

08.45 Welcome address

Session I

Objectives and planned activities of EPIRARE

Chairs: **Domenica Taruscio, Luciano Vittozzi**

9.00 Introduction and actions of the EU Commission on rare diseases
Antoni Montserrat

9.15 General presentation of the EPIRARE project
Domenica Taruscio

9.30 Legal basis
Tobias Schulte

9.45 Policy scenarios, governance and long-term sustainability
Fabrizia Bignami

10.00 Common data set
Fabrizio Bianchi

10.15 Data quality, validation and data sources integration
Manuel Posada, Manuel Hens

10.30 Current needs of existing registries: Questionnaire
Sabina Gainotti

10.45 *Question Time*

11.00 *Coffee break*

11.30 *General Discussion*

Session II

Experiences of existing registries (lessons learned: difficulties, opportunities, weaknesses, strengths) - Part I

Chairs: **Bruno Dallapiccola, Edmund Jessop**

12.00 Patient driven registry
Christine Lavery

12.20 Treat-NMD
Hanns Lochmuller

12.40 Creutzfeldt-Jakob
Maurizio Pocchiari, Anna Ladogana

13.00 *Lunch*

Session III

Experiences of existing registries (lessons learned: difficulties, opportunities, weaknesses, strengths) - Part II

Chairs: **Edmund Jessop, Rumen Stefanov**

14.00 From the cystic fibrosis to a Generic Rare Diseases Registry
Anil Mehta

14.20 The Italian National Registry of Rare Diseases
Yllka Kodra, Domenica Taruscio

14.40 Rare Tumors
Gemma Gatta

14.50 *Discussion*

15.10 *Coffee break*

Round Table

Improvements and implementation strategies of the project objectives and activities

Chairs: **Antoni Montserrat, Luciano Vittozzi**

Fabrizia Bignami, Maurizio Clementi, Wills Hughes-Wilson, Jansen Herwig, Paola Facchin, Sandor Janos, Monica Pace, Angela Brand, Ingeborg Barisic, Fabrizio Bianchi, Elena Nicod, Edmond Jessop

17.30 *General discussion with all participants*

18.00 *Conclusions of day I*

09.00 Welcome address

Summary of day I

Luciano Vittozzi

9.30 Indications for the Working Groups
Domenica Taruscio

9.45 – 13.00

Parallel sessions

3 Working Groups (WG) will discuss in parallel all sections of the Questionnaire on current and future needs of the existing registries. Discussion will be facilitated by a WG leader and a rapporteur.

Which information has to be collected from the existing registries to devise a useful, feasible, attractive platform while allowing freedom to participating registries?

11.00 *Coffee break*

Working Groups:

A) WG Leader: Fabrizio Bianchi; Rapporteur: Sabina Gainotti

B) WG Leader: Manuel Hens; Rapporteur: Tobias Schulte

C) WG Leader: Luciano Vittozzi; Rapporteur: Fabrizia Bignami

13.00 *Lunch*

Plenary session on the Questionnaire

WG Rapporteurs will summarize the main outcomes of each WG (20 minutes each)

Chairs: **Karaman Pagava, Edmond Jessop**

15.00 *Conclusions of the open part of the Meeting*

SESSION OPEN ONLY TO EPIRARE ASSOCIATED PARTNERS

15.40 *Dissemination*
Domenica Taruscio

15.40 *Evaluation of the project*
Rumen Stefanov

15.50 **Georgios Margetidis**

16.10 *Project management, budget and economic reporting*
Pierpaolo Mincarone, Tania Lopez

17.00 *Closing remarks*

GENERAL INFORMATION

Ingeborg Barisic - EUROCAT Steering Committee, University of Zagreb, (Croatia)
Fabrizio Bianchi - National Council of Research (Italy), EPIRARE WP Leader – WP6
Fabrizia Bignami - EUORDIS (France), EPIRARE WP Leader – WP5
Angela Brand - Leader of PHGEN II, University of Maastricht (Netherlands)
Franco Cavallo - Università di Torino (Italy), EPIRARE WP co-Leader – WP3
Maurizio Clementi - Italian COMP-EMA Member, Università di Padova (Italy)
Bruno Dallapiccola - Ospedale Bambino Gesù, Roma (Italy), EUCERD Member, Orphanet Italia
Paola Facchin – Italian Interregional Group on Rare Diseases, Università di Padova (Italy)
Sabina Gainotti - National Centre for Rare Diseases, Istituto Superiore di Sanità (Italy)
Gemma Gatta – Fondazione IRCCS, Istituto Nazionale dei Tumori di Milano (Italy), EUCERD Member
Holm Graessner - University of Tübingen (Germany)
Manuel Hens - Istituto de Salud Carlos III (Spain), EPIRARE WP Leader WP7
Jansen Herwig - Institut Scientifique de Santé Publique (Belgium)
Wills Hugues-Wilson -Joint EBE-EuropaBio Task Force on Rare Diseases and Orphan Drugs, EUCERD Member
Sandor Janos – Pécs University, Institute of Applied Health Science (Hungary), EUCERD Member
Edmund Jessop - London Strategic Health Authority (UK)
Yllka Kodra - National Centre for Rare Diseases, Istituto Superiore di Sanità (Italy)
Anna Ladogana - Istituto Superiore di Sanità (Italy)
Christine Lavery - Society for Mucopolysaccharide Diseases (UK)
Hanns Lochmuller – Treat NMD (UK)
Tania Lopez - National Centre for Rare Diseases, Istituto Superiore di Sanità (Italy), EPIRARE Project Manager
Georgios Margetidis –Executive Agency for Health and Consumers
Anil Mehta - University of Dundee (Scotland)
Pierpaolo Mincaroni - EPIRARE Project Manager
Antoni Montserrat – DG SANCO, EU Commission
Elena Nicod – London School of Economics and Political Science (UK)
Monica Pace – Istituto Italiano di Statistica (Italy)
Filippo Palumbo – Ministero della Salute (Italy)
Karaman Pagava -Tbilisi State Medical University (Georgia)
Maurizio Pocchiari - Istituto Superiore di Sanità (Italy)
Manuel Posada - Istituto de Salud Carlos III (Spain), EPIRARE WP Leader WP7
Tobias Schulte - University of Maastricht (Netherlands), EPIRARE WP Leader WP4
Rumen Stefanov - Information Centre for Rare Diseases and Orphan Drugs (Bulgaria)
Domenica Taruscio – National Centre for Rare Diseases, Istituto Superiore di Sanità (Italy), EUCERD Member, EPIRARE Coordinator
Luciano Vittozzi - National Centre for Rare Diseases, Istituto Superiore di Sanità (Italy)

GENERAL INFORMATION

EPIRARE (European Platform for Rare Disease Registries) is a three-year project co-funded by the European Commission within the EU Program of Community Action in the field of Public Health.

EPIRARE is coordinated by the Italian National Centre for Rare Diseases (Istituto Superiore di Sanità) and involves 22 Partners in 13 Countries.

For more information: www.epirare.eu

Venue

Aula Pocchiari – Aula Marotta
Istituto Superiore di Sanità
Viale Regina Elena, 299 – Rome - Italy

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First EPIRARE Meeting
July 11-12, 2011

Istituto Superiore di Sanità (ISS)
Viale Regina Elena, 299 - Rome (Italy)



The project is co-funded by the European Commission within the framework of the EU program of Community Action in the field of Public Health. The project activities will develop from 2011 to 2013.