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Supporting young people and adults born with a heart condition

formerLY KNOWN AS THE GROWN UP CONGENITAL HEART PATIENTS’ ASSOCIATION

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TheSomervillle Foundation

Supporting young people and adults born with a heart condition

GUCH NEWS

Autumn 2012
News from our Chairman...

The long running issue of the childrens cardiac surgical centres (Safe and Sustainable) took a significant step forward in the decision over which centres will in future be doing surgery and which will not.

It may be a disappointment to those who have been operating on one of the centres that will cease surgery, but there had to be a reduction in centres to achieve the required increase in viability and outcome. It should also be remembered that although some centres will stop performing surgery, they will continue to be places where patients can see specialist cardiologists as outpatients.

If there is no surgery for children at a centre then it may be less likely that there will be adult surgery for GUCH patients either. However, whether this will be the case will be determined as part of the adult standards implementation as well as the implementation of the changes due to the decision over children's surgery.

My position remains the same as it has been from the start of these processes: the worst outcome is no change. We need improvement in the services for GUCHs, and designation of adult congenital heart services was only to be done after the children's surgical review had concluded. The worst thing now is further delay.

The engagement process on the proposed model of care and draft designation standards for adult congenital heart services has been very significant over many years. All at the Somerville Foundation send our huge thanks to Clinton Cards for the amazing loyalty to our charity and wish Clinton Lewin all the best for the future. I have written to him telling him this. The loss of funding from Clinton Cards has made the need for widening the base from where we get our funds even more necessary, and we are taking this matter very seriously by drawing up plans which we can implement. Anything you can do to help us in this process will be very much welcomed.

Insurance for GUCHs

Travel and life insurance can be an issue for GUCHs. We have in the past tried to find the more friendly insurers but they seem to change their attitude towards people with long-term conditions, and those that used to be reasonable sometimes become less so. I would like to try again and this time speak to the underwriters so we can try to get them to understand that today people living with congenital heart conditions, whilst still being a higher risk in terms of insurance, are not as high a risk as they were in the past. Our survival and fitness does not seem to have filtered through to insurers. To be able to continue to do this for GUCHs is very important to us and we will need your help. We stop performing surgery, they will do something else. However, whether this will be the decision over which centres will in future be doing surgery and the worst thing now is further delay.

In issue 69 on page 14 we printed an article titled Heart Transplant – The Facts. This article stated that, “The Freeman (in Newcastle) is the only hospital carrying out transplants on adult congenital patients.” This is incorrect and we would like to take this opportunity to clarify the current adult heart transplantation services in the UK.

Whilst The Freeman Hospital is one of two specialist transplant centres for children requiring heart transplants (the other being Great Ormond Street), it is not the only hospital performing heart transplants on adult patients with congenital heart disease. Any UK heart transplant centre will consider any patient (including those with a congenital heart condition). The current UK heart transplant centres are:

- Papworth Hospital - Cambridge
- Harefield Hospital - London
- Freeman Hospital - Newcastle
- Wythenshawe Hospital - Manchester
- Queen Elizabeth II - Birmingham
- Golden Jubilee Hospital - Glasgow

We apologise unreservedly for any distress or confusion caused by the inaccurate statement.

Editor’s letter

Hello and welcome to the Autumn issue of GUCH News. I hope you’ve had a lovely summer and enjoyed the Olympic festivities that have swept the country and engaged the nation. Now that sport and summer is over, we at The Somerville Foundation are gearing up for our Autumn and Winter activities, which will see us in Glasgow hosting our annual national conference in October, and rolling out a brand new website to go alongside our brand new name. We are so excited to be going up to Scotland and meeting our members – if you’re not yet booked on and would like to join us, please contact our office ASAP! It would be wonderful to see you there!

In this issue we are delighted to share with you some of the most heartfelt and truly inspiring stories from some of our members and readers. From the scariness of surgery told with humour and brutal honesty by Thomas Sparks (p12 ft 13) to a long life lived well and full and still going strong at 80 years old by Jean Smith (p8), we hope you enjoy sharing a glimpse into fellow GUCH patients’ lives, adventures, fears, tears and hope. We also have a profile on the rare condition Ebstein’s Anomaly (p10 ft11), as well as lots of other articles packed with experiences, help and information.

If you have a heart condition, you may be at greater risk of complications from the nasty old virus called flu. It is coming up now for flu season and, as ever, we urge all our readers to consider having the flu vaccination (p15). Speak to your GP or cardiologist if you have any questions – but don’t leave it to chance!

And lastly, we have a fabulous competition where you can win a £25 voucher to spend at Interflora.co.uk (p19). Why not see if you can spot the differences and be in with a chance of winning?

Take care,

Victoria

PS: Please note the next deadline for content is October 30th.

Unfortunately it’s not always possible to print all the content we receive. It’s strongly advisable to contact us first to discuss any ideas you may have to ensure we are expecting your work. We reserve the right to edit content as we deem appropriate.

Volunteering Opportunities

We are proud to have been awarded the Investing in Volunteers quality standard from Volunteering England. We strive to offer stimulating, interesting volunteer opportunities and we are committed to providing regular, ongoing support to our volunteers.

WANTED

Do you have a story to share? Whether writing from your own experience as a GUCH patient, relative or friend, or supporting the team to research and write features, we would love to hear from you and discuss some ideas.

GUCH News depends upon high quality, interesting content. Can you help?

Contact Victoria Goldsmith on 0207 4220630 or email victoria@thesf.org.uk

Fundraise for us

We love celebrating the amazing achievements of our fundraisers – they are our bread and butter and are so appreciated. If you’d like to join Team Somerville and take on a money raising challenge, look out for some events happening near you where you could enter and raise promo material if you need it and whatever else we can help with. Get in touch with our office today to chat about fundraising and help support the Somerville Foundation.

Contact Helen or Fipipa on 01422 252077 or email fundraising@thesf.org.uk

If you are interested in any of the opportunities detailed here, or if you would like to register your interest for future opportunities, please contact me on 0207 4220630 or email victoria@thesf.org.uk. Alternatively you can write to me c/o our head office.

www.facebook.com/thesomervillefoundation

www.twitter.com/_thesf

www.thesf.org.uk

http://thesfblog.wordpress.com/
My life with Warfarin

I have been taking the drug warfarin since I was just six months old. I’m now 23, and when I tell people I take warfarin, they are sometimes confused and shocked. Why would a seemingly healthy 23-year-old woman be on a drug commonly associated with elderly heart care? Having had a Fontan procedure at six months old, followed by a shunt placed in my heart at 18 months, my heart is working a lot harder than it should have to. So, I take warfarin to prevent my blood from clotting.

Growing up, I never really understood why I was taking it. As far as I was concerned, my heart defect had been corrected with surgery, and now I was just taking the medication as a “precaution.” To me, warfarin seemed pointless. I took it every day but it never really made me feel any different. The only issues that bothered me were the bruises that would appear on me for no reason, and, whenever I cut myself, I would bleed a lot more than anyone else I knew. However, it was only when I reached my late teens that I finally noticed I was different to a “healthy” person.

Like most teens, I started going out a lot more when I turned 18. I would go out most weekends with my friends to a pub or a bar. They would all be drinking bottles of wine like it was pop. But me? I sat there with a glass of coke. I researched drinking alcohol thins your blood and so does alcohol. Combined, the effect can be very dangerous if an accident occurs, I fall over, or simply cut myself. It was for this reason I decided it was best to stick to soft drinks!

As previously mentioned, the random bruises I kept getting for no reason were also a concern for me. I hated my friends noticing the difference. Seeing my friends enjoying a glass of wine, I started to feel I was having a panic attack. I couldn’t get my breath back no matter how hard I tried, so I was taken to hospital. When I arrived I had many blood tests and scans, and I was informed that I had several blood clots in both of my lungs. So, it finally made sense, why I had been taking warfarin for the past 23 years: it was to stop something like this happening. I was very surprised when I was told I had blood clots, I thought it was impossible while I was on warfarin. But my doctor explained that the warfarin stopped the blood clots becoming a lot worse, and he also said that if I had not been on warfarin, they may have gone undiagnosed, which obviously would have made things much worse. But at least now I knew why I had been feeling so poorly for so long. I was relieved to have a diagnosis and to be able to get it treated, and, although I currently still have the blood clots, I feel a lot better than I have for months.

So, now I know why I take warfarin, and it isn’t really just a ‘precaution.’ As far as I am concerned, warfarin is a life saving drug.

Warfarin: The Facts

You may know people who are taking warfarin, but do you know why they take it and what it does for them?

Warfarin is an anticoagulant drug. This means that it increases the time it takes for the blood to clot. If your body makes a clot it can cause serious problems.

Warfarin comes in tablet form and is taken by mouth. It binds with vitamin K found in the blood, reducing the amount of vitamin K available to the liver for use in the body’s clotting cascade. The clotting cascade is the series of processes that occurs within the blood from the time that you (for example) cut yourself to the time the body has made a clot to stop the bleeding. Warfarin is used to reduce the likelihood of clots forming and can help stop clots from getting larger. It can also be used to treat existing clots, e.g. for someone with deep vein thrombosis or pulmonary embolism.

The length of time a person is on warfarin depends on the condition for which it has been prescribed. Everyone who is prescribed the drug should be given a booklet about anticoagulants which contains lots of information on warfarin and advice about food, alcohol and possible interactions with other drugs, as well as a space where they can record their blood results and warfarin doses.

The drug is used to prevent and treat health conditions including:

- complex congenital heart disease
- mechanical heart valve replacement
- atrial fibrillation or atrial flutter
- heart attack
- Transient Ischemic Attack (stroke)
- pulmonary embolism (clot in the lungs)
- deep vein thrombosis (clot in the veins in the legs)
- Other surgical procedures (some procedures place a person at a high risk of developing a blood clot)

Whilst on warfarin, the person’s blood will be regularly monitored by blood tests/finger prick tests to measure its INR (International Normalized Ratio). A normal INR result for someone not taking warfarin is 1.0. The higher the reading the more anticoagulated the patient is. The required level of the INR will differ depending on the reason the patient is anticoagulated.

If the INR level goes below the required level, this means that the blood is able to clot more easily and places that patient at higher risk of developing an unwanted clot. Treatment for this is simple: a higher dose of warfarin will be prescribed. If the INR goes above the target range this means the blood will take longer to clot and a lower dose of warfarin will be prescribed.

There are many factors that can affect a person’s INR result. These include a change in diet, a change in medications, the onset of a new illness, or having to stop taking warfarin because of undergoing a procedure. There are no symptoms of a low INR. However a high INR may result in:

- bruising more easily
- bleeding from the nose
- bleeding from gums
- blood in the urine
- blood in stools
- unexpected vaginal bleeding/ excessively heavy periods

For these reasons it is very important that patients ensure that they get their INR levels checked regularly.

People who take warfarin may need to make minor adjustments to their lifestyle. Ideally, they should not participate in contact sports e.g. rugby or horse riding, due to the increased risk of serious injury and associated bleeding. Alcohol elevates the INR result in everyone, but this effect is greatly increased in those patients taking warfarin. For this reason binge drinking is not advisable – but then, binge drinking is not really advisable for anyone!

Vitamin K is an essential element of the clotting cascade and is found in large quantities in leafy green vegetables, cranberry juice, liver/feet meats and soya products to name a few. One of the most important lifestyle adjustments that people with heart conditions can make is to ensure that they have a healthy, balanced diet.

Therefore these food groups should be totally avoided – just not eaten in excessive amounts. People who take warfarin should be monitored regularly by their healthcare provider; who should ensure that their warfarin dose is suitable, taking their normal diet into account.

Congratulations to Professor Somerville

Following the article in the Spring 2012 issue of GUCH News, our President, Jane Somerville, has been recognized as one of only five Legends of Cardiovascular Medicine by the American College of Cardiology (ACC). Her appearance at the ACC-12 conference in Chicago earlier this year was eagerly anticipated. Large queues had formed some time before her lecture was due to start, recognising her well deserved place in CHD history and the straightforward, truthful candour for which she is renowned.

She did not disappoint. Her historical account of CHD surgery was described in the ACHD Review, published by the ACC, as “entertaining and informative.” She also spoke about her upbringing and what brought her to surgery and congenital heart disease cardiology.

She discussed her work in opening the first adolescent CHD ward in 1976 at the National Heart Hospital in London, stating modestly, “the idea really came from the Toronto Hospital for Sick Children. They knew the sick kids who survived congenital heart disease grew up, but they were a kids’ hospital. GUCH was a way to use that idea. We didn’t invent anything; we built on what went before.”

Jane was reflective about her life and career, displaying an emotional side rarely seen by those who have followed her career. Jane said of the event: “It was amazing. I felt I had achieved something in medicine. The Americans were so generous in their recognition. I felt proud to be included amongst the giants of cardiovascular diseases who had made such huge contributions. GUCH is so small but I got so much recognition for what a GUCH is. This is a fitting tribute to Professor Somerville’s achievements and to her steadfast belief that the unique needs of a GUCH is renowned.

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An exploration into Psychology - could you benefit?

Part 3: Some more Psychological Therapies

Dr Liza Morton

In Part 1 (GUCH News issue 68, p14) we explored some of the unique emotional challenges that might arise from living with a heart condition from birth. These included feeling different, living with hidden symptoms, feeling out of control, enduring traumatic experiences, missing out and feeling unsafe. In Part 2 (GUCH News issue 69, p18) we considered what psychology can offer us, exploring SelH, Emotional Support, Person Centered Counselling and Cognitive Behavioural Therapy (CBT) as possible sources of psychological support.

We noted that although not everyone who is born with a heart condition would need this support there is no harm in being aware of these options and deciding for ourselves, especially since a holistic account of living with CHD (congenital heart disease) might offer better physical and emotional health and a better quality of life.

Interpersonal Psychotherapy (IPT)

IPT focuses on reducing mood problems by developing a more supportive social circle. Early sessions review the key people in your life. Therapy focuses on one of four areas; an Interpersonal Dispute (such as an argument with someone who is important to you), a Role Transition (like moving house), a Grief or Loss and Interpersonal Sensitivities (general problems with making and keeping relationships). These four focus areas could be appropriate depending on the trigger for your current mood difficulties. A focus on Interpersonal Disputes might help if you are having problems navigating the medical system or if you are being bullied. Role Transitions might benefit you during the move from childhood to adult care, adapting to having a cardiac medical device fitted, and is offered by some Chartered Psychologists and some other therapists both privately and within the NHS.

Body Psychotherapy

Recent approaches within psychology offer a more holistic account of human experience than previous approaches. During a threatening situation the body reacts by preparing to defend itself through its flight, fight or freeze response. Sometimes even though the threat is gone the body is left stuck in this mode which can cause a number of physical and psychological symptoms including sleep disturbance, panic attacks, exhaustion, feeling unsafe, flashbacks and nightmares. This is known as post-traumatic stress.

Body psychotherapy is an integrated method of psychotherapy that addresses thoughts, emotions and bodily sensations. The aim of therapy is to help you manage your anxiety, establish feelings of safety and process traumatic experiences. This kind of therapy could be useful if you find that you are suffering from post-traumatic stress as a result of medical trauma.

The Human Givens

The Human Givens approach is based on the idea that we each have a basic set of needs (such as security, attention, autonomy, emotional intimacy, status, meaning and purpose) and if these are not met then we feel emotional distress (see the Human Givens Institute www.hgi.org.uk). This approach works to help you adjust your life so that all these needs are being met with the aim of reducing psychological distress.

Finding the right therapist

The quality of the therapeutic relationship is at least as important as the therapeutic method. Therefore, finding the right fit with a therapist that you feel comfortable and safe with is as important as finding the type of therapy that you feel would help you the most.

How to access help

Referral to a Clinical or Counselling Psychologist, CBT Therapist or Counsellor in the NHS should be done via your GP or another doctor such as your cardiologist. Therapists typically charge between £35-70 per hour. The British Association for Behavioural and Cognitive Psychotherapies (BABCP) lists accredited private CBT therapists. We noted that although not everyone who is born with a heart condition would need this support there is no harm in being aware of these options and deciding for ourselves.

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Born the youngest of four in 1955, I was diagnosed with pulmonary and infundibular stenosis as a baby. My early childhood memories are of train trips to London to see my cardiologist Dr. Baker, and of a week in Guy's aged five for various tests and catheters. I remember long lines of cot beds, a strict regime, and parental visits of only an hour once a day.

ECGs were done with metal plates, gel and red rubber straps around wrists and ankles, red rubber suction cups on the chest, and a great deal of goo.

Often after an appointment in London my treat was to go to Trafalgar Square to feed the pigeons—now I chase them out of my garden!

My mother was advised to let me lead as normal a life as possible, and I experienced the normal rough and tumble of family life. Climbing trees, ladders, the garage roof etc was normal, and we had a zip wire down the garden that I used to hang on by my knees. I also did lots of headstands etc—Mum’s theory was that it got blood to my brain! When we went for walks we would race to the ‘winning tree’ on the local golf course. I was given a headstart, but always lost as I ran out of breath halfway! My older sister rekons Mum kept chocolate in her pockets to give me if I went blue, but I don’t remember it! (I’m not sure what Mum felt it would do— but doubtless I made the most of it!)

When I was about nine Mum talked to me about a possible operation on my heart. I recall that I was not keen on the idea. However I was taken to see Russell Brock, and plans were made for me to have surgery about a month before my 10th birthday. I gathered they waited until then to allow the bypass techniques and outcomes of open heart surgery to improve. I recall Mr Brock seemed quite a shy man—not very tall, and with black heavy rimmed specs. I think he did talk to me, but I was on the fringe of the appointment— assessed, but not included in the discussion!

Prior to surgery I had to have a month off school to avoid the risk of picking up any infections. My sisters were sent to stay with relatives for the half term in case they gave me anything— they were not impressed! I was admitted to Guy’s a week before the op and had my own room with a basin on a private floor. I think perhaps it would have been more fun on a children’s ward, but maybe it allowed Mum to visit more often. Maybe it also related to the risk of infection.

The week included lots of pre-op tests and x-rays, and, because I would be in an oxygen tent, I also had a physiotherapist teaching me breathing exercises. They told me they would chill my body right down, and that I would only be warmed up gradually. In the pre op preparations I recall being horrified when they asked if I needed a pubic shave (I was nowhere near puberty!). I locked myself in the bathroom and refused to let the nurse ‘have a little look’ to check! Then I remember being wheeled through the basement to the theatre on a trolley, teddy in my arms, staring at pipes in the ceiling.

Post op I remember waking with that horrid burning in the chest feeling of being ventilated. I was stark naked, freezing cold, and surrounded by huge machines. It seemed as if numerous doctors in white coats came and went, and I felt very self conscious. Once I was weaned off the ventilator, the oxygen tent was put on— I thought it smelt funny. I also remember seeing my parents standing together looking at me (memorable as they had by then been divorced for over two years).

I had to lie flat for a week. VERY boring, no TV, just lots of books read by Mum, and probably ‘listen with mother’ on the radio. Time was also taken up with doctors, nurses and physio (breathing exercises including trying to blow bubbles through a straw in a jug of water). I don’t remember pain as a problem, and wanted to be able to do more than was allowed.

Week Two, I was allowed to sit up, but not allowed out of bed. The repertoire of activity could be extended to playing cards, battleships and squares on paper.

I think a teacher also came to see me a few times, but don’t remember doing much work [obviously I wasn’t that bored]!
I was born in 1952 and diagnosed with Ebstein’s Anomaly at birth. The prognosis was that I would not survive with this condition. I spent my first few years in and out of Sully Hospital in South Wales. During this time I underwent two lots of cardiac catheterisation. The doctors advised my parents not to wrap me in cotton wool and to let me have as normal a life as possible. I learnt to live with my condition and managed to play netball and took up horse riding, which all helped to strengthen my heart.

In 1975 I moved to Jersey where I met my husband. We were married in 1976 and then I was given several tests to see if my heart was strong enough to go ahead with a pregnancy. Unfortunately, my condition was too severe and I was advised that sterilisation was the best option. I am sure that with the advance of medical science it would be different in this day and age.

My condition was stable until 1985 when I was taken into hospital in Jersey suffering from fast atrial fibrillation with a constant rate of 150 beats per minute. My cardiologist prescribed flecainide, which kept my symptoms under control until around 2004 when I was diagnosed with a suspected blood clot. Warfarin was prescribed with regular blood tests.

In 2006 I was once again taken into hospital with atrial flutter, severe tricuspid regurgitation and cyanosis. After spending four days in intensive care, Dr Peter Strauss managed to get a transfer for me to The Heart Hospital in London. I was flown out of Jersey by air ambulance to Biggin Hill and then taken by ambulance to London. On admission I was examined by Dr Shay Cullen. He spent time with me explaining my condition and the operation that was going to be performed, which was an ablation. An amazing team at the hospital carried this out. After a few days, I was discharged back to Jersey with the contact number of my nursing specialist who I could call at any time.

Twelve months later my heart started to deteriorate again and my blood saturation was anything between 60 and 85 bpm. I received a cardiobypass but this was not successful. Dr Mitchell, my cardiologist in Jersey, prescribed Amiodorone. This kept me stable but this was not successful. Dr Mitchell then in the right ventricle and also the atrium the heart muscle in the right sided pumping chamber may be abnormal. The abnormality of the tricuspid valve can vary from mild to severe, which will affect the onset and severity of symptoms and means that no two cases are the same. In other words, the appearance of symptoms depends on the severity of the valve abnormality and may present at any age. We don’t know how many people have Ebstein’s because it can be mild and people may have no symptoms over decades until they are diagnosed. On the other hand, it can be very apparent in newborn babies or later on in life and can be so severe that surgery is necessary. To right heart failure more complicated, different types of valve repair surgery may be performed. However, it is important to emphasise that people with Ebstein’s Anomaly can have a good quality of life.

Symptoms and Surgery

Key symptoms are irregular heartbeat (atrial fibrillation), breathlessness, fatigue, poor exercise tolerance, chest pain and peripheral (blue discolouration of the finger and toes) and/or central cyanosis (bluish tinge of the skin). The usual indications for surgery are the appearance of heart failure, cyanosis, arrhythmia and deteriorating exercise capacity. The European Society of Cardiology recommends that surgery should be performed in patients with more than moderate tricuspid valve regurgitation and the presence of symptoms. The aim of surgery is to repair the valve. If this is not possible a valve replacement will be performed. Surgery to treat the arrhythmia may also be required at the same time.

Anatomical approach

The surgery for Ebstein’s anomaly has been performed by only a few pioneering surgeons. In recent years, eminent Brazilian cardiologist, Dr D. da Silva proposed a radical way of repairing the Ebstein’s tricuspid valve using an anatomical approach. The repair is to construct a cone or funnel-like valve out of the patient’s own tissue. The large valve ring is reduced in size. The repaired cone shaped valve is then attached to the valve ring. The repaired cone valve opens with central blood flow and closes with all the leaflet tissue. The cone repair programme started in 2009 at the Heart Hospital in London. From 2009 to 2011, eight adult patients (plus 11 patients at Great Ormond Street Hospital) with Ebstein’s Anomaly have undergone surgery. Pre- and post-operative evaluation was undertaken, including MRI and exercise testing with a follow-up 12 months after the operation.

Results

This surgical technique has been performed in over 100 patients with a good clinical outcome and no need for tricuspid valve replacement. Echo results showed good anatomic and functional tricuspid valves at immediate and long-term post-operative follow-up. Symptomatic improvement was reported in seven out of eight adult patients. The remaining patient needed re-operation to stabilise the valve ring repair, which was successful. The right heart circulation appears more efficient with more forward flow and less tricuspid valve leak. In addition, the left heart fills better and produces more pumping action.

This initial experience of the cone tricuspid valve repair in adults is promising and will be supported with ongoing assessment of further patients.

Ebstein’s Anomaly

Fiona Kennedy, GUCH Nurse Specialist at London’s Heart Hospital explains the condition Ebstein’s Anomaly, its associated valve problems and the pioneering new surgery describes Margaret Smith in her accompanying article, “Ebstein’s and me”.

Ebstein’s Anomaly is a rare condition that affects the tricuspid valve, which is on the right side of the heart between the upper collecting chamber (atrium) and pumping chamber (ventricle) and can also affect the heart muscle itself.

The tricuspid valve does not develop properly early on in foetal life and is not positioned as it should be inside the heart.

Ebstein’s Anomaly was first described in a publication by German physician Wilhelm Ebstein in 1866. The condition occurs in 0.5% of people born with congenital heart disease and is frequently associated with other congenital heart problems such as atrial septal defect (ASD), ventricular septal defect (VSD), pulmonary stenosis and pulmonary atresia. There are often problems with cardiac rhythm, most commonly atrial flutter or fibrillation. Quite a large proportion of patients with Ebstein’s anomaly have arrhythmias. This is often associated with an additional strand of muscle which lies between the atria and the ventricle. This is sometimes known as Wolff-Parkinson White syndrome or WPW. WPW can occur with other forms of congenital heart disease or may occur as a sole abnormality. WPW can usually be treated by medications or by an ablation procedure. This is a keyhole operation where the additional strand of muscle is removed at the time of cardiac catheterisation.

Ebstein-like abnormalities of the tricuspid valve may also occasionally occur in conditions such as Tetralogy of Fallot and congenitally corrected transposition of the great arteries. It is important to understand that Ebstein’s anomaly is not just a valve disease because it can also involve the heart muscle.

If you have Ebstein’s, it is vital that you are seen and assessed in a specialist GUCH centre where GUCH cardiologists agree the necessary investigations and treatment that are right for you.

Margaret Smith

Do you have Ebstein’s Anomaly? You may find further information and support at www.ebstein anomal y.org
I was born with Aortic Stenosis. I had a valvotomy at birth and have a fine scar to show for it!

I had a normal life; holidays, sports and never any issues. Family and friends steered me away from rollercoasters, rugby and long distance running and selected suitable alternatives so I never felt that I missed out on anything. As I got older, I knew that another operation was going to happen, the only question was when.

I developed Ulcerative Colitis, which, after many stays in hospital, including several birthdays and several operations, left me with a huge fear of hospitals. I would run away from the ward and hide from family and staff.

I passed 16, the "critical years", no valve replacement needed. I continued my 6 monthly checks.

At 23 I moved to London. I began to take care of my own health and decided that the 6 monthly appointments were now pointless. I stopped attending and became discharged from the cardiac unit.

Years passed with no symptoms. Ignoring advice from family and friends I still didn’t go for checkups. In the end it was a girlfriend who issued an ultimatum, almost certainly spurred on by family and friends. Reluctantly, I contacted my cardiologist and arranged an appointment. After several tantrums I was sat in the waiting room, seen by the cardiac physiologist, scanned and then given the news. My aortic valve had narrowed a lot over the years; although not quite enough for surgery, enough for me not to be able to climb Mount Kilimanjaro, in fact the thoughts were not to have it done. Aside from occasional pain, I was still hadn’t felt any pain. Once on the ward, having been given a pot of pills, several staff came along, checked I was me, my blood pressure, allergies etc. My consultant also came along.

Time flew by, my girlfriend arrived, occasionally bursting into tears, my blood pressure continued to climb. Andreas visited me. He had been there the previous evening and was over the moon. The next day I was discharged, that day I was back on the Cardiac ward. I was told exactly what was happening as I walked over. The next morning my catheter and neck lines were removed. I became aware of my scar for the first time, dressed neatly in the shape of a upside down "T".The physiotherapist came along to see me. I was surprised to be up and about, moving my arms, walking and sitting in chairs. By 2pm that day I was back on the Cardiac ward. I walked over. The next day I was discharged, three days post op and out!!

It is just over four weeks since my operation and I am amazed. I do get a fair amount of chest pain, controlled by medication, over 20 tablets a day! I am still a bit confused and I get tired easily. Before my operation I didn’t think I would be going out for lunch, playing with my nieces and nephews, cooking for friends and family and being "Chief Kitchen Cleaner" but I am!!

Although I was utterly distraught about this procedure, probably more so than even those closest to me knew, I am so glad I had it done and so grateful to the staff at MRI, my family, friends and girlfriend.
The flu, the vaccine, and you.

As sad as we are to see summer slipping by for another year, there are still plenty of great things to look forward to as we welcome the winter season. Cosy coal fires, outdoor ice skating, getting that “festive feeling”, snowmen and snow fights. One thing we most certainly are not looking forward to is the flu. Each year, without fail, the flu makes millions of people feel awful for ages, and in some cases, can lead to very dangerous complications.

Certain groups of people are considered to be more vulnerable to developing serious complications from the flu. One such group are congenital heart patients.

What is the flu?

Anyone can get the flu. A highly infectious illness, it can spread quickly through coughs and sneezes. Because it is viral and not bacterial, antibiotics do not work as a treatment. It is typical for people to suffer effects of the flu for around one week, and symptoms can hit quite suddenly and quite severely, including chills, a fever, aching muscles, headaches and a sore throat.

What is the flu vaccine?

An annual vaccine designed to protect against the year’s most anticipated strains of the flu virus. Made up of three different types of flu, the viruses are grown in hen’s eggs, and then killed and purified before being made into the vaccine. Because of this there is no way you will catch the flu through having your vaccination, as it is always possible. It can take between 10 and 14 days for your immune system to react fully to the vaccine. Because there are different types of the flu virus in circulation, it’s not possible to create a vaccine that protects against all of them. However, by having the vaccine you can greatly reduce your risk of catching the flu, and if you do catch it, often people experience much milder and shorter lived symptoms if they have had the vaccine.

Who can have the flu vaccine?

The NHS recommends the flu vaccine to those who:

- are 65 years old or over
- are pregnant
- have a serious medical condition (including congenital heart disease)
- are living in a long-stay residential care home or other long-stay care facility (not including prisons, young offender institutions or university halls of residence)
- are the main carer for an elderly or disabled person whose welfare may be at risk if you fall ill
- are a frontline health or social care worker

Who can’t have the flu vaccine?

If you are allergic to one of its ingredients, you should not have the flu jab and should consult your GP for alternative options.

Are there side effects?

It’s not usual for people to experience side effects, but those who do have reported a sore arm around the injection point, achy muscles and sometimes a temperature. These symptoms tend to pass after a day or two and are not serious. Allergic reactions to the vaccine are rare.

Who can’t have the flu vaccine?

If you have had an allergic reaction to a flu vaccine in the past, or if you are allergic to one of its ingredients, you should not have the flu jab and should consult your GP for alternative options.

If you suffer from an egg allergy, your doctor may decide to give you an egg free vaccine or, if this is not available, your GP may identify a suitable low egg vaccine which would be a suitable alternative.

If you are the parent of a child with a heart condition who is over 6 months old, speak to their GP and cardiologist about your child having the vaccine.

Where and when can I get the flu vaccine?

It’s easy! If you are a congenital heart patient then you are entitled to have the vaccine. Simply contact your GP surgery and enquire about their vaccination process. Many surgeries will hold clinics during the autumn where people can go along without an appointment and receive the vaccination. Alternatively, you can contact your local pharmacy, who will be able to give you advice and information about when and where the vaccine will be available. It’s recommended that people receive the vaccine from September to November, as the flu virus usually circulates for a few weeks during the winter. Every year you will need a new vaccine, because every year, the virus can change and you will need updated protection.

For more information, visit http://www.nhs.uk/conditions/flu-jab or phone NHS Direct on 0845 4647.
A journey to the heart

I was two when I was diagnosed with aortic stenosis, a narrowing of the aortic valve.

A few years ago I started to become very tired and breathless. My legs, ankles and hands began swelling. The symptoms began gradually and, being a busy working mum, I became used to them quite quickly and wasn’t particularly alarmed or aware when they occurred.

At my annual review, I told the doctor about my symptoms. I was sent for an exercise tolerance test. Turning up in my expensive trainers looking like Zola Budd minus the headband, everything looked okay but when I got home I fainted. I assumed it was tiredness, so I ignored it. Later that week I collapsed again. The next day I called Jim Mearns, clinical nurse specialist, who spoke to the adult congenital team and told me I was going into theatre. I told the doctor and he was happy going into theatre. I had no fear, just hope.

Surgery was scheduled for an aortic valve replacement.

A few days later, I met my surgeon, who I will forever know as The Genius I was surprised at his calmness. I asked him one question that day: I asked him if he was good. He didn’t reply, but I knew he was. I thought about giving him a wink to let him know that I also had an insight into this surgery, because I was a weekly follower of Holby City, where the patients are up and running the next day. I felt happy, hopeful that this would improve my quality of life. Late that afternoon I met the anaesthetist. People in this admirable profession do a very important job, making sure patients don’t feel anything. My anaesthetist was a true gentleman, possessing a calmness that only brought me more hope. That night nurse Mark Dyer, spoke to me about the Intensive Care stay. I will always appreciate those words, and amazingly, the following day I was happy going into theatre. I had no fear, just hope.

The operation was a long one and more complicated than anticipated. When I awoke I couldn’t quite understand what was going on but there seemed to be an angel with me that night. I literally thought she was an angel because with no contact lenses or glasses on and with the drugs the anaesthetist gave me I didn’t know where I was. My husband kept notes for me on my goings on in ICU. I would tap my heart and he would tell me how the surgery went.

The recovery was long. I kept a book under my pillow for names of the staff that took a little time to help me so I could thank them. Looking back, even the quality of my writing showed me how sick I was.

Nine months later, during an outpatient’s appointment, it was confirmed that there was a leak in my mitral valve. I looked at my husband with his head in his hands as my inspirational consultant told me there was another murmur. We were in disbelief. That night not a word was said except to tell our parents. I returned to work later that week, not one aware of what was about to happen again. The call came on the Friday from the hospital, quicker than anticipated. Open heart surgery was scheduled for Tuesday to repair the mitral valve.

After eight weeks of work I had to tell everyone that my return would be shorter than anticipated. Everyone was shocked, their faces showing their utter disbelief. My daughter, now old enough to really understand, was devastated.

After admission, The Genius came to see me. He was bringing in another surgeon, Mr Kenneth MacArthur. To this day I have never met Mr MacArthur, neither when vertical or awake, but I will always be eternally thankful to him. Again the anaesthetist came, talking gently and providing a sense of calm, and my inspirational consultant sat just chatting when she should have been at home with her own family.

I don’t know what is for the best: going to theatre knowing what is about to happen, or not knowing. This time, I set myself goals. I tapped my heart for my husband to tell me the news and I remember him saying those words: another metal valve! I could feel the tears trickle down my cheek. Again, a diary of who helped me and what happened on the days I missed was kept. Nae didn’t respond, how I snored far too loudly. It was another long recovery, with infection, fluid and a CT scan confirming another trip to theatre, all the time my wonderful consultant trying to soften the blow. Amazingly, a few days later it all seemed to come together. Day by day I felt stronger, until it was time to recuperate at home.

My mitral valve has a small leak. I think it’s a bit of an attention seeker, and if I could talk to it and if it could listen, I would say, “please give me a break. It’s okay to leak as long as it’s a small one. You can click loud and fast if you like but don’t give up because I love you as much as I love my aortic valve. Okay, I didn’t embrace you like I did the first one and I’m sorry for that, but together we can have a good life and go on a brand new journey. I’m in my heart and that’s a very special place to be.”

Who am I? I am an adult congenital heart patient and I hope that I have inspired even one person to have hope and faith in a specialised service that will make your journey a little easier, the fear more bearable, and provide you with an understanding that you will embrace, even when it is a little tougher than expected.

I would like to extend special thanks to The Golden Jubilee National Hospital Clydebank, the home of the genius Mr Andrew McLean, wonderful surgeons Mr MacArthur and Dr Bhawal, the inspirational consultant Dr Nikki Walker and the gentleman anaesthetist Dr Stephen Hickey. Thanks too to the team including Dr Hamish Walker, Dr Richard Dobson and clinical nurse specialist Jim Mearns, nurses Sandra Jansz and Mark Dyer, and to one person whom I shall forever refer to as the Angel of ICU – because you took care of me that night but I never learned of your name. Finally, thank you to the patients, whose laughter and tears I shall always treasure as we all continue on our journey.

There’s an app for that!

The Medical Alert app is an electronic version of Medical ID jewellery, and it can be found on your iPhone or Android phone allowing more details of your conditions to be communicated in an emergency situation. The app can easily be positioned on the home screen or in the dock on an iPhone for high visibility and ease of access.

After purchasing the app for £1.99 you can update your name, conditions, allergies and any other information, such as what tablets you take. The last box is for an emergency telephone number. The great thing about this is that when this button is clicked on the app homepage, it automatically rings the number.

This app would be brilliant for situations where you feel unwell and need assistance or for the emergency services to use if they need to call an emergency phone contact.

This should not be used instead of your existing Medical ID but maybe used in conjunction.

Tamryn Jones
With thanks to Cardiac Nurse Specialist Jane Hill.
Living with a congenital heart condition can be very tough. We understand, and we are here to listen.

We can also help with a range of queries and concerns from travel insurance, money worries, support and information.

You can call us for free from a landline on 0800 854 759 (costs from mobiles may vary) or you can email us at helpline@thesf.org.uk

We are open Monday – Friday and offer an answerphone service for when we are unavailable. We will return all phone messages and emails as soon as possible.

We are here. We care.

Your photographs are needed

Over the autumn I am going to develop some new advertising postcards and online resources to help support people to take care of their emotional and mental health. Members of The Somerville Foundation are invited to send in their photographs for consideration for use in online resources and advertising postcards. The two themes for your focus in these photographs are:

1. A relaxing and peaceful scene
2. A picture of something that ‘lifts your spirits’

I have already received a number of lovely photographs and it would be great to have some more. A big thank you to those of you who have already sent me photographs. Here is one I took of Matt and Ashley enjoying the bowling.

At the recent Young People’s Get Together at the Bloomsbury Bowling Lanes in London I asked people what helps them relax. Here is what they said:

“music, bowling, my cat, chocolate, singing, my dog, karaoke, reading.”

How do you relax? What helps lift your spirits? It would be great if you would please send me a photograph, or drop me a line to let me know.

Remember that you are welcome to contact me if you would like more information or to talk through any emotional or mental health concern.

Anne Crump, Mental Health Support Worker
anne@thesf.org.uk 020 8240 1165

Please note: Photographs need to be your own and will be credited to the person who took them. As the photographs will be used online and in other advertising materials, please be aware that the images would be public. If any photographs contain images of individuals, these individuals will need to give permission for their image to be used.

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We are here to listen.
Let us know what you’d like to see in future issues of GUCH News. We’d love your feedback, so give us some food for thought!

October 20th & 21st 2012. See inside for more details or contact us today to reserve your place!