



# Alliance for Biomedical Research in Europe

Brussels, 15 May 2018

To: President of the European Commission, Mr Jean-Claude Juncker  
Cc: Vice-President for Jobs, Growth, Investment and Competitiveness, Mr Jyrki Katainen  
Commissioner for Health and Food Safety, Dr Vytenis Andriukaitis  
Commissioner for Research, Science and Innovation, Mr Carlos Moedas  
Commissioner for Budget and Human Resources, Mr Günther H. Oettinger

Re.: The European Reference Networks (ERNs)

Dear President Juncker,

Well over a year since the launch of the first European Reference Networks, [the Alliance for Biomedical Research in Europe](#) (BioMed Alliance) would like to express its strong support for the ERNs and laud the European Commission for its crucial, indispensable role in establishing them. We are convinced of the great potential of these networks, not just for diagnosis and treatment but also for research. We therefore call upon the European Commission to ensure the success and continuity of the ERNs by making available solid and long-term funding.

Enthusiasm among members of the BioMed Alliance for the ERN concept is widespread and genuine. Not only are the cross-border networks of healthcare providers seen as crucial for bringing together the scarce and scattered expertise needed to diagnose and treat patients with rare, low-prevalence and complex diseases; they also hold great promise for health research. By building patient registries, collecting clinical data and identifying gaps in education and research, the ERNs – theoretically, at least – could provide a significant boost to both fundamental and clinical research into rare diseases.

For the ERNs to achieve their goals – both the primary goal of improving patient access to diagnosis and treatment across Europe, as well as the complementary (but equally promising) research-supporting and educational objectives – more and sustained funding will be essential. The consensus among ERNs and organisations supporting them is that current funding is vastly inadequate, even to realize short-term objectives.

Out of concern for the quality, effectiveness and continuity of the European Reference Networks, and for their prospects of building up substantial research capabilities, the BioMed Alliance strongly recommends:

- Securing increased, sustained and long-term funding for the ERNs.
- Prioritising EU over Member State funding. To us, it is evident that funding must come from the EU, rather than from Member States. Relying on Member State contributions seems overly optimistic, causes uncertainty and risks increasing the concentration of expertise in certain centres and countries rather than spreading it more evenly across Europe. The added



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value of ERNs is in their cross-border nature, which makes EU funding both logical and essential.

- The creation of a European Council for Health Research. The ERNs are a good example of successful EU-funded initiatives that would benefit from the establishment of a scientific council which can guide implementation, prioritize funding allocation and provide strategic direction, coherence and long-term planning. By ensuring the continuity and quality of projects with a clear and direct benefit for EU citizens, such as the ERNs, the European Council for Health Research (see also the [BioMed Alliance's recommendations for FP9](#)) would be instrumental in getting more value for EU money.

If successful, the networks will boost diagnosis, treatment, education and research in the field of rare and complex diseases. Directly benefiting patients across the EU, the ERNs, in our view, are a prime example of how EU funding can add value for EU citizens, achieving something that cannot be achieved at the national level and without EU funding.

On behalf of the BioMed Alliance, I thank the European Commission for launching and supporting the European Reference Networks. Please let us know if you think we can be of help in making them a lasting success.

With kind regards,

Prof Dr Axel Pries  
President, BioMed Alliance

**BioMed Alliance - the Alliance for Biomedical Research in Europe ([www.biomedeuropa.org](http://www.biomedeuropa.org))**

The Alliance for Biomedical Research in Europe (BioMed Alliance) is a non-profit organization representing 29 leading European research and medical societies uniting more than 400,000 researchers and health professionals. The BioMed Alliance is committed to promoting excellence in European biomedical research and innovation with the goal of improving the health and well-being of all European citizens.