

## MEETING MINUTES – 6<sup>TH</sup> SC MEETING IN MILAN

9 September 2017, 19:00 – 21:30, Melia Milano

### PUBLICATIONS IN PROGRESS

1. Samy Suissa is finishing the first publications from EMPIRE registry: send to all SC members for reviewing, will be submitted to ERJ
2. One manuscript already accepted in the Clinical Respiratory Journal – Czech part of the registry – Doubkova et al.

### PROPOSALS FOR INVESTIGATOR INITIATED STUDIES (IIS)

1. Prof. Müller – Bleeding complications
2. Prof. Müller - Cross country differences in EMPIRE (different profile of IPF patients per country)
3. Prof. Müller – rapid decliners – prolong to 1 year
4. Prof. Kramer – transplantation
5. prof. Vašáková – Overall and country analysis on treatment of pirfenidone and nintedanib

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

### CHANGES OF CRF

1. GAP score – automatically calculated
2. CPI – composite physiology index
3. In FUP – patient consider for lung transplantation (Y/N). If no, specify the reason – patient refused, comorbidities, age.
  - a. SC members please respond if you agree with suggested items.

### OTHER INFORMATION FROM THE MEETING:

1. Overview for all recent votes of SC members. Discussed Boehringer Ingelheim request of analysis – no data on pirfenidone treatment will be provided, but for SC members will be analyzed. Responsible person for IIS is Martina Vašáková.
2. Involvement of Roche as another sponsor of registry – based on secondary data use. Necessary to ensure long-term financial support of the registry.
3. Israel joined the registry and start entering data. More sites will join the registry.
4. Austria and Bulgaria are joining the registry. Waiting for regulatory affairs and contracts to be negotiated.

5. HRCT scans – retrospectively checked if sites want to do that. Not for all scans will be performed (time consuming). In the registry will be stated that no personal data can be uploaded in the registry, blinded data only.
6. EMPIRE registry transferred into Faculty of Medicine, new rules for data operation set up, new version of protocol. Sent to all SC members.
7. Changes of reimbursement of follow-up forms – paid in current calendar year, no retrospective FUP forms will be reimbursed.
8. Change of project manager of EMPIRE registry since October 2017: Marketa Janotova MSc. – [janotova@iba.muni.cz](mailto:janotova@iba.muni.cz)

The next meeting will be held during CIPF meeting in Budapest, during 16.-17.4 2017.

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