

Little Hearts Matter

Supporting every step of the half a heart journey



Annual Report 2022

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Chair's Report


David Baumber

2022 has been a challenging year for the whole of the country and equally so for Little Hearts Matter (“LHM”). It has also been a rewarding year with support given to families at their moment of need.

As you will see from this Annual Report, LHM has achieved so much in the last year and it gives me an incredible sense of pride to have been the Chair over this period supported by the Board of Trustees and a great office team to ensure that our members get the support they both need and deserve.

The office team have been exceptional in the face of ongoing Covid and cost of living challenges and again provided unwavering support to both the members and the charity's operation and income.

The income uncertainty continued into 2022 but we have seen the levels grow compared to the previous year. Careful budgeting and planning, however, ensured that this has not impacted the services and support offered by the Charity. Through careful cost control, a surplus has been realised, enabling the Trustees to designate some of the general funds to provide bursaries to ensure all members can access the support of LHM.



Throughout these recent challenging years, children have continued to be born with a single ventricle heart; many have required surgery, some have sadly passed away and for others, there has been considerable anxiety. Through all of this, the office team and support line volunteers have been there as a friend and shoulder to support children, young adults, parents, grandparents and friends. Further details of the support provided and our new services are included later in this report.

A clear highlight of the year was our first face-to-face open day since the start of Covid. This required careful planning to ensure the safety of all attendees. The opportunities for families affected by a child with only half a heart to meet one another must always be taken. This was also the first event with a dedicated agenda for adults with half a heart.

Now at the end of 2022, LHM is in an exceptionally strong financial position and the continued support of the members, who provide the steer and direction of the Charity, is relatively assured. Our focus has therefore never been clearer, and I look forward to another rewarding year ahead.



Chief Executive's Report

Suzie Hutchinson

Surrounding yourself with a good team, who understand the vision of an organisation and are prepared to pull up their sleeves and work to reach the charity's goals, is essential for a Chief Executive in the third sector. LHM is very lucky to have attracted great staff and committed volunteers and to be supported by a hardworking and invested team of Trustees.

Any organisation is the sum of the whole team. It is no different at LHM. Understanding the needs of the charity's members, young and old, and working to support them as they hit every crisis and experience every challenge sits at the heart of what LHM does and must be reflected in every area of the charity's inward and outward-facing work.

The growth of the organisation needs to directly mirror the projected growth of the number of children, teenagers and adults living with half a heart and the growing service needed to support

their needs. It is essential that as the charity's membership multiplies, the charity can grow sustainably.

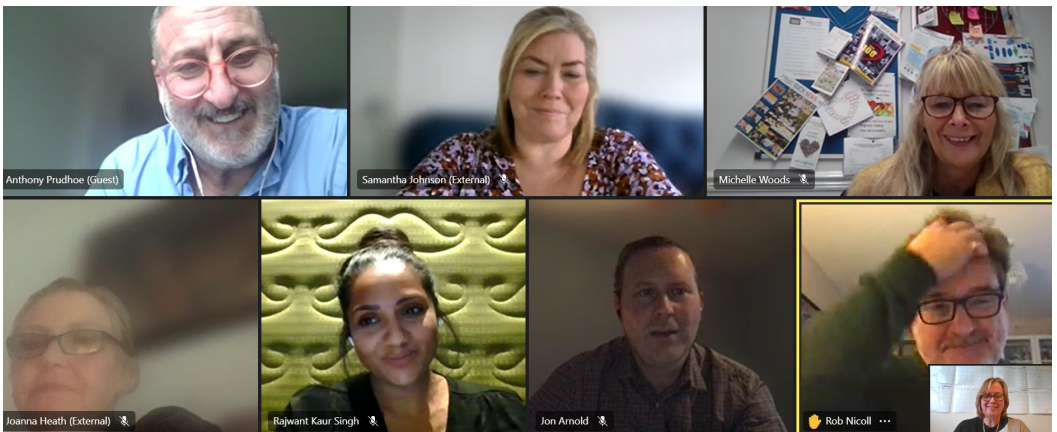
It is also crucial that LHM can grow the voice of the organisation both within arenas for change and within the third sector as a whole. Thirty years ago most children with single ventricle heart disease did not survive. Now there are thousands of young people living with the disability that their heart condition creates but a society who do not understand their needs.



The vision of the LHM team is to build on the professional reputation that the charity has developed over the last thirty years and by using the financial cushion created through prudent financial management, work towards the next dynamic growth step for the charity.

The next three years will see the organisation strengthen its leadership in three areas of the charity's work. The overarching management of the charity as a not-for-profit business. The growth and management of the charity's service provision, which always sits at the centre of the charity's work, and an investment in the awareness and campaign structure to drive a greater understanding of the member's needs.

The charity team has never been more important. No one member can drive the growth that is needed to make LHM relevant, up-to-date, visual and sustainable. Exciting times are ahead.





Youth Services Report

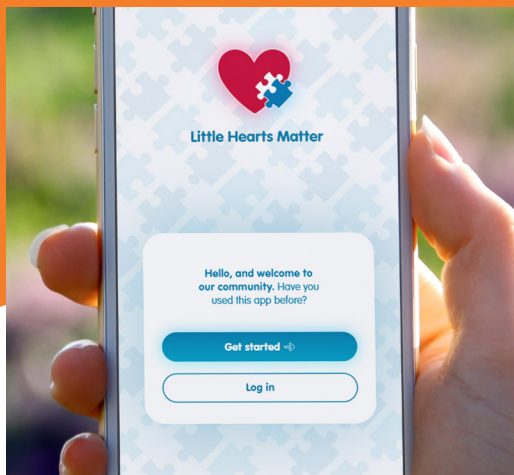
Lexie Katsaitis

2022 saw the implementation of new youth support services and the return of in-person youth events that had been greatly missed. The combination of our new custom-made digital support services (the youth hub) and in-person support events enabled us to connect more effectively with our youth members around the UK and Ireland and bring another layer of inclusivity.

The new youth hub was a necessary implementation to ensure that the platform we use is a safe, accessible, and inclusive online space.

The launch was a successful one seeing the popular LHM online youth groups continue onto this private custom-built platform rather than a public social media platform. This also combined text support, youth group sessions, links to youth information and access to create friendships onto one platform. Work to raise awareness for this new support platform started in 2022 and will be ongoing as will the work to evolve and grow the platform itself.

In March at the LHM Open Day, we offered multiple workshops for our youth members aged 11-17, hosted by medical professionals, mindfulness specialists and LHM staff. In August the youth activity residential returned, offering youth members an opportunity to join LHM on a three-night stay at PGL Caythorpe. Here our youth members aged 11-17 are able to safely challenge themselves to activities such as archery, wall climbing, giant swing and more as well as participate in LHM ran workshops to learn about medication/compliance and energy management.



The aspiration our youth members show remains low, due to a lack of understanding regarding not only their heart condition but the challenges this can create in their day-to-day life. We have set out to increase access to age-appropriate information about the different single ventricle hearts, the impact this has and the ability to create friendship circles with young people that can relate to each other's journey in order to provide empowerment, increase confidence and raise aspirations.

The lifestyle section of the youth zone (LHM website) was updated with brand-new youth-specific heart information. Previously this section linked the youth member to the parent information created for each of the single ventricle heart conditions, after this update the youth members have their own information pages written in a language and tone catered to them so that the information is easier to digest.

This section includes quizzes and the new heart animations to further support learning. The new youth hub support section links directly to this resource for the youth members.

In 2022 it became clear that youth work in the cardiac community was growing with many youth work specialists being hired within other third-sector organisations and within the NHS. Because of this LHM created the cardiac youth worker group. A working group consisting of youth work specialists from LHM, Echo, BHF, Youth@Heart, Cardiomyopathy UK and within the NHS. This group now meets quarterly to discuss best practice, collaboration, and trending issues as well as work together to create solutions or give professional advice on cardiac-related youth challenges. This group have been asked to feedback to various NHS trusts which they have agreed to in the future once it is more established.



Single Ventricle Heart (SVH) Adults

Suzie Hutchinson

One of the charity's biggest areas of growth has been the provision of services for adults living with half a working heart. Many of this age group of members have grown up through the charity but LHM is also seeing the adults with single ventricles hearts approaching the charity having never been involved before.

Just like every other member this group experience isolation, fear and a lack of understanding because of their heart conditions so the charity is working to build services to help them cope on a day-to-day basis with the disability their heart creates. Reduce their lack of understanding and fear through Information.

This group of members have asked to be known as SVH Adults. They now have their own website platform within the LHM site. They have bespoke information on areas of medical and lifestyle care specific to the challenges they face as they grow older with their heart condition.

There is a better focus on transplantation for this age group.

To reduce their isolation, the closed Facebook chat service has allowed so many adult members to talk to each other, express their fears and explore their challenges. The group usually bursts into action at 10 pm and they chat on into the night.

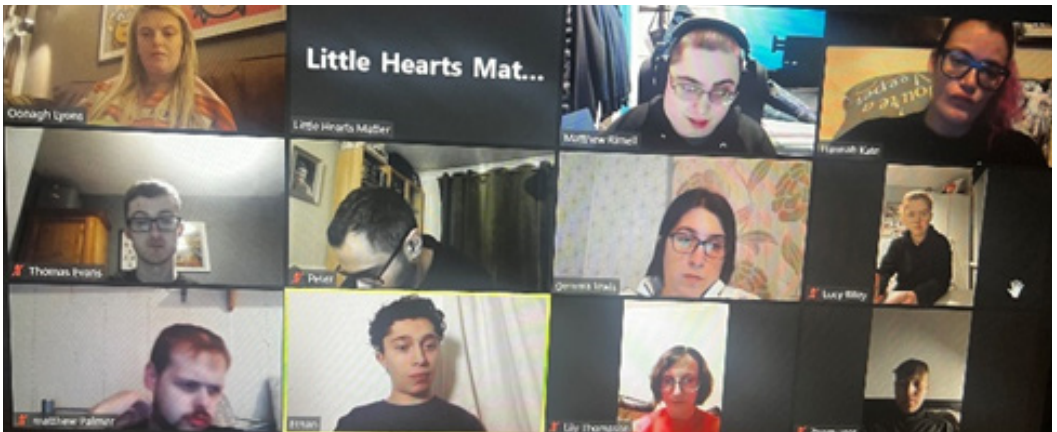
In 2022 the charity held its first adult focussed section to the annual Open Day. Their very own conference session and then a social get-together. The group also meet for workshops online and the first activity weekend is planned for 2023.



“Being able to talk to others with similar conditions to me allowed me to discover I wasn’t the only one, my experiences were shared with loads of other people. It’s allowed me to finally understand more about my condition and my limits - limits which I had previously been told were down to laziness. I have also made some good friends from it. Having this I am certain has had a huge impact on my recent positive mental health changes.

I have also been taking time to read the information provided on the website; finally getting answers to questions I have had for decades and felt unable to ask.”

SVH Adult Council



The charity has worked with the adult group to form an Adult Council. A group of adult members who seek the views of their fellow members and then work to report their needs and wishes to the main Board and management team. A truly member-led service.

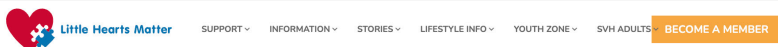
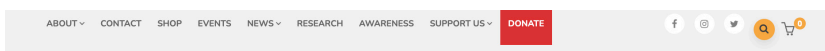


Social Media

Sam Jones

Evolution of the LHM website

In 2022 we have continued to make improvements to the LHM website to make our support and information accessible and inclusive for all. LHM support in your pocket, on the go. A new mobile menu has greatly improved searching and navigating. The lifestyle section has been re-designed to give easier access to the wealth of information. The main menu has been reorganised with a new rolling banner to signpost people to key updates and information.



Antenatal Diagnosis

We're here to help you understand your baby's heart problem.



Support

Learn more about the ways that we help people on the half a heart journey.



Benefits

Free support and information for LHM members applying DLA and PIP.





Information update of medical animations

In 2021 we launched updated medical diagrams and text, explaining single ventricle heart conditions and the potential treatment pathways. In 2022, we have supplemented this written information with animated videos that help to explain each single ventricle condition. This includes the production of the Fontan Pathway Film, describing every step of the main surgical treatment. These videos accompany the updated written information to help people understand their condition in an engaging and mobile-friendly way.



LHM Kidz - Expansion of support for 7 to 10's.

In 2021, LHM members highlighted a need for more support for LHM members aged 7 to 10. Our response was to create LHM Kidz, a new arch of support leading into the LHM Youth Zone. LHM Kidz is spearheaded by the introduction of a new comic book series – The Half a Heart Gang, specially created to help empower and support young people with half a working heart aged 7-10. All issues of the comic are available digitally on the website and in hard copy.



LHM Achievements

New Comic for 7 to 10-year-olds

Written for young members living with half a heart and their brothers and sisters that help them understand their heart and how to use their energy, like the Half a Heart Gang.

The New Youth Hub Launch

The youth hub was launched in September 2022, giving youth members aged 11-17 a safe online space to talk to each other, their LHM youth leader and youth mentors. There are currently 79 young members either registered or awaiting acceptance to the youth hub.

The New Fontan Pathway Film

An animated description of the path through all stages of treatment for anyone with half a working heart.

Single ventricle heart (SVH) adult group

A bespoke website section has been created with all adult-focused information, support and advice.

Lottery Funding

Achieved Lottery Funding to support the Social Media Lead role for a further five years.

New look website launched
Feb 2022.

24

balloons have been sent from LHM to children after their Fontan operation.

1,597

Birthday cards were sent to LHM children, teenagers and adults living with half a heart.

2022

Youth Condition Information

2022 saw the launch of single ventricle heart condition information written in a language and format younger members can understand and access easily. This is accessible via both the youth hub and the zone of the LHM website.

The Youth Activity Weekend

LHM youth members returned to PGL Caythorpe in August 2022. Our first activity weekend since the pandemic. 19 youth members attended, created friendships and challenged themselves in a safe way.

LHM Open Day

Held the first Face to Face Open Day for three years with bespoke parent, SVH adult, youth and 7 to 10-year-old conferences and workshops. Member delegates travelled from around the UK or joined us online.

Post Fontan medical information

LHM has added to the wealth of medical information by creating PLE, Fontan focussed Liver Disease and adult transplant information resources.

LHM Awareness Week
May 2022.

Updated SVH and LHM Facts
& Figures Sheet published
September 2022.

360

in memory cards were sent
to families.

478

people have joined the LHM
family over the past year.



Treasurer's Report

Peter Groves

This set of abbreviated accounts for the financial year has been extracted from the full set of accounts for LHM, which has been subject to an independent examination and is available from the LHM office or website.

The Statement of Financial Activities (SOFA) shows a net inflow of funds in 2022 (circa £30,000) which is split between both general and restricted funds. This net income has arisen despite the challenges of the Coronavirus pandemic and the cost-of-living challenges.

With the easing of Coronavirus measures, LHM was able to hold a face-to-face open day and AGM for the first time in three years. The event was very well attended with members able to meet and share experiences.

LHM was also able to expand other services across the membership with a new comic for younger members, the first activity weekend for teenagers since the start of the pandemic and

dedicated support for adults affected by half-a-heart.

New information has also been created such as a film explaining the Fontan surgery, a new app to support teenage and young adults, and other surgical information.

The total incoming resources increased by circa £13,000 compared to 2021. Costs increased by circa £52,000 year on year primarily driven by increased salary costs. This increase was due to a full year of dedicated support for the adult members and other roles being increased to full-time from part-time roles as the charity continues to increase support post-Coronavirus.

The balance sheet shows the financial position of the Charity as at 31 December 2022 remains strong with over £455,000 of net assets, predominantly represented in cash. The Board of Trustees deem this position to be essential due to the cost-of-living challenges for the economy as we move into 2023. The budget agreed for 2023 has been set with this in mind and shows a slight surplus in the general fund but this will be highly dependent on the recovery of the UK economy.

The Board of Trustees monitor the cash position closely to ensure that there are enough unrestricted funds to meet day-to-day demands. At 31 December 2022, the unrestricted cash position represents almost six months of funding compared to the budget set for 2023 reflecting the position described above.

The constant support for the membership and expansion of services could not be achieved without the wonderful support of the LHM office team, the Board of Trustees and volunteers. We are very grateful for all this commitment, especially through the challenging times we have seen in recent years.

**Thank you to everyone who supports
Little Hearts Matter and our membership.**

Statement of Financial Activities

	Year ended 31 December 2022 £		Year ended 31 December 2021 £	
Incoming resources				
Donations	119,420	26.9%	80,351	18.7%
Fundraising	94,449	21.3%	124,357	28.9%
Corporate/grant funders	210,449	47.5%	200,748	46.7%
Tax refunds	14,412	3.2%	19,600	4.6%
Other	4,725	1.1%	4,906	1.1%
Total income	443,455	100.0%	429,962	100.0%
Resources expended				
Cost of Generating Funds	11,169	2.7%	16,034	4.4%
Charitable activities:				
Salaries	230,054	55.7%	188,205	52.1%
Building costs	49,764	12.0%	47,952	13.3%
Open day/Summer event	22,152	5.4%	22,640	6.3%
Database	13,230	3.2%	6,162	1.7%
IT support	11,518	2.8%	11,251	3.1%
Depreciation	8,685	2.1%	4,395	1.2%
Printing/photocopying	7,293	1.8%	19,157	5.3%
Telephone	6,261	1.5%	5,600	1.6%
Newsletter	6,243	1.5%	5,123	1.4%
Training	4,555	1.1%	2,005	0.6%
Travel and hotels	4,234	1.0%	1,655	0.5%
Subscriptions	3,813	0.9%	1,937	0.5%
Recruitment	3,797	0.9%	694	0.2%
Youth activities	3,697	0.9%	2,239	0.6%
Postage	2,983	0.7%	3,254	0.9%
Insurance	2,787	0.7%	3,922	1.1%
Activity weekends	2,228	0.5%	-	0.0%
Gifts	1,865	0.5%	3,307	0.9%
Meetings	1,621	0.4%	391	0.1%
Pensions administration	1,123	0.3%	1,123	0.3%
Bereavement events	961	0.2%	2,670	0.7%
Other	7,325	1.8%	4,769	1.3%
Governance costs	5,928	1.4%	6,570	1.8%
Total expenditure	413,286	100.0%	361,055	100.0%
Net income	30,169		68,907	
Opening fund balance	425,793		356,886	
Closing fund balance	455,962		425,793	

Balance Sheet

	31 December 2022		31 December 2021	
	£	£	£	£
Fixed assets				
Intangible fixed assets		22,172		3,122
Tangible fixed assets		2,723		4,125
		<u>24,895</u>		<u>7,247</u>
Current assets:				
Debtors	26,272		24,317	
Cash	422,434		404,546	
	<u>448,706</u>		<u>428,863</u>	
Creditors:				
Amounts due within 1 year	(17,639)		(10,317)	
Net current assets		431,067		418,546
Net Assets		455,962		425,793
Analysed as:				
Unrestricted funds:				
General		205,368		179,494
Designated		80,521		75,000
		<u>285,889</u>		<u>254,494</u>
Restricted funds		170,073		171,299
		455,962		425,793

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