



Annual review: 2022/2023

A message from our Chair

Looking back to previous years always demonstrates to me how much our small organisation can achieve.

Highlights for me over the last year include getting the opportunity to engage with the public again at Healthy Lungs for Life in Barcelona, having a key role in some new and exciting EU projects and holding our first-ever stakeholder event.

This introduction to our annual review is bittersweet, as I am not only reflecting on our success in the previous 12 months, but I am also thinking of the success that we have had across all of my time leading ELF as I end my 3-year mandate as Chair.

This role has meant a lot to me, and it has been inspiring to work alongside so many of you as fellow patient representatives, campaigners, advocates and volunteers. I came into ELF with a vision to challenge the perceptions of what our organisation can do. I wanted to push ELF to keep innovating and advance the great work it already did, and ensure that people living with lung conditions are the driving force behind everything we do. I leave being truly proud of our achievements and am delighted to pass the reigns onto our incoming Chair, Dimitris Kontopidis, who I know will move ELF onto the next level.

On the following pages you can see how we have managed to achieve all of the objectives that we set out in 2020, and I hope that you can take real pride in the key role you all played to get us there.



Contents:

1. Strategy update	P. 3
2. Improving knowledge & understanding	P. 4
3. Being patient-led	P. 5
4. Patient focus	P. 6
5. Engaging effectively	P. 7
6. Having a strong voice	P. 8
7. Our 2022 ELF award recipient	P. 9
8. Improving resources and outreach	P. 10
9. Ensuring good governance	P. 10
9. Financial review	P. 11
10. Supporting ELF	P. 12

A handwritten signature in black ink, appearing to be "Dimitris Kontopidis", is written on a white background.

Strategy update 2020-2023



Be patient led

- Ensured that patients and patient organisations drive ELF's work and that they are at the heart of all that we do
- This included restructuring the ELF Council and increasing the number of Patient Advisory Groups.

Improve knowledge and understanding

- Further developed health and science communication for patients and the public
- This included producing a new website better aligned to our strategy and providing resources in the widest number of languages possible.

Engage effectively

- Published experiences and methods for patient engagement and involvement and continued working to improve diagnostics and treatment in all lung conditions
- This included engaging people with experience of COVID for the DRAGON project to ensure a focus on patient need.

Have a strong voice

- Actively advocated for improved lung health in Europe
- This included opening and developing an office in Brussels and ensuring patients are at the heart of a new MEP Lung Health Group.

Ensure good governance

- Strengthened management systems and encouraged collaboration and capacity building of member organisations,
- This included revamping and expanding the languages of the European Patient Ambassador Programme and using digital tools to restructure work flow.

Increase resource and reach

- Continued to be core funded by ERS, but found new sources of income to ensure we can deliver on our aim to reach more people
- This included employing a professional to deliver on a new short- and long-term fundraising plan.

You can read a full overview of the [ELF Strategy Report on our website.](#)

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.

- Our air travel database was updated covering 152 airlines
- 23 lay news articles were written and shared
- Our sarcoidosis patient charter was produced



★ 4 new or updated resources



- Remote care
- Data sharing
- Organ donation
- Palliative care for chronic obstructive pulmonary disease (COPD) and interstitial lung disease (ILD).

★ 2 lay guidelines



- Diagnosing adult asthma
- Pulmonary arterial hypertension

★ 2 EPAP webinars



The first EPAP Live! webinar took place on 'Fundraising' and the second on 'Advocacy'. A planned series of these events aims to complement the skills and knowledge gained by our EPAP users in this new learning format.

Being patient-led

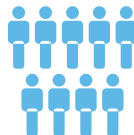
The best people to tell us what patients want and need are patients. That it why it is so important that we work with patients directly, continue to be led by them, and find new ways to ensure they get to have their say about their healthcare. This year our Patient Advisory Groups attended a total of 96 meetings and events. This means that you gave us a staggering 6,408 hours of your time!

Our 2022/23 highlights:

Patient conferences were co-developed with patients and delivered on the topics of chronic cough, living with COVID-19, severe asthma and bronchiectasis with 1,347 total attendees and 3,373 recording views.



19 videos were recorded by patients willing to share their stories with others.



Our 13 patient advisory groups continued to drive our activities in the different disease areas.



Patients were involved in more than 40 ERS projects, including 19 Task Forces and 17 Clinical Research Collaborations.



Lung Cancer
Patient Advisory Group

#LCAM

Olivia Fulton

ELF Asthma PAG member



Being a severe asthma patient advocate is something I will always be able to do no matter what. In some way severe asthma has destroyed my life and prevented me from doing so much, but I am now able to use this very negative situation for good and to help others.



Patient focus: Jean-Michel Fourrier

Jean-Michel Fourrier was diagnosed with idiopathic pulmonary fibrosis (IPF) in 2017. This year, Jean-Michel has become an active member of the ELF Pulmonary Fibrosis Patient Advisory Group and the ELF Patient Advisory Committee. He is a passionate patient advocate who believes that healthcare should be a collaborative effort, where patients and healthcare professionals work together to achieve the best possible health outcomes.

“As soon as I was diagnosed, I felt alone with a disease that no one around me knew anything about. I was facing a new and unfamiliar world. It took me a long time to understand the healthcare system. I had not previously appreciated all the difficulties that patients must face in their daily lives. I also realised that for many patients, the things they must manage are too difficult for them – they need help and the help available needs to improve.

“It is essential that patients have a voice in healthcare. It promotes patient-centredness, fosters trust and collaboration and leads to better treatment outcomes. This ultimately improves the healthcare system for everyone involved. Healthcare should be a collaborative effort, where patients and healthcare professionals work together to achieve the best possible health outcomes. Healthcare professionals know the disease and how it affects the body, and the treatments available, but patients are the only people who know what life is like living with the disease.



It is essential that patients have a voice in healthcare



“The role of the patient is changing – they are not just a passive recipient of care but are becoming an active participant and partner in the healthcare process. Patients are encouraged to become educated, empowered and engaged. Their input is seen as essential for shaping the future of the healthcare system.

“I hope that in the future meaningful patient engagement will lead to a healthcare system that truly values and incorporates the patient perspective. This involves active engagement, shared decision-making in research and healthcare, improved communication and policy changes that prioritise patient-centred care and equitable access to healthcare across Europe.”

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



13,751

Twitter followers



1,728

Instagram followers



7,710

Facebook followers



1,163

LinkedIn followers



11,600 newsletter subscribers.



We continued to make improvements to our website, including a restructure of our information hub restructure in order to make it more user friendly and easier to find each lung condition.



We ran our first stakeholder event to help develop our budget and workplan for 2023/24, giving us the opportunity to hear directly from you and ensure that we are prioritising your key issues.



We provided training in lay writing to ELF staff members and ERS early career members.

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.

To ensure that the respiratory patient voice was heard in EU consultations we contributed to responses on:

- EU4Health 2023 Priorities Survey (June 2022)
- “Healthier together” EU non-communicable diseases initiative (February-June 2022)
- Revision of 2009 Recommendations on Smoke-free Environments (July 2022)
- Proposal on the European Health Data Space (July 2022)
- Global Health – new EU strategy (September 2022)
- Single market – Proposal for a legislative initiative on cross-border activities of associations (November 2022)
- A comprehensive approach to mental health” (February 2023)

By working on EU projects we can ensure that patients are at the very heart of state-of-the-art research and policy changes. We have been proud to be part of:



ELF Award 2022 recipient: Rosamund Adoo Kissi-Deborah

The ELF award 2022 was given to Rosamund Adoo-Kissi-Debrah for her outstanding work campaigning for everyone's fundamental right to breathe clean air.

Rosamund became a clean air advocate after her 9-year-old daughter, Ella, died in 2013 from asthma, exacerbated by air pollution. After years of campaigning for a second coroner's inquest into Ella's death, a landmark decision was reached in December 2020, making Ella the first person in the world to have air pollution listed as a cause of death on their death certificate.

In 2014, Rosamund founded the Ella Roberta Foundation in honour of her daughter. It was set up to change the air we breathe by campaigning for the coroners recommendations to be followed by governments, councils, medical professionals and the general public, all over the world.

“Air pollution is a public health crisis that is damaging every organ in our body. I want people around the world to finally understand the deadly dangers lurking behind every breath we take, and demand that political leaders respect, and protect, our fundamental right to breathe clean air.”

Rosamund Adoo Kissi-Deborah



”

“Rosamund Adoo-Kissi-Debrah is an outstanding lung health advocate. We are inspired by her work and honoured to announce Rosamund as the recipient of the ELF Award this year. There is still work to be done – air pollution is still a major issue worldwide.

Alongside the work of the Ella Roberta Foundation, the European Lung Foundation believes there is a pressing need for action on air quality, both in terms of awareness and education, and in order to take active measures to reduce pollution levels. *ELF Chair, Kjeld Hansen*

The ELF Award 2023 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 2024, please email info@europeanlung.org

Improving resources and reach

In 2022, with thanks to the support of the Forum of International Respiratory Societies (FIRS), ELF was able to offer 10 grants to organisations around the globe to promote the Healthy Lungs for Life campaign. The events and activities reached tens of thousands of people in countries including Pakistan, Nepal and Ghana. They also educated people on the impacts of indoor and outdoor air pollution, the importance of vaccinations, and the dangers of tobacco products.



A new initiative was launched to reach children with the key messages about lung health - "HLfL for Schools". In this first stage:

- Content was defined
- Schools were identified
- A pilot was run in Barcelona



ELF grew its annual fundraised income to €70,000. This has shown us that we are able to attract donors, and we continue to work towards building this income, with big ambitions for the next financial year.

Ensuring good governance

In 2022/2023 we went through the process of finding the next ELF Chair and are delighted that it will be Dimitris Kontopidis.

Dimitris has years of experience in patient advocacy, working with the cystic fibrosis (CF) community and changing the face of CF care in Greece and across Europe. Dimitris is determined to drive forward three areas in his time as chair, including patient empowerment, building communities and self-management.

ELF knows that to truly represent the voice of patients that it must be driven by patients. If you are interested in helping to lead ELF in a voluntary capacity, then please do email info@europeanlung.org.

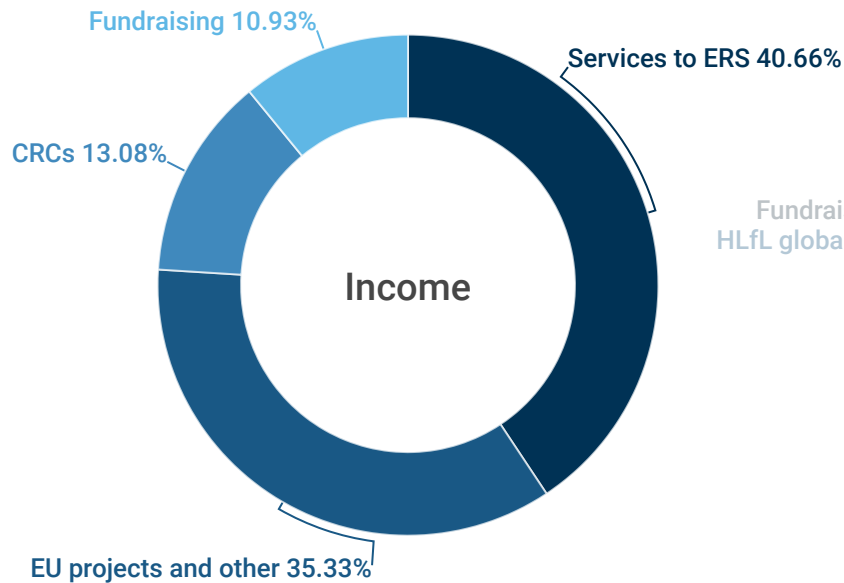
In 2022, ELF published its sustainability policy, ensuring that it reflects in its working practice what it campaigns for. Climate change is having a negative impact on lung health globally, and by making lower carbon choices we are striving to minimize our impact.



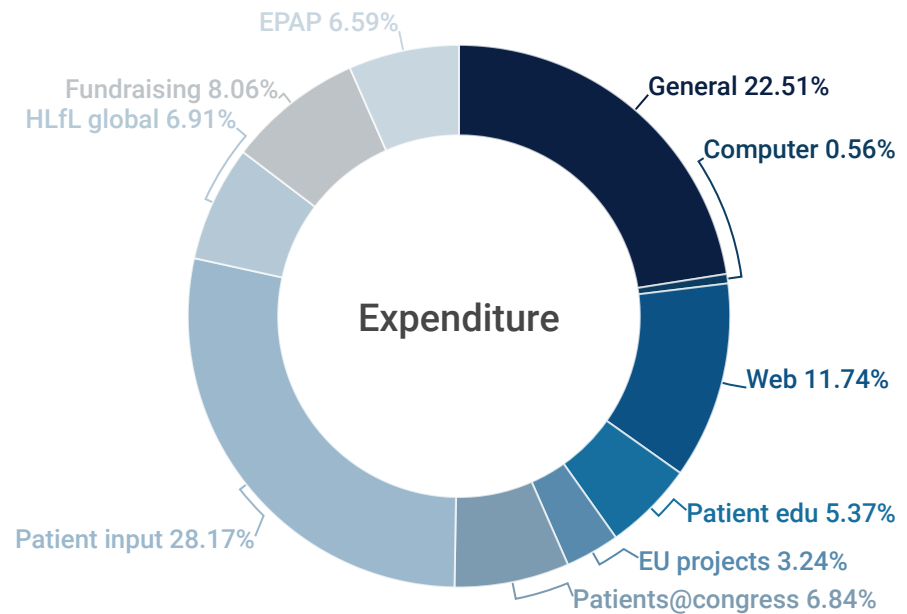
Financial overview 2021/22



Income: €523,811.85



Expenditure: €444,795.30



Supporting our work

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:



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

Volunteer your skills

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](#).



UK Office:

442 Glossop Road
Sheffield
S10 2PX
UK



+44 114 322 0635

Brussels Office:

51 Rue de Treves
Brussels
1040
BE



+32 2 238 53 60



info@europeanlung.org



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