

update



children's heart
FEDERATION

Spring 2009

Welcome to the spring edition of Update! After braving an unusually cold winter, we're all looking forward to warmer, brighter days as well as lots of exciting plans over the coming months.

It's already been a busy start to the year as we set about organising the official UK launch of Corience, the first ever European congenital heart disease web platform, in January. We were delighted with the overwhelming support that this new European venture received from policy makers, professionals and families alike. Read more about the event and what some of the speakers had to say on page 2.

With our Heart Awareness week taking place in May this year (to coincide with many other European countries) preparations are also well under way for various activities and events from 9th to 17th May. Uniting under a collective campaign called Hearts 4 Hearts, Children's Heart Federation and several member groups will turn the focus on the issue of sports and exercise for children and young people with heart conditions. We know that many parents and heart children still face hurdles when it comes to being fully included in physical activity at school, but at the same time are cautious about what is safe for them. On page 4, Lynne Kendall, congenital cardiac clinical physiotherapist, addresses some of the key concerns relating to the issue.

Finally, as we enter the milder weather, you may be tempted to dust off those running shoes again. If you or any of your friends or family are looking for a physical challenge, there are plenty of runs, marathons and many other exciting events that you could get involved in on behalf of Children's Heart Federation. Have a look at what's on offer on page 7 and the back page.

I wish you all a wonderful and blossoming spring.

Very best wishes,

Anne Keatley-Clarke
Chief Executive



Let's Get Moving!



This year's awareness week for children and young people with heart conditions will take place from 9th to 17th May. As well as raising awareness about congenital and acquired heart conditions generally, we're also going to be turning the spotlight on the issues and concerns that heart families have around sports and exercise.

The government is on a huge drive to get everyone moving, and NICE has recently published new guidance on 'Promoting physical activity for children and young people'. Whilst the guidance includes those with a medical condition, when it comes to heart children, there is still a lot of confusion about what is appropriate as well as a lot of concern over inclusion in activities at school.

We want to find out more about your views and experiences, either as a parent or heart patient. For instance, how good is your school at adapting to your needs and making sure you can participate fully in activities? Look out for a questionnaire on our website which you can fill out to tell us your views - www.chfed.org.uk. Alternatively, please call the infoline on 0808 808 5000 and we can send you a hard copy.

This May 2009, watch out for a week full of activities, including:

- ♥ BBC Radio 4 Appeal
Sunday 10 May
- ♥ Parliamentary Reception
Thursday 14 May
- ♥ Family Sports Day
Saturday 16 May
- ♥ Series of local activities

“We have lift off!”

CHF launches European web platform



Harry Spurling (who talked about his experience of living with a heart condition) and Katherine Perkins reveal the new site

Uniting patients, parents, doctors, nurses, support groups and policy makers across borders – that is the foundation on which Corience, the European congenital heart disease (CoHD) web platform was created. On Friday 30 January, the Children’s Heart Federation officially launched the UK version of the new web network at the Science Museum in London.

Over 65 delegates spanning the full range of audiences that Corience is aimed at, came to learn more about this unique venture. Administered by a team of medical professionals and support group representatives from across Europe, Corience provides accessible and authoritative information on good practice in the diagnosis, treatment and support of people with CoHD.

Keynote speaker, John Bowis OBE, Conservative Member of the European Parliament (MEP) for London and Conservative spokesman on Health in the European Parliament, reminded us that behind the statistics – five million people in Europe living with CoHD and 5000 new cases in UK each year – there are individuals coping with extensive medical treatment, anger, anxiety and loss.

Mr Bowis declared, “When a child is born with a heart defect, your life will change, but it need not be devastated. To have a web network means that, at the touch of a button, you are able to share experience and expertise across your own country and reach out to people across our continent. It means contact between patient or parent and professionals and scientists. Finding and sharing best practice is at the heart of European Health policy, and it will be the gift of Corience.”

The potential for sharing information and practice across countries was also recognised by Dr David Low, National Clinical Lead (Paediatrics and Child Health) for NHS Connecting for Health, “Wherever we are, the needs of children and families are the

“Having a child with a heart defect puts everything else into perspective. As a parent, you are desperate for information that will help them get the best treatment and care. Corience presents information in a clearly understandable way. To see what works well right across Europe is a great benefit because sharing knowledge will help improve things for heart children in every country.”

Ulrika Jonsson (mother of Bo, who was born with a heart condition)

same but the way we do things professionally may be different. Corience provides a wonderful opportunity to share information across country boundaries, across professional boundaries and also across those artificial boundaries between professionals and families.”

Anne Keatley-Clarke, CHF Chief Executive, pointed out how Corience will help to reveal the variations in treatment and support across countries, “Corience highlights what works well and is also a powerful signposting tool, referring heart-families to their local support organisations for advice, information and practical help.” The UK version of Corience will be followed in the autumn by versions in Spanish and German and later in Polish.

We are grateful to all the speakers who helped to make the launch such an insightful and informative event. We continue to work closely with the Corience group and look forward to seeing this valuable information platform grow and develop. Visit www.corience.org to see what the fuss is all about for yourself!

New resources on Special Educational Needs

As many parents will testify, getting the right help and support for heart children at school can often be a complicated process. It helps to know what your child is entitled to and what the school and other organisations can do to help. The Children’s Heart Federation have a fact sheet for parents called ‘**Your child and special educational needs**’ which you can download from the website www.chfed.org.uk or call to order 0808 808 5000.

There are now a couple of new resources available to parents. Contact a Family have recently produced a podcast on SEN which you can listen to – visit www.cafamily.org.uk. As well as going through what to do if you are concerned that your child has SEN, the podcast also has more information about how to request a ‘statutory assessment’, the ‘statementing’ process, how to make sure any provision best meets your child’s needs, and what to do if you are unhappy or want to appeal against a decision.

The Advisory Centre for Education (ACE) has a number of useful advice booklets for parents which are now free to download from their website. They cover a range of issues, including, asking for a statutory assessment, disability discrimination, extra help in early years, and getting the statement right. Visit www.ace-ed.org.uk for more information.



Working With Heart Children



Tracy with one of her young patients outside the Evelina Hospital

In this issue we find out more about the work that play specialist, Tracy Sutherland, does to help heart children and their families.

Where do you work?

I work at the Evelina Children's Hospital. I qualified as a play specialist about 17 years ago and I'm part of a team of eight play specialists across the Evelina. I've worked in Paediatric Cardiology for nearly 22 years now.

What does your job involve?

Like most health care professionals my role is diverse and I have to be very adaptable. Play specialists offer creative, recreational and social activities for children and young people. The aim is to help them adjust to the hospital environment and also to just relax and have a bit of fun. So I use therapeutic play to help heart children understand their hospital experiences. I also help them to recognise and form coping strategies for dealing with hospital procedures. My observations and interactions with patients are also valuable to the medical team in making clinical judgements.

What happens during a typical day?

I usually start at 8.15am on the ward, find out who the inpatients are and attend the doctor's ward round. This all helps me to prioritise my work for the rest of the day. Although I do try to see some children and young people referred as outpatients, my priority is to see the patients on the ward first.

Every day is so different – it may start with an art activity like painting with a child postoperatively, attending a meeting on transition for our young adult patients, distracting a patient having a pleural tap, preparing a patient for

surgery, teaching staff or managing highly distressed children. I'm also currently working with the radiologists on a research and audit project on patients undergoing MRI without anaesthetic.

What sort of help do heart children need most?

I feel that we sometimes forget as health care professionals that patients and their families have a life outside of the hospital and have needs other than just medical. Some children need extra support to enable a good balance between their social, educational, physical and health issues.

What is the hardest part of your job?

It's always difficult when a patient needs a procedure and isn't quite ready. Perhaps they are anxious and scared because they do not fully understand the reason for having it, or they know the risks and need a bit more time to prepare for it. Helping them to understand and prepare for the procedure by being supportive and non-judgmental, while at the same time working within medical time constraints, is always a challenge.

What is the most satisfying part of your job?

Being in a job where you are in a position to help others in whatever way it may be is always rewarding. Seeing our patients growing up and then bringing their own children to show me, may make me feel old but is very rewarding.

Fancy an adventure?

Last year, Children's Heart Federation teamed up with another charity, Over the Wall, to offer heart children aged between 8 and 17 and their siblings the chance to go on fun and exciting adventure holidays.

The holidays are available again this year, so make sure you book your place soon to avoid disappointment! Organised within a residential camp located in idyllic settings, each trip is normally a week long. There are trained staff and volunteers to help with medical and personal care needs, so parents can be assured their child will be in safe hands.

As well as a chance to get away from the folks, it's also an opportunity to make friends, have fun and try some of the great activities on offer – from archery and kayaking to drama and talent shows. And the best part is – it's all free!

Go on, book your place now! Call Samantha Johnson on 020 7422 0630 to find out more.



Getting Active

“How much is too much?” This is the question many parents wonder about their heart child doing any physical activity.

Whilst in the past some congenital heart patients were told that exercise could be dangerous, the overwhelming evidence now is that regular physical activity benefits long-term health, even for people with congenital heart conditions. However, a lack of specific guidelines in this country regarding exercise in congenital heart disease patients, means a lot of parents still struggle to know what's best for their child. So we decided to ask Lynne Kendall, congenital cardiac clinical physiotherapist and a long time advocate for getting heart kids moving, to clarify some of the main concerns.

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

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 is recommended for children and young people with heart conditions?

Recently published public health guidelines (NICE, January 2009), 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. 'Moderate intensity' means enough to make you breathe harder (feel a bit 'puffed') and feel warm. So everyone, including children and young people with heart conditions, should try to do regular physical activity. The important thing is to do what you can at your own pace and your own level.

Ultimately, how much exercise heart children can do, will depend on their own condition – the cardiologist can tell you this.

Are there certain types of exercise that are better than others for children and young people with heart conditions?

There are two types of exercise – cardiovascular (isotonic) and static or weight resistant (isometric) exercise. The first type includes things like swimming, cycling, walking, and dancing, and is generally better for people with congenital heart problems. Isometric exercise often uses weights and machines and also includes activities like rock climbing, boxing and some martial arts - some congenital heart patients may be advised against this type of exercise as it can put more of a strain on the heart.

It is important to remember that everyone is different and heart problems may change over time so the information people have must be up to date. Always ask the cardiologist if you are unsure.

Remember, you do not have to be 'sporty' or join a gym in order to take part in physical activity. Walking or dancing to your favourite music is also great exercise and costs nothing. **Any activity is better than none at all!**

What can schools do to make sure that young people with heart conditions can participate fully in activities and sport?

Schools should encourage young people with heart conditions to take part in physical activity at their own pace and within their own limitations. This may mean making modifications to some activities, or finding an alternative during strenuous activity (e.g. help with recording or timekeeping duties) to keep them included with their peer group as much as possible.

Exercising with care

It's normal to feel warm, breathe harder and feel your heart beat faster during exercise. But here are some things to watch out for:

- ♥ Stop to rest if you feel dizzy, faint, sick, become very breathless or experience any pain or discomfort;
- ♥ As a general guide, heavy weight-lifting or activity that requires intense effort is probably better avoided if you have a heart;
- ♥ Some heart problems mean you may be advised to avoid high-intensity, competitive activities such as basketball, triathlon, (competitive) swimming, distance running or cycling;
- ♥ If you take anticoagulants such as warfarin, or have a pacemaker, avoid contact sports such as hockey, rugby, football, and judo.



It is important that schools are provided with up to date information about the child's heart condition and given detailed guidance for physical activity - parents can ask their cardiologist or cardiac liaison nurse for help with this.

Is there a general consensus amongst clinicians and professionals on the guidance for young people with heart conditions and exercise?

Different clinicians will often have different opinions on patient management but European and American guidelines are available (Hirth et al, European Journal of Cardiovascular Prevention and Rehabilitation, 2006 & Maron et al, Circulation, 2004). These guidelines mainly refer to competitive sports but provide a useful benchmark for reference. However, it is essential that patients always ask their own cardiologist for individual guidance.

What is becoming clear from research among adults with congenital heart disease is that it is fairly common for them to feel uncomfortable about the idea of doing exercise. There are several reasons for this, some of them stemming from childhood, including fears or misconceptions about the severity of the heart defect, lack of information, family/teachers preventing the child from doing any exercise and sometimes teachers pushing the child to do more exercise than is safe for their condition.

We should all try to promote 'healthy living' for people with congenital heart disease and provide timely, detailed individual information regarding exercise.

Flying the nest

By Paul Wilgoss (a GUCH who has lived away from home for 20 years)

There are a few milestones in your life that should be made special, and you should always remember - riding your bike without stabilisers, passing your driving test, buying your first pint ... and getting that first set of keys to your very own place without your parents.

It's the last one that can often give GUCHs (grown up congenital heart patients) the most worries. A quick look at the message-board on the GUCH website (www.guch.org.uk) will show that many young people do worry about living on their own, or just away from those who know about their heart conditions.

The main worries are about what happens if something goes wrong with our hearts, what happens if we're lonely, and who we can talk to in an emergency. In addition, we also need to consider the same things as anyone else living on their own; where we live (close to work, friends or family), money (both earning and spending it!), and who we live with (on our own or sharing with friends or strangers).

Some of the best general advice on leaving home can be found on the connexions website (www.connexions-direct.com - in the housing section under leaving home).

For most GUCHs, following the general advice is all we need to do, but there are some extra tips that can make all the difference:

- ♥ have a summary of your condition somewhere where it's easy to find (medical tags such as the SOS talisman or medic-alert bracelets are two good options);
- ♥ if you're living in a shared house leave a "call in emergencies" number by the phone (that way you don't have to explain your condition unless you want to);
- ♥ if you're having a bad spell let friends or relatives know - it's always better that someone is aware to give you a bell if they've not heard from you in a couple of days;
- ♥ if you have problems with stairs or generally getting around, talk to your council. Or if there's an independent living group near where you live they'll be able to provide hints, tips and possible sources of equipment and funding.

Finally, when you move in to your own place enjoy it. Getting your own 'pad' is an exciting time - there really is nothing like the feeling of getting in, closing the door on the world and sinking into the sofa knowing that you can watch what you want, eat what you and the world will carry on spinning without you!



Caring GUCH gives back to local support group

In the last issue, we told you how one young GUCH, Kieran Wardrop, decided to help out his local support group, the Scottish Association of Heart Disorders (SACHD), by offering to be their family events organiser. Fifteen-year-old Kieran took up the challenge of organising the group's annual family trip when an opportunity came up a few years ago. We caught up with Kieran and asked him to tell us a little bit more about himself.



Kieran prepares to head off on one of the trips

What heart condition were you born with?
I was born with Tetralogy of Fallot.

Has your heart condition affected your school life in any way?

No, I don't feel that my condition has restricted me in any way. I do get tired more quickly than others though. But most people I know at school know about my condition anyway, so they understand. I did once miss a school trip because I was in Yorkhill Hospital. And after my operation, I needed time to recover so it affected me then. That's about it though.

Has your heart condition ever stopped you from doing things with your friends?

No, again I get a bit tired, for example when playing football, but I tend to just have a rest for a bit and then I'm fine.

How did you end up organising the annual family weekend for SACHD families?

Well, the man who did it before me said he would like to stand down from doing it. I fancied helping out so I expressed an interest in taking over. For the first year, I went along with him and he took me through it all to see if I would still be interested. I have done it ever since.

What does organising a family weekend away actually involve?

We usually take about 25-30 people in total. So I need to

book accommodation, organise all the activities (cycling, boating, swimming, etc.) and arrange the rooms for everyone at the Atholl Centre in Pitlochry.

What do you enjoy most about organising these trips?

I enjoy speaking to different people who go on the trips every year and meeting new people. I also like to ask new families that I meet at different events if they would like to come along.

Apart from organising family weekends, what are your favourite pastimes?

I enjoy going to Boys Brigade each week, and am doing my Duke of Edinburgh Silver award at the moment.

What would you like to do when you leave school?

I haven't really decided yet, probably something to do with money and finance. I am going to be doing some work experience with an accountancy firm nearby soon. Not sure whether I'd prefer to be an accountant or work in a bank - I need to see if I enjoy the work experience first!

Kieran's predecessor, Jim Kelman, is very proud of his invaluable efforts, "This year on May 8th - 10th our families will meet in Pitlochry knowing that everything will be in place for another happy and successful weekend, thanks to a very capable and confident young man, of whom we are all immensely proud."

Understanding the risks of surgery

By Dr Tim Rakow, Senior Lecturer, Department of Psychology, University of Essex



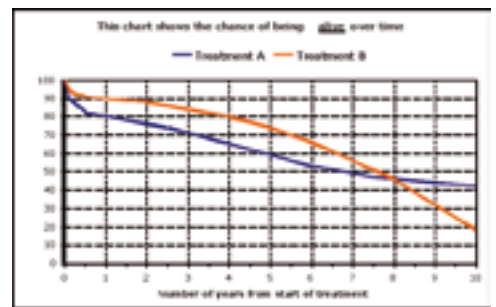
Over the past few months, I have been working with researchers at the University of Essex on a project that examines the information about surgical risk that is available (or could be made available) to parents. Our main aim has been to find out how easy it is for parents to understand two different types of graphs showing information about surgical outcomes. The project has been sponsored jointly by the Children's Heart Federation, Great Ormond Street Hospital, and researchers at the Universities of Essex and Cambridge. We are grateful to all the parents and family members of children with congenital heart disease who have helped us with this research.

First, we examined **survival curves** - a graph that shows the percentage of patients who have undergone a specific operation that are alive at different points of time (e.g. one, five or ten years after surgery). These appear routinely in medical journals, but are not widely used when doctors talk to patients or parents about long-term outcomes. We presented carefully chosen examples and asked people a range of specific questions about the information shown. Most people were very accurate in making sense of the information in the graphs - even those who weren't too confident about it!

Second, we examined **funnel plots**. This type of graph is used by the health service to monitor the outcomes of surgery at all the paediatric cardiac units in the UK. The graph shows the survival rates and the number of operations performed by each paediatric cardiac unit for a given procedure. It also shows when the performance of a particular unit should cause concern. These plots are published on the web (www.ccad.org.uk) - but we wanted to know if they could be easily understood. We provided people with a brief guide

to help them understand the graphs. When presented with a range of plots, most people were able to interpret the plots without too much trouble.

Overall, we were encouraged by our findings. We feel that we can recommend both types of graphs as suitable for communicating complex information about the risks associated with treatment, and can make recommendations about their use. For instance, understanding is much better if the language used is clear and "matches" well with what people see. So if you are looking at a scale marked with "survival", then it is better to discuss survival rates rather than mortality rates.



Survival curves for a pair of treatments

We know that the information that people want varies from person to person. But, we feel that we have learned something about how to provide information to those parents who want to know more about the likely outcomes of their child's treatment. The next step is to explore how the web can be used to provide better information about treatment outcomes. We will again be looking for volunteers to help us test different possibilities - so watch this space!

New software improves outcomes for heart children

Children who have to have heart surgery may now have a better long term health outlook thanks to new software developed by scientists in Atlanta, USA. Researchers at the Georgia Tech College of Computing in Atlanta, have developed ingenious new technology which allows surgeons to manipulate digital 3D models of a patient's actual heart and explore surgical options before even setting foot in the operating theatre.

The technology, known as image-based surgical planning, produces a three-dimensional model of the heart. This helps surgeons to gain a better understanding of each child's unique heart defect. In addition, the research team has also built in another crucial component to the system - the ability to simulate how the heart will work after surgery. So surgeons not only understand the heart condition better, but they can also explore and test different treatment options to see which would be most effective. The result is that children with heart conditions, especially those who will need several surgeries over the years, are more likely to have smoother recoveries and an improved quality of life after operations.



Paediatric cardiologists and surgeons at the Emory University and Children's Healthcare of Atlanta have already started using the new software. Kirk Kanter, chief of paediatric heart surgery at the centre, used the software to prepare for two complex heart procedures, and has seen the difference it can make to treatment, "It [The software] eliminates a lot of the guesswork. We've designed the surgery beforehand and analyzed it on the computer. So rather than trying to guess what would be the best way, we already know which option will work best for this child's anatomy."

Scientists believe that with time, as surgeons refine their treatment choices to achieve the best possible outcome for heart children, this new technology could lead to better health and fewer deaths after rates in paediatric heart surgery.

FUNDRAISING NEWS

A night with the stars



Samantha Johnson gets up close and personal with Vanessa Feltz and Ben Ofoedu

On 2nd December 2008, Children's Heart Federation were invited to an awards ceremony for some of Britain's best medical and scientific talent - the Medical Futures Innovations Awards. The distinguished audience on the night included celebrities such as Vanessa Feltz, Jonathan Ross, David Mitchell, Ben Ofoedu, Andrew Marr and Anthea Turner.

As well as mingling with the stars, we are also grateful for the generous support we received on the night from BBC presenter, Vanessa Feltz, who kindly offered to auction an hour on her BBC radio show followed by a special lunch with her and fiancé Ben Ofoedu.

Family Support Appeal

We have all seen the price of fuel, utility bills and food increase sharply recently. But it's the families with children with complex needs who have been hardest hit by the credit crunch. Travel expenses, hospital parking and having to take unpaid leave from work, all add to the pressures for many heart families already struggling to get by.

We would dearly like to be able to help the hundreds of families that have approached us for small grants.

Donate to our **Family Support Appeal** to help transform the lives of families in need – call us now on **020 7422 0630**.



Experience the high life



Claire Watson took the plunge, quite literally, when she did a parachute jump on 12th October 2008 to raise vital funds and awareness for the Children's Heart Federation. Well done Claire and thank you for helping to support heart children and their families!

"It was an experience I'll never forget and I'm pleased to have been able to do something so amazing in aid of such a great cause."

If you fancy doing something just as exhilarating, why not have a look at some of the exciting challenges we have on offer – from white water rafting to trekking through Peru, there is something for everyone. Go on, do something amazing today and sign up for an experience of a lifetime – contact **020 74220630** or fundraising@chfed.org.uk.

Get Active for the Heart

<p>British 10k Run 12th July 2009</p>	 
<p>London Triathlon London 1st & 2nd August 2009</p>	  
<p>Great North Run Newcastle 20th September 2009</p>	 

PLACES AVAILABLE NOW! For more information please call Jackie on 020 7422 0630, or email us at fundraising@chfed.org.uk

Children's Heart Federation – List of Member Groups

Barth Syndrome Trust
Tel: 01794 518 785
www.barthsyndrome.org

Children's Heart Unit Fund
Tel: 0191 213 1365
www.chuf.org.uk

Evelina Children's Heart Organisation
Tel: 01273 248948
www.echo-evelina.org.uk

Little Hearts Matter
Tel: 0121 455 8982
www.lhm.org.uk

Cardiomyopathy Association
Tel: 0800 0181 024
www.cardiomyopathy.org

CRY
Tel: 01737 636222
www.c-r-y.org.uk

Gift - The Children's Transplant Charity
Tel: 0845 094 5810
www.giftctc.org.uk

Max Appeal
Tel: 0800 389 1049
www.maxappeal.org.uk

Children's Heart Association
Tel: 01706 221988
www.heartchild.info

Down's Heart Group
Tel: 0845 166 8061
www.dhg.org.uk

Grown Up Congenital Heart Patients Association (GUCH)
Tel: 08800 854 759
www.guch.org.uk

South West Children's Heart Circle
Tel: 0870 125 2307
www.heartcircle.org

Heartbeat
Tel: 028 4376 8786
www.heartbeatni.org.uk

The Brompton Fountain
Tel: 020 7776 9000
www.bromptonfountain.co.uk

Heart Children Ireland
Tel: 00 3531 874 0990
www.heartchildren.ie

The Scottish Association for Children with Heart Disorders
Tel: 0131 447 2711
www.sachd.org.uk

HeartLine Association
Tel: 01276 707636
www.heartline.org.uk

Tiny Tickers
echo1078114@yahoo.co.uk
www.echocharity.org.uk

Heart Link
Tel: 0500 382152
www.heartlink-glenfield.org.uk

Wessex Children's Heart Circle
Tel: 02392 570601
www.wchc.org.uk

Young at Heart
Tel: 0121 357 8200
www.youngatheart.org.uk

Young Hearts
Tel: 01235 526 414
www.younghearts.co.uk



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