

Little Hearts Matter Newsletter

Winter 2009

Little Hearts Matter
Half a heart
...not half a life

Sports and Exercise



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'Lights of Love'

Come and see YOUR 'Lights of Love' this and every Christmas time on Sunday 6th December.



Our very own Little Hearts Matter 'Lights of Love' tree is now ready and we are counting down the days until the official lighting ceremony on Sunday 6th December, when your tree, festooned with little white lights will twinkle throughout the crisp winter darkness of December and into the New Year.

Although the tree lives here in the Midlands we hope that our very own 'Lights of Love' Christmas tree will become an annual focal point for you and your wider families from all across the UK.

Our aim is to fill your tree with bright white lights

every Christmas time. Your light or lights can represent remembrance, love, celebration, anniversaries, achievements, reflection and happiness or indeed anything you wish.

So the tree is ready, a date is fixed to turn on the lights, mince pies and mulled wine have been ordered as have the Brass Band and a few Christmas songs! Why not join Suzie and the rest of the team in the West Midlands on the 6th December at 4.30p.m. and help us turn on the lights; we would love to see you all there!

If you would like to come, please let us know on 0121 455 8982 or email info@lhm.org.uk or if

you would like to dedicate a light or lights we ask for a minimum donation of £5 per light. The annual income from the tree will help offset the cost of our vital service provision. Please help us to make your tree a real beacon of love this and every Christmas time.

You can reserve your light by sending a cheque payable to 'Little Hearts Matter' to the usual address or you can buy one online at www.justgiving.com/lhmlightsoflove. Don't forget to include your message which will be posted on the website and in a special dedication book.

NEWS

Suzie's News



Find it difficult to believe that Deb and I have both been working for Little Hearts Matter, formerly Left Heart Matters, for ten years.

As we look back we are astounded at how much growth the charity has undergone over that time. When we started we had less than 100 members and very few funds in those days, in fact it was a Lottery grant that had allowed the charity to employ staff for the first time.

Andrew Shaw, a Trustee parent, very kindly gave us a room at the back of his offices, from there we were able to build the first constant support system and begin to produce written information.

The Trustee team worked very hard to help Deb and I develop the volunteer support services and ultimately to open up the charity to all families affected by single ventricle heart disease in 2004. Every day brought new challenges but it also brought new families, families that Deb and I had an opportunity to get to know as we offered them help.

As we plan the work of 2010 we can predict that the membership family numbers will be above a thousand, that there will be 200 children over the age of ten learning to live with their heart condition. There is now a team of six in the office and over 40 volunteers spread throughout the country and we still have a very hard working team of Trustees.

Even though the charity has grown there is still a new challenge every day. There is still so much potential for the charity to grow. Families still need more support and information

services and we hope to provide new services for the children from age 5 to 10 before they take a place as a youth member. We hope there will be further growth of the filofax, education information and added medical explanations. We also hope to build the networks so that there is more support closer to home and also build on our reputation as the voice of single ventricle heart disease.

Ten years ago we relied on the support of members in so many ways, you provided the volunteer support line service and links between members. You also raised most of the funds that supported the charity's growth.

It is no different today. The challenges that await us in 2010 mean that we will need the support of all our members. If you have the time to offer your experience to support other families that could help us develop the network groups, if you would like to have a larger voice in the management of the charity or the national voice of the charity or you have ideas that will help with our urgent need to fundraise - do give us a ring.

I still feel privileged that my job allows me to get to know so many amazing families and it really is wonderful to get to know the children as they learn to voice their own needs. Thank you all for the last ten years. I look forward to many more.

Suzie Hutchinson
Chief Executive



Everyone at Little Hearts Matter would like to send warm wishes to all our members at this time of year. Please remember we are here. Love Suzie, Tina, Gwen, Kev, Jon and Debx



LHM In The Media

with
Emma Pelling
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0207 624 7533



Time seems to travel fast at LHM. The summer has flown by and as autumn approaches we've been busy preparing for a number of events and activities. As I'm writing this, many of you will be recovering from the Shugborough Run – 'On Your Marks for Little Hearts'. Central TV produced a fantastic piece for us on the eve of the run with Will Goodenough and his friends who were running on his behalf. We were delighted to get such a positive piece which really communicated the work of the charity to thousands in the region. Many thanks to Will and his friends and to his school – Pershore High School – for hosting the film crew!

During the summer a few of our young people were invited as special guests to Birmingham City Football Club to meet one of the players. It was a great opportunity and also opened up links with this premier league club – we even met Karren Brady in the reception area who was delighted to see us! The pictures taken on the day were picked up well by the regional media.

Work is currently taking place with the launch of the new Zipper Zone website. Journalists are interested in speaking to our young people about the site and their views on living with their heart condition.

As we approach Christmas journalists are on the look-out for stories so please do contact me if you would like to tell your story on behalf of the charity. As you know, I'm always happy to hear from you!

Emma



Barry Ferguson, Blues Midfielder paid a visit to St Andrew's to meet some of our young members.



Just Giving

It is great to announce that this month you have all reached a fantastic milestone.

Since we started to use the services of Just Giving you have raised over £100,000 - yes **ONE HUNDRED THOUSAND POUNDS** plus gift aid.

That money has helped your charity to provide so much for so many people. Thank you to all of you who have used this service.

It makes fundraising so much easier. Go on, have a look at www.justgiving.com or go to one of our current pages such as www.justgiving.com/lhlightslove

Congratulations



We would like to pass on our best wishes to Isabel, David, Matthew and Rachel Baumber on the birth of their son and baby brother, Thomas. Isabel is a Trustee of the charity and the Chair of the Information Service group. David is Treasurer and Trustee of Little Hearts Matter.

We would also like to congratulate Lindsey, Paul and Thomas Hooks on the birth of their son and baby brother, Samuel. Lindsey has been a member of our Information Service group for many years.



Competition Winners

Thank you to all the children who sent in their drawings of a hospital appointment. The three lucky winners were

Lucy White
Age 4



Olivia Smith
Age 7



Calum Hamilton
Age 9



MAKE-A-WISH

Granting magical wishes to children and young people fighting life-threatening illnesses.

If you would like a wish to come true for your child please contact them.

website: www.make-a-wish.org.uk/
telephone: 01276 405060
email: info@make-a-wish.org.uk

Fundraising Idea Yellow Moon

Many of you will be aware of the Yellow Moon catalogue company who sell thousands of Arts and Crafts products for both the young and not so young. Yellow Moon gives a donation of up to 25% of the purchase price on any order you may place to us.

Why not take a look at their catalogue at www.yellowmoon.org.uk

Should you decide to order please quote Source Code **SLI 12789** on your order form.



Medical

The article below looks at sport and exercise for children with single ventricle heart disease.

Written by
Lynne Kendall
Clinical Specialist Physiotherapist Congenital Cardiology
Leeds General Infirmary



Is it safe for children and young people with single ventricle heart conditions to exercise?

Absolutely Yes! There are very few people who will be advised not to do **any** exercise at all. Your cardiologist will tell you what you can do and if there is anything you are better to avoid. Everyone is different so you must get individual advice about your own heart problem.

How much exercise?

Everyone (yes that does mean you too) should try to do **regular** physical activity. It may be that you have symptoms, such as breathlessness, from your heart problem that limit the amount of activity you can do, that is okay, just do what you can but at your own pace and your own level.

A really good guide to how much activity you should do is the '**Talk Test**', you should apply this to all activities/sports/play that you do. You should always be able to talk when doing any activity even when you are a bit 'puffed'.

If you have enough breath to sing then you need to put a bit more effort in, but if you are too breathless to talk you need to **STOP** and **REST** until you can speak again! You are much better to stop and rest **BEFORE** you get to this point though as it is not good for your heart to work so hard. Try to learn to 'pace' yourself and recognise when you are exercising at the right level.

Current public health guidelines for children¹, which apply to everyone including those people with medical conditions, recommend a daily total of 60 minutes moderate intensity physical activity on most days of the week. Now, before you all yell 'no

way!!' please read on:

- ♥ For children with single ventricle (or any congenital heart disorder) the daily total of 60 minutes can be 'collected' in 10-15 minute periods throughout the day if necessary.
- ♥ 'Moderate intensity' means enough to make you breathe harder (feel a bit 'puffed') and feel warm, this may happen at quite a low level of activity but this is okay as long as it is more than YOU normally do.
- ♥ 'Most days' means at least five times a week; it is very important to exercise regularly to feel the benefits; now and again is just not good enough!

What kind of sports/activities are okay and what is it better to avoid?

You probably need to think about the **type** of sports/activity that you do, especially if you are a bit breathless and/or are taking medicines such as Warfarin, because some activities are better than others for people with heart problems.

How **much** you can do depends on your own heart problem and how well your heart functions during exercise (your cardiologist can tell you more about this).

It is important that you exercise but it is important to stay safe too; this means choosing activities that you enjoy but maybe avoiding some things which could make your heart too tired.

- It is usually better to avoid the really strenuous team sports or competitions where you have to race against other people as these will make your heart work too hard. For example,

activities such as basketball, triathlon, competitive level swimming or cycling, distance running.

- Sports where you can get badly knocked or pushed over are generally not a good idea, especially if you take medicines such as Warfarin or if you have a pacemaker, for example, hockey, rugby, football, judo.
- If you have symptoms such as dizziness or fainting then avoid water-based activities; horse riding; motor sports; climbing etc where a fall could be very harmful.

It might help to think about what exercise involves:

There are two basic types of exercise called isotonic and isometric. Most activities will involve a bit of both but there are some important points to think about when choosing an activity/sport:

1. Isotonic exercise (may also be called dynamic or cardiovascular exercise).

This type of exercise includes things like swimming, cycling, walking and dancing. This type of exercise is generally better for people with congenital heart problems as long as you remember to **always use the 'Talk Test'** as a guide to how much you can do and when to rest.

2. Isometric exercise (may also be called static, weight or resistance exercise).

This includes exercise often using weights and

REFERENCES

1. NICE public health guidance Jan 2009; PH17

Promoting physical activity for children and young people: www.nice.org.uk/PH17

2. Pelliccia A, Fagard R, Bjornstad HH, Anastassakis A, Arbustini E, Assanelli D, Biffi A, et al. (2005).

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disease: A consensus document from the study group of sports cardiology of the working group of cardiac rehabilitation and exercise physiology and the working group of myocardial and pericardial diseases of the European society of cardiology.

European Heart Journal 26: 1422-1445.

3. Hirth A, Reybrouck T, Bjarnason-Wehrens B, Lawrenz W, Hoffman A. (2006).

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4. Graham TP, Driscoll DJ, Gersony WM, Newburger JW, Rocchini A, Towbin JA. (2005). 36th Bethesda Conference:

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Task force 2: Congenital heart disease. J Am Coll Cardiol 45: 1326 - 1333.





machines, such as weight-lifting, some athletics throwing events and gym equipment. Others include: rock-climbing, boxing, some martial arts, rowing/canoeing. Some people may be advised against some of this type of exercise because it may put more of a strain on the heart and blood vessels; others may be able to do some of them but at a low level of intensity. Always ask if you are not sure.

Remember, you do not have to be 'sporty' or athletic, or join a gym, or play for a school team, in order to take part in physical activity/exercise. Walking your dog, drama groups, using a Wii sports/fit, or dancing to your favourite music for example can be excellent exercise. If you do enjoy sport that is okay, but if you don't it really does not matter, just find another way to keep active doing something **you** enjoy. Any activity is better than none at all!

What about PE and sports at school?

Young people should be encouraged to take part in physical activity at school at their own pace and within their own limitations. This may mean the school making modifications to lesson plans for individual pupils to allow them for example to take part fully in skills and rules teaching sessions, but during strenuous activity finding an alternative for young people (maybe help with coaching, or recording/timekeeping duties) to keep them included with their peer group as much as possible. It is important that schools are provided with up-to-

date information about individual's heart conditions and given detailed guidance for, or limitations to, physical activity; parents can ask their cardiologist/liaison nurse for help with this.

General advice

If there are any concerns about physical activity and exercise then always ask your cardiologist and/or cardiac liaison nurse or congenital cardiac physiotherapist for individual guidance and advice; remember everyone is different and heart conditions may change so always ask about exercise at clinic appointments and ring or write if queries come up in between appointments.

Any new or unusual symptoms during, or immediately following exercise should always prompt you to stop and rest and if they do not resolve then report them to your doctor. It is 'normal' and indeed recommended to feel warm, breathe harder and feel your heart beat faster during exercise. You should stop to rest if you feel dizzy or faint; feel unwell in any way; or become unusually breathless.

There are both European^{2,3} and American^{4,5} guidelines which are the consensus opinions of worldwide expert congenital cardiologists. They mainly refer to competitive sports participation but provide a useful benchmark for reference; they have recently been revisited comparing the different guidelines⁶. However, it is essential that patients always discuss their exercise participation with their own cardiologist as clinicians may have different opinions on patient management.

What is becoming increasingly evident from research in the adult congenital cardiac population is that exercise intolerance is not uncommon in this patient group. The reasons for this are multifactorial but some non-clinical problems arising from childhood include: fears or misconceptions about the nature/severity of the cardiac defect; lack of information or understanding about the condition and exercise; relatives/teachers either preventing the child from doing any, or unnecessarily limiting exercise; some teachers pushing the child to do more exercise than safe/recommended for their condition; misunderstanding between (perceived) cardiac symptoms and lack of fitness.

We should all try to promote 'healthy living' for this patient group and provide timely, detailed individual information regarding exercise.

KEY POINTS

- Think about how much effort you put into your activity but always listen to your body, use the 'Talk Test' and stop to rest when tired.
- Remember, mainly dynamic (isotonic) is usually preferable to high static (isometric) exercise.
- Being short of breath when you exercise may be because you are unfit and not anything to do with your heart problem. Most people can do more than they think!

Alfie Yeoman



Our son Alfie was born with Hypoplastic Left Heart Syndrome 11 years ago. Although we have always been blessed with the fact that he came through all three stages of the Norwood Procedure very well, as he grew older it became apparent that he could not participate in full with any of the contact sports that his friends were playing.

It was whilst driving a golf buggy during a game of golf that his dad was playing in, that Alfie showed some interest. From this we decided to let Alfie have group lessons to see if he enjoyed the game or indeed showed any potential.

Over and above any expectations we could have had it became very obvious that Alfie had some extraordinary natural talent.

He has progressed to having two lessons a week. Joining his local course, Crowlands Heath, and participating in competitions generally held fortnightly.

He has participated in the Essex under 12 championship

for the last two years and more than held his own with two top 15 places.

Guided by the professional at his club, Marcus Radmore, we are all hoping he can fulfil his potential and hopefully become a professional in the future.

We have found that the sport offers Alfie a very healthy exercise and surroundings and obviously a sport that he can participate in despite his condition.

Janet Yeoman



5. Maron BJ, Chaitman BR, Ackerman MJ, et al. (2004).

Recommendations for physical activity and recreational sports participation for young patients with genetic cardiovascular diseases. *Circulation*; 109: 2807-2816.

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Feature

Safe and Sustainable Services

Children's Cardiac Surgery Services Review and Service Planning.

What this means for Little Hearts Matter's members.

"I am writing formally to request that the National Specialised Commissioning Group undertake a review of the provision of paediatric cardiac surgical services in England with a view to reconfiguration".

Professor Sir Bruce Keogh
NHS Medical Director

Little Hearts Matter has been involved with the work to improve congenital heart disease surgical services since the review and report compiled following the crisis at Bristol Children's Hospital in 1998.

The aims of the report and subsequent reviews and services recommendations have been discussed by cardiac teams throughout the country.

- Kennedy Report, 2001 (the Bristol Royal Infirmary inquiry).
- Paediatric and Congenital Cardiac Services

Review Group, 2003 (the Monro report).

- Professor Boyle and Dr Shribman workshop, 2006.

To date only a few of the recommendations made have been taken forward.

Minimum Standards

This was a nationally recognised set of surgical medical and care standards worked on by the British Congenital Cardiac Association, Congenital Cardiac Nurses Association, Children's Heart

Federation (LHM input) and the British Cardiac Society. These were supposed to form the basis of all audit and service improvements.

Central Cardiac Audit Database - CCAD

This is a national audit of surgical results that has, for the first time, allowed comparisons to be made between units. The results are available to professionals and the general public.

Unit's results are measured against the national standards and results are policed by the CCAD team and BCCA.

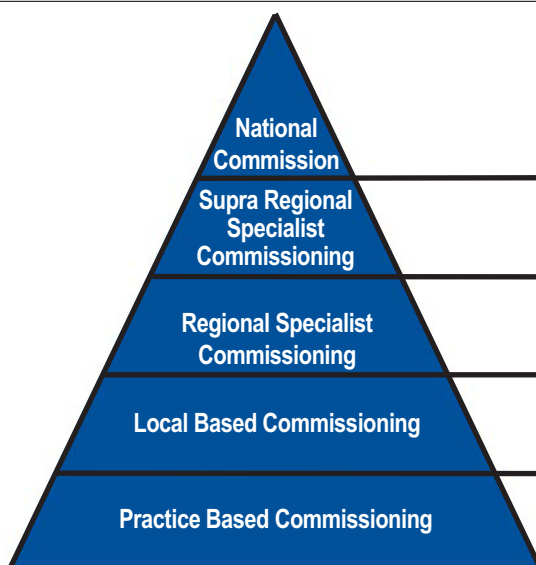
So why do national services need to be reviewed and surgical provision rationalised?

- Sub-specialisation is increasing. This means that there are more specialist doctors needed to provide top class care in each hospital team.
- Training and mentoring of doctors requires large centre experience.
- Working time legislation - European directive requires larger numbers of doctors.
- Critical mass of procedures - there is evidence that larger units, with lots of experience, provide higher surgical success rates.

Who are the review team?

- Children's Heart Federation - the voice of the user (LHM is one of the voices)
- British Congenital Cardiac Association
- Association of Cardiothoracic Anaesthetists
- Society for Cardiothoracic Surgery in Great Britain and Ireland
- Royal College of Paediatrics and Child Health
- Paediatric Intensive Care Society
- NHS Commissioners
- NHS in Scotland and Wales

How is the NHS medical service funded? - each team of commissioners budget for their area of work



Examples

- Transplants (not Renal) • Rare Cancer • Rare Neuro Muscular Disorder.
50 million people
- Paediatric Cardiac and Neuro-muscular Services • Severe Burns Care • Cleft Lip and Palate.
5 to 50 million people
- Children's and Young People's Cancer • Haemophilia • Renal Transplant
1 to 50 million people
- General Acute Medicine and Surgery
100,000 to 1 million people
- Minor Surgery • Endoscopies • District Nurses
100,000 people





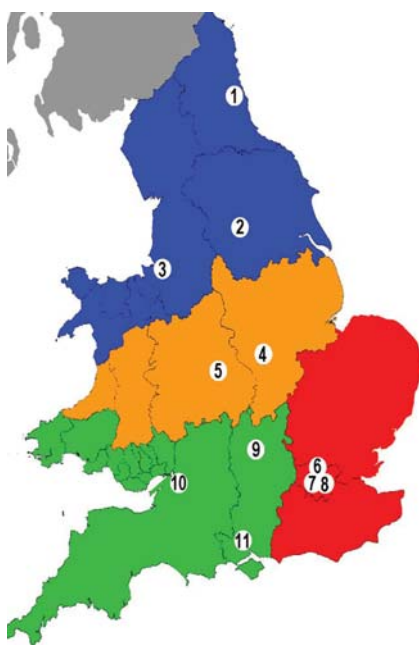
What are the aims of this review and the subsequent service recommendations?

- The NHS must provide only the very highest standard of care for children and their families, regardless of where they live or which hospital provides their care.
- A world class congenital cardiac surgical service.
- Centres should provide care that is based around the needs of the child and the family and which takes account of the transition to adult services.
- All relevant treatment other than surgery, including follow up, should be provided as locally as possible to the family.
- Clinical standards should be agreed and met by all centres.

It is important to remember that the centres offering surgery or specialised Cardiac Catheter treatment might change.

All other Cardiac Care will remain at centres spread throughout the country as they are now.

Where are the units situated now?



SCG Collaborative	NHS Trust
Northern Zone	1. The Newcastle-upon-Tyne Hospitals NHS Foundation Trust 2. Leeds Teaching Hospitals NHS Trust 3. Alder Hey Children's NHS Foundation Trust
Midlands Zone	4. University Hospitals of Leicester NHS Trust 5. Birmingham Children's Hospital NHS Foundation Trust
South Eastern Zone	6. Great Ormond Street Hospital for Children NHS Trust 7. Royal Brompton and Harefield NHS Trust 8. Guy's and St Thomas' NHS Foundation Trust
South Western Zone	9. Oxford Radcliffe Hospital NHS Trust 10. University Hospitals Bristol NHS Foundation Trust 11. Southampton University Hospitals NHS Trust

Currently there are 11 Congenital Paediatric Cardiac Surgery centres in England. There are 30 surgeons working between them doing some 3,800 procedures.

What does the review and recommendations mean for users?

That there will be 30 plus surgeons doing over 3,800 operations per year in centres that can offer the **highest** level of surgical treatment, the best ITU care and ongoing medical support for all children and well informed cardiac and general health support closer to home.

What happens next?

Draft standards circulated for comment	Sept 2009
National stakeholder event	Oct 2009
Final version of standards circulated	Nov 2009
Assessment of centres against standards	Jan 2010
SCG's submit recommendations	July 2010
NHS Management Board considers recommendations	July 2010
Public consultation begins	Sept 2010
Implementation of recommendations	Jan 2011

Formulate Standards

1. Network approach
2. Prenatal screening
3. Making choices
4. Patient and family experience
5. Access to services
6. Age appropriate care
7. Excellent care
8. Team delivered
9. Safe and Sustainable services

The LHM team will keep you informed throughout the process.





Fundraising



Did anyone notice summer happening? Did anyone have lovely BBQ's every weekend!! No, I didn't either but lots did happen during the summer and loads of you helped me to raise the funds for everyone to receive services that they need, when they need them and for free too!

Like everyone else LHM has not been immune from the credit crunch and at times we have struggled to raise the £25,000 that is needed every month to carry out our work for you all. So with that as a background where do I get my motivation from?

Well it's you and your children who motivate me on a daily basis. Whenever I meet with the children as I did at Birmingham City Football Club recently I am in awe of their determination not to let their heart condition get in the way of living a full and as active a life as possible. They are amazing kids who receive so much support from you the mums, dads and families. It's great being in your company.

Kev's News



Then of course there are those of you who step forward and really do help us to help everyone by organising a fundraiser or taking part in one of the ideas that I put in the fundraising pack or on our website or by opening a door for us to get to businesses or by finding a location for a clothing bin for me...

These members inspire me all the time and that's why we introduced the Inspirational Fundraiser of the Month Award to recognise someone doing something a bit special for us all. And you too can see that motivation on the website and throughout this and every edition of the newsletter. Every day I speak to or hear from

members and their families who have joined with me to help raise the income that we need to keep going and more importantly to respond to your needs and expand our services where needed.

So thank you to everyone again for your support and thank you also to the children who have written to me over the past few months and who have become involved in fundraising. It's a pleasure to be involved with you all.

Oh and thank you to those who supported my 100 mile personal walkaround during September. You are a great reason and I had great fun doing it for you.

Website - please join with others and have a look at the Fundraising pages and do try and get involved. Your support can in many ways help us achieve our aims for this and next year.

On Your Marks for Little Hearts - thank you to all of you who turned up and supported our third run at Shugborough Hall. It was great to see so many of you and great to get the chance to talk.

Can I ask if you have raised sponsorship money, that you get it to us before Christmas.

Finally and as always, it is so difficult to feature everyone in the newsletter or on the website, I do try but please accept my apologies if your story does not feature. It does not make your efforts any less important.

Best wishes for a lovely time this Christmas and thank you for making work so worthwhile.

Kev Bazeley
Fundraising Manager
kevin@lhm.org.uk

Three Men in a Boat

Three intrepid fundraisers Andy Hey with mates Denis O'Mahoney and Mike Shun under the name of 'Three Men in a Boat' took on the high seas, well the River Thames, from the 5th to 11th July and rowed the 92 miles from Richmond Bridge in London to Oxford and all to raise funds to help all the families supported by Little Hearts Matter.

A great supporter of ours, Andy says when asked why he helps us.

"Why? you may ask. Indeed, we asked that of ourselves... The reality is the



friendship, the fun, the challenge and the opportunity of raising a HUGE amount of money for a very special charity."

Well they did, Andy and his team and of course his supporters have raised well over £14,000 from this adventure alone!

Well done and a LHM hug to everyone involved in this tremendous effort.

A Very Special Lady

We had a lovely letter from Charlie and William Jones from Stithians in Cornwall telling us all about their wonderful Great Nan Mary who sadly passed away in March.

Much loved Great Nana Mary, pictured with the boys played a huge part in their lives and they, family and friends gave a very generous donation in her memory, a donation that will help us to support other families just like theirs.

Thank you boys and thank you Mary.





Wonderful Bikers

Samantha and Robert Todd literally got on their bikes to help raise funds for us all recently when they rode the 69 miles from St David's to Aberystwyth and raised £483. It took them 6 hours and 10 minutes. Thanks guys that's brilliant

Another wonderful mum who has taken to the road for us is Donna Cornock who lives in Scotland.

Donna rode from Lanarkshire to Leeds, that's over 200 miles and in memory of her little boy Jack has raised over £2000 for us this year.

Donna tells Kev that she gets so much from



being able to help other mums and dads and in Jack's name.

Thank you Donna, you are a true inspiration.

Edward Shaw's Aunty, Lisa Marshall and her family who live on the London to Brighton Bike Ride route set up a refreshment stall at the side of the road for us and selling pancakes raised a wonderful £150.

Thanks Lisa



Junior Triathlon



Three sporty schoolgirls put on their running shoes... and got on their bikes... and made a splash at the swimming pool to raise money for LHM! Pictured from left to right, Kathryn Morris (11), Kate Rodway (11) Rachel Morris (9) decided to do a sponsored junior triathlon for Little Hearts Matter and raised a whopping £174.61 in the process. They each ran for more than a mile, cycled around three miles and swam 160 metres. The girls, from Marshfield, Cardiff, are neighbours of Charlie Turner, who has HLHS, and wanted to do something to help children like him, who are born with only half a working heart. Thank you girls, and well done!

Friends like these

Lucy McAllister is so lucky to have so many friends in her school in Ballycarry, Northern Ireland. They had great fun when they had a huge cookie bake and made delicious chocolate chip and raisin cookies. Wow, they sound so yummy.

And guess what they raised loads of money and appeared in the local paper!! Superstars - everyone of them.

Thanks kids you're just grrrrrrrrrrrrreat!



Shifnal Golf Club

Again, inspired by the work of LHM, Val Davies the Lady Captain at Shifnal Golf Club and her members have spent the year holding golf days, raffles, auctions etc and have donated over £5,000 to enable us to offer further services to all our families.

Val tells me that they are all so proud to have helped so many children. Val, we at Little Hearts Matter are proud to know you. Thank you so much.

Can your golf club top the efforts of Shifnal? Go on have a go



Murray takes the plunge!

Dad Murray Ratcliffe from Ayr, Scotland along with 20 colleagues from the Belhaven Brewery Group took their lives in their hands on 17th May when they leapt into space to raise vital funds.

Murray whose son Dylan is his inspiration has been behind a number of outstanding fundraising activities during the last year. This latest team effort has raised over £5,000.

A huge thank you to all at Belhaven Brewery Group for their wonderful and continued support.

Marks and Spencer

Encouraged by a member of staff, Lisa Haile, whose little girl Paige has HLHS every member of staff at the Erdington branch of M & S took part in raffles, bikeathons, wet T-shirt competition and dinners to raise over £5,000 for your charity.

Well done to Patrick at M & S and all who supported Little Paige - Thank you

Over 60's Club



Great friends of John and Mandy Hands - the over 60's Club at Welford-on-Avon held a raffle and Strawberry tea and raised £60. Well done to you all. Kev says "Any chance of an invite next time - I love strawberries!"

Wacky Dress Down

Kathleen and Laura Galloway from Duneane Primary School whose little brother James has HLHS joined with all their school mates to raise funds. The children held dress down and wacky hair days as well as a sportathon! There are only 35 children in the school and they managed to raise a staggering £800 for us.

Some of the children are pictured along with James' mum and LHM's Jaclyn McAllister receiving the cheque from some very proud children. Humbling isn't it!





Spotlight On...

In every issue we will feature articles where we will talk about different aspects of education and cover ideas about possible sources of financial support to help you.

Written by
Isabel Baumber

Please don't hesitate to contact the LHM office if you have any queries about any aspect of education. We currently have booklets published on 'Early Years and Infant School' and 'Junior School', which are available free of charge to members. Further publications about education are currently being written. We also have a Benefits Booklet, which covers a whole range of ideas.

We'd also be really pleased to hear about any other ideas members have.

Education

Developing a Healthcare Plan

Education is so vital to all children, and every parent will want to ensure that their child's heart condition does not become a barrier to them accessing a good education in order to move towards an independent fulfilled life as an adult.

In this first article, we are focusing on how to develop a healthcare plan. Every child with a single ventricle heart condition should have a healthcare plan in place in school. Some children need support with their education, however many manage very well in mainstream schools with some thoughtful adjustments to suit their needs. We will cover other aspects of education in future newsletters, such as how to access additional support if your child needs it.

A healthcare plan is a way of making sure that medical information about your child is available in an easily accessible and understandable format. It is a document held in school identifying the level of support your child needs throughout the day, signs and symptoms to look out for and what to do in an emergency. It should be written in non-medical language which can be

understood by a range of school staff. The healthcare plan should be used as a tool to help everyone to understand your child's needs.

When developing the plan, it can be a good idea to go through a typical school day and write down every aspect of care which your child needs which is different to their peers in any way. This section needs to include all the common challenges for the children within their day at school: ability to exercise, need for energy-filled snacks, coping in cold weather, concentration levels, homework, etc. The plan should also include information on your child's diagnosis, treatment plans, medication (and effects) plus any specific limitations your child may have. The plan should also set out the best course of action in the case of an emergency, for example:-

- if a child on anti-coagulation therapy should fall;
- if they become uncontrollably breathless;
- if they complain of chest pain.

What action should the school take?

Who should the school call?

It can be really helpful to have a laminated information card with a plan of the actions needed if a child falls ill in school. When displayed on the school office wall, the PE

department, the staff room and in any relevant classroom it allows school staff easy access to the emergency information. It is also useful to have the child's medical information available to take to hospital in the case of an emergency.

If other health or social teams are involved with a child's care it is important that they are able to add to any health plans or education plans. For example a physiotherapist may have exercises that could be incorporated into a PE lesson. Or a psychologist may advise that a supportive approach to hospital should be introduced into the classroom.

People who can help with writing your child's healthcare plan are the health visitor (for under 5s), the school nurse, your community nurse (if you have one) and your Cardiac Liaison Nurse. Once the healthcare plan is written, the health visitor or school nurse should then talk it through with the school staff, and provide any training necessary, such as administering medications.

Little Hearts Matter can provide you with sample healthcare plans used by other parents - you will of course need to remember that every child is different, but some of the formats and ideas used by other families may be helpful.

Benefits

Help with Hospital Costs

In this article we thought we would focus on costs associated with a stay in hospital. When your child is in hospital, there can be many extra expenses involved, such as car parking, not being able to cook your own meals, accommodation, travel, and of course for some people there may be a loss of earnings while they care for their child.

If you are finding it hard to cover these costs, the first person to talk to should be your Cardiac Liaison Nurse or the hospital's social worker, who should advise you about any hospital specific sources of funding. They will know whether there is currently money available and what the criteria are for applying. This is sometimes referred to as an emergency fund, and may be held by a local charity. Other hospitals may have money specifically to help with parking.

If your family is on a low income, and you know in advance about your child's hospital stay, you could approach either the Social Fund or the Family Fund.

The Social Fund gives various types of payments designed to help people on a low income with specific costs. The purpose of the fund is "to ease exceptional pressures on families". Community Care Grants may be applicable for families with disabled children e.g. costs of hospital visiting. Further information is available by visiting www.dwp.gov.uk then type 'guide to social fund' into the search box or you can contact your local Jobcentre Plus.

The Family Fund gives grants to low-income families to meet the additional needs of caring for a severely disabled child. The value of the grant depends on the items requested, family circumstances and the funding available. There is no entitlement to a grant from the Family Fund. Hospital visiting costs have been funded. Eligibility includes income related points (gross income less than £23,000 or £25,000 in Wales

and savings of £18,000 or less). Further information is available by telephone **0845 130 45 42** or from www.familyfund.org.uk

Families on income-related benefits should be in contact with the hospital benefit office to find out about help with travel costs to and from hospital appointments.

If you live in Scotland, you could try approaching Chest, Heart and Stroke Scotland, a charity which offers welfare grants e.g. for holidays, hospital visiting, heating, white goods. You will need a sponsor (e.g. health visitor) to apply on your behalf. Further information is available from www.chss.org.uk or telephone **0131 225 6963**.

If your family has private medical insurance which includes cover for your child (this isn't always possible, as many insurers will not cover pre-existing medical conditions), you can apply for a payment for each day that your child is being treated in an NHS hospital rather than being treated as a private patient.



Ask the Experts

Here we ask professionals to answer some of the common questions asked by our members.

Dr Oliver Stümper,
Consultant Paediatric Cardiologist
Birmingham Children's Hospital



I have been told my child has collaterals - what does this mean and how does it affect his treatment ?

Children who are born with complex congenital heart disease associated with a reduced blood flow to their lungs can sometimes develop collateral vessels.

What are collaterals?

If a baby is born with a malformation of the heart and a lack of blood flowing to the lungs to collect oxygen, the child will have low oxygen saturations (The amount of oxygen in their blood). They are cyanosed, (blue coloured lips and finger nails) and may be breathless on mild exercise or feeding.

Collaterals are connections, like normal blood vessels, that can develop in children with cyanotic heart disease.

There are two types of collaterals.

Systemic arterial collaterals

These abnormal vessels originate from the body blood vessels, in particular the aorta, and grow towards the lungs. They can form when a child has had a long period of cyanosis (blue lips and fingernails). The collaterals aim

to take more blood to the lungs where it can collect oxygen. This is the body's response to the long standing low oxygen saturations. These collaterals make the child less blue but create more work for the heart!

Systemic venous collaterals.

These are abnormal blood vessels that originate from the veins taking the blue blood back to the heart. They develop normally after the second operation, the Cavo Pulmonary shunt. After this operation the pressure in the veins in the upper body half is greater than the pressure in the lower body half. With that small veins can enlarge and can allow blue blood from the upper body to run down to the lower body rather than having to squeeze through the lungs. These collaterals make the child more blue, but do not increase the work for the heart.

How are collaterals diagnosed?

When children with single ventricle disorders undergo cardiac catheterization or MRI scanning investigations it is possible to clearly

see the collateral vessels. When there is a large collateral vessel it may be seen during a routine ECHO (echocardiography).

How are collaterals treated?

Once collateral vessels have been found the Cardiac team will assess if they need closing (occlusion). Small systemic arterial collaterals will normally disappear after the Fontan procedure has been performed. Large systemic arterial collaterals should normally be closed by a catheter procedure as they put strain on the heart and raise the pressure in the lung arteries. The child may be more cyanosed after this, and the Fontan operation may have to be performed earlier.

Large systemic venous collaterals in young children after Cavo Pulmonary shunt operation should be closed by catheter. This will make them less cyanosed, as more blue blood goes to the lungs, and frequently the Fontan operation can be delayed. Small systemic venous collaterals identified just before the Fontan operation can be ignored.

Lights of Love and Cards - Christmas 2009

2 New Christmas Fundraisers

Firstly, and a lovely new idea for 2009, is our Tree decorated with your Lights of Love.

As you know the idea is to give us all a collective focal point for Celebration, Remembrance, Happiness, Joy or any other emotion that you wish.

Every year and starting right now you are invited to purchase your own light or lights for a minimum donation of £5. Your lights of

love will shine on our tree throughout the Christmas period. You can of course make a larger donation if you wish.

Your Light(s) of Love will be switched on at 6p.m. on the 6th December 2009 and will shine right through until the 12th day of Christmas.

To purchase your light of love you can visit www.justgiving.com/lhmlightsoflove where you can see messages already left by others. Or you can complete the form enclosed with this

newsletter.

Our second new idea is the alternative christmas card which you should already have received. They are designed for the office wall or classroom. They invite people to write their Christmas greetings on the card and pay a fee for doing so - you set the fee as you see fit - simple idea, you raise funds for LHM and everyone saves time.

If you would like some more please contact the office.





Personal Story

Below Kay and Colbie-Kate Ross share their story.

Written by
Kay & Colbie-Kate Ross

Well, here we are two days before Colbie-Kate's 7th birthday, we can hardly believe it, we never thought we would see her get here.

The morning after she was born a nurse came into the room, had a look at Colbie-Kate then told me she needed to take her away for some tests. I phoned Stuart, her daddy, and told him to get up as soon as possible. When he arrived we were taken into this horrible little room - we just knew this was a bad news room. We were told her heart hadn't formed properly, there were lots of things wrong with it so they couldn't really give us a name, but a couple of names of the things wrong were Pulmonary Atresia, AVSD and Right Atrial Isomerism. They said that it would probably be kinder just to let her go as they didn't think she would survive the operation that they could give her.



We thought a little different and didn't think there was a choice, we had to try and give our tiny baby a chance. We had to have hope. So after getting transferred from the special baby unit in Edinburgh to the The Sick Children's Hospital at Yorkhill in Glasgow, our precious baby had her first operation at six days old. I can remember being in the waiting room in ICU and asking out loud, why us, when another lady who was waiting told us we were special parents picked for a special baby. It gave us a different view on things.

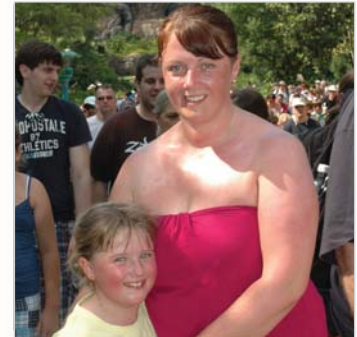
She was doing well and before long she was moved up to the ward. It wasn't easy trying to feed her with a tube through her nose into her stomach but we had to until she learned to suck on the bottle. Her little body was so tiny but it now had a huge scar under her tiny armpit. We were scared to touch, hold or cuddle her in case we hurt her. After two weeks she proved everyone wrong and for the first time in her little life we were taking her home, a place we never thought she would get to see. This was a huge milestone for us, but we were told that although she had done so well there would be more operations and she probably wouldn't do as good. There was no way of fixing her heart, there is so much wrong with it and that they could just improve things for her. As long as we still have her here with us and she's happy we can only take one day at a time.

After we were home, Colbie-Kate made good progress and was walking at nine months old and a proper little chatterbox, she was on special milk called Infatrini to give her more calories but luckily she kept well.

Then in June 2003 just before her first birthday we were sent to Yorkhill for a catheter test and was told there was a slot for the following Monday for her next operation (another BT Shunt like her first one but on the other side under her arm). We don't know how we didn't notice how blue she was, I think you must just get used to it, but we didn't realise how much she was needing the operation!

Two big scars already and she wasn't even one yet. Again, she proved them wrong and recovered well and was home in plenty of time for her first birthday.

May 2004 and Colbie-Kate had her second catheter test, then the doctor came to talk to us and said they weren't sure what to do next. They were going to discuss it again and talk to us at the next outpatient appointment. We were told then that in six months to a year, Colbie-Kate would have to go through a major operation to try and repair some of her arteries; this was a huge operation, a lot bigger than the other two. We could only go home and enjoy our time with her, every minute was precious. We had a lovely Christmas and tried to fill her life with as many



lovely memories as possible and now we had her little sister Charlie with us, she had someone else to enjoy it all with! (After lots of scans and lots of worry, Charlie was born healthy).

The waiting for the postman every morning for a letter with her operation date was awful, I'm sure he thought I was stalking him behind the door! The consultant had told us to telephone Yorkhill if we didn't get a date soon so we did, and found out it would be in about three weeks time. Then one day, there was a message on our answer machine so I phoned back and was told she would be admitted on Friday (three days away), with her operation being on the Monday.



We waited until they took her to theatre, then luckily we got a room at the Ronald McDonald House as we had done on previous times, which is a godsend as we live 100 miles away. We got settled in the room, Stuart was playing some shooting games on his laptop and I decided to write all my feelings down and my memories from Colbie-Kate's birth onwards, not something I usually like doing - writing, but I think it helped me take my mind off things and now I'm glad I





did as I have notes for writing this!

The pager went off about seven hours after she had gone to theatre. We went to ICU to see her and the surgeon came to tell us she was doing well and the operation couldn't have gone better, I knew she was still not out of the woods but it was a bit of relief to hear it had gone well. This was her first zipper scar and it was a bit frightening at first for her, I can remember getting

her a mirror to have a look.

That was in April 2005, after she got home things were good again, she seems to thrive and is a happy little girl. In May the following year we took Colbie-Kate and Charlie to Walt Disney World in Florida where we all had a fantastic time, and we could look forward for a little while. We had a little boy called Boyd in May 2007 and again he was heart healthy. Colbie-Kate started

mainstream school in August 2007 and apart from not being able to do as much physically than the other children she copes well.

Now, I'm going to pass you onto Colbie-Kate as she wants to tell you the rest of her story herself, what a big girl - we are so proud of her.

My Story

I had my last operation on May the 1st 2008 at Yorkhill Hospital. I remember waiting for the appointment coming in the post and it seemed to take ages, but once we got it we had to get my daddy home, he is in the Royal Navy and was away, far away. My daddy managed to get home in time only for my operation to be cancelled for an emergency. I got a new date for two weeks later. As it was getting closer I was getting more terrified about what was going to happen to me, would I be okay? Would it be sore? Would they draw lines on me to see where they were going to cut open? I had so many questions and they were frightening me.

We arrived at Glasgow on the Tuesday to get the pre-op tests done and I got to say hello again to all the nurses and doctors that have looked after me since I was a tiny baby. The night before my operation I had to start fasting but I had to go on a drip of glucose as sometimes I go funny when fasting. They already put the cannula in my hand and it is very sore, this is the worst bit. In the morning when we got to the theatre I felt sick and started crying, I didn't want to go, even though it was going to help me. My daddy took me through then they gave me special medicine in my cannula to make me go to sleep - I started counting. Daddy said I'm a red rogue as I got to eleven!

Waking up in intensive care isn't very

nice, I wanted a drink and they wouldn't let me take sips of water as I kept being sick. I had come off the ventilator quickly but still had the little tubes up my nose for oxygen. I had lots of other tubes and wires all over my body and my chest was very sore, I remember them giving me an x-ray and it was very sore trying to get me in place for it.

The next day they let me go up to the ward, but I was still being sick so they were giving me anti-sick medicine to try and stop it. Then they stopped the morphine they were giving me to stop me being sore as sometimes it makes people sick. I was sick for about five days, eventually it started being less each day and I managed to eat a little more. I have always been sick a lot from being a little baby but not as much as that. I had two drains with two tubes going into my chest, we used to call them my handbags when we were trying to get to the toilet!

Before my operation I would wake at night with very sore legs and mum or dad would give me Calpol, put cold wet cloths on them and sit and rub them until I got back to sleep. One night just after my operation mum had to phone dad at Ronald McDonald to come over as she was worried as I was screaming in pain with my legs, again the nurses could only give me paracetamol. The next day I started on Warfarin, which I'm going to be on for life, and I've not had sore legs since. Two special nurses came and showed me, mum and dad how to do an INR test and we (luckily) managed to get a home testing machine as we live so far from the hospitals that do finger pricking. We are getting on well with it and haven't had any major problems (it even came to Florida with us!)

I had lots of visitors and got lots of cards and lovely presents from family and friends. The hospital teachers came to see me and we wrote a story, did some sums and played some instruments while singing! I got to go to the medi-cinema which was fab and me and mum watched 'The Ugly Duckling'. The down doctors visited me too and they really cheered me up and made me laugh, they are so funny.



I got home the day before my little brother's first birthday and I was so glad, I didn't want to miss seeing him. I managed to get back to school before the end of term and I really enjoyed being in P2D.

In February we decided to do another Cookie Bake like we had done in P1 for LHM, and we had great fun baking them then I went around all the classrooms selling them. Shortly after we did a sponsored walk to raise funds for books for the school. It was a very long walk but I managed it with just a few breaks in the wheelchair.

In May this year we went to Florida again and one year to the day since my operation I got to swim with the dolphins, which was fantastic, we all had a great time.

In June, my dad got a phone call from our Headteacher, Mrs Easton, to say the school had nominated me for a PC Karen Balfour award. We got invited to the new High School in Eyemouth where we live for a big presentation night. I was a little nervous but when they said I had won, my mum and dad said they were so proud of me. I got nominated because of the fundraising I've done and how I get on with everyday life even though I have a broken heart.

Colbie-Kate





Feature

The article below looks at medical transition for our young members as they transfer from children's hospitals to adult units.

Written by
Suzie Hutchinson
Chief Executive, Little Hearts Matter



More and more of our young members are growing to the age where they will need to transfer from children's hospitals to adult units.

This is all part of growing up and becoming independent but leaving the doctors and nurses that you have grown up with and learnt to trust, to meet a new team, usually based in another hospital; can leave young LHM members and their families feeling nervous and unsure.

Here we have tried to answer some of the most commonly asked questions.

When will I be transferred to the adult hospital?

Most young adults begin the transfer process once they reach 16, that does not mean that they need to move over to the adult unit straight away. Some young people are happy to move straight away others would rather wait until they are nearer to 18 when they have to move.

Many of the cardiac units have a transfer process - Transition Clinics. Consultants from both the children's and adult services meet the young transferring patient together, this can help with building confidence that everyone knows about each child's heart problem.

Other units introduce their young patients to their

GUCH Nurse. This is a nurse who is very similar to the liaison nurse. Their job will partly be to answer any questions about medical or lifestyle care and to offer support to the patient and their family.

The team have parallels with the same experts in both children's and adult services.

Child Congenital Team	Adult Congenital Team
Consultant Congenital Cardiologist	Consultant Congenital Cardiologist
Consultant Congenital Cardiac Surgeon	Consultant Congenital Cardiac Surgeon
Cardiac Liaison Sister	Grown Up Congenital Heart Nurse
Intensive Cardiac Care Team	Intensive Cardiac Care Team
Children's Cardiac Nurses	Adult Cardiac Nurses
Children's Cardiac Junior Doctors	Adult Cardiac Junior Doctors
Echo and ECG Technicians	Echo and ECG Technicians

Which hospital will I be sent to?

Each children's hospital has a direct route to refer each patient to the adult congenital team linked to the local children's services. Many children's hospitals and adult teams work together meeting each week to discuss patients. They are seen as a region's Congenital Heart Team. Most congenital

heart surgery is done by the same surgeons that operate on children.

Will my new doctor understand my heart operation?

Most of the adult congenital cardiac cardiologists have been trained specifically in the care of young people and adults with congenital heart problems.



Hello everyone,



Matt Luck here, thought I would share my experience of medical transition to adult care with you.

Now that I am 18 my care has been transferred from Birmingham Children's Hospital to the Queen Elizabeth Hospital,

with a Grown Up Congenital Heart Unit (GUCH). My new Cardiologist, Mr Clift, specialises in congenital heart conditions and made me feel welcome as we chatted about Hypoplastic Left Heart Syndrome. He knew all about my past medical history and asked me how I was coping with day to day living and if I had any concerns I wanted to discuss. He explained to me that he would like me to have a number of tests, just so that he knew what was 'normal' for me, these included cardiac MRI, 24hr tape and cardiac echo. I have received a copy of my ECG with advice to keep it with me when I am out and about, just in case I am admitted to another hospital with chest pain. I also keep the number of the heart unit and nurse specialist in my phone.

I will be seen in clinic once a year, which is the same as BCH unless my condition changes. My medication - Warfarin and Lisinopril remains the same. My transition to adult care has been okay and I am positive about the future, I like my new Cardiologist and feel confident with him.

I hope you all have a good transition to adult services, I know that it will be different for all of you, some of you will be told when the transition will take place with little personal preparation (my experience) and others will have a phased transition with good preparation and forward planning.

Good Luck!





There are some adult cardiologists who treat patients with heart problems that they have acquired in later life but also offer care to patients who were born with congenital heart problems. This is a gradually reducing service as the numbers of patients with congenital problems reaching adulthood has become greater so there is a national push to increase the specialised adult congenital service.

The doctors will have been sent a full record of your medical history and most of them will have met with your paediatric cardiologist. As explained above you may attend joint Transition Clinics.

They may ask you to explain what you have been through when you first meet them so that they gain a greater understanding of how you feel about your condition and it's treatments.

The number of adult patients who have only half a working heart makes up 10% of an adult congenital cardiologist's patients but they take up to 50% of the cardiologist's working time so patients with a Fontan circulation are very, very important.

Adult congenital cardiologists have been treating patients with a Fontan circulation for many years.

Will my parents be allowed to be with me when I go to see the doctor?

- ✓ If you would like your parents to be with you when you visit the cardiologist they can.
- ✓ If you would like at the appointment for them to be present for only part of the visit that is also ok.
- ✓ If you feel that you would like to attend the appointment without your parents then that is also ok.

Your parents or guardians will probably have been with you for most of your visits to the children's hospital so for a while you may still want them to be with you when you move to adult care. They have known your condition since you were born so talk to them about what treatments you had as a child so that you can understand what happened to you.

When you see the adult cardiologist they will direct all the questions about your care and how you are feeling directly to you. If you don't know the answer but you think that your parents might then ask them to fill in any gaps.

It is a really good idea to think about any outpatient appointments a couple of days before you go. Write down any questions that you have so that you don't miss asking them during your visit. This is a good idea whilst you are still treated at the children's hospital.

If I need to stay on the ward in the adult hospital what will be different from the children's hospital?

The first and most noticeable difference will be that the other patients will be adults, no more crying babies, some of them might be the age of your grandparents. Actually this can be a great laugh because they often try to look after a younger patient, to help them feel at home. An iPod can be useful so that you can listen to your type of music.

Family and friends can visit but the times might be restricted. It would be very unusual for a parent to be able to stay the night.

If there is a doctors round where a treatment plan is going to be discussed it is possible to organise for another adult to be present if that is

what the patient wants.

Why do I need to move hospitals and change doctors?

The care of children's illnesses is organised at children's hospitals. They become expert at dealing with babies and young children as well as their families. They are used to caring for young adults but these days most surgery and admissions for congenital services are done in a child's first five years of life so the beds are too small and the wards are filled with all ages. The privacy most teenagers want is not there.

Adult hospitals are made for adults. You can be tall or short, you will fit into the bed.

You are able to be independent taking a lead in your own health care.

It is easier to talk about adult issues such as alcohol and sex, getting a job and maintaining a family.

You are treated and cared for by a team who are used to adults with heart disease. They provide a fresh pair of eyes to maximise your cardiac health in adulthood.

Useful Links

<http://www.dh.gov.uk> - has quite a few different resources including videos

Click on 'Health Care', 'Children and Maternity' then 'Transition from children's to adult services'

<http://www.guch.org.uk/info/>

TRANSITION INFORMATION DAYS AT THE EVELINA CHILDREN'S HOSPITAL

Transition Information Days take place at the Evelina Children's Hospital twice a year, and are aimed at young people aged 15+ who are about to start going through the Transition to Adult Congenital Cardiac services.

The day takes the form of a series of workshops and interactive sessions and the young people are separated from their parents to enable the workshops to be tailored to their requirements and level of understanding. The Day is run by senior nursing staff from both the Paediatric and Adult units and sessions are facilitated by the Cardiologists, a Psychologist, a Senior Play Specialist and a number of adult Congenital patients.

For the young people, the emphasis is on empowerment, knowledge and confidence building, and this is achieved by breaking the ice and playing games, before undertaking some fun role-playing activities, as well as providing information and guidance on important Issues such as:

- What life as a "GUCH" will be like, and how the adult clinics & wards differ from the paediatric ones.
- Knowing and understanding their heart condition as well as what

medication they take (sounds elementary, doesn't it, but we were amazed at how many 15 and 16 year olds didn't know this!).

- Understanding why alcohol, smoking and recreational drugs should be avoided but also how to "say no" without losing face amongst their peers.
- Leaving home for college or university (and remembering to attend outpatient appointments).
- Learning to take responsibility and ownership of their health in a positive way.

We try to emphasise what they CAN do, rather than what they CAN'T, and to give them the tools to live life to the full, given the restrictions that their heart condition has placed on them.

For parents, the workshops cover the same information, but are aimed at reassuring them about the Transition process and the care their child will receive once he or she has made the daunting leap across to Adult services.

The feedback from both young people and their parents who have attended Transition Days has been really positive ...

"The day was different to what I expected. I expected it to be just

talking about moving to adult congenital care and not as interactive. At the beginning of the day I was nervous and shy but as the day went on I got more and more confident. It was interesting to meet other children with heart conditions because I haven't had the chance of meeting any other children with heart conditions before. Overall the day was very informative to me and my mum. I would recommend it to anyone!"

For more information about future Transition Information Days please contact Jo Wilson on director@echo-evelina.org.uk.

**Jo Wilson
ECHO**

Birmingham Transition

The Birmingham Congenital Cardiac Service have just employed a Transition Nurse, Nichola Pope. Her role will be to support young people as they move from the Children's Hospital to the Queen Elizabeth Hospital site.

As soon as she takes up her post we will invite her to write a piece for the newsletter.





Zipper Zone



Jon gives an overview on some of the things he has been working on with our young members.

Written by
Jon Brunskill
Youth Development Officer

Always start with a joke...

Through the pitch-black night, the captain sees a light dead ahead on a collision course with his ship. He sends a light-signal to the approaching ship: "Change your course 10 degrees east."
The light signals back: "No, you change your course 10 degrees west."
Angry, the captain sends: "I'm a navy captain! Change your course, sir!"
"I'm a seaman, second class," comes the reply. "Change your course, sir."
Now the captain is furious. "I'm a battleship! I'm not changing course!"
There is one last reply. "I'm a lighthouse...Your call."



Now for the serious stuff...

Together, we can make a difference for all children with half a heart, and for all of the children in the future. Please help us to help them.

Dear parents,

Recently you will have received a letter from me explaining about a research project that Little Hearts Matter is undertaking. I know that you would probably like some more information on why this project is taking place, who will benefit, and how you can help? I'd like to use this space to answer these questions, and explain how important it is that we have as many people as possible taking part in this project.

Why is this project being undertaken?

In short, to help us identify exactly which issues are important to the 10-18 age group and how these young people feel about these issues.

We all know that life can get tough for families with a child with a single ventricle heart condition. Many parents contact us after experiencing problems with their child's school or teachers, or it could be that you are having trouble communicating with your child's doctor at the consultancy meetings. Life can be frustrating for the young people too. At an age of natural boundary pushing they have to be taught that taking risks can have much more severe consequences than with 'normal' children. When you are a teenager, all you want to be is the same as everybody else.

The challenge that we all face is trying to gain a solid understanding of the young person's heart condition, and how having it affects them. Only then can we provide the best services to help give the children the support and guidance that they need and deserve.

'How I Feel' is the research project that will address some of the most pertinent issues affecting the 10-18 age group. It will find out exactly how the children feel about day to day issues. This questionnaire based study will ask the children to voice their feelings on seven topics:

Hospital and Medication

Family and Friends

School

Feelings and...stuff

Big Kids (For teenagers aged 13 and above)

Sports and Activities

Diet and Food



This will not only give us a much better understanding of the children's needs, it will give us a quantified piece of evidence that can be used to influence medical and healthcare professionals. This piece of evidence will also give LHM a much louder voice when lobbying for change on issues such as paying for prescriptions once the children reach adulthood.

How did we create the questionnaire?

Suzie and I have been working very closely with the young people at various events over the last few years to engage with them on which issues are important to them. Earlier this year, we established a Youth Council which has been very vocal in identifying the needs of young people with a single ventricle heart disease.

We also sought input from the medical professionals who work with these young people, including a clinical psychologist. All of

these inputs combined with years of anecdotal evidence have meant that we have been able to create a concise questionnaire addressing the most important issues which need to be addressed as soon as possible.

The questionnaire should take between 30 and 60 minutes to complete.

What is the video stage?

Most questions in the questionnaire are tick boxes so that the data can be quantified and presented as statistics. The participants may wish, however, to elaborate on a particular issue beyond the constraints of the questions. They will be given the opportunity to do this in an 'interview' scenario with a facilitator, who will go through the young person's questionnaire with them to give them a chance to talk about their specific feelings on an issue. These feelings will be transcribed and used in the final evaluation to add weight and a human element to the statistics. No names will be attributed to the quotes in the evaluation process. If you or your child wish, the footage will be destroyed as soon as it has been transcribed.

The footage may be used when presenting the results of the study. Explicit and written consent from both you and your child will be sought if this avenue is chosen.

Who will benefit from this questionnaire?

There will be both short term and long-term benefits that will come from the outcomes of this project. Little Hearts Matter will be able to use the information gathered and immediately apply it to our service provision, giving tailor-made support





to the needs that they have identified as the most important.

This sort of evidence will also allow LHM to access funding to help pay for the new services that will be necessary from the outcomes of this project.

In the longer term, LHM hopes to use this evidence to persuade governmental change on issues such as DLA, benefits, getting the most out of the education system, and much more. This will pave the way for a brighter future for tomorrow's babies being born with a single ventricle heart disorder.

How can I help?

Over the next few months you will be receiving a letter from me inviting your attendance at a research event. We will be running these all over the country, and will send you a letter when we are close to your area. If you are unable to make the event, but would like your child to participate, please get in touch so that we can try and arrange a session at a more convenient location.

We currently have 150 young people aged 10-18. We hope to talk to as many of these

young people as possible. The more people that we are able to talk to, the more weight our study will hold.

If you have any concerns about this study, or would like to discuss this project further, please contact me, Jon Brunskill or Suzie Hutchinson on 0121 455 8982 by day or 07590 531153 by night.

Thank you,
Jon Brunskill

Youth Project Development Officer and Youth Research Project Lead

Zipper Get Together

The best way to give our young members the service that they want is to ask them what is important to them.

"I learnt a lot about my heart and how it works. Now I understand my heart better."



The Little Hearts Matter Youth Council told us that they wanted to understand their hearts better, in an easy way that they can understand. They said that doctors often use long or complicated words, and that they feel stupid if they ask what they mean.

"Swimming was my favourite bit. It was weird seeing so many other kids with scars on their chests."



are ready to start to understand their condition, and take some control over it.

"I made loads of new friends with hearts just like mine."

"I like being able to come to these days without parents."

It was also important to the young people that they had a session without parents. This is a very important step towards independence. These young people obviously feel that they

Little Hearts Matter ran a Zipper Get Together in September for any young members (and their brothers or sisters) aged between 10 and 18. Almost 30 young people attended, here are some of their comments and some pictures from the day.

One of our young members, Matthew Flavell entered a national poetry competition and we are very proud to report that his poem was selected to be published in a book.

The poem was inspired by the last LHM activity weekend. At which the children made clay monsters called 'Guardits' for their dens that they built to create a defense against the beast of Bodmin Moor.

Well done Matthew - what a star

The Beast of Bodmin Moor



I'm prowling on the grassy moor.

My name's the beast of Bodmin Moor.

I eat and sleep all day long, I never do any wrong.

Some say I'm a pet cat, imagine me with a rat!

So when you walk on the moor, think about the beast of Bodmin Moor

Matthew Flavell





The Review



Every issue we feature a review of a book or website or film that our members may find interesting. In this issue, Gill Cloke, has reviewed www.healthtalkonline.org

Written by
Gill Cloke



Healthtalkonline is the website of the DIPEX charity, which aims to make available a range of patient's perspectives of a particular condition or illness through creating a database of personal experience. Healthtalkonline has been set up to let folk share in these experiences of health and illness, by watching or listening to videos of interviews, reading about people's experiences and offering the chance to find out information about conditions, treatment choices and support. The information on Healthtalkonline is based on detailed research into patient experiences conducted by interviewers at the University of Oxford. The website was set up with the laudable aim that offering personal stories of health and illness would enable patients, families and healthcare professionals to benefit from the experiences of others.

The website is arranged by types of condition, and topics of common concern such as living with disability, intensive care, and the somewhat strangely named 'living with dying'.

There's a section on heart disease containing an extensive area for 'parents of children with congenital heart disease'. This is arranged by subject and includes such topics as: discovery (after birth and during pregnancy), preparing for birth and labour, telling others, adapting to life, feeding and medication, impact on family, talking to your child about their heart, death of a child, surgery and cardiac catheterisation, child's quality of life and development. Within these you're then offered a range of interviews of real people talking about how their experience and how this issue has affected them and their family, and how they've handled it; you can either download the transcript or watch clips of the interviews.

The interviewers have taken care too, to make sure different viewpoints are covered; e.g. in the bit I looked into in detail about preparing your child for surgery, besides talking about how to prepare your child, they'd also covered some people who'd chosen not to tell their child - and how this had worked in

one case, but been very much regretted in another. In the Resources and Information section they then have the cardiac teams and diagnoses, with more information on these and the treatments offered.

This site is easy to use, easy to navigate around, and they offer options alongside each interview to email it to a friend. You have to register to use the forum. One small gripe is the way they show the transcript of each interview alongside the film clip of it, and in a screen just as big, so it actually serves to distract from watching the person talking. I'm not sure why they do this - for people wanting to read rather than watch the interviews, the options for getting the transcript are very obvious, so why put it here to distract as well? But this is a small niggle in a very valuable website - totally gripping, in fact, I had to tear myself away!

Strongly recommended.

Getting Reliable Health Information from the World Wide Web

It's so easy to go to the internet to look for information - we all do it at different times and for different reasons. Many of the things we find will be very useful information. However, sometimes when thinking about medical information, we can come across misleading or unreliable information.

To help members make the most of the benefits the web can bring, we've had a look for some information so you can distinguish a trustworthy health website from one which may not be as useful as it first seems.

The Health on the Net Foundation is a non-governmental organisation, which works in the field of health information ethics, and has established a code of conduct and an accreditation mark for health websites. They suggest considering the following points:

1. Are the qualifications of authors of health

information given?

2. Does the information complement and not try to replace the doctor-patient relationship?

3. Is there a privacy policy for personal information submitted by site visitors?

4. Is the source(s) of the health information provided and are dates of publication / last update on the pages? Is the person qualified to give this kind of information?

5. Are justifications given for claims about the benefits and disadvantages of products, treatments or services?

6. Is the ownership of the site transparent, e.g. is there a contact address? Is the site owned by a recognised body or institution?

7. Is the source of funding of the site clear?

8. Is advertising and editorial content clearly

separated?

They also recommend an overall approach of vigilance, advising people not to trust promises of miracle treatments and never to take information found on the internet as medical advice.

Please remember that there is a wealth of medical and lifestyle information on the LHM website, and all our medical information has been verified by the charity's medical adviser Dr Oliver Stümper, Consultant Paediatric Cardiologist. If you ever want to discuss information you find on the internet, please don't hesitate to contact us, or to discuss it with your child's medical team. We don't want to discourage anybody from using any information source they find helpful; we just want to make sure you are getting good information. Happy surfing!



Noticeboard

Please Tell Us

Lots of you are having a go at at Dress Up, Dress Down or Dress Silly, Walkaround UK and many other things, please do let us know what you are up to, especially if you are taking part in one of the fundraising initiatives either from the website or from the Fundraising Pack you received earlier in the year.

I would love to get involved in all that you are doing.

If you are planning a fundraiser you think may be of interest to others or would like others to get involved, let me know and we will publicise it on the website.

*Thanks as always,
Kev*

LHM Publications

Little Hearts Matter now has the following publications and packs available free of charge to members - to get your copy just call the office on 0121 455 8982 or email info@lhm.org.uk or visit www.lhm.org.uk.

- Antenatal Information Booklet
- Preparation for Hospital Booklet
- Preparation for Hospital Pack - to loan for a period of 3 weeks.
- Benefits - a guide for parents
- Feeding at Home - a guide for parents.
- Early Years and Infant School Education Booklet
- Junior School Education Booklet
- Dental Care
- Fundraising Pack

Your Newsletter

Thank you so much to everyone who has contributed to this newsletter - it has been wonderful to receive all your stories and photos and ideas.

This is a bumper 20 page issue. The next issue is expected to be sent out at the end of January 2010.

If you would like to send your ideas and stories/photos for the next edition please send them to Deb - deb@lhm.org.uk by the end of the year.

Also if there is something you would like to see in the newsletter do let us know.

We very much look forward to hearing from you.

DIARY DATES

Lights of Love - Switch On

Sunday 6th December 2009

West Midlands

To confirm attendance and for more details please contact us - 0121 455 8982; info@lhm.org.uk

LHM Open Day & AGM

Saturday 13th March 2010

Bretby Conference Centre, Burton Upon Trent

On Your Marks for Little Hearts

Sunday 28th March 2010

Mote Park, Maidstone

Sunday 3rd October 2010

Shugborough Hall, Staffordshire

Inspirational Fundraiser of the Month

I get inspired almost every week when some of you step forward and go that extra mile to give something back to your charity, and it is your charity.

One such person is Mandy Pearce who put to one side her fear of heights, boarded a little aircraft, climbed to 5000 feet and jumped out!!!

Well done Mandy, not only for beating your fear but really going for it for the children. Mandy was our first inspirational Fundraiser of the Month. There have been lots more since.

Kev



Little Hearts Matter

11 Greenfield Crescent, Edgbaston
Birmingham, B15 3AU
Telephone: 0121 455 8982;
Email: info@lhm.org.uk

Over To You

Watchminder 2 Training and Reminder System

Fran contacted us with a great idea - a watch which reminds children to do things such as take medication.

"It has been an amazing boost for Dom not to have to rely on an adult to remember when to take his medicine at school, even though he still has to go to the office to collect it as he can't keep it on him. The watchminder can be set to vibrate discreetly at the set time and shows a message saying MEDS so he knows what to do...we have also set it to help him get organised with other things and it is working a treat.

We have also found that preparing a week ahead and putting all the boys meds into separate labelled containers, for each day, saves time and hassle and means that if I am not there my husband can get it right without worrying! Eventually they will be responsible for doing it themselves...

I love all this stuff, it just makes things more possible! Anyone with more ideas for us? We would love to know how the older kids manage everything!

It is hard to gradually let your children go, but that is our job as parents isn't it... let them go so they can grow..."

Fran bought hers from Relax UK - www.relax-uk.com/product.asp?id=212
price £59

You can also find more details on www.watchminder.com/

This page is just for you - the members of LHM. We want you to tell us what you've been up to! Send us your pictures or stories - achievements, things that have made you proud - however big or small. If your child has swum a length of the baths, conquered the bouncy castle, or gone off to their first day at school or nursery, we want to know about it! We also want to include any of your ideas to make life easier or recipes for foods to tempt the children! This is YOUR page - if there's something you'd like to see - let us know.

Email your pictures, stories, recipes and ideas to info@lhm.org.uk



- ABOVE LEFT: Michael Smith (5) doing the egg and spoon race.
- ABOVE: AdriannaTupaz, age 9 months and eager to keep up with her sister.
- ABOVE RIGHT: Samuel Robinson (3) meeting The Wiggles at the NIA.
- RIGHT: Matthew Luck (18) tearing up his L plates after passing his driving test.
- BELOW RIGHT: Lucy Pearson (9), doing her favourite thing in the world... reading.
- BELOW: Cora Banyard (3) riding her first bike - what a grown up girl!
- BELOW LEFT: Maks Szatkowski born on the 24th June 2009.
- LEFT: Arlo Kent-Rose (3) proud owner of a scooter!

