



## Monthly Newsletter- December

<b>Included patients</b>	<b>Total: 177</b> <b>new since last newsletter: 16</b>  Munich, LMU 26 patients Hannover, MHH 22 patients Paris, UPMC 20 patients Ankara, Hacettepe University 16 patients
<b>Running Peer reviews</b>	<b>Total: 18</b>  Munich, LMU 8 patients Hannover, MHH 3 patients Edinburgh, RHSC 2 patients London, RBH 2 patients Heidelberg, University 1 patient Homburg, University 1 patient Bristol, RHC 1 patient
<b>Completed Peer reviews</b>	<b>Total: 14</b>  München, LMU 7 patients Hannover, MHH 2 patients Amsterdam, Academ. medical center 1 patient Aberdeen, RACH 1 patient Leeds, General Infirm 1 patient London, KKC 1 patient Nottingham, RCPCH 1 patient

**We thank Nico for doing a great job with peer reviewing for the other centers!**



## News and Notices

### Matthias Griese:

- **Appeal:** This is to announce a specific project aiming to build a large cohort of alive subjects with surfactant dysfunction disorders.

All prevalent (and new/incident) cases < 20year of age should be asked for consent to be entered into the chILD-EU data base.

This means all patients with

- a) mutations in

**SFTPC**

**ABCA3**

**TTF1**

**SFTPB (possibly some non-lethal)**

**GMCSFRa**

**GMCSFRb**

**HPS2**

- b) lung histology without other organ involvement of

**NSIP**

**DIP**

**LIP**

**PAP**

**CPI**

The first goal is to follow natural history in the observational trial. **Please indicate potential cases to the national coordinator and to [chILD-EU.register@med.uni-muenchen.de](mailto:chILD-EU.register@med.uni-muenchen.de)**

**We will support you as best as we can.**



News and Notices

## Invitation

**2-day “hands on” life and web-based  
case review and discussions  
of children’s interstitial lung diseases  
with European experts present from 5 countries  
The chILD-EU-Symposium  
Munich**

Orphans Unite: chILD better together –?  
European Management Platform for Childhood Interstitial Lung Diseases  
Grant Agreement number 305653

**Meeting Venue:**

Klinikum der Universität München, Dr. von Haunersches Kinderspital, Lindwurmstr. 4, 80337  
München, Hörsaal

**Meeting Schedule:**

**Friday, 16th January 2015 from 11 am to 6 pm**

**Saturday, 17th January 2015 from 9 am to 5 pm**

Present your own cases, upload previously and follow on your own laptop

**We are looking forward to seeing you!**

Please fill in the pre-registration form below to improve Symposium organisation.

More information: [www.childeu.net](http://www.childeu.net)



**News and Notices**

**Preliminary Agenda**

<b>Friday, 16th January 2015 from 11 am to 6 pm TIME</b>	<b>TOPIC</b>	<b>WHO</b>	<b>ACTION</b>
11:00 – 11:15h	Welcome, introduction of participants	Griese, all	Guest WLAN available
11:15 – 11:35h	First results observational trial	Cunningham	
11:35 – 11:55h	chILD-EU register: Biomaterials	Hengst Burmeister	
11:55 – 12:55h	Peer review of cases: Lead UK-Team (10 min demonstration, 10 min discussion)	Cunningham Bush all	Bring your laptop, mobil phone, Secutrial login and have a case to work on it, if you wish also CD for radiological upload
12:55 – 14:00h	Lunch break / Group Photo	Wölke, all	
14.00 – 14:20h	chILD-EU: Contracts, competent authorities, ethics	Kronfeld Eismann	
14:20 – 14:40h	Data export tool, part I	Rock Antony	
14:40 – 15:40h	Peer review of cases: Lead Italian-Team (10 min demonstration, 10 min discussion)	Barbato Snijders all	
15:40 – 16:00h		Short Break / Snack	
16:00 – 16:20h	Web-based initiation of sites for EAA and HCQ trial	Kronfeld	
16:20 – 16:40h	Data export tool, part II (French data mapping)	Rock Antony	
16:40 – 17:40h	Peer review of cases: Lead French-Team (10 min demonstration, 10 min discussion)	Clement Epaud all	
18:00h		Fingerfood	
<b>Saturday, 17th January 2015 from 9 am to 5 pm TIME</b>	<b>TOPIC</b>	<b>WHO</b>	<b>ACTION</b>
09:00 – 09:15 h	Welcome, introduction of participants	Griese, all	Guest WLAN available
09:15 – 09:35h	Clinical trials EAA / HCQ - eCRFs	Rock Antony	
09:35 – 09:55h	Patient reported outcomes in the register	Goldbeck Seidl	



**News and Notices**

<b>09:55 – 10:55h</b>	<b>Peer review of cases: Lead Turkish-Team (10 min demonstration, 10 min discussion)</b>	Kiper Emiralioglu all
10:55 – 11:10h		Short Break / Snack
<b>11:10 – 11:30h</b>	<b>Current papers/project ideas</b>	All
<b>11:30 – 11:50h</b>	<b>Safety reporting flows in the clinical trials</b>	Kronfeld
<b>11:50 – 12:50h</b>	<b>Peer review of cases: Lead German-Team (10 min demonstration, 10 min discussion)</b>	Griese Schwerk Hengst Burmester
12:50 – 13:50h	Lunch break / Group Photo	Wölke, all
<b>13:50 – 14:50h</b>	<b>Peer review of cases: Lead German-Team (10 min demonstration, 10 min discussion)</b>	Schwerk Griese Hengst Burmester
14:50 – 15:00h		Short Break / Snack
<b>15:00 – 16:30h</b>	<b>Patient education and Training education</b>	Goldbeck Niemitz Schwerk
<b>16:30 – 17:00h</b>	<b>Press Conference: - Status / News CHILD-EU Project - Presentation of the parent booklet</b>	Griese Schwerk
17:00h		Many thanks for your attention and have a good journey

**We wish you all a happy Christmas and a happy, healthy and content new year!**