

11TH STEERING COMMITTEE MEETING MEETING MINUTES

Date and venue: 18 May 2020, 13:00–14:30 CET, online meeting (videoconference)

Participants:

Martina Vašáková	Jasna Tekavec-Trkanjec
Dragana Jovanovic	---
Mordechai Kramer	Jakub Gregor
Katarzyna Lewandowska	Michael Kraft
Nesrin Mogulkoc	Klaus Kirchgässler
Veronika Müller	Julia Spielhofer
Natalia Stoeva	Teo Soon-Siong

Absent:

Michael Studnicka	Biserka Jovkovska Kaeva
Martina Šterclová	Marta Hájková

The meeting minutes accompany the official presentation of the 11th SC meeting and summarise discussion from the 11th SC meeting.

Current state, contracts

- Total number of registered patients have risen to 3,651, of which 3,535 are valid patients (April 2020)
- The registry now covers 50 centres from 11 countries
- 1 Polish centre terminated the cooperation due to unacceptance of proposed contract (Krakow)
- 1 Slovak centre joined the project (Banska Bystrica)
- Amendments to existing contracts or full new contracts have been sent to centres
- The new contracts between Masaryk University (MU) and centres have been already signed at 27 centres 23 centres have not been signed yet.
- Pending communication with Romanian representatives (last reminder sent on 7 April 2020, no reaction to date)
- Proposal of a new form of contract between MU and Ege University (donation – **Nesrin Mogulkoc and IBA to proceed**)
- Contracts with BI and Roche on the general EMPIRE support effective from 10/2019 to 06–09/2022.
- There is an opportunity to submit independent EMPIRE-based IIS to BI to obtain additional sources, possibly Intercountry differences by V. Müller and Risk assessment by N. Mogulkoc – official proposal submission is necessary – **IBA, V. Müller, N. Mogulkoc**

News in the registry

- New comorbidities added in order to allow for the calculation of Charlson Comorbidity Index

- COVID-19 added in order to record/follow-up IPF patients with the disease
- Correction of the 2011 ATS/ERS classification (code list and records corrected accordingly)
- New classification (ATS/ERS 2018) from 10/2019

Overview of SC members' votes since previous meeting

- HRCT repository and cooperation with OSIC
Approved option: building the EMPIRE-HRCT repository and subsequent provision of images to the OSIC database (11/0)
- Use of EMPIRE data in BSc/MSc theses at Masaryk University
Approved option: yes (11/0)
- Addition of COVID-19 into the list of associated disorders
Approved option: yes (11/0)
- Summary report (autumn 2019)
Approved option: yes (11/0)

Overview of SC members' votes during the 11th meeting

- Writing a paper based on the “SDU pirfenidone” study and Dr Klaus Kirchgässler (Roche) as co-author
Approved option: yes (8/0)
- N. Mogulkoc: writing the article on risk assessment and contacting Samy Suissa to get statistical advice. Help from Paul William Bishop as a native English speaker for medical writing and inviting him as a co-author
Approved option: yes (8/0)
- N. Mogulkoc: collaboration with a researcher from David for Genetics in Czech and Turkish cohorts
Approved option: yes (8/0)
- N. Mogulkoc: other ILDs that are liable to clinical progression with advancing fibrosis to the database from now on
Approved option: preliminary yes (8/0), **to be discussed by M. Vasakova and IBA** and specify possible ways how to proceed

Outcomes & publications

- New paper by Tanja Tran, Samy Suissa et al. published in Respiratory Research; there are 4 IF papers from the EMPIRE registry published in total
- 7 papers in various stages of preparation (1 to be submitted after revision, 1 to be revised, 5 in preparation)
- 5 analyses and summary report underway, 3 to be specified and initiated

HRCT subproject

- Financial support – reduction of costs for launch and 1st year operation (71,000 euro). Half of costs from Roche (official proposal submitted), remaining half of costs should be obtained from other sources.
- Cooperation with OSIC approved, but currently not on the table
- **SC members** will address centres in their countries to find out, which of them are willing to participate in the study. Materials for this communication will be

delivered to SC members by IBA. Czech centres were already addressed and most of them will be involved in the study.

- Expected kick-off and pilot images collection – autumn 2020.

PD-L1 project

- Support of the study from Roche approved
- Centres with the highest numbers of patients have already been asked by EMPIRE helpdesk to express their interest in the study and answered several queries regarding the study
- Feedback to date: 3 Czech and 1 Turkish centre

Summary of tasks for the next period

- IBA, N. Mogulkoc will discuss alternative ways of contract between MU and EGE University
- IBA and M. Vasakova will discuss the “other ILD” issue and IBA will subsequently inform SC about possible ways and eventually initiate voting
- One or two IIS will be officially submitted to BI in order to obtain additional support for the EMPIRE project: risk assessment (N. Mogulkoc), intercountry differences (V. Müller)
- IBA will provide materials on HRCT to SC members. The SC members will contact centres in their countries and collect information about their willingness to participate in the study (i.e. provide their HRCT images to the repository).
- IBA will collect and complete information about participation of centres in the PD-L1 study.

The 12th Steering Committee will be held in September 2020 either online via videoconference, or face-to-face at ERS Congress in Vienna.

Drafted by: Jakub Gregor

Approved by: Martina Vašáková