CEE GN Central & Eastern European Genetic Network

Working together for a voice in research & health policies and benefiting from genetics, genomics & biotechnology

DECLARATION

We, the representatives of parent and patient organisations for genetic and rare diseases from 11 Central and Eastern European (CEE) countries (Poland, Bulgaria, Czech Republic, Turkey, Croatia, Slovenia, Bosnia, Romania, Russia, Slovakia, Estonia), **assembled in Prague on 24 - 25 January 2009** to discuss the common problems and needs of people with genetic and rare conditions in this region, as well as to establish the plan and programs needed to address those needs.

We have founded the **Central and Eastern European Genetic Network (CEEGN)** with aim to raise awareness and promote the need for early diagnosis and treatment of genetic diseases, medical genetic services, research and development for the causes and cures of these diseases, education of public, patients and science, in CEE countries in order to alleviate the burden of genetic conditions for individuals, families and communities, with the **ultimate goal to improve the quality of life** of patients and their families in those countries.

The declaration is in support of the **Patient-Centered Healthcare** of the International Alliance of Patients' Organizations. We agreed that there is a **need for stronger organization in local genetic networks** to ensure adequate information in local languages to parents and patients, healthcare professionals, media and politicians; to **influence the healthcare policy**; to encourage **research and development** in genetic field. We agreed that there is a need for the CEE regional genetic networks to ensure that news and information reach patients and parents, health professionals, media and politicians in CEE countries which will support their effective involvement in European genetic projects, their education, and encourage sharing of needs and practices.

We state, that there is:

- a need for more transparency and less discrimination in reimbursement procedures of medicinal costs;
- a need for more timely and reliable information on genetic/rare diseases in the native languages;
- a gap between the first symptom, diagnosis and treatment across Europe;
- relevance of research and treatment outcomes for patients

We declare that, CEEGN:

- will work towards enlarging the number of members;
- will support building and strengthening of national genetic networks as well as national information centres;
- will seek partnership with expert organisations from science and from industry;
- will work on several priority projects: Preconception care and folic acid prevention in CEE countries, Neonatal screening, Improving genetics awareness and information in member countries
- will take part in ongoing European projects and draft its own projects.

We request that:

- all national governments should take into consideration the Communication and proposal for a Council Recommendation on rare and genetic diseases, announced by the European commission on 11 November 2008;
- European national healthcare policies should include robust primary prevention measures and the availability of clinical genetic services to facilitate timely, well informed decision-making on own health and offspring.
- the number of diseases for neonatal screening should be increased in accordance with the current medical scientific and treatment development;

Prof. Grzegorz Wegrzyn
Chairman of CEEGN