

TIF NEWS

A QUARTERLY E-MAIL NEWSLETTER

A Huge Success for the TIF European Thalassaemia & SCD Symposium

With more than 400 participants from 56 countries of the European Region and beyond.



ALSO IN THIS ISSUE:

TIF.ACCESS

Meetings with EU Health Commissioner & EHA
Renzo Galanello Fellowship 2020
THALIA Mobile App

TIF European Symposium: Bringing Together Haemoglobinopathies Patients & Specialists from the EU & Beyond

The current scientific developments in the field of hemoglobinopathies, the recent authorisations of revolutionary innovative drugs & treatments for thalassemia and sickle cell disease, together with the latest information on the optimal multidisciplinary clinical management of these diseases, were at the heart of the **TIF European Thalassemia and Sickle Cell Disease (SCD)**

Symposium for Patients and Doctors, organized virtually by TIF on **11-13 December 2020**.

The 3-day Symposium, inaugurated by the Welcome Addresses of the Cypriot Minister of Health, Mr Constantinos Ioannou, and TIF President, Mr Panos Englezos, hosted a faculty of more than 50 international experts and patient advocates. Dr Androulla Eleftheriou, TIF Executive Director, highlighted in her keynote presentation the plethora of challenges faced both in Europe and globally by patients, seeking access to appropriate clinical management that will enable them to improve their quality of life.

A full-day was devoted to the capacity building of patient associations through the discussion of emerging concerns (e.g. ageing), and the empowerment of patient advocacy through presentation of best practices and new TIF initiatives, such as TIF.ACCESS, THALIA Mobile App, RAIN, etc. The Symposium aimed to highlight the importance of patient knowledge, unity, engagement and contribution to the improvement of services, through meaningful and productive participation in decision-making processes at the national, regional and international levels.



NOTE!

**A comprehensive report of the Symposium
is expected to be published
by the end of January!**



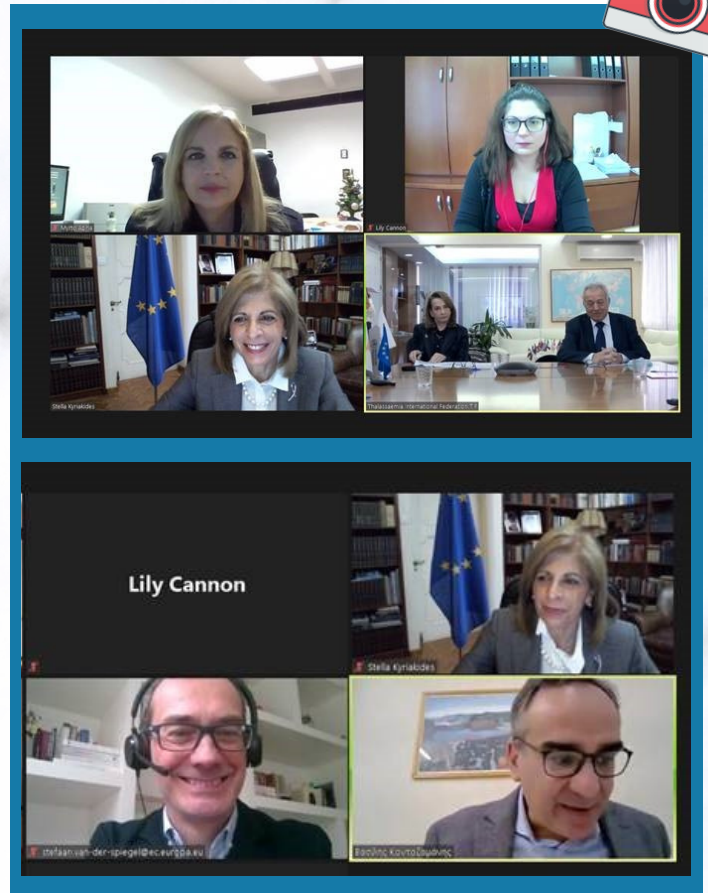
TIF Meets the EU Health Commissioner: To Discuss Thalassaemia & Migration



A High-level Virtual Meeting between TIF, the European Commissioner for Health & Food Safety, Mrs Stella Kyriakides, the Greek Deputy Minister of Health, Dr Vassilis Kontozamanis, and Senior Medical Officer of the Cyprus Ministry of Health, Dr Myrto Azina, was held on 10 December 2020.

The connection between migration and thalassaemia was firmly placed on the Commissioner's radar by TIF whilst Dr Michael Angastiniotis, TIF Medical Advisor, called for synergies to be developed between EU Member States, where more experienced countries, such as Cyprus and Greece, could share their expertise with the competent health authorities in other Member States, witnessing a rise in numbers of patients with thalassaemia recently.

The Commissioner expressed her interest to continue the discussion, so as to find the appropriate solutions to these increasing challenges, in collaboration with her counterpart Mr Margaritis Schinas, Vice-President of the European Commission, responsible for migration-related issues.



TIF at the EHA Patient Organization Leadership Meeting



EUROPEAN
HEMATOLOGY
ASSOCIATION



Dr Androulla Eleftheriou, TIF Executive Director, has participated in the **EHA- Patient Organization Leadership Meeting, held virtually on 17 December 2020**, to discuss the formation of an EHA Advocacy Committee as a formal part of the EHA structure.

This Committee would seek to provide an elevated status and voice to the patient community, in addition to undertaking joint activities to develop best practices for supporting the mutual priority of providing patients with affordable and equal access to innovative treatments.

TIF Hands In Recommendations for Access to Novel Therapies to Cypriot President Nicos Anastasiades



On 16 November 2020, TIF's Recommendations for Access to Novel Therapies were presented to the President of the Republic of Cyprus, Mr Nicos Anastasiades, and Mr Constantinos Ioannou, Minister of Health by Mr Panos Englezos and Dr Androulla Eleftheriou, TIF President and Executive Director, respectively.

The meeting's agenda involved mainly the access of patients with thalassaemia and rare diseases to innovative drugs and therapies, within the framework of the National General Health System, as per the efforts encompassed by the TIF.ACCESS programme at the national level. The quality assurance of healthcare services and the establishment of a National Institute for Health and Care Excellence in the country, and the development of a national strategy for thalassaemia prevention, management and research were also extensively discussed.

1st PanItalian Associations Meeting on New & Innovative Therapies for Haemoglobinopathies



The **"1st PanItalian Associations Meeting on New and Innovative Therapies for Haemoglobinopathies"** was successfully organised by TIF and UNITED Onlus – the Italian Federation of Thalassaemia, Rare Hemoglobinopathies and Drepanocytosis, on the 18th of December 2020.

Over 120 patient/parents, treating physicians, healthcare professionals and other interested stakeholders joined the virtual meeting that sought to provide information about the newly authorised therapies in the field, and stimulate interactive discussions regarding their availability and accessibility to the Italian patient community.



On behalf of the Federation, Dr Androulla Eleftheriou provided a global overview relating to Access to Innovative Drugs and Therapies.

Discover more about the TIF.ACCESS initiative at:
<http://bit.ly/3qgGBve>



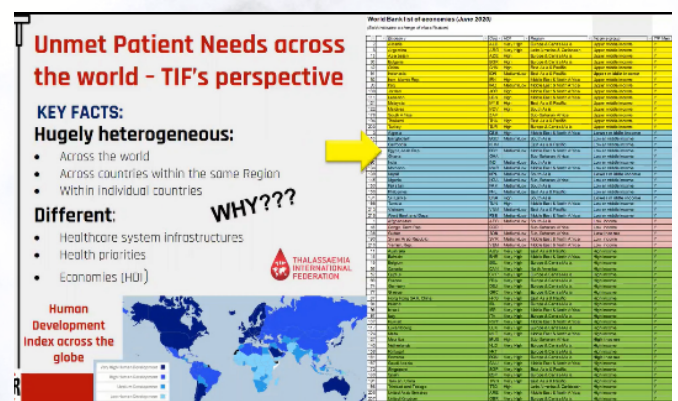


Upon invitation from Mrs Shobha Tuli, TIF Vice-President and President of FIT, Dr Androulla Eleftheriou actively participated as a member of the faculty of this event, presenting an overview of 'Disability in Haemoglobin Disorders'.



Egypt

TIF was represented by its Executive Director, Dr Androulla Eleftheriou, and member of TIF's International Scientific Advisory Board, Dr Perla Eleftheriou, Consultant Haematologist, UK, who discussed unmet patient needs after COVID-19 and the appropriate management of haemoglobinopathies during the pandemic, respectively.



THALIA Mobile App: The Skilled Digital Assistant of People with Thalassaemia and Sickle Cell Disease



Committed to continuing efforts to develop useful tools for individuals with thalassaemia and haemoglobin disorders worldwide, TIF introduces a novel mobile health application for patients with thalassaemia and sickle cell disease, the **THALIA Mobile App**.

The main feature of the application is a calendar, tailored to the needs of people with haemoglobin disorders, that can be easily synchronized with the user's personal calendar on his mobile phone. In it, users will be able **to note everything related to the management and treatment of their disease**, such as upcoming blood transfusions, doctor appointments and medication reminders, score pain levels, as well as record and track other symptoms of the disease (e.g. fatigue and mood swings).

In addition, the app will enable patients to **share, if they wish, useful statistics for their health**, such as haemoglobin and ferritin levels, the frequency of blood transfusions, etc., with their treating and supervising physicians.



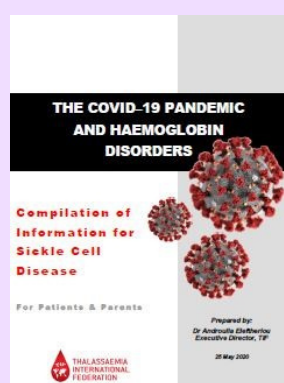
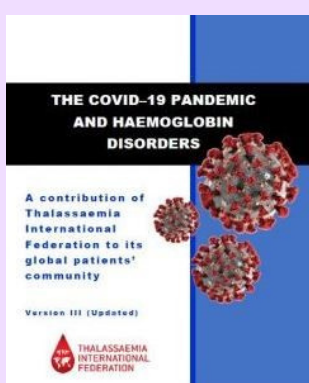
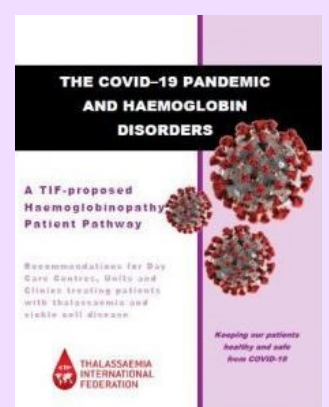
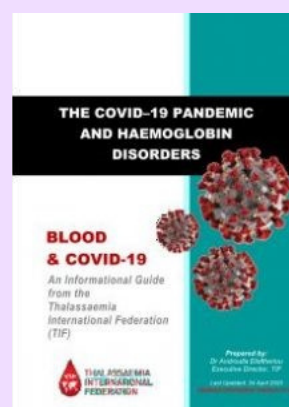
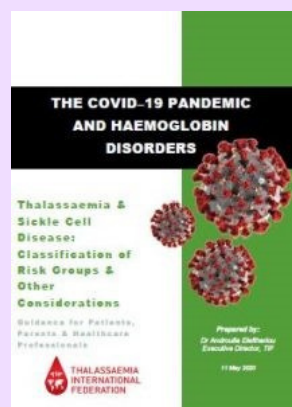
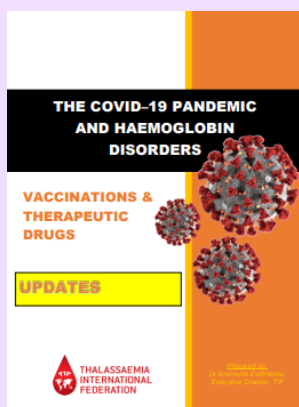
GET IT NOW!

COVID-19 & HAEMOGLOBIN DISORDERS: New TIF Educational Resources



With a constant focus on serving in the best way possible its worldwide patient community, TIF has been working tirelessly since the start of the COVID-19 outbreak to ensure the creation of valuable and reliable resources and tools for the thalassaemia community.

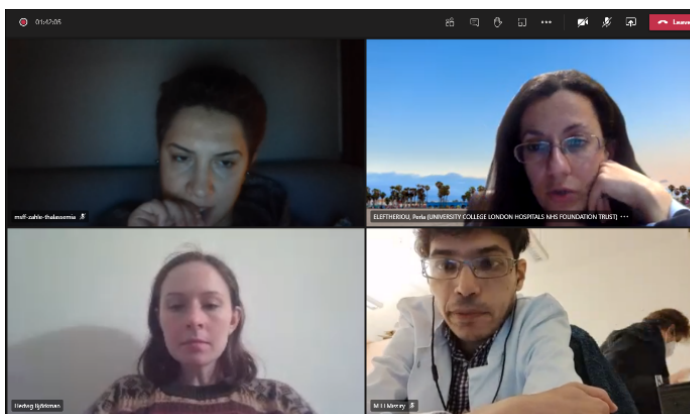
Our publications have recently been complemented by a **Position Statement** on the **"COVID-19 Vaccines & Haemoglobin Disorders"** and the updated **"Vaccinations & Therapeutic Drugs for COVID-19 Guide"**.



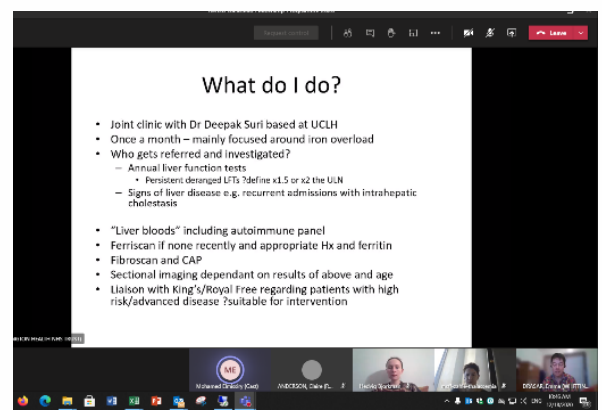
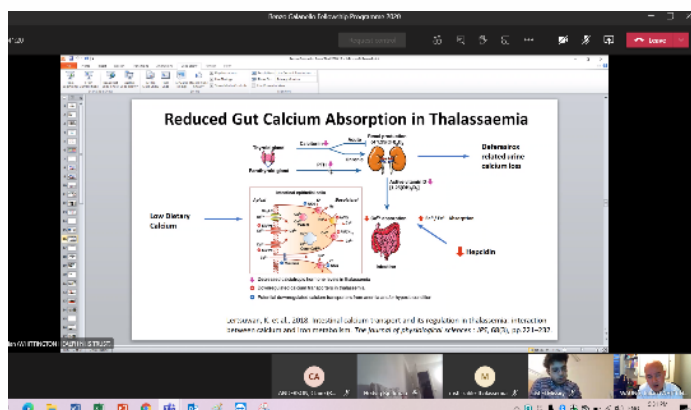
RENZO GALANELLO FELLOWSHIP 2020: Online High Level Training in Haematology For 3 Successful Candidates

Due to some difficulties and restrictions encountered as a result of the COVID-19 pandemic, the **Renzo Galanello Fellowship Programme 2020** was not offered physically and in its full duration, as initially scheduled between 12th October-11th December 2020.

Alternatively, TIF has offered an online training to **3 successful candidates – medical doctors from Sweden, Germany and Lebanon** between 14-18 December 2020 through the Joint Red Cell Unit, Haematology Department University College London NHS Foundation Trust in London, UK, under the supervision of Professor John Porter, Professor of Haematology, the coordination of Dr Perla Eleftheriou Consultant Haematologist and the participation of distinguished medical specialists across different relevant disciplines.



Despite the fact that this year's training was condensed and virtual, it was extremely beneficial and valuable to the work of the physicians attending the course, towards strengthening the quality of healthcare provided to our patients in their respective countries.



Learn more ►

<http://bit.ly/3ia89zL>





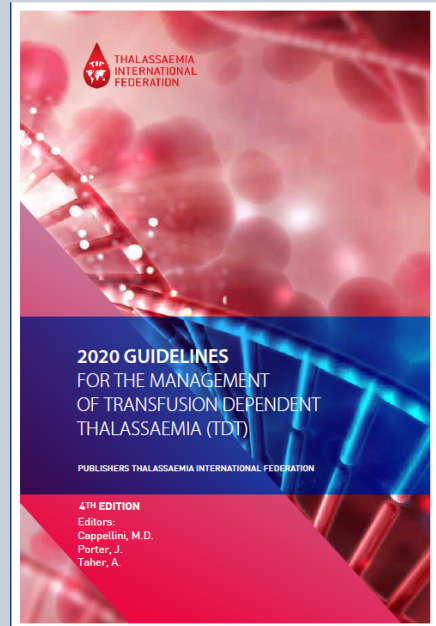
New TIF Publications & Activities Coming Up!



The 4th edition of the Federation's most acclaimed and sought-after publication, **"TIF Guidelines For The Management of Transfusion Dependent Thalassaemia (TDT)", will be available in February 2021!**

Since the publication of the 1st edition in 1999, the TIF Guidelines have been widely used as the only evidence-based reference text by academics, researchers and healthcare professionals involved in the treatment of patients with TDT.

The upcoming 4th edition will include brand new chapters on the recently approved modalities of patient treatment, the importance of the Reference Centres' contribution to patient care, and much more.



The final dates of the Thalassaemia International Federation **"15th International Conference on Thalassaemia & other Haemoglobinopathies"** & the **"17th TIF Conference for Patients & Parents"** have been announced!

Both conferences will be held on July 16-18, 2021. The events' format and venue will be announced shortly.

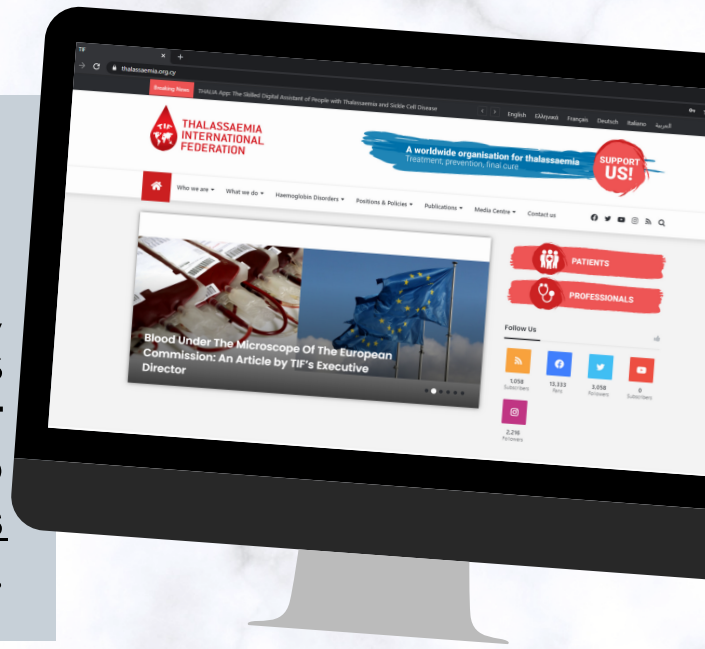
Two parallel programmes will be featured – a Scientific Programme for Healthcare Professionals and another for Patients/Parents.

**Follow closely our website and social media pages
to get our updates first!**

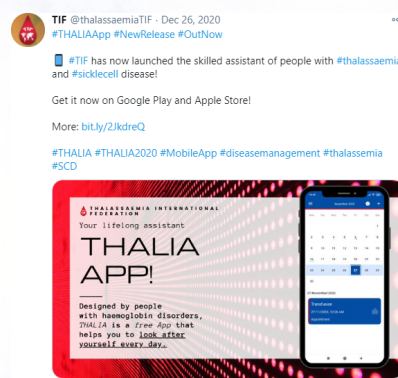




2020 MARKED AN IMPRESSIVE RISE FOR TIF'S SOCIAL MEDIA AND WEBSITE, WITH THE LATTER INCREASING ITS OVERALL PERFORMANCE AND IMPACT BY MORE THAN 34% (COMPARED TO 2019), HAVING HOSTED VISITORS FROM 203 COUNTRIES GLOBALLY.



We would like to **THANK YOU** for embracing our consistent *efforts* to provide you with the most up-to-date news, information and educational resources for haemoglobin disorders, created either by TIF or reproduced by other reliable sources, and we renew our commitment to keep working towards the achievement of *quality* healthcare for every patient with thalassaemia and other haemoglobin disorders across the world.



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THANK YOU FOR READING!