



July 2018



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

With this year's European Respiratory Society (ERS) International Congress taking place in less than two months, preparations are well underway within the ELF team.

There is so much to look forward to at this year's Congress in Paris – and I hope that many of you will be joining us at this key meeting, which is the largest gathering of people with an interest in lung health in the world. This year's programme is brimming with cutting-edge scientific and educational activities – and we have hand-picked a selection of these that we think will help you get the best from this year's Congress. You will find our picks later in this newsletter.

On Saturday 15 September, patient organisations will have the opportunity to catch up with one another, hear from inspiring speakers, and take part in group discussions around the themes of medical and patient education. You can have a look at the draft programme of the patient organisation networking event here. If you are from a patient organisation that has not yet registered to attend this free event and would like to attend, please get in touch with us as soon as possible. We would love for you to join us!

And for those of you unable to make it to the Congress, I have an exciting announcement. We want as many people as possible to be able to stay up-to-date with the key research findings presented at the Congress, so we are going to create a dedicated patient section on the Live @ ERS on-demand video platform.

In its first year, Live @ ERS Patients will feature interviews with healthcare professionals from a range of specialist backgrounds, patient organisations and national respiratory societies as they share the latest findings and highlights from each lung condition – and what this information could mean for patient care moving forward. The videos will be in Dutch, English and French.

Patients will be able to watch these videos free of charge through a dedicated section of the Live @ ERS platform shortly after the Congress. We will let you know when they are available and how you can access them closer to the time. I am looking forward to launching this new initiative – and hope that we can grow it in the years to come.

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Healthy diet reduces asthma symptoms

European Medicines Agency starts lung infection medications review Sleep disorder linked with changes to brain structure typical of dementia

Find out more

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## AIR TRAVEL WHEN YOU HAVE A LUNG CONDITION: NEW FACTSHEET TRANSLATIONS AVAILABLE

With the summer holidays in full swing, we are pleased to share new translations of our factsheet on air travel when you have a lung condition.

The factsheet covers the key things you should consider when planning a trip, and gives some tips on keeping well while you are abroad.

Download the factsheet in:

- English
- <u>Albanian</u>
- <u>Bulgarian</u>
- <u>Danish</u>
- <u>German</u>
- <u>Greek</u>
- <u>Finnish</u>
  Hungarian
- Hungarian
- <u>Italian</u>
  Swedish
- Slovak
- Turkish

# PATIENT PROGRAMME FOR THE ERS INTERNATIONAL CONGRESS NOW PUBLISHED

We have gone through the programme of this year's ERS International Congress and highlighted sessions and activities that patients and patient organisations may find particularly beneficial and interesting. Have a read and start planning your Congress activities now.

Access the full patient programme.



# SURVEY: WHAT DO YOU EXPECT FROM PATIENT INVOLVEMENT IN THE MEDICINES LIFECYCLE?

PARADIGM is a new EU Innovative Medicines Initiative project that aims to learn more about what constitutes meaningful patient engagement in the development of medicines and to develop tools and guideance.

As part of the project, they have produced a survey and would like to hear from people that have been involved in medicine development about their expectations of patient engagement.

Read more and take the survey.



# **BRONCHIECTASIS PATIENT** FEEDBACK INFLUENCES CHANGE IN FUTURE TRIAL DESIGN

Last month, members of the ELF bronchiectasis patient advisory group took part in a US Food and Drug Administration workshop on the design of clinical trials for bronchiectasis treatments.



Read more.

## PATIENT ORGANISATION ROUND UP, **JULY 2018**

Learn more about how patient organisations throughout Europe and beyond have been advocating for lung health in the last month.

Read the full round-up.

Picture: Participants at the first patient seminar on Alpha-1 antitrypsin deficiency in Germany.



FOUNDATION

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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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