

Action points of the Informal meeting of the “Stuurgroep Weesgeneesmiddelen”
Leuven, March 23 2006 10.30 – 12.30

Present: Yolande Avontroodt, Andre L'hoir, Leo Neels, Marc Bogaert, Erik Tambuyzer,
Rik Serpentier, Mario Reget, Marc Abramovicz, Jean-Jacques Cassiman

Guests: Bert leufkens, Sonja Van Weely, Jolanda Huizer

Apologies: François Eyskens

1. Yolanda Avontroodt presented the proposed Resolution on orphan medicines and rare diseases which she is filing with the Chambre of Parliament. The Resolution is foreseeing the creation of a Belgian Steering Group for orphan medicines.
2. B. Leufkens presented the philosophy, the history and the activities of the Dutch Steering Group for Orphan Drugs (see attached slides). We retain that the Dutch group officially started in 2001 and has acquired a very influential position in The Netherlands in relation to the field. The group provides advice on orphan drug issues either upon request or on its own initiative to the Minister and other authorities. The ministry provides 450.000 € per year for 3 full time personnel (2 staff plus a secretary), travel and costs of functioning.
3. Different suggestions were made about the way forward. It was proposed not to concentrate in the beginning on the funding for a Steering Group for Orphan medicines, but to first build awareness and support for the topic. Networking will be important. All stakeholders should be represented in the Steering Committee, and the EU Regulation on Orphan medicines (EC 141/2000) should be used to convince the Belgian parliament to act in favor patients in need of Orphan medicines. Also, a link should be established with similar initiatives at the EU level.
4. All members of the current group confirmed their interest in being a member of the Steering Group. Suggestions for additional members of the Steering Committee: a member of the Intermutualistic college, a few more representatives of clinicians and researchers, and preferably some committed members from the French speaking community.
5. The members of the different political parties represented in the committee on public health should be approached to support the proposed Resolution of Yolande Avontroodt (see attached)
6. A symposium under the high patronage of Prinses Astrid could be planned for the fall of 2006. **JJC** to draft a proposal before the second meeting of this group.

**The next meeting will be held in the parliament in Brussels
on Thursday June 1, 10.30 – 14-30 to prepare the symposium.**