



The magazine of the
Grown Up Congenital Heart
Patients Association
Issue 64 // SPRING 2011

GUCH NEWS

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IT'S OFFICIAL... WE'VE GOT INVESTING IN VOLUNTEERS STATUS!

As many of you know, we've been on a long journey over the last 12 months to achieve the UK-wide recognised *Investing in Volunteers* quality standard. We wanted to work towards this so that, in the process, we can make sure we are delivering a great service to our volunteers, and in turn, all our volunteers are being as productive and involved as possible.

We haven't done this on our own.

To EVERYONE: we would like to say a very big thank you for your time, hard work, effort, comments, encouragement and constructive feedback. As a result of teamwork and intense development, we are absolutely thrilled, delighted and proud to announce that GUCH PA has now been awarded the Investing in Volunteers status – the UK quality standard for good practice in Volunteer Management.

So, what does this mean for us now? We'll certainly not be resting on our laurels. We know that it took a lot of work to get to this point and we are committed to maintaining and further improving the volunteer experience all round. So. One journey ends, and another just begins. We look forward to seeing you along the way!

Victoria Goldsmith



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EDITOR'S WELCOME

Hello and welcome to the first 2011 issue of GUCH News!

I hope you are enjoying a great start to the year, and keeping nicely wrapped up and warm!

This issue is bursting with amazing stories, helpful information, inspiring articles and of course all the latest from GUCH PA. As ever, we have a fabulous competition with the chance to bag a luxurious pamper gift. Check out page 19 for all the details.

We are excited to be running another event, this time exclusively for people aged 16-24: come watch Thriller Live in Birmingham and meet other young people from around the country. See page 11 for more info and how to sign up.

As well as all that lovely goodness, as you will have seen from our front page, we have some very exciting news to share with everyone: we have successfully qualified to hold the national quality standard in volunteering! After a lengthy, in depth and at times downright intense assessment, we are so proud of all our staff and all our volunteers and are happy to announce that we now hold official accreditation from Investing in Volunteers. Thank you to everyone who helped make it happen!

With exciting news also unfortunately comes some sad news. Our former Health Liaison Manager, Paula Banda, has left GUCH PA due to redundancy. We wish her very well and you can read more about her departure and what lies ahead for GUCH PA now on page 9.

We really rely upon interesting, exciting, insightful and inspirational contributions from our readers to help continue to make GUCH News a worthwhile and enjoyable read all round. If you'd like to contribute, please get in touch with me to have a chat about your ideas. I'd love to hear from you.

So. With all that to look forward to what are you waiting for? Get stuck in and enjoy!

Victoria

P.s. The next deadline for submissions is April 4th 2011



Grown Up Congenital Heart Patients Association
Registered Charity No 1138088

ACCESSING EXPERTS AND NHS CHANGES TO GP COMMISSIONING

For GUCHs, being seen by an expert, so that their care plan can be properly considered, is of utmost importance. It is therefore necessary that all GUCHs have access to these experts.

This is something GUCH PA gets involved in from time to time to assist those who are finding it difficult to get to an expert. There have been occasions when we have not only written to the GP but also the Primary Care Trust (PCT) to support someone who is having difficulty getting a referral to a Specialist GUCH Cardiologist. We have even gone to the Department of Health to resolve it too. This is what we are here for: to work on behalf of GUCHs, but it would be better if access was not a problem in the first place.

But why does it happen? Often it is because the GP knows no better than to refer the person to an Adult Cardiologist, they either do not know what the problem is or even if they do, they don't know where the GUCH Specialists are.

There are times when it seems that the PCT is resisting allowing a GUCH to be sent to a GUCH Specialist because they do not have an agreement with the service and always try to refer within the agreements they already have in place. This may have something to do with money. The GP cannot refer if the PCT doesn't agree.

The most important thing to be is an 'expert' patient. When the GP isn't aware of the specialist services for GUCHs, tell them. Print off a copy of the list of Specialist GUCH Centres which are published on our website or phone the office and ask for a copy and take it to the GP. Everyone is entitled to be referred to the service which is right for them.

Is the change to GP Commissioning which is currently being implemented going to make things better or worse? The Government are closing the PCTs and moving the funding directly to GPs, cutting out the PCT structure all together. As it is often the PCT which stands in the way of a referral then it is possible that things will be better as it will be the GP who has the funds to refer. At least it is only one person to persuade and it should be more likely that the GP will be willing to refer. There is still the possibility of them trying to save money by referring to an Adult Cardiologist instead, but doing so would actually cost more as hopefully the Adult Cardiologist will say that they need to be referred on, making this a wasted consultation.

Again, when faced with the problem of not getting to a GUCH Specialist, stand your ground with the GP, and provide them with information on the need for an expert opinion.

Don't forget too that there is help at hand if you need it. GUCH PA is here to support the needs of GUCHs and we can write a letter pointing out the need for referral to specialist services, and like we have done before, get the person to the expert that they need. Most of all, our aim is to enable all GUCHs to be expert patients, by providing them with the information to understand their needs and how to deal with them.

Michael Cumper
GUCH PA Chairman of Trustees



VOLUNTEERING OPPORTUNITIES

Our volunteers are very important to us, and we strive to offer interesting, useful and relevant projects, with appropriate ongoing support and training. Our opportunities are limited at the moment but we are still in great need of the following:

FUNDRAISING:

We are always really grateful for people fundraising on our behalf. We have a fundraising "how to" guide which offers information and inspiration on holding a range of different events, and we are on hand to help as we can along the way.

If you would like to be a fundraising volunteer and receive a guide today, let us know!

GUCH NEWS CONTRIBUTOR:

Got a story you're keen to tell? If you would like to get involved with GUCH News by writing an article or investigating a particular subject for us then get in touch, we'd love to hear from you! We're on hand to discuss your ideas and help you develop your writing.

*Please email our Volunteer Development Manager:
victoria@guch.org.uk*

**REQUEST OUR
FUNDRAISING PACK**



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GET CONNECTED!

NATIONAL DIRECTOR'S UPDATE

Hello and a very Happy New Year to all our readers. I hope you enjoyed the holiday period and are having a great start to 2011!

It's been busy at GUCH PA, as usual, and we have been working hard alongside units to assess hospital waiting times – we hope to use this information to take stock of and improve the experience for all. Thank you very much to those who have taken part so far.

As we move forward into Spring we can look

forward to the planning of our next National Patient Conference so be sure to keep an eye on our website and future issues of GUCH news for updates.

GUCH News is free to subscribe to and you can receive it straight to your door or email inbox. If you've not yet registered with us, do it today – and enjoy GUCH News and our services as a priority customer!

John Richardson

EMOTIONAL AND MENTAL HEALTH SUPPORT UPDATE

From January 2011, I am delighted to say that my new job title will be Mental Health Support Worker for GUCH Patients Association. This means that I am available to offer emotional and mental health support to all our members across all ages.

Over the past three years, because of specific funding from Comic Relief, I particularly had to target support to teenagers and young adults. This work culminated in the very successful Young People's Conference that ran alongside our usual GUCH Conference, co-produced with the Children's Heart Federation. As well as broadening out support to all adults with congenital heart conditions, we hope to continue to run some events for the younger age group, to build on this success.

Things happen in life, difficulties at school, home or work, relationship concerns or dealing with health issues. Sometimes people have a sense of uncertainty about the future when living with a heart condition. It can also be hard going managing the ups and downs if you have ongoing symptoms or need to have surgery or other interventions. Feelings and situations can at times seem overwhelming and hard to cope with. At these times it can be helpful to reach out to others, talk things through or find out more about self help measures and sources of support. As well as sharing with people you know, it can at times be helpful to speak with someone outside your circle.

This is where my role with GUCH PA comes in, offering a range of support and information to members. Here are some examples of the type of support I can offer:

Telephone and email support:

I am happy to talk to you via phone or email about what's going on for you at the moment, discuss possible ways forward and the resources and other supports available. There aren't always easy answers but I can offer a listening ear. Some people find it helpful to talk through specific self-help measures they could try, such as breathing exercises and relaxation techniques.

Providing information on emotional and mental health issues:

I can help put you in touch with relevant information on a variety of issues, from depression and anxiety to a whole range of other diagnoses. There is also some information on the GUCH website in the 4teens

section and the Information > Emotional Health section. There are also many self-help initiatives that can help people manage and cope with their feelings.

Put you in touch with local resources and services:

As I have worked extensively in mental health and voluntary sector services, I am aware of the different sorts of support services that might be available locally for patients (not just NHS and Social Services). If I have someone's age, postcode and the type of concern they have, I can investigate what might be available in their locality (unfortunately this varies enormously across the country).

Patient and social events:

In 2011, I hope to continue to be involved with and meet members and their friends and families at our patient events, conference and social occasions. If you see me, please come and say 'hello' and feel free to ask me any questions you might have. I also aim to run some more focused workshops such as my 'Mini Chill Out' sessions.

Are there any issues or concerns that you would like me to explore further or write about in GUCH News? Please email me (or write c/o head office) any thoughts you might have.



Anne is on hand to help

So don't be shy if you have any concerns or questions, big or small, please get in contact and I'll do my best to help.

Anne Crump, Mental Health Support Worker
guchmh@googlemail.com 020 8240 1165

The vast majority of GUCH patients are successfully working in a range of physically and mentally demanding careers.

EMPLOYMENT ISSUES AND YOUR HEALTH

Whilst there are some occupations where restrictions apply, these are relatively few and are often the result of specific workplace and/or an individual's conditions or requirements. With flexibility and perseverance, GUCHs can find work suited to their skills and interests with their health presenting little, if any, difficulty.

However, having any illness or disability, combined with normal workplace stresses, can be challenging. Hidden or non-visible conditions present further issues because they are not immediately apparent.

PHYSICAL AND PRACTICAL DIFFICULTIES

- Tiredness, fatigue and other physical symptoms can impair concentration and create difficulty in carrying out certain tasks.
- Deteriorating health whilst awaiting surgery
- Post-operative effects and rehabilitation.
- Effects of medication.
- Absence when unwell and for surgery, routine appointments and tests, which can be as regularly as weekly.

PSYCHOLOGICAL ISSUES

- Concerns about what to tell employers or colleagues and their reaction.
- Becoming isolated, both physically and emotionally, through a reluctance to talk about the condition.
- Not wanting to be seen to have any weakness, vulnerability or "disability" due to personal pride and fears about future prospects or long-term employment. This can lead to a reluctance to request or accept help.
- Lack of control / powerlessness.
- Concerns about the social and financial effects of being unable to work or having to reduce hours.

LEGISLATION

- The Equalities Act 2010 (EA) came into effect on 1st October 2010 and prevents employers from asking if an applicant has a disability without having a specific reason (e.g. a particular

physical ability being essential for carrying out the job or to monitor discrimination).

- The EA incorporates previous legislation, including the Disability Discrimination Act 1995 (DDA) which placed a responsibility on employers to provide reasonable adjustments to enable disabled staff to carry out their job. Disability is defined as any long-term condition that significantly affects day-to-day activities. What is considered reasonable depends on what the specific organisation can be expected to provide but can include flexible working patterns, reduced hours or a change in duties. Disability Adjustment Leave (DAL), paid time off for appointments or illness relating to a specific condition, is also considered a reasonable adjustment.



- Under The Health and Safety at Work Act 1974 (HSWA) employees have a responsibility to enable employers to meet health and safety obligations. You must inform your employer of any health issues and risks affecting your work but are not obliged to provide details of your diagnosis or treatment.
- Under the Data Protection Act 1998 (DPA) an employer cannot disclose the fact that an employee has a disability to other members of staff without the consent of the individual.



HELP AVAILABLE

- The Access to Work scheme, available through your jobcentre, provides disabled people and their employers with assistance in overcoming obstacles to entering or remaining in work.
- Your jobcentre can also provide details of the Pathways to Work, Work Choice and New Deal for Disabled People schemes, designed to assist disabled people with finding suitable employment.
- A booklet published by the British Heart Foundation, Returning to Work with a Heart Condition can be ordered or downloaded from their website, www.bhf.org.uk
- The Employers Forum on Disability publishes a number of guides for managers on disability issues, available through their website; www.employers-forum.co.uk. Subjects include non-visible disabilities and reasonable adjustments.
- Your manager and colleagues can provide support and help with specific tasks on a day-to-day basis.
- Some employers provide welfare services offering counselling, support and legal advice.
- Occupational health services provide advice on the effects of work and health on each other and any necessary adjustments.
- Trade Unions can provide advice and representation for members.
- ACAS provide an arbitration service. Their website www.acas.org.uk has a section on health, work and wellbeing.
- The Information & Advice Page of the Useful Links section of the GUCH website provides details of other organisations and websites dealing with disability and discrimination issues, including the Equality and Human Rights Commission, Citizens Advice Bureau, Royal Association for Disability and Rehabilitation (RADAR) and the Directgov website www.direct.gov.uk.

Sarah Barker

SCARRING – A SENSITIVE SUBJECT

Although published almost a year ago, our issue on scarring (Issue 61) is still provoking a strong response. Some readers write to us to tell their own stories, some to comment on the bravery of the authors, and some to ask for further advice about learning to accept their own scars.

Here, Rachel Robinson from North Yorkshire tells us how she had never heard of anyone else with a Y-shaped scar before we ran our feature:

I was born in North Yorkshire in 1968, with Transposition of the Great Arteries. This was corrected with the Mustard operation in 1970 at Great Ormond Street Hospital.

I have a Y-shaped scar and I've never met anybody else with this type of scar. This is my biggest scar, although I have scars all over my body from the operation.

School was very difficult for me, especially because nobody, other than medical professionals, really knew anything about heart defects at that time.

I have had a love-hate relationship with it, but now I'm very proud of my Y-shaped scar, because not many people have this shape of scar. I've only ever met two other people with a heart defect. One was a girl I went to school with, with whom I've lost touch and the other one was a boy who is about 22 now.

I have two children, boys aged 17 and 13. Neither of them have any problems with their hearts.

CORNER

FEEDBACK

ARE YOU EXPERIENCING PROBLEMS IN YOUR WORKPLACE BECAUSE OF YOUR HEART CONDITION?

If so, we may be able to help. GUCH PA has recently partnered with a highly experienced and very friendly firm of solicitors who specialise in employment law to provide 30 minutes of expert legal advice on your situation at absolutely no cost to you.

Speak directly to a specialist solicitor and get advice on your employment situation. All calls are treated confidentially and there is usually an option to personally pursue further consultancy on a no win, no fee basis.

Please note that to qualify for this service, you must be a GUCH patient and you must be experiencing an employment issue directly resulting from your health condition.

For further information and to request this service, please contact our office on 01473 252007 or email admin@guch.org.uk



Adam at the very start of his massive adventure!

Thank you very much to Adam Draige, 20, for his amazing fundraising – a staggering £2700! Adam undertook the mammoth challenge of cycling from Land's End to John O'Groats in summer 2010, in memory of his friend Euan Lankester who sadly passed away earlier in the year.

Adam was rightfully very proud of his achievements, which took an impressive ten and a half days to complete. Speaking to GUCH News he told us; "Undertaking this journey has always been an ambition of mine, so to complete the whole thing was always going to be very rewarding but earlier this year I was unfortunately dealt with a reason to dedicate the cycle to someone very close to me."

From everyone at GUCH PA, to Adam and everyone who supported this incredible cycle, THANK YOU!

YOU ARE NOT ALONE...

Contact our freephone helpline service
for advice, information, or if
you just need someone to listen...

0800 854 759

2011 brings many things for many people – a fresh start, a new resolution, time for change.

GOODBYE PAULA! WE WILL MISS YOU

For GUCH PA, a new year means a new development organisationally. Following careful and close assessment of all areas of GUCH PA, it was felt that having more freelance workers spread across the UK would benefit the organization long-term in ways that static posts could not. Paula Banda's role was therefore as a result, regrettably redundant. Whilst we look forward optimistically to the changes ahead and the development and growth of our organisation, it is undoubtedly a sad fact that Paula can no longer be part of the team.

Paula joined GUCH PA in September 2001 and since then has gone on to help develop the organisation's services and relationships with healthcare professionals, companies and members alike. She has been passionate about improving the care for all GUCHs, including those who were not known to the established specialist services. With a warm humour, a generous heart, and a tenacious work ethic, Paula's vibrancy within the organisation will be missed by many.

On a personal note I, along with the staff and many of our readers, shall miss her deeply and wish her all the very best for a shining future. To Paula, thank you – you star!

It is with much regret that I have left GUCH Patients Association. I would like to thank my colleagues for their help and support, all the GUCH nurses for their dedication and the superlative care they give and the GUCH Consultants whose expertise, enthusiasm and passion for their work are leading the way in giving the best care available to their patients. As you know, there is still so very much to do to get equitable, timely and correct care for all GUCH patients and this group of dedicated professionals are tirelessly working on your behalf.

Most of all, I would like to say goodbye to each and every one of you. I have learnt so much from the time I have spent with you, I will always cherish the memories I have, not only the hard times, mainly of the fun and laughter we shared together.

It has been my privilege to work on your behalf.

With very best wishes for the future,
Paula

Victoria Goldsmith



Sima is a big fan of GUCH News and loves being a member

HELLO FROM SIMA!

GUCH member Sima Goyal, from Maidenhead, Berks, loves receiving GUCH News and tells us she looks forward to it every quarter; "I enjoy reading the articles and hearing from other members. I can relate to the stories because I was born with a congenital heart defect in 1971."

*"Thank you for all the work you do, you are all brilliant!"
- Reader Katie Wintle*

CORNER

FEEDBACK

Hello, my name is Tom. I was born in 1969 with Fallot's Tetralogy. It sounded very posh but didn't mean a thing to me.

TAKE HEART... LIFE'S WHAT YOU MAKE IT

If they had explained that I was a blue baby, with holes in my heart, an abnormal aorta and other complications, I still wouldn't have been any wiser. Nowadays, when I get out of breath, I come out with quips like 'Aorta know better' – pity really.

At the beginning, it was simply a case of hanging on. I was good at that. My heart and I worked overtime – all the time. My mother was brilliant and calm, my sister cared for me and my dad went to work. Dad, a pilot, always said 'I must fly' when he left the house.

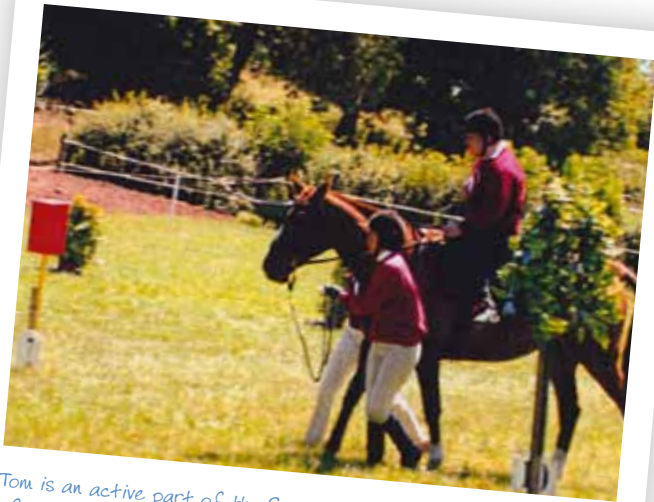
Things all went a bit wrong again when I was nine months old. I had a stroke. That made me 'right-sided hemiplegic' – more fancy names – with some brain damage and a limited right field of vision in both eyes.

After five weeks in a coma in Lincoln's St George's hospital, they decided to send me for heart surgery to London's world famous Great Ormond Street Hospital. An American surgeon did my palliative operation. This was to keep me going for a few years until I was strong enough to have a more complex procedure. He was the first of a truly inspirational sequence of specialists who have kept me going forward all this time. I went in blue and came out pink.

Before my next big operation, I lived in Cyprus, where my dad did lots of Vulcan flying for the RAF. Back in England, Mr. de Leval, the Belgian surgeon, did my main heart operation in 1977. The procedure took over eight hours, and my parents had to stay overnight. They were amazed to see how I appeared the next morning, in intensive care. I had wires and tubes going into and out of me absolutely everywhere. I was in an oxygen tent, and my machines and dials bleeped regularly. The nurses floated around like angels, always quietly, with a smile and an occasional little wave. I didn't see any of this; my eyes were tight shut. But then my dad whispered: "Hi Tom! It's Mum and Dad." I nodded very, very vigorously. They were astounded.

Nearly all my schools were part of the Spastics Society (now called SCOPE). They were excellent and fun. At Delarue School, near Tonbridge in Kent, I went ocean sailing in a tall ship to help the design phase of STS Lord Nelson, the flagship of the Jubilee Sailing Trust. I also did normal lessons at every school, earning several certificates, including a Duke of Edinburgh Bronze.





Tom is an active part of the Scope team and enjoys a range of hobbies.

When I was 30, the heart specialists said that I needed to have a pulmonary valve transplant. My old valve would probably only last for another two years, they said, whereas a 'new' one might give me another 25 years. But there was a risk with the operation, they added, so what did I think? "Let's do it, no hesitation" I said.

It was my sister who helped me to start recovering properly from the operation in 2001. I had been sent back into intensive care for a second time, because I was hardly eating or drinking anything, and my breathing was very shallow. When she was leaning over me and trying to make me have a sip of water, she heard me murmur through my oxygen mask: "I wouldn't mind a coke." She quickly got some cans from the machine, and the rest, as they say, is history.

My career has been in horticulture since 1987. I live and work with SCOPE in beautiful Dorset. I have plenty of hobbies, like horse riding and swimming, sometimes for charity. But I can't gallop and my swimming is steady, not speedy.

If they ever dissect me, they will probably find that I am 50% diet coke, 25% heart, and 25% spare parts. But I'm not ready for that yet; I've still got loads more to do. So if you ever feel blue, just take heart, like me. Life can be brilliant, if everyone pulls together. Life is exciting, life is family and life is teamwork.

Thomas Charles Davies

AT A LOOSE END IN THE EASTER HOLIDAYS?

How about coming along to our Young People's Theatre Trip to see Thriller Live at the Birmingham Hippodrome?

Wednesday 20th April 2011
1pm–5.30pm.

For young people aged 16–24 years, born with a heart condition. A great chance to meet up with others, see a fab show and maybe practice your 'moonwalk' afterwards. Tickets to the show are free.

For more information or to book a place, please contact Anne Crump on 020 8240 1165 or guchmh@googlemail.com.



ONE STEP AT A TIME

It is commonly perceived that people who climb up and down hills and mountains must be very fit and healthy and I must admit that I probably would have agreed with that statement a few years ago.

However, it was during a holiday in Scotland in 2007 that my opinion changed and I found that with the right mindset, people can achieve whatever they want to.

With my right ventricle severely dilated, a defibrillator recently fitted, awaiting a transplant assessment and in grade 3-4 heart failure, I knew I was deteriorating fast and really quite ill. I needed plenty of breaks in order to get through the day; I was tired and breathless on exercise and could not go up any inclines without having to stop to catch my breath.

My wife Karen and I decided to go for a relaxing break in Fort William where we were going to take a train journey along the line they use for the Hogwarts Express in the Harry Potter films. Whilst looking for other non-energetic things to do, we saw there was a cable car journey to a viewing point of Ben Nevis. As we sat in the cable car, we were treated to watching some mad people on mountain bikes flying down the steep hill. At the top we saw a sign for a cafe but also for a walking path further up the hill to the summit. I looked at the path and saw how high it went and thought the view from the top must be stunning. At this point I would usually head for the cafe but something stirred in me and I turned to Karen and said: "I'd like to go up the path. What do you think?"

"Why not? We can certainly try; we'll take it one step at a time and see how we go", she replied sensibly but enthusiastically.

"Great, let's go."

The path would take most people about 20 minutes to get to the top. We were overtaken by both young and old as we took it very slowly. During our ascent, a range of emotions came over me but the first was excitement and optimism. Here I was, doing things that others could do quite easily and I was joining them. But after being overtaken by endless amounts of couples and groups, a certain sadness fell upon me. I felt conspicuous. I felt paranoid that everyone was wondering why I was going so slowly. We were only about a tenth of the way up there.

Resentment followed as a 50 year old man steamed past us, cruising effortlessly up the steep slope. What has happened to me? Why was my body letting me down? Why me? I became increasingly frustrated and as tiredness set in, my spirits plummeted. I started to cry. Not in the form of big soppy wailing but just a few sad tears rolling down my cheeks. I wanted to turn back. 'What was I thinking of, trying to walk up this big hill?', I thought negatively.

"Come on, if you still want to reach the top you can do it, just take it one step at a time. We have all day. Forget the others. Sit down on each step if need be. We'll get there", Karen said, reading the situation perfectly.

"One step at a time? Yes, you're right. One step at a time and forget the others", I replied.



Kieran was determined to walk and took it step by step

We carried on and to this day, I look at those few minutes as a pivotal moment in my life. It changed my outlook on my congenital heart disease (TGA) and how I should approach things.

So over the next hour and a half, we plodded up the hill, stopping after every step at times. I still felt that everyone was looking at me so in order to make myself feel better we came up with a range of 'stopping' excuses. I adjusted items of clothing, re-tied my shoelaces, sipped a drink, re-arranged Karen's rucksack and stopped to take many photos and they all seemed to make me feel better. The most logical one was to simply stop and admire the view. I felt less conspicuous and my spirit rose.

On nearing the top, I found that I didn't need to use these excuses. I just stopped and didn't care what others thought. I began feeling that even with all the people coming up and down around me, there was only the two of us on this hill. This was my climb and I was succeeding both physically and emotionally.

I cannot tell you the elation I felt when we eventually reached the peak. We sat down and were treated to a sensational view of Ben Nevis and the surrounding peaks. As I looked back at our route and what I had achieved, I was overcome with emotion. This climb had changed my outlook.

Once safely back in our B&B, my aching body slept for the rest of the day but it was worth it. I had climbed a 100 foot hill – one step at a time.

I joined the GUCH Walking club soon after this trip, where I found they all have the same attitude as me, and I have enjoyed many of their walks. However you do it and whatever the speed, you can get always get from A to B and see the most amazing countryside. Our heart conditions shouldn't dictate what we can and can't do, but our attitude towards life can.

Kieran Sandwell

GOODBYE ELIZABETH!

I'd like to express huge thanks and gratitude to volunteer Elizabeth Connolly, who has provided excellent support and help with GUCH News over the years as final copy proof reader.

Elizabeth, along with the other amazing proof readers we are lucky enough to have at GUCH News, has worked so hard to ensure that each issue of GUCH News is as good as it can be and accurate and linguistically correct.

Without Elizabeth on board, I would have really struggled as I settled into the role of Editor, and I'm sure the standard of quality would have struggled a little too!

Elizabeth is stepping back from the world of volunteering for a while (and after working so long and so intensely on the magazine, I can't say I blame her!). I wish her luck and look forward to her coming back into the fold when she is refreshed again.

Victoria Goldsmith

WHEN FINDING OUT ABOUT YOUR HEART CONDITION IS COMPLETELY OUT OF THE BLUE

MY STORY

The first indication that I might have a heart condition was in October 2009, when I started to experience mild chest pain and palpitations at rest. These symptoms started after I ran two marathons within 6 months of each other. After the Berlin marathon, I felt very nauseous, faint and as if my heart was racing. My mum had to take me back to the hotel room without any post race celebrations. I put these symptoms down to exhaustion, the heat and over-training.

Over the next two months, I continued to suffer palpitations and twinges of chest pain, even when just sat on the sofa relaxing. I looked up my symptoms on the internet and delved into my nursing knowledge looking for possible causes. Surely at 27, being fairly fit and exercising 10 hours a week I couldn't have a heart condition. I pondered this, continuing to train. My running ability began to decline, I felt slower and was getting very out of breath. After being outside in the cold, I would have blue or dark purple lips, fingers and toes. People started to comment about this. My initial thoughts were that I might have a faulty valve.

By December 2009, I got so concerned about my symptoms that I went to see my GP on New Year's Eve. I explained that I was getting regular palpitations, pain and blue lips. He told me this was probably nothing to worry about but organised tests.

January 2010 brought a series of tests including Echo tests, MRI, blood tests and an ECG. By March, I was finally given the diagnosis of an atrial septal defect. The hole in my heart was 2 x 3 cm in diameter. This news came as a shock and I wasn't sure how to take in it. My immediate feeling was fear for my fitness in the future and ability to race. I was told to give up any strenuous exercise as my heart was quite enlarged and was showing signs of failure. Doctors were uneasy about giving me answers to my questions about completing another marathon or triathlon. It transpired that the blue lips were as a result of shunt of blood backwards through the top chambers of my heart. This was a worrying time but I found strength in planning for the future.

At the end of May, I was told I required open heart surgery to close the hole. I was almost glad to hear this, as I wanted to be sure it was going to be repaired properly. Waiting to hear of a decision about the type of surgery I needed was the worst part. The surgeon asked me which scar I would prefer, particularly as a young woman. I opted for a vertical scar as, for me, it meant the best chance of recovery back into an active lifestyle. Funnily, of all the concerns surrounding heart surgery, the scar was one of the lowest on the list. The determination to get better was my main priority, whatever it took.

During this experience, I found it useful to speak to others going through a similar experience. I found this support online and in the GUCH forum. Asking simple or seemingly silly questions helped with feelings of loneliness. Knowing others had been through the same anxieties was a huge relief. During my recovery, I kept a blog which recorded my progress week



Corinne had no idea about her heart condition

by week. Writing about my feelings and experience after my operation enabled me to remain positive, even on my worst days. Following advice from the cardiac rehabilitation team, I walked every day and slowly increased the time and distance. At 8 weeks, I began to run again.

Whilst having open heart surgery is a physical experience, I found recovery a test of my mental strength. Having to spend a large period of time resting was frustrating, as was missing out on a summer of activity. My daily diary of activity gradually increased and my focus was on what I could do, rather than what I couldn't. If it wasn't for exercise, my heart defect may not have been picked up for another ten years and for that I will always be grateful.

The future is now an exciting prospect. In April, I will run the London Marathon. This challenge is two fold,

firstly to raise much needed funds and awareness for GUCH PA, which helped me through my diagnosis, surgery and recovery. Secondly, I will be returning to a race I love and running with a new pride that I can achieve great things despite having a congenital heart defect.

Corinne Ellison

Editor's note:

*You can read Corinne's blog here;
www.corinneellison.com*

Support Corinne as she supports GUCH PA by sponsoring her here: www.justgiving.com/corinneellison4GUCH

THE P.R.G. – A REFLECTION

As the last Chairman of the PRG (Patient Representative Group) I have recently been fielding questions surrounding what has happened to the group and how people can continue to get involved. There have been many changes in organisation and staffing at GUCH PA over the last few years, the latest of which you will be able to read about in this issue of GUCH News. The PRG (formerly ManCom) was originally put in place when the charity was much smaller and had fewer members, but as both grew it became increasingly difficult to ensure that the PRG remained effective and focused in its remit.

Following much discussion, in the middle of last year it was decided that having a small, elected group was not the optimal way for the most number of GUCHs to have input into the work of the charity, and the PRG was therefore disbanded.

Following Victoria Goldsmith's appointment as the Volunteer Manager in April 2009, there are now many more opportunities for all GUCHs, not just those formally elected to the PRG, to assist with the current and future work of the charity.

My time as the Chairman of the PRG was deeply satisfying on a personal level, but with the closure of that small group come many more openings for GUCHs of all ages and abilities to get involved. I remain an enthusiastic volunteer for GUCH PA, and continue to give my time and experience to assist wherever and however it can best be used. It is often said that as one door closes another opens, and this is very much the case for me, and hopefully, GUCH PA as a whole.

Beth Greenaway, former PRG Chair

GUCH PA is a charity and we rely heavily upon the kind donations from our members, friends and well wishers.

We are very lucky to have some truly fantastic supporters who continue to go to creative, demanding, weird and wonderful lengths to raise us funds and help keep us going.

We'd like to say a huge THANK YOU to each and every person who has either held a fundraising event, or supported one, on our behalf. Because of you, we can be here.

FUNDRAISING

Massive thanks and congratulations to Janis Hitchcock and friends for raising an amazing £696 for GUCH PA.

The intrepid team completed a 34 mile trek in Norfolk in the Spring.

Melany Stevenson donned her Santa Suit again this year and took part in the festive Santa Run for GUCH PA – raising an impressive £100 in the process. Thank you to Melany and all her supporters.

JOHN LAING CHARITABLE TRUST

We would like to say a big thank you to the John Laing Charitable Trust who recently made a very generous donation of £1000 to GUCH PA. John Laing employee Holly Bunning (who has previously volunteered for GUCH) personally nominated GUCH PA to receive the money in memory of her brother and is delighted that the donation will be used to help others.

John Laing is a specialist owner, operator and manager of public sector infrastructure assets in the UK and internationally.

Could you help too?

If, like Holly, your company runs any charitable donation schemes or sponsorships GUCH PA would be delighted to be nominated. Holly simply contacted us for some information to put forward for consideration and would encourage others to do the same.



Holly stands proud with the donation cheque in memory of her brother

THANK YOU

LET US KNOW!

Don't forget to let the Editor know if you're planning any fundraising events for GUCH PA – we can help promote your event (if we are given enough notice), and we would love to report back on your achievements.

Please note that although GUCH benefits from these services/activities, they are not official GUCH events and no GUCH staff has had any involvement at all with the organisation, financing, or directing. Member advertisement only

INTERNATIONAL COMMITTEE

The GUCH International Group [GIG] has been busy since our last update at the Patient Conference in October. We have changed as a team. With regret, Louise Boyd has decided to stand down to concentrate on other commitments; we send Louise our best wishes and thank her for her efforts. I am pleased to say that in her place, we now have Beth Greenaway, formerly chair of the Patient Representative Group (PRG). As a team, we have found our feet. 2010 was a year of us getting to know each other and deciding on what we should focus on to begin with. Our team now consists of Roderick Skinner [GUCH Trustee and GIG Chair], Victoria Goldsmith [Volunteer Development Manager], Beth Greenaway, Gill Mitan, Graham Ellis, Paul Willgoss and Peter Atwal.

Our main work to date has been the development of a GUCH Directory, as suggested by GUCH President Professor Jane Somerville and Michael Cumper [GUCH Chairman]. This is a guide to all of the patient groups we currently have links with, including some in Europe, with contact details and information about each organisation. We plan to expand this directory as we develop links with other international patient groups, and hope to include hospitals in Europe soon.

In 2011, we specifically wish to develop the Directory further, to work closer with European Congenital Heart Defects Organisation [ECHDO], to build an International page on the main GUCH PA website, and to prepare a presentation to give at the next Patient Conference. We are always happy to listen to ideas about international topics which affect GUCHs that you would like us to look at.

Gill Mitan



GET INVOLVED! COME TO CANTERBURY WITH GUCH PA

We are excited to announce that the 2011 social weekend will this year be in the beautiful and historical city of Canterbury.

Open to all, our weekends away provide the opportunity to meet others with heart conditions from all around the country in a fun, relaxed and safe way.

We are waiting final confirmation of the exact date and cost but it will definitely be a weekend in June and GUCH PA will be subsidising the cost to ensure it is as accessible as possible for everyone to enjoy.

To register your interest and get further details hot off the press, contact the office on 01473 252007 or email admin@guch.org.uk

Hope to see you there!

I have a congenital heart condition. Sometimes it's bad but most of the time there's very little wrong with me. I try to adopt this outlook as often as I can.

IT'S NOT JUST YOU ON THAT JOURNEY...

I've always been told that I am very brave to view things in this way. Being brave isn't really something I've necessarily felt, but then because my condition is something I have always lived with, I just accept it as a part of life and I'm lucky that it could be managed relatively straightforwardly.

Something I never picked up on until I've got older is that it is not, and never has been, just me that has to live with my heart disorder. Any fears, anxieties or worries are double for my parents, family and friends. As a child, whenever I was sick I would get a new teddy bear and I thought it was great. However, I never realised the level of panic or relief that I was alright that went along with those gifts.

As an adult having heart surgery, my personal experience has been to think that if I don't have the operation then, well, I might as well give up, so there's really not much point in worrying about it. To a certain extent, that is how my family must see it. However, when the reality of seeing someone they care about in hospital with lots of tubes in them and very ill hits home, I think the people who are truly brave at these times isn't the person in the bed – it's the relatives and friends of that person, those who come to visit, because they are the ones who will remember those images of their loved one.

I cannot imagine the pain my illness has caused my family and I imagine that this is the case for many people.

I suppose the experience of having heart surgery as an adult has made me realise and appreciate little things over the years. For example, when I may have been stopped from getting up to no good with my friends, it was not because my parents wrapped me up in cotton wool, I was simply taught to be careful. The reason for this was because they never want to see those scenes in hospital again, or at least as little as possible.

I have found that having my heart condition isn't much fun for many, many reasons, one being that people don't understand that generally I'm fine and they treat me differently to others. However, as annoying as this can be, I've learnt over the years that most people do this with the best of intentions so I should afford them a little more patience.

I know that in the next few years I will need another operation. I know that once again before that happens, I will become unwell again, but that after the operation and the recovery time, I will be fine. I also know that it won't just be me going through all the stages. In a way, it is a comfort to know that I have a close network of people going through it with me. Even though they won't have any of the physical symptoms, they will be going through just as much worry and stress as me. Something I will try to remember is that once I'm better, their recovery time begins.

Rebecca Khosah



SPOT THE 5 DIFFERENCES AND YOU COULD WIN A FANTASTIC PRIZE!

With it being the season of love and romance, what better prize to win than a gorgeous bath goodie set courtesy of Ren, AND a delicious box of indulgent choccies?!

Whether you're single or loved up, this is an indulgent treat sure to pamper you through the winter blues.

To be in with a chance of winning, simply take a look at the two pictures below and spot the 5 differences.

Email your answers, along with your name, full postal address and contact number to: victoria@guch.org.uk Alternatively, send your answers in to our head office.

The winner will be announced in the next issue.



CONGRATULATIONS!

CONGRATULATIONS TO LAST
ISSUE'S WINNER –
PHILIPPA DAVID FROM ESSEX –
WHO SCOOPS THE JEWELLERY,
PLUS MEMBERSHIP TO MEDICALERT.

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Contact the office on **01473 252 007**
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**DEADLINE FOR ARTICLES
FOR NEXT ISSUE IS
4TH APRIL 2011**

Are you aged 16-24? Fancy joining us for a fun-filled, musical afternoon in Birmingham city centre? Meet other young members and enjoy Thriller Live (and lunch!). For more info or to reserve a place, contact Anne Crump on 020 8240 1165 or guchmh@googlemail.com.

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