COMPANY REGISTRATION NUMBER: 06400879 CHARITY REGISTRATION NUMBER: 1122071

The Lily Foundation
Company Limited by Guarantee
Unaudited Financial Statements
31 August 2022

Company Limited by Guarantee

Financial Statements

Year ended 31 August 2022

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Company Limited by Guarantee

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

Year ended 31 August 2022

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 2022.

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

Since 2008 we have invested heavily in diagnostic research through initiatives such as our Lily Exome Sequencing Project. We are diagnosing more patients and identifying new genes that can cause the condition, adding to the overall disease understanding. Our research strategy involves working closing with existing NHS diagnostic services to build collaborations between research institutes, doctors and patient groups. By facilitating the sharing of data and resources we have been able to streamline diagnostic pathways to make it easier for families to get the answers they need to plan their futures and open-up options for prenatal testing during pregnancy and IVF procedures for subsequent children. For doctors and scientists, genetic diagnoses can help guide patient management, and are the basis for research into new drug treatments.

As well as improving diagnosis, our research into mitochondrial genetics has also led to new ways to prevent transmission of severe mitochondrial disease, with new clues to how mitochondrial disease may be treated emerging all the time. We continue to run an annual internationally peer-reviewed research call, to draw in new and innovative projects for treating mitochondrial disease or alleviating symptoms. We are currently funding 9 exciting UK based projects looking at new treatments and therapies for mitochondrial disease and have ongoing international research collaborations with groups in Canada, Europe, and the USA.

Investing in this area, combined with our ability to campaign for better therapies and involving other linked disease areas, will open up a new era of mitochondrial research and fresh hope for patients and families.

Support

As diagnosis of mitochondrial diseases and awareness of The Lily Foundation continues to increase, so do the demands on our support services. The Lily Foundation continues to be the leading UK charity offering support to everyone affected by mitochondrial disease. 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 were able to offer a Lily Foundation Family weekend, providing face to face support for families affected by mitochondrial disease. The weekend presented the opportunity for parents and carers to receive education seminars and small group information sessions delivered by the UK leading mito specialists, while their children were cared for in an all inclusive kids club. There was plenty of opportunity too for social interaction between families over dinner and during Sunday's family fun day.

Unfortunately patient information days and our young adult weekend were not able to go ahead due to COVID restrictions.

Our weekly virtual coffee mornings, which were introduced during covid, are still running and still very popular. 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.

Our psychological support service continues, as we have access to one day a week of psychological support which is 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.

We continue to offer respite breaks for families to Center Parcs and have co-funded specialist equipment for those who suffer from mitochondrial diseases.

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 12%, Twitter by 5%, Facebook by 5% and LinkedIn we now have 272 followers.

We continue to improve and update our Lily Website 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 website continues to be an excellent resource for families and professionals all over the UK.

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 objective for the year ended 31 August 2022 was to raise £40k per month (£480k for the year). This was agreed by our board as being realistic to achieve as we emerged from the covid pandemic and gradually returned to face to face events. £480k was calculated to cover our fixed charity costs and avoid eating into our charity reserves where possible. We were delighted to have nearly doubled this target with £939K raised in the year.

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 2022/23 at £900,000 gross and £700,000 net before expenditure on charitable activities.

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 and function of the charity, which equates to £567,000 (2021: £434,000). This reserve amount includes salary freelance costs directly relating to charitable activities. 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 2022, the charity had free reserves of £1,237,093 (2021: £981,341), being unrestricted reserves less fixed assets. Of this amount £567,381 has been set aside in line with the charity reserves policy and a further £669,910 has been designated to charitable activity leaving £-197 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 £259,303 (2021: net revenue £72,549).

Reserves at the year end, before designation to specific charitable activities stood at £1,240,795 (2021: £981,492) and after designation to specific charitable activities was £570,885 (2021: £534,017).

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 patents 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 Renumeration

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.

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. 5 members of staff work in this area and we have invested £1,331,234 in this area to date. (2021: £1,091,842)

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 £2,953,846 in this area to date. (2021: £2,797,682)

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 £826,378 in this area to date. (2021: £697,128)

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.

Covid-19

Covid-19 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 did not impacted our day to day capabilities. Demand for our support services 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 were forced to cease e.g. events, staff were placed on furlough. Charitable activities which involved bringing patients together in large groups, like our patient residential weekends and information days, were temporarily suspended, but we are delighted that these have no all recommenced.

From a financial perspective, our low fixed cost base and prudent reserves policy ensured we were able to operate on low income. We are pleased to report that community fundraising and charitable events can now continue as they did pre-pandemic.

Although the impact of covid-19 caused delay in our longer-term research funding plans, we have designated funds to complete all contractually committed medical research and support services. All ongoing 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 maintained our core activities throughout the pandemic and 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 fundraising ball in Dec 2021 and our face-to-face Family Weekend in July 2022, both of which were huge successes. Overall, we feel confident that we not only survived the pandemic, but we have come out the other side stronger.

Plans for future periods

The Lily Foundation is committed to funding innovative research into 'Treatments for Mitochondrial Disease' which we hope will lead to medical breakthroughs to improve the lives of those living with mito. We plan to continue with our annual research call and increase our impact on a global scale by strengthening strategic partnerships and research collaborations with mitochondrial specialists and charities around the world.

The UK has always been at the forefront of genomic medicine and we have seen recent technological advances that could provide a real opportunity to improve diagnostic rates for patients. The Lily Foundation propose to collaborate with the three NHS Highly Specialised Services for mitochondrial disease (London, Newcastle, Oxford) as well as other UK specialist sites, to implement a new 'precision medicine genomic pipeline' across the whole UK, that will complement existing NHS services (not compete with them), will improve overall mito diagnostic rates, and will provide a proof of concept for a patient-centred approach to diagnosis that can be integrated into our National Health Service and replicated internationally.

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 continue 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.

With regards to supporting our patients and families, we aim to be responsive to the needs and wishes of our community. Our facebook groups are very active and we use these to assess the needs of our mito patients. Our family and young adult weekends are planned for next year. We are in talks with the HSS to extend our support to co-host patient information days for adults alongside each centre.

We aim to broaden the emotional and practical support we offer to all of patients, by employing a benefits advisor for one day a week and extending our psychological support to all patients, not just limited to young adults.

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. We support hospital accommodation costs when loved ones are in intensive care and cover travel and accommodation costs for those undergoing reproductive treatments in Newcastle.

We continue to raise awareness of The Lily Foundation and mitochondrial disease, last year, mitochondrial disease featured in a Coronation Street storyline, The Lily Foundation was very involved with the producers, script writers and actors to ensure the story was as true to a real life experience as possible. We are still benefiting from this exposure.

Our involvement in the passing of regulations to allow mitochondrial donation continues to throw us in the spotlight, as any news items around this topic will recognise our input. We continue to support patient groups around the world in their quest to have access to similar techniques in their own countries.

As a UK patent organisation we run a number of campaigns throughout the year to raise awareness of mitochondrial disease, its impact on individuals and families, within our patient, medical, pharma, social work and education communities to support those living with mitochondrial diseases.

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 2022.

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.

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 2022 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

Reference and administrative details

Registered charity name The Lily Foundation

Charity registration number1122071Company registration number06400879

Principal office and registered 31 Warren Park office 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.

Company secretary Mrs S Hanks

Independent examiner 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.

The trustees' annual report was approved on 24 May 2023 and signed on behalf of the board of trustees by:

Mrs H Rider

Trustee

Company Limited by Guarantee

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

Year ended 31 August 2022

I report to the trustees on my examination of the financial statements of The Lily Foundation ('the company') for the year ended 31 August 2022.

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).

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.

Mr S Joberns FCA Shipleys LLP Independent Examiner 10 Orange Street Haymarket London WC2H 7DQ 24 May 2023

The Lily Foundation

Company Limited by Guarantee

Statement of Financial Activities

(including income and expenditure account)

Year ended 31 August 2022

			2022		2021
		Unrestricted	Restricted		
		funds	funds	Total funds	Total funds
	Note	£	£	£	£
Income and endowments					
Donations and legacies	5	603,690	153,420	757,110	556,537
Other trading activities	6	180,888	_	180,888	24,187
Investment income	7	1,124	_	1,124	230
Total income				939,122	580,954
Expenditure					
Expenditure on raising funds:					
Costs of raising donations and					
legacies	8	(95,868)	(5,000)	(100,868)	(90,019)
Costs of other trading activities	9	(134,242)	(5,000)	(139,242)	(30,491)
Expenditure on charitable activities	10,11	(296,289)	(143,420)		(387,895)
Total expenditure		(526,399)		(679,819)	
Net income and net movement in fun	nds	259,303	_	259,303	72,549
Reconciliation of funds					
Reconciliation of funds Total funds brought forward		981,492	_	981,492	908,943

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

Company Limited by Guarantee

Statement of Financial Position

31 August 2022

		2022	2021
	Note	£	£
Fixed assets			
Tangible fixed assets	17	3,702	151
Current assets			
Debtors	18	52,608	75,562
Cash at bank and in hand		1,511,579	
		1,564,187	1,396,489
Creditors: amounts falling due within one year	19	(327,094)	(373,011)
Net current assets		1,237,093	
Total assets less current liabilities		1,240,795	1,023,629
Creditors: amounts falling due after more than one year	20	_	(42,137)
Net assets		1,240,795	981,492
Funds of the charity			
Unrestricted funds		1,240,795	981,492
Total charity funds	22	1,240,795	981,492

For the year ending 31 August 2022 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 24 May 2023, and are signed on behalf of the board by:

Mrs H Rider Trustee Director and Treasurer

Company Limited by Guarantee

Statement of Cash Flows

Year ended 31 August 2022

	2022	2021
	£	£
Cash flows from operating activities		
Net income	259,303	72,549
Adjustments for:		
Depreciation of tangible fixed assets	1,184	95
Other interest receivable and similar income	(1,124)	(230)
Accrued expenses	707	72,362
Changes in:		
Trade and other debtors	22,954	(25,930)
Trade and other creditors	(88,761)	(135,655)
Cash generated from operations	194,263	(16,809)
Interest received	1,124	230
Net cash from/(used in) operating activities	195,387	(16,579)
Cash flows from investing activities		
Purchase of tangible assets	(4,735)	(150)
Net cash used in investing activities	(4,735)	
Net increase/(decrease) in cash and cash equivalents	190,652	(16,729)
Cash and cash equivalents at beginning of year	1,320,927	1,337,656
Cash and cash equivalents at end of year	1,511,579	1,320,927

Company Limited by Guarantee

Notes to the Financial Statements

Year ended 31 August 2022

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.

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.

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.

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. 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 (2021 - 8 members).

5. Donations and legacies

	Unrestr F	ricted Ro unds £	estricted Funds £	Total Funds 2022 £
Other donations and legacies		2	4-	~
Donations & Sponsorship	603,690	153,420	757,	
	Unrestri	cted Re	stricted	Total Funds
	Fu	unds	Funds	2021
		£	£	£
Other donations and legacies				
Donations & Sponsorship	420,141	136,396	556,	537

Within unrestricted funds there is an amount of £0 (2021: £8,688) 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

6. Other trading activities					
	Unre	stricted	Total Funds	Unrestricted	Total Funds
		Funds	2022	Funds	2021
		£	£	£	£
Activities for generatir	ng funds	180,888	180,888	24,187	24,187
7 (
7. Investment income					
	Unre	estricted	Total Funds	Unrestricted	Total Funds
		Funds	2022	Funds	2021
		£	£	£	£
Investment income		1,124	1,124 	230	230
8. Costs of raising donation	ons and legacies				
· ·	v		Unrestricted	Restricted	Total Funds
			Funds	Funds	2022
			£	£	£
Costs of raising donat	tions and legacies - Donations		95,868	5,000	100,868
Goods of falling dorlar	nono ana logacico Donanono				
			Unrestricted	Restricted	Total Funds
			Funds	Funds	2021
			£	£	£
Costs of raising donat	tions and legacies - Donations		90,019	_	90,019
9. Costs of other trading a	ctivities				
			Unrestricted	Restricted	Total Funds
			Funds	Funds	2022
			£	£	£
Costs of other trading	activities		134,242	5,000	139,242
			Unrestricted	Restricted	Total Funds
			Funds	Funds	2021
			£	£	£
Costs of other trading	activities		30,491	_	30,491
	· · · ·				

10. Expenditure on charitable activities by fund type

Total grants

To. Experience on one make a convictor by	rana typo	Unrestricted	Restricted	
		Funds	Funds	
		£	£	
Research Expenditure		37,163	19,000	•
Patient & Family Support		119,972	119,420	
Awareness & Education		124,250	5,000	
Support costs		14,904		- 14,904
		296,289	143,420	
		Unrestricted	Restricted	Total Funds
		Funds	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
		251,499	136,396	
11. Expenditure on charitable activities by	activity tyne			
The Experience on one made don miles by	Activities			
	undertaken		Total funds	
	directly	Support costs	2022	Total fund 2021
	£	£	£	£
Research Expenditure	56,163	_	56,163	148,726
Patient & Family Support	239,392	_	239,392	121,998
Awareness & Education	129,250	_	129,250	108,202
Governance costs	_	14,904	14,904	
	424,805	14,904	439,709	387,895
Support costs relate wholly to governance cos	sts. A breakdown is a	as follows:		·
			2022	2021
			£	£
Independent Examiner's Fee			750	750
Depreciation			1,184	95
Sundry Governance Costs		1	1,799	7,001
Insurance			1,172	1,123
		1	4,905	8,969
12. Analysis of grants				
, ,		2022	2021	
		£	£	
Grants to institutions				
University of Sussex		_	45,278	
Fondazione per la Ricerca Biomedica Avanza	ta Onlus - VIMM, Ita	ly –	25,432	
Oxford University / St John Radcliffe Hospital		_	29,229	
			99,939	

99,939

13. Net income

Net income is stated after charging/(crediting):

	2022	2021
	£	£
Depreciation of tangible fixed assets	1,184	95
Operating lease rentals	6,382	4,880
14. Independent examination fees		
	2022	2021
	£	£
Fees payable to the independent examiner for:		
Independent examination of the financial statements	750	750

15. Particulars of employees

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

	2022	2021
	£	£
Wages and salaries	287,155	218,433
Social security costs	26,667	15,235
Employer contributions to pension plans	6,259	4,833
	320,081	238,501

The average head count of employees during the year was 9 (2021: 7). The average number of full-time equivalent employees during the year is analysed as follows:

	2022	2021
	No.	No.
Management	3	3
Other staff	4	2
	7	5

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

	2022	2021
	No.	No.
£60,000 to £69,999	2	1

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 £180,612 (2021:£169,242).

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

v	Fixtures and fittings	Equipment £	Total £
Cost	~	~	_
At 1 September 2021	284	3,139	3,423
Additions	_	4,735	4,735
At 31 August 2022	284	7,874	8,158
Depreciation			
At 1 September 2021	284	2,988	3,272
Charge for the year	_	1,184	1,184
At 31 August 2022	284	4,172	
Carrying amount			****
At 31 August 2022	_	3,702	3,702
At 31 August 2021		151	151
18. Debtors			****
		2022	2021
		£	£
Prepayments and accrued income		52,608	75,562
19. Creditors: amounts falling due within one year			
		2022	2021
		£	£
Trade creditors		2,004	1,563
Accruals and deferred income		223,094	222,387
Social security and other taxes		13,142	7,897
Other creditors		88,854	141,164
		327,094	373,011

Within 'accruals and deferred income' there is an amount of £221,894 of deferred income (2021: £221,637) which relates to income received in advance for fundraising events and charitable activities taking place in the next financial year. Deferred income of £196,818 (2021: £20,585) was released during the period. Income of £197,075 (2021: £93,412) was deferred during the year. Movement in grant commitments within 'other creditors' is stated in the table below:

		2022	2021
	£	£	
Grant commitments at the start of the year		183,301	318,484
New grant commitments charged to the SoFA in the year	_		102,282
Grants paid during the year		(94,447)	(237,465)
Amount of grant commitments at the end of the year		88,854	183,301
		2022	2021
	£	£	ı
Amounts falling due within one year		88,854	141,164
Amounts falling due after one year	_		42,137
Amount of grant commitments at the end of the year		88,854	183,301
20. Creditors: amounts falling due after more than one year			
		2022	2021
		£	£
Other creditors		_	42,137

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 £ 6,259 (2021: £ 4,833).

22. Analysis of charitable funds Unrestricted funds

	At 1 September				At 31 August
	2021	Income	Expenditure	Transfers	2022
	£	£	£	£	£
General funds	534,017	785,702	(526,399)	(222,435)	570,885
Designated Funds	447,475	_	_	222,435	669,910
	981,492	785,702	(526,399)	-	1,240,795
	At 1 September				At 31 August
	2020	Income	Expenditure	Transfers	2021
	£	£	£	£	£
General funds	493,871	444,558	(372,009)	(32,403)	534,017
Designated Funds	415,072	_	_	32,403	447,475
	908,943	444,558	(372,009)	_	981,492

The charity had the following designated funds:

	2022	2021
	£	£
Research Projects	374,800	275,000
Family Support Projects	257,110	78,000
Awareness/Education	30,000	12,000
Medical Database	_	20,000
Charity Variable Costs & Systems Updates	8,000	62,475
	669,910	447,475

Restricted funds

	At 1 September				At 31 August
	2021	Income	Expenditure	Transfers	2022
	£	£	£	£	£
Restricted Funds	_	153,420	(153,420)	_	_
	At 1 September				At 31 August
	2020	Income	Expenditure	Transfers	2021
	£	£	£	£	£
Restricted Funds	_	136,396	(136,396)	_	_

During the year restricted donations and grants totalling £153,420 (2021:£136,396) were received from private donors and companies who wish to remain anonymous.

£19,000 was restricted to medical research projects (2021:£72,032), £119,420 was restricted to patient support services (2021:£62,864), £5,000 was restricted to awareness (2021:£1,500), £5,000 towards trading activities and £5,000 was restricted to fundraising (2021:£nil).

23. Analysis of net assets between funds

	Unrestricted	Total Funds
	Funds	2022
	£	£
Tangible fixed assets	3,702	3,702
Current Assets	1,564,187	1,564,187
Creditors less than 1 year	(327,094)	(327,094)
Creditors greater than 1 year	_	_
Net assets	1,240,795	1,240,795
	Unrestricted	Total Funds
	Omodinolog	rotar rando
	Funds	2021
Tangible fixed assets	Funds	2021
Tangible fixed assets Current Assets	Funds £	2021 £
-	Funds £ 151	2021 £ 151
Current Assets	Funds £ 151 1,396,489	2021 £ 151 1,396,489
Current Assets Creditors less than 1 year	Funds £ 151 1,396,489 (373,011)	2021 £ 151 1,396,489 (373,011)

24. Analysis of changes in net debt

	At 1 Sep 2021	Cash flows	At 31 Aug 2022
	£	£	£
Cash at bank and in hand	1,320,927	190,652	1,511,579

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

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).

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