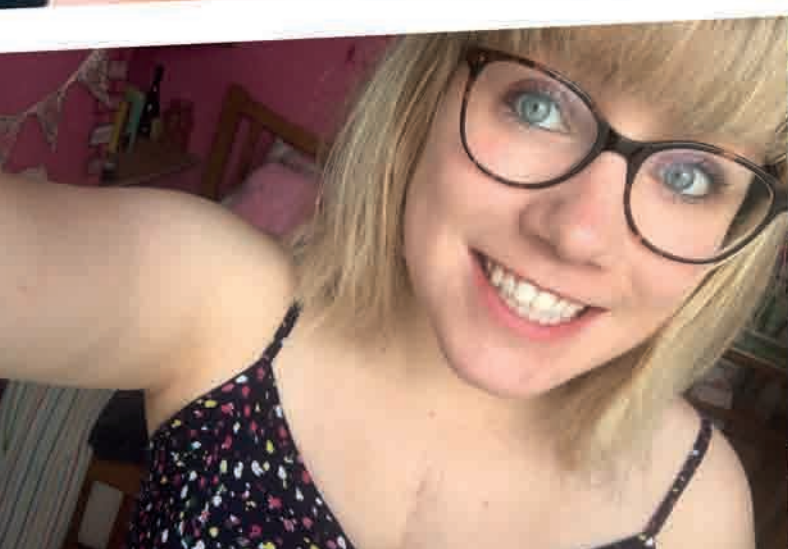


## Will, Amy and Hannah share their journeys



[Read more inside](#)

### In this issue...



Having another  
baby  
Pages 4 - 5



Pregnancy with  
half a heart  
Pages 8 - 9



Structured exercise  
programmes  
Pages 18 - 19

**Supporting every step of the half a heart journey**

# Suzie's news



Written by: Suzie Hutchinson

Oh my goodness me, 25 years of LHM. I can't believe that the charity has grown so much and yet, I hope, we have never lost the care for each and every family that we want to give. Members sit at the very heart of what we do, every step of our growth has been led by them and I have been honoured to be there from the beginning.



Coming to terms with the stress and fear created when a child has only half a heart is the same for families now as it was 25 years ago, that was why Little Hearts Matter was created. The difference, I hope, is that now families have somewhere to reach out to for support.

In the early days, before LHM existed, families had to travel to Birmingham Children's Hospital to seek out treatment for Hypoplastic Left Heart Syndrome because Birmingham was the only unit offering surgery. I was the Cardiac Liaison Sister there at the time, Fontan patients and their families were my main focus and I have to say my passion. I could see how difficult it was for them travelling a long way from home, desperately seeking surgery that offered their baby a chance of life. Although I could offer support and information I knew they needed something extra. Parent-to-parent understanding and support seemed to offer exactly what they were looking for so I called on some wonderful local families to offer them help. Donna and Mandy, two amazing mums, used to come into the hospital, share photos of their children and sit and talk to families. From this simple beginning the charity gradually grew.

Left Heart Matters, as it was known as in those days, formally registered in 1996 and developed to offer family support, newsletters and an annual Open Day. Eventually we wrote the first parent-focussed information on HLHS. As other hospitals started to offer surgery the charity expanded to offer support to anyone who needed help. Everyone was working as a volunteer in those days. There was no office, no dedicated phone line or social media. There wasn't even a website.

It became clear that the charity had to be able to respond to members whenever they needed help so the Trustees applied for a grant from the Lottery. The grant paid for a Development Officer and some admin support. I had completed 20 years in the NHS and wanted to be able to focus on supporting HLHS families. I applied and got the job. The first thing I did was to appoint Deb and the two of us, in different evolving roles, have worked for the charity ever since. This September we celebrated 20 years of

working for LHM.

Over the next ten years, as surgery for the children improved and more and more parents had their diagnosis made antenatally, the charity grew and grew. In 2004 it was agreed that there were many families seeking help along the Fontan pathway who did not have anywhere to go for support so LHM went to the Charity Commission to change our name and broaden our remit. We were now able to offer support to anyone affected by the diagnosis of a single ventricle (secretly we had been doing that over the years anyway).

With Trustee support, Deb and I started to create information that answered all of the questions parents came to us with. The filofax was created and then antenatal support, information about schools and DLA. Every time we had a question we would start to look for answers. And we created a website to hold all the information and help people find our support. The phone was always busy with people seeking help so gradually the number of staff increased.

One of the greatest joys has always been the chance to meet up with members at Open Days, workshops and activity weekends. The friendships formed when the children are small or between the teenagers have lasted for many years. Watching them grow up and begin to live independently is just wonderful. The Little Hearts Matter family has grown and grown, sadly we have lost children along their journey but the family has always been there for them and we will continue to be there for every member.

As the charity has grown we are also being asked to provide a voice within arenas for change. The medical units started to seek our help with moving treatment and care forward. The NHS sought out our help setting new Standards of Care. The Department for Education wanted help creating Health Care Plan support in schools and the Department for Work and Pensions, the people responsible for DLA and PIP, started to respond to our calls for change.

I gradually caught up with social media and with the

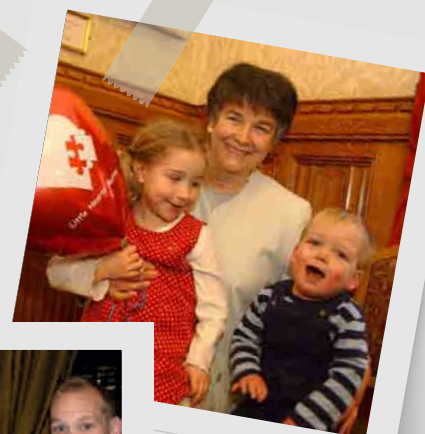




# Suzie looks back over her time with Little Hearts Matter, 25 years old this year.



Youth weekend 2013



House of Lords 2004



Open day 2003



House of Commons 2010

expertise of the growing office team we developed a social media service that not only told people about LHM but also created a great safe space for families to meet. It revolutionised the charity's ability to communicate with members but also allowed members to speak to each other and seek each others support, right back to the very core of our work.

We are all very proud of the service we have built over the last 25 years. There is of course more that we can do because we grow every year with more families seeking our help and more services to build to help them. The

biggest challenge over the next few years will be building the support for our child, teenager and young adult members living with their heart condition. It is amazing that so many of them are seeking our help and we love supporting them, but their needs are different from their families so we are working to extend our family.

To end on a personal note I would like to thank our members for allowing me to travel part of their half-a-heart journey with them. I know that I, and the great LHM team, feel very honoured to be part of the LHM family.

# Having another baby



Written by: Dr Anna Seale, Consultant Fetal and Paediatric Cardiologist

Most parents who have had a child with major congenital heart disease become very scared and anxious when considering having another child. This is a totally understandable reaction. Parents are particularly anxious about risks of their new baby having congenital heart disease. But what is the risk and can heart problems be detected earlier?

## The risk of having another child with congenital heart disease:

Congenital heart disease affects up to 8 of 1000 newborns making heart defects the most common malformation that children are born with; the risk in the normal population is 0.8%. The defects are comprised of all sorts of differences ranging from insignificant defects to complex forms such as single ventricle conditions. If you have one child or pregnancy affected with congenital heart disease there is an increased risk of your new baby having congenital heart disease. In general, considering all forms of congenital cardiac problems, the risk of having another child at least doubles to about 2-3% (2-3 of 100). Even if baby is a half sibling there is an increased risk, but this is less, about 1.2% (just over 1 of 100). This means the overwhelming likelihood is that, despite this increased risk, your next baby will not have congenital heart disease.

If you are one of these rare people to have another child with congenital heart disease, the type of heart problem is not necessarily the same as your previous child. However, some specific heart problems e.g. Tetralogy of Fallot, can run in families.

For parents who have a baby with Hypoplastic Left Heart Syndrome, future children are more likely to have heart problems where the left side of the heart is involved but not necessarily have Hypoplastic Left Heart Syndrome. These other heart problems include coarctation of the aorta and aortic stenosis. These do require intervention but often a two-ventricle (pumping chamber) circulation is possible. When there is recurrence of congenital heart disease in a family previously affected with Hypoplastic Left Heart Syndrome, about one third of the new babies will have Hypoplastic Left Heart Syndrome like their sibling.

For single ventricle heart problems the risk of having another child with a single ventricle heart does vary according to several factors:

1. The type of congenital cardiac condition: There are many different types of functionally univentricular circulation and risk of recurrence depends upon the exact diagnosis of your previous child. For example,

in classical Hypoplastic Left Heart Syndrome the risk of having another child with Hypoplastic Left Heart Syndrome has been reported to be as high as 8% (8 in 100) although this has not been my personal experience and I have found the recurrence much less. Some babies born with a functionally univentricular heart have “heterotaxy” otherwise known as “left atrial isomerism” or “right atrial isomerism”. These heart lesions are more likely to re-occur with the risk being as high as 25% or above (1 in 4). Families where parents are related are particularly at risk of having children with heterotaxy and these groups are also vulnerable to recurrence.

2. Whether parents are related e.g. cousins. If parents are related there is an increased risk of recurrence.
3. Whether a genetic cause has been found. Genetic tests are improving all the time and what can be tested is constantly changing. This is a fast-moving field and beyond the scope of this article. There is much ongoing research in identifying genetic causes for congenital heart disease. New techniques, such as whole genome sequencing, may be useful in the future, however currently few types of congenital heart disease have an identifiable causative gene and therefore early ultrasound (see below) is the most practical way of finding out whether your new baby may have congenital heart disease. Referral to a clinical geneticist can be helpful particularly if there is recurrence of congenital heart disease in your family, if a causative gene has been found in your previous child with congenital heart disease, or if the heart anomaly was part of several structural anomalies. If this is the case, you should ask for a referral before you start trying for another child.

## How early can a heart problem in my new baby be detected?

The best time to assess the fetal heart is 18-21 weeks gestation, however this is really quite far into pregnancy (4-5 months) and most parents who have already had a child affected with congenital heart disease want to know



sooner if their new baby is also affected.

As technology has changed, the ultrasound equipment used for assessing babies in the womb has improved and we can now get some idea of whether baby is at risk of congenital heart disease in the first trimester by assessing the nuchal translucency (NT) and other features. The nuchal translucency is measured at your first fetal anomaly scan but the other specialist tests are available in some fetal medicine units. If you have had a previous child or pregnancy affected by congenital heart disease, you should ask your GP for a referral when you first know that you are pregnant – the early scans are performed between 11 and 14 weeks gestation.

From early to mid second trimester (14-18 weeks gestation) sonographers/doctors can get a relatively good idea of baby's heart structure, however the people doing these early assessments need adequate skill and training. These scans are not universally available around the

United Kingdom and will depend upon local expertise. In addition, sometimes the views are just too difficult to make a diagnosis, especially if mothers have a high body mass index (BMI).

It is also important to understand that the heart is still developing and even if an early scan appears normal, follow-up later in pregnancy is needed to see how the heart is growing. In addition some types of heart abnormalities can be very hard to pick up before birth.

Despite all the caveats, one of the easier features to assess at scans in early pregnancy is whether there are one or two ventricles. This is very important information for a family who may already have had a child with a single ventricle circulation. Early detection gives you a choice much earlier in pregnancy as to whether you want to continue with the pregnancy or not. It also enables you to psychologically prepare yourself, whichever choice is made.

## Important messages

- ✿ The risk of having another child with a single ventricle circulation is relatively low and should not deter you from having another child.
- ✿ However, some people may be at particularly high risk and discussion with your fetal medicine team or cardiologist is important to understand the risk for you.
- ✿ Some people may benefit from meeting a clinical geneticist before trying for another baby especially if a causative gene has been found, if there is recurrence of congenital heart disease in the family or if the heart anomaly was part of several structural anomalies.
- ✿ Specialist echocardiography in the first trimester can help determine whether your new baby is at risk of developing congenital heart disease. More detail of the heart structure can be gained at 14-18 weeks gestation but this is not always possible and some heart problems become more evident as pregnancy progresses.
- ✿ Discuss your anxieties with your GP, cardiologist, and fetal medicine doctors and find out what is available locally.



# An update from Will, five years on...



Written by: Will Goodenough

Twenty five year old Will Goodenough is a trailblazer for other young people with life-threatening heart conditions. Will first spoke at a cardiac convention when he was just eight years old and since then has spoken at numerous high profile events including the House of Lords and House of Commons. Five years ago he wrote us an update on his life at age 20 years, below he updates us as to what has been happening in his life over the last five years.



Over the last five years since my last update a lot has changed in my life. I have had new challenges to face along with new and exciting experiences.

In 2016 I graduated from Sheffield Hallam University with a degree in Business Economics after four years of studying and a little bit of partying. During my time at university I found the work/social life balance difficult to manage and was often frustrated that I couldn't always do both like my friends could.

Like most I faced the financial struggles of being a student, however, unlike my peers I was unable to get a part-time job as I wouldn't have been able to cope with the added pressure. I was fortunate to be a recipient of DLA (PIP) and this helped relieve the financial stress and allowed me to live independently.

Whilst I thoroughly enjoyed my time at uni it wasn't without its challenges; during my placement year I fell ill and had to take the year out. My university were very supportive during this time. I would strongly recommend meeting with your university support team before you start so they can have a clear understanding of your condition and needs.

Since graduating I have continued to live independently in Sheffield while holding down a full-time job in the financial sector. I worked in Leeds for a little over a year; however

the travelling proved to much for me and after a short stint in hospital I decided it was best for me to apply for jobs in Sheffield to shorten my day. In April 2018 I started working for Aviva in their Sheffield offices, my commute is considerably reduced and as a result I have much more energy to do the things I enjoy.

Working at Aviva has allowed me to thrive in a working environment, in the short year I have worked there I have managed to progress and gain many new skills. Aviva have proved to be a great company to work for, not just because of the progression but because of how they look after their staff. They are very understanding when I have hospital appointments and I don't have to take annual leave; a benefit I haven't received at any other company. It is really important to find an employer that is supportive of your condition while also understanding it and how it affects you. The only way to do this is for you to be open and honest with them.





The change in my job and increase in energy has allowed me to have a better social life over the weekends and I will often meet my uni mates for drinks or even a round of golf. Whilst living in Sheffield I also met my girlfriend Emily.

Emily is very understanding of my condition and has joined me for both my hospital appointments and LHM charity events to both support me and to increase her understanding. I think it is really important to have a relationship with someone that accepts the limitations of my condition.

The biggest and most exciting development in my life in the last five years has to be the arrival of my son. On the 3rd March 2019, Emily gave birth to a perfect and healthy little boy; Ezra Stanley Goodenough.

Although the thought of becoming a dad is an exciting one, as any father to be would tell you, it doesn't come without apprehension and worry. For me, this was made worse by the fear that he would be born with health issues. Despite having the understanding that my condition is not hereditary, I still had this fear. Throughout Emily's pregnancy all the healthcare professionals were aware of my condition and we were offered a specialist fetal cardiology scan - which we obviously accepted. The results of this were the best you could expect and came back all clear. In addition to this scan, one day old Ezra had an echo on his heart which again came back all normal. This was a huge weight off my shoulders and I could fully enjoy having a baby boy!

I aim to continue my progression within Aviva and I am looking forward to buying our first family home with Emily and Ezra within the near future. I do however fear that I will find it difficult to get the right mix between work and

family life. I would love to have the energy to run around a football field with Ezra but I know this may not always be possible as I still need to work to provide for my family. Having Emily understand my condition helps me cope with these fears as she puts my mind at ease and gives me a more positive outlook for the future.

I can't wait to see what this next chapter in my life brings and maybe I can update you all in five years time!



# Pregnancy with half a heart



Written by: Maggie Simpson, Senior Nurse Specialist; Dr Niki Walker, Consultant Cardiologist

You may not have thought about sex, relationships or pregnancy yet. Or you might have thought about it but just didn't know what to ask or where to get advice. Some of you might be wondering why this is relevant to you as a young adult. We will discuss why it's important to start the conversation about contraception and pregnancy for both guys and girls living with a single ventricle.

## What happens to the body during pregnancy?

During pregnancy there are a lot of changes to the body. These changes happen to allow enough oxygen and nutrients to reach the baby growing in the womb. These include:

- ✦ Blood volume increases by at least 50% by mid-pregnancy and stays at this level for the rest of the pregnancy.
- ✦ The woman's heart rate increases by up to 15 beats per minute.
- ✦ Blood pressure drops during the first trimester before returning to normal towards the end of pregnancy.

Following delivery, it takes around three to six months for these changes to get back to pre-pregnancy levels in a woman with a structurally normal heart.

For any woman, these changes put a strain on her body. That is why you will often see pregnant women say they are breathless or complain of palpitations.

## What about pregnancy for a woman with a single ventricle?

As healthcare professionals, we now know a lot more about the effects of pregnancy in women with a single ventricle. Recently in the UK, several hospitals gathered information about women with single ventricles who had had a pregnancy<sup>1</sup>. We learned a lot about the effect of pregnancy on a single ventricle for both the mum and on the baby.

Sadly, this is not an easy subject to discuss because in a lot of the pregnancies either the mum or the baby had a complication. These were often serious. The rate of miscarriage was around 50% compared to around 15% for women with two ventricles. Babies born were more likely to be born early and be smaller than a baby of the same age born to a woman with no heart problems. There were also a number of complications for the mum. These included heart failure (the heart doesn't pump as well as it should), arrhythmias (abnormal heart rhythms) and pulmonary embolism (blood clot in the lungs).

Therefore, pregnancy for a woman with a single ventricle is

high risk.

## What about after a pregnancy?

While we have information about outcomes for women and their baby during pregnancy, we do not have good information about the long-term effects of pregnancy on a single ventricle. Some women who have a change in their heart function in pregnancy do not get better after a pregnancy and some do. This is something we are working to understand better because we want to be able to give you information to help you make decisions about your future.

## Should I get pregnant?

The decision to have a pregnancy is yours. No one else can make that decision for you. It is important to have a conversation with your congenital cardiac team to find out more. If you do want a pregnancy then a planned one is better than unplanned. This allows you and your heart team to make sure you are as healthy as you can be and that you have a plan to change medications if required. If you feel after this conversation you do not want to have a pregnancy but still want to be a parent there are other options such as adoption.

## Why is contraception important?

Contraception is used to prevent pregnancy. Sometimes women with a heart condition are told 'you can't get pregnant because of your heart'. When women are told this some assume they are not able to conceive and do not then see the need for contraception. Often what the healthcare specialist means is that pregnancy is not recommended. You will likely still have the ability to conceive but it may be that a pregnancy is high risk. For this reason it is important to use contraception if you are sexually active (or if you think you might be!).

The type of contraception you use will depend on whether or not you want a pregnancy, your health condition and your personal beliefs. When making a decision about contraception you should ask:





How effective is this method of contraception?

How safe is this method of contraception for me?

For women with a single ventricle the general recommendation is to avoid contraceptives containing oestrogen. This is because these contraceptives are linked with a small increase in the risk of blood clots for all women, but a blood clot to the lung is very serious for a woman with a single ventricle. This still leaves several options such as the 'mini-pill' (progestogen only), the implant and the depo injection. The coil is a type of contraception that is safe from a hormonal point of view. However, there is a small chance of a fainting-type episode when the coil is inserted into the uterus. A woman with a single ventricle will not tolerate that and will feel unwell. If this is felt to be the best method of contraception for you, this should be carried out in a hospital environment and your congenital cardiac team should be informed.

### What about men with a single ventricle?

Obviously you will not have a pregnancy, however the questions above about effective contraception are important for you too. Condoms are safe to use and they also prevent sexually transmitted infections. However, they carry a 15% failure rate when not used correctly.

Being a parent is hard work and it would be important to

think about whether your heart condition will let you do all the things you would want to do as a dad. Some people with a single ventricle get tired easily or get breathless when exerting themselves. This can upset some parents when they can't look after or play with their kids as they would like. Some men with single ventricles don't have any symptoms. Yet they might worry about future problems with their heart and how that might affect their family.

It's a good idea to talk to your partner about how you feel about being parent. This will help them understand any concerns you or a partner may have.

If you want to know more about your heart condition and have questions about the future please speak to your congenital heart team who will help provide advice.

#### Reference <sup>1</sup>

*Retrospective UK multicentre study of the pregnancy outcomes of women with a Fontan repair. Cauldwell, M., Steer, P.J., Bonner, S., Asghar, O., Swan, L., Hodson, K., Head, C., Jakes, A.D., Walker, N., Simpson, M., Bolger, A.P., Siddiqui, F., English, K.M., Maudlin, L., Abraham, D., Sands, A.J., Mohan, A.R., Curtis, S.L., Coats, L. and Johnson, M.R. Heart 2018;104:401-406*

### How do I find out more?

LHM will soon publish an information booklet about sex, contraception and pregnancy.

It is really important that you speak to your congenital cardiac specialist team about what pregnancy means for YOU!

Talk to your parents, carer or partner about what you are thinking and feeling about a pregnancy. They will be able to support you in finding out more information and also in the decisions you make in the future.

# Fundraising



Written by: Ian Carr & Rebecca Wilkes



Hi everyone, If you want to speak about any fundraising ideas, you can call me at the office or email [rebecca@lhm.org.uk](mailto:rebecca@lhm.org.uk)

## GNR and London to Brighton

This September saw Team LHM celebrate the 25th anniversary in style as two events in consecutive weeks raised a whopping £16,000!

Great North Run was a great day for all 11 of our runners who all completed the world's most popular half marathon. After 13.1 miles of running and walking their way round the course, our fantastic fundraisers raised over £6,000 for Little Hearts Matter and included mum of half-a-heart warrior, William, Catherine Spencer who describes her experience:



“The morning of my first Great North Run dawned sunny but chilly. I proudly wore my LHM vest which had my then and now photo of William, our 18 year old heart warrior on my back and a ribbon dedicated to a person in support, celebration

or memory for each mile. As the gun went off for the start, I felt quite emotional, knowing I was running for a charity that has given us so much support over the last 18 years. I had dedicated mile 1 to all the LHM heart warriors and the people were amazing, providing sweets, water, orange segments, ice lollies and at mile 11, even cans of lager! I danced along to the bands that lined the route and talked to other runners. The last 1.1 mile was dedicated to William, celebrating all he had gone through, with his heart surgeries and becoming an adult

back in February. The crowds were five deep as I ran that last mile along the sea front. Catching a glimpse of my hubby Andrew cheering me on spurred me on. I raised my hands in celebration as I ran across the finish line, I had done it, I'd finished the GNR and raised over £500 for LHM. It was lovely to meet Suzie and finally sit down and get a long, cold drink.



Thank you to all our great runners and cyclists!

## London to Brighton Cycle





# Spotlight on...

## Fiona & James Pollard's Ball



Back in early 2018, our great friends Sam and Paul Mardlin said the words, "we're going to do a Ball for you" to us and so our charity Ball adventure began!

Sam and Paul have given amazing support to me, James and our family since Lucia's diagnosis in 2012 and they've got years of experience in staging Balls and charity events. I know we wouldn't have managed it without them, that's for sure.

The prospect of arranging an event of this scale seemed daunting, however, once the foundations (venue, date, etc) are in place, it was just down to fine tuning.

So, after 18 months of planning, the Stewkley Summer Ball took place on Saturday 22nd June in a large marquee. The Scharff family kindly allowed us to host the Ball on their land; an incredible 420 people attended and after canapés and welcome drinks, the guests were entertained by a wonderful Frank Sinatra tribute act, enjoyed a three-course meal and were mesmerised by magician Paul Megram.

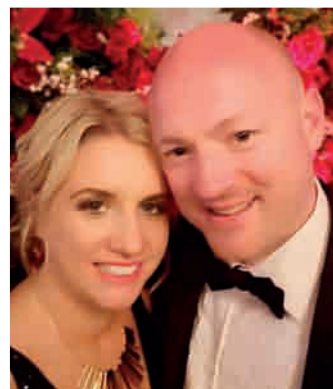
James and I then told guests Lucia's and my family's half-a-heart journey and Ian Carr from LHM told the audience how their fundraising will help, then it was time for the big fundraiser of the evening, the auction. We were so lucky with the generosity of friends and contacts providing prizes such as VIP Liverpool FC tickets, This Morning VIP tour, Six Nations Rugby tickets, Robbie Williams VIP tickets...I could go on!

Of course no Ball would be complete without a dance and as guests boogied the night away we knew it was an evening me, James and all the people there will never forget!

We raised a staggering £22,500 with 50% going to Little

Hearts Matter and 25% each to Ronald McDonald House and Lucia's school. We were amazed by the generosity of all the guests and everyone just kept digging deep.

Overall, the end result was worth the effort and we are delighted to give something back to the charities who have given us so much support. We enjoyed the experience so much that Sam, Paul, James and I are planning to host another one in June 2020!



### Fiona's top tips for staging a Fab Fundraising Ball!

- ✿ Give yourself plenty of time to get organised.
- ✿ Decide on your date and book a venue early.
- ✿ Get an event committee together, but keep it small.
- ✿ Have lots of helpers to be on hand on the day.
- ✿ Use social media to see who can help... you never know who is out there!
- ✿ Be prepared to work hard.
- ✿ Enjoy it! It's fantastically satisfying and worthwhile.

Only a week later, and at the opposite end of the country, saw our biggest challenge event of the year. Our London to Brighton cycle team included Chief Executive, Suzie Hutchinson. Suzie said,



Having worried for weeks before the ride I set off in trepidation but the sun shone and the atmosphere was so welcoming that the day really was a lovely event. The sense of achievement I felt as I started the

descent into Brighton from the highest peak at Ditchling Beacon was fabulous. Not only had I, and so many other LHM riders, completed the difficult 55 mile course we had all raised thousands of pounds for LHM too.



# Hannah's journey



Written by: Hannah Palmer

//

I was born in 1994 with Double Inlet and Outlet Left Ventricle, Transposition of the Great Arteries, AVSD and Pulmonary Stenosis. 25 years ago, the outlook for babies with a single ventricle heart defect wasn't fantastic. My parents were told after I was born that I may only live until I was 15.

//

Since 1994, I have had two open heart surgeries, the Glenn in 1995 and the Fontan in 2003. I've also had several catheters for various other reasons, all heart related. My last operation was in 2009, to partially close my Fontan fenestration. I don't have any more planned, but I take life as it comes!

those who have been lucky enough not to experience it!)

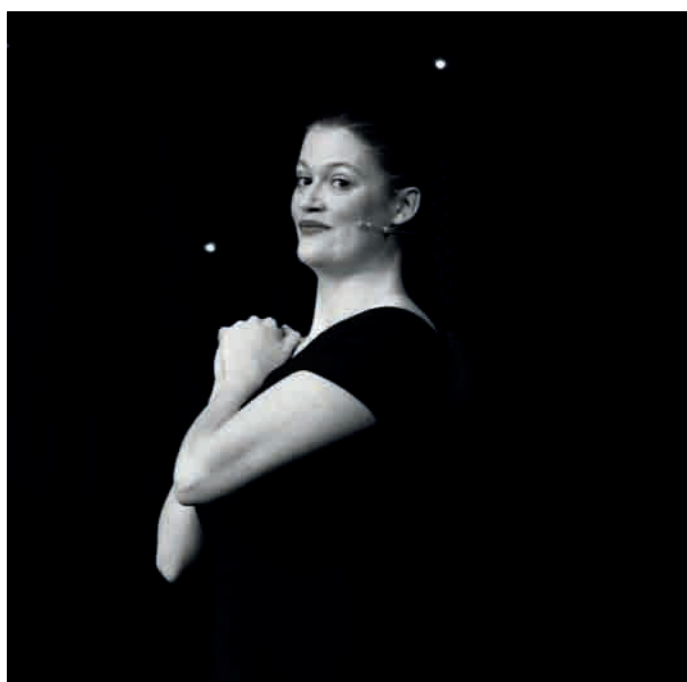
When my brother and sister came along, I did my best to keep up, but Matthew was like a massive ball of energy!! I wish I could have bottled that up, to borrow when I got tired!!

Managing school over 14 years was a massive challenge. Teachers didn't always understand my issues or what adaptations they needed to make. My dad created a sort of fact sheet about me that was passed to all my teachers in High School. I struggled with energy a lot, but I got extra time in exams and access to the school lift. Going to university was a massive achievement for me, and they were very helpful with extra time for essays and exams. I also had Disabled Student Allowance (DSA) which provided a laptop and other helpful things that made university much easier!

Despite the struggles, I've gotten involved in a lot of theatre. I was in as many school shows as I could be in. I've performed in shows in university and continue to be involved both on and off stage!! I love being as dramatic as possible, so it is the right hobby for me.



As a child, I had to learn to adapt to the challenges that having half a heart brings. I learnt very quickly that I couldn't keep up with other people my age, which was especially hard when it came to sports days and things that involved any energy. I did win the egg and spoon race one though, the Friday before I had a catheter to fix my SVT! (Supraventricular Tachycardia for







Since joining Little Hearts Matter in 2004, I have become such a different person. I have made some excellent friends, learnt a lot about how to manage my condition, and mostly, I've learnt I'm not alone. Becoming a Trustee in 2014 made me so proud. I'm now able to help all the young members like me and I hope I'm doing the best I can.

I now work for Admiral Insurance and I love it! I never knew car insurance could be so interesting! They have been fantastic with all the support they have shown me and the adaptations they have made for me. I highly recommend working for a big company, they tend to be able to provide better support for those with disabilities.

If you'd have told my parents 25 years ago the things that I've achieved despite my condition, I'm not sure they would have believed you. Now, thanks to them, Little Hearts Matter and my amazing friends, I live my life as fully as I can. I cannot wait to see what the future holds for me. Sometimes having half a heart sucks, but it doesn't define me. I'm currently producing a pantomime and looking

forward to all the things I have planned for next year.

25 years ago, not many people would have thought I'd make it to 25, but I'm here, alive and kicking. I've accepted my lot and I roll with it. I have bad days, where I can barely get of bed and function at all. But I don't let those days define me. Having half a heart doesn't have to mean I have to live half a life. And I'll make it my mission, on behalf of every kid born with a single ventricle heart condition to live life to the full and have the time of my life while I do.



# Zipper zone



Written by: Lexie Katsaitis & Jon Hutchinson (former Youth Leader)

## Development of LHM's youth services

My first LHM experience was an activity weekend in the New Forest. I was volunteering to impress my new girlfriend, whose mum ran a charity that supported families affected by a single ventricle heart disease diagnosis.



Over a decade later that girlfriend is now my wife, and LHM has become one of the most important parts of my life both professionally and personally. I can't describe how much fun I'd had on the activity weekend, and how amazing all of the people were. So when a full-time position as a Youth Development Officer was advertised in 2008, I put my uni plans on hold and jumped at the opportunity.

My main remit was to manage services for young members aged 10 to 25. As I write this, I realise that even the youngest of those members will now be old enough to vote! Reflecting back on my time working for LHM is bittersweet. I'm filled with the warmest memories, as well as the pang of deeply missing a tight-knit community of the kindest, bravest, funniest folk I've ever met. With a lot of help - from the incredibly skilled staff at LHM, but also from the young people themselves - we were able to achieve an awful lot during my years at the charity.

As a charity, we were very keen to give the children and young people themselves a strong voice within LHM. Too often, our young members told us that they felt placated, misunderstood or just flat out ignored. We wanted to change that. Quickly, we established a Youth Council who would

represent the growing young memberships within the charity. After an open election, successful nominees took their place and got to work writing a constitution, which set out what they hoped to achieve.

They established a few priorities. One was to increase the opportunities to connect with other young people who had a similar diagnosis, or who had siblings with a complex congenital heart abnormality. The charity already hosted fairly regular activity weekends, but the young membership wanted an easier way to communicate with their ZipperClub friends.

In response, we built a website specifically for our young members, which included a space to speak to each other, as well as gain expert advice from Suzie about health and lifestyle issues. Organisationally, this was very powerful for us, as it helped give us an insight into what our young membership really wanted to know.



This links to the second priority set out by our Youth Council - to give impartial, non-judgemental information in plain English, exploring and explaining their condition and its implications. We had already begun to publish a regular youth newsletter, but this call from your youth councillors resulted in us creating a DVD that could be sent to teachers, parents and young people alike.

The young membership were directly involved in every aspect of the DVD. They planned, wrote, filmed and edited it. They interviewed each other and a range of experts. They even came up with the name "I've only got half a heart... understand me?"

More and more young people got in contact with us and





//

As a charity, we were very keen to give the children and young people themselves a strong voice within LHM. Too often, our young members told us that they felt placated, misunderstood or just flat out ignored.

//

started to build connections and networks. Our activity weekends and open days were extremely popular, and the strong bonds being forged were clear for everyone to see. A single ventricle heart condition is such a rare and unique thing, and it was such a privilege to bring together people who all shared this in common, it was like our own secret little club. I remember during one weekend a young member walked out of the changing rooms at the swimming pool with his hands covering his chest. After a few moments, they looked at me and said, "Wait, it's not just me - everyone's got a scar. Actually you're the odd one out because you *don't* have one!"

It was moments like these that stay with me the most. LHM is a charity made up of a million of these small moments. Human and personal and sprinkled with just a little bit of magic. It was a tremendously difficult decision to leave my full-time post and (finally) take myself off to university in 2010. I haven't lost my passion for working with children and young people though - they are far more interesting and fun than grown-ups. After training as a primary teacher in 2013, I'm now an Assistant Headteacher at an all-through school in London. Alongside that, I've been lucky enough to work with the government to advise on some educational policy matters, another job that I cut my teeth on at LHM.

I very much hope to have the chance to return as a volunteer at future weekends and events, and hope to see you there.



I started as the Youth Leader at LHM just over two years ago and it has been an absolute pleasure so far. I was very lucky that Jon and the other youth leaders before me developed a solid youth service for me to build upon and I'm excited to show you the evolution of youth services from where Jon started to where we are now.

Continued on next page...

# Zipper zone continued...



The service is now for young people with a single ventricle and their siblings aged between 11 and 17 as we recognised that our youth members needed different types of support depending on where they are in their journey. The number of youth members in this bracket has increased dramatically but I'm happy to say due to advances in technology and the age of social media our youth group is still as tight knit and supportive of each other as it was when it was much smaller. The peer support these amazing young people offer to each other at events and online is a privilege to see. Thanks to the wonders of technology we are able to offer a weekly youth group evening online. Here we have movie nights, game nights and Q&A sessions. Youth members from all over the UK and Ireland are able to join in and attend right from home which is great for inclusion and tackling that feeling of isolation we know so many of our youth members experience.

The service is still very much led by the youth. Their voice leads the way in terms of our strategy and service, it is great that the youth members feel comfortable enough to let us know what they want and need. Over the years we have tried lots of ways to get the voice of our youth heard including six-monthly youth forums and virtual chat groups however sometimes it's best to go back to what has worked so well in the past. We are looking forward to reintroducing a long-standing Youth Council to Little Hearts Matter.

Our youth members are now getting more involved in the work of the charity. Many create vlogs, newsletter articles and social media posts and others share hints and tips to help not only their peers but the adults in their lives. They come to us when they feel an aspect of their life is misunderstood knowing that we will support them by either creating resources or assisting them in getting their voice heard.

We have started to introduce youth focused e-books alongside the well-received LHM publications. The youth

members are a huge part of this process from telling us the type of e-books and information they need to being in youth reading panels where they have input on the style, text and overall design.

Our youth events are getting bigger and we are delighted to add more variety and locations. Our activity weekends are still as popular as the first year they were introduced - we have even more young people attending and we include LHM workshops for our members as well as all the fun activities. Our open days now include youth workshops from outside organisations as well as the LHM youth team and each year I have seen the number of young people attend rise. We now try to provide additional youth events around the UK so that our youth members have the opportunity to attend one no matter where they live. This takes time but hopefully we will be hosting a youth event near you in the coming years. The youth events are an amazing chance for our young people to have fun and create lasting friendships with people that understand their journey.

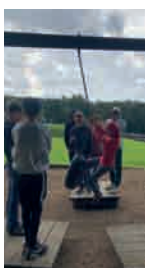


Overall it's been an amazing journey for me to be able to work with such fantastic and inspirational young people and hopefully make their journey a little easier and more fun.

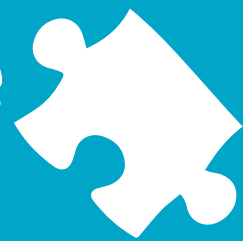




Our recent activity weekend for our young members was another great success - below are some photos from the weekend...



# Structured exercise programmes



Written by: Emma Beaglehole, Physiotherapist

Below is a summary of a two year project which involved the development of a new exercise programme for people with a Fontan circulation at Leeds Teaching Hospitals.

Patients with a Fontan circulation are amongst the most complex of all forms of congenital heart disease (CHD). In the normal heart the right ventricle pumps blood to the lungs and the left ventricle pumps blood to the body. In a single ventricle heart there is only one ventricle large enough to do the normal job of pumping blood. We therefore need to maximize the efficiency of this single ventricle by re-routing the circulation to the lungs, thus creating the Fontan circulation.

Despite advancements in medical management, those living with a Fontan circulation have a reduced ability to carry out activities of daily living and general exercise tolerance can be significantly limited. There has however been evidence to suggest that this can be improved through a structured exercise programme and promoting an active lifestyle. Given this existing evidence, the Congenital Cardiology team at Leeds General Infirmary sought the opportunity to run a two year project dedicated to working with their patients with a Fontan circulation which was kindly funded by the charity, The Children's Heart Surgery Fund (CHSF).

The charity facilitated the development of a new exercise programme that was devised and managed by myself, Emma Beaglehole, a Physiotherapist based at Leeds Teaching Hospitals. Patients above the age of 18 years were invited to join the project either from clinic appointments or contacted by myself. The programme included standardised assessment of strength, perceived quality of life and cardiac function by using cardio pulmonary exercise testing (timed walk on the treadmill) to establish a baseline for all patients. Each individual was given a personalised plan designed for them to conveniently fit into daily life and which could be completed from the comforts of their own home. These programmes were adapted and progressed through regular one-to-one appointments with myself, and patients also had the opportunity to keep in touch regularly via email. Those who consented to reassessment over 12 months had their initial assessments repeated at six and 12 months to establish whether they had changed over the 12 months.

All patients who undertook the programme and had regular appointments with me over the 12 months demonstrated an improved ability to exercise and had boosted perception of quality of life.

In addition to the positive results found from the project, the main benefits of completing regular activity was that patients appeared to be more confident in their abilities to carry out activities of daily living and as a result of their

greater ability to exercise, found enjoyment in living an active lifestyle. I particularly found a sense of achievement from educating patients and their families that exercise can be enjoyable and can be learnt to become part of everyone's daily routine. It's about finding the right starting place to ensure activity is achievable in order to create healthy sustainable habits. Exercise is often mistaken for gruelling gym sessions or has to be 'sweaty' and 'hard'; however exercise is about finding something that you enjoy that at the same time gets you moving! This could include a walk to the shop, getting out of your chair three times when making a cup of tea or doing mini knee bends when brushing your teeth!

**The team have received positive feedback from those who participated in the programme, where comments have included:**

I feel much healthier and stronger in general. I find it very enjoyable and rewarding and also think it's improved my overall well-being as well.

I never thought I would join a gym and I now find exercise enjoyable and rewarding which I didn't expect to. I am constantly getting stronger and can see the improvement on a monthly basis.

The programme has helped me feel a little stronger than I used to be. I notice this most when carrying heavy bags. My arms take longer to get tired and I don't have to stop and rest as much as I used to. I also struggle less climbing several flights of stairs.

As I continue with the programme I am constantly aiming to get stronger and to beat my previous records. I have already done this, doubling my previous time on the step test. I am always looking to better myself and this programme helps me do that.





As part of the project, the congenital cardiology team and myself also hosted a Fontan Education Day in June 2018. This was very well attended by patients and their families and extremely well received. Both patients and their families found benefit from meeting others both living with and/or supporting those with a Fontan circulation. There was tremendous enthusiasm expressed for the exercise programme. Those present were keen to see it expand and also mentioned that it would be good to make it available during adolescence.

#### Feedback from this day included:



10 years too late.

I would have loved to have had this opportunity when I was a teenager.

Great to meet others that have been through what I have!

I've been exercising in secret in my bedroom!



I found that the most rewarding thing of all following the Fontan Education Day was to see individuals mingling with one another and sharing experiences. I think a big thing for our patients is to feel listened to and supported with the added opportunity to meet others. It would be great to create a community where patients and families can have annual meet ups or keep in touch through secure closed groups such as Facebook.

The team at Leeds would encourage those who are interested in finding out more about activity whilst living with a Fontan, to contact their specialist nurses or consultants at their local centre in order to find out more and seek

professional support and advice.

The team would also like to pay special thanks to the Children's Heart Surgery Fund and all our patients who have worked hard with them during this two year project, it's been an honour to work with you all.

#### Team Fontan's Top Tips

- Start small.
- Little and often.
- Find something you enjoy.
- Fitness can be FUN.
- Get outside when you can.
- Listen to music you love or which makes you happy.
- Seek encouragement from friends and family as well as support from your cardiology team.



# Amy's story



Written by: Amy Morrell

My name is Amy and I am nearly 21. I was born with Hypoplastic Left Heart Syndrome in the Guy's and St Thomas' Hospital London in November 1998 and had my Fontan operation just before I was four years old.



I have two brothers and a sister, I am number two! We all attended the primary school across the road so getting there was easy and I was well supported. Everyone knew our family!

Secondary school was more difficult - I had school transport and didn't do PE, but there were times when I was still very tired. For college I studied Child Care and had most of my placements at my old primary school across the road. I have been so very fortunate as through this I ended up getting employment there as an Individual Needs Assistant. I now work with a lot of the teachers who knew me when I was blue and four!

People who know me describe me as sunny, happy and friendly with a positive attitude and a love of life. This is all true but there are times when I find my life very hard. Transitioning into adult life is difficult. I am still learning to accept myself and my disability, but not to let it define me. I hated my scars, but over the last year I have come to understand they are part of me and my battle to be here. I struggle with huge anxiety and often this is a bigger hurdle to day-to-day living than my actual heart condition. I try to juggle my home, work and social life, but I have never been good at this. Self-regulation has never been my strong point! I rely heavily on a few good friends and my family to support me. They obviously must be very understanding!

Making new friends is difficult as my disability is invisible. Many just do not understand that I can appear "healthy and full of life" and yet my energy levels are so unreliable. I can have a really great time out with friends, but then I come home and just cry due to sheer exhaustion. I rarely go to parties or sleepovers. Holiday options are limited. I am only

able to work part-time and sometimes feel very isolated. I am apprehensive for the future.

But I love life. I am sunny, laugh a lot and have many friends. My family love me. I am slowly managing my life better. It is not easy but actually a coffee and cake with friends gives as much pleasure as late drinks in a bar and doesn't make me tired. I am respected at work and do a good job. I go to the cinema and theatre, I like shopping, coffee and cake, meeting my friends for pizza, going to the beach and this year I went to Bath on holiday with my oldest friend.

People care about me so I must care about myself. The future is scary but the present is getting better. Life is good!







# Fundraising wall

Thank you so much for all of the brilliant stories and images that you have sent us. If you are organising an event, taking part in a run or holding a bake sale then we'd love to see your photos. They may be used on our Facebook page, our website or in our newsletter. Send us your snaps to [info@lhm.org.uk](mailto:info@lhm.org.uk).



- Jemima and Grace fundraised for LHM
- by swimming 25 miles for 25 years and raised just under £400



- The George family raised £1,060
- in memory of Jessica by travelling from John O'Groats to Lands End



- Staff from Ridgeway Ward, Chesterfield Royal Hospital raised £940 by taking part in a colour run



- Isabella had 16.5
- inches cut off her hair and raised £320



- Sophia made and
- sold cakes on her street raising £43.55



- Newtown Male Voice Choir raised £100

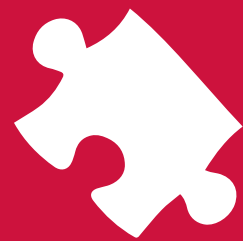
Coming soon!

## Big Hearted Friday

Friday 14th February is a day where everyone can be **Big Hearted** and make a difference to children born with half a working heart.

It's easy to join in, just wear **red** and **blue** at your work, school or nursery.

# LHM Awareness Week update



Written by: Suzie Hutchinson

Wow, the Little Hearts Matter team are so delighted with the great response we had to our very first Awareness Week. Running from the 1st to 7th May, the LHM team worked to create lots of different awareness tools, LHM stories and new challenges for members to join in with.

## Our aims for the week were to:

- ♥ Raise the profile of single ventricle heart disease (SVHD). Members requested that we raise a greater general awareness that they hoped would lead to a greater focussed awareness.
- ♥ Create a better understanding of the needs of children, teenagers and adults with SVHD.
- ♥ Create a voice for teenagers and adults with SVHD.
- ♥ Create a viral energy that allowed for all of the above.

Through the week we created Twibbons and a profile picture. We collected young LHM member stories and impact statements that members could share.

We launched the Half a Heart Beat Challenge and we created daily news updates shown through social media each night.

## So how far did we reach?

The Twibbon or Profile picture was seen by **35,000** people  
Our impact statements reached over **13,000** people.

The stories about Amber, John and Will that were in the Mail, the Mirror and the Metro News reached a staggering **452,885,320**, yes you read it right, millions and millions of people.

The LHM Half a Heart Beat film was seen by **57,000** people.

Some of our members created short half a heart beat films and shared them. Thank you to all who got involved. This is the first year of setting the challenge so we hope that next year it gains more traction and spreads further.

We loved all the members and friends of the charity's comments and the way that everyone got involved and helped us to spread the work.

We will be holding another  
**Awareness Week**  
during the first week of May next year.



So here it is the final post of the #LHMAwarenessWeek. From all of the LHM family we thank you for supporting us and helping us create awareness.







# Corporate fundraising

Written by: Ian Carr

It's been another good year for Corporate Fundraising and a number of companies have joined us to make our 25th anniversary a really special one. Little Hearts Matter is always looking for connections with businesses, so if your business could help, please let us know.



## ATV City

ATV City responded to LHM's request for more businesses to get involved in supporting Little Hearts Matter by having a charity month throughout May. Timed to coincide with LHM's Awareness Week, ATV City, who are owned by Ewen Sarah (Dad to LHM member Ethan), donated a percentage of its profits and asked their suppliers for donations throughout May. Over £5,000 was given to Little Hearts Matter.



## Mortgage Bureau

Long-time supporters of Little Hearts Matter, Mortgage Bureau, have pulled out all the stops for our 25th year, by going the extra mile for kids with half a heart -



literally! In June, its staff set themselves the challenge of a 25km gym-based triathlon. Each of the mortgage brokers' offices took part in gyms near to them and completed a 1km swim, 14km cycle and 10km run. In total, they raised an amazing £6,000. They also hosted a ball in October that featured a comedian and live music. This also raised a further £4,000. We are constantly amazed by the efforts of our friends at Mortgage Bureau, so thank you again guys!

## Lily and Me

Lily and Me has continued its support of Little Hearts Matter throughout the year. The online clothing company ([www.lilyandmeclothing.com](http://www.lilyandmeclothing.com)) owned by Joanne and Ben Haywood has been asking its customers if they want to donate to Little Hearts Matter and they've responded brilliantly! The year to date has seen over £3,000 donated to Little Hearts Matter.

## B&M Truck Pull

Little Hearts Matter's supporters, B & M Waste have been pulling their weight for children with half a heart!

We're delighted to tell you that the 2019 champions are Little Hearts Matter. Each of the Waste Management business's charities were represented in the truck pull and with a time of 18.55 seconds, the eight-strong team that represented LHM were the winners!

B & M have generously donated £1,000 to the winning team as well as £750 to the runners up and £500 to all the other charities. We are so grateful for their support and well done to Team LHM on the win!!



# Birmingham Fontan Conference



Written by: Suzie Hutchinson

In recognition and support of Little Hearts Matters and the charity's 25th anniversary this year's Birmingham Children's Hospital teams Workshop Meeting, an annual conference meeting had the theme 'Lifetime Management of the Single Ventricle Circulation'.

The Birmingham team focused on optimising the care and quality of life for patients born with a single ventricle. The meeting incorporated fetal, neonatal, child and adult care including diagnosis, intervention, surgery and transplantation.

Suzie was asked to present a 20 minute talk on 'Little Hearts Matter - a 25 year journey'.



The conference was a brilliant example of care throughout the different stages of the Fontan pathway. Speakers from many units across the UK talked about the different approaches needed for all the treatments and the lifestyle issues experienced by anyone with a single ventricle heart.



## Talks included:

### Important morphological findings and differences

*Bob Anderson*

### Antenatal diagnosis as a predictor of outcome

*Anna Seale*

### Physiological predictors of short-and long-term outcome

*Marc Gewillig*

### Can MRI predict the outcome for functionally single ventricle circulations?

*Vivek Muthurangu*

### Outcomes and evolution of the Fontan over 25 years, the Birmingham Experience

*Tim Jones*

### The role of mechanical support and transplantation

*Asif Hasan*

### Rhythm problems and management

*Joe De Bono*

### Little Hearts Matter - a 25 year journey

*Suzie Hutchinson*

### Research priorities in functionally single ventricle circulations

*Nigel Drury*

### What less invasive strategies improve the longevity of the functionally single ventricle?

*Marc Gewillig*

### ACHD and the functionally single ventricle population - experiences and expectations

*Paul Clift*

It is extremely important for doctors to highlight improving treatment and positive support of the single ventricle heart patient. The opportunity to learn about new techniques in the long-term care and support of patients is essential.

Common themes were looking to protect the lungs from early stages of treatment, looking at the longer-term support of the Fontan circulation, encouraging some exercise and balanced diets and looking at the challenges that young adults with single ventricle heart disorders have as they take steps from childhood into independent adulthood.

The LHM team use the information gained to inform all of the advice and information available for members.



There were many lovely comments made about LHM's anniversary and the work of the charity to promote better healthcare for children with single ventricle hearts. It is very heartening to hear the positive comments about our work and the confidence that medical teams have in referring their patients and families to LHM for support.

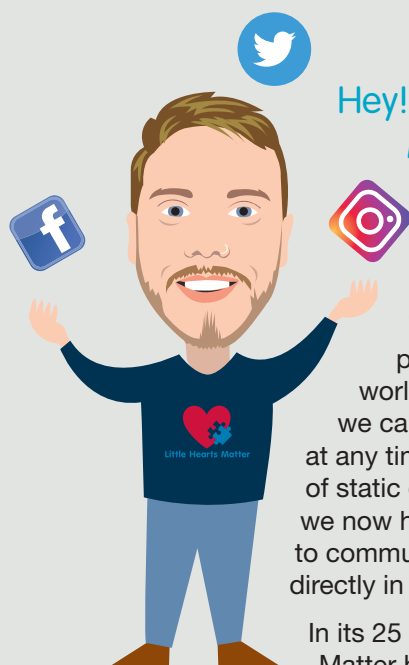






# Social media

Written by: Sam Jones



Hey! Sam here... I'm the new Service Support Officer at Little Hearts Matter. I'll be focusing on creating digital content for social media and the LHM website. You'll also catch me helping out at events, come and say hi!

There's no denying the power of Social Media. The world is at our fingertips and we can reach out to anyone, at any time. Gone are the days of static one-way conversations, we now have the tools we need to communicate with each other directly in real time.

In its 25 years, Little Hearts Matter has seen considerable growth across its membership and support services. A key aspect of this is the growth of our social media community, as well as the development of our online resources. We are a service-driven organisation, so it's really important for us to be able to offer all of our members the information, care and support they need, wherever they may be. By extending our services to social media, LHM guidance and information is easily accessed from a phone, at a time that suits you best.

Social media is our place for conversation and our digital communities are thriving! From members to supporters, volunteers to fundraisers, everyone has a role to play and you can join the discussion now. Wherever you are in the half-a-heart journey, however you have been affected, your views are so important to us and your input will help us to shape the future of our digital services moving forward for the next 25 years.

Our Facebook groups, for example, have been specially created to give our members a voice, offering them a secure place to connect and share their half-a-heart experiences with each other. If you have been affected by the diagnosis of half a working heart, we would encourage you to explore our private groups. Head over to [facebook.com/pg/littleheartsmatter/groups](https://facebook.com/pg/littleheartsmatter/groups) where you will be warmly welcomed by the LHM family.

We want to keep you updated with all things Little Hearts Matter, so our social media pages are regularly updated too! Read the stories of our heart heroes, get involved

with our awareness campaigns and keep up to date with upcoming events. We want to tell the world about children born with half a heart - every like, comment and share goes a long way to helping us raise awareness, we would love for you to join us there.

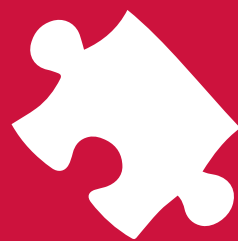
Join us on Facebook: [Facebook.com/littleheartsmatter](https://Facebook.com/littleheartsmatter)

Join us on: Twitter: [Twitter.com/LHM\\_UK](https://Twitter.com/LHM_UK)

Join us on Instagram: [instagram.com/littleheartsmatteruk](https://instagram.com/littleheartsmatteruk)



# Noticeboard



## MEDIC ALERT

MedicAlert is the original provider of medical ID services in the UK. The charity has been trusted since 1964, to keep those with medical conditions safe in an emergency.

Members' custom-made medical ID jewellery features the internationally recognised MedicAlert emblem and is engraved with the most vital medical information to ensure fast and accurate care in an emergency. Each member's full medical record is then available, if required, via the 24/7 emergency line which is accessible from anywhere around the world, in more than 100 languages. Medical professionals only need to simply quote the unique membership number that is also engraved on the jewellery.



"My name is Jacob Clark. I wear my bracelet if I go on school trips. If the teachers don't know what to do, I can show them this bracelet and I can flip it over to show my details and the MedicAlert phone number to call up. Mummy thinks it looks really cool!"

"When Jacob wears his MedicAlert, it gives me peace of mind when he's away from me. In the unlikely event that there is a medical emergency, MedicAlert are just a phone call away, so Jacob can get the treatment he needs." - *Jacob's Mum*

For particularly young or vulnerable members, MedicAlert's advocacy function allows one or more individuals to help the member manage their record.

In addition, the in-house team of registered nurses checks all records when they are created or updated, ensuring the information is medically sound and optimised for use in emergencies.

To become a member and view MedicAlert's range of jewellery, visit [www.medicalert.org.uk/](http://www.medicalert.org.uk/)



The Brave Heart Awards have been created to recognise young people aged between 8 - 18 years

The awards are not just for young people with health conditions, they also include their brothers and sisters and interests

They are awarded four times a year; the nomination forms need to reach us by **29th November**

To find out more and to send an application

[www.lhm.org.uk/youth-zone/lhm-brave-heart-awards](http://www.lhm.org.uk/youth-zone/lhm-brave-heart-awards)



## SINGLE VENTRICLE HEART REGISTRY

Many of our members have heard of the *Antipodean Fontan Registry*. A collection of data all about the medical treatment of Fontan patients in Australia and New Zealand.

The UK medical teams have been looking to create a similar database here but have decided to broaden the remit to include all single ventricle patients from the time of diagnosis. The data collected, with parents and adults with a single ventricle heart's permission, will help to inform research projects and ultimately the treatment of anyone with a single ventricle heart.

As well as medical data it is hoped that data that relates to education and disability can help to create a greater understanding of patients' needs both within hospital care and through their day-to-day lives. Little Hearts Matter is fully involved with the project and helped to chair the inaugural meeting that collected together medical representatives from around the country.

As the project is established we will work to keep members up to date.

## Little Hearts Matter

75 Harborne Road, 4th Floor, Edgbaston, Birmingham, B15 3BU  
0121 455 8982 | [info@lhm.org.uk](mailto:info@lhm.org.uk) | [www.lhm.org.uk](http://www.lhm.org.uk)



@LHM\_UK



Littleheartsmatter



littleheartsmatteruk

reward our young members  
of age.

half a heart, we also want to  
ed and supportive friends.

next applications  
er 2019  
ation visit:

e-heart-awards



## Publication list

Don't forget the following publications and packs are available free of charge to members.

- Antenatal information pack
- Preparation for hospital booklet
- Benefits - a guide for parents
- Early Years Foundation Stage (EYFS) and Key Stage 1 education Booklet
- Key Stage 2 - Junior School education booklet
- Transition to Secondary School education booklet
- Key Stage 3 secondary school booklet
- Key Stages 3 - 4 secondary school booklet
- Healthcare Plans for Children and Young People with a Single Ventricle Heart Condition
- Support for a Child with Special Educational Needs within Nursery, School or Further Education
- Baby / child DLA booklet and sample pack
- Fontan booklet
- MCT diet
- Living with anticoagulation
- Information filofax
- Travel and trips
- Sports and exercise
- Heart transplantation - a guide for families
- Your guide to university with half a heart
- Puberty for young people with half a heart

# Christmas merchandise



## NEW FOR 2019

### Silvery reindeer

116mm x 160mm  
Greeting inside

'With Best Wishes for Christmas and the New Year'

Price £3.50



## NEW FOR 2019

### Hanging the stocking

125mm x 125mm  
Greeting inside

'With Best Wishes for Christmas and the New Year'

Price £3.50



### Both of You

125mm x 125mm  
Greeting inside

'Seasons Greetings'

Price £3.50

## Christmas cards

All cards come in packs of 10.

To purchase our lovely Christmas cards and see all of our jewellery gifts visit the Little Hearts Matter website [www.lhm.org.uk](http://www.lhm.org.uk)

## This Christmas Wrap a Blanket

This Christmas, Little Hearts Matter is asking for you to help wrap a blanket of care and support around families at every stage of their half-a-heart journey.

This Christmas around 50 families in the UK will learn that their baby has only half a working heart. These families can be left feeling very alone, frightened and confused until they receive help. This is why LHM exists but we need your help.

£10 could support a family following diagnosis, providing them with an antenatal pack and the antenatal support line.

## How you can help

- ❄ Buy a blanket patch to help make sure the blanket of care and support is there for families when they need it most.
- ❄ Share the leaflet enclosed in the newsletter at work, school or with a friend.
- ❄ Go to [www.lhm.org.uk](http://www.lhm.org.uk) for more details or scan the QR code on the flyer to buy your patch.

