



## Flash report

### Commission Expert Group on Rare Diseases 7th meeting, 5-6 April 2016

#### INTRODUCTION

The meeting of 5-6 April 2016 focused on social services for rare diseases patients, the European Reference Networks; the European Platform on Rare Diseases Registration and research on rare diseases.

#### ADOPTION OF THE RECOMMENDATIONS TO SUPPORT THE INCORPORATION OF RARE DISEASES INTO SOCIAL SERVICES.

The Expert Group discussed and adopted the Recommendations on social care for rare diseases patients. These recommendations mainly focus on empowering health services' attempt to facilitate integrated care provision to enable them to play the role they need to play in supporting the incorporation of Rare Diseases specificities into mainstream social and support services, within a holistic and person-centred approach and a human rights perspective.

#### *Link to recommendations:*

[http://ec.europa.eu/health/rare\\_diseases/docs/recommendations\\_socialservices\\_policies\\_en.pdf](http://ec.europa.eu/health/rare_diseases/docs/recommendations_socialservices_policies_en.pdf)

#### 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. The European Commission has recently launched the first a call for highly specialised healthcare providers to establish European Reference Networks. The call will run until 21 June 2016. The Commission has organised an info day on 7 April 2016 to help candidates with the technicalities of the call.

#### EUROPEAN PLATFORM ON RARE DISEASES REGISTRATION

The Expert Group was informed about the developments of the Platform on Rare Diseases Registration. Patient registries and databases constitute important instruments to serve research in the field of rare diseases, to improve patient care and healthcare planning. The principal goal of the European Platform on Rare Diseases Registration is to enable data analysis within and across many RD and to facilitate clinical trials, other studies, research and health policy guidance and support.

#### JOINT ACTION UPDATES

An update on the new Rare Diseases Joint Action, which was then kicked-off in September 2016, 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. The Expert Group was informed about policy support and working package developments, and state of the art resource.

#### 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 28-29 November 2016 in Luxembourg.