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Plenary 3: The How Of HTA: Methods, Tools, & Capacity For System Shaping

Dimitrios Athanasiou | Board Member and Patient Advocate | World Duchenne Organization

Biography

Dimitrios Athanasiou holds a BA in Business Administration and an MBA in Financial Management.

He speaks three European languages and has more than 25 years of experience with international business projects, working in various countries in consulting, developing, and reorganizing companies. When his son was diagnosed with Duchenne Muscular Dystrophy, a fatal and incurable rare disease, he became a strong international patient advocate in Duchenne and Rare Diseases.

Having a passionate personality and technocratic background, he educated himself with basic rare disease and advocacy knowledge via the EURORDIS Summer School and then with the 14-month Patient Expert Course of the European Patient Academy of Therapeutic Innovation (EUPATI) acquiring basic biotech and regulatory knowledge, where he served as a Member of EUPATI's Course Committee for the next year, representing the patient voice. Being an EUPATI fellow, he established the Greek EUPATI National Liaison Team.

Locally in Greece was the Duchenne patient representative of MDA HELLAS, created an active network of patient advocates, and became a board member of the World Duchenne Organization (WDO) promoting a vibrant network of patient organizations where children with DMD will have access to the best care irrelevant to where they live. He was a board member of the European Patient Forum EPF, the umbrella of the patient organizations in Europe. He is a founding member and serves on the Board of the Greek Patients Association the 95 Rare Alliance Greece and is the chair of Rare Diseases Greece.

In his role as a patient advocate, he interacts with Regulators, HTA authorities, Industry, and Academia promoting the rights of patients with rare diseases to have access to the best care possible and to new, safe, and affordable drugs for rare diseases.

As a strong and committed patient advocate for DMD and rare diseases, he serves the patient community through various roles. He was a board member of EPF, a EURORDIS EPAC/TAG member, served on the Board of the European Forum for Good Clinical Practice (EFGCP), Co-Chairing the Children Medicines Working Party (CMWP), Patient Advisor in TREAT-NMD Advisory Committee for Therapeutics (TACT), DIA's Program Committee Member and many others.

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In 2014 he was nominated patient expert by EMA for DMD and has participated in several of EMA's Scientific Advice, SAG, Protocol Assistance, and CHMP pilot meetings for Duchenne, providing the essential patient representative perspective when companies request regulatory advice or approval. He was a PDCO member in the European Medicines Agency till 2023 and is currently a PCWP member.