

Workshop “Science and Innovation: Closer than Rare!”

hosted by MEPs Maria da Graça CARVALHO, and Mario DAVID

under the patronage of the Presidency of the Portuguese Republic

First Lady of Portugal Maria Cavaco Silva

17th February 2014 from 15h00-16h30

European Parliament room A5E3

Commissioner Tonio Borg,

Distinguished guests,

Ladies and gentlemen

Let me begin by extending a warm welcome firstly to the Commissioner for Health, Tonio Borg, who has kindly accepted our invitation to say a few opening remarks. Secondly, I should like to express my gratitude to the four speakers who have all agree to speak today.

Before starting, however, let me also apologise on behalf of my co-host Mario David, who, unfortunately, is unable to attend today's event.

This event is organized in the context of the different initiatives that will culminate in the Rare Disease Day 2014 (to be celebrated on 28 February 2014). The problem posed is considerable. 6 to 8% of the European population suffer from a rare disease: a figure that represents around 35 million patients.

The overall goal is to raise awareness of the many aspects of care for people living with a rare disease and to encourage constructive action on the part

of policy makers. To this end, this workshop is accompanied by a 3-day exhibition on rare diseases under the high Patronage of Her Excellency the Portuguese First Lady, Maria Cavaco Silva, and organized by Rarissimas, the Portuguese patient organisation to whom I would like to pay my tribute.

Rare diseases are a priority for the European Union and this is reflected in the focus devoted to the question in Horizon 2020. As you will know, H2020 is the European programme for research and innovation, for which I was one of the rapporteurs here at the European Parliament.

For my part, I should like to stress that H2020 is more than a simple funding instrument: it is a multi-disciplinary, scientific led approach that will coordinate health research across the pillars of Horizon 2020. As such, Horizon 2020 should be used in such a way as to ensure a structural effect across the different scientific domains, including health research.

Indeed, Europe already has a well-established tradition of excellence in health related research and there are currently many pools of excellence that are responsible for undertaking valuable work across Europe as a whole.

However, much of European research lacks overall coordination and remains a little fragmentary.

The European Union is well placed to overcome this difficulty. In particular, the European Parliament has introduced in Horizon2020 mechanisms that are able to ensure the effective coordination of efforts at regional, national *and* European level.

This improved coordination will be crucial personalised medicine, rare diseases and tumour response evaluation.

By way of conclusion, let me say that reducing the fragmentary nature of research into rare diseases will enable us to help patients and professionals to share expertise, exchange information and best practices. In so doing, we will be able to offer direct help to patient organisations and their families and contribute to – at least – significantly reducing the frequency of rare diseases in the foreseeable future.

At this point, let me hand over to Commissioner Tonio Borg and thank you once again for taking the time to attend this workshop.