







January 2019



Message from Isabel Saraiva, Chair of the European Lung Foundation:

Firstly, I want to wish you all a very Happy New Year. I hope that you are feeling restored after the holidays and are ready for the year ahead!

2019 looks set to be another busy and exciting year for ELF. As I am sure is the case for many of you, January is the time of year where we do a lot of planning. This period culminates in the European Respiratory Society (ERS) and ELF executive meetings in Geneva at the end of the month, which is a chance to get together and set high-level goals for the year ahead.

This year we hope to build on and expand ELF's activities - involving more patients in scientific and educational projects; producing new high-quality patient information materials in many different languages; and further developing the Healthy Lungs for Life campaign so that more people can learn about how they can look after their lungs.

On the topic of Healthy Lungs for Life – are you planning on holding an event this year? We have just made some grants available to support different events, so now is the time to get planning! You will find more information on these grants and how to apply later in this newsletter.

Elsewhere in this newsletter, you can read our interview with ERS President, Professor Tobias Welte, about his plans for ERS this year and the role ELF can play. We have also shared some exciting news from our sarcoidosis patient advisory group, who have just published a letter on their treatment priorities and the outcomes of a survey that over 1,800 patients took part in. I am very proud of this work and want to congratulate everyone who was involved.

January highlights and key dates:

 Thursday 17 January: ELF webinar on submitting a patient research abstract to the ERS Congress

Learn more about getting your research into the ERS Congress - more details below

- Thursday 17 January: European Clinical Research Alliance on Infectious Diseases (ECRAID) kick-off meeting, Brussels ELF is a stakeholder advisory board member of this new clinical research network for infectious diseases
- Tuesday 29–Wednesday 30 January: RESPIRE3 fellowship interviews, Geneva An ELF staff member and patient representative is taking part in these interviews for this EUfunded research fellowship as a pilot to ensure that candidates are patient-focused
- Wednesday 30 January: European Industrial Gases Association (EIGA) seminar Isabel Saraiva is presenting at this industry event about how to improve the experience for patients who require oxyen
- · Wednesday 30 January-Friday 1 February: ERS and ELF Executive meetings, Geneva

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FREE WEBINAR TODAY: SUBMITTING A PATIENT RESEARCH ABSTRACT TO THE ERS CONGRESS

TODAY: Thursday 17 January, 2019 17:30-18:30 (CET)

We want to encourage more patient organisations and patient representatives to share their research at next year's ERS International Congress and so are offering a free webinar on writing and submitting an abstract.

The webinar will cover the submission process, deadlines, designing a poster and presenting your findings. It will be led by ELF and patient organisation representatives who have successfully done this.

You can register your interest in the webinar ahead of time by emailing <u>barbara.johnson@europeanlung.org</u> – or you can simply join via the link.

PATIENT TREATMENT PRIORITIES FOR SARCOIDOSIS PUBLISHED

A joint letter about the treatment priorities for people living with sarcoidosis, written by the ELF sarcoidosis patient advisory group and healthcare professionals working in the field, has been published in ERJ Open Research.

The paper includes results from the survey we carried out last year, where we asked people living with sarcoidosis to rate the importance of different treatment outcomes.

Read more.



PLAN YOUR HEALTHY LUNGS FOR LIFE EVENT – GRANTS NOW AVAILABLE

A new scheme to support Healthy Lungs for Life events has been launched, with 5x €1,000 grants now available to individuals, not-for-profit organisations, patient groups and respiratory professionals.

Read more.



GET INVOLVED WITH A PROJECT ON CENTRAL SLEEP APNOEA IN CHILDREN

We need patients and parents to input into the development of the first ERS guidance about central sleep apnoea in children.

Read more.



INTERVIEW WITH PROFESSOR TOBIAS WELTE, PRESIDENT OF THE EUROPEAN RESPIRATORY SOCIETY

We asked Professor Tobias Welte, the current President of ERS, about his career; his priorities and goals for his presidency, and about some of the biggest challenges for lung health in the coming years and how ELF and ERS can contribute to solutions.

Read the full interview.



AND PLANS FOR 2019

For the first Patient Organisation Round-up of 2019, we asked patient organisations to share their recent news as well as their goals for 2019.

Read the full-round up.

Picture: The A.M.O.R O₂ Christmas party for patients and their families







The European Lung Foundation (ELF) was founded by the European Respiratory Society (ERS) in 2000 with the aim of bringing together patients, the public and respiratory professionals to positively influence respiratory medicine.

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