



Included patients	Total: 162
	Hannover, MHH and Munich, LMU: 21 patients
	Paris IPMC: 20 patients
Running Peer reviews	Ankara, Hacettepe University: 16 patients
	Munich, LMU: 15 patients
	Hannover, MHH 3 patients
	Heidelberg, University: 1 patient
	Homburg, University: 1 patient
	Amsterdam, Academ. Med. Centre: 1 patient
Completed Peer reviews	London, RBH: 1 patient
	Hannover, MHH: 1 patient
	Leeds General Infirmary: 1 patient

News and Notices

Matthias Griese:

Monthly reminder - Cohort of alive patients with surfactant dysfunction disorders - November 2014

Dear All,

this reminds you of the active project
"build a large cohort of alive subjects with surfactant dysfunction disorders in Europe".

All prevalent, i.e. you know patient already and you are caring for,
and all new/incident patients < 20year of age
should be asked for consent to participate in the chILD-EU project. Thus all patients with

a) mutations in
SFTPC
ABCA3
TTF1
SFTPB (possibly some non-lethal)
GMCSFRa
GMCSFRb
HPS2

b) ILD and lung histology of
NSIP
DIP
LIP
PAP
CPI
UIP
RB-ILD

First goal is to follow natural history in the observational trial, including quality of life, health economics.



News and Notices

Next steps are inclusion into HCQ trial, and disease specific projects.

Please indicate potential cases to the national coordinator and to chILD-EU.register@med.uni-muenchen.de

We will support you as best as we can.

Meike Hengst/ Nico Schwerk:

- Pitfalls of the database:

1. Wherever you write something in the database, which implicates an automatical e-mail to other participants it is **ABSOLUTELY NECESSARY** to mark the corresponding field (e.g. Peer review completed)

Peer Review: opinion clinician Document-No. 8551 - 2

- * For a timely review process you may immediately read the case, even if you have not received the reports of the Radiologist, Pathologist or Geneticist, if requested. You may
- * Get an overview of the clinical data of patient by clicking on > Patient > in the line just above the dark blue bar of this form; you may navigate through all forms
- * After considering all information go to the MOST RECENT peer review form family in the Visit schedule
- * Open the "Peer Review: Final diagnosis from peer review" form (the last form)
- * Make sure that you enter all information necessary to completely define the final diagnosis.
- * Open the "Peer Review: Opinion Clinician" form again (found under Peer review in the Visit schedule)
- * Check the "Peer review complete" box and the rest of the form opens
- * Fill in your Comments and Recommendations from Peer review (preferred) or upload it as a file
- * Press Save at the end of the form, to send off the review

Peer Review complete



Date of review

19 - 11 - 2014 dd.mm.yyyy *

Comments and Recommendations from Peer review

Slide Thickness of the CT scan is >5 mm. So validity is restricted. In principle Clinic and radiologic findings are compatible with NEHI. Please add FBB to the diagnosis. If the child recovered under antibiotic therapy, the diagnosis NEHI has to be questioned

File

Or „Send notification of new comment ...” If you forget to mark this field no emails will be sent.

The first time a comment is submitted, the national Coordinating Centre will receive a notification of the new contribution to the discussion, and will select automatically

NOTE: All participants in the patient's = your current centre will receive these discussion notifications by default too.

Send notification of new comment to the National Coordinating Centre / participants of the Discussion.



You MUST check the "Send notification..."-box and then press SAVE to dispatch the notification to your national coordinating centre/the other participants of the Discussion

NOTE: If you do not check the "Send notification..."-box, NO notification will be send at all.

Entries

Discussion entry # 1

Date

19 - 11 - 2014 dd.mm.yyyy *

Name of person writing this comment (extendable)

Schwerk
Others

Comment

Why do you treat a child with NEHI like a patient with Athma (Budesonide, Montelukast, Salbutamol, Ipratropiumbromide)?



News and Notices

2. (for clinical Experts only): You have to fill in the MedDRA cods
It is necessary to fill in the MedDRA Diagnoses before you complete the FINAL Peer review.
Therefor fill in the Pulmonary diagnosis and click **Catalog** (no short cuts accepted!)

German kids lung register disease classifications
[\(Click here to see the complete list\)](#)
Category: < Please choose >
Subcategory: < Please choose >

French kids lung register disease classifications
[\(Click here to see the complete list\)](#)
Category: < Please choose >
Subcategory: < Please choose >

Pulmonary diagnoses (MedDRA coded)

1.) **Catalog** Pulmonary diagnosis (MedDRA - LLT):
(s. Help for introduction) 2.) **Neuroend**
LLT Code:
Delete
More

The according diagnosis with the LLT code will appear. Double-click at the diagnosis.

MedDRA-16.1_SOC_Respiratory_disorders

Search for: Search Reset

Search in:
 System Organ Class SOC Code
 High Level Group Term HLGT Code
 High Level Term HLT Code
 Preferred Term PT Code
 Lowest Level Term LLT Code

System Organ Class	SOC Code	High Level Group Term	HLGT Code	High Level Term	HLT Code	Preferred Term	PT Code	Lowest Level Term	LLT Code
Respiratory, thoracic and mediastinal disorders	10038738	Lower respiratory tract disorders (excl obstruction and infection)	10024967	Parenchymal lung disorders NEC	10033979	Neuroendocrine cell hyperplasia of infancy	10072968	Neuroendocrine cell hyperplasia of infancy	10072968

The diagnosis and LTT Code will be filled in automatically. Press save.

(MedDRA coded)

Pulmonary diagnosis (MedDRA - LLT):
(s. Help for introduction) **Neuroendocrine cell hyperplasia of infancy**
LLT Code: **10072968**

(MedDRA coded)

Diagnosis (MedDRA - LLT):
(s. Help for introduction)
LLT Code:

Cancel **Save** Check data



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

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