



CHD-UK© E-NEWSLETTER

*Educating and Raising Awareness of
Congenital Heart Defects*

5th Edition, August 2009

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

Welcome to August's e-newsletter. I hope that you have had a nice summer. I continue to raise awareness of congenital heart defects and currently CHD-UK is organising a gig night to raise awareness of CHD-UK and to raise money for various charities.

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 is still collecting in the money from the organised a skydive here in Spain and will be donated to Fundación Española del Corazón in Spain and Tiny Tickers in the UK.

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

This was a success

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.

Update on Wii's Pulse Oximetry Monitor

[Click here for GeneRef article](#)

A New Plug For The Hole In The Heart: New Procedure May Help

[Click here for the Medical News Today article](#)

What is NEW on the website?

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

Types of CHD's

- ♥ Atrial Septal Defects

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:

Personal Stories added:

- ♥ Heart of a Father by Jeni Busta's Father
- ♥ Jeni Busta's Beginnings of Life with HLHS by Jeni's Mother
- ♥ Nicole Borek with Tetralogy of Fallots
- ♥ Rhys born with 4 different CHD's which are Tricuspid and Pulmonary Valve Defect, Hypoplastic Right Ventricle (HRHS) and an Artrial Septal Defect (ASD)
- ♥ Tiana with Alcapa (Anomalous Left Coronary Artery from the Pulmonary Artery and Mitral Valve Regurgitation).

Personal Stories

My name is Nicole Vickery Borek, and I was born in May 1970 with a seriously defective heart. I was a "Blue Baby" (cyanotic) born with Tetralogy of Fallot. At 7 days old, I had my first visit with the Cardiologist at the University of Alabama in Birmingham Medical Center (UAB), who would save my life multiple times. In the 1970's, there were many innovative breakthroughs in open-heart surgery, especially for pediatrics. I had a Waterston shunt performed in 1971 as a way to allow blood flow & keep me alive until I was old enough for corrective surgery. At the time, a child had to be 5 years old and/or weigh close to 50lbs before they could operate; today, they are able to perform the correction much younger.

Gaining weight has never been my problem, and just 1 month shy of my 5th birthday, I lost consciousness and became critical with difficulty breathing. It was 1975 and my parents had to rush me to Birmingham from Huntsville (approx. 2 hour drive then), as there was no Med-Flight! They proceeded with open-heart surgery correcting the four things wrong with my heart (Ventricular Septal Defect), Atrial Septal Defect, Pulmonary Stenosis, hole in my heart). Just as they were finishing the surgery, the lead surgeon noticed my Pulmonary Valve was too small so they put me back on the heart/lung machine and extended it 3mm. The operation was a success.

My parents continued taking me for regular check-ups while raising me as a normal healthy child. They encouraged me in all my endeavours: Band, Choir, Softball, Student Government, Social & Academic Clubs; and I always excelled in everything, rising to leadership roles across the board while maintaining two jobs in high school. I never thought of myself as a Heart Patient (aside from the scars on my chest) until I was an adult.

In 2004, I noticed a sudden unexplained weight gain but thought nothing of it, just cut back on my eating as I had been overweight before. In the last 6 weeks of 2006, I gained 20 to 25lbs while eating less and moving more. My energy disappeared completely, and I began to notice pain in my left arm and chest. Just after Christmas, I even wrote my Will because I was so scared. Finally, on March 1, 2007, I mentioned the symptoms to my husband who said, "CALL THE DR!" The Dr. sent me straight to the hospital, and I spent my first night on a Lasix drip removing over 10lbs of fluid in less than 12 hours. Diagnosis: Congestive Heart Failure; Prognosis: Sudden Death will always be a possibility & we do not do Pediatrics in Huntsville, get a consultation at UAB - STAT! I was back at the Pediatric Cardiology office where it all began 37 years later with my original doctor's protégé.

In March 2007, the Dr. originally said, "You need a new Pulmonary Valve, it's normal for adult Tetralogy repairs; (turns out I should have had one at age 18, but in 1988 the procedure had not quite been perfected), however, we are working on less invasive procedures in the Cath Lab that should be ready in about 5 years. You can wait that long." So there we had it and we moved forward, and I headed off to Ft. Lauderdale on a family vacation then Mobile to spend my 37th birthday and Mother's Day with my daughter...Memorial weekend I landed back at the hospital 20lbs heavier again. Suddenly it was evident my heart & lungs were drowning. I had been in Congestive Heart Failure for several years (10 to 15); and, my right heart enlarged. Kidney failure was possible; surgery was critical. In June while my husband was in Germany on business, I went back to the University of

Alabama in Birmingham to have my pre-op heart catheterization only to find out my potassium levels were way too low. Just a word of caution to those who may have this problem too: if you have tiny, veins NEVER let them give you a bag of Potassium through an IV unless it is through a PIC line. They had me on the Pediatric Wing that day, and I swear my parents and those kids learned expletives I did not even know I knew as it was so painful. Death row inmates get tons of drugs before KCL is administered, but I could not even garner a Tylenol from what my daddy tells me; I do not remember the experience, thank God. So, after spending the weekend in an adjacent hotel (alone in deep prayer), I doubled my oral dosage of potassium, and they performed a heart catheterization and finally found the source of my problems (not Tourette's). :-). My pulmonary artery that had been repaired by the Waterston Shunt in 1971 had re-narrowed not allowing blood exchange between the heart & lungs. As for my pulmonary valve it was working double-time pushing the same blood out that would wash back in again thus creating the fluid retention.

Going into this last surgery my question was: "Is the 3rd time the charm?" or "Are 3 strikes then you are out?" Definitely, the third time is the charm! Mentally & emotionally, it was stressful facing this as an adult because I carry the load my parents carried when I was a child. I have more energy now than I have had in years, and the prognosis is great for me to go on another 10+ years before I have to think about any further heart surgeries as long as I continue to practice good heart health. My life changed forever by this experience in many ways. Body image is tough not because of my scar - my father and I have always called that my "life line," but the constant weight gain/loss is difficult to handle. Each day I awake is different, sometimes I am my perfect "dry" weight, and others (especially when I travel) I can be up 5 to 10 lbs just over night no matter how much I restrict the salt in my diet. Learning to love the skin I am in regardless of the water weight has been a big hurdle, but overcoming that alone allows me to teach our younger heart patients that it CAN BE DONE! If I can help impart good self-esteem to our younger generation now, so they do not have to wait until they hit 40 as I did, it will be great for them.

The positive changes are an absolute necessity to honor the next phase of life given me. I eat a high fiber, low fat, low sodium diet, no sodas or anything with high-fructose corn syrup. I have never been a smoker and I only drink the occasional glass of wine with dinner. Exercise has been the hardest because just like Oprah I hate it! Two weeks after surgery, though, I was walking 1 mile a day in 15 minutes, now my goal is to walk 2 miles in 15 minutes. Believe the health-care providers when they promote exercise because I let my routine fall to the wayside causing a huge set back in recovery; however, the beauty is like all things we just pull ourselves up and get back on that wagon.

The worse part about Congenital Heart Disease is the biggest blessing of my life; at age 25, I learned I could not have children due to the effects of pregnancy on the heart. It is an issue that Doctors should educate parents of girls about. My personal experience was emotionally paralyzing because in 1980 (I was 10 yrs old), the Dr. told my parents, "Sure she'll have kids! Let her play NFL Football if she wants!" He was not even sure I would make it to 20 at that time. After many consultations and some poor advice resulting in a premature hysterectomy, I adopted the joy of my life, a Chinese girl in 1996 at 8 months old; she is 13 years at the time of this writing, and the best daughter a mother could want. In fact, her father (my ex-husband) is a 43 yr old ToF repair patient too; the first I had ever met since my roommate at UAB in 1975, whom I will never forget! When you are the one left with life out of 2 suffering the same defects; your life's purpose immediately grows beyond oneself; quite a burden for such a young child.

Life as a Heart Patient can be really tough if you let it, but if you take it one step at a time, smile/laugh as much as possible, keep moving, and encouraging others by telling your story you will find yourself well-grounded while surrounded by the best, most fascinating people on this earth!

To read Nicole's blog, go to the Nicole Borek with Tetralogy of Fallots link on page 3.

- ♥ [Heart of a Father by Jeni Busta's Father](#)
- ♥ [Jenni Busta's beginnings of life with HLHS](#)
- ♥ [Nicole Borek with Tetralogy of Fallots.aspx](#)
- ♥ [Rhys born with 4 different CHD's which are Tricuspid and Pulmonary Valve Defect, Hypoplastic Right Ventricle \(HRHS\) and an Artrial Setpal Defect \(ASD\)](#)
- ♥ [Tiana with Alcapa \(Anomalous Left Coroanry Artery from the Pulmonary Artery and Mitral Valve Regurgitaion](#)

CHD World websites

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

1) **Spain: Cardiopatías Congénitas**

<http://www.cardiopatiascongenitas.net/>

This website is dedicated to parents with children and adolescents and adults with congenital heart. / Esta página web está dedicada a los padres de niños cardiopatas y los adolscentes y adultos con cardiopatía congénia



2) **Australia: Heartkids (AU)**

<http://www.heartkids.org.au/>

The aim of this site is to provide useful information regarding our organisation and its mission, along with providing an avenue of support for HeartKids and their families.

Tandem Skydive to raise money for HeartLine

Our son Rhys was born 4 weeks prematurely but weighed in at a healthy 6lb 4oz, this was in June 2004. A few weeks later, whilst having a routine baby check, it was noticed that Rhys seemed to have a 'little murmur' on his heart. Nothing to worry about we thought, it will just pass we thought. That is when we started our journey as a CHD family.

Over the next weeks, months & years Rhys has undergone Echo's and ECGs as his condition was confirmed as Sub Aortic Stenosis, a lesion under the Aortic Valve which is restricting the flow of blood to the body. Rhys also had Left Ventricular Hypertrophy, the left side of his heart was enlarged as it was working so hard to pump his blood into his body, and then in July of this year Rhys was also diagnosed with Aortic Regurgitation, meaning there was a little leak on the aortic valve. This was when the doctors at the University of Wales Hospital (The Heath) told us it was time to take Rhys' case to the Joint Cardiac Clinic at Bristol to discuss the option of surgery.



Now we knew that open heart surgery was coming but that day blew us away, we just struggled to think of our little man going through such a trauma. But if that is what is needed then that is what has to happen.

Well I decided that I needed to occupy my mind with something other than the thoughts of surgery, it was then that I noticed a post on Heartline that suggested a charity Tandem Skydive, and within 2 days I had booked up. Now this is no mean feat for me as I am scared of heights!!



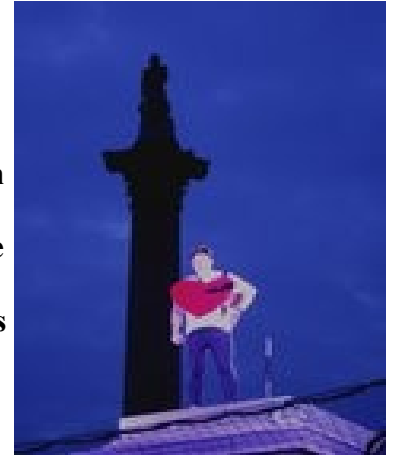
So on August 29th, the day before my 36th birthday, I will be jumping (or pushed) out of a plane 10,000ft above the ground to raise funds for Heartline. It's only a small thing I can do to show my gratitude to the many mummy's and daddy's who have helped me by answering questions or just being a shoulder to cry on when it's all become a little too much.

You can help too, log on to www.justgiving.com/tracysobey and you can sponsor me to do the jump. Every penny counts, please help if you can.

I am a Plinthian!

There will only ever be 2400 of us on the planet, that makes us rarer than GUCHs, if not hens teeth!

So what did I do to earn such an honour? I was lucky enough to be chosen to stand on Antony Gormley's (he of Angel of the North fame) latest piece of work, which was to fill the empty 4th stand in Trafalgar Square. Centre of London, live feed to the world, what else could a GUCH do but walk up and down to raise awareness of a cause I'm committed too. The Children's Heart Federation is running a campaign to highlight the need for heart kids to be included in PE lessons at school, to try and get this campaign noticed I've decided to walk or run 1000km in a calendar year...



The Plinth gave me my first "milestone" and the first media splash of the campaign - and on it I walked a 1150m, which given I was on a plinth of less than 2m by 4m I was moderately impressed by, I also kept up a nearly coherent flow for an hour of why I was doing what I was doing... Though there was some critique of my singing!

Although I'm in CHF colours this is really about awareness for all affected by heart conditions, be they happy, healthy, facing further surgery, recovering from surgery or even for those who have died. I've lost 2 GUCH friends from Europe in the last month, Peter from Denmark and Linus from Switzerland - both loved life and lived to the full and would've enjoyed the site of the "Polo" prancing about on a plinth for an hour as dawn broke over London.

The awareness work has started, with the local papers to me picking up the story, inc a small front page piece in the Bootle Times!

So if you want to read about my exploits please have a look at my blog, it does get update 2 - 3 times a week and I've promised I'll be honest so it will be a rocky ride.

<http://walkingforheartkids.blogspot.com/>

And for anyone wanting to know what a GUCH on a plinth looks like:

<http://www.oneandother.co.uk/participants/PaulWillgoss>

So for Peter and Linus, and for all the GUCHs out there I was, and am a Plinthian!

Written by: Paul Willgoss



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.



SEPTEMBER

- ♥ 3rd September 1956, Una M Kennedy, Coarctation of the Aorta
- ♥ 4th September, had severe mitral regurgitation due to supra-ventricular membrane and is on the heart transplant waiting list (3 years old)
- ♥ 7th September, Daniel Lush, had a VSD, which was repaired in February (1st birthday)
- ♥ 8th September 1996, Logan, HLHS, (13 years old)
- ♥ 15th September, Casey Lynn Bauer, Ebsteins Anomaly, ASD, VSD, (3 years old)

OCTOBER

- ♥ 9th October, Emyr Jones, Double Outlet Right Ventricle and a VSD (4 years old)

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:



SEPTEMBER and OCTOBER

- ♥ 12th September 2006, CHD Angel: Jackson, HLHS Angel, Forever 9 months 8 days, <http://www.jacksonsheart.com/>

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 Join the fight for free prescriptions in England!



We believe that you shouldn't have to pay if you are a heart patient, someone living with heart disease or at risk of heart disease.

[Join the fight for Free Prescriptions in England](#)

CHD AWARENESS: Ellie's story

The moving story of Ellie O'Neill, the daughter of CHD-NI's committee members Sinead and Paul was featured in two local newspapers during the last month, the Lurgan Mail and the Sunday Life (Belfast telegraph) .

You can read the published article in the Lurgan Mail here:
[Article in the Lurgan Mail](#)

Coeurs de L'Espoir Fund

CHD-NI visited Morocco in July 2009.

There was a meeting in Hospital Ibn Sina in Rabat, with the paediatric cardiologist Dr. Bemnani. The outcome of this meeting was that the Healthcare system is very poor and not sufficient for the demand.

In general the health care system includes 122 hospitals, 2,400 health centres, and 4 university clinics, but they are badly maintained and lack adequate capacity to meet the demand for medical care. Only 24,000 beds are available for 6 million patients seeking care each year; including 3 million emergency cases. The health budget corresponds to 1.1 percent of gross domestic product and 5.5 percent of the central government budget.

When you have a Congenital Heart Defect(s) or your child was born with Congenital Heart Defect(s), the prospects are very grim.

Most CHD's are detected months or even years after birth because there are no routine scans during pregnancy unless you pay for it.

Money, or lack of it, is the biggest problem. In Morocco you have to pay for every single consult with a doctor, as well as for ECG's, scans, medication or any other medical intervention.

When life saving surgery is required the patient has to pay for everything involved to do the procedure, for example, the oxygen that will be used, syringes and even the thread for the stitches to close the wound...

Open heart surgery will cost €6000 (60,000 Moroccan Dirhams) and with an average income of just €300 a month (if you are lucky to have work) this is out of reach for the majority of people.

CHD-NI has decided to set up a fund:

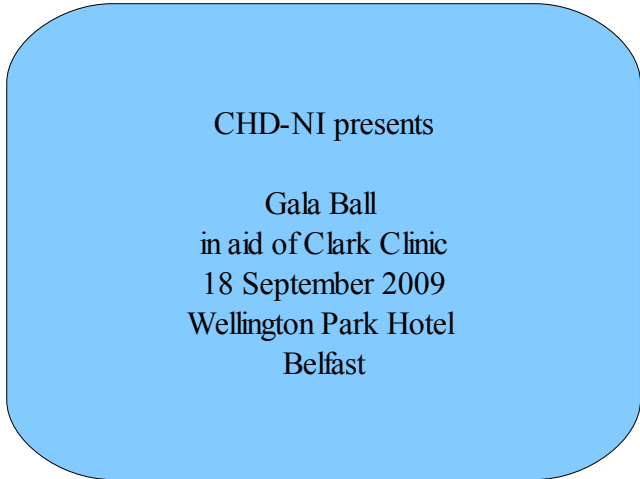
Coeurs de l'Espoir Fund (translation: Hearts of Hope Fund) which aims to raise money for urgent cases in need of life saving surgery.

You can read more and donate on: [Coeurs del Espoir Fund](#)

or/and join the cause Save a Heart in Morocco on Facebook to help and show your support:
[Save a Heart in Morocco Cause on Facebook](#)

Your money will save a precious life!!!





More information and ticket sale on: <http://www.chd-ni.co.uk/Upcomingevents.html>

Wrote by: CHD-NI

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:

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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 September and October.

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.generef.com/newsstory.rss.html?pid=68816>
- ♥ <http://www.medicalnewstoday.com/article/159795.php>
- ♥ <http://congenital-heart-defects.co.uk/heartofafather.aspx>
- ♥ <http://congenital-heart-defects.co.uk/jenibustasbeginningsoflifewithlhs.aspx>
- ♥ <http://congenital-heart-defects.co.uk/nicoleborekwithtetralogyoffallots.aspx>
- ♥ <http://congenital-heart-defects.co.uk/rhyswithfourdifferenttypesofchds.aspx>
- ♥ <http://congenital-heart-defects.co.uk/tianawithalcapaandmitralregurgitation.aspx>
- ♥ <http://www.cardiopatascongenitas.net/>
- ♥ <http://www.heartkids.org.au>
- ♥ <http://justgivig.com/tracysobey>
- ♥ <http://walkingforheartkids.blogspot.com/>
- ♥ <http://www.oneandother.co.uk/participants/PaulWillgoss>
- ♥ <http://www.jacksonsheart.com>
- ♥ <http://congenital-heart-defects.co.uk/chdukspetitions.aspx>
- ♥ http://.bhf.org.uk/news-and-campaigning/our-campaign/prescription-charges.appx?utm_source=Font+Page&utm_medium=Promo4&utm_campaign+Prescription+charges%2009
- ♥ <http://chd-ni.co.uk/Mediaandpress.html>
- ♥ <http://chd-ni.co.uk/CoeursdelEspoirFund.html>

 <http://apps.facebook.com/causes/335017?m=4ff5b46>

 <http://www.chd-ni.co.uk/Upcomingevents.html>

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

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