

Name: Blaz Urbanc

Birth: 23.01.1998

Country: Slovenia

Name of the Organization:

European Alliance of Neuromuscular Disorders Associations

About my Organization:

- raises awareness on neuro-muscular disorders (NMD) across Europe and more
- organizes expert discussions and activities (workshops, symposiums, youth camps, international conferences on NMD)
- cooperates actively with pharmaceutical companies
- plays a significant role on discussions about healthcare devices or accessories and social services for people with disabilities
- supports and monitors of the Convention on the rights of persons with disabilities implementation in the member countries.

How to contact me:

Facebook: www.facebook.com/blaz.urbanc/



About me:

Dear all! My name is Blaž, and I live in Ljubljana, Slovenia. At 2 years I was diagnosed with rare disease, so-called spinal muscular atrophy which caused reduced mobility and because of it I am categorical wheelchair user. For sure, when I was growing up, I realized that it will not prevent from doing me what I want to, i. e. being active part of society and thinking critically, so I am an advocator of all who are in need of support in terms of protecting rights of people with disabilities. Let it be on a realm of disability policy or social care in the broadest sense of word. With disease progressing and schooling I realized I shall stay strong and progressive in implementing notions of inclusive, egalitarian society and values of equality in every segment of everyday life.

Because of own curiosity, engagement and wish of active lifestyle I am inspired in active multidisciplinary lifelong integration of disabled people and those with kinds of chronic diseases in relation to the environment where I live in and participate in socio-political issues and events.

For this reason, I am honored to be part of a unique Youth group and having an opportunity of sharing different experiences, knowledge. I firmly believe in future based on prevailing values such as human dignity, non-discrimination, inclusion, and most importantly I support struggles to provide better health care standards for everyone of us!

Blaz comes from Slovenia and has SMA, a rare neuromuscular disorder. He actively participates in executive committee of MDA of Slovenia and is engaged in the Programme Committee for Programmes for the disabled people within the national institution Radio Television Slovenia (RTV Slovenia). In that light he strives to improve quality of life of all people with disabilities either on a national level or international. In spite of being a disabled person I try to be active by struggling to raise awareness on needs and obstacles that we face with.