EURORDIS Call for a European Year for Rare Diseases

We, rare disease patient representatives from more than 600 patient groups, on behalf of the 30 million people affected by rare diseases in Europe, hereby call upon the EU and the Member States to support the designation of 2019 as the European Year for Rare Diseases.

In order to be considered as rare, each specific disease cannot affect more than a limited number of people out of the whole population, defined in Europe as less than 1 in 2.000 citizens. It is estimated that there are 6 000 to 7 000 identified rare diseases today.

A European year will help raise awareness and encourage researchers to focus on these rare, mostly unknown, seriously debilitating and often life-threatening diseases, which affect children and adults, in their physical, mental, emotional and behavioural capacities.

We need solutions to address the health and social challenges that we face in our daily life; we need solutions to tackle the obstacles faced by researchers and by therapy developers; we need a European approach to overcome the chronically lacking critical mass of patients, data, experts, and resources; we need to involve all interested parties, including industry and decision-makers, in order to create the conditions for better health and social care for all, including the ones affected by diseases that leave little hope to patients and their families. We need a European Year for Rare Diseases.

Rare Diseases have been widely recognised as an area of high European added value. In the scientific field, research into rare diseases has led to huge medical progress, ranging from genomic sequencing to the development of medical devices, from the discovery of the genes responsible for diseases to innovative drug development, and there has also been spectacular improvement in diagnostic tools, genetic counselling and pre-natal and pre-implantation diagnosis.

Despite undeniable successes in various fields, most of the journey to reduce health inequalities between rare disease patients and patients affected by common diseases is still ahead of us. Awareness and political willingness are needed to face the many up-coming challenges.

The year 2019 will mark a turning point in the history of rare diseases as we will celebrate 20 years since the adoption of the EU Regulation on Orphan Medicinal Products, which has boosted orphan drug development; 10 years, since the Commission adopted its Communication on Rare Diseases: Europe's Challenges and the Council its Recommendation on an action in the field of rare diseases, delineating a common strategy for rare disease patients. It will also be the time to take stock of the progress made by the Health for Growth and Horizon 2020 EU Programmes and start operating in view of the new EU multi-annual financial framework 2020-2025.