

MEETING MINUTES

10 March 2016, 18:30 – 19:30, Hotel Hilton Old Town, Prague

POINTS FOR SC MEMBERS:

1. What do we store from patients?
 - a. Blood
 - b. Lung tissue
 - c. BALF

Please send the response to Jana Strenková - strenkova@iba.muni.cz

2. All SC members should send their proposal of investigator Initiated Studies – for the EMPIRE registry and/or for local registry. Data from EMPIRE registry are available after approval of proposal and voting of SC members.

Other information from the meeting:

1. Data from registry will not be given automatically to the pharmaceutical companies (as regular reports). It can be given based on specific proposal and after voting of members.
2. Other sites from involved countries could join the registry. All regulatory and ethical requirements must be met (responsibility of Principal investigator of the country), then separate contract with investigator is concluded.
3. Israel would like to join the registry EMPIRE – needs to be discussed with IBA and Amnon Ariel.
4. In the process of preparing separate contract with Boehringer Ingelheim Turkey and IBA.
5. No changes of CRF are now needed. Changes of calculation of FVC will be discussed and evaluated later on the next meeting.

Next meeting will be probably held on 3 September 2016 in London, before the start of ERS congress.

Drafted: Jana Strenková

Approved by: Martina Vašáková