



**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	Soumitra Bose	Angela Terry
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>

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



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

**IN £**

	Year Ending 31st March		Year Ending 31st March	
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<b>PAYMENTS</b>				
<b>Cost of Operating Activities</b>				
Advocacy	19,353		2,460	
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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
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**STATEMENT OF ASSETS AND LIABILITIES**  
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IN £

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ended

31 March 2024

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