



BOARD MEMBER NOMINATION FORM

To be completed by the nominee

Name of Nominee: **Ivanka Jovanovic**

Position: **Board member**

Organisation: **European Alliance of Neuromuscular Disorders Associations (EAMDA)**

Please give brief biographical details below:

(Less than 300 words)

I am Disability Movement activist since the age of 18. From foundation (2007) I am Executive Director of National Organization of Persons with disabilities of Serbia (NOOIS), representing over 800,000 PWDs, and also working on inclusion of PWDs in the society. My key duties within NOOIS are: advocacy for human rights, cooperation with different stakeholders – state institutions, DPOs and CSO and international organizations, organization development, program and project management. With excellent knowledge of disability policy and human rights advocacy for people with disabilities, I am one of the prominent leaders of the Disability Movement in Serbia with years of experience in the domestic and international disability movement.

Also, I have University level degree from Faculty for political science, University of Belgrade.

At the same time, my current positions in disability movement in Serbia, as well as in civil society and at international level, are: Research Assistant in Muscular Dystrophy Association of Serbia, member of the Council for disability issues of the Government of the Republic of Serbia, Board member of European Alliance of Neuromuscular Disorders Associations (EAMDA), member of EDF Assembly (European Disability forum).

Author and co-author of many manuals and researches: “Right to Employment of Persons with Disabilities, Assistive Technologies in Serbia”, Rights of Persons with Mental Disabilities”, Guide through the Rights of Persons with Disabilities” (NOOIS, several editions), “Situational Analysis of the Position of Children with Disabilities in Serbia”, “Analysis of the implementation of the recommendations of the CRPD in the RS”, “Disability Etiquette” etc.

Please outline why you believe that you are suitable to be a Board Member of EFNA – with particular emphasis on details of your skills, knowledge, interest and experience in this sector:

(Less than 500 words)

I very closely collaborate with several important European organizations such as - European Alliance of Neuromuscular Disorders Associations (EAMDA), European Disability forum and European Federation of Neurological Association (EFNA). Key areas of my expertise relevant to EFNA are: many years of dealing with issues in the field of improving the position of PWDs and good knowledge of the concept of human rights, including domestic and international regulations, especially the UN Convention. Also, my priority

activities include monitoring the UN Convention implementation and working on harmonizing Serbian regulations and practices.

One of the main activities of the organization in which she has a leadership role is legislation and advocacy, including the monitoring the implementation of regulations with a focus on the harmonization of all domestic regulations in accordance with the UN Convention on the Rights of Persons with Disabilities.

I have participated in various activities related to the harmonization of Serbian regulations in the areas: abolishing guardianship and introduction of decision-making with support; in the field of deinstitutionalization; work and employment; in the field of systematic introduction of prohibition of disability-based discrimination in new legislation; in the process of amendments to the Criminal Code criminalizing disability-based discrimination and increasing penalties for acts of sexual violence against persons with disabilities; in the process of recent ratification of the Marrakesh Treaty.

Moreover, I had very active role (within a working group) in the process of writing the new National Disability Strategy of Serbia for the period 2020/2024, particularly through systematic incorporation of recommendations from the Committee's Concluding Observations to Serbia into the new National Disability Strategy, as well as first and second Action plan.

As a EFNA Board member of the Committee I could link all my previous experience. The situation regarding the position of one of the largest marginalized groups in the world is still very bad. PWDs around the world and especially in less developed and underdeveloped countries continue to face enormous poverty, barriers and discrimination.

For all these reasons it is a great challenge for me to make a personal contribution to the promotion of human rights of PWDs, with a focus of people with neuromuscular disorders, especially in the field of: new therapies for NMD patients, linking with pharmaceutical companies which they dealing with rare diseases ETC.

Signature of Nominee:

Date: November 2, 2022



To be completed by the nominating organisation

Please briefly outline why your organisation would like to be represented on the EFNA Board:
(Less than 300 words)

EAMDA is a nonprofit umbrella organization that connects together neuromuscular diseases associations across the European Union. Our mission is to represent, protect and enforce the rights of people with NMD, as well as to raise awareness about these diseases and ensure a support network for patients all over Europe.

The aims EAMDA are:

- to advocate the rights and interests of everyone living with a neuromuscular disorder,
- raise awareness
- promote related research,
- prevent the consequences of associated disability
- support efforts towards new treatments for neuromuscular disorders



- access to new treatments available worldwide;

EAMDA cannot compete in the field of basic researches, but it can creatively contribute to strengthen the organisation and increase the efficiency of national NMD organisations, especially in Central and Eastern Europe, in partnership with strong organizations, like EFNA.

Also, policymakers at the national and EU level should be aware that it is possible to make conditions in the society for better position of persons with NMD (with the technological support, making preconditions for good health condition and appropriate medical care). It means that we can be equal citizens and play active social roles in private and public life.

One of our key priorities is better access to healthcare in sense to provide information about new medical treatments for neuromuscular disorders, to improve healthcare systems on local and international level and to work for better access to quality healthcare of people with neuromuscular disorders. Also to cooperate with scientists, medical doctors, pharmaceutical companies and other hi-tech industries in order to achieve more efficient communication between them and NMD patients' associations.

This is why EAMDA wants to be represented on the EFNA Board.

Please briefly outline why you feel the above-mentioned nominee is suitable for the role of EFNA Board Member:

(Less than 300 words)

Ms. Ivanka Jovanovic has its second term as EAMDA Executive member and as EAMDA Vicepresident. I have been cooperating with her successfully for more than a decade. She showed enormous support to the neuromuscular disorders (NMD) community on the European level. As an active EAMDA Executive member Ms. Ivanka Jovanovic has always been in favor of developing effective political and process solutions to ensure better access to human rights of people with different disorders, especially in order to respect the equity, access to medical treatment and better quality of life. Her skills to show real-based evidences on critical points of human rights insufficiency among NMD community has always been noticed and respected in EAMDA and with her touch to the social sensibility she helped us to develop long-term solutions for people with NMD across the European Union. Her candidacy for EFNA Board is important for EAMDA due to establishing an accessible and inclusive environment for people with neuromuscular disorders as well as to ensure better connection between researchers into new and effective therapies for neuromuscular disorders.

Signature of Representative from Nominating Organisation: Arabela Acalinei

Position: President of EAMDA

Date: November 2, 2022



Please send your completed form to EFNA Executive Director, Orla Galvin: orla.galvin@efna.net