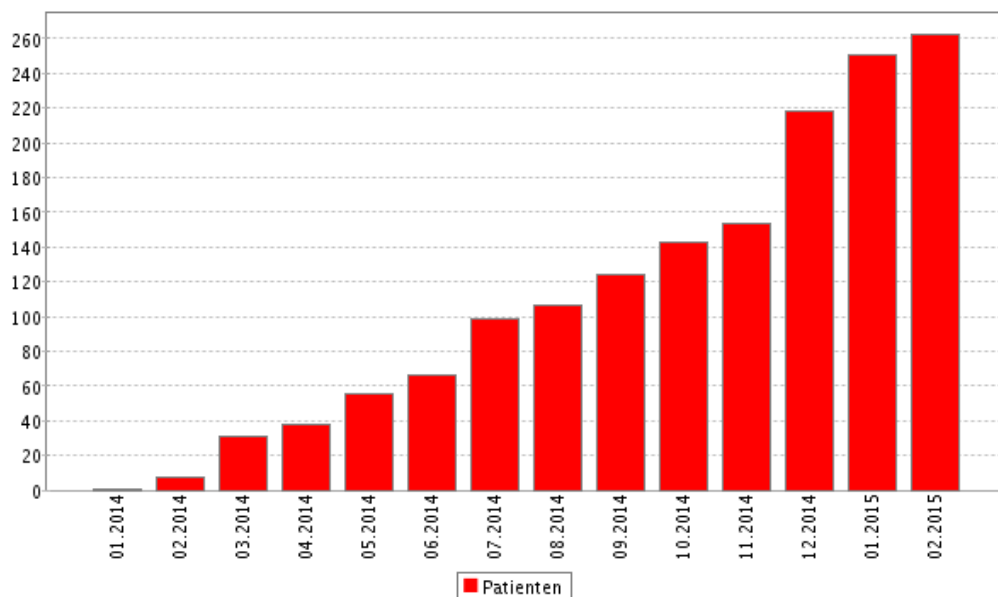




Observational trial

Patients included: 213

Patients over time



Completed Peer reviews and long term followed patients

Germany 21 (+2)

UK 8 (+2)

Netherlands 1

Turkey 1 (+1)

The project is living from your participation. As we were growing rapidly in December and January, there is a plateau in February. Moreover just 5 Peer reviews had been completed since the last newsletter. So we kindly appeal to you to include patients, complete your included patients and do Peer review!!!

Project: Natural history

Cohort of alive subjects with surfactant dysfunction disorders and related diseases -

Include all patients with SFTPC, ABCA3, TTF1, SFTPB (non-lethal), GMCSFRA/B, lung histology pattern: NSIP, DIP, LIP, PAP, CPI, other/mixed



WP4 Patient's education

The child brochure is now finalized in German language and progress was made in translate them into English.

Thank you Nico Schwerk for this great and important work!

If you wish you can download the child brochure with the following link:

<https://www.dropbox.com/s/5g9Intjeqqijuj8/Leben%20mit%20chILD-Final.pdf?dl=0>

Interventional Trials

Initiation process in Germany for stop-EAA and Start-HCQ and Stop HCQ is in progress.

To start the Studies in all other countries we need your signed contracts immediately.

ICs in German and English are available for all three studies, as well as in Italian for Stop EAA.

Upcoming meeting Padua 27-28. February

FRIDAY, FEBRUARY 27th

08.30 - 09.00 Registration
09.00 - 09.10 Welcome
A. Barbato, A. Clement, G. Perilongo

SESSION 1: Discovering chILD
Chair: F. Midulla

09.10 - 09.35 Why is ILD a different disease in children? Classification of chILD
D. Snijders

09.35 - 10.00 Etio pathophysiology of chILDs
A. Clement, N. Nathan

10.00 - 10.25 Clinics of chILDs
R. Cutrera

10.30 - 11.00 **Coffee break**

11.00 - 11.20 Radiologic diagnosis of chILDs
T. Toffoluti

11.20 - 11.40 Histologic diagnosis of chILDs
F. Calabrese

11.40 - 12.05 Monitoring and follow up in chILDs
S. Cunningham

12.05 - 12.30 Translational research in chILDs and options for the future
M. Griese

12.30 - 12.50 Living with chILD: a patient and family perspective
tbd

12.50 - 12.50 **Lunch**

FRIDAY, FEBRUARY 27th

SESSION 2: chILD cases
Chair: A. Barbato

14.00 - 14.30 chILD case presentation

SESSION 2: Treatment options in chILD
Chair: A. Bush

14.30 - 14.45 The utility of aerosol/O2
N. Schwerk

14.45 - 15.00 The utility of steroids
E. Lombardi

15.00 - 15.15 The utility of antibiotics
S. Cazzato

15.15 - 15.30 The utility of pulmonary rehabilitation
A. Kantar

15.30 - 15.45 The utility of off-label drugs - initiate HCQ
M. Hengst

15.45 - 16.00 The utility of nutritional management
N. Kiper

16.00 - 16.15 Discussion

16.15 - 16.45 **Coffee break**

SESSION 3: chILD: an overview
Chair: E. Bignamini

16.45 - 17.00 Neuroendocrine hyperplasia of infancy (NEHI)
G.A. Rossi

FRIDAY, FEBRUARY 27th

17.00 - 17.15 Surfactant deficiency disorders
R. Epaud

17.15 - 17.30 PAP
A. Hadchouel, J. De Blic

17.30 - 17.45 Initiate stop EAA
M. Griese

17.45 - 18.00 chILD in rheumatologic diseases
F. Zulian

18.00 - 18.15 chILD in immunologic and hematologic diseases
M.C. Putti

18.15 - 18.30 Closing of the Congress
Leave evaluation test Italian CME

SATURDAY, FEBRUARY 28th

chILD-EU Meeting
08.30 - 12.30 Meeting with all chILD EU members (programm to define)



News and Notices

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.

You have information, upcoming activities, news, which you would like to add to the newsletter? All your comments are welcome! Please contact meike.hengst@med.uni-muenchen.de until the 15th each month!