INTERNATIONAL THALASSAEMIA DAY 2022

#ITD2022 #BeAwareShareCare #InternationalThalassaemiaDay

United to achieve better thalassaemia awareness

Marking the 28th International Thalassaemia Day on 8 May 2022, the Thalassaemia International Federation (TIF) brought the global haemoglobin disorders community together, by raising awareness, sharing knowledge and bringing thalassaemia to the attention of as many people as possible worldwide.

The International Thalassaemia Day (ITD) 2022 selected theme, "Be Aware. Share. Care: Working with the global community as one to improve thalassaemia knowledge", was an open call to action to everyone, everywhere 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 disorder.

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

Together, we showed the world that not only is raising our voices about thalassaemia essential but that our attention and support so that every patient can receive the care they need. A huge thank goes out to our members, partners and supporters all over the world for joining us and making a difference!

The ITD2022 global campaign

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 Global Campaign** with rich communication and informational resources to disseminate the messages and useful information of the "Be Aware. Share. Care." theme, and to foster the active participation of all supporters.

A core set of diverse resources and materials was compiled to help communities and individuals in their awareness-raising efforts and help them promote the campaign's advocacy messages, facts, and information both on social media and offline activities for increased impact.

Moreover, 4 educational brochures were developed with the objective to explain in a simple and concise way a wide range of topics pertaining to thalassaemia.

For the first time in the history of TIF's work, this material has been made available **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.

Impact in numbers

- A total of 154 countries participated in the ITD2022 global observation
- 1,000+ photos were submitted only to TIF for its virtual Photo Exhibition

- 1,220,000+ individuals have seen the ITD2022-related posts only on the TIF Facebook page
- 390,000+ people have read at least one ITD2022-related email blast or Press Release

TIF's participation in national events

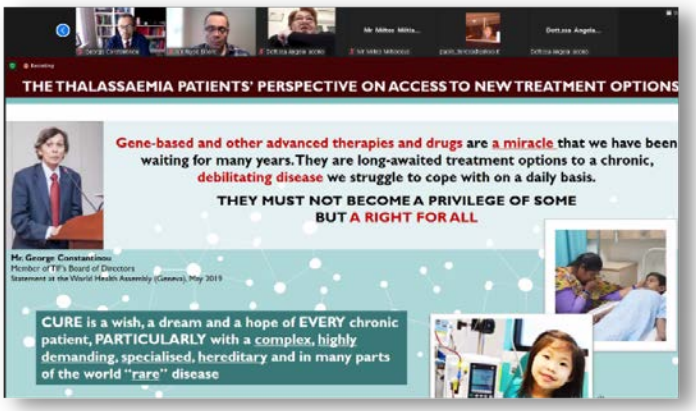
A multitude of awareness-raising events, including blood drives, educational activities, scientific meetings, awareness-walks, and many other initiatives took place for the ITD2022 all across the world.

TIF co-organized with or contributed to several virtual and physical events of its member patient associations in 7 countries; Italy, India, Brazil, Greece, France, Egypt, and Turkey.

ITALY

A special online Capacity Building Event, entitled "Exploring the value of patient advocacy for better thalassemia care", organized by both TIF and the Italian Foundation 'L.Giambrone' (FITHAD), took place on the eve of the ITD2022, May 7.

More than 150 participants, mainly patients from Italy, joined the meeting and had a chance to learn more on the pivotal role of patient advocacy in enabling their active and meaningful participation in decision-making processes regarding their condition and in achieving more inclusive and accessible care for themselves and their communities.



GREECE

The Greek Thalassaemia Association with the support and participation of TIF and under the auspices of the Medical School of the Democritus University of Thrace, Greece, organised the "1st Northern Greece Symposium for Thalassemia and Sickle Cell Disease", on May 6-8, 2022.

The Symposium, held as part of the celebrations for the ITD2022, highlighted topics of interest for both patients and healthcare professionals, such as the latest advances on innovative therapies for haemoglobinopathies, the pediatric patients' management, practical issues of blood transfusion and iron chelation therapy, COVID-19 infections and vaccinations in patients with haemoglobin disorders, and so on.

BRAZIL

The "2nd International Meeting for People with Thalassemia' was organized on May 14, 2022, by TIF and the Brazilian Thalassaemia Association (ABRASTA).

This meeting represented a unique opportunity for patients with thalassaemia from all over the world to exchange experiences with their peers and engage in meaningful discussions over issues, such as relationships, treatment, mental health, and much more.

Through an online platform, segmented by age group and topics of interest, with simultaneous translation in Portuguese, English, and Spanish, all participants were able to share experiences from their everyday life with the disorder and acquire new knowledge.

INDIA

Dr Androulla Eleftheriou represented virtually the Federation at the grand International Thalassaemia Day Awareness Meeting, held on May 7, 2022, by the Thalassemics India and the Thalassemia Patients Advocacy Group at the hotel Le Meridien, Delhi.

Her presentation, entitled 'Time For Action: Create Change & Help Address Existing Challenges for Patients Living in Developing Countries', explored the past and present situation with haemoglobinopathies in the Southeast Asian region and underscored the TIF's view and perspective in achieving improved thalassaemia prevention and care for affected patients.

The event was attended by the Social Welfare Minister of the Delhi Government, Hon. Shri Rajendra Pal Gautam, and gathered a total of more than 250 participants.

FRANCE

To honour the ITD2022, the French Federation of Associations of Sickle Cell and Thalassemia Patients 'SOS GLOBI' put together a webinar (with the help of the MCGRE Filière), in order to contribute to a better knowledge of this disease, which affects about 800 people in France.

Covered topics included the national beta thalassaemia registry, iron chelation treatments, growing up and aging with the disease, blood donation, and more. The Federation was represented in this webinar by Dr Maria Sitarou, Thalassaemia Clinic, Larnaca General Hospital, and TIF's Scientific Collaborator.

EGYPT

The 23rd International Thalassaemia Conference, organized by the Egyptian Thalassemia Association الجمعية المصرية لمرضى أنميا البحر المتوسط, took place on May 24-26, 2022, in Cairo.

The event featured a wealth of scientific sessions on various thalassaemia-related, timely topics, presented by renowned local and international speakers.

Dr Androulla Eleftheriou, TIF's Executive Director, represented the Federation delivering an engaging presentation entitled 'Unmet Needs and Global Efforts in the Control of HB Disorders'.

TURKEY

In the context of the International Thalassaemia Day 2022, TIF participated in a meeting that was organised by the Blood Disease Federation in Alanya, Turkey, on May 6-8, 2022.

During the course of this meeting, TIF had the opportunity to deliver a message related to this annual occasion to the gathered audience, comprised of doctors, healthcare professionals and patients with thalassaemia and other haemoglobin disorders.

Partners with vision

Many industry representatives, international and regional medical associations, national health authorities, and other health-related stakeholders stood by the global thalassaemia community, sharing statements and messages of solidarity and support for and during the ITD2022. Here is a small sample.

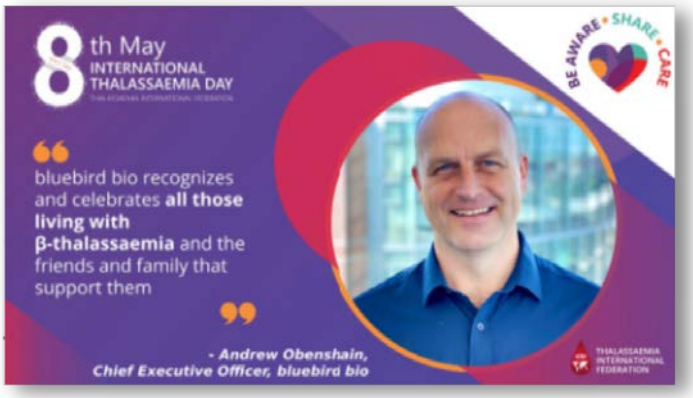
BRISTOL MYERS SQUIBB

A Bristol Myers Squibb (BMS) video prepared exclusively for TIF and the ITD 2022, reaffirmed the company's commitment to continue working to improve the lives and well-being of the thalassaemia patient communities all across the world.

BMS also collaborated with TIF and local partners in the Middle East region, including the Emirates Thalassemia Society and the Sheikh Sultan Bin Khalifa Al Nahyan Humanitarian and Scientific Foundation, to light up the world's tallest tower, Burj Khalifa, in Dubai.

Patients, families, carers and support organisations looked on as the iconic landmark carried a message of support and solidarity for thalassaemia patients, promoting awareness and improving the understanding of thalassaemia.

BLUEBIRD BIO



On International Thalassaemia Day, bluebird bio used social media to amplify the need to improve thalassaemia-related education and knowledge, by sharing useful educational resources. This message was further highlighted with a quote from Andrew Obenshaine, bluebird bio's Chief Executive Officer.

CHIESI GLOBAL

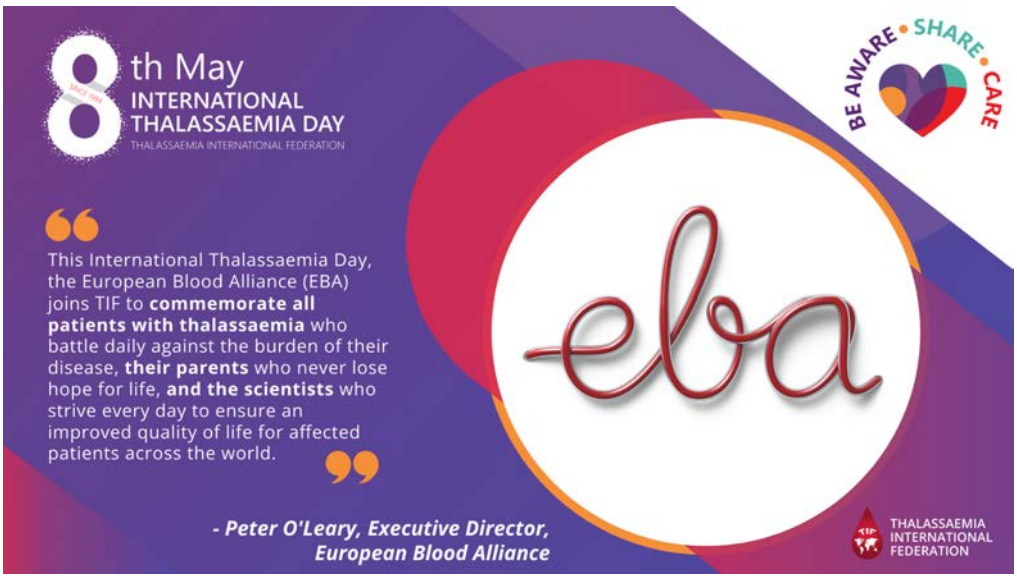
Chiesi Global Rare Diseases drew attention the challenges that people with thalassaemia major face in their everyday lives by posting a video on its #LifeWithThal initiative, created to raise valuable awareness about this disease across different cultures.

The company has even developed a dedicated website for those wanting to find out more on how to support people with thalassaemia in dealing with their disease.

VERTEX PHARMACEUTICALS

Vertex drew attention to its work so far in improving care for patients with thalassaemia and asked everyone to used their video and resources to promote awareness for beta thalassaemia and its global impact.

EUROPEAN BLOOD ALLIANCE



The European Blood Alliance (EBA) which contributes to the availability, quality, safety and cost-effectiveness of the blood and tissue supply for the citizens of Europe, shared with TIF an inspirational quote pf its Executive Director, Peter O' Leary, for the ITD2022.

INTERNATIONAL PEDIATRIC ASSOCIATION

A statement by Prof. Enver Hasanoğlu, President, and Prof. Aman Pulungan, Executive Director, on behalf of the International Pediatric Association (IPA), encouraged greater awareness of thalassaemia and stressed the need to ensure that every child and adolescent with thalassaemia, especially those in developing countries, receive the treatment and care they deserve.

IPA International Pediatric Association

Every Child · Every Age · Everywhere

IPA Statement for International Thalassaemia Day 2022

As the leading voice for children globally, the International Pediatric Association (IPA) stands together to take action and support to all partners to promote awareness about thalassaemia and its global impact. With 80 to 90 million people worldwide estimated to be carriers of beta-thalassemia and 60,000 symptomatic individuals born annually, it is important to elevate thalassaemia as a global public health concern. It is time for us to be aware, not only of the symptoms of thalassemia itself, but also whether or not we are carriers ourselves, to share knowledge and increase understanding to the people around us, and to care and ensure that every child and adolescent with thalassaemia, especially those in developing countries, receive the care and treatment they need and deserve.

IPA: working for Every Child, Every Age, Everywhere

Prof. Enver Hasanoğlu
IPA President

Prof. Aman Pulungan
IPA Executive Director

On behalf of
IPA Standing Committee

CYPRUS MINISTRY OF HEALTH

The message from the Minister of Health of the Republic of Cyprus, Mr. Michalis Hadjipantela, for the International Thalassaemia Day 2022.

Thank you to the thousands and thousands of supporters who spoke up, tuned in, sparked conversations, and supported their communities to make an change this International Thalassaemia Day!

Our heartfelt gratitude goes out to all the TIF member associations and friends, as well as to the international thalassaemia community whose work and efforts each and every day show that our actions matter and are becoming more impactful year by year!

THE TIF TEAM