



ThalassemiaNEWS

A quarterly newsletter keeping the medical and patient community in touch with thalassemia developments

Special Edition

To celebrate International Thalassaemia Day 2025, this ThalassemiaNews Special Edition is dedicated to the Thalassaemia International Federation (TIF).



**THALASSAEMIA
INTERNATIONAL
FEDERATION**

Perhaps best known for its thalassemia guidelines and bi-ennial international congress, TIF's overarching mission is to ensure equal access to quality healthcare for all patients with thalassemia globally. Founded as a National Cypriot patient group, TIF has expanded to a large umbrella Federation with more than 240 member associations across 67 countries

IN PROFILE

An in-depth view of an organization or individual involved in thalassemia

Here we present an in-depth profile of TIF, courtesy of a behind-the-scenes interview with Dr Androulla Eleftheriou, TIF's Executive Director, facilitated by Lily Cannon, Deputy Director.

How did you come to be involved with the organization?

My journey into the world of thalassaemia and ultimately to my role as Executive Director of Thalassaemia International Federation is a unique one, rooted in my background as a microbiologist-virologist. At the time I was leading the reference laboratory for the Ministry of Health in Cyprus, I had a primary focus on public health, particularly in relation to the discovery of the Hepatitis C virus. During this period, the global medical community, including the World Health Organization (WHO), was intensely focused on the progression of viral hepatitis, its chronicity, and the development of antiviral treatments.

Cyprus, at the time, had a significant population of transfusion-dependent thalassaemia patients,



and this became a central issue for public health authorities. Special attention was given to the screening of blood supplies, the introduction of nucleic acid testing, and the close monitoring of patients receiving regular blood transfusions. I found myself deeply involved in the scientific and public health aspects of thalassaemia care, particularly as

new technologies, like polymerase chain reaction, became essential in monitoring viral infections in these patients. This role brought me into close contact with both the thalassaemia patient community and the healthcare professionals dedicated to their care.

Over time, I became more aware of the tireless efforts of patient support groups, particularly those led by parents and caregivers, who were working hand in hand with doctors and the Ministry of Health to improve the lives of thalassaemia patients. I became fascinated by the power of voluntarism in healthcare, seeing firsthand how these groups helped strengthen the healthcare system and made a tangible difference in patients' lives.

My engagement with the national patient support group, under the leadership of Dr. Panos Englezos, who was also the President of TIF, deepened over the years. Since 1993, I have been involved on a voluntary basis, contributing to initiatives at both the national and international levels. This involvement grew, and by 2005, it became clear that my dedication to the cause had positioned me to take on a more active leadership role. After years of service and experience in public health,



Dr Androulla Eleftheriou
Thalassaemia International Federation
Executive Director

the Board of TIF invited me to become the Executive Director.

Transitioning from a permanent government position to a contract-based role



at a non-governmental organization was a significant leap, one that brought with it considerable uncertainty. However, after discussions with my family, I embraced the challenge. I was motivated by a deep belief in the mission of TIF and the opportunity to serve patients on a global scale. It was a privilege to step into this role and to be part of such a passionate and dedicated team.

As Executive Director, my focus has been

to bring TIF's vision to life through strategic actions and initiatives. This includes advocating for the rights of patients, forging collaborations with international bodies like WHO, and working closely with academic, research, and industry leaders to develop clinical guidelines and support research efforts. Over the years, my commitment to this cause has only deepened, and I am profoundly honoured by the trust the TIF Board has placed in me to lead these efforts.

Now, after nearly two decades with TIF, I continue to be inspired by the dedication of the volunteers and patient advocacy groups worldwide. Every day, they confront challenges and unmet needs, turning their struggles into meaningful policy advocacy that improves health outcomes and enhances the social integration of thalassaemia patients. At the heart of this work is the fundamental belief in human rights – that every patient, no matter where they live, deserves access to quality care and the right to live a full and healthy life.

What is TIF most proud of?

It's challenging to pinpoint just one aspect of TIF that we are most proud of, as there are so many milestones that speak to the heart of our mission. However, if I had to highlight a few, I would emphasize our transparency, passion, and unwavering commitment to patient-centered care, which is evident in everything we do.



One of the most impactful activities we've undertaken – and continue to carry out – is our educational program. This initiative spans from organizing events at local, regional, and international levels to publishing a wide range of educational resources, including books and clinical guidelines. What sets TIF apart is that we are the only patient-oriented organization that has taken on the responsibility of creating, publishing, translating, and distributing these essential guidelines free of charge to healthcare professionals worldwide.



We have made a significant impact in the field of transfusion-dependent beta-thalassaemia, providing clear, evidence-based



management guidelines for healthcare professionals. More recently, we expanded this effort to include guidelines for beta-thalassaemia intermedia, a group for which no standardized management recommendations existed until TIF stepped in. We have also pioneered the development of guidelines for alpha-thalassaemia, marking a crucial milestone in providing much-needed information on early diagnosis, monitoring, and treatment options for these patients.

What makes our work even more impactful is that we regularly update these guidelines to reflect the latest research and clinical developments. These guidelines, distributed at no cost to doctors globally, indirectly serve patients by ensuring that healthcare professionals are well-equipped to provide the best possible care.

Beyond our educational programs, TIF takes great pride in supporting and networking with patient organizations worldwide. We facilitate connections between these groups, enabling them to share best practices and support each other. We also work closely with the academic community, research organizations, and the pharmaceutical industry to further empower research and the development of new treatments that can enhance the health and well-being of thalassaemia patients.



One of our greatest achievements is the ongoing, productive collaboration we have with key global and regional partners. TIF is fortunate to maintain a strong working relationship with organizations like the World Health Organization (WHO), the European Union (EU), the Association of Southeast Asian Nations (ASEAN), and the Arab Forum. We also partner with global health bodies like the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), and the European Centre for Disease Prevention and Control (ECDC). Our collaborations extend to medical professional organizations such as the European Hematology Association (EHA) and the International Society of Blood Transfusion (ISBT), where we work together on crucial issues related to blood safety, advocacy, education, and so many others.

These partnerships have been instrumental in advancing our mission, and we are incredibly proud of the work we do with all of these stakeholders to improve the

lives of thalassaemia patients worldwide. Our ability to drive change through collaboration and education is something we hold dear, and it is a key aspect of what makes TIF stand out as an organization.

What are TIF's current top priorities?

TIF's current priorities centre around continuing to enhance and expand our educational programs, while fostering deeper networking and collaboration with all our stakeholders, especially patient groups worldwide. A key area of focus is integrating cutting-edge technologies, such as artificial intelligence, into our initiatives. We've already made progress on this front, with a project that aims to improve our reach and impact, helping us connect with healthcare professionals and patients globally in a more structured and evidence-based manner.



Another priority is to further strengthen these networks, allowing them to provide more informed recommendations to policymakers and decision-makers. By facilitating this exchange of knowledge and experiences, we can help guide policy development that directly improves patient care.



At this moment, it is crucial for us to ensure that decision-makers fully recognize the value of providing quality care to patients with thalassaemia. This is not only vital for the well-being of the patients – who are at the centre of everything we do – but also for the sustainability and resilience of healthcare systems. Addressing the care of chronic, complex genetic diseases like thalassaemia is directly linked to the long-term stability of health and social care systems. If these conditions are inadequately treated or prevented, they can lead to significant morbidity and premature death, placing a heavy burden on national healthcare resources.



Therefore, a top priority for TIF is to help decision-makers understand the impact of these diseases on national disease burdens and encourage the integration of research, innovation, and new technologies into treatment practices. By supporting research, we can reduce the rates of



morbidity and premature death, ultimately giving patients the life they deserve. This is a fundamental human right – to provide patients with access to quality care – while also ensuring the long-term sustainability of healthcare systems.

In terms of the future, what are you excited about?

Despite the significant global challenges we've faced in recent years – ranging from economic, geopolitical, environmental, and climatic crises to public health emergencies like the COVID-19 pandemic – there is much to be



optimistic about. We are particularly excited by the remarkable scientific advances happening across many areas of healthcare, including in the treatment of haemoglobin disorders. For many years, research in this field faced delays, and progress was slow. However, in the past decade, we have seen truly impressive breakthroughs that offer new hope for patients with these disorders.

As we look ahead, our focus is on ensuring that these scientific advances become accessible, affordable, and available to the patients who need them. It's crucial that these



developments are not just theoretical but translated into real-world treatments that can improve the lives of those affected. Science needs to serve the patient first and above all. We are proud to collaborate closely with industry, academia, and research communities that are dedicated to developing new therapies and drugs. Our goal is to provide patients with the opportunity for holistic care and, for some, a potential cure.

This collaboration between science and patient care gives us great hope for the future, and we are excited to be part of this transformative journey toward better outcomes for patients worldwide.

For more information about TIF and its global programs, visit the website at <https://thalassaemia.org.cy/>



INTERNATIONAL THALASSAEMIA DAY #ITD2025 #WEARE1 #PATIENTSFIRST



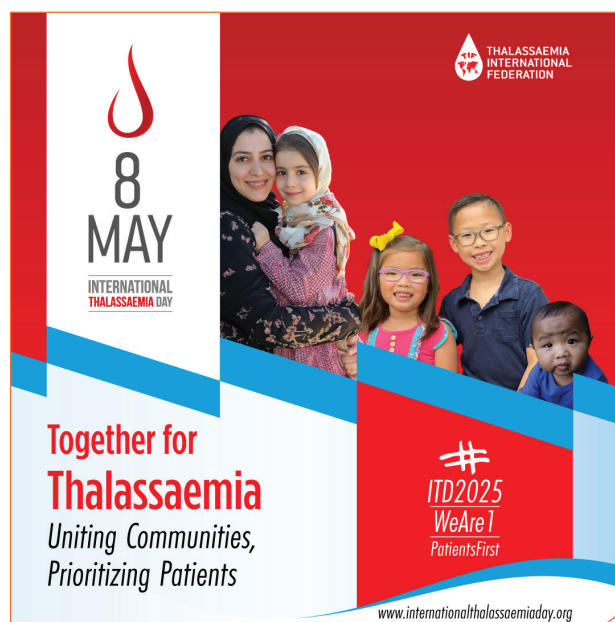
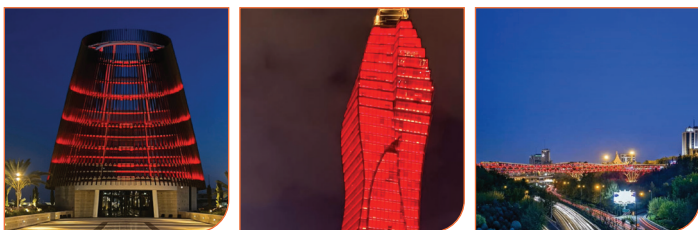
On May 8th each year the global thalassaemia community comes together to celebrate International Thalassaemia Day.

The aim of International Thalassaemia Day is to raise awareness of thalassaemia among the general public and decision-makers as a genetic disease that has a profound impact on many individuals and families across the globe. This is achieved through a unified, collaborative program of activities involving the entire thalassaemia community.

2025 marks the fifth anniversary of International Thalassaemia Day and this year's theme is *'Together for Thalassaemia: Uniting Communities, Prioritizing Patients.'*

There are two key initiatives for 2025;

'Bring Thal to Light' involves illuminating iconic buildings and monuments around the world in red. The aim for 2025 is to surpass the 78 illuminations achieved last year.



'Share Your Journey, Strengthen Our Community' shares personal stories to raise awareness, empower others, and to encourage dialogue about building a future where thalassaemia care is more holistic and patient-centered.



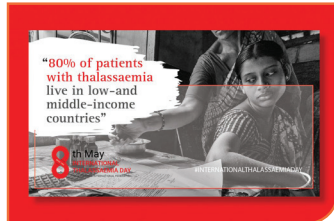
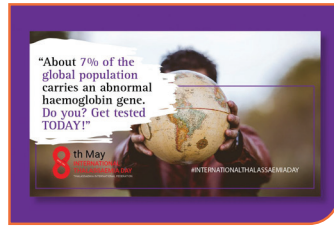
A host of resources and inspiring stories can be found on the website <https://internationalthalassaemiday.org/resources/>



Previous International Thalassaemia Day themes

ITD 2021

Addressing Health Inequalities
Across the Global Thalassaemia
Community



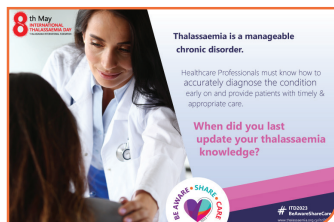
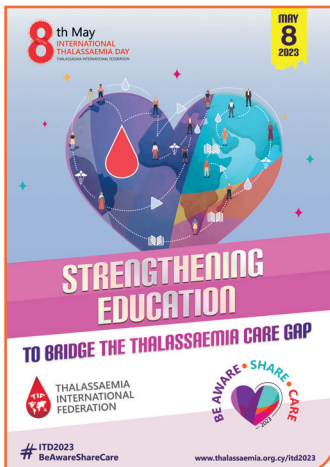
ITD 2022

Be Aware. Share. Care: Working with the global community as one to improve thalassaemia knowledge



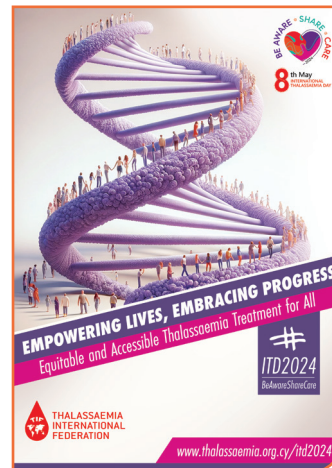
ITD 2023

Be Aware. Share. Care:
Strengthening Education to Bridge the Thalassaemia Care Gap



ITD 2024

Empowering Lives, Embracing Progress: Equitable and Accessible Thalassaemia Treatment for All



A host of resources and inspiring stories can be found on the website
<https://internationalthalassaemiaday.org/resources/>



EDITORIAL POLICIES & TEAM

The objective of this newsletter is to provide updates on new scientific information, resources, and activities of interest to the thalassaemia medical and patient community. The newsletter content is prepared by thalassaemia experts in collaboration with Agios Pharmaceuticals. All of these experts serve as paid consultants for Agios Pharmaceuticals.

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