

Charity registration number 1201757

Company registration number CE031265 (England and Wales)

KEEP ME BREATHING

ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS

FOR THE PERIOD ENDED 29 FEBRUARY 2024

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LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Mr J D Oakley Miss S L Roberts Miss E L Lucas Mrs E F Kent	(Appointed 27 January 2023) (Appointed 27 January 2023) (Appointed 27 January 2023) (Appointed 15 April 2023)
Charity number	1201757	
Company number	CE031265	
Registered office	83 Rowan Avenue Hove England BN3 7JH	
Independent examiner	Carpenter Box Amelia House Crescent Road Worthing West Sussex BN11 1RL	

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TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE PERIOD ENDED 29 FEBRUARY 2024

The trustees present their annual report and financial statements for the period ended 29 February 2024.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's governing document, the Companies Act 2006 and "Accounting and Reporting by Charities: 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)" (effective 1 January 2019).

Objectives and activities

The charity sets out to advance health and save lives through:

- Promoting public awareness of congenital central hypoventilation syndrome (CCHS) and the issues surrounding the condition.
- Promoting or assisting the promotion of research.
- Publishing or ensuring the publication of the useful results of such research.
- Educating the medical profession, other healthcare professionals, patients and their families and the public at large about congenital central hypoventilation syndrome, its treatment and associated research.
- Undertaking research to pursue the development of new and advanced treatments.

The main activities that the charity does that enable the above purposes include:

- Fundraising events
- Media outreach and wider communication online
- Product research and development
- Patient and professional networking events

Public benefit

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

In order to further the charity's purposes for the public benefit, the charity:

- Organises media interviews to explain about CCHS and unmet need;
- Attends festivals and events to educate about CCHS while also raising money;
- Speaks at events such as business networking meetings;
- Provides a website providing up-to-date information and resources about CCHS; and
- Undertakes research and development to create enhanced products for those affected by CCHS.

Achievements and performance

The charity has secured a world class advisory board made up of ten medical, scientific and business professionals. In total more than 130 Scientists, Medical, Rare Disease and Healthcare Professionals have signed up to our Keep Me Breathing Letter of Support.

We have run over 30 fundraising events ranging from sports challenges, charity balls, local business charity days, auctions and musical performances.

We have secured individual grants worth over £50,000 specifically to support our research and development projects.

We have worked with national and local media to generate over twenty pieces of significant media coverage to raise awareness and educate about CCHS.

The charity has attended numerous networking events with other patient groups, healthcare professionals, scientists and businesses.

To date over £400,000 has been raised to meet the main purpose of the charity, the research and development of advanced treatments for CCHS.

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TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE PERIOD ENDED 29 FEBRUARY 2024

The research and development team has developed a prototype of an initial product and a protocol and framework for testing is currently being finalised. Research is also underway into the development of a second device, an advanced diaphragm pacer.

Financial review

The charity received income of £345,092 for the 2023/24 financial period. The total expenditure of the charity for the period was £32,103. The amount of total funds the charity holds at the end of the reporting period to 29 February 2024 was £312,989, made up of £199,158 restricted and £113,831 unrestricted funds.

Reserves policy

Keep Me Breathing aims to hold an amount as a reserve which is intended to cover regular monthly outgoings for around four to five months, including financial, IT charges and staff costs, which currently amounts to £35,000.

Plans for future periods

We are progressing our 5-year product development plan which was developed by Cambridge University and backed by over 130 experts with backgrounds in genetics, medicine, clinical research, engineering, innovation and business.

The implementation of this plan is well underway with a team of scientists and medical engineers, who are harnessing new technologies such as 3D printing and rapid prototyping to accelerate our progress. The goal is an implantable biofeedback diaphragm pacer system that will be capable of sensing and automatically adjusting to the patient's ventilatory needs. It won't need a wired connection to an outside device and works like a cardiac pacer.

Plans are also underway around the clinical testing of the device within a robust protocol that will provide all the necessary safeguards whilst providing feedback data needed to ensure long-term safety and efficacy. We are working in accordance with latest regulatory frameworks as set out by the Food and Drug Administration (FDA) and the European Union Medical Device Regulation (EUMDR) in order to gain straightforward Medicines and Healthcare products Regulatory Agency (MHRA) and ethics approvals for clinical studies. CE marking will allow wider access to the technology for other conditions that will benefit from its mode of action, phrenic nerve stimulation.

We are also exploring other avenues such as investigating clinical trial data around drugs that have had some positive results in supporting breathing in CCHS patients.

We are working continuously to grow our network of stakeholders invested in supporting us on our product development journey, both from a clinical, academic and business perspective. This support is growing as our research and development work continues to take pace.

We have added to our team at Keep Me Breathing since the period-end, having taken on two members of staff to support the day-to-day running of the charity and in particular to enhance our communication, to run fundraising activities and to seek new donors and supporters for our work. As we achieve more funding we will look at building on our team further, to bring other skills into the organisation which will enable us to work at an even greater pace to realise our goals. We know there are families around the world counting on us to help them transform their lives and we are deeply committed to make this happen as quickly as we can.

Structure, governance and management

Keep Me Breathing, charity number 1201757, is incorporated as a charitable incorporated organisation (CIO), registered in England and governed by its governing document, called "The Constitution" dated 8 October 2022.

The trustees, who are also the directors for the purpose of company law, and who served during the period and up to the date of signature of the financial statements were:

Mr J D Oakley	(Appointed 27 January 2023)
Miss S L Roberts	(Appointed 27 January 2023)
Miss E L Lucas	(Appointed 27 January 2023)
Mrs E F Kent	(Appointed 15 April 2023)

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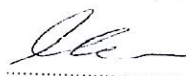
TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE PERIOD ENDED 29 FEBRUARY 2024

Recruitment and appointment of trustees

There are only four current charity trustees. The two founders, Mr J Oakley and Miss S Roberts, plus another parent with a child diagnosed by CCHS, Mrs E Kent, who also has skills and expertise in marketing and running events. The fourth trustee, Miss E Lucas, works for a local large business and is well-networked in the local area. All trustees are chosen for their interest in the charity's work and the skills they are able to provide to the charity.

The charity's trustees, its one employee (employed post year-end) and all contractors are aware of the charity's principles and working framework as set out within its Constitution, especially in relation to financials; benefits and payments including appropriate use of the charity's funds when paying for goods and services required by the charity. There is an expense policy in place to cover use of expenses by trustees and its employee.

The trustees' report was approved by the Board of Trustees.

 J. OAKLEY

Mr J D Oakley
Trustee

Date: 25/11/24

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INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF KEEP ME BREATHING

I report to the trustees on my examination of the financial statements of Keep Me Breathing (the charity) for the period ended 29 February 2024.

Responsibilities and basis of report

As the trustees of the charity (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 financial statements of the charity 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 charity's financial statements carried out under section 145 of the Charities Act 2011 (the 2011 Act). In carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

Since the charity'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 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 that in any material respect:

- 1 accounting records were not kept in respect of the charity 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 financial statements to be reached.



Robin Evans BA FCA CTA DChA

Amelia House
Crescent Road
Worthing
West Sussex
BN11 1RL

Dated: 26/11/2024

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STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE PERIOD ENDED 29 FEBRUARY 2024

	Notes	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Income from:				
Donations and legacies	3	138,451	199,158	337,609
Other trading activities	4	7,483	-	7,483
Total income		<u>145,934</u>	<u>199,158</u>	<u>345,092</u>
Expenditure on:				
Raising funds	5	6,020	-	6,020
Charitable activities	6	26,083	-	26,083
Total expenditure		<u>32,103</u>	<u>-</u>	<u>32,103</u>
Net income and movement in funds		<u>113,831</u>	<u>199,158</u>	<u>312,989</u>
Reconciliation of funds:				
Fund balances at 27 January 2023		-	-	-
Fund balances at 29 February 2024		<u>113,831</u>	<u>199,158</u>	<u>312,989</u>

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

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

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BALANCE SHEET

AS AT 29 FEBRUARY 2024

	Notes	2024 £	£
Current assets			
Debtors			
Cash at bank and in hand	10	500	
		331,989	
		<u>332,489</u>	
Creditors: amounts falling due within one year	11	(19,500)	
Net current assets			<u>312,989</u>
The funds of the charity			
Restricted income funds			
Unrestricted funds	13	199,158	
		<u>113,831</u>	
			<u>312,989</u>

The charitable company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the period ended 29 February 2024.

The trustees acknowledge their responsibilities for ensuring that the charity keeps accounting records which comply with section 386 of the Act and for preparing financial statements which give a true and fair view of the state of affairs of the company as at the end of the financial period and of its incoming resources and application of resources, including its income and expenditure, for the financial period in accordance with the requirements of sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the company.

The members have not required the company to obtain an audit of its financial statements for the period in question in accordance with section 476.

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

The financial statements were approved by the trustees on 25/11/24

 J. OAKLEY

Mr J D Oakley
Trustee

Company registration number CE031265 (England and Wales)

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NOTES TO THE FINANCIAL STATEMENTS FOR THE PERIOD ENDED 29 FEBRUARY 2024

1 Accounting policies

Charity information

Keep Me Breathing is a charitable incorporated organisation (CIO) incorporated in England and Wales. The registered office is 83 Rowan Avenue, Hove, BN3 7JH, England.

1.1 Reporting period

These are the first financial statements of the charity and are presented for a period longer than one year from incorporation.

1.2 Accounting convention

The financial statements have been prepared in accordance with the charity's governing document, the Companies Act 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" ("FRS 102") and the Charities SORP "Accounting and Reporting by Charities: 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)" (effective 1 January 2019). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £1.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

1.3 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

Based on these assessments and having regard to the resources available to the entity, the trustees have concluded that there is no material uncertainty in relation to the appropriateness of continuing to adopt the going concern basis in preparing the annual report and accounts.

1.4 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

1.5 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

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NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE PERIOD ENDED 29 FEBRUARY 2024

1 Accounting policies

(Continued)

1.6 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably.

Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources.

1.7 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks.

1.8 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

Basic financial liabilities, including creditors are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

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NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE PERIOD ENDED 29 FEBRUARY 2024

2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

3 Income from donations and legacies

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Donations and gifts	135,951	-	135,951
Grants receivable	2,500	199,158	201,658
	<u>138,451</u>	<u>199,158</u>	<u>337,609</u>

4 Income from other trading activities

	Unrestricted funds 2024 £
Fundraising events	<u>7,483</u>

5 Expenditure on raising funds

	Unrestricted funds 2024 £
Fundraising and publicity	
Other fundraising costs	<u>6,020</u>

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NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE PERIOD ENDED 29 FEBRUARY 2024

6 Expenditure on charitable activities

	Total 2024 £
Direct costs	
Travel expenses	4,761
Materials for projects	265
	<u>5,026</u>
Share of support and governance costs (see note 7)	
Support	12,914
Governance	8,143
	<u>26,083</u>
Analysis by fund	
Unrestricted funds	<u>26,083</u>

7 Support costs allocated to activities

	Total 2024 £
Bank charges	136
Professional services	12,778
Governance	8,143
	<u>21,057</u>
Governance costs comprise:	2024 £
Legal and professional	3,134
Accountancy	4,500
Meeting expenses	509
	<u>8,143</u>

The expenditure for support and governance costs basis of allocation are all direct.

Governance costs include payments to the independent examiner of £1,900 relating to independent examiner fees, and £2,600 for accounting services.

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NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE PERIOD ENDED 29 FEBRUARY 2024

8 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the period.

9 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

10 Debtors

	2024
Amounts falling due within one year:	£
Other debtors	500
	<u> </u>

11 Creditors: amounts falling due within one year

	2024
	£
Borrowings	15,000
Accruals and deferred income	4,500
	<u> </u>
	19,500
	<u> </u>

12 Loans and overdrafts

	2024
	£
Other loans	15,000
	<u> </u>
Payable within one year	15,000
	<u> </u>

13 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 27 January 2023 £	Incoming resources £	At 29 February 2024 £
CAFAMERICA funds	-	199,158	199,158
	<u> </u>	<u> </u>	<u> </u>

CAFAMERICA grant is being used to fund the research being conducted across two key projects: the development of a neurostimulator device to be fitted into the ear, and the advancement of an implanted pacer system which will stimulate the phrenic nerve with control and feedback system from sensors. The grant is funding the scientific research, covering the cost of skilled engineers, the use of their laboratory and equipment.

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NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE PERIOD ENDED 29 FEBRUARY 2024

14 Analysis of net assets between funds

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Fund balances at 29 February 2024 are represented by:			
Current assets/(liabilities)	113,831	199,158	312,989
	<u>113,831</u>	<u>199,158</u>	<u>312,989</u>

15 Related party transactions

During the period, there were £5,277 reimbursed expenses relating to one trustee for travel, subsistence and accommodation for meetings.

Mr J Oakley is the managing director of James Oakley Media Limited. James Oakley Media Limited provided a start up loan to the charity of £20,000 during the period, of which £5,000 has been repaid, leaving a balance outstanding of £15,000 at the period-end. No interest is payable on this loan and is not secured on any of the assets of the charity.

Mr G Roberts, who is the father to a trustee, Miss S Roberts, made donations totalling £15,000.

Mrs S Roberts, who is the mother to a trustee, Miss S Roberts, made donations totalling £15,137.

Mr A Kent, husband to trustee Mrs E Kent, is a director for Tents N Events Ltd, who made a donation of £2,000 to the charity.

Total donations from related parties amounted to £32,137 during the period.