



CHD-UK© E-NEWSLETTER

*Educating and Raising Awareness of
Congenital Heart Defects*

6th Edition, October 2009

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

Welcome to October's e-newsletter. I hope that you having a good autumn. I continue to raise awareness of congenital heart defects and CHD-UK have done their first ever interview (see below). I am still organising a gig night to raise awareness of CHD-UK and to raise money for various charities. A Walk-a-thon is being arranged by a fellow CHD'er to raise awareness of CHD-UK see article. I shall keep you updated via Twitter and the website.

However, over the last two weeks we have lost two wonderful adult CHD'ers Amanda Eisa and Kelly Reynolds. They were two great people with fantastic personalities and they cared about everyone. Please take a moment to think to them. RIP Kelly and Amanda.

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

CHD-UK Raising Awareness and funds.

I (Zoe Dickson) have organised a Sponsored Walk-a-thon in Weymouth in aid of CHD-UK. This Event will take place on 21st November, along The Esplanda in Weymouth. It will start at 12:00 midday.

We are meeting at the bus stop by Kings Statue and it will be finishing in the Old Rooms Inn by Brewers key.

Can everyone please donate a pound towards CHD-UK.

The reason behind the walk is a fellow CHD'er Hazel who had her life saving operation 36 years ago which is very near to the time that I had my own life saving operation 22 years ago.

Hazel's website CHD-UK (<http://www.congenital-heart-defects.co.uk>) helps people who have or knows anyone with a CHD. Hazel has helped me since I first spoke to her last year about my own heart defect known as Transposition of the Great Arteries. If anyone is interested in doing the Walk-a-thon please contact Zoe via [CHD-UK/CHD-NI group on Facebook](#).

CHD-UK's First Ever Interview

What is your charities name and Mission?

CHD-UK. It's mission is to educate and raise awareness as well as promoting the need for testing prior to birth. Connect parents with adults and parents with other parents, adults with other adults.

How long have you been using [Twitter](#) and who's idea was it?

Since Jan 2009, it was my idea. I started off on [Facebook](#) when no one else was using it for raising awareness and I also have a site on MySpace. I think I was one of the first to take advantage. It has taken other charities a lot longer to use these sites.

What have you enjoyed so far whilst using Twitter?

Being able to meet Dr's, other congenital heart survivors and getting volunteers.

Has there been any incidents of followers doing something wonderful for you?

Offering to help, give me advice when I need it. Giving me great contacts.

What has been your biggest challenge to date?

Try to get the name CHD-UK out there, getting people to sit up and realise that CHD-UK is what it says it is. People are all too aware of the big named charities but not so much of the small named charities. But thanks to Facebook, Twitter and MySpace it is slowly happening. Some people even choose CHD-UK as their first charity now. Also, getting people to realise that CHD stands for congenital heart defects and not coronary heart disease - that is quite hard.

I have had trouble trying to raise money for CHD-UK partly because it is not a big name and partly due to the fact of the current credit crisis but it is slowly working ;)

Do you have a Twitter tip for other charities?

Let people know what you are doing, put logos of twitter, facebook with links on your website pages to get them to follow you. Let people know that the person behind it is real and not just some worker lol

OK, I made a few errors but I didn't know it was going to be published on the internet or I would have done it better.

To also view it click here [CHD-UK's Fist Interview by Technicavita](#)

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.

Athletes should be screened for Heart Abnormalities to Prevent Sudden Death

[Click her for Medical News Today](#)

Half of Specialist Heart Units for Children Face Closure under Radical Government Plans

[Click here for Telegraph UK article](#)

11 month baby undergoes Double Switch Heart Surgery

[Click her for 1888 Press Release article](#)

What is NEW on the website?

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

Types of CHD's

- ♥ Fontan Procedure
- ♥ Norwood Procedure

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.

Organ Donation

- ♥ Organ Donation and Transplants

CHD Angels: A place of remembrance has unfortunately been updated.

Books Related to Congenital Heart Defects

- ♥ I have added a section on books related to CHD's. The books vary from children's to parents.

Other new articles are:

Personal Stories added:

- ♥ Stuart Watson – a Heart Transplant recipient.
- ♥ Charlie with Pulmonary Atresia with Ventricular Septal Defect.

Personal Stories

MY 15-MONTH-OLD son was his usual happy self as he woke up and greeted me with a beaming grin. I smiled back – trying to disguise the feeling of dread deep in my stomach.

I knew only too well that just a few hours later my lively little boy would look very different. For a start he would be unconscious, lying flat on his back, with a tube in his throat hooked up to a ventilator to help him breathe. There would be a deep, freshly cut wound running down the middle of his chest, covered by a dressing but nevertheless vulnerable to infection. An array of dangling wires and drips would be attached to his body, supplying intravenous fluids and doses of morphine to numb the pain. Another tube, the grisly-looking chest drain, would be punched through the side of his torso, drawing off any fluid on his lungs.

Charlie didn't know it, of course, as he waved across at his dad that morning, but he was about to undergo his fourth heart operation. And the prospect of what was in store for him that day was filling my mind.

As I was thinking things over, the surgeon paid an early-morning visit to our room in the Children's Heart Unit at Newcastle's Freeman Hospital. Mr Asif Hasan had carried out Charlie's three previous operations, which were squeezed into a whirlwind 10-day period in the first seven weeks of his life.

"Charlie will live to be a happy old man," Mr Hasan had told me and my wife a couple of hours before he first operated on our son.

We had to cling to his encouraging words during those rollercoaster few weeks, when we were spinning back and forth between the hospital and our home in South Shields, where Charlie's twin brother George was just settling into his new surroundings.

Charlie was born with a structural heart condition called pulmonary atresia with VSD. One of the heart's four valves, the pulmonary valve, had not formed properly, meaning his blood had no way of getting into his lungs to take in oxygen. He also has a VSD (ventricular septal defect) – a hole in the heart between the left and right ventricles, the two pumping chambers.

The normal course of action with this condition is to divert blood around the blockage where the valve should be using shunts, tiny teflon-coated tubes just a few millimetres wide. Then, when the child is older and the heart has grown sufficiently, a full repair is carried out, with an artificial pulmonary valve grafted into place and the VSD sewn shut.

The workload of the paediatric heart surgeon is staggering, with several hundred operations

performed each year by the team at the Freeman.

So while this summer morning was a momentous one for Charlie and his family, it was an ordinary day in the office for Mr Hasan. He outlined the plan for the latest operation – to add another shunt and widen Charlie’s pulmonary artery, which was too narrow.

Surgery went well, but just under 48 hours later we almost faced our ultimate nightmare. Charlie had taken a turn for the worst the day after his operation, and his breathing had become erratic and laboured. His respiratory system was having some kind of breakdown, and on the Sunday morning he went into cardiac arrest. This happened just as his mum and I arrived at the intensive care ward.

At first staff wouldn’t let us in but they didn’t say why. This is not uncommon, so we took a seat in the parents’ room, unaware of the drama our boy was causing. Then the relative of another patient blurted out how horrible it had been when “the baby in the end bed” stopped breathing.

That was Charlie’s bed.

We leapt up in a blind panic, buzzed the intercom again and this time we were allowed in. The doctor explained what had just happened. The arrest had lasted three minutes, and Charlie had needed cardiopulmonary resuscitation (CPR) to get his heart working properly again. The doctor felt that, as Charlie’s blood pressure had been stable throughout, it was unlikely he had suffered any brain damage. As we struggled to take it all in, he laid his hand on my arm, adding: “Happy Father’s Day.” I would have settled for a bacon sandwich and the Sunday papers, but hey, you can’t have everything.

All families whose children have had heart surgery can recount their own extreme episodes. It is certainly no easy ride, but at least the outlook for young heart patients nowadays is better than at any time in the past. Just a few decades ago mortality rates were high – many children died during or shortly after operations in which new techniques were put to the test, or lost their lives simply because nothing could be done.

One early attempt at open heart surgery in the 1950s was made using cross-circulation, where the blood vessels around a baby’s heart were clamped off and he was kept alive using his father’s blood, which was pumped around both their bodies. The operation itself, to close the boy’s VSD, was a success, but the youngster died a few days later from pneumonia and cross-circulation was later abandoned. Thankfully, things have moved on a lot since then.

It’s now almost three years since Charlie last had surgery, and his next operation is on the horizon.

The stories of youngsters with heart conditions regularly feature in the pages of the Chronicle and one contained the following quote from a mum as her son prepared to go into hospital: “Every time he goes into the operating theatre I feel worse and worse because I love him more and more”.

Couldn’t put it better myself.

CHARLIE and his brother George share the bond of being identical twins. My three-year-old boys also share something else – the same heart condition.

Charlie has had surgery for the defect relating to the structure of his heart – the plumbing, in other words. But he and George also have a separate problem with the rhythm of their hearts – the electrics. Regular check-ups at the Freeman threw up abnormal readings a couple of years ago, and it’s thought the boys have a condition known as Long QT Syndrome. The heart resets itself after every beat, then an electrical impulse flashes through, causing it to beat again. With Long QT Syndrome, this resetting period – the QT interval – is longer than it should be, which throws

everything out of balance and can lead to a dangerously fast heartbeat. It can be fatal, and in many children the condition lies undiscovered – often until it's too late. My boys both have a daily dose of beta blockers, which should keep things under control.

The sad truth, however, is that there are many children out there with the same condition – and their parents have no idea their kids have something wrong with their hearts. Not to mention the teenagers and adults who have grown up unaware they have a problem.

For more information about Charlie and to keep up with Charlies progress click on the link below.

- ♥ [Stuart Watson - Heart Transplant Recipient](#)
- ♥ [Charlie with Pulmonary Atresia with Ventricular Septal Defect](#)

CHD World websites

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



1) Africa: The Kanu Nwanko Heart Foundation

<http://www.kanuheartfoundation.co.uk/>

This website is a charity organisation established by the Nigerian International and English Premier League football striker, Nwankwo Kanu (a.k.a Papilo) -MON, OON, who is also a UNICEF Goodwill Ambassador. The foundation was established in 2000, to help underprivileged African children and young adults, living with different heart ailments in Nigeria and other African countries respectively, obtain the cardiac surgical operations needed.

2) South Africa: The Heart and Stroke Foundation

<http://www.heartfoundation.co.za/>

This site is a community-based organisation established to reduce the incidence of heart disease and stroke in the population of South Africa by providing education and supporting research.

Tandem Skydive to raise money for HeartLine

Tracey Sobey thoroughly enjoyed doing the tandem skydive and in the process raised £1,000 for Heartline. Congratulations Tracey.

Heartbreak Soup: A play

Children's Heart Federation members can get 2 for 1 on tickets on a production called Heartbreak Soup.

The story of heartbreak soup would be suitable for all families and young people who have had to or will need to spend time on a cardiac unit waiting for surgery. We have not yet seen this production but it has excellent reviews and feedback.

They would love some of our group members to be represented at this event:

- ♥ Saturday the 7th there will be a post show discussion with a cardiac surgeon, and
- ♥ Sunday the 8th a discussion with Laura Lindow who created the play.

We would really like to meet up with families and group members for this event so if you are buying tickets please let us know, we have managed to get a great deal from the production company, all CHF

members will be able to get 2 tickets for the price of 1!

Heartbreak Soup is coming to **London**.

"Warms and lifts up your heart like a hot-air balloon"
The Guardian

Heartbreak Soup stole the hearts of audiences at the Edinburgh Fringe Festival 2008, gathering a clutch of 4 and 5 star reviews, Guardian Pick of the Day and a Total Theatre Award nomination. And now it's coming to **London**:

Jacksons Lane 269a Archway Road, London N6 5AA [alt="Heartbreak Soup | Edinburgh ... "](#)



[title="View image on Bing"](#)

[v:shapes="_x0000_s1026">](#)

Saturday 7th November 8pm

Sunday 8 November 2pm

Tickets £6.95

if you call the booking office and quote Children's Heart Federation you can get 2 tickets for the price of 1!!

Box Office 0844 406 8666

<https://tickets.lighthousepoole.co.uk/public/show.asp>

Inspired by writer and director Laura Lindow's experiences on a children's ward Heartbreak Soup follows the life and times of Cuddy Gill - an 11 year old boy undergoing his second heart transplant. For Cuddy the heart is more than just a muscle, it's the bit that makes him him so he's sorting out all his best bits to make sure he doesn't wake up a whole different person. This poignant story of a blueberry blue boy playing a game where life meets death in a single heartbeat is suitable for adults and older children (although it's not recommended for under 9s).



[alt="Heartbreak%20Soup%20salute ... " title="View image on Bing" v:shapes="_x0000_s1027">](#)

"Beautiful and imaginative"

The Scotsman

Heartbreak Soup is generously supported by The Wellcome Trust. If you can't make it to London the full tour list can be found at <http://theemptyspace.org.uk/producing/touring/heartbreak-soup>

CHD Warrior's Birthdays

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



NOVEMBER

♥ 4th November, Hazel Hunt, Transposition of the Great Arteries (TGA)

- ♥ 11th November 2004, Olivia Faith Benn, Large Ventricular Septal Defect (VSD), Transposition of the Great Arteries (TGA) and DoRv (5 years old)
- ♥ 18th of November, Savanna O'Connors, HLHS (17 years old)
<http://www.myspace.com/437378261>
- ♥ Emilia Steele, Ventricular Septal Defect (VSD) she is now 12 weeks today, and still only weighs 9lb 9oz,

DECEMBER

- ♥ 5th December, Stuart Watson, Transposition of the Great Arteries (TGA) and now a Heart Transplant recipient.
- ♥ 16th December 2007, Tiana Mackay, Alcapa and Mitral Regurgitation (2 years old)
- ♥ 21st December, Katherine Bankuti, Transposition of the Great Arteries (TGA)

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:



OCTOBER, NOVEMBER and DECEMBER

- ♥ James Clint "Baby Clint" Schaffer 26th October 1992 - 2nd January 1993
- ♥ Amanda Eisa: 3rd December 1970 - 23rd October 2009.
- ♥ Hannah Collie: 25th October 2009
- ♥ Kelly Reynolds: 9th October 2009 (28 years old). Kelly was waiting to be put on the heart transplant list.

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 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>

CHD AWARENESS:

The Gala Ball that CHD-NI held in September was a great success. They raised €5,000 which will be going to Clark Clinic in Belfast. Unfortunately Alexandra has not had time to write an article for this month's e-newsletter but she will be back in December.



Congenital Heart Defects N-Ireland

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: 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 November and December.

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.facebook.com/home.php?ref=home#/group.php?gid=2361087995&ref=ts>
- ♥ <http://www.technicavita.org/index.php/interviews/twitter-interviews/chd-uk-twitter-charity-interview.html>
- ♥ <http://www.medicalnewstoday.com/articles/163244.php>
- ♥ <http://www.telegraph.co.uk/health/healthnews/6359356/Half-of-specialist-heart-units-for-children-face-closure-under-radical-Government-plans.html>
- ♥ <http://www.1888pressrelease.com/11-month-orissa-baby-undergoes-double-switch-heart-surgery-t-pr-117860.html>
- ♥ <http://congenital-heart-defects.co.uk/fontanprocedure.aspx>
- ♥ <http://congenital-heart-defects.co.uk/norwoodprocedure.aspx>
- ♥ <http://congenital-heart-defects.co.uk/organdonationtransplantssaveslives.aspx>
- ♥ <http://congenital-heart-defects.co.uk/chdangelsaplaceofremembrance.aspx>
- ♥ <http://congenital-heart-defects.co.uk/Booksrelatedtocongenitalheartdefects.aspx>
- ♥ <http://congenital-heart-defects.co.uk/stuartwatsonafterhearttransplant.aspx>
- ♥ <http://www.kanuheartfoundation.co.uk/>
- ♥ http://www.heartfoundation.co.za/heartcondition/heartcondition_10.htm
- ♥ <http://tickets.lighthousepoole.co.uk/public/show.asp>
- ♥ <http://theemptyspace.org.uk/producing/touring/heartbreak-soup>
- ♥ <http://www.myspace.com/437378261>

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