Issue 6
October 2017

Co-funded by
the Health Programme
of the European Union

European
Reference
Networks



## Message from the Coordinator

There is good news and there is not so good news. Let's hear the good news first: we have won the competition for a grant from the EU for establishing REGISTRIES within ERN-LUNG where they are still lacking, and for making those registries fully interoperable which are already existing. We have proposed to build a comprehensive infrastructure for patient data management within ERN-LUNG and we are in the process of preparing the grant contract. We, i.e. ERN-LUNG as a whole specifically supported by James Chalmers (Dundee, nonCF-BE), Heymut Omran (Münster, PCD), and Olivier Sitbon (Paris, Evaluation) can proudly say that we achieved only nines and tens (of ten) evaluations for this application. This is nice but what is more important to me is the fact that the model of ERN-specific calls really brings more resources to our network and in this case we have the proof that the Members of ERN-LUNG will be the beneficiaries. We hope that the next application (IT-Helpdesk) will be successful as well. The good message in this is that we are doing something right, actually this is what we have been doing for many years: Writing applications and raising money for projects.

But ERN-LUNG is more than just another way of raising money and organizing projects. We have a mission. Not so good news is that we may function as a network by communicating, mapping und planning activities, but we have not even started to do what these ERNs are made for. We have not started to refer patients, we do not have teleconferences discussing difficult patients and we do not have numerous requests from patients or from colleagues to do so. This may be due to the fact, that we do not have the tools, yet (the ERN-IT-Platform is not yet supporting this). We have to be aware though, that serving patients and colleagues is our main objective which we have not addressed so far – at least not at all better than before. We are so much preoccupied with self-management of the networking, with questionnaires and surveys, with "networking" but we must not forget to plan and advertise our special services to patients and colleagues. We are in the position now to disseminate the fact that we are there, that we are happy to help, so you are more than welcome to spread the word. We will do so during the next ERS Congress (Paris) but wherever you go, wherever you give a talk think of telling patients and doctors that they can ask for our help with difficult patient problems and tricky questions.

## 1. ERN-LUNG Operational IT-Helpdesk

On behalf of ERN-LUNG we have submitted the application for funding of "ERN-LUNG Operational IT-Helpdesk" in the context of the call "2017 CEF Telecom Call - eHealth (CEF-TC-2017-2)"

Scope and objectives of the proposed Action:

The European reference network for rare diseases of the respiratory system (ERN-LUNG) has been established to develop innovative care models and improve cross border care for patients suffering from rare lung diseases. ERN-LUNG will develop and provide eHealth tools, will contribute to medical solutions and device development, and will offer services such as cross border health care for those affected by rare diseases of the Respiratory System. ERN-LUNG will boost research through large clinical studies and contribute to the development of new pharmaceuticals, and will lead to economies of scale and ensure a more efficient use of costly resources, which will have a positive impact on the sustainability of national healthcare systems, and for tens of thousands of patients in the EU suffering from rare and/or complex diseases and conditions.
The main objective of this application is to support members of ERN-LUNG to ensure adequate and efficient use of the European Reference Networks Collaborative Platform and Clinical Patient Management System IT solution. With this effort, the introduction, implementation, and sustained utilization of the ERN IT Platform throughout ERN-LUNG will be possible in a timely manner increasing the efficacy of the efforts going into this European initiative of bringing together the best centers of care and clinical research in the attempt to improve patient centered care for rare lung diseases.

## 2. ERS –Support

Marc Humbert managed to bring together Guy Brusselle, Science Council Chair of the ERS, and Thomas to discuss the future collaboration of ERS and ERN-LUNG. This was a nice and productive meeting leaving the impression that the ERS is willing to closely cooperate with ERN-LUNG because they think we are an important addition to the respiratory scene assets. ERS is finally willing to embed ERN-LUNG in the ERS and help and support ERN-LUNG.
Next steps will be another request for financial support covering some of the co-financing needs of ERN-LUNG. A joint symposium during the next ERS Congress (Paris, France from 15-19 September, 2018) was discussed. A draft version of the program will be sent to the ERS soon, so please mark your calendar in order not to miss this event in Paris.

## 3. ERN-LUNG registry application successful

We have been informed that our joint grant application titled "RD REGISTRY DATA WAREHOUSE" has been positively evaluated and that we are invited to prepare the grant agreement. This project will enable us to achieve interoperability for all existing registries in our field and will offer open source registry software for easy set-up of new registries wherever needed. Partners involved are discussed. Heymut Omran and Petra Pennekamp, Münster, Germany (PCD Core network), James Chalmers, Dundee, UK (Non-CF Bronchiectasis Core Network), Olivier Sitbon, Paris, France, together with Holger Storf and TOF Wagner, Frankfurt, Germany (Registries and Biobanks Functional Committee). The project has a planned budget of 669.000€ and we are optimistic that we will receive sufficient co-funding project. Details will follow shortly. If you are interested in setting up a new registry, please contact the Network Coordination Team.

## 4. ERN-LUNG´s Supporters Association

ERN-LUNG will need to be sustainably funded. We are in the process of bringing together a group of possible supporters of ERN-LUNG. Just recently we received an unrestricted yearly grant of 25.000€ from the Christiane Herzog Stiftung, a Charity Organization founded by Christiane Herzog, former First Lady of Germany. We will try to attract more Charity Organizations, Academia and other Supporters to co-fund ERN-LUNG.
If you are in contact with academic or commercial putative contributors, please refer them to the Coordinator so we can discuss with them how they could possibly help ERN-LUNG and thus help patients affected by rare respiratory diseases.

## 5. MDS consented (Registries and Biobanks FC)

Data interoperability is one of the major issues in RD patient data registration. It is self-understood that you will only be able to combine data if they are compatible and if e.g. “height” is always meaning the same thing in all registries trying to cooperate. During the EUCERD Joint Action, we therefore started to define a “Minimum Data Set” (EUCERD-MDS) for all RD patient registries in Europe. In this context “Minimum” means that these data elements should be contained in each and every RD patient registry. The European RD Patient Data Registration Platform (JRC, Ispra, Italy) now managed to have this “Minimum data set” (MDS) consented among the groups having published their slightly different MDS/CDS (EPIRARE, RD-CONNECT, and OSSE/EUCERD-MDS). This consented MDS will serve as the standard to be used by the European RD Registries platform consented between EPIRARE and RD-CONNECT and THE OSSE/EUCERD-MDS: Please click following link for more information: EU RD Platform_CDS_final.pdf-Link

Co-funded by
the Health Programme
of the European Union

European
Reference
Networks

ERN - LUNG Newsletter

European
Reference
Network
for rare or low prevalence
complex diseases

Network
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
Issue published on: August 30, 2017

UNIVERSITY
HOSPITAL FRANKFURT
GOETHE UNIVERSITY