

The ERN-LUNG Network Coordination Team would like to thank you all for your friendship, support and collaboration during 2020. We wish you all the best for the holiday season and hope to see many of you soon virtually at the Annual Board Meeting in March 2021!

ERN-LUNG POPULATION REGISTRY READY TO GO ONLINE

Within the [ERN-LUNG Registry Data Warehouse project](#), we proposed to develop an ERN-LUNG Population Registry, which is now more or less ready to go online. This Population Registry will have a patient interface, i.e. patients or parents can do the registering of data themselves. We hope to attract patients to register who do not know of any registry in their country and/or for their disease. As soon as the patients add their data, they will be asked whether they agree to share these data with existing registries – in case such registries exist. This will allow the existing registries to check whether they already know of these patients and if not, get in contact with this patient to add his or her data to the existing disease-specific registry. We will inform you of the go-live of this new registry application.

THE ERICA PROJECT PROPOSAL HAS RECEIVED FUNDING

The European Rare disease research Coordination and support Action (ERICA) joint project proposal submitted by all 24 ERNs has received a positive evaluation for a H2020 grant of €2.3 million to establish a structural framework in support of the research activities of the ERNs. ERICA will strengthen research and innovation capacity by integration of ERN research activities, outreach to European research infrastructures to synergistically increase impact and innovation. This will result in safe, accessible and efficient access of therapies for the benefit of patients suffering from rare diseases and Conditions. ERN-LUNG will be primarily involved in the workpackages centred around data collection, integration and sharing, and clinical trial support.

PATIENT JOURNEYS DEVELOPED BY ERN-LUNG EPAG

This is a joint initiative between ERN, EURORDIS and the European Lung Foundation (ELF) that allows ERN members to develop Patient Journeys (PJ, personal patient testimonies validated by HCPs) as a baseline reference document to further develop publications and guidelines addressing the patient needs. The idea is to develop a document akin to a disease 101 / disease for dummies that has everything about the disease encapsulated in 1 page. The following conditions covered by ERN-LUNG have completed their PJs – sarcoidosis, idiopathic pulmonary fibrosis, pulmonary hypertension, primary ciliary dyskinesia. They will be available for download from our website before the end of the year.

THIRD CEF2020 APPLICATION SUBMITTED

The Connecting European Facility (CEF) is a funding programme of the Europe 2020 Strategy in the sectors of transport, energy and telecommunications. ERN-LUNG won this grant twice - towards the “ERN-LUNG IT Helpdesk” in the first call, and “e-Learning and e-Teaching (e-Support)” in the second call. A new application has been submitted and in contrast to the previous projects, for the new project we have asked for grant money that we can share with all Members of ERN-LUNG.

The last project (e-Support) is still work in progress and is being executed by a few members of ERN-LUNG - Bologna, Hannover, Utrecht and Frankfurt, in liaison with the European Respiratory Society (ERS). The new call allows for continued funding of both the IT Helpdesk and the e-Learning activities, and in addition, we are asking for funding of some support for a monitoring data set: this will ease our work with the new patient numbers that we all have to provide every six months to the European Commission for continuous monitoring purposes. In summary, this means we have three parts of the new grant:

1. IT-Helpdesk: Continued support of the CPMS and related issues
2. e-Learning/e-Teaching: We plan to prepare a library of e-Modules that might be used for a post-graduate curriculum for rare diseases of the respiratory system. This library will have e-Learning/e-Teaching modules, webinars, e-Cases, and an e-Evaluation system (including CME Online credits). Some other ERNs have already established such post-graduate qualifications and we should consider implementing such a curriculum as well. This, of course, would be a fundamental decision that would have to be prepared by the “Professional Training and Continued Medical Education Functional Committee” and implemented after a decision by the Board of ERN-LUNG. We will work on such a library of e-Documents anyway, irrespective of whether we will decide for or against a post-graduate curriculum in “Rare Respiratory Diseases”. What will make a difference is the fact that we will offer a remuneration on a per case basis to those contributing e-Modules and e-Cases. We will ask the Core Networks and all HCPs to contribute. This is a first step in the direction of allowing all Members of ERN-LUNG to get some financial compensation for their efforts.
3. ERN-LUNG monitoring data set: As a new area of activity within this funding scheme, we are going to develop an ERN-LUNG reporting data set which is exactly within the scope of the call. We all have to report our new patient numbers twice a year, but we should try to get these data in a more or less automatic fashion. Since we do not need personal data nor pseudonymized data, it is rather simple to export aggregated and anonymized data. This would allow us to know where we have how many patients. All you have to do then is to add your patients’ anonymized data to the ERN-LUNG REGISTRY, which has been built within the ERN-LUNG RD registry data warehouse project. You will only have to create such a reporting data file once - and we would transfer some of the project money to each of you. We would then take the continuous monitoring reporting data from the registry.

FUTURE OF ERN-LUNG : STRATEGY TASK FORCE TO BEGIN WORK

We are now in Year 4 of the first five-year funding period of ERN-LUNG. We expect to see another call for the next funding period sometime next year and we should prepare for this. I would like to gather a small group of enthusiastic supporters of the idea of ERN-LUNG to build a strategic group (not a writing group). I have thought of involving some new people with a somewhat outside view and for sure, we should involve some young clinicians as well. We will certainly invite all Core Networks and all Functional Committees to be part of this group. So, if you would like to contribute actively to this process, please, get in touch with the Network Coordination Team. The group will mainly be working via videoconferences, but that has become our default anyway these days.

HOW CAN CLINICIAN-PATIENT LIAISON BE IMPROVED IN ERN-LUNG?

Patient representatives still complain of lack of information about activities within their respective core networks. This may in part be due to the fact that clinicians have been overwhelmed by Covid-19 resulting in ERN-related activities being downgraded in their priority list. We do think, though, that having one person (clinician) from each Core Network as the patient liaison between the ePAG and that Core Network might be an efficient step to address this issue. He/she will serve as the point of contact for the patient representative for general communication as well as for fixing the annual ePAG objectives for that Core Network or for working on specific projects. We will soon contact each Core Network to ask for volunteers for this role.

UPCOMING ERN-LUNG CPMS PANELS

The next Clinical Patient Management System (CPMS) Panel has been scheduled on 18 January 2021 at 3pm CET. A patient case with lung involvement in Erdheim-Chester-Disease will be discussed. We would like to emphasize here that the use of CPMS continues to be one of the main parameters by which ERNs will be evaluated. Every Member HCP of any ERN is expected to make use of the CPMS at least once per semester. The lack of utilization will lead to de-activation of the accounts of inactive users in the short run, and eventually termination of insufficiently operating and performing ERNs in the long run.

ERN-LUNG MEMBERSHIP

Following discussions during the ERN-LUNG Board Meeting in February this year, the Network Coordination Team has successfully implemented revised and more adequate definitions for the different membership modalities that may be viewed [here](#). You may find the list of [Full Members](#), [Supporting Partners](#), [Affiliated Partners](#) and [Patient Organizations](#) on the website.

LAUNCH OF EXCHANGE PROGRAMME FOR HEALTHCARE PROFESSIONALS IN EUROPEAN REFERENCE NETWORKS

Knowledge sharing and stimulating collaboration between health care professionals in European Reference Networks (ERN) - that is the aim of the Exchange Programme 2020-2022, funded by the European Commission. In the coming two years, three different rounds of exchanges will take place between professionals of Health Care Providers that are members of an ERN. The first round of short-term visits (five days) are being planned to start in March 2021. The objective of the ERN Exchange Programme is to palliate disparities in specific knowledge or gaps in expertise by facilitating the arrival of high-level expertise in a considerable number of diseases to a big number of Healthcare Providers. [Ecorys Ltd](#) will provide services to all European Reference Networks in the framework of the Exchange Programme of the European Commission. More information on the Exchange Programme will follow soon.



SAVE THE DATE

[ERS Webinar](#): COVID-19 and Current Challenges in ILD
21 December 2020, 18-19h CET

ERN-LUNG Annual Board Meeting (virtual)
3 March 2021