



On the occasion of **World Rare Disease Day** ^[1] (28 February), Dr Roberto Frontini, President of **the European Association of Hospital Pharmacists** ^[2] (EAHP), has added his voice to calls for all European countries to design and implement national rare disease plans.

A 2009 European Council Recommendation ^[3] encouraged all EU Member States to put in place national strategies to improve care for citizens living with a rare disease by the end of 2013. However at the beginning of 2014 **only 19** ^[4] of the EU's 28 member countries have published and shared such plans.

Dr Frontini described the situation as “regrettable” and urged the remaining national health systems to make meeting the 2009 Recommendation a greater priority:

“Hospital pharmacy should be a key part of rare disease plans, for example, in ensuring efficient discharge and interface management of medicines, and enabling patients to receive individually prepared medicines - together with the information that they need to use them effectively.

Hospital pharmacy is also central to improving the pan-European knowledge base in rare disease. Rare disease treatment and the conduct of clinical trials are key parts of our professional specialisation.”

Speaking more widely, Dr Frontini said:

*“The theme of this year’s Rare Disease Day, ‘**join together for better care**’^[5], is an excellent motif for the way we need to work together to deliver better care for rare disease patients. It reminds of the need for health professionals to work collaboratively, and for European countries to combine resource and expertise in rare disease treatment.*

I hope the spirit of cooperation between national health systems that was at the heart of the 2009 Recommendation can be met via its full realisation, and further progress made from there.”

ENDS

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NOTES TO EDITORS:

1. The European Association of Hospital Pharmacists (EAHP) is an association of national organisations across 34 countries representing hospital pharmacists at European and international levels. More information about the EAHP and its history [here](#)^[7].

2. The European Council's 2009 Recommendation on rare diseases is available [here](#)^[3].

3. Published national plans by 19 EU countries meeting the 2009 Recommendation are available [here](#)^[4]

4. More information about the theme of World Rare Disease Day 2014 is available [here](#).^[1]

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Links

[1] <http://www.rarediseaseday.org/> [2] <http://www.eahp.eu/> [3] [http://eur-](http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:151:0007:0010:EN:PDF)

[lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:151:0007:0010:EN:PDF](http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:151:0007:0010:EN:PDF) [4]

http://ec.europa.eu/health/rare_diseases/national_plans/detailed/index_en.htm [5]

<http://www.rarediseaseday.org/article/theme-of-the-year-care> [6] <https://www.eahp.eu/contact/info/eahp/eu>

[7] <http://www.eahp.eu/about-us>