Observational trial

Patients included: 426

Completed Peer reviews and followed patients: 206

Observational trial – News I

1

GOAL: prospective (less biased) observations
We want to collect „valuable", as correct/accurate as possible data: this is prospective

Advantage: all what happened until the time point when the patient was included into the database will be compiled at a single baseline visit. *(see below)

All following information is prospectively collected information if done in time (and not retrospectively)!

DEFINITIONs:
***Incident case** = newly manifesting or newly discovered/diagnosed disease
Definition: onset of symptoms within 1 year maximum and naïve to specific chILD treatments (if patient had antibiotics or steroids in the past for short periods/unsystematically counts as naïve)
➔ **we have the opportunity to closely observe natural disease manifestation**

***Prevalent case** = known case ➔ **we also have the opportunity to prospectively observe course of disease**

Thus a main difference between incident / prevalent is the density of observation!

Observational trial - News II

2

Please always decide for the observational type and click "new visit" to establish the future visit plan. Only this will generate an e-mail reminding you ONCE only for upcoming visits.

Observational trial

| Visit schedule | Long Term Medication & Effect | BAL / Lung biopsy / Histology | Genetics | Diagnoses / Epicrisis / Letters | Discussion |

Baseline data for peer review and inclusion   New visit

Planned visits
28.08.14
"28.08.2014"

Informed consent / Visit date / Observation type / Retrospect

Demographics / Initial diagnoses / Family & neonatal history

Med. history, Signs, PFT, PHT, Lab., Treatment, Prophylaxis

Radiology

Questionnaires for Parents and Patients reported outcomes

Peer Review

Biomaterials

Peer Review Request   Ready for Peer Review? / Selection of Reviewers   Peer Review: opinion radiologist   Peer

3

  We have plenty of new reports available! Check them out. You will find them in the chILD EU database under "reports" at the Welcome page.

Examples:
  For National coordinators the report CONTROLLING: ready for peer review? Will help you to get an overview which of your cases are ready for Peer review.
  CONTROLLING: diagnosis, course lists the final diagnosis of your completed Peer reviewed cases.
  And for Peer reviewer the Overview CONTROLLING: Peer Review-er what to do next? Helps you to check the status of your Peer reviews.

  Please notice that not all reports are visible for all participants and that you will see only the centers you are working in.

**If you have any questions give notice to chILD-EU.register@med.uni-muenchen.de.
Send YOUR news for this newsletter to meike.hengst@med.uni-muenchen.de.**