

MEETING MINUTES – 5TH SC MEETING IN KRAKOW

23 March 2017, 18:00 – 20:00, Andel's by Vienna House Cracow

PUBLICATIONS IN PROGRESS

1. Samy Suissa is working on publications from EMPIRE registry:
 - i. Description of EMPIRE registry, including description of the IPF population already registered to date.
 - ii. Evaluation of the timing (timeliness of diagnosis) and imaging (HRCT findings) at diagnosis on survival and decline in lung function using the EMPIRE registry.
 - iii. Evaluation of antifibrotic treatments on survival and decline in lung function using the EMPIRE registry.

PROPOSALS FOR INVESTIGATOR INITIATED STUDIES (IIS)

1. Prof. Müller – Cross country differences in EMPIRE (different profile of IPF patients per country)

For all proposals will be filled in the form for analysis specification.

CHANGES OF CRF

1. GAP score – automatically calculated
2. In FUP – patient consider for lung transplantation (Y/N). If no, specify the reason – patient refused, comorbidities, age, not applicable

OTHER INFORMATION FROM THE MEETING:

1. Data already entered into the EMPIRE registry should not be shared with different registry. Genetic studies are different issue and data can be used.
2. Votes of SC members – recently some members decline the vote. In the future, try to always closely discuss – ideally personally in SC meetings or at least in TC if urgent. For TC discussion, IBA will organize doodle to pick up suitable term and organize WebEx meeting.
 - i. Data for BI Israel – will not be given, not ethical to provide data from other countries for economic reasons (prof. Kramer)
 - ii. Providing the protocol to prof. Studnicka – protocol of EMPIRE registry is an intellectual property. It will not be given to those who does not want to join the registry.
3. Rules for analysis:
 - i. Data of EMPIRE registry – IIS needs to be approved by SC members
 - ii. Local/country analysis – SC member has to be informed and approve
 - iii. Data of center – available data export only
4. EuroQol questionnaire – no changes in the validation.

5. Israel is joining the registry. Waiting for the contract. App. 5 centers will join.
6. New centres from Poland, Serbia and Croatia recently joined the registry.
7. Any planned publication (written, oral or audio-visual) has to be sent to BI prior to submission. This is requested by BI to ensure that there is no legal consequences for the company and to allow comments on the content as a non-binding consultancy.
8. For ERS submitted 5 abstracts.
9. IBA MU is under process of transition into Faculty of Medicine. There will be some changes in contracts with investigators and some changes will come with upcoming EU regulation on GDPR.

The next meeting will probably be held on 9 September 2017 in Milan, before the start of ERS congress.

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