



WORD FROM THE COORDINATOR

Future of ERN-LUNG

When it comes to plans and forecasts of the EU, in the end most everything turns out to be a little or a little more than little different from what it was thought and announced it would be. This may also be true for the future of the ERNs. We never know for sure until the very last moment. This said as a word of caution not to expect this will really happen exactly the way I will be describing here, I can tell you we have good reasons to think that ERN-LUNG will be continuously funded after the end of the first five-year funding period (ending in February 2022). We will probably have some kind of bridging until the EC comes up with a new call and a new grant contract in 2023, but we expect to have some funding for the remaining part of 2022 as well. For you and for the Network Coordination Team this means, that we can continue to plan and work and we will have all the tools and connections of ERN-LUNG available without interruption.

Hope to see you soon—stay healthy—Thomas (Coordinator)

ANNOUNCEMENTS

We are very sorry to announce that two of our ERN-LUNG project managers, Sabine Stemler and Keerthana Iyer have left their position as project managers this year in March and April in order to move to other challenges. We thank them for their great work and wish them all the best for their future!

INEA E-LEARNING

Ali Merzouk, E-learning Senior Coordinator, ERS, has informed us that in addition to the ERS web offer (ERS CME Online: learn from the experts) we can now promote the ERN-LUNG web teaching [modules](#). Here you will find recent posts concerning ILD, CF, and PH. If any other CN should feel they would like to include additional section(s) we will be very happy to do so.

PUBLICATION BY BOMS MEMBER AND 8 COORDINATORS ON CHALLENGES AND OPPORTUNITIES FOR ERNs

Birute Tumiene, BoMS member for Latvia and clinical geneticist, and 8 ERN coordinators wrote a paper on the challenges and opportunities of ERNs. The [paper](#) is now online in the Journal of Community Genetics.



PRIORITY AND CONTRAINDICATION LISTS FOR COVID-VACCINATION FOR RARE LUNG DISEASE PATIENTS SUBMITTED TO ERN-SECRETARIAT

Rare respiratory disease patients with priorities for COVID-19 vaccination:

- Patients with a rare disease of the respiratory system, such as Alpha-1-Antitrypsin-deficiency, Pulmonary Hypertension, Interstitial lung diseases, especially in those with severe manifestation of the disease and with impaired pulmonary function.
- All bone diseases affecting chest wall abnormalities consequently causing respiratory insufficiency.
- Patients with upper airway obstructions that require respiratory support (CPAP, BiPAP, tracheostoma etc.): specifically Apert, Crouzon and Pfeiffer syndrome, facial dysostosis (e.g. Treacher Collins, Nager and Miller syndrome), Robin sequence, laryngeal and tracheal cleft and stenosis.

CLINICAL TRIAL NETWORK FOR PCD ESTABLISHED

The clinical trial network for Primary Ciliary Dyskinesia (PCD-CTN) was founded in 2020 under the framework of ERN-LUNG with the aims to improve clinical and translational research and facilitate development of new treatments in the field of PCD. This disease-specific CTN initially consists of 18 clinical trial sites in 12 countries in Europe and the United Kingdom and includes over 1100 adult and over 1100 paediatric individuals with PCD so far. The PCD-CTN is headed by a coordinating centre and will be equipped with a steering and executive committee, a data safety monitoring board as well as committees for protocol review, training and standardization. A strong association with patient organizations and industrial companies will be further cornerstones for this newly established PCD-CTN, with the aim to gain evidence-based treatment and knowledge about management for this orphan disease and bring new personalized treatment approaches to the patients. For more information, please contact the Chair Prof. Kim Nielsen (Kim.G.Nielsen@regionh.dk). To keep up with regular updates of the ERN-LUNG PCD-CTN, do follow the official Twitter page https://twitter.com/PCD_CTN

INTEGRATION OF ERNs IN THE NATIONAL HEALTHCARE SYSTEM

The pre-proposal document of the integration working group has been revised and submitted. The working group is in the process of a proposal of a European Joint Action on "Integration of ERNs in the National Health Care Systems".



ERN-LUNG POPULATION REGISTRY LAUNCHED

As you may have heard, we have launched our new ERN-LUNG Population registry, which is now online. The Population Registry is a European registry that records as many people as possible who are affected by rare respiratory diseases.

How can patients use the Population Registry?

Affected persons or their relatives can register themselves and then share medical data with the scientists. For some patients this entry will be made even though they are already recorded in disease-specific registries. Other patients whose attending physicians do not know about such registries or when the care team cannot afford the effort of entering data are recorded for the first time for various research tasks. Data protection is always guaranteed. As soon as patients have entered their data and consented to their data being passed on to the previously named colleagues, this group of experts will be informed of the new registration. The researchers can now contact the patients via an e-mail function in the registry and, e.g. inform them about disease-specific registry use cases or clinical trials and motivate them to cooperate. This gives patients the opportunity to be informed about new studies and registry projects at any time and to support research in the field of rare respiratory diseases, which is most important to them. The Population Registry in turn enables experts to learn more about rare respiratory diseases and to be able to better help these and other patients.

Where can I find the Population Registry?

The Population Registry can be reached here <https://ern-lung-population-registry.mig-frankfurt.de/> and is available in German and English. If you have any questions, please contact the address provided or the ERN-LUNG team directly at the email address: ern-lung-administration@mig-frankfurt.de.

THIRD CEF2020 APPLICATION STATUS

ERN-LUNG has applied for another grant within the “Connected European Facilities” (CEF) funding scheme and has been granted the whole amount we asked for. This time we choose a mono-beneficiary grant, which sounds like we get all of the money. This is not true, though, since we have proposed to share the funds with the ERN-LUNG Members who are willing to contribute to the program, i.e. prepare eCases and other eTeaching material for our ERN-LUNG postgraduate training in rare lung diseases. We don’t have a contract yet, but we will start soon and inform you which kind of contributions you are invited to send to us and what the remuneration will look like. The project will also help with the twice per year reporting of new patients.



ERN COORDINATORS GROUP MEETING

TOF participated in the ERN Coordinators group meeting together with the European Commission and some representatives of the Board of Member states. The most important info is the promise made by the EC, that there will be uninterrupted funding for all ERNs during 2022. The Grant Agreements we have so far will end with February 2022, but there will be a bridging grant to insure continuous operation of the ERNs. We will have to apply for a new funding thereafter. The future funding will be a 100% funding scheme, which ERN-LUNG has always been fighting for.

UNDIAGNOSED PATIENT PROGRAM

Alexandra Berger from the Frankfurt Center for Rare diseases has published a [paper](#) in the Journal of Rare Diseases on “How to design a registry for undiagnosed patients in the framework of rare disease diagnosis: suggestions on software, data set and coding system”. This might be interesting for all Members of ERN-LUNG since we all see undiagnosed patients typically having a long odyssey of seeking a diagnosis. All of these should be registered for future assessment, but HOW? The proposed Registry for undiagnosed patients is an open access registry framework.

ERN-LUNG WEBSITE INTERNAL MEMBERS AREA UPDATED

A new member area of the ERN-LUNG website has been programmed and is now up and running – we now need to fill the content – one proposal from the PCD CN has already been submitted.

How can you get access to the Internal Members Area?

Due to the fact that the Internal Members Area contains confidential information a prior registration is necessary.

For access, please contact the NCT via e-Mail (o.steinmann@med.uni-frankfurt.de and michelle.erbe@kgu.de), stating your full name, email address and name of institution. We will then provide you with login details. As an internal member, you will have access to several features, which includes our “what’s cooking?”-list, which contains information on all our past/ongoing activities as well as a Core Network communication platform, where all the CNs can exchange news on their current activities.



PATIENT JOURNEYS ADDRESSING UNMET PATIENT NEEDS

A “Patient Journey” is a personal testimony that reflects the clinical pathway and needs of patients for a specific disease, showing in a comprehensive way the goals that are recognized by both patients and clinical experts. Up to now, there have been developed for 4 diseases (Idiopathic Pulmonary Fibrosis, Pulmonary Hypertension, Sarcoidosis, Primary Ciliary Dyskinesia) and available on our [website](#).

EJP RD WORKSHOP - ADVISORY COMMITTEES FOR THERAPEUTICS IN RARE DISEASES

A total of 6 ERN-LUNG members have shown great interest in this project. At this point we would like to thank them very much for wanting to contribute to this project. We have happily forwarded their contact information to the organizing committee but they have responded by saying that one (maybe max. 2) representatives per ERN can participate. They also stated that we would have to make a decision within ERN LUNG which of the interested persons can contribute to the workshop and benefit from it, as well as help establish such an ACT model in the respective ERN after the workshop. Thus, the participants in this workshop would be pre-endorsed by the respective ERN-coordinator. ERN-LUNG has endorsed Jacobo Sellares and Kors van der Ent and we are very much looking forward to what the two nominees will have to report about the project. If we all come to the conclusion that having a working group would make sense we can later decide who and how...

ERN-LUNG WEBSITE UPDATED

Several sections of the network website have been updated to include more information on the network's activities and functioning for the benefit of clinicians and patients.

ERN-LUNG ACKNOWLEDGEMENTS

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 using the [definitions](#) proposed by MetabERN and endorsed by DG Sante. You may find a curated list of such publications on our [website](#).

ERS RESPIRATORY CHANNEL NOW ONLINE!

The ERS respiratory channel is now online and available at <https://www.ersnet.org/ers-respiratory-channel/>



PAST WEBINARS AND MEETINGS



ERN-LUNG CPMS PANEL DISCUSSION, MAY 19, 2021

ERN-LUNG has had several case panel meetings and discussions although the number of participants have been a little disappointing for those who took the pain of preparing these discussions. The next CPMS panel discussion has been scheduled for July 14, 15:00 CET. If you want to discuss a case, don't hesitate to get in contact with the NCT-we will help you...

ERS GUIDELINES MEETING, APRIL 30, 2021

The ERS has an outstanding reputation for the work done in the field of European and International Guidelines. This is why it is only natural that ERN-LUNG has decided early not to develop guidelines of its own but rather monitor what guidelines are in the pipeline and make sure rare diseases are adequately included.

ERN-LUNG has, therefore, decided not to actively contribute to the action of the European Commission to foster European RD Guideline development, but rather to take a passive role in this project. Guideline development will be supported and closely monitored by ERN-LUNG and ERN-LUNG will endorse guidelines whenever RD are covered and ERN-LUNG members have been involved in the process of guideline development.

AMEQUIS STAKEHOLDER CONFERENCE, 15 FEBRUARY / 12. & 13. APRIL 2021

The AMEQUIS project, which aims to develop an integrated assessment, Monitoring, Evaluation and Quality Improvement System (AMEQUIS) for ERNs, is currently ongoing (official start in February 2021). The first stakeholder conference, on April 12-13, 2021, aims to bring together ERN Coordinators and Project Manager, ERN Board of Member States, the European Commission/HaDEA and patient representatives to provide input to identify the strengths and weaknesses of current procedures and possible areas of improvement, in particular, related to the assessment, monitoring, and evaluation processes.



ERICA KICK-OFF MEETING, 27 & 28 MAY, 2021

In early March 2021, the European Rare Disease Research Coordination and Support Action (ERICA) was launched. The ERICA consortium consists of 29 partners, amongst which are all 24 European Reference Networks (ERNs), EURORDIS, EJP RD, Orphanet, Mapi Trust Research, and EATRIS. ERICA is coordinated by Alberto Pereira (Endo-ERN coordinator, Leiden University Medical Center, the Netherlands). The kick-off meeting and the first General Assembly of the European Rare Disease Research Coordination and Support Action (ERICA) took place on Thursday 27th & Friday 28th May 2021, which was a very interesting and informative meeting. For more information, please take a look at the ERICA website at <https://erica-rd.eu/>

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