THALASSAEMIA INTERNATIONAL FEDERATION

PATIENTS · FAMILIES · ASSOCIATIONS

TIF Patient Newsletter

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A message from TIF

Dear friends,

Welcome to the latest edition of the TIF Patient Newsletter. Patients and families are central to our work for better haemoglobinopathy care. In this issue, we bring you progress in treatment, blood safety and prevention, alongside opportunities to build stronger patient organisations, exchange experience and access reliable information.

At TIF, we believe that progress has its greatest value when it reaches people, supports informed choices and strengthens patients' participation in decisions affecting their health and lives. We hope these pages help you stay informed, connect with new opportunities and see how our global community continues to turn knowledge, advocacy and collaboration into better care.

In this edition, we give particular attention to our forthcoming Capacity Building Workshop and Annual General Assembly in Athens and the MENA Thalassaemia Experience, developed with Medscape Education Global. We also share highlights from ASCAT 2026 and the launch of a new Mediterranean network for haemoglobinopathies.

We warmly welcome your questions, feedback and suggestions for future editions. Please contact us at info@thalassaemia.org.cy to share your association's news, your experiences or the topics you would like us to cover.

Dr Androulla Eleftheriou

TIF Executive Director

Building stronger patient organisations in Athens

20–22 November 2026 · Athens, Greece



Patients and advocates from across TIF's international network will gather in Athens on 20–22 November 2026 to strengthen patient organisations and help shape the Federation's priorities. The Capacity Building Workshop for Patients and Associations and Annual General Assembly will take place at the Titania Hotel, bringing association representatives and emerging leaders together for three days of learning and exchange.

The workshop will focus on the practical skills that help associations turn patients' priorities into effective action. Sessions will address advocacy and engagement with policymakers, organisational leadership and governance, strategic communication, meaningful patient involvement and the use of digital tools to support associations' work.

Learning from one another will be central to the experience. Participants will exchange approaches to common challenges, strengthen connections across countries and consider how to apply new ideas within their own organisations.

Alongside the workshop, the Annual General Assembly will provide an important forum for TIF's membership to discuss shared priorities and the Federation's direction.

Visit the event page for the programme, participation requirements, registration and practical information on accommodation, travel and visas.

View the Athens programme and participation details

The MENA Thalassaemia Experience with TIF and Medscape

30–31 October 2026 · Virtual masterclass for physicians





TIF and Medscape Education Global will deliver The MENA Thalassaemia Experience as a fully virtual, two-day masterclass for physicians involved in thalassaemia care across the Middle East and North Africa. The CME-accredited programme will bring international expertise into practical discussions about patients' needs and clinical care.

Interactive patient journeys, expert panels, case-based learning and a fellows' clinical forum will explore prevention, novel therapies and the changing needs of people living with thalassaemia. Patients' perspectives and lived experiences will be an integral part of the discussions.

Participation is subject to selection, and selected physicians are expected to attend both days. Share the programme with your care team and visit the event page for application and participation details.

Explore the MENA masterclass

TIF at ASCAT 2026

7–10 October 2026 · London



TIF actively participated in ASCAT 2026, the 21st Annual Sickle Cell and Thalassaemia Conference, held at Central Hall Westminster in London. The conference brought colleagues from across the international haemoglobinopathy community together to exchange knowledge, strengthen partnerships and discuss sustainable, equitable care.

Representing TIF were Executive Director Dr Androulla Eleftheriou, Medical Advisor Dr Michael Angastiniotis, Board Member George Constantinou and Deputy Director Lily Cannon.

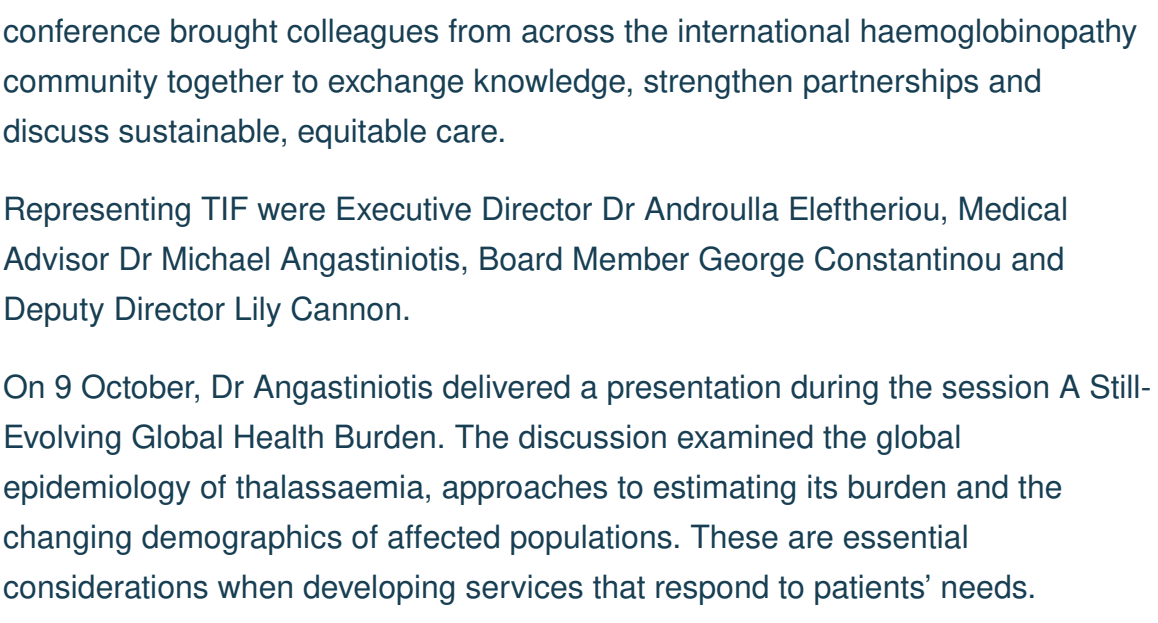
On 9 October, Dr Angastiniotis delivered a presentation during the session A Still-Evolving Global Health Burden. The discussion examined the global epidemiology of thalassaemia, approaches to estimating its burden and the changing demographics of affected populations. These are essential considerations when developing services that respond to patients' needs.

A highlight of the opening session was the launch of Thalassaemia revisited: from health burden to breakthroughs, a new series from The Lancet Haematology and The Lancet Regional Health – Southeast Asia. Bringing together a broad international group of experts, the series examines epidemiology, prevention, therapeutic advances and the future of care.

Its authors include Dr Eleftheriou and Dr Angastiniotis, several of TIF's scientific partners and members of its International Scientific Advisory Board, alongside colleagues from around the world.

A Mediterranean network for more equitable care

16 September 2026 · Rome



The Mediterranean Network for Haemoglobinopathies was formally launched at an event and press conference organised by UNITED, one of TIF's member organisations in Italy. The new platform connects patient organisations and healthcare professionals from Cyprus, Greece and Italy to strengthen cooperation in the prevention and care of haemoglobin disorders.

Its purpose is to share expertise and good practice, identify solutions to unmet patient needs and reduce avoidable inequalities in access to high-quality care. Priorities include adequate, safe and sustainable blood supplies, access to specialist expertise and treatment innovation, and stronger patient and association participation in healthcare decisions.

TIF was invited to participate as a founding member and is represented on the Steering Committee by Dr Androulla Eleftheriou.

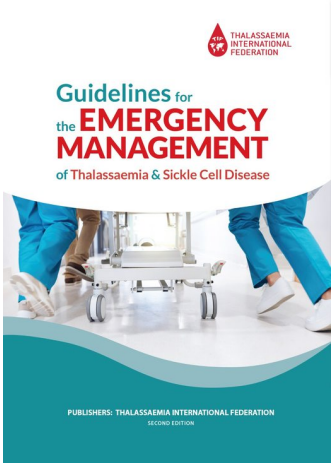
Dr Eleftheriou and Prof Antonio Piga co-moderated the launch, which featured a keynote presentation by Prof Maria Domenica Cappellini and separate clinical and patient panels. Participants included patient organisations, clinicians, blood transfusion services, regulatory representatives and diplomats.

The Steering Committee's next steps include agreeing an initial programme of activities to turn these shared priorities into practical opportunities for exchange and collaboration.

Read more about the Mediterranean network

Resources for your care

Updated guidance for emergency care



TIF's second edition of the Guidelines for the Emergency Management of Thalassaemia and Sickle Cell Disease is now available. Written for healthcare professionals, it supports the recognition and initial management of urgent complications, including when to involve specialist services.

The guide connects specialist haemoglobinopathy care with emergency medicine, particularly in settings where these conditions are less familiar.

Access the emergency care guidelines

Understanding access to thalassaemia care in the United States



TIF's Guide to Navigating the US Healthcare System for Thalassaemia Patients and Families examines the barriers people can encounter when seeking care. This landscape analysis brings together research and patient and family experiences to explain specialist access, insurance and costs, and challenges such as distance, language and administrative processes.

It offers patients, families and advocates a clearer understanding of the system and the factors that can affect continuity of care.

Explore the US healthcare guide

Thalassaemia Explained is coming soon



Thalassaemia Explained – What I Need to Know is in design and expected by mid-November 2026. Drawing on TIF's guidelines for transfusion-dependent thalassaemia, non-transfusion-dependent β-thalassaemia and α-thalassaemia, this new publication will present practical information in language that patients and families can understand and use in discussions about their care.

TIF Annual Report 2025 has been published

TIF's Annual Report 2025 is now available, offering a closer look at the Federation's work with patients, associations, healthcare professionals and national partners. Highlights include updated clinical and nursing guidelines, the first TIF Pan-American Conference on Thalassaemia and Other Haemoglobin Disorders, and nine newly recognised Collaborating Centres. Read about the activities and partnerships supporting better care and stronger patient representation worldwide.

Read the TIF Annual Report 2025

Patient participation and nursing expertise in Greece

2–3 October 2026 · Thessaloniki





The Panhellenic Meeting on Thalassaemia and Sickle Cell Disease, organised by the Greek Thalassaemia Association (ESTHA) with TIF, explored new therapies, including gene therapy, alongside everyday priorities such as transfusion safety, iron chelation, complications and psychosocial support. Discussions also considered the Innovation Fund's role in access to new therapies.

Its first Panhellenic Nursing Symposium gave nurses from specialist units across Greece a dedicated forum. TIF Executive Director Dr Androulla Eleftheriou emphasised patient education, nurses' contribution to person-centred care and equitable access to innovation.

Austria brings patients and professionals together

25–27 September 2026 · Vienna



The patient symposium Medical Innovations in Haemoglobinopathies brought together people affected by haemoglobin disorders, families and healthcare professionals to learn and exchange experiences. Co-organised by TIF member Thalsifo — Thalassämie & Sichelzell Forum and Thalassämieverein Ulm e.V. (Thavu), the meeting made space for both scientific developments and the questions that matter in daily life.

Cyprus formalises its longstanding partnership with TIF

8 September 2026





On 8 September 2026, TIF reached an important institutional milestone with the signing of a Memorandum of Understanding (MoU) with the Ministry of Health of the Republic of Cyprus.

The MoU was signed by the Minister of Health, Neophytos Charalambides, on behalf of the President of the Republic of Cyprus, Nikos Christodoulides, and by TIF President Panos Englezos.

The agreement strengthens TIF's longstanding partnership with the Cyprus Government and reinforces the Federation's institutional recognition, role and impact both in Cyprus and internationally.

Read more about the TIF–Ministry of Health agreement

Cyprus discusses equitable access to treatment innovation

23 September 2026



On 23 September 2026, Bristol Myers Squibb (BMS) organised a press conference in Cyprus on advances and emerging challenges in the management of β-thalassaemia and myelodysplastic syndromes (MDS).

Representatives of the Ministry of Health, the Health Insurance Organisation, the National Thalassaemia Committee, patient organisations, TIF, and the medical and academic communities came together to discuss progress in care. The event highlighted Cyprus' pioneering model of thalassaemia care and the importance of collaboration in ensuring equitable access to innovative treatments.

TIF Executive Director Dr Androulla Eleftheriou presented Cyprus' international contribution to thalassaemia prevention and care, alongside the Federation's global development and impact. Referring to the new National Blood Strategy and the recently signed MoU with the Ministry of Health, she emphasised that structured cooperation between government, healthcare professionals and patient organisations is essential to improving access to innovation and continuously strengthening patients' care.

Supporting continued progress in Türkiye

25 September 2026



TIF welcomed Prof Yeşim Aydinok, paediatric haematologist at Ege University Hospital and member of its Collaborating Centres Advisory Board, to its headquarters. Discussions considered progress and remaining challenges in thalassaemia prevention and management in Türkiye, and how TIF could support national efforts.

Build your knowledge with the TIF e-Academy

Explore learning opportunities for patients and families, including courses on thalassaemia and sickle cell disease. The TIF e-Academy also offers dedicated education for healthcare professionals and laboratory scientists.

Explore the TIF e-Academy

A new accredited e-course in Genetic Counselling



Clear, sensitive genetic counselling helps people understand inheritance, testing and family-planning options. TIF's free, self-paced Genetic Counselling for Healthcare Professionals course develops both scientific understanding and skills in communication, consent, family dynamics and cultural awareness.

Developed by international experts, the course is open to eligible healthcare professionals and accredited by the European Board for Accreditation in Hematology (EBAH). Successful participants can obtain a Certificate of Achievement and claim 19 continuing medical education credits. Share it with a professional who may benefit.

View the genetic counselling course

Nordic fellows take home lessons for coordinated care

21–25 September 2026 · Copenhagen, Denmark





Dr Aba Sarr and Dr Marte Holmboe Berg, both from Norway, completed TIF's inaugural Henrik Birgens Fellowship at the Danish Red Blood Cell Centre, Copenhagen University Hospital. Their programme covered adult and paediatric clinics, laboratory services and multidisciplinary discussions.

The fellows highlighted closer collaboration between adult and paediatric teams, better support during transitions between services and stronger Nordic professional connections. TIF acknowledges the expertise and support of Dr Andreas Glenthøj, Dr Marianne Hoffmann and the Danish Red Blood Cell Centre team in delivering this inaugural fellowship.

Specialist training for haemoglobinopathy nurses in Greece

12–14 October 2026 · Laiko General Hospital, Athens

ΛΑΪΚΟ
ΓΕΝΙΚΟ ΝΟΣΟΚΟΜΕΙΟ ΑΘΗΝΩΝ
ΠΑΝΕΠΙΣΤΗΜΙΟ ΑΘΗΝΩΝ

TIF's Fellowship for Haemoglobinopathy Nurses supports registered nurses in Greece's public healthcare sector. The three-day programme at Laiko General Hospital was designed to combine clinical observation, case-based learning and mentorship for two selected nurses.

Dr Maria Dimopoulou, Head of the Thalassaemia Unit at Laiko General Hospital, Athens, and Ms Elpida Georgiadi, Head Nurse of the same unit, provided specialist supervision and guidance.

Two physicians selected for the TIF–PGICH Fellowship

16–27 November 2026 · Noida, India



Two physicians from India have been selected for the TIF–PGICH Thalassaemia Fellowship at the Post-Graduate Institute of Child Health (PGICH) in Noida, India. Clinical exposure, case discussions and mentorship will develop their experience in comprehensive thalassaemia and sickle cell disease care, with learning to share with their teams. Applications for this placement have closed.

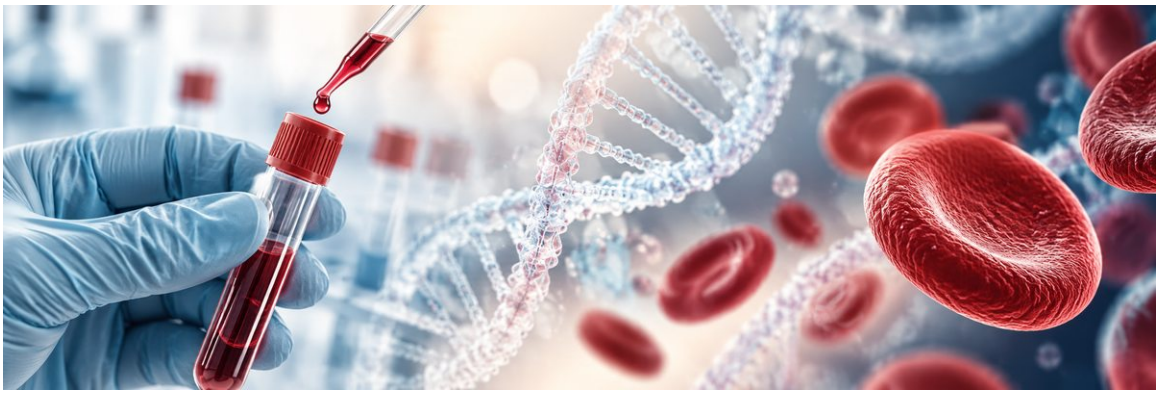
Discover TIF's collaborating centres



The three fellowship host institutions featured above are among TIF's Collaborating Centres for Haemoglobinopathies. Through training, knowledge exchange and the sharing of good practice, the network helps specialist teams strengthen the quality of care for patients.

Explore TIF's collaborating centres

Clinical Trial Updates



Keep up with treatment and clinical trial updates



Casgevy™

Gene editing therapy



Zynteglo™

Gene addition therapy



Reblozyl™

Erythroid maturation agent



Mitapivat

Pyruvate kinase activator

Pyrukynd® / Aqvesme™

TIF's Clinical Trial Updates brings together information on medicines and therapies for thalassaemia and sickle cell disease, covering approved treatments alongside therapies still being studied.

Explore study findings and regulatory updates, and use the information to support conversations with your care team. Approval, eligibility and availability vary between countries, and treatments under investigation may not be available outside clinical trials.

Visit TIF Clinical Trial Updates

New TIF members

A warm welcome to three new TIF members



Our network is growing. We are delighted to welcome three organisations and the communities they represent:

Aussie White Lion Foundation · **Australia**
Supporting children and families living with sickle cell disease through awareness, action against stigma and efforts to address barriers to care.

Azan Ali Kazmi Foundation · **Pakistan**
Promoting thalassaemia awareness and blood donation, and encouraging communities to learn about and support patients' needs.

Stowarzyszenie Kierunek Zdrowie · **Poland**
Supporting people affected by blood cancers and other blood disorders, and their families, through education, rehabilitation and advocacy.

We look forward to learning from their experience and working together.

Meet TIF's member associations

Help shape the next edition

What would you like to read about next? Send your questions, association news or suggestions to info@thalassaemia.org.cy. We welcome contributions from across our patient community.

Contact TIF

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