



## **International Thalassaemia Day 2022 - Official Global Press Release**

*On International Thalassaemia Day, the Thalassaemia International Federation (TIF) brings the global haemoglobin disorders community together, by raising awareness, sharing knowledge and bringing thalassaemia to the attention of as many people as possible worldwide.*

**NICOSIA, April 26, 2022 / Thalassaemia International Federation (TIF)**

- This International Thalassaemia Day, 8 May 2022, we recognize and celebrate the power of knowledge. The International Thalassaemia Day (ITD) 2022 theme, ***“Be Aware. Share. Care: Working with the global community as one to improve thalassaemia knowledge”***, is an open call to action to all supporters to promote awareness about thalassaemia and its global impact and share essential information and knowledge to support the best possible health, social and other care of people affected by this disease.

With this core message, the global campaign conducted by TIF for the 18th consecutive year underscores the value of each individual contribution to reducing the prevalence of thalassaemia, whilst stressing that collective action to enhance awareness and understanding around the condition is crucial for its effective treatment.

*“Despite the ‘spread’ of thalassaemia at an increasing rate worldwide, public awareness and information about the condition, in addition to concrete and tangible actions by competent healthcare authorities at the local level towards its effective prevention, control and management, remain significantly limited in many countries. Today we call for the intensification of concerted efforts and collective mobilization by all related stakeholders to change that”,* affirmed **Dr Androulla Eleftheriou, TIF Executive Director.**

It is indeed noteworthy that 8 out of 10 people with thalassaemia across the world are unaware that they have the mutated gene that causes the disease

and that they could have a child with a severe form of thalassaemia, if their partner is also a carrier of the disease. As a result, more than half a million children are expected to be born with thalassaemia and other haemoglobin disorders worldwide by 2030<sup>1</sup>.

*"Improving awareness is the first, critical step to any kind of change. Although its value has been jointly recognized by governments, civil societies and healthcare professionals alike as a key component of sensitization towards thalassaemia, we need to do more to achieve greater understanding of this serious and potentially debilitating genetic blood condition and to allow the establishment and strengthening of disease-specific, patient-centred policies for better health, social inclusion and quality of life of affected individuals and their families"*, added **Mr Panos Englezos, TIF President**.

In celebration of the ITD2022 and seeking to reiterate that thalassaemia awareness and control must become a priority in public health at national, regional and global scales, TIF has launched [a massive online campaign](#) with rich communication and informational resources to disseminate the messages and useful information of the "Be Aware. Share. Care" campaign, and to foster the active participation of all supporters.

Moreover, the Federation has developed 4 brochures that explain in a simple and comprehensive way a wide range of topics pertaining to the disease. This material has been made available **for the first time in the history of TIF's work**, in more than 20 languages in an effort to reach out to as many individuals, stakeholders and NGOs as possible from all over the world and provide them with valuable insights into thalassaemia diagnosis, prevention, treatment, and research.

The International Thalassaemia Day 2022 will be observed in over 110 countries across the globe, where a multitude of awareness-raising events, blood drives, educational activities, scientific meetings, etc. will take place. TIF will actively join initiatives organised in Italy, India, Brazil, Greece, Egypt and Turkey.

Scientific advances for better care, quality of life, and even cure of patients with thalassaemia are at our doorstep and we all need to work towards making them accessible and available to our patients.

---

<sup>1</sup> TIF Publication. Global Thalassaemia Review <https://thalassaemia.org.cy/what-we-do/global-thalassaemia-review/> (2021)

To learn more about International Thalassaemia Day, please visit <https://thalassaemia.org.cy/itd2022/>

---

**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](mailto:thalassaemia-cs@thalassaemia.org.cy)  
+357 22 205 848

**ABOUT TIF:** The Thalassaemia International Federation (TIF), a non-governmental, patient driven umbrella organisation, established in 1986, supports the rights of patients for access to quality health, social and other care through its work with over 235 national thalassaemia associations in 62 countries across the world. Founded by a small group of doctors and patients/parents who represented National Patient Associations, mainly from Cyprus, Greece, Italy, UK and USA i.e., countries where thalassaemia had been recognized early as a genetic, hereditary disorder with huge medical, public health, social and economic repercussions if left unaddressed in terms of both effective prevention and management.

**Our Mission:** The prioritisation of thalassaemia on national health agendas and the development and implementation of effective disease- specific control (prevention and clinical management) programmes within national healthcare systems based on universal coverage

**Our Vision:** To support the provision of equal access of every affected patient to high quality health, social and other care in a truly patient-centred healthcare setting

**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 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.

To find out more about TIF, please visit [www.thalassaemia.org.cy](http://www.thalassaemia.org.cy)