

**Resolution
of the First National Conference
"Ukraine and EUROPLAN-2: development of national strategy
for rare diseases till 2020"**

March 27, 2013

Kyiv, Ukraine

Coordinating Committee, that represents the project EUROPLAN-2, the European Organization for Rare Diseases EURORDIS, the All-Ukrainian Council of patients' rights and safety, Kharkiv Charitable Foundation "Children with spinal muscular atrophy" and participants:

After hearing the reports of international experts, representatives of patient organizations, public authorities, the Academy of Medical Sciences of Ukraine and the pharmaceutical industry;

In consideration of:

- Legislation of Ukraine;
- Ukraine's international legal obligations;
- Proposals of the Conference's participants;

Taking into account Council recommendations on an action in the field of rare diseases and the Communication from the Commission to the European Parliament on rare diseases;

Having EUROPLAN recommendations for the development of National Plans and Strategies for rare diseases and implementation it for a development of the national program for rare diseases;

Recognizing:

- of Ukraine commitments to the Council of Europe before the end of 2013 to develop and approve the National Plan of Action on Patients' Safety;
- an actual stage of developing of the National Plan of Action on Patients' Safety in Ukraine;
- necessity to expand the National Plan of Action on Patients' Safety of part reflecting measures that address the needs of patients with rare diseases and the need to create a state program for rare diseases;

Decided:

1. Create at the All-Ukrainian Council of patients' rights and safety expert group with representatives of all stakeholders: public authorities, academia, international organizations and patient organizations, businesses, and independent experts for the following tasks:

1.1. Conduct a comprehensive analysis of the situation with the availability of treatment and the needs of patients with rare diseases at a maximum level of knowledge.

1.2. Amend the National Action Plan on patient safety (paragraph 1.4.1., CoE Action Plan for Ukraine for 2011-2014 "Partnership for Reform") action plan for rare diseases which has become the basis for the creation of relevant national policies.

2. Present developments of the expert group at the First National Congress of the rare disease in late 2013.

3. The Resolution to direct all interested parties and make efforts to ensure their participation in the implementation of the Resolution.

Coordinating Committee of the Conference

**Vitaliy Matyushenko
Viktor Serdyuk
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