



Attendance Report

**Conference: “17th European Patients' Rights Day:
Advanced Therapy Medicinal Products in Europe:
Combining Sustainability, Innovation and Respect for
Patients' Rights”**



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**WP3 / T3.2 : Participation in EU
Policy Events**

The Thalassaemia International Federation (TIF), represented by Mrs. Eleni Antoniou, Senior International Affairs Officer, participated in a conference held on 26 April 2023 at the European Parliament, hosted by the MEP Brando BENIFEI (Italy), S&D and the MEP Tomislav SOKOL (Croatia), EPP, in collaboration with the MEP Interest Group "European Patients' Rights & Cross-Border Healthcare" and the TRANSFORM MEP Interest Group.

Entitled “17th European Patients' Rights Day: Advanced Therapy Medicinal Products in Europe: Combining Sustainability, Innovation and Respect for Patients' Rights”, the event was dedicated to Advanced Therapy Medicinal Products in Europe, a topic related to several patients' rights, namely access to care, personalised treatment, innovation and information - proclaimed by the European Charter of Patients' Rights.

Mrs. Antoniou actively participated in the first roundtable discussion focusing on innovation, highlighting the importance of providing targeted incentives to researchers, whether academic or industry, as well as patient engagement from the very early stages of drug product design to clinical trials, regulatory processes, market access and beyond to ensure patient acceptance and adherence. She took note of the importance of increased transparency with regard to clinical trial participants and outcomes, making reference to how lack of transparency led to the withdrawal of Zynteglo, the first EMA-approved gene therapy for beta thalassaemia, from Europe in 2021. Mrs. Antoniou stressed that advanced therapies should be considered as an investment instead of a cost, noting the current cost of thalassaemia care in several EU countries and the importance of data collection and disease-specific registries.

Event Details: <https://www.activecitizenship.net/insights/1103-advanced-therapies-time-to-consider-them-an-investment-instead-of-a-cost.html>



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