

INNOVATIVE SUMMER CAMP FOR PEOPLE WITH NMD

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This article presents important activity EAMDA organizes for people with neuromuscular disorders (NMD) from different European countries. The article content is structured through question/answer methodology and in lay way draw the purpose of European Alliance of Neuromuscular Disorders Associations (EAMDA), meaning characteristics of neuromuscular disorders, importance of the camp for people with NMD, answers the question who qualify to attend the camp, why it has such importance for the community, and finally what are positive effects of swimming to people with NMD. Promoting social activities for people with NMD is as important as ensuring good quality of life with supportive services (i.e. personal assistance, supportive technology, accessible environment, inclusive society,...) as well as leisure activities to enhance social network of the individual diagnosed by NMD.

What is EAMDA?

European Alliance of Neuromuscular Disorders Associations (EAMDA) is an umbrella organization, which connects together different neuromuscular disorders (NMD) associations in Europe. Our members are therefore European associations of people with neuromuscular disorders. EAMDA's mission is to be influential voice of patients with NMD on European level. The main goal is to increase the awareness of public about neuromuscular disorders and different networks of patients associations and to represent and enforce the rights of people with neuromuscular disorders, improving the quality of life in terms of equal treatment, personal assistance, accessibility and standards of care. The purpose of EAMDA is to work with partner organizations across Europe to increase the awareness about NMD and to improve the quality of life of people with this condition.

What are neuromuscular disorders (NMD)?

Neuromuscular disorders is a broad term that refers to a group of genetic, hereditary, chronic, degenerative and progressive disorders that affect infants, children, young people and adults. NMD have an impact on muscles and direct nervous control system and can lead to muscle weakness and wheelchair dependence. These are chronic and rare disorders which may result in additional secondary medical consequences. Most types of NMD are multi-system disorders with manifestations in body systems, affecting mainly the heart and lungs. People with NMD are usually highly intelligent individuals with an active social life, having families of their own and participating in the society. The only precondition for that is to have adequate physical support provided by personal assistants, who are taking care of individual diagnosed with NMD. The important aspect in social development of people with NMD is open barrier-free environment based on educational opportunities and equal rights.

What is the Summer Camp for people with NMD?

EAMDA Summer Camp is one of the most important events in the annual calendar of activities of the organization. It is organized every summer on the Croatian seaside in cooperation with Croatian Muscular Dystrophy Association. The main purpose of the Summer Camp is to provide people with NMD professional training on different medical and social aspects of life with neuromuscular disorder. The camp consists of workshops, focused on the equal access to healthcare, prevention of the secondary disease consequences, standards of care and latest innovations in technologies. The daily program of the camp also includes rehabilitation with physiotherapy for all participants in fully accessible environment. Attendants can use efficient physical and anti-pain therapy devices, which have positive effect on health condition and are important for muscle stimulation. Important aspect of the camp is possibility of all people with NMD to practice swimming in the sea. There is a special section in the program, which is focused on the development of technologies and establishment of cooperation between technological companies and people with neuromuscular disorders. For younger participants special games are organized to train social skills with peers and to practice English language.

Who can attend?

The Summer Camp gathers together people with neuromuscular disorders from different European countries, providing them an opportunity to exchange information on disease and to build community network. This event is primarily designed for young people with NMD, ages of 10 to 25 years, but the praxis shows it has great importance for older people too. We encourage participants to apply intergenerational solidarity. The camp perspective is to offer educational aspect to people with neuromuscular disorders, their caregivers and most important to draw a nice atmosphere for spending active summer time at the Adriatic seaside.

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HELLO
SUMMER





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Why the Summer Camp for people with NMD is so important?

EAMDA Summer Camp is unique event, which is organized once a year by and for people with neuromuscular disorders. It is focused on different challenges of life with NMD, providing first-hand experience of participants and useful recommendations for patients' daily life. This camp is an innovative way to establish network of support between young and adult people with NMD and to host attendants with variety backgrounds, nationalities and NMD disorders. It is also a great opportunity to present the needs of people with neuromuscular disorders to medical and other experts. The Summer Camp is important for patients with neuromuscular disorders, because it provides educational training, opportunities for professional rehabilitation, swimming and quality care in one of the most beautiful places on the Croatian seaside.

Why the Summer Camp is organized in the summer time?

Summer is the warmest season when people can slow down their daily activities and go on holiday, creating new friendships and learning new things. This is the best time to gather together people from different ages with different neuromuscular disorders, providing them an opportunity to exchange knowledge and experience. Also this is the best time to provide opportunities for swimming for people with NMD, which is an essential part of the rehabilitation process. In general summer time provides much more opportunities for people with NMD to be active as cold temperatures are not our ally.

Why swimming in water is so beneficial for people with neuromuscular disorders?

Swimming in water is highly recommended for people with NMD, because it helps to eliminate the gravity and to increase the extension of movements. It provides many benefits, including development of physical capacity, rehabilitation of breathing and lung function, augmentation of movements. Swimming helps to maintain good physical condition and to slow down the progress of the disease. It is very important part of our daily rehabilitation. There exist several scientific publications that support positive effects on individual diagnosed with NMD.

Where the Summer Camp is organized?

The Summer Camp takes place at the seaside of Croatian coast. This is one of the most beautiful and fully accessible areas on the Adriatic seaside.

Who are our partners?

Partners of the EAMDA Summer Camp are Croatian Muscular Dystrophy Association and Croatian Union of Associations of persons with disabilities, as well as other local, national and international supporters.

How you can help the camp to be available to more people with NMD?

The Summer Camp is one of the most important social events in the EAMDA calendar, which helps people with neuromuscular disorders from Western, Central and Eastern Europe to gather together and to establish united network of support. This camp enhances the collaboration between people with NMD, proving the fact that together we can achieve better integration in the global community. You can support the camp by disseminating information about it and promoting its activities. This is unique event, which deserves higher popularity among patients and European patients' organizations.

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