

HEADQUARTERS

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Press Release

TIF's EUROPEAN CAPACITY BUILDING WORKSHOP IN ROMANIA: Knowledge, Networking and Empowerment for Patients with Thalassaemia and Rare Anaemias

Over 200 patient association representatives, patients, caregivers, and researchers, joined by medical experts specializing in thalassaemia and haemoglobinopathies, convened in Bucharest, Romania, from May 16 to 19, for the **TIF Capacity Building Workshop for Thalassaemia Patients and Healthcare Professionals**. This collaborative event was dedicated to networking and the exchange of vital knowledge regarding ground-breaking research in haemoglobinopathies and recent advancements in treatment approvals aimed at enhancing patient care.

The workshop, conducted as part of the esteemed Federation's educational program, was deemed successful. It boasted attendees from over 25 countries, including but not limited to Cyprus, Greece, Italy, the United Kingdom, Germany, Spain, Sweden, Romania, the United States, Canada, Saudi Arabia, India, the Maldives, and Malaysia. Focused on patient education and skill-building during its three-day agenda, the event significantly contributed to empowering patients and their caregivers, an essential component for their active involvement in decision-making and influencing health policies that impact their lives and well-being.

Concurrently with the workshop, the **1st Rare Anaemias International Network (RAIN) Patients' Summit** took place, highlighting the most recent advancements that are transforming the field of rare anaemias. Topics such as early diagnosis, mental well-being, and patient access to specialized care received meticulous analysis from experts in the field.

A standout moment of the event was when patients from Saudi Arabia, France, Italy, Canada and Malaysia who live with thalassaemia and other rare anaemias, shared their personal stories,

providing attendees with a vivid glimpse into the daily challenges they endure because of their conditions.

"This workshop serves as a poignant reminder that we are truly a global family—an extended community recently widened to embrace patients and their families living with various rare anaemias. We share the same doctors, healthcare services, and to some extent, similar necessities, and priorities," stated **Mr. Panos Englezos, President of TIF**. He added, *"Knowledge is more vital than ever given the significant advancements in the care and treatment of hemoglobinopathies. At the dawn of these new horizons, patients must be prepared, strong, and most importantly, united. This unity will enable them to recognize the impressive scientific developments in recent years and understand the importance of incorporating these innovations into our care protocols."*

Since its inception in 1986, the Thalassaemia International Federation (TIF) has been staunchly committed to educating individuals with thalassaemia about their condition, their rights to high-quality medical services, and their comprehensive healthcare needs. Representing 232 patient associations across 63 countries, TIF advocates for those affected by thalassaemia and other hematological disorders and offers a broad and regularly updated array of informational and educational resources to both patients and healthcare providers.

The Capacity Building Workshop for Thalassaemia Patients and Healthcare Professionals was organized as a part of the "THALassaemia In Action 2024" (THALIA 2024) project. This significant project, now in its seventh year, continues to be supported by European co-funding and is executed by TIF.

Agios Pharmaceuticals, Vertex Pharmaceuticals, and Bristol Myers Squibb were the proud sponsors of this year's event.





