

ERN-LUNG ACTIVITIES

PROTOCOL FOR APPLICATION, STANDARDISATION AND VALIDATION OF THE FORSKOLIN-INDUCED SWELLING ASSAY IN CYSTIC FIBROSIS (CF) HUMAN COLON ORGANIDS

The protocol, available [online](#), describes the isolation, handling, culture of, and experiments carried on human colon stem cell organoids in the context of Cystic Fibrosis (CF). In CF, the functioning of proteins called cystic fibrosis transmembrane conductance regulator (CFTR) is impaired. In human colon organoids, the function of cystic fibrosis transmembrane conductance regulator (CFTR) protein and its rescue by CFTR modulators can be quantified using the forskolin-induced swelling assay. Implementation procedures and validation experiments are described for six CF human colon organoid lines, and representative CFTR genotypes are tested for basal CFTR function and response to CFTR-modulating drugs. This project has been supported by the Dutch Cystic Fibrosis Foundation (NCFS). These protocols have been endorsed by the European Cystic Fibrosis Society (ECFS) and by ERN-LUNG in 2019, and aim to standardise methods to ensure high reproducibility and correct interpretation of results among different laboratories.

COVID-19 IN PULMONARY HYPERTENSION (PH) PATIENTS: REFERENCE CENTRE SURVEY RESULTS OUT

To cover the experience of PH patients since the start of the pandemic in different countries, a survey was jointly initiated by the ERS Assembly 13 on Pulmonary Vascular Diseases, ERS Clinical Research Collaboration PHAROS, European Reference Network for rare lung diseases (ERN-Lung), and endorsed by patient association PHA Europe. The survey aimed to collect data on the clinical course and treatment of COVID positive PH patients (concerns only group 1 and 4, PAH and CTEPH) and data on hospitalisations, ICU admissions and outcomes. The results from this survey are now out – you may view them [here](#).

UPCOMING ERN-LUNG CPMS PANELS

Two CPMS Panels have been scheduled in the coming months - 12 October (patient case prepared by Helge Hebestreit) and 9 November (patient case prepared by Jacobo Sellares). 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. The lack of usage 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.

2019 CALL FOR MEMBERSHIP TO THE EXISTING ERNs STATUS UPDATE

All positively evaluated applications have been uploaded, but the European Commission has already advised us that it may take 6 months or more to get to a final decision by the Board of Member States. ERN-LUNG, though, internally will from now on treat all positively evaluated applicants the same as Members or Supporting partners.

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THIRD CEF GRANT APPLICATION

The Connecting European Facility (CEF) is a funding programme of the Europe 2020 Strategy in the sectors of transport, energy and telecommunications. As you may know we won this grant twice - towards the “ERN-LUNG IT Helpdesk” in the first call, and “IT-Helpdesk and E-Learning and E-Teaching” in the second call. This time we will – as encouraged to do – add a new topic and ask for support for our ERN-LUNG Registry (spin off from our ERN-LLUNG Registry Data Warehouse project). We will combine this with further funding for the IT-Helpdesk and the E-Learning activities. ERN-LUNG Registry needs a specific data set and we think with that we should be able to collect the continuous monitoring data for the European Commission and some internal ERN-LUNG information at the same time without increasing but rather reducing the work load on our Members’ side.

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](#).

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.

EUROPEAN JOINT PROGRAMME – RARE DISEASE (EJP-RD) FUNDINGS & CALLS

The EJP-RD [ERN Training and Support Program](#) is open - this includes the second call for ERN Research Mobility Fellowship and the Research Training Workshop Call. In addition, the EJP-RD has made some pre-announcements for the annual [Joint Transnational Call \(JTC\) 2021](#) and an internal 2020 call to foster clinical trial methodology. You may find a list of the past and open research funding calls and training programs [here](#).

ERNS IN EU4HEALTH 2021-2027 – ADVOCACY WORK TO SECURE FUTURE FUNDING FOR ERNs

The ERN-coordinators together have drafted a position paper on the major issues in the context of the future of ERNs (funding and sustainability were among the highest ranked key issues). There is some dispute on how to sustainably organize something like the ERNs although we still have to prove that the way ERNs are right now is the right solution. We will have to work hard to show proof that the money we get is money well spent. We had some discussion with Members of the Board of Member states but we haven't got any feedback. Nevertheless we all expect and hope that we secure another funding period of five years.

CROSS-ERN SURGICAL AND SPECIFIC DIAGNOSTIC SERVICES WORKING GROUP

The working group just lists what we offer in terms of surgical expertise but will not go into detail where which offering is available. We have therefore started to do a mapping of special services offered by members of ERN-LUNG. This will be a stepwise procedure:

- 1) We ask to list everything every Member or Supporting Partner has to offer - surgical skills, special rarely done operations, specific diagnostic or therapeutic techniques including translational work, biochemical testing, genetic investigations, etc.
- 2) After having gathered a comprehensive list, we will ask all Members and Supporting Partners whether they have this skill available - in house or in collaboration.
- 3) As soon as we have the complete comprehensive list, we will give this to the Core Networks to evaluate whether all of these tests and techniques can be considered state of the art, or whether some of these are no longer advisable.

Thus we hope to come up with a quality controlled map of special services ERN-LUNG can offer and give some guidance on where to find the respective services.

INFORMATION ON PLANNED MEDICAL TREATMENT ABROAD

All citizens of the European Union have the right to cross-border healthcare. Rules are provided for facilitating the access to safe and high-quality healthcare in not only ones own country, but within another EU member state as well. The EU promotes cooperation on healthcare between Member States, in full respect of national competencies in organising and delivering healthcare. You may find more information [here](#).