



Central European Countries Plan Extensive Cooperation for Rare Diseases

- **Participants from six countries at meeting of experts in Salzburg**
- **Successful initiative of the EHFG and Austrian Ministry of Health**
- **Cross-border centres of expertise are to enable an improved exchange of information and additional therapies**

Leading experts from six Central European countries (Germany, Italy, Austria, Slovenia, Czech Republic, Hungary) discussed possibilities for a comprehensive improvement of cross-border cooperation in the treatment of rare diseases at an informal meeting in Salzburg. The “Informal Meeting on Rare Diseases” took place on 24 and 25 August as a follow-up to last year’s meeting of numerous EU health ministers in Salzburg. The possibility for the practical implementation of the close cooperation sought in this specialised area of medicine was discussed at the expert level. Both the meeting of ministers and the meeting of experts took place at the initiative of the Austrian Ministry of Health and the European Health Forum Gastein, the most important health policy event in the EU (30 September to 2 October 2009 in Bad Hofgastein).

“In hardly any other area does an international network promise such enormous improvements as with rare diseases”, EHFG President Günther Leiner explains. “The small number of cases in each country results in a frequent lack of consideration of rare diseases in the allocation of research funding and that physicians lack experience in diagnosis and therapy. For this reason medical progress is slower in this area than it actually should be and there is a relatively high risk that a rare disease is not discovered until it is too late and cannot be optimally treated.

Robert Schlögel, Director General in the Austrian Ministry of Health, emphasises the commitment of the Ministry: “Rare diseases always affect only a few people, yet they, too, are entitled to the best possible treatment for their afflictions, and with close international cooperation we can decisively improve the conditions for this.”

These problems are to be responded to with internationally oriented centres of expertise. The experts’ plan specifies the following points:

- The participating Central European countries agree to cross-border cooperation in research and care in the area of rare diseases.
- The countries develop a coordinated profile of requirements stipulating the criteria that have to be met by the future centres of expertise.
- In each of the participating countries centres of expertise for certain diseases or disease groups will be identified and established. Existing specialised hospitals and institutes are to be involved in order to utilise their knowledge as efficiently as possible.
- Networking the centres of expertise is meant specifically to facilitate a more intense transfer of know-how; patients are to be provided with simple and rapid options for taking advantage of the services in centres of expertise abroad, and the development of a patient database is to create a better basis for studies and research projects.
- In every country a coordination office is to be established to which physicians and patients can turn.

Cooperation is open for additional partners. “Smaller countries have especially big advantages resulting from cooperation in the area of cross-border diseases, thus in this regard we intend to play a vanguard role,” Ministry of Health Director General Schlögel says. “Our goal is for our initiative to be seized by as many European countries as possible and for that reason cooperation for every country is open.”



The results of the meeting of experts will be presented to the health authorities of the countries represented. The aim is to be able to open up the first centre of expertise beginning in 2010.

photolink: <http://www.ehfg.org/gallery/2009/treffen-sc-august-salzburg/EHFG24080976.jpg.php>

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