

## HEADQUARTERS

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## International Thalassaemia Day 2019:

### A massive call for universal access to quality thalassaemia healthcare services

**On May 8, 2019, the global thalassaemia community and the Thalassaemia International Federation (TIF) will come together to celebrate the International Thalassaemia Day.** The International Thalassaemia Day is an annual landmark devoted to the strengthening of the lifelong and difficult struggle against thalassaemia, and an opportunity to commemorate those who are no longer with us and renew our promise to keep fighting, until the final cure for thalassaemia is found.

Every year, TIF proposes a different theme and encourages member associations and officials to focus on it with related activities and actions. The International Thalassaemia Day 2019 brings once more patients with thalassaemia to the forefront, with the theme ***“Universal access to quality thalassaemia healthcare services: Building bridges with and for patients”***.

Despite the progress that has been attained over the past decades, millions of people still lack physical or financial access to free-of-charge public healthcare services. The significance of this prominent issue has been emphatically underlined in the United Nations (UN) Sustainable Development Goals, according to which countries all over the world need to achieve universal health coverage and improve access to healthcare by 2030.

Universal and improved access to quality, safe and sufficient healthcare services is also one of the most essential challenges for patients affected by thalassaemia. Expanding the range of the healthcare coverage available to individuals and populations with the disease, as well as the numbers of people who can benefit from such coverage, and ameliorating the affordability and provided quality of healthcare services for thalassaemia, represent some challenging tasks that need to be effectively tackled with and for patients, no matter where they are in the world.



The International Thalassaemia Day 2019 activities include a series of events and activities, such as the organization of a series of online awareness-raising contests, connected to this year's theme, inviting patients with thalassaemia worldwide to fill this day with truly educational and rewarding experiences. To access the International Thalassaemia Day resources, such as a downloadable poster and social media badges, visit <https://thalassaemia.org.cy/news/international-thalassaemia-day-2019-get-involved/>

### **The establishment of the International Thalassaemia Day:**

The 8th of May was established in 1994 by the Thalassaemia International Federation (TIF) as the International Thalassaemia Day, in loving memory of George Englezos, and all thalassaemia patients who are no longer with us. The decision to adopt one day of the year to spread awareness and knowledge on aspects of prevention and management of thalassaemia, derived from the need to unite and strengthen the patients' voice worldwide: an essential pre-requisite to achieve TIF's mission towards the promotion of equal access to quality health care.

### **About thalassaemia:**

Thalassaemia is a genetic disorder of the blood and specifically, the haemoglobin protein, which is contained in the red blood cells and is responsible for carrying oxygen to all the tissues and organs of the body. Thalassaemia belongs to the wider family of haemoglobin disorders. Approximately 7% of the world population is a carrier of a severe haemoglobin disorder, including thalassaemia, and between 300-500 thousand children are born each year with a severe haemoglobin disorder. There are both transfusion-dependent and non-transfusion dependent forms of the disease.

### **About the Thalassaemia International Federation (TIF):**

The Thalassaemia International Federation (TIF) is a global umbrella organisation of 227 members from 61 countries across the world, based in Nicosia, Cyprus. It works in official collaboration with the WHO (World Health Organization) and is dedicated to promoting equal access to appropriate care for all patients with thalassaemia. Most remarkably, TIF has been awarded, in the context of the 68th World Health Assembly in May 2015, the 'Dr Lee Jong-wook Memorial Prize' for the Federation's outstanding contribution to public health.

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