

Press release concerning material being considered by the Czech Government

"National Strategy for rare diseases 2010-2020"

Rare diseases are complex, mainly genetic (or congenital) diseases with low incidence among the population which have an impact on the patient's quality of life and social integration and can even be life-threatening. Although the individual diseases are rare, taken together their morbidity and mortality rate in the EU is as high as 8 %. In most rare diseases there is no effective causal treatment, yet it is possible to improve the person's quality of life and life expectancy by means of suitable care.

Among current shortcomings in the field of rare diseases are insufficient identification of rare diseases in the International Classification of Diseases, deficiencies in their timely diagnosis and treatment, imbalance and insufficient quality of services provided, inadequate research, shortcomings in data collection and lack of effective care for patients with rare diseases.

In the Czech Republic there is as yet no unified approach to rare diseases. The proposed National Strategy sums up the issue of rare diseases from the EU's and the Czech Republic's point of view and proposes major targets and measures for improving the situation in the Czech Republic. These targets and measures will be specified in more detail in the National Action Plan, which establishes sub-tasks, instruments, responsibilities, dates and indicators for fulfilling individual tasks.

The National Strategy is intended to ensure the effective diagnosis and treatment of rare diseases, ensure that all patients with rare diseases have access to the indicated, high-quality health care, and ensure their subsequent social integration on the basis of equal treatment and solidarity.

The purpose of the National Strategy is also to make use of expert cooperation with other countries, to enable Czech patients to take part in international clinical studies of new medicines, including treatment abroad in strictly identified cases when it is not possible to obtain adequate specialised care in the Czech Republic.

[On 11 November 2008](#), the European Commission adopted the "Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions on Rare Diseases: Europe's challenges" and, within that communication, the Council Recommendation on an action in the field of rare diseases, which was adopted by the Council on 9 June 2009 during the Czech Republic's Presidency of the EU Council.

