

At a recent conference European Commissioner for Health John Dalli outlined the Commission's role in improving rare disease treatment and access to medicines.

Speaking at the European Conference on Rare Diseases and Orphan Products ^[1] Mr. Dalli reflected on the difficulty patients with rare diseases have in receiving an accurate diagnosis and appropriate treatment, including locating a suitable centre for treatment or an expert consultant.

The Commissioner considered that key to improving treatment for rare conditions is tackling fragmentation of knowledge and improving cross-border access to treatment. He saw a strong role for the European Commission in meeting both these challenges.

Assessing work conducted by the Commission to date, Dalli highlighted a 2008 Commission Communication on rare diseases ^[2] as paving the way to a number of joint actions under the EU Health Programme ^[3] and the creation in 2010 of the EU Committee of Experts on Rare Diseases ^[4].

At a European Council level he looked forward to Member States meeting their commitments to adopt national plans or strategies for rare diseases by the end of 2013, and which are intended to follow common Commission-sponsored guidelines.

The Commissioner took pride in the achievement of the "Orphannet ^[5]" database, made possible by EU funds, which had now developed into a global reference tool for rare disease knowledge. A new goal for his Directorate-General is the establishment of a system of European Reference Networks ^[6] to bring together specialised centres for rare diseases from across Europe. 4.5m euros has been set aside by the Commission to establish new networks and rare disease registries.

Turning to medicines development, Mr Dalli highlighted the 300m euro the Commission has made available to assist rare disease medicines research since 2008 and the EU's membership of the International Rare Disease Research Consortium ^[7]. This consortium brings together the EU, the USA and other countries to mobilise rare disease research and has the ambition of delivering 200 new therapies for rare diseases, and diagnostic tools for most rare diseases by 2020.

He ended his speech by reassuring his audience that rare diseases would feature prominently in the European Commission proposal for the new Health Programme and the new Research Programme for 2014 onwards

More [here](#) ^[8].

1 June 2012

Links

[1] <http://www.rare-diseases.eu/2012/6th-European-Conference-on-Rare> [2]
<http://www.eurordis.org/content/ec-communication-and-council-recommendation-rare-diseases> [3]
http://ec.europa.eu/health/programme/policy/index_en.htm [4] <http://www.eucerd.eu/> [5]
<http://www.orpha.net/consor/cgi-bin/index.php> [6]
http://ec.europa.eu/health/rare_diseases/european_reference_networks/index_en.htm [7]
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