

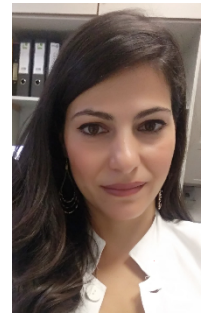
MDA Hellas

Greece



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1. About

MDA Hellas was founded in Greece in 2000 in order to improve the quality of life of people living with Neuromuscular Diseases (NMD). Its action is based on raising awareness and mobilizing private initiatives as well as volunteering. During all these years, MDA Hellas has founded and supports 4 equipped Special Units for Neuromuscular Diseases in state hospitals of our country, in Athens, Thessaloniki and Patras, so much for children as for adults with NMD. We support medical research, promote public awareness through educational programs, organize activities for our members aiming to their integration in all areas of social life and participate in European programs of research into NMD. More than 1500 families are registered in the Association nationwide today, some of which with more than one member being a patient.

My role in the organization is that of the Scientific Advisor.

2. Mission

Our mission is to improve the quality of life for people living with Neuromuscular diseases by assisting them with all available means and ensuring that no-one is left behind, by taking actions that are aiming to their equal inclusion in the Greek society.

One of the most important purposes of the Organization is to raise awareness and educate the public on neuromuscular diseases through various activities such as informative and educational meetings, fund-raising activities and other events of social character.

Our members by own are our driving force! Witnessing their improved well-being through our actions is most motivating.

Our priority is to ensure the proper function of the 4 Special NMD Units, to support our members by all possible means (for example in the provision of indispensable equipment for their condition), to incorporate SMA in the National Newborn Screening Program and continue to inform and raise public awareness for NMD.

3. Focus

- The creation and functional support of 4 properly equipped Special Units for Neuromuscular Diseases in state hospitals of our country, in Athens (2), Thessaloniki and Patras, which continue their successful operation.
- The decisive intervention of the Organization to the Ministry of Health after their initial negative opinion to the application of the family of a baby with SMA, requesting to be supported to travel abroad in order for their child to receive gene therapy in a timely manner.
- Supporting our members by all possible means, such as by providing them with the so needed indispensable equipment for their condition (power wheelchairs, cough assist, braces).
- The Organization's co-operation with various Research Institutes in order to conduct studies related to NMDs and addressing their results to the Ministry of Health aiming to ameliorate the quality of life for people living with neuromuscular diseases.

4. Coming up

Financial sustainability is always a challenge for non-profit organizations in order to be in the position to support their members in their needs which are numerous and unfortunately only partially or even at all reimbursed in Greece. MDA does not have and never had any state subsidy throughout the course of its work. Therefore, all of its actions aiming at supporting its members are implemented by raising the awareness of private initiative. The most important source of income, but also a means of notifying its work to the general public, are the events organized every year.

Our biggest challenge is to implement Newborn Screening for SMA in Greece.

At the moment, we are concluding our SMA Patient Journey Project, which is an effort to map and evaluate the cost that Greek SMA patients and their families bare during their journey from diagnosis and on through a survey.

