chILD- Newsletter- July 2015

Mailing lists: ML_1; ML_2; EU_1/2/7/8/9

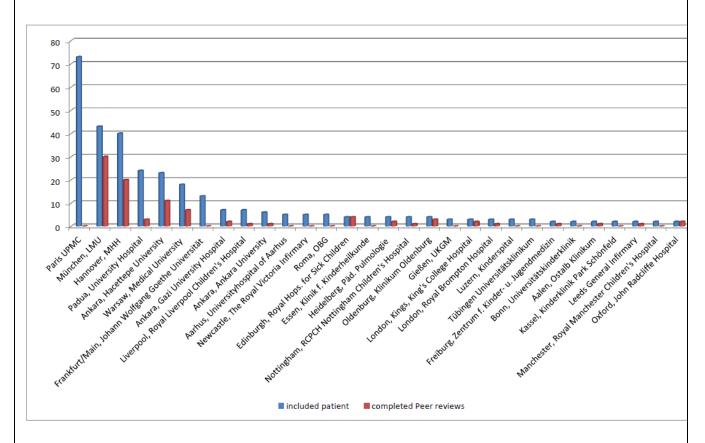
Observational trial

Patients included: 333;

completed Peer reviews and followed patients

- Germany 59
- UK13
- Turkey 14
- Poland 9
- Italy 3
- Switzerland 3
- Netherlands 1

Figure below shows all included and peer reviewed patients according to centers (Only centers were listed with \geq 2 patient included).



Special thanks to our Peer reviewers! You did a great job!!!

Our Top Peer reviewer are:

Clinicians:

Nicolaus Schwerk, Hanover, Germany (43) Mathias Griese, Munich, Germany (33)



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Observational trial

Radiologists:

Birgit Kammer, Munich (22) Julia Ley-Zaporozhan, Munich (21)

Pathologists:

Simone Reu, Munich, Germany (14) Andrew Nicholson, London, UK (5)

Project: Natural history

Participate actively in the build of a cohort as well of all alive subjects with

- NSIP: The project is in its final throes for clinical, histological and radiological Peer reviews. If you have another patient with histologically proven NSIP please include the patient to the database and/or give notice to meike.hengst@med.uni-muenchen.de!
- SFTPC
- ABCA3
- All incident cases with TTF1, GMCSFRA/B, lung histology pattern of DIP, LIP, PAP, CPI, pulmonary eosinophilia, pulmonary hemosiderosis or entities those you are interested in!

Interventional Trial

Germany: EAA / HCQ studies have started (see the homepage as well)

Thank you Essen for including 2 patients!!

Remember to include

- 1. all newly diagnosed patients with Exogen allergic alveolitis
- 2. all subjects planned to treat with **Hydroxychloroquine (HCQ)**
- 3. all subjects planned to take off **Hydroxychloroquine (HCQ)**

Turkey, UK, Italy, France: please take administrative hurdles!



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News and Notices

TIPS for Imaging and Radiology

Most people will have trouble with the <u>upload</u> of imaging from clinical network because of fire wall issues. One problem is that the system will not tell you, it will just not work.

Solutions:

- 1. Use a non-hospital system.
- *A very good option is **EDUROAM**, a secure, world-wide roaming access service developed for the international research and education community worldwide system https://www.eduroam.org/
- Inform yourself if you have it at your University (it made Matthias Griese's life much easier!)
- 2. Test your hospital system
- *Try upload of an x-ray or CT after following the detailed instructions in the download area on Upload of Imaging.
- *Get in contact with us to solve the problem
- * If it doesn't work: send CD to register in Munich for upload or to national coordination center
- => Always use dicom files, as Secutrial upload automatically anonymizes the files

<u>Download</u> of files from Secutrial usually is not a problem. Best is not to use the dicom browser implemented, but to download .zip file, unzip locally and open with "Syngo fast".

Please include all potential cases into the register! We will support you as best as we can. Give notice to child-EU.register@med.uni-muenchen.de

Send YOUR news for this newsletter to meike.hengst@med.uni-muenchen.de