

Registry Meeting Minutes

2013, EACTS Vienna

Members present: Jochen Schäfers, Jolanda Kluin, Hanneke Takkenberg, Jan Vojacek, Emmanuel Lansac, Carlos Porras, Yutaka Okita, Laurent De Kerchove, Gianclaudio Mecozzi.

Agenda

1. Centers

Two centers have applied successfully, others have tried without reaching to register. We need to improve the application procedure. The letter of understanding needs to be sent out again with clear instructions. Mailing list should be complete including all members (for exemple Laurent De Kerchove). Sarah should centralize with Joost the coordination of code distribution. When she receives the letter of understanding she should be able to send directly the access code to the data base. Jolanda manage this with Sarah and Joost.

2. Entering data

- The aviator database is much too slow
- if a special navigator or particular version is best it needs to be precise on the front page of the website
- Demo testing should be deleted.
- It needs to present with better friendly user aspect in order to succeed. Direct access to list of patients after entering the code with the possibility to add a new patient or return to list of patients in one click. The step "subjects" that needs to be closed before re accessing to the list of patients should be deleted.
- 'discharge date' should allow dates anterior to 2013 in order to include retrospectively patients in the database
- grade 0 should be added in the echo table
- Jolanda will contact the Julius center and a meeting will be organized rapidly in Utrecht with the Julius center (Emmanuel Lansac, Hanneke Takkenberg, Jolanda Kluin and Gianclaudio Meccozzi), in order to solve these issues.

3. What is in it for participating centers?

In a recruiting mail we should mention why to participate, how to participate and what benefits can be expected from participation to the registry. It should include easy access to own participant data set, annual summary and comparison with full database results as well as safe database environment.

Julius center needs to detail precisely what can be offered as it was discussed originally. (meeting with Julius center) (Emmanuel Lansac will prepare a draft letter).

4. Web visibility

We need a recognizable web address for the aviator database, it is still the Julius test address. A link directly from the SHVD aortic valve repair web page to the Aviator database should be created. It should be also accessible from the Julius center webpage.

5. Regarding scientific committee

This point is not yet an issue. It is of first importance to solve technical issues related to the database. Once the database will have started up, and multiple centers are actively including patients, a scientific committee will be elected.

6. Regarding the Medical Registry

We should first focus on technical issues on surgical database, then on the Medical registry. A taskforce should be designated to create the medical registry forms.

7. Finances

UMC Utrecht has invested 30.000 euros to start the database and ensure 5-10 years running of the database. This money came out of overhead of other projects from Jolanda Kluin.

Potential investors: we need a business plan and a bank account. Hanneke Takkenberg will ask SHVD en PRRI to facilitate the bank account. The business plan needs to be developed. Jolanda Kluin will make a draft for a business plan. Gianclaudio Meccozzi will draft a letter to industry.

Hanneke will talk to Arturo Evangelista, who is working on European grants, or find other people with experience in writing European grants or Leducq foundation for internationally collaborative research. Look for W.H.O funding? Alternative is funding by industry.

Timeline: is defined within the next few weeks. The letters should be directed at high level people within the companies, but try to find out within the companies who would be the best appropriate. Ask finances from SHVD and others scientific societies (EACTS, ESC, AHA, ACC, STS, AATS, ASCVTS).