signatures onto the Organ Donor Transplant List. Catriona has said "Take time this week to have one of the most important Heart to Hearts you can have and help raise awareness of the NHS Organ Donor Register. You could have a group discussion over a meal, the downloadable meal pack can provide the necessary information or privately, by sending a message to a friend, colleague or loved one through the 'secrets' website". <http://www.organdonation.nhs.uk>



Safe and Sustainable: Children's Cardiac Surgery Services Programme

We thought we should mention about what is currently happening in regard to Children's Cardiac Surgery in the UK. We know this is rather late as this has been going on for sometime but we just haven't had the time to write about it. So here it is. (below is an extract taken from Children's Heart Surgery in England – The Need for Change, an adobe file on their website, link to the site is [Safe and Sustainable information on the changes](#))

In 2006 a panel of experts agreed that the current layout of services in England was unsustainable and recommended fewer, larger centres of excellence delivering the best possible care for children and their families. This was also the view of the Royal College of Surgeons which recommended in 2007 that 'there should be fewer but larger paediatric cardiac surgery services'. The NHS Medical Director

has asked the NHS to respond to these conclusions by delivering recommendations for a safe and sustainable children's heart surgery service.

The job of the National Specialised Commissioning Group (NSCG) is to make sure that heart surgery services deliver the best possible results for today's children and for the children of tomorrow.

We have called this process Safe and Sustainable. Our work is being guided by four key principles:

- ♥ **High standards:** All children in England who need heart surgery must receive the very highest standards of NHS Care, regardless of where they live or which hospital provides their care.
- ♥ **Personal service:** The care that every centre provides must be based around the needs of each child and family
- ♥ **Local where possible:** Other than surgery and interventional procedures all relevant treatment should be provided as close as possible to where each family lives
- ♥ **Quality:** Standards are being developed and must be met to ensure that services deliver the best care.

This process is now well underway with changes expected in 2011.

Attached with this month's e-newsletter is the Safe and Sustainable E-newsletter.

What the month of May means to one Mother.

Wrote by Sarah Scott, Australia

As I write this article the entire CHD world is in mourning. We lost a warrior this week who has struck a chord with the world. Her story has been in our hearts since we first heard her name, the life of her family has been written on our souls.

Katie Williams may have only been 4 in years (although I bet if asked she was not 4 but "nearly 5") but she lived a lifetime. When we heard that she was in trouble with her new heart we collectively held our breath. I checked her page every day for progress and was amazed that the messages kept flowing, she stayed in our thoughts and will always remain in our hearts. To her twin sister Lauren, her brother Simon Jr and her parents Simon Williams and Louise Snape we know there are no words to take your pain away. We sit in silence with you, too numb and shocked to speak, sad when we think of a world without her gorgeous smiling face, and horrified at the reminder of how fragile life is and how our children can be taken from our lives too easily and too suddenly.

On top of all these emotions though another one lurks and that is awe. Katie fought her battle with strength and determination. She held on and we championed her from the sidelines. She amazed us all with her spirit and her fight and I think we all believed that she would return home to her family. The depth of sentiment and sadness in the messages left all over Katie and her parent's facebook pages speaks volumes of the amount of people in the world watching, hoping and praying. Some people wrote every single day offering support and love. She was an incredibly special child to garner that much support so quickly from strangers.

My one regret is that I never met her, those that were lucky enough to be part of Katie's life spoke with love for her and her family. She was loved, she is loved and she will always be missed.

Katie's godmother Julie Chambers has been here before. This July marks the 2nd year that her gorgeous daughter Zoe went to play with the angels. Julie has been a strong voice in the CHD community and beyond for the vital importance of organ donation. This year, as Zoe and Katie play in heaven together, let's support this cause like never before. It is up to our community to be the passionate voice of organ donation. We need to talk to anyone who will listen about the urgency that

exists for kids and adult's with congenital heart defects on our transplant list right now. We need to have the discussion with our loved ones and our families about our choices and theirs.

I am an organ donor. Before Hannah was born I was always adamant they could have any part of me except my heart, now I have ticked that box. It was a big thing for me but it was the right thing to do. My last, and most important, gift to the world besides my children. I have spoken to my eldest daughter who is 9 about her choices with her body. want her to be informed and have understanding of this incredible gift that she could give another family. Of course, I pray to each and every God that this is not a decision we ever have to make but I believe it is hers, part of her rights to her body. She is thinking about it and asking lots of questions. She is talking to her friends about it too, awareness can be spread and started young. I have spoken to my husband and conveyed my wishes as well as heard his. As a family we are talking about it and making plans. I urge you to do the same.

The UK is currently celebrating National Transplant Week. This is the week to visit www.organdonation.nhs.uk/ukt/ and with Katie and Zoe in your hearts take the steps to register yourself and your family. Spread the word to your extended family and loved ones too.

Here are some facts I discovered from the LLTGL (Live Life then Give Life) website www.lltgl.org.uk

- ♥ You are more likely to need a transplant than to become a donor.
- ♥ Although 90% of the population support organ donation, only 28% are on the [Organ Donor Register](#).
- ♥ Over 8000 people are currently waiting for a transplant.
- ♥ Less than 3000 transplants are carried out each year.
- ♥ Last year, over 1000 people died whilst waiting for a transplant.

Heart hugs

Sarah

Mother to Hannah (2) – TOF, Cooper (4) – heart healthy and Abby (9) – heart healthy

What is in the News

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

Wanted Heart Doctors.

[Click here for the Dispatch.com article](#)

Heart Baby heart was kept beating whilst in a deep freeze

[Click here for the article from the Daily Mail](#)

Life of CHD Mum - Getting back to normality

Wrote by Amanda Prentice, UK

Getting back to “normal”, whatever that actually is, can be pretty tough. My CHDer came into the world in July 2007. It has taken me this long to find some semblance of normality.

I had a career with a famous high street bank, and was making progress through different jobs there both upwards and sideways. My job had dropped a few positions on my priority list following the

birth of my HH (healthy heart) daughter, but I still had the desire to come back full time one day and continue to impress the top bods, and maybe even take over the company (well, maybe not, but you get the idea!!) Lucy was born, and along with her came, Tetralogy of Fallot, ASD and developmental delays. That in turn brought, seemingly endless hospital visits, a ton of grey hairs, and of course, that honorary degree in Cardiology!!

When I was first told about Tet Spells, that was it. I decided that there was no way on Earth I would leave my child with someone else. There was no way I could give that level of responsibility to someone else. No one would do as good a job as me anyway.... right?

Lucy had her TOF repair in April 2008 and by June, I had managed to convince myself that the world wouldn't fall apart if I re-joined the workforce. My depleted bank account agreed, and so I decided to look for some casual work that would lull me back into things gently. I don't want to stray off the subject here, but has anyone else noticed how having an ill child eats into your finances a tad...?????

Anyway, job number one was working in a pizza restaurant, serving and taking orders. It was a good laugh, with a nice bunch of people, and was just what I needed to remember how much I enjoy customer interaction. I then went on to a village store, where I did the usual mix of serving, filling shelves etc etc. I now work part time for a supermarket. I love the job!! I hate leaving my kids - I do, but I think that it is important to go out and be me. I joked with a doctor's receptionist recently when she wasn't sure what I was called. I said "that she could call me Katie's mum or Lucy's mum. I don't mind". Those are both great jobs to have, but do you know what? Sometimes, it is great to go out and be just me.

Hugs
Amanda Prentice

What is NEW on the website?

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

Types of CHD's

- ♥ Sorry, I haven't not had time to add any the last two months but next e-newsletter there will be at least 2 added.

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.

Information Related to CHD's

- ♥ [Organ Donation](#) (I am inserting this in again because of the need for donors).
- ♥ [Transplant verses Religion](#) (again I am inserting this in again due to Zoe's Angel Anniversary and for Katie).

Other new articles are:

Personal Stories added:

- ♥ None, but I shall be adding some over the following months apart from the stories for European CHD Week..

Personal Stories

To read the full stories and others click on the link below.

♥ [7 Days = 7 European Personal CHD Stories](#)

CHD World websites

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



1) **Denmark: Hjerteforeningen**

www.hjerteforeningen.dk/

The Hjerteforeningen Association follows the development of cardiovascular disease in Denmark at all levels, such as risk factors, treatment, patients, research, etc. etc. We have assembled a number of facts that can help you with an overview of the situation on the ground here and now. We continuously update the figures and provide new insights on our website, whenever we have knowledge.

(translated by Mand Bland)

2) **Philippines: Philippine Heart Association**

www.philheart.org

Mission: The PHA is an organization of cardiovascular specialists and lay members that ensures accessible, affordable and quality cardiovascular education and care for every Filipino.

Vision 2012: The PHA shall be a leading organization of cardiovascular specialities in the Asian Pacific region in the prevention and management of cardiovascular diseases.

CHD Warrior's Birthdays

CHD-UK would like to wish a Happy Birthday to the following warriors whose birthday's are in July and August



JULY

♥ 8th July Lauren Williams, Dilated Cardiomyopathy (5 years old)

AUGUST

♥ 2nd August, TJ Smith, Tetralogy of Fallot with Ventricular Septal Defect and PVS with DiGeorge Syndrome (8 years old)

♥ 16th August, Dounya Mouhsine, complete AVSD (2 years old)

♥ 19th August, Christy, Tetralogy of Fallot with VSD, PVS and DiGeorge syndrome

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:



JULY AND AUGUST

♥ Zachary Phillips, HLHS, 6th July 2005 (5 years old)

Carepages: (<http://www.carepages.com/jamieandzachary>) and MySpace page: (<http://www.myspace.com/nannies5angels>)

♥ Katie Williams, Dilated Cardiomyopathy 8th July 2005 - 4th July 2010

Always in our hearts and forever an angel.

We have the petition for Echocardiogram. Please sign the petition and also could you sign the Media Awareness for HLHS. 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 2009 but we are keeping the Go Petition one open.

The Media Awareness for CHD Petition has been re-opened by Sandra Kay in order to obtain more signatures.

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

More Support for CHD-UK

We would like to welcome onboard Actual Admin run by Lisa Lathane who does PA work from home via the internet and as the founder of CHD-UK is a former PA, we thought this was a great place to be supported by and to support them.



Actual Admin

Lisa got to know CHD-UK through her daughter Robyn who was born with Aortic Stenosis. Robyn was featured on Children's Emergency on the BBC which ran through May and June. She was featured in the episode that was aired on the 23rd June 2010.

CHD-NI News

It has been quiet the last couple of months on the CHD-NI front, for several reasons but the main one was that yours truly is now the proud mummy of 5 kids. But I am happy to say that I am back and ready to focus on CHD-NI again.



Congenital Heart Defects N-Ireland

We are in the process of starting to work together with Heartbeat NI and so we are joining hands here in Northern-Ireland which is a very positive step. Heartbeat has also launched a new website www.heartbeatni.com.

CHD-NI has plans for another fundraising gala ball like we had last year and which was very successful.

Coeurs de L'Espoir is still trying to raise funds to help children with a CHD in Morocco but it is a real struggle. We are aiming to highlight the need more over the coming months

I would like this opportunity to thank Hazel for keeping things running on Heart2Hearts while I was not able to do that and keeping me updated on all things that happened in the world of CHD.

Alex
Chair of CHD-NI

Next Edition

The next Edition of the CHD-UK e-newsletter, will feature more exciting ideas, but we would like your input. If there something you would like to add or need help with then please email us. This e-newsletter is yours too.

Please contact us either on:

<mailto:chduk@hotmail.co.uk>

or

[mailto: chdukdeputyfundraiser@hotmail.com](mailto:chdukdeputyfundraiser@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>

As we look forward to summer spare a thought for the children/adults that are going to be having life saving operations during the following months and for the ones who have sadly been lost to us. CHD-UK and CHD-NI Wishing you all a good July and August.

Hazel, **CHD-UK**, Founder

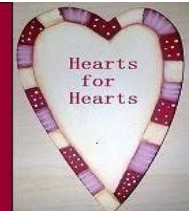
Alexandra, **CHD-NI**, Founder

Zoe, **CHD-UK**, Deputy Fundraiser

Helen, **CHD-UK**, Assistant Fundraiser

Teresa, **CHD-UK**, Promotor and Researcher for articles/publications

A Huge Thank you to our Supporters



Clare Bruton-Young
Unique Jewellery Design

Actual Admin



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.organdonation.nhs.uk/ukt/campaigns/other_campaigns/details.jsp?id=9
- ♥ <http://ncg.nhs.uk/index.php/safe-and-sustainable-programmes/>
- ♥ <http://www.lltgl.org.uk>
- ♥ <http://www.organdonation.nhs.uk/ukt/Consent.do?campaign=1160>
- ♥ http://www.dispatch.com/live/content/local/_news/stories/2010/06/18/wantedheartdocs.html
- ♥ <http://www.dailymail.co.uk/health/article-1287075/Baby-chilled-surgery-Boy-survives-heart-op-doctors-freeze-4-days.html>
- ♥ <http://congenital-heart-defects.co.uk/organdonationtransplantssaveslives.aspx>
- ♥ <http://congenital-heart-defects.co.uk/TransplantationversesReligion.aspx>
- ♥ <http://www.hjerteforeningen.dk/>
- ♥ http://www.philheart.org/index.php?option=com_content&task=view&id=214&Itemid=208
- ♥ <http://congenital-heart-defects.co.uk/>
- ♥ <http://www.myspace.com/nannies5angels>
- ♥ <http://www.carepages.com/jamieandzachary>

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

 <http://www.chd-ni.co.ni>

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

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