



Little Hearts Matter



Annual Report 2016

Supporting every step of the half a heart journey

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Little Hearts Matter exists because of the isolation, fear and lack of understanding created when a child is diagnosed as having only half a working heart. Our vision is to ensure families are able to cope with the diagnosis, treatment and lifestyle challenges created by a single ventricle heart.

Our aims



Alleviate isolation by offering support, friendship and understanding from the time a diagnosis is made, through treatment decisions, hospital care and into life at home eventually introducing parents and patients to other families who have similar experiences and shared concerns helping them to build a network or support.



Reduce fear by offering patients, parents siblings and the extended family a greater opportunity to understand the diagnosis and treatment paths available.



To reduce confusion and a lack of understanding by producing and supplying for free, user focused information that supports and aids understanding from the time of diagnosis, through treatments and into life at home.



To raise a greater awareness within medical, educational, Social and governmental circles of the needs to children, and their families, as they travel through every stage of their lives.

Our achievements in 2016

Brand new website launched and the creation of a Grandparent only Facebook group.



Gained 362 new families



Drama and filming workshop for our young members to produce a new film 'Half a heart half the energy'



Education information booklets produced for supporting children through secondary school and information on accessing support when a child has added educational needs.



Activity weekend held for our youth members



Collaborative working with

- NHS England to represent the voice of families with complex heart conditions.
- The DWP to highlight discrepancies with the provision of DLA information.



Publications sent out in 2015

- 6900 newsletters
- 327 medical filofaxes
- 223 antenatal information packs
- Brand new Fontan booklet



Road-show events in Scotland, London and Cardiff

Chair's report



I am pleased to look back on 2016 as another successful year for Little Hearts Matter. We have seen our membership continue to increase, and our services have reached more families across the whole UK.

Offering information and support to our members remains at the core of our strategy and we remain a strong, member-led organisation.

The range of services offered to our membership continues to grow. We launched a new website for our members and continue to grow our social media channels. We held events across the UK, including our annual Open Day attended by nearly 400 members and held two activity weekends for our young members. To help achieve this, we raised nearly £300,000 last year, with the majority of income coming from donations and fundraising by our members and friends of the charity and without their continued support we would be unable to provide the services we do.

Our Trustee Board sets the strategy

for the charity and continues to monitor our income and costs to ensure we have a clear view of our risks, and are delivering the services for our members. Over two-thirds of the board are members of the charity, ensuring membership remains at the heart of our organisation.

I would like to pass on my thanks to everyone that works for and on behalf of our charity. This starts with the office team, who are the people who manage Little Hearts Matter on a day-to-day basis and are the first point of contact for our members and supporters. We also have a wonderful team of volunteers who offer peer-to-peer support to our members, raise vital funds for us and help run the charity. As this is my last report

before standing down as Chair at our 2017 AGM, I would personally like to thank the Trustees who have supported me over the last 10 years.

Looking to the future, we have a growing membership, and we need to be able to meet their ever more diverse and growing needs. As a charity, we are committed to evolving to meet those needs, and will continue to put member support at the centre of everything we do.

Pete Turner



“

We felt all alone in a big busy hospital ward, reading LHM information packs filled us with hope for the future.

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We felt as though the world was closing in on us, and we were the only ones going through this. But, after reading all the information on the LHM website, we saw there was a massive 'heart' community out there. I realised I wasn't alone and that support was there when I needed it.

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New Chair's report



Becoming Chair of the Trustee Board at such a crucial point in the ongoing discussions over the most appropriate provision of surgery for single ventricle conditions requires strategic navigational skills.

It is imperative that we are able to steer through and beyond some tough challenges that lay ahead, but that we're able to respond to a plethora of fantastic opportunities also.

Last year we launched our new website and this has given the charity a much more visible shop window to help existing and new members, plus the many others trying to find accurate and useful information about living with a single ventricle heart condition.

We're viewed by the medical world as the trusted supplier of information and advice on single ventricle heart disease. Our literature and support packs are solely relied upon by the NHS and they constantly signpost parents to

us for the invaluable support they know we will give.

As a result, the level of visitors to our website has increased month on month, and our aim to ensure it works hand-in-hand with our ever-growing social media presence has also paid dividends as members find more ways to connect and support each other.

Our closed Facebook group allows families to openly and safely talk to other families dealing with the same issues. Our events then give them the chance to chat with each other face-to-face, making life-long friends who are travelling down the same path.

Supporting this even further, we're viewed as the friendly, caring and

knowledgeable voice at the end of the phone to these families and it is the Trustee Board's mission to ensure that we will always be there for them.

With our membership numbers continuing to rise and rise, we're without a doubt filling the void in support and information, but we must ensure our families remain as connected with each other and with the charity as possible.

Looking forwards, the Trustee Board are therefore focussed on investing in the longevity of the organisation. It is our aim to ensure we have the optimum blend of skills within the office team and at Trustee level to strategically drive the charity forward in supporting our members, raising greater awareness and having a clear voice in the key arenas for change.

Our families actively refer to the charity as being their 'rock' and that we 'empower them with the strength to carry on'. It is our responsibility to ensure this strength remains resolute.

Julie Fairman

“

We always feel inspired and empowered by the Open Days. To see parents who truly understand our issues and experiences helps.

”





Chief Executive's report

Over the past 22 years Little Hearts Matter has grown to meet the needs of its ever expanding membership.

New challenges for the children, young adults and their families have always led the development of new support or information tools that answer a question, provide much needed loving care or which seek a response to the fears of the future.

The potential of every young member is compromised by their heart condition, but their condition should never be the excuse that allows others to restrict their potential or their journey to independence. The needs of our young membership play a big part in the building of exciting future services.

Responding to need sits at the very heart of Little Hearts Matter work and should always remain the core and focus of the way that the organisation works. Investing in communication tools, information sources and providing a voice within arenas for change must always be a priority. But in parallel

the charity must also act as a fully accountable business, with a transparent shop window and financial and ethical clarity that informs all of the organisations stakeholders, giving them confidence in the professionalism of the charity.

Keeping abreast of charitable law, governmental law, child protection, data protection and financial safeguarding are all essential parts of running a trustworthy business so must take their equal part in the work of the organisation.

2016 has seen the beginnings of investment in the infrastructure of the organisation with the building of a new website and work done on the staffing and Trustee structure and accountability. 2017 will see more of the same.

Outwardly our members will clearly see our gradual service growth as the charity continues to build to



meet their ever evolving needs but they should be confident that sitting behind every new service there will be investment in the structure, considered and reviewed policy and a strengthening of the resource and funding needed to make sure that the charity will always be there in times of need, fear or loneliness.

Suzie Hutchinson



“

I started feeling most alone when we got home from the hospital. Would this beautiful baby of mine ever make it to adulthood? The worries never go and when they come, the LHM team are always there.

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Youth services



Little Hearts Matter's youth services have continued to expand into 2016, with new opportunities and experiences being offered to our youth members.

Spoon Theory

In 2016, we had an increase of children struggling to balance their energy levels with their day-to-day activities. This was due to their energy levels depleting faster than a child with a full working heart and therefore they are unable to monitor what activities would reduce their energy levels faster than others. This was also found to be an issue within the teaching environment as teachers did not fully understand why our young member's concentration levels were perhaps lower than their classmates.

The Spoon Theory is a concept we introduced to seven of our young members. It is a way to represent an individual's energy levels throughout the day by using spoons. It aims to help people plan and reserve energy for different activities.

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I really enjoyed filming the new LHM DVD about hidden disabilities with LHM. It's always good to catch up with other kids who have hearts like mine, and to work with them to help raise awareness of what life's like with only half a heart. I'm really looking forward to showing it to my teachers.
”

Our seven young members adapted this theory, and instead of the suggested 12 spoons, they discussed that people with a normal heart will have 20 spoons of energy, so children with half a heart start their day with 10 spoons of energy. Our young members produced and starred in a film that aimed to introduce the Spoon Theory and help other children and young adults to manage their energy levels.

It is hoped that this will become an educational tool for our young members to help explain their lack of energy to others. Little Hearts Matter has run a pilot of the adapted Spoon Theory to gather feedback in order to further the concept and increase its engagement. We hope to continue this into and beyond 2017 to reach all of our 526 young members aged 8-18 years of age.

Jasper

“

I am Jasper and I am 12 years old and I have half a working heart.

I wanted to show my teachers and friends in my year about my heart because I thought it would help them understand more about me.

I showed them by using the half a heart, half the energy film that a couple of us made. The result was good, they asked a few questions at the end but not as many as I would have expected. The main questions they asked were “were you born with it?” and “how did you get the condition?”.


After the film people kept telling me how good the film was and were asking me the same questions over and over again. People that sat in my tutor group kept asking me how many spoons I had left as well.

The teachers didn't ask as many questions as everyone else did but I think it helped them and it helped the teachers know how I struggle at school. It tells them to keep a closer eye on me and make sure I get along with other people in my tutor group. It also helped my friends understand to watch out for me.

”







Activity weekend

Thanks to our continued fundraising support, we were able to take 22 young members to our activity weekends, here our young members were able to complete new challenging activities and learn more about their heart.

The aim of these weekends is to reduce isolation within children living with half a heart and also learn more about their heart condition.

Zipper chat and website

Our youth website went live along with the youth forum in which we hope to bring young members from the age of eight to come together as well as share experiences and any worries they may have.

This will especially help the young members who may be unable to travel to our youth events.

Nicole Terry

“

Last year, I had a great time during the Little Hearts Matter activity weekend. My favourite thing about it was when I went on the giant swing, because it was fun and thrilling. I was able to meet other children with the same heart condition as me, which was good.

”

Treasurer's report



The Statement of Financial Activities (SOFA) shows a significant outflow of funds in 2016 (£26,317). This outflow is mainly from the general (or unrestricted) funds. This outcome has arisen due to lower income than anticipated with a year on year reduction of £5,031 whereas higher levels had been anticipated when setting the cost budgets throughout the year.

Even though income reduced by a small amount, the change in source is significant with membership income falling as a percentage of the total from 64.3% to 60.6%. This is despite a 12% increase in members. As LHM looks to replace this income, there is a consequential movement in fundraising costs which have increased by circa £10,000 year on year.

The costs for the year have increased by 2% when compared to the previous year. This was mainly driven by increased salary costs where the Trustees agreed in 2015 to in-source tasks to obtain

a better return on cost. The chart to the right shows an analysis of costs with salaries allocated based on task area. The chart shows that nearly 50% of all costs relate to direct spend on the membership. The governance and running costs provide indirect support to the membership.

The Balance Sheet shows the financial position of the charity as last 31 December 2016. Despite the net outflow described above, the current financial position of the charity remains strong with nearly £150,000 of net assets which is predominantly represented in cash.

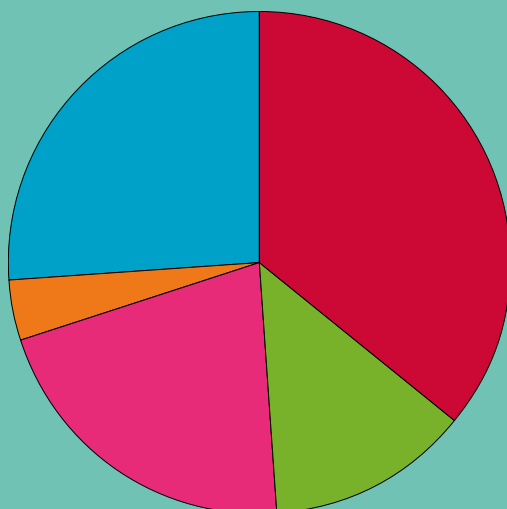
The Board of Trustees monitor the cash position closely to ensure that there are enough unrestricted funds to meet day-to-day demands. At 31 December 2016, the unrestricted cash position represents four months of funding compared to the budget set for 2017 which is within the target range set by the Trustees of three to six months.

Areas of expenditure

Analysis of £345,104 of costs

This set of abbreviated accounts for the financial year has been extracted from the full set of accounts which has been subject to an independent examination. Queries with regards to the document can be addressed to the Treasurer through the Little Hearts Matter (LHM) office or website. A copy of the full set of accounts, including the Independent Examiner's Report, can be provided upon request to the LHM office.

David Baumber



■ **36%**
Service

■ **13%**
Awareness

■ **21%**
Fundraising

■ **4%**
Governance

■ **26%**
Running costs

Statement of Financial Activities

	Year ended 31 December 2016 £		Year ended 31 December 2015 £	
Incoming resources				
Donations	77,257	24.2%	67,716	20.9%
Fundraising	115,785	36.3%	140,624	43.4%
Corporate/grant funders	107,685	33.8%	60,081	18.6%
Tax refunds	12,420	3.9%	22,641	7.0%
Legacy	-	0.0%	20,000	6.2%
Other	5,640	1.8%	12,756	3.9%
Total income	318,787	100.0%	323,818	100.0%
Resources expended				
Cost of Generating Funds	20,024	5.8%	11,107	3.3%
Charitable activities:				
Salaries	182,405	52.9%	173,926	51.7%
Building costs	41,966	12.2%	33,133	9.8%
Open day	21,216	6.2%	23,873	7.1%
Printing/photocopying	10,422	3.0%	16,875	5.0%
Governance costs	9,629	2.8%	10,848	3.2%
Newsletter	9,867	2.9%	11,557	3.4%
Travel	9,291	2.7%	6,843	2.0%
IT support	6,354	1.8%	3,146	0.9%
Activity weekends	4,324	1.3%	2,964	0.9%
Depreciation	3,876	1.1%	5,328	1.6%
Postage	3,117	0.9%	3,798	1.1%
Public relations	3,078	0.9%	4,312	1.3%
Roadshow	2,985	0.9%	-	0.0%
Telephone	2,852	0.8%	3,499	1.0%
Insurance	2,493	0.7%	2,437	0.7%
Training	1,288	0.4%	4,683	1.4%
Office move	-	0.0%	6,817	2.0%
Other	9,917	2.8%	11,402	3.4%
Total expenditure	345,104	100.0%	336,548	100.0%
Net (expenditure)/income	(26,317)		(12,730)	
Opening fund balance	174,889		187,619	
Closing fund balance	148,572		174,889	

Balance Sheet

	31 December 2016		31 December 2015	
	£	£	£	£
Tangible fixed assets		11,762		1,172
Current assets:				
Debtors		7,968		6,330
Cash		136,863		175,035
		<u>144,831</u>		<u>181,365</u>
Creditors:				
Amounts due within 1 year		<u>(8,021)</u>		<u>(7,648)</u>
Net current assets		136,810		173,717
Net Assets		148,572		174,889
Analysed as:				
General funds		128,529		153,259
Restricted funds		20,043		21,630
		<u>148,572</u>		<u>174,889</u>

Little Hearts Matter

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Littleheartsmatter



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