

**Françoise Grossetête**

Députée européenne  
Vice-Présidente du Groupe PPE

Brussels, on November 8, 2016

Dear Colleagues,  
Dear Friends,

It is a real honour for me to be given the possibility to address, at such an important moment, the global community on rare diseases. My long-standing commitment to health issues and to rare diseases is now well known. Since 16 years indeed, working at European level to improve the life of patients affected by rare diseases has indeed always been the sense of my engagement.

It all started almost out of pure chance, in 2000, when, a rather new Member of the European Parliament, I was asked to take over from a colleague, who wasn't re-elected, in bringing forward the adoption of a new piece of legislation on orphan medicinal products. We put up a great fight, and, a few months after, the EU Regulation on Orphan Medicinal Products was officially adopted.

It defined my commitment in the health field, and most of all, it remains one of the piece of legislation I am the most proud of. I believe it made a real difference for patients, contributing to improve the regulatory framework, with more support for innovation and better patient access to care in the field of rare diseases. Making a difference for citizens is what stirred my political engagement, and rarely in my career was I given such an opportunity to work towards concretely improving people's lives.

Prior to the implementation of this Regulation, only 8 products had been authorised to treat rare diseases in Europe. There are now 123 of those products currently on the market. It is an achievement we can all be proud of, as it would not have been possible without the engagement of civil society, such as scientific organisations, patients' associations or the industry. I wish here to pay particular tribute to EURORDIS-Rare Diseases Europe, which tirelessly works to advance the cause of rare diseases. I myself largely benefited from their wealth of experience and expertise.

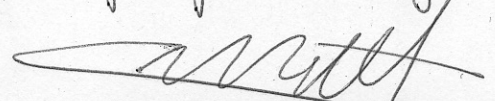
This is not to say, however, that problems do not exist. I am aware that huge unmet medical needs remain to be addressed. Further than scientific challenges, I believe political and economic challenges are also laying ahead in the way of improved treatments for rare diseases. It is at the core of my continued engagement for your cause in the European Parliament, whether, for example, through supporting efforts and budgets for research and innovation or through fighting the dangerous belief that costs reductions can help us achieve more sustainable health systems.

The launch of this NGO committee for rare diseases is therefore an initiative that I wish to fully support. Even though not being able to be here in person, I can assure you that I will closely follow the outcomes of this first meeting.

Let's altogether make rare diseases a global priority!

Thank you

*All the best for your meeting!*



Françoise Grossetête

Member of the European Parliament

Vice-President of the European People's Party Group

Former Parliament's rapporteur on the EU Regulation on orphan medicinal products