Curriculum Vitae

Personal information

Dimitrios Athanasiou

Work experience

I speak three European languages and have more than 25 years of experience with international business projects, working in various countries in consulting, developing, and reorganizing companies.

When my son was diagnosed with Duchenne Muscular Dystrophy, a fatal and incurable rare disease, I became a strong international patient advocate in Duchenne and Rare Diseases.

I hold a BA in Business Administration and an MBA in Financial Management.

1. Employer: WORLD DUCHENNE ORGANIZATION / UPPMD
   - Start date: 012015
   - End date:
   - Position: Board Member
   - Activities:
   - Country: Greece

Education and training

1. I hold a BA in Business Administration and an MBA in Financial Management.
2. I have educated himself with basic drug development in rare diseases in the EURORDIS Summer School and
3. the 14-month Patient Expert Course of the European Patient Academy of Therapeutic Innovation (EUPATI) acquiring basic biotech and regulatory knowledge,
4. Served as a Member of EUPATI's Course Committee for the next year, and I am a tutor in EUPATI since

Additional information

Publications

Co Author in

Book title and edition number:	"Essentials of Translational Pediatric Drug Development" - 1st edition
Author:	GASTHUYS
ISBN:	9780323884594
Date book posted:	30 July 202

Recommendations by the European Network of Paediatric Research at the European Medicines Agency (Enpr-EMA) Working Group on preparedness of clinical trials about paediatric medicines process April 2021 Archives of Disease in Childhood 106(12):archdischild-2020-321433 DOI: 10.1136/archdischild-2020-321433

European regulators' views on a wearable-derived performance measurement of ambulation for Duchenne muscular dystrophy regulatory trials June 2019 Neuromuscular Disorders 29(7):514-516 DOI: 10.1016/j.nmd.2019.06.003

The complexity of funding rare disease research: an IRDiRC assessment of the landscape *Rare Dis Orphan Drugs J* 2024;3:27. 10.20517/rdodj.2024.18

EURO-NMD registry: federated FAIR infrastructure, innovative technologies and concepts of a patient-centred registry for rare neuromuscular disorders Orphanet Journal of Rare Diseases † February 2024 Orphanet Journal of Rare Diseases 19(1) DOI: 10.1186/s13023-024-03059-3

Social/ economic burden and health-related quality of life in patients with Spinal Muscular Atrophy (SMA) in Greece October 2023 Journal of Health Policy & Outcomes Research DOI: 10.7365/JHPOR.2023.2.6

607P A patient-centered registry for rare neuromuscular disorders with federated FAIR infrastructure: the EURO-NMD Registry Hub September 2024 Neuromuscular Disorders 43:104441.556 DOI: 10.1016/j.nmd.2024.07.565

Propelling Healthcare with Advanced Therapy Medicinal Products: A Policy Discussion December 2020 Biomedicine Hub 5(3):1-23 DOI: 10.1159/000511678

EP.48Informing paediatric clinical research participants: an innovative approach September 2019 Neuromuscular Disorders 29(1):S115 DOI: 10.1016/j.nmd.2019.06.280

Unmet Medical Need: An Introduction to Definitions and Stakeholder Perceptions August 2019 Value in Health 22(11) DOI: 10.1016/j.jval.2019.07.007

A Multimodal dataset for authoring and editing multimedia content: The MAMEM project October 2017 Data in Brief 15 DOI: 10.1016/j.dib.2017.10.072

The MAMEM Project - A dataset for multimodal human-computer interaction using biosignals and eye tracking information. July 2017 DOI: 10.5281/zenodo.834154

Projects

ACRONYM	TOPIC ID	PROGRAMME
VISION DMD	PHC-14-2015	H2020
BIND	SC1-BHC-01-2019	H2020
EURO-NMD Registry	PJ-01-2019	3HP
ERDERA	HORIZON-HLTH-2023-DISEASE-07-01	HORIZON
SHARE4RARE	ICT-11-2017	H2020
MyHealth_at_MyHands	DIGITAL-2024-CLOUD-AI-06-HEALTHACCESS	DIGITAL
Trials@Home	IMI2-2018-14-04	H2020
BEAMER	IMI2-2020-23-06	H2020
ENKORE	HORIZON-JU-IHI-2023-04-05-two-stage	HORIZON
BRECISE	HORIZON-JU-IHI-2024-07-03-singe-stage	HORIZON

Memberships

Board member of the World Duchenne Organization (WDO), was board member of the European Patient Forum EPF and currently is chairing EPFs Ethics Board. He is a founding member and serves on the Board of the Greek Patients Association the 95 Rare Alliance Greece and is currently the Chair of Rare Diseases Greece.

Other Relevant Information

I am a patient representative

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 currently 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.

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. e was a PDCO member in the European Medicines Agency till 2023 and is currently a PCWP member.