

PECTUS MATTERS

Charity No 1208486

TRUSTEES' REPORT AND ACCOUNTS

FOR THE PERIOD FROM

FORMATION ON 31 MAY 2024

TO

31 DECEMBER 2024

PECTUS MATTERS
A Charitable Incorporated Organisation

OFFICERS AND ADMINISTRATIVE INFORMATION

TRUSTEES

Mr Simon Kendall	Chair
Mrs Lynne Evans	
Ms Ellie Musgrave	
The Revd Barry Nichols	Treasurer until 13 January 2025
Mrs Rachel Royan	Treasurer since 13 January 2025

PRINCIPAL OFFICE

c/o Society for Cardiothoracic Surgery
Royal College of Surgeons of England
38-43 Lincolns Inn Fields
London
WD2A 3PE

CHARITY NUMBER

1208486

COMPANY NUMBER

CEO 36343

BANKERS

CAF Bank Ltd
23 Kings Hill Avenue
Kings Hill
West Malling
Kent
ME19 4JQ

NatWest Bank plc
250 Bishopsgate
London
EC2M 4AA

PECTUS MATTERS
A Charitable Incorporated Organisation

TRUSTEES' REPORT

For the period ended 31 December 2024

The Trustees of Pectus Matters present their report and accounts for the period from incorporation on 31 May 2024 to 31 December 2024

Objectives, activities and the public benefit

Objectives and the public benefit

The objects of Pectus Matters are for the public benefit to relieve the needs of people suffering from and affected by Pectus malformations or deformities, their families and carers in particular but not exclusively by:

- providing or assisting in providing information and sources of advice about Pectus malformations and deformities;
- advancing education and knowledge about Pectus malformations and deformities with the aim of raising awareness of them and improving standards of care for those suffering from them;
- supporting research into the causes, prevention and treatment of Pectus malformations and deformities and disseminating the results of such research; and
- providing financial assistance to support travelling expenses and accommodation costs incurred by patients receiving treatment for Pectus malformations or deformities.

Significant activities

Since formation on 31 May 2024 the Trustees have focussed on:

establishing a website to provide information about Pectus malformations and disabilities, as a source of fund-raising for the charity and information about the charity's activities;

establishing policies and procedures;

securing on-going support and free training from GDPR, Safeguarding and SEND specialists;

preparing fund-raising activities;

giving presentations about the effect of Pectus at National Health Service seminars;

attending meetings of the Society for Cardiothoracic Surgery;

working with cardiothoracic surgeons to improve knowledge of and access to treatment for Pectus malformations and disabilities within the NHS;

giving advice to enquirers about ways to access treatment for Pectus malformations and deformities.

Achievement and performance

During this period the CIO has made significant progress:

- We have become properly established as a charity, recruiting a suitable range of trustees, including ensuring that all trustees have been cleared by the Disclosure and Barring Service with Enhanced DBS checks, and establishing procedures which comply with GDPR.
- The Charity has developed a website which has widened knowledge about the activities of the charity. This was achieved at a cost of only £444 during the period as a result of expert help on a free basis from a graduate student at Buckingham University.
- The Charity has given advice to 55 enquirers about ways to access treatment for Pectus malformations and deformities.
- The Charity has been intimately involved in consulting NHS England Specialised Commissioning in expanding from one adult Pectus centre in England (St Bartholomew's, London) to a further adult centre in South Tees, Middlesbrough and a children and young people's centre in Alder Hey, Liverpool.
- Due to the efforts of the Charity, patients with very severe pectus excavatum are discussed at the weekly national Pectus MDT and have access to surgery. Prior to the Charity's input there was no surgery available to Pectus patients in NHS England.
- The Charity has received insightful feedback from patients/carers about their experiences of treatment and in turn given constructive feedback to the relevant hospitals/clinical teams/clinicians. The Charity now has an online questionnaire/survey for patients to share their experience of care.
- The Charity has been closely involved in the initiation and administration of the first randomised trial of Pectus surgery in the world, known as the RESTORE trial. This is for patients who have severe Pectus Excavatum. Recruitment has exceeded expectations and may well have a major influence on choices of treatment.
- The Charity has encouraged the sharing of good practice – the best example of this is learning about the national Pectus service in Scotland (based in Glasgow) and promoting this model of care as a potential for the service in England.
- The Charity has been asked to collaborate with the James Lind Alliance as part of their Thoracic surgery priority setting partnership.
- The Charity has actively learnt about the lack of access to Pectus treatment in Wales and Northern Ireland.
- The Charity is actively involved in monthly meetings with the Society for Cardiothoracic Surgery Great Britain and Ireland. This involves clinical representation from several clinical units including Scotland.
- The Charity has given a webinar on Pectus and Pectus care to the Marfan's Trust.

- The Charity is intimately involved in shaping future Pectus care in England - by sharing the experience in Scotland the aim is to focus on a hub and spoke model in England where patients can be seen as soon as possible in the development of their chest deformity - in the hope that non-invasive conservative treatments, such as external bracing or vacuum bell therapy, may prevent progression and potentially correct the shape of the chest. This would avoid major surgery; would hopefully prevent the psychological sequelae to these young people at a critical time of their lives; and prevent the physiological impairments in the severe cases. Furthermore, this model of conservative treatment is more cost effective.
- The Charity presented at the NHSE Pectus Event at Vintner's Hall January 2025. The patient presentations received the highest scores for delivery and impact to an audience of national and international leaders in Pectus care.
- Since the year end the Charity has been registered with the Fundraising Regulator.

Financial review

The Statement of Financial Activities for the period and the balance sheet of the Trust are set out on pages 7 to 10

During the period the Charity received income totalling £3,926, including a donation of £990 to cover legal advice relating to the establishment of the CIO. Formation and administration expenses were £1,531, leaving funds carried forward into 2025 amounting to £2,291.

Plans for future periods

In 2025 the Charity aims to:

- Increase our income through increasing the number of Friends of Pectus Matters requesting a minimum subscription of £5 per month and also by encouraging fundraising events and activities.
- Continue the development of the website to facilitate donations, membership and gift aid.
- Develop a beneficiary grants strategy for accommodation and travel, to enable grant applications to be considered once funds become available.
- Visit each Pectus clinic in the United Kingdom to promote the charity, including by donating a charity banner.
- Support NHSE to define a Pectus Care Pathway.
- Support NHSE to deliver a national referral process with a single point of access.
- Support NHSE to deliver a hub and spoke model of care promoting conservative non-surgical treatments.
- Continue to support the RESTORE trial to completion.
- Recruit and enthuse a network of volunteers.

- Recruit corporate members / sponsors avoiding conflicts of interest.
- Further improve support for patients and families to navigate their care pathway – with a view to establishing a Monday to Friday help line in 2026.
- Continue to support our online questionnaire for patients' experience of their care - and feedback to Pectus units.

Structure, governance and management

Governing document

The CIO was registered by the Charity Commission for England and Wales on 31 May 2024 under charity number 1208486 and company number CE036343.

Recruitment and appointment of trustees

The founding trustees, who are listed below, gathered under the leadership of Mr Simon Kendall, a retired Cardiothoracic surgeon, because they either had Pectus malformations and deformities (Pectus) themselves or they had family members with these conditions and they had a commitment to seek to improve the information available to people with Pectus about how to access appropriate treatment. Now that the CIO has been formed, new trustees are recruited through a formal advertisement and interview process. Such new trustees are being recruited to ensure that the Charity has an appropriate range of skills to manage the development of the Charity.

Induction and training of trustees

The policies and procedures of the CIO and the responsibilities of trustees are explained to new trustees by the chairman.

Organisational structure and decision making process

The CIO is controlled by the trustees who meet online at least once a month when they consider all the day to day affairs of the CIO.

Related parties and wider networks

The CIO is gradually establishing connections with other charities working with similar disabilities.

Risk management

The major risks to which the CIO is exposed have been reviewed and procedures have been established to mitigate those risks.

Trustees' statement of responsibility in relation to the accounts

Under charity law, the Trustees are responsible for preparing the Trustees' Annual Report and the financial statements for each financial year which show a true and fair view of the state of affairs of the charity and of the excess of income over expenditure for that period.

In preparing these financial statements, generally accepted accounting practice entails that the trustees:

- Select suitable accounting policies and apply them consistently;
- Make judgements and estimates that are reasonable and prudent;
- State whether the recommendations of the Statement of Recommended Practice have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue its activities.

The Trustees are required to act in accordance with the trust deed of the charity, within the framework of trust law. They are responsible for keeping proper accounting records, sufficient to disclose, at any time, with reasonable accuracy the financial position of the charity at that time, and to enable the Trustees to ensure that, where any statements of account are prepared by them under section 132(1) of the Charities Act 2011, those statements of account comply with the requirements of regulations under that provision. They have general responsibility for taking such steps as are reasonably open to them to safeguard the assets of the charity and to prevent and detect fraud and other irregularities.

Reference and administration details

The administrative information set out on page 1 forms part of this report.

The trustees of the CIO at the date of this report are listed on page 1. Those who served during the period since 31 May 2024 were:

Mr Simon Kendall	Chair	UK	Appointed 31 May 2024
Mrs Becky Blount		UK	Appointed 31 May 2024 – resigned 6 May 2025
Mrs Lisa de-Laune		UK	Appointed 31 May 2024 – resigned 16 January 2025
Mrs Lynne Evans		UK	Appointed 31 May 2024
Ms Ellie Musgrave		UK	Appointed 31 May 2024
The Revd Barry Nichols		UK	Appointed 31 May 2024
Mrs Rachel Royan	Treasurer	UK	Appointed 13 January 2025

Trustees

The Trustees would like to thank Mrs Lisa de-Laune and Mrs Becky Blount, who have resigned since the year end, for their significant and enthusiastic contributions to the formation and establishment of the charity. We wish them well for the future.

Simon Kendall

Chair

14 July 2025



PECTUS MATTERS
STATEMENT OF FINANCIAL ACTIVITIES
For the period rom 31 May 2024 to 31 December 2024

	Unrestricted funds 2024 £
<i>Incoming resources</i>	
Fundraising	2,575
Donations	1,125
Friends subscriptions	120
Gift aid on donations and subscriptions	44
Interest	62
Total income	<u>3,926</u>
<i>Expenditure</i>	
<i>Administration</i>	
Legal advice re formation	990
Website costs	444
Insurance and DBS costs	97
	<u>1531</u>
<i>Fundraising costs</i>	104
Total expenditure	<u>1635</u>
Net income for the period	<u>2,291</u>
Fund balance carried forward at the end of the period.	<u><u>2,291</u></u>

PECTUS MATTERS
BALANCE SHEET
at 31 December 2024

	2024
	£
Current assets	
Cash at bank	1,922
Gift Aid recoverable	44
Other debtors	159
Prepaid expenses	304
	<u>2,429</u>
Liabilities	
Creditors falling due within one year	138
Net current assets	<u>2,291</u>
Net assets	<u><u>2,291</u></u>
Funds	
Unrestricted income funds	2,291
Total funds	<u><u>2,291</u></u>

Simon Kendall
Chair of Trustees

14 July 2025



PECTUS MATTERS

Notes to the accounts

31 December 2024

1 Constitution

Pectus Matters is a Charitable Incorporated Organisation (CIO) registered with the Charity Commission for England and Wales on 31 May 2024 as charity number 1208486 and company number CE036343

2 Accounting policies

The principal accounting policies adopted, judgements and key sources of estimation of uncertainty in the preparation of the accounts are as follows:

Basis of financial statements

The accounts have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) and the Charities SORP 2015 (SORP 2015) as amended by Updated Bulletin 1

The CIO is a public benefit entity as defined by FRS 102 .

The accounts have been prepared under the historical cost convention and include all transactions, assets and liabilities for which the CIO is responsible in law.

The trustees consider that there are no material uncertainties about the ability to continue as a going concern.

Preparation of the accounts on a going concern basis

The CIO's expenditure is carefully controlled by the trustees who only incur expenses out of available income. During the period from formation on 31 May 2024 to 31 December 2024 the CIO had an excess of income over expenditure of £2,291. The trustees are not aware of any circumstances that might affect the going concern status of the CIO in the foreseeable future. For this reason, the trustees are of the opinion that the CIO can be considered a going concern for the foreseeable future, this being a period of at least twelve months from the date of approval of the balance sheet.

Funds

Unrestricted funds are funds set aside by the trustees that are not subject to any restrictions. *Designated funds* are general funds set aside for a particular purpose by the trustees. They are also unrestricted.

PECTUS MATTERS

Notes to the accounts

31 December 2024

Accounting policies (cont'd)

Funds (cont'd)

Restricted funds represent donations or grants received for a specific object or invited by the trustees for a specific object. The funds may only be expended on the specific object for which they were given. Any balance remaining unspent at the end of the year must be carried forward as a balance on that fund.

Income

All income is recognised once the CIO has entitlement to the income, it is probable that the income will be received and the amount of the income can be measured reliably.

Donations are recognised when the CIO has been notified in writing of both the amount and settlement date.

Legacies are recognised on a case by case basis following the granting of probate when the administrator/executor for the estate has communicated in writing both the amount and the settlement date.

Interest on funds held on deposit and income from investments is included when receivable and the amount can be measured reliably by the CIO; this is normally upon notification of the interest or investment income paid or payable by the bank or investment institution.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the CIO to that expenditure, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Expenditure on charitable activities comprises direct expenses incurred on the defined charitable purposes of the CIO and includes staff costs attributable to the activity.

Grants payable are accounted for once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Governance costs comprise expenditure on compliance with and advice on constitutional and statutory matters.

Irrecoverable VAT is included in the items of expenditure to which it relates.

Taxation

The CIO, as a registered charity, is exempt from taxation on its income and gains falling within Section 505 of the Taxes Act 1988 or Section 256 of the Taxation of Chargeable Gains Act 1992 to the extent that they are applied to its charitable objectives. No tax charge has arisen in the period.