Maria Da Graça CARVALHO

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Horizon 2020 - Rheumatic and Musculoskeletal Diseases

Dear Ms Da Graça CARVALHO,

In my function as President of the EULAR, the umbrella organisation of all European scientific, health professional and patient societies in the area of **rheumatic and musculoskeletal diseases** (RMDs), I am writing to you to share with you our concerns regarding the draft HORIZON 2020 texts currently under discussion at the European Parliament.

Our organisation represents about 120 million European citizens who suffer from rheumatic and musculoskeletal conditions, from **low back pain** (lifetime prevalence of 60% to 85%) to **osteoarthritis** (more than 40% of people over 60 years of age), from rheumatoid arthritis to ankylosing spondylitis (the most common chronic inflammatory rheumatoid diseases), from **gout** to **osteoporosis** (21% of women aged 50-84), and all persons caring for these patients.

The purpose of this letter is to ask for your support for rheumatic and musculoskeletal diseases to be **prioritised** and thus **fairly recognised** in the Horizon 2020 Framework Programme together with other major chronic diseases. Therefore EULAR drafted the attached amendments on the proposal for Horizon 2020 -Framework Programme for Research and Innovation 2014-2020- and on the proposal for the specific programme implementing Horizon 2020.

Despite the fact that rheumatic and musculoskeletal diseases are one of the most **prevalent**, **disabling** and **costly** conditions in Europe, we are alarmed to see that the current Commission draft texts for HORIZON 2020 do not mention them.

While we understand arguments in favour of a more generic and more bottom-up approach for HORIZON 2020 comparing to the 7th Research Framework Programme, we cannot accept that rheumatic and musculoskeletal diseases, in contrast to other disease areas, are not included among the **major chronic diseases** mentioned in the draft, since RMDs are equally or, in some cases, even **more important in terms of prevalence or impact on public health systems**. In particular, RMDs are not mentioned when it comes to listing the major disabling diseases, despite the fact that they are indeed the **most frequent cause of disability**. We are aware of the rather general character of the above mentioned documents which may be followed by more precise Commission proposals at a later stage. It is however of utmost importance to make sure wordings in the texts are balanced and sound, since they will determine further development of the Horizon 2020 package – and will meet the appraisal and critique of the people in Europe. Furthermore, it would be coherent with previous initiatives of the European Parliament which has, in two Written Declarations, called for an increase of European research funding for rheumatic and musculoskeletal diseases.

EULAR and other organisations in the field of rheumatic and musculoskeletal diseases would be pleased to provide you with more information about the dramatically growing impact of these conditions. Evidence from many sources and studies including the EUMUSC.NET project (co-financed by the European Commission, <u>www.eumusc.net</u>) show that musculoskeletal conditions -more than most of other chronic diseases- are at the core of several of the main societal and economic challenges identified by the European Union and Member States (healthy and active ageing, disability, efficiency of healthcare services, etc.). We would like to bring the following facts to your attention:

- RMDs affect around **25% of the overall European population** (around 120 Million people)
- RMDs are the largest single cause of work loss in Europe and their effect on worker participation gives rise to substantial work productivity costs;
- RMDs represent 39% of all occupational diseases;
- **RMDs are the main cause of early retirement**, impeding a high proportion of European citizens to remain economically and socially active when becoming older;
- RMDs also give rise to significant health resource utilisation with associated health and non-healthcare costs for society (it is estimated that RMDs represent a burden of EUR 240 billion every year, while direct costs represent 2% of the European GDP);
- RMDs are in the top 5 diagnostic groups in Europe in terms of health care costs.

It is also worth mentioning that after the loss of innovative drugs and pharmaceutical companies from the EU to the US in the 1990s and early 2000s, EU pharmaceutical industry has now recovered and produces a variety of promising innovative drugs for RMDs. Omitting (or actually: proactively excluding) RMDs from being specifically mentioned in the programme already at this point in time and subsequently in a special research programme with specific calls not only neglects the ailments of a quarter of the people in the EU, but also jeopardizes the fate of the promising innovative developments in the pharmaceutical industry of the EU – a risk, that if the sell-out happened again, would have to be blamed on the EU politics.

We do hope you will find our request reasonable and support and realise our suggestions. We will be glad to provide any further information you may require. We would also be pleased to provide you with more input in the framework of a personal encounter whenever requested.

Yours sincerely,

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Prof. Maxime Dougados EULAR President