

9th Workshop on Partnering for Rare Disease Therapy Development
Orphan drugs: partnering along the chain and across the borders
Sharing strategies and tools for access to diagnosis and treatment
French Parliament - Assemblée Nationale
Paris, October 16-17, 2008

The European Platform for Patients' Organisations, Science and Industry (EPPOSI) is pleased to announce that its 9th Workshop on Partnering for Rare Disease Therapy Development will be hosted by the French Parliament (Assemblée Nationale) on Thursday 16 – Friday 17 October 2008 in Paris, with the support of the Parliament's Working Group on Rare Diseases (Groupe Parlementaire d'Etudes sur les Maladies Orphelines). The event will be co-chaired by Mr. Yann Le Cam (EURORDIS, representing Patients), Dr. Kerstin Westermark (COMP-EMEA, representing Science), Mrs. Wills Hughes-Wilson (Genzyme Europe, representing Industry)

The timing of this year's workshop is important, since during the French Presidency, key policy conversations regarding orphan drugs and rare diseases will happen at EU and national level. Decisions taken in this period will affect Europe's ability to treat rare disease patients for many years to come.

Key themes to be covered by this year's workshop include:

- **Improving diagnosis and access to care**
How to improve early diagnosis? How to optimize access to up-to-date standard of care?
- **Improving Access to Orphan Drugs**
How to assess clinical added value of orphan medicinal products? How should reimbursement policies ensure access to treatment?
- **Awareness and solidarity**
Will national plans deliver equitable access and social justice for rare diseases patients and their families?

The aim of this Workshop is to provide a platform for discussion on current subjects in the field for consensus building, and on the cultivation of partnerships between patients, academia, and industry as well as European and member state authorities, so as to convert policy issues and scientific developments into therapies for rare diseases.

All Workshop sessions will feature high-level speakers and experts, representing the different EPPOSI stakeholders, and will allow ample time for debate and discussion with the audience.

For any further information about this EPPOSI event, please email info@epposi.org

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