European Union Committee of Experts
on Rare Diseases

THIRD MEETING OF THE EUROPEAN UNION COMMITTEE OF EXPERTS ON RARE DISEASES

Luxembourg, 24-25 October 2011

Abstract

The third meeting of the European Union Committee of Experts (EUCERD) took place on 24-25 October 2011 in Luxembourg. The plenary was preceeded, for the first time, by preparatory meetings by stakeholder groups, a format which will be continued in future meetings.

The first item on the agenda was the unanimous adoption of the EUCERD's first set of recommendations : « EUCERD Recommendations on Quality Criteria for Centres of Expertise for Rare Diseases in Member States ». It was also decided that the EUCERD will start the process to elaborate a EUCERD recommendation on European Reference Networks for rare diseases, along the same lines as the methodology used to elaborate the first set of recommendations.

The EUCERD then was informed about the next steps concerning the implementation of the directive of the European Parliament and the Council on the application of patients' rights in cross-border health care. The EUCERD will closely collaborate with the committee in charge of implementing the Directive. The EUCERD also requested to be informed in a future meeting of the Heath Technology Assessment (HTA) elements of the Directive.

An update on the latest draft of the Road Map for the implementation of the Commission Communication and Council Recommendation on an action in the field of rare diseases for the period 2011-2013 was given. The EUCERD were asked to give any last comments on this version before finalisation as a document of the Commission.

The EUCERD then had the opportunity to hear the results of the call for tender study on a mechanism of knowledge exchange on the clinical added value of orphan drugs (CAVOD) led by Ernst & Young and discuss the EUCERD's implication in the next steps. It was decided that a short EUCERD recommendation on the implementation of the CAVOD process would be written and that a workshop to discuss this will be scheduled in 2012. In addition, a member of EUnetHTA will be invited to the next EUCERD meeting to strengthen collaboration.

Updates were given on the next EU Public Health Programme 2014-2019 and on the contents of the DG Health and Consumers 2012 work plan in the field of rare diseases (RD). RD will continue to be a priority and funding will be available for EU information networks on RD.

DG Research and Innovation activities were presented in the field of RD, including current calls in Framework Programme 7 and the progress made by the International Rare Disease Research Consortium (IRDiRC) to date including the next steps to be made in establishing its governance and adopting a policy document in 2012. EUCERD members were encouraged to take note of the nomination process now open for participation in the Scientific Committees of the IRDiRC which will propose research priorities to the Executive Committee and assess the progress made by research funded by the Consortium.

An update on the EUCERD Scientific Secretariat activities included a discussion of the editorial procedure for the « 2012 EUCERD Report on the State of the Art of Rare Disease Activities in Europe » with the decision taken to consult all Members on the content of the new overview section (Part 1). An update on workshops planned in 2011 by the EUCERD was presented along with a presentation of the progress made in incorporating RD in the revision of the International Classification of Diseases. All EUCERD members were encouraged to comment on the chapters concerning their speciality available on the site www.eucerd.eu.

The conclusions and consensus reached during the EUCERD workshop jointly held with the EMA on 4 October 2011 on public-private partnership for registries in the field of rare diseases were highlighted in. A number of next steps were discussed, including the process towards establishing EUCERD recommendations in the are of public-private partnerships for registers in the field of RD. It was decided at the workshop that disease registries should be favoured above product registries in the future.

In terms of support for the EUCERD's work from 2012 onwards, the content of the final application for the Joint Action to support the EUCERD, which has been approved and will start in early 2012, was presented with all MS urged to participate in the activities supported by the grant. The tentative schedule for workshops in 2012 was presented to the EUCERD. In order for the workshops foreseen by the Joint Action to be planned effectively, Members planning additional workshops via other EC-funded contracts were asked to make these dates known to the EUCERD Bureau and the EC.

The theme for Rare Disease Day 2012 (29 February 2012) was announced ('Rare but strong together') and EUCERD members were urged to become involved, especially to support their National Alliances for RD and by encouraging public institutions to become 'Friends of Rare Disease Day' and participating in the meeting in Brussels on the 29 February organised by EURORDIS in close collaboration with the EC. The themes of the European Conference on Rare Diseases and Orphan Drugs (23-25 May 2012, Brussels) were also presented and the ways in which the EUCERD will be involved were discussed, as chairs, speakers and at a dedicated «Meet the EUCERD members» networking reception.

The next meeting of the EUCERD will be held on 26-27 January 2012 in Luxembourg.

The full public report of this meeting can be found here :

http://www.eucerd.eu/upload/file/EUCERD3PublicReport.pdf