

MEETING MINUTES – 7TH SC MEETING IN BUDAPEST

Date, place: 15 April 2018, 17:00 – 20:30, Intercontinental Budapest, Panorama I

Participants:

Martina Vasakova	Veronika Müller
Jasna TekavecTrkanjec	Michael Studnicka
Nesrin Mogulkoc	Marta Hájková
Natalia Stoeva	Markéta Janotová
Samy Suissa (first hour)	Ruza Stevic (radiologist on behalf of prof. Jovanovic – last hour)

CURRENT STATUS OF EMPIRE REGISTRY

Currently 9 countries have been involved.

Newcomer-countries:

Since previous week IBA MU has been in touch with Austria again, only contract between IBA and Austrian center is missing. The e-mails with core information were sent to Romania and Latvia. There has been no response yet. Possible contact for the negotiation in Romania – Assoc. Prof. Irina Strambu.

Newcomer-centers:

1 Polish site joined the registry. With Israeli center and one Hungarian center IBA started the negotiation regarding the contract. The e-mails with the core information were sent to Serbian center and rest of Hungarian centers.

DISCUSSION WITH GUEST PROFESSOR SUMY SUISSA

Discussion with professor Suissa about possible cooperation with the registry. He was invited as co-worker of the registry, as epidemiological and analytical adviser.

Professor mentioned the power of the registry in the number of patients and compared to other registries they are not so powerful in the writing of manuscripts. In the future the registry should write a few papers with right questions and answers to show the value of the registry.

ARIANE IPF

Introduction and discussion about the project ARIANE IPF.

Based on the information that there is a number of questions that remain unanswered in the field of IPF this project plan to pull more European IPF registries together.

According to experiences of professor Suissa this type of network can take longer time. Based on the common discussion the Empire will not join this project, nevertheless the registry can offer the participation in some tasks. Every task will require an approval of all SC members.

PUBLICATION, ANALYSIS AND PROPOSALS FOR IIS STUDIES

Publications in progress:

Samy Suissa is finishing the first publications from EMPIRE registry: send to all SC members for reviewing, will be submitted to ERJ

Proposals for IIS studies:

1. Study testing new radiological criteria: Prognostic roles of HRCT by new Fleischner society

Open discussion about the pausing of Dr. Walsh in communication with professor Vasakova. Last e-mail with Dr. Walsh related the idea how to pull all HRCTs scans together.

Approximately month ago, Professor Mogulkoc was addressed by John Joseph to pull patients HRCT scans of her center together to carry out the study.

Professor Vasakova will contact Dr. Walsh to check the situation. Anyway, based on the approval of participating members the study would be done. There is possibility to upload the HRCT scans into database. This item would be obligatory for all patients with HRCT at admission and with at least one more HRCT during follow-up. The HRCT scans without personal data would be uploaded. Based on the confirmation from Dr. Stevic, blinding of personal data on HRCT scans is easy procedure.

Responsibility: Professor Vasakova

2. Risk assessment analysis: Statement of the risk assessment

Responsibility: Professor Mogulkoc

3. Effect of antifibrotic treatment on survival and progression of lung functions

The voting regarding the approval of this study will be done in following days.

Responsibility: Professor Vasakova

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

RULES OF THE REGISTRY

According to the contract all results should be submitted to BI (at least 60 days in advance), for information only. BI has no right to change the wording of the results.

Don't forget to add a statement regarding BI support.

CHANGES OF CRF

CPI index – 2 years ago the voting regarding the calculation of predicted values was performed. IBA will check the situation in the database. CPI index should be calculated according to the predicted values calculated in the database.

Other dose of Pirfenidone in Turkey – professor Mogulkoc mentioned other dosing of Pirfenidone in her country. It will be discussed via email and the database will be updated accordingly.

Blood gases – saturation listed twice - SaO2(%) and O2 saturation (%), this field will be clarified with professor Vasakova and members will be informed.

Lung function - on the part of Lung functions associated with measurement of diffusion capacity (Total lung capacity, Transfer factor, Transfer coefficient) there should be more options expressing the possibility of performance of these tests (at this moment there is option Yes/No only). Inability to perform those tests have a strong impact to the GAP score - it gives 3 points more and announces worse prognosis.

Dr. Tekavec-Trkanjec would like to have a choice between "unable to perform" and "not perform because of technical reason". In the case of "unable to perform" it should be associated with increased GAP score

Comment box - would it be possible to add comment box in the field "Validations of patient" to send the comment/answer directly to Helpdesk without necessary to send the e-mail.

HRCT uploading – the situation with Dr. Walsh will be checked. After the agreement of all SC members the database will be updated with the possibility to upload the scans.

The next meeting will be held in Paris before official start of ERS congress (15.-19.9.2018).

Drafted by: Markéta Janotová

Approved by: Martina Vašáková