



Approximately 30 Million EU Citizens Suffer from a “Rare Disease”

- **More than 6000 rare diseases affect five percent of the population**
- **EU programme “e-rare” is to integrate the fragmented landscape of research**
- **Number of countries participating in e-rare will grow considerably in 2010**

Rare diseases are surprisingly frequent in occurrence. Altogether, more than 25 million people suffer from one of the 6000 to 8000 known “rare diseases” in the countries of the European Union. Viewed as a whole, they affect between five and eight percent of the population and thereby reach the level of a widespread disease. In the scope of the European Health Forum Gastein (EHFG), the most important health policy conference for experts and decision-makers in the European Union, experts demanded that the fight against rare diseases be granted higher priority.

The programme “e-rare” initiated and financed by the EU Commission occupies a key position in this regard. Its aim is the intensive integration of still strongly fragmented research activities: the advantages of international cooperation in rare diseases are greater than in every other medical area. “In practice, the low number of cases often makes high-quality research in individual countries impossible, explains Sophie Koutouzov, secretary general of the French Institute of Rare Diseases Research (GIS) and coordinator of the project; “e-rare enables an intensive exchange of knowledge and cross-border cooperation on a common theme and ensures the availability of sufficient amounts of clinical and genetic material and the development of relevant databases for the purposes of research,” Koutouzov explains. “With it we are creating the conditions for greater efficiency and better research results.”

Research institutions from eight countries (Germany, France, Italy, Spain, Netherlands, Belgium, Turkey and Israel) are currently participating in e-rare. In 2010 when the extension of the programme by another four years is on the agenda (note: the extension is applied for in the scope of a new project application, but approval only occurs after a decision-making process by experts and policymakers and is not yet guaranteed) at least three additional countries will join (Greece, Austria, Portugal).

Smaller countries with naturally even smaller numbers of patients, like the three probable new e-rare member countries, can especially benefit from cross-border cooperation. Recently an initiative was launched by the Austrian Ministry of Health for cooperation between several countries in Central Europe. “We hope we can also promote and accelerate the desired European cooperation,” explains Prof. Robert Schlögel, section head in the Austrian Ministry of Health. The regional initiative and Europe-wide programme do not compete with one another, but complement each other instead.



Rare diseases:

By definition, rare diseases affect a maximum of one half of one tenth of a percent of the population. Viewed on a global basis, the number of people affected throughout the EU by one of the 6000 to 8000 rare diseases spans from several dozen to several hundred thousand. A majority concern serious chronic illnesses, most of them with genetic causes.

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