

COMPANY REGISTRATION NUMBER: 06400879
CHARITY REGISTRATION NUMBER: 1122071

The Lily Foundation
Company Limited by Guarantee
Unaudited Financial Statements
31 August 2020

The Lily Foundation

Company Limited by Guarantee

Trustees' Annual Report (Incorporating the Director's Report)

Year ended 31 August 2020

The trustees, who are also the directors for the purposes of company law, present their report and the unaudited financial statements of the company for the year ended 31 August 2020.

Structure, governance and management

Nature of the Governing Document and constitution of the charity.

Constituted as a Private Limited Company operated by a Board of Trustees. Governed by a Memorandum and Articles of Association and a Governing Document following the Charity Commissioners template.

The methods adopted for the recruitment, appointment, induction and training of new trustees.

Potential trustees make it known to the board that they are interested in becoming a trustee, or they are approached by an existing director.

- They are invited to attend a meeting to discuss the benefits they can bring to the charity.
- Existing trustees vote on whether the candidate is suitable.
- If the candidate is suitable, they are offered a position.
- The candidate then decides whether they will accept the position.
- Once accepted, the trustee is given promotional literature about the charity and directed to the charity website for further background information, however most new trustees are already familiar with the charities aims and objectives, having attended a number of fundraising events in the past.
- New trustees are invited to attend an introductory meeting with the CEO and other staff to meet the team and understand the charity structure. They are encouraged to ask questions and are given information about their obligations as a trustee of the charity.
- Throughout their term, trustees are encouraged to attend appropriate external training events and reading where this will facilitate the undertaking of their role.

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 August 2020

Structure, governance and management *(continued)*

The organisational structure of the charity and how decisions are made.

The board of trustees consisted of 8 individuals at 31st August 2020.

All policy decisions are made by the Board with any final decision in the event of a tied vote being made by the Chairperson.

Elizabeth Curtis, as CEO, is responsible for the day-to-day organisation of the charity, working closely with the chairperson and senior management team on decision making matters.

In addition, there are several sub-committees to organise different aspects of the charities work. There are regular board meetings throughout the year to discuss charity matters, culminating in an AGM.

Sub- committees covering events, fundraising, patient support and awareness normally meet monthly. Sub-committees for research and finance meet quarterly.

Risk Management

The trustees conduct annual reviews of the major risks to which the charity is exposed, and these are recorded in a risk register. Where appropriate, systems or procedures have been established to mitigate the risks the charity faces.

The charity has identified that financial sustainability is the major financial risk for the charity. A key element in the management of financial risk involves production of quarterly management accounts with analytical review of income and expenditure, as well as active management of available liquid funds to settle debts as they fall due, and of trade debtors and creditors balances to ensure sufficient working capital. External risks to funding are regularly reviewed and the charity's strategic plan addresses these risks and allows for the diversification of funding and activities. Internal control risks are minimised by the clearly defined procedures for authorisation of all transactions and projects.

Non-financial risks arising from operational activities, compliance, and environmental factors have also been identified and these risks are managed by having robust policies and procedures in place, and regular awareness training for staff working in these operational areas.

All procedures are periodically reviewed to ensure that they continue to meet the needs of the charity.

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Year ended 31 August 2020

Objectives and activities

A summary of the objects of the charity as set out in its governing document.

1 - To promote the physical and mental health of sufferers of mitochondrial disease and other metabolic disorders through greater awareness and funding.

Activities undertaken to achieve this include provision of telephone helpline, email support, closed patient support groups, virtual coffee mornings, social networking, website and printed resources, patient hospital accommodation, patient crisis funding, provision of specialist equipment, family breaks, residential weekends, patient information days, benefits advice and mental health support. 3 members of staff work in this area and we have invested £969,844 in this area to date. (2019: £833,873)

2 - To provide funds for further research into the disease.

Activities undertaken to achieve this include mitochondrial gene testing program, annual peer reviewed research call for treatments for mitochondria disease, funding of UK research studentships, research fellows and research nurses. Participation in global research collaborations. 1 member of staff works in coordinating this area and we have invested £2,560,323 in this area to date. (2019: £2,321,988)

3 - To provide greater awareness to the public of mitochondrial disease.

Activities undertaken to achieve this include public speaking, press and media campaigns, social media presence, NHS website providing reliable disease information, school visits, conference attendance, professional training and information videos. 3 members of staff work in coordinating this area and we have invested £588,926 in this area to date. (2019: £445,392)

Public Benefit that is provided by the charity

1 - To support families affected by mitochondrial disease.

2 - To fund research which will improve accuracy of diagnosis and treatment options for sufferers of mitochondrial disease.

3 - To educate and raise awareness of mitochondrial disease to the public and the medical community, to increase recognition of these conditions.

We have referred to the Charity Commission's guidance on public benefit when reviewing our aims and objectives and in planning our future activities.

Contribution of volunteers

The charity relies on voluntary help to host fundraising events, patient residential weekends and information days. Around 30 volunteers regularly assist the charity at events helping reduce costs.

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Year ended 31 August 2020

Covid-19

Covid-19 has inevitably had an impact on our charity however due to our size, we were able to adapt quickly to this crisis and put in place measures to try and minimise the effect of the pandemic on our vital work.

From an operational perspective all staff already have home-work set up, so social distancing measures have not impacted our day to day capabilities. Demand for our support services has dramatically increased within our vulnerable patient community, but we are fortunate to have a flexible staffing team with diverse skill sets, so where possible, staff were redeployed to areas of most need. In areas where activities ceased e.g. events, staff have been placed on furlough. Certain charitable activities which involve bringing patients together in large groups, like our patient residential weekends and information days, have been temporarily suspended, but we will look at resuming these when it is safe for our community to do so. We have restricted funds set aside to do this.

From a financial perspective, our low fixed cost base and prudent reserves policy ensures we can continue to operate for 12 months on little or no income. We acknowledge that covid-19 will have a significant impact on our ability to fundraise going forward as most of our income is generated through community fundraising and charitable events which involve bringing large numbers of supporters together and these are currently restricted or cancelled. We have adapted quickly to the changing situation and continue to identify new and innovative ways to generate funds through online quizzes and virtual sporting events. We have also been applying for grants to maintain ongoing projects and expand projects involving the mental health of our patient community which is an area of significant additional need.

The impact of covid-19 will inevitably delay some of our longer-term research funding plans, however we have designated funds set aside to complete all contractually committed medical research and support services. We are confident we will be able to maintain our core activities through these challenging times and continue to serve the mitochondrial patient community which relies so heavily on our work.

Achievements and performance

Summary of the main achievements of the charity during the year.

What is Mitochondrial Disease?

Mitochondrial disease, or 'mito', is the term given to a group of medical disorders caused by mutations in mitochondria, the tiny organelles that are present in nearly every cell in our bodies and which generate about 90% of the energy we need to live. Cells cannot function properly without healthy mitochondria, so when they fail the consequences can be serious and wide-ranging. Mitochondrial diseases can present in a person as 'any symptom', in 'any organ' at 'any age', making it particularly difficult to diagnose and frequently mis-diagnosed.

Research

Many families have to wait months and sometimes years before a diagnosis of mitochondrial disease is made, and even in cases where a diagnosis is confirmed, treatment options that may stabilise the condition and improve quality of life are limited, and not always effective. The Lily Foundation hopes to change this.

Through funding research, the Lily Foundation aims to improve diagnosis and find treatments for Mitochondrial Disease.

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 August 2020

What we have achieved so far: -

We pioneered the first national diagnostic collaboration for mitochondrial disease in the UK - accepting samples from all 3 major mitochondrial specialist centres in London, Oxford and Newcastle. Our principal goal was to ensure all UK families had access to fast and accurate genetic testing for their mitochondrial disease, and we continue to achieve this, with over 70% of our families receiving confirmed, or highly probable genetic diagnoses.

Recent changes in the NHS diagnostic services mean that equivalent genetic testing is now available on the NHS, so we have moved our focus to other vital areas of mitochondrial diagnostics including analysis of newly discovered disease-causing genes to validate their role in mitochondrial disease. This continues to advance our understanding of the genetic causes of this disease.

Alongside this diagnostic work, we also run an annual internationally peer-reviewed research call, to draw in new and exciting concepts for treating mitochondrial disease or alleviating symptoms. We are currently funding 12 exciting UK based projects looking at new treatments and therapies for mitochondrial disease. This year we also embarked on a new international project in collaboration with mitochondrial disease charity partners in Australia, Italy and the USA.

Support

In November 2019 we held our first Lily Young Adult support weekend, which brought young adults with mitochondrial disease together in one place, for the first time. The weekend provided them with a relaxed environment in which they were able to meet each other and share stories, as well as offering organised activities for all abilities which they may never have had the opportunity to try. Building a strong support network for these young adults is vital to ensure they are able to cope with the uncertainties of this condition, and by providing positive challenges combined with psychologist led emotional support sessions we managed to achieve this.

We planned to run 3 patient information days during the year, providing a combination of education with a social event to help empower patients and reduce isolation, but sadly 2 of these were cancelled due to Covid-19.

Demand for our phone support increased 10-fold through April/May. This surge was caused by fear, anxiety and confusion regarding work, family, self-isolation and shielding as a result of Covid-19. Our social media support group became a lifeline as patients turned to Lily for guidance and reassurance.

Sadly, our annual 'Lily Family Weekend' which brings together families with children affected by mitochondrial disease had to be cancelled because of Covid-19. These weekends usually provide a lifeline for these families and it was devastating to have to cancel this huge event.

We continue to offer our 'Lily's Helping Hand' scheme, which works in partnership with families to co-fund items that will enrich the lives of children with Mitochondrial Disease. This initiative continues to prove a huge success, allowing us to work with families to fund items such as special needs pushchairs and trikes, sensory equipment and specialist chairs and beds which would otherwise not have been available to them.

We continue to be able to offer short breaks to Centre Parcs for families with affected children, to allow special family time to build memories that will be cherished, although many breaks scheduled in the year were postponed due to Covid-19. We continue to fund specialist NHS nursing around the country, which is vital to maintaining links between families and doctors to ensure families feel supported.

We continue to offer our families a dedicated benefits advice service through our relationship with

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 August 2020

Newcastle University. This ensures they receive the benefits they need to manage their condition without the added stress of financial worries. This support is vital during the current economic climate where patients may find themselves in a different financial situation as a result of not being able to work safely through Covid-19.

We continue a strong relationship with Child Bereavement UK (CBUK) who specialise in emotional support and advice after child loss.

We continue to offer direct support through e-mail, phone and in person, to listen to family's stories and to help them understand the implications of a mitochondrial disease diagnosis. We can put them in contact with other families that are in a similar situation to help them build a support network.

We continue to run 2 incredibly popular closed Facebook support groups: one for families with affected children and another for adults living with the disease. These support groups have proved invaluable to connect patients and families with others who understand. During the events of this year, the importance of this service has been highlighted as with the support of our medical teams we were able to respond to patient queries directly, relieving significant pressure from our NHS services.

We also launched virtual coffee mornings for patients that were shielding and parents of affected children who were also shielding. The coffee mornings have been a great opportunity to bring people together to discuss anxieties and fears of being vulnerable during Covid-19.

Awareness

Through public speaking, press and radio interviews, and using educational tools like our animation entitled 'What's Mitochondrial Disease?', we continue to push Mitochondrial Disease into the mainstream media and significantly raise awareness of this complex condition.

With social media becoming increasingly popular, we extended our Facebook and Twitter profiles to promote the charity and raise awareness of mitochondrial disease through campaigns during 'Mitochondrial Disease Awareness Week', 'Rare Disease Day' and in the run up to Christmas.

In April 2020, Coronation Street launched a storyline involving a three old child diagnosed with a mitochondrial disease. This attracted a huge amount of nation and local press, as well as TV coverage on 'This Morning' and 'Lorraine'. The cast involved were interviewed and made sure they mentioned The Lily Foundation and signposted viewers and readers in the direction of our website. We have seen a huge surge in visitors to our website and an increase in followers on our social media platforms.

We continue to improve and update our Lily Website www.thelilyfoundation.org.uk which offers detailed information about Mitochondrial Disease as well as children's inspirational stories and information on what the charity can offer affected families in terms of support. We hope this site continues to be a useful resource for both patients and supporters.

We continue to work in partnership with the NHS Rare Mitochondrial Disease Service to administer a new NHS website resource to give affected families information about the mitochondrial services available to them in the UK and advice and information for patients and professionals working in the field. The www.mitochondrialdisease.nhs.uk website continues to be an excellent resource for families and professionals all over the UK.

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 August 2020

We continue to work closely with all three UK specialist centres for mitochondrial disease to improve patient and professional access to quality information and we attend and speak at UK and international events to achieve this goal.

We remain heavily involved in the process of ensuring families can benefit from Mitochondrial Donation Therapies. Access to these ground-breaking therapies, pioneered in the UK through Newcastle University, were granted through the House of Commons and Lords by large majorities in February 2015 and could give families affected by maternally inherited Mitochondrial Disease the chance to have their own healthy child. We continue to be involved in helping develop NHS care pathways, to ensure families who are eligible for these new therapies are well supported.

Financial review

Policies on Reserves

In accordance with Charity Commission guidance, the Trustees regularly monitor and annually review the adequacy of the charity's reserves and the reserves policy.

The trustees have forecast the level of income for 2020/21 at £480,000 gross and £150,000 net before expenditure on charitable activities. This takes into account the likely impact of covid-19 of the ability of the charity to raise funds with our own, and organised events cancelled.

The charity's reserves policy is to hold back sufficient funds to cover the fixed charity running costs, salary/freelance costs for 12 months and any essential variable costs necessary for healthy growth of the charity, which equates to £330,000 (2019: £402,000). All reserves over and above this retained amount reviewed annually and a proportion are designated to specific charitable activities on an annual basis. The trustees do not consider a reserve fund is necessary to cover the cost of event organisation as historically charity run events have covered such costs and resulted in profit. Such events would not take place if a loss was anticipated.

At 31st August 2020, the charity had free reserves of £908,847 (2019: £1,016,646), being unrestricted reserves less fixed assets. Of this amount £330,000 has been set aside in line with the charity reserves policy and a further £415,072 has been designated to committed charitable activity leaving £163,775 available free reserves.

Transactions and Financial position

The financial statements are set out on pages 13 to 15. The financial statements have been prepared implementing the Statement of recommended Practice for Accounting and Reporting by Charities (FRS 102) issued by the Charities Commission for England and Wales. The trustees consider the financial performance by the charity during the year to have been satisfactory.

The principal sources of funding are through voluntary donations and this income stream continues to grow as the charity becomes more well known. In addition, income continues to be generated through organised fundraising events which ensures we have sufficient resources to fund research into mitochondrial disease, raises awareness of the condition and support affected families.

The Statement of Financial Activities show net expenditure for the year of a revenue nature to be £108,014 (2019: net income £205,744).

Reserves at the year end, before designation to specific charitable activities stood at £908,943 (2019: £1,016,956) and after designation to specific charitable activities was £493,871 (2019: £402,000).

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 August 2020

Financial review *(continued)*

Grant Making Policy

Once a year at the AGM, trustees decide the main focus of the charities grant making activities for the coming year, in line with the main charity aims and objectives. The CEO and relevant staff then engage directly with organisations that may be able to fulfil those objectives and once satisfied, contracts are drawn up and awards are made.

The charity has established its grant making policy to achieve its objects for the public benefit. The charity's aim is to improve the lives of patients with mitochondrial disease and their families, to raise awareness of the condition and to seek effective treatments and a permanent cure in the future. We review our grant making policy annually to ensure that it reflects the charity's objects and thereby advances public benefit.

Our research and educational programmes fund students, researchers, research institutions and healthcare bodies who use these funds in their work to improve the lives of patients with mitochondrial disease and their carers, by developing therapies, potential medications, symptom management and improvements in the personal care of sufferers.

The charity invites applications for research grants from institutions by advertising on our website and social media, at specialist conferences, and via direct email. Eligibility is restricted to applicants having an expertise in the field, in order to ensure high quality results for mitochondrial disease sufferers. Institutional applicants submit a summary of their proposals to the trustees in a specific format, together with outline ethics approval. The charity follows best practice in maintaining the independence of research funding and ensuring that sponsored researchers and research institutions abide by best practice in research ethics and animal testing; our aim is to maximise the efficacy of the research programme whilst minimising the likelihood of harm to research volunteers and animals. Applications made in the correct format are peer reviewed by our international expert scientific review board against the scientific research criteria established by our Research Sub Committee and our research objectives.

Continuation of the grants is subject to a six monthly assessment by the Research Sub Committee. In all cases, continuation of funding is subject to the research undertaken being in the interests of the charity and a satisfactory progress assessment.

Our patient support programmes provide short breaks, specialist equipment and hospital accommodation for patients with mitochondrial disease, through direct contact with the service provider. Support is offered on a first come first served basis and patients are not means tested.

Share Capital

The company is limited by guarantee and therefore has no share capital.

The members of the Board of Trustees of the Charity during the year ended 31st August 2020 were:-

Mrs Helen Rider
Mr John Symons
Mr Benjamin Carter
Mrs Sarah Povey
Mrs Suzie Saggat (resigned 1st September 2019)
Mrs Rupinder Bains
Mr John Spyrou
Mr Dean Curtis
Mrs Claire Gore

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 August 2020

Financial review *(continued)*

All the directors of the company are also trustees and members of the charity, and their responsibilities include all the responsibilities of directors under the Companies Acts and of trustees under the Charities Acts.

The members of the Board of Trustees of the Charity at the date the report and accounts were approved were:-

Mrs Helen Rider
Mr John Symons
Mr Benjamin Carter
Mrs Sarah Povey
Mrs Rupinder Bains
Mr John Spyrou
Mr Dean Curtis
Mrs Claire Gore

Key Management and Personnel Remuneration

The directors consider the board of directors, who are the charity's trustees, and the senior management team make up the key management personnel of the charity in charge of directing and controlling, running and operating the charity on a day-to-day basis. All directors give their time freely and no director received remuneration in the year. The pay of the senior staff is reviewed annually and normally increased in accordance with the rate of inflation. In view of the nature of the charity, the directors benchmark against mid-point pay levels in other organisations of a similar size run on a voluntary basis, with flexibility to adjust upwards for additional responsibilities.

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 August 2020

Plans for future periods

PLANS FOR FUTURE PERIODS

Recent improvements in diagnosing mitochondrial disease, coupled with the development of large living cohorts of patients living with mito, means there is a real opportunity to focus future research efforts on discovering new treatments for patients. We are committed to funding innovative research into 'Treatments for Mitochondrial Disease' which may lead to breakthroughs in this area. We hope to increase our impact on a global scale by developing strategic partnerships and research collaborations with mitochondrial specialists and charities around the world.

We continue to fund professional training for doctors and nurses working in the field of mitochondrial medicine, and we also attend professional conferences to ensure the services we can offer patients in their care. Through extending our professional contact, we hope to be able to reach out to families seen in all hospitals around the UK.

We continue to work closely with the three specialist centres for mitochondrial disease and listen to how we can support their NHS service to improve the experience for families. We plan to extend this support to non-specialist centres who also see mitochondrial patients. We are committed to improving science communication by bringing together patients and professionals to ensure families are aware of studies and trials that might benefit them.

In terms of support, we continue to listen to our families about what they most need and based on the huge success of our Lily family weekends and young adult support weekend, we hope to be able to hold similar events annually.

We aim to broaden our adult support service to include more patient information days, social events to reduce isolation and psychological support for adult patients. We aim to work closely with the NHS to develop technologies that will enhance remote patient care.

We will continue to offer short breaks for affected families to Centre Parcs, continue with our Helping Hand scheme to co-fund items that will enrich the lives of children with Mitochondrial Disease, and to support hospital accommodation costs when their loved ones are in intensive care.

In term of awareness, we remain in the spotlight throughout involvement in the passing of the regulations to allow Mitochondrial Donation Therapies - IVF techniques which could prevent the transmission of maternally inherited mitochondrial diseases from mother to child, providing huge hope for many affected families. We continue to be involved in this process, working together with the NHS, to ensure proper care pathways are in place for families who wish to apply to use the techniques, as well as supporting patient groups around the world in their quest to have access to similar techniques in their own countries.

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 August 2020

Reference and administrative details

Registered charity name The Lily Foundation
Charity registration number 1122071
Company registration number 06400879
Principal office and registered office 31 Warren Park
Warlingham
Surrey
CR6 9LD

The trustees

Mrs H Rider
Mr J Symons
Mr B Carter
Mrs S Povey
Mrs S Saggart (Resigned 1st September 2019)
Mrs R Bains
Mr J Spyrou
Mr D Curtis
Mrs C Gore

Company secretary Mrs S Hanks

Independent examiner Mr S Joberns SHIPLEYS LLP
10 Orange Street
Haymarket
London
WC2H 7DQ

Bankers Barclays
1 Churchill Place
London
E14 5HP

Small company provisions

This report has been prepared in accordance with the provisions applicable to companies entitled to the small companies exemption.

The trustees' annual report was approved on 20/5/2021 and signed on behalf of the board of trustees by:



Mrs H Rider
Trustee

The Lily Foundation

Company Limited by Guarantee

Independent Examiner's Report to the Trustees of The Lily Foundation

Year ended 31 August 2020

I report to the trustees on my examination of the unaudited financial statements of The Lily Foundation ('the company') for the year ended 31 August 2020 which are set out on pages 13 to 15.

Responsibilities and basis of report

As the trustees of the company (and also its directors for the purposes of company law) you are responsible for the preparation of the unaudited financial statements in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the company's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

Since the company's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales (ICAEW), which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the company as required by section 386 of the 2006 Act; or
2. the unaudited financial statements do not accord with those records; or
3. the unaudited financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
4. the unaudited financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Steve Joberns

20/5/2021

Mr S Joberns FCA
SHIPLEYS LLP
Independent Examiner

10 Orange Street
Haymarket
London
WC2H 7DQ

The Lily Foundation

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Statement of Financial Activities (including income and expenditure account)

Year ended 31 August 2020

			2020		2019
	Note	Unrestricted funds £	Restricted funds £	Total funds £	Total funds £
Income and endowments					
Donations and legacies	5	527,629	155,838	683,467	795,695
Other trading activities	6	21,023	–	21,023	153,582
Investment income	7	4,903	–	4,903	3,237
Total income		<u>553,555</u>	<u>155,838</u>	<u>709,393</u>	<u>952,514</u>
Expenditure					
Expenditure on raising funds:					
Costs of raising donations and legacies	8	103,282	–	103,282	91,534
Costs of other trading activities	9	74,447	–	74,447	135,633
Expenditure on charitable activities	10,11	483,840	155,838	639,678	519,602
Total expenditure		<u>661,569</u>	<u>155,838</u>	<u>817,407</u>	<u>746,769</u>
Net (expenditure)/income and net movement in funds		<u>(108,014)</u>	<u>–</u>	<u>(108,014)</u>	<u>205,745</u>
Reconciliation of funds					
Total funds brought forward		1,016,957	–	1,016,957	811,212
Total funds carried forward		<u>908,943</u>	<u>–</u>	<u>908,943</u>	<u>1,016,957</u>

The statement of financial activities includes all gains and losses recognised in the year.
All income and expenditure derive from continuing activities.

The notes on pages 16 to 26 form part of these unaudited financial statements.

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Statement of Financial Position
31 August 2020

	Note	2020 £	2019 £
Fixed assets			
Tangible fixed assets	17	96	310
Current assets			
Debtors	18	49,632	30,019
Cash at bank and in hand		1,337,656	1,273,696
		<u>1,387,288</u>	<u>1,303,715</u>
Creditors: amounts falling due within one year	19	366,245	175,956
Net current assets		<u>1,021,043</u>	<u>1,127,759</u>
Total assets less current liabilities		<u>1,021,139</u>	<u>1,128,069</u>
Creditors: amounts falling due after more than one year	20	112,196	111,112
Net assets		<u>908,943</u>	<u>1,016,957</u>
Funds of the charity			
Unrestricted funds		908,943	1,016,957
Total charity funds	21	<u>908,943</u>	<u>1,016,957</u>

For the year ending 31 August 2020 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

- The members have not required the company to obtain an audit of its unaudited financial statements for the year in question in accordance with section 476;
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of unaudited financial statements.

These unaudited financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

These unaudited financial statements were approved by the board of trustees and authorised for issue on 20/5/2021, and are signed on behalf of the board by:



Mrs H Rider
Trustee Director and Treasurer

The notes on pages 16 to 26 form part of these unaudited financial statements.

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Statement of Cash Flows

Year ended 31 August 2020

	2020 £	2019 £
Cash flows from operating activities		
Net (expenditure)/income	(108,014)	205,745
<i>Adjustments for:</i>		
Depreciation of tangible fixed assets	214	214
Other interest receivable and similar income	(4,903)	(3,237)
Accrued expenses	83,937	55,659
<i>Changes in:</i>		
Trade and other debtors	(19,613)	15,538
Trade and other creditors	107,436	43,700
Cash generated from operations	59,057	317,619
Interest received	4,903	3,237
Net cash from operating activities	<u>63,960</u>	<u>320,856</u>
Cash flows from investing activities		
Purchase of tangible assets	—	(151)
Net cash used in investing activities	<u>—</u>	<u>(151)</u>
Net increase in cash and cash equivalents	63,960	320,705
Cash and cash equivalents at beginning of year	1,273,696	952,991
Cash and cash equivalents at end of year	<u>1,337,656</u>	<u>1,273,696</u>

The notes on pages 16 to 26 form part of these unaudited financial statements.

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Notes to the Unaudited Financial Statements

Year ended 31 August 2020

1. General information

The company is a public benefit entity and a private company limited by guarantee, registered in England and Wales and a registered charity in England and Wales. The address of the registered office is 31 Warren Park, Warlingham, Surrey, CR6 9LD.

2. Statement of compliance

These unaudited financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (Charities SORP (FRS 102)) and the Companies Act 2006.

With effect from 1 September 2019, the charity has adopted the amendments to FRS 102 published in the Triennial Review 2017 and the subsequent changes to the Charities SORP (FRS 102). There are no adjustments to the current or comparative period in relation to these amendments.

3. Accounting policies

Basis of preparation

The unaudited financial statements have been prepared on the historical cost basis, as modified by the revaluation of certain financial assets and liabilities and investment properties measured at fair value through income or expenditure.

The unaudited financial statements are prepared in sterling, which is the functional currency of the entity.

The Lily Foundation meets the definition of a public benefit entity under FRS 102.

Going concern

There are no material uncertainties about the charity's ability to continue. The charity has scaled back physical fundraising activities due to covid restrictions on social interaction but has replaced these with virtual online events which are providing sufficient funds to support the conclusion that the charity is a going concern.

Debtors

Other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid after taking account of any trade discounts due.

Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

The Lily Foundation

Company Limited by Guarantee

Notes to the Unaudited Financial Statements *(continued)*

Year ended 31 August 2020

Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

Judgements and key sources of estimation uncertainty

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported. These estimates and judgements are continually reviewed and are based on experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

There are no significant areas requiring material judgements, estimates or assumptions.

Taxation

The charity is exempt from tax on income and gains to the extent that these are applied to its charitable objectives.

Pension costs

Contributions to defined contribution plans are recognised as an expense in the period in which the related service is provided. Differences between contributions payable in the year and the contributions actually paid are shown as either accruals or prepayments on the balance sheet.

Fund accounting

Unrestricted funds are available for use at the discretion of the trustees to further any of the charity's purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal and fall into one of two sub-classes: restricted income funds or endowment funds.

The Lily Foundation

Company Limited by Guarantee

Notes to the Unaudited Financial Statements *(continued)*

Year ended 31 August 2020

3. Accounting policies *(continued)*

Income

Income is accounted for when the charity has entitlement to the funds, receipt is probable, and the amount is measurable. Where income is received in advance of an event it is deferred until the charity is entitled to the income.

Income from donations and grants is included in income when these are receivable. When donors impose conditions, which have to be fulfilled before the charity becomes entitled to use such income, the income is deferred and not included in income until the pre-conditions for use have been met. Interest is included when receivable by the charity.

Expenditure

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is classified under headings of the statement of financial activities to which it relates:

- expenditure on raising funds includes the costs of all fundraising activities, events, non-charitable trading activities, and the sale of donated goods.
- expenditure on charitable activities includes all costs incurred by a charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities.
- other expenditure includes all expenditure that is neither related to raising funds for the charity nor part of its expenditure on charitable activities.

All costs are allocated to expenditure categories reflecting the use of the resource. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs are apportioned between the activities they contribute to on a reasonable, justifiable and consistent basis.

Operating leases

Lease payments are recognised as an expense over the lease term on a straight-line basis. The aggregate benefit of lease incentives is recognised as a reduction to expense over the lease term, on a straight-line basis.

The Lily Foundation

Company Limited by Guarantee

Notes to the Unaudited Financial Statements *(continued)*

Year ended 31 August 2020

3. Accounting policies *(continued)*

Tangible assets

Tangible assets are initially recorded at cost, and subsequently stated at cost less any accumulated depreciation and impairment losses.

Depreciation

Depreciation is calculated so as to write off the cost or valuation of an asset, less its residual value, over the useful economic life of that asset as follows:

Fixtures & Fittings	- 25% straight line
Equipment	- 25% straight line

Impairment of fixed assets

A review for indicators of impairment is carried out at each reporting date, with the recoverable amount being estimated where such indicators exist. Where the carrying value exceeds the recoverable amount, the asset is impaired accordingly. Prior impairments are also reviewed for possible reversal at each reporting date. For the purposes of impairment testing, when it is not possible to estimate the recoverable amount of an individual asset, an estimate is made of the recoverable amount of the cash-generating unit to which the asset belongs. The cash-generating unit is the smallest identifiable group of assets that includes the asset and generates cash inflows that largely independent of the cash inflows from other assets or groups of assets.

Financial instruments

A financial asset or a financial liability is recognised only when the entity becomes a party to the contractual provisions of the instrument.

Basic financial instruments are initially recognised at the amount receivable or payable including any related transaction costs, unless the arrangement constitutes a financing transaction, where it is recognised at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Current assets and current liabilities are subsequently measured at the cash or other consideration expected to be paid or received and not discounted.

Debt instruments are subsequently measured at amortised cost.

4. Limited by guarantee

The charity is incorporated under the Companies Act and is limited by guarantee, each member having undertaken to contribute such amounts, not exceeding one pound, as may be required in the event of the company being wound up whilst he or she is still a member or within one year thereafter.

There are 8 members of the company (2019 - 8 members).

The Lily Foundation

Company Limited by Guarantee

Notes to the Unaudited Financial Statements *(continued)*

Year ended 31 August 2020

5. Donations and legacies

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Other donations and legacies			
Donations & Sponsorship	<u>527,629</u>	<u>155,838</u>	<u>683,467</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £
Other donations and legacies			
Donations & Sponsorship	<u>759,011</u>	<u>36,684</u>	<u>795,695</u>

Within unrestricted funds there is an amount of £17,297 which relates to a grant received from the Government Coronavirus Job Retention Scheme. This grant was provided to support the cost of furloughed charity staff. The charity has not benefitted from any other kinds of government assistance during the current year.

6. Other trading activities

	Unrestricted Funds £	Total Funds 2020 £	Unrestricted Funds £	Total Funds 2019 £
Activities for generating funds	<u>21,023</u>	<u>21,023</u>	<u>153,582</u>	<u>153,582</u>

7. Investment income

	Unrestricted Funds £	Total Funds 2020 £	Unrestricted Funds £	Total Funds 2019 £
Investment Income	<u>4,903</u>	<u>4,903</u>	<u>3,237</u>	<u>3,237</u>

8. Costs of raising donations and legacies

	Unrestricted Funds £	Total Funds 2020 £	Unrestricted Funds £	Total Funds 2019 £
Costs of raising donations and legacies - Donations	<u>103,282</u>	<u>103,282</u>	<u>91,534</u>	<u>91,534</u>

9. Costs of other trading activities

	Unrestricted Funds £	Total Funds 2020 £	Unrestricted Funds £	Total Funds 2019 £
Costs of other trading activities	<u>74,447</u>	<u>74,447</u>	<u>135,633</u>	<u>135,633</u>

The Lily Foundation

Company Limited by Guarantee

Notes to the Unaudited Financial Statements *(continued)*

Year ended 31 August 2020

10. Expenditure on charitable activities by fund type

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Research Expenditure	281,390	69,601	350,991
Patient & Family Support	63,235	72,737	135,972
Awareness & Education	130,033	13,500	143,533
Support costs	9,182	–	9,182
	<u>483,840</u>	<u>155,838</u>	<u>639,678</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £
Research Expenditure	195,271	–	195,271
Patient & Family Support	158,774	36,684	195,458
Awareness & Education	120,062	–	120,062
Support costs	8,812	–	8,812
	<u>482,919</u>	<u>36,684</u>	<u>519,603</u>

11. Expenditure on charitable activities by activity type

	Activities undertaken directly £	Grant funding of activities £	Support costs £	Total funds 2020 £	Total fund 2019 £
Research Expenditure	36,493	314,498	–	350,991	195,271
Patient & Family Support	135,972	–	–	135,972	195,458
Awareness & Education	129,627	13,906	–	143,533	120,062
Governance costs	–	–	9,182	9,182	8,812
	<u>302,092</u>	<u>328,404</u>	<u>9,182</u>	<u>639,678</u>	<u>519,603</u>

Governance (support) costs are broken down as follows:

	2020 £	2019 £
Independent Examiners Fees	750	750
Depreciation	214	214
Sundry Governance Costs	7,622	7,053
Insurance	596	795
	<u>9,182</u>	<u>8,812</u>

The Lily Foundation

Company Limited by Guarantee

Notes to the Unaudited Financial Statements *(continued)*

Year ended 31 August 2020

12. Analysis of grants

	2020 £	2019 £
Grants to institutions		
Newcastle University / WCMR	93,033	94,984
Oxford University / St John Radcliffe Hospital	64,715	2,631
University College London	30,000	42,371
University of Cambridge	64,656	31,216
United Mitochondrial Disease Foundation	76,000	—
	<u>328,404</u>	<u>171,202</u>
Total grants	<u>328,404</u>	<u>171,202</u>

13. Net (expenditure)/income

Net (expenditure)/income is stated after charging/(crediting):

	2020 £	2019 £
Depreciation of tangible fixed assets	214	214
Operating lease rentals	<u>2,511</u>	<u>1,680</u>

14. Independent examination fees

	2020 £	2019 £
Fees payable to the independent examiner for:		
Independent examination of the unaudited financial statements	<u>750</u>	<u>750</u>

15. Staff costs and emoluments

The total staff costs and employee benefits for the reporting period are analysed as follows:

	2020 £	2019 £
Wages and salaries	241,917	213,515
Social Security	24,846	19,089
Pension Costs	<u>5,249</u>	<u>3,827</u>
	<u>272,012</u>	<u>236,431</u>

The average head count of employees during the year was 8 (2019: 7). The average number of full-time equivalent employees during the year is analysed as follows:

	2020 No.	2019 No.
Number of staff - Management	3	3
Number of other staff	<u>2</u>	<u>2</u>
	<u>5</u>	<u>5</u>

The Lily Foundation

Company Limited by Guarantee

Notes to the Unaudited Financial Statements *(continued)*

Year ended 31 August 2020

The number of employees whose remuneration for the year fell within the following bands, were:

	2020	2019
	No.	No.
£60,000 to £69,999	<u>1</u>	<u>1</u>

Key Management Personnel

Key management personnel include all persons that have authority and responsibility for planning, directing and controlling the activities of the company. The total compensation paid to key management personnel for services provided to the company was £170,733 (2019: £160,402).

16. Trustee remuneration and expenses

No remuneration or reimbursement of expenses were paid to the trustees during the current or prior year.

17. Tangible fixed assets

	Fixtures and fittings £	Equipment £	Total £
Cost			
At 1 September 2019 and 31 August 2020	<u>284</u>	<u>2,989</u>	<u>3,273</u>
Depreciation			
At 1 September 2019	284	2,679	2,963
Charge for the year	—	214	214
At 31 August 2020	<u>284</u>	<u>2,893</u>	<u>3,177</u>
Carrying amount			
At 31 August 2020	<u>—</u>	<u>96</u>	<u>96</u>
At 31 August 2019	<u>—</u>	<u>310</u>	<u>310</u>

18. Debtors

	2020	2019
	£	£
Prepayments and accrued income	<u>49,632</u>	<u>30,019</u>

19. Creditors: amounts falling due within one year

	2020	2019
	£	£
Trade creditors	583	4,857
Accruals and deferred income	150,025	66,088
Social security and other taxes	9,349	7,149
Other creditors	206,288	97,862
	<u>366,245</u>	<u>175,956</u>

The Lily Foundation

Company Limited by Guarantee

Notes to the Unaudited Financial Statements *(continued)*

Year ended 31 August 2020

19. Creditors: amounts falling due within one year *(continued)*

Within 'accruals and deferred income' there is an amount of £148,810 deferred income (2019: £57,392) which relates to income received in advance for events taking place in the next financial year.

Deferred income of £57,392 was released from the prior period.

Movement in grant commitments within 'other creditors' is stated in the table below:

	Year ended 31/08/2020 £
Grant commitments at the start of the year	208,974
New grant commitments charged to the SoFA in the year	328,404
Grants paid during the year	(218,894)
Amount of grant commitments at the end of the year	<u>318,484</u>
Amounts falling due within one year	206,288
Amounts falling due after one year	<u>112,196</u>
Amount of grant commitments at the end of the year	<u>318,484</u>

20. Creditors: amounts falling due after more than one year

	2020 £	2019 £
Other creditors	<u>112,196</u>	<u>111,112</u>

The Lily Foundation

Company Limited by Guarantee

Notes to the Unaudited Financial Statements *(continued)*

Year ended 31 August 2020

21. Analysis of charitable funds

Unrestricted funds

	At 1 September 2019 £	Income £	Expenditure £	Transfers £	At 31 August 2020 £
General funds	1,016,957	553,555	(661,569)	(415,072)	493,871
Designated Fund - Research Projects	—	—	—	273,572	273,572
Designated Fund - Family Support Projects	—	—	—	121,500	121,500
Designated Fund - Medical Database	—	—	—	20,000	20,000
	<u>1,016,957</u>	<u>553,555</u>	<u>(661,569)</u>	<u>—</u>	<u>908,943</u>

	At 1 September 2018 £	Income £	Expenditure £	Transfers £	At 31 August 2019 £
General funds	811,212	915,830	(710,085)	—	1,016,957
Designated Fund - Research Projects	—	—	—	—	—
Designated Fund - Family Support Projects	—	—	—	—	—
Designated Fund - Medical Database	—	—	—	—	—
	<u>811,212</u>	<u>915,830</u>	<u>(710,085)</u>	<u>—</u>	<u>1,016,957</u>

Restricted funds

	At 1 September 2019 £	Income £	Expenditure £	Transfers £	At 31 August 2020 £
Restricted Fund	—	155,838	(155,838)	—	—

	At 1 September 2018 £	Income £	Expenditure £	Transfers £	At 31 August 2019 £
Restricted Fund	—	36,684	(36,684)	—	—

During the year restricted donations and grants totalling £155,838 were received from private donors and companies who wish to remain anonymous. £69,601 was restricted to medical research projects, £4,000 was restricted to our Adult Support Weekend, £23,060 to patient psychological support, £3,281 to our Helping Hands Scheme, £2,491 to Patient Information Days, £39,905 to support staffing and £13,500 to global communications.

The Lily Foundation

Company Limited by Guarantee

Notes to the Unaudited Financial Statements *(continued)*

Year ended 31 August 2020

22. Analysis of net assets between funds

	Unrestricted Funds £	Total Funds 2020 £
Tangible fixed assets	96	96
Current Assets	1,387,288	1,387,288
Creditors less than 1 year	(366,245)	(366,245)
Creditors greater than 1 year	(112,196)	(112,196)
Net assets	<u>908,943</u>	<u>908,943</u>

	Unrestricted Funds £	Total Funds 2019 £
Tangible fixed assets	310	310
Current Assets	1,303,715	1,303,715
Creditors less than 1 year	(175,956)	(175,956)
Creditors greater than 1 year	(111,112)	(111,112)
Net assets	<u>1,016,957</u>	<u>1,016,957</u>

23. Analysis of changes in net debt

	At 1 Sep 2019 £	Cash flows £	At 31 Aug 2020 £
Cash at bank and in hand	<u>1,273,696</u>	<u>63,960</u>	<u>1,337,656</u>

	At 1 Sep 2018 £	Cash flows £	At 31 Aug 2019 £
Cash at bank and in hand	<u>952,991</u>	<u>320,705</u>	<u>1,273,696</u>

24. Operating lease commitments

The total future minimum lease payments under non-cancellable operating leases are as follows:

	2020 £	2019 £
Within 1 year	<u>—</u>	<u>1,680</u>

25. Related parties

No transactions with related parties were undertaken such as are required to be disclosed under the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).