

**Meeting of the “Steering Group (SG) Weesgeneesmiddelen/
Medicaments orphelins”** Academy of Medicine, Brussels,
December 18, 2006 10.30 – 12.30

Present: Marc Bogaert, Erik Tambuyzer, Tim De Kegel, Marc Abramowicz, Vincent Bours, Claude Sterckx, François Sumkay, Vera De Groof, Lut De Baere, Thierry Velu, François Eyskens, Ilse Weeghmans, Jean-Jacques Cassiman

Apologies: Andre Lhoir,

Absent: Yolande Avontroodt, Leo Neels

1. Debriefing of the Symposium of December 7:
 - ✓ About 1/3 of the registered participants did not show up. Maybe a registration fee of 20€ would help preventing this next time.
 - ✓ Few politicians and little reaction in the press.
 - ✓ Most people, medical and others do not know what Orphan diseases and drugs are
 - ✓ Some members found the debate a bit short, while interesting.
 - ✓ Some companies have not yet paid their sponsoring. **TDK** to check

2. The report:
 - ✓ The Flemish text is available. Corrections can be sent to Peter Raeymaekers, with copy to all members, by Wednesday evening at the latest. The French version should be ready this WE. The same procedure will be followed for corrections.
 - ✓ An executive summary, starting with some positive realizations in Belgium, followed by what remains to be done, will be drafted by Peter. This summary will serve as press release.
 - ✓ The most important issues from the discussion will be added.
 - ✓ An insert explaining what orphan drugs are will be added.
 - ✓ The press release and text will be sent to the press, politicians, ministry of health, learned societies, and to the participants of the symposium. Members of the SG should present the conclusions at their respective society meetings. Please provide addresses of societies to Iris. **ALL**
 - ✓ The text will not be printed but sent as print out and will be placed on the website (see further).

3. Website:
 - ✓ A website needs to be developed. The domain name will be blocked: weesziekten.be and maladiesrares.be giving access to the same site. **JJC**
 - ✓ A website developer will be contacted asap. **JJC**
 - ✓ All info of the Symposium, report, pp presentations, pictures will be placed on the web. **JJC**
 - ✓ The website developer will be asked to make a proposal for logo. **JJC**
 - ✓ Pharma.be will also have a special section on orphan drugs on their website.

4. The future:
 - ✓ Three main objectives for the activities of the Steering Group were identified:

- 1) Information gathering about who does what in Belgium for rare diseases; include the clinical centers in this activity; make information available to lay and expert people, media, politicians, health authorities etc. The French and Dutch example will be checked.
- 2) Draft a project about rare diseases management in Belgium based on the French and Dutch experience
- 3) Elaborate a European dimension; orphan drugs as a pilot project for the future of the health insurance.

To realize these objectives the following practical decisions were taken:

- 1) Create two ad hoc working groups to prepare the discussion for next meeting: a group on issue 2, the project, composed of **F. Eyskens (coordinator), L. De Baere, T De kegel, I. Weeghmans, C. Sterckx**; a group on the EU dimension: **A. Lhoir (coordinator), F. Sumkay, E. Tambuyzer, V. De Groof**. De two groups will prepare an outline for next meeting.
- 2) Unless the proposal of **Y. Avontroodt** is voted by the parliament soon, the creation of a Foundation under Belgian law should be examined. **JJC**
- 3) Financial support for these activities, requiring secretarial and scientific support, can possibly be obtained from different sources such as The KBS-FRB, Mutualités, industry... possibilities to be investigated by the members.

5. Varia: A letter should be written to minister De Motte with the report of the symposium and a request to send a representative to our next meeting. **JJC**
A representative of the hospital pharmacists will be asked to join the group. **JJC**

**The next meeting will be held on Monday February 5,
10.30 – 13hrs at the Academy**