



update

CHF Welcomes Its New Chief Executive



I have been impressed with all that CHF and its member organisations have achieved and feel very privileged to have been given the opportunity to join the CHF team.

I have worked in the voluntary sector for almost twenty years and have run several health campaigning organisations. I also sit as Non-Executive Director on a Strategic Health Authority, so I hope that my experiences and contacts will be of real benefit. As a mother of children living with long-term conditions, I know how important it is that the views of parents and children are heard and aim to do as much as is possible to ensure that the needs of children with heart conditions are properly met. I am really looking forward to working with everyone to take forward our work.

Anne Keatley-Clarke

Save our Standards

John Spall, CHF Representative on the PCCSRG, speaks out:

Hundreds of parents contributed thousands of hours of their own time to expressing their frustrations, ambitions and commitment to the paediatric cardiac services for their children, as part of the Children's Heart Federation's input to the Paediatric and Congenital Cardiac Services Review Group (PCCSRG).

As a result of these efforts and the earlier work in drawing up the CHF publication "Children's Heart Services – a guide to care standards" a great deal of the improvements that parents sought to the services were incorporated in the national standards which were recommended by the Review. In that sense these standards are our standards into which we have put huge effort, commitment and emotional investment.

What has happened to that investment?

Can we be confident that we are receiving healthy dividends from it?

While it is still relatively early days and the evidence is patchy, sadly I believe the answer is "No".

Why is this? Well, some is no doubt down to the in-built inertia of a large organisation like the NHS, some to an unwillingness by individuals and institutions to change long held ways of doing things or break away from loyalties going back into the past. But by far the major cause is lack of money.

As CHF said in its response to the PCCSR Group's report:

"CHF considers the proposals if accepted, with adequate resources for their implementation, would provide a high class, patient centred, paediatric cardiac service."

and further:

"CHF is disappointed at the failure of

the Government to provide any earmarked money to stimulate and assist the implementation of these far reaching proposals. We are fearful that without this the pace of change will be ponderous and uncertain. We strongly urge the Government to think again on this issue. After the huge amount of time, energy and emotion expended over some six years by parents, we believe they deserve better."

That prediction is turning out to be true. More than two years after the publication of the National PCCSR Group's proposals:

- After an initial good start by the regional PCCSR Groups, those for the North and the South of England have not met for nine months.
- The London PCCSR Group has just held its first meeting in more than a year.
- The Midlands PCCSR Group only held its FIRST meeting about three months ago.

- The only serious new money that has been introduced into the service is from charitable sources via the British Heart Foundation, with their funding additional cardiac liaison nurses at a number of units. This is very welcome and we are grateful to BHF for taking this initiative. These CLNs are already making a difference on the ground and proving yet again how much they are valued by parents. But with no statutory money going in, not a single unit in England has yet met the standard for staffing of CLNs.
- No progress has been made on rationalising catchment areas or setting up managed clinical networks; key elements in raising standards throughout the patient journey and ensuring equality of service across a region.
- Our professional colleagues tell us that serious issues are emerging about meeting the requirements of the European Working Time Directive (EWTD) at consultant level. This directive restricts the hours that employees may work and it has already

been applied to junior doctors. Once again CHF and others were predicting at the time of the review that this legislation would have a big impact on staffing levels and size of units. But we on the national PCCSRG were specifically prohibited from discussing this.

- Concern about this was one of the reasons for the PCCSRG proposing that a unit should undertake a minimum of 300 operations a year with a minimum of three surgeons doing about 100 operations each. Indeed, a number of members of the PCCSRG wished to go further. This advice was rejected at political level by the Minister.
- It doesn't take a mathematical genius to work out that if there is a need for 3 surgeons to operate a rota which meets the EWTD in a unit which currently has 2 doing 200 operations, they will end up undertaking less than 70 operations each. This is below the standard recommended, is leading us back towards occasional practice (one of the causes of the Bristol scandal) and compromising patient safety.

We now all need to join together to stand up for our standards and demand that the paediatric cardiac services are given the resources to implement the recommendations of the PCCSRG, without further delay and procrastination.

CHF is to spearhead a campaign to achieve this, which it hopes all our federated groups and individual parents across the country will support. We will shortly be issuing material to groups and through them to their members, to enable them to do this.

Alternatively you can write yourself to the Minister responsible:

Dr Stephen Ladyman MP
Department of Health
Richmond House
79 Whitehall
London SW1 2NL

A copy of the Summary of CHF response to the PCCSRG report can be ordered by calling the helpline on **0808 808 5000**.

A note from our Chair

Dear reader,

CHF made a good start to 2005 by welcoming our new Chief Executive, Anne Keatley-Clarke. Many of you will know that last year was quite "a bumpy ride" (to borrow a catchy phrase from the latest Harry Potter film!) and a challenge for the staff and trustees who, particularly Carol Davidson the Groups Development Officer and John Spall the former Chair of Trustees, have gone the extra mile.

The Midlands PCCSRG held its first meeting in Leicester at the end of last

year and thus closed the "hole" referred to in a previous Update edition that caused a few ripples in the pond. Discussions were frank and open and a further meeting is planned for the summer.

CHF led the member organisations to form the parent/patient representation in the successful drive to establish standards through the PCCSR. It is now vital that we support the BCCA (formerly BPCA) and apply increased pressure for resources to enable changes for services to meet those standards. I would urge people to

put pen to paper!

The weekend of 1st October will see us, with the able assistance of Wessex Children's Heart Circle, in Southampton for our annual conference where the implementation of the PCCSR Standards with particular reference to the patients journey and outreach and primary care services long with many other pertinent issues will be discussed. Please do join us.

Best wishes,

Julie Wootton

Parent Power – CHF Conference 2004

CHF has been running a Department of Health (DoH) funded Parent Empowerment Project for the last three years. In September 2004 members of the federated groups gathered at the conference at Alder Hey Hospital, Liverpool to look at the main outcomes from this project.

Delegates were addressed by the Acting Chief Executive, Carol Davidson, and Shirley Law, who had been Director of CHF over the years of the project.

They pointed out the achievements to an audience that included parents whose heart child had not been born when parents had been given their first voice at government level at the 2001 consultation.

The 2001 conference had successfully collated the views and concerns of parents across a range of issues, and presented them to the review of services that Department of Health undertook. We were reminded of the need for that review. The Kennedy Report on the loss

of the lives and mismanagement of treatment of our children had pointed to the many flaws that exist within the NHS. Our Chair's involvement in the review meant that we were able to involve parents at all the relevant points.

The DH review accepted the majority of the recommendations from the 2001 CHF conference. Of course, this involved a mass of work, mainly in reaching and publishing agreed standards to which all the paediatric units will have to conform at some time in the future. Unfortunately no extra money was provided to pay for these standards and the changes necessary, so progress has been limited and patchy.

The last few years have also seen the publication of material to help build parent's confidence on seeking a second opinion and talking to health care staff. We also consulted with parents on their perceptions of care and support after leaving the paediatric cardiac unit.

Consultation with parents also highlighted that some of the main areas of concern included the need for more outreach and liaison nurses and the transition to adult services. These have largely been addressed with BHF liaison nurses now working out of a number of units. But no unit has yet reached the national staffing standard for these nurses. There are also issues at consultant level with meeting the requirements of the European Working Time Directive in some of the smaller and medium size units. Involving parents and support groups in the monitoring of services, and supporting those services is our ongoing task.

While some progress has been made much remains to be done before we can say that the national standards are in place across the country. In addition, parent empowerment needs to focus on the social and emotional problems faced by children at school, within the family, and as they take their place in the adult world.

Conference Workshops



Last year's conference marked the end of the three-year project and the focus for the day was on looking at ways to enhance and strengthen the influence and involvement of parents in further improving services.

A total of four workshops were held. We received positive feedback from the New to Conference workshop with parents saying that they were pleased to have the opportunity to voice their opinions and share their experiences – "It was good to hear other people's stories and experiences". The general feeling was that everyone present was committed to improving services for heart children.

As one parent put it, "Everyone is here to make a difference". The main areas of concern for parents included the greater need for information about cardiac services so parents knew "who's who and what they do". It was also agreed that GP's need more information on congenital heart defects, particularly the implications for e.g. immunisation, prevention of infections, etc.

Janet Barwen led a workshop on Assertion Skills. This workshop aimed to build greater confidence in parents and hence empower them to press for good standards of care for their children. The workshop explored the differences between passive, assertive and aggressive behaviour, clearly explaining the different effects of each. Useful tips and guidance on how to deal with different scenarios was given, e.g. how to respect others even when a difference of opinion is apparent. Participants were taught the effects of

body language, particularly on how to read and change body language to facilitate better communication. Feedback from this particular workshop was excellent and Janet Barwen, an experienced NHS trainer, made this an enjoyable and positive experience.

Other workshops held looked at Empowerment and Talking to Doctors. Discussions revealed that for most parents, being empowered meant "being in control", "being treated as an equal and involved in decision-making", "having a voice", "having the relevant information", and "being listened to, valued and respected".

There was an opportunity to discuss ways of improving communication and getting the best out of the doctor/parent relationship. Examples include: taking a list of questions with you; writing notes during consultations; asking

for a letter from the doctor following any consultation; taking a friend or relative along; challenging what you don't understand; asking for a clear picture of the hierarchy of the medical team; and of course using the various support groups for help with preparation for the consultation and understanding information.

This and other useful advice is also covered in our publication Talking to Doctors available on request from CHF.

Publications available from CHF:
Now you're out; Children's Heart Services – a guide to care standards; Second Opinion; Talking to Doctors; Report of CHF Conference 2001.

CHF Helpline 0808 808 5000

Unfortunately, we are still receiving reports from parents on negative experiences with doctors and other health care staff. One parent shares a frustrating experience with her local hospital:

When our daughter was diagnosed with CHD at 12 weeks we were told that she would receive shared care between our local hospital and a specialist cardiac centre. To me this meant that there would be clear lines of communication and that we would receive the care and support that was required for our daughter. Unfortunately this wasn't the case. Two of our local consultants appeared to have a very lax attitude towards the care of our daughter. On many occasions we were made to feel like over anxious parents of a healthy

child! There was an obvious disparity between what the hospital were doing and what the cardiac centre thought they were doing, such as follow up appointments that just weren't made, referrals to dieticians which again were not made, continued monitoring etc

After our daughter had undergone a successful repair I decided to take steps to ensure that other parents wouldn't be made to feel the way we had. I arranged a meeting with one of the local consultants. I thought that he would perhaps show some level of understanding and empathy. Instead I was confronted with comments like "mothers are often over anxious" and "Bronchiolitis is no more of a risk to a cardiac baby than it is to a non cardiac

baby" and "yes we have been told that before and I will speak to the nurses about that". As I sat there I felt like getting up and walking out. He was being really obnoxious and still undermining the seriousness of my daughters condition. Then came the killer blow when he told me that my daughter wasn't that ill on the last occasion that she was admitted to hospital. She was subsequently put on the semi urgent operating list!

I'm left feeling "What was the point?". I am sure that parents caring for children with serious health complaints will continue to be subjected to this severe lack of understanding. At least I tried though!

Activities and Events

A Joint CHF & GUCH Teenage Weekend



Thanks to a substantial grant from Comic Relief, CHF have launched a Teenage Project to encourage young people aged 14-19 yrs old to come together, share experiences, make new friends and most importantly – have fun! Several CHF Member groups have organised Teenage Weekends previously which have been a roaring success, however, this was the first of it's kind for CHF in partnership with GUCH – Grown Up Congenital Hearts.

Twelve young people descended on the Outward Bound Centre in sleepy Ullswater in the Lake District to embark on a weekend of fun and friendship, some not quite knowing what to expect! Carol Davidson and Sharon Herzog from CHF and Paula Bandon and Paul Wilgoss (a grown up congenital heart participant) from GUCH were there to greet them and introduce them to their tutors for the weekend – Hamish and Re.

Many of the teenagers had not met before however within the first few hours – they chatted as if they were old friends and the fun began! An important part of the planning for this event was to ensure that the activities were suitable and appropriate for the young people and considered their individual needs and limitations, while also ensuring that each and every participant reached their potential and a sense of achievement. Orienteering and the tasks completed by the teenagers enabled the staff to gain a sense of this capability and set the pace for the weekend.

Fun, fun, fun was the agenda and the next day – after taking part in the cleaning rota of the centre (a bit of a shock for some!) – the group headed for the indoor climbing wall in Keswick where each and every teenager managed to climb up the wall, some with great ease and some with a little more persuasion

(for example, Sharon!). Well, how could the CHF and GUCH staff allow the teenagers to steal the limelight! After lunch the teenagers chose to go potholing at the centre and then were led on a 'night walk' where each person was blindfolded. This exercise, designed to build up trust amongst the group was very interesting and certainly brought out the personalities of each and every teenager.

The evening found everyone completing an exercise on the low ropes with a partner generating much amusement, followed by the high ropes the following day. For the teenagers who were a little apprehensive the previous day – these activities were very popular and by the end of the second day everyone had achieved a set goal and was having a great time. The finale of the weekend was a turn on the zip wire with teenagers flying through the air with the greatest of ease!

On a serious note – although the weekend did have an Outward Bound Theme, we did facilitate a very serious workshop looking at issues that face young people with heart conditions covering a wide variety of topics including adolescence, personal issues and growing up with a heart condition. This information from the young people themselves will be used to produce literature aimed at teenagers from both CHF and GUCH.

Transition and dealing with the needs of teenagers on their level has been a recurrent theme over the past few years



and it is hoped that bringing teenagers together in this atmosphere will increase independence, self esteem and most importantly self belief. Each teenager

achieved goals they had set for themselves in many different areas ranging from the daredevil activities at the Centre to travelling on a train independently and spending time away from home – a first for some of the group! Feedback from parents was excellent with one parent commenting that the weekend had helped to prepare her teenager for forthcoming surgery, as he was able to discuss his feelings with the group.

We are currently planning further teenage events throughout the UK. However, we would be very grateful for your input as well. Beauty Therapy weekends and City Breaks are amongst the current suggestions so please contact us with your ideas. Please contact Sharon Herzog or Carol Davidson with suggestions, venues and for further information:

Tel: 020 7820 8517.

Carol Davidson

Lapland 2004

Seventeen of CHF's member groups were once again invited to nominate one child and one parent, to take part in this year's Lapland Trip. CHF Trustee and Down's Heart Group Chair Cliff Lake was this year's Group Leader and Irwyn McKibbin, CHF Trustee and Heartbeat Chair acted as Deputy Group Leader. This year's Medical Team were Dr Neil Patel and cardiac liaison nurse Kathleen O'Kane, from Yorkhill Hospital. I am extremely grateful to all of them, for giving up their precious free time just before Christmas!

20th December 2004

Families were invited to gather for a meal at the Gatwick Worth Hotel the night before the trip. This gives the families, Group Leaders and Medical Staff a little time to get to know each other. It also ensures that all the travellers are in the same place and not floating around the country!

The Gatwick Worth, once again, provided us with a wonderful meal. We had three special guests – Rosie and Barry Jones, who are organising a Charity Golf Day for us and Kit Symons, the Assistant Manager at Crystal Palace Football Club. After dinner, Kit and Rosie gave goody-

bags filled with presents to all the children, including the brothers and sisters of those actually travelling to Lapland.

21st December 2004



Daniel meets Father Christmas

After an early alarm call at 4.30 am., the travellers met in the restaurant for a light breakfast then it was into the coach and off to Gatwick.

From the reports I received from both children and adults, everyone seemed to enjoy the day immensely. There were reindeer rides on Santa's own reindeer, sleigh rides with a husky dog team, lots of playing and fun in the snow, and of course the main attraction, meeting Father Christmas himself! One parent recalls –

"The snowmobile dropped us in the heart of the woods and we walked along a candlelit trail to a log cabin. One of the

elves opened the door, in we boldly walked and there he was.....the real Santa, sitting, smiling and greeting everyone by name!"

All in all everyone seemed to have a very magical and memorable day. One mum summed it up saying " We had a fantastic time – it was something that will stay in our memories forever! "

All to soon it was time to board the bus back to the airport to start the journey home again. Two CHF staff met the party at Gatwick Airport that evening and took several very tired children (and adults!) back to the hotel.

22nd December 2004

After getting up and having breakfast at a more reasonable hour, families took the opportunity to exchange names and addresses with the new friends that they had made. I took this opportunity to talk to the families about their experience, what they enjoyed best etc. I have asked all the families to send me a written piece about their day. This I hope, along with photos and pictures, can be turned into a 'newsletter'. This year's families can keep it as a memento and next year's families can see exactly what is in store for them!

Sharon Herzog

Fundraising News

Tony Norman walks from coast-to-coast in April 2005



Photo courtesy of www.sporting-heroes.net

April will see Tony Norman, Goalkeeper for Sunderland FC from 1988-1995, putting on his boots for the Children's Heart Federation.

But this time they won't be football boots, they'll be his walking boots as he walks the 190 miles

from St Bees Head across mountainous terrain to Robin Hood's Bay in the east in order to raise funds for our work.

(Tony is pictured during the 1-0 win against Norwich City on 5/4/1992 in the semi-final of the F.A Cup)

HSBC Walks

Walking seems to be the theme this month because this Spring staff from many of their branches will be organising sponsored walks in aid of the Children's Heart Federation. They'd like lots of Heart families to join them, don't worry they're not expecting you to do the walk (although you can if you would like to) – so if you would like details of a walk near you call The CHF Office on 020 7820 8517.

We're really grateful to all the HSBC walkers who are prepared to risk getting blisters in order to support our work for Heart Children.

Golf at The Mere – 27th September 2005

Farouk Engineer the former Test cricketer who had a long and successful career with India as an outstanding wicket-keeper and batsman is hosting a celebrity golf-day at the champion standard golf-course in Knutsford Cheshire.

It will be a brilliant day with excellent golf, exciting company and wonderful food so if you would like information on how to join us all The CHF Office on 020 7820 8517.

Research & Treatment Update

National Patient Safety Agency

The NPSA are conducting a project investigating the risks associated with inaccurate prescribing, dispensing or administration of anticoagulant drugs. They have approached CHF in the hope of recruiting participants for this project, the ultimate aim of which is to reduce unintended harm taking place for people using anticoagulant drugs such as Warfarin and Heparin. One of the groups of people they are particularly interested in involving are those who give anticoagulants to someone else such as a mum/dad.

If you are interested in this project and would like to participate or find out more about it, please contact our helpline 0808 808 5000 or contact archanad@chfed.org.uk.

CONQOL Research

A quality of life measure for children with CHD

British Heart Foundation funded a project that was carried out by the BHF Care & Education Research Group at University of York to develop a questionnaire measuring health-related quality of life in children with congenital heart conditions, the ConQol.

The questionnaire is based on feedback received from interviews with children to ensure that it represents what they see as the important elements of health-related quality of life. It is aimed at children and young people aged between 8 and 16 years.

The measure can be used in a variety of different ways. For example, to assess whether children coming into units for care are experiencing problems in a particular area of their life. It can also be used for audit purposes to compare different treatment methods, or to investigate treatments and interventions and checking that these are meeting the needs of the patient.

The researchers that lead this work are currently discussing with BHF ways of disseminating the questionnaire and manuals to paediatric cardiology centres across the UK. Electronic copies of the Users Guide, Manual and the questionnaires can be downloaded from <http://www.cardiacrehabilitation.org.uk/conqol.htm>.

Dates for the Diary

- Council Meetings 23/04/05
- AGM 01/10/05
- HSBC Walks April – May 05
- Golf Day 27/9/05
- CHF Conference 01/10/05

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

Association for Children with Heart Disorders
26 Elizabeth Drive
Helmshore
Rossendale
BB4 4JB
01706 213632

Association for Children with Heart Disorders (Scotland)
7 Park View
North Donside Road
Bridge of Don
Aberdeen
AB23 8DF
01224 702963

Cardiomyopathy Association
40 The Metro Centre
Tolpits Lane
Watford WD1 8SB
Herts
0800 0181 024

Children's Heart Unit Fund
Freeman Hospital
Newcastle on Tyne
NE7 7DN
0191 213 1365

Down's Heart Group
17 Cantilupe Close
Eaton Bray
Dunstable
LU6 2EA
0845 166 8061

Evelina Children's Heart Organisation
204 St James's Road
Bermondsey
London
SE1 5LN
020 7237 1745

Grown Up Congenital Heart Patient's Association (GUCH)
75 Tuddenham Avenue
Ipswich
Suffolk IP24 2HG
0800 854 759

Heartbeat
9 Turloughs Hill
Annalong
Newry
BT34 4XD

Heart Children Ireland
The Carmichael Centre
North Brunswick Street
Dublin 7
Ireland
00 3531 874 0990

Heart Transplant Families Together
36 Guildford Rd
Worthing
West Sussex
BN14 7LL

HeartLine Association
Community Link
Surrey Heath House
Knoll Road
Camberley
GU15 3HH
01276 707636

HeartLink
33 Windsor Avenue
Groby
Leicester
LE6 0YF
0500 382152

Little Heart Matters
11 Greenfield Crescent
Edgebaston
Birmingham
B15 3AU
0121 455 8982

Max Appeal
13 Meriden Avenue
Woolaston
Stourbridge
DY8 4QN
Tel: 01384 821227

South West Children's Heart Circle
17 Cynder Way
Badminton Park
Downend
Bristol
BS16 7BT
0117 956 3181

Wessex Children's Heart Circle
81 Goodacre
Orton Goldhay
Peterborough
PE2 5LZ
01733 238643

Young at Heart
5 Orchard Close
Handsworth
Birmingham
B21 9PH
Tel: 0121 523 7840

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