

# The role of Patient Organizations in supporting diagnosis and beyond

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# Patients Association

1. PATIENS

2. Medical  
community

3. STATE

Three different audiences, with different needs for information, communication and approach



# The role of Patient Organization

## 1. Patients

Before and during diagnosis:

- Mentoring and referral to specialized services
- Presence in breaking bad news/ Immediate connection of families to the patients association by health professionals

After diagnosis:

- Patient interconnection
- Participating in Support groups
- Reference to social services and community resources, information on their rights
- Adequate information on standards of care, the importance of prevention, the importance of compliance, developments in the field of their disease
- Logistics support



# The role of Patient Organization

## 2. Health professionals

- Informing on the problems and needs of patients both in Greece and abroad through similar social services of other patients associations around the world
- Training for the appropriate Patients' management and their problems, mainly for non-medical issues such as doctor-patient communication, but also for a more holistic approach
- Developing a communication “bridge” between patients and doctors for a holistic treatment of their health, thus addressing the communication gap that may exist between them
- Assistance to bureaucratic issues, involvement in the communication of doctors with the industry, assistance in the process of conducting clinical trials and in their effort for patients' access to drugs.



## The role of Patient Organization

### 3. State

- Information on the needs of both patients and doctors as well as submission of proposed solutions
- Representation of patients and their needs, by promoting legislative changes in the health system.
- Prevention, eg suggestions for prenatal and neonatal screening.
- Raising public awareness



## Difficulties and obstacles faced by MDA Hellas

- ❖ The rarity of diseases
- ❖ The lack of referral of patients by health professionals  
Health professionals do not always attempt to connect patients with social services / patients' organizations
- ❖ Collaboration with medical staff
- ❖ Funding



## Breakthroughs of MDA Hellas

- ✓ Recognition by the medical community
- ✓ Participation in respective European and world associations
- ✓ Patients' access to innovative orphan drugs when applicable
- ✓ Research support and ongoing collaboration between medical staff, industry and government agencies



## Breakthroughs of MDA Hellas

- ✓ Creation and support of 3 Multidisciplinary Neuromuscular Units in Public Hospitals
- The NMD Unit at the General Hospital of Patras is the first center of expertise for specific diseases
- The Agia Sofia Children's Hospital NMD Unit is currently conducting 3 clinical trials in DMD and SMA
- The NMD Unit at AHEPA is currently conducting a clinical trial at DMD





## Clinical trials in the Units of Neuromuscular Diseases

In progress:

- In Athens, an interventional study, phase IIb, of ReveraGen for the drug Vamorolone - a synthetic steroid. 5 of our Members with DMD, 4-7 years old, are participating
- In Athens and Thessaloniki, an observational study , phase IV, for Translarna, by PTC Therapeutics, involving 5 patients with DMD
- In Athens, a retrospective and prospective observational registry to explore the epidemiology, clinical profile and therapeutic management of SMA patients in Greece, of Genesis Pharma - Biogen, with the participation of 8 of our patients.





**Thank you!!!**