



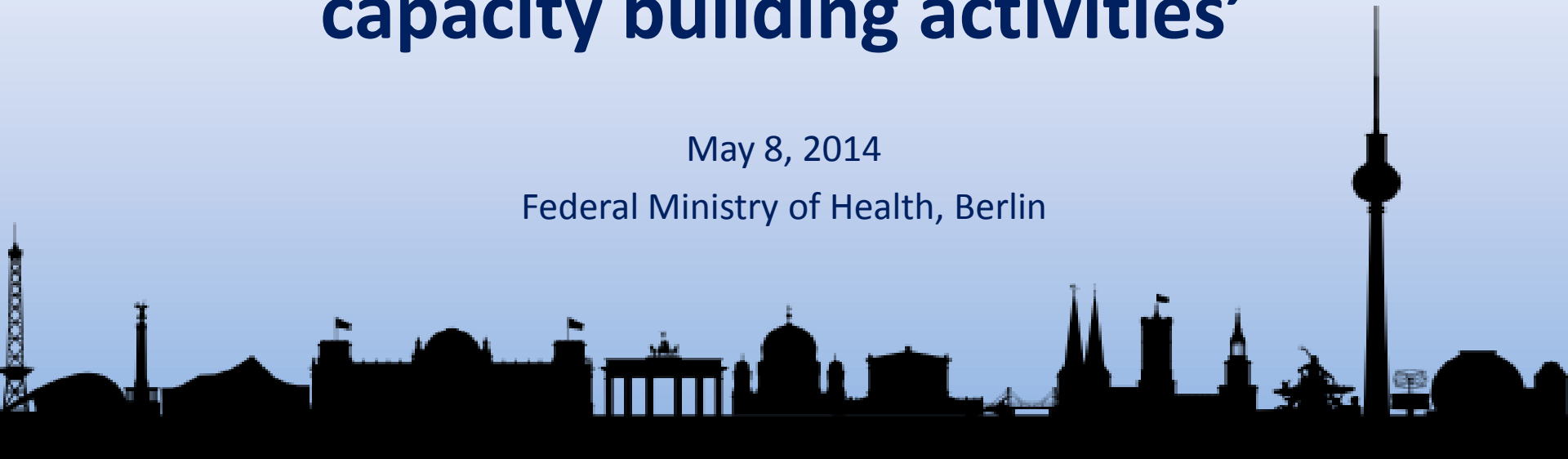
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of the European Union

EUCERD Joint Action Workshop

'EUROPLAN National Plans/Strategies capacity building activities'

May 8, 2014

Federal Ministry of Health, Berlin



OBJECTIVES

- Highlight the implementation status of the National Plans/Strategies for rare diseases across Europe
- Translate Member States (MS) needs into effective actions

TARGET Ministry of Health Representatives of EU Member States

PROGRAMME

13:00 *Light lunch*

14:00 *Welcome*

D. Taruscio (*EUROPLAN Leader*), K. Bushby (*EJA Leader*)

14:10 **Overview of the Rare Disease National Plans/Strategies (NP/S) in Europe**

A. Montserrat Moliner (*European Commission*)

14:25 **Analysis of specific aspects of the Rare Disease NP/S**

R.G. Frazzica, A. Polizzi (*EUROPLAN Coordinating Team*)

14.40 **EUROPLAN National Conferences - Key priorities and way forward**

V. Bottarelli (*EURORDIS*)

14.55 **EUROPLAN Debrief Sessions: identifying strengths and areas for support and development**

A.E. Gentile (*EUROPLAN Coordinating Team*), V. Hedley (*EJA Team*)

15.10 **Use of Core Indicators in Member States: study results**

R.M. Ferrelli, M. De Santis (*EUROPLAN Coordinating Team*)

15.25 **Working Groups with the participation of all MS Representatives**

Translate MS needs into a capacity building operational plan

Facilitators: EUROPLAN Coordinating Team Members

17.25 **Presentation of results and general discussion**

Chairpersons: D. Taruscio (EUROPLAN Leader), V. Bottarelli (EURORDIS), K. Bushby (EJA Leader)

18:00 **End of Workshop**

COUNCIL RECOMMENDATION
of 8 June 2009
on an action in the field of rare diseases
(2009/C 151/02)

... **RECOMMENDS THAT MEMBER STATES:**

Elaborate and adopt a plan or strategy as soon as possible, *preferably by the end of 2013 at the latest*

Take action to integrate current and future initiatives at local, regional and national levels into their plans or strategies for a comprehensive approach

Define a limited number of priority actions within their plans or strategy, with objectivs and follow-up mechanisms

Take note of the development of guidelines and recommendations of the ongoing european project EUROPLAN

www.europlanproiect.eu

AREAS OF THE COUNCIL RECOMMENDATION



7. SUSTAINABILITY

6. EMPOWERMENT OF PATIENT ORGANISATIONS

5. GATHERING THE EXPERTISE ON RARE DISEASES AT EUROPEAN LEVEL

4. CENTRES OF EXPERTISE AND EUROPEAN REFERENCE NETWORKS FOR RARE DISEASES

3. RESEARCH ON RARE DISEASES

2. ADEQUATE DEFINITION, CODIFICATION AND INVENTORING

1. PLANS AND STRATEGIES IN THE FIELD OF RARE DISEASES



Indicators for National Plans

The development and use of indicators is an integral part of planning and designing health and social services for Rare Diseases [\[website\]](#)

Reports and Publications

Visit this section and download all the EUROPLAN documents reports and publications [\[website\]](#)

News

Adopted the first Ukrainian law for Orphan Diseases

15 April 2014

[\[website\]](#)

Published the paper "European Recommendations for Primary Prevention of Congenital Anomalies"

April 2014

[\[website\]](#)

European Commission adopted two Decisions on the establishment of European Reference Networks (ERNs)

March 2014

[\[document\]](#) - [\[website\]](#)

Belgium has approved the National Plan for Rare Diseases

February 2014

Debrief Sessions: Italy



Rome (Italy) 28 January 2014

The "Debrief Session" is a specific activity post-National Conference in order to identify and

Any help?



A instrument for who need support in the process of national planning

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