



Little Hearts Matter Newsletter

Oct 2023

The LHM Summer Event 2023

Turn to page 14 to read about our LHM family event.



Our brand new
LHM Kidz page
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Supporting every step of the half a heart journey



Suzie's News

Written by: Suzie Hutchinson

What a busy summer the LHM team and members have had!

It was great to see our youth members, families and adults (at our first-ever SVH adult activity event) in August. We so hope you had a lot of fun. We just loved seeing members climbing high, screaming on the giant swing, learning how to TikTok, creating crowns, and taking part in parties, sports days, games and activities. It was amazing to have our very own music event. Great pictures will be spread throughout this edition so go and see if you can find yourself.



We are collecting feedback from everyone who attended the event. We have sent out surveys for you to complete, but we had lots of no-shows, even from families who had completed all the forms for the different events. We would like to understand why members were unable to attend.

When we plan and pay for events they are organised using the number of signups, even when people do not attend we have to pay. Of course, we understand that illness can mean a change in plans but it would be so helpful to know a little more. Just email us at info@lhm.org. Thank you.

Lots of hard work went into planning and running the summer activity events. I would like to say a huge thank you to all of the staff and volunteer team for the amazing ideas, the planning and for working such long days to make the weekend so memorable.

We are not sitting back now though. Lexie and I are back off around the country catching up with members and medical teams. Lexie is doing wonderful work linking with hospital transition teams. The transfer of patients from children's to adult services is a priority for the NHS and cardiac teams as well as our members of course. Lexie is taking her knowledge of young people's needs to the hospitals to help them as they create their new services.

We are planning the 2024 Open Day, book the 23rd of March in your diary. There will be more information to come. As well as a multi-dimensional conference it will also be a party.

We have welcomed Olivia as our new Children's Services Lead. She has been working with the team to create some fantastic new resources for the 7 to 11-year-olds. Check out more about these services later in the magazine.

As next year is our 30th anniversary, we have lots of special things planned. Look out for Sam's article explaining how you can get involved in our plans for greater awareness.

Sam is beginning his new freelance career so leaving his post as Social Media Lead but he will continue to work with us as we plan the awareness for 2024. Sam has been an amazing Social Media and Website lead. Thank you so much Sam for all of your hard work and inspiration. Joy will be taking on the job moving forward and will become the day-to-day communications link for the membership, there is more about her role in the section on Service Support later in the newsletter.



Welcome Joy. If you want to tell your story or send in a social media message email her at: joy@lhm.org.uk.

We have a brilliant new annual report available to tell everyone about our last financial year. We achieved such a huge amount in 2022. Go to www.lhm.org.uk/annual-reports/ to find the online version of the annual report.

My final news is a bit of a handover. As many of you know I have always had two jobs: CE and Service Lead. I have been working with the Board to split my jobs for a long time because the workload has grown so much as the charity has grown. I have asked to be Head of Services so that I can further grow the support we offer to members, my first love. For many of you, my role will not change. I am still here to help you if you need me, just get in touch. suzie@lhm.org.uk

I am delighted to announce that Lisa Davies will be taking on the role of Chief Executive at the end of October. Her background is in fundraising so she will concentrate on bringing in new funds that can support the service team's work.

A huge welcome Lisa. You could not be coming to work for a more wonderful organisation.

As I move across to focus wholly on members' needs, I want to say a massive thank you to the staff, over many years, the Trustees and you the membership. I feel between us we are able to hand the leadership reins over to Lisa with a charity that is respected, loved and which pulls out all the stops for families and individuals who need us when they are at their lowest. Thank you all!



Lisa's Introduction

Written by: Lisa Davies

Hello! I'm Lisa, and I want to express my gratitude to the amazing Little Hearts Matter team for their warm welcome as I step into my role as your new Chief Executive.

I've transitioned from the East Midlands Leicester Hospitals Charity, where I held the position of its first Charity Director. During my time there, I spearheaded the capital appeal to raise funds for constructing the new East Midlands Congenital Heart Centre, which now stands proudly as part of the Leicester Children's Hospital. Being a part of that journey was truly an honour, collaborating closely with incredible colleagues. Together, we united to create a genuine impact on the lives of children, families, and caregivers across the Midlands.

I've also had the privilege of working with the University of Leicester and a number of health and social care charities in Canada.

I am overflowing with excitement as I embark on this new chapter at Little Hearts Matter. I can't quite put into words the level of respect this organisation commands across the UK. My passion runs deep for the team's dedication to assisting children and families dealing with the news of a diagnosis. I've walked in those shoes myself, experiencing the immense relief, the power of support, and the wealth of information that devoted

charities like Little Hearts Matter provide. The care, the love – it's unparalleled and incredibly essential.

While I know I have a lot to learn and discover, I know that I want to ensure that the exceptional care, and the boundless compassion – all the qualities that define Little Hearts Matter – continue to shine brightly. I'm committed to expanding the reach of LHM so that more people can access its support when they need it most.

In case you're curious about my life beyond work, I share my home with my husband, two amazing sons, and of course our two furry feline friends. When I'm not immersing myself in the world of charity, you'll find me spending quality time with them. I'm also a devoted green-thumb enthusiast, nurturing my own allotment and dabbling in art as well.

So, there you have it, a glimpse into my world and what ignites my passion. I'm eagerly looking forward to what lies ahead for me at Little Hearts Matter. I am looking forward to meeting many of you, our members, in the months ahead. Please do feel free to reach out and say hello!



Trustee News

Written by: Warren Manger

The coming year promises to be incredibly exciting as Little Hearts Matter celebrates its 30th anniversary.

It is a moment to reflect on how the charity has grown and all it has achieved during that time, welcoming more members and providing a wider range of services and support. At the same time, it is a fantastic opportunity to build for the future.

I mentioned in my last newsletter article that the Trust Board were working with Suzie to develop a new management structure and to recruit a new Chief Executive.

This would allow Suzie to take up a new role as Head of Service and focus on delivering the best possible support for our members (a move she has wanted to make for some time). It would also enable us to add an experienced charity leader with strong management and fundraising skills to help LHM meet the needs of its expanding membership.

I am delighted to report that following a carefully considered and competitive recruitment process, we have been able to appoint Lisa Davies as our new Chief Executive.

Lisa impressed the recruitment panel with her passion for LHM and our work, her collaborative leadership style, and her achievements as Director of the Leicester Hospitals Charity. We are confident that she will be a great asset to the charity and look forward to working with her. I hope you will join me in offering Lisa a very warm welcome to the LHM family.

Inevitably, this process has taken up a great deal of time and energy in recent months, but the Trust Board has remained busy in other areas too.

We assisted Suzie with the recruitment of a new Child Service Lead to provide more support for our members aged between seven and ten years old. We are thrilled to welcome back Olivia Hutchinson, a long-standing LHM supporter, who has made an immediate impact by working with colleagues to make our website more accessible and appealing for our younger members.



We have continued to strengthen the Trust Board by co-opting a new Trustee, Vikki King, and reviewing our policy documents.



Vikki has been a member of LHM and a regular fundraiser for more than a decade, since losing her daughter Isabel in 2012. She has more than 20 years of experience in social work, supporting people with disabilities. However, a neurological condition means she is no longer able to work and she is keen to share her wealth of experience and expertise with Little Hearts Matter.

Vikki will be a strong advocate for our members, especially our bereaved families, helping to ensure all areas of our membership are involved in making decisions.

It was a pleasure to see many of our families, including several of my fellow trustees, at our Summer Event in August and our memorial event at the National Arboretum in May.

This was the first time that I had attended the whole event with my family and we had a wonderful time. My son Haydn had recently turned seven years old and thrived in an environment where he could meet other children with similar heart conditions and step outside his comfort zone in a safe space, tackling the tree-top trail, riding on the giant swing, and making new friends.

Another highlight was seeing our adult members and young families come together for the inaugural festival on Saturday evening – something I hope we are able to develop as a charity in future.

As a Trust Board, we were able to approve travel bursaries for members who needed help with the cost of attending the Summer Event to ensure no one missed out due to financial hardship. This is really important to us as a charity and something we will be repeating for future events.

We have also filed our 2021 accounts with Companies House and the Charity Commission. Carefully balancing the charity's finances is part of the Trust Board's legal responsibilities. It safeguards the charity's future and gives funders confidence that we will put their money to good use.

We are hugely grateful to David as Treasurer and to Suzie for all their hard work to ensure we have maintained a secure financial position in a challenging climate for charities. As a result, we can look ahead to our 30th anniversary and beyond with a sense of optimism and a shared goal to provide the best possible support to each of you as our members.



Support and Information Services

Written by: Suzie Hutchinson

Little Hearts Matter exists because of the fear, isolation and lack of understanding created by single ventricle heart disease. The charity works to offer Support, Information, Advocacy and Care to members, of any age.

The organisation has grown and the number of people seeking our support has grown as well. When we started, we just supported parents, mostly at the beginning of their half-a-heart journey. As we move into our 30th anniversary year in 2024 we offer our care to parents, grandparents, children, young people and adults as well as extended family members.

We never stand still: as our member's needs evolve, so does our support. Moving forward, the charity is committed to investing in more and more of the services our members are seeking, and we are developing the team that is going to provide it.

Suzie will be the Head of Services.

Suzie has over 37 years of experience of single ventricle heart disease, especially medical, lifestyle and advocacy and has been involved with LHM since its inception. She will be working with the whole service team to build and deliver the support, information, advocacy and care that members are asking for.



As well as heading up the team, she will be working with parents at every stage of their half-a-heart journey from antenatal diagnosis right through to supporting the parents of our adult members. Helping them all to understand the diagnosis, and treatment of their children, their lifestyle restrictions, and the ways to hurdle them as they travel the Fontan journey. She will also specialise in benefits applications and appeals, healthcare plan and Education, Health and Care Plan support in education, medical and lifestyle publications and added support for the adult members. She and the team will also continue to link with medical teams around the country and plan and deliver events that are both national and local.



Olivia is Child Support Lead working especially with children aged 7 to 11.

Olivia has a raft of experience teaching, empowering and supporting young people to reach their full potential. She was a past LHM youth leader and has been involved as a member of the staff and volunteer team for many years. Her main role will be to support, inform and empower young LHM members between the ages of 7 and 11 and will work with the youth team to create a smooth handover between child and youth services. She has been working on developing new information on the heart and living with a heart condition specifically geared to the 7 to 11-year-old members. She is also introducing her new pal Jigzy who will help to explain lots of the medical information.



Lexie is the Head of Youth Services for 12 to 18-year-olds.

Lexie has been a youth worker for many years, previously working with young people with learning disabilities who also come from complex backgrounds. She has been heading up LHM youth services for over seven years and has developed a great relationship with young members. She has created a new native app that can safely bring young people together under an LHM-controlled umbrella and she provides one-to-one and group support, in partnership with her youth mentors. One of Lexie's special projects is to work with medical transition teams in all the hospitals to help them create a better move from children's to adult services for their patients. The youth role is supported by a grant from Children in Need.



Child and Youth Service

We are so delighted to be able to offer support and information to children from the age of seven all the way up to when they turn 18 and join our adult group.

The team has been working with young members over the summer and has, following their feedback, decided to make some very small changes to the ages of the members in each of our support groups. This will not affect anyone who has already joined the youth group.

7 to 11-year-olds will be part of the LHM Kidz group, which offers support, information and get-togethers aimed at children in primary school.

12 to 14-year-olds will be part of the LHM Youth Juniors. Now in secondary school all of the support, information and get-togethers will be aimed at young people of this age group who are beginning to go through the early stages of hospital transition.

15 to 17-year-olds will be part of LHM Youth Seniors. Being just that little bit older and stepping towards hospital transfer and independence the charity will gear support and information to their growing need for support as a young adult.

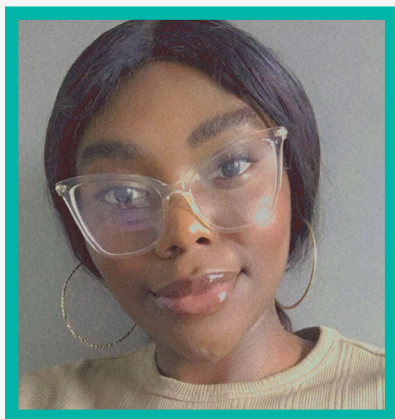
18 + will be introduced to the growing adult support and information services.

SVH Adult Services Lead for the 16 to 25+ age group of members.

Currently, the LHM team is working to recruit a new adult services lead. This position aims to offer support to the SVH adults and their partners. The adult group have asked for someone to help coordinate their support and information but also someone who can help support their mental health concerns. This position is supported by the Paul Hamlyn Foundation.

Joy is our new Social Media and Website Lead.

The focus of her Lottery-funded role is to support the members' communication through LHM-focused social media and to work to ensure that the LHM website resources remain up-to-date and appealing.



Sam, the past post holder, is moving on to set up his own business but will be working with us on focused projects.



If you need us, we are only a call away on 0121 455 8982, or you can email us at info@lhm.org.uk

Beckie is the Junior Creative Designer.

She works with all members of the LHM team to produce the visual copies of the Newsletter, Comic and written booklets. She also brings a design eye to our online information and works as part of the general LHM team to support the design needed for awareness and fundraising.



Tracy and Paula are the Admin Team for LHM.

These ladies do so much to support the LHM members. They answer the phone to callers and listen to their worries. They pick up member messages, and post out information, cards and invitations. They maintain the LHM database and generally support the service team so they can do their job. Suzie relies on them to check letters and appeals for spelling mistakes. What would we do without them?



LHM Volunteers – We are so lucky to have a team of members who support other members. They offer support and their personal experience to members on the support line and watch social media, mentor the youth group, fundraise and raise awareness. Thank you all so much.

Although the fundraising team are not members of the service team they are essential to the charity being able to offer any support so thank you to Rebecca and Juliet, soon to be led by our new CE, Lisa. who comes with a wealth of fundraising experience.

Ivy's Story

Written by: Sam Jones

Little Hearts Matter is delighted to tell you about an amazing achievement from one of our inspiring Kidz Zone members. Ivy who is six and lives with Hypoplastic Left Heart Syndrome, is to be awarded the Medal of Honour from the British Citizen Youth Awards at the Palace of Westminster.

“The award recognises individuals aged under 18, who positively impact others and highlight the positive aspects of multi-cultural communities, schools and places of education, community groups and charities throughout the UK.”

Ivy will receive this award in recognition of her ongoing fundraising efforts for Alder Hey Children's Hospital, Little Hearts Matter and Tiny Tickers. Ivy's decision to raise funds was inspired by the treatment she received at Alder Hey and the support both she and mum Clare have received from LHM and fellow heart charity Tiny Tickers.

At just six years old, Ivy has raised more than £8000. She has also helped to raise masses of awareness for single ventricle heart conditions in the UK. A very well-deserved award that is only presented to a small number of exceptional young people every year.

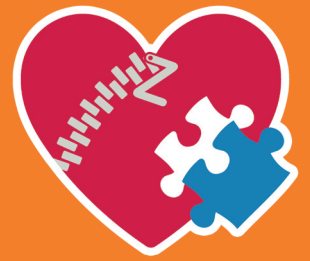
The Little Hearts Matter family sends our congratulations to Ivy. You have shown us all what is possible with a can-do attitude and a passion to help others, thank you so much for all you have done.

You can read Ivy's story on our website here: lhm.org.uk/kidz





Youth Zone



Written by: Lexie Katsaitis

Youth Hub Launch

We were so happy to bring back our youth activity residential this year in a brand new location, Pioneer, near Kidderminster. A new place with all the activities we know and love and some new ones added too!

Here we saw a large group of our youth members create lasting friendships, challenging themselves physically in a safe way, start or continue their journey to become independent and learn about their half-a-heart journey in a Little Hearts Matter workshop. It was a busy few days, to say the least.

Our youth members soared through the air on the big swing, scored big in archery, bounced their way through races on the inflatable challenge, zipped down the zip wire and so much more! The smiles were huge, their fears were faced, and it was absolutely amazing to see them support each other as they did so. These activities are designed to support our youth members as they challenge themselves and bring the group together and create lasting friendships as they support each other.



This year we also hosted a workshop to support and prepare our youth members for the transfer to adult units which they will experience in their teenage years. We need to listen to their worries about this change and alleviate any fears they may have whilst also giving them a space to safely have their voice heard, and boy did they use their voices!

All in all, our youth activity residential was a great success even with a large cohort unable to come after signing up. It was a privilege to watch our youth members' confidence grow, independence rise and knowledge increase over the three days we were together. It really makes our youth events worthwhile.

Also, a big thank you to Justyna Rybicka, an ACHD consultant from the Freeman Hospital, for being our medic and joining us for our event.



LHM Youth Event Volunteers

Each year the LHM youth service looks to run fun-packed youth events for our youth members to attend so that they can learn, create community and increase confidence. They come in many different forms, from our activity residential and fun day trips to our biennial open day conference in which we host workshops just for our youth members.

These events are such an important part of the half-a-heart journey for so many young people aged 11 to 17, in fact, a few have said it is their top moment of the year. Our events provide a chance for our youth members to feel less isolated and meet other young people their age who can understand both the challenges they have overcome and the apprehension about the challenges that they are yet to face.

In order to continue offering these wonderful youth events we need volunteers.

The Little Hearts Matter youth team are looking to create a team of enthusiastic, fun, and energetic youth event volunteers. We are looking for volunteers who can help supervise our youth events and provide a safe space for our youth members. Without them we can't offer the youth events our members love so much.



Does this sound like something you could do? Are you a safe person over the age of 18 that our youth members would feel comfortable with at a youth event? Can you support the youth leader in the running of the event whilst encouraging and supporting our youth members to reach their targets and overcome challenges safely?

Do you have great listening skills that you use to provide support and encouragement?

Maybe you have a brother or sister with a single ventricle heart, or you might be a young adult with a single ventricle heart yourself. You might even have an interest or experience in youth work without a link to LHM.

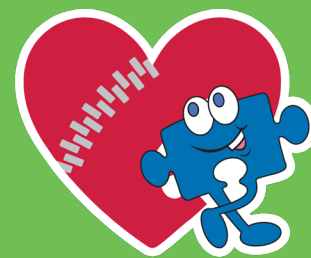
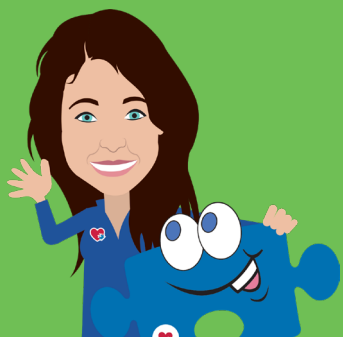
If you are successful and become part of the team you will always have the support of the youth leader and take part in safeguarding training beforehand. It is a great role to add to any CV whilst simultaneously helping the LHM community. Unfortunately, we cannot accept parent members for this volunteer role.

Good volunteers are hard to find, yet so important to keep these wonderful types of support going.

If this is something you are interested in or want to know more about, please get in touch with Lexie our head of youth services by sending an email to lexie@lhm.org.uk

Thank you.





Written by: Olivia Hutchinson

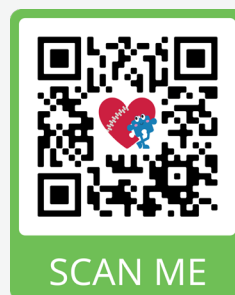
Since taking up my role as LHM Kidz lead in July, we've been very busy developing the service provision that our 7 to 10-year-old members have asked for.

This has started with our brand NEW LHM Kidz webpage, which launched in September. The aim of this page is to provide information for our Kidz about their conditions in a way that is accessible and unthreatening. We are aware that discovering that they have a heart condition and therefore are different from their peers is potentially very scary for our young members, and so we aim to provide the right information, in the right way to make sure the acquisition of this knowledge is done in a supportive and gentle way. There is now a series of downloadable resources available on our webpage for this age range that takes them through the information about their conditions, medication, medical testing they may come across and what having a special heart can mean for their lives. The idea with these info booklets is that you can work through them with your child when you feel it is the right time to start discussing their conditions in more detail.

We have aimed to make the webpage a hive of activity, making it fun and engaging but also to showcase the community that exists within LHM. We share stories and achievements of our young members so that children exploring the webpage can see that they aren't alone, that others understand the struggles they go through on a daily basis and that great things can still be achieved. We also have a whole section on energy and how to manage it with a range of downloadable resources.

Another way we help to combat any feelings of isolation our Kidz can feel is by encouraging them to engage with our LHM hub. For those of you that haven't yet heard, we have produced our own safe and monitored platform for our young members to

communicate with each other. We also run monthly group chats where issues can be discussed with me or Lexie, our youth leader, leading the discussions. This is currently in webpage format, but we are soon to launch the LHM hub app, which will mean this is easier to use, navigate and receive notifications for.



We would love to see more of our young members taking an active role in our hub and joining our chats as we really see the benefits for our young members who do engage. If your child isn't already signed up, please do so now by scanning this QR code.

Our mascot, Jigzy, is being used a lot more now, on our website and in print. He is interested in science and learning and doesn't forget a thing so he is a great companion for our children as they learn about their heart conditions. Jigzy is now being voiced by the wonderful Miles Noonan, aged ten, one of our sibling members who won our 'Find the voice of Jigzy' competition earlier in the year. Miles is very outgoing and keen on drama, playing the saxophone and clarinet and building Lego!





He recently spent a whole morning with me recording voiceovers for our films that explain each of the single ventricle heart conditions. These will be coming to our webpage as a great new resource for our Kidz in the new year!

It was really fantastic to meet some of our members at our summer family event at the Pioneer Centre. Campfires may have been rained off and the Lionesses didn't quite manage to 'bring it home' but that didn't stop the smiles and fun. There were banana-eating competitions, doughnut hilarity, music quizzes and people even building washing machines out of their bodies, not to mention ice cream and great live music. The event really was so much fun and it was great to see our young members getting to know each other and having a giggle.



Bullying

I wanted to include a small note on bullying as this was the recent topic of our Heart gang comic. Sadly, this is an issue that many of our young members come across in their lives and so it's an issue we thought essential to tackle in our comics. In our comic Isaac, who has Hypoplastic Left Heart Syndrome, is being bullied at school because he's not able to take part in particular sports and activities the way his peers can. In the comic, his parents and teachers work to help Isaac feel confident enough to stand up for himself but also

to explain to his schoolmates about his condition so that they understand and stop bullying him. As we know, bullying often comes from a place of insecurity and lack of understanding so if your child is being bullied you can always suggest a teacher does an assembly on having a heart condition. LHM has lots of resources that can be used in schools for this very reason.



If your child is being bullied and you need additional support, you can always speak to us at LHM by emailing info@lhm.org.uk or calling **0121 455 8982**.

Here are some other places you can find support:

- The National Bullying Helpline: 0300 323 0169
- Young minds – youngminds.org.uk
- NSPCC – nspcc.org.uk

As always, I'd love to hear from you or your children if you have any queries, questions or suggestions. My email address is olivia@lhm.org.uk.

Those of you who saw me at the summer event will know that my second baby is due to come earth side very soon so the 7 to 10 service will be being watched until the new year when I'll be ready to spring back into action.



Family Event



Written by: Suzie Hutchinson

A youth activity event into an SVH adult activity event alongside a family activity weekend, a big summer fun day and our very own music festival. What an amazing week!

The aim of any of our events is to encourage members to mix, share their experiences and create bonds that will travel with them over the years of the Fontan journey.

The feedback we have had from this year's events has been that lots of friendships have been made. Lots of new experiences have been explored and the children, teenagers, adults and their families have done things they never thought they could do. They threw themselves off a pole towards a trapeze. They travelled on a swing 60 feet up in the air, they climbed and abseiled down walls and shrieked as they travelled the zip wire.

The LHM team are always there to witness their achievements and cheer them on as they conquer a fear.



One of the nicest things to see was the adult group getting together. Swapping stories, sharing concerns, and playing a lot of Uno. Many of them met as children at their first activity events. Their friendship has stayed with them into adulthood. The very reason we run events.

This year's summer fun day saw members of all ages making TikTok videos with the Physics Institute, making crowns with Creation Station, hooking ducks and throwing balls at coconuts. They took part in party games, played game shows with Lexie, danced and sang with Monkey Mayhem and learnt more about animals with the Safari Park.

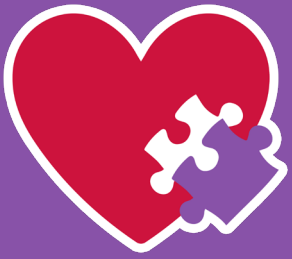
We had pizzas and a hog roast, tea and cakes, milkshakes and ice creams and an amazing non-alcoholic bar.

The final event was a first for LHM: our very own music event, "our very own mini-Glastonbury." Singers and musicians came from our very own membership, Sarah and her red guitar, Charlie and Violet singing and then the Sheffield University Jazz Band. What a night of entertainment!

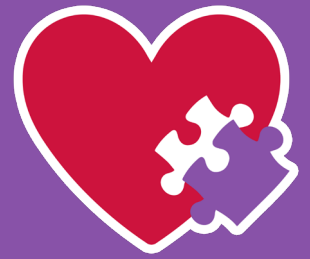
Sadly, we did not have as many families as we were expecting, which was such a shame as everything was ready for them.

Of course, these things don't happen without a huge amount of work. Firstly, from the LHM team, thank you so much Tracy, Paula, Sam, Beckie, Lexie, Olls, Rebecca and Juliet. We would also like to thank our volunteers – the bar maker Martin and bartenders Jade and Sean. The wonderful WI for making tea, and homemade cakes that were provided by the LHM staff. Milkshakes and lots of support from Rachel and the Mawley Milk team and Jon for running great sports events over the whole weekend. Wonderful bunting was made for us by the very clever Dawn. We were all exhausted, especially Lexie and I who were there for all the events, but we packed up with huge smiles on our faces. We love seeing the members looking relaxed and happy.





SVH Adults



Written by: Suzie Hutchinson

The Little Hearts Matter summer has been filled with opportunities for members to meet, socialise and explore activities and new experiences together.

LHM was delighted to be able to organise the first SVH adult group get-together. 33 adults, young people with half a heart and some of their partners, came together at the Pioneer Centre for a weekend of Uno, wet campfires, high ropes, giant swings, abseiling, zip wiring, archery and a great opportunity to meet with their fellow adult LHM members.

They were joined on Saturday morning by James Anthony, a Specialist ACHD nurse. This gave them an opportunity for some deep discussion about managing their heart condition, medications, heart failure and transplantation. They were in need of chocolate biscuits and coffee after that.

As well as playing huge games of Uno and chatting together they joined the LHM Music Festival in the evening. Sarah H, one of their group, even performed.

“ I felt really honoured to be invited to perform at Little Hearts Matter's first-ever music event. I have wanted to do a live performance for them for a while as I hoped it would benefit families and younger members to see the things we can achieve despite limitations that might have been put on us. Little Hearts Matter has been with me and my family since I was small and has been incredible at supporting us through many ups and downs with having half a heart.



I have been singing and playing guitar since I was in primary school and have begun to write my own songs, building a name for myself as a singer-songwriter. LHM has been an incredible support for me and my music.

I thoroughly enjoyed playing my set and had many positive comments from many of the members with parents coming up to me and saying their child now wants to learn how to play the guitar.

It was lovely to meet other performers who each had a connection to the charity. They all had their unique styles and wonderful talents. It was such a supportive atmosphere and it was amazing for us all to give back to a charity which has helped us so much.

Sarah

”

The feedback the LHM team gained following the event proves that we need to make sure that adults with single ventricle hearts have an opportunity to meet with each other regularly, online and face-to-face. It is so essential that they can gain support from each other as they hurdle the challenges that having half a heart creates.

The LHM team is grateful to the Paul Hamlyn Foundation for helping us to fund the support we offer our

“ I remember when I heard about the weekend, I was very excited as I hadn't done many LHM activities before as I'm up in Scotland and I would be able to go down for them. So of course I signed up right away. I was super excited to meet people just like me with SVH as I knew no one who had it. Although I was a bit nervous to meet everyone as they were new to me I was more excited. The weekend was amazing, we did so much and it was good as I felt I wasn't slowing people down as we all were going at the same pace, we all felt tired at the same time and it meant I wasn't feeling left out as I might have felt with my friends. We did so many activities and my favourite was probably the free fall trapeze as I got so much adrenaline from climbing up high and trying to catch the trapeze (which I did). The talk we had about jobs, mental health and medicine was really interesting. ”

Hannah

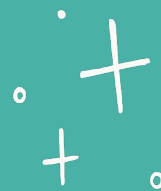


“ I thoroughly enjoyed the adult LHM activity weekend, it gave me the opportunity to meet with my friends and also make new friends along the way, this was my first LHM event as an adult and meeting other adults with single ventricle heart conditions has given me hope for my future. ”

Lucy



Grandparent Page



Written by: Suzie Hutchinson

Being helpful.

Being the grandparent of a child with any sort of disability can be a challenge. As we have said before we know that you worry about your children, as they navigate parenting, and your grandchild and their siblings.

Knowing what the best sort of support you can offer can also be a challenge. As grandparents you want to help but you also don't want to make a difficult situation worse.

LHM have been seeking ideas and comments from other charities and we have combined the comments and suggestions that might be helpful. These have been written from grandparents to grandparents.

What is helpful for grandparents to know?

1. Every family is unique. Each family member takes time to find their way.

LHM comment- Sometimes grandparents feel left out of conversations. This often happens because parents are trying to get their heads around the situation before they reach out to others. Offer help but wait until the offer is taken up. It takes some people longer than others to be ready for help.

Understand your grandchild's condition – Understanding your grandchild's heart condition is helpful - www.lhm.org.uk/conditions/ but it may also be important to understand any other medical conditions or learning difficulties they may have, for example autism, ADHD or other learning difficulties.

2. You may feel afraid and not know how to help. If you are flexible and prepared to think about the situation, there may be something you can do that can make life easier for your

family. Sometimes it is the little things that matter like making a meal, doing shopping or babysitting so the parent can take a break.

LHM comment - We know that LHM parents can be reluctant to leave their heart children. It can really help if grandparents can get involved from early days so that parents gain confidence that they know what to do in a crisis. Having days off or an evening out can help so much when it comes to coping with the stress of a long-term illness in a child.

3. Try not to assume that help has been offered from social services or a GP. Parents may feel unsupported even if services are in place. Some parents might need support to apply for benefits. You may not have money to share with your family, but information is very important too.
4. There may be some particularly difficult times for parents, such as around the time of diagnosis or when no medical diagnosis can be given. Finding a school, changing schools, and transitioning to adult services can be stressful times and extra support may be welcome.

LHM comment – Young people with a disability go through puberty just like other young people, which may mean mood swings and arguments with parents. The worry is often greater because of the heart condition, medications, hospital appointments and lifestyle restrictions. Grandparents can often be a sounding board for a young person. Grandparents need to know the facts so they can bridge the gap in knowledge or understanding but also it is easier for them as they are not in the battleground.



5. Parents often must deal with a range of services, including health, education and social services and can feel exhausted. Help with phone calls, support at meetings, or offering to care for grandchildren while the parent goes to meetings can ease the pressure.

LHM comment - Offering to take on one specific responsibility can be really helpful – DLA or PIP applications or healthcare plans or Education, Health and Care Plans.

6. Parents often gain the most support from other parents with disabled children. Whilst advice won't always be welcome from you, encouraging your son or daughter to access such support may be good for the whole family.

LHM comment - Remember that being a member of LHM is free for families. Parents can gain access to the closed private and safe LHM social media groups, which are perfect for a chance to chat with other parents.

Support for Grandparents.

Remember that you are not on your own. There is a whole grandparent community at LHM. If you want to talk to other grandparents just ask to join the grandparent closed group. www.facebook.com/groups/533344713535976

Other grandparents will be further along the half-heart journey and able to help answer questions. The office team are also here. Just give us a ring at **0121 455 8982** or email us at info@lhm.org.uk

Come to an LHM event. The next Open Day is Saturday 23rd March 2024. We would love to see you there.

Resources you might like to see

- **From Contact a Family –**
contact.org.uk/wp-content/uploads/2021/03/Grandparents.pdf
- **Parenting Children with Special Needs –**
www.parentingspecialneeds.org/article/fabulous-grandparents-special-needs/
- **Next Avenue – USA**
www.nextavenue.org/raising-and-supporting-grandchildren-with-disabilities/



Individual Healthcare Plans

Written by: Suzie Hutchinson

As you read this newsletter your children will be halfway through the autumn term. This is a perfect time to do a quick review of the Healthcare Plan you wrote, with the school, at the beginning of the term. Your child will have begun to settle into the year's routine and any challenges will have become clear.

Every child with a single ventricle heart condition will have added needs within the school environment, although everyone's needs will be different. Most of these needs will be related to their reduced energy levels but they may also have additional needs relating to other medical conditions or their ability to learn.

Every child with single ventricle heart disease, a long-term condition, should have a Healthcare Plan. It is not to be confused with an Education, Health and Care Plan which is not needed for a child with a heart condition unless they also have an educational deficit, have problems learning or their absence from school has seen their progress delayed.

What is a health care plan?

A school Healthcare Plan is a plan for teachers and school support staff that sets out the needs of a child with a long-term medical condition. The aim of the plan is to make sure that a child's medical condition is supported fully so that it does not affect their ability to learn in school.

It needs to include:

- A photo identifying the child with their name and their preferred name.
- Details and explanations of their medical condition.
- A brief explanation of how the condition affects them on a day-to-day basis.
- What is normal and okay on a day-to-day basis? They may naturally get a little breathless or cyanosed (blue).
- What parts of a school day or the environment will be challenging? For example, a PE lesson, walking between classrooms, or getting cold in the playground.
- A clear plan for what support has been put in place to solve the issues identified. For example, a child can stay in at playtime when the weather is cold and wet or be able to leave a classroom early so that they have time to move from class to class, highlighting the golden rule for PE teachers.
- Signs to observe that indicate when a child's condition is deteriorating and clearly set down response processes. For example, if the child experiences increased breathlessness that does not get better the plan would be to call for an ambulance.
- A list of contacts and when to call them.



Who writes the Healthcare Plan?

Key to the school's understanding of the child's needs is the creation of strong positive links between the school's SENCO, parents, older children, and specialist nurses. In some cases, it will also be important for the school nursing service to become involved on a more local support level.

The plan needs to be written in collaboration between all the identified people above but in reality, it is often parents who take the lead so it can be useful to create a draft Healthcare Plan to be used as the basis for any conversations with the school. To find our LHM Healthcare Plan booklet, scan the QR code below:



Who needs to know about the Healthcare Plan?

Having agreed on what areas of each child's school day will require added support and established who their key educational and support team will be, it is essential that everyone meets together to ensure a good understanding of the child's needs. It is also important that other members of staff learn about the plans for each individual child.

In many schools, it is seen as good practice to have photographs of any pupil with a health need up in the staff room, medical room and perhaps in the tutor's office and/or department's office. Although details of a child's condition and response plan for concerns should be in every classroom it is not seen as advisable to put a photograph of any individual child up on public display.

Moving forward the Healthcare plan will need to be reviewed yearly unless there are any changes to the child's medical condition or new challenges are recognised.

Every time there is a change in teaching staff, or the child moves classes the team need to revisit the plan and make sure that the team are up to date with their needs in school.

What do we do if the school refuses to create a Healthcare Plan or says that an Education, Health and Care Plan is not needed?

Most schools will be more than willing to set out a plan of care to ensure that a child can be kept safe within school. They are responsible for a child during the school day, and they will want to make sure that all the school team have a good awareness of the child's medical challenges.

In the rare case where there is a dispute about a child's needs, there are a number of approaches to getting the issue sorted.

- Arrange to have a private meeting with the head of the school and the SENCO. Give them a copy of the LHM information pack. www.lhm.org.uk/3d-flip-book/healthcare-plan-booklet/. The law is set out here: medicalconditionsatschool.org.uk/documents/Legal-Situation-in-Schools.pdf
- Ask the hospital medical team to write a letter to the head of school explaining the added needs.
- If the head of school will not take the issues forward contact the chair of the Governing body at the school. One of the school Governors will have responsibility for SEN provision.



As always if you have any questions about accessing the support your child needs at school just give the LHM team a call on 0121 455 8982.



Social Media

Written by: Sam Jones

Your invitation to join LHM's 30th



As you know, Little Hearts Matter will celebrate its 30th anniversary in 2024. 30 years of being there for families at every stage of the half-a-heart journey. This is a remarkable milestone for the charity, but also an epic opportunity to bring greater public awareness of life with half a working heart. We want to make a huge splash about our 30th, a cannonball in fact, and we want you to be part of the celebrations. So we are delighted to announce an open invitation to everyone in the LHM family, can you help make our 30th a success?

A case of 'who you know'

The LHM team is working hard to get everything in place for our 30th year. Lots of exciting things are planned, but sadly our reach only extends so far. To celebrate this momentous year, we want to push the envelope, break new ground and get the LHM name in places it has never been before.

So, this is an open call-out, are you able to link us with any of the following?

- Sports teams who would be proud to wear the LHM badge on their kit.
- Visual artists who would like to create an LHM mural.
- Historic buildings that would be willing to be illuminated in red and blue.
- Social media personalities who would be willing to share our message.
- Any other influential people, brands or platforms that you think could help.



30 years of LHM Support.
Let's join together for the biggest awareness push ever! To tell the world about us and our amazing members, just like Chloe here!

Become an awareness ambassador

We are excited to be recruiting a team of awareness ambassadors for our 2024 campaign. Joining our team will put the LHM message in your hands and equip you with the tools and resources that you need to self-advocate for our special cause. We want this initiative to be as inclusive as possible.

So we have created two levels of ambassadorship;

- **Storytelling**

Stories are a very effective way to raise awareness. As a storytelling ambassador, you will share your journey, online and in person, to help shine a light on life with half a working heart. We can support you throughout the storytelling process. We can also offer you the opportunity to be featured on the LHM website, LHM social media pages and potentially in wider media outlets.

- **Community**

The second level of ambassadorship is for people who want to raise awareness in their local community. Are you part of a club, workplace or community group where you are able to display awareness posters, hold a fundraiser or deliver an awareness presentation? As part of our ambassadors team, you will have access to a resource pack that will help make all of those things a reality.

To learn more about becoming an awareness ambassador for Little Hearts Matter, and to apply, please email info@lhm.org.uk with the subject 'awareness team 2024'.



Hayley and Dexter's LHM story reached more than 20,000 people online.
Yours could too. Share your story for our 30th anniversary by emailing info@lhm.org.uk

We are so excited to hear what you come back with, The Little Hearts Matter team sends a huge thank you to each and every one of our awareness supporters past, present and future. Your help means the world to us and we can't wait to take on 2024 together as the LHM family.

Thank you



Amelia's Story

Written by: Elizabeth Fisher (Amelia's mum)

My daughter Amelia is eight years old and was born with Hypoplastic Left Heart Syndrome.

Almost two years ago, Amelia was placed on the routine heart transplant list. We are still waiting to this day, but it doesn't stop us from having lots of fun, so I am delighted to show you what we have been up to over the summer. As you can see, we have been super busy.

Amelia loves to go underwater, so we have been to the beach and also have a splash about at the pool every week. She's an ultimate gamer and loves her PlayStation and also lots of Roblox. She adores her kitten Bingo! And she enjoys having a little game of football in the garden.

I am so proud of Amelia and her achievements. She has her limits but that doesn't stop her from having fun and living life to the max. Amelia is going back to school part-time this September, to help her keep some energy for more adventures.

"One day at a time" that's my motto! Always have fun things in the future planned to look forward to. And make the most of every day, even on the tired days.



Fundraising Wall

Written by: Juliet Hanlon and Rebecca Wilkes

Are you feeling inspired? There are so many ways that you can fundraise or volunteer for LHM from simple birthday donations instead of gifts to full-blown sky-dives! Whatever you choose, the fundraising team is here to help so please get in touch at fundraising@lhm.org.uk, we'd love to hear from you!

In June, Single Ventricle Heart Adult, Alex Webb, walked for 3 days across the Isle of Wight, raising over £1,000. Well done Alex!



Sibling member, Charley Price, has completed her 6 of 6 Challenge, raising over £700 between April and September. What an amazing personal achievement, thank you Charley!

Once again, Team LHM took on the Great North Run and London to Brighton challenges. A huge thanks to all our amazing participants who battled through high temperatures and lashing rain to complete their challenges and raise an incredible £10,000!



Huge thanks to the friends and family of Rod Hutchinson for cycling over 4 days from Utrecht to Stafford in his memory, raising over £5,000.



Young member Charlie Taylor, with mum Courtney, organised "Charlie's Funday". Thanks to Charlie for being a fundraising superstar by helping to raise £500!



In May, Darren Avery completed his first marathon in Edinburgh. Congratulations on your achievement and thank you for raising over £2,000!



Jess and Jordan Loak-Finch organized a Skate Jam in July in memory of their son, Theo, raising an incredible £5,000. Thank you for all your hard work, and thanks to all the friends, family and businesses who supported the event!

Extra thanks to:

- Janet and Gareth Hicks raised £700 by asking for donations instead of gifts for their Golden Wedding Anniversary.
- Victoria Watson is fundraising for Little Hearts Matter in her role as Lady Captain for Castle Hawk Golf Club during 2023.



Fundraising



Written by: Juliet Hanlon and Rebecca Wilkes

Summer Event 2023: The Fundraising Tent!

It was so lovely to meet so many of our amazing families in our fundraising tent at this year's Summer Event. We'd like to thank you all for your generosity in taking part in our raffle and Name the Teddy competition, and for buying our LHM logo merchandise!

With your fantastic support, we raised over **£1000** for Little Hearts Matter!

Congratulations to all our raffle winners, especially Wendy Sarah who won the star prize of a 7-night Family holiday in beautiful Barmouth – we hope you and your family have a wonderful time!



The name of our big teddy bear was revealed as Billy. He was won by Jacob but very kindly gifted to Elsie. Thank you, Jacob, we are sure Billy will be well looked after with lots of cuddles from Elsie!



Don't forget to check out our online shop if you missed out at www.lhm.org.uk/shop/

Award Winner

We would like to say a huge well done to Colin Barrett, amazing LHM Grandparent who won the Fundraiser Award in the BBC Hereford & Worcester Make a Difference Awards! The announcement was made at a ceremony held at West Midlands Safari Park on Thursday 14th September.

Colin has been tirelessly fundraising for LHM since his grandson Thomas was born 19 years ago, and this year alone has raised over £16,000 towards his 80/80 walk to mark his 80th birthday later this year. A well-deserved award for a fantastic fundraiser. Thank you Colin from all of the LHM Team!



Big Hearted Bake 2023

You've been busy creating some yummy cookies and cakes for your Big Hearted Bake events and we can't thank you enough for all the support you've given to our appeal! So many families, schools and offices signed up to get involved, we would love to see your photos and news about what you've achieved! Email us at fundraising@lhm.org.uk – we want to hear all about what you've been up to!

Missed out this time, or couldn't make that date? Don't worry – you can hold a Big Hearted Bake on any date of your choosing! Visit our website at www.lhm.org.uk/big-hearted-bake/ to find everything you need.



Get in the Festive Spirit!



Check out our Christmas Card range! We are excited to share our new design for 2023 - now available to order from our shop with the rest of our range.

If paperless is your preference, we are offering an e-card option at bit.ly/lhmcards. Select your favourite and make a donation to LHM instead.

Look out for our Christmas Campaign launching soon!



Noticeboard

Dates for your diary!

2023

November

- **Wednesday 22nd** – Preparation for the Fontan workshop.

2024

January

- **Monday 15th** – Brave Heart Award nominations open.

February

- **Wednesday 14th** – International CHD Awareness day.

March

- **Monday 11th** – Brave Heart Award nominations close.
- **Saturday 23rd** – Little Hearts Matter Open Day (Yarnfield Staffordshire).

May

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

September

- **Monday 2nd** – Brave Heart Award nominations open.
- **Sunday 29th** – World Heart Day

November

- **Monday 4th** – Brave Heart Award nominations close.

Little Hearts Matter

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@LHM_UK



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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 schoolteachers
- 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

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