



## 1. New Website [www.ern-lung.eu](http://www.ern-lung.eu)

We are delighted to officially announce the launch of our ERN-LUNG website with a fresh look and user-friendly navigation.

Our goal is to provide our visitors an easy way to learn more about rare lung diseases, the network itself and the goals/aims of ERN-LUNG.

The website remains a work in process and we will constantly be updating our content with helpful information, articles, newsletters and events. If you have any questions, comments or suggestions, please send them our way.

**You can find us at [www.ern-lung.eu](http://www.ern-lung.eu)**

You may use the contact form or send an e-mail directly to: [info\(at\)ern-lung.eu](mailto:info(at)ern-lung.eu)

Just in case the [website](#) should not look as the screen shot it may be necessary to clear the cache in your browser. If you do not know how to do it, please find a guide here: <http://www.refreshyourcache.com/en/home/>



### EUROPEAN REFERENCE NETWORKS (ERN)

European Reference Networks (ERNs) are virtual networks involving healthcare providers across Europe. They aim to tackle complex or rare diseases and conditions that require highly specialised treatment and concentrated knowledge and resources.

Health systems in the European Union aim to provide high-quality, cost-effective care. This is particularly difficult with rare or low-prevalence complex diseases or conditions. Between 5 000 and 8 000 rare diseases affect the daily lives of around 30 million people in the EU.

European Reference Networks (ERNs) create a clear governance structure for knowledge sharing and care coordination across the EU to improve access to diagnosis and treatment, as well as the provision of high-quality healthcare for patients. They are networks of centres of expertise and healthcare providers that are organised across borders. The first 24 ERNs were launched in 2017, involving more than 600 highly-specialised healthcare units from over 300 hospitals in 26 Member States.

It can be a challenge to provide highly specialised treatment or care for patients who have complex



#### NEWSLETTER

► Issue 3 – June & July 2017

► Issue 2 – May 2017

► Issue 1 – March 2017

#### PLEASE SELECT

► Videos





## 2. SAVE THE DATE: ERN-LUNG Board Meeting 2018

As agreed upon during our Kick-off meeting in April this year the **next Board Meeting** of ERN-LUNG will take place in **Frankfurt** on **March 7 - 8, 2018**.

Please save the date in your agenda!

P.S.: On September 11, 2017 the Medical Steering Committee of ERN-LUNG will meet at the ERS Congress in Milan.



## 3. Supporting Partners - CN Specific Requirements

Several Core Networks of ERN-LUNG already accepted Supporting Partners who met the requirements indicated in the [SOP of ERN-LUNG](#) that was sent to the Core Network leaders (they also have access to the mentioned “self-assessment” PDF).

Some Core Networks, e.g. the PCD Core, included some additional requirements that have to be met by a Supporting Partner, for example, the participation in the European PCD registry. It is up to the Core Networks to add more requirements if they feel it is reasonable and necessary.



## 4. Survey “Local Patients and Data Registries”

In the framework of our work plan deliverable “Inventory of existing registries and biobanks”, both the members of the functional committee “registries and biobanks” Olivier Sitbon and Angelo Corsico were so kind as to design a survey on Local Patients data registries, which will be available and ready to be forwarded to the official representatives of the HCPs shortly who then can distribute it to the respective Core Networks.

They will receive the relevant link to this survey via email as soon as we set up the questionnaire in SurveyMonkey, which should be at the beginning of September.

Screen shot of the survey that will be sent below:

ERN-LUNG Core Network survey on local patients data registries

Dear members,

In the framework of our ERN-work plan (Deliverable 3.1.c registries and biobanks) you will find below a questionnaire, which was designed by Olivier Sitbon and Angelo Corsico from the Functional Committee “Registries and Biobanks”, intended to get an overview of Local Patients Data Registries.

All the information below is about your HCP’s activities in a specific Core Network. Please do not give any confidential information in your answers.

If your HCP belongs with more than one Core Network, please fill in appropriate number of questionnaires (e.g. if your HCP belongs to the Core Networks ILD and CF, please make sure that the questionnaire is answered for both CNs).

**1. Adresse**

Name of ERN-LUNG member

Healthcare Provider (HCP)

City/Town

Country

**\* 2. Core Network**

Next



European  
Reference  
Network

for rare or low prevalence  
complex diseases



Respiratory Diseases  
(ERN-LUNG)

Responsible for the content of this newsletter:

Coordinator of ERN-LUNG  
Prof. Dr. T.O.F. Wagner  
University Hospital Frankfurt / Germany

Email: [t.wagner@em.uni-frankfurt.de](mailto:t.wagner@em.uni-frankfurt.de)  
Issue published on: August 30, 2017

