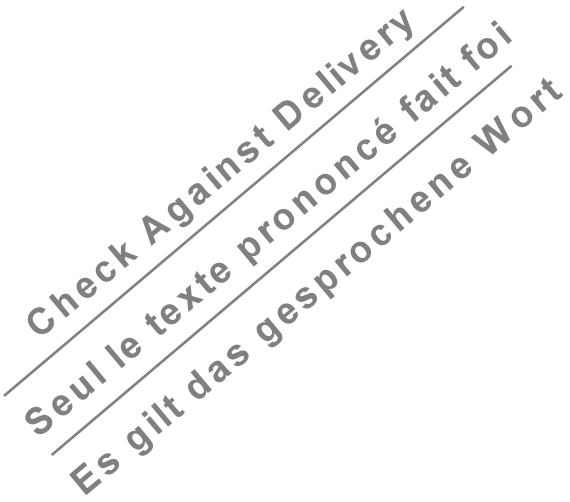
Tonio Borg

Member of the European Commission, responsible for Health

Commissioner Borg delivers speech on rare diseases



Tonio Borg, European Commissioner for Health, attends a workshop and exhibition at the European Parliament for Rare Diseases Day (28 February 2014)

Brussels, Belgium, 17 February 2014

Commissioner Tonio Borg

participates at the Workshop “Science and Innovation: Closer 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

Monday 17th February 2014, 15:00hrs

European Parliament room A5E3

SPEECH

Professor Graça Carvalho, ladies and gentlemen

I am very pleased to be here with you today.

I would like to congratulate Professor Graça Carvalho and Dr Mário David for hosting this event on rare diseases, in association with the Portuguese Association for Rare Diseases, Raríssima.

This workshop – and the exhibition that follows – are an excellent opportunity to raise awareness on rare diseases and to discuss what Europe can do to improve the lives of people with rare diseases.

Indeed over 30 million Europeans suffer from a rare disease. This is like the population of Portugal, Sweden, and the Czech Republic added together.

I know that people suffering from a rare disease struggle to find the right health professional who can diagnose their particular condition.

Just last week I met two organisations representing people with rare diseases and was touched by how hard it is for patients - and their families - to face the uncertainty about what they are suffering from, who can help them, what the best treatment is, whether or not there is a cure.

People with rare diseases often spend years in "isolation", waiting for the disease to be diagnosed, waiting for treatment.

Indeed, the specialised doctor who can diagnose and treat such a rare disease may live in another region or across the border in another country. Scientific knowledge on the rare disease in question is likely to be insufficient and scattered.

This is why the European Union dimension and the co-operation between Member States can make a difference.

The European Commission can help in pooling together knowledge and expertise, in funding research on rare diseases and also in authorising the best possible medicines for these diseases.

Let me stress here that the Commission is fully committed to help improve the lives of people with rare diseases.

Back in 2008, the Commission adopted a strategy on rare diseases. This was followed in 2009 by a Council Recommendation calling on Member States to adopt national plans for rare diseases.

Since then, the Commission has put in place a Joint Action on Rare Diseases and the EUROPLAN project to support Member States in implementing such plans.

The Commission is supported in its work by the expert group on rare diseases, which brings together Member State stakeholder organisations and experts on rare diseases.

Easy access to information about rare diseases for patients and health professionals is a prerequisite for good quality care for patients.

Perhaps the best example in disseminating knowledge about rare diseases is the "Orphanet" database supported by the Commission and Member States. Orphanet is a world reference on rare diseases and it continues to grow.

One of our goals is to help Member States in ensuring patients' access to high quality healthcare.

But when diseases are rare, expertise is rare as well.

Some national centres of expertise have knowledge and experience on certain rare diseases which can be used by professionals and patients from other countries.

This is why the Commission has been supporting, over the years, pilot European Reference Networks on rare diseases.

In the next few months, the Commission will define the rules for establishing European Reference Networks, including those for rare diseases.

The Networks will connect highly specialised 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.

Moving on, I know you are particularly interested in research on rare diseases and there will be a presentation on this later this afternoon.

I would just like to stress two things. First, that Research on rare diseases is a priority for the European Commission. Under FP7 alone, from 2008 to 2013 we invested over 600 million euros on rare diseases research.

Second, I would like to mention the International Rare Disease Research Consortium. This is an ambitious international initiative, in which we are involved, to pool resources, so as to deliver 200 new therapies for rare diseases by 2020.

In addition, to develop treatments for rare diseases we need data and quality data repositories.

This is why the Commission supports the development of rare diseases registers and networks of information through the Health Programme, and the Framework Research Programme.

Finally, before I conclude, a few words about medicines for rare diseases.

EU legislation on Orphan Medicinal Product Regulation aims to create incentives to encourage the research, development and marketing of medicines to treat, prevent or diagnose rare diseases.

Over 80 new orphan medicinal products have now received a marketing authorisation for the treatment of rare diseases.

In addition, over 1,000 medicines have already been designated by EMA as orphan medicinal products, but are still undergoing clinical tests.

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To conclude, we have made much progress in fostering co-operation on rare diseases in Europe.

There is however still a long way to go to secure that each and every rare disease patient gets the right diagnosis and the best possible treatment.

Your initiative is a valuable contribution to endeavours towards this goal.

Thank you.