



European Rare Diseases Day

Commissioner Vassiliou hosts the launch of the book
“The Voice of 12,000 Patients”

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Launch of "The Voice of 12,000 Patients" by Commissioner Vassiliou, 3 March 2009

To mark the European Rare Disease Day 2009, Commissioner Androulla Vassiliou hosted the launch of a new book entitled "The Voice of 12,000 Patients" in Brussels, on 3 March 2009. This book was produced by the European Organisation for Rare Diseases (Eurordis) and co-funded by the European Commission.

The book focuses on the patients' perspectives of diagnosis, treatment and care as well as on their expectations and experiences. The report presented in the book highlights that 25% of patients with rare diseases wait between 5 and 30 years to get the right diagnosis. All this time and efforts generate avoidable sufferance and costs, said Eurordis CEO, Yann Le Cam.

Commissioner Androulla Vassiliou said: "This book is an important step forward in our effort to raise awareness on rare diseases under the 'Europe for patients' umbrella campaign. We need to listen to the voices of patients across Europe in order to develop policies that are patient-centred and where sharing expertise and knowledge across Europe will bring real benefits to those in need. I am convinced that the implementation of the Community Strategy on Rare Diseases that we adopted in November will provide real progress in tackling rare diseases in Europe."

She emphasized that action is desperately needed and that, as adopted in the Strategy for action in Rare Diseases, the Commission will focus on Improving the visibility of rare diseases, supporting national plans and strengthening coordination among Member States. The Commissioner also thanked the Czech Presidency for their hard work to achieve a Council Recommendation in this field.

Commissioner Vassiliou concluded by expressing her wish that the Rare Diseases day will contribute to provide a platform and to raise voices on this field.

Prof Milan Macek, who represented the Czech Presidency at the meeting, expects and hopes that an agreement should be reached by June 2009.

Eurordis calls for better facilities for sufferers. These include the establishment of rare disease national plans in each member state and the creation of 'centres of expertise' and European 'reference networks'.

Prof Thomas Otto F. Wagner presented the important EU added value in the field of rare diseases, including EU Centers of Expertise, which would help to provide the same quality of healthcare to all EU citizen, from all Member States.

Background

Rare diseases are conditions that affect fewer than 5 in every 10,000 people. There are between 5,000 and 8,000 such conditions. These conditions are predominantly genetic in

origin, but also include rare cancers, auto-immune diseases and congenital malformations. The limited number of patients affected and the fragmentation of knowledge about them across the European Union makes rare diseases a prime example of where working at European level is necessary and beneficial

The Community Strategy for action in Rare Diseases, part of the 'Europe for Patients' campaign, was adopted in November 2008. It sets out an overall Community strategy to support Member States in diagnosing, treating and caring for the 36 million EU citizens with rare diseases. It calls for action by : (a) Improving recognition and visibility of rare diseases; (b) Supporting national plans for rare diseases in the Member States; and (c) Strengthening cooperation and coordination for rare diseases at European level.

European Reference Networks (ERNs) for Rare Diseases play an important role in tackling rare diseases and other conditions requiring specialised care. ERNs also serve as research and knowledge reference points, updating and contributing to the latest scientific findings, for the treatment of patients from other Member States, and ensuring the availability of subsequent treatment facilities where necessary.