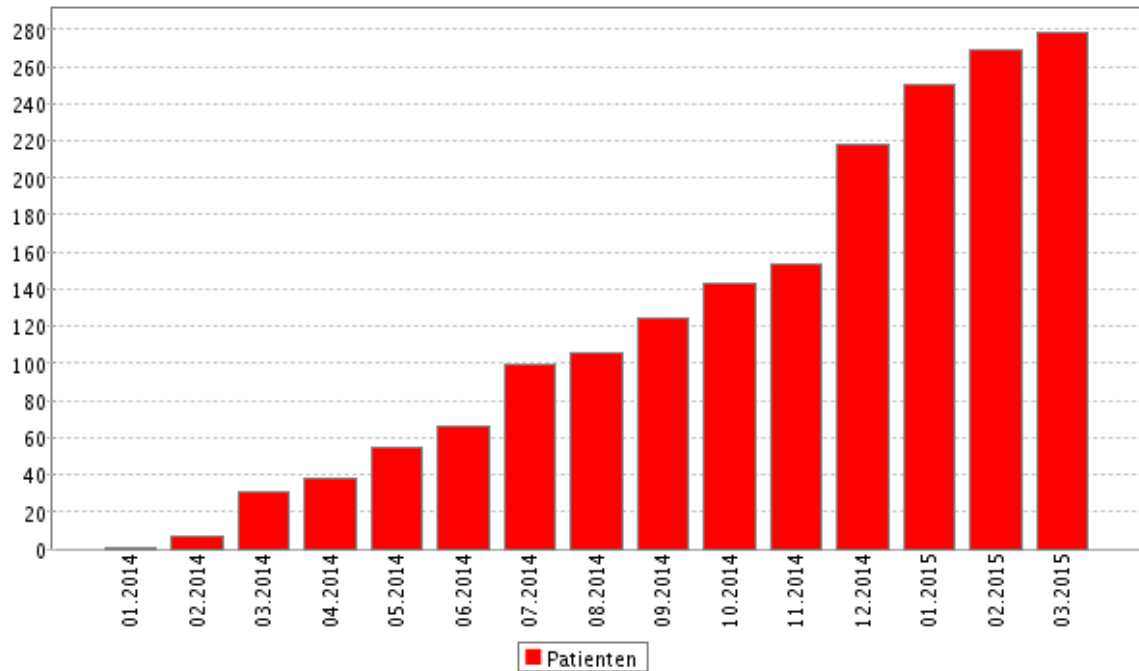




Observational trial

Patients included: 227



Completed Peer reviews and long term followed patients

Germany 30

UK 8

Netherlands 1

Turkey 1

Poland 1

The project is living from your participation. There were just some more Peer reviews in Germany and one in Poland 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

Patient education study starts in Munich (25.3.) and Hannover; other countries may follow as they are interested. Please actively approach Lutz Goldbeck, Nico Schwerk or Matthias Griese.

Interventional Trials

EAA / HCQ will start soon: the initiation in Germany will be on 30th March 2015 in Munich; 29th April in Essen and in April as well in Hannover.

As the interventional trials are running now, please include:

1. **For STOP EAA:** all newly or previously diagnosed patients with not appropriately treated EAA
2. **For START HCQ:** all subject currently not on Hydroxychloroquin treatment (last dose >12 weeks ago) and the intention to widen the treatment.
3. **For STOP HCQ:** all subjects on chronic (>3 months) treatment on Hydroxychloroquin and intention to reduce the treatment.

Upcoming meeting: ATS Denver 15-20. May 2015

Meeting with US network, and EEAB, please sent Matthias Griese an e-Mail, if you will participate.

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!