

Actions & vision of the Cyprus Association of Inherited Metabolic Diseases 'Aspida Zois'

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Theme 7: Rare Disease Patient Groups Innovations

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Abstract

"Aspida Zois" (Life Shield) is a non-profit Association for patients, families and friends of patients suffering from Inherited Metabolic Diseases (IMDs). It was officially established on 2013 and it is based in Cyprus. It is a full member of EURORDIS and the Cyprus Alliance for Rare Disorders (CARD). The president of the association is a member of the European Reference Network for inborn errors of metabolism MetabERN. The aim of the Association is to support the improvement of health services for people with IMDs in Cyprus by qualified personnel (metabolic physicians, metabolic dietitians, neurologists, geneticists, laboratory scientists, psychologists, occupational therapists and others). 'Aspida Zois' morally supports patients suffering from IMDs and their families, and it contributes to the protection of patient rights. Through educational seminars co-organized with the Cyprus Institute of Neurology & Genetics, as well as with medical schools of the country, we invite expert lecturers in the field of inherited metabolic diseases from abroad, providing continuous and updated information to Cypriot physicians and patients' families. We support the promotion of scientific research to increase knowledge on IMDs, hoping eventually for new and/or improved therapies. Through media, representatives from our association inform the public about IMDs and the social implications of the difficulties incurred, as well as the government officials through personal meetings with them, outlining specific measures that will help resolve various issues. Representatives from our association attend various conferences abroad, having the opportunity to share knowledge and ideas with other patient organizations and health care professionals in the fields of inherited metabolic diseases and rare diseases in general; sharing experiences and strengthening bonds with them.

Association Purpose

- The improvement of health conditions and treatment of people with IMDs
- The protection of the rights of patients suffering from IMDs
- Continuous updating of patients, parents and guardians concerning their IMD and the effects it has on the present and the future, through educational seminars organised by our association
- The promotion of scientific research
- The development of relationships and ties with other similar associations in the EU and worldwide
- The promotion of public awareness and any competent government about IMDs & the social implications of the difficulties incur
- Communicating with doctors and specialists to establish meetings with patients suffering from IMDs either in Cyprus or abroad

Major Activities

- Organizing seminars and low protein cooking events by inviting professional experts on the field of IMDs from abroad. The audience are patients and families of patients with inborn errors of metabolism, health care professionals and academics



- Organizing Social Events for both, entertainment and at the same time raising awareness for rare IMDs



- Raising awareness through the media (TV, radio stations, newspapers, internet)



- Offering compassion and presents to patients at the Children Hospital during Christmas time



Conclusions

Visions of the Association 'Aspida Zois':

- Establishing an official agreement between Cyprus Ministry of Health with an accredited metabolic center abroad aiming a metabolic pediatrician and metabolic dietitian from abroad to visit Cyprus every 6 months to examine patients (in progress)
- A pediatrician and a dietitian from Cyprus to get trained to become metabolic specialists (Long term - initiative created)
- A metabolic Clinic to be established in Cyprus (Long term goal)