

# EAMDA - European Alliance of Neuromuscular Disorders Associations

## Slovenia



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#### 1. About

EAMDA stands for the European Alliance of Neuromuscular Disorders Association. It was founded in 1971, in London, by patient organizations from 9 countries: Belgium, Denmark, Germany (FRG), France, Great Britain, Italy, The Netherlands, Sweden and Yugoslavia. Since then, EAMDA has been working as a European umbrella organization for neuromuscular associations, with the aim to advocate the rights and interests of people living with NMDs, to raise awareness, to promote research activities and knowledge sharing, to help reduce the consequences of disability and to support efforts towards new treatments for neuromuscular diseases. Empowering Lives, Inspiring Hope: EAMDA envisions a future where individuals affected by neuromuscular disorders stand together in solidarity, fostering cooperation to ensure improved access to healthcare and elevate the standard of living in their respective countries.

#### 2. Mission

EAMDA's mission is to serve as a united and influential voice for individuals with neuromuscular disorders at the European level. As a European organization, our primary goals include raising public awareness about neuromuscular disorders and various NMD associations, representing and safeguarding the rights and interests of those affected, and enhancing the quality of life. We strive for equal treatment, personal assistance, accessibility, independent living, and full societal participation. Additionally, EAMDA aims to provide information on new medical treatments, advocate for improved access to quality healthcare, and foster collaboration among national associations and individuals with NMD. We support the development of neuromuscular disorders associations across Europe, empowering individuals and facilitating cooperation at the European level.



#### 3. Focus.

In order to achieve EAMDA goals, we organize meetings and workshops with the aim to disseminate information about new treatments and practices in the field of neuromuscular disorders. Also, EAMDA supports different research in the area of early diagnosis, adequate medical treatment and rehabilitation services.

The organization develops opportunities for distribution and exchange of specialized knowledge in this field and invests efforts for higher education about the specifics of neuromuscular disorders. That's why EAMDA encourages development of different associations working in the field of neuromuscular disorders.

The main task of the organization is to build supporting network for people with neuromuscular diseases that is going to improve their standard of living and will advocate their rights, which includes also cooperation with local authorities and related national and international organizations.

### 4. Coming up

EAMDA is currently spearheading impactful initiatives, including regular webinars focusing on specific neuromuscular diseases like SMA, DMD, CMT, ALS etc.

Our ongoing educational workshops for physiotherapists and rehabilitation specialists, beginning in Istanbul this December, will expand to other countries.

Next year holds exciting projects, such as addressing independent living challenges and launching a comprehensive initiative to improve access to professional personal assistants across Europe. EAMDA is committed to nurturing strong youth communities and reviving our summer camps for teenagers and young adults. Looking ahead, we aim to fortify collaboration among medical experts in the NMD field through the establishment of the EAMDA Medical Advisory Board.



