

Registry Meeting Minutes

2014, EACTS Milan

Members present: HJ Schäfers, JJM Takkenberg, J Kluin, Frederiek de Heer, Jan Vojacek, Pavel Zacek, Laurent De Kerchove, Diana Aicher, Isabelle Di Centa, Jarda Hlublocky, Maciej Matuszewski, Cristiano Amarelli, Emmanuel Lansac.

Agenda

The aortic valve repair Group had a very productive meeting. It started with 2 very good news. The first one is that Frederiek Heer for UMC Utrecht who is already deeply involved on the registry will be officially 2 days full time working on the aviator data base which will be also the subject of her PhD. The second one is the allocation of a 100 000 Euros grant from the Association of operated patients ADETEC promoting research in Cardiac surgery.

1. Financial issues

- Grant from Adetec of 100 000 Euros has been allocated for
 - finalization of Aviator surgical data base
 - fusion from homemade data base into aviator
 - Aviator medical registry
- Why do we need more money in the future:
 - Maintenance of the database
 - Annual monitoring in each center
- Financial source :
 - Grant : information was given by Hanneke Takkenberg
 - European grant : None of the thematic fits with our subject
 - Leduc foundation : worthwhile to try
 - Maciej Matuszewski offer his help. Any other help is more than welcome
 - Industry :
 - Needs to be involved, Up dated information needed from Gianclaudio Meccozi

2. Aviator surgical data base issues

- Registry form :

Reduction of the number of items was achieved after a very productive and long meeting. The final version of registry form are now entirely oriented towards publication according a guidelines for reporting valve related events.

- Aortic Valve Repair Group raised questions on whether the Julius Center is able to serve as a competitive and flexible technical database support organization that is service-oriented rather than a scientific-oriented institute. We need to provide an Aviator database according to the needs of the Group and standards of the Heart Valve Society. It is currently ask to the Julius Center to present a detailed service package that meets our demands and includes a time schedule and estimation of costs. Others data base provider options are also welcome in order to choose the best one. Our request are as follows:
- Improvement of the friendliness:
 - Visibility of the patient name only by the Investigator site
 - Speed of the system
 - Within the same "topic", for example within the Operative form, continuous view of items (with the mouse) without having to switch to a next page
 - Summary of all positive items for each patients (clinical tool)
- Extraction issues:
 - Complete extraction (e.g. echo follow up each time is missing)
 - Possibility to extract data online (SPSS and Excel files)
 - Friendly personal (center) report of the data base online (usable by the surgeon)
- Security of the system : 24/7(or another form of service) in case of technical problems

3. Aviator medical registry

- Medical working group: G Jondeau, Bernard Iung, Maurice Sarano, Jean Louis Vanoverschelde, Arturo Evangelista,
- Objective: finalization of the medical registry for next shvd in Monaco