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European
Reference
Networks

ERN - LUNG Newsletter

## 1. New Website 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**

You may use the contact form or send an e-mail directly to: 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/


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## 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).

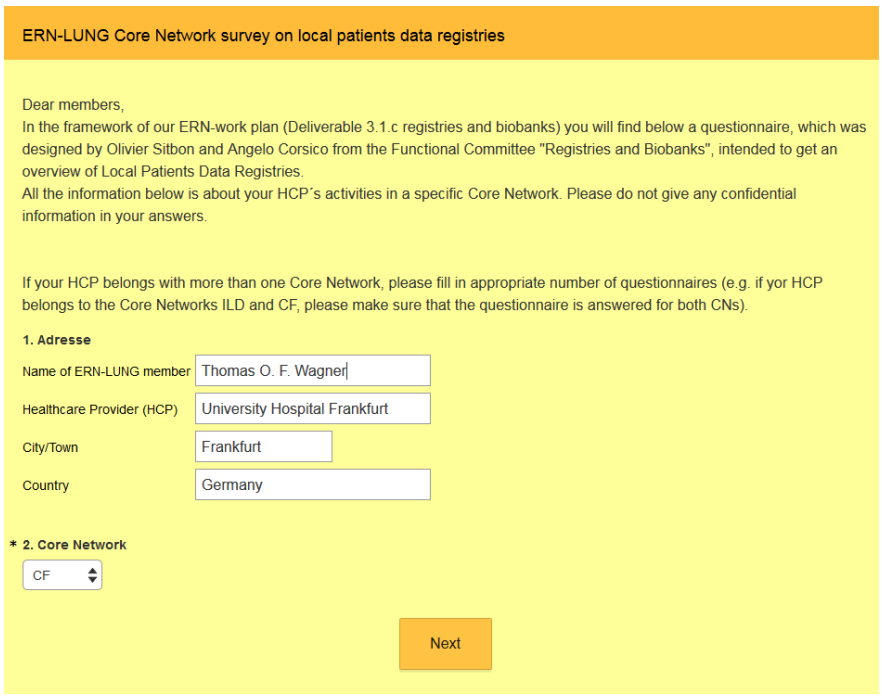
Some Core Networks, e.g. the PCD Core, included some additional requirements that have to be met by a Supporting Partner, for example, the participation in the European PCD registry. It is up to the Core Networks to add more requirements if they feel it is reasonable and necessary.

## 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 yor 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: Thomas O. F. Wagner
Healthcare Provider (HCP): University Hospital Frankfurt
City/Town: Frankfurt
Country: Germany

*** 2. Core Network**

CF

Next

European
Reference
Network
for rare or low prevalence
complex diseases

Network
Respiratory Diseases
(ERN-LUNG)

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