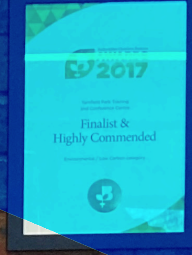




Little Hearts Matter

Supporting every step of the half a heart journey



Annual Report 2021

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Chair's Report

David Baumber

2021 has been a challenging year for the whole of the country and equally so for Little Hearts Matter.

It has also been a rewarding year with support given to families in their moment of need and the ability to hold a face-to-face event for the first time in eighteen months. The office team have been exceptional in the face of ongoing Covid challenges and again provided unwavering support to both the members and to support the operation and income of the Charity.

The income uncertainty continued and despite the great work of the team and friends of Little Hearts Matter, this has fallen for the first time in three years.

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 and this has enabled the Trustees to designate some of the general funds for future service costs. This fund provides continuity to enable further dedicated resources to be brought in to support the members over and above those funds provided by various grant providers.

Throughout the Covid pandemic, 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. The office team and support line volunteers have been there as a shoulder to lean on and a friend to support children, young adults, parents, grandparents, and friends. Further details of the support provided are included later in this report.

A clear highlight of the year was the summer party/event. This required careful planning to ensure safety for all attendees and with all the activities for many families who opted to stay for the whole weekend. The opportunities for families affected by a child with only half a heart to meet one another must always be taken. The happy faces of both children

and adults alike combined with the formal feedback received show the importance of these events in reducing the isolation and fear that so many of our members face.

Now at the end of 2021, Little Hearts Matter 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.

For us as a Board, it really is another marker of how far we have come in the last 25 years when once parents and families were our members and now we're seeing so many of our children, the patients themselves, turning to the charity for help.





Chief Executive's Report

Suzie Hutchinson

The international Covid crisis hit everyone, but it hit the families of children with half a heart harder than most. Every day they have lived with the knowledge that their children, already at risk from their heart condition, are also highly vulnerable to Covid and need to shut themselves away to keep safe.

Little Hearts Matter members have always looked to us for support through a crisis. This crisis added to their isolation, fear, and lack of understanding. All the normal health support resources had shut down. Referrals to the charity increased and families who had not used the charity before came looking for help.

LHM had to step up to the plate.

The team had to be agile, negotiating the stress that each family was feeling and seeking clear medical advice whilst juggling the need to shut the office, manage a reduced income and the necessity to use social media to support, inform and guide.

The team used their imagination, ingenuity, experience, and care to find a way to support members in every part of the UK.



Coming out of the crisis the charity team have learned so much.

The most important lesson is that we can reach out across social media and the internet to more people, connecting parents, children, teenagers, and adults, reducing their isolation. The use of the LHM hug was a simple way to show we were available to support anyone who needed it.



We have strengthened our links with hospital teams and the NHS and have been able to seek answers about the care and treatment that we can pass on to our members.

We have mastered the internet and social media to be able to run parties, conferences and workshops, coffee and chat sessions, wine and cheese evenings and Christmas parties.

Although the charity will always run face-to-face events (last summer's get-together was brilliant) we know we can reach more people online - parties, workshops, and conferences. We can pull in experts from around the world, we can expand the voice of the charity and more importantly take the voice of our members into arenas for change. Most importantly we can join families, who previously felt remote from support, together helping them feel less alone.





“LHM has been a lifeline during Covid-19 and lockdown. There have been times when it feels like some of us have been in and out of the LHM Facebook page 24/7 for days on end. They’ve really stepped up their game for this crisis, it feels like they’re always there and looking out for us. This has been a terrifying time for anyone with a heart child, but it could have been so much worse without LHM.”

-

Shared by a parent member



Youth Services Report

Lexie Katsaitis

In 2021, the pandemic highlighted what direction the Little Hearts Matter youth services should grow digitally and physically, in order to be completely inclusive to all youth members, no matter their location within the UK and Ireland.

During the pandemic, we saw an unfortunate lack of aspiration within the youth membership and a huge impact on mental health. Due to this, there was an increase in contact between youth members, parents, and the youth support service regarding mental health support.





Youth Support (social media, forum and phone)

Our virtual youth group on Facebook messenger ran consistently, following a month-by-month timetable. During certain times of the year as our youth members started returning to some form of normality, we saw the need to decrease the number of youth sessions per week. Our youth chat forum is no longer fit for purpose. Due to this, we are working with an independent coder and designer to build a purpose-built Little Hearts Matter web-based app so that we can offer virtual youth groups and access to one-to-one support for all youth members via phone, tablet or desktop. The aim is to launch this in June 2022.

Youth Events

This year we were given the go-ahead to start running the youth activity weekend at PGL. Unfortunately, due to positive coronavirus tests within the staffing team, we were forced to cancel this event. Although this was disappointing for all we were able to work with PGL to transfer the booking to 2022. A number of Zoom- themed youth parties ran through 2021. The intake of this is slowly decreasing as our youth members are able to go out and socialise more.

Youth Council

The Little Hearts Matter Youth Council have been integral in their own projects within the Little Hearts Matter youth services as well as reviewing any proposed material/projects.

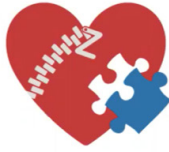
Multiple council members turn 18 next year so we are currently creating a process to recruit new members and turn over/start new Youth Council projects.

Youth Mentors

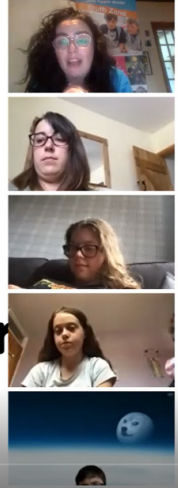
A team of young adults living with half a working heart were trained by Little Hearts Matter to offer mentorship to our youth members. The team grew by two mentors this year, which was great to see, and up-to-date training has been given to all.

Youth Research

This year the youth service team were able to participate in and complete two great research studies. The CHAMPION study that started in 2020 and the 'Children's informed signified and voluntary consent to heart surgery' study.



Preparing for your outpatient appointment



We have been making progress this year towards a new normal, supporting our youth members as they transition to a bigger world once again. This has been a difficult process for some but as always Little Hearts Matter is here to support every step of the half-a-heart journey.



Single Ventricle Heart (SVH) Adults

Lorna Carruthers

The growth in the number of adults seeking support from Little Hearts Matter has grown exponentially over the last few years.

Recognition that this group of young people needed support led the charity to set a strategy that sought to develop a new and evolving service for these members. Funding from The Paul Hamlyn Foundation has enabled the charity to appoint an adult service lead to take the strategic plan forward.

A survey conducted in August 2021 has been a starting point to assess adult members' needs about having an understanding of their condition, their current needs, disabilities, and areas in which LHM can offer support.

Three principal areas were identified within the survey that affect the adult population the most.

- Lifestyle challenges
- Mental health
- Socialisation

We began by introducing the 'new' adult service on social media platforms and on the Little Hearts Matter website. A poll across social media asked the adults what they would like to be known as; they chose Single Ventricle Heart adults or SVH adults.



The next task was to find a logo to represent the adults but still incorporate the charity's logo: the adult members chose the colour scheme, so they had their own identity.



Little Hearts Matter launched its new website that now includes a dedicated section for the SVH adult members. Work on this is ongoing to update and add to current information. A Facebook page and private messenger chat group already existed for adult members.

The adult members feel they now 'have a voice.'

2022 and beyond.

At the heart of the work over the next year and beyond will be the aim to increase inclusion for the

adult members both within the work of the charity and by raising their voices in arenas for change.

The formation of a council of adult members will be the first step toward clear governance and accountability. This voice will be used in partnership with the adult voice sitting on the Board of Trustees, to lead on the evolution of adult services.

Information will be developed to answer questions on medical and lifestyle care.

Research will be carried out and tools will be developed to help the SVH adult members understand their heart condition and the lifestyle challenge it creates.

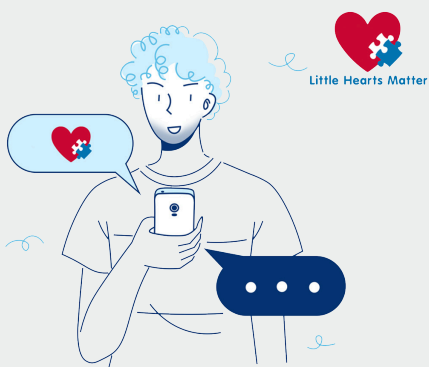
Events, both social and educational, will be created using online and face-to-face formats to help reduce feelings of isolation and exclusion.



Cuppa & Catchup for SVH Adults



The voice of adults with single ventricle heart conditions will be heard and disseminated into arenas for change.



**New Text Support Service
for SVH Adults
Lorna - 07751 930638**



Social Media

Sam Jones

Throughout Covid-19, Little Hearts Matter social media has provided a lifeline to families on the half-a-heart journey.

Helping with boredom

Boredom was prevalent during the pandemic, particularly for our young members who were housebound for much longer than their friends. This contributed to a serious decline in their mental well-being. To help combat this, we organised live-streamed events to offer our followers some entertainment in lockdown and to help them feel less alone in their situation. We also found these events to be an effective awareness tool.





Keeping our members informed

In 2021, the LHM team worked flexibly to deliver a virtual open day using Zoom Webinars. It was a new style of working for the team, but an effective way to deliver the information our members needed, and we were able to easily link with international speakers

and organisations

The team also used social media to share the latest Covid-19 updates, reactively as they happened. With so much fear and uncertainty in our membership, it was important to be able to provide members with clear, verified guidance in an efficient way. Social media made that possible.



BRITISH CONGENITAL CARDIAC ASSOCIATION

Empowerment and raising awareness

In 2021, we entered a culture of “the new normal”. People wanted to rush back to their old life, but for our members, it is not that simple. Throughout the year we have highlighted the many challenges our members have been facing.

Our content has covered the lack of educational support, the disruption to their medical services, hidden disabilities, and the need for social distancing. Social media is a microphone that we have used to amplify the many voices of our members.

Helping with isolation

At the heart of what we do is bringing our heart families together to help them feel less alone in their situation. 2021 presented us with a continued need to host online events that allowed Little Hearts Matter members to join easily and privately. These events have worked well as a reminder to our members that they are not alone and are part of the LHM family.





2021 ended with the launch of our new website, offering huge improvements to the accessibility of our support and information. As we move into 2022 and come out of the pandemic, the team looks onward to more growth in our social media services – running in parallel with the needs of our members as they change and evolve.

LHM Achievements

New Condition information with new outcome information

Virtual music event with acts performing from all around the country.
70,000 people watching

New Sibling booklets preparing for a baby with a single ventricle heart condition

We have sent out **32** get-well balloons after Fontan operations

100,000 interacting with
the May Awareness week
'My Normal is Different'

Children in
Need grant to
support the
Head of Youth
Service role

Summer
Event

2021
Virtual Open Day with
international speakers

Over **10,000**
birthday cards

360 in
memory
cards



Treasurer's Report

Peter Groves

This set of abbreviated accounts for the financial year has been extracted from the full set of accounts for Little Hearts Matter 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 significant net inflow of funds in 2021 (circa £69,000) which is split between both general and restricted funds. This net income has arisen despite the challenges of the Coronavirus pandemic which affected most of the year.

In response to the pandemic, the Charity took immediate action to ensure the safety of the charity team and, where service provision created a direct face-to-face risk, the membership. This meant that our flagship open day event was cancelled for the second year running. With the improvements in the middle of the year, LHM was able to hold a summer party which was a great success with many families staying for the whole weekend.

Coronavirus continued to present challenges to LHM throughout the year and the office team have continued to provide a very high level of support to the members and ensure fundraising and governance continued. This effort is despite being short-staffed in the first half of the year. The trustees are thankful for all of their wonderful support.

Despite the challenges, the services of LHM expanded in the year and there is now dedicated support for the adults affected by half a functioning heart. It is wonderful to see the growth of this group reflecting the advances in medical understanding, technology, and techniques in recent decades. The team are planning to also provide wider support for other age groups. This extra support requires new colleagues for LHM and to ensure continuity in the upcoming years the trustees have now designated £75,000 from the general fund to help cover the associated salary costs.

The total incoming resources reduced by circa £40,000 compared to 2020 – this was expected with specific Covid grants not being available in 2021. This drop of £96,000 ‘Covid’ income was partly offset by £30,000 of

extra income from the membership and friends of LHM as well as a further £28,000 from grants and companies. Costs have increased slightly year on year due to the summer party, printing publications, and the cost of fundraising.

The balance sheet shows the financial position of the Charity as at 31 December 2021 remains strong with over £425,000 of net assets, predominantly represented in cash. The Board of Trustees deems this position to be essential due to the ongoing economic impact of Coronavirus and general challenges for the economy as we move into 2022. The budget agreed for 2022 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 monitors the cash position closely to ensure that there are enough unrestricted funds to meet day-to-day demands. At 31 December 2021, the unrestricted cash position represents over five months of funding compared to the budget set for 2022 reflecting the position described above.

Statement of Financial Activities

	Year ended 31 December 2021		Year ended 31 December 2020	
	£		£	
Incoming resources				
Donations	80,351	18.7%	84,372	18.0%
Fundraising	124,357	28.9%	89,276	19.0%
Corporate/grant funders	200,748	46.7%	172,667	36.7%
Covid donations/grants	-	0.0%	95,652	20.3%
Tax refunds	19,600	4.6%	25,493	5.4%
Other	4,906	1.1%	2,576	0.5%
Total income	429,962	100.0%	470,036	100.0%
Resources expended				
Cost of Generating Funds	16,034	4.4%	8,117	2.4%
Charitable activities:				
Salaries	188,205	52.1%	208,278	60.4%
Building costs	47,952	13.3%	48,043	13.9%
Open day/Summer party	22,640	6.3%	6,496	1.9%
Printing/photocopying	19,157	5.3%	8,360	2.4%
IT support	11,251	3.1%	11,922	3.5%
Database	6,162	1.7%	4,359	1.3%
Telephone	5,600	1.6%	3,768	1.1%
Newsletter	5,123	1.4%	3,971	1.2%
Depreciation	4,395	1.2%	5,223	1.5%
Insurance	3,922	1.1%	2,408	0.7%
Gifts	3,307	0.9%	2,881	0.8%
Postage	3,254	0.9%	6,273	1.8%
Bereavement events	2,670	0.7%	143	0.0%
Youth activities	2,239	0.6%	1,328	0.4%
Training	2,005	0.6%	1,363	0.4%
Subscriptions	1,937	0.5%	1,946	0.6%
Travel and hotels	1,655	0.5%	347	0.1%
Pension administration	1,123	0.3%	1,123	0.3%
Public awareness	900	0.2%	2,302	0.7%
Membership roadshow	-	0.0%	1,747	0.5%
Activity weekends	-	0.0%	1,080	0.3%
Other	4,954	1.4%	6,444	1.9%
Governance costs	6,570	1.8%	6,772	2.0%
Total expenditure	361,055	100.0%	344,694	100.0%
Net income	68,907		125,342	
Opening fund balance	356,886		231,544	
Closing fund balance	425,793		356,886	

Balance Sheet

	31 December 2021		31 December 2020	
	£	£	£	£
Fixed assets				
Intangible fixed assets		3,122		-
Tangible fixed assets		4,125		2,172
		<u>7,247</u>		<u>2,172</u>
Current assets:				
Debtors		24,317		13,733
Cash		404,546		349,500
		<u>428,863</u>		<u>363,233</u>
Creditors:				
Amounts due within 1 year		(10,317)		(8,519)
		<u></u>		<u></u>
Net current assets		418,546		354,714
Net Assets		425,793		356,886
Analysed as:				
Unrestricted funds:				
General		179,494		195,261
Designated		75,000		-
		<u>254,494</u>		<u>195,261</u>
Restricted funds		171,299		161,525
		425,793		356,886

Little Hearts Matter

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