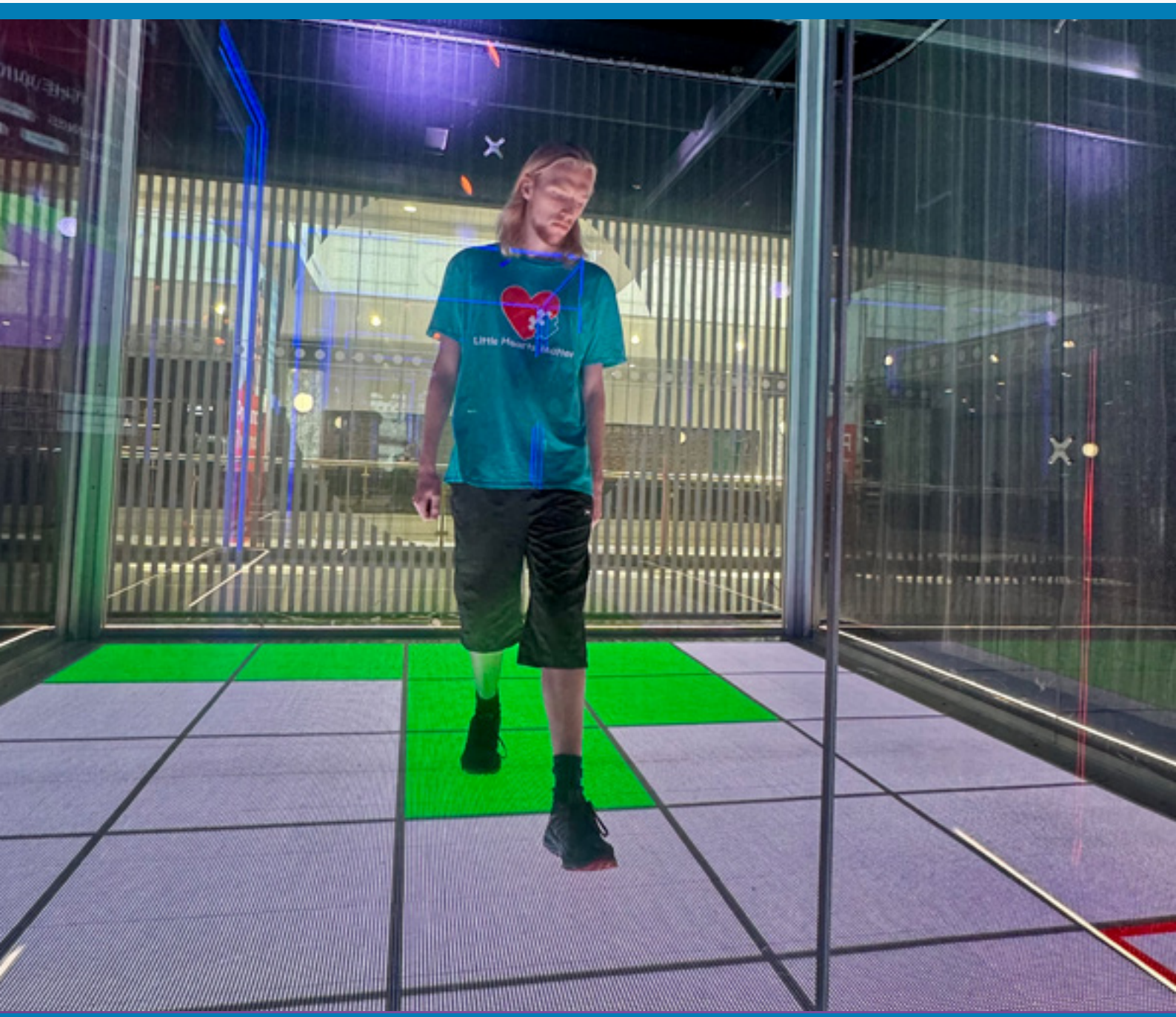
Little Hearts Matter Newsletter

October 2026



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Supporting every step of the half a heart journey



Meeting Our new Chief Exec

Written by **Dr Laura Walton-Williams**

Hello,

My name is Dr Laura Walton-Williams, and I am delighted to join Little Hearts Matter as your new Chief Executive. Thank you to everyone I met during the recruitment process - I am thrilled to have been selected and to be joining such an inspiring organisation.

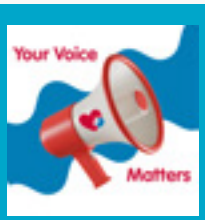
I began my career as a forensic biologist before moving into senior leadership roles in higher education, alongside serving as a trustee for domestic abuse charities. These experiences have shaped my commitment to supporting people through challenging times, and I am excited to bring that combination of skills and experience to this role.

Little Hearts Matter is an incredible charity that has transformed the lives of so many families. Having experienced the loss of a cousin due to a congenital heart condition, I understand how vital it is to have access to trusted information, compassionate support and a strong community at every stage of living with a single ventricle heart condition.

I have seen the dedication, expertise and kindness of our staff, volunteers, members and supporters. Thank you for everything you do. I am honoured to be part of this remarkable community and look forward to meeting many more of you—please do come and say hello.

Best Wishes,

Laura



Your Voice Matters: Our Biennial Member Survey is now live

Every two years, we ask you, our members to share your experiences with us. Not because we need to tick a box, but because it's one of the best ways we have of making sure Little Hearts Matter continues to support you in the ways that matter most.

Living with a single ventricle heart condition, whether as a parent, child/youth/adult, or family member, brings its own challenges that grow with you. What helped two years ago might look different today. Our survey helps us spot the trends, gaps, and emerging challenges across our whole community, so we can keep shaping a support service that's right for you.

Little Hearts Matter have created a survey, just head to our website to fill it in. It won't take long to complete, and every response however big or small, helps us build a clearer picture of what our community needs next.

As always, this is your service, and your experiences and voice guides everything we do. Thank you, as ever, for being part of the Little Hearts Matter family.

To complete the survey **scan the QR code**

Click here to access the survey online

Trustee news

Written by **Asha Ghosh**



Trustee News

Our staff team have worked incredibly hard this year to keep supporting members, maintain services, raise vital funds and continue developing new resources, including our new *Taking Your Baby Home* booklet. They have done all of this with real care and commitment during what has been an exceptionally difficult year for charities and public fundraising.

I'm also delighted to welcome three new trustees to the Board: Jon Hinchliffe, who will take on the role of Treasurer, Amy Parkinson, and Katie Oerton. They bring valuable financial, marketing and HR experience, but just as importantly, a real commitment to the future of LHM.

And of course, a very warm welcome to our new permanent Chief Executive, Dr Laura Walton-Williams, who joined us in September and is already making a positive contribution.

This has been a challenging year, and there have been difficult decisions along the way.
So, my heartfelt thanks go to our staff, trustees, volunteers, members and supporters for the patience, care and support you have shown one another.

Here's to Christmas, some well-earned rest, and a hopeful new chapter for LHM in the year ahead.

Asha Ghosh

Written by Asha Ghosh
Chair of Trustees

Our CRM (a database to help us manage our membership and supporters) is run by a company called Beacon. We wrote to you in early August to let you know that along with over 1,500 other charities it was hacked. Both Beacon and we have taken steps to increase security of your information and as of late August the system is running smoothly and securely.

Keep Moving – Exercise

Written by **Dr Louise Coates**

Keep Moving: Why Exercise Matters if You Have a Single Ventricle or Fontan Circulation

For many people born with a single ventricle heart, the Fontan circulation has made it possible to live well into adulthood. As increasing numbers of children with a Fontan circulation grow up and enjoy longer, fuller lives, there is growing interest in how lifestyle choices can help keep the heart and body as healthy as possible. One of the most important of these is regular physical activity.

Many people with a Fontan circulation wonder whether exercise is safe. The reassuring news is that, for most clinically stable children and adults, regular physical activity is not only safe but actively encouraged. Exercise has important benefits for both physical and mental wellbeing and plays a key role in maintaining long-term health. However, every Fontan circulation is unique. Factors such as heart function, heart rhythm, oxygen levels, and other medical conditions may influence the type and intensity of exercise that is most appropriate for you. For this reason, exercise advice should always be considered in the context of your individual circumstances and discussed with your congenital heart disease (CHD) team.



Why does exercise feel different?

A Fontan circulation works differently from a typical heart. In a normal heart, one pumping chamber sends blood directly to the lungs. In a Fontan circulation, blood flows to the lungs passively, without being pumped by the heart. Because of this, it can be more difficult to increase blood flow during exercise and deliver enough oxygen to working muscles. Your heart rate may also increase more slowly during activity and may not reach the same level as someone without congenital heart disease. As a result, you may become breathless or tired more quickly.

Other factors can also affect how much exercise you can do. These include lower oxygen levels, leaking heart valves, reduced heart function, loss of muscle fitness (deconditioning), and low iron or vitamin D levels. Understanding these differences can help explain why exercise may feel more challenging than it does for friends or family. However, becoming tired more easily does **not** mean that exercise should be avoided. Regular physical activity is important for maintaining fitness, strength, wellbeing, and overall health.

Exercise really does make a difference

Research consistently shows that regular exercise can improve fitness, muscle strength, quality of life and confidence in people living with a Fontan circulation. Exercise also helps keep your muscles healthy and more efficient at using oxygen. Strong leg muscles are particularly important because they help push blood back towards the heart and lungs, supporting circulation. The best exercise is often the one you enjoy and continue doing regularly. Walking, cycling, swimming, dancing and gardening all count towards your weekly activity.

In the UK, guidelines generally recommended that adults aim for around **75-150 minutes of moderate intensity aerobic activity each week**, spread over several days, alongside **muscle-strengthening exercises at least twice a week**.

However, if you are currently doing little or no exercise, do not worry about reaching these targets straight away. The greatest health benefits often come from increasing activity from very low levels. For example, increasing from 0 to 50 minutes of exercise per week provides more benefit than increasing from 100 to 150 minutes per week. Whatever your starting point, increase your activity gradually by a few minutes at a time.

Strength training is particularly valuable but should be performed with low-to-moderate resistance and good breathing technique. If you are needing to hold your breath during lifting, your weights are too heavy, breath holding should be avoided in the Fontan circulation as this can temporarily reduce blood flow back to the heart.

with a Fontan Circulation

Verified by **Dr David Crossland**

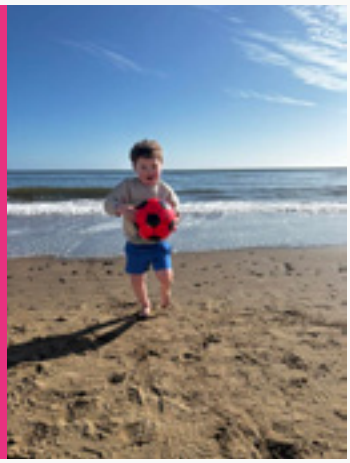
Flexibility and balance exercises, such as stretching, yoga or Tai Chi, are also worthwhile as they help maintain mobility and reduce the risk of falls as we get older.

Looking after your body

Exercise is only one part of staying well with a Fontan circulation. Good hydration is particularly important because it helps maintain blood flow through the lungs and supports the body's ability to regulate temperature during physical activity. Eating a balanced diet, maintaining a healthy weight, and getting enough sleep can all improve energy levels, recovery, and overall wellbeing.

Iron deficiency is common in people with a Fontan circulation and can reduce the amount of oxygen carried in the blood to working muscles. This may contribute to tiredness, breathlessness, and reduced exercise capacity. Vitamin D deficiency is also common and may affect muscle strength and function. If you are feeling more fatigued than usual, it is worth discussing this with your congenital heart disease (CHD) team, who can advise whether these levels should be checked.





Most adults with a well-functioning Fontan circulation can travel safely on commercial aircraft and enjoy holidays at moderate altitude. However, higher altitudes may place additional demands on the circulation and may require individual assessment. If you are planning strenuous physical activities, travelling to mountainous regions, or taking part in competitive sport, it is sensible to seek advice from your specialist CHD team beforehand.

Taking a holistic approach to your health by staying active, eating well, keeping hydrated, sleeping adequately, and attending regular follow-up appointments can help you get the most from your Fontan circulation and maintain the best possible quality of life.

Keep the conversation going

No two people with a Fontan circulation are exactly the same. Factors such as heart rhythm abnormalities, valve disease, reduced heart function, pregnancy, or implanted devices such as pacemakers and defibrillators may influence the advice that is most appropriate for you. For this reason, exercise recommendations should always be considered alongside your individual medical history and discussed with your congenital heart disease (CHD) team.

At your next clinic appointment, consider asking:

"Can you summarise exactly what you think I can do safely, what I should avoid, and why?"

This can help ensure that you have clear, personalised guidance and the confidence to remain active. The overall message from research is reassuring and encouraging. Although a Fontan circulation presents unique challenges, regular physical activity remains one of the most effective ways to support long term health and wellbeing. Exercise can improve fitness, strengthen muscles, enhance quality of life, and help you maintain independence as you get older.

Start from where you are now, build up gradually, and choose activities that you enjoy and can sustain. Whether it is a walk around the neighbourhood, a swim, a cycle ride, or a session at the gym, every bit of activity counts. Regular movement is an investment in your future health, and even small increases in activity can make a meaningful difference over time.

Meet the team



Written by **Joy Illori**

LHM Team Intro: staff edition

Tracy

Meet Tracy Eley, Office Manager and PA to Management and Governance, who has been part of the Little Hearts Matter team for four years. Inspired by the strength of the families we support, Tracy loves being part of a caring organisation where every role makes a difference. Her favourites? *City of Angels*, countryside walks, and springtime



Juliet

Meet Juliet Hanlon, our Fundraising Manager, who has been with Little Hearts Matter for three and a half years. Juliet is inspired by the strength, determination and generosity of our families, who continue to support others despite their own challenges. She loves hearing members' stories and helping build the supportive community that makes LHM so special.



Paula

Meet Paula Hughes, our Administrator, who has been with Little Hearts Matter for 11 years. Paula's favourite part of the role is connecting with members and meeting families in person. She is continually inspired by their strength and resilience and is passionate about raising awareness of the support and resources available through LHM. A book lover, Paula enjoys the seaside and sunny summers.

Lexie

Meet Lexie, our Head of Service, who has been part of Little Hearts Matter for nine years. Passionate about supporting families on their half a heart journey, Lexie is inspired by the determination and positivity she sees every day. A keen reader, she is proud that LHM has spent more than 30 years supporting every family affected by a half a working heart diagnosis.



Rebecca

Meet Rebecca, our Grants & Trusts Manager, who has been part of Little Hearts Matter for seven and a half years. Rebecca is inspired by the journeys, stories and achievements of the families we support. From Community Fundraiser to grant fundraising expert, she has grown alongside the charity and is passionate about securing vital funding for every family on the half a heart journey.



Sophiella

Meet Soella, our Assistant to the Head of Service, who joined Little Hearts Matter in April 2026. Although new to the team, she is already inspired by the bravery and resilience of the families we support. Soella loves helping create memorable events for members and is passionate about raising awareness of LHM's fantastic Youth Hub.



Volunteer Call Out

Written by **Soella Taylor**



Thank You to Our Little Hearts Matter Volunteers

At Little Hearts Matter, our volunteers are at the heart of everything we do. They give their time, energy and compassion to support families affected by a Single Ventricle Heart Condition, also known as half-a-working heart. Whether they are answering questions, sharing reassurance, raising funds, helping behind the scenes or guiding the charity as trustees, their contribution makes an extraordinary difference.

Why Our Volunteers Matter

For families facing diagnosis, treatment, hospital stays and navigating life at home, having someone who understands can be life changing. Many of our volunteers bring their own personal experience of the half-a-heart journey, offering empathy, practical insight and a listening ear when families need it most.

Though much of our information is found digitally, our volunteers provide human connection and understanding. Their support reminds parents, young people and adults that there is a community beside them with real people — one that understands the challenges, celebrates transitions and milestones and offers comfort during the difficult moments.

The Work They Do

Our volunteers support Little Hearts Matter in many different ways. Some provide direct support to families through conversations during the Antenatal period, helping make sense of a diagnosis at the beginning of the journey. Others provide a safe, listening ear through peer connection via our telephone support service, 7 days a week.

We also have volunteers who help raise vital funds, spread awareness, or bring professional knowledge and strategic guidance through trustee roles. Every hour given helps us continue offering support, information and brings families together across the UK.

Thank You

To every Little Hearts Matter volunteer, we thank you.

Thank you for showing up, for sharing your time, for offering kindness, and for helping families feel seen, heard and supported. Your commitment strengthens our whole community, and we are deeply grateful for all that you do.

As a UK charity, we simply could not function without the support of our volunteers. We often hear from members how much they value the specialist advice and lived experience our volunteers share, helping them feel just a little less alone.

Could You Volunteer With LHM?

We are always keen to welcome new volunteers who want to make a difference. Whether you have lived experience of a Single Ventricle Heart Condition, skills to share, or a passion for supporting families, there is a place for you within the LHM volunteer community.

We currently have volunteering opportunities in the following areas:

- Service Support
- Leading Online Youth Sessions
- Administration
- Fundraising
- Trustee roles

If you would like to find out more, please contact us at info@lhm.org.uk using the subject line 'Volunteer', or visit https://www.lhm.org.uk/22824-2/

The SVH Adult Social

Finding Your People: Little Hearts Matter Adult Social Weekend by Sjoerd Jones

Saturday Arrival…

We arrived in Manchester on Saturday afternoon for a 3pm check-in. Early arrivals at the accommodation were able to catch up after seeing each other in person, or for some, since a previous Youth Event. Now we have transitioned into adult members, it was nice to ease into conversations about our long journeys which helped break the ice. We all put our bags away in our designated rooms and met back at the café ahead of our walk in the sunshine. At 5pm, it was time for us to all head over to the venue for our medical seminar by Dr. Louise Coates on Congenital Heart Disease and Exercise.

What We Learned…

In opening, the seminar was titled; 'Exercise for Congenital Heart Disease and Fontan Patients in Adulthood.' As a collective, we were previously discouraged to exercise as youth and the focus was on taking our medication and doctors' appointments to maintain our health. Across the board, many of the adult members found exercise difficult and found they ran out of breath when taking part in it. The talk focused on which kinds of exercise to do, cardio being the preferred option, provided that aerobic respiration and a moderate intensity were maintained. Advice was also provided on weight and resistance training. There was strong encouragement towards light, high-repetition exercise focusing on balance and control to build strength, rather than heavy weights and reduced/altered breathing rates.

My key takeaway from this talk was to do as much exercise as you can for as many years physically possible but just do not knacker your heart whilst doing it!

Once the seminar was complete, we were all ready for dinner after a busy day travelling and learning. Our next stop and only a short walk away was The FireHouse Restaurant – it was time to refuel! We got comfortable and once seated, a delicious assortment of food arrived at our table and we began tucking in. As plates were passed and food devoured, conversations sparked amongst the group. There were the infamous horror stories about P.E lessons at school and experiences of engaging in challenging conversations with nurses and doctors.



We discussed moments and some quoted; 'do you know you have a heart condition?' a statement that is relatable to most of us. Some reminisced over attempts at SATs and expectations of us during our school years. What many might think would be uncomfortable conversations, ended up providing humour and solace amongst the group over dinner.

Written by **Sjoerd Jones**

Dinner came to an end, and everyone felt restored. As it was World Cup season, we then decided to head back to the hotel to watch the England Vs Norway match together. As we sat and watched on, this encouraged more conversations and connection. England had a victorious win and the game was over; it was now time for us to head off to bed to rest up for the busy day ahead.

As Sunday morning arrived, it's safe to say the ice was well and truly broken. We woke up to a lovely Greggs breakfast, courtesy of Lexie's early rising and organisation. With bags packed, it was time to head out again. We had more glorious weather as it was time to walk over to the venue where we would take part in the CUBE Experience. The competition commenced. Our team names were proudly displayed and shone a light on ownership of our heart conditions. We began competing in coordination, memory games and teamwork which helped forge stronger bonds on that Sunday afternoon. By manifesting destiny, the winning team scored the most points overall, a whopping 6,250, a team I may or may not have been a part of – I won't disclose!

After a fun filled morning, it was time to say our goodbyes, and head on the long journeys home. Most of all, this experience was a chance to connect with other adults who experience the stresses and strains of Congenital Heart Conditions.

How it Felt…

From start to end, the adult weekend allowed members to feel connected to a community unlike any outside LHM. Having such a sense of belonging within a group of people and being able to talk about the hard parts of life felt fulfilling. It was nice to be in a room full of others who have faced similar challenges and be able to make jokes without someone being offended on our behalf. I delved into different topics such as marriage, death, relationships, health and hopes for the future, with people who truly understand.

In comparison to previous adult socials, this event felt truly special and was the most wonderful weekend I've had in quite some time.

We hope you can come and join us for our next Adults Social Weekend in June 2027 – details will be shared on our social media channels



Championing CHD in schools

Written by **Lexie Katsaitis**

Championing CHD in Schools: An Update from LHM and the Health Conditions in Schools Alliance

Little Hearts Matters have been working as part of the Health Conditions in Schools Alliance, pushing to make sure children living with single ventricle heart conditions are properly recognised and supported in the classroom. We're delighted to share some real progress, alongside an honest update on where the wider picture stands.

The win: CHD is now included in the government's list of medical conditions with dedicated guidance for schools, and, crucially, that guidance now links directly to LHM's own education information eBooks. This means teachers, SENCOs and pastoral staff looking for support around single ventricle conditions will be pointed straight to resources written by LHM for children with half a working heart, rather than having to rely on generic health information that doesn't reflect the realities our families live with. It's a small part in a government document, but it's the result of sustained advocacy, and it matters enormously for the children who'll benefit from it.



The wider picture: The Department for Education has now published its response to the consultation on medical conditions in schools. The volume of feedback the consultation received was substantial, and while the response overall was positive, it also surfaced some genuinely difficult questions, particularly around where the line sits between the responsibilities of education staff and those of healthcare professionals. Rather than rush out guidance that didn't properly resolve those questions, the DfE has decided that further work is needed before the full statutory guidance can be published.

The DfE has been clear that this isn't the end of the road, just the end of this stage. LHM will keep representing the voice of the single ventricle community as this work continues, making sure CHD stays firmly on the agenda as the next pieces of guidance take shape.

We'll keep you posted as things progress, and thank you, as ever, for your support in helping us get single ventricle hearts conditions and CHD generally recognised where it matters.



Digital Support Update

Written by **Lexie Katsaitis**

LHM's Digital Support

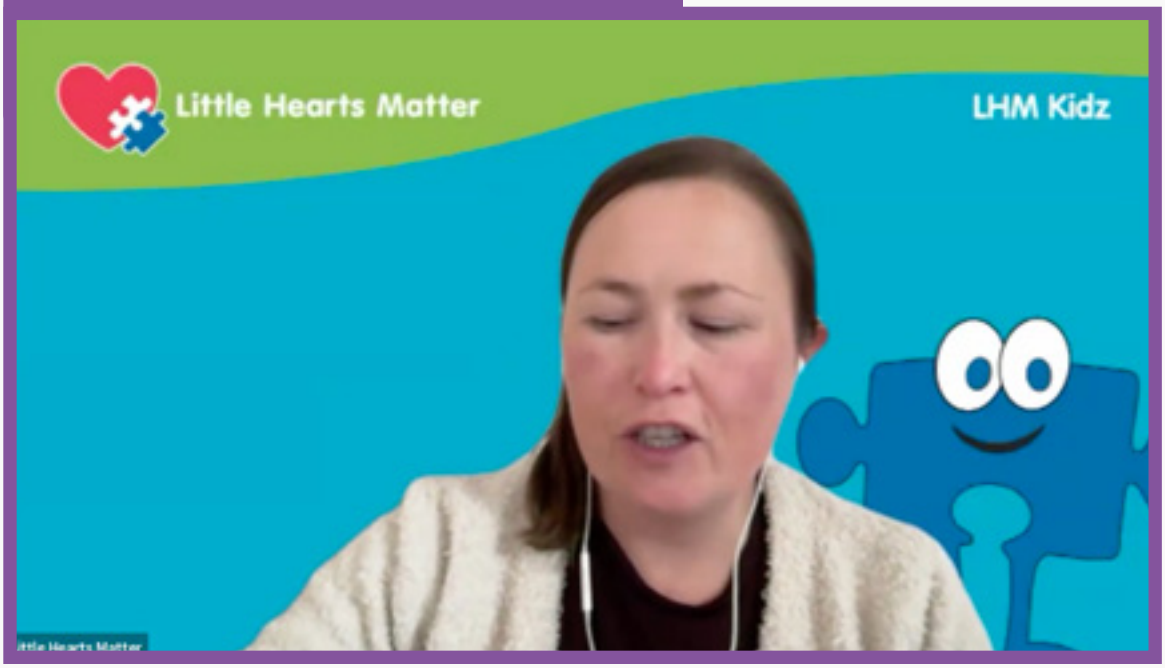
Little Hearts Matter runs two dedicated Zoom sessions for children and young people living with half a working heart, giving them the chance to connect with others who understand their experience without ever leaving home.

'Jigzy Does' is a session for 7–11 year olds, using games and chat to help younger members build friendships and feel less isolated by their condition. Alongside this, a Youth Zoom Catch-Up runs for our 12–17 year olds, offering teenagers a relaxed, informal space to talk, connect with peers, and share what it's like growing up with a heart condition. They join our youth mentors (adults with half a working heart) to talk about topics from hospital appointments to everyday life.

Both sessions run every other month, alternating so that members have something to join every single month. This is an informal, camera-on meet which means young people can drop in from wherever they are, meet others their own age, and build a sense of community that's often hard to find locally given how rare single ventricle conditions are.

These digital sessions are a key part of LHM's wider support offer, extending peer connection beyond in-person events and ensuring no member feels alone, regardless of where they live.





A members story

Written by **Claire**

National Champion Tia Proves That Dreams Have No Limits



Fifteen-year-old Tia has achieved something truly remarkable. Living with Hypoplastic Right Heart Syndrome (HRHS) and epilepsy, she recently became a National Champion in baton twirling – an achievement that reflects years of determination, resilience and hard work.

Tia first discovered baton twirling after a friend from school invited her to try a local club. From the very beginning, she loved it. The club welcomed her warmly and focused on her abilities rather than her condition, giving her a place where she felt accepted and able to thrive.

The sport has transformed Tia's confidence. Before baton twirling, she would never have considered performing in front of an audience. Today, she confidently competes in front of hundreds of people, enjoying every opportunity to learn new skills, perform and spend time with friends.

Watching Tia compete at the National Championships was an emotional experience for her family. They knew how much effort she had put into training while balancing school, medical appointments, fatigue and ongoing health challenges. Simply stepping onto the competition floor was an achievement in itself.

When Tia was crowned National Champion, her family were overwhelmed with pride.

Tia's mum, Claire, said: *"She couldn't quite believe she'd won! Seeing her face light up with excitement is a moment we'll never forget."*

For Tia, the achievement represents far more than trophies. It is proof that her heart condition does not define her and that she can achieve things she once thought were impossible.

Tia's journey has not been easy. Born with half a working heart, she underwent multiple open-heart surgeries and spent the first six months of her life in hospital. Following a cardiac arrest as a baby, she required ECMO support and suffered a brain bleed, resulting in right-sided hemiplegia. Despite these significant challenges, she continues to approach life with positivity and determination.

Her family also praised the inclusive environment at the championships, where organisers provided support for para-athletes, including a sensory room and adjustments that allowed competitors to perform at their best.





Claire said: *"The adjustments allowed Tia to compete safely while still challenging herself. The sensory room gave her space to rest and regulate, and the encouragement shown by the organisers and judges made the whole experience incredibly positive."*

Throughout their journey, Little Hearts Matter has also been an important source of support.

"Little Hearts Matter has helped us feel less alone," said Claire. "They've provided information, encouragement and a community that truly understands life with a single ventricle heart condition. We love attending meetups and have made many friends through Little Hearts Matter."

Looking ahead, Tia hopes to continue developing her baton twirling skills and inspire other young people with disabilities and health conditions to pursue their dreams.

"Never let anyone tell you what you can't do. Your heart may work differently, but your dreams are just as big." 💙🏆

Fundraising for Little

Written by

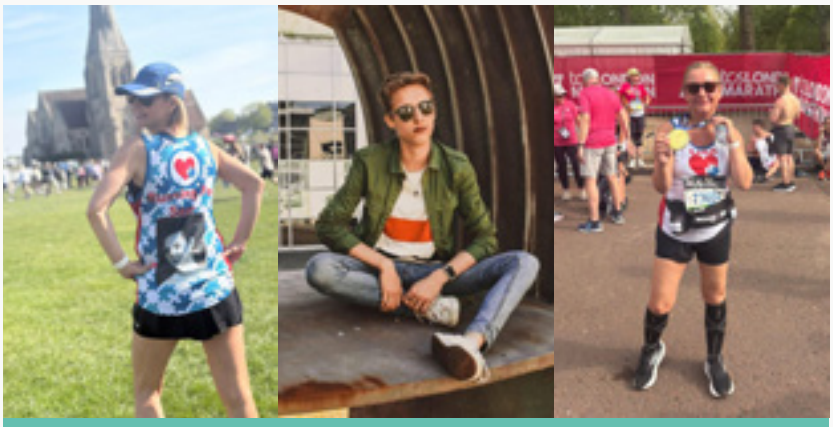
A Family Legacy for Sam

When Harry Tucker had the opportunity to nominate a charity for his employer, HPE, his choice was a charity that had supported his family for over 20 years. Inspired by his brother Sam, who lived with Hypoplastic Left Heart Syndrome, Harry nominated Little Hearts Matter. Sadly, Sam died not long after Harry's nomination, at just 23 years old. The wonderful team at HPE Bristol rallied together: they ran, baked, and volunteered to raise over £30,000 in Sam's memory.

However, the Tucker family didn't stop there. For over 15 years Sam's mum Lisa had entered the London Marathon ballot, with a dream of completing this iconic run. In 2025 she became one step closer to her dream as she secured a coveted spot in the Marathon. Lisa said "I like to think Sam had a hand in getting me the ballot place. I really want to help raise some money for Little Hearts Matter who helped us throughout Sam's life & help his memory live on."

Just a week before the event, Lisa suffered from an ankle injury. Spurred on by her purpose, Lisa completed the run and raised over £2,000 in a fantastic tribute to Sam. Lisa's achievement then inspired her sister, Amy, to take on the 2026 London Marathon as she approached her 50th birthday. Running in memory of her nephew, Amy raised over £3000 for Little Hearts Matter.
Seeing her family along the route and reaching Tower Bridge made the experience especially emotional. **"I just wish I could bottle up that feeling. It was amazing,"** Amy said.

From Harry's nomination and the incredible support of HPE Bristol to two unforgettable marathons, the Tucker family have created a remarkable fundraising legacy for Sam.



Celebrating our Little Lives Appeal

Last Christmas, our Little Lives Appeal brought the Little Hearts Matter community together to support families facing the life-changing news that their baby has half a working heart.

Thanks to our supporters, the appeal raised an amazing **£17,687** – far exceeding our £12,000 target.

Throughout the appeal, Laura, Kashala, and Susan generously shared their families' experiences, helping others understand how important clear information, emotional support and connection can be from the moment of diagnosis.

Every donation, shared post and conversation helped make the appeal a success. We are grateful to Candis Club – Newhall Publishing Ltd and Touchwood, whose match funding helped gifts go even further.

Together, you have helped Little Hearts Matter continue providing trusted information, one-to-one support, and a welcoming community for families when they need it most.



Christmas can hold many different emotions and memories for families across the Little Hearts Matter community. We're making plans for the season with all our families in mind and look forward to sharing more once they are confirmed. Watch this space!

Hearts Matter





Juliet Hanlon and **Rebecca Wilkes**

Five runners, one incredible Team LHM

On 26th April, Sally, Amy, Paul, Ed, and Josh completed the **London Marathon** as Team LHM 2026. Together, they ran 131 miles and raised over £15,000 for children, young people and families living with half a working heart.

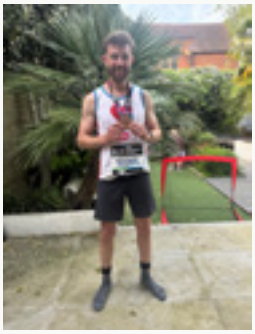
Each runner reached the finish line after months of training and determined fundraising, driven by a deeply personal reason for taking part. We are enormously proud of all five runners and grateful to everyone who cheered, donated, or supported them along the way.

Next year, five new runners will proudly carry the LHM colours through London. We are excited about introducing **Team LHM 2027** soon.









Red, blue, and brilliantly big-hearted!

Big Hearted Friday is one of the brightest dates in the Little Hearts Matter calendar – our own annual celebration of Heart Month.

It's a day for schools, nurseries, workplaces and families to wear red and blue, get creative, have fun, and shine a light on life with half a working heart.

This year, our big-hearted community baked, crafted, dressed up, and took on challenges, raising an incredible £7,300 for LHM. A huge high-five to everyone who made the day so colourful, creative, and full of heart!

Big Hearted Friday will return on **Friday 12th February 2027.** We can't wait to see schools, workplaces and communities turn red and blue again!



Thank you

To every donor and fundraiser: your kindness is behind the achievements celebrated on these pages and helps Little Hearts Matter be there for children, young people and families living with half a working heart. Please know how much we appreciate your support.

Our fundraising team is always here to help: fundraising@lhm.org.uk

Noticeboard

More dates will be added to our event page on the website throughout the year.

Final merch and Xmas card order

Event Date:
9th December 2026

Big Hearted Friday

Event Date:
12th February 2027

In Memory member event

Event Date:
9th May 2027

SVH Adult Social Weekend

Event Date:
June 2027
(date to be confirmed)

Youth Activity Weekend

Event Date:
20th- 22nd August 2027

Great North Run

Event Date:
12th September 2027

Little Hearts Matter

Hagley Court, 40 Vicarage Road,
Edgbaston, Birmingham B15 3EZ

0121 455 8982 | info@lhm.org.uk
www.lhm.org.uk

@LHM_UK
littleheartsmatter
@littleheartsmatter

Publication List

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

Antenatal
- Antenatal information pack
- Taking your baby home

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