

# Registry Meeting Minutes

3 October 2016, EACTS Barcelona

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Members present: Rita Milewski, Jaroslav Hlubocky, Hajime Kin, Martin Ledecy, Tomas Toporcer, Igor Rudez, Pavel Zacek, Jan Vojacek, Bardia Arabkhani, Bo Yang, Laurent de Kerchove, Jolanda Kluin, Hanneke Takkenberg, Frederiek de Heer, Emmanuel Lansac, Shelagh Kelley.

## Agenda

### 1. AVIATOR Surgical

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An overview of patient enrollment was given per center: close to 4000 patients included in total. Over the last 6 months the database is growing steadily with 92 patients per month. There was an open discussion regarding any issues uploading / updating patients.

- Milewski – Patient inclusion was lower than expected in Philadelphia. She will check with the research assistants who worked all summer.
- Yang – What is the criteria of the patients? Opened an additional slide show with the inclusion criteria. What is the main question? To evaluate the repair and the database is a tool for institutions to evaluate their results and compare techniques.

### 2. Update submission grant Foundation Leducq

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Foundation Leducq is a Transatlantic Networks of Excellence Program and it provides \$6,000,000 over five years. Letter of intent was submitted on September 6, 2016 (coordinated by Jolanda Kluin). Notification of application status will be expected in November 2016. The full application deadline will be February 14, 2017. The project title is: Dynamic Multiscale Modeling to support personalized clinical decision making in aortic valve regurgitation (DynaValve). PI's are Hans-Joachim Schäfers (EU) & Joseph E. Bavaria (USA). Objective is: To achieve a breakthrough in treatment of AR, the first aim of the proposed network is to establish a reliable scientific research database spanning the entire course of AR from diagnosis to long-term follow up after surgical treatment.

What we want in practice is: fee for each enrolled patient with a complete echo follow-up at e.g. 1 year, 5 year and 10 years.

Changes for Leducq are minimal, so what could be other possibilities?

- Will need to start adding Industry. Will need funding for AVIATOR Kids, AVIATOR Medical.
- Crowd funding (gofundme?)

### 3. Scientific Committee

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Objective: Want to be open to everyone and receive high quality data from AVIATOR.

Proposed bylaw: Multi center analysis is open for all active participants. Research proposal submission to the SC is possible twice a year (e.g. a month before HVS and EACTS). The SC will review the proposal, to assess the validity of the research question and proper use of the data. Submitted proposals will be discussed in detail during the AVIATOR meeting at the Annual Meeting of HVS and EACTS. Proposals are validated when the majority of the participants agree. Each center will be notified about the accepted proposals and their data will be used automatically (Non-opposition Procedure). If a center does not agree, his opposition should be justified to the SC. The research team will receive an anonymous data set, without patient and center identifying variables. After data extraction, the team will be given a deadline of 6 months to perform the analysis and write a draft publication that should be presented at the next meeting. When the deadline is exceeded, the topic could be passed on to another group.

First and second authorship is for the person who did the job (ideally young investigators). Last authorship is for the PI of the proposal. Regarding Authors in between several option were possible :

- Authors in between consists of those who really contribute to the works (analysis and paper writing) and all participating centers (data of patients included in the study) with names of investigators will be cited in an Appendix at the end of the paper (proposed by Dr. Igor Rudez).
- Authors in between consists of those that contributed data to the specific research question in order how many patients were included. The other active AVIATOR centers will be acknowledged.
- Dr Yang will give models his center uses for examples for the group to review particularly the Irad and Bavcon authorship rules.

Final decision regarding authorship bylaws will be decided at Monaco HVS meeting.

### 4. AVIATOR Kids

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In summary: Concept CRF is ready and very similar to adult CRF. Two page PDF. Experts in the field will review it.

### 5. AVIATOR Medical

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In summary: review by group, it's difficult to get cardiologist involved/working. Idea is to have a parallel database. Need names for experts to review data. Richard Devero?

## 6. Attendees

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