"A Rare Exhibit"
Ms. Anastasia Semaan, Youth Ambassador of "Unique Smiles" and Member of European Patient Forum Youth Group
Tuesday, 25 February 2020

Honorable Minister of Foreign Affairs Mr. Nicos Christodoulides, Honorable Minister of Women, families and Human Rights Mrs. Damara Alves, Ambassador Mr. George Kasoulides, Mrs. Rachel Young, distinguished guests,

My name is Anastasia Semaan and I am the Youth Ambassador of Unique Smiles which is the association that supports individuals who have Rare Genetic Diseases in Cyprus. Today we are here to recognize all of the accomplishments of those with Rare Diseases and how we are all uniquely part of the 1 in 300 million. We each have our own story, but we are still are bonded together as a strong community.

My story began when I was diagnosed with Noonan's Syndrome when I was born in San Diego, California. I was fortunate that there was a very strong healthcare system that was able to diagnose me early, and able to meet my needs at birth and throughout my early childhood. During my early years until the age of nine I received various sorts of therapies such as occupational therapy and physiotherapy due to my developmental delay. This along with innovative medication, became very costly and caused financial hardships to my family.

When it came to me being prescribed an innovative medication, my parents were told that without it I would die, but with it because it was still newly released I could also either die or it would save my life. Having had access to an innovative medication is the reason that I am standing in front of you today. This is a kind of decision that only 5% of patients with rare diseases have the luxury of being able to take, because the other 95% of patients are diagnosed with diseases that cannot be supported through medication. At the age of nine things changed when I moved to Cyprus. In order to meet my medical needs, I had to change the form of the medication that was given to me as it was not available in Cyprus. Despite all of this, I was always fortunate to be in various school systems that supported my academic and non – academic needs. One of the additional symptoms of my rare disease is Attention Deficit Disorder or A.D.D. Even though this has an impact on the speed at which I retain and comprehend information, with hard work and self-motivation I graduated school with honours and am currently in the 2nd Year at university studying Education Studies combined with Special Educational Needs and Inclusion Studies in England.

As an adult in the UK who is experiencing one of their first times of living independently and away from home, there are some challenges that I have faced. The most significant challenge is often having to accept that there are ignorant and closed – minded individuals in our world. I would not say that being an adult who is also a patient has not been a challenge, but it has required a lot of adapting; whether it be the new culture of living in the UK, working and communicating with new people or becoming accustomed to different policies and practices. I have gained new experiences that in the long run have and still are increasing my drive to make change in the world for adults and children who are also patients. This change needed to support patients with Rare Diseases needs to come soon because human rights are currently being violated, partially due to people being ignorant about the issues and that challenges that we face, but also that they are indirectly causing. Therefore, Rare diseases need a UN resolution with clear directions that supports the needs of the patients. Values, beliefs and practices are what needs to be changed. For instance, having accessible hospitals which is very important, is not enough because it doesn't mean that patients also have access to therapies. Additionally, having accessible schools doesn't mean that we have equal access to education. Rare diseases are so complex unless there is a clear resolution with specific guidance, that is written in an inclusive way that is comprehendible by all. Once the barrier of "the unknown" is broken, then not only can policy chance, but more importantly people can change and become more inclusive and understanding. As the Youth Ambassador of Unique Smiles, I have unfortunately witnessed devastating and unfair situations regarding children with Rare diseases and their parents due to the healthcare system. Each family having to go through their own hardships and fight their own battles to save their child's life, is a kind of love that only those experiencing it would be able to understand.

My condition does not and will never define me, but it definitely has given me the inner motivation to highlight all of the accomplishments of those who are 1 in 300 million. Today I shared with you a summary of my story but remember that everyone's story is different. We should never assume what anyone can or can't do and disregard any of their human rights because at the end of the day this exhibition is celebrating everything that we with Rare disease HAVE done, and CAN do and is only a glimmer of what we will continue doing and striving towards.

Thank you and Enjoy