



Name: Jana Popova

Age: 27

Country: Bulgaria

Name of the Organization(s):
Bulgarian Association for NMD &
EAMDA

About my Organization:

- EAMDA increases the awareness in public about neuromuscular disorders.
- The Organization represents, protects and enforces the rights of people with NMD.
- EAMDA provides equal access to health care and social service for all.

How to contact me:

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About me:

Hi, everybody! My name is Jana and I live in Sofia, the capital of Bulgaria. When I was 10 months old, I was diagnosed with Spinal Muscular Atrophy (SMA), rare neuromuscular disorder, which leads to muscle wasting and mobility impairment.

Since I was 15, I have been involved in the activity of the Bulgarian Association for Neuromuscular Diseases. In October 2017 I become a member of the Executive Committee of EAMDA. I'm very inspired by the work in the organization. My personal goal is to increase the awareness about NMD, to help patients with NMD to improve their quality of life and to overcome the physical limitations.

I'm very lucky to be part of the EPF Youth Group since the beginning of 2018. I think this is great opportunity to share our experiences and knowledge in different fields and to pay more attention to different chronic disorders. I believe the cooperation between organizations is essential part of our work and only if we stand together, we can achieve better results in the global society.