

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 £**

	<b>Year ending 31st March 2023</b>		<b>Year ending 31st March 2022</b>	
<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 £**

	<b>Year ending 31<sup>st</sup> March 2023</b>	<b>Year ending 31<sup>st</sup> March 2022</b>
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.