



Little Hearts Matter



Annual Report 2018

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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A young girl with brown hair, wearing a pink and blue floral hospital gown, is sitting in a hospital bed. She is holding a large, round, yellow balloon with a black smiley face. The background shows a hospital room with medical equipment and a purple chair.

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Chair's Report

Julie Fairman

There's no denying that 2018 proved to be a challenging, yet extremely fulfilling year for Little Hearts Matter.

Ongoing uncertainty regarding Brexit made for much choppy waters with the impact of both reduced donations and support being felt across the entire third sector. People especially became more conscious of protecting their own finances and carefully scrutinising the amount of physical time they could give, whilst corporate organisations increasingly, and quite rightly, concentrated on their bottom line.

As a result of this backdrop of uncertainty, Little Hearts Matters' Board of Trustees and CEO worked hard to balance the charity's finances over the 12

months whilst also continuing to supply the services our members so desperately needed. This was no easy task, however our ability to remain agile and quick to respond enabled us to safely navigate our way through such an unpredictable landscape.

Agility therefore remains a core necessity for any charity these days, but so too is the need for a clear and resolute purpose which enables organisations to not only intrinsically respond to the very heartbeat of its membership but also provide solid foundations on which services can be evolved over time.



With the support of Little Hearts Matter and the group of parents behind it, I have managed to get through every stage of Elijah's ups and downs. Just to be able to share with like-minded people, the highs and lows of caring for a child with a heart condition, finding out what we can apply for, what help we can get and where to go if we need to talk to someone has been a saving grace.

Our purpose has never wavered in our 25 year existence and it remains firmly on supporting families at every step of the half a heart journey, filling the void that is the isolation, fear and lack of understanding when a child is diagnosed with having half a working heart.

As a member-led organisation, it remains our mission to always listen to what our members need, and these needs have never been so desperate as they are now. Specifically, the fall out of years of NHS England reviews still hasn't delivered the optimum service we so desperately need, and the Department for Work and Pensions process changes have left far too many families struggling with their DLA and PIP applications.

We've therefore seen our ever-growing membership expand still further as families reach out for the help and support that Little Hearts Matter is now so well known for being able to provide. Our strong social media presence has become an important channel for signposting them to the expert

advice and guidance that our passionate office team provides each and every day, and our participation in the key arenas for change continues to enable our members' voice to be heard and understood.

However, we're also seeing an increasing demand for support and services coming from our teenage and young adult members, and as a result, we deliberately set out to shape more focused services for this group. These included a series of activity weekends around the country, a specific University information pack as well as the introduction of a dedicated text helpline that gave them a place to flag their concerns and share their worries about living with their conditions.

For us as a Board, it really is another marker of how far we've 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.



We're also seeing an increasing demand for support and services coming from our teenage and young adult members

486

of our members
are teenagers
and young adults
with half a heart



Chief Executive's Report

Suzie Hutchinson

Third sector organisations are at the very heart of society, filling the holes left by statutory services and the changes in society that mean local communities are no longer there for people in distress.

In response, Little Hearts Matter has shaped a community of its own, a family of members from around the UK linked by their shared feelings of isolation, fear and lack of understanding, created because their children have half a working heart. We work to fill the holes or at least help families to hurdle them so that they can travel the half a heart journey feeling cared for, informed and supported.

The charity has a positive track

record. 2019 brings with the charity's 25th Anniversary, 25 years of slowly building, always with the same core focus to help anyone travelling the half a heart journey. 25 years ago we had to fight for the best treatment for newborn babies, now that many of the children survive we are looking to promote their voice because their condition is never cured but remains invisible which sadly means no-one understands their ongoing needs.



Belonging to a charity specifically supporting single ventricle hearts has been amazing. It has helped us to understand Amelia's condition and its limitations, given us insight into what her future might hold and introduced us to other heart families who are becoming lifelong friends.



Over the last year the charity has grown its membership by 12%. Much of this has come from our broader reach through social media and a growing need, in all age groups, for expert support to access individualised help in school, access to benefits that help young people to gain and maintain their independence or support for the growing mental health issues only now recognised

in young people living with a long-term disability. All of Little Hearts Matter services are growing but we also have calls to create new support. Some for our younger children who don't understand their heart condition but also the growing need to serve our newly adult members who are always the pioneers teaching us what will be needed in the future.





We have seen a
growing need in
all age groups
for expert
support.

16,514

Facebook followers

1,172

members use our
Facebook support
groups to support
and chat to
each other



Youth Services Report

Lexie Katsaitis

During the past year the Little Hearts Matter's youth members have grown, as have they - with that growth comes new challenges and demands that our service is having to evolve and grow to meet.

The fear, lack of understanding and isolation is still prevalent in this community of young people but how they present may be changing so we need to grow alongside this change to ensure that every single youth member is supported.

Creating a safe place where our youth members can access one-to-one support, peer support, lifestyle and medical information they can access and comprehend as well as celebrating their

successes and providing a platform so their voices can be heard has been the focus.

2018 saw two great youth residential events and a successful youth workshop programme at the annual LHM open day.

This year we introduced a new residential youth event at The Eden Project in Cornwall. 13 youth members came along from all over the UK, including quite a few new youth members that hadn't been



I had a great time on this trip meeting a few friends, some of whom I have stayed in contact with and have seen at future Little Hearts Matter events.

to a LHM youth event before which was great to see. The 13 youth members that came included young people with single ventricle heart conditions as well as their brothers and sisters. A great chance for siblings to understand the heart condition more.

This was a great opportunity for our youth members to visit an absolutely beautiful place and experience different climates and walk around with their peers, making great friendships. Games were played, quizzes were taken and great food was eaten by all. During the evening the youth members had time for reflection and learnt about the energy project, which looks at monitoring their energy levels and is a great way of explaining to others how their energy is affected by life with a single ventricle heart.

Some of our youth members created a vlog of their experience which is now on the Little Hearts Matter YouTube page. All in all a great success and lots of fun.

We took 20 of our youth members to the PGL Centre in Lincolnshire. Detailed planning ensured that both our heart affected young members and their siblings could enjoy the weekend and challenge themselves whilst being and feeling safe. We decided to

extend the activity weekend to three nights this year, so that the guys had more time to relax and recharge. This proved to be a great idea as energy levels were sustained and we've been told that recovery time was substantially shorter this year. This also gave the guys longer to create bonds and lasting friendships. Friendships which are still going via social media.

Much like the previous year, the giant swing was a favourite as well as the quad biking, a new addition this year. Our youth members were able to try new challenges even if they had been to our activity weekends before!

This year we blocked out an entire afternoon for energy project sessions, anti-bullying chats and filming for an up and coming music video that we're particularly excited about. The energy project was a big hit for those young members that hadn't used it before. In fact they are in contact with us and using their 'spoons' to tell us all about their energy.

The 2018 Open Day proved successful with 25 youth members aged 11 and above attending multiple workshops which included talks on lifestyle, careers, mental health and medical topics. Multiple outside agencies ran a workshop



My name is Imaan, I'm 13 years old with a Hypoplastic Right Heart condition.

PGL 2018 was one of my favourite experiences... we did everything from quad biking to campfires. I met many amazing, spirited people. People who could really relate to me and understood what I go through.

When I arrived at the camp, I was welcomed by a young girl, with the same condition as me, called Daisy - by the end of day one we were inseparable! Later on came Sophie... the three of us had so much in common - birthdays in March, crazy Harry Potter fans and similar medical problems.

When our parents left we got talking... the chemistry was great, we got on so well. We talked about medication, how others react when they know you have half a heart and the difficulties and differences with our condition.

The next three days were packed with exciting activities. High swings, archery, rifle shooting and dave! Quad biking was one of my favourites, but nothing can beat S'mores and cheesy songs at the campfire!

Overall my experience at Caythorpe PGL was incredible!



in their expert area which was a huge benefit to our member including The Rainbow Trust - a great charity supporting the siblings of a child with a terminal illness.

The LHM Zipper Facebook page is being used more regularly to give information and spotlight achievements made by our youth members. Some of our youth members are now taking a more active part in our social media in particular the YouTube channel. We have uploaded multiple youth created vlogs made at the Eden Project as well as a vlog created by young people about life at university.

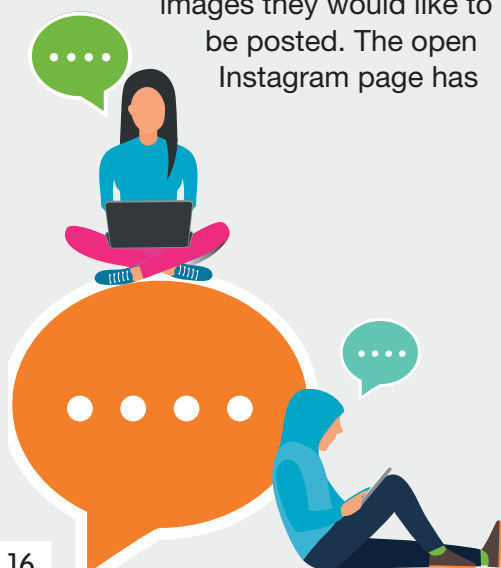
The Instagram private group is proving to be successful in terms of more young people making contact as well as sending in images they would like to be posted. The open Instagram page has

received 188 more followers including members and outside organisations thus spreading awareness.

The text support service was launched and has proven successful. This gives our youth members a point of contact with the youth leader out of school hours.

The Zipper Zone chat on the website is proving popular with our youth members and multiple new members are discovering this service.

2018 saw the start of the new Youth Forum. We had seven young people become members. The role of the Forum is fourfold: to be representative of the young members of LHM, to review information that LHM produces for young members, to respond to legislation changes and other relevant governmental, social, medical and educational developments that affect the youth membership and to contribute ideas for the improvement of support, education and events for LHM youth members. Finally our members have been part of a Youth Readers panel and highlighted social skills, friendships and bullying as topics of interest moving forward as well as contributing to videos.





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The spoon theory is an amazing way for us and others to understand how much energy we have left and how to manage our daily tasks. The video helped me realise that what I'm experiencing in getting tired a lot is normal with people with half a heart. I've also learnt how to manage my spoons and how to replenish them. The workshop was incredibly helpful and the spoon theory pack is going to be very useful in day to day life.

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Fundraising Report

Ian Carr

2018 saw LHM grow in so many ways. There are more members, social media followers, more (and better attended) youth events and a higher number of staff and volunteers to support families on their half a heart journey.

This is great and the pattern of growth shows no sign of slowing any time soon. However, the charity wants to do even more as greater numbers of children survive; the number of people needing our support grows too.

I may be stating the obvious here, but before we can grow with the needs of the members, we need the money to be able to do so. As a small (albeit growing) charity with no statutory or government funding, we start each year

from scratch. We also have a responsibility to our members to only spend funds that we receive and starting from zero and trying to raise approximately £400,000 a year means we have to be creative in raising the profile of our cause in order to get to this somewhat daunting figure.

I am particularly keen to develop what we started to see signs of in 2018 and that is a mixed portfolio of income. What I mean by this is



It was a real honour to run for LHM. My niece was diagnosed with Pulmonary Atresia with VSD and the charity has been a huge support to her and our family.

we need to resource funds from a wide variety of sources.

Previously at Little Hearts Matter, we have relied heavily on the generosity of the families we support, their communities and fundraising efforts such as runs, cycles, bake sales and events from people affected by single ventricle heart condition have allowed us to provide 25 years of help.

However, this is not sustainable and if we are to grow, we need to vary the income we receive. These other sources include corporate partnerships, grants and trusts,

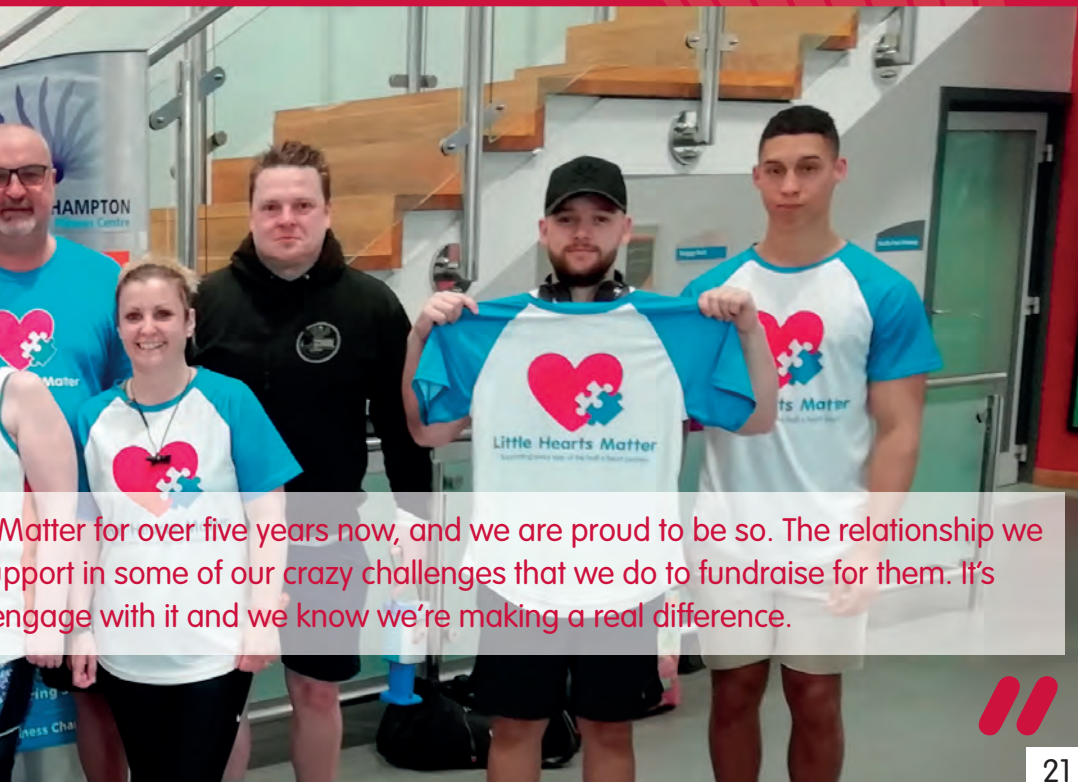
legacies, community fundraising without a direct link to LHM, regular giving... the list goes on and the possibilities plentiful!

2018 saw us develop and significantly increase our grants income thanks to the investment made in our Grants and Trusts Fundraiser and we also enjoyed some good corporate partnerships; particularly Mortgage Bureau, money.co.uk and Shoosmiths. In the future I'd like the split to be more evenly spread and I will be working throughout 2019 and beyond to ensure that



We've been charitable partners with Little Hearts Matter and the support we have with them is fantastic and we always get so much out of it. It's great to help a charity like this as the staff really e

this mixed portfolio continues to show less reliance on community fundraising. If we're able to do this, it allows us to have greater sustainability and a more secure footing from which to grow the charity. Ultimately, that is mine and the charity's aim and to be part of seeing LHM grow further and thrive into another 25 years would be amazing.



Matter for over five years now, and we are proud to be so. The relationship we support in some of our crazy challenges that we do to fundraise for them. It's engage with it and we know we're making a real difference.





Treasurer's Report

David Baumber

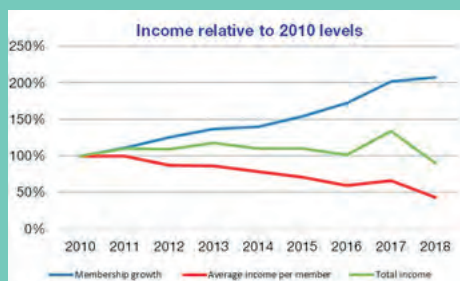
This set of abbreviated accounts for the financial year has been extracted from the full set of accounts which has been subject to an independent examination.

The Statement of Financial Activities (SOFA) shows a slight outflow of funds in 2018 (£24,875) and is split between both general and restricted funds. This outcome follows the net inflow of funds seen in the previous year (£33,626) as these surplus funds were utilised as planned.

The gross income for LHM decreased by 13% year on year with the fall mainly seen in the donations and fundraising by the membership.

The chart to the right shows how the membership income (fundraising

and donations) has changed since 2010 along with the increase in membership and average income per member. Even though the absolute value of this income has remained consistent, the average per member has fallen significantly.



Income from corporate and grant bodies (not on the graph) has increased by 324% over the same period (from £33,000 to £140,000). Many of the charity's corporate relationships have started with an introduction from the membership.

The costs for the year have increased by just 3% when compared to the previous year. The increase in cost primarily relates to the set-up of a new membership database, the funds for which were received in 2017.

The Balance Sheet shows the financial position of the charity as at 31 December 2018 and this remains strong with over £157,000 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 2018, the unrestricted cash position represents four months of funding compared to the budget set for 2019 which is within the target range set by the Trustees of three to six months.

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.



This was our first open day visit. It has been a fantastically supportive, life-affirming and empowering experience. Thank you! for all your time, energy, compassion and hardwork.

Statement of Financial Activities

| | Year ended 31 December 2018 £ | | Year ended 31 December 2017 £ | |
|---------------------------------|-------------------------------------|---------------|-------------------------------------|---------------|
| Incoming resources | | | | |
| Donations | 75,410 | 22.4% | 98,795 | 25.7% |
| Fundraising | 95,529 | 28.6% | 154,878 | 40.4% |
| Corporate/grant funders | 139,768 | 41.8% | 113,359 | 29.5% |
| Tax refunds | 20,910 | 6.3% | 15,188 | 4.0% |
| Other | 2,865 | 0.9% | 1,690 | 0.4% |
| Total income | 334,482 | 100.0% | 383,910 | 100.0% |
| Resources expended | | | | |
| Cost of Generating Funds | 17,416 | 4.8% | 18,222 | 5.2% |
| Charitable activities: | | | | |
| Staff costs | 195,325 | 54.4% | 185,299 | 53.0% |
| Rent and service charges | 41,873 | 11.7% | 40,093 | 11.4% |
| Open day | 21,208 | 5.9% | 20,947 | 6.0% |
| Database | 11,986 | 3.3% | - | 0.0% |
| IT support | 9,916 | 2.8% | 7,709 | 2.2% |
| Printing/photocopying | 9,532 | 2.7% | 8,833 | 2.5% |
| Activity weekends | 6,738 | 1.9% | 4,368 | 1.2% |
| Travel and hotels | 5,163 | 1.4% | 9,421 | 2.7% |
| Depreciation | 4,806 | 1.3% | 3,851 | 1.1% |
| Newsletter | 3,987 | 1.1% | 5,918 | 1.7% |
| Telephone | 3,750 | 1.0% | 3,238 | 0.9% |
| Postage | 2,844 | 0.8% | 3,478 | 1.0% |
| Gifts | 2,273 | 0.6% | 2,506 | 0.7% |
| Bereavement events | 1,949 | 0.5% | 2,444 | 0.7% |
| Training | 1,378 | 0.4% | 2,643 | 0.8% |
| Pension administration | 1,123 | 0.3% | 2,515 | 0.7% |
| Recruitment/temporary staff | 648 | 0.2% | 4,605 | 1.3% |
| Public awareness campaigns | - | 0.0% | 2,712 | 0.8% |
| Other | 8,482 | 2.4% | 12,269 | 3.5% |
| Governance costs | 8,960 | 2.5% | 9,213 | 2.6% |
| Total expenditure | 359,357 | 100.0% | 350,284 | 100.0% |
| Net (expenditure)/income | (24,875) | | 33,626 | |
| Opening fund balance | 182,198 | | 148,572 | |
| Closing fund balance | 157,323 | | 182,198 | |

Balance Sheet

| | 31 December 2018 | | 31 December 2017 | |
|---------------------------|------------------|-----------------|------------------|-----------------|
| | £ | £ | £ | £ |
| Tangible fixed assets | | 7,387 | | 9,260 |
| Current assets: | | | | |
| Debtors | | 9,913 | | 6,834 |
| Cash | | 150,896 | | 176,729 |
| | | <u>160,809</u> | | <u>183,563</u> |
| Creditors: | | | | |
| Amounts due within 1 year | | <u>(10,873)</u> | | <u>(10,625)</u> |
| Net current assets | | 149,936 | | 172,938 |
| Net Assets | | 157,323 | | 182,198 |
| Analysed as: | | | | |
| General funds | | 123,575 | | 140,447 |
| Restricted funds | | 33,748 | | 41,751 |
| | | <u>157,323</u> | | <u>182,198</u> |

In 2018 LHM raised
£334,482 to provide
its services to families
on their half a heart
journey. None of this
was statutory funding.

50%

came from
community
fundraising





Thank you

to all of the
people who have
made our work
possible

Little Hearts Matter

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Littleheartsmatter



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