

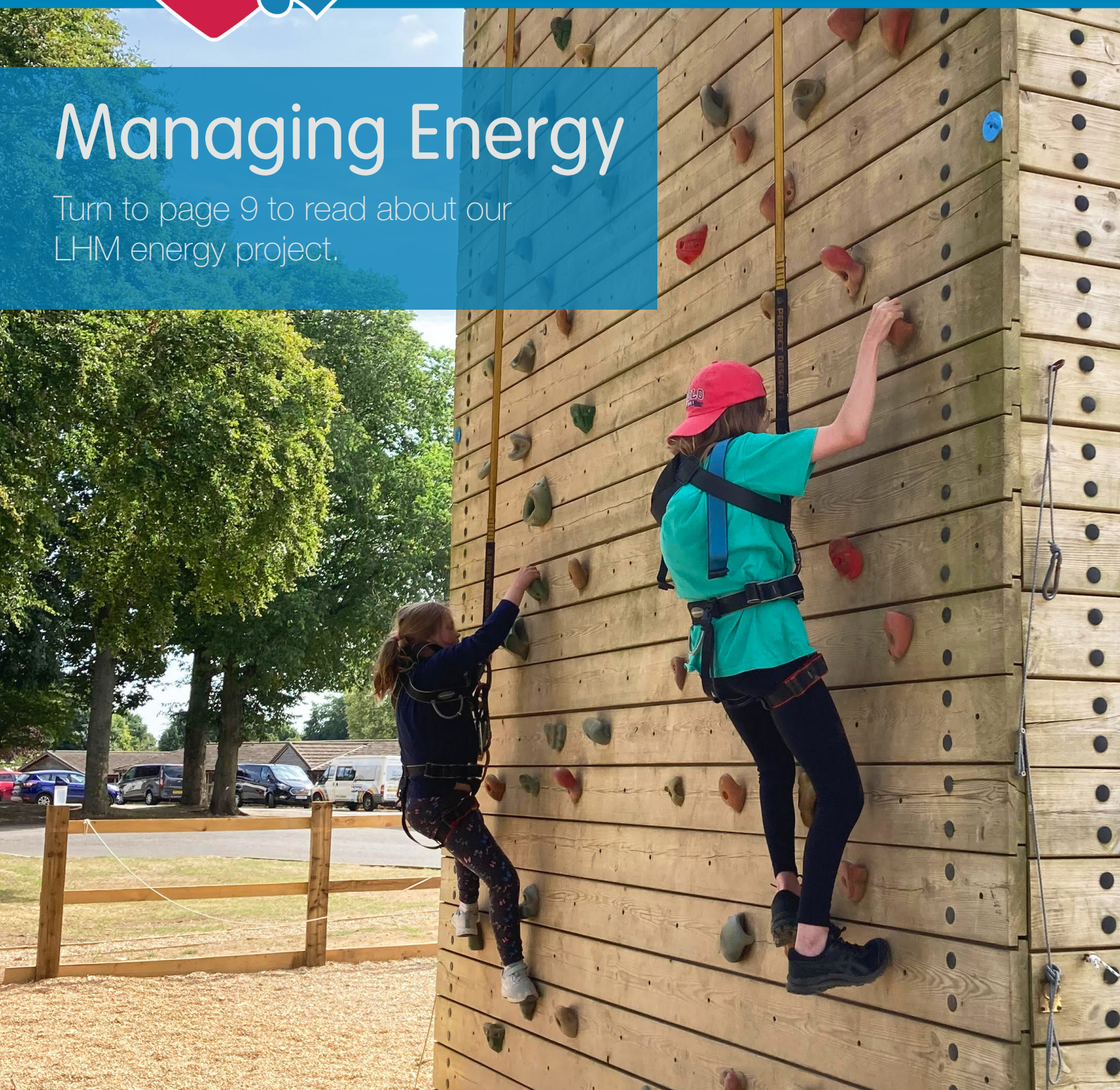


Little Hearts Matter Newsletter

July 2023

Managing Energy

Turn to page 9 to read about our LHM energy project.



The launch of the
Youth Hub App

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Grandparents Page

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Supporting every step of the half a heart journey



Suzie's News

Written by: Suzie Hutchinson

Welcome to the first newsletter of the year. This edition is packed full of useful articles about living with half a working heart. We hope you find something that will answer questions about some part of your heart journey. If you would like us to include a specific article for you in future, you just have to ask. Email us at info@lhm.org.uk.

We are so excited about the year ahead but we also hope you have liked what we have already offered. The new youth app provides a brilliant opportunity

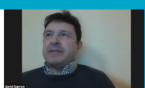
for young members to chat with each other in a safe place. For more information about the Youth Hub app, go to page 8!

We held an online DLA and PIP workshop that offered members a chance to explore how to apply and appeal applications for these benefits. We recorded the workshop, visit www.lhm.org.uk/benefits/ if you would like to watch the recording.

We held an online Open Day in April, attracting two key speakers, David Barron (surgeon) and Maggie Simpson (Heart Failure Specialist Nurse) and an amazing adult panel answering questions from the audience. Thank you to everyone who took part. If you would like to see the recordings of the sessions follow the links below:

Big Questions in Cardiac Surgery: Current Situation and Future Directions In the Management of Little Hearts

David Barron
Hospital for Sick Children, Toronto



David's talk: vimeo.com/820252686



Suzie Hutchinson

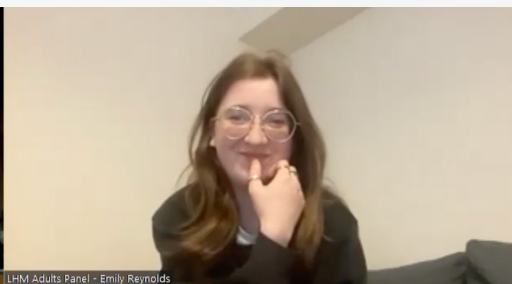


Maggie Simpson

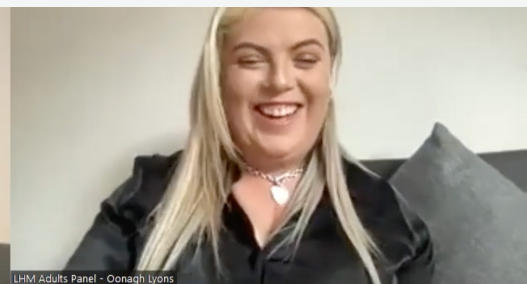
Maggie's talk: vimeo.com/820226675



LHM Open Day - Suzie Hutchinson



LHM Adults Panel - Emily Reynolds



LHM Adults Panel - Oonagh Lyons

Adult panel
Q&A: vimeo.com/820259300



LHM Adults Panel - Dillon Morley



LHM Adults Panel - Matthew Rimell

We held our annual Memorial Event at the National Arboretum in May. It was lovely to hear Boldzbrass play throughout what is always a special event for us, remembering the children, teenagers and adults who have been lost to their heart conditions.



Over the summer we have three events planned for different groups of members:

- A PGL-style event for our youth members running from the 16th to the 18th of August.
- An adult with SV hearts event running from the 18th to the 20th of August.
- A family event running from the 18th to the 20th of August, which includes a family day on the 19th.

For more details follow this link to the events page of our website <https://www.lhm.org.uk/events/>



Finally, I would just like to say thank you to everyone for the thoughtful comments and support I received following the loss of my darling husband Rod. Sadly, he fell ill just before Christmas with an untreatable brain tumour. I was able to nurse him at home throughout, partly thanks to the LHM team and trustees helping me to work flexibly over the past few months. Rod was a great friend to LHM. He always had my back and promoted and fundraised for the charity whenever he could. As you can imagine, losing him has broken my heart.

Dates for your diary!

2023

July

- **Wednesday 5th** – Online workshop – Planning to write a Healthcare Plan for school.

August

- **Wednesday 16th to Friday 18th** – Youth Activity Event.
- **Friday 18th to Sunday 20th** – Family Activity weekend (LHM focussed event on Saturday the 19th).
- **Friday 18th to Sunday 20th** – Adult Activity Event.

September

- **Sunday 10th** – London to Brighton and the Great North Run.
- **Wednesday 13th** - Online workshop – Hospital Transition.
- **Friday 29th** – World Heart Day.

October

- **Friday 27th** – Big Hearted Bake.

December

- **Friday 1st** – The LHM Christmas Appeal returns.

2024

March

- **Saturday 23rd** – Little Hearts Matter Open Day.





Trustee News

Written by: Warren Manger

Change can be scary. Our members know that better than most. For many of us, life is punctuated by medical appointments where the words “no change” are cause for celebration. But in many circumstances, change can be hugely positive. Little Hearts Matter is constantly changing to meet the needs of our growing community.

We have new ways of communicating, including the Jigzy comic and a range of animations explaining different single ventricle heart conditions and treatments.

We have new ways of connecting our members, such as the LHM app and the summer party. And we are adding new staff to provide more support for children and adults with half a heart.

Now LHM is embarking on another important change. As the charity has grown, so has the number of responsibilities that Suzie has each day as Chief Executive.

For several years, we have been exploring the possibility of separating this workload into two jobs. We believe this proposal, put forward by Suzie, will bring many benefits.

First and foremost, it will allow Suzie to move into a new role as Head of Service for the charity and devote her time to developing our services and supporting our members.

As many of you know, Suzie was a cardiac specialist nurse before LHM began and has supported some of our families for more than 30 years. She is passionate about providing the best service for our members and is keen to concentrate on that part of her existing job.

Therefore, we aim to recruit a new Chief Executive with strong management and income generation skills who can help the charity grow and meet the needs of our ever-expanding membership.

Suzie has been the heartbeat of the charity for three decades, offering comfort and counsel to our members, tirelessly championing the needs of those living with half a heart, and providing incredible leadership for our team of dedicated staff.

The trustees are hugely grateful for everything she has done for LHM and look forward to working with her to find the right person to lead the charity going forwards.



There have also been several changes to our Board of Trustees. This is a group of people who represent our members, help the chief executive set the strategic direction of LHM, and have a legal responsibility to oversee how the charity is managed.

Peter Groves has stepped down after 17 years of outstanding service as a Trustee and Treasurer. Peter shared his accounting expertise to help LHM maintain a strong financial position through periods of growth and challenges such as the COVID-19 pandemic. He also represented our bereaved members on the trust board and will continue to support bereaved families and provide some financial services to the charity free of charge. Words cannot express our gratitude for your contribution Peter.



We also bid farewell to another two trustees. Molly O'Herlihy, one of our young adults with a single ventricle heart, decided not to stand for re-election and will focus on supporting LHM through the adult council and as a mentor to our youth members.

Alex Pearce, a Cardiac Physiologist and parent member, has also tendered his resignation after relocating to Newcastle with his family.

We would like to thank Molly and Alex for their support.

It is always sad to say goodbye to valued colleagues, but I am delighted to welcome two new trustees in their place. Kim Botham and Sophie Murphy both have congenital heart conditions and will help to represent our adult members on the trust board.

They will also add invaluable education expertise, an area which is so important to so many of our members. Kim is a qualified teacher and former SENCO who now specialises in Education, Health and Care Plans (ECHPs), and Sophie is a primary school teacher.



In addition to those changes of personnel, David Baumber has stepped down as Chair of the Board of Trustees to replace Peter as Treasurer. This was a logical step as David is an accountant and has contributed a wealth of financial expertise to LHM for many years.

To facilitate that, I have stepped up from my position as Vice-Chair to succeed David and will continue to work with the LHM team to raise awareness about the charity, single ventricle heart conditions, and the challenges our members face.

It promises to be a busy and exciting time for the trust board, managing these changes while helping LHM to provide its core services and preparing for the charity's 30th anniversary next year.



Youth Zone

Written by: Lexie Katsaitis

Young People and their Transitions

When we hear the word transition several different meanings come to mind. This is to be expected, our youth members go through several different transitions in their teenage years: the medical transition from their paediatric unit to an adult unit, educational transition to further education, physical transition as they grow through puberty and transition within Little Hearts Matter as they progress from a youth member to an adult member.

In this article, we will be looking specifically at medical transition and the transition within Little Hearts Matter that our youth members will experience. Knowing and understanding the changes that come in the teenage years can help all of us to support young members as they grow into independent adults, though supporting this time of their life can be challenging with the hormonal changes affecting their behaviours. The amount of change experienced in a short amount of time can be overwhelming so the right support during these teenage years is paramount.

What can be expected when a young person starts to medically transition from a paediatric unit to an adult one?

Medical transition is something that can sometimes prove challenging to our youth members, with many of them coming to Little Hearts Matter for a chat or some advice to ease their anxiety. Medical teams can start the discussion of the medical transition to an adult unit from the age of 12 with the medical transition usually occurring between the ages of 16 to 18. This is dependent on the unit you are in and the needs/ability of the young person. Some young people will stay in the paediatric service a little longer if they live with a learning difficulty.

Some cardiac units will offer a transition event to support this move, but not all. If you are offered the opportunity to attend, it's a good idea to go.

Here both you and your young person will get the chance to meet your new team before the first adult appointment and get a feel for the adult unit. You may get a tour and an opportunity to sit in on some talks. If you are at a cardiac unit that does not offer a transition event, remember your cardiac team are there to help and answer any questions you have so a phone call to them is a good idea.

The paediatric and adult consultants normally offer a joint clinic before the final move. This appointment also offers an opportunity to meet your new Adult Congenital Heart Disease (ACHD) specialist nurses. If you or your son/daughter feel you are not ready to transition to adult care or struggle with anxiety about this move when it is brought up raise your worries with your cardiac team, they are there to have a chat.



The journey of a teenager moving into adulthood is quite different to that of a child so the questions and worries they might have will change.

Worries or stress surrounding topics such as relationships, sex, life expectancy, future treatment and future educational or work placements are common in young adults with a single ventricle heart. The cardiac team in an adult unit are better equipped to answer these questions; reminding your young person of this may help alleviate any fears they have of moving to adult care.

A fear we hear often from our youth members is that they will be fully responsible for their care and expected to take the lead in their appointments straight away. This is not the case. Medical transition is a journey, not a quick handover to an adult unit and your cardiac team is there to support you. The end goal is for your young person to feel empowered and confident enough to take responsibility eventually. In the lead-up to the medical transition, encouraging your son/daughter to start asking and answering questions in their appointments alongside you can help prepare them and make the move smoother.

We know that this phase in a young person with half a heart's life can be challenging to the parent/guardian also, so we are here to support you too. If you or your young person want to check in, chat or have questions about the transition for Little Hearts Matter we are happy to help and are looking further into what we can do to support, however, it is a very good idea to contact your medical team to discuss the specific plan for transition for your young person.

Transitioning from an LHM youth member to an adult member.

The LHM adult support service is a new growing service for our members aged 18+ living with half a working heart. Though the service has similarities to our youth support it is shaped for the adult members by the adult members. We know that the transition to this adult service after years as a youth member needs to be supported, to ensure that our young adult member feels comfortable at a time when they are experiencing lots of change in their life. Many of our youth members come to our youth support team to talk through experiences they are having, looking for support or with questions.

A change to yet another team and the feeling of having another trusted network no longer around is something we want to avoid. Many of our youth members moving into adulthood are not prepared for the typical changes you would see in an adult support network, the onus and responsibility and topic change in conversation.

It is our responsibility to prepare, support and move forward jointly so that it is a smooth transition for them. To do this we are working to implement a number of support mechanisms;

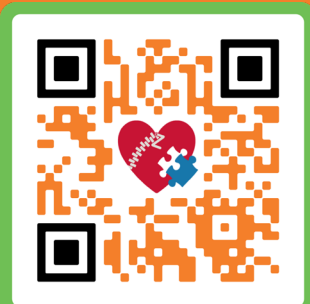
Joint work between the head of youth services and adult lead for our senior youth members. This will solidify a relationship and create rapport ready for when they turn 18. The ability to work with and build a rapport with the adult lead in the familiar youth service will provide an opportunity to continue this positive relationship in the adult service.

A transition mentor team, consisting of four young adult members that have experienced this move to adult services from youth. Our transition mentors will be available to chat with and support our senior members so that they move into adult services with positive friendships. It will also give lived experience and advice on what to expect. We have found that many of our youth and adult members work well when prepared.

A continued relationship with the head of youth services. We don't want our young adult members to feel like they are losing a positive relationship when they turn 18. So, they will still be able to chat with the head of youth services as they build a relationship with the adult lead and their fellow adult members once they have turned 18.



We know that the teenage years bring crossroads, transitions and responsibility to our youth members in all aspects of life. We are working hard to create consistency and support to help our youth members in their half-a-heart journey.



Youth Zone

SCAN ME

Written by: Lexie Katsaitis

Youth Hub Launch

It has been over eight months since the launch of the LHM Youth Hub, and what an exciting time it has been. We have seen such progression with our youth hub in a short space of time so thought it a good idea to update you on it.

What is the youth hub?

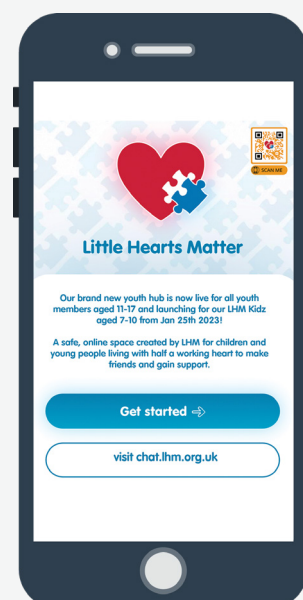
For those not aware, Little Hearts Matter launched our youth hub in October 2022. This was a great achievement as we had spent over a year working with a great coder/designer to create a safe, accessible, online space for our youth members.

We knew how invaluable it was for our youth members across the UK and Ireland to be able to chat and create friendships with other young people with hearts similar to theirs in a digital forum from our Facebook groups. We needed to find a way to recreate this digital space so that it could be extended to include all of our youth members aged 11-17 (social media did not facilitate this), could be safeguarded to Little Hearts Matter standards and purpose built so that it could be developed in the future.

We achieved this and more, adding space for our youth members to create profiles, access LHM youth information and participate in weekly youth group evenings with the youth leader and mentors. We saw an impressive number of youth members sign up for launch day and have been running twice weekly youth sessions on lifestyle topics trending.

What's new?

A challenge we have seen with the youth hub in general, is the lack of notifications. This could at times impact the engagement with the youth members. We see this challenge being solved once we have launched a safe native app but, in the meantime, have worked with our coder to now enable notifications on laptops and androids. Very exciting! If your young person is on the youth hub, ask them to enable notifications so that you know when people are chatting!



Since the start of the new year we have been able to introduce an LHM Kidz for our Kidz Members aged 7-10 giving them the opportunity to engage in one group chat a month with the youth leader and other kids their age living with a single ventricle heart. This has proved very successful, giving them the opportunity to engage with other children who might face the same challenges they do, to start to understand their heart in an age appropriate way and to build relationships in preparation for them turning eleven and becoming youth members.

All in all, we are very proud of the youth hub and how it has been used and grown in a short period of time. If your child or young person aged 7-17 is not yet on the youth hub but would like to be, scan the QR code at the top of the page.

Upcoming events		
31 May 7:00pm LHM JUNIORS - Month Review with Lexie A chance to look back at the last month with Lexie. What ...	31 May 7:45pm LHM SENIORS - A months review with Lexie A chance to look back at the last month with Lexie. What ...	5 Jun 7:00pm LHM JUNIORS - Energy catch up with Molly Join youth mentor Molly to go over how the month of may ...
5 Jun 7:45pm LHM SENIORS - Energy Chat with Molly Join youth mentor Molly to go	7 Jun 7:00pm LHM JUNIORS - Mindfulness check in with Lexie Join Lexie for a mindfulness	7 Jun 7:45pm LHM SENIORS - Mental health check in with Lexie Join Lexie for a mindfulness



Understanding the LHM Energy Project

Written by: Suzie Hutchinson

How is energy made?

Energy is made in every cell of the body from the oxygen, food and water transported in the blood and pumped around the body by the heart.

What is different when you have half a working heart?

Children, teenagers and adults with a single ventricle heart (half a working heart) have less energy than their peers because they may have less oxygen in their blood and only have one of the two pumps needed to drive blood around to every cell. Doctors who have researched this say that most heart-healthy teenagers run at 100% energy level at rest and can increase that to 500% on activity. Young people with half a heart run on a normal energy level of between 50% and 75% which can only rise to 200% when active.

When you have only half a heart you have a great deal less energy than your peers. One of the greatest challenges for anyone living with just half a heart is understanding how to manage their energy levels.

To help our young members understand how much energy they have to use each day we present their energy as spoons. Healthy people, with a normal heart, have twenty spoons to use each day, whereas people with half a heart have just ten. Those ten spoons can be nice and full if you keep fit (within your half-a-heart restrictions), eat well, keep hydrated, sleep well and take the medication prescribed to keep your heart working well.

The LHM energy project works to help young members understand how they use their energy every day. They need to learn to balance when they use their energy. For example, some children may use up energy before they get into the classroom, if they walk or cycle to school; this might affect their concentration and planning through a lesson.

We have a chart of energy use that can help members to think about which activities might use up a lot of energy and which ones use less.

For example, climbing the stairs could take up three spoons. The spoon number may be different for everyone so the chart is just a guide.

We also teach members that they can borrow a little energy from the next day, but they have to understand that they will have to pay it back. For example, if one of our youth members decided they want to go to a party on Saturday night they may borrow some energy from Sunday. To borrow, they would know that they will have to rest up on Sunday because they have less energy to use that day.

The energy project has not been created to stop young people from doing things, it has been developed to help our young members do as much as possible. By helping them think about what is important to them and where they want to use their energy every day, we hope to empower them to have a full life. It also helps them to explain their energy levels to people who do not understand what having half a heart means. Teachers, club leads, or employers all find it easier to understand what having less energy means when they hear about the spoons of energy we have to use every day.



For more information on the energy project follow the link to our website:

<https://www.lhm.org.uk/youth-zone-energy/>

Our young members have just received an LHM energy pack with their Spring comic. Help them to explore their energy by using the spoons and resources provided.

Approaching a DLA or PIP appeal

Written by: Suzie Hutchinson

Many applications for DLA or PIP are not awarded on the first application. They move through to mandatory reconsideration and then on to full Appeal.

The first thing to say is if you are turned down, do not despair. 90% of applications end up going through review or appeal. It is frustrating and unfair, but it also does show that you are not alone. The LHM philosophy is to approach an appeal with positivity but to prepare for it well.

When you receive the letter asking if you want to appeal the Department of Work and Pensions' decision not to award DLA or PIP, prepare your answer carefully. You need to explain, point by point, why they got their decision wrong. You then need to seek independent, professional evidence that will support every point you have raised. Sadly, this evidence cannot be from your family.

- Letters about HealthCare, Education, Health and Care Plans from schools.
- Letters about adaptations that have been made in places of work.
- Letters about restrictions and adaptations that have been made in clubs and extracurricular activities.
- Last letters from the hospital if they add weight to your points.
- Letters from any community teams if they add weight to your concerns, for example Speech and Language Therapists, Physios, District Nurses.
- Letters from anyone offering Counselling, Psychology or Psychiatry support.

The Little Hearts Matter team will be happy to write a letter in support of your appeal if we have not sent one to you as part of your application. We will need to see a copy of the original application and a copy of your last clinic letter.

The aim of our letter will be to walk the assessors through the challenges that the child or adult with half a working heart faces every day.

All of the appeal paperwork will be assessed by an independent assessment panel. The panel is made up of a lawyer, who chairs the discussion, a doctor or someone who has a medical background and someone from the charitable or social service sector. If you would like a face-to-face appeal, it can help because you can answer questions and the panel will have read your information before the meeting.

You and the DLA/PIP team will both have to explain why you think the decision was right or wrong. To prepare for the meeting, use the LHM letter as a guide because it will set out the care and mobility needs.

Here is the information we will include if it is relevant for you or your child.

1. Explain the heart condition in detail including the fact that it is not correctable. Talk about Fontan-created complications.
2. Medication and ongoing treatment – anticoagulation and cardiac medication are very important as they are recognised as treatments for single ventricle heart disease. Include letters from the hospital where they describe the treatment and challenges.

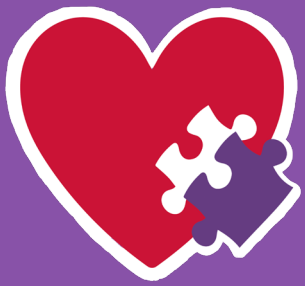
3. Any other medical conditions and care needed.
4. Talk about reduced energy levels and how they are balanced, also how decisions have to be made about where the energy is used to maximise each day. Include exercise tolerance test results.
5. Circulation – reduced ability to keep warm, leg pains, headaches/migraines.
6. Mobility – What added care has been put in place for mobility? Always explain that a child or adult can walk (if they can) but that they have problems maintaining exercise. Do they have a wheelchair?
7. Daily life – describe added care needed with everyday life. What should they be able to do independently at their age? Childhood: washing, helping with household jobs. Adulthood: shopping, cooking, washing and cleaning.
8. Nutrition – if there are any difficulties with eating or taking in calories, describe them but also explain that early years growth can be difficult as the children have to take in more calories than other children. As young people age and move into adulthood, balancing calories and reduced activity can be difficult. Fontan circulation depends on the good fluid intake so maintaining hydration is very important.
9. Development – any developmental delay (normal in a child with half a working heart) or diagnosed educational deficit. Include any educational psychology reports.
10. Education – What support has been put into school, college or university- copies of HealthCare Plans, Education, Health and Care Plans.
11. Workplace – what support has been put in place, have any benefits for reduced working been put in place.
12. Mental health. Are there any concerns or treatment for mental health problems? Psychologist or school pastoral care.

13. Social life – explain how much inclusion there is or is not.
14. Aspirations and how the support of benefits will help them to be reached.
15. Talk about inclusion.
16. Talk about reaching their full potential.
17. Talk about reducing discrimination.

The LHM team will be happy to have a conversation on the phone with you about your appeal but sadly we are not able to attend the face-to-face appeal.

Most people who seek an appeal will be awarded the allowance but it may not always be at the top level. That will depend on the amount of added care or help needed with mobility.





SVH Adults

Written by: Hannah Palmer

Hi! Most of you will know me by now in various capacities, but my name is Hannah Palmer, and I was born in 1994 with DILV. I have been a member of Little Hearts Matter for nearly 20 years and throughout my time I have been honoured to have had several volunteer roles within the charity. I was a member of the original LHM Youth Council, I have been a Trustee since 2014 and I am currently the Chair of the new ACHD Service Council.

As the surgeries and treatments for SVHD get better, we are living longer and there has become more and more need for a bespoke Adult Service within the SVHD Community, so within the last few years, LHM has looked to fill this hole.

Our new Adult Service is there to support anyone born with a Single Ventricle Heart Condition who is 18 plus. We currently have a very active Facebook chat, where we can discuss both questions about our heart conditions but also life in general with people who understand what it is like to be us! We also arrange online discussions and events which proved key during COVID with a lot of us shielding and unable to leave the house.

We are currently recruiting for a new lead for this service so that we can look to get the support we need to be implemented as soon as possible! We have recently formed an ACHD Council within the new service.

I and five other adults with half a heart meet regularly to discuss the ongoing needs of the SVH Adult group. We then present to the Service Team and Trustees to help get the support that we need. We look to get the



input of the other adult members so that we are basing discussions on the feelings of the majority of the members, and recently held a session where we asked them what they want from the service and the new Service Lead. Once the new Adult Lead is implemented, we will also work with them to develop the best service that we can.

Last year we ran a specific ACHD Open Day, in conjunction with the Somerville Foundation, with workshops and presentations aimed at adults with a Single Ventricle Heart. This was very popular, and we are looking into making this a regular thing that we can do to help support our ever-growing ACHD population.

This year, even though the Open Day was online, some of our adult members took part in a panel where parents and young members can ask questions about our lives and experiences. This is always a key part of the Open Day, and highly requested.

The Summer Event will have an ACHD event running at the same time, where we can all meet, some of us for the first time since the pandemic. There are bursaries available for those attending who may struggle with costs, however, accommodation will be covered for all adults attending.



I am looking forward to seeing how the ACHD Service develops in the next 12 months and would like to thank LHM for providing the support that we really need as we work through both being adults and dealing with a significant health condition.



The Membership of Little Hearts Matter Explained

Written by: Suzie Hutchinson

Little Hearts Matter is often seen as a family, the family is made up of many people who need our help. We call them our members and we have many different types of member who we offer different support to.

Full members – parents/guardians and grandparents of children or adults, over the age of 18, living with a single ventricle heart. Full Membership is free for everyone and allows the members to access:

- Closed support groups and links to other LHM members.
- Invitations to and attendance at LHM member events.
- Hard copies of all of LHM's written information.
- Support with benefit claims and appeals.
- Support with accessing HCP and EHCP support.
- One-to-one support from volunteer or staff team members.
- The opportunity to vote for Board members and scrutinise the finance and management of the charity.

Child and Youth members – anyone living with half-a-heart under the age of 18 can access for free:

- Closed support groups and links to other young LHM members. This support runs from the age of 7 to 17.
- Invitations to and attendance at LHM member events.
- Hard copies of all of LHM's written information.
- One-to-one support from volunteer or staff team members.

Sibling Membership – brothers and sisters of children or young people with half a working heart can access:

- Invitations to and attendance at LHM member events.
- Hard copies of all of LHM's written information.
- One-to-one support from volunteer or staff team members.

Family Associate Members – extended family members can access:

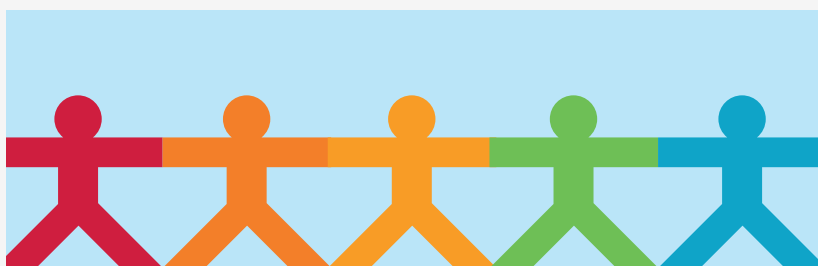
- Invitations to and attendance at LHM member events.
- Hard copies of all of LHM's written information.
- One-to-one support from volunteer or staff team members.

Professional Members – doctors, nurses, health professionals, teachers, carers, social workers, in fact any professional who would like to understand more about living with half a heart.

- Invitations to and attendance at LHM member events
- Hard copies of all of LHM's written information for individual use and large numbers of publications for use with patients (lifestyle booklets are usually purchased if large numbers are required).
- One-to-one support from volunteer or staff team members.

What do we need from our members?

We always need your input on the future of the charity, as members are the owners of the charity. Keep in touch about your challenges and support needs, and look out for opportunities to respond to questionnaires to help with our planning. Come to events when you can and when they look useful for you, and full members should ensure their voice is heard if there is an option to vote by proxy or by post for formal meetings such as the Annual General Meeting if they can't be there.



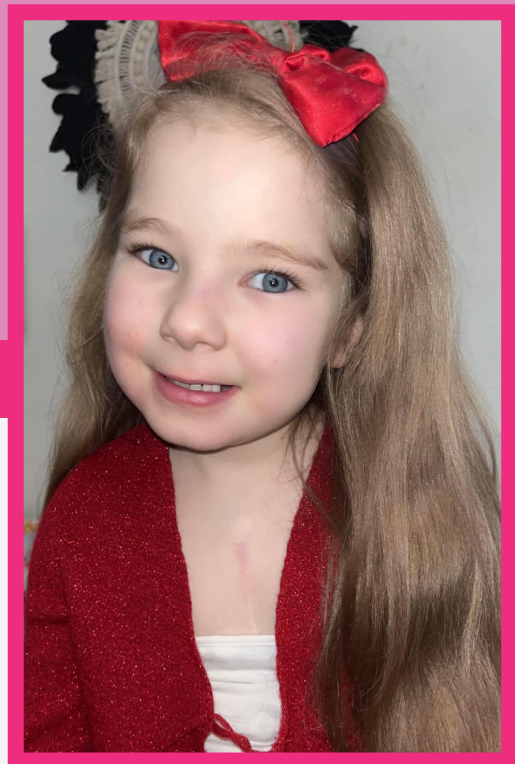
Layla's Story

Written by: Aimee Hay (Layla's mum)

My daughter Layla was born with Hypoplastic right heart syndrome. It was clear from a young age that Layla was facing challenges related to her energy levels. At just age three, Layla received her first wheelchair, and her wheels have massively helped us as a family.

We also quickly learned that Layla wasn't meeting her daily calories or fluid levels on the days she was tired, resulting in a peg being fitted. Again, this has been amazing for us, in both the medication and nutrition.

Layla was granted an EHCP last year, quoting the LHM managing your energy with spoons resource. Our reason to secure an EHCP was the struggles we faced with energy levels at school. Often missing the back end of the week, Layla wasn't able to access every opportunity to learn. It was also very upsetting not being able to play at break times or get involved in PE because of the breathlessness.



Now we have found a balance: spend half of the break time indoors and the second half outside. In PE, we have decided to let Layla join in, but without any pressure to overdo it. It's important for us that Layla feels included. We also decided to cut out Wednesday afternoons, to allow a chance to recharge.

Meeting with the local authority, and the team that works with children with life-limiting conditions, was very helpful for us. After a few meetings, we decided to trial home tutoring on a Thursday, which meant if she was tired, Layla could stay in her PJs and learn from the comfort of her own home.

Home tutoring has worked amazingly for us, school have recognised that when Layla is in school, she is thriving and so willing to learn. Our home tutor has become a favourite person in Layla's life and we look forward to Thursdays with her.

Making the small adaptations around school life has really given Layla the boost she has needed, we have noticed not only is she wanting to walk further distances, but she's also working well towards school levels again and her eating has improved massively.

Although we would all love Layla to be in full-time education right now, that isn't the best thing for her energy levels. The plan we have in place to keep Layla thriving and safe from exhaustion is working well and I hope some of the ideas we have used can help other families who also struggle with school.



Social Media

Written by: Sam Jones

30 years of LHM

Next year, in 2024, we will celebrate 30 years of LHM. Our little charity has grown immensely over the years and yet we have never lost the care and drive to support our families travelling at different stages of the half-a-heart journey. Our members still sit at the forefront of everything we do.

The stress and fear that come from life with half a working heart are still present to this day, but thanks to Suzie, the LHM team, our trustees and volunteers, we have built up an ever-growing network of support, to offer hope, empowerment and a better understanding for our members.

The 30th anniversary of Little Hearts Matter is a very exciting milestone in our history, but it also reminds us that the half-a-heart journey is ongoing. More people are seeking our support than ever before and this gives us the drive to grow and evolve even further.



On top of support and information, our members are seeking a greater general awareness out in the public sphere. If more people understood the challenges of life with a complex heart condition, the better opportunities our members will have to live life to its full potential that their heart will allow.

We are inviting all members of the LHM community to help us make 2024 an awareness-filled year for the 30th anniversary of LHM. Wouldn't it be amazing, to see new awareness raised in schools, universities, workplaces, in the media and beyond, to see our followers turning from thousands into millions.

Your support could help us achieve that, so please get in touch with the team if you can help at info@lhm.org.uk. Thank you.





Summer Event

As a charity, we learned a lot from 2020. On the one hand, we learned about the possibilities of delivering support and information in a completely online format. On the other hand, it highlighted the urgent need for in-person connections and community amongst our members.

There is no denying that physical events offer our members a special type of empowerment and friendships. With that said, and with pure joy, we are inviting you to join us for our LHM summer family event taking place at the Pioneer Centre in Cleobury Mortimer, August 18th - 20th.

We will transform the grounds of the Pioneer Centre into an LHM village with a fantastic variety of fun, games, food and music.

Now we can tell you more about our exciting plans:

- An LHM music festival takes centre stage, with professional sound, stage and lighting and a line-up of awesome musicians, some themselves travelling on the half-a-heart journey.
- Performers will have a blast at our drama and musical theatre parties.
- The Institute of Physics will run interactive physics workshops.
- The Creation Station will host creative challenges and arty workshops.
- A sports day will be taking place on the grassy grounds.



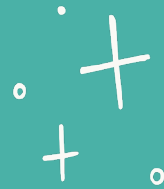
- Giant swings and zip-lining courtesy of the Pioneer Centre.
- A holistic therapies tent with complimentary massages for parents.
- Street food, sweet treats and a non-alcoholic bar.

Phew. There are more line-up additions coming, too! Spaces are limited so if you would like to join us, on the Saturday, or for the weekend, please visit this link: www.lhm.org.uk/event/summer-event-2023/





Grandparent page



Written by: Suzie Hutchinson

In this issue, we are introducing a new page to the newsletter, a page specifically for grandparent members focussing on some of the issues raised in the recent questionnaire. As well as helping to answer the grandparents' questions we also hope that parents will read the section to give them an idea of how their parents want to help.

How can grandparents help their grandchildren and their children?

When a baby is diagnosed with just half a working heart parents are involved in all of the discussions and the complex decision-making. It is important that they have the space in which to make the difficult decisions but equally, they need to be able to draw on the support of family, friends and charity support like LHM. Some parents want to discuss everything with their parents but sometimes it is difficult to involve close family. This may be because they don't want to worry them but also because they don't want their decision-making to be led by them.

Grandparents want to help of course, they have a double worry. They are worried about their grandchild but they are also very worried about their children. They want to help but they don't want to get in the way. Sometimes it is difficult for them to judge what their children want or need.



From the insights that the LHM team have picked up over the years our suggestions would be for grandparents to offer support but be guided by the expectant parents as to how much to ask and how much advice to give, especially in the early days after a diagnosis.

Sometimes parents find it difficult to discuss or explain the medical information but they are happy for grandparents to seek information from other sources. That is where LHM can help. Little Hearts Matter is always there for grandparents, as well as parents. We can help by providing information that explains the diagnosis, sharing stories that talk about life with half a heart and offering an opportunity for one-to-one discussion with someone from the team or links to the grandparent social media pages where the experience of others can help support grandparents travelling a similar journey.

Grandparents offering practical help can be so useful: lifts to hospital appointments, cooked meals, offering parents an opportunity to have a break away from home, offers to look after other grandchildren, especially around the time of the baby's delivery or surgery. Grandparents offer parents a great source of support as they learn to look after their new baby.

As the grandchildren grow older grandparents can help share their care, having engaged and informed babysitters is brilliantly helpful. Sleepovers offer fun for the grandchildren but also offer a break for their parents.

If you would like to tell us your story, you can contact the LHM team via our email, info@lhm.org.uk.



“

When I found out about Lucy's tricuspid atresia I had never heard of it so found out everything I could about it from media and internet etc so I knew a little about how to help my daughter when she was faced with questions and we could discuss them. As for helping Lucy I have visited her each time she was in hospital, visited her at home when she was poorly, playing games and reading to her to distract her as much as possible for the reasons for her being in hospital.

The pride I have got for our heart warrior and the joy I've had, she's amazing.

”

Linda, grandmother to Lucy.

“

So proud of our heart warrior Linus. An ocean separates us, but we get to see our grandkids at least once a week thanks to modern technology. Also, thanks to modern technology we get and give support to other half a heart grandparents. Thanks to LHM and all the other support for our heart warriors, so glad you are there for us.

”

Suzanne, grandmother to Linus.



Finley's Story

Written by: Louise Grimes (Finley's mum)

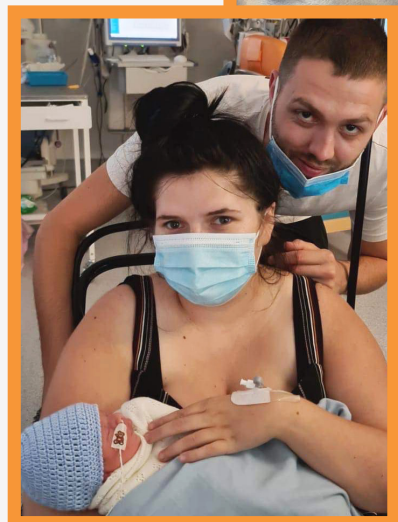
At our twenty-week scan, we discovered our little boy, Finley, had something wrong with his heart. The sonographer's words were 'I'm unable to see all four chambers, let me go and get somebody else to check'. As soon as I heard those words I instantly lay there and felt like it was a bad dream. Two weeks later we had a scan at the fetal medicine unit in Manchester to confirm that our beautiful baby boy has hypoplastic right heart syndrome - Tricuspid atresia, pulmonary stenosis and a large VSD. From that date, I instantly worried every single day as the information they gave us didn't sound promising.



Finley was born at 36 weeks and to hear his little cry was the best sound I could have ever heard. Finley was placed in NICU for two weeks and was doing well considering, until he had to be intubated at 3 am one morning as his oxygen levels had dropped to the 30/40s not long after this he was emergency transferred to Alder Hey Children's Hospital for surgery. Finley managed to get surgery at three weeks old and had a stent put in his PDA. We eventually got discharged at eight weeks old as Finley caught sepsis and had a blood clot in his leg from the surgery, so needed to be kept in for strong antibiotics. The following weeks from discharge we had to go for weekly blood tests at the local hospital to ensure Finley was on the correct dose of enoxaparin for his blood clot.



Before you knew it, the Glenn surgery was slowly approaching which we were dreading but we knew he needed it due to the sweatiness, cyanosed spells, and poor weight gain. At six months old, Finley underwent his first open heart surgery and he did absolutely amazingly! He woke up a little bit earlier than expected and tried getting his breathing tube out and instantly wanting his milk! We spent six short days in Alder Hey after his surgery and we were allowed home as he recovered so well.



At the moment, Finley is doing as well as he can and he does try to not let his condition gets in his way but sometimes he just doesn't understand. Finley attends nursery two days a week, which he loves! We are currently waiting for a request from Finley's cardiologist for Finley to have a cardiac catheter to see when his Fontan surgery should be due. We are truly blessed to have such a beautiful strong little boy and we are very proud of how amazingly he is doing.

Little Hearts Matter has helped us a lot regarding advice, and meeting families who are going through the same as us. We can never repay anyone for helping us but what Finley's dad (Daniel) and Finley's aunts (Ashleigh & Meghan) did was a charity boxing match and raised money for LHM.

Thank you to everyone for supporting our family

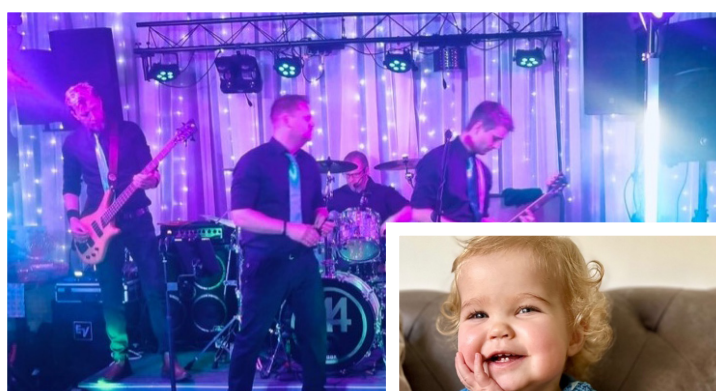
Fundraising Wall

Written by: Juliet Hanlon and Rebecca Wilkes

Your fundraising is vital to Little Hearts Matter!

Everything we do is made possible through the support and generosity of people like you. There are so many ways that you can fundraise or volunteer for LHM to help us be there for families through every step of their half-a-heart journey.

We're excited to share what a few of our brilliant fundraisers have been up to – could you be inspired by their fundraising challenges this year? Please get in touch if you are planning an event, a challenge or a bake sale –we'd love to hear all about your ideas!



Sam Attwood and her husband held a Fundraiser Event including a beard shave, raffle, silent auction and kids' fancy dress competition. Well done for all your hard work to raise an incredible £5,567!



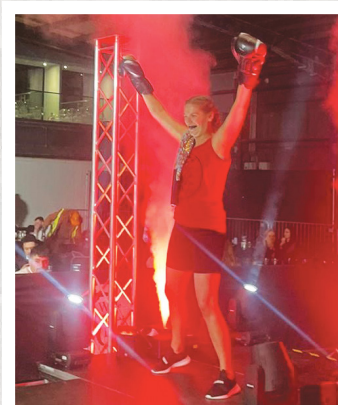
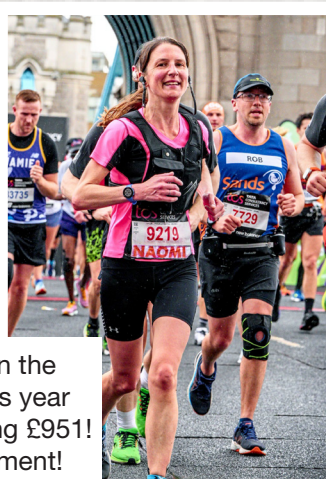
Naomi Geffen took on the London Marathon this year and raised an amazing £951! what a great achievement!



Young member Evie Hinchliffe held a yummy Easter raffle, raising a fantastic £320 AND gained a new Brownie badge in the process. What a fundraising superstar!



Liverpool John Moores University students Ellie Clement, Joshua Topham and their team raised an amazing £938 by hosting a Mindfulness Matters Event as part of their Events Management Degree Course.



Ashleigh Wilson and her sister Megan took part in a Boxing Challenge, raising an incredible £1,035! Well done on a tough challenge ladies!

Extra thanks to:

- Janet Burrell, who raised over £700 with her Saturday Singers Choir.
- 7-year-old Adriana Gentile skipped her way to raising £121.
- Garry Watson and the Castle Hawk Golf Club raised £1,400 through a Charity Night and Auction.



Fundraising



Written by: Juliet Hanlon and Rebecca Wilkes

We set you a challenge for Christmas 2022 to try to raise £10 in the lead-up to Christmas, and “Elf Yourself” on the 12th of December. We can’t thank you enough for rising to this challenge so well and helping us to raise an amazing £3500 A massive thank you from Eve the Elf to everyone who supported us!

We can’t wait to see what’s in store for Christmas 2023!

A Christmas shout out to Ben Curries for completing 25 Festive jogs raising £1,120! Thank you Ben!



Big Hearted Friday 2023

Our fourth year of Big Hearted Friday was a great success, raising over £2,700 with some mouthwatering cakes and incredible crafts made by some very talented fundraisers. Schools and nurseries have once again been a great support by wearing red and blue so thanks to all the parents, teachers and pupils giving us their support. If you missed out on celebrating Big Hearted Friday in February, why not pick another date with your school, nursery or workplace? To sign up and receive your fundraising materials, head to our website. Any Friday can be Big Hearted Friday!





Are you ready for a Challenge?

Whether you want to ride, run or cycle with friends, or even create your own personal target, challenge events are a great way to support Little Hearts Matter!

We currently still have spaces for The Great North Run on 10th September – the deadline to sign up is **31st July** so email fundraising@lhm.org.uk to get involved!



Spotlight on: Personal Challenges

Charley Price: 6 in 6 Challenge

Charley and her family have fundraised for Little Hearts Matter on many occasions already but this year, Charley has set an amazing personal challenge for herself – to complete six running events in six months from April to September! She's already halfway to completing her challenge, and we know she's going to smash the final three events to meet her target! Well done, Charley! You can donate to Charley's JustGiving page here:



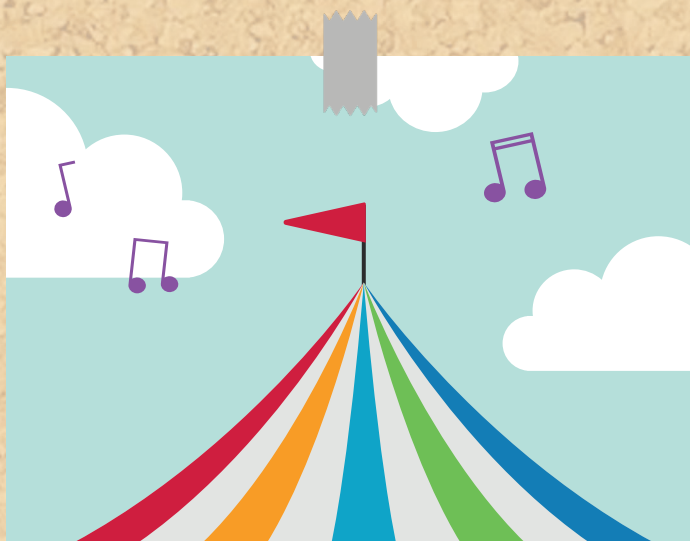
Colin Barrett: 80/80 Walk

Colin has set himself a challenge to walk 80km for his 80 birthday this year - as well as this, Colin is a familiar face at various supermarkets across Warwickshire and the West Midlands with collection buckets to raise even more funds! Christine, Colin's wife, also helps to fundraise by selling greetings cards and his daughter, Sally, recently held a coffee and cake afternoon! Could you support Colin in his challenge?



Would you like to set up your own personal challenge? We hope Charley and Colin can inspire you to get involved! Give the fundraising team a call on **0121 455 8982** or email fundraising@lhm.org.uk – we want to hear all your fantastic ideas!

Noticeboard



Little Hearts Matter's Summer Event
will be held over the weekend of the
18th - 20th of August 2023

with a big family event on the
19th of August

For more information,
scan the QR code!



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
- My new baby sister has something wrong with her heart - storybook for brothers and sisters

Lifestyle

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