

Official Global Press Release

International Thalassaemia Day 2024: The #BeAwareShareCare Movement Rallies for Change Amid a Transforming Thalassaemia Treatment Landscape



International Thalassaemia Day, observed annually on 8 May, is a global movement devoted to raising awareness and understanding of the condition amongst the public and policymakers, while uniting the thalassaemia community worldwide in advocating for improved healthcare and quality of life for patients.

NICOSIA, May 8, 2024 / Thalassaemia International Federation (TIF) – This International Thalassaemia Day (ITD), the Thalassaemia International Federation (TIF) calls all stakeholders and the broader society to join forces and break down the barriers that hinder equal access to both current and future treatment options as well as comprehensive care, for people with thalassaemia.

Building on recent breakthroughs in the field of haemoglobinopathies, marked by regulatory approvals of cutting-edge therapies for thalassaemia in the US, UK, and EU, the 2024 theme—'***Empowering Lives, Embracing Progress: Equitable and Accessible Thalassaemia Treatment for All***'—highlights the critical need for a united effort to guarantee patients' access to all safe and approved treatments.

The theme also underscores the importance of continuous concerted efforts in awareness and advocacy to drive real change in the lives of those impacted by this inherited genetic condition.

Currently, an estimated 100 million people worldwide carry genes responsible for thalassaemia, and an approximate 300,000 infants are being born each year with severe forms of the condition.

Panos Englezos, TIF President, stated: *“Though the medical world has leaped forward in the treatment of thalassaemia, access to even rudimentary care remains a stumbling block for countless individuals. Against a backdrop of global recession, growing inequalities and geopolitical turbulence, International Thalassaemia Day 2024 calls for the health of individuals with thalassaemia to be prioritized ensuring that national infrastructures and services make basic and advanced care options available for every affected patient”*.

Equitable access implies not only groundbreaking treatments but also traditional ones—especially critical in low- and middle-income countries most affected by the disease. Here millions are still deprived of vital disease-specific care, directly disregarding their rights to timely and appropriate healthcare.

“Enhancing access to current and emerging therapies necessitates collaborative solutions developed with all key stakeholders: the pharmaceutical industry, health regulators, healthcare authorities, providers, insurers, and most importantly, patients and their families,” added **Dr. Androulla Eleftheriou, TIF Executive Director**.

United for Change

To mark International Thalassaemia Day on May 8, 2024, the Thalassaemia International Federation (TIF) is launching an extensive range of activities for stakeholders worldwide. Central to the event is a substantial online awareness campaign offering a rich array of multilingual communication resources and educational materials for advocates.



The day will be commemorated in more than 120 countries with a series of events designed to increase awareness. These include blood drives, awareness walks, workshops, festivals, scientific conferences, and more. Participants can explore these events via the interactive International Thalassaemia Day [Events Map](#).

Moreover, the [#BringThalToLight](#) initiative encourages global solidarity by illuminating iconic landmarks, monuments, and buildings in red. This symbolic act aims to connect individuals worldwide in our collective mission to transform the narrative for those affected by thalassaemia.

Discover more about International Thalassaemia Day and how to get involved by visiting <https://thalassaemia.org.cy/itd2024/>.

CONTACT:

If you are interested in arranging an interview with a TIF representative or would like more information, please contact:

Catherine Skari

Senior Communications Officer thalassaemia-cs@thalassaemia.org.cy
+357 96108454

ABOUT TIF: The [Thalassaemia International Federation \(TIF\)](#) is a patient-driven umbrella organization established in 1986. TIF works with over 235 national thalassaemia associations in 62 countries worldwide to support patients' rights to access quality health, social, and other care.

It was founded by a small group of doctors and patients/parents representing National Patient Associations, primarily from Cyprus, Greece, Italy, the UK, and the US. These countries were among the first to recognize thalassaemia as a genetic, hereditary disorder with significant medical, public health, social, and economic consequences if left unaddressed, both in terms of prevention and management.

Our Mission: Prioritizing thalassaemia in national health agendas, along with the development and implementation of targeted control programs (encompassing prevention and clinical management) within national

healthcare systems, which is essential to ensure universal coverage.

Our Vision: To ensure that every patient affected receives equal access to high-quality health care, social services, and other support in a genuinely patient-focused environment.

Our Work: Education | Advocacy | Collaborations/ Networking | Research | Awareness Raising

Our Partners:

- World Health Organisation: In official relations, since 1996
- United Nations Economic and Social Council: In special consultative status, since 2017
- Council of Europe: Participatory status at the Conference of International Non-Governmental Organisations, since 2019
- European Commission: Official partners in the field of Health, since 2018

ABOUT THALASSAEMIA: The thalassaemia syndromes are inherited and genetic blood disorders that affect the production of the normal adult haemoglobin component of red blood cells. Beta thalassaemia is the most frequent and severe form of the disease, leading to the excessive destruction of red blood cells and thus to severe chronic haemolytic anaemia.

Affected patients require lifelong regular blood transfusions from early childhood, combined with iron chelation therapy to prevent complications due to iron overload, such as cardiac morbidity, liver disease, cancer and endocrine dysfunction. To effectively manage the complications of the disease, consequent to disease pathology and treatment, the provision of multidisciplinary care is mandatory. A holistic approach to care also includes social participation and protection that lead to increased quality of life.

Transformative therapeutic approaches are anticipated to radically change the management of thalassaemia in the near future, featuring new medicinal products and cell and gene therapies following rigorous clinical trials.



To find out more about TIF, please visit www.thalassaemia.org.cy