

update



children's heart
FEDERATION

November 2006

Lake District Adventure Week

A half term trip to the Calvert Trust Centre in the Lake District provided plenty of excitement and challenges for a group of young people with heart conditions this October. The centre is located in the Lake District National Park, in a converted farmstead built in traditional Cumbrian style and set in two acres of land with amazing, panoramic views over Bassenthwaite Lake and the nearby fells.

Our group, with the help of qualified instructors, Nick and Jill, were determined to take advantage of everything the centre had to offer. Over the next few days, they tried their hand at outdoor climbing, exploring a disused mine, archery, indoor rock and rope work and an assault course. The Centre has its own stables just outside Keswick, and the group went horse riding and experienced the excitement of 'driving' in traps. They also made full use of the centre's indoor swimming pool, the large games room and the sports hall which has an indoor climbing wall.



"I have had a great time at the Calvert Trust. I enjoyed meeting new people, we all got on really well."

Pavandeep, 16yrs



In the evenings, some slightly more relaxed and less energetic activities were planned – an ice-breaker for the first evening, a session run by a GUCH patient and sessions on 'Planning Future Activities' – a chance for the young people to express their ideas and have an input into the planning of forthcoming events.

All too soon it was time to leave the Lake District behind. At a final meeting, everyone agreed that they had had a great time. If you would like to be put on the mailing list to hear about future trips for young people please email info@chfed.org.uk with your name and address.

CHF HAS A NEW HOME

After a number of years based at Oval House in Vauxhall, CHF has finally packed up and moved to a new and bigger office in the lively, bustling city area near Liverpool Street Station.

The new office has a Meeting Room available for hire which can accommodate up to 15 people. It is available both during the week and at

weekends and we offer a discounted rate to member groups. Please call the CHF office on **020 7422 0630** for details.

Please note our **new contact details:**

**2-4 Great Eastern Street,
London, EC2A 3NW
T: 020 7422 0630;
F: 020 7247 2087.**



Supporting the Growing Heart Child

CHF Conference 2006



This year's conference "Supporting the Growing Heart Child" took place on Saturday 23rd September in the Conference Centre at the National Centre for Deafblindness in Peterborough.

Delegates were welcomed by CHF Chair Julie Wootton before listening to the first presentation of the day, which was given by Dr Piers Daubeney, Consultant Paediatric & Foetal Heart Cardiologist at Royal Brompton & Harefield Hospital. Dr

Daubeney gave an extremely informative talk on the importance of parent involvement in the process of medical decision making.

Norma Jun-tai from Action for Sick Children then delivered a presentation on 'Patient Involvement' in which she explained the importance of involving and informing children appropriately and recognising that adolescents have different needs to those of younger children and adults.

Sailish Bechar then offered a parent's perspective. He described his son, Anik's journey to adulthood and the challenges he has had to face and overcome along the way. This warm and insightful talk really helped the audience to understand what it is like to be a parent trying to support a heart child as they grow up.

Finally, the delegates were given a very engaging personal account of growing up with and living as an adult with congenital heart disease from Paul Willgoss, a former Vice Chair of Grown Up Congenital Hearts Patients' Association who is living proof that being a heart patient need not hold you back in life.

In the afternoon, delegates were able to attend a series of workshops including Claiming Disability Living Allowance, Linking with Kids – CHD Information via the Web, Physical Activity in Congenital Heart Disease and Supporting a Young Person through Transition.

We would like to thank all the speakers, workshop facilitators and delegates for helping to make this a really successful day.

HELPLINE NEWS

Recently, a number of calls to our helpline have been from parents experiencing difficulty in getting a second opinion on their child's condition. In some cases their GPs were reluctant to make referrals and there were also problems getting their child's notes transferred.

At the CHF conference, we asked Piers Daubeney, a Cardiologist at Royal Brompton & Harefield Hospital for his opinion. He said that GPs should be willing to make referrals for second opinions and that cardiologists may be willing to see a child without their notes, provided that they see any letters that the parents have received regarding their child's condition.



We thought it would also be helpful if we shared the advice that the British Medical Association (BMA) gives Consultants. The BMA does not believe patients have an automatic right to a second opinion. However, they advise doctors that they should respect a patient's wish to obtain a second opinion unless there are justifiable reasons for refusal, e.g. that the patient might come to harm as a result. They also advise that requests for a second opinion be handled sensitively and wherever possible dealt with by the consultant. Patients should not be made to feel a nuisance or a 'bad patient'.

As Piers Daubeney advised, the responsibility for finding a suitable consultant to give a further opinion rests, strictly speaking, with the referring GP. However, it is often helpful if the original consultant suggests a name which the patient can discuss with their GP.

When a referral is made for a further opinion, there may be particular questions which can be best dealt with by a consultant-to-consultant letter, but the GP should also receive a copy (and CHF reminds parents of their legal right to receive copies of doctor's letters about their child). Finally, the BMA advises that all patient records should be forwarded as soon as possible.

If you are a medical professional with an opinion on this issue or a parent who has had a good or bad experience of asking for a second opinion, please let us know by e-mailing info@chfed.org.uk so we can continue to monitor this issue and take action if necessary.

CAMPAIGNING NEWS

Review of Paediatric Cardiac Services

Representatives from the Children's Heart Federation recently participated in a special workshop jointly chaired by Professor Roger Boyle, National Clinical Director for Heart Disease and Dr Sheila Shribman, National Clinical Director for Heart Disease for Clinicians.



Together with clinicians and representatives from other professional organisations, public and specialist services we discussed:

- ♥ our concerns about pressures on paediatric cardiac surgical centres
- ♥ what an optimal service would look like,
- ♥ the factors that needed to be considered in moving to an optimal service
- ♥ the key steps to be taken to achieve the optimal service

Everyone present agreed on the need to change the existing services and develop them in line with regional networks. However, before detailed discussion and consultation can take place, the Department of Health is keen to complete its review of current use of services. CHF has undertaken to get parents views so if you have a view of the service you would like to see please e-mail us at info@chfed.org.uk requesting a questionnaire.

Collecting data on treatment



CHF is an active member of The Central Cardiac Audit Database (CCAD) Project Board which has recently been conducting a Paediatrics Cardiac Surgery and Congenital Heart Disease Audit. All paediatric hospitals

in England are participating in this audit and at present over 30,000 records are held within the central database. Data is submitted for every patient undergoing cardiac surgery or a catheter interventional procedure. Annual validation visits are made to every centre to check the accuracy and completeness of data submitted and it is hoped that this audit will be instrumental in providing validated centre-specific and national outcome analysis for the treatment of children with congenital heart disease.

CHF is determined that the data that has been collected is made available to parents so that they are better informed about the skill and experience of the specialist treating their child and are able to use that knowledge in decisions they may have to make about the treatment of their child. However, there is a danger that the data

might be misunderstood. For example, a particular clinician may appear to have poor results. Whilst this could be a reflection of their lack of skill or experience it could also be because they are recognised as being the best at performing a particular procedure and are therefore being given the most difficult and serious cases.

The CCAD Board understands our concerns and is currently developing a public and professional portal on the internet and considering how best to present the information. A demonstration version will be available by the beginning of 2007 and CHF have agreed to help co-ordinate parents' views and comments. If you would like to know more or be involved in this consultation, please let us know – telephone 020 7422 0630 or e-mail info@chfed.org.uk.

CHILDREN'S HEART WEEK



**Children's
Heart Week
2007**

Earlier this year we organised a reception at The House of Commons which was attended by many politicians, representatives of interested organisations and policy makers. The reception resulted in a number of discussions on improvements to services for children with congenital heart disease.

CHF are determined that the promised service improvements do materialise and that the current financial issues faced by the NHS do not impact adversely on the services offered to our children and their families. Any changes that are made to service delivery must be motivated by a desire to improve treatment and support and not to save money.

We are currently planning our programme for Children's Heart Week 2007 and again would love to have as many families and organisations as possible involved. Maybe you could organise a fun event at your child's school – or something at work – a great way to make everyone aware of congenital heart disease. We're currently putting together Heart Week Packs – so if you want to get involved – let us know. Contact us on 020 7422 0630 or e-mail info@chfed.org.uk.

Groups & Staff News

CHF welcomes new staff

We have recently been joined by two new members of staff:



Catherine McEvoy is our new Office Manager. As well as performing general reception and secretarial duties, liaising with other service providers and being PA to Anne Keatley-Clarke, Catherine will also be the central contact for CHF member groups.



Lizzie Bruce has been appointed Head of Communications at CHF. Lizzie will be developing and implementing CHF's communication strategy and managing the communications team. Her role includes handling PR and coordinating media requests for interviews. She will also work closely with Archana, the Information Officer, to promote the work of CHF through our website and printed material such as our Annual Review.

NEW MEMBERS OF THE FEDERATION

We are delighted to announce that *The Brompton Fountain* and *CRY (Cardiac Risk in the Young)* are now official members of Children's Heart Federation.



CRY was founded in 1995 to raise awareness of cardiac risk in the young – sudden cardiac death and sudden death syndrome (SDS, SADS). They provide information, advice, counselling and have a CRY Surgery Supporters Club for young people who have had, or are about to have, potentially life saving surgery of defibrillator implantation, pacemaker or ablation. In addition, CRY operate a number of cardiac screening programs and fund medical research and the CRY Centre for Sports Cardiology. For contact details see page 8.



The Brompton Fountain is a parent support charity for families whose children are being treated for cardiac and respiratory conditions at the Royal Brompton & Harefield NHS Trust. It aims to provide an open channel of communication between families through a mutual support network, provide appropriate and understandable information, and offer links with relevant health professionals and other organisations. For contact details see page 8.

Carnival Girl



Summer seems a long time ago now, but we just had to share this beautiful photograph of Carole (Database Manager, CHF) in her gorgeous 'People of the Nile' costume at the famous Notting Hill Carnival in August.



WEDDING BELLS

There's been a spurt of weddings recently among the Children's Heart Federation staff and we'd like to offer our congratulations to the following couples:

Our helpline manager, Jenna & her new husband Garrie.

Our fundraisers Jamy and Dianne and their husbands Anthony and Kevin respectively.

We wish them all a long and happy life!

FUNDRAISING NEWS



On a sweltering July day, the British 10k London Run wound its way around picturesque and exciting landmarks in central London. A total of 30,000 entrants streamed past the start line at Hyde Park Corner. Congratulations and a big thank you to David Miskin, Parvathy Mohan and James Carvell who all ran for CHF.

Next year, the British 10k London Run is on 1 July 2007. If you would like to take part in aid of the CHF, please contact Jeremy Hobson on 020 7422 0630.



Iron Man UK Triathlon

We are very grateful to George Wimpey, one of UK's largest house builders, who have chosen CHF to be one of the main beneficiaries of the fundraising events they hold around the country including golf days and a football tournament.

Ian Pay (pictured), from George Wimpey's North Yorkshire branch, did the UK Iron Man Triathlon for CHF in August. This gruelling challenge involves a 2.4 mile swim, followed by a 112 mile bike ride and then a 26.2 mile run!!! Needless to say, we were all in complete awe! A very big thank you to Ian from everyone at CHF.



Launch of Elyon's Heart Foundation

A new group called the Elyon's Heart Federation (EHF) was launched at a 'Back to School Family Fun Day' on 9 September in North London. CHF helped to organise the day which saw lots of people enjoying themselves and raising money for the new group.

Sherelle Hutchinson (pictured, middle), formed EHF following the diagnosis of her son King Elyon with congenital heart block in 2003. Sherelle, who runs the charity herself, said "At the moment there is no form of support for these kids and their parents in the borough (Enfield), which is a real shame." The group offers a local helpline, fact sheets and the chance for members to get in touch with other local people with similar experiences.



Elyon's Heart Foundation 01992 850748 info@ehf.org.uk

Research & Health News

THE NEW TONIC FOR TUMMIES



Ginger root is an ancient traditional medicine used in China to treat nausea and vomiting. Several studies over the last decade or so have suggested that its use may reduce the incidence of postoperative nausea and vomiting. In the most recent study, researchers in Thailand pooled data from 363 patients to assess the efficacy of ginger relative to a placebo.

Compared with the placebo, ginger cut the risk of nausea and vomiting in the 24 hours after surgery by 31%. The researchers concluded that, *“Ginger is an effective therapeutic option in prevention of postoperative nausea... and because of its widespread availability and low cost may be an attractive option at least as a component in the combined antiemetic regimen.”* The dose suggested is at least 1g ginger.

Information Prescription to put Patients in Control

Under a new initiative launched by Health Minister Rosie Winterton on 18 October, patients with long term conditions will soon receive “information prescriptions” from their doctor which will tell them how to find out more about their condition. The idea behind this is to empower patients to take control of their own illness and make informed choices about their health care. Thus the initiative focuses on easy access to high quality information to support choice and will point people to information about conditions and treatments, information from voluntary organisations, where to get benefits advice, contact details for local and national support groups, etc.

Initially, a series of pilots to trial this new idea will be run with some voluntary organisations until the end of 2007. The initiative is part of the 2006 White Paper *Our Health Our Care Our Say* which contains a commitment to introduce Information Prescriptions for everyone with a long term condition or care need by 2008. Commenting on the initiative, Ms Winterton said:

“We are all busy people. We don’t want to have to trawl through endless websites or publications to find the help we need. We want to be able to lay our hands on the right information and advice as quickly as possible...I want to help patients to help themselves. Better access to information at the point of diagnosis and throughout the care pathway will empower people to manage their condition more effectively, taking greater control over their own lives.”

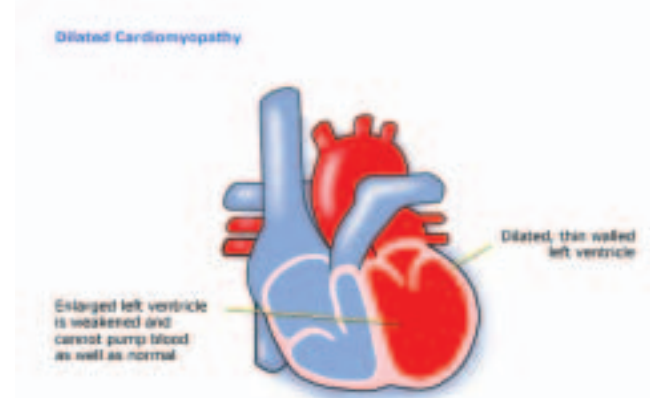
For more information visit the Department of Health website <http://www.doh.gov.uk/>



Dilated Cardiomyopathy – The Underlying Causes

The mystery behind this commonly untreatable and undetected heart muscle disease in children was partially revealed for the first time on 17 October 06 in the Journal of the American Medical Association.

Dilated cardiomyopathy (DCM), which occurs when the left ventricle becomes enlarged and cannot pump effectively, is the most common form of cardiomyopathy and cause of cardiac transplantation in children.



The research, conducted by researchers at Baylor College of Medicine (BCM) and Texas Children's Hospital, studied a total of 1426 children under 18 with DCM. The study found that in terms of incidence, DCM was more common in boys than girls and also in black children than white children. It was also found that infants (less than one year old) were almost ten times more likely to develop DCM than any other paediatric age group (up to 18 years old). The most common causes of DCM were myocarditis (inflammation of the heart) and neuromuscular disease. With regard to outcome, it was found that around 70% live beyond the first year of the disorder's onset, and about 50% survive past five years.

Dr Jeffrey Towbin, professor of paediatrics at BCM, says despite these findings much work remains to be done: *"Despite advances in diagnosis and treatment, we are still having significant problems with outcomes in these children just like we are in adults. There needs to be more support for research in this area."*

THE CHANGE STUDY Congenital Hearts: A National Gene/ Environment Study

This is a brief update on the CHANGE Study which was featured in our previous newsletter. The study is a National Research Project funded by the British Heart Foundation established in 2003 and to be undertaken over a 5-year period. The aim of this research is to develop a better understanding of why Congenital Heart Disease (CHD) occurs and it is specifically looking at the genetic and environmental factors.

At the moment, the study is focusing on the congenital heart condition called Tetralogy of Fallot. It involves collaboration between several of the Paediatric Cardiology Units throughout the UK and we hope to enroll the help of 1,000 families nationwide. So far we have collected samples from over 400 families, so we are almost half way to our target. When the data has been analysed we will put summaries of the findings on the CHANGE study website -

<http://www.ncl.ac.uk/ihg/research/change/>.

We are very grateful to all the families who have already taken part and would be pleased to hear from anyone who may be interested in participating. Anyone who would like further information can visit the website, which has details of how to contact the local CHANGE study team.

Useful Resources

- **One parent families**

Visit <http://www.oneparentfamilies.org.uk> for information on lone parents caring for a child with a disability or long term health problem.

- **NICE Website launch**

The National Institute for Health and Clinical Excellence (NICE) has updated its website to be comprehensive, user-friendly, authoritative and up to date source of information on public health and clinical guidance for NHS professionals, patients and others working in public and voluntary sectors. Visit <http://www.nice.org.uk>.

- **The NHS GUCH guide** was recently launched. This is a big step forward for GUCH patients and sets out what should be available to them in terms of care and structure of services nationally. It can be downloaded from the DoH site at: <http://www.dh.gov.uk/assetRoot/04/13/46/96/04134696.pdf>

- Bryan and Mandy Edwards, parents of Bethan who has a Hypoplastic Left Heart Syndrome have launched a website www.bethan.org.uk and have also published a book called 'Bethan – A year in the life of the baby with half a heart'. You can order a copy of the book on their site (20% of all sales will be donated to Birmingham Children's Hospital and Edward's Trust).

Dates for the Diary 2006

- British Congenital Cardiac Association AGM, Bath **22nd – 23rd November**
- Childrens Heart Federation Lapland Trip **18th – 20th December**
- Children's Heart Week **12th – 16th February '07**

Children's Heart Federation – List of Federated and Affiliated Groups

Barth Syndrome Trust

1 The Vikings
Romsey
Hampshire SO51 5RG
Tel: 01794 518 785
www.barthsyndrome.org.uk

Cardiomyopathy Association

40 The Metro Centre
Tolpits Lane
Watford WD1 8SB
Tel: 0800 0181 024
www.cardiomyopathy.org

Children's Heart Association

26 Elizabeth Drive
Helmshore
Rossendale BB4 4JB
Tel: 01706 221988
www.heartchild.info

Children's Heart Unit Fund

Freeman Hospital
Newcastle on Tyne
NE7 7DN
Tel: 0191 213 1365
www.chuf.org.uk

CRY

Unit 7
Epsom Downs Metro Centre
Waterfield, Tadworth
Surrey KT20 5LR
Tel: 01737 363222
www.c-r-y.org.uk

Down's Heart Group

P O Box 4260
Dunstable
LU6 2ZT
Tel: 0845 166 8061
www.dhg.org.uk

Evelina Children's Heart Organisation

Linden Lea
Leigh Place
Cobham, Surrey KT11 2HL
Tel: 020 7237 1745
www.echo-at-guys.org.uk

Grown Up Congenital Heart Patients Association (GUCH)

75 Tuddenham Avenue
Ipswich, Suffolk IP24 2HG
Tel: 0800 854 759
www.guch.org.uk

Heartbeat

9 Turloughs Hill
Annalong
Newry BT34 4XD
Tel: 028 4376 8786
www.heartbeatni.org.uk

Heart Children Ireland

The Carmichael Centre
North Brunswick Street
Dublin 7, Ireland
Tel: 00 3531 874 0990
www.heartchildren.ie

HeartLine Association

Community Link
Surrey Heath House
Knoll Road
Camberley GU15 3HH
Tel: 01276 707636
www.heartline.org.uk

HeartLink

Geoff Smart (Chair)
68 Rockhill Drive
Mountsorrel, Leicestershire
Tel: 0500 382152
www.heartlink-glenfield.org.uk

Heart Transplant Families Together

P O Box 4633
Worthing
West Sussex BN11 9EL
Tel: 01903 606826
www.htft.org.uk

Little Hearts Matter

11 Greenfield Crescent
Edgbaston
Birmingham B15 3AU
Tel: 0121 455 8982
www.lhm.org.uk

Max Appeal

13 Meriden Avenue
Woolaston
Stourbridge DY8 4QN
Tel: 01384 821227
www.maxappeal.org.uk

South West Children's Heart Circle

67 Rycroft Rd
Frampton Cotterell
Bristol BS36 2HJ
Tel: 01454 854 656
www.heartcircle.org

The Brompton Fountain

1 Love Lane
London
EC2V 7JN
Tel: 020 7776 9000
www.bromptonfountain.co.uk

The Scottish Association for Children with Heart Disorders

104 Comiston Road
Edinburgh EH10 5QL
Tel: 0131 447 2711
www.youngheart.info

Wessex Children's Heart Circle

48 South Avenue
Sherbourne
Dorset DT9 6AP
Tel: 01935 816156
www.wchc.org.uk

Young at Heart

10 Knoll Croft
Great Tindall Street, Ladywood
Birmingham B16 8DY
Tel: 0121 357 8200
www.youngatheart.org.uk

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(contact details under review – coming soon)



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