

European Integration, Small States and Health - SMSHealth.eu

Workshop: Rare diseases policies in small states
30th May 2018

National Museum of Iceland
Suðurgata 41, Reykjavík

8:30 – 9:00 **Welcome coffee / registration**

9:00 – 9:30 **Opening session**

Sigurbjörg Sigurgeirsdóttir, coordinator of SMSHealth.eu project in Iceland

Opening Address, Svandís Svavarsdóttir, Minister of Health

9:30 – 9:40 **Rare diseases in Iceland**

Þór G. Þórarinnsson, specialist from the Ministry of Welfare

9:40 – 10:00 **Preliminary results from interviews on public policy-making regarding rare diseases in the participating countries**

Sigurbjörg Sigurgeirsdóttir, Coordinator of SMSHealth.eu project in Iceland

10:00 – 10:20 **Representative from Eurordis (TBC)**

10:20 – 10:50: **Questions and discussion**

10:50 – 11:10 Coffee break

11:10– 11:30 **SMSHealth.eu project findings**

Natasha Azzopardi Muscat, Department of Health Services
Management, University of Malta

11:30 – 12:40 **Experiences of Malta and Slovenia on rare diseases policies**

Dr. Neville Calleja, Director, Department for Policy in Health, Ministry for Health, Malta
Prof. Dr. Borut Peterlin, Clinical Institute of Medical Genetics, University Medical Center Ljubljana

12:40 – 13:30 **Lunch**

13:30 – 14:30: **Experiences of Estonia and Iceland on rare diseases policies**

Dr. Vallo Tillmann, MD, PhD Professor of Pediatrics, Director and Chairman, Tartu University, Childrens Hospital.

Dr. Ingólfur Einarsson, MD, MRCPCH, pediatrician and Head of Division at the State Diagnostic and Counselling Centre

14:30 – 15:15 **Interactive discussion**

15:15 – 15:30 **Summary of the workshop**

Sigurbjörg Sigurgeirsdóttir, coordinator of SMSHealth.eu project in Iceland
Timo Clemens, Department of International Health – Maastricht

15:30 – 16:00 Coffee break

16:00 – 17:30 Technical Project Meeting

19:00 Dinner