



# LIETUVOS RESPUBLIKOS SVEIKATOS APSAUGOS MINISTERIJA

## MINISTRY OF HEALTH OF THE REPUBLIC OF LITHUANIA

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Re: 03-02-2017 No. -

### **SUBJECT: TREATMENT OF PATIENTS WITH RARE DISEASES IN SMALL EU MEMBER STATES**

Dear Dr Androulla Eleftheriou,

With reference to your letter of 3 February 2017 we would like to inform you that Lithuania has coordinating centres for children and adults' rare diseases and competence-reference centres for various rare diseases. It is foreseen that during the 3<sup>rd</sup> European Reference Networks Conference on 9-10 March 2017 in Vilnius the members of European Reference Networks, approved by the European Commission, will be announced. Certificates confirming this membership will be given to:

1. Vilnius University Hospital Santariškių Klinikos (in areas of rare cancers (pediatric), rare haematological diseases, rare hereditary metabolic diseases, rare malformations and developmental anomalies and rare intellectual disabilities, rare neurological diseases, rare renal diseases, pediatric transplantation);
2. Hospital of Lithuanian University of Health Sciences Kauno Klinikos (in areas of rare cancers (adults), rare endocrine conditions, rare eye diseases, rare skin disorders).

Henceforth the specialists of these hospitals will share comprehensive information and databases with European colleagues and it will enable them to provide better diagnostic and treatment services for the patients.

In Lithuania the National Plan for Rare Diseases was approved on 18 October 2012 and now is being implemented. The National Rare Diseases Coordination Committee was formed including delegated experts from university hospitals, universities, non-governmental organisations and state institutions to oversee the implementation of the plan. The plan aims to establish a common approach on rare diseases, to raise public awareness, and to ensure prevention, early diagnosis, efficient treatment, improvement of quality of life and social support for patients suffering from rare diseases. It also includes the optimisation of health care services and rational allocation of available resources, as well as measures for improving the assessment of medicinal products and medical devices. The National Plan for Rare Diseases has its list of measures for the period of 2013-2017, which is expected to be reviewed and developed for the period of 2018-2022.

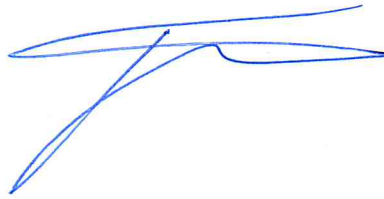
Lithuanian specialists are in collaboration with other European Reference Centres and research institutes by participating at national/international multicentre clinical studies and international rare diseases registries. We have availability of specialists (nephrologists, cardiologists and others) 24

hours a day, 7 days a week for patients with rare diseases. There are policies and procedures for managing cross border patients within the European Reference Networks' area of expertise. Lithuanian specialists use information and communication technologies, such as health tools, telemedicine/tele-expertise.

Also in Lithuania the Association of Children's Rare Diseases uniting patients and their parents was established and successfully develops its activities.

Sincerely,

Minister of Health



Aurelijus Veryga

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Lithuania  
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