

# 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>	<b>39,789</b>	<b>2,927</b>
<b>PAYMENTS</b>		
Cost of operating activities		
Trustees expenses	1,493	-
	1,493	-
<b>TOTAL PAYMENTS</b>	<b>1,493</b>	<b>-</b>
<b>NET (PAYMENTS) / RECEIPTS</b>	<b>38,296</b>	<b>2,927</b>
<b>CASH FUNDS AT 31 MARCH 2021</b>	<b>2,927</b>	<b>-</b>
<b>CASH FUNDS AT 31 MARCH 2022</b>	<b>41,223</b>	<b>2,927</b>

**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	38,296	2,927
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	1,493		-	
		1,493		-
<b>Surplus funds for the year</b>		<b>38,296</b>		<b>2,927</b>