



Little Hearts Matter Newsletter

September
2024



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Supporting every step of the half a heart journey



Written by **Lisa Davies**

Welcome to a special edition of our member newsletter, celebrating our 30th Anniversary Year!

This milestone year has been filled with exciting events and achievements. Since our Open Day in March, we've hosted our first Roadshow event in Crealy, launched our 30th Anniversary Awareness Film, and held our May Awareness Week, focusing on PIP and DLA campaigns. We've celebrated our London Marathon runners and numerous members who have fundraised tirelessly to support our cause. Additionally, we held a meaningful Bereavement Day at the National Arboretum, among many other activities. We hope you enjoy this issue and find inspiration and valuable information within its pages. We value your feedback and would love to hear from you. Please feel free to email me at lisa@lhm.org.uk with any comments or suggestions. Thank you for being part of our community during this special year!

Lisa Davies
Chief Executive, Little Hearts Matter



Trustee News

Written by **Warren Manger, Chair**

It is a privilege and a pleasure to wish you a happy 30th anniversary from everyone at LHM.

We have come a long way during the last three decades. LHM now has 7,000 members, approximately 2,000 of whom are children or adults living with a single ventricle heart.

But our mission remains the same – to provide support and information to families to reduce the isolation, fear, and lack of understanding that accompanies an incurable condition.

I want to thank our incredible staff team and volunteers who work so hard to ensure we meet the needs of our ever-expanding membership.

I would also like to welcome Laura Hewitt as a co-opted member of the Board of Trustees.

Laura has been a member of LHM since 2021, when her son Edward (Ted) was diagnosed with Double Outlet Right Ventricle. She brings 20 years of marketing experience in the private and not-for-profit sector and her expertise will be a valuable addition to the Board.



Written by **Suzie Hutchinson**

New tips for completing your DLA or PIP application forms

The LHM team are very grateful for the help of one of our members, who was a DLA assessor, in gaining a greater insight into the way that benefit assessors look at a benefit claim.

Here we have set out a few more tips to add to our benefits information which can be found at lhm.org.uk/benefits

When an assessor is looking at an application form, they need the following information.

Medical Conditions

They need a clear **understanding** of the medical, and other, conditions that affect a child's or adult's ability to live life like their peers. They do not know what having half a heart means so you have to describe – the condition, treatments, regular tests, medications and future treatments. Tell them single ventricle heart conditions cannot be cured, tell them that the future is uncertain. Talk about heart failure and heart transplantation. Explain their reduced energy.

Evidence

Ask for good letters from doctors and nurses who look after you or your child. The letter needs to confirm restrictions as something that would be expected for someone with half a heart. Other supporting information from school or the workplace needs to set out what changes have been made to include their pupil or employee. Swimming coaches, Brownie or Cub leaders, dance or drama teachers will all have made adjustments to include you or your child. Get them to write a letter setting out the changes.
Independent expert evidence.

DLA assessors use the **STAR** system to look at your submission.

Safely

Highlight risks of harm. Do they need prompting to be safe, do they need supervision, do they need aid. An example for our members would be do they remember their medication, can they take it safely, what would happen if they don't take it. Other examples are the side effects of an anticoagulant or increased breathlessness.

Timely

How long does a task or journey take in comparison to their peers. If they are walking how long does it take, how many stops do they need to rest. If they are eating a meal how much longer does it take in comparison to their friends?

Acceptable

Do adjustments have to be made to help them achieve a reasonable standard of life. For example, planning of meals, changes to the school or work environment, sleeping arrangements or heating the house.

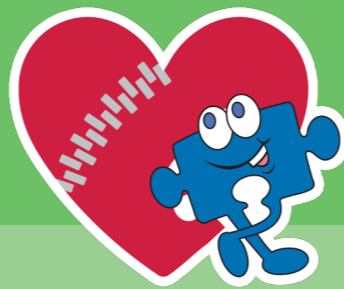
Repeatable

Can they repeat what they have been doing, with a short rest. Here you need to mention the **spoon theory** as the assessor will understand it is a measurement of what they can achieve energy wise in a day.

Explain how they feel and how they cope.

Living with half a heart is emotional, scary and energy draining. Many people with half heart suffer with PTSD (Post Traumatic Stress Disorder), anxiety, phobias and depression. It is essential that this is included in any claim as it gives an insight into the complexity of a child's or adult's life with a single ventricle heart condition.

Remember that LHM is always here if we can help with a DLA or PIP application or appeal.



I am delighted to be able to let our members know about some new services that we have recently introduced for our LHM Kidz.

We now offer monthly video call catchups for our 'Jigzy knows' sessions. These are a chance for the children to get to know each other while our mascot, Jigzy, who is extremely knowledgeable, talks the children through an aspect of life with a special heart to give encouragement, support and tips. Our first session was all about 'Checking in with yourself', the aim being to get the children to start listening to how they are feeling and noticing what their minds and bodies need. This was such a fantastic session, with our young members really keen to get involved and was full of energy and giggles.

We have also produced some fantastic new videos that explain to our under 11s about their special hearts. Jigzy, he really does know his stuff, walks the children through each heart condition and explains it in a more accessible way. Jigzy has been voiced by our fantastic sibling member Miles, he really brings the character of Jigzy to life. **You can watch these films by following this QR code.**



Our autumn LHM Heart Gang comic follows Tilly and Isaac as they start back at school. As I'm sure many of our parent members know, this time of year can be extremely difficult for our young members as they struggle to balance their energy levels with the demands being made of them. Tilly is pretty good at planning ahead and has a lot of strategies for conserving her energy. Unfortunately, Isaac isn't so great at managing his spoons!

If you find your child also struggles managing their reduced energy levels then they can find lots of tips and tricks on our Kidz webpage and you can also find a pull-out energy planner in the recent comic, which is also available for download on the webpage.



As always, we want to hear if your child is having any specific issues that you think we, at LHM, could be doing more to support so please email me at olivia@lhm.org.uk with any feedback.

LHM Roadshow: Crealy Theme Park

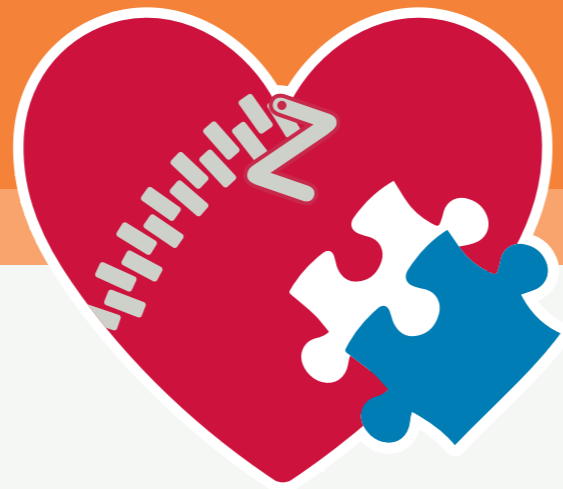
Suzie and I made the trip down to Exeter in June to meet up with some of our families in the Southwest of the country. We were delighted by the turnout and it was really wonderful to see some of our families in this region out for the day.

We met at Crealy Theme Park and the sun was shining for the first time in a while. The theme park was a perfect location, with loads of rides suitable for our members. One of our families in particular got extremely wet on the aqua blasters ride, an attraction where you sit in a rubber dingy and shoot water at each other. You can also get fired on by super soakers on dry land. Thank goodness it was a hot day and they dried off pretty quickly! As well as rides there were also SO MANY playgrounds, slides and soft plays to explore as well as a soak zone! It was great fun. I was forced into doing the 'Buzzard's Swoop' which boasts being the 'scariest drop slide in the Southwest.' A vertical drop which I would absolutely have chickened out of if there hadn't been witnesses! Terrifying!

After a morning of fun, we all met for lunch and it was lovely to see our families getting to know each other over fish and chips and pizza! As with all of our in person meet-ups, the most wonderful thing is seeing our young members getting to know each other and at Crealy they all went off to the soft play and the rides together while the adults had a chat.

For me, the best thing about the day was meeting some more of the young people in my LHM Kidz age range, getting to know them and hearing about what they are getting out of the services we are already offering and what we can be doing to improve the support for this age range! And of course, surviving the 'Buzzard's Swoop!'





Written by Lexie Katsaitis

Secondary School Life With Half A Working Heart

It's September which means that many of our youth members are either starting or returning to secondary school this month. This time of year is often accompanied by a spectrum of emotions from excitement to anxiety.

To prepare and support your child no matter the emotion there are some things you can either work through together or remind them of if they prefer working independently.

Let's look at all five year groups in secondary school and how proactive planning can make school life easier with half a working heart.



Year 7/8

Year 7 is a transitional year for all children. Moving into secondary school from primary comes with lots of changes and more responsibility. Add to this the energy management problems, mental health challenges and learning/developmental delays that sometimes come with life with half a working heart and this move might seem even more daunting.

Meeting with the school to ensure the smooth transition of your child's HCP (Healthcare Plan – all children with single ventricle heart conditions are entitled to this) and EHCP (Education, Health Care Plan – only children with diagnosed learning and developmental delays can apply for this) from primary school and the implementation of support that comes with this can really help.

Updating your child's plan with support for energy management particularly between classes and in PE lessons is a good idea. Does the school have lifts your child can access with a pass? Can they leave 5 minutes earlier to walk to the next class? Does the PE teacher know how to make their lessons inclusive for your child?

Ensuring that any one-to-one support that is funded by your child's EHCP is implemented and that the pastoral team know of your child if they have any mental health diagnosis is also a great idea. Speaking with the school and advocating for your child as early as possible will make this transition smoother for your child.

Continuing this support into Year 8 is necessary.

Year 9

Year 9 is often referred to as a crossroads year as choices are made that impact the rest of a young person's educational career, choices such as what GCSE subjects they will be studying.

When you have half a working heart there are some additional questions to think about when making these choices.

How many subjects can your child manage with their energy levels?

Lower energy levels also impact concentration, sometimes opting to study fewer GCSE subjects is a better choice for young people with half a working heart, allowing them more time to allocate to each of their subjects so that they can manage their energy accordingly.

Is there a big physical aspect to their GCSE options?

Subjects such as PE have a big physical aspect to them and the same can be said for subjects like Drama or Music. If your child/young person is passionate about this subject and wants to take it, it's worth a conversation with them and their teacher to see what days of the week and times of day the lessons are, what subjects fall on the same day and what physical aspects are involved in the assessments, in order to prepare for this.



Year 10/11

Years 10 and 11 are a huge transitional period for young people with half a working heart. There is a lot of pressure and expectation coming in from a lot of directions.

During these years there will be a lot of focus on coursework completion. Working with your young person to support them with energy management and stress is crucial. How busy are their weekends? Do they need more time to concentrate on coursework? Are they doing fewer subjects so they can allocate free time at school for coursework?

On top of coursework there is exam preparation and the exams themselves. Are there certain (realistic) ways the school can support during exams? Are there any support mechanisms you can put into the HCP or EHCP at the beginning of Year 10 specific to exams to give the school plenty of time to get them into place? Ideas such as a scribe to help if their energy is low, a separate room to avoid distraction if their low energy impacts concentration, the ability to keep hydrated by having a drink, or the option. The sooner these are put forward the more likely they are to be put into place.

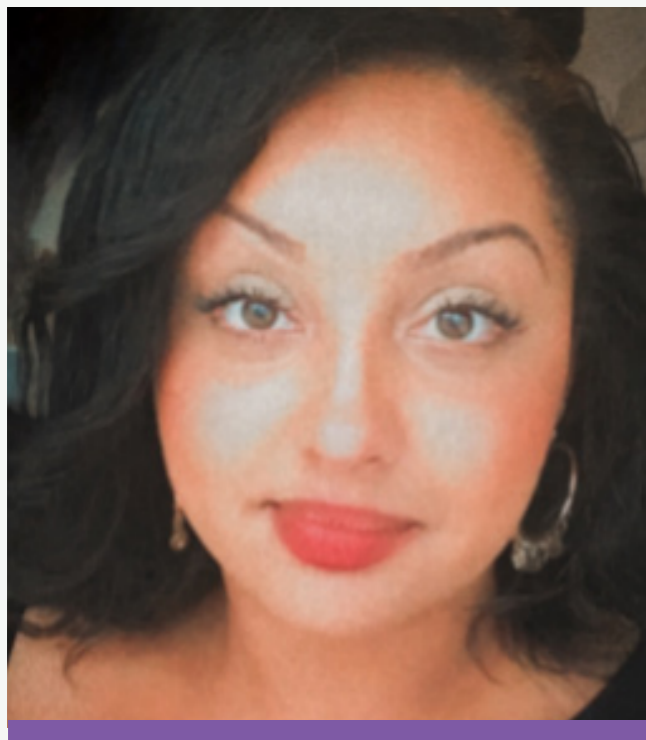
Please remember that during this time your young person might be experiencing their hospital transition, stress about the future and the unknown with further education and work so support from home is that comfort and structure they need.

Our youth programme
is generously funded
by Children in Need





We are delighted to introduce the new SVH Adult Services Lead.



Hi, my name is Sharna and I am a qualified youth and community worker. I have a background in the youth industry; mainly youth mentoring and community engagement.

I am a mother to one and spend the majority of my time outside of work making memories with my child.

I enjoy listening to music and looking at art (although I really wish I could draw too!)

As your new adult service lead, I will be working at Little Hearts Matter three days a week.

Some things that motivated me to apply for the role of Adult Services Lead at LHM were the potential to make a difference to the lives of the LHM community, develop my knowledge about the conditions and whilst contributing to fun and happier memories with as many of you as possible, also ensuring you do not feel alone on those harder days.

You are inspirational people, and meeting Hannah (the chair of the SVH adult council) at my interview was evidence of that.

Within my role as your SVH Adult Services Lead, I am looking forward to creating a service with you, for you. I'd be really interested in hearing your ideas for things you'd like the service to include, so I can consider what may be possible; after all- the service is yours.

Some ideas I have been thinking about so far may include creating local meet ups to do activities together or create a space for face-to-face discussions or activities (coffee morning, walks, etc) Thinking wider, I plan to see if it would be possible to have online guest speakers to discuss various topics that may be relevant to your age range or based on concerns you may have (sex education, fitness/yoga, women in STEM, mental health support, opportunities at university, etc), as well as online interaction via games such as bingo, quizzes, scavenger hunts, charades and book club. It would be great to hear your thoughts and ideas around this, email me at sharna@lhm.org.uk

To make your transition to the new service more comfortable for you, I will be working with other staff at LHM to ensure a smooth transition to adult services.

Our adult service receives funding from the Paul Hamlyn Foundation



Immunisations

Children with half a working heart are just as susceptible as other children to catching infections, but their heart condition may mean that they take a great deal longer to recover. This often leads to periods of time away from nursery or school.

It is important to include details of slow recovery in Healthcare Plans.

In most cases it is recommended that children with a heart condition have all of the immunisations set out for them throughout their childhood.

Immunisations should be given at the age prescribed if a child is well. Newborn baby immunisations may need to be delayed if a baby has been in hospital but they need to be given as soon as they are well enough after discharge, or occasionally when they are in hospital.

Nationally there has been a rise in cases of measles because there has been a drop in the take up of immunisations. Past scares about the MMR vaccination, now all dismissed, have created a drop in use and a rise in the infections the vaccination covers. If parents still have a personal concern about this vaccination, it can be split into three jabs. Talk to your Health Visitor or GP if you have concerns.

Protection against diphtheria, polio, mumps, measles, meningitis, hepatitis, pneumococcal infection and flu, to name just a few, is really important for children who already have a long-term condition. Protecting them from infections means there are a few less worries about their health.

For more information on each of the immunisations, scan the QR code to follow the link to the NHS website:



Annual flu and Covid inoculations 2024 should be available from September.

Flu

There are two ways to ensure that children are protected from the most common flu bugs each year.

They can have the nasal spray from the age of 2 to 17 if they have a long-term medical condition. School age children will be offered the nasal spray with their classmates at school.



Children under two or over 17 and all adults are offered the jab inoculation.

If a child is on Aspirin, a Salicylate, it is better for them to have the jab rather than the nasal spray because there is an increased risk of them getting a condition called Reye's Syndrome.

This can be organised with the GP or Health Visitor.

Medical teams suggest that a child on Aspirin has a day away from school when other children have their nasal spray unless they had their vaccination two weeks before. It takes two weeks after their jab for them to become immune.

Flu is a horrid and sometimes scary infection when you have a heart condition. It is very important to protect the children if you can.

Covid

Details of the autumn immunisations are yet to be announced but vulnerable people will be offered a vaccination from September.

There are pharmaceutical companies looking at a combined vaccination for both flu and Covid which may be available this winter.

Many GPs will book for parents and siblings to have protective vaccination to reduce the risks of bringing Covid or flu into the house.

Book yours or your child's flu jab as soon as they are available at your GP practice in September.

Arrhythmias and half a working heart

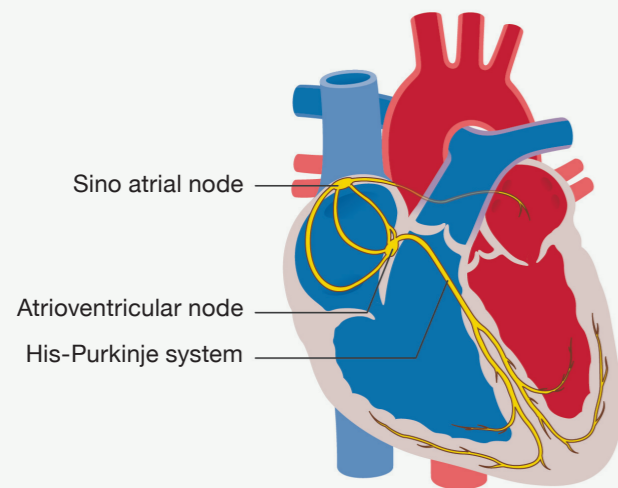
Written by **Suzie Hutchinson** edited by **Dr David Crossland**

The heart is a powerful pump. Its job is to make sure that the body has all the oxygen it needs to make energy. It does this by driving blood around the body.

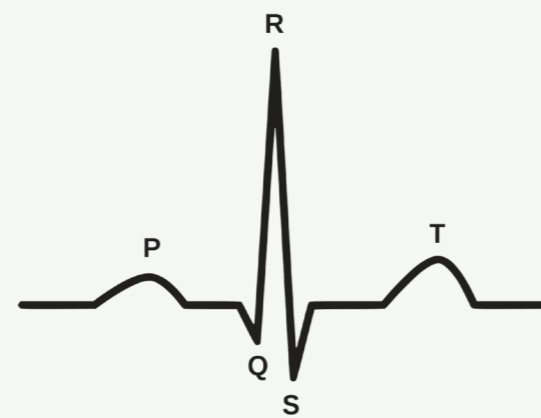
To work effectively the heart has to ensure that the chambers (atria), the valves and the pumping chambers (ventricles) work in perfect harmony so blood can be pumped efficiently. The pumping is initiated by the heartbeat (electrical activity), this beat sends messages to each part of the heart to tell it to pump.

The normal heartbeat:

The heartbeat starts in the top of the right-sided collecting chamber, this is the sinus node (the heart's natural pacemaker), and then spreads across both the right and left collecting chambers causing them to contract and push blood into the pumping chambers. The beat is then caught by the atrioventricular node that sits in a small area between the collecting and pumping chambers. This allows a short delay for the blood flow to catch up with the electrical flow and then activates special conduction tissue, the His-Purkinje System, in the pumping chambers. The electrical wave spreads across the pumping chambers telling them it's time to contract pushing blood around the body. There is then a recovery phase where the heart relaxes and the atria fill with blood from the lungs and the beat starts again.



The various stages of the cardiac cycle can be seen on an ECG. Atrial contraction is represented by the P wave, the wave then moves on creating a contraction of the ventricles, which is depicted by the QRS wave which in turn then relaxes into the T wave. When the electrical system is functioning normally, with normal time between each section, it is referred to as sinus rhythm.



When the heart beats too fast it is referred to as tachycardia, if it is too slow it is bradycardia. Fast and slow heartbeats can be in sinus rhythm.

The heart rate goes up and down in order to meet the supply and demand of the body and it is normal for the heart to speed up during exercise or when excited and slow down during rest, particularly at night.

When the heartbeat is not in rhythm it is referred to as an arrhythmia.

Maintaining normal sinus rhythm is important for the function of the heart and circulation, especially a Fontan heart. If the heart is beating too fast for prolonged periods of time it can affect the function of the heart muscle. If the heart is beating too slowly, particularly if the beat doesn't go up with activity this can lead to symptoms like dizziness and exhaustion. If sinus rhythm is interrupted and the heart is

going too fast there might not be time for the heart to fill with enough blood to run the circulation efficiently and if it is going very slowly the heart might not pump out blood frequently to run the circulation efficiently.

The heart rhythm in a single ventricle heart is often affected by the malformation in the heart or as a result of necessary surgery. As many as 50% of children and adults with a Fontan circulation have changes to their heart rhythm. This is why ECGs (electrocardiograms), which record the heartbeat, are often performed at outpatient appointments or inpatient visits. An ECG that shows a problem with the rhythm or if the team suspect there might be a problem with the rhythm, despite a normal ECG, may be followed up with a 24-hour ECG that shows the heartbeat over a whole day.

The most common problems that are seen in a single ventricle heart are:

Supra Ventricular Tachycardia's (SVT) – this is an abnormally fast heartbeat, out of sinus rhythm, due to a fault in electrical activity in the upper part of the heart. This affects the ability of the heart to pump efficiently. The most common type of SVT in Fontan patients is Intra Atrial Tachycardia.

Ventricular Tachycardia (VT) – this is an abnormally fast heartbeat that starts in the lower part of the heart. This affects the ability of the heart to pump smoothly and efficiently.

Bradycardia – this is a very slow heartbeat. It might be in sinus rhythm but if the rate is too slow and does not increase with activity it can cause symptoms (sinus node dysfunction). Another type of bradycardia is heart block where the atrioventricular node is not working well enough to allow the electricity to move from the collecting chamber to the pumping chamber. This can affect the way blood is pushed around the body, which then affects the way the other organs in the body work, or if intermittent, can cause blackouts.

Symptoms of an arrhythmia

The symptoms can vary from no symptoms at all to:

- chest pains
- dizziness
- tiredness
- palpitations, when you feel your heart is out of rhythm
- shortness of breath
- blackouts

Medical teams may insert a Reveal Device, a small device that is inserted under the skin near the heart that can record the heart rhythm for as long as three years. The device can send its readings directly to the medical team or they can be downloaded and sent.

Treatments for Arrhythmias

Medications – medications work in different ways. Digoxin can slow and strengthen the heartbeat. Amiodarone and Propranolol can regulate a fast heartbeat.

Pacemakers – different types are used in different ways.

- It can take over the job of the heart's own pacemakers (either the sinus node or the atrioventricular node, or both).
- It can act as a defibrillator.
- It can help the electrical impulse reach all areas of the pumping chambers at the same time to help the heart pump to be more coordinated.

Insertion of a pacemaker is likely to be done surgically.

Ablations – via a cardiac catheterisation abnormal electrical pathways, which affect the heart rhythm, can be blocked, ablated.

For more information about arrhythmias and their treatments visit the Arrhythmia Alliance website heartrhythmalliance.org/aa/



Parent Member Survey

Little Hearts Matter is a member-led charity. As parent members, it is your needs and priorities that direct the services we build, and create the voice that we take out into arenas for change and inspiration for the stories we tell to raise awareness.

We need to understand more about how having a child, of any age, affects your, and your family's life. Please help us to learn more.

The LHM team have created a survey aimed at parents that explores your feelings and needs at different stages of your journey. We also need to know if what we offer helps you at different stages of your child's life, 'Half a Heart Milestones'.

Our aims as a charity are to reduce the fear, isolation and lack of understanding created when a child, young person or adult has half a working heart. As we develop support and information for all age groups we are also always there for you, and as their parents, they will always be your children.

As you travel through the survey just complete the section that relates to your child's age group now. We want to learn as much as we can about your current stage of the journey.

The information gathered will be used by us to improve our services, to collect and to support your voice to raise awareness, and support our fundraising, all essential parts of Little Hearts Matter's work.

The survey can be anonymous but if you would like to leave your details at the end you will be entered into our prize draw.

**Thank you
so much for
taking the
time to help.**

To take our survey, visit:
[www.surveymonkey.com/
r/2MCW896](http://www.surveymonkey.com/r/2MCW896)
or scan the
QR code below:



30th Anniversary Film to Raise Awareness for Children Born with 'Half a Heart'

We are thrilled to share the launch of a 30th anniversary awareness project: an animated film produced by the award-winning Media Co-Op.

Created in collaboration with, and narrated by, LHM parents, the film captures the daily challenges faced by families dealing with single ventricle heart conditions. It highlights parents' journeys, detailing the medical, emotional, and practical hurdles they encounter. From multiple surgeries to navigating everyday life, the animation reveals the barriers they face, and the resilience they show in the face of adversity.

You, our members, have been amazing at helping us spread the word—our publicity campaign has already reached over 600,000 viewers at the time of writing, and the film has had over 50,000 views. It's a testament to the collaborative spirit of the LHM community. Our goal is to raise urgent awareness of the challenges of supporting a child with a life-limiting condition like a single ventricle heart and to inspire others to learn how they can make a difference.

Creating this film involved a meticulous process where families shared their personal stories, medical journeys, and the emotional impacts of living with the condition. Their narratives offer a real-life perspective on the struggles of frequent hospital visits, surgical procedures, and the constant need for vigilant care, all while living with an uncertain future.

Claire, one of the participating parents, shared: "Being involved in the film has really helped me process everything we have been through. It has validated that we are not alone, and that other parents feel the same struggles as us."

Ben, another parent, spoke about the vital support provided by Little Hearts Matter: "We have been so grateful for the support throughout our daughter's life, particularly in helping our two eldest daughters understand her condition."





Written by **Juliet Hanlon, Liz Hodson and Rebecca Wilkes**

Honouring Theo: A Skate Jam in His Memory Supports LHM Families

We're so grateful to LHM bereaved members Jessica and Jordan Loak-Finch, who held their second Skate Jam event in memory of their son, Theo, who they sadly lost to Hypoplastic Left Heart Syndrome and Aortic Atresia in 2023. The event, held on 27 July 2024 raised awareness of Theo's condition and an incredible amount of money, in addition to the £5,001 they raised last year.

Jess shared, "The loss of a child is a void that can never be filled. The only thing we could do was try and help others that might be in the same or a similar situation. We hope what we raise goes a little way to helping other families and parents."

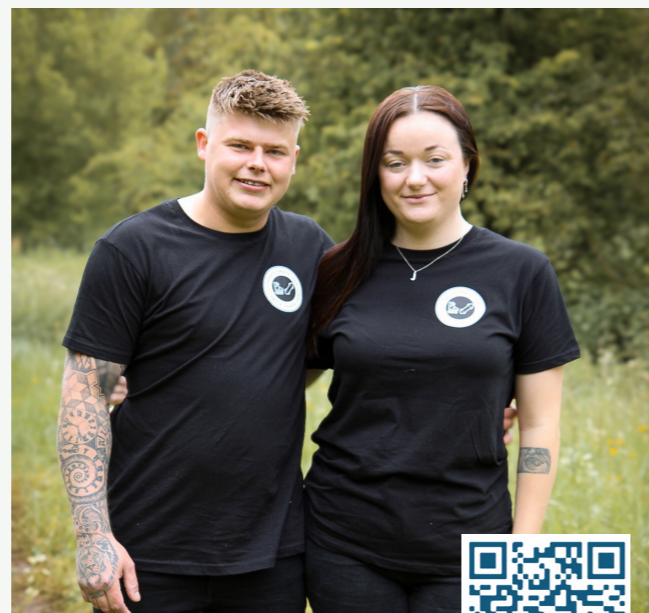
In the spirit of healing and remembrance, Jess and Jordan - an avid inline skater, turned to their passions to inspire their fundraising. And thus, the Skate Jam was created.

The Skate Jam welcomed skaters and non-skaters alike to their local skatepark, creating a vibrant and uplifting atmosphere. The day was filled with activities, including a tombola, a dessert van, and live music from DJs. BMX riders and skateboarders also showcased their skills, adding excitement to the day.

When organizing the Skate Jam for the second time, Jess needed to set up a new fundraising page and gave us feedback that she felt frustrated with not having one dedicated place to share Theo's story and keep his memory alive. In response, we've developed 'Little Hearts Forever' remembrance pages for members like Jess to remember their child, family member, or friend.

Many members have shared how much comfort it brings to set up a page in the name of someone they have lost. With this in mind, we designed the 'Little Hearts Forever' pages to be personal, meaningful, and supportive.

These pages offer a space to share memories, photos, and stories, providing comfort and a way to remember significant moments like birthdays, anniversaries, and other memorable days. They also serve as a platform for collecting donations or raising funds in memory of a child, family member, or friend, if you wish.



If you'd like to find out more about setting up a 'Little Hearts Forever' page, scan the QR code or visit www.in-memory.lhm.org.uk/

Laura's 2024 Big Six Challenge: A Mother's Love in Action

We are excited to share with you the incredible journey of LHM parent member Laura Cwiklinski. A mum from Cheshire, who is taking on a series of endurance challenges throughout 2024 to raise £6,000 for LHM.

A decade ago, Laura and her son Lewis had a heartfelt conversation where Lewis declared, "My life sucks." Lewis shared his six biggest struggles: achy legs, difficulty regulating body temperature, fatigue and breathlessness, fear of needles, challenges in asking for help, and moments of wanting to stop but pushing through. Motivated to better understand her son's experiences, Laura took on six challenges in 2014.



Now, as Laura and Lewis celebrate milestone birthdays in 2024, Laura is tackling six new challenges:

- ♥ **May:** Laura began with the Cumbrian Challenge, a gruelling 28-30km trek through the Lake District.
- ♥ **June:** She completed the Coniston Chillswim, a 5.25-mile swim across Lake Coniston.
- ♥ **July:** In Manchester, Laura faced the Tough Mudder UK, symbolising her family's daily hurdles.
- ♥ **August:** Laura took a leap of faith with a 14,000ft skydive from Cark Airfield.
- ♥ **September:** This month, Laura is preparing for the Yorkshire Three Peaks 12-hour Challenge.
- ♥ **October:** Her challenge will end with the Yorkshire Marathon, 26.2 miles of endurance and purpose.

Laura told us,

Through these challenges, I find moments of escape from the dreaded brown envelopes on the doormat. It's a chance to leave it all behind and revel in the simple joy of pushing our limits in nature. Lewis continues to thrive. He's completed his GCSEs and has started Sixth Form. His cardiologist still refers to him as 'the healthiest sick' he's ever seen, which is music to our ears.

We've been so proud to benefit from Laura's Big Six Challenge, and it's been a pleasure to support her every step of the way. Have you seen our range of challenges that you, your family, and friends can take on throughout the UK?



Join in today by scanning the QR code or visiting: www.lhm.org.uk/challenge-events/
We'd love to welcome you to Team LHM.

Fundraising dates for the calendar

Edinburgh 10K

Event Date:
22nd September 2024
Registration Deadline:
12th September 2024

Run Aintree

Event Date:
29th September 2024
Registration Deadline:
19th September 2024

Run Alton Towers

Event Date:
16th/17th November 2024
Registration Deadline:
6th November 2024

Santa in the City

Event Date:
4th/5th December 2024
Registration Deadline:
26th November 2024

Paris Marathon

Event Date:
13th April 2025
Registration Deadline:
31st October 2024



The deadline for final orders for merch and Xmas cards:
16th December 2024

Noticeboard



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Publication List

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

Antenatal

- Antenatal information pack

Diagnosis

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

Treatments

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

Education

- Support for a Child with Special Educational Needs within Nursery, School, or Further Education
- Healthcare Plans for Children and Young People with a Single Ventricle Heart Condition
- Understanding what having half a working heart means for a child in school – a guide for school teachers
- Early Years Foundation Stage (EYFS) and Key Stage 1 education booklet
- Key Stage 2 - Junior School education booklet
- Transition to Secondary School education booklet
- Key Stage 3 Secondary School booklet
- Key Stages 3 - 4 Secondary School booklet
- Your guide to university with half a heart

Benefits/DLA/PIP

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

Resources for Children

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

Lifestyle

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