



REPUBLIC OF ESTONIA  
MINISTRY OF SOCIAL AFFAIRS

Androulla Eleftheriou		
The Cyprus Alliance for Rare Disorders	03.02.2017	
31 Ifigenias		
2006 Strovolos	14.03.2017	Our ref. 1.4-2/667-2
Cyprus		

### Rare diseases in Estonia

Dear Dr Androulla Eleftheriou

Thank you for the letter about treatment of patients with rare diseases in small EU Member States. Your information regarding the situation in Cyprus and Cyprus Alliance for Rare Disorders (CARD) has been most useful. Hereby we try to answer your questions.

Estonia has worked out a National Rare Diseases Development Plan in 2014. All necessary activities in the field of rare diseases has been planned in the action plans of our National Health Plan 2009-2020, the process of which has been synchronised with the planning process of our state budget.

You can find our National Health Plan 2009 – 2020 in our web site (in English): [http://www.sm.ee/sites/default/files/content-editors/eesmargid\\_ja\\_tegevused/Tervis/Aruanded/rta\\_2009-2020\\_2012\\_eng.pdf](http://www.sm.ee/sites/default/files/content-editors/eesmargid_ja_tegevused/Tervis/Aruanded/rta_2009-2020_2012_eng.pdf)  
Also Estonian Rare Diseases Development Plan (in English) is findable in the web: [http://www.sm.ee/sites/default/files/content-editors/eesmargid\\_ja\\_tegevused/Tervis/Tervishoiususteem/harvikhaiguste\\_arengukava\\_en.pdf](http://www.sm.ee/sites/default/files/content-editors/eesmargid_ja_tegevused/Tervis/Tervishoiususteem/harvikhaiguste_arengukava_en.pdf)

Our main centre of excellence in the field of rare diseases is Tartu University Hospital (TUH). TUH is also designated as a national centre of expertise for the participation in the European Reference Networks (ERN) ENDO-ERN and ERN-BOND.

In the field of rare eye diseases we designated East-Tallinn Central Hospital as a national centre of expertise for the participation in the ERN-EYE. The Eye Clinic of East-Tallinn Central Hospital acts as a centre of expertise for Baltic States in the field of some rare ophthalmologic diseases (eye tumours etc). A number of patients from Latvia and Lithuania are sent to this hospital for the diagnostics and treatment every year.

We expect a development of more systematic and coordinated cooperation in the field of rare diseases through the ERN-s in the near future.

Our doctors send every year some patients to other countries for the diagnostics and treatment of rare conditions if the services are not available in Estonia. Our Health Insurance Act provides an opportunity to receive planned treatment all over the world, in practice, however, the doctors treating the patient refer their patients primarily to EU member states. For example in 2015, patients went to receive planned treatment mostly in Germany (29 people), in Finland (31 people) and in Sweden (10 people). The most genetic research was conducted in Germany (58 times), Denmark (48 times) Netherlands (22 times) and Belgium (21 times).

In some cases, the Estonian Health Insurance Fund exceptionally compensates for medicinal

products also on patient's individual request. Such an arrangement is applied mostly in cases where in Estonia there is no marketing authorization for the medicinal products needed for the patient and used on an outpatient basis, and, therefore, the medicinal products cannot be included in the pharmaceuticals list of the Health Insurance Fund. Compensation by way of exception allows the pharmaceuticals made available also in the case of a number of rare diseases. In 2015, 2436 persons received compensation by way of exception totals 1.1 million euros.

We have some specialised health care professionals in our centres of expertise and in case of need they use also a help of specialists from other countries for diagnostics and treatment. We also ask sometimes experts from abroad to train our health professionals and send our specialists for the training to other countries.

We hope this information prove useful for you. Please do not hesitate to ask any additional information if needed.

We also apologise for the slight delay of the answer.

Yours sincerely



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