Name: Anastasia Sofia Semaan

Age: 21

Country: Cyprus

Name of the Organization:

Μοναδικά Χαμογελά (Unique Smiles)

About me:

Hi everyone, my name is Anastasia Sofia Semaan. I am from and currently live in Cyprus, but I am a university student studying Education Studies combined with Special Educational Needs and Inclusion Studies (SENI) in England, and I was born and raised in the United States of America. I was born with, but at 3 months old I was diagnosed with Noonan's Syndrome, which is a Rare Genetic Disease. However, before this certified diagnosis I was misdiagnosed multiple times. Even though I was diagnosed in America, when living in England from the age of 19, when I registered with the GP, I was shocked when their approach to my unknown diagnosis was that "it did not exist". This is something that I face on a day to day basis, but this motivates to continue my advocacy work.

Advocacy has been a huge part of my life, since I was a young child when I would help at the reception of the children's hospital in America. When I moved to Cyprus, I was not impressed by the healthcare system and the lack of support for individual with additional needs, when my mother got involved in forming a non-profit organization with other parents, so did I. By the age of 14 I became their Youth Ambassador and since then have been supporting them anyway that I can, within schools and also in society. In November 2019 I also joined the Youth Group after attending the STYPA in 2019 helping me develop as a patient advocate.

My ultimate goal as a patient and an advocate is to promote inclusivity and change legislation to ensure that all children and adults, especially those with rare genetic diseases are supported and included in society.

About my Organization:

- Raises awareness about rare genetic disease in Cyprus
- Supports all people in Cyprus with rare diseases and their families
- Works to challenge and change legislation in Cyprus in order to include the rare disease community
- Provides financial support and therapy to children and families with rare disease

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