

Action points of the Informal meeting of the “Stuurgroep Weesgeneesmiddelen”
Brussels, June 1 2006 10.30 – 13.30

Present: Yolande Avontroodt, Andre Lhoir, François Eyskens , Marc Bogaert, Erik Tambuyzer, Mario Reget, Marc Abramowicz, Vincent Bours, Claude Sterckx, Thierry Velu, Jean-Jacques Cassiman

Apologies: Leo Neels

1. The three new members were welcomed after a general introduction by each member.
2. The following suggestions were made for further membership:
 - a) A representative of the intermutualistic college: the president Marc Justaert to be contacted to ask for a representative of the mutualités, not of the patients. **JJ**
 - b) For industry: Erik en Leo should agree on how to respond to individual companies who apply for membership
 - c) The Vlaams platform will be contacted to find an additional representative of the patients.
3. A tentative program of the symposium of December 7 was discussed (see attached).
 - a) A letter will be send to Yolande requesting a room in the federal parliament. **JJ**
 - b) **Yolande** will confirm the availability of the room and find out whether sponsoring of the meeting is allowed and whether simultaneous translation can be provided. Then a letter requesting sponsoring can be drafted and send to potentially interested industries.
 - c) **Yolande** will also approach Prinses Astrid to ask for her presence or patronage.
 - d) Once the venue has been confirmed invitations will be send to:
 - Federal and regional Parliamentarians: **Yolande**
 - Industry: **Leo**
 - Geneticists and clinicians, the BSHG : **Marc A**
 - Faculties of medicine and Pharmacy: **JJC** through B. Himpens
 - FNRS – FWO: **Marc A**
 - Artsenkrant – J du médecin –Tijdschrift voor geneeskunde: **JJC**
 - Medical journalist: **Marc B to send coordinates to JJC**
 - e) For the debate, Peter Raymaekers and Karin Rondia will be asked, possibly through the KBS-FRB. They will also be asked to write a summary of the meeting, providing we can pay them. **JJC**
 - f) If sponsoring can be obtained, a professional organizer will be contacted to take care of the mailings and registration of participants. If not???
 - g) The speakers will be asked to provide an abstract (1pg) and their pp presentations before the meeting, so that they can be handed out to the participants.
 - h) A lunch for speakers and organizers can be organized in the restaurant of the Flemish parliamentarians after the symposium.

**The next meeting will be held on Monday September 25,
10.30 – 14hrs to review the preparations of the symposium.**