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President of the Foundation Culture of Peace,
Chairman of the Scientific Council
of the Foundation Ramón Areces,
Director-General of UNESCO (1987 – 1999)*

To the attention of the NGO Committee for Rare Diseases:

Many thanks for inviting me to the inauguration of the NGO Committee for Rare Diseases, to be held in New York, UN Headquarters, in November 11th, 2016.

Congratulations and in-depth recognition for your initiative of setting up the NGO Committee at the UN Level. You are absolutely right: the "world forward", particularly when we are facing processes potentially irreversible, is to prevent in all possible scenarios and extent.

You describe perfectly the percentages situation and very relevant health interest of rare diseases. The percentages have only epidemiological value, because for those affected it represents the 100%. Every human being is unique and therefore all must be taken into account in order to achieve a progressive personalized medical attention, and whenever possible, diagnosis and *timely* treatment.

The prevention of neonatal molecular diseases has been my first field of research and medical action. From 1967, after working in the Department of Biochemistry of the University of Oxford with Professor Hans Krebs, I started to practice in the neonate early diagnosis of diseases that, if not timely treated, led to irreversible neuronal damage.

In 1970, always with the collaboration of Professor Magdalena Ugarte, we detected and treated the first case of phenylketonuria. Afterwards, the National Plan of Prevention of Disability in Children was approved in Spain and from the CIAMYC (Research Centre for Molecular and Chromosomal Alterations) in Granada, we started to work in 1974 in the Autonomous University of Madrid. The diagnosis was considered compulsory after 48 hours of the birth (neonatal heel prick) and later on was transferred to the responsibility of the different Autonomous Communities of Spain. In the Autonomous University, Prof. Magdalena Ugarte set up the CEDEM (Centre for the Diagnosis of Molecular Diseases) with a very big data bank on molecular pathology, open to pediatric consultations for newborns with unidentified symptoms.



The Global Gathering for Rare Diseases

Friday 11 November 2016, United Nations, New York



In a simultaneous way, seminars and special courses on "perinatal biochemistry" were in 1978 promoted in the Foundation Ramón Areces as one of its priorities. Today, rare diseases are the first research activities of the Foundation. In the last decades, the CIBERER (network of research groups of rare disease in Spain) has given a big boost to the physiopathology diagnosis and treatment of this very important medical field.

For all these reasons you can imagine until what point we are highly interested in participating in the very important initiative of the "NGO Committee for Rare Diseases". Unfortunately, I will not be able to accompany you in New York but I wish you the best of luck and look forward to our future collaboration.

Cordially,

Federico Mayor