



Message from the Coordinator

First of all, we like to thank all our ERN-LUNG members for their numerous appearances at our 2nd Board Meeting March 7 & 8, 2018 in Frankfurt and their fantastic participation and presentation of many very interesting and fruitful introductions on what is planned and lies ahead of us for year 2. After spending year one with organizational issues, we look forward to focusing on ERN-LUNG's main concern, which are the patients, and disseminating the possibilities for those suffering rare lung conditions.

Above that, it was great to get together after the meeting in one of Frankfurt's famous "Apfelwein Kneipe" to mingle and get to know each other a little better. The minutes were sent to the participants and can also be downloaded at

[ERN-LUNG Board Meeting Report](#)

We hope you enjoyed your journey to Frankfurt and look forward to seeing you next year at our third Board meeting.



Photograph of ERN-LUNG members at the Board meeting in March, 2018 in Frankfurt Germany



1. New NCT member

We are happy to welcome a new member to the ERN-LUNG NCT, her name is Keerthana Iyer, and she is a member of Marc Humbert's working group in Paris and will be supporting us from afar. We look forward with pleasure to working with her.

2. All deliverables for year 1 completed

We have very good news: despite several obstacles and delays at the beginning of ERN-LUNG, we still managed to complete all our deliverables in due time. This wouldn't have been possible without you, which is why we would like to thank all of you for putting in your time and work to accomplish this, though we know that you are all very tied up with your everyday tasks in the framework of your working days. In order for you to get an overview of all completed deliverables at a glance, please click on link below to view our ERN-LUNG final report:

[Annual Reporting](#)

3. Online Expert Advice Tool (software) for ERN-LUNG

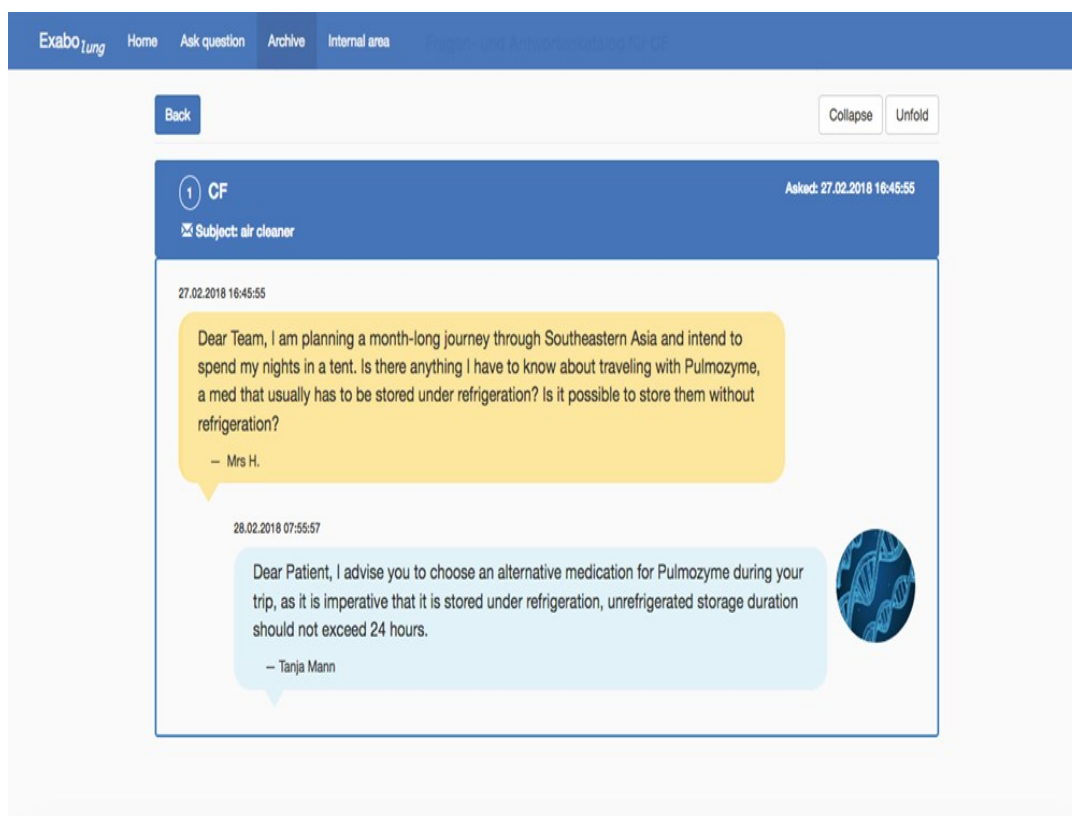
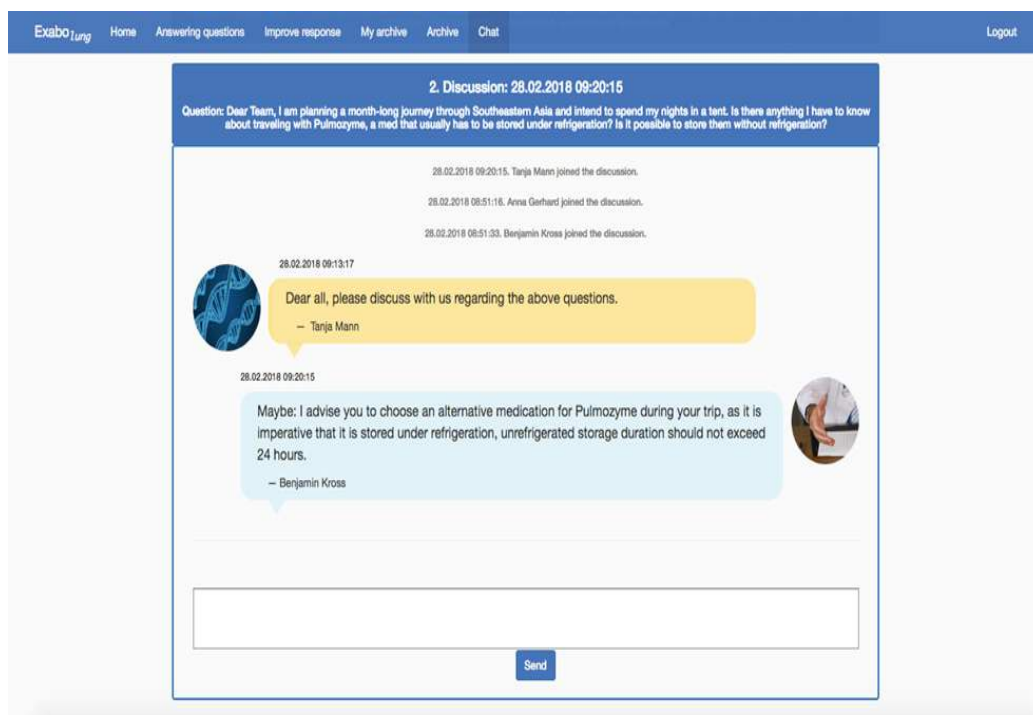
As we have reported in previous Newsletters, our "Medical Informatics Group" at the University Hospital Frankfurt has developed a software program for an online expert advice tool for ERN-LUNG.

The pan-European Internet platform EXABO, is an Expert Advisory Board, which is developed within the framework of the European Reference Network for rare respiratory diseases (ERN-LUNG) and aims to help people who are suffering or have questions regarding rare respiratory diseases to get a better understanding about rare pulmonary conditions. With the Online Expert Advice System, patients and physicians can address their specific questions concerning rare respiratory diseases to experts who are specialized and experienced in this field.

We plan to beta test the system shortly.



Screenshots of the Online Expert Advice System





4. Letter of Support

Due to frequent requests concerning a letter of support of ERN-LUNG, we would like to inform you that we will be happy to issue an attestation confirming your activities within the framework of ERN-LUNG.



Responsible for the content of this newsletter:

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