

Little Hearts Matter



**Annual
Report
2017**

**Supporting every step
of the half a heart journey**





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.





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Our Achievements in 2017

Activity weekend held
for the Youth Group.



Participated in two
hospital transition
events.



Youth member events
held at the zoo and a
gaming exhibition.



House of Lords event
held to promote the start
of the Half a Heart, Half
the Energy project.



15,316

Number of Facebook
followers.



534

New full members
gained.



115

People attended our
first memorial walk.



In 2017 the following closed Facebook groups were created -

- adults with single ventricle heart disease
- parents of children going through hospital transition.

Total number of members in our closed Facebook groups

836



Membership and youth membership questionnaire circulated.



New booklets produced in 2017 'Transplantation', 'MCT diet' and 'Your guide to university with half a heart'.



Highly Commended in the 2017 BMA Patient Information Awards for the Fontan booklet.



Patient information awards
Highly commended

Worked alongside the Newcastle, Birmingham and Great Ormond Street Hospital teams on a variety of research projects.

Worked with NHS England to represent the voice of families with complex heart conditions.

Brand new data controls put in place. All members consent to contact them sought.

Funding for a new charity CRM system awarded from Morrisons Foundation.

Chair's Report

Julie Fairman



2017 was another busy and challenging, yet very successful year for Little Hearts Matter. With good income achieved following a strategic change in focus made at the beginning of the year, the charity has also built firm foundations for growth and development as we move forwards.

However, over the past 12 months, we've equally seen one of our biggest rises in membership alongside a heightened buzz in communication and activity between families, and with the LHM team.

Whilst it's always a delight for us to welcome more members into the LHM family, both these increases stem from the ongoing lack of reliable information, support and guidance available for families struggling to cope with living with a child with a congenital heart condition. This growth has therefore brought new challenges for us, especially in light of the fact that our services have never been more

needed than they are now.

With the uncertainty caused by the recent NHS England service review, changes to the process for applying for benefits and a general reduction in the support available to children at school especially, families have felt more isolated too and it has been our mission to ensure LHM reaches out to and helps as many families across the whole of the UK as we can.

Offering information and support to our members therefore remains at the core of our strategy. However, with the way charities hold data for communicating with their members coming under intense scrutiny recently, as a strong, member-led

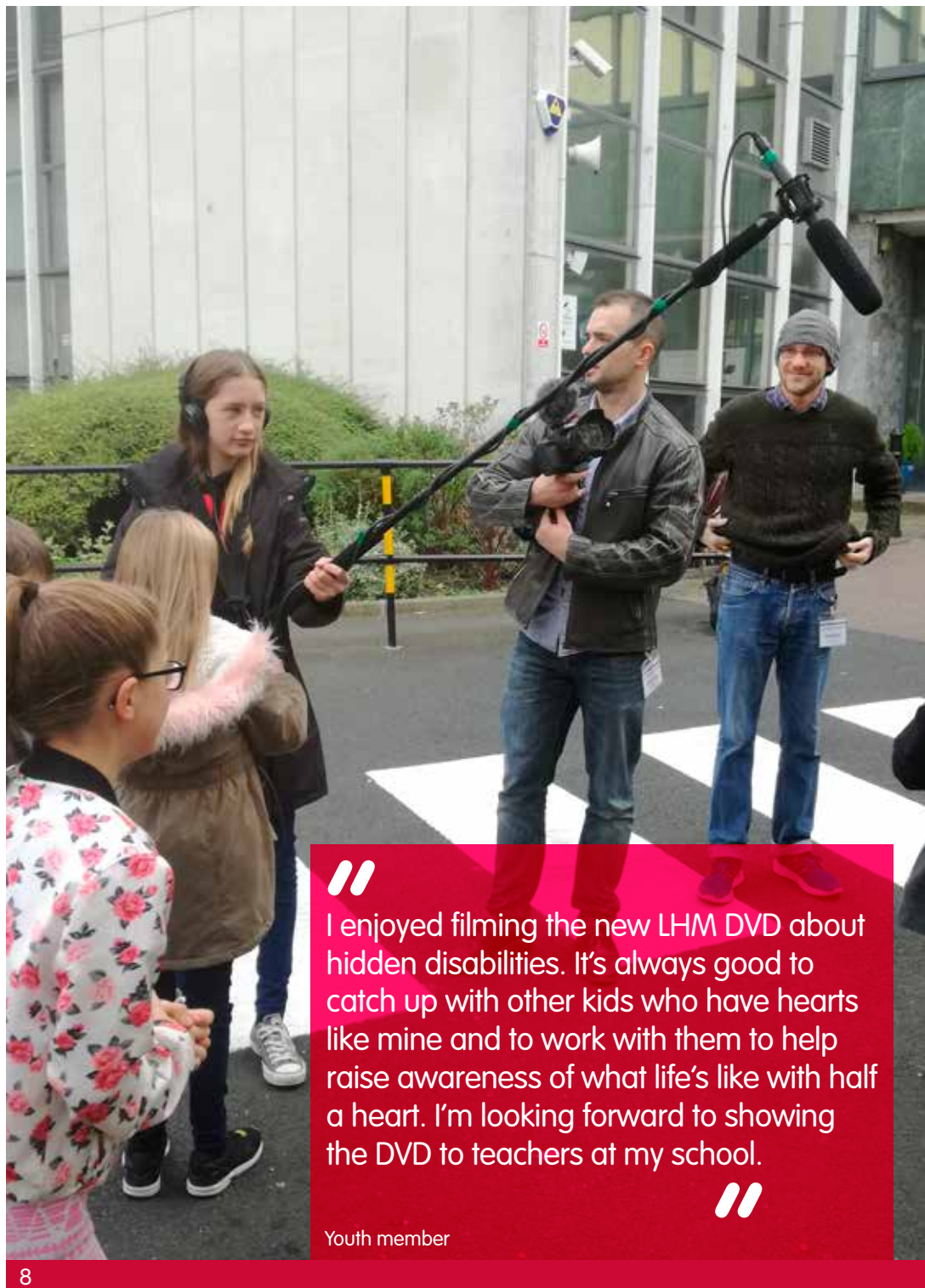


The LHM community gave me an insight in to the life of other children with single ventricle conditions. Initially everything was so unknown to me, but being able to read about other families' experiences really helped and gave me so much hope.



Parent member





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I enjoyed filming the new LHM DVD about hidden disabilities. 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 half a heart. I'm looking forward to showing the DVD to teachers at my school.

//

Youth member



organisation we decided to be one of the first organisations of our kind to embark on a massive data project to obtain clear communication consent from our members.

If this significantly important activity wasn't enough, over the year we also set out to introduce a number of new initiatives that would not only help our members, but also inform the medical profession and our growing bank of supporters about the challenges our families face.

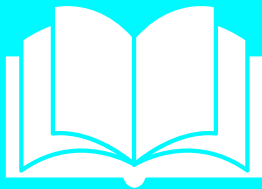
We kicked off the year with an event at the House of Lords where we launched our new Spoon Theory to help people understand our children's need to manage their energy levels. This was swiftly followed by our annual Open Day and AGM which again proved so popular for members to come together, learn and share.

Alongside a range of new booklets, an activity weekend for our youth group, and new youth forum created plus almost 3500 newsletters sent out, plus many more activities, it's

been a busy year for the office team and I'd personally like to thank Suzie and her wonderful staff for keeping on top of all our wishes and wants. Without our members' support and fundraising, none of these activities could be undertaken, but without our passionate team, nothing would be delivered.

Facilitating this, our Trustee Board continues to set the strategy for the charity and to monitor our income and costs to ensure we have a clear view of our risks, and are delivering the services for our members. With over two-thirds of the Board being members of the charity, we're also very clear about how we can ensure membership remains at the heart of our organisation.

I'm looking forward to another challenging yet rewarding year ahead. 2019 also marks our 25th birthday and there's lots to plan over the coming months so that we can all participate in marking this very special anniversary.



Publications sent out in 2017

3500 newsletters

184 medical filofaxes

127 antenatal information packs

Chief Executive's Report

Suzie Hutchinson



Each new stage feels more challenging than the last - the diagnosis before birth was extremely challenging but then the first surgery was worse because she was actually here and we loved her so much; then the second surgery was even harder because we knew her so well and loved her even more by then, and now, facing her third surgery, it's even more challenging because we know her so much better than before and love her even more still. And the day-to-day life and looking to the future is so challenging because there are so many unknowns. Will she be able to do the things she wants to do? Will she be able to achieve qualifications? Will she be able to do a job she enjoys and earn money and live independently? What will life be like for her as an adult? Will someone love her



enough to marry her and care for her even though she has difficulties and the future is uncertain? How long will she live?



Parent member

Like many Little Hearts Matter members, this parent, and the others quoted here, is travelling the roller coaster journey that is life when a child has half a working heart. There are good times, holidays, momentous birthdays and periods of near normal life but in between there are lots of ups and downs and a constant need to fight for every added service.

For many families, this creates immense pressure and stress on their lives.

“It’s a roller coaster ride of emotions.”

Parent member

Little Hearts Matter works to be there for every step of that half a heart journey, mainly offering support, information and guidance at the most stressful times.

It is clear from the work we do with families everyday, from their comments on our closed member Facebook sites and from the results of

our recent membership questionnaire that not all members find us at the beginning of their journey or are unaware of some of our specialised services, so a big part of our work over the next year will be to improve awareness and communication.

Through roadshows to hospitals, events spread throughout the UK, an increased social media presence and joint working with other third and statutory organisations we hope to make it easier for families to find us and to know what support is available. Ultimately, in our 25th year, we hope to raise a greater awareness of our work and the congenital heart families’ journey with the general public.





The stress mentioned previously comes from worries of an unknown future but also the every day battles to achieving the best support, treatment and care that every child needs.

“Sometimes you feel you have to fight for whatever everyone else gets without a fight.”

Parent member

Over the next year the charity hopes to invest in the services team enabling the organisation to offer more support with benefits and to help families access all parts of education. Offering advocacy and

empowerment to initiate change is very important; often families do not have the energy to fight every fight themselves. Little Hearts Matter can help by taking some of the load.

The mental health of our families but most importantly the young members struggling to live their lives as fully as their condition will allow, has come to the fore over the last year. More young people are being referred to the charity as they battle with their disability. A key focus for the development of the charity’s youth work is to offer more youth events closer to home and to strengthen social media and website forums.

To empower young members to contribute their voice within their own





care and within arenas for change. To create a network of support services that offer opportunities for young members to access counselling and support in their own community. Reducing isolation, fear and lack of understanding is key to ensuring that our young members are able to reach their potential.

Our members have requested that we spend more time linking into research. It can be an important way to help with members' fears of the future, research often offers explanations about care and a view into the future needs of their patients. Medical teams are looking for not only answers to medical questions but also seeking ways to maximise

the outcome and quality of life for the children and young adults they treat.

Being able to share the results of research can help families gain more confidence about the future for their children.

Above all, throughout the next year the charity will continue to provide the support, care and friendship that our members seek as part of the Little Hearts Matter family.

“Fantastic support I received when I was at rock bottom. Thank you.”

Parent member



Going home to the unknown with little support, as unaware of LHM and unsure as to what the diagnosis meant as it was a postnatal diagnosis, creates ongoing mental health implications and increased anxiety for the child as well as the family.



Parent member





“

I had a fantastic time, I made new friends who had heart problems also. The staff were really helpful and very encouraging. I can't wait for next year.

”

Youth member



Youth Report

Lexie Katsaitis

Little Hearts Matter's youth services are evolving and expanding. The services provided and created in 2017 were no exception. Ideas for new communication tools and services have been planned, some already implemented, with the overarching aim of ensuring that the youth voice is heard and ultimately able to influence how the charity's youth services move forward.



YOUTH EVENTS

There were multiple youth events that ran throughout 2017. These served to not only create a safe space where our youth members could have fun and broaden their horizons, but enabled them to create bonds and tackle isolation and their fear of the unknown.

The PGL activity weekend offered 15 young members the opportunity to experience time away together, setting and achieving new challenges, the chance to explore their heart condition and seek solutions to

hurdles with their fellow heart friends. They also had a chance to study the 'Half a Heart, Half the Energy project' which empowered them to balance their energy needs and explain to others how important balancing their daily energy allowance is. It was great to see them calculating the spoons it would take to walk to the canteen and how many spoons might be gained when they ate breakfast.

The Twycross Zoo visit was a great event where some of the youth members were able to get up close and visit some great animals as well as get to know their fellow LHM youth members.

One youth member came because he loves Meerkats but ended up befriending other teenagers and linking with them through social media. This was his very first LHM event.



Different young people need different opportunities to meet and explore their heart conditions and the challenges that they all face.

Youth member



and young adult members to communicate with each other, share their stories and explore their fears and concerns. All these sites are manned by the LHM team to ensure that difficult questions can be supported and safe responses can be ensured.

The youth team are also able to talk together in the Youth Forum, a group of young members who have put themselves forward to review publications and help set the direction of the youth services.

YOUTH QUESTIONNAIRE

THE EGX GAMING EVENT

Mini youth events were created this year where youth members with the same hobbies could experience a day out, meet each other and attend an activity they enjoy. This convention was informative and fun, the boys that attended tried new and previewed unreleased games as well as learnt about possible career options in this field.

COMMUNICATION

Young people use social media to communicate so the LHM team have worked to evolve a number of different LHM communication tools to encourage teenage

A youth questionnaire that ran parallel with a full member questionnaire was distributed to enable LHM to identify the voice of the youth and how to shape youth services moving forward. Our young people were able to comment on topics that were surfacing regularly including education, sports and exercise and stress management.

This, alongside the full member questionnaire, brought to attention the need to ensure that youth events were accessible throughout the UK, as well as the work that needs to be done to support and signpost any stress and other mental health queries. This is something we will concentrate on in 2018 with an increased online presence as well as working closely with outside organisations.



“

I would just like to get together and speak to other teens with heart conditions because I very rarely get to meet up with others because of where I live.

”

Youth member



Fundraising Report

Ian Carr



In 2017, we faced a number of challenges in fundraising and had an overall successful year in managing to raise funds to continue to grow the organisation and provide more services for our families.

We also launched our campaign called 'Open Doors' an initiative aimed at securing corporate support.

There's always more we can do though.

When I started my role as Fundraising and Marketing Manager in May 2017, it was immediately obvious to me what a fantastic affinity there was to the charity from the families of the children with half a heart that we support.

It was also apparent how the charity needs to grow with a greater reliance on the services we offer. This growth is only possible if we grow the income of the charity.

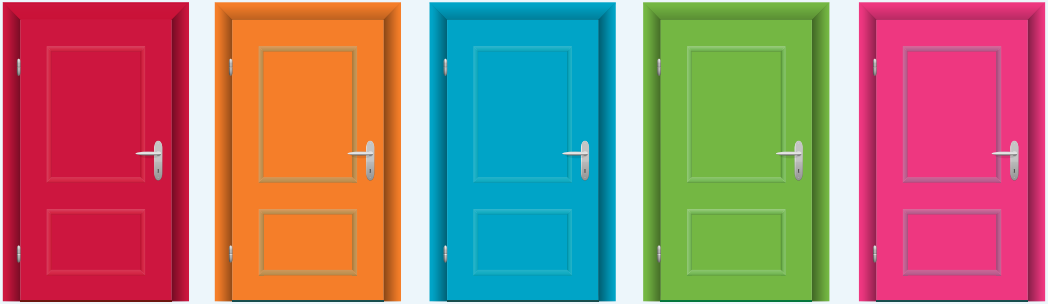
I pinpointed a major area of potential growth as corporate fundraising. As a small charity, we often find

ourselves not being considered by businesses for their charity of choice. It is a very competitive market and therefore we need to give businesses a specific reason for any partnership with LHM.

It was with this in mind that we launched Open Doors. The aim of this campaign was to reach out to members and their work connections and to introduce Little Hearts Matter to the businesses they work for or with.

Open Doors manifested itself in a month of marketing using a variety of messages, real life examples, video, social media posts and emails that

DO YOU HAVE THE KEYS TO OPEN THESE DOORS?



If you work for a business then you can help Little Hearts Matter.



Thousands of people have donated to LHM over the years and if you are one of those people on behalf of everyone at LHM thank you so much. Your support gives people like me a chance at life, but they need help to continue. We are looking to partner with more companies to be able to provide support and care to families affected by congenital heart disease.



Youth member



“
 My son, Sean and his partner, Lauren recently gave birth to my first grand-daughter Poppy. Sadly Poppy passed away, but LHM were fantastic and have offered a support network that we didn't know existed. We at Kavanagh's just wanted to thank the charity and do our bit by giving back.
 ”

Grandparent member



asked members and supporters to 'open the doors' to companies of any size in any industry by contacting LHM with details of the business they work for or know.

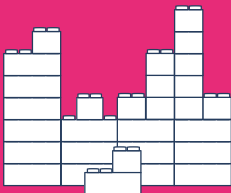
The responses to start with were slow, but then a video message from Andrew, one of our members, showing where the money would go and how it would help children like him boosted the campaign and number of responses significantly. It was apparent that a message coming from a beneficiary of the charity made people realise how important corporate partnerships are to the future of Little Hearts Matter and people like Andrew.

At the conclusion of the campaign we received 18 links to businesses and managed to secure five corporate partnerships from the campaign.

I see Open Doors as very much the building blocks for corporate fundraising and having secured these partnerships, to fulfil the needs of the members, there is a necessity to continue to secure more in 2018 and beyond. Building from here will therefore see a continued dialogue and marketing effort from us towards its members to ensure that they

continue to share details and put LHM forward when it comes to business and LHM working together.

Now we've opened some doors, I've really embraced the corporate partnerships we currently have and thoroughly enjoyed exploring how we can make the relationships as mutually beneficial as possible. I now just want to open even more in 2018!



In 2017 we rebuilt the fundraising strategy and team.

Treasurer's Report

David Baumber



2017 has continued to see the strong financial support the membership gives to the charity.

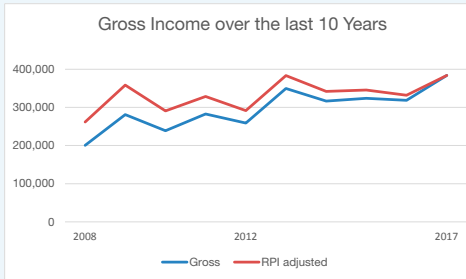
This set of abbreviated accounts for the financial year has been extracted from the full set of accounts which has been subject to an independent examination. Queries with regards to the document can be addressed to the Treasurer through the Little Hearts Matter (LHM) office or website. A copy of the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

The Statement of Financial Activities (SOFA) shows a significant inflow of funds in 2017 (£33,626) and is split between both general and restricted funds. This outcome has arisen

due to exceptional levels of income during the year combined with the prudence of the charity to spend money where it will add the most value in support of the membership.

The gross income for LHM increased by 20% year on year and this has been reflected across all areas. Direct income from the membership increased significantly both as an absolute value (£60,000), but also as a proportion of the total income (66.1% in 2017 versus 60.6% in the previous year). LHM has always been an organisation close to its membership, and friends, and this level of donation and fundraising

reflects the appreciation of the services provided.



The chart above shows the income growth over the last ten years on both an absolute cash (gross) basis in blue and then also on an alternative basis where the effect of inflation has been taken into account (the red line). On the gross basis the income has increased by 91% over the last ten years and taking inflation into account, the growth has been 47%.

The costs for the year have increased by just 2% when compared to the previous year. This was mainly

driven by the introduction of the new Workplace Pension arrangements. Other costs incurred have then varied as LHM tried to focus the services as required by the membership.

The Balance Sheet shows the financial position of the Charity as at 31 December 2017 and this remains strong with over £180,000 of net assets which is predominantly represented in cash. The increase in restricted funds is due to funds received for the new membership database and these will be spent over the next three years.

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 2017, the unrestricted cash position represents six months of funding compared to the budget set for 2018 which is at the upper end of the target range set by the Trustees of three to six months.



“
 Lovely, poignant morning spent with special friends old and new, remembering our precious heart angels at the National Arboretum.
 ”

Parent member

Statement of Financial Activities

	Year ended 31 December 2017		Year ended 31 December 2016	
	£		£	
Incoming resources				
Donations	98,795	25.7%	77,257	24.2%
Fundraising	154,878	40.3%	115,785	36.3%
Corporate/grant funders	113,359	29.5%	107,685	33.8%
Tax refunds	15,188	4.0%	12,420	3.9%
Other	1,690	0.4%	5,640	1.8%
Total income	383,910	100.0%	318,787	100.0%
Resources expended				
Cost of Generating Funds	18,222	5.2%	20,024	5.8%
Charitable activities:				
Staff costs	185,299	52.9%	182,405	52.9%
Rent and service charges	40,093	11.4%	41,966	12.2%
Open day	20,947	6.0%	21,216	6.1%
Travel and hotels	9,421	2.7%	9,291	2.7%
Printing/photocopying	8,833	2.5%	10,422	3.0%
IT support	7,709	2.2%	6,354	3.2%
Newsletter	5,918	1.7%	9,867	2.9%
Recruitment/temporary staff	4,605	1.3%	2,079	0.6%
Activity weekends	4,368	1.2%	4,324	1.3%
Depreciation	3,851	1.1%	3,876	1.1%
Postage	3,478	1.0%	3,117	0.9%
Telephone	3,238	0.9%	2,852	0.8%
Public awareness campaigns	2,712	0.8%	3,078	0.9%
Training	2,643	0.8%	1,288	0.4%
Pension administration	2,515	0.7%	-	0.0%
Gifts	2,506	0.7%	1,736	0.5%
Bereavement events	2,444	0.7%	-	0.0%
Other	12,269	3.5%	11,580	3.4%
Governance costs	9,213	2.6%	9,629	2.8%
Total expenditure	350,284	100.0%	345,104	100.0%
Net income/(expenditure)	33,626		(26,317)	
Opening fund balance	148,572		174,889	
Closing fund balance	182,198		148,572	

Balance Sheet

	31 December 2017		31 December 2016	
	£	£	£	£
Tangible fixed assets		9,260		11,762
Current assets:				
Debtors		6,834		7,968
Cash		176,729		136,863
		<u>183,563</u>		<u>144,831</u>
Creditors:				
Amounts due within 1 year		<u>(10,625)</u>		<u>(8,021)</u>
Net current assets		172,938		136,810
Net Assets		182,198		148,572
Analysed as:				
General funds		140,447		128,529
Restricted funds		41,751		20,043
		<u>182,198</u>		<u>148,572</u>



Some of our Activities







Little Hearts Matter

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Littleheartsmatter



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