

Exhibition "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 at 16h30

European Parliament room A5E3

Commissioner Tonio Borg

Paula Brito, FEDRA Chairwoman,

Juan Carrion FEDER Chair/representative,

Yann de Com EURORDIS Chair/representative,

Dear colleagues,

ladies and gentlemen,

It is a great honour for me to have been asked to open this exhibition on rare diseases under the Patronage of Her Excellency, the Portuguese First Lady, Maria Cavaco Silva.

Unfortunately, my colleague and co-host – Mario David – is unable to attend due to an engagement that he was bound to accept outside of Europe. He has asked me to apologise for his absence on his behalf. I know how much he regrets not being able to be here in person.

I will deliver this speech on his behalf.

Before going further, I should like to thank the

the Portuguese Federation for Rare Diseases (FEDRA)

and particularly my fellow Portuguese countrywoman

(and, I dare say, friend) Paula Brito  
the Chairwoman, the Spanish Federation (FEDER)  
and the European Organization for Rare Diseases (EURORDIS)

I know the degree of dedication and commitment they have put into organising this exhibition.

“Patient organisations such FEDRA, FEDER and EURORDIS play a highly relevant role in

raising public awareness for rare diseases,  
supporting of patients and their families  
and in providing additional incentives for the development of  
orphan drugs and treatments.

As politicians, it is imperative that we recognise and support their achievements.

“By making rare diseases less rare –

by increasing the number of patients for each diagnosis,  
by encouraging joint actions and pooling scarce resources  
that are currently spread across the EU Member-States –

the EU is able to help patients and professionals to share expertise and to exchange information and best practices.

However, it remains the case that more research into rare diseases – along with a stronger will to foster the engagement of centres of expertise and European reference networks for rare diseases – is still required.

“The Health Programme 2014-2020 is designed to support action concerning rare diseases, in particular  
exchange of information,  
the creation of rare diseases registries  
and European Reference Networks.

The Networks will connect highly specialised medical centres across Europe to enable the sharing of medical knowledge and to allow patients with rare diseases to get the treatment they need anywhere in Europe.”

After all, rare diseases are not as rare as all that. Between 5 and 10% of the European population are likely to suffer from one of these diseases, representing an astonishing figure in the region of 35 million patients.

From the European perspective, rare diseases are the object of particular attention in the new EU Research and Innovation Programme Horizon 2020. These efforts represent a particularly pertinent example of the way in which the European Union is able to confront challenges at a trans-national level and to coordinate the different efforts made by the Member States.

Indeed, patient organisations, doctors, politicians and public institutions from at a European and a national or even regional level must work together. As an African proverb has it:

If you want to go fast go alone. if you want to go far, go together!

Hopefully, we will be able to both go far and go quickly. And, on that optimistic note, let me declare this exhibition officially open.

Thank you very much.