



CHD-UK© E-NEWSLETTER

*Educating and Raising Awareness of
Congenital Heart Defects*

9th Edition, April 2010

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

Welcome to April's e-newsletter. This is our 9th edition and we'll be focusing on the European CHD Awareness Week in May. We have an article from our regular writer Sarah who tells us how the month of May affects her so much. As well as wanting people to run in a Marathon to dressing up like Sex in the City for a night of fun and fundraising.

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

European CHD Awareness Week.

During one week in May, there is a European CHD Awareness Week which aims to raise awareness of CHD's around Europe.

European CHD Awareness Week
9th to 17th May

CHD-UK will be posting up stories during the week, so make sure you view them.

Wallace and Gromit's Grand Appeal

I would like to invite you to join the Grand Appeal Charity team in the Bristol Half Marathon on Sunday 5th September 2010!

If you would like to run with us, please email me at lauren@grandappeal.org.uk as our charity golden bond places are now available!



As long as you can raise £175 in sponsorship we would love you to join the team and help us raise vital funds for our Cots for Tots Appeal which supports the Neonatal Intensive Care Unit at St Michael's Hospital, Bristol.

The Unit cares for over 600 critically ill babies a year from all over Bristol and the South West with the most complex medical and surgical needs requiring life saving surgery, treatment and care.

The Cots for Tots Appeal is currently supporting a major upgrade of the Unit to create more space to

treat babies in a warm and welcoming environment with life-saving equipment, comforts and to create a dedicated accommodation unit for parents and families with sleeping, washing and cooking facilities.

Your support can make a real difference and help towards saving the lives of the hundreds of babies treated in the Neonatal Intensive Care Unit each year.

You have 4 months to train and we will support you all the way to the finish line! Your support will make such a difference to the children of the South West and Bristol. Please get in touch if you would like an application form or any further information.

**Best wishes,
Lauren Vincent
Grand Appeal Fundraiser**

What the month of May means to one Mother.

Wrote by Sarah Scott, Australia

The month of May is proving a hard month for me this year. Two years ago my daughter was born and diagnosed in April but it was May when she started to show noticeable signs of her CHD. It was May when she had 2 admissions to the children's hospital. One lasted a week and the other lasted until September. It was May when we realised that she was not going to have the supposedly average journey that comes with her condition. It was May when I suddenly had a crash course in what it means to be the mother of a child with a heart condition. Her first ICU admission was in May. Her first cardiac ECHO.... yes you guessed it was May. Last year we headed to Melbourne for her second open heart surgery in May. Next week is her cardiology appointment, I think I am slightly more anxious because May and I have such a long history together. Lets hope that this is the year that May comes full of good news and positive signs. We are hoping that this will be our first every appointment where will receive good news from our cardiologist, if it wasn't being held in May I would probably be more optimistic.

But something important has happened to me this year. There is a shift in perspective and a greater feeling of calm. This year I have facebook. People can rubbish this fabulous social networking tool all they like. They can talk about it being a waste of time. They can talk about people who add 'friends' they have never even met. They can disparage the need to post photos and to share your personal life with others and they can wax lyrical about the dangers of publicly sharing information for all the serial killers to get a hold of. They have never been the parents of a desperately sick child. For the first 12 months of Hannah's life I lived in a world of fear. I did not know anyone else with my daughter's specific condition. I was the parent of the sick child in a healthy community. That is extremely isolating. People didn't get it, and they didn't have to. I was trying hard to maintain a normal life while living in this world of fear. Good friends stood up and I will always be extremely grateful for their practical and emotional support but even they knew they didn't get it. They knew they didn't want to get it. At the end of the day they returned home to their healthy children and thanked the stars that they weren't me.

Then about a year ago I started a group for Hannah on facebook called Hannah's vigil. The idea of the group was to ask my friends and family to make Hannah their profile picture on the day of her surgery, in my mind I saw it as a virtual candle. It meant that when I logged on during that long and hard day her gorgeous face would be looking back at me, telling me everything was alright. Within a week I had 30 women from all around the world add me, all heart mums, all living with CHD. Suddenly I wasn't alone. If I woke at 2am having a panic attack there was always someone online to calm my nerves and comfort me with stories of their own methods of coping. If I was given a diagnosis by a doctor then a quick question on my status meant that I was informed by some of the most

knowledgeable people in the world who had literally lived through it themselves. Over the past year we have laughed together, cried together, crossed fingers together and unfortunately grieved together as well. I consider some of the people who share my facebook my greatest friends, even though we will probably never meet. Our children belong to all of us, our journeys are intertwined and the knowledge that we are no longer walking alone is priceless.

I feel sorry for mums who don't know about this fabulous online community, where possible I tell them. I think regularly about all those families who 10 years ago and beyond didn't have the ability to jump online and ask a simple question. Lives are being saved thanks to facebook and a small team of dedicated women who are desperately trying to make a difference. If you don't believe me then check out groups such as 1 in 100.org and Cora's Story – women campaigning for public awareness and research and training for our doctors so that children with CHDs are detected earlier and not sent home undiagnosed from hospital. Journal articles and news stories are shared on facebook. When I see Hannah's cardiologist next week I will be armed with a very important article relating to Hannah's condition. I will make him work harder for my girl, I have facebook to thank for that.

So to all of you in my personal facebook community or in other support networks of your own I ask you to take a minute to think of how lucky we are and to share the knowledge of this incredible tool in saving our children's lives and offering invaluable support to families at times they need it the most. If you aren't on facebook yet then what are you waiting for!! Look me up when you get there – I have some people to introduce you to

Heart hugs
Sarah

Hearts for Hearts

This website is a blog that was created in order to show you the designs available.

The artwork is created to order and every piece is different, and therefore takes time to create.



This is not for profit - all proceeds go to your nominated charity:

- ♥ Children's Heart Unit Fund at The Freeman,
- ♥ Newcastle, Heartline, or
- ♥ CHD-UK

[Hearts for Hearts](#)

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.

Teenage boy is youngest to receive artificial heart pump
[Click here for the Telegraph article](#)

Online medical information influences treatment
[Click here for the article from InPharm](#)

International 22Q11 Deletion and Max Appeal Conference

Where: Ricoh Arena, Coventry, UK
When: 29th to 31st July 2010

www.maxappeal.org.uk
Max Appeal
Supporting families affected by Di George Syndrome/VCF5/22q deletion



The scientific programme on the 29th and 30th July with Peter Scambler (UK), Donna McDonald-McGinn (USA), Tony Simon (USA), Anne Bassett (Canada), Bernice Morrow (USA), Solveig Oskarsdottir (Sweden), Nicole Philip (France), Ann Swillen (Belgium), Jacob Vorstman (The Netherlands), Alex Habel (UK), Peter Aagergaard (Denmark), Sarah Prasad and Sarah Howley (Ireland), Bronwyn Glasser (Switzerland) and about 40 others. A truly international event with speakers from five continents!! Also two days CPD accreditation from the Royal College of Paediatricians should prove an added bonus for professional delegates.



The family programme will run on the 30th and 31st July. Good use will be made of the national and international experts to bring you new and exciting information. In addition there will be opportunities to explore common issues in smaller group sessions with professionals and other parents who 'have the t-shirt', such as education, mental health and encouraging concentration. There will be an evening's entertainment on the Friday night in conjunction with the scientific delegates at the venue, with music and dancing being in order!

The children's and young people's programme is exceptional! We have organised visits to Warwick Castle and the Royal Shakespeare Company. Warwick Castle dates back to 914AD when Ethelfleda, daughter of Alfred the Great, ordered the building of a 'burh' or an earthen rampart to protect the small hill top settlement of Warwick from Danish invaders and is now famous for its dungeons and crowd thrilling live jousting shows. The trip to the Royal Shakespeare Company in Stratford upon Avon is to take part in workshops on the comedy Twelfth Night, for the youngsters with its confusions over the twins' identities, and the gory tragedy of Macbeth for the older ones. An exhibition space at the arena will house a climbing wall and high wires from a company called Closer To The Edge. Other activities will take place on site, such as making a pod-cast/ video-clips with and a music CD to take home. Supervision is being carried out by a specialist crèche, Max Appeal volunteers (with child protection training and enhanced Criminal Records Bureau clearance), cardiac nurses and hospital play therapists.

How to get there:

Fly to Birmingham International Airport or East Midlands Airport, each is within 25 miles or so of the venue. London is just over an hour by train for Heathrow and Gatwick. Manchester Airport is about an hour by car up the M6 Motorway.

Keep an eye on www.22qdeletion.com for on-line registration for the conference and hotel accommodation AND make sure you enjoy the early-bird rates!

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

♥ I shall be adding information about Reflux in the coming months.

Other new articles are:

Personal Stories added:

♥ **7 Days = 7 European Personal CHD Stories.** Between the 9th - 17th May 2010 CHD-UK will be adding personal stories from around Europe for each of the days during European CHD Awareness 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 April's editions of two websites from around the world:

1) **France: Heart and Coeur**

<http://www.heartandcoeur.com/>

This charity is an international association that provides reliable information, support services and resources to families, to adults, to children with congenital heart defects, and professionals.

We strive to be your most reliable source of congenital heart defects information.

It is in French and English.



2) **Belgium: Hartekinderen**

www.hartekinderen.be

This site is an independent, non profit parent organisation which aim is to bring together parents whose children suffer from congenital heart defects. The organisation contributes to solutions for medical, psychological, social and pedagogical problems to which parents and children are faced: housing, education, medical accompaniment, transport, study choice, employment, recreation and family planning e.g.

Fundraising for Evelina's Children's Hospital

This event was a success and they raised £530 for ECHO (Evelina's Children's Hospital Organisation).

Heartline Disco

This is the first article and event night that our Promotor and Researcher for articles/publications, Teresa Hawes is doing. Please support her in this.

I'm doing a Heartline disco on 11th September in Plymouth, Devon and on the night I want to show the faces of the people who have CHD by creating a poster of some of the people we are raising money for!

So I am writing this to ask for your help! I fully understand if you do not want to help, so please do not feel that you have to!

But if you do then here's how - I would like to do some posters, and on the poster I would like to put two pictures of your child(ren): one when they were very ill and one of them now with a small statement of how Heartline has helped you!

If you no longer have your child with you, you can still get involved by sending me a picture of your beautiful child and again writing a statement how heartline has helped you!

If you are an adult CHD'er then you can still do it.

If you would like to have your child's/adult chd'er picture included then please email me the pictures and your quote by 31st May 2010 to [Teresa Hawes](mailto:Teresa.Hawes@heartline.org.uk)

Furthermore, if you would like to attend the disco it starts at 7pm; tickets are £10 per adult, they must be bought in advance so please email me for details.

Thank you for reading, much love!
Teresa

CHD Warrior's Birthdays

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



MAY

- ♥ 11th May 2007 Kian Taylor, Pulmonary Stenosis, Heart Arrhythmia (low irregular HR), 2 VSD's (3 years old)
- ♥ 14th May 2005, Amelia, Interrupted Aortic Arch, ASD, large VSD, Sub-aortic Stenosis, and DiGeorge Syndrome (6 years old)
- ♥ 19th May 2004, Alex Howarth, ToF, (6 years old)
- ♥ 24th May 2005 Thomas "David" Moore, HLHS, May 24, 2005 (5 years old (www.kentuckianalefthearts.com/))

JUNE

- ♥ 7th June, Oliver King, AVSD and PDA (repaired October 2007). Repair caused a residual VSD, mitral regurgitation, tricuspid regurgitation and Pulmonary hypertension. Other conditions include a rare form of long gap oesophageal atresia with multiple complications, completely gastrostomy fed and has an oesphagostomy stomas, sleep apneas, significant hearing loss, downs syndrome and the most infectious smile you could imagine,
- ♥ 19th June 2004 , Rhys Sobey, Sub Aortic Stenosis - awaiting surgery (Resection of the Heart), (6 years old) (<http://mystorybyrhys.blogspot.com/>)

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:



MAY and JUNE

♥ Eliza Steele: 2 VSD's, Born 18th May 2004 Gained her wings on 2nd January 2005

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 was closed in December by Sandra Kay -it had been open for over 2 years.

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

4th Annual Phoenix Francis Have a Heart Walkathon

Mark June 27th on your calendar's folks as we prepare for the 4th Annual Phoenix Francis Have a Heart Walkathon! This event will be taking place at the Garnet Graham Lakeshore Park in Fenelon Falls (if raining, it will be in the Fenelon Falls arena), Ontario, Canada in memory of Phoenix Francis (May 7th, 2006 – June 23rd, 2006 HLHS).

Last year we collected close to \$20,000 CDN for Toronto's Hospital for Sick Children and this year we plan to raise more than that! Grand prize is....drum roll please... TWO (2) ROUND TRIP TICKETS TO ANYWHERE WEST JET FLIES! If you collect more than \$1,000 CDN you will be entered into the draw to win the grand prize. The person who collects the most will get THREE (3) ballots into the draw and the person who collects the second most will get TWO (2) ballots into the draw to increase your chances of winning!

Can't make it to Fenelon Falls for the walk? That is perfectly fine! Get a few friends together where you live and walk anyways. Be sure to go to <http://tinyurl.com/4PHOENIX> and let us know where you're walking from!

Can't make it to Fenelon Falls and you want to donate? Once again, that's fine! A page has been set up on Join the Fight: CHD's website! Go to <http://tinyurl.com/4DONATE> to donate!

If you can make it, there will be lots of fun and games. Including a BBQ put together by Fisher's Your Independent Grocers, a silent auction, a return of the Phoenix Francis Shakedown crew, and much, much more!

Registration begins at 11 and ends at 12.

Please be there to register within this time period.

CHD-NI News

Alexandra has given birth to a baby girl called Amani on the 18th April, baby girl was born with no heart defects and is doing well. Please, continue to view CHD-NI website.

Alexandra Mouhsine
Chair of CHD-NI



Congenital Heart Defects N-Ireland

Sex in the City Nite Hosted by Perfect Day, Lurgan.

Wrote and Organised by Bernie O'Neill

Perfect Day are pleased to announce they are hosting a Sex in the City Nite in aid of Clark Clinic RVH.

As many of you know I have already helped raise money for little Ellie O'Neill (her mother is a member of my staff) - if you don't know about Ellie here is her story.

"Hello, my name is Ellie Maureen O'Neill. I was born at 8.38am on Tuesday 24th October 2006 by emergency section as my heart rate had slowed down. I spent my first two days in the neonatal unit in Craigavon Area Hospital. When I was six weeks old, the doctors found out I was sick and rushed me down to Clark Clinic in The Royal Belfast Hospital for Sick Children.



I am a wee miracle, as my Ductus Arteriosus stayed open for those six weeks and kept me alive. Usually it closes a few days after birth. My Mummy and Daddy met with Dr Frank Casey the Consultant Cardiologist. He explained that I was a very sick wee girl and had complex congenital heart disease. I have Pulmonary Atresia, which means that I have no Pulmonary Artery, so blood from the right side of my heart cannot go to my lungs to pick up oxygen. This means that I go blue a lot, like a smurf!!

I also have a double-inlet single ventricle and major aortopulmonary collateral arteries (MAPCAs). Normally, the heart has a right and left ventricle. The right ventricle normally pumps blue blood (without oxygen) out of the heart through the pulmonary artery to the lungs for oxygen and the left ventricle normally pumps red blood (with oxygen) through the aorta out of the heart to the body. Double Inlet Left Ventricle is one of the so-called Single Ventricle heart defects, as there is effectively only one pumping chamber in the heart.

Operation Number One - BT SHUNT:

I went to Clark Clinic on Friday 1st December 2006. The doctors gave me prostaglandins to keep my Ductus open until they were ready to operate on me. I had my first operation on Wednesday 6th December 2006. It was called a Blalock-Taussig shunt. Mr Gladstone was the surgeon. He was a very nice man with big, long fingers! He is very good at his job and I am glad he operated on me. I was away for about five hours and Mummy and Daddy were very worried about me.

After the operation I went to Paediatric Intensive Care to recover. I was so small in the cot and I was wired up to lots of machines. Around 9pm that night my oxygen levels began to drop. They were sitting at 80/90% and the doctors were very happy, but then they dropped down to the 40's and 50's. My shunt was blocked by a clot and I was dying. Dr Sands, another cardiologist spent hours working on me and told Mummy and Daddy to expect the worst. He went home after 2am and I was stable for

the time being. I went back to the operating theatre the next morning to get the clot unblocked. This time it worked great. Mr Gladstone was very upset that it hadn't worked first time round and could not understand how I made it through the night. I was in PICU for five days and then went back to Clark Clinic and finally got home on the 20th December. I was in great form and had a big scar to show everybody (thoracotomy).

Operation Number Two - The Glenn Operation:

I went back to Clark Clinic on Wednesday 4th July 2007 for a cardiac catheterisation. I was in for three days and it was to make sure I was ready for the second stage of my surgery, the Bidirectional Cavopulmonary Shunt or Glenn Operation.

The Glenn operation is open heart surgery and I underwent it on the 17th January 2008. This operation diverts all the blood coming back from the upper body through the Superior Venacava. Now, all of the blood coming from my upper body is diverted to the lungs so more pink blood is coming back from the lungs to the left side of my heart. They also removed my old shunt. The operation took five hours and I was home after 6 days, which amazed the doctors and the nurses.

Operation Number Three - The Fontan Operation:

Operation number three is the Fontan Operation. I will need to get this when I am three or four. I will have to get it sooner than later as I am very tall for my age and this puts extra pressure on my heart. It is the last of the three planned operations and will make me nice and pink!!

The Future:

Ten years ago, there was little hope for children like me. Recent advances in medicine have enabled me to live a much more fulfilling life. I will be on anti-coagulants for the rest of my life (I am on aspirin now and will be on warfarin later). This stops a potentially fatal clot, but unfortunately long-term use has its side-effects too.

To look at me I look like any other child of my age. People comment on my blond curly hair and my height. They don't see my lips going purple and my body of scars. I often forget my physical capabilities and tire easily. I love to play with other children and do not realise that this scares the wits out of my mummy and daddy. A simple blow to the chest when playing can be very dangerous for me although it doesn't stop me enjoying life to the full.

The doctors say I will need a heart transplant in my late teens. I try not to think that far ahead and take inspiration from other CHD patients who have done amazing things with their lives. "

So guys come along to our fundraising nite, have a few cosmopolitans or a wee glass of wine, watch our fashion show - where we will be showcasing our new collections of both evening wear and guest/occasion wear, and buy some raffle tickets - be in with a chance to win some fantastic prizes kindly donated by several local businesses.

We will also have a great prize for the Best Dressed Sex in the City Lady-you will be in with a chance to have some amazing fashion style images taken at the Award Winning Studio - Ciaran O'Neill Photography.

So come along have a great nites craic with your mates and help us raise some funds for Clark Clinic RVH.

10% of any items purchased on the nite will also be given to the charity.

To let them know that you will be attending please go to Sex in the City Evening Hosted By Perfect Day, Lurgan on Facebook or [click on this link](#)

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 coming spare a thought for the children/adults that are going to be having life saving operations during the coming months. CHD-UK and CHD-NI Wishing you all a good May and June.

Hazel, **CHD-UK**, Founder

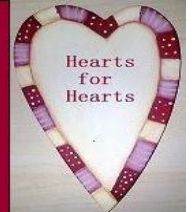
Alexandra, **CHD-NI**, Founder

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.grandappeal.org.uk/>
- ♥ <http://heartsforhearts.blogspot.com/2010/04/welcome.html>
- ♥ <http://www.telegraph.co.uk/health/healthnews/7636208/Teenage-boy-is-youngest-to-receive-artificial-heart-pump.html>
- ♥ <http://www.inpharm.com/news/digital-pharma-online-medical-information-influences-treatment>
- ♥ <http://www.facebook.com/home.php?ref=home#/group.php?gid=2361087995&ref=ts>
- ♥ <http://www.22qdeletion.com>
- ♥ <http://www.heartandcoeur.com>
- ♥ <http://www.hartekinderen.be>
- ♥ <http://congenital-heart-defects.co.uk/>
- ♥ <http://kentuckianalefthearts.com>
- ♥ <http://mystorybyrhys.blogspot.com/>
- ♥ <http://congenital-heart-defects.co.uk/chdukspetitions.aspx>
- ♥ <http://tinyurl.com/4DONATE>

 <http://tinyurl.com/4PHOENIX>

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

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

 <http://www.facebook.com/event.php?eid=112969128735812&ref=ts>

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