

# EGFR Positive Lung Cancer UK

England & Wales · Charity number 1189722

## Details

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Other names	EGFR POSITIVE UK
Status	Registered
Legal form	CIO
Registered	2020-05-29
Register	<a href="#">View on the Charity Commission register</a>

## Contact

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Address	2 Bateman Grove Ash Surrey GU12 6QG
Phone	07763782070
Email	<a href="mailto:contact@egfrpositive.org.uk">contact@egfrpositive.org.uk</a>
Website	<a href="http://www.egfrpositive.org.uk">www.egfrpositive.org.uk</a>

## Activities

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**Objects:** THE OBJECT OF THE CIO IS: TO PRESERVE AND PROTECT THE GOOD HEALTH OF UK EPIDERMAL GROWTH FACTOR RECEPTOR (EGFR) POSITIVE LUNG CANCER PATIENTS BY:- A. PROVIDING AN INFORMATION RESOURCE, IN PARTICULAR ACCESS TO INFORMATION ABOUT LATEST DEVELOPMENTS AND CLINICAL TRIALS; B. IDENTIFYING AND LOCATING UK EGFR PATIENTS AND OFFERING SUPPORT AND GUIDANCE ON THE LOCATION OF UK EGFR SPECIALISTS AND SERVICES; C. LIAISING WITH AND INFLUENCING DECISION MAKERS, E.G. NICE, NHS, DVLA; D. RAISING AWARENESS OF EGFR LUNG CANCER, PARTICULARLY AMONGST THE MEDICAL PROFESSION SO AS TO PROMOTE THE BEST TREATMENT FOR PATIENTS; E. LIAISING WITH RELEVANT ORGANISATIONS, IN PARTICULAR ROY CASTLE LUNG CANCER FOUNDATION AND THE PHARMACEUTICAL INDUSTRY; F. RAISING FUNDS FOR THE ABOVE PURPOSES.

**Activities:** EGFR Positive UK works to promote the needs of EGFR mutation positive lung cancer patients across the UK.

## Classification

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- **How:** Provides Services
- **What:** The Advancement Of Health Or Saving Of Lives

## Geography

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- Northern Ireland
- Scotland
- Throughout England And Wales

## Finances

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Period end	Income	Expenditure	Assets	Employees
2025-03-31	£88,938	£57,122	-	-
2024-03-31	£58,616	£50,722	-	-
2023-03-31	£23,392	£9,823	-	-
2022-03-31	£38,296	£1,493	-	-
2021-03-31	£2,927	£0	-	-

## Trustees

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Name	Role	Appointed
<b>Nicola Cowland</b>	Chair	2026-01-30
Charlotte Judyth Maxwell		2024-09-09
Dr Virginia Mary Harrison		2023-05-20
Elizabeth Lucy Baker		2024-12-01
Ismet Jabeen Sadiq-Shirley		2025-10-13
Soumitra Bose Treasurer		2023-05-20

**EGFR Positive Lung Cancer UK**

England & Wales - Charity number 1189722

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# Accounts

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# Trustees' Annual Report

1 April 2024 to  
31 March 2025



EGFR POSITIVE UK  
Charity No. 1189722

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# Key Achievements



## Community

Membership crossed 1,000+, strengthening our voice as the largest EGFR+ community in the UK.



## Membership

Became a member of LuCE (Lung Cancer Europe) and participated in its Annual General Meeting in April 2025.



## Campaigning

Successfully delivered the 'All You Need is Lungs' campaign in partnership with ALK+ UK and Ruth Strauss Foundation, raising awareness nationally.



## Events

Expanded our Regional Ambassador programme to 15 Ambassadors, with a well-attended conference in Manchester.



## Support

Continued core support services — online sessions, counselling, workshops — with consistently high participation and feedback.



## Survey

Conducted an updated Member Survey to capture community needs and guide future strategy.

The Charity was established on 29 May 2020. This is the Trustees' Fifth Annual Report.

EGFR positive non-small cell lung cancer (NSCLC) is a rare form of lung cancer caused by a genetic mutation which affects approximately 10-15% of those diagnosed with lung cancer. Patients are, on average, much younger than most other lung cancer patients and are often female and non-smokers.



# 1. Our Mission, Vision & Values

Our Mission and Vision were formally reviewed and updated in August 2025, ensuring that they continue to reflect the evolving priorities and aspirations of our community. The updated Vision reflects our renewed commitment to :

A future where every person with EGFR+ lung cancer:

- is diagnosed earlier and treated faster.
- receives consistent, equitable care regardless of where they live in the UK.
- has the knowledge, confidence, and tools to advocate for themselves.
- feels connected, supported and seen as part of a strong, active community.
- benefits from a united lung cancer sector where charities work together to amplify impact.

This vision is guided by our Values of:

- Community
- Equality & Equity
- Trust
- Empowerment
- Collaboration

## 2. Objectives & Activities

Since its inception in 2020, EGFR Positive UK has established itself as an important source of support and practical advice for patients living with EGFR positive lung cancer. It has also become a highly regarded 'voice of the patient' for clinicians, regulators and the pharmaceutical industry.



We have created a support network in the UK for patients with Epidermal Growth Factor Receptor (EGFR) positive non-small cell lung cancer and their families. The advice and information we provide empowers and enables patients to have meaningful conversations with their healthcare professionals about their care and treatment. We advocate on behalf of EGFR positive lung cancer patients at a national level to ensure as many patients as possible receive a high level of care, wherever they live in the UK.

The overall objective of the Charity is to enable patients and their families to live well with and beyond EGFR positive lung cancer.

To achieve this, we:

- have created a strong supportive community of EGFR+ patients and their loved ones.
- support these patients, their families and caregivers by providing a secure platform where they can give and receive mutual support and exchange experiences about their treatment.
- create opportunities for members to connect with each other through local, in-person and online events
- empower patients by providing information that enables them to demand a high level of care.
- advocate on behalf of patients to ensure they receive the best care irrespective of where they live in the UK.
- liaise and collaborate with relevant organisations such as other lung cancer charities and the pharmaceutical industry, to work to raise awareness of EGFR positive lung cancer and campaign for early diagnosis amongst non-smokers.
- undertake research to better understand the well-being needs of patients and their loved ones and provide practical accessible resources to meet these needs.
- raise funds for the above purposes.

# 3. Achievements & Performance

Two patients met in February 2019 with the aim of establishing a UK group of EGFR positive patients who could exchange experiences and give and receive mutual support. Later that year, as the activity of the group grew, they decided to form a Charity and it was registered by the Charity Commission on 29 May 2020.

The initial aim of the charity was to support and inform patients, their families and carers through our peer support group. It became clear however, that there was a need and an opportunity to advocate for better, equally accessible and equitable care anywhere in the UK. This led to involvement with bodies such as NICE where the Charity now regularly represents patients affected by this rare form of lung cancer and takes part in the decision-making processes that approve new drugs and treatments.

## A Year of Growth and Impact

In our fifth year we have continued the transition from a founder-led start-up, to a fully-fledged sustainable not-for-profit organisation capable of serving the needs of patients and their families living in the UK with EGFR Positive lung cancer. The priority has been to create an organisation whose internal infrastructure makes the Charity both sustainable and scalable. The initiative taken last year has continued to establish collaborative working practices backed by shared technology systems ensuring that we have a spread of involvement beyond the Trustees.



Our activities, performance and growth in our fifth year has exceeded our expectations. Going forward our emphasis will continue to be to support the well-being of EGFR+ patients and their families.

We will do this by:

- expanding our membership through the implementation of our digital influencing strategy.
- offering individual counselling and workshops.
- advocating for the best care possible by continuing our involvement with key decision makers in regulatory authorities, pharmaceutical companies and clinicians.
- in collaboration with other onco-gene driven cancer charities, research the patient experience thereby adding to the body of knowledge that will drive progress and change for patients and their families.
- roll out our nationwide initiatives that will enable members to meet locally with fellow EGFR+ patients and their caregivers ,e.g. run 4 regional conferences that will enable members to connect with each other, learn more about how to live well with EGFR+ lung cancer and understand developments in the treatment of this disease.

### Evidence based practice at our core

We carry out a survey of our members each year to gather vital real-world data on the experiences of people living with EGFR-positive lung cancer. This survey helps us understand the full picture of diagnosis, treatment and care, while identifying gaps in support, highlighting regional disparities, and uncovering the impact of the disease on patients' daily lives. These insights help us to shape the support that we give to those affected by the disease, and directly informs our advocacy work—strengthening our voice in discussions with healthcare professionals, pharmaceutical companies, and during NICE treatment appraisals.

The results from our surveys will be shared at key academic conferences (such as the British Thoracic Oncology Group and Lung Cancer Nurse UK conferences), as we remain committed to sharing our findings through academic channels and continuing to influence care and policy for the benefit of the EGFR community.



## 3.1 Support of Patients



### Website

The website continues to be an essential resource, offering information about the charity and the disease. It helps patients and carers become better informed about EGFR-positive lung cancer and encourages them to join the Peer Support group on Facebook for additional support.



### Members' Forum

We held a successful in-person event for members in Manchester in 2024. These focus groups helped us better understand support needs and experiences.



### Online Activities

'Ask the Expert' Zoom sessions continued with eight presentations from EGFR Clinical and holistic health experts. Recordings are available on our website. Monthly Zoom coffee mornings and evening drop-ins provided important peer interaction.

We also facilitated individual coaching and group sessions to support mental resilience. These six-week programmes focused on understanding the emotional impact of cancer and fostering self-management strategies.



### Peer Support Group

Our Facebook group remains core to our support services. Membership has grown from 707 to nearly 1,000 by March 2025. Daily posts from patients share experiences and offer emotional support. New members are warmly welcomed. A member survey showed that 98% would recommend the group to other EGFR-positive patients.

Further online support is provided via the monthly 'Meet and Chat' forums which is held via Zoom. The charity supports Regional Ambassadors who host face-to-face meetings in fifteen different regions of the UK. These meetings are held every two months in each region.

## 3.2 Advocacy

EGFR Positive UK continues to act as a trusted patient voice in national regulatory processes. We engage with NICE, SMC, NHS, and pharmaceutical companies to ensure that EGFR-positive patients are represented in treatment and care decisions.

During 2024–25, we collaborated in campaigns such as ‘All You Need is Lungs’ with ALK+ UK and The Ruth Strauss Foundation. This campaign addressed the misconception that only smokers get lung cancer and promoted early diagnosis among younger, fit non-smokers.

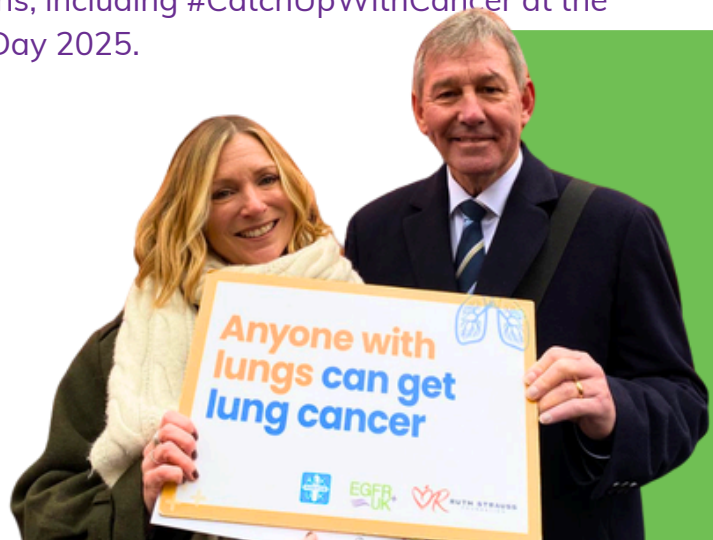
We are members of the United Kingdom Lung Cancer Coalition (UKLCC) and sit on the Clinical Excellence Group (CEG) for Lung Cancer alongside eminent Clinicians. We also became a member of Lung Cancer Europe (LuCE) and participated in their AGM in April 2025.

Our Regional Ambassadors distributed information materials in clinics and helped connect with local patients. We also grew our presence on social media platforms—X, LinkedIn, Instagram, and Facebook—to expand our digital advocacy.

We represented patients in five NICE drug appraisal hearings and one SMC appraisal, providing detailed patient experience submissions.

We have contributed to and consulted on multiple clinical trial protocols and research grant applications, strengthening our role in Patient and Public Involvement and Engagement.

We amplified the patient voice with MPs and representatives of the House of Lords, and have taken part in key national campaigns, including #CatchUpWithCancer at the Houses of Parliament on World Cancer Day 2025.



## 3.3 Fundraising

*£86,653*

In 2024–25, EGFR Positive UK's total donations was £ 67,484 – 88% came from fundraising and an additional £ 19,169 from Gift Aid, enhancing the impact of such donations.

24 individuals and families raised funds, many in memory of loved ones. These were raised primarily through the fundraising platforms Just Giving and Much Loved. The most notable was the Wysocki family, who raised over £20,000 in memory of Alex Wysocki, who sadly passed away at age 24. These funds are earmarked for the production of a short film about youth lung cancer, expected to be ready by Autumn 2025. More activities are planned in the FY 2025-26 to fundraise for supporting this project. The charity is deeply grateful to the Wysocki family and all supporters, as well as all the other fundraisers.

*thank you*

Going forward, our emphasis will continue to be to support the well-being of EGFR+ patients and their families. We will do this by expanding our membership through more focused Digital Influencing, offering individual and group counselling and workshops, advocating for the best care possible by continuing our involvement with key decision makers in regulatory authorities, Pharmaceutical companies and Clinicians, in collaboration with other onco-gene driven cancer charities, research the patient experience thereby adding to the body of knowledge that will drive progress and change for patients and their families.

## 4. Financial Review

The Charity currently receives donations through members' contribution, fund raising through crowd funding platforms and grants from pharmaceutical and other companies /trusts. The Charity prepares its accounts on a receipts and payments basis.



Total receipts during FY 2024–25 were £88,938 – 51.7% over last year, primarily through fundraising by our members and gift aid thereon. We do not have premises and we do not employ staff; hence, DBS checks are not applicable. Trustee costs primarily relate to reimbursement of travel and subsistence for attending conferences/workshops and meetings. The funds are mainly available to promote the charity's objectives in advocacy and outreach through in-person members' events and activities. We have a low level of fixed costs e.g. website maintenance, subscriptions to other organisations, insurance etc.

Restricted funds of £18,212 were set aside for the film project funded by the Wysocki family. A general surplus of £13,712 was added to Reserves. The Charity invested £70,108 in fixed deposits and held £24,502 in its bank at the year-end.



## 5. Structure, Governance & Management

The Charity is a Charitable Incorporated Organisation, and the governing document is its Constitution.

The Constitution provides that there shall be between three and eight Trustees.

The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.

## 6. Reference and Administrative Details

Charity Name : EGFR Positive UK

Other name the charity uses: EGFR+ UK

Registered charity number: 1189722

Charity's Principal Address: 2 Bateman Grove, Ash, Surrey, GU12 6QG

## 7. Name of the Charity Trustees who Managed the Charity

Trustee Name	Office (if any)	Dates Acted if not for whole Year	Name of person or body entitled to appoint trustee (if any)
Angela Ada Mary Terry	Chair	Trustee From 15 Aug 2020. Chair from 12 Jan 2022	
Soumitra Bose	Treasurer	From 20 May 2023	
Virginia Mary Harrison	Research	From 20 May 2023	
Natasha June Loveridge	Marketing	From 10 Aug 2023 to 31st March 2025	
Elizabeth Lucy Baker	Member Support	From 1 Dec 2024	
Charlotte Judyth Maxwell	Events	From 9 Sept 2024	

Corporate Trustees – n/a

Names of Trustees holding title to property belonging to the Charity – n/a

Funds held as custodian trustees on behalf of others – nil

## 8. Declarations

The Trustees declare that they have approved the Trustees' Report as above.  
Signed on behalf of the Charity's Trustees:

Signatures	<i>Soumitra Bose</i>	<i>Angela Terry</i>
Full Names	Soumitra Bose	Angela Terry
Positions	Treasurer	Chair
Date	Oct 13, 2025	Oct 13, 2025



**Section A**

**Independent Examiner's Report**

**Report to the trustees/  
members of**

Charity Name  
EGFR Positive UK

**On accounts for the year  
ended**

31 March 2025

**Charity no  
(if any)**

**Set out on pages**

3-5

*(remember to include the page numbers of additional sheets)*

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/03/2025.

**Responsibilities and  
basis of report**

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**Independent  
examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

*\* Please delete the words in the brackets if they do not apply.*

**Signed:**

**Date:**

13/10/2025

**Name:**

Neil Horan

**Relevant professional  
qualification(s) or body  
(if any):**

ICAEW – Chartered Accountant

**Address:**

8 St Ronan's Close, Harrogate, North Yorkshire, HG2 8LF

**Section B**

**Disclosure**

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

**Give here brief details of any items that the examiner wishes to disclose.**

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**EGFR POSITIVE UK  
FINANCIAL STATEMENTS  
RECEIPTS & PAYMENTS  
FOR THE YEAR ENDED 31 MARCH 2025**

IN £

	Year Ending 31st March 2025			Year Ending 31st March 2024		
	Restricted Funds	Unrestricted Funds	Total	Restricted Funds	Unrestricted Funds	Total
<b>RECEIPTS</b>						
Donations & Fund Raising	16,664	50,820	67,484		58,254	58,254
Gift Aid	4,428	14,741	19,169			
Advisory & other receipts		1,157	1,157		362	362
Interest on Deposits		1,128	1,128			
<b>TOTAL RECEIPTS</b>	<b>21,092</b>	<b>67,846</b>	<b>88,938</b>		<b>58,616</b>	<b>58,616</b>
<b>PAYMENTS</b>						
<b>Cost of Operating Activities</b>						
Advocacy		7,858	7,858		19,353	19,353
Patients' Outreach		12,097	12,097		7,139	7,139
Patients' Counselling		600	600		1,585	1,585
Digital Communications		19,040	19,040		14,663	14,663
Travelling & Reimbursements		6,600	6,600		3,576	3,576
Publicity Materials		1,285	1,285		1,538	1,538
Information Technology Costs		2,847	2,847		2,289	2,289
Rentals					75	75
Film Production	2,880		2,880			
Postage & Stationery		350	350		273	273
Insurance					142	142
Consultancy fees		2,177	2,177			
Subscriptions		1,252	1,252			
Corporation Tax		100	100			
Bank Charges		36	36		88	88
<b>Transfer to Fixed Deposit</b>	<b>10,000</b>	<b>20,000</b>	<b>30,000</b>		<b>40,000</b>	<b>40,000</b>
<b>TOTAL PAYMENTS</b>	<b>12,880</b>	<b>74,242</b>	<b>87,122</b>		<b>90,722</b>	<b>90,722</b>
<b>NET (PAYMENTS)/ RECEIPTS</b>	<b>8,212</b>	<b>(6,396)</b>	<b>1,816</b>		<b>(32,106)</b>	<b>(32,106)</b>
<b>CASH FUNDS AT 31 MARCH 2024</b>		<b>22,686</b>	<b>22,686</b>		<b>54,792</b>	<b>54,792</b>
<b>CASH FUNDS AT 31 MARCH 2025</b>	<b>8,212</b>	<b>16,290</b>	<b>24,502</b>		<b>22,686</b>	<b>22,686</b>

**FINANCIAL STATEMENTS  
STATEMENT OF ASSETS AND LIABILITIES  
FOR THE YEAR ENDED 31 MARCH 2024**

IN £

	Year Ending 31st March			Year Ending 31st March		
	2025			2024		
	Restricted Funds	Unrestricted Funds	Total	Restricted Funds	Unrestricted Funds	Total
<b>CASH FUNDS</b>						
Savings Account with Lloyds Bank		24,502	24,502		22,686	22,686
Fixed Deposit with Lloyds Bank	10,000	60,108	70,108		40,000	40,000
<b>TOTAL ASSETS</b>	<b>10,000</b>	<b>84,610</b>	<b>94,610</b>		<b>62,686</b>	<b>62,686</b>
<b>ACCUMULATED FUNDS</b>						
Surplus Funds brought forward		62,686	62,686		54,792	54,792
Surplus Funds for the Year ( Note 1)	18,212	13,712	31,924		7,894	7,894
Surplus Funds carried forward	18,212	76,398	94,610		62,686	62,686

**1 SURPLUS FUNDS**

	Year Ending 31st March			Year Ending 31st March		
	2025			2024		
Total Receipts	21,092	67,846	88,938		58,616	58,616
Accrued Interest on Deposit		108	108			
Less : Cost of Operating Activities	2,880	54,242	57,122		50,722	50,722
<b>Surplus Fund for the year</b>	<b>18,212</b>	<b>13,712</b>	<b>31,924</b>		<b>7,894</b>	<b>7,894</b>

2 The financial statements are prepared on a receipts & payments basis.

3 Previous year's figures have been re-classified, where necessary.

**Notes accompanying Review of EGFR+ Accounts for FY24/5.**

**Direction 1 - Check whether the charity is eligible to have an independent examination.**

EGFR Positive UK is a charity with receipts of under £250k. Audit is not, therefore, required and the charity is eligible for an independent examination. The accounts may be prepared on a receipts and payments basis.

**Direction 2 - Check for any conflict of interest that prevents the examiner from carrying out their independent examination**

What I am friends with a member of the charity and her husband, I am not otherwise involved with the charity and do not see any conflicts of interest.

**Direction 3 - Record your independent examination.**

This document will form the record of my examination.

**Direction 4 - Plan the independent examination**

Independent examination will include:

- Review of Charity governing documents
- Verification of closing balance to bank statements
- Review of significant transactions during the year - receipts and payments
- Review of records maintained by charity
- Review of financial statements to ensure they match underlying records.

**Direction 5 - Check that accounting records are kept to the required standard**

The Charity uses an online accounting package called Quickfile which is a change from prior year. I was granted read-only access to the package for the purposes of this review. I interrogated the software package and am satisfied that this is more than suitable for maintaining accounts to the required standard. Documents may be attached to the accounts package and for large transactions, receipts/expence forms and any communication relating to those transactions have been added, providing an audit trail of these transactions. The financial statements also include a statement of assets and liabilities at the period end.

**Direction 6 - Check that the accounts are consistent with the accounting records.**

The opening and closing Bank balances agree with physical balances at Bank. I reviewed a sample of key transactions during the year, all of which were substantiated with appropriate invoices and expense claims. The Accounts as presented by the Charity agree with the accounting package accurately reflect the underlying transactions.

**Direction 7 - NA, accounts are prepared on a receipts and payments basis.**

**Direction 8 - Check the reasonableness of the significant estimates and judgments and accounting policies used in accounting for the types of fund held and in the preparation of the accounts**

The accounts are prepared on a receipts and payments basis so there are no estimates/judgements applied.  
The charity does not own any physical assets, other than cash, so there are no valuation related judgements to review.  
The funds are all held in the Treasurer's account at Lloyds or on Fixed Deposit.

**Direction 9 - Consideration of financial circumstances of charity at end of reporting period.**

A review of the accounts package for the period since year end shows the Charity continues to operate with positive net funds. I am satisfied that there are no solvency issues facing the charity.

**Direction 10 - Check the form and content of the accounts**

The charity is entitled to prepare accounts on a receipts and payments basis due to income being below £250k, the prepared accounts reflect this.

**Direction 11 - Analytical Review**

Revenue increased again in FY25 compared to FY24 (£51.7%). This reflects higher underlying fundraising receipts, bolstered by the commencement of G.H Aid during FY25, which added c £20k of additional income not available in the prior year. This increased revenue is consistent with the charity continuing to grow and establish its presence in the EGFR space. Costs also increased in FY25 (+7%), which is not unexpected given the growth and investment the charity is making in its underlying infrastructure and the number of outreach events being held. Compared to prior year, Digital communication, Patient outreach and Traveling and Re-imbusement costs all increased. As noted above, this is consistent with the growth focus of the Charity. I am satisfied that the FY25 accounts are an accurate reflection of the activities undertaken by the charity in the year.

**Direction 12 - Compare the trustees' annual report with the accounts.**

The trustees' annual report is consistent with the underlying accounts and provides a good summary of activity undertaken by the Charity in the year.



**Section A**

**Independent Examiner's Report**

**Report to the trustees/  
members of**

Charity Name  
EGFR Positive UK

**On accounts for the year  
ended**

31 March 2025

**Charity no  
(if any)**

**Set out on pages**

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- the accounts do not accord with the accounting records

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**Signed:**

**Date:**

13/10/2025

**Name:**

Neil Horan

**Relevant professional  
qualification(s) or body  
(if any):**

ICAEW – Chartered Accountant

**Address:**

8 St Ronan's Close, Harrogate, North Yorkshire, HG2 8LF

**Section B**

**Disclosure**

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**EGFR POSITIVE UK  
FINANCIAL STATEMENTS  
RECEIPTS & PAYMENTS  
FOR THE YEAR ENDED 31 MARCH 2025**

IN £

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<b>Cost of Operating Activities</b>						
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Patients' Counselling		600	600		1,585	1,585
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Travelling & Reimbursements		6,600	6,600		3,576	3,576
Publicity Materials		1,285	1,285		1,538	1,538
Information Technology Costs		2,847	2,847		2,289	2,289
Rentals					75	75
Film Production	2,880		2,880			
Postage & Stationery		350	350		273	273
Insurance					142	142
Consultancy fees		2,177	2,177			
Subscriptions		1,252	1,252			
Corporation Tax		100	100			
Bank Charges		36	36		88	88
<b>Transfer to Fixed Deposit</b>	<b>10,000</b>	<b>20,000</b>	<b>30,000</b>		<b>40,000</b>	<b>40,000</b>
<b>TOTAL PAYMENTS</b>	<b>12,880</b>	<b>74,242</b>	<b>87,122</b>		<b>90,722</b>	<b>90,722</b>
<b>NET (PAYMENTS)/ RECEIPTS</b>	<b>8,212</b>	<b>(6,396)</b>	<b>1,816</b>		<b>(32,106)</b>	<b>(32,106)</b>
<b>CASH FUNDS AT 31 MARCH 2024</b>		<b>22,686</b>	<b>22,686</b>		<b>54,792</b>	<b>54,792</b>
<b>CASH FUNDS AT 31 MARCH 2025</b>	<b>8,212</b>	<b>16,290</b>	<b>24,502</b>		<b>22,686</b>	<b>22,686</b>

**FINANCIAL STATEMENTS  
STATEMENT OF ASSETS AND LIABILITIES  
FOR THE YEAR ENDED 31 MARCH 2024**

IN €

	Year Ending 31st March			Year Ending 31st March		
	2025			2024		
	Restricted Funds	Unrestricted Funds	Total	Restricted Funds	Unrestricted Funds	Total
<b>CASH FUNDS</b>						
Savings Account with Lloyds Bank		24,502	24,502		22,686	22,686
Fixed Deposit with Lloyds Bank	10,000	60,108	70,108		40,000	40,000
<b>TOTAL ASSETS</b>	<b>10,000</b>	<b>84,610</b>	<b>94,610</b>		<b>62,686</b>	<b>62,686</b>
<b>ACCUMULATED FUNDS</b>						
Surplus Funds brought forward		62,686	62,686		54,792	54,792
Surplus Funds for the Year ( Note 1)	18,212	13,712	31,924		7,894	7,894
Surplus Funds carried forward	18,212	76,398	94,610		62,686	62,686

**1 SURPLUS FUNDS**

	Year Ending 31st March			Year Ending 31st March		
	2025			2024		
Total Receipts	21,092	67,846	88,938		58,616	58,616
Accrued Interest on Deposit		108	108			
Less : Cost of Operating Activities	2,880	54,242	57,122		50,722	50,722
<b>Surplus Fund for the year</b>	<b>18,212</b>	<b>13,712</b>	<b>31,924</b>		<b>7,894</b>	<b>7,894</b>

2 The financial statements are prepared on a receipts & payments basis.

3 Previous year's figures have been re-classified, where necessary.

**Notes accompanying Review of EGFR+ Accounts for FY24/5.**

**Direction 1 - Check whether the charity is eligible to have an independent examination.**

EGFR Positive UK is a charity with receipts of under £250k. Audit is not, therefore, required and the charity is eligible for an independent examination. The accounts may be prepared on a receipts and payments basis.

**Direction 2 - Check for any conflict of interest that prevents the examiner from carrying out their independent examination**

What I am friends with a member of the charity and her husband, I am not otherwise involved with the charity and do not see any conflicts of interest.

**Direction 3 - Record your independent examination.**

This document will form the record of my examination.

**Direction 4 - Plan the independent examination**

Independent examination will include:

- Review of Charity governing documents
- Verification of closing balance to bank statements
- Review of significant transactions during the year - receipts and payments
- Review of records maintained by charity
- Review of financial statements to ensure they match underlying records.

**Direction 5 - Check that accounting records are kept to the required standard**

The Charity uses an online accounting package called Quickfile which is a change from prior year. I was granted read-only access to the package for the purposes of this review.

I interrogated the software package and am satisfied that this is more than suitable for maintaining accounts to the required standard.

Documents may be attached to the accounts package and for large transactions, receipts/expence forms and any communication relating to those transactions have been added, providing an audit trail of these transactions.

The financial statements also include a statement of assets and liabilities at the period end.

**Direction 6 - Check that the accounts are consistent with the accounting records.**

The opening and closing Bank balances agree with physical balances at Bank. I reviewed a sample of key transactions during the year, all of which were substantiated with appropriate invoices and expense claims. The Accounts as presented by the Charity agree with the accounting package accurately reflect the underlying transactions.

**Direction 7 - NA, accounts are prepared on a receipts and payments basis.**

**Direction 8 - Check the reasonableness of the significant estimates and judgments and accounting policies used in accounting for the types of fund held and in the preparation of the accounts**

The accounts are prepared on a receipts and payments basis so there are no estimates/judgements applied.

The charity does not own any physical assets, other than cash, so there are no valuation related judgements to review.

The funds are all held in the Treasurer's account at Lloyds or on Fixed Deposit.

**Direction 9 - Consideration of financial circumstances of charity at end of reporting period.**

A review of the accounts package for the period since year end shows the Charity continues to operate with positive net funds. I am satisfied that there are no solvency issues facing the charity.

**Direction 10 - Check the form and content of the accounts**

The charity is entitled to prepare accounts on a receipts and payments basis due to income being below £250k, the prepared accounts reflect this.

**Direction 11 - Analytical Review**

Revenue increased again in FY25 compared to FY24 (£51.7%). This reflects higher underlying fundraising receipts, bolstered by the commencement of G.H Aid during FY25, which added c £20k of additional income not available in the prior year.

This increased revenue is consistent with the charity continuing to grow and establish its presence in the EGFR space.

Costs also increased in FY25 (+7%), which is not unexpected given the growth and investment the charity is making in its underlying infrastructure and the number of outreach events being held.

Compared to prior year, Digital communication, Patient outreach and Traveling and Re-imbusement costs all increased. As noted above, this is consistent with the growth focus of the Charity.

I am satisfied that the FY25 accounts are an accurate reflection of the activities undertaken by the charity in the year.

**Direction 12 - Compare the trustees' annual report with the accounts.**

The trustees' annual report is consistent with the underlying accounts and provides a good summary of activity undertaken by the Charity in the year.

**EGFR Positive Lung Cancer UK**

England & Wales - Charity number 1189722

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# Accounts

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**EGFR POSITIVE UK**  
Charity No. 1189722  
**TRUSTEES' ANNUAL REPORT**  
**1 April 2023 to 31 March 2024**

The Charity was established on 29 May 2020. This is the Trustees' Fourth Annual Report.

EGFR positive non-small cell lung cancer (NSCLC) is a rare form of lung cancer caused by a genetic mutation which affects approximately 10-15% of those diagnosed with lung cancer. Patients are, on average, much younger than most other lung cancer patients and are often female and non-smokers.

## 1. Our Vision

For everyone in the UK who is diagnosed with EGFR Positive lung cancer:

- to receive the best care possible
- to live their best lives possible
- to live for as long as possible

The core principles that help us deliver our Vision are:

- a sustainable, scalable organisation
- robust Infrastructure that gives us a solid foundation
- our values:
  - Community – strong support networks
  - Advocacy – influential in shaping care standards and protocols
  - Research – advancements in EGFR+ treatment and care
  - Empowerment – knowledge and confidence as the basis of self-advocacy

## 2. Objectives and Activities

Since its inception in 2020, EGFR positive UK has established itself as an important source of support and practical advice for patients living with EGFR positive lung cancer. It has also become a highly regarded 'voice of the patient' for clinicians, regulators and the pharmaceutical industry.

We have created a support network in the UK for patients with Epidermal Growth Factor Receptor (EGFR) positive non-small cell lung cancer and their families. The advice and information we provide empowers and enables patients to have meaningful conversations with their healthcare professionals about their care and treatment. We advocate on behalf of EGFR positive lung cancer patients at a national level to ensure as many patients as possible receive a high level of care, wherever they live in the UK.

The overall objective of the Charity is to enable patients and their families to live well with and beyond EGFR positive lung cancer.

To achieve this, we:

- have created a strong supportive community of EGFR+ patient and their loved ones
- support these patients, their families and caregivers by providing a secure platform where they can give and receive mutual support and exchange experiences about their treatment.
- create opportunities for members to connect with each other through local, in-person and on-line events.
- empower patients by providing information that enables them to demand a high level of care.
- advocate on behalf of patients to ensure they receive the best care irrespective of where they live in the UK.
- liaise and collaborate with relevant organisations such as, other lung cancer charities and the pharmaceutical industry, to work to raise awareness of EGFR positive lung cancer and campaign for early diagnosis amongst non-smokers
- undertake research to better understand the well-being needs of patients and their loved ones and provide practical accessible resources to meet these needs.
- raise funds for the above purposes.

### 3. Achievements and Performance

Two patients met in February 2019 with the aim of establishing a UK group of EGFR positive patients who could exchange experiences and give and receive mutual support. Later that year, as the activity of the group grew, they decided to form a Charity and it was registered by the Charity Commission on 29 May 2020.

The initial aim of the charity was to support and inform patients, their families and carers through our peer support group. It became clear however, that there was a need and an opportunity to advocate for better, equally accessible and equitable care anywhere in the UK. This led to involvement with bodies such as NICE where the Charity now regularly represents patients affected by this rare form of lung cancer and takes part in the decision-making processes that approve new drugs and treatments.

#### A Year of Growth and Impact

In our fourth year we have continued the transition from a founder-led start-up, to a fully-fledged sustainable not-for-profit organisation capable of serving the needs of patients and their families living in the UK with EGFR Positive lung cancer. The priority has been to create an organisation whose internal infrastructure makes the Charity both sustainable and scalable. This led to a deal of internal focus in the first half of the year whilst we established collaborative working practices backed by shared technology systems to ensure we have a spread of involvement beyond the Trustees.

Our activities, performance and growth in our fourth year has exceeded our expectations. Going forward our emphasis will continue to be to support the well-being of EGFR+ patients and their families.

We will do this by:

- expanding our membership through the implementation of our digital influencing strategy
- offering individual and group counselling and workshops. Both of which were piloted in 2022/23
- advocating for the best care possible by continuing our involvement with key decision makers in regulatory authorities, pharmaceutical companies and clinicians
- in collaboration with other onco-gene driven cancer charities, research the patient experience thereby adding to the body of knowledge that will drive progress and change for patients and their families

- roll out our nationwide initiatives that will enable members to meet locally with fellow EGFR+ patients and their caregivers.

The main activities undertaken in 2023/24 to further our objectives were:

## 3.1 Support of Patients

### Website

The website has been further developed. It provides information about the charity and is a source that members can access to research aspects of their disease and care. The aim of the website is to help patients and their carers be better informed about EGFR-positive lung cancer and encourage them to join the Peer Support group that is hosted on Facebook and where they will find additional individual help and support.

### Peer Support Group

The Facebook group continues to be a great success and core to our support offering. The number of users has steadily increased from 98 in March 2020 to 707 in March 2024. Each day, there are posts by patients sharing experiences and giving and receiving emotional support. It is particularly pleasing that new members receive a very warm welcome from existing members. A survey of members showed that 98% would recommend the group to other EGFR-positive patients.

### Members' Forum

We ran a very successful in-person event for 35 members in Birmingham in April 2023. The focus of the event was to inform, engage and connect. All of the formal sessions were recorded and are on our [website](#) so that those who were unable to attend can view them. At the close of the event one participant said "now I have found a place where I belong. Being with people who are in the same position as me, I no longer feel lost."

Two further events in November 2023 and March 2024 were joint initiatives with ALK+UK and the Ruth Strauss Foundation. These events were focus groups made up of people living with EGFR+ and ALK+ lung cancer, to better understand their support needs. These Study Days enabled us to gather valuable insight into the patient and caregiver experience of living with mutation driven lung cancer.

### Online Activities

We continued to offer 'Ask the Expert' Zoom sessions and have provided 3 presentations from EGFR Clinical and holistic health experts. Recordings of these sessions are on our website.

We also offer monthly Zoom coffee mornings for all members and evening drop-in sessions. These sessions are well attended and give an opportunity to meet with other patients and share concerns, ideas and alert the Charity to issues that need to be addressed.

This year we offered individual coaching and facilitated two six-weeks' evening group sessions for those who wanted more in-depth support in terms of understanding and learning how to manage the ups and downs of living with a cancer diagnosis and treatment. A cancer diagnosis can cause loss of identity and self. Through self-management, individuals are empowered to regain control of their lives by understanding thoughts and emotions, strengthening mental resilience, identifying challenges, exploring different perspectives and setting goals.

### Member Surveys

We carry out a member survey each year to gather real-world data on all aspects of member's diagnosis, treatment and care. The findings give insights into patients' symptomatology, diagnostic and treatment pathways, and the impact of the disease on their wellbeing; as well as identifying areas for improvement

in terms of patients care and support. It also highlights deficiencies and variations in the level of services our members receive, including regional variations. This data gives us an invaluable evidence-based platform from which to advocate for the needs of EGFR patients in the UK.

Our third survey of member's experience was completed in April 2023, and our fourth was conducted during Feb/March 2024. The results of both were presented at the annual Lung Cancer Nurse UK conference (in 2023 and 2024 respectively), allowing us to share key findings from this research with those who play such a crucial role in the care of EGFR patients. Furthermore, our most recent survey consisted of 234 respondents, making it the largest EGFR+ NSCLC survey available.

By collaborating with researchers at the Open University, we have been able to grow our research quality and profile, producing publishable, reliable and valid research that we can draw upon both in our advocacy work with health care professionals and pharmaceutical companies, and which has proved invaluable to our role in NICE treatment appraisals. We plan to continue to disseminate the findings of our research through suitable academic avenues, with the view to significantly contributing to the body of knowledge that informs care and policy.

### Member activity

Towards the end of the year, twelve of our members from many parts of the country volunteered to be Regional Ambassadors to arrange local meet-ups for members. The Charity believes that these social gatherings are important for the mental well-being of patients and, for this reason, we subsidise the cost of meals. As it evolves, the Regional Ambassador Network, is becoming an important communication channel to and for members and a very valuable source of ideas and initiatives for the Charity. All Regional Ambassadors are required to abide by the Code of Conduct and other policies of the Charity.

Other social events and challenges for members have included a Thames-side walk and climbing Scarfell Pike.

Living Well with EGFR+ Lung Cancer is always at the forefront of our minds. We have facilitated a small number of online breathing and yoga sessions in early spring, as well as seasonal art therapy classes. We even had an online Christmas Quiz.

We run monthly online Meet and Chat sessions that members can access. Topics of discussion are far reaching and cover diagnosis and side effects, as well as personal news of events that happen in everyday life. These sessions are paramount to the wellbeing of many members.

We attempt to run monthly online sessions where we invite guest speakers to discuss a range of topics that are relevant to our membership cohort. We have had positive feedback about how useful and informative these sessions are.

## 3.2 Advocacy

Since its inception in 2020, EGFR positive UK has established itself as an important source of support and practical advice for patients living with EGFR positive lung cancer. It has also become a highly regarded 'voice of the patient' for clinicians, regulators and the pharmaceutical industry.

Establishing the Charity as a credible voice for EGFR+ patients and their caregivers involved liaising with and influencing a range of decision makers and national governing bodies e.g. National Institute for Clinical Excellence (NICE), NHS, Scottish Medicines Consortium (SMC).

We represent mutation driven lung cancer patients in the decision-making processes of both the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC), the bodies responsible for recommending the use of new medicines and treatments within the NHS.

Working with ALK+ UK and the Ruth Strauss Foundation we ran two parallel awareness campaigns during Lung Cancer Awareness Month in November 2023. The first, 'All You Need is Lungs' targeted the public's perception that only smokers are at risk of lung cancer. This campaign was run on several social media platforms and had very good engagement. The second, 'See Through the Symptoms' was aimed at local health care professionals i.e. GPs, Physiotherapists and Community Pharmacists. This campaign used the images and materials from the highly successful 2021 'See Through the Symptoms' Campaign developed with the ALK +UK charity. The focus here was on the importance of early diagnosis especially in those who are younger, fit and have never smoked. Both campaigns gave access to additional information for members of the public and health care professionals.

Our team of Regional Ambassadors have been distributing two information leaflets in a variety of healthcare settings e.g. oncology units, A&E, Maggie's Centres, GPs etc. The See Through the Symptoms leaflet is targeted at health care professionals and focuses on identifying symptoms of lung cancer. The second leaflet is aimed at EGFR+ lung cancer patients and signposts patients to EGFR+ resources via our website and online patient support group.

We have increased our presence on social media and now have active accounts on Instagram, LinkedIn, X and Facebook where we regularly post up-to-date research and support materials as well as advertising social events and online sessions that may be happening soon.

We have presented at several meetings and conferences with healthcare professionals and pharmaceutical organisations where we raised awareness of EGFR-positive lung cancer and advocated on behalf of patients. It is important that healthcare professionals are aware of the charity and the support that we provide so that they direct their patients to us. The growth in members indicates that we are having some success in raising this awareness.

Our involvement in NICE Technical Appraisals for new drugs and treatments in the area of EGFR positive NSCLC continued. This involves completing detailed submissions on the patient's perspective of living with EGFR positive NSCLC (informed by our own personal experience, but also by the results of our member surveys) and explaining the difference the new drug regimens would make to patient's lives. Each appraisal culminates in a committee hearing where we provide an expert patient representative to speak on behalf of EGFR Positive NSCLC patients.

We are in regular contact with a number of pharmaceutical companies who are currently developing drugs and treatments for EGFR Positive NSCLC. We sit on several steering committees, are involved in the creation and review of patient and Health Care professional's support material and are consulted on the development of patient friendly trial protocol. We continue to attend and speak at meetings run by pharmaceutical companies to highlight the needs and concerns of EGFR positive NSCLC patients.

In January 2024, we were invited to present to an audience of MPS at a Parliamentary meeting organised by Astra Zeneca. The session was designed to emphasise the importance of early biomarker testing for all patients diagnosed with lung cancer. We also took part in an action at the Houses of Parliament, under the banner of 'Catch Up with Cancer' to press the case for urgent action in relation to the back log in cancer care. In February we had a question and debate raised in the House of Lords in relation to the withdrawal of a drug that left a proportion of EGFR+ patients in the UK severely disadvantaged in relation to the treatment offered to them through the NHS.

We are members of the United Kingdom Lung Cancer Coalition (UKLCC) and sit on the Clinical Excellence Group (CEG) for Lung Cancer alongside eminent Clinicians. We have recently become a member of Lung Cancer Europe (LuCE).

We have continued to grow our use of social media and are active on Twitter, LinkedIn and Instagram. Our “See Though the Symptoms” early diagnosis campaign, developed with EGFR Positive UK and the Ruth Strauss Foundation, was taken up by Gateway C, the leading GP education provider, and they now provide an online never-smoker lung cancer course as part of their curriculum.

### 3.3 Fundraising

Our Funds are raised in the main from legacies, sponsored events organised by members or their friends and families and bereavement donations. We do not work with professional fundraisers or commercial participators.

Our members and their families undertook a wide range of activities. One of our fundraisers said “I was diagnosed with Stage 4 EGFR positive lung cancer. I have 3 young children and am 37 years old. This group has become incredibly important to me. I could not have dealt with this had I not had the positive support of these people who share their experience and insights so generously. For me this group has made the intolerable, tolerable and as a result I set myself challenges to raise funds through sponsored running.’

Going forward our emphasis will continue to be to support the well-being of EGFR+ patients and their families. We will do this by expanding our membership through more focused Digital Influencing, offering individual and group counselling and workshops, advocating for the best care possible by continuing our involvement with key decision makers in regulatory authorities, Pharmaceutical companies and Clinicians, in collaboration with other onco-gene driven cancer charities, research the patient experience thereby adding to the body of knowledge that will drive progress and change for patients and their families.

## 4. Financial Review

The Charity currently receives donations through members’ contribution, fund raising through crowd funding platforms and grants from pharmaceutical and other companies /trusts. These are unrestricted funds and any year-end surplus is transferred to general reserve for use in subsequent years.

The Accounts are drawn up on cash basis. During the last financial year, the total receipts from donations and grants was £58,284 (2022-23: £ 23,392). About 70% of these receipts are through the fund-raising platforms, primarily Just Giving and CAF.

We do not have premises and we do not employ staff; hence DBS checks are not applicable. Trustee costs primarily relate to reimbursement of travel and subsistence for attending conferences / workshops and meetings. The funds are mainly available to promote the charity’s objectives in advocacy and outreach through in-person members’ events and activities. We have a low level of fixed costs e.g. website maintenance, subscriptions to other organisations, insurance etc.

After all payments, the total surplus for the year was £7,894 (2022-23: £ 13,569).

Considering the limited reserves held by the Charity, excess funds, if any, are invested in fixed deposits with the bank. During the year, we had transferred £40,000 to fixed deposits with a balance of £22,686 in our savings account at the end of the year (2022-23: £ 54,792).

We have recently received the approval from HMRC for GiftAid. Claims against the same will commence during the FY 2023-24.

## 5. Structure, Governance and Management

The Charity is a Charitable Incorporated Organisation, and the governing document is its Constitution.

The Constitution provides that there shall be between three and eight Trustees.

The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.

The Charity has a published Code of Conduct applicable to its Trustees and Volunteers. In addition, the Charity has policies and procedures in place in respect of :

- Financial control, reserves and investments
- Trustee Expenses
- Conflict of interest
- Social Media.

We sought advice on the General Data Protection Regulations to ensure that we are compliant.

## 6. Reference and Administrative Details

Charity Name	EGFR Positive UK
Other name the charity uses	EGFR+ UK
Registered charity number	1189722
Charity's principal address	32 Manning Gardens, Croydon, Surrey, CR0 7DT

## 7. Names of the Trustees who manage the Charity

Trustee Name	Current Office (if any)	Dates acted if not for whole Year	Name of person or body entitled to appoint trustee (if any)
Angela Terry	Chair	Trustee From 15 Aug 2020. Chair from 12 Jan 2022	
Elizabeth Ann Brazier	Secretary	24 April 2021 to 21 April 2024	
Soumitra Bose	Treasurer	Appointed 20 May 2023	
Richard Kenneth Warren	Trustee	From 15 Aug 2020 to 3 Jul 2024	
Natasha Loveridge	Trustee	Appointed 10 Aug 2023	
Virginia Mary Harrison	Trustee	Appointed 20 May 2023	

- Ms Elizabeth Ann Brazier, Secretary passed away on 21<sup>st</sup> April 2024. Mr Richard Kenneth Warren stepped down as a Trustee w.e.f. 3<sup>rd</sup> July 2024. We record our thanks and sincere appreciation for their support to the Charity during their tenure.
- Corporate Trustees – n/a
- Names of Trustees holding title to property belonging to the Charity – n/a
- Funds held as custodian trustees on behalf of others – nil

## 8. Declarations

The Trustees declare that they have approved the Trustees' Report as above

Signed on behalf of the Charity's Trustees

Signatures	<b>Soumitra Bose</b>	<b>Angela Terry</b>
Full Names	Soumitra Bose	Angela Terry
Positions	Treasurer	Chair
Date	9 <sup>th</sup> September 2024	9 <sup>th</sup> September 2024

**EGFR POSITIVE UK  
FINANCIAL STATEMENTS  
RECEIPTS & PAYMENTS  
FOR THE YEAR ENDED 31 MARCH 2024**

**IN £**

	Year Ending 31st March		Year Ending 31st March	
	2024		2023	
<b>RECEIPTS</b>				
Donations & Fund Raising	58,254		23,392	
Advisory & other receipts	362	58,616	-	23,392
<b>TOTAL RECEIPTS</b>		58,616		23,392
<b>PAYMENTS</b>				
<b>Cost of Operating Activities</b>				
Advocacy	19,353		2,460	
Patients' Outreach	7,139		1,720	
Patients' Counselling	1,585			
Digital Influencing	14,663		2,033	
Travelling	3,576		2,704	
Publicity Materials	1,538			
Information Technology Costs	2,289			
Rentals	75			
Postage & Stationery	273		722	
Insurance	142		96	
Bank Charges	88	50,722	87	9,823
<b>Transfer to Fixed Deposit</b>		40,000		
<b>TOTAL PAYMENTS</b>		90,722		9,823
<b>NET (PAYMENTS)/ RECEIPTS</b>		(32,106)		13,569
<b>CASH FUNDS AT 31 MARCH 2023</b>		54,792		41,223
<b>CASH FUNDS AT 31 MARCH 2024</b>		22,686		54,792

**FINANCIAL STATEMENTS**  
**STATEMENT OF ASSETS AND LIABILITIES**  
**FOR THE YEAR ENDED 31 MARCH 2024**

IN £

	<b>Year Ending 31st March</b>	<b>Year Ending 31st March</b>
	<b>2024</b>	<b>2023</b>
<b>CASH FUNDS</b>		
Savings Account with Lloyds Bank	22,686	54,792
Fixed Deposit with Lloyds Bank	40,000	
<b>TOTAL ASSETS</b>	<b>62,686</b>	<b>54,792</b>
<b>ACCUMULATED FUNDS</b>		
Surplus Funds brought forward	54,792	41,223
Surplus Funds for the Year ( Note 1)	7,894	13,569
Surplus Funds carried forward	<b>62,686</b>	<b>54,792</b>

1. **SURPLUS FUNDS**

	<b>Year Ending 31st March</b>	<b>Year Ending 31st March</b>
	<b>2024</b>	<b>2023</b>
<b>Total Receipts</b>	58,616	23,392
Less : Cost of Operating Activities	50,722	9,823
<b>Surplus Fund for the year</b>	<b>7,894</b>	<b>13,569</b>

2. The financial statements are prepared on a receipts & payments basis.
3. Previous year's figures have been re-classified, where necessary.



**Section A**

**Independent Examiner's Report**

**Report to the trustees/  
members of**

Charity Name  
EGFR Positive UK

**On accounts for the year  
ended**

31 March 2024

**Charity no  
(if any)**

1189722

**Set out on pages**

3 - 4

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/03/2024**.

**Responsibilities and  
basis of report**

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**Independent  
examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

*\* Please delete the words in the brackets if they do not apply.*

**Signed:**

**Date:**

23/08/2024

**Name:**

Neil Horan

**Relevant professional  
qualification(s) or body  
(if any):**

Institute of Chartered Accountants for England and Wales

(Membership no: 9224166)

**Address:**

20 St Helens Road

Harrogate

HG2 8LB

**Section B**

**Disclosure**

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

**Give here brief details of any items that the examiner wishes to disclose.**

A large, empty rectangular box with a thin black border, occupying the central portion of the page. It is intended for the user to provide details as requested in the text above.

**EGFR POSITIVE UK  
FINANCIAL STATEMENTS  
RECEIPTS & PAYMENTS  
FOR THE YEAR ENDED 31 MARCH 2024**

**IN £**

	Year Ending 31st March		Year Ending 31st March	
	2024		2023	
<b>RECEIPTS</b>				
Donations & Fund Raising	58,254		23,392	
Advisory & other receipts	362	58,616	-	23,392
<b>TOTAL RECEIPTS</b>		58,616		23,392
<b>PAYMENTS</b>				
<b>Cost of Operating Activities</b>				
Advocacy	19,353		2,460	
Patients' Outreach	7,139		1,720	
Patients' Counselling	1,585			
Digital Influencing	14,663		2,033	
Travelling	3,576		2,704	
Publicity Materials	1,538			
Information Technology Costs	2,289			
Rentals	75			
Postage & Stationery	273		722	
Insurance	142		96	
Bank Charges	88	50,722	87	9,823
<b>Transfer to Fixed Deposit</b>		40,000		
<b>TOTAL PAYMENTS</b>		90,722		9,823
<b>NET (PAYMENTS)/ RECEIPTS</b>		(32,106)		13,569
<b>CASH FUNDS AT 31 MARCH 2023</b>		54,792		41,223
<b>CASH FUNDS AT 31 MARCH 2024</b>		22,686		54,792

**FINANCIAL STATEMENTS  
STATEMENT OF ASSETS AND LIABILITIES  
FOR THE YEAR ENDED 31 MARCH 2024**

**IN £**

	<b>Year Ending 31st March</b>	<b>Year Ending 31st March</b>
	<b>2024</b>	<b>2023</b>
<b>CASH FUNDS</b>		
Savings Account with Lloyds Bank	22,686	54,792
Fixed Deposit with Lloyds Bank	40,000	
<b>TOTAL ASSETS</b>	<b>62,686</b>	<b>54,792</b>
<b>ACCUMULATED FUNDS</b>		
Surplus Funds brought forward	54,792	41,223
Surplus Funds for the Year ( Note 1)	7,894	13,569
Surplus Funds carried forward	<b>62,686</b>	<b>54,792</b>

**1. SURPLUS FUNDS**

	<b>Year Ending 31st March</b>	<b>Year Ending 31st March</b>
	<b>2024</b>	<b>2023</b>
<b>Total Receipts</b>	58,616	23,392
Less : Cost of Operating Activities	50,722	9,823
<b>Surplus Fund for the year</b>	<b>7,894</b>	<b>13,569</b>

2. The financial statements are prepared on a receipts & payments basis.
3. Previous year's figures have been re-classified, where necessary.



**Section A**

**Independent Examiner's Report**

**Report to the trustees/  
members of**

Charity Name  
EGFR Positive UK

**On accounts for the year  
ended**

31 March 2024

**Charity no  
(if any)**

1189722

**Set out on pages**

3 - 4

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/03/2024**.

**Responsibilities and  
basis of report**

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**Independent  
examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

*\* Please delete the words in the brackets if they do not apply.*

**Signed:**

**Date:**

23/08/2024

**Name:**

Neil Horan

**Relevant professional  
qualification(s) or body  
(if any):**

Institute of Chartered Accountants for England and Wales

(Membership no: 9224166)

**Address:**

20 St Helens Road

Harrogate

HG2 8LB

**Section B**

**Disclosure**

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

**Give here brief details of any items that the examiner wishes to disclose.**

A large, empty rectangular box with a thin black border, occupying the central portion of the page. It is intended for the user to provide details as requested in the text above.

**EGFR POSITIVE UK  
FINANCIAL STATEMENTS  
RECEIPTS & PAYMENTS  
FOR THE YEAR ENDED 31 MARCH 2024**

**IN £**

	Year Ending 31st March		Year Ending 31st March	
	2024		2023	
<b>RECEIPTS</b>				
Donations & Fund Raising	58,254		23,392	
Advisory & other receipts	362	58,616	-	23,392
<b>TOTAL RECEIPTS</b>		58,616		23,392
<b>PAYMENTS</b>				
<b>Cost of Operating Activities</b>				
Advocacy	19,353		2,460	
Patients' Outreach	7,139		1,720	
Patients' Counselling	1,585			
Digital Influencing	14,663		2,033	
Travelling	3,576		2,704	
Publicity Materials	1,538			
Information Technology Costs	2,289			
Rentals	75			
Postage & Stationery	273		722	
Insurance	142		96	
Bank Charges	88	50,722	87	9,823
<b>Transfer to Fixed Deposit</b>		40,000		
<b>TOTAL PAYMENTS</b>		90,722		9,823
<b>NET (PAYMENTS)/ RECEIPTS</b>		(32,106)		13,569
<b>CASH FUNDS AT 31 MARCH 2023</b>		54,792		41,223
<b>CASH FUNDS AT 31 MARCH 2024</b>		22,686		54,792

**FINANCIAL STATEMENTS  
STATEMENT OF ASSETS AND LIABILITIES  
FOR THE YEAR ENDED 31 MARCH 2024**

**IN £**

	<b>Year Ending 31st March</b>	<b>Year Ending 31st March</b>
	<b>2024</b>	<b>2023</b>
<b>CASH FUNDS</b>		
Savings Account with Lloyds Bank	22,686	54,792
Fixed Deposit with Lloyds Bank	40,000	
<b>TOTAL ASSETS</b>	<b>62,686</b>	<b>54,792</b>
<b>ACCUMULATED FUNDS</b>		
Surplus Funds brought forward	54,792	41,223
Surplus Funds for the Year ( Note 1)	7,894	13,569
Surplus Funds carried forward	<b>62,686</b>	<b>54,792</b>

**1. SURPLUS FUNDS**

	<b>Year Ending 31st March</b>	<b>Year Ending 31st March</b>
	<b>2024</b>	<b>2023</b>
<b>Total Receipts</b>	58,616	23,392
Less : Cost of Operating Activities	50,722	9,823
<b>Surplus Fund for the year</b>	<b>7,894</b>	<b>13,569</b>

2. The financial statements are prepared on a receipts & payments basis.
3. Previous year's figures have been re-classified, where necessary.

**EGFR Positive Lung Cancer UK**

England & Wales - Charity number 1189722

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# Accounts

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**EGFR POSITIVE UK**

Charity No. 1189722

**TRUSTEES' ANNUAL REPORT**

**1 April 2022 to 31 March 2023**

The Charity was established 29 May 2020. This is the Trustees' Third Annual Report.

EGFR positive non-small cell lung cancer (NSCLC) is a rare form of lung cancer caused by a genetic mutation which affects approximately 10% of those diagnosed with lung cancer. Patients are, on average, much younger than most other lung cancer patients and are often female, non-smokers.

## **1. Objectives and Activities**

We provide a support network in the UK for patients with Epidermal Growth Factor Receptor (EGFR) positive lung cancer and their families. The advice and information we provide empowers and enables patients to have meaningful conversations with their healthcare professionals about their care and treatment. We advocate on behalf of EGFR positive lung cancer patients at a national level to ensure as many patients as possible receive a high level of care wherever they live in the UK.

The overall objective of the Charity is to enable patients and their families to live well with and beyond EGFR positive lung cancer.

We support, empower and advocate on behalf of EGFR positive lung cancer patients by:-

- a) Providing a forum where patients and their families can exchange information about their diagnosis and treatment and give and receive mutual support.
- b) Providing an information resource for patients. Being better informed about their condition gives patients greater confidence to personally advocate for the best care possible.
- c) Identifying and locating EGFR positive patients and offering support and guidance on the location of UK EGFR positive specialists and services. This includes access to information about the latest treatment developments and clinical trials.
- d) Advocating on behalf of patients to ensure they receive a high level of care wherever they live in the UK. This involves liaising with and influencing a range of decision makers and national governing bodies e.g. National Institute for Clinical Excellence (NICE), NHS, Scottish Medicines Consortium (SMC).
- e) Liaising and collaborating with relevant organisations such as other lung cancer charities and the pharmaceutical industry, we work to raise awareness of EGFR positive lung cancer and campaign for early diagnosis amongst non-smokers.
- f) Raising funds for the above purposes.

In the 4 years since its inception, EGFR positive UK has established itself as an important source of support and practical advice for patients living with EGFR positive lung cancer. It has also become a highly regarded 'voice of the patient' for clinicians, regulators and the pharmaceutical industry.

## 2. Our Vision

We want everyone in the UK who is diagnosed with EGFR Positive lung cancer

- To receive the best care possible
- To live their best lives possible
- To live for as long as possible

To achieve this we will:

- Support patients, their families and caregivers by providing a secure platform where they can give and receive mutual support and exchange experiences about their treatment.
- Empower patients by providing information that enables them to demand a high level of care.
- Advocate on behalf of patients to ensure that they receive the best care irrespective of where they live in the UK.
- Campaign to raise awareness of non-smoking lung cancer and the importance of early diagnosis.

## 3. Achievements and Performance

Two patients met in February 2019 with the aim of establishing a UK group of EGFR positive patients who could exchange experiences and give and receive mutual support. Later that year, as the activity of the group grew, they decided to form a charity and it was registered by the Charity Commission on 29 May 2021.

The main aim is to support and inform patients, their families and carers through the Facebook peer support group. It became clear however that there was a need and an opportunity to advocate for better, equally accessible and equitable care anywhere in the UK. This led to involvement with bodies such as NICE where the Charity now regularly represents patients affected by this rare form of lung cancer and takes part in the decision-making processes that approve new drugs and treatments.

Our third year has been challenging. Our Chair and last remaining Founder of the Charity died in Dec 2021. This necessitated the need to move from a founder led start-up to a fully-fledged sustainable not-for-profit organisation capable of serving the need of patients and their families living in the UK with EGFR Positive lung cancer. The priority was to create an organisation whose internal infrastructure makes the Charity both sustainable and scalable. This led to a deal of internal focus in the first half of the year whilst we established the new Chair and a team working ethos within the Trustees. Collaborative working practices backed by shared technology systems has led to a wider spread of involvement.

Given this however, our activities and performance in our third year have exceeded our expectations. We still achieved a great deal and the charity remains patient-driven and led.

Going forward our emphasis will continue to be to support the well-being of EGFR+ patients and their families. We will do this by:

- expanding our membership through the implementation of our Digital Marketing strategy
- offering individual and group counselling and workshops. Both of which were piloted in 2022/3

- advocating for the best care possible by continuing our involvement with key decision makers in regulatory authorities, Pharmaceutical companies and Clinicians
- in collaboration with other onco-gene driven cancer charities, research the patient experience thereby adding to the body of knowledge that will drive progress and change for patients and their families
- roll out our nationwide initiatives that will enable members to meet locally with fellow EGFR+ patients and their caregivers

The main activities undertaken in 2022/23 to further our objectives were:

### **3.1 Support of Patients**

#### Website

The website has been further developed. It provides information about the charity and is a source that members can access to research aspects of their disease and care. The aim of the website is to help patients and their carers be better informed about EGFR-positive lung cancer and encourage them to join the Peer Support group that is hosted on Facebook and where they will find help and support.

#### Peer Support Group

The Facebook group continues to be a great success and the number of users has steadily increased from 98 in March 2021 to 481 in March 2023. Each day, there are posts by patients sharing experiences and giving and receiving emotional support. It is particularly pleasing that new members receive a very warm welcome from existing members. A survey of members showed that 98% would recommend the group to other EGFR-positive patients.

#### Member's Forum

We ran a very successful in-person event for 35 members in London in October 2022. The focus of the event was to inform, engage and connect. All of the formal sessions were recorded and are on our Website so those who were unable to attend can view them. At the end of the day one participant said "now I have found a place where I belong. Being with people who are in the same position as me, I no longer feel lost."

#### Online Activities

Following the pandemic, like many others, we continued to offer Zoom sessions and have provided 3 presentations from EGFR Clinical and holistic health experts. Recordings of these sessions are on our website. We also offer monthly Zoom coffee mornings for all members and evening drop-in sessions for Caregivers and loved ones.

Our 'Good Practice from the Patient's Perspective' guide which was endorsed by three leading EGFR Positive Oncology experts, continues to be well received especially by those who are newly diagnosed.

## Surveys

We conducted our 3rd annual survey of members. A more comprehensive analysis this year gave us invaluable information which we used extensively both in our advocacy work with health care professionals and pharmaceutical companies and during NICE and SMC drug appraisals.

### **3.2 Advocacy**

For Lung Cancer Awareness month in 2022, in partnership with ALK+ UK and the Ruth Strauss Foundation, we re-purposed our award winning advertising campaign: 'See Through The Symptoms' to raise awareness amongst Cancer Alliances, hospitals and primary healthcare professionals of the need for early diagnosis. The initial campaign had the support of the British Thoracic Oncology Group, the British Lung Foundation, the Taskforce for Lung Health, Macmillan Cancer Support, Gateway C and the Primary Care Respiratory Society as well as leading Respiratory Consultants and Oncologists.

We have presented at several meetings and conferences with healthcare professionals and pharmaceutical organisations where we raised awareness of the Charity and of EGFR-positive lung cancer and advocated on behalf of patients. It is important that healthcare professionals are aware of the charity and the support that we provide so that they direct their patients to us. The growth in members indicates that we are having some success in raising this awareness.

Our involvement in 6 NICE and 3 SMC Technical Appraisals for new drugs and treatments in the area of EGFR positive NSCLC continued well into 2022. This involved completing detailed submissions on the patient's perspective of living with EGFR positive NSCLC and explaining the difference these new drug regimens would make to patient's lives. Each appraisal culminates in a Committee hearing where we provide an expert patient representative to speak on behalf of EGFR Positive NSCLC patients.

We are in regular contact with a number of pharmaceutical companies who are currently developing drugs and treatments for EGFR Positive NSCLC. We sit on several steering committees, are involved in the creation and review of patient and Health Care professional's support material and are consulted on the development of patient friendly trial protocol. We continue to attend and speak at meetings run by pharmaceutical companies to highlight the needs and concerns of EGFR positive NSCLC patients.

We are members of the United Kingdom Lung Cancer Coalition(UKLCC) and sit on the Clinical Excellence Group (CEG) for Lung Cancer alongside eminent Clinicians.

In conjunction with the ALK+ UK Charity and the Ruth Strauss Foundation we submitted an abstract to the British Thoracic Oncology Group Conference that reported on the very positive impact of the early diagnosis 'See Through The Symptoms' campaign.

### **3.3 Fundraising**

Our Funds are raised in the main from legacies, sponsored events organised by members or their friends and families and bereavement donations. We do not work with professional fundraisers or commercial participators.

Our members and their families undertook a wide range of activities. One of our fundraisers said “I was diagnosed with Stage 4 EGFR positive lung cancer. I have 3 young children and am 37 yrs old. This group has become incredibly important to me. I could not have dealt with this had I not had the positive support of these people who share their experience and insights so generously. For me this group has made the intolerable, tolerable and as a result I set myself challenges to raise funds through sponsored running.’

Going forward our emphasis will continue to be to support the well-being of EGFR+ patients and their families. We will do this by expanding our membership through more focused Digital Marketing, offering individual and group counselling and workshops, advocating for the best care possible by continuing our involvement with key decision makers in regulatory authorities, Pharmaceutical companies and Clinicians, in collaboration with other onco-gene driven cancer charities, research the patient experience thereby adding to the body of knowledge that will drive progress and change for patients and their families

## **4. Financial Review**

The Charity had £54,792 in its bank account at the end of the financial year.

We do not have premises and we do not employ staff.

We have a low level of fixed costs, e.g. website maintenance, subscriptions to other organisations, insurance. Incidental costs related to Trustee’s travel and subsistence, our in-person patient events and conference attendance. As a result of this, our end of year balances are largely available to promote the charity’s objectives.

## **5. Structure, Governance and Management**

The Charity is a Charitable Incorporated Organisation, and the governing document is its Constitution.

The Constitution provides that there shall be between three and eight Trustees.

The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.

## 6. Reference and Administrative Details

Charity Name	EGFR Positive UK
Other name the charity uses	EGFR+ UK
Registered charity number	1189722
Charity's principal address	32 Manning Gardens, Croydon, Surrey, CR0 7DT

## 7. Names of the Charity Trustees who Manage the Charity

Trustee Name	Current Office (if any)	Dates Acted if not for whole Year	Name of person or body entitled to appoint trustee (if any)
Angela Terry	Chair	Trustee From 15 Aug 2020. Chair from 12 Jan 2022	
Elizabeth Ann Brazier	Secretary	From 24 April 2021	
Steve Macdonald	Treasurer	23 Mar 2022 to 20 May 2023	
Richard Kenneth Warren		From 15 Aug 2020	
Deborah Mary Littell		From 24 April 2021 to 10th Aug 2023	
Soumitra Bose	Treasurer	From 20 May 2023	
Virginia Mary Harrison		From 20 May 2023	

Corporate Trustees – n/a

Names of Trustees holding title to property belonging to the Charity – n/a

Funds held as custodian trustees on behalf of others – nil

## 8. Declarations

The Trustees declare that they have approved the Trustees' Report as above

Signed on behalf of the Charity's Trustees

Signatures	<b>Soumitra Bose</b>	<b>Angela Terry</b>
Full Names	Soumitra Bose	Angela Terry
Positions	Treasurer	Chair
Date	10th August 2023	10th August 2023

**EGFR POSITIVE UK  
FINANCIAL STATEMENTS  
RECEIPTS & PAYMENTS  
FOR THE YEAR ENDED 31 MARCH 2023**

**In £**

	Year ending 31st March 2023		Year ending 31st March 2022	
<b>RECEIPTS</b>				
Donations & Fund Raising		23,392		39789
<b>TOTAL RECEIPTS</b>		<b>23,392</b>		<b>39789</b>
<b>PAYMENTS</b>				
<b>Cost of operating activities</b>				
Members' Forum Expenses	1,720			
Advocacy Expenses	2,460			
Digital Marketing Costs	2,033			
Travelling	2704		1493	
Postage & Stationery	722			
Bank Charges	87			
Insurance	96	9,823		1493
<b>TOTAL PAYMENTS</b>		<b>9,823</b>		<b>1493</b>
<b>NET (PAYMENTS)/ RECEIPTS</b>		13569		38296
<b>CASH FUNDS AT 31 MARCH 2022</b>		41223		2927
<b>CASH FUNDS AT 31 MARCH 2023</b>		<b>54792</b>		<b>41223</b>

**EGFR POSITIVE UK**  
**FINANCIAL STATEMENTS**  
**STATEMENT OF ASSETS AND LIABILITIES**  
**FOR THE YEAR ENDED 31 MARCH 2023**

In £

	Year ending 31st March 2023		Year ending 31st March 2022	
<b>CASH FUNDS</b>				
Bank Account		54792		41223
<b>TOTAL ASSETS</b>		<b>54792</b>		<b>41223</b>
<b>ACCUMULATED FUNDS</b>				
Surplus Funds brought forward		41223		2927
Surplus Funds for the year (Note 2)		13569		38296
Surplus Funds carried forward		<b>54792</b>		<b>41223</b>

**1. ACCOUNTING POLICIES**

The financial statements are prepared on a receipts and payments basis. As the annual income for the year falls below £ 25,000, no independent examination of the financial statements have been conducted as per guidance.

**1. SURPLUS FUNDS**

In £

	Year ending 31 <sup>st</sup> March 2023	Year ending 31 <sup>st</sup> March 2022
Total Receipts	23392	39789
Less: Cost of operating activities	9823	1493
Surplus Funds for the year	13569	38296

Previous year's figures have been re-classified to make them comparable.

**EGFR Positive Lung Cancer UK**

England & Wales - Charity number 1189722

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# Accounts

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EGFR POSITIVE UK

Charity No. 1189722

## **TRUSTEES' ANNUAL REPORT**

**1 April 2021 to 31 March 2022**

The Charity was established 29 May 2020, and this is the Trustees' second Annual Report.

EGFR positive non-small cell lung cancer (NSCLC) is a form of lung cancer caused by a genetic mutation which affects approximately 10% of those diagnosed with lung cancer. Patients are, on average, much younger than most other lung cancer patients and are often non-smokers.

### **1. Objectives and Activities**

The objectives of the Charity are to support, preserve and protect the good health of UK Epidermal Growth Factor Receptor (EGFR) mutation positive lung cancer patients and their caregivers by:-

- a. providing an information resource, including access to information about latest developments and clinical trials.
- b. Identifying and locating UK EGFR patients and offering support and guidance on the location of UK EGFR specialists and services.
- c. Liaising with and influencing decision makers eg. NICE, NHS, SMC
- d. Raising awareness of EGFR positive lung cancer, particularly amongst the medical profession to promote the best treatment for patients.
- e. Liaising and collaborating with relevant organisations such as other lung cancer charities and the pharmaceutical industry.
- f. Raising funds for the above purposes.

### **2. Our Vision**

We want everyone in the UK who is diagnosed with EGFR Positive lung cancer

- To receive the best care possible
- To live their best lives possible
- To live for as long as possible

To achieve this we will:

- Support patients, their families and carers by providing a secure platform where they can give and receive mutual support and exchange experiences about their treatment.

- Empower patients by providing information that enables them to demand a high level of care.
- Advocate on behalf of patients to ensure that they receive the best care irrespective of where they live in the UK.

### **3. Achievements and Performance**

Two patients met in February 2019 with the aim of establishing a UK group of EGFR positive patients who could exchange experiences and give and receive mutual support. Later that year, as the activity of the group grew, the decision was made to form a charity and it was registered by the Charity Commission on 29 May 2021.

As well as supporting and informing patients, their families and carers through the support group, it became clear there was a need and an opportunity to advocate for better, more consistent and equitable care anywhere in the UK. This led to involvement with bodies such as National Institute for Health and Care Excellence (NICE) where the Charity now regularly represents patients affected by this rare form of lung cancer and takes part in the decision making processes.

Our activities and performance in our second year have exceeded our expectations. Despite many of our planned activities for 2021 being severely curtailed by the Covid-19 pandemic we still achieved a great deal.

The charity remains patient-driven and led. The main activities undertaken to further our objectives were:

#### **3.1 Support of Patients**

##### Website

The website has been further developed. It provides information about the charity and is a source that members can access to research aspects of their disease and care. The aim of the website is to help patients and their carers be better informed about EGFR-positive lung cancer and encourage them to join the Facebook group where they will find help and support.

##### Facebook Group

The Facebook group continues to be a great success and the number of users has steadily increased from 98 in March 2020 to 228 in March 2021. Each day, there are posts by patients sharing experiences and giving and receiving emotional support. It is particularly pleasing that new members receive a very warm welcome from existing members. A survey of followers showed that 95% would recommend the group to other EGFR-positive patients.

##### Online Activities

The pandemic meant, like many others, we took to Zoom and have provided 5 presentations from EGFR Clinical and holistic health experts. Recordings of these sessions are on our website. We also offer monthly Zoom coffee mornings.

Our 'Good Practice from the Patient's Perspective' guide has been reviewed and updated and this was endorsed by three leading EGFR Positive experts.

## Surveys

We conducted a major annual survey of members to ascertain information about their treatment. The data obtained will inform our advocacy at meetings with health care professionals.

## **2.2 Advocacy**

In partnership with ALK+ UK and the Ruth Strauss Foundation we launched an award winning campaign to raise awareness amongst primary healthcare professionals of the need for early diagnosis. The campaign had the support of the British Thoracic Oncology Group, the British Lung Foundation, the Taskforce for Lung Health, Macmillan Cancer Support, Gateway C and the Primary Care Respiratory Society as well as leading Respiratory Consultants and Oncologists.

As a result of our campaign, there were 1.2M impressions across the social media platforms utilised, with 10,000 views of the microsite (our target based on national data for click through rates was 4.3k). Following the campaign in April, we held a UK wide GP training webinar in collaboration with the PCRS (Primary Care Respiratory Society) where non-smoking lung cancer was the topic with several speakers endorsing our messages.

We have also shared the campaign with two Cancer Alliance Groups, who were keen to utilise our material in one of their public health campaigns.

We attended meetings with healthcare professionals where we raised awareness of the Charity and of EGFR-positive lung cancer and advocated on behalf of patients. Following Covid these meetings have continued online. It is important that healthcare professionals are aware of the charity and the support that we provide so that they direct their patients to us. The growth in members indicates that we are having some success in raising this awareness.

This year we have been involved in 6 NICE Technical Appraisals for new drugs and treatments in the area of EGFR positive NSCLC. This has involved completing detailed submissions on the patient's perspective of living with EGFR positive NSCLC and explaining the difference these new drug regimens would make to patient's lives. Each appraisal culminates in a Committee hearing where we provide an expert patient representative to speak on behalf of EGFR Positive NSCLC patients. In addition we have fulfilled a similar role with the commissioning body in Scotland – The Scottish Medicines Consortium (SMC) for the approval of new drugs for use in NHS Scotland.

We are in regular contact with a number of Pharmaceutical companies who are currently developing drugs and treatments for EGFR Positive NSCLC. We sit on several steering committees, are involved in the creation and review of patient and Health Care professional's support material and are consulted on the development of patient friendly trial protocol. We continue to attend and speak at meetings run by pharmaceutical companies to highlight the needs and concerns of EGFR positive NSCLC patients.

We are members of the United Kingdom Lung Cancer Coalition and sit on the Clinical Excellence Group for Lung Cancer.

In conjunction with the ALK+ Group we published in the medical press, a report on the role of UK oncogene-focused patient groups in supporting and educating patients with oncogene driven non-small cell lung cancer. We submitted an abstract on "The Importance of Support Groups" to the British Thoracic Oncology Group.

## 2.3 Fundraising

Our Funds are raised in the main from legacies, sponsored events organised by members or their friends and families and bereavement donations. This activity has increased as the Covid restrictions have been relaxed.

Despite the restrictions of the pandemic, our members and their families undertook a wide range of activities. One of our fundraisers said “I was diagnosed with Stage 4 EGFR positive lung cancer. I have 3 young children and am 37yrs old. This group has become incredibly important to me. I could not have dealt with this had I not had the positive support of these people who share their experience and insights so generously. For me this group has made the intolerable, tolerable and as a result I set myself challenges to raise funds through sponsored running.’

## 4. Financial Review

The Charity had £41,224 in its bank account at the end of the financial year.

We do not have premises and we do not employ staff.

We have a very low level of fixed costs, e.g. website maintenance, subscriptions to other organisations, insurance. Incidental costs related to Trustee’s travel and subsistence, our in-person patient events and conference attendance. As a result of this our end of year balances are largely available to promote the charity’s objectives.

## 5. Structure, Governance and Management

The Charity is a Charitable Incorporated Organisation, and the governing document is its Constitution.

The Constitution provides that there shall be between three and eight Trustees.

The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.

## 6. Reference and Administrative Details

Charity Name	EGFR Positive UK
Other name the charity uses	EGFR+ UK
Registered charity number	1189722
Charity’s principal address	35 Clissold Road, London, N16 9EX

## 7. Names of the Charity Trustees who Managed the Charity in until Year End 2022

Trustee Name	Office (if any)	Dates Acted if not for whole Year	Name of person or body entitled to appoint trustee (if any)
Angela Terry	Chair	From 12 Jan 2022	
Lizzi Brazier	Secretary	From 24 April 2021	
Steve Macdonald	Treasurer	From 23 Mar 2022	
Richard Warren		From 15 Aug 2020	
Debs Littell		From 24 Apr 2021	

Corporate Trustees – n/a

Names of Trustees holding title to property belonging to the Charity – n/a

Funds held as custodian trustees on behalf of others – nil

## 8. Declarations

The Trustees declare that they have approved the Trustees' Report as above

Signed on behalf of the Charity's Trustees

Signatures	<b>Steve Macdonald</b>	<b>Angela Terry</b>
Full Names	Steve Macdonald	Angela Terry
Positions	Treasurer	Chair
Date	22 Jan 2023	22 Jan 2023

**INDEPENDENT EXAMINERS REPORT  
TO THE TRUSTEES OF EGFR POSITIVE UK**

I report on the financial statements of the charity for the year ended 31 December 2021, as set out on pages 7 to 9. The accounts have been prepared in accordance with the historical cost conventions and the accounting policies as set out on page 9.

**Respective Responsibilities of Trustees and Examiner**

As the Charity's Trustee's you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 (the Act); you consider that the audit requirement under section 144 of the Charities Act 2011 (the Charities Act) does not apply.

It is my responsibility to:

1. Examine the accounts under section 145 of the Charities Act,
2. Examine whether the accounts agree with the provided records,
3. To follow the applicable Directions given by the Charity Commission under section 145(5) (b) of the Act,
4. To state whether particular matters have come to my attention.

**Basis of Independent Examiner's statement**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the Charity and a comparison of the financial statements presented with those records. It also includes consideration of any unusual items or disclosures in the financial statements and seeking explanations from you as Trustees concerning such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently I do not express an opinion as to whether the accounts present a 'true and fair' view and my report is limited to those matters set out in the statement below.

**Independent Examiner's statement**

In the course of my examination, no matter has come to my attention which gives me cause to believe that, in any material respect:

- accounting records were not kept in accordance with section 130 of the Charities Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination of the accounts to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.



Mark Hooton  
Mark Hooton Chartered Accountants  
2 Butlers Close  
Lockerley  
Romsey  
Hants  
SO51 0LY

22 January 2023

**EGFR POSITIVE UK  
FINANCIAL STATEMENTS  
RECEIPTS AND PAYMENTS  
FOR THE YEAR ENDED 31 MARCH 2022**

	Year ending 31st March 2022	Year ending 31st March 2021
<b>RECEIPTS</b>		
Donations and fundraising	39,789	2,927
<b>TOTAL RECEIPTS</b>	<u><u>39,789</u></u>	<u><u>2,927</u></u>
<b>PAYMENTS</b>		
Cost of operating activities		
Trustees expenses	1,493	-
	<u>1,493</u>	<u>-</u>
<b>TOTAL PAYMENTS</b>	<u><u>1,493</u></u>	<u><u>-</u></u>
<b>NET (PAYMENTS) / RECEIPTS</b>	38,296	2,927
<b>CASH FUNDS AT 31 MARCH 2021</b>	2,927	-
<b>CASH FUNDS AT 31 MARCH 2022</b>	<u><u>41,223</u></u>	<u><u>2,927</u></u>

**EGFR POSITIVE UK  
FINANCIAL STATEMENTS  
STATEMENT OF ASSETS AND LIABILITIES  
FOR THE YEAR ENDED 31 MARCH 2022**

	Year ending 31st March 2022	Year ending 31st March 2021
<b>CASH FUNDS</b>		
Bank account	41,223	2,927
<b>TOTAL ASSETS</b>	<u>41,223</u>	<u>2,927</u>
<b>ACCUMULATED FUNDS</b>		
Surplus funds brought forward	2,927	-
Surplus funds for the year      Note 2	<u>38,296</u>	<u>2,927</u>
Surplus funds carried forward	<u>41,223</u>	<u>2,927</u>

**EGFR POSITIVE UK  
FINANCIAL STATEMENTS  
NOTES TO THE FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 MARCH 2022**

**1 ACCOUNTING POLICIES**

The financial statements are prepared on a receipts and payments basis.

**2 SURPLUS FUNDS**

Total receipts	39,789	2,927
Less:		
Cost of operating activities	<u>1,493</u>	<u>-</u>
	1,493	-
<b>Surplus funds for the year</b>	<u><u>38,296</u></u>	<u><u>2,927</u></u>

**EGFR Positive Lung Cancer UK**

England & Wales - Charity number 1189722

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# Accounts

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**Registered Charity Number 1189722**

**Report of the Trustees and  
Unaudited Financial Statements for the Period Ended 31 March 2021  
For  
EGFR Positive UK**

## EGFR Positive UK

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## EGFR Positive UK

### Directors and other information

<b>Trustees</b>	Jenny Abbott Asgarali Rajabali Richard Warren Angela Passmore Angela Terry Lizzi Brazier Deborah Little Jackie Dolaghan
<b>Charity number</b>	1189722
<b>Principal office</b>	35 Clissold Road London N16 9EX
<b>Independent Examiner</b>	Asad Rajabali, ACA ICAEW Reg No. 2846676 Amafh & Co 44-45 Calthorpe Road Edgbaston Birmingham B15 1TH

## EGFR Positive UK

Trustees report  
Year ended 31 March 2021

EGFR POSITIVE UK  
Charity No. 1189722  
**TRUSTEES' ANNUAL REPORT**  
**1 January 2020 to 31 December 2020**

The Charity was established 29 May 2020, and this is the Trustees' first Annual Report.

EGFR mutation positive lung cancer is a form of lung cancer drive which affects approximately 10% of those diagnosed with lung cancer. Patients are, on average, much younger than most other lung cancer patients and are often non-smokers.

### 1. Objectives and Activities

The objectives of the Charity are to relieve sickness and to preserve and protect good health of UK Epidermal Growth Factor Receptor (EGFR) mutation positive lung cancer patients by:-

- a. providing an information resource, including access to information about latest developments and clinical trials.
- b. Identifying and locating UK EGFR patients and offering support and guidance on the location of UK EGFR specialists and services.
- c. Liaising with and influencing decision makers eg. NICE, NHS, DVLA;
- d. Raising awareness of EGFR lung cancer, particularly amongst the medical profession in order to promote the best treatment for patients.
- e. Liaising with relevant organisations, in particular Roy Castle Lung Cancer Foundation and the pharmaceutical industry.
- f. Raising funds for the above purposes.

### 2. Achievements and Performance

The charity was registered with the Charity Commission on May 29<sup>th</sup>, 2020. The charity grew from a support group for EGFR patients established in February 2019 by two patients. It became clear there was a need for more support and information for EGFR patients and their families and a desire from bodies such as NICE for patients affected by this form of lung cancer to take part in decision making

**The notes on pages 10 to 11 form part of these financial statements.**

## EGFR Positive UK

processes which would affect them.

Our activities and performance in our first year have greatly exceeded our expectations. The charity remains patient- driven and led. The main activities undertaken to further our objectives were:

### **2.1 Support of Patients**

#### Website

The website was established. It provides information about the charity and is a source of information for members to be better informed about EGFR-positive lung cancer.

#### Facebook Page

The Facebook page continues to be a great success and the number of users has steadily increased. Each day, there are posting by patients sharing experiences and giving and receiving emotional support. It is particularly pleasing that new members receive a very warm welcome from existing members. A survey of followers showed that 95% would recommend the group to other EGFR-positive patients.

Other activities included organising talks from EGFR experts which members were able to attend via Zoom and the introduction of Zoom coffee mornings which have been held on a regular basis.

We also published our guide 'Good Practice from the Patient's Perspective'

Patients Forum Meeting – our first meeting was held in November 2020 in London. Approximately forty members attended to hear talks from EGFR experts and to meet each other.

### **2.2 Advocacy**

We attended meetings with healthcare professionals where we raised awareness of the Charity and of EGFR-positive lung cancer and advocated on behalf of patients. These meeting were in person in the first quarter of the year and then online thereafter. It is important that healthcare professionals are aware of the charity and the support that we provide so that they direct their patients to us. The growth in members indicates that we are having some success in raising this awareness. We were consulted by the National Institute for Health and Care (NICE) on applications by pharmaceutical companies for approval of their products and we attended online meetings with NICE where we have given the patients' perspective.

We have attended and spoken at several meetings run by pharmaceutical companies to highlight the needs and concerns of EGFR patients.

We have become members of the United Kingdom Lung Cancer Coalition and sit on the Clinical Excellence Group for Lung Cancer.

### **2.3 Fundraising**

**The notes on pages 10 to 11 form part of these financial statements.**

## EGFR Positive UK

Due to COVID and the fact that the charity was still establishing itself our fundraising activities have been minimal.

### 3. Financial Review

The Charity had £2,927 in its bank account at the end of the financial year.

We do not have premises and we do not employ staff. We have a very low level of fixed costs, e.g. website maintenance, subscriptions to other organisations, insurance, and our end of year balances are largely available to promote the charity's objectives.

### 4. Structure, Governance and Management

The Charity is a Charitable Incorporated Organisation, and the governing document is its Constitution.

The Constitution provides that there shall be between three and eight Trustees and there were eight throughout the period to the end of March 2020.

The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.

### 5. Reference and Administrative Details

Charity Name	EGFR Positive UK
Other name the charity uses	EGFR+ UK
Registered charity number	1189722
Charity's principal address	35 Clissold Road, London, N16 9EX

### 6. Names of the Charity Trustees who Managed the Charity in until Year End 2020

Trustee Name	Office (if any)	Dates Acted if not for whole Year	Name of person or body entitled to appoint trustee (if any)
Jenny Abbott	Co-Chair		
Kathy Beattie	Co-Chair		
Asgarali Rajabali	Treasurer		
Mark Bradshaw	Secretary		
Jacqueline Harvey	Fundraising		
Richard Warren			
Angela Terry			
Angela Passmore			

The notes on pages 10 to 11 form part of these financial statements.

## EGFR Positive UK

Corporate Trustees – n/a

Names of Trustees holding title to property belonging to the Charity – n/a

Funds held as custodian trustees on behalf of others – nil

### 7. Declarations

The Trustees declare that they have approved the Trustees' Report as above

Signed on behalf of the Charity's Trustees

Signatures	<b>Asgarali Rajabali</b>	<b>Jenny Abbott</b>
Full Names	Asgarali Rajabali	Jenny Elizabeth Abbott
Positions	Treasurer	Chair
Date	22 November 2021	23 October 2021

The notes on pages 10 to 11 form part of these financial statements.

## EGFR Positive UK

### EGFR Positive UK Year ended 31 March 2021

#### **Independent examiner's report to the trustees of EGFR Positive UK**

I report to the charity trustees on my examination of the accounts of EGFR Positive UK for the year ended 31 March 2021.

#### **Responsibility and basis of report**

As the charity trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act')

I report in respect of my examination of the Trust's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

#### **Independent Examiner's statement**

I have completed my examination. I confirm that no material 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 kept in respect of the charity as required by section 130 of the Act: or
2. The accounts do not accord with those records: or
3. The accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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.

*ARajabali*

Asad Rajabali, ACA  
ICAEW Reg No. 2846676  
Amafh & Co  
44-45 Calthorpe Road  
Edgbaston  
Birmingham  
B15 1TH

Date 22 November 2021

**The notes on pages 10 to 11 form part of these financial statements.**

## EGFR Positive UK

	Note	2021 £
<b>Turnover</b>		2,927
<b>Profit before taxation</b>		<u>2,927</u>
Tax on profit		-
<b>Profit for the financial year and total comprehensive income</b>		<u>2,927</u>

All the activities of the company are from continuing operations.

The notes on pages 10 to 11 form part of these financial statements.

**EGFR Positive UK**  
**Company limited by guarantee**

**Statement of financial position**  
**31 March 2021**

	Note	2021	
		£	£
<b>Current assets</b>			
Cash at bank and in hand		2,927	
		<hr/>	
		2,927	
<b>Net current assets</b>			2,927
<b>Total assets less current liabilities</b>			<hr/>
			2,927
<b>Net assets</b>			<hr/>
			2,927
			<hr/>
<b>Capital and reserves</b>			
Profit and loss account			2,927
			<hr/>
<b>Members funds</b>			2,927
			<hr/>
			<hr/>

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime and in accordance with FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

These financial statements were approved by the board of directors and authorised for issue on .23<sup>rd</sup> October 2021, and are signed on behalf of the board by:

Jenny Abbott  
Chair and  
Trustee

Charity Number 1189722

**The notes on pages 10 to 11 form part of these financial statements.**

**EGFR Positive UK  
Company limited by guarantee**

**Statement of changes in equity  
Year ended 31 March 2021**

	Profit and loss account £	<b>Total</b>  £
<b>At 1 April 2020</b>	-	-
Profit for the year	2,927	2,927
<b>Total comprehensive income for the year</b>	<u>2,927</u>	<u>2,927</u>
<b>At 31 March 2021</b>	<u>2,927</u>	<u>2,927</u>

## EGFR Positive UK

### Notes to the financial statements Year ended 31 March 2021

#### 1. General information

The charity principal address is 35 Clissold Road, London, N16 9EX.

#### 2. Statement of compliance

These financial statements have been prepared in compliance with the provisions of FRS 102, Section 1A, 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

#### 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 profit or loss.

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

##### **Turnover**

Turnover is measured at the fair value of the consideration received or receivable for goods supplied and services rendered, net of discounts and Value Added Tax.

Revenue from the sale of goods is recognised when the significant risks and rewards of ownership have transferred to the buyer, usually on despatch of the goods; the amount of revenue can be measured reliably; it is probable that the associated economic benefits will flow to the entity and the costs incurred or to be incurred in respect of the transactions can be measured reliably.

##### **Taxation**

The charity is exempt from tax on its charitable activities.

**EGFR Positive UK**

**Notes to the financial statements (continued)  
Year ended 31 March 2021**

**The following pages do not form part of the statutory accounts.**

**EGFR Positive UK**  
**Company limited by guarantee**

**Detailed income statement**  
**Year ended 31 March 2021**

	<b>2021</b>
	<b>£</b>
<b>Turnover</b>	
Sales	2,927
	<hr/> 2,927
<b>Gross profit</b>	<hr/> 2,927
<b>Gross profit percentage</b>	100.0%
<b>Operating profit</b>	2,927
<b>Operating profit percentage</b>	100.0%
<b>Profit before taxation</b>	<hr/> <hr/> 2,927