



# Annual review: 2021/2022

# A message from our Chair

As we move into somewhat easier times following two years of restrictive measures due to COVID-19, we can now begin to see how much work we achieved through a difficult period.



As well as setting up a new office together with ERS under the name of Lungs Europe in Brussels, we were involved in the formation of the International Respiratory Coalition. We sat on numerous committees, and worked with more people with lung disease than ever as we continued to increase our online events and Patient Advisory Groups.

Working under lockdown restrictions has made us better understand how inclusive we can be if we look to new tech solutions to increase our audiences, and instead of asking you to travel we use these to come to you. Something which also helps the fight against climate change.

Over the next few pages, you will find details on how we achieved the goals set out in our strategy, and notes on the exceptional successes that we have had. You can also read interviews with the winner of our ELF award, hear from one of our patient representatives and learn how you can help support the work we are doing.

As always, we want to thank you and all of our stakeholders for the work you do and the guidance you give. ELF and all it achieves is a direct reflection of those individuals who contribute to it. We are proud of the difference we are able to make thanks to your input.

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A handwritten signature in black ink, appearing to be 'K. Jansen', written in a fluid, cursive style.

# Improving knowledge and understanding

ELF continued to produce evidence-based information in a variety of formats for patients and the public, in multiple languages. This ensures that people can access the right information as needed, and that they continue to be informed on lung health issues and related developments.



## ★ 4 new factsheets



Diagnosing adult asthma  
Lung volume tests  
Gas transfer tests  
Pneumonia

## ★ 7 lay guidelines

Diagnosing adult asthma  
Diagnosing and treating non-cystic fibrosis bronchiectasis in children and young people  
Diagnosing childhood asthma  
Managing bronchiectasis in adults  
Treating obstructive sleep apnoea using alternatives to CPAP  
Treating sarcoidosis

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I liked learning about new developments and at the same time being able to understand better the basics. Patients sharing experiences was also so important. Made me feel I am not alone and that there are others like me having similar problems.

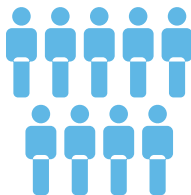
- Bronchiectasis Patient Conference attendee

# Being patient led

The best people to tell us what patients want and need are patients. That it why it is so important that we work with patients directly, continue to be led by them, and find new ways to ensure they get to have their say about their healthcare.

## Our 2021/22 highlights:

We now work with 13 Patient Advisory Groups  
380 volunteers gave their time to support our work and inform our decisions



We enabled patient input into 8 EU funded projects

We held 2 online patient conferences  
>100 attendees @ Patient Organisation Networking Day  
We ran a patient guidelines webinar



Patients were involved in 22 ERS Task Forces and  
17 ERS Clinical Research Collaborations

## Linda Clephane



- Chronic cough patient
- Member of the ELF Cough PAG
- Co-chair of the Chronic Cough Patient Conference

“ I am delighted to hear that health professionals recognise the effect a constant cough has on the mental, social and physical health of patients, and that they are taking active steps to reduce that burden through their research and development of treatments. ”

“ It is a way of making something positive from a negative experience. ”



ELF

Lung Cancer  
Patient Advisory Group

#LCAM



## Patient focus: Helen Parks

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Helen Parks was diagnosed with asthma in her 20s. During the pandemic she was hospitalised with COVID-19. When Helen came out of hospital she found that she had no follow-up. Helen turned to Twitter to talk to others who had similar experiences and to share her story, and that is where she found ELF.

'I felt it was vital to share my experiences of COVID-19 and long-COVID. First, to let people know just how serious COVID-19 was. I had no one to look to when I was ill, no one who could tell me what to expect. I felt by telling my story, it might help other patients after me, but also others who underestimate its impact.

I think it's really important that specialists grasp what the patient experience is like. They should see that we have a part to play in decisions about us, and importantly to let them hear us talk and reflect on how we all got the privilege of sharing in this journey! We have had to learn from each other. Speaking about my COVID-19 experience has helped me understand what I've gone through.

In my lifetime the role of the patient voice has definitely changed. Often patients are in awe of healthcare professionals and are afraid to speak up. Other times, I've felt my voice hasn't been important or needed. However, COVID-19 changed that. I have had the opportunity to work with wonderful experts in respiratory medicine. I think healthcare professionals have wanted to know and understand what it's been like to go through COVID-19.

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I think we still have a way to go in being heard. I think it's vital that patients are listened to and have input into their care. We need 'buy in' from both sides. The best example I can think of is the existence of Long Covid. The patient voice and experience is key to understanding it. The healthcare professionals need to trust the patient that this condition exists. Having 'doubters' is soul destroying and leaves the patient feeling their voice doesn't matter or isn't heard. Working together helps bring change and opens the channel of information which is vital in any understanding of a medical condition.

You can read more on Helen's experiences with COVID-19 by following [this link](#)


# Engaging effectively

We have continued to look for new ways to engage different audiences and connect with people across the globe. As well as continuing to increase our social reach, we work with volunteer translators to ensure we can offer information in as many languages as possible.




1.15 m

Website visitors




13,253

Twitter followers




1,200

Instagram followers



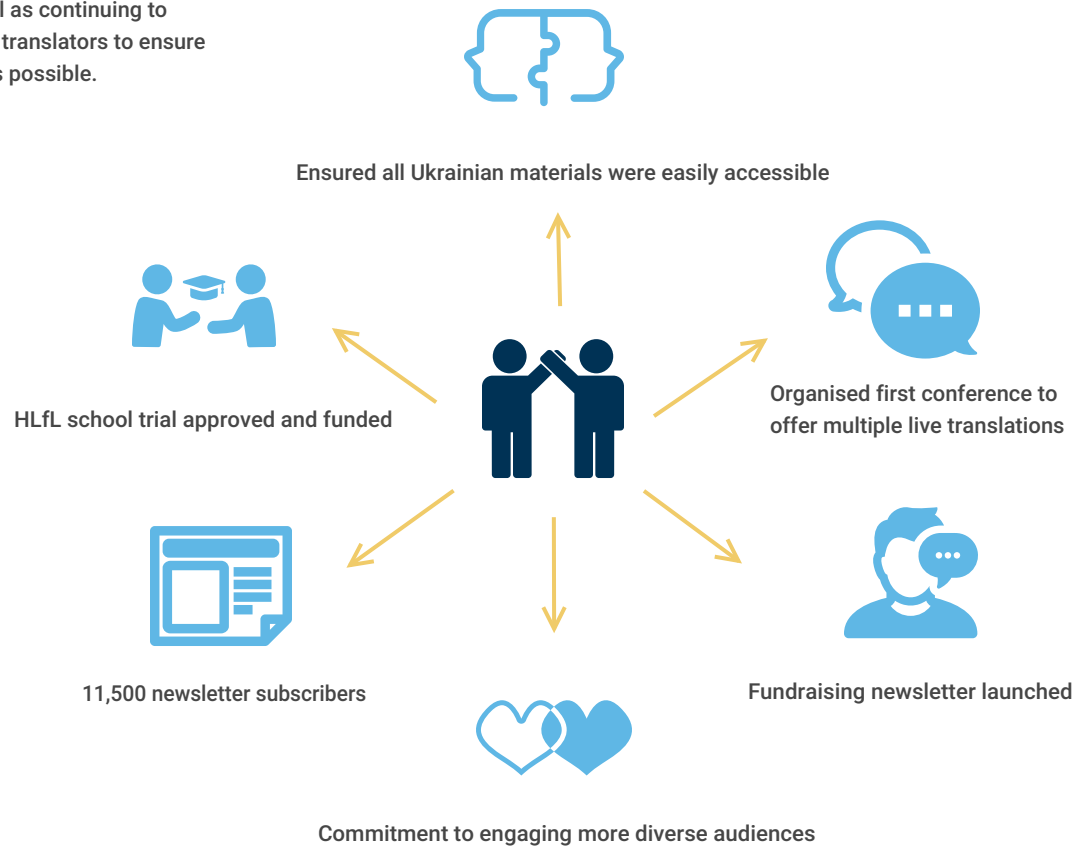
7,119

Facebook followers



703

LinkedIn followers



# Having a strong voice

Our involvement with EU projects and international committees is vital to ensure that patients' voices are at the centre of decision making.

ELF has sat on a number of International Committees represented by staff or volunteers including the Lancet, World Health Organization and COMET (Core Outcome Measures in Effectiveness Trials).

As a member of the steering group for the MEP Lung Health Group, which now has 27 MEPs sitting on it, we are able to ensure that patients' voices are represented in policy debates.



## Patients at ERS Congress:

At the ERS Congress 2021, 13 patients shared their stories to provide the patient perspective on important topics and debates.



## ELF has been involved in:



## ELF contributed to:

EU consultation submission on cancer screening

7 position papers and statements

4 MEP Lung Health Group events

# ELF Award 2021 recipient: Dimitris Kontopidis

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Dimitris Kontopidis, Vice President of Cystic Fibrosis Europe, cystic fibrosis patient and advocate was 2021's ELF award winner. Dimitris chose not to have a lung transplant and by doing so bringing 'medicine for all' to the forefront of Greek politics and helping to save the lives of many people with cystic fibrosis. He spoke to us about his experience.

## What made you decide to make this decision?

The only survival solution for patients with cystic fibrosis at the time was lung transplantation. However, our cooperation with the transplant center in Austria had just stopped and, in Greece, transplants would be delayed as we were one of the last countries to donate organs. I was lucky because I was the last on the list in Austria, but there were other patients who did not have a solution. So, when a drug that could save lives was approved in the USA, with a "list price" of \$300,000 annually per patient, I knew it would take many years to come to Greece, so patients with end-stage respiratory failure were doomed.

As long as there is medicine, I could not accept that it would be delayed due to bureaucratic procedures or financial priorities. And I was the only one who could change those priorities, given my position and the preparation that had been done. Because it was not a trivial decision of the moment, but part of a well-thought-out strategy.

## What happened next? What kind of difficulties arose along the way?

The next day after I turned down the transplant, the Minister of Health responded immediately. At a press conference, he called on the pharmaceutical company to give early access to the medicine and



start negotiations. But time passed without result. When we lost an 18-year-old in January and a 35-year-old in February, who were both eligible for the drug, I felt that he might have overestimated my physical strength and I worried that the drug would not be made available quickly enough. With the appearance of COVID-19 the game seemed lost. Then we gave our last push, using our experience in guerrilla marketing, lobbying, and the support of CF Europe and Greek society, we created our "safety net" on time and we succeeded. We got access to the drug and we literally saved lives.

## What does the ELF award mean to you?

The ELF Award is very honorable and has value for me personally. In the most difficult decision of my life, in my most vulnerable moment, I received a lot of pressure. Most did not realise that I was playing chess with my life and there were 2 options: to win the game with drugs for everyone or I would fall first. When the European Lung Foundation awards an unconventional act and recognises the denial as an act of claiming life, it sends a strong message.

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The ELF Award 2022 recipient will be announced at this year's ERS Congress. If you would like to nominate someone who deserves to receive the ELF award in 2023, please email [info@europeanlung.org](mailto:info@europeanlung.org)

## Improving resources and reach

In 2021 we welcomed a new fundraiser into the ELF team. Her experience and passion for the cause are already having an impact for the financial year 22/23 and we look forward to updating you next year.

Our other highlights include:



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Healthy Lungs for Life global grants given for events in Ukraine, Pakistan, Italy, Canada and Nepal



€150,500

EU project and ERS Clinical Research Collaboration income continued to increase



Income

New revenue streams developed, including YouTube

## Ensuring good governance

ELF has a new Brussels office, together with ERS, under the name Lungs Europe. With the UK leaving the EU in December 2020, it is essential to ensure that we are still able to represent patients from within the EU and across all of Europe.



>50 committee meetings, including the ELF Council and PAGs, ensuring our governance is patient driven.



ELF's diversity policy has been written and published.



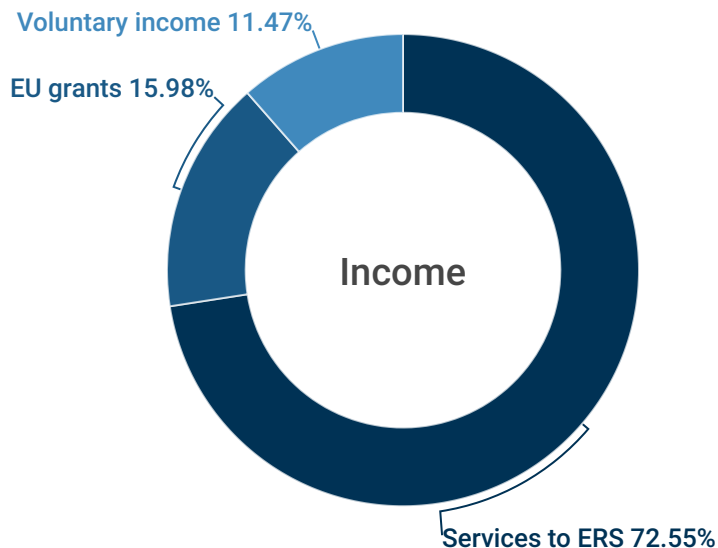
We began discussions on a new green policy to be agreed and published in late 2022.



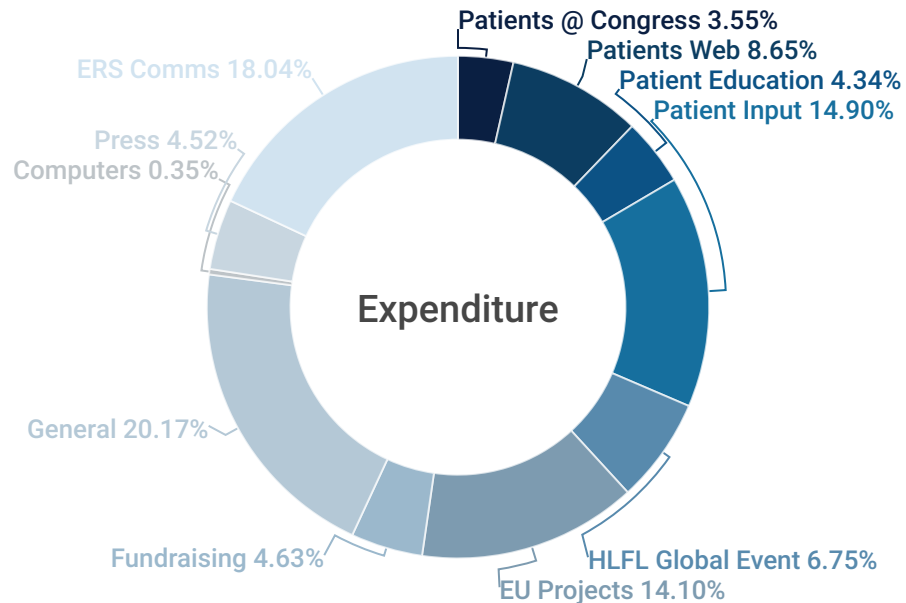
Our European Patient Ambassador Programme (EPAP) was revamped and relaunched. EPAP trains patients to better understand how to effect policy change, support R&D, work with the media and much more, building a pipeline of future ELF volunteers and Council members.

# Financial overview 2021/22

**Income: €632,996**



**Expenditure: €627,862**



# Supporting our work

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## Volunteer



We are appreciative of everything our volunteers do, from helping to offer spirometry tests at the ERS Congress, to translating our lay texts into multiple languages.

The time you give helps us to keep costs down and focus our resources on trying to engage new audiences, launch new campaigns and take part in more projects.

If you think you can help us by giving us your time then please [follow this link](#).



## Donate



ELF continues to ensure that patients' voices are at the heart of its work. To have the freedom to work in this way, we avoid taking sponsorship from the pharmaceutical industry. Please help us to continue with our autonomy and become a regular donor today.

Regular monthly donations help us to plan for our future. They can let us know how much income we expect in any given quarter and to budget appropriately. By giving in this way you will support the work that is so important to you, and ensure that lung health patients for years to come will have their voices heard on a European and global level.

To make a donation please [follow this link](#) or alternatively you can set up a regular payment to our account using the IBAN: GB45HBUKGB4109B

## Use your voice



Patient voices need to be heard by healthcare professionals. This is why we organise our disease specific Patient advisory groups (PAGs).

If you want to use your experiences to help others, to inform healthcare professionals and to shape policy decisions then please consider joining a PAG. [Follow this link](#) for more information:



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Thank you for taking the time to read our annual report. We are proud of the work we have achieved and hope that you are too.

Charity number: 1118930