

COMPANY REGISTRATION NUMBER: 06400879  
CHARITY REGISTRATION NUMBER: 1122071

**The Lily Foundation**  
**Company Limited by Guarantee**  
**Unaudited Financial Statements**  
**31 August 2021**

# **The Lily Foundation**

## **Company Limited by Guarantee**

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

#### **Year ended 31 August 2021**

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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 2021.

#### **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 £1,091,842 in this area to date. (2020: £969,844)

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 £2,797,682 in this area to date. (2020: £2,560,323)

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 £697,128 in this area to date. (2020: £588,926)

##### **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.

# **The Lily Foundation**

## **Company Limited by Guarantee**

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

**Year ended 31 August 2021**

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#### **Objectives and activities *(continued)***

##### **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.

Although the impact of covid-19 has caused delay in our longer-term research funding plans, we have designated funds to complete all contractually committed medical research and support services. Since the end of the year, all of our research projects have fully resumed and we launched two new research calls in September 2021 and May 2022 which attracted high quality applications so we are confident that our research ambitions will soon be back to pre pandemic times. We have maintained our core activities throughout the pandemic and also developed new ways of serving our mitochondrial patient community like regular virtual coffee mornings which were so popular they will stay with us moving forward. We also held a hugely successful fundraising ball in Dec 2021 and have planned to proceed with a face to face Family Weekend in July 2022 which has caused significant excitement amongst our families. Overall we feel very hopeful that we not only survived the pandemic but we have come out the other side stronger.

# **The Lily Foundation**

## **Company Limited by Guarantee**

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

**Year ended 31 August 2021**

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#### **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.

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 embarked on new research collaborations with international mitochondrial disease groups in Canada and Italy.

# **The Lily Foundation**

## **Company Limited by Guarantee**

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

#### **Year ended 31 August 2021**

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##### **Achievements and performance *(continued)***

###### **Support**

Demand for our support services increased during the covid pandemic and continues to remain high. We offer support via phone, social media platforms, our charity website and email. Our phone support line is often the first port of call for families who have recently been diagnosed with a mitochondrial disease. 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 proven invaluable to connect patients with others who understand. During the pandemic we worked with NHS services to respond directly to general patient queries through these channels, relieving significant pressure from our NHS services.

We had hoped to offer three patient information days, a family weekend and a young adult weekend during the year, but unfortunately all face-to-face support had to be postponed.

During lockdown, we introduced weekly virtual coffee mornings. These events provide an opportunity for our community to come together and meet new people who suffer from mitochondrial diseases, and these now form a regular part of our ongoing support service.

In February 2021 we set up a psychological support service which has been a lifeline to many families. We have been able to offer professional support and guidance to young adults, siblings, parents of newly diagnosed children, and families who have been bereaved during the pandemic.

We continue to offer respite breaks for families to Center Parcs and have co-funded specialist equipment for those who suffer from mitochondrial diseases although Covid has influenced the take up of these services.

# **The Lily Foundation**

## **Company Limited by Guarantee**

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

#### **Year ended 31 August 2021**

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##### **Achievements and performance *(continued)***

###### **Awareness**

Through public speaking, press exposure, radio interviews and our animation entitled 'What is Mitochondrial Disease?' we continue to push Mitochondrial Disease into the mainstream media and raise awareness of this complex condition.

Followers on all our social media platforms have grown in number. Instagram by 30%, Twitter by 12%, Facebook by 5% and LinkedIn we now have 272 followers.

We continue to improve and update our Lily Website [www.thelilyfoundation.org.uk](http://www.thelilyfoundation.org.uk) which offers detailed information about Mitochondrial Disease, 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](http://www.mitochondrialdisease.nhs.uk) website continues to be an excellent resource for families and professionals all over the UK.

Raising awareness on television - Josh Widdicombe appeared on celebrity Catch Phrase and he spoke about the charity. We are still benefitting from the coverage from a mitochondrial disease storyline on Coronation Street in 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.

###### **Fundraising**

Our fundraising objectives for the year ended 31 August 2021 were to raise £40k per month (£480k for the year). This was agreed by our board as being realistic to achieve in the absence of face to face events and focusing only on virtual campaigns, grants and online events. £480k was calculated to cover our fixed charity costs and avoid eating into our charity reserves where possible. We were delighted to have raised £100k more than this target (so £580K over all).

# **The Lily Foundation**

## **Company Limited by Guarantee**

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

#### **Year ended 31 August 2021**

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##### **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 2021/22 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 £434,000 (2020: £330,000). 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 2021, the charity had free reserves of £981,341 (2020: £908,846), being unrestricted reserves less fixed assets. Of this amount £433,866 has been set aside in line with the charity reserves policy and a further £447,475 has been designated to committed charitable activity leaving £100,000 available free reserves.

##### **Transactions and Financial position**

The financial statements are set out on pages 14 to 16. 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 income for the year of a revenue nature to be £72,549 (2020: net expenditure £108,014).

Reserves at the year end, before designation to specific charitable activities stood at £981,492 (2020: £908,943) and after designation to specific charitable activities was £534,017 (2020: £493,871).

# **The Lily Foundation**

## **Company Limited by Guarantee**

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

**Year ended 31 August 2021**

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#### **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.

##### **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.



# The Lily Foundation

## Company Limited by Guarantee

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

**Year ended 31 August 2021**

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#### **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 as supporting patient groups around the world in their quest to have access to similar techniques in their own countries.

# **The Lily Foundation**

## **Company Limited by Guarantee**

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

#### **Year ended 31 August 2021**

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##### **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.

###### **The organisational structure of the charity and how decisions are made**

The board of trustees consisted of 8 individuals at 31st August 2021.

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.

# **The Lily Foundation**

## **Company Limited by Guarantee**

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

**Year ended 31 August 2021**

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#### **Structure, governance and management *(continued)***

##### **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.

##### **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 2021 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

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 Rupinder Bains  
Mr John Spyrou  
Mr Dean Curtis  
Mrs Claire Gore

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# The Lily Foundation

## Company Limited by Guarantee

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

Year ended 31 August 2021

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#### Reference and administrative details

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

#### The trustees

Mrs H Rider  
Mr J Symons  
Mr B Carter  
Mrs S Povey  
Mrs R Bains  
Mr J Spyrou  
Mr D Curtis  
Mrs C Gore

Mrs S Povey retired as a director on 7 February 2022.

<b>Company secretary</b>	Mrs S Hanks
<b>Independent examiner</b>	Mr S Joberns FCA Shipleys LLP 10 Orange Street Haymarket London WC2H 7DQ

#### Small company provisions

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

30/5/2022

The trustees' annual report was approved on ..... 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 2021**

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I report to the trustees on my examination of the financial statements of The Lily Foundation ('the company') for the year ended 31 August 2021.

#### **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 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 financial statements do not accord with those records; or
3. the 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 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).

# **The Lily Foundation**

## **Company Limited by Guarantee**

### **Independent Examiner's Report to the Trustees of The Lily Foundation** *(continued)*

#### **Year ended 31 August 2021**

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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.

*Stephen Joberns*

Mr S Joberns FCA  
Shipleys LLP  
Independent Examiner

10 Orange Street  
Haymarket  
London  
WC2H 7DQ

30/5/2022

# The Lily Foundation

## Company Limited by Guarantee

### Statement of Financial Activities (including income and expenditure account)

Year ended 31 August 2021

		Unrestricted funds	2021 Restricted funds	Total funds	2020 Total funds
	Note	£	£	£	£
<b>Income and endowments</b>					
Donations and legacies	5	420,141	136,396	556,537	683,467
Other trading activities	6	24,187	–	24,187	21,023
Investment income	7	230	–	230	4,903
<b>Total income</b>		<u>444,558</u>	<u>136,396</u>	<u>580,954</u>	<u>709,393</u>
<b>Expenditure</b>					
Expenditure on raising funds:					
Costs of raising donations and legacies	8	(90,019)	–	(90,019)	(103,282)
Costs of other trading activities	9	(30,491)	–	(30,491)	(74,446)
Expenditure on charitable activities	10,11	(251,499)	(136,396)	(387,895)	(639,679)
<b>Total expenditure</b>		<u>(372,009)</u>	<u>(136,396)</u>	<u>(508,405)</u>	<u>(817,407)</u>
<b>Net income/(expenditure) and net movement in funds</b>		<u>72,549</u>	<u>–</u>	<u>72,549</u>	<u>(108,014)</u>
<b>Reconciliation of funds</b>					
Total funds brought forward		908,943	–	908,943	1,016,957
<b>Total funds carried forward</b>		<u>981,492</u>	<u>–</u>	<u>981,492</u>	<u>908,943</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 17 to 28 form part of these financial statements.

# The Lily Foundation

## Company Limited by Guarantee

### Statement of Financial Position

31 August 2021

	Note	2021 £	2020 £
<b>Fixed assets</b>			
Tangible fixed assets	17	151	96
<b>Current assets</b>			
Debtors	18	75,562	49,632
Cash at bank and in hand		1,320,927	1,337,656
		<u>1,396,489</u>	<u>1,387,288</u>
<b>Creditors: amounts falling due within one year</b>	19	(373,011)	(366,245)
<b>Net current assets</b>		<u>1,023,478</u>	<u>1,021,043</u>
<b>Total assets less current liabilities</b>		<u>1,023,629</u>	<u>1,021,139</u>
<b>Creditors: amounts falling due after more than one year</b>	20	(42,137)	(112,196)
<b>Net assets</b>		<u>981,492</u>	<u>908,943</u>
<b>Funds of the charity</b>			
Unrestricted funds		<u>981,492</u>	<u>908,943</u>
<b>Total charity funds</b>	22	<u>981,492</u>	<u>908,943</u>

For the year ending 31 August 2021 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 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 financial statements.

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

These financial statements were approved by the board of trustees and authorised for issue on 30/5/2022, and are signed on behalf of the board by:



Mrs H Rider  
Trustee Director and Treasurer

The notes on pages 17 to 28 form part of these financial statements.



# The Lily Foundation

## Company Limited by Guarantee

### Statement of Cash Flows

Year ended 31 August 2021

	2021 £	2020 £
<b>Cash flows from operating activities</b>		
Net income/(expenditure)	72,549	(108,014)
<i>Adjustments for:</i>		
Depreciation of tangible fixed assets	95	214
Other interest receivable and similar income	(230)	(4,903)
Accrued expenses	72,362	83,937
<i>Changes in:</i>		
Trade and other debtors	(25,930)	(19,613)
Trade and other creditors	(135,655)	107,436
Cash generated from operations	(16,809)	59,057
Interest received	230	4,903
Net cash (used in)/from operating activities	(16,579)	63,960
<b>Cash flows from investing activities</b>		
Purchase of tangible assets	(150)	—
Net cash used in investing activities	(150)	—
<b>Net (decrease)/increase in cash and cash equivalents</b>	(16,729)	63,960
<b>Cash and cash equivalents at beginning of year</b>	1,337,656	1,273,696
<b>Cash and cash equivalents at end of year</b>	1,320,927	1,337,656

The notes on pages 17 to 28 form part of these financial statements.

# **The Lily Foundation**

## **Company Limited by Guarantee**

### **Notes to the Financial Statements**

**Year ended 31 August 2021**

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#### **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 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.

#### **3. Accounting policies**

##### **Basis of preparation**

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

##### **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.

##### **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.

# The Lily Foundation

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

Year ended 31 August 2021

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#### 3. Accounting policies *(continued)*

##### **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.

##### **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 Financial Statements *(continued)*

Year ended 31 August 2021

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#### 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.

# The Lily Foundation

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 August 2021

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#### 3. Accounting policies *(continued)*

##### 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.

##### 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.

##### 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.

##### Defined contribution plans

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.

#### 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 (2020 - 8 members).

# The Lily Foundation

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 August 2021

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##### 5. Donations and legacies

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
<b>Other donations and legacies</b>			
Donations & Sponsorship	<u>420,141</u>	<u>136,396</u>	<u>556,537</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
<b>Other donations and legacies</b>			
Donations & Sponsorship	<u>527,629</u>	<u>155,838</u>	<u>683,467</u>

Within unrestricted funds there is an amount of £8,688 (2020: £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 2021 £	Unrestricted Funds £	Total Funds 2020 £
Activities for generating funds	<u>24,187</u>	<u>24,187</u>	<u>21,023</u>	<u>21,023</u>

##### 7. Investment income

	Unrestricted Funds £	Total Funds 2021 £	Unrestricted Funds £	Total Funds 2020 £
Investment income	<u>230</u>	<u>230</u>	<u>4,903</u>	<u>4,903</u>

##### 8. Costs of raising donations and legacies

	Unrestricted Funds £	Total Funds 2021 £	Unrestricted Funds £	Total Funds 2020 £
Costs of raising donations and legacies - Donations	<u>90,019</u>	<u>90,019</u>	<u>103,282</u>	<u>103,282</u>

##### 9. Costs of other trading activities

	Unrestricted Funds £	Total Funds 2021 £	Unrestricted Funds £	Total Funds 2020 £
Costs of other trading activities	<u>30,491</u>	<u>30,491</u>	<u>74,446</u>	<u>74,446</u>

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# The Lily Foundation

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

Year ended 31 August 2021

#### 10. Expenditure on charitable activities by fund type

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Research Expenditure	76,694	72,032	148,726
Patient & Family Support	59,134	62,864	121,998
Awareness & Education	106,702	1,500	108,202
Support costs	8,969	—	8,969
	<u>251,499</u>	<u>136,396</u>	<u>387,895</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Research Expenditure	281,389	69,601	350,990
Patient & Family Support	63,235	72,737	135,972
Awareness & Education	130,033	13,500	143,533
Support costs	9,184	—	9,184
	<u>483,841</u>	<u>155,838</u>	<u>639,679</u>

#### 11. Expenditure on charitable activities by activity type

	Activities undertaken directly £	Grant funding of activities £	Support costs £	Total funds 2021 £	Total fund 2020 £
Research Expenditure	48,787	99,939	—	148,726	350,990
Patient & Family Support	121,998	—	—	121,998	135,972
Awareness & Education	108,202	—	—	108,202	143,533
Governance costs	—	—	8,969	8,969	9,184
	<u>278,987</u>	<u>99,939</u>	<u>8,969</u>	<u>387,895</u>	<u>639,679</u>

Support costs relate wholly to governance costs. A breakdown is as follows:

	2021 £	2020 £
Independent Examiner's Fee	750	750
Depreciation	95	214
Sundry Governance Costs	7,001	7,624
Insurance	1,123	596
	<u>8,969</u>	<u>9,184</u>

# The Lily Foundation

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

Year ended 31 August 2021

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#### 12. Analysis of grants

	2021 £	2020 £
<b>Grants to institutions</b>		
University of Sussex	45,278	–
Fondazione per la Ricerca Biomedica Avanzata Onlus - VIMM, Italy	25,432	–
Oxford University / St John Radcliffe Hospital	29,229	64,715
Newcastle University / WCMR	–	93,033
University College London	–	30,000
University of Cambridge	–	64,656
United Mitochondrial Disease Foundation	–	76,000
	<u>99,939</u>	<u>328,404</u>
Total grants	<u>99,939</u>	<u>328,404</u>

#### 13. Net income/(expenditure)

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

	2021 £	2020 £
Depreciation of tangible fixed assets	95	214
Operating lease rentals	<u>4,880</u>	<u>2,511</u>

#### 14. Independent examination fees

	2021 £	2020 £
Fees payable to the independent examiner for: Independent examination of the financial statements	<u>750</u>	<u>750</u>

#### 15. Particulars of employees

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

	2021 £	2020 £
Wages and salaries	218,433	241,917
Social security costs	15,235	24,846
Employer contributions to pension plans	4,833	5,248
	<u>238,501</u>	<u>272,011</u>



# The Lily Foundation

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 August 2021

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##### 15. Particulars of employees *(continued)*

The average head count of employees during the year was 7 (2020: 8). The average number of full-time equivalent employees during the year is analysed as follows:

	<b>2021</b>	2020
	<b>No.</b>	No.
Management	3	3
Other staff	2	2
	<u>5</u>	<u>5</u>

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

	<b>2021</b>	2020
	<b>No.</b>	No.
£60,000 to £69,999	1	1
	<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 £169,242 (2020:£170,733).

##### 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 £	<b>Total</b> £
<b>Cost</b>			
At 1 September 2020	284	2,989	3,273
Additions	–	150	150
<b>At 31 August 2021</b>	<u>284</u>	<u>3,139</u>	<u>3,423</u>
<b>Depreciation</b>			
At 1 September 2020	284	2,893	3,177
Charge for the year	–	95	95
<b>At 31 August 2021</b>	<u>284</u>	<u>2,988</u>	<u>3,272</u>
<b>Carrying amount</b>			
<b>At 31 August 2021</b>	<u>–</u>	<u>151</u>	<u>151</u>
At 31 August 2020	<u>–</u>	<u>96</u>	<u>96</u>

# The Lily Foundation

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 August 2021

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##### 18. Debtors

	2021 £	2020 £
Prepayments and accrued income	<u>75,562</u>	<u>49,632</u>

##### 19. Creditors: amounts falling due within one year

	2021 £	2020 £
Trade creditors	1,563	583
Accruals and deferred income	222,387	150,025
Social security and other taxes	7,897	9,349
Other creditors	<u>141,164</u>	<u>206,288</u>
	<u>373,011</u>	<u>366,245</u>

Within 'accruals and deferred income' there is an amount of £221,637 of deferred income (2020: £148,810) which relates to income received in advance for events taking place in the next financial year.

Deferred income of £20,585 (2020: £57,392) was released from the prior period. Income of £93,412 (2020: 148,810)

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

	2021 £	2020 £
Grant commitments at the start of the year	318,484	208,974
New grant commitments charged to the SoFA in the year	102,282	328,404
Grants paid during the year	<u>(237,465)</u>	<u>(218,894)</u>
Amount of grant commitments at the end of the year	<u>183,301</u>	<u>318,484</u>

  

	2021 £	2020 £
Amounts falling due within one year	141,164	206,288
Amounts falling due after one year	<u>42,137</u>	<u>112,196</u>
Amount of grant commitments at the end of the year	<u>183,301</u>	<u>318,484</u>

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

	2021 £	2020 £
Other creditors	<u>42,137</u>	<u>112,196</u>

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# The Lily Foundation

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 August 2021

#### 21. Pensions and other post retirement benefits

##### Defined contribution plans

The amount recognised in income or expenditure as an expense in relation to defined contribution plans was £4,833 (2020: £5,248).

#### 22. Analysis of charitable funds

##### Unrestricted funds

	At 1 September 2020 £	Income £	Expenditure £	Transfers £	At 31 August 2021 £
General funds	493,871	444,558	(372,009)	(32,403)	534,017
Designated Funds	415,072	–	–	32,403	447,475
	<u>908,943</u>	<u>444,558</u>	<u>(372,009)</u>	<u>–</u>	<u>981,492</u>

  

	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 Funds	–	–	–	415,072	415,072
	<u>1,016,957</u>	<u>553,555</u>	<u>(661,569)</u>	<u>–</u>	<u>908,943</u>

The charity had the following designated funds:

	2021 £	2020 £
Research Projects	275,000	273,572
Family Support Projects	78,000	121,500
Awareness/Education	12,000	–
Medical Database	20,000	20,000
Charity Variable Costs & Systems Updates	62,475	–
	<u>447,475</u>	<u>415,072</u>

# The Lily Foundation

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 August 2021

#### 22. Analysis of charitable funds *(continued)*

##### Restricted funds

	At 1 September 2020 £	Income £	Expenditure £	Transfers £	At 31 August 2021 £
Restricted Funds	—	136,396	(136,396)	—	—

  

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

During the year restricted donations and grants totalling £136,396 (2020:£155,838) were received from private donors and companies who wish to remain anonymous.

£72,032 was restricted to medical research projects (2020:£69,601), £nil was restricted to our Adult Support Weekend (2020: £4,000), £4,300 to patient psychological support (2020: £23,060), £nil to our Helping Hands Scheme (2020: £3,281), £nil to Patient Information Days (2020: £2,491), £15,814 to support staffing (2020: £39,905), £3,000 to respite breaks (2020: £nil), £30,000 to CRM development (2020: £nil), £4,750 to the "Manage my Mito" App (2020: £nil), £5,000 towards Patient Registry (2020: £nil) and £1,500 to global communications (2020: £13,500).

#### 23. Analysis of net assets between funds

	Unrestricted Funds £	Total Funds 2021 £
Tangible fixed assets	151	151
Current Assets	1,396,489	1,396,489
Creditors less than 1 year	(373,011)	(373,011)
Creditors greater than 1 year	(42,137)	(42,137)
<b>Net assets</b>	<b>981,492</b>	<b>981,492</b>

  

	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)
<b>Net assets</b>	<b>908,943</b>	<b>908,943</b>

# The Lily Foundation

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 August 2021

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#### 24. Analysis of changes in net debt

	At 1 Sep 2020 £	Cash flows £	At 31 Aug 2021 £
Cash at bank and in hand	<u>1,337,656</u>	<u>(16,729)</u>	<u>1,320,927</u>

  

	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>

#### 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).