2006/2007 ANNUAL REVIEW

LEADING THE WAY FOR HEART CHILDREN

children's heart FEDERATION

Who We Are

The Children's Heart Federation is a national charity and the umbrella body for voluntary organisations working to meet the needs of children and young people with congenital heart conditions and their families. Our vision is of a society where all children with heart conditions have both their medical and social needs met so that they can live life to the full.

Our Member Groups are based throughout the UK and Ireland. Some work with children being treated at a particular paediatric cardiac unit whilst others work with children with particular conditions. Our network of members is growing every year and currently includes: The Barth Syndrome Trust, The Brompton Fountain, Cardiomyopathy Association, Children's Heart Association, Children's Heart Unit Fund, CRY, Down's Heart Group, Evelina Children's Heart Organisation (ECHO), GIFT, Grown Up Congenital Heart Patients Association (GUCH), Heartbeat, Heart Children Ireland, HeartLine Association, HeartLink, Little Hearts Matter, Max Appeal, The Scottish Association for Children with Heart Disorders, South West Children's Heart Circle, Tiny Tickers, Wessex Children's Heart Circle, Young at Heart and Young Hearts.

The Children's Heart Federation was registered with the Charity Commission in 1988. The charity is run on a day-to-day basis by our Chief Executive, Anne Keatley-Clarke and we are administered and managed by a Board of Trustees: Chris Bowser, Irwyn McKibbin, Richard Preedy (Treasurer), Janet Rathburn, Chris Stringfellow and Julie Wooton (Chair).

www.chfed.org.uk

Welcome to the Children's Heart Federation Annual Review 2006/7

It has been another busy and successful year for the Children's Heart Federation. The move to new offices in central London has been a great success and enabled us to make a number of important new appointments. We have also been able to start doing all our fundraising in-house which has significantly reduced our fundraising costs.

We are very pleased by the progress we have made during the last year and excited about our goals for the coming year. First and foremost we are there for the parents of heart children but we are doing increasing amounts of work with children and young people and we are also in frequent contact with medical professionals, teachers, grand parents and many other people who have a connection with a heart child.

Our first hand knowledge and expertise makes us the ideal voluntary sector partner to advise health and social care providers on how the needs of children with heart conditions should be met. In the past year we have worked with many different organisations including NICE, the Department of Health and a number of charities.

Sadly, it is not all good news. There are a growing number of applications for our emergency grant programme and for the INR (blood monitoring) machines that we provide for children and we are struggling to help all the families who apply to us. You can read more about the work we do and the assistance we provide in the following pages. If you think you or your company might be able to help us to help more heart children, please do get in touch.

Anne Keatley-Clarke
Chief Executive

Julie Wootton
Chair

Our Mission

We aim to provide support and information to children with heart conditions and their families.

We do this by:

Producing a range of fact sheets and different resources to better inform people about congenital and acquired heart disease

Providing a free infoline to support and empower the parents of heart children

Campaigning to improve the clinical and social care of those affected by congenital and acquired heart disease

Supporting our member groups and helping them to grow and develop

Organising short breaks to brighten the lives of heart children and their families

Making grants to families who are struggling to pay for the medical equipment and support they need

Working in partnership with statutory bodies and with other organisations such as the Department of Health, the British Heart Foundation and the Royal College of Nursing

Some Statistics

Heart defects are the most common birth defect, and a leading cause of birth-defect related deaths world-wide. In the UK, one in every 133 babies is born with a heart condition, a total of about 5,000 babies a year. Over 70% of those babies are only diagnosed after birth. Every year, a further 500 to 1,000 children develop heart conditions after birth.

www.chfed.org.uk

Thanks to You...

During the last year, your support has enabled us to:

Launch "Overcoming Obstacles" a new booklet to tell parents about the non-medical support available for heart children

Organise trips for heart children and their families to Lapland, the Lake District and Chester Zoo.

Hold a successful conference "Supporting the Growing Heart Child" in Peterborough

Develop our website so that by the end of the year over 2000 fact sheets were being downloaded from it every month

Give over **65** children a Molly's Dolly which had a scar in the same place as their new owner, helping these children come to terms with their treatment, scar and self-image

Provide over **80** children with specialist medical equipment so that they could spend less time in hospital and more time at home

Support Children's Heart Federation member groups and enable their voices to be heard at a national level

Extend our awareness raising work with black and minority ethnic groups and appoint our first Diversity Officer

Raise awareness of congenital heart conditions by delivering talks to student nurses

Produce 3 issues of our free newsletter for parents, nurses and cardiologists.

Children's Heart Awareness Week

This year we held a special event at the Headquarters of the Magic Circle bringing together heart children, their parents and professionals. The children practised their magic skills and met top magician Fay Presto, while the adults heard from a speakers including lawyer, David Ruebain who is internationally recognised for his work in fighting for the rights of individuals with special needs and whose department has been repeatedly ranked number one in the area of Education Law.

Supporting Families

The Children's Heart Federation supports children with heart conditions and their families in many different ways. More people than ever before are visiting our website to download our free fact sheets and information booklets. We also send out a free newsletter to parents and health professionals all over the country giving them news about our work, updates on the latest research developments as well as lots of other fun and topical articles. Parents can also call our free infoline for help and information and every week we respond to dozens of e-mails from parents, teachers, nurses and many others.

We offer financial support too and medical equipment, although we are struggling to meet the demands for these services. Organising family breaks is another important part of what we do and we are hugely grateful to all the donors who help to make these possible. Below are some examples of the children and young people we have been able to help in the past year.

Chloe

Chloe is 14 and takes warfarin, an anticoagulant drug which helps her blood to flow easily and prevents clots from forming. To check that Chloe is getting the correct dose of warfarin, she has to have frequent tests to measure how long it takes for a drop of her blood to clot. This test is done using an INR machine and until recently Chloe spent a lot of time travelling to and waiting for appointments at her local surgery to have her tests. Thanks to Children's Heart Federation, Chloe now has her own machine and can do the tests as often as necessary and at a time that suits her.

> ***"Having an INR machine has made life a lot easier as I do not have to go to the doctors all the time. I've watched the doctors doing the test loads of times so it was easy to learn how to do it myself."***
>
> **Chloe**

Harry

Just minutes after he was born Harry stopped breathing and had to be resuscitated. Doctors discovered that he had four different heart defects and would need several operations. During the next two years Harry spent more time in hospital than at home. Harry's parents contacted the Children's Heart Federation to find out more about his condition and the treatment options available. We gave them the information they needed and also put them in touch with other heart families. Being able to talk to other parents who know what they are going through has really helped.

> ***"We have learned to live one day at a time and to make the most of each precious moment with him."***
>
> **Harry's Dad**

Olivia

Olivia is 5 years old and was born with a single ventricle condition – Mitral Atresia. Olivia had two operations when she was younger and has recently begun to notice her chest scar and ask questions about why it is there. Her parents are trying to be honest with Olivia without giving her too much information. However Olivia will have her third heart operation within the next year so we sent Olivia one of our Molly's dollies. The doll has a scar just like Olivia's and comes with advice on how to explain about scars and prepare Olivia for her next operation.

> ***"I would like to say thank you so much on behalf of my daughter Olivia for sending her a Molly's Dolly. We are delighted with her and I am sure she will be a great benefit through Olivia's next heart surgery."***
>
> **Olivia's Mum**

The Figures

Balance Sheet as at 31 May

	Note	2007 £	2007 £	2006 £	2006 £
Tangible Assets					
Tangible Fixed Assets	1d, 6		23,052		6,390
Current Assets					
Debtors	7	8,904		5,713	
Cash at bank and in hand		170,791		256,432	
		179,695		262,145	
Creditors					
Amounts falling due within one year	8	23,220		46,748	
Net Current Assets			156,475		215,397
Total assets less current liabilities			179,527		221,787
Funds					
Restricted	11		51,586		97,076
Unrestricted					
Designated		—		57,533	
Other		127,941		67,178	
			127,941		124,711
Total			179,527		221,787

The summary information on these pages relating to the Statement of Financial Activities and Balance Sheet has been extracted from the statutory accounts. Copies of the full accounts are available on request from the Children's Heart Federation. The annual accounts were approved on 22nd September 2007. The annual report and accounts have been submitted to the Charity Commission.

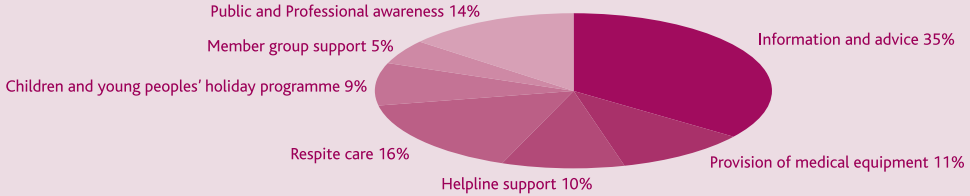
CAF Bank Ltd
Kings Hill
West Malling
Kent
ME19 4TA

HSBC Bank
281 Chiswick High Road
London
W4 4HJ

Sheen Strickland
Chartered Accountants
Registered Auditors
7 East Pallant
Chichester
West Sussex
PO19 1TR

	Note	Year ended 31 May 2007 Unrestricted Funds £	Restricted Funds %	Total Funds £	2006 Total Funds %
Incoming Resources					
Incoming resources from generated funds	1b				
Voluntary Income					
Donations		400,804	54,575	455,379	369,256
Nominated Charity		156,394	—	156,394	200,000
Legacies		22,000	—	22,000	18,500
Investment Income		8,798		8,798	10,173
Total Incoming Resources		**587,996**	**54,575**	**642,571**	**597,929**
Resources Expended					
Costs of generating funds					
Costs of generating voluntary income	2	200,098	—	200,098	138,966
Charitable Activities	3	366,263	100,065	466,328	489,910
Governance Costs	4	18,405	—	18,405	8,650
Total resources expended		**584,766**	**100,065**	**684,831**	**637,526**
Net incoming/outgoing resources before transfers		3,230	(45,490)	(42,260)	(39,597)
Net movement in funds		**3,230**	**(45,490)**	**(42,260)**	**(39,597)**
Reconciliation of Funds					
Total funds brought forward		124,711	97,076	221,787	261,384
Total funds carried forward		**127,941**	**51,586**	**179,527**	**221,787**

Analysis of charitable expenditure to 31 May 2007



Family Breaks

Going Wild in the Lake District

In October, we organised another successful adventure week for young people with heart conditions. This time the group went to the Calvert Trust Centre in the Lake District where they were able to try activities like archery, climbing and abseiling. The centre has its own stables so they also went riding and learnt to drive traps. Everyone had a great time and enjoyed trying new things, sharing experiences and making new friends.

> ***"I have had a great time at the Calvert Trust. I enjoyed meeting new people and we all got on really well."***
>
> **Pavandeep, 16**

Meeting Santa in Lapland

Just before Christmas a group of very excited children and their carers set off to Lapland to meet Santa Claus. Well muffled up in special snow suits they went on sleigh rides, met huskies and reindeer and visited the beautiful Snow Castle. The real highlight of the trip though was the visit to Santa Claus, who welcomed every child by name and gave them a special present. Our thanks to everyone who helped to fund and organise this magical trip.

Family Fun at the Zoo

Having a child with a heart condition affects the whole family, including any brothers and sisters so it is good to give families the chance to meet and support each other. This year we took 44 children and their families to Chester where they enjoyed a two-night stay in a hotel and a trip to the world-famous Chester Zoo where the children got the chance to see a host of exotic animals. The day ended with a special dinner and goody bags of toys for all the children. We had lots of great feedback from the families and we would like to thank the Redrow Foundation for funding this wonderful break.

The Year Ahead

During the coming year we plan to:

Promote better services for heart children and their families by

- Working with Paediatric Cardiac Units throughout the UK and Ireland
- Influencing developments in services for children by working closely with the Department of Health and Professional Groups
- Expanding the reach of our Information Service including re-writing our fact sheets and getting many of them Crystal Marked

Assist our member Groups to develop strong voices and services by

- Organising a Federation Day with speakers and workshops tailored to the needs of our members
- Recruiting new Groups to the Federation to expand our knowledge and experience
- Using Children's Heart Week 2008 to continue to draw attention to the needs of heart children

Supporting individual children and their families by

- Expanding our Family Grant Programme so that more families in need benefit
- Providing more medical equipment to children and young people in need
- Giving more heart children and young people the opportunity to take part in trips

Strengthen our influence on policy making by

- Actively participating in national and regional policy groups
- Working closely with the media to ensure the voices of heart children and their families are heard by the general public

Thank you!

We would like to thank everyone who has supported our work during the past year. Our particular thanks go to the staff of George Wimpy who both made us one of their charities of the year.

During the last year we have been fortunate to receive particularly generous donations from the following companies:

Cedar Systems Ltd, Doughty Hanson & Co Ltd, Drager Medical U.K Ltd, Enterprise Rent-A-Car, G & B (North West) Ltd, John Menzies Plc, Kiln Group, Legal & General, Nottingham City Transport Ltd, Owl Optical Ltd, Russell Investment and Verbatim Ltd

Case Study: Redrow Foundation

This year Redrow Foundation sponsored our annual summer trip which saw 45 children and their parents enjoying a two night stay in Chester complete with evening entertainment and a trip to the world-famous Chester Zoo.

Sebastian Hare, Head of Fundraising at Children's Heart Federation, said: *"These breaks make a huge difference to the children and their families. Despite the wet weather all the families had a wonderful time in Chester. The children loved the zoo and their parents really enjoyed meeting one another and having the chance to talk and share experiences."*

The weekend was made possible thanks to a generous donation by the Redrow Foundation. Paul Pedley, Executive Deputy Chairman for Redrow plc and a trustee of the Foundation, said, *"The Redrow Foundation is honoured to support such a worthwhile charity."* Our thanks go to Redrow and all the families who helped make this a really memorable and fun weekend.

How Companies Can Support Us

The Childrens Heart Federation relies on the financial contributions from trusts, businesses and other organisations in order to carry out our work.

Here are some of the ways in which you might be able to help us:

- Make a donation towards our work and with Gift Aid we can add 28% at no extra cost to you
- Businesses and other organisations can support us through sponsorship, charity of the year partnerships and corporate social responsibility programmes
- Grant-making bodies can fund projects, positions and other aspects of our work
- Employees can raise money for us by taking part in sponsored events like the British 10k London Run

How your donation could help:

£1000 could pay for 200 families to receive all the information and support they need throughout the year

£10,000 could cover the cost of our summer family event

£30,000 could cover the costs of our annual trip to take children and their carers to Lapland to meet Father Christmas

£54,000 could cover the cost of running our free infoline for a year

Case Study: HSBC

A fantastic group of HSBC employees showed real team work when they travelled to America and ran the New York Marathon in aid of Children's Heart Federation.

How Individuals Can Support Us

The Children`s Heart Federation relies entirely on voluntary donations to continue our vital work. There are many ways in which you can help:

Here are some of the ways in which you might be able to help us:

- Make a one off donation
- Give regularly by setting up a direct debit
- Ask your company if they run a payroll giving scheme
- Consider leaving a legacy in your Will or donate in memory of someone
- Take part in a fundraising event such as a fun run or marathon
- Use a special occasion like a birthday or anniversary to ask people to donate money to us through celebratory gifts
- Become a volunteer with the Children's Heart Federation

How your donation could help:

£70 could pay for us to give a child on our Lapland trip a special Christmas stocking full of toys

£100 could enable us to make a grant towards travel costs to parents who may live many hours drive from the hospital where their child is being treated

£200 could buy a specially adapted buggy to help a child who cannot walk without becoming breathless to go on outings with their family

£600 could cover the cost of supplying specialist medical equipment to a heart child and training a family to use it, dramatically reducing the number of visits that child needs to make to hospital

Direct Debits are one of the best and simplest ways to help the Children's Heart Federation's on-going work. Monthly gifts provide the reliable income that we need to plan our projects effectively

www.chfed.org.uk

Thank You for Helping Heart Children!

First Name _____ Last Name _____

Company Name (if appropriate) _____

Address _____

_____ Post Code _____

Email _____ Telephone _____

REGULAR GIFT

I would like to give £5/10/15* other £_____ Monthly/Quarterly/Annually*

Please debit my account on the 1st/15th* of the month *(*delete as appropriate)*

Name on account:_____

Account number: ☐☐☐☐☐☐☐☐ Sort code: ☐☐ ☐☐ ☐☐

SINGLE GIFT

☐ Please accept my gift of £_____ ☐ I enclose a cheque for £

☐ Please take £_____ from my visa/master card/CAF Charity Card/Switch/Maestro

Card Number: ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐

Card expiry date: ☐☐ ☐☐ Issue date: ☐☐ ☐☐

Issue No. (Switch only): ☐☐☐ Card Security Code: ☐☐☐ (last 3 digits on signature strip)

Signature:_____ Date:_____

Leading the way for **Heart Children**

We may, from time to time, wish to keep you informed regarding the work of Children's Heart Federation. Please tick if you do not wish to receive such information ☐

DIRECT Debit

Please let me know if you qualify for or are interested in any of the following:

☐ Matched funding ☐ Payroll Giving

☐ Information on fundraising events ☐ Other ways in which I can help

giftaid it

Please treat my past, recent and future donation to the Children's Heart Federation since the 6th April 2001 as gift Aid donations*

Today's Date ____ /_____ /_____

Please complete both sides of this response card and return it to:
The Children's Heart Federation, 2-4 Great Eastern Street, London EC2A 3NW
Telephone: 0207 422 0630 Fax: 0207 247 2087
Freephone Infoline: 0808 808 5000 E-mail: info@chfed.org.uk

Childrens Heart Federation is a Registered Charity No: 1120557 and a registered company limited by guarantee in England & Wales No: 6329763

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