



PRESS RELEASE

Fourth EPPOSI Workshop on Partnering for Rare Disease Therapy Development Orphan Therapies : from clinical development to equitable access

The Hague, 13-14 November 2003

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Paying for the treatments of rare disorders demands a new approach. "Having a rare disease is not a matter of choice" said Alistair Kent, board member of EPPOSI and Director of the Genetic Interest Group (UK) at the 4th EPPOSI conference on rare diseases. "Life is more difficult, access to treatments is an uphill struggle and we get no kudos for having something that few have heard about", he added.

The two day conference at The Hague was opened by Minister Hoogervorst, Dutch Ministry of Health, Wealth and Sport. It was attended by representatives of patient groups, academia, clinical medicines, industry and the regulatory and pricing agencies laid out an agenda whereby the hopes of patients, for a cure, could be met.

Yan Le Cam, CEO of EURORDIS, the European patient organisation for patients with rare disorders called on both the European Commission and European Parliament to take action to ensure that European research initiatives take account of the impact of rare diseases on 30 million affected European families. While the cost of these medicines may be high the benefits are substantial. This in terms of the relief from suffering that high quality medicines bring to those affected, and the potential gain to the health care system that accrues from the application of cutting edge biomedical research.

However, simply looking at the price is not enough. Health care systems across the EU are under pressure. Rising consumer and patient expectations, the costs of new medicines and the need to raise health professional's awareness of early diagnosis and treatment possibilities all need to be addressed. European states must also find a way to examine the benefits of treatment to families who would otherwise continue to suffer from serious diseases. Member States must become more responsive to issues related to equity in the health care systems that have to care for, and support them.

"We are in a steep learning curve" stated Professor Bert Leufkens summing up the conference. "We have to find a way of turning good science into the treatments and services that will benefit families living with the consequences of rare and currently untreatable diseases. This is a target that we need to achieve if we are to respond to the legitimate aims and expectations of patients and their families".

EPPOSI's Mission: a European partnership of patients' organisations, science and industry working on health care policies towards treatment and prevention of serious diseases.

For more information, please contact the EPPOSI Secretariat:

Telephone: +32 2 761 66 77 - E-mail: info@epposi.org - www.epposi.org