



Recognition · Research · Rehabilitation

LONG COVID SOS

**ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED
31 MARCH 2023**

Charity Number 1199120
(England and Wales)

LONG COVID SOS

ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS

FOR THE YEAR ENDED

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GENERAL INFORMATION

Registered charity name	Long Covid SOS
Charity number	1199120
Company Number	
Principal & registered office address	11A Westland Road Faringdon Oxfordshire SN7 7EX
Trustees at 31 March 2023	Dr L Baines Dr K Matthews Professor A Banerjee Mr P Haylock Mr D Broad
Secretary	
Accountants	N/A
Independent examiner	N/A
Bankers	Lloyds Bank

Objectives and Activities

Our charity was founded on 30 May 2022. The charity was originally formed by a group of volunteers in 2020 who suffered from the aftereffects of catching COVID-19. Many people do not recover from COVID-19 and are diagnosed with Long Covid.

The objects of the CIO are for the advancement of health and relief of need among people with Long Covid, their families and carers for the public benefit by: 1. Raising awareness of Long Covid, its treatment, recovery and rehabilitation among health policymakers, healthcare providers and the general public; 2. Advocating for and making known to healthcare providers, health policymakers and other relevant policy makers the views and lived experience of members of the general public suffering from or affected by Long Covid; 3. Supporting or carrying out research into the causes, prevention, diagnosis and treatment of Long Covid, and publishing the useful results of such research. For the purpose of the objects 'Long Covid' means Post-Acute Covid-19 syndrome, where symptoms and/or long-term complications occur beyond four weeks from initial infection or symptom onset to include any post viral illness, with a suspected or evidenced link to Covid-19. Our purpose can be found in our Memorandum and Articles of Association.

The three pillars of the organisation are recognition, research and rehabilitation. Activities are designed to fit within these categories as follows:

Recognition: Long Covid SOS campaigns for recognition and support from government organisations, international bodies, employers, healthcare providers and the general public. These campaign objectives are amplified through social media channels, by means of press and broadcast media, and by direct interaction with health policymakers. The organisation also collaborates with other advocates both in the UK and abroad in order to strengthen the message and increase impact. The organisation is now working with NHS England and other charities to increase recognition among those in under-served communities. The charity is also working with medical professional societies such as the Royal College of General Practitioners (RCGP) and Royal College of Speech and Language Therapists to raise awareness of Long Covid within these professions.

Research: Long Covid SOS works closely with academics and scientists to ensure that research is timely, appropriate, fulfils the needs of those with Long Covid, and that people with lived experience are involved in the development, implementation, and dissemination of research. Volunteers in the organisation are involved as advisors, co-investigators and members of expert panels/steering committees for several research projects funded by the National Institute for Health Research (NIHR). A key outcome of one of these projects is the development of a new Patient Reported Outcome (PRO) measure, the Symptom Burden Questionnaire for Long Covid (SBQ-LC). This is in recognition of the inability of other widely used PROs to adequately reflect the burden within the condition due to its relapsing and remitting nature. The organisation uses its social media channels to inform the Long Covid community about current and future research projects and liaises with researchers to find individuals with lived experience to better inform their projects. The organisation disseminates amongst its communities any updates and outcomes on the research it supports.

Prior to becoming a Charity in May 2022, volunteers from the organisation belonged to the NIHR Expert Panel on Long Covid, which advised on research questions and the panel assessing the suitability of research projects for the two funded calls into Long Covid. Long Covid SOS also campaigns for better research; After an appeal to the Secretary of State for Health and Social Care in a roundtable meeting in 2021 for research funding into therapeutics for Long Covid, and a subsequent letter, the second NIHR £20m funding call was announced. In addition, Long Covid SOS carries out its own research projects including a major survey into the impact of COVID-19 vaccination on Long Covid symptoms which has been published in academic preprint and cited widely by institutions such as NICE, the ONS, SAGE and the CDC.

Rehabilitation: Through extensive connections with the NHS and other healthcare providers, Long Covid SOS advocates for appropriate care and rehabilitation for Long Covid patients. The views of followers on social media and members of support groups are transmitted to those responsible for making policy decisions on healthcare, informally in further meetings and also through surveys and reports. Membership of the NHS England Taskforce, its subgroups and

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the Long Covid roundtable ensures that the patient voice is heard by decision makers. In addition to these three broad aims, Long Covid SOS provides information and support to people living with the condition.

Long Covid SOS is a stakeholder with NICE for the Covid-19 technology appraisals and Long Covid guidelines.

We aim to deliver our objectives by improving the recognition of Long Covid so that patients do not struggle to get care. Recognition of the condition leads to more attention from government, better funding of services, priority setting on the part of the NHS and more understanding from medical professionals. Long Covid SOS works with researchers and institutions to promote research which can establish the mechanisms which cause Long Covid in order to facilitate the study, testing and implementation of treatments to help alleviate the symptoms and establish strategies to prevent the development of the condition. Long Covid SOS encourages the inclusion of the lived experience voice through patient and public involvement and engagement within research projects. Long Covid SOS improves the health of those living with Long Covid by advocating for healthcare services that are appropriate, beneficial, comprehensive, local and available to all sections of society.

Achievements and Performance

May 2022: Long Covid SOS joined the coalition of organisations which form the Covid Safety Pledge campaign, which has been set up to encourage workplaces – and specifically those which are also public spaces such as bars, restaurants, cinemas, libraries etc. – to adopt measures designed to minimise the spread of Covid infections. This will both meet legal Health & Safety requirements and reassure all customers/service users that they can visit in safety.

July 2022: Long Covid SOS launched the Take the Plunge campaign to encourage people to fundraise and experience the benefits that cold water can bring to many Long Covid symptoms. £3,504 has been raised to date

Sept 2022: a letter written by Long Covid SOS to Secretary of State for Health and Social Care Thérèse Coffey was published in the British Medical Journal

October 2022: along with two other Long Covid advocacy groups, Long Covid SOS were granted Core Participant status in Module 2 of the UK Covid-19 Inquiry. Core participant status for Module 3 was granted in February 2023

December 2022: Long Covid SOS calendar launched, all copies sold raising £1,000

January 2023: Long Covid SOS, in collaboration with 20 other organisations, wrote to Secretary of State for Health and Social Care Steve Barclay MP calling on him to support an Act to ensure that clean air is available to people in public indoor spaces to ensure their safety

January 2023: members of Long Covid SOS were co-authors in a rapid response to a BMJ published paper on Long Covid which contained misleading assertions

March 2023: Long Covid SOS took part in International Long Covid Awareness month and released a new short film which has had tens of thousands of views online and which was broadcast on BBC East Midlands Today

March 2023: along with other Long Covid charities we successfully advocated for the BBC to withdraw an inappropriate headline relating to Long Covid, prompting public apologies from the parties quoted

In addition:

- Long Covid SOS and its team members were featured in 30 news media articles during the year
- 25 blog posts were published on the Long Covid SOS website
- Long Covid SOS is in the process of an application to be formal partners with the World Health Organisation under their Framework of Engagement with Non-State Actors (FENSA) programme

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Information Assurance

The Long Covid SOS Trustee Board oversees information security policies and systems for the processing of all personal information of our subscribers, volunteers, funders and strategic partners. An information assurance management team exists to ensure that confidentiality, integrity and availability of all personal and sensitive data is maintained to a level which is compliant with the requirements of the UK General Data Protection Regulation and Data Protection Act 2018.

Structure, Governance and Management

The charity is run entirely by volunteers and as such we do not have any paid staff. The running of the organisation is overseen by a Trustee Board of eight individuals. Five of these individuals were appointed in 2022/23 and a further three have been appointed since 1 April 2023.

The charity has no premises responsibility, as all volunteers and Trustees conduct charity business remotely.

Risk Management

The Trustees have worked on and agreed a Risk Management strategy, register and plan during the year. The Trustees recognise that any major risks to which the charity is exposed need to be reviewed and systems put in place to mitigate those risks. To this end, we are continually monitoring and managing our risks, reviewing the risk register and ensuring action plans are in place to mitigate the key risks.

Public Benefit

The Trustees take into account the Charity Commission guidance on public benefit and are confident that the activities of Long Covid SOS are fully in line with that guidance.

Financial review

Our Financial Position

Since its formation in 2021 and up until 31 March 2023, Long Covid SOS has delivered a surplus of £9,724. The main source of income generated is from donations through various fundraising activities.

With one of the charity's objectives for 2023/24 being to generate further income through fundraising, we are anticipating that we will be able to generate significantly more income than we did in 2022/23, and continue to work closely with our strategic partners in delivering the much-needed support for those members of the population who suffer with the impact of Long Covid. We anticipate that this will enable us to maintain a financially stable position, however, this is something which the Board will continue to closely monitor.

Reserves Policy

The charity has a policy of retaining sufficient unrestricted reserves to finance its planned programme and meet its future financial obligations.

For this purpose, the Trustees have established systems to monitor financial performance and to forecast future commitments and reserves for a minimum of 12 months ahead. Where any potential shortfall is identified, the charity has a policy of amending future activities or cutting overhead costs in order to maintain a sufficient level of unrestricted reserves. The policy is reviewed on an annual basis.

Trustee Responsibilities

Charity law requires the Trustees to prepare the accounts for each financial year which provide a true and fair view of the state of affairs of the charity and of the surplus or deficit for that period. In preparing those accounts the Trustees are required to:

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- Select suitable accounting policies and apply them consistently
- Make judgements and estimates that are reasonable and prudent
- State whether applicable accounting standards and statements of recommended practice have been followed, subject to any departures disclosed and explained in the financial statements; and
- Prepare the accounts on the going concern basis unless it is appropriate to presume that the charity will continue in operational existence.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the charity and hence taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees annual report was approved on 13 November 2023 and signed on behalf of the Board of Trustees by:

A handwritten signature in blue ink that reads "Linda Baines". The signature is written in a cursive, flowing style.

Linda Baines
Trustee

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STATEMENT OF FINANCIAL ACTIVITIES including INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 MARCH 2023

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Income from:							
Donations and legacies	3	9,957	420	10,377	-	-	-
Sales	4	912	-	912	-	-	-
Total income		10,869	420	11,289	-	-	-
Expenditure on:							
Charitable activities	5	455	420	875	-	-	-
Raising funds	6	690	-	690	-	-	-
Total expenditure		1,145	420	1,565	-	-	-
Net income / (expenditure)		9,724	-	9,724	-	-	-
Transfers between funds		-	-	-	-	-	-
Net movement in funds		9,724	-	9,724	-	-	-
Reconciliation of funds:							
Total funds brought forwards		-	-	9,724	-	-	-
Total funds carried forward		9,724	-	9,724	-	-	-

The Statement of Financial Activities includes all gains and losses in the year and therefore a statement of total recognised gains and losses has not been prepared.

All of the above amounts relate to continuing activities.

The notes on pages 9 to 12 form part of these financial statements.

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BALANCE SHEET AS AT 31 MARCH 2023

		2023		2022	
	Note	£	£	£	£
Fixed Assets					
Tangible assets	13		-		-
Current assets					
Cash at bank and in hand		9,724		-	
		<u>9,724</u>		<u>-</u>	
Net current assets			9,724		-
Net assets			<u>9,724</u>		<u>-</u>
The funds of the charity					
Funds					
Unrestricted income funds			9,724		-
Restricted income funds			-		-
Total funds	8		<u>9,724</u>		<u>9,724</u>

These accounts were approved by the Trustees on 13 November 2023 and are signed on behalf of the board by:



Linda Baines
Trustee

1. COMPANY STATUS AND STATEMENT OF COMPLIANCE

The charity is a public benefit entity and is a registered charity in England and Wales.

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)).

2. 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

The accounts have been prepared on a going concern basis as, in the opinion of the Trustees the Charity will continue in operation for the foreseeable future.

Fund accounting

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity.

Designated funds are unrestricted funds earmarked by the trustees for a 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

All income is included in the statement of financial activities when the charity is legally entitled to the income and the amount can be quantified with reasonable accuracy.

Voluntary income is received by way of grants, donations and gifts and is included in full in the Statement of Financial Activities when receivable. Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes unconditionally entitled to the grant.

Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Expenditure represents amounts invoiced, including value added tax.

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

It is our policy to capitalise all items costing in excess of £500 which have a useful life exceeding one year. Tangible assets (excluding investments) are initially recorded at cost and subsequently stated at cost less any accumulated depreciation and impairment losses. Any tangible assets carried at revalued amounts are recorded at the fair value at the date of revaluation less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

An increase in the carrying amount of an asset as a result of a revaluation, is recognised in other recognised gains and losses, unless it reverses a charge for impairment that has previously been recognised as expenditure within the statement of financial activities. A decrease in the carrying amount of an asset as a result of revaluation, is recognised in other recognised gains and losses, except to which it offsets any previous revaluation gain, in which case the loss is shown within other recognised gains and losses on the statement of financial activities.

Depreciation

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

- Fixtures and fittings – 25% straight line
- Leasehold improvements – over the length of the lease

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 charity 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.

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.

Where investments in shares are publicly traded or their fair value can otherwise be measured reliably, the investment is subsequently measured at fair value with changes in fair value recognised in income and expenditure. All other such investments are subsequently measured at cost less impairment.

Other financial instruments, including derivatives, are initially recognised at fair value, unless payment for an asset is deferred beyond normal business terms or financed at a rate of interest that is not a market rate, in which case the asset is measured at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Other financial instruments are subsequently measured at fair value, with any changes recognised in the statement of financial activities, with the exception of hedging instruments in a designated hedging relationship.

Financial assets that are measured at cost or amortised cost are reviewed for objective evidence of impairment at the end of each reporting date. If there is objective evidence of impairment, an impairment loss is recognised under the appropriate heading in the statement of financial activities in which the initial gain was recognised.

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NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

For all equity instruments regardless of significance, and other financial assets that are individually significant, these are assessed individually for impairment. Other financial assets are either assessed individually or grouped on the basis of similar credit risk characteristics.

Any reversals of impairment are recognised immediately, to the extent that the reversal does not result in a carrying amount of the financial asset that exceeds what the carrying amount would have been had the impairment not previously been recognised.

Creditors

Creditors are recognised when the goods or service have been received and payment is crystallised. They are valued at the amount invoiced, or expected to be invoiced, including value added tax.

Taxation

The Charity is exempt from corporation tax on its charitable activities.

3. DONATIONS AND LEGACIES

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £	Total Funds 2022 £
Donations				
Donations	9,957	420	10,377	-
	<u>9,957</u>	<u>420</u>	<u>10,377</u>	<u>-</u>

4. INCOME FROM OTHER ACTIVITIES

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £	Total Funds 2022 £
Sales				
Sales	912	-	912	-
	<u>912</u>	<u>-</u>	<u>912</u>	<u>-</u>

5. EXPENDITURE ON RAISING FUNDS

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £	Total Funds 2022 £
Calendar Printing				
Calendar Printing	388	-	388	-
Purchase of Hoodies for sale				
Purchase of Hoodies for sale	302	-	302	-
	<u>690</u>	<u>-</u>	<u>690</u>	<u>-</u>

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NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

6. EXPENDITURE ON CHARITABLE ACTIVITIES

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £	Total Funds 2022 £
Website Costs	309	420	729	-
Other Costs	50	-	50	-
Governance costs	96	-	96	-
	<u>455</u>	<u>420</u>	<u>875</u>	<u>-</u>

7. TRUSTEE REMUNERATION AND EXPENSES

No remuneration or other benefits from employment with the charity or a related entity were received by the Trustees.

8. ANALYSIS OF CHARITABLE FUNDS

Unrestricted funds

	At 1 April 2022 £	Income £	Expenditure £	At 31 March 2023 £
General funds	-	11,289	1,565	9,724
	<u>-</u>	<u>11,289</u>	<u>1,565</u>	<u>9,724</u>