



CHD-UK© E-NEWSLETTER

*Educating and Raising Awareness of
Congenital Heart Defects*

4th Edition, June 2009

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

Welcome to June's e-newsletter. I hope that you have all a pleasant April and May. I am continuing with the theme of raising awareness due to the fact that CHD-UK organised a skydive on the 6th June 2009 to raise awareness and also in May it was CHD-UK's second anniversary. I can say I have come along way since I first started the unregistered charity. Also included in this month's e-newsletter is a personal story of a teenager from the UK as well as a first event for New Zealand Heart Children's Awareness Week and the GUCH Thames Walk.

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.

CHD-UK organised a skydive here in Spain with two friends (one an English Teacher and the other who owns a bar and supports CHD-UK). The aim of the skydive was to raise awareness of CHD-UK whilst raising money for Fundación Española del Corazón in Spain and Tiny Tickers in the UK.

The skydive happened on the 6th June at 16:00 hours on a gorgeous, hot sunny afternoon and I can say that Jason (one of the jumpers) was literally scared, it didn't help that he was also petrified of heights – he wanted to do the jump to help me raise money for all the children out there who have heart conditions and Clive who had previously done a jump before was also just as scared as he knew what to expect. All I can say is thank you for helping raise awareness.

The skydive was successful whereby awareness of CHD was raised as well as a total of €250.00 as of 10th June 2009). The money raised was split between two very important charities that are close to CHD-UK's heart.

CHD-UK celebrated their 2nd Anniversary in May

As you have probably noticed CHD-UK didn't really do anything to announce or celebrate their anniversary but they are extremely happy that it has grown from a few people on Facebook and MySpace to having at least 100 visitors to the website everyday.

CHD-UK has held several fund-raisers this year to raise awareness of CHD-UK and to raise awareness of congenital heart defects whilst raising money for other charities. CHD-UK is planning an awareness night in August – details will be announced in the next edition.

CHD-UK and CHD-NI have now started a personal network group whereby people can set up their own pages and chat to others in similar situations (more details under Heart2Hearts: A social

network).

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

This was a roaring success....

GUCH "Young people's get together in London - Saturday July 11th 2009!"

GUCH PA is organizing a fun afternoon along the Southbank, London, taking in an amazing acrobatic show by the river, then heading to a nearby coffee shop for refreshments and chat. This is all offered absolutely free of charge and reasonable travel expenses will be met too. Meeting on the Southbank between 1.15 and 1.30pm, we will be finishing up around 4.30/5pm .

This is open to anyone born with a congenital heart defect aged between 16 and 21 (14 and 15 year olds will be considered if they have parental consent).

Places are limited and offered on a "first come first served" basis. I

f you're interested or want to ask more questions please get in touch with Victoria on 0207 422 0630, victoriag@guch.org.uk or Anne Crump on 020 8240 1165, guchmh@googlemail.com

We need to confirm numbers by June 25th so please be sure to get in touch by then!

Thank you
Victoria

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.

Expert Opinion: Atrial Fibrillation Ablation: Long-term Cure or Palliation?

[Click here for the Cardiosource Article](#)

Comprehensive cardiogenetic testing for families of sudden unexplained death victims can save lives

[Click here for the Gene.Ref.com Article](#)

What is NEW on the website?

Unfortunately, we have not had the time to add articles about different types of CHD's or information related to CHD's but we are aiming to add more in the following months. In the meantime, 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

Personal Stories added:

- ♥ A mother with two children with CHD,
- ♥ Emily-Jayne's CHD Story

Personal Stories

Emily, 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.

I'm Emily. I was born in February 1993. I had a normal birth and everything was fine with me. My mum and dad were overjoyed they had a girl as they had already had two boys.

Everything was going great with me until I was about one year old, my lips turned blue and I became ill. My mum and dad took me to the doctors and they told them to take me straight to hospital. This is where it all started...

The doctors took an x-ray of my heart and it showed I had Ventricular Septal Defect which is a hole in the bottom two chambers of the heart. My arteries had also started to develop and then got blocked off and more had grown.

I had my first operation when I was about 16 months that was when I had a shunt inserted to fix my arteries. I then had another one on the other side with another shunt inserted about 2 years after.

In between all of this my mum and dad had another boy in January 1995.

Then the time came, I had the open heart surgery to 'fix' the hole in my heart, this was around February 1999 because I remember having my sixth birthday in hospital. I had a "Spice Girls" cake and my class at school all got me presents. I also still have a teddy all the nurses gave me.

I had quite a quick recovery and when I went back to school I was only in year one so I was 6 and I remember having to sit at the office with a friend reading books every break and dinner time because I couldn't go out, my school was really supportive, they all bought me a present.

I had a lot of check-ups through my school life but I never really thought anything about it, I just thought of my scar as a scar and didn't think it was serious or anything.

Until, I think it was in October 2008 when I had my routine heart check-up and everything was going good, the doctor mentioned something about a narrow artery but said it was nothing to worry about. Then a few days later in the post I had a letter and it was from the nurse saying she forgot to mention about a youth club called 'Hearts 4 Teens' they gave me the website address and an invitation to go bowling with them for Christmas.

I thought yeah it sounds good, so I went on the website and noticed a few people had joined and I added an msn address. A girl called Andrea accepted me and that is when my life changed. I felt an instant connection with her. Like we already knew each other, and we soon got it organised to go bowling. We spoke everyday and counted down the days till we got to meet each other. We have so much in common even the same Cardiologist! I couldn't believe it, and then bowling came. I did get talking to the other girls from 'Hearts 4 Teens' on msn so I was looking forward to meeting them too.

But at that point I realised I didn't even know the name of my condition or anything so I booked an appointment with my doctor and he explained it to me. Because it kind of got to me when other people could say what they had and I was like I don't know.

I saw Andrea sat down outside the shop that we said we would meet outside and at that moment I'd never felt happier; I wasn't shy or anything around her. We met up with everyone else and we were dancing to the songs and even though I had only just met everyone I felt like I could be myself for once after all those years of not thinking anything about my heart condition, I didn't know how meeting people just like me could affect me I was so happy. We were all asking each other what CHD we had

and that and I loved it.

I then joined groups on Facebook for CHD's and got talking to alot more people. It's really weird talking to someone with a CHD because it's like I have an instant special bond with them. I have spoke to people of all ages with all kinds of CHD's.

Having a CHD has affected a few things in my life. I get out of breath easily and don't really like doing P.E because I can't do things as well as the other pupils; I have to have antibiotic cover at the dentist so I don't get Endocarditis, which is a serious infection. I can still do pretty much anything I want and have had a normal life.

I have met some amazing people through having a CHD and I got involved in helping my school with the British Heart Foundation sponsored skipping fund raising, I only helped with the music but I felt better knowing I had participated in raising money for more research of CHD's.

All my friends and teachers know about my CHD and they don't really bother to be honest. There are some times that I will wished I died on the operating table but who doesn't have bad times? We all have rough times and it's best just to sit back, think about it and get through it. When it comes to relationships boys haven't really had problems with my scars or anything and if they do bother and if they laugh at me for it then they obviously aren't worth it!

I really didn't know what could come out of having a CHD and I am so happy the hospital informed me of 'Hearts 4 Teens'.

I also have hearing and speech problems. I am slightly deaf, but I get on with my life as best as I can, I enjoy things to be honest, I am so grateful to be here today I didn't give up, my body was strong enough. Most of all I think I owe it all to the doctor who operated on me. I haven't met him/her and don't even know his/her name but someday I hope I'll get to meet the person who saved my life.

To read more stories like Emily'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.

- ♥ [A Mother with TWO children with CHD](#)
- ♥ [Emily Jaynes CHD Story](#)

CHD World websites

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

1) Europe: Coreince

<http://www.corience.org/about-heart-defects/>

This website is an independent European platform on congenital heart defects. For patients, parents, doctors and scientists.

2) Europe: European Congenital Heart Groups (ECHG)

<http://www.echg.net/cms/index.php>

This website was created in Norway in July 2006 in an attempt to effectively engage congenital heart groups across Europe. The ECHG committee consists of seven elected people from various European countries.



Heart2Hearts: A New Social Network

The original forum on CHD-NI was replaced by the social network Hear2Hearts to have a more interactive way of sharing experiences and to make contact with other heart parents and adults with a CHD. This is the unique concept - being a place for EVERYONE affected by CHD.

At the moment Heart2Hearts has 72 active members and it is managed by both CHD-NI and CHD-UK.

www.heart2hearts.ning.com

You can also find a link on the sites of CHD-NI and CHD-UK

Wrote by: CHD-NI

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

- ♥ 6th July 2005: Zachary Phillips, HLHS (4 years old). Carepages: <http://www.carepages.com/jamieandzachary> and MySpace page: <http://www.myspace.com/nannies5angels>

AUGUST

- ♥ 2nd August 2002: TJ, TOF w/ VSD and PVS with DiGeorge Syndrome
- ♥ 16th August 2008: Douyna, complete AVSD (1 year old)
- ♥ 19th August 1977: Christy Smith, TOF with VSD and 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:



JUNE AND AUGUST



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>

British Heart Foundation Petition to the Government



We need a new government plan.

Why? Because the Government has yet to commit to a new plan for tackling heart and circulatory conditions in England over the next decade and you deserve better.

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

British Heart Foundation Booklets: Understanding your Child's Heart.

The British Heart Foundation from this year until the final publication of all booklets which they are aiming for in 2010 are uploading booklets onto their website for parents of children with CHD and for health professionals. At the moment they currently have:

- ♥ Aortic Stenosis
- ♥ Coarctation of the Aorta
- ♥ Large ventricular septal defect
- ♥ Pulmonary stenosis
- ♥ Tetralogy of Fallot
- ♥ Transposition of the Great Arteries

To download a booklet, click on [Understanding your Child's Heart](#)

MEETING CHD-NI in Clark Clinic, Belfast

On 20 May CHD-NI was invited to a meeting at the Clark Clinic in Belfast with the 3 consultant cardiologists and the local charity Heartbeat to see how we can work together. The Clark Clinic is in the Royal Belfast Hospital for Sick Children (RBHSC) and provides inpatient care for children with cardiac conditions from all over Northern-Ireland.

The purpose of this meeting was to avoid duplicating what Heartbeat is doing and to improve the way people can find either one of us. The cardiologists were very enthusiastic about the CHD-NI website and support what we do. We agreed that CHD-NI continues on the path that we are doing and to stay as a mostly web based support group and raising awareness for CHD.

The brochure for CHD-NI will be included in the Clark Clinic information pack for parents, which is given when a child is diagnosed with a CHD.

When CHD-NI does fund-raisers for Clark Clinic we will donate that money to Heartbeat, because that way we are sure that it really goes to the Clark Clinic and not to a general fund of the Royal Victoria Hospital.

So all in all a promising meeting.
Wrote by: CHD-NI

CHD-NI's Brochure

The CHD-NI brochure is available to download from the CHD-NI website.

[CHD-NI's Downloadable Brochure](#)



Congenital Heart Defects N-Ireland

Walking the Thames Path from Windsor to Westminster (and beyond...)

On the morning of Monday 1 June a group of people set off from Windsor to walk more than 60 miles to the Houses of Parliament along the Thames Path before Friday. Quite a change from the average week at work! Hailing from all over the country, we were raising money for GUCH Patients Association (<http://www.guch.org.uk>), the charity which supports young people and adults with a heart condition. The weather was warm, the sun was out, our spirits were high and we stepped out along the path anticipating a lovely walk in a beautiful part of England. And perhaps the odd blister.

This was no ordinary group though: we were all born with heart conditions and in our lives have had plenty of open heart surgery and catheters (details – and more entertainment – here: <http://www.youtube.com/watch?v=VZeozjbChvk>). The current medication list would probably fill a page in itself! But we're all active and though some people were able to walk further than others, everyone challenged themselves and proved that we can do it.



By the end of Friday we had walked 68 miles, from Windsor to Westminster and then on to the Thames Barrier beyond Greenwich, used up several packets of Compeed (miracle blister-patches), admired the riverside houses, suffered in the heat and the rain and were more than ready to enjoy the boat trip back up the Thames. But we had the satisfaction of knowing we'd achieved so much. The thought of walking 68 miles in 5 days terrifies plenty of people without heart conditions, but we'd made it! We'd raised about £1,300 for GUCH PA and everyone who saw the group saw our flag: it raised plenty of awareness of congenital heart defects. We're still accepting sponsorship: <http://www.justgiving.com/guchwalkingclub> – it would be great to get to £1,500 before we're done.

If you want to find out more about the GUCH Walking Club, please get in touch:
<http://www.guchwalkingclub.org.uk/contact.htm>



Written by: Elizabeth Connolly



Heart Children New Zealand was founded in 1994 and is the only official charity in New Zealand dedicated to the support of Heart Children and their families.

Every year in May, Heart Children NZ hold their annual Heart Children Awareness week.. This is a snippet of some the event we held throughout NZ, this year.

The Heart Stopper Challenge.

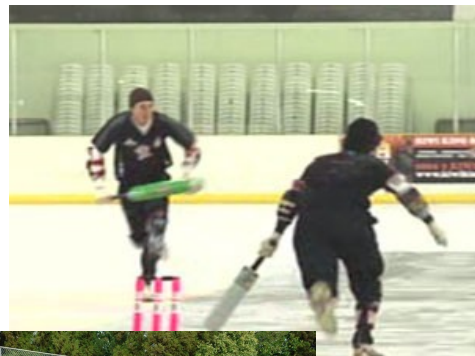
Corporate teams are challenged to raise money for HCNZ by way of sponsorship and their challenge is to hop into a pool of cold water and Ice for 5 minutes. The inspiration behind this event is to portray the ice slurry our babies hearts are put in to slow the rate down before operating.



of NZ's MP's

Ice Cricket.

Yes that's right Ice cricket, cricket played on Ice. A large number of international past and present players put this event together with the purpose of raising funds for Heart Children. Humorous entertainment is grossly understating the hilarity of this event.



Heart Jam.

A brand new event created this year which saw over 5000 children exercising all at the same time, to a very popular aerobics program JUMPJAM that is spread right throughout NZ. This year saw Heart Jam trialled in one area of NZ, and was a huge success. Many of the schools that took part, had 100% attendance of the event. The idea behind Heart Jam is to reach more people than ever before via one event. Primarily to raise awareness, children were also asked to bring a gold coin donation. In 2010 we will see Heart Jam run nationally where the potential is to have have up to 500,000 children exercising all in the name of Heart Children.



Written by Stuart Watson, who has just undergone a heart transplant and the idea of the HeartJam was Stuart's

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 July and August.

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.medpagetoday.com/Cardiology/CHD/13442>
- ♥ <http://www.congenital-heart-defects.co.uk/typesofchdandoperations.aspx>
- ♥ <http://www.congenital-heart-defects.co.uk/fundraisingevents.aspx>
- ♥ <http://ow.ly/cPLj>
- ♥ http://www.eurekalert.org/pub_releases/2009-05/esoh-cct052109.php
- ♥ <http://congenital-heart-defects.co.uk/amotherwithtwochildrenwithchd.aspx>
- ♥ <http://congenital-heart-defects.co.uk/emilyjaynescohdstory.aspx>
- ♥ <http://corience.org/about-heart-defects/>
- ♥ <http://www.echg.net/cms/index.php>
- ♥ <http://www.heart2hearts.ning.com/>
- ♥ <http://www.carepages.com/jamieandzachary>
- ♥ <http://www.myspace.com/nannies5angels>
- ♥ <http://congenital-heart-defects.co.uk/chdukspetitions.aspx>
- ♥ <http://www.newheartplan.org.uk>
- ♥ <http://extras.bhf.org.uk/online/Understanding%20your%20childs%20heart%20email.html>
- ♥ <http://www.chd-ni.co.uk>
- ♥ <http://www.chd-ni.co.uk/Downloads.html>
- ♥ <http://www.guch.org.uk>
- ♥ <http://www.youtube.com/watch?v=VZeozjbChvk>

 <http://justgiving.com/guchwalkingclub>

 <http://www.guchwalkingclub.org.uk/contact.htm>

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

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

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