



Name: Anastasia Sofia Semaan

Age: 21

Country: Cyprus

Name of the Organization:

Μοναδικά Χαμογελά (Unique Smiles)

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

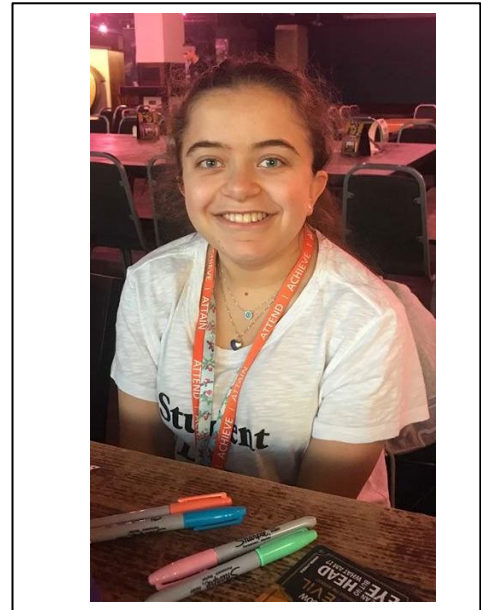
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About me:

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.