



Little Hearts Matter Newsletter

April 2024

The Little Hearts Matter Open Day 2024



Turn to page 12 to read about our LHM family event.



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Supporting every step of the half a heart journey



Lisa's News

Written by: Lisa Davies

Dear members,

As we mark our 30th year, I want to take a moment to acknowledge the journey we've been on together. Little Hearts Matter started with a simple goal: parents helping other parents dealing with single ventricle heart conditions to help reduce the fear, isolation and lack of understanding. Now, three decades later, we're reflecting on the impact we've had as a community.

Throughout this special year, we'll be shining a light for the general public on single ventricle heart conditions and showcasing the practical help we've been offering for 30 years. This anniversary is a reminder of the collective strength we share, motivating us to keep doing what we do.

We are also celebrating the recognition of Suzie Hutchinson's lifelong commitment to empowering and supporting children, young people and their families, through the award of an MBE in the 2023 King's Birthday Honours.

Please scan the QR code to find out how you can take part in our 30th Anniversary Year activities.



Lisa Davies, CEO, Little Hearts Matter



Trustee News

Written by: Warren Manger

I often describe Little Hearts Matter as a family. We support each other through the tough times and celebrate each other's achievements, forging lasting friendships along the way.

Now that family is growing. As we announced at our Annual General Meeting, we are extending our membership to include the partners of adults living with single ventricle heart conditions.

It is wonderful that more young members are reaching adulthood, finding love, and entering into long-term relationships. But it is vital that we provide their partners with the support and the information they need, as we would with other family members.

As a Board of Trustees, we have been updating our governance procedures and discussing the services we provide as a charity to ensure we are ready for that change.

We have also been supporting our amazing staff as they deliver a range of exciting projects to mark our 30th anniversary year.





Suzie's Top Tips

Written by: Suzie Hutchinson

Leg pains and Congenital Heart Disease (CHD)

For many years, parents have contacted me to talk about the pains that their children have in their legs, especially after a long day of activity and normally during the night.

Many doctors said it had nothing to do with their heart condition but was normal 'growing pains'.

We decided that we would create a survey, in partnership with the CHD research team in Newcastle, to have a look at the number of cases reported.

Results

Of the 220 patients who responded, 94% reported leg pains compared to 30% of siblings (n=107; p<0.001). In respondents, pain was typically reported to occur in the lower legs or around the knees or ankles, often associated with crying and screaming (49.0%) and most commonly occurring at night-time (82.0%). Individuals taking aspirin and those who were more active were more likely to report leg pains. Older age was associated with leg pain that occurred with stress (p=0.02) and at night (p=0.05). Analgesia (64.1%) or massage (53.9%) was the preferred option for alleviation. There was no gender bias, association with diagnosis, surgical history and/or relationship with diagnosed orthopaedic issues. To see the full study follow this link: www.lhm.org.uk/youth-champion-study/

Having agreed that this is a normal problem for children with CHD, further research will be needed to find a cause. The best treatment is to rub the pain away and to give a dose of Calpol/ Paracetamol. Making sure the children's legs do not become cold can reduce the number of disturbed nights, and making sure that the children drink enough and they are well-hydrated can help.

Suzie Hutchinson MBE

Suzie attended an investiture at Windsor Castle on the 7th of February. She was awarded an MBE for her work supporting, informing and advocating for anyone affected by congenital heart disease, especially single ventricle heart disease.

"It was an honour to receive my MBE from HRH The Prince of Wales. He was interested to hear more about the work of LHM and commented on how difficult this diagnosis must be for families affected. It's been the privilege of my life to work with children, young people and their families affected by half a working heart. This is a particularly special year as it marks Little Heart Matter's 30th anniversary year and I've been with the charity since its inception. Advocacy will always remain a priority for the charity and I, and the LHM team, will continue to champion the needs of all those affected and struggling to get the recognition and support they deserve."

It is great to see the survival of young members improving but there is still much to do to raise a greater awareness of the day-to-day needs of all members of the families the charity supports. We hope to use our 30th anniversary year, and Suzie's recognition, to raise a greater awareness of the needs of LHM members both with government and the NHS.

For more information read about the LHM Campaign on **page 11**.



History of Single Ventricle Treatment and Little Hearts Matter

Written by: Suzie Hutchinson

Children with only one heart ventricle were often called blue babies. Their inability to pump oxygen-filled blood around their body led them to be cyanosed at birth and inevitably led to their death because, for many years, there was no treatment for such complex heart conditions.

Over the last 80 years, a variety of treatments have been developed that can be used to help children with just half a working heart. Conditions that affect the flow of blood to the lungs, like Tricuspid Atresia have been treated for longer than conditions on the left side of the heart.

In 1943 the team of Blalock, Thomas and Taussig developed a shunt, a plastic tube (now made of Gore Tex), that could route blood flow to the lungs bypassing the blockages they had in the heart. It mimicked the Ductus Arteriosus present in the baby in utero. Although this operation was originally developed for children with Tetralogy of Fallot (another cyanotic congenital condition) it was eventually used as the first step in treating right-sided single ventricle conditions. For the first time, it gave these babies a chance at life. However, the shunt only gave a baby time, there needed to be better solutions.

The next solution came along as the Bidirectional Glenn. Developed in 1956, the procedure used the Superior Vena Cava (the main blood vessel that brings blood from the head and neck to the right side of the heart) to direct blood straight back to the lungs via the Pulmonary artery. The advantage of this operation was that the blood vessel was the child's own and it grew with the heart. Although the children were still cyanosed they had more energy and had a better quality of life.

Doctors needed to find a way to further reduce the cyanosis; they knew that children would need more oxygen flowing around their bodies to help their growth and development.

In 1970 Francis Fontan developed the Fontan procedure. He created an operation that directed all the blue (de-oxygenated) blood from the lower body straight to the lungs, again bypassing the blockages in the heart. This operation completed by doctors aims to separate blue (de-oxygenated) and red (oxygen-filled) blood in the heart and the circulation, allowing children with hypoplastic right heart conditions to develop and grow better and live longer than they had done before.

Tweaks to the surgery made outcomes better over the years, for example the introduction of Guillermo Kreutzer's fenestration helped children with a Fontan heart cope with the pressure that built up in their circulation.

One problem was that babies often died before any treatment could be offered. When babies are born, they still have the circulation that aids their oxygen flow whilst inside their mother. Once they are born these connections and holes in the heart start to close. For babies with half a heart this is a big problem because their hearts depend on this circulation until surgery can be done. The introduction of Prostaglandin treatment in the 1980s saved many babies' lives because it delayed the closure of the fetal circulation giving doctors time to prepare for surgery.

Alongside the surgical developments, improvements in antenatal diagnosis allowed parents to make decisions about the onward care for their unborn babies. Doctors could improve outcomes because they could make sure that babies were safer at birth.



Eventually, this combination of operations was used for more and more conditions that affected the blood travelling to the lungs for example Double Outlet Right Ventricle and Double Inlet Left Ventricle.

Throughout all these developments, there was still no surgery that could save babies with Hypoplastic Left Heart Syndrome (HLHS). Doctors tried a series of operations to try to give these children a chance of life but sadly the majority of babies with this diagnosis died.

In 1981 Dr William Norwood reported on surgery that he had developed for babies with HLHS. He knew children needed a pump to drive oxygen-filled blood around their bodies, so he developed an operation that used the right heart pump to do the job of the left. This complex surgery was very high risk and many surgeons who tried to use it in the early years failed. Norwood followed up his first stage with the Glenn Shunt and then later the Fontan procedure. At last there was treatment for HLHS.

The first team in the UK to create a consistent programme of care and treatment for babies with HLHS was Birmingham Children's Hospital. Led by William Brawn the team realised that you needed brilliant surgery, but you also needed great ITU support, long-term cardiac care and support for the families, especially when they went home.

Babies were sent to Birmingham from all around the UK and Europe. The parents were frightened, isolated and confused by the complex information they were given about their baby's heart. The risks of the surgery were high and babies who survived were often in the hospital for a long time.

This was so stressful for parents, often a long way from home so in 1994 the charity's support began. At first, all we could do was offer parents a visit from other parents at the bedside of a new baby. Left Heart Matters, a charity focussed on HLHS, grew out of that support. Run by parents Donna, Melanie, Chris, Eddie, John, Andrew, Nikki and the liaison sister at Birmingham Children's Hospital, that was me, we started to link parents together by phone. We worked to write the first booklet to explain HLHS and created a newsletter to keep families linked together. In 1996 we gained charity status and ran our first LHM Open Day. Gradually the number of people using the charity grew with everyone involved offered their support for free.

As other units started an HLHS programme calls for support and information started to come from families around the country.

The charity's board knew that LHM needed to have a team who could provide regular support so in 1999 they secured a grant from the Lottery to employ staff. The first member of the team was me, as the Development Officer, quickly joined by Deb who provided the admin and eventually design support.

We built a website, wrote condition-related information, gathered members together around the country and created a database. Most importantly we were there at the end of a phone offering support to anyone in distress. LHM also had contact with many people affected by other single ventricle conditions seeking support. They, and their medical team, wanted somewhere to go for the support that the HLHS families had. Their needs were further supported by research that showed that the families of children with HLHS coped better than those with other conditions because they had a community of support available to them.



In 2004 the charity expanded its remit to welcome anyone affected by any single ventricle condition, travelling the Fontan pathway. It also changed its name to Little Hearts Matter. We updated our information and continued to develop the work of the charity in line with what members asked for and started to grow the staff, trustee and volunteer teams.

National recognition of the work of the charity grew and the collective voice of members was sought in many arenas for change. The team expanded and the services expanded to meet the needs of a growing membership. As the children survived they grew to need support and information geared especially for them. Now Little Hearts Matter has a support service for adults living every day with the challenges that having half a heart brings.

As we celebrate our 30th anniversary we can rejoice in the improved outcomes for children born with single ventricle hearts. There are still many challenges for anyone living with just half a heart: they have less energy than their peers, they may have delays in their development and difficulties in education, and their hearts and bodies will start to show the strain of having only one heart pump, so Little Hearts Matter has grown and developed into a well-respected national charity with over 7,000 members. Be assured that the organisation, led by members' needs, will continue to support, inform and advocate for anyone seeking the charity's help.



LHM Timeline



In 1994, a group of local parents joined forces with a specialist nurse at Birmingham Children's Hospital (BCH) to create a volunteer team. Together they began to offer dedicated support to families with a diagnosis of Hypoplastic Left Heart Syndrome (HLHS). At the time, BCH was the only centre treating this complex heart condition in the UK. The charity was originally known as Left Heart Matters.



A new logo marked a new era of LHM

The 2000s

In the 2000s, LHM introduced new support and information services, to help anyone affected by the diagnosis of a single ventricle heart condition, not just HLHS.

In 2004, LHM was renamed Little Hearts Matter and established itself as the leading UK charity for people with half a working heart.



LHM Supports thousands of children across the UK

30 years of LHM

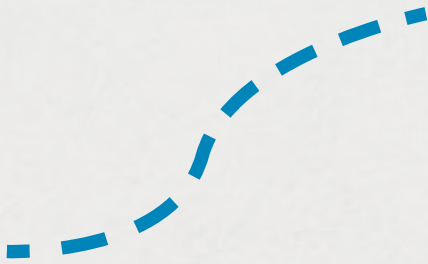
Today, LHM supports over 7,000 members nationwide with bespoke children's, young people's and adult services as well as the support for parents from the beginning of the half a heart journey and at every stage beyond.



The 1990s

Throughout the 1990s, the charity's services expanded to meet the needs of a growing membership. LHM was awarded charitable status in 1996.

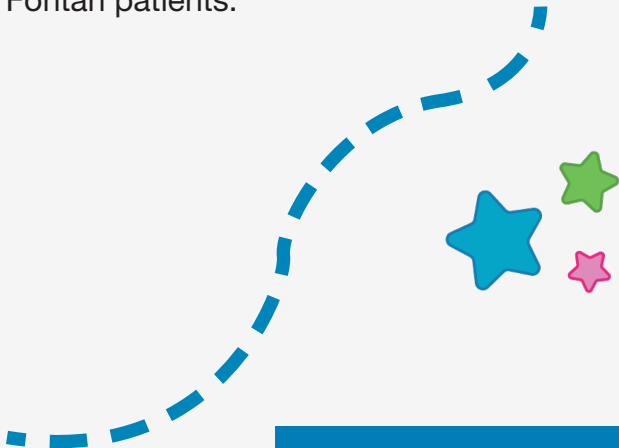
In 1999, a Lottery grant allowed LHM to offer telephone support, build a regional network service and offer parents specialised lifestyle and medical information. Eventually, clinicians began to make direct referrals to Left Heart Matters.



LHM's first open day
Birmingham, 1996.

The 2010s

In the 2010s, LHM saw exponential growth with more inclusive support and information services than ever before. The charity also developed a reputation for taking its members' voices into arenas for change. LHM worked with the NHS and government to improve the treatment and support available for Fontan patients.



LHM received funding for its first staff through the Big Lottery, allowing us to change from Left Hearts Matter to Little Hearts Matter



The Bullring bull gets
an LHM makeover



LHM Comic

One of the fantastic resources we have for our Kidz members aged 7-11 is our Half a Heart Gang comic. Our most recent comic features Tilly and Isaac's trip to the hospital for some routine tests, explains what those tests are for and also gives some advice for those who are afraid of needles. Some BIG themes.

All of our kids will have come across these tests and procedures but will have varying degrees of understanding and our comic aims to help de-mystify and normalise these procedures so that check-ups and trips to the hospital become less daunting. No matter how excellent, kind and friendly your child's cardiac team are, trips to the hospital and being poked and prodded with needles and various pieces of equipment can be a very scary experience. We hope that being able to sit down and read about the different tests in advance gives your children a level of understanding that will allow them to feel more in control.

Clinical Psychologist, Kathryn Thomson has written two excellent articles for us about fear of needles, one of which is written for our Kidz members and features in our comic. The other is for our parent members and gives guidance on how to handle any potential fears around trips to the hospital and how to come up with strategies to help your child manage any fears or worries they may have. You can find it on our website: www.lhm.org.uk/helping-your-child-with-a-needle-phobia/. There is also a downloadable "plan for having injections" that you can talk through with your child ahead of any procedures.

We hope you and your child are finding our Half a Heart Gang comics useful, if there are any topics you would like to see us cover in future editions, please email olivia@lhm.org.uk with your suggestions.



Our dedicated Kidz comic has been generously funded by **St. James's Place**

St James's Place Charitable Foundation



Sports and Exercise - Then vs Now

Little Hearts Matter turns 30 years old this year, and within that 30 years we have seen many changes, changes both within the charity as we have grown and with the advice given to families affected by a half-a-heart diagnosis as their children and the understanding of the condition has grown.

One of the changes has been the advice around sports and exercise when you have a child or young person with a single ventricle heart. This change, though necessary, has caused some confusion within our families wanting to do the best for their child.

When Little Hearts Matter was a new charity the initial advice was to minimise the sports and exercise we saw children and young people with half a working heart participate in. For many years our child and youth members would abstain from sports and exercise because of this advice. 30 years on the advice is now very different.

We know that the healthier we can keep a child or young person's body, the more likely they are to be able to fight off infections, have improved circulation and increase the effectiveness of their heart muscle. By keeping fit our children and young people are more likely to maximise the potential of their hearts. So, participating in some sport and exercise is now the best advice.

Many of our youth members ask what type of exercise is safe for them and how much is realistic with their lower energy levels. Honestly, every single youth member is an individual so their abilities will differ, however, there are some tips and a very handy golden rule to help ensure all our youth members can access exercise in a safe way.

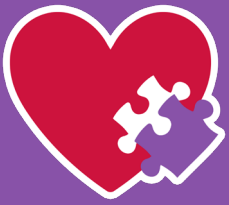
- **GOLDEN RULE – If you become breathless and cannot speak, it's time to take a break, catch your breath and have a drink of water.**
- It is best to avoid contact sports due to anticoagulation medication.
- Most sports can be adapted so that they are safe. Working with organisers or PE teachers can ensure youth members with half a working heart don't miss out.
- Stay hydrated – dehydration makes it more difficult for a Fontan circulation to perform well.
- Gym equipment such as treadmills and rowing machines can be a positive thing if used correctly, free weights and too much upper body weight should be avoided. Too much upper body muscle can cause resistance for blood flow to the head and as it then return to the heart and lungs.

It is great to see that over the last 30 years, the understanding of single ventricle hearts has improved and led to our young people being able to participate in activities with their peers to an extent. We enjoy seeing our young people keeping fit and healthy. If anyone has any questions about participating in sports and exercise with half a working heart please feel free to contact the service team, and remember your doctor will also be able to chat about what is best for your child or young person.

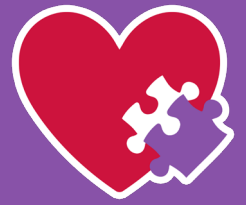


Our youth programme is
generously funded by
Children in Need





SVH Adults



Written by: Will Goodenough

Will's Story

I last provided an update for LHM back in 2019. Life has definitely changed in the last five years. The most obvious change is that I am now 30, along with LHM.

You might also remember that my partner and I had just welcomed our baby boy into the world. It is hard to believe that he is now five years old; he's just started school where he is really thriving and making us so proud. He is a very energetic little boy and keeps Emily and me on our toes, I can sometimes find this difficult, but he is starting to understand a little about my condition and how it can affect me.

In 2020 we bought our first family home in Sheffield, a real renovation project, but after 15 months of hard work and living with Emily's parents, we moved in. We have been here for two years and are happily settled. Sheffield is a great home for us, we are never stuck for things to do as a family or with friends. I still love to play golf; I find this a great way for me to stay active as I find more traditional ways of exercising too strenuous.

Career-wise, I am still working in the financial industry, but I am now training to be a Financial Advisor. I have obtained half my qualifications and am looking to be fully qualified by the end of the summer. Juggling work, study and family life can sometimes be a struggle but this is a career path that I have always wanted to pursue to benefit myself and my family.



Our adult service receives funding from the Paul Hamlyn Foundation



Denying benefits to anyone with half a heart means they can only live half a life

Help us to enable a new generation of heart children and young adults to access and secure the benefits they need to live to their full potential

The Little Hearts Matter DLA/PIP Campaign

We will be asking you, our LHM members, to support the Disability Living Allowance and Personal Independence Payment Campaign.

We need your views in our 30th anniversary year, as Little Hearts Matter is working to make a difference. At the end of last year, we sought members' opinions about the changes you would like to see that would help the most with the half a heart journey. DLA and PIP were an area where you told us you would like to see a difference.

We know that disability benefits can empower people with single ventricle hearts to live as full a life as their heart condition will allow. The charity works to support members with their DLA and PIP applications and appeals so we know how challenging securing the benefits can be and also how emotionally draining the process is, especially if the award is denied.

Over the next few months the charity will be collecting members' experiences of the award process, seeking information about the awards from the Department of Work and Pensions, helping to update medical teams on the process of support needed for an application and then, during the LHM Awareness Week from 1st to 7th May, we will work to raise the profile of the needs of children and adults with half a heart with politicians and government.

We will have a number of asks of members as we work through the campaign:

- We will need your views via a survey. Scan this QR code to take part.
- We will be collecting your DLA and PIP stories.
- We will be creating a poll for change.
- We will be asking you to contact your MPs to help us raise awareness of the DLA/PIP needs of members.



To keep up to date with the progress of the campaign and to contribute your views and concerns please keep looking at our updates on the Little Hearts Matter website. Follow this link: www.lhm.org.uk/little-hearts-matters-dla-and-pip-campaign/ or scan the QR code.



Little Hearts Matter
Supporting every step of the half a heart journey

Denying people with half a heart benefits means they can only live half a life.




SCAN ME

To learn more about our Benefit Campaign, scan here.

lhm.org.uk

littleheartsmatter @LHM_UK @littleheartsmatter

Little Hearts Matter is the only charity in the UK offering specialised support to children, young people, adults and their families with a diagnosis of a single ventricle heart condition.
A company limited by guarantee, registered in England and Wales, number 06442071.
Registered charity number 1123290.

The LHM Open Day

World Record Attempt

What an amazing event! This year, the Little Hearts Matter Open Day drew together parents, grandparents, SVH adults, youth members, LHM child members, medics, nurses and other CHD charities. Fantastic speakers explained Fontan Associated Liver Disease (FALD), talked about the importance of exercise for anyone with a Fontan heart, explored pregnancy for SVH adults and helped the children and teenagers think about dental care. The youth group quizzed Dr Paul Clift about their hearts and the 7 to 11-year-olds worked with Olivia, the Child Services Lead, to understand their bodies and what the heart does a little better. The conference part of the day ended with the much-loved adult member and doctor panel where lots of questions about living with a single ventricle heart were asked and answered. The parent conference was streamed live and recordings of the conference and the SVH adult sessions were taken and will be uploaded to the LHM YouTube channel soon.

To end the day we invited our young members to a party followed by dinner and a fantastic evening of music from some of our members, Sarah and Violet, and the Sheffield Music Players Society.

Throughout the day we collected members' views, and lots of photos and tried to create a first by having as many people as possible with half a heart in the same place at the same time.



Thanks to all our members who have fundraised for us this year, without your support we would not be able to offer our amazing free events. Each and every one of you is vital to our success.



Grandparent Page

Written by: Lisa Davies

Colin's Story

Colin and Christine Barrett are two of our most active grandparents. We have frequently shared updates about their activities in support of Little Hearts Matter.

We asked Colin and Christine about what in LHM has been particularly helpful for them. Colin emphasised that telephone support and Open Days were invaluable when their grandson, Thomas, was born, offering a supportive platform to discuss challenges with like-minded people.

Christine shared that LHM support helped them focus on the positive aspects and celebrate the joy that Thomas brought to their lives. This positive perspective enabled them to better support their daughter and son-in-law.

Christine fondly recalled the first time Thomas said "mummy," his first word at two years old. Colin reminisced about tears of joy at his first birthday party. Both proudly witnessed his first day at primary and secondary school, his achievement of three A-levels, and him securing a place at University.

Throughout their journey, Christine and Colin found strength and resilience. They concentrate on the positives, doing everything they can to support Thomas's parents through any challenges. Colin values LHM staff and trustees as valuable sounding boards, appreciating their optimism and the information they provide.

On Thomas's diagnosis, they were in the dark. The first Open Day was eye-opening, witnessing children playing and families having fun. They urge all new parents to attend, and hear other parents' stories.

Colin has raised over £50,000 for Little Hearts Matter, recently organising an 80km relay to mark his 80th birthday. When asked about his motivation, Colin stated,

"When a charity depends on its member family for the vast majority of its funding, I feel it is incumbent on all of us to create fundraising events or, if circumstances prevent this, give a donation. Unlike other charities, LHM does not charge an annual membership fee, showing appreciation through fundraising and donating."

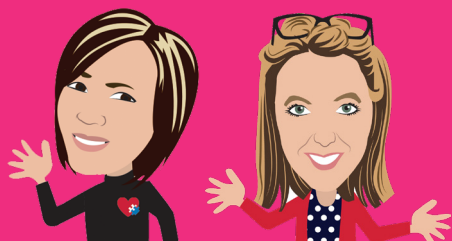
In addition to solo and team challenge events, Colin enjoys bucket collections and was pleased to share his "no fail" top tips:

1. Say hello to everyone.
2. Smile.
3. Be gracious, no matter what. You are ambassadors for the charity, so be friendly to staff and customers alike.

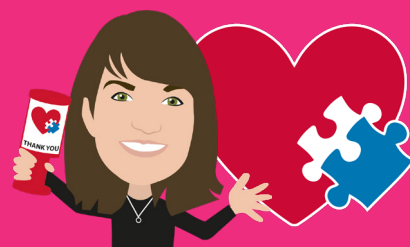


SCAN ME

Thank you Colin and Christine! Please find family stories here: www.lhm.org.uk/parent-and-children-stories/ or by scanning the QR code.



Fundraising



Written by: Juliet Hanlon, Liz Hodson and Rebecca Wilkes

Brave Heart Fundraising Award

Little Hearts Matter is delighted to award Ava our Brave Heart Fundraising Award. The Fundraising Award is awarded to young half a heart members, brothers, sisters or friends who have taken on a fundraising activity on behalf of Little Hearts Matter, and who have shown imagination, enterprise and enthusiasm.

Ava chose Little Hearts Matter for her Brownies fundraising badge as she knew they supported her friend Tia who has half a working heart. To work towards her Brownies badge Ava had to come up with her own ideas to raise money as well as research the charity she had chosen.

For her fundraising activity, Ava decided to do a 30-minute sponsored trampolining session as well as a cake sale. Ava researched about Little Hearts Matter, our aims and who we support, all the while linking this back to her friend, Tia. She let people know about her planned activity. People enthusiastically sponsored her trampolining and purchased all her delicious cakes. Ava raised an amazing £409 for Little Hearts Matter.

Tia's mum nominated Ava for this award saying, 'We feel she deserves this award for all her hard work'. The Braveheart panel agreed and was proud to present Ava with her Braveheart Award. Fundraising support from our community of members and friends is vital to ensuring Little Hearts Matter is always there for the families who need us. Thank you, Ava!



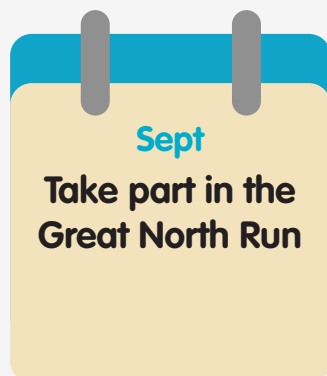
The Brave Heart Awards have been generously supported by one of our grandparent members.



SCAN ME

And if you'd like to take on a fundraising activity of your own, please scan the pink QR code.

Keep your eyes peeled for exciting announcements!



Noticeboard

Dates for your diary!

April

- **Thursday 18th** – Transition Workshop

May

- **Wednesday 1st to Tuesday 7th** – Little Hearts Matter Awareness Week.

June

- LHM Roadshow - Southwest

August

- **Wednesday 21st to Friday 23rd** – Youth Activity Residential

September

- **Sunday 1st**– Brave Heart Award nominations open.
- **Monday 30th** – Fontan Symposium Conference

October

- **Tuesday 1st** – Brave Heart Award nominations close.
- LHM Roadshow - Southwest

Little Hearts Matter

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littleheartsmatter



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Publication List

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

Antenatal

- Antenatal information pack

Diagnosis

- Fontan Associated Liver Disease (FALD)
- Left-sided single ventricle heart conditions
- Single ventricle heart conditions that affect the flow of blood to the lungs

Treatments

- Fontan booklet
- Heart transplantation - a guide for families
- MCT diet
- Preparation for hospital booklet
- Living with anticoagulation

Education

- Support for a Child with Special Educational Needs within Nursery, School, or Further Education
- Healthcare Plans for Children and Young People with a Single Ventricle Heart Condition
- Understanding what having half a working heart means for a child in school – a guide for school teachers
- 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
- Your guide to university with half a heart

Benefits/DLA/PIP

- Benefits - a guide for parents
- Baby/child DLA booklet and sample pack

Resources for Children

- Jessica has a heart operation - children's storybook
- Jack has a heart operation - children's storybook
- My baby sister has something wrong with her heart - storybook for brothers and sisters before a baby is born.
- My new baby sister has something wrong with her heart - storybook for brothers and sisters after a baby is born.

Lifestyle

- Sport and exercise
- Travel and trips
- Puberty for young people with half a heart
- Sex and relationships with half a heart