



Annual review  
1 April 2020- 31 March 2021

## A message from ELF Chair

2020/2021 has been a year marked by COVID-19, which has included relative physical isolation and remote consultations and meetings. But it has been a year that has unveiled our communities' resourcefulness, adaptability, innovation, fresh ideas and approaches to deal with uncertainty. This is also true for ELF.

This spring we launched our new website, after developing the new content throughout 2020/2021. The website ensures a better link and synergy with ERS, has improved usability and is more people-focussed. The website also contains patient input process details and a new fundraising section.

One of our other new innovations this year is the introduction of a new format we call a patient conference. The idea with a patient conference is to have our disease-specific patient advisory groups lead on defining the content and co-host the patient conference with ERS professionals. This is a format that we plan on developing further in the coming year.

We continue to drive forward our new fundraising strategy. Our first venture into fundraising was the Virtual Congress Challenge that took place in connection with the ERS Congress in 2020. This activity raised funds for our Healthy Lungs for Life campaign, which has never been more important than now, in light of the impact of COVID-19 on lung health.

The past year has been extraordinary in terms of developing and strengthening patient input through digital tools and platforms. We hope to be able to develop our approaches in the coming year – We look forward in the coming year to investing in lung health, thinking particularly about air quality and climate change, working on new European projects in the fields of lung cancer and TB, and working together with healthcare professionals to improve understanding and care for people living with lung conditions across Europe.



ELF Chair Kjeld Hansen being physically active with family

## A new ELF strategy

In 2020, along with the induction of the new ELF Chair – Kjeld Hansen – we set out our new strategy for the coming years. The strategy includes a revised Mission and Vision, and 6 clear goals:

Our achievements over the course of the next few years will be matched with the strategy to monitor progress.

### Our mission

In partnership with the European Respiratory Society (ERS), the European Lung Foundation (ELF) brings patients and the public together with healthcare professionals to improve lung health and advance diagnosis, treatment and care.

### Our vision

People living with lung conditions will be centrally involved in lung healthcare and research, and everyone in Europe will have clear, reliable information they can trust about lung health and disease in their own language.

### Our 6 goals

- Be patient led
- Improve knowledge and understanding
- Engage effectively
- Have a strong voice
- Increase resource and reach
- Ensure good governance

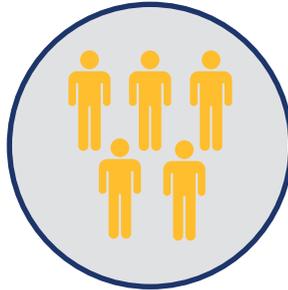


Patient Organisation Representatives

# Being patient led

## This year's highlights:

More than 250 patients and patient organisation representatives gave their time to support and grow the work of ELF



We modified the ELF Council from majority healthcare professionals to ensure a 50/50 split between healthcare professionals and patients



We established 4 new Patient Advisory Groups (PAGs) for COVID-19, primary ciliary dyskinesia (PCD), pulmonary fibrosis (PF) and aspergillosis; and a new United-PAG dealing with issues across different diseases



Patients were involved in more than 35 ERS projects, including 20 Task Forces and 15 Clinical Research Collaborations (CRCs)

## What impact has this had?

- Patients involved in childhood bronchiectasis and alpha 1 anti-trypsin deficiency CRCs have set priorities that will drive future research
- People with severe asthma have been at the heart of developing a patient-centred core outcome set for future research studies
- 38 images were submitted by patients from all over the world for the ELF Photo Contest

***“After many years of trying to get a correct diagnosis for our son, contributing to the task force as a parent patient representative has meant that our journey and frustration has not been in vain. Future patients will hopefully get access to a diagnosis and treatment far more easily than our son did directly as a result of this work.”***

Member of an ELF PAG



Severe asthma patient and winner of the ELF Photo Contest

## Improve knowledge and understanding

### This year's highlights:

In February 2020 we held our first patient conference, which covered bronchiectasis

ELF created 7 new factsheets in 24 languages to support people living with lung conditions, including a COVID-19 factsheet and a COVID-19 easy read factsheet for people with learning disabilities

ELF created, updated and maintained a COVID-19 Q&A and information hub during the pandemic

We launched a website dedicated to sarcoidosis to provide trusted information and raise awareness of what matters to people with sarcoidosis

### What impact has this had?

- Over 1 million people, from more than 227 countries and territories, visited our COVID-19 Q&A
- More than 53,000 people downloaded our factsheets from our website
- More than 1,500 people registered to be part of the bronchiectasis patient conference with 826 attending on the day. There have been more than 2,800 views online

***“The information, presentation and simplicity of the event was remarkable – something I’ve waited for all my life.”***

Attendee of the bronchiectasis patient conference



**Almost everyone knows what asthma is but to explain bronchiectasis isn't that easy**

# Engage effectively

## This year's highlights

We held our first virtual Patient Organisation Networking Day on the topic of psycho-social wellbeing

We completed the development work for the new ELF website, ready for the launch in early April 2021

We have made sure that the public and patients were engaged in EU projects on topics including COVID-19 (DRAGON), the lung atlas (DiscovAIR) and asthma and COPD (3TR)

We launched a new Instagram channel, which has over 800 followers so far

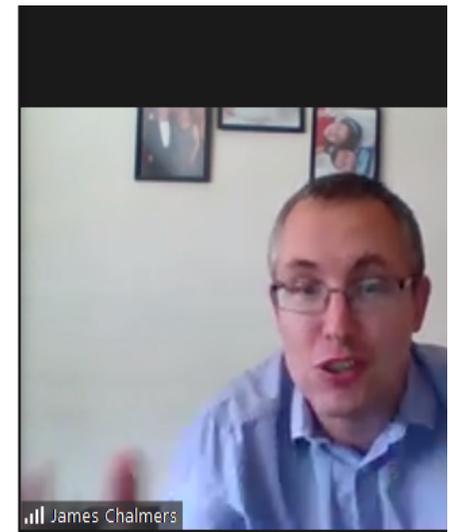
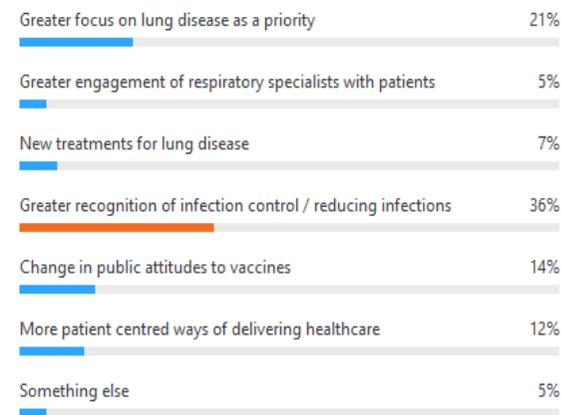
## What impact has this had?

- Over 1.4 million users of the ELF website
- Monthly Twitter impressions of 90,850 and Facebook page reach of 228,731
- More than 115 delegates from 31 countries registered for the ELF Patient Organisation Networking Day
- The European Patient Ambassador Programme hosted 197 learners from 55 different countries who fully completed 325 modules.

***“I liked feeling part of a huge group of people committed to improving our own and other patients’ lives. It was great being able to join from my own home - much easier for patients, saving money, time and better for the climate. We all benefitted from patient-focused expertise of health professionals at the leading edge of their field.”***

Attendee of ELF Patient Organisation Networking Day 2020

### 1. What gives you hope coming out of the COVID-19 pandemic?



Professor James Chalmers at the ELF Patient Organisation Networking Day

# Have a strong voice

## This year's highlights:

6 patients spoke at the virtual ERS International Congress 2020 in 7 different sessions



We worked with ERS to form the first Members of the European Parliament (MEP) Lung Health Group

Our patients were involved in 11 different publications in well-respected journals

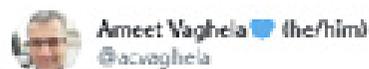


We gave out 10 grants for Healthy Lungs for Life events in Pakistan, Africa, Nigeria, UK, Nepal, Bulgaria, Croatia and Tanzania

## What impact has this had?

- More than 27,000 views of the full journal publications
- Incredible feedback about patient speakers from the virtual ERS International Congress 2020
- Patients have provided their input regarding the psycho-social factors relating to lung disease leading to greater focus on mental wellbeing in ELF materials

### Tweet



Patient experience fear and anxiety and psychological distress for people with long term lung disease  
[#breathlessness](#) [#anxiety](#) [@EuroRespSoc](#)  
[@EuropeanLung](#) thank you [@TriathARon](#) for sharing your story



3:03 PM - Sep 8, 2020 - Twitter Web App

## Improve resources and reach

### This year's highlights:

We have developed a fundraising plan to increase income and improve the financial sustainability of ELF

We held our first virtual fundraising event

We were successful in three EU grant applications and will be playing a key role in UNITE4TB (tuberculosis), OPTIMA (lung cancer) and EU-REST RISE (smoking cessation)

We worked with partners on a COVID-19 and the workplace tool (with UK Health and Safety Executive) and on an Australian version of the Yours Lungs at work tool (with Lung Foundation Australia)

### What impact has this had?

- €45,000 raised through fundraising plan
- €4,500 raised through first virtual fundraising event
- €9,000 of HLfL grants given

*"I wish to sincerely thank the Healthy Lung for Life initiative (under the European Lung Foundation) for providing the grant to conduct this events. The PAPAH project successfully created awareness to all that participated either as resource persons, volunteers or the targeted adolescents within the selected schools. We also believe that an underestimate-able number of individuals in the general public may have come across our project details and benefitted. There is a need to continually do this kind of program for the purpose of sustaining and increasing awareness among adolescents for them to live physically active lives in future"*

Recipient of a HLfL grant in Nigeria



Recipients of a HLfL grant in Nigeria

# Ensure good governance

## This year's highlights:

We produced a Terms of Reference to clarify the roles and expectations of PAG members

We have implemented a written consent procedure for patients taking part in video and audio recordings

We have launched and begun to implement our new strategy

The ELF Award was given to all healthcare professionals working on the frontline of the COVID-19 pandemic



## Financial overview

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These figures outline the total operating income and expenditure for ELF during the financial year April 2020- March 2021. Full audited accounts are available on the ELF website.

### Income



- Other income (grants, donations, services)
- Services to ERS
- EU grants (income earned in year)

### Expenditure



- Patients @ Congress
- Patients Web
- Patient Education
- Patient Input
- HLFL Global Event
- EU Projects
- Fundraising
- General
- Computers

## Patient Organisation involvement



Action for Pulmonary Fibrosis support during lockdowns



Alpha-1 Spain publishes comic book "Soy Alfa"



**Some examples of the many activities run by organisations who make up the ELF Patient Organisation Network**



Irish Cancer Society launches campaign



650 km IN 6.5 DAYS



Worldwide Pneumonia Awareness Campaign



We would like to acknowledge:

All of our volunteers and everyone who has worked  
with ELF

Our major donors:

National lottery

HSE

LFA

and

The ELF award winners



## Donation Ask

Please help ELF to continue supporting people living with lung conditions by making a donation or leaving a gift in your Will.

Make a donation

<https://europeanlungfoundation.enthuse.com/donate#!/>



Leave a gift in your Will

<https://europeanlung.org/en/support-us/leave-a-legacy/>

