

MEETING MINUTES – 4TH SC MEETING IN LONDON

03 September 2016, 18:00 – 20:00, Crowne Plaza London Docklands

PROPOSALS FOR INVESTIGATOR INITIATED STUDIES (IIS)

1. Prof. Müller – Study of risk factors for rapid decline of lung function or acute exacerbation- (Rapid decliners= more than 10% decline per 6 months when compared with previous value) compare to all parameters – age, gender, smoking etc.
2. Prof. Jovanovic – Blood sample evaluation – biomarker study. Prof. Vasakova – in that case there should be some sponsorship to do that and the biomarkers should be well chosen.
3. Prof. Mogulkoc – Prevalence of lung cancer in IPF + risk factors

For all proposals needs to be provided a short protocol, hypothesis and aim of the study. Please provide to prof. Vašáková and IBA (Strenková). The analysis will be processed at the beginning of the year 2017 and possibly submitted to ERS as abstracts. Prof. Mogulkoc will enrol her IPF patients to the registry before the analysis.

CHANGES OF CRF

1. FUP form – Lung function test, will be added more specifics for oxygen saturation – PaO₂, PaCO₂, pH, SaO₂
2. Oxygen saturation – arterial/ capilar checkbox will be added
3. FUP form – 6MWT – will be added question: performed yes/no
4. FVC calculation – IBA will check if possible to change the calculation of already entered data, if yes then the calculation will be updated – Prof. Jovanovic will offer the equations

OTHER INFORMATION FROM THE MEETING:

1. Croatia and Turkey are joining the registry. Prof. Mogulkoc will enter app. 200 patients into the registry by the end of year.
2. The offer of REGENERON will not be used. Blood sample evaluation and DNA sequencing be rather evaluated by prof. Schwartz from Colorado, samples will be collected on behalf of EMPIRE. Two possibilities for evaluation: selected DNA or the whole blood.
3. Countries can ask for data analysis of national data. According the scientific aoutputs, the first author is author of the IIS proposal, then the authors are listed by the number of patients, the last given is senior.
4. National reports and whole report of EMPIRE registry will be issued regularly annually in January.
5. SC meeting will be held twice a year – during CIPF meeting and ERS congress.
6. SC members should inform centers in their countries about changes in CFR and important decisions of the SC meeting.

The next meeting will be probably held during CIPF meeting in Krakow, in March 2017.

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Approved by: Martina Vašáková