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AGENDA

RARE DISEASES REGISTRIES PROJECTS' KICK-OFF MEETING

17 APRIL 2018

HTC Building - Room: 02/280

11, Rue E. Ruppert, L-2557 Luxembourg

09:00-09:15

Opening

09:15-10:00

Projects monitoring and reporting requirements. Q&A – Hristina Mileva, Klara Kasnyik,
CHAFEA

10:00-10:30

Using CPMS with Disease Registries. Q&A – Ruth Ni Bhraonain, DG SANTE.A4

10:30-11:00

European Rare Disease Registry Infrastructure (ERDRI) – part of the EU RD Platform.

Q&A - Simona Martin, JRC

Project coordinators presentations (in alphabetical order)

11:00-11:30 ERK-REG: Core Registry for Demographics and Treatment Monitoring of
Rare Kidney Diseases

11:30-12:00 Coffee break

12:00-12:20 EuRRECa – European Registries For Rare Endocrine Conditions.

12:20-12:50 ERN-PAEDCAN Partner: Paediatric Rare Tumours Network - European
Registry — PARTNER

12:50-13:20 RD REGISTRY DATA WAREHOUSE — REGISTRY
WAREHOUSE

13:20-13:40 U-IMD: Unified Registry for Inherited Metabolic Disorders

13:40-14:00 Q&A

14:00 Closure of the meeting

14:30 – 16:30 (or later)

Afternoon session for ERK-REG and PARTNER (HTC rooms 01/175 and 02/280)