



## **“A Rare Exhibit”**

**Mrs. Katia Kyriacou, President, Pancyprrian Association of Rare Genetic Diseases “Unique Smiles”**

**Tuesday, 25 February 2020**

Honorable minister of Foreign Affairs Mr Nicos Christodoulides, honorable Minister of women, families and Human Rights, Mrs Damare Alves, Ambassador Mr. George Kasoulides, Mrs Rachel Yang, distinguished guests. It's a great honor for the PAFRGD “Unique Smiles” to present “Unlimited Possibilities” as part of “A Rare Exhibit.” An effort to raise visibility of rare disease on a political stage, stresses the importance of including Rare diseases in the Vision of no one left behind!

If you ask a Rare disease patient or parent of a child living with a rare disease, what they wish for their child, they will most probably tell you: I want my child to be happy! And if you meet a child with a rare disease you will be amazed by their thirst to live a happy life and their stubbornness to make it! They build resilience as hospitalizations and daily therapies are a routine, but their thirst for life makes them wake up every day, take the challenge and even give strength to those that surrounds them.

However are we ready to take the challenge?

Bringing Rare Disease on the spot light we primarily need to establish a Rare disease Multidiciplinary team of experts under one roof locally, which will be able to collaborate in Virtual Centers Of expertise, in mobility of experts as well as of patients in a world wide Network .

Health systems need to be adapted to rare disease even more they need to be adapted to Undiagnosed cases. More policies are required to meet our specific needs without exposing the patient and their family to financial hardship: Access to quality Health care, timely access to Orphan Drugs, rehabilitation for life, social and educational support must be included in a United Nations Resolution.

Lastly Rare diseases call for more research and collaborations between the industry, academics, governments, and research foundations.

I wish that the vision of a world in which no one is left behind will take the challenge by including Rare Disease patients into consideration and their true needs.

With this opportunity I would like to Thank The honorable ministers for their support, Ms. Paloma Tejada, Director of RDI, the Cypriot mission, especially Ms. Koktsidou, Both Photographers Mr Petros Petrides and Mr. Aldo Soligno because as Unique smiles motto says “Alone we are Rare, but Together we can be strong!”

Thank you