







April 2020



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

Dear friends,

We are sending you this newsletter in difficult times for everyone across the globe, but particularly for those of us involved in respiratory health. As someone living with COPD, I truly understand all of the questions, worries and concerns that you have been sending to us about COVID-19.

We have been working hard with experts from the European Respiratory Society (ERS) to answer as many of those questions as we can, which we have put together on our Q&A. We have translated them to allow people across Europe and the world to benefit from the advice and expertise that we are privileged to have access to.

Please do continue to share these questions and concerns with us, especially as the situation changes in each country. We can learn from each other and support each other. We are updating the Q&A each week. Access it here: europeanlung.org/en/QA-covid-19

If you want to share stories of your experiences with COVID-19 - symptoms, coping mechanisms, after-effects, stories of positivity, words of warning – you can download the Flixie app and share a video with us. These can then be used to support others in a similar situation to you.

We are truly grateful to all the healthcare professionals and volunteers on the frontline caring for us all, and for friends and family who are helping those who are in self-isolation.

I feel positive, and I am sure that we will get through this as a community of patients and carers, professionals and volunteers. The strength and determination that I have seen from countries such as Italy is an inspiration.

We hope to develop some other tools in the coming weeks, including exercise videos for people at home with lung conditions, and helpful hints and tips to keep ourselves mentally healthy.

We would also like to hear what you want us to do. So please let us know and we will do our best to support you.

#### Key dates this month

· Launch of sarcoidosis patient priorities website

#### Awareness days

· World Sarcoidosis Day: 13 April

European Immunization Week: 20-26 April

World Day for Safety and Health at Work: 28 April

Newest developments of Symptoms of COPD are lung research presented at the ERS Congress 2019 Symptoms of COPD are worse during the day, new the ERS Congress 2019 research finds People with cystic fibro

people with cystic fibrosis to keep active

Find out more

Find out more

Find out more



### NEW FACTSHEETS: PATIENT INFORMATION LEAFLET FOR PEOPLE HOSPITALISED WITH COVID-19

We have produced a factsheet for people going to hospital with COVID-19 to explain what will happen and what decisions they may have to make. We have also produced a factsheet for families and friends of patients going to hospital. They are currently available in English, with more languages to follow.

Find out more and download the factsheets.

#### COVID-19: RESEARCH ROUND-UP

Below are some summaries of recent research findings for COVID-19:

**Developing vaccines for COVID-19** 

Research suggests that antimalarial drugs may not be effective for COVID-19

<u>Understanding the risk of underlying health conditions</u> for Covid-19



## **COVID-19 - YOUR QUESTIONS** ANSWERED BY A RESPIRATORY **EXPERT**

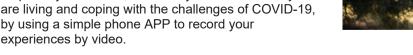
We have been working closely with experts from the European Respiratory Society (ERS) to answer as many of your questions related to COVID-19 as possible. It is available in up to 11 languages and is being updated each week.

Read the Q&A.



# COVID-19: SHARE HOW YOU ARE LIVING AND COPING WITH THE **CHALLENGES**

During this very worrying time for many people with respiratory conditions, we invite you to share how you are living and coping with the challenges of COVID-19, by using a simple phone APP to record your





Find out more.

## **UPDATE: PATIENT** REPRESENTATIVES AT THE ERS CONGRESS 2020

In light of continued uncertainty around the ability to hold large events across the globe, ELF will not close bursary applications for Patient Organisation Networking Day on 17 April as planned. Registration and bursary applications will stay open until further notice.

Find out more.



## BETTER-B: IMPROVING TREATMENT AND CARE FOR SEVERE BREATHLESSNESS



ELF is currently collaborating with an international team of experts to improve treatment of severe

breathlessness among people affected by respiratory diseases.

Find out more.

# SHARE YOUR EXPERIENCES AND PRIORITIES FOR COVID-19 **OUTCOMES IN A NEW RESEARCH PROJECT**

**DEADLINE TODAY - 10 APRIL** 

The COMET Initiative has launched a COVID-19 Core Outcome Sets (COS) project. They have created a survey asking people to rate what outcomes are most important to those with suspected or confirmed COVID-19 and their families. Everyone is invited to take part by filling in a survey, available in English, Spanish and

Italian.



Find out more.

#### INTERVIEW WITH PROF. TOBIAS WELTE

Prof. Tobias Welte held an online Q&A for the working for both ERS and the ELF on 25 March, 2020. Prof. Welte answered some of our questions about COVID-19. We wanted to share this with you, so we have written-up some of the questions and answers.

Read the Q&A.



#### PATIENT ORGANISATION ROUND-UP: **APRIL 2020**

In the last month, patient organisations from across the globe have been involved in various activities to tackle the issues faced by people with lung conditions and help improve outcomes.

They have also produces some COVID-19 resources for people with specific respiraory conditions.

Find out more.







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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