



Attendance Report

11th European Conference on Rare Diseases and Orphan Products



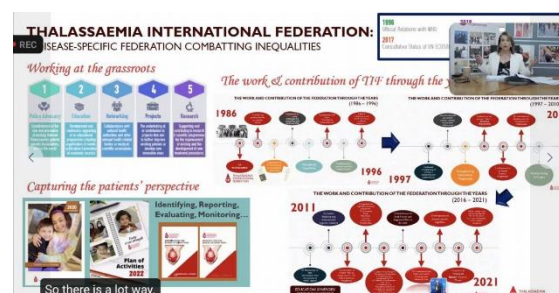
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WP3 / T3.2 : Participation in EU Policy Events

The European Conference on Rare Diseases & Orphan Products (ECRD) is a patient-led rare disease event in which collaborative dialogue, learning and conversation takes place, forming the groundwork to shape goal-driven rare disease policies and allow for important and innovative discussions on a national and an international level to take place. An official event of the 2022 EU French Presidency, the ECRD 2022 took place online from 27 June to 1 July 2022, gathering over 800 stakeholders from across the community to drive reflections on rare disease policy in Europe through 2030. During the five days of the Conference, policy makers, researchers, academia, and civil society debated on a range of issues facing the rare disease community: from ensuring healthy lives and promoting well-being for all people living with a rare disease, through reducing inequality, to building resilient infrastructure and fostering rare disease innovation.

The Thalassaemia International Federation (TIF), represented by Ms Eleni Antoniou (TIF Senior Policy Officer) actively participated in the programme committee and thus in the organisation of the ECRD sharing the policy priorities of the thalassaemia patient community.

Dr Androulla Eleftheriou, Executive Director, delivered a presentation on the existing inequalities in thalassaemia, how these are being reduced and outline the role of TIF. After explaining the complexity of disease management, Dr Eleftheriou outlined the global unmet needs, as presented in TIF's Global Thalassaemia Review 2021 and then shed light onto the activities of the Federation and how these combat inequalities, given the added value of education, awareness-raising and stakeholder engagement to this end. Dr Eleftheriou indeed supported that visibility is a pre-condition for inclusion of people with thalassaemia in society and called upon the patient community to be more active, as the patients' voice needs to be heard at all levels.



Disclaimer: This publication is funded by the European Union (Grant Agreement No 101083240). Views and opinions expressed are however those of the author(s) only and do not reflect those of the European Union or HaDEA. Neither the European Union nor the granting authority can be held responsible for them.