

WORD FROM THE COORDINATOR

Nobody wants to be kicked out. This is what I presume. If I want to leave, I would rather go on my own instead of being excluded. The European Commission has shared a document that describes how to get rid of inactive Members of ERNs. I am not sure we really need this. Having said that, the Network Coordination Team has experienced some frustration with non-responders among our Members. However, we think these non-responders have simple explanations for their silence, which are not an indication of their disinterest or desire to not be involved anymore. Lack of communication (e.g. the emails do not reach the right persons) or lack of time in times of COVID-19 are just a few of the many possible causes of not responding.

ERN-LUNG is happy to have many active Members and Affiliated or Supporting Partners and we can withstand a few who are quiet or invisible at times. If we realize some Member HCP or a care team member we have been working with is no longer responding, we will try to find out why this may be the case. If we cannot find out the reason for non-responding, we do not plan to kick anybody out. We keep on sending our mails. We are inclusive and we are patient.

But, being patient does not mean that we don't go by rules. ERN members have duties. Whoever disregards his duties and does not deliver what he is supposed to and does not even care to explain – such behavior will be interpreted as a statement meaning “I want to leave” and we will certainly respect this. In such a case we might need to look for the document prepared by the Commission, because the Member States have been involved in the process of making HCPs become Members of ERN-LUNG, i.e. we will have to involve the Board of Member States in such cases.

But as I said before: We are inclusive, we are patient, and we do not plan to kick anybody out.

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ERN-LUNG MEMBERSHIP MODALITIES

Following discussions during the ERN-LUNG Board Meeting in February, the Network Coordination Team has successfully implemented revised and more adequate definitions for the different membership modalities. Please find the outcome summarized [here](#).

SUCCESSFUL ERN-LUNG CANDIDATES SELECTED FOR ERS CLINICAL TRAINING FELLOWSHIP

Under the ERS/ERN-Lung Clinical Training Joint Fellowship [scheme](#), two successful candidates have been selected for training at two ERN-LUNG Member HCPs - Louis Pradel University Hospital - Hospices Civils de Lyon under the supervision of Dr. Vincent Cottin and Thorax Clinic - Heidelberg University Hospital under the supervision of Dr. Michael Kreuter. ERN-LUNG would like to congratulate the awardees and thank the ERS for funding as well as the host HCPs for attracting new talent and providing training.

ERN-LUNG COVID-19 WEBPAGE

ERN-LUNG has created a [webpage](#) dedicated to COVID-19 information, especially for patients with rare lung conditions and clinicians treating COVID-19 patients with rare lung conditions. The page is continuously updated with the most relevant information.

FIRST EVIDENCE-BASED PHARMACOTHERAPY FOR THE RARE DISEASE PRIMARY CILIARY DYSKINESIA

The first ever international trial in Primary Ciliary Dyskinesia (PCD) has led to amazing results improving patient care reducing exacerbations and ERN-LUNG would like to congratulate members of the PCD Core Network on this achievement! The first multinational randomised controlled trial on pharmacotherapy in PCD showed that azithromycin maintenance therapy for 6 months was well tolerated and halved the rate of respiratory exacerbations. Azithromycin maintenance therapy is an option for patients with PCD with frequent exacerbations potentially leading to reduced need for additional antibiotic treatments and preventing irreversible lung damage. This study was carried out under the framework of BESTCILIA, the COST Action BEAT-PCD and ERN LUNG. Read more [here](#).

ERN-LUNG LATEST PUBLICATIONS & EU CALLS WEBPAGE

You may find a list of the past and open research funding calls and training programs, some of them with revised deadlines due to the pandemic, [here](#). We remind you that any publications, clinical trials or guidelines arising from the collaborative work of ERN-LUNG members (at least 2 HCPs from at least 2 Member States) linked to ERN activities, are encouraged to mention ERNs either in the acknowledgement section or in the authors' affiliation. Such publications are curated [here](#).

ERN - SEARCHABLE TOOL

The European Commission website now hosts a [searchable interface](#) with details about ERNs for the public to search. The data concerned includes ERN names and details and ERN clinical centres names and details.

H2020 CSA ERICA JOINT APPLICATION SUBMITTED

ERN-LUNG was part of the application consortium that successfully submitted the H2020 joint proposal on behalf of all 24 ERNs entitled 'European Rare disease research Coordination and support Action' (ERICA). This was in response to the call SC1-HCO-20-2020: Coordination of clinical research activities of the European Reference Networks. ERN-LUNG has volunteered to be primarily involved in the workpackages centred around data collection, integration and sharing, and clinical trial support.

ACADEMIA DEVELOPING MEDICINES FOR RARE DISEASES TO RECEIVE FREE EMA SCIENTIFIC ADVICE

The European Medicines Agency (EMA) has decided to waive all fees for scientific advice for academic researchers developing orphan medicines, to further encourage the development of treatments for rare diseases. Read more [here](#).

IN CASE YOU MISSED

- [Webinar](#) on COVID-19 in patients with rare diseases of the respiratory system (Q&A), 30 April 2020
- 10th European Conference on Rare Diseases & Orphan Products ([ECRD 2020](#)), 14-15 May 2020
- [Webinar](#) on the impact of COVID 19 for people living with a Rare Disease, 9 June 2020
- [Webinar](#) on Second Wave of COVID-19: Preparatory actions - Consultation with Clinicians, 11 June 2020



SAVE THE DATE

[ERN-LUNG Symposium at ERS 2020](#): Acting for improved cross-border management of rare diseases
7 September 2020, 15h40 – 16h40 CET

ERN-LUNG ePAG meeting
16 September 2020, 9h30 – 11h CET

ERN-LUNG Medical Steering Committee (MSC) meeting
16 September 2020, 11h – 13h CET

All events will be held online. Links and agendas will be sent soon.