Flash report

Commission Expert Group on Rare Diseases
6th meeting, 12-13 November 2015

INTRODUCTION

The meeting of 12-13 November 2015 focused on cross-border genetic testing, social services for rare disease patients, progress towards the implementation of European Reference Networks, and information on medicines adaptive pathways to patients.

ADOPTION OF THE RECOMMENDATION ON GENETIC TESTING IN RARE DISEASES

The Expert Group discussed and adopted the Recommendation on cross-border genetic testing, based on the work conducted by the previous Joint Action in this area and the outcomes of three workshops in the field in 2012, 2014 and 2015.

The recommendation underlines the importance of adequate access to genetic testing for Rare Diseases - including cross-border genetic testing - when there is a clear clinical indication. It supports cross-border collaboration between laboratories, clinical genetic centres and research initiatives.

SPECIALISED SOCIAL SERVICES FOR RARE DISEASES

The draft recommendation on social care for rare diseases was presented and discussed. It was decided to develop the document by streamlining and restructuring various parts.

The overall discussion on social services was supported by presentations on EU policy on disability and European initiatives on disability and social exclusion.

EUROPEAN REFERENCE NETWORKS

An update on the progress made to date in the implementation of article 12 of the Directive on patients' rights in cross-border healthcare was given, in particular on the study on services to be provided by the European Reference Networks. Furthermore the group was informed about the outcomes of the Board of Member States on the European Reference Networks meeting of 7 October and the Conference in Lisbon on 8-9 October.

INFORMATION ON MEDICINES ADAPTIVE PATHWAYS TO PATIENTS

The Expert Group was informed about the medicine adaptive pathways approach which is aimed at improving timely access for patients to new medicines.

Various presentations from the perspective of payers, patients and industry were given. In addition the European Medicines Agency presented experiences gained from a pilot project in this field.

JOINT ACTION UPDATES

An update on the new Rare Diseases Joint Action, which was then kicked-off in a meeting on 16 September, was given.

The Joint Action supports the activities of the Orphanet database, the implementation of appropriate coding of rare diseases in Member States using Orpha codes, and support to the work on the development and implementation of policy recommendations by the Expert Group on Rare Diseases.

UPDATE ON ACTIVITIES IN THE MEMBER STATES

The latest advances in the development of national activities in the field of Rare Diseases were presented. The Member States mentioned the state of play concerning centres of expertise and national plans.

NEXT MEETING

The next meeting of the Expert Group will take place on 5-6 April 2016 in Luxembourg.