



## CHD-UK© E-NEWSLETTER

*Educating and Raising Awareness of*

*Congenital Heart Defects*

7th Edition, December 2009

[www.congenital-heart-defects.co.uk](http://www.congenital-heart-defects.co.uk)

and

[www.chd-ni.co.uk](http://www.chd-ni.co.uk)

**Welcome** to December's e-newsletter. This is our 7<sup>th</sup> edition and it is also one year since we sent out our first ever e-newsletter. In that time, we have added a lot of information to the website and we have seen it grow through the visits and the emails that we receive.

We have provided in each e-newsletter two websites from various countries in our 'CHD World Websites' section and we will continue to do so. This edition will have links for charities that help others in countries where they cannot afford to have the necessary operation. We are always looking for personal stories to add to the website to give hope to others, to show that they are not alone with living with a congenital heart defect or dealing with your child's congenital heart defect. Every one of us deals with the realisation that our child has got a congenital heart defect or grown up with one differently but we all have one thing in common and that is we all understand how each other feels. We have a special article wrote by a mother on what Christmas now means to her.

Unfortunately I have had to put the gig on hold due to unforeseen circumstances. TheWalk-a-thon was a great success, see CHD-UK Raising Awareness and Funds section.

In regard to CHD Awareness week in February, we are doing red and blue pyjamas and non-school uniforms more details in a special edition in January.

We are including our usual CHD'ers birthdays CHD Angels as well as the usual What's in the News and links?

### **CHD-UK Raising Awareness and funds.**

Zoe Dickson organised a Sponsored Walk-a-thon in Weymouth in aid of CHD-UK on the 21<sup>st</sup> November and raised valuable awareness.

### **CHD-UK's Newest Committee Members**

I would like you all to give a warm welcome to Helen Howarth, Teresa Hawes and Zoe Dickson who have come aboard CHD-UK to raise awareness and to hold fund-raisers for various other charities.

### **Children/Babies having open heart surgery in the New Year.**

Tristan (Kerry Card's son) will be having his 3rd open heart surgery (the Fontan), Jack (S L Robson's son) will be having his open heart surgery in January. Also, Gonzalo may be having a pulmonary valve repair done in January, it all depends on how the appointment goes on the 17th/18<sup>th</sup> December.

Please take a moment for Arlyn, who has had open heart surgery this month but is having a hard time since, she will be spending Christmas in hospital and Sarah Scott has asked if you could please send a Christmas greeting to her and she will forward it on. Please email all greetings to [chduk@hotmail.co.uk](mailto:chduk@hotmail.co.uk) and I will forward them on to Sarah.



Sending positive vibes to all the families.

### **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.

Heart Clinic opening up in India

[Click here for India Times](#)

Heart Defect killed Rugby Player

[Click here for the BBC News Article](#)

### **What is NEW on the website?**

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

#### **Types of CHD's**

- ♥ Pulmonary Atresia

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**

- ♥ RSV (Respiratory Sincytial Virus)

Other new articles are:

#### **Personal Stories added:**

- ♥ Rob Ward – Coarctation of the Aorta
- ♥ Charles Miller talking about his now grown up daughter
- ♥ A mothers letter to her 7 year old son on his heart day.

### **Personal Stories**

Who am I?

My name is Rob Ward, and I am 23 years old. I grew up in Surrey but have also lived, North Wales and Chester, as well as travelling to Australia and Indonesia for work experience and scientific research. I have a degree in Zoology, and am now a zookeeper specialising in Reptiles, Amphibians and Invertebrates. The reason that I am writing this is that I am an adult with CHD, specifically Coarctation of the Aorta.

#### **My CHD history**

A school health check picked up a heart murmur, and so I was then referred to a consultant. Further investigation then showed that I had CoA – narrowing of the main artery leading from the heart and supplying oxygenated blood to the majority of the body. In my case, for me it was most noticeable as the muscles in my legs weren't getting as much oxygen as they would like! One of the questions that the consultant asked me before making the diagnosis was whether my legs would ache when I was running around. My answer was yes! It turns out that this can be a sign of CoA due to the restricted

blood and oxygen flow. At least it gave me a chance to prove to my parents I wasn't just being lazy if I moaned about walking somewhere. The CoA was most likely a congenital defect that I had from birth but that had gone unnoticed. No one else within my immediate family suffers from CHD.

I was referred to the paediatric cardiology unit at the Royal Brompton hospital in London, and they have since been responsible for my all of my cardiac consultation and treatment. Whilst I was still young it was decided that major surgery would be too dangerous. Cardiac catheterisation was used a couple of times for investigative reasons (basically inserting a very thin tube into my artery in my groin and leading it up to the heart / artery to have a look). The last catheterisation was intended to be used for angioplasty (blowing up a balloon to expand my artery), but it was deemed too risky at a young age as it may have caused damage to my artery.

Finally, at the age of 15 I was admitted in the Royal Brompton for surgery to repair/replace the narrowed section of my aorta. In the end the surgeons had to remove the section of the aorta that was narrowed, but the gap was too large to bridge with existing arterial tissue and so a Dacron graft was used. One of the reasons that this surgery waited until I was 15 is that it is less likely that I will need the graft replaced as I had less growth ahead of me compared to if I had been younger.

When I woke up from the surgery I was still intubated which was soon removed, and replaced with oxygen via a tube to my nose. As well as this I had 2 chest drains which I can only describe as being like 2 hose pipes coming out of the left side of my chest. There were also IV's in my neck, hand, and a wonderful catheter so I didn't leave the bed to go to the toilet.

Soon I was moved out of the intensive care room, and into another room. This was when my physiotherapy started. Something that I have not yet pointed out is that the CoA repair surgery meant that the left side of my chest including ribs was cut open to access my insides, leaving me with what is now a scar of about a foot long leading from just under my left armpit, round to the top of my shoulder blade. During the surgery my left lung was collapsed to provide easier access to my artery, this unfortunately led to me getting a chest infection. The physiotherapy involved me mainly trying to cough the muck out of my lungs...easier said than done when your left side is partially open and your ribs are trying to heal.

After a week in hospital it was time to leave, and for the stitches closing my chest drain holes to be removed. I was off school for about 7 weeks after getting out of hospital to allow my body to recover, and in this time had to make a couple of trips to the local doctors just to check my progress and change dressings. As this was just before my GCSE's, I did get some tutoring in hospital as well as some at home to try and help me and make sure that I wasn't falling behind. These were provided by both the hospital and the local council/school respectively.

Now, 7 and a half years on I am doing well. I still have the scars, and check ups at the Brompton every year or so. In the last year I have had an exercise test, 24 hour blood pressure, cardiac MRI and along with the usual ECG, ECHO and blood pressure tests. The extra tests were due to some high blood pressure readings, and I am now on Irbesartan (an Angiotensin II receptor blocker for those more medically minded) which lowers my blood pressure. Initially this medication did slow me down quite a lot, but now I am capable of being almost as active as I was before this medication. My high blood pressure is unsurprising due to the changes that my cardiovascular system has undergone during my life, and is unlikely to be attributed to any other to any other medical reason.

I try to keep as active as possible, and currently train Capoeira twice a week (a Brazilian Martial Art), usually rock climb once a week, and cycle to work every day. Over the past few years I have also done a lot of hiking and jogging to keep my fitness levels up.

As far as I am aware I will probably be on blood pressure medication for the rest of my life, but this is

only one tablet a day. Apart from this there is no reason why I won't live a relatively normal life. I may not have lived a 'normal' life by most children's standards due to being less active during certain periods of my life, but I have no regrets. I am most grateful to my parents and to the doctors, nurses and other staff at the Royal Brompton hospital in London for their fantastic care.

For more information about Rob click on the link below.

- ♥ [Rob Ward - Life with Coarctation of the Aorta](#)
- ♥ [Alex's story wrote from her Father's perspective](#)
- ♥ [A letter from mum to her 7 year old son on his heart day](#)

## CHD World websites

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



### 1) World: Big Love Little Hearts

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

This charity is the first and only organization that matches children with CHD who need lifesaving surgery but do not have access to appropriate care, with the many generous organizations, surgeons and healthcare professionals who donate their time, talent and resources to perform these repairs for free.

### 2) Poland: Cor Infants

<http://corinfantis.com/>

This site is A foundation for children with heart defects and the page is in polish. They help children to have the necessary operations that the would not be able to afford. It is a bit like Big Love Little Hearts but only concentrates on the children of Poland.

## New Supporter

CHD-UK is pleased to announce they have a new supporter: Rave-on-DJ's

Rave On DJ's radio is a family run partnership and was set up by Catherine D'Alquen, Terry D'Alquen and Charlie D'Aalquen.

Catherine says "We are proud to support CHD-UK. I myself have a congenital heart defect and it makes me feel proud and honoured to really get the word out there, via my online radio."

[www.rave-on-djs.co.uk](http://www.rave-on-djs.co.uk)



A Mother's Approach to Xmas  
Wrote by Sarah Scott, Australia

Since becoming the mum of a CHD baby Christmas time has started to hold a special meaning for me, suddenly the true meaning of what this season really means has become clear.

Now of course I am not so caught up in meaning that I am not spoiling them purely rotten, but everything I buy and wrap and place under the tree is all for the look in their eyes on Christmas

morning, it is all for the memories I realise it is so important to make as a family. It isn't about the presents anymore it is simply about that moment as a parent when you realise that is all is right with the world.

My CHD baby is Hannah, she is 19 months old and was born with TOF, a common condition with a complicated series of defects that can range from extreme to mild, like everything it is a roll of the dice exactly what you get. Hannah's condition is the most difficult seen but she has certainly thrown some curveballs into the mix throughout her journey and like all heart parents we have experienced the full rollercoaster ride of emotions. With 2 surgeries under her belt so far and more to come within the next few years our girl amazes us everyday with her strength and determination, we delight in her and her gorgeous nature and cheeky personality. Hannah has 2 older siblings Abby who is 8 and Cooper, 3, both of whom are heart healthy.

So why is Christmas so special now when it wasn't before? Because before I took for granted the fact that we would always be together and we would always have something to celebrate. I thought Christmas was just another day of presents and long drawn out lunches and worried about the cost of it all and the logistics, how my perspective has changed.

During our journey I have met some incredible families. I have cried for babies I have never met and mourned the loss of children to this cruel disease that has no reason when it chooses its angels. I have held my baby close and listened to the sound of a heart in need of a helping hand and I have sat still for hours and hours, too overcome with worry to move or speak. This is the life of a family with CHD. We live with fear and knowledge that frightens and overwhelms. We monitor coughs and colds and temperatures while that small voice at the back of our head tries to keep us reasonable and rational, we know what can potentially happen if we look away even for a second and it is unthinkable.

I think now of families who are in hospital during this time. Maintaining bedside vigils in ICUs and wards all over the world. I think of the incredible bravery and strength they show while the rest of the world celebrates. I think of their biggest hope for Christmas being a healthy child they can take home and I send them prayers and love and strength. My goddaughter Arlyn will be spending her very first Christmas in a hospital after a rocky few weeks, I send her love and magic for this very special day.

But most importantly I think of those incredible parents who have to face our worst nightmare every single day. The parents who have angels to pray to and seek strength from instead of Christmas cuddles. I think of how much I draw from their journey and I wish with all my heart that somehow and somehow they find a moment of calm and peace with their memories of a child gone way too soon. If Christmas miracles really do happen I hope that each and every one of these families receive one. This year I have personally said goodbye to a gorgeous angel by the name of Lara, who gained her wings in February aged 10 months. I will light a candle for her and say a prayer asking her to visit and stay a while, asking that her families feel her presence at the table and beside the tree on Christmas morning. I know they never leave us even if we sometimes have trouble seeing them.

So Christmas for me is a day to remember the angels that have made us cry and the battlers that have kept us strong. It is a day to try to capture every single smile and hold it in your heart for when you are feeling low. It is a day to celebrate our girl being here to open presents, to sing Christmas carols, to wear a Santa hat and pull all the decorations off the tree... we have seen the alternative and it will never ever leave us. But most of all it is a day to be a family, to share a moment that no one else can, to celebrate our life and our love and our commitment to each other's happiness.

I hope you all have a peaceful Christmas and a fabulous 2010. I wish you all good tidings and great cheer and a day filled with the magic that only love and family can bring.

## 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.



### JANUARY

- ♥ 11<sup>th</sup> January, Thea , TGA, (2 years old)
- ♥ 17<sup>th</sup> January, Sarah, Truncus Arteriosus and VSD, (16 years old)
- ♥ 28<sup>th</sup> January, Eleonora, TGA, (2 years old)

### FEBRUARY

- ♥ 13th february 2007, William Broadbank, Hypoplastic left Ventricle, Hypoplastic Left Aortic Arch, AVSD, VSD, Complex Subaortic Stenosis, Aortic valve Stenosis, COA, PDA, Interrupted IVC with azygous continuation to SVC, (3 years old)
- ♥ 21st February 2007, Rhys Jones, ASD (Atrial Septal Defect) a Hypoplastic Right Ventricle and a dysplastic pulmonary and tricuspid valve, (2 years old) ([Rhys Jones, My Miracle! Group on Facebook](#))
- ♥ 20th February 2006, Thomas, TGA, VSD and Pulmonary Stenosis, (4 years old)
- ♥ 27th February 06, Cordelia Griffin aka Deedee's, TGA, (4 years old)
- ♥ February 29th 2008, Lilyana Annsaleigh~ Coartation of the Arch, Ventricular Septal Defect, Arterial Septal Defect, Left Ventricle Outflow Tract Obstruction (LVOTO), Aortic Stenosis, Double Outlet Right Ventricle (DORV), Dextrocardia Situs Inversus, Leap Year! (2 years old) [www.lilyangelheart.blogspot.com](http://www.lilyangelheart.blogspot.com) or [www.myspace.com/lilyangelheart](http://www.myspace.com/lilyangelheart)

## 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:



### JANUARY and FEBRUARY

- ♥ Ethin RaiLuc Twigg: Hypoplastic Left Heart Syndrome (HLHS), Born: 9th January 2009 Died: 27th June 2009
- ♥ Anthony Murphy: Double outlet right ventricle, large pulmonary non committed VSD and a straddling tricuspid valve, Born: 12<sup>th</sup> February 2003. Gained his wings: 5<sup>th</sup> July 2005
- ♥ Natalie Jean Yakalis, Interrupted Aortic Arch: Born: February 10, 2008. Gained her wings: April 3rd, 2008.. Always in our hearts and forever an angel
- ♥ Ashley Bunnell, Hypoplastic Left Heart Syndrome (HLHS) Born: 24th February 2006 Gained her wings: 3rd October 2008
- ♥ Cody Kirkham-Bradley, CHD: Tricuspid Valve Dysplasia with severe regurgitation, Downs Syndrome, Still born at 25 weeks on the 30th January 2009, Cody was buried on 9th February 2009

**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 7<sup>th</sup> April 2009 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:**

**A Christmas thought....**

With Christmas coming up most of us are busy preparing ourselves for this festive time of year. But the spirit of Christmas means much more than buying presents and indulging ourselves in lovely food. Caring and thinking about each other, especially those who are facing the difficulties that life can bring us. If you have a child that is born with a CHD or you are an adult with a CHD means that it can have a huge impact on your daily life and that this time of year might even lose its sparkle when surgery is around the corner. I know this only too well myself...this time last year my daughter Dounya was very poorly and transferred to The Clark Clinic in Belfast to have her surgery as soon as possible.



As a family we passed Christmas in a very strange way because our thoughts were filled with worry - one year on it is a very different story: Dounya is a ray of sunshine and a happy and healthy child who since a week ago is able to walk on her own. To look at her you wouldn't know that she has faced such an ordeal in the first months of her life. Being born with a heart condition makes you special by being an inspiration to so many people in showing your spirit and strength. I have found inspiration and hope in the stories of other children and adults with a CHD, and especially my own daughter who has taught me to keep on battling whatever it takes with a smile and not to give up.

This time of year we celebrate the birth of a special child, but I am celebrating also the births of all those amazing children from the past, present and future who are teaching us to not lose hope .

#### **Recipe for Christmas All Year Long**

Take a heap of child-like wonder  
That opens up our eyes  
To the unexpected gifts in life—  
Each day a sweet surprise.

Mix in fond appreciation  
For the people whom we know;  
Like festive Christmas candles,  
Each one has a special glow.

Add some giggles and some laughter,  
A dash of Christmas food,  
(Amazing how a piece of pie  
Improves our attitude!)

Stir it all with human kindness;  
Wrap it up in love and peace,  
Decorate with optimism, and  
Our joy will never cease.

If we use this healthy recipe,  
We know we will remember  
To be in the Christmas spirit,  
Even when it's not December.

*By Joanna Fuchs*

**CHD-NI news:**

The British Heart Foundation division Northern-Ireland is interested in the work of CHD-NI and we are in the process of getting affiliated with them, which would be fantastic. It is still early days but it looks promising

Further we are concentrating on CHD Awareness week which will be 7-14 February. We are trying to get schools to have a uniform less day if possible hold presentations about CHD.

Alexandra Mouhsine  
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 Christmas and New Year spare a thought for the children/adults that we have lost this year to CHD.

CHD-UK and CHD-NI Wishing you all a Merry Christmas and a happy and healthy New Year.

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



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://news.bbc.co.uk/2/hi/uk\\_news/wales/8374518.stm](http://news.bbc.co.uk/2/hi/uk_news/wales/8374518.stm)
- ♥ <http://timesofindia.indiatimes.com/city/nagpur/OCHRI-to-start-a-heart-care-clinic-for-children/articleshow/5277352.cms>
- ♥ <http://congenital-heart-defects.co.uk/PulmonaryAtresia.aspx>
- ♥ <http://congenital-heart-defects.co.uk/RSVRespiratorySyncytialVirus.aspx>
- ♥ <http://congenital-heart-defects.co.uk/RobWardLifewithCoarctationoftheAorta.aspx>
- ♥ <http://congenital-heart-defects.co.uk/FathersStoryofDaughterbornwithmultipleCHDs.aspx>
- ♥ <http://congenital-heart-defects.co.uk/Aheartmumslettertoher7yearoldboy.aspx>
- ♥ <http://congenital-heart-defects.co.uk/>
- ♥ <http://www.biglovelittlehearts.org/>
- ♥ <http://corinfantis.com/>
- ♥ <http://www.rave-on-djs.co.uk>
- ♥ <http://www.facebook.com/group.php?gid=36527517905>
- ♥ <http://www.lilysangelheart.blogspot.com>
- ♥ <http://www.myspace.com/lilysangelheart>

 <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>