



Lung Cancer Europe

8th LUCE REPORT ON LUNG CANCER



Financial impact in people impacted
by ALK-positive lung cancer

An initiative of: 
Lung Cancer Europe

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 ALKPOSITIV
DEUTSCHLAND

 ALK+ International
Furthering ALK+ Cancer Research



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Table of contents:

Page 04 • Introduction

Page 05 • Project description and methodology

Page 06 • Results

Page 15 • Call to action

Page 16 • About us



INTRODUCTION

ALK-positive lung cancer patients are individuals who have been diagnosed with a specific type of non-small cell lung cancer (NSCLC) that is characterized by a genetic alteration known as anaplastic lymphoma kinase (ALK) gene rearrangement. This genetic mutation results in the overexpression of the ALK protein, which plays a key role in the growth and spread of cancer cells. ALK-positive lung cancer is relatively rare, accounting for approximately 5% of NSCLC cases.

Patients with ALK-positive lung cancer often present with certain clinical characteristics, such as a younger age at diagnosis, a history of never or light smoking, and a higher likelihood of developing distant metastases. Approximately 50% of those diagnosed are under 50 years old so likely to have young families. The vast majority of patients are in the middle of their working lives. Many patients can no longer pursue their professional careers which may create financial toxicity. We should also acknowledge that any financial losses will also affect their children.

The results of a recent survey on financial toxicity for ALK-positive lung cancer patients have revealed several differences compared to lung cancer patients in general. Financial toxicity, a term used to describe the financial burden and distress experienced by individuals as a result of their medical treatment, has been found to have unique implications for ALK-positive lung cancer patients. This survey sheds light on the specific challenges and disparities faced by this subgroup of lung cancer patients in terms of financial impact. In this report, we will explore the key findings and differences identified in the survey, highlighting the distinct financial challenges faced by ALK-positive lung cancer patients compared to the broader population of lung cancer patients.



DESCRIPTION AND METHODOLOGY

DESCRIPTION:

This report is a descriptive research analysis that explores the economic burden of ALK-positive lung cancer, as reported by people diagnosed with the disease and those in a caregiving capacity in Europe. This project is part of a wider pan-European 8th LuCE Report ‘Financial impact of lung cancer: A European perspective’.



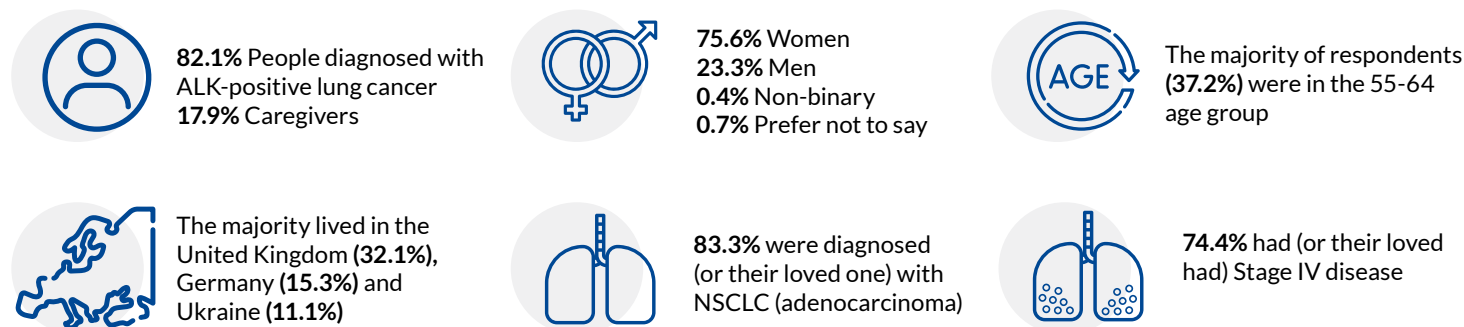
Access the full report here www.lungcancereurope.eu.

METHODOLOGY:

An online survey was self-filled by people impacted by lung cancer in the WHO European Region. The survey, which was confidential and did not include questions related to personal information, was active from May 6th until July 5th, 2023.

This Report includes results obtained from 262 participants. This represented 22.6% of the total number of participants for the 8th LuCE Report (262 / 1,161). The figures in this report compare data collected from people affected by ALK-positive lung cancer with the average collected from all participants impacted by this disease.

Overview of ALK+ participants characteristics:

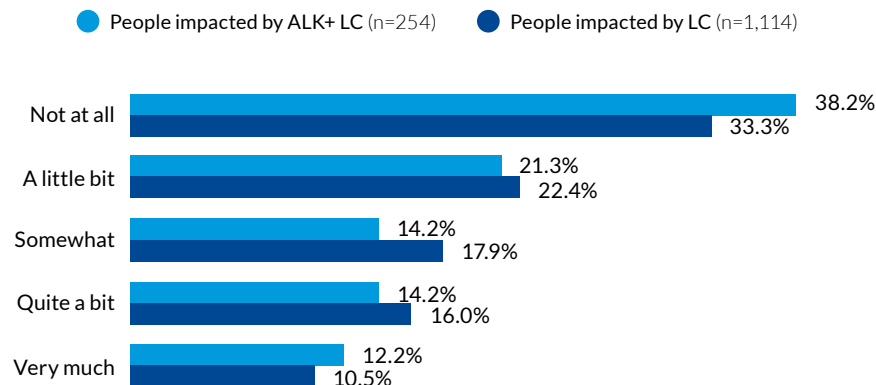


RESULTS

Financial toxicity is the negative impact of the cost of care on financial well-being. People impacted by lung cancer face high out-of-pocket expenses associated with medical care, which is not covered or completely reimbursed by government or insurers. Apart from medical costs, other factors contributing to this financial burden include non-medical and indirect costs.

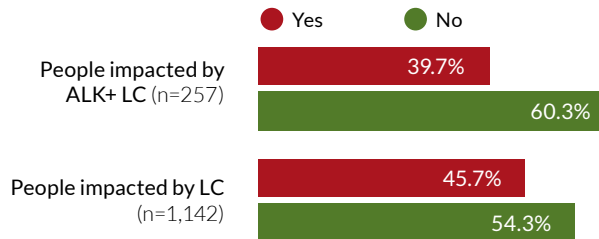
The following shows the magnitude of the economic impact: 61.8% of people affected by ALK-positive lung cancer reported financial challenges as a result of the disease. The impact was very significant (quite a bit / very much) for 23.4% of participants.

To what extent have you experienced financial difficulties as a result of lung cancer care and treatments?

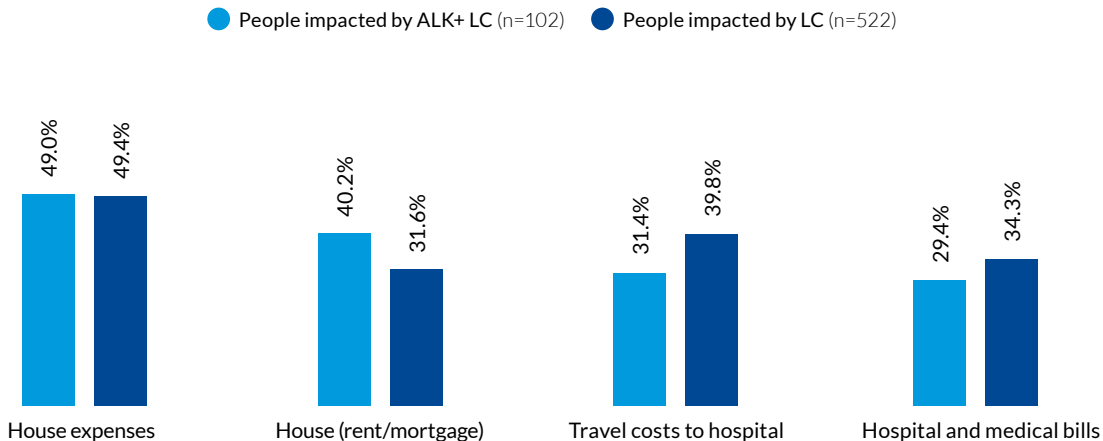


The severity of lung cancer financial toxicity was so high that 4 out of 10 people impacted by ALK+ lung cancer in Europe had trouble paying for certain expenses. According to those who reported these problems (n=102), house expenses (49.0%), house rent and mortgage (40.2%) and travel costs to hospital (31.4%) were the most difficult expenses to pay.

Have you had difficulties paying for certain expenses?



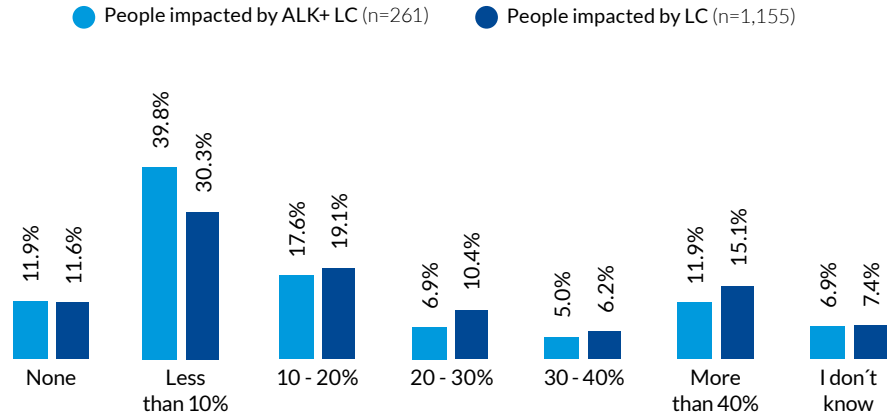
Difficulties paying expenses



One of the main factors associated with financial strain is the amount of income required to pay for expenses related to lung cancer.

Our findings show that 23.8% needed more than 20% of their household income to pay for expenses related to lung cancer.

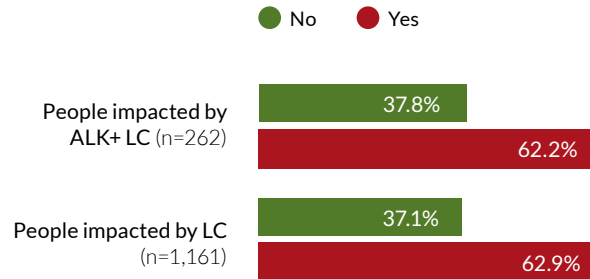
What percentage of your household monthly incomes are used to pay for expenses related to lung cancer?



Indirect costs are caused by the loss of resources and opportunities due to lung cancer. After diagnosis, people may experience varied levels of income reduction.

According to our survey, 62.2% of people impacted by ALK+ lung cancer reported reduced household income since diagnosis. Around 1 out of 3 identified inability to work as one of the reasons for the decrease in income, followed by retirement due to illness (28.5%) and work absence (27.2%).

Has your household income been reduced after the lung cancer diagnosis?



Main reasons for the household income reduction (n=158)



Unable to work
36.1%
(All participants: 39.7%)



Retirement due to illness
28.5%
(All participants: 26.8%)



Work absence
27.2%
(All participants: 27.9%)

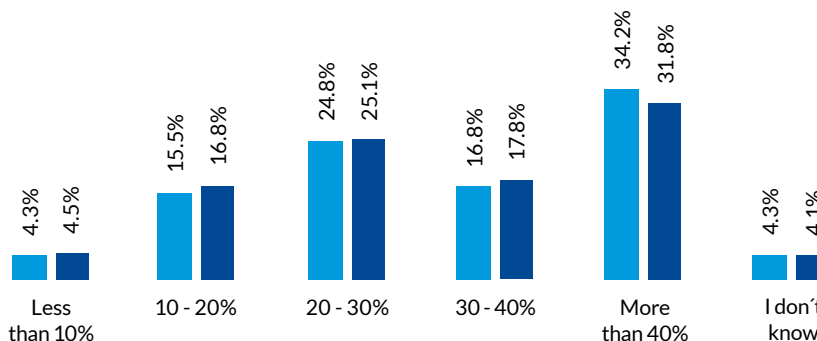


Reduction in work time
24.7%
(All participants: 18.3%)

Of the 161 respondents who experienced a reduction in income, it is remarkable that 75.8% of them experienced a decrease higher than 20% and half experienced a decrease higher than 30% compared to life before lung cancer.

How much would you say the household income has decreased compared to your life before lung cancer?

● People impacted by ALK+ LC (n=161) ● People impacted by LC (n=710)



I started by receiving a full salary during sick leave. Now I get only 70%, which is a big difference.

Cancer costs and economic burdens impact patients and families forcing them to make sacrifices.

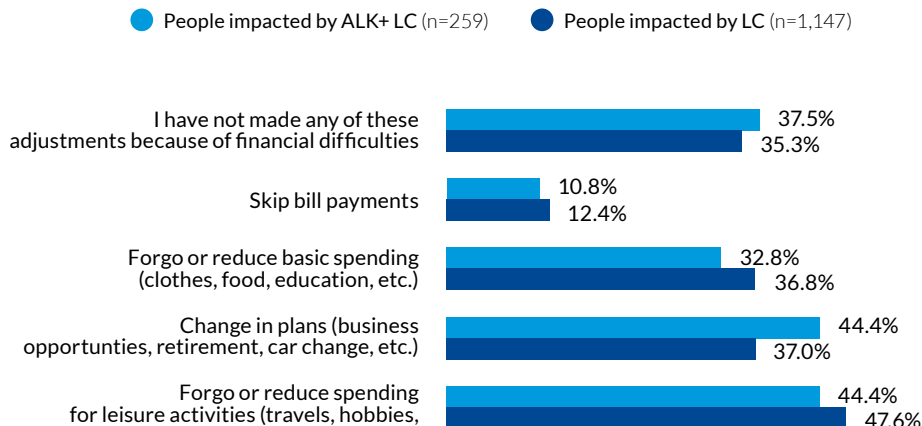
The majority of participants (62.5%) had been forced to reduce their household expenses to deal with expenses after their ALK+ lung cancer diagnosis. People surveyed reported life changes to adapt to the situation such as cutting down leisure activity (44.4%) or changing plans (44.4%). It is worth noting that individuals who have altered their plans demonstrate that patients may no longer be able to pursue their career aspirations, leading to financial burdens.

“Due to the less financial security, I do fewer things with family than before.”

Financial adjustment also included strategies to cashing in and having additional resources to deal with difficulties. In order to mitigate the financial burden, 26.6% utilised savings and 19.9% borrowed money.

“My husband stopped working to take care of me.”

Have you made any of the following financial adjustments to reduce your household expenditures after the lung cancer diagnosis?



Other financial adjustments

People impacted by ALK+ LC (n=252); People impacted by LC (n=1,108)



Withdraw money from retirement or saving funds
26.6%
 (All participants: 22.6%)



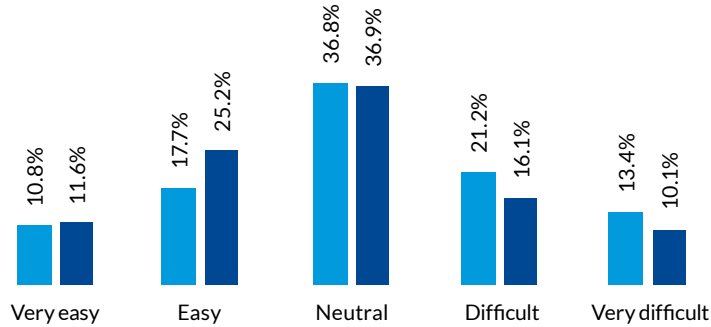
Borrow money
19.9%
 (All participants: 17.9%)



Sell assets or possessions
17.1%
 (All participants: 14.7%)

How difficult is it for you to live on your total household income right now because of the lung cancer diagnosis?

● People impacted by ALK+ LC (n=231) ● People impacted by LC (n=988)



Expenses related to lung cancer affected the capacity for managing finances in such a way that, according to our research, 34.6% of people impacted by ALK+ lung cancer found it difficult to live on their household income.

“As a self-employed person, there is no social safety net and not all costs can be absorbed by my partner.”

“Income has declined so everything is more difficult to finance.”

Our research suggests that lung cancer is a risk factor of financial distress. The percentage of people that did not feel in control of their financial situation increased from 13.3% (before diagnosis) to 38.1% (at the time of completing the survey). Similarly, 4 out of 10 reported feeling financially stressed, 18 points higher than before the diagnosis. It is important to note that 27.6% stated that their debt level had increased after the lung cancer diagnosis.

Household financial situation: vulnerability after diagnosis

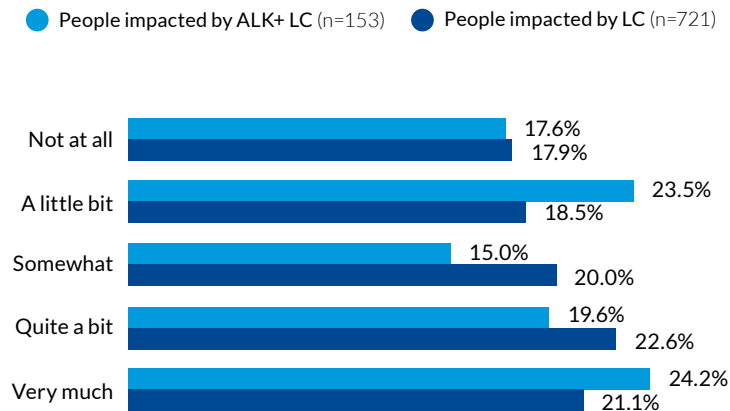
	People impacted by ALK+ LC (n=254)		People impacted by LC (n=992)	
	Before diagnosis	After diagnosis	Before diagnosis	After diagnosis
Not in control of my financial situation	13.3%	38.1%	15.8%	36.9%
Financially stressed	22.6%	41.0%	27.7%	46.8%
Not able to meet monthly expenses	10.8%	27.6%	14.5%	28.6%
Debt level increased	-	22.3%	-	26.9%

The financial strain of lung cancer affects the quality of life of people impacted by lung cancer. It is also very important to note that 82.4% of people with ALK+ lung cancer facing financial difficulties agreed that their financial situation had an impact on their access to treatment and care.

Many survey respondents (with or without financial difficulties) stated that their personal finances impacted their access to healthcare.

A substantial number of people impacted by ALK+ lung cancer considered that their personal finances influenced their access to supportive services (35.9%) and early or rapid diagnosis (30.7%).

To what extent do you perceive your financial situation to impact your response to treatment, recovery or care?



IMPACT OF FINANCIAL REPERCUSSIONS ON ACCESS



Supportive services
35.9%
 (All participants: 40.5%)



Early or rapid diagnosis
30.7%
 (All participants: 38.6%)



Innovative treatments
27.7%
 (All participants: 35.0%)

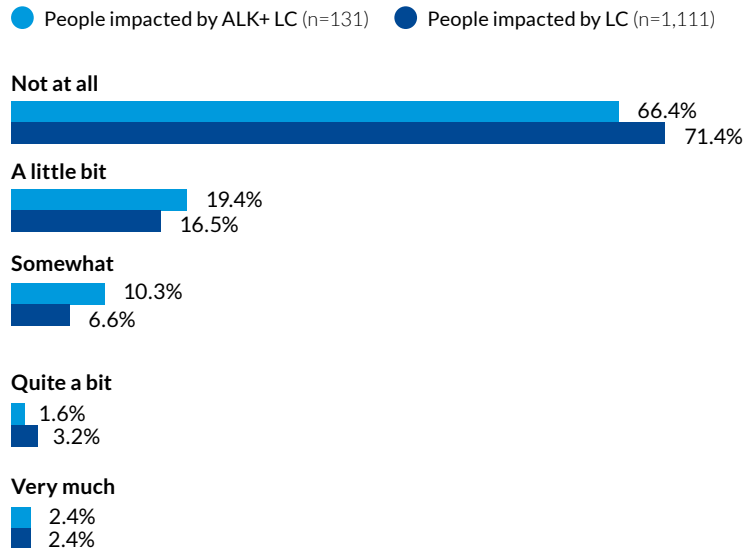


Clinical trials
15.6%
 (All participants: 23.4%)

One of the best strategies to reduce the impact of financial consequences is channelling information through healthcare teams. Discussions between these teams and people impacted by lung cancer can help manage potential economic effects.

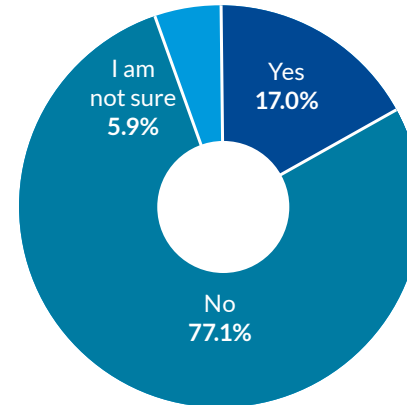
However, a great majority of participants had never, or barely ever, talked about financial concerns with their healthcare teams. In fact, only 33.6% had ever discussed finances, and only a small percentage (4.0%) did it frequently.

Have you talked with your healthcare team about financial issues associated with lung cancer?



Social workers are considered to be the most appropriate individuals equipped to handle these conversations and offer financial education. However, only a minority of people (17.0%) who reported economic difficulties had ever talked with these professionals or attended social services.

Have you ever talked with a social worker or someone from social services about your financial situation? (n = 153)



All participants (n=720)		
Yes	No	Not sure
17.4%	78.3%	4.3%



This research shows the importance of addressing the financial impact of ALK+ lung cancer. A total of 61.8% of people affected by this type of lung cancer reported financial challenges as a result of the disease. It is also very important to note that 82.4% facing financial difficulties agreed that their financial situation had an impact on their access to treatment and care.

Indirect costs should not be underestimated. A total of 62.2% of participants reported reduced household income since diagnosis. Additionally, 41.0% reported feeling financially stressed, 18 points higher than before diagnosis.





4. CALL TO ACTION

Screen for financial toxicity and provide programmes to assist with costs, if financial vulnerability is detected.

Healthcare teams should encourage discussions with people impacted by lung cancer to help explore their financial needs. Those affected should be directed to resources and information which can help to reduce expenses associated with treatment and care and to mitigate increased costs because of the disease situation.

Increase income replacement programme coverage for people unable to work because of lung cancer or caregiving.

Reduction of income due to changes in employment is one of the biggest repercussions of a lung cancer diagnosis. Employed individuals are more likely to experience a drop in income due to the disease. Appropriate compensation benefits should be funded through social welfare systems by governments and provided for those unable to work because of lung cancer.

ABOUT US



Lung Cancer Europe (LuCE) is a not-for-profit umbrella organisation established in 2013 to provide a platform for lung cancer patient advocacy associations and networks at a European level.

LuCE is the voice of Europeans impacted by lung cancer. We collaborate with members and other stakeholders to destigmatise the disease and ensure that those impacted by lung cancer get the care they need to achieve the best possible outcomes. We empower members to ensure strong and effective lung cancer patient advocacy across Europe.

info@lungcancereurope.eu

www.lungcancereurope.eu

ALK+ LuCE Members supporting this Report



ALK Positive Belgium

We are committed to Alk lung cancer patients and everyone close to them. We strive to provide the best Alk lung cancer care. It is important to us that this care always takes into account the wishes of the patient.

We provide information about the disease Alk-lung cancer and bring fellow sufferers into contact with each other. We do this, for example, by giving information meetings and by offering closed Facebook groups.

www.alkpositivebelgium.be



ALK Positive UK

A registered charity established by patients, their families and friends. Our Vision: People with ALK-positive lung cancer in the UK will thrive and live a long and fulfilling life unhindered by their disease. ALK Positive UK exists to:

- Support the ALK+ lung cancer patient community.
- Empower people affected by ALK-positive lung cancer.
- Advocate for improvements in the diagnosis, treatment and care of ALK-positive lung cancer across the UK.
- Represent the voice of the ALK-positive lung cancer community.

alkpositive.org.uk



ALK Positive Deutschland

ALKpositiv Deutschland is a patient network with an associated online group. In our network, ALK-positive patients as well as caregivers exchange information on all topics relating to the disease. We organise online meetings several times a year and also organise regional, face-to-face meetings. We are the voice of ALK-positive patients in Germany. Our aim is to support each other in the group and provide health literacy through webinars and talks. We are advocating for state-of-the-art diagnostics as well as access to treatments and clinical trials in Germany.

www.alkpositiv-deutschland.org



ALK+ International

ALK+ International is a patient and family-led charity, created with a single mission: to improve the life expectancy for ALK+ cancer patients.

We aim to achieve this by fundraising for ALK+ research, providing grants, advocacy and education. Our team is committed to making a difference and is passionate about our goal. We believe that #TogetherWeCan further ALK+ cancer research.

www.alkinternational.org



Lung Cancer Europe

Many Faces, One Voice

www.lungcancereurope.eu

Lung Cancer Europe (LuCE) is the voice of people living with lung cancer and their families at European level

info@lungcancereurope.eu

