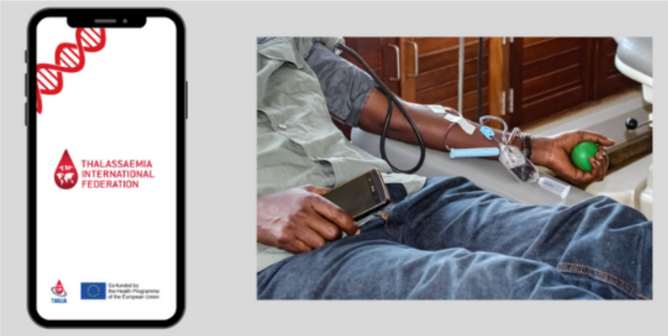
OCT. 2020, ISSUE 7

TIF NEWS

A QUARTERLY E-MAIL NEWSLETTER

Shifting Towards Digital Resources & Tools To Address Patients' Challenges




FRIDAY, OCTOBER 23RD, 2020
15.00 EEST | 13.00 BST

WEBINAR FOR PATIENTS & PARENTS

HEART DISEASE IN THALASSAEMIA

THALASSAEMIA INTERNATIONAL FEDERATION

SPEAKERS & TOPICS

Prof. Malcolm Walker
Heart Disease in Thalassaemia: Past, Present & Future

Dr. Dimitris Farmakis
Heart Disease in Thalassaemia Intermedia

FREE REGISTRATION AT:
https://forms.gle/qWDDJ6CJSKqYELKa8

IN THIS ISSUE:

TIF.ACCESS
THALIA Mobile App
TIF Webinars

Lebanon

TIF has continued its efforts to support the patient community in Lebanon as the country struggles with recession, the COVID-19 pandemic, in addition to the consequences of the explosions of past August and political unrest, all of which are affecting thalassaemia patients to varying extents.

Thus far, essential medical supplies and personal protection equipment have been secured from donors, and safely delivered to the Chronic Care Centre and Mrs Michele Maalouli Abi Saad, TIF Board Member, with the help of the WHO Office in Lebanon.

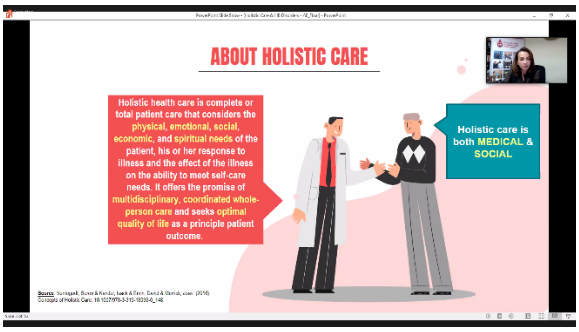
The deep appreciation and recognition of TIF's humanitarian effort by Mrs Mouna Haraoui, former first lady of Lebanon and a beloved TIF friend and Board Member for many years, has been truly moving.

It is noted that Lebanon is experiencing an exceptional period of calamity, however accessibility to the country is not affected as is the case with other countries that experience warfare and political instability, and which may have similar needs, thus allowing the Federation to provide such support as described above.

Serbia

The Serbian Alliance for Rare Disorders (NORBS) organised on 23rd and 24th of October 2020 the "Caring for Rare" online regional conference to allow the exchange of knowledge and facilitate collaboration between rare disease patient organisations, active in the Eastern European region.

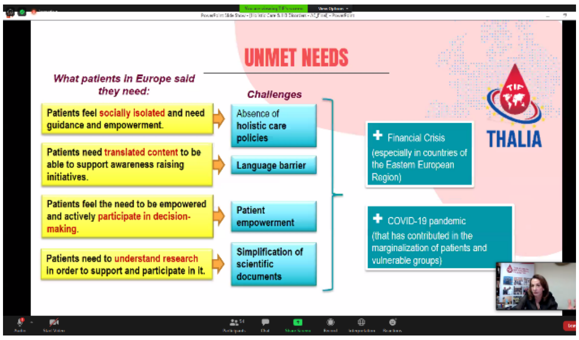
An array of topics was addressed by the speakers, including access to treatment, the role of patient organisations, how the pandemic affects patients and holistic care. Dr Androulla Eleftheriou, the Executive Director of our Federation, was invited to share TIF's views on holistic care and haemoglobin disorders and showcase success stories of multidisciplinary and holistic care to inspire patients of the region.



ABOUT HOLISTIC CARE

Holistic health care is complete or total patient care that considers the physical, emotional, social, economic, and spiritual needs of the patient, his or her response to illness and the effect of the illness on the ability to meet self-care needs. It offers the promise of multidisciplinary, coordinated whole-person care and seeks optimal quality of life as a principle patient outcome.

Holistic care is both MEDICAL & SOCIAL



UNMET NEEDS

What patients in Europe said they need:

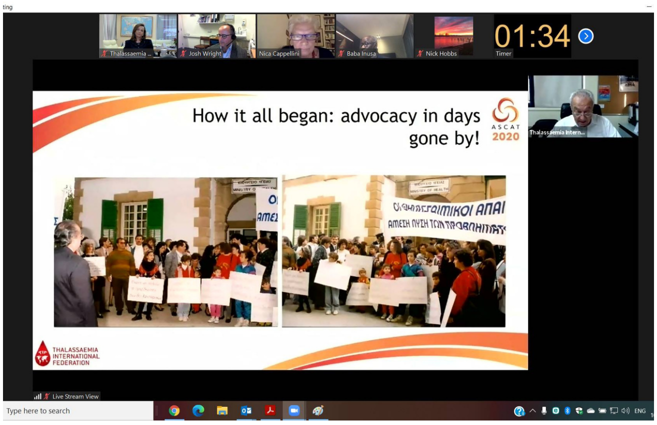
Challenges

- Patients feel socially isolated and need guidance and empowerment. → Absence of holistic care policies
- Patients need translated content to be able to support awareness raising initiatives. → Language barrier
- Patients feel the need to be empowered and actively participate in decision-making. → Patient empowerment
- Patients need to understand research in order to support and participate in it. → Simplification of scientific documents

- Financial Crisis (especially in countries of the Eastern European Region)
- COVID-19 pandemic (that has contributed in the marginalization of patients and vulnerable groups)

15th Annual Sickle Cell and Thalassaemia (ASCAT) & 1st EHA European Sickle Cell Conference

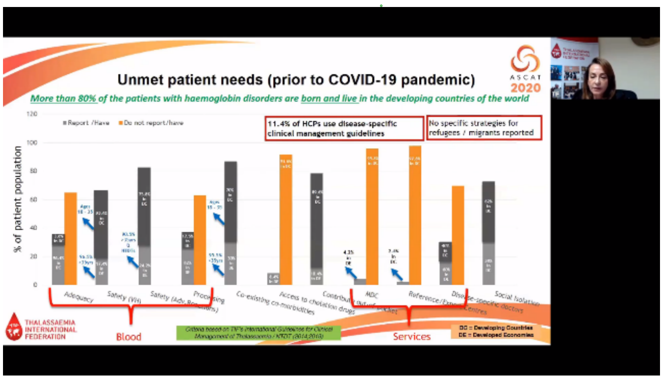
INTERNATIONAL RELATIONS



How it all began: advocacy in days gone by!

Mr Panos Englezos, TIF President, Dr Androulla Eleftheriou, TIF Executive Director and Mr George Constantinou, TIF. Ass. Secretary & Expert Patient, participated in the 15th ASCAT & 1st EHA European Sickle Cell Conference, held on 26-31 October 2020.

The Virtual Global Conference was jointly organised by the British Society for Haematology and European Haematology Association.



Unmet patient needs (prior to COVID-19 pandemic)

More than 80% of the patients with haemoglobin disorders are born and live in the developing countries of the world

11.4% of HCPs use disease-specific clinical management guidelines

No specific strategies for refugees / migrants reported

Mr Englezos delivered a presentation focusing on the added-value of a patient organisation for national and international advocacy, highlighting the example of the Thalassaemia International Federation and its contribution to the education and advocacy of the patient and medical communities, as well as sensitisation of decision-makers for the creation of disease-specific policies to improve the quality of lives of patients.

Moreover, Mr Constantinou and Dr Eleftheriou represented TIF in a Physician/Patient Interactive Session, outlining the global epidemiology of thalassaemia and the current unmet patient needs identified across the world by TIF's research activities over the past 2 years. The data presented are based on a preliminary analysis, and will form the basis of the relevant chapter in the Global Thalassaemia Report, expected to be published within 2020.

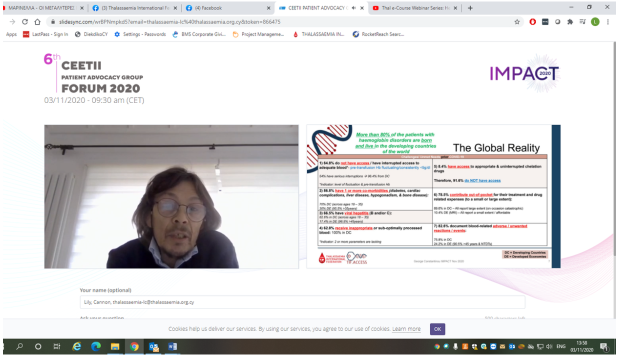
Learn more ▶ https://bit.ly/3pbLdmD

TIF Takes Active Part At The IAPO 9th Global Patients Congress

The International Alliance of Patients' Organizations (IAPO) conducted online the 9th Global Patients Congress #GPC2020 on 16-17 September 2020, under the theme "Co-creation of Innovative Healthcare". The Congress featured a total of 1200 attendees from 101 countries and 2 days of interactive discussions about healthcare strengthening and preparedness through patient-led innovative solutions, and the impact of the pandemic on the global patient community and health systems. GPC2020 also marked the annual World Patient Safety Day, which took place on September 17, and emphasized the importance of health workers' safety as priority for patient safety.

TIF participated in the Congress with Dr Michael Angastiniotis, TIF Medical Advisor, and Dr Androulla Eleftheriou, TIF Executive Director, who chaired the "Blood Disorders & Access to Healthcare Services & Therapies" session, dedicated to the memory of the late Carol Ossai, former Chair of the Global Alliance of Sickle Cell Disease Organizations (GASCDO) and IAPO Board Member. The session explored health inequality and the opportunity to deliver better healthcare, especially around sickle cell vaso-occlusive crises and access to new biologic therapies and future gene therapies.

6th Annual CEETII Forum: Supporting A New Decade of Patients' Advocacy



Learn more ▶ https://bit.ly/3llEe8o

The Forum, organised by Bristol Myers Squibb on 3 November 2020, brought together patient advocates from Central and Eastern Europe, India, Russia and India to discuss patient needs, engagement, support and awareness in relation to existing and new challenges in diagnostics, treatment and R&D.

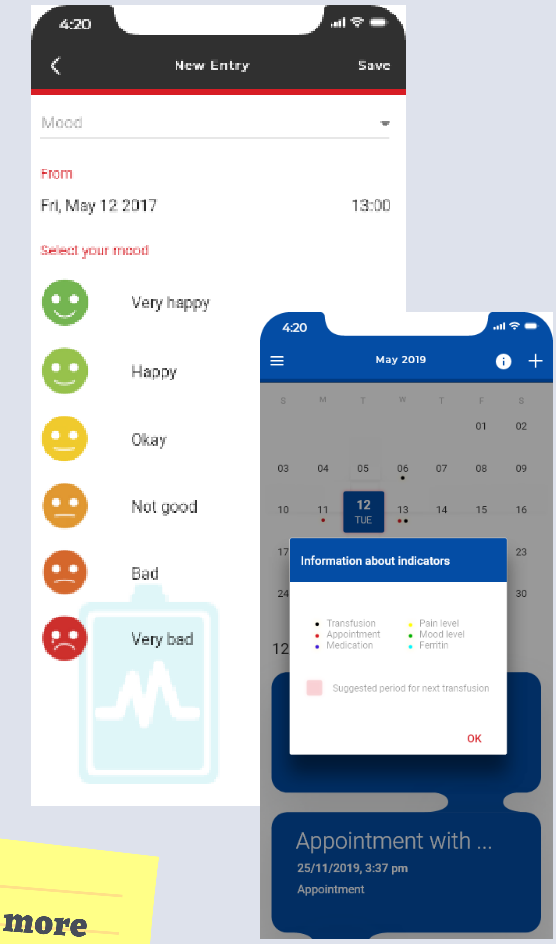
Mr George Constantinou, TIF Board Member and Expert Patient, represented TIF through a presentation focusing on the unmet needs of thalassaemia patients, and highlighting the ways that the Federation works towards alleviating them and thus improving the lives of patients globally.

TIF Develops Mobile Application To Support Patients With Thalassaemia

As part of its enduring efforts to develop useful tools for individuals with thalassaemia and haemoglobin disorders worldwide, TIF will soon launch a novel mobile health application, named "THALIA Mobile App". This application is primarily designed to constitute a digital assistant for patients which will help them self-manage their disease more effectively on a daily basis.

The main feature of the application is a calendar that can be easily synchronized with the user's personal calendar on his mobile phone. In it, the patient will be able to note everything related to the management and treatment of his disease, such as upcoming blood transfusions, doctor appointments and medication reminders, to score pain levels, as well as record and track other symptoms of the disease, for instance fatigue and mood swings.

The application will be initially released in Greek and English for Android and iOS devices, and versions in French, German and Arabic will follow.



Fri, May 12 2017 13:00

Appointment with ...
25/11/2019, 3:37 pm
Appointment

Learn more ▶ https://bit.ly/3ka5d5u

Discover more about the TIF 'THALIA' Project on our website!

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Intensifying Efforts To Ensure Equal Access Of Patients with Haemoglobin Disorders To Novel Therapies

What Exactly is TIF.ACCESS?

The “TIF’s International Forum on ACCessibility, Effectiveness and Sustainability of TherapieS for Haemoglobin Disorders (TIF.ACCESS)” was officially launched in 2019 with the aim to promote information and education of patient groups, healthcare professionals, national health authorities, reimbursement agencies and other involved stakeholders on the rights of patients with haemoglobin disorders across the world for prompt and equal access to every existing and future therapy.

On September 24, TIF organised a scientific informational meeting in collaboration with the Embassy of the Cyprus Republic in Germany, regarding the innovative treatments in the field of haemoglobin disorders.

Key speakers Dr Michael G. Kiehl, Head of The Dept. of Internal Medicine and Mrs Manuela Meyer, Head Nurse for Oncology, both from the Klinikum Frankfurt (Oder) Hospital, Germany, discussing the topics on ‘Gene therapy in ß-thalassaemia‘ and ‘Autologous stem cell transplantation’, respectively.

COMING SOON ...

✓ **A TIF.ACCESS High-level Virtual Event**

✓ **A TIF.ACCESS Patient Associations Online Meeting**

More details will follow!

Mrs Lily Cannon, TIF Operations Manager, attended the 6th Annual Clinical Trials Patient Experience Summit, held virtually on 21 September.

The Summit sought to improve the patient experience in clinical trials by focusing on the patients’ role in the drug development process, while developing solutions to make the clinical trial process more convenient for patients and more efficient for researchers.

TIF e-Academy Webinar Series:
Exploring Hot Topics of Haemoglobin Disorders

The TIF Thal e-Course and eThalED Webinar Series, which sought to equip patients and healthcare professionals with sound knowledge on important topics associated to thalassaemia, were successfully concluded.

The fervent response of participants from all over the world to these online educational events exceeded our expectations and we would like to warmly thank everyone involved in their fulfilment.

Thal e-Course Webinars

LIVER DISEASE IN THALASSAEMIA - 28/09

SPEAKERS

THALASSAEMIA INTERNATIONAL FEDERATION PRESENTS:

WEBINAR FOR PATIENTS
LIVER DISEASE IN THALASSAEMIA
MONDAY, SEPTEMBER 28TH
15.00 - 16.00 EEST

REGISTER FOR FREE AT:
HTTPS://FORMS.GLE/9NEVPWOI1FDPB7FZ9

Prof. Geoffrey Dusheiko

Prof. John Koskinas

TOPICS

i. Liver Disease in Haemoglobinopathies, in particular Thalassaemia: Past, Present & Future with Professor Dusheiko

ii. Viral Hepatitis in Thalassaemia: Prevention, Eradication & Treatment with Professor Koskinas

IRON MONITORING IN THALASSAEMIA - 09/10

FRIDAY, OCTOBER 9TH 2020
15.00 EEST | 13.00 BST

WEBINAR
IRON MONITORING IN THALASSAEMIA
THALASSAEMIA INTERNATIONAL FEDERATION

A webinar for patients presented by Dr. Paul Telfer

REGISTER FOR FREE AT
https://forms.gle/afVoqdjf2waz8Q8PA

HEART DISEASE IN THALASSAEMIA - 23/10

FRIDAY, OCTOBER 23RD, 2020
15.00 EEST | 13.00 BST

WEBINAR FOR PATIENTS & PARENTS
HEART DISEASE IN THALASSAEMIA
THALASSAEMIA INTERNATIONAL FEDERATION

SPEAKERS & TOPICS

Prof. Malcolm Walker
Heart Disease in Thalassaemia: Past, Present & Future

Dr. Dimitris Farmakis
Heart Disease in Thalassaemia Intermedia

FREE REGISTRATION AT:
https://forms.gle/qWDDJ6CJSKqYELKa8

BLOOD TRANSFUSION IN THALASSAEMIA - 30/10

FRIDAY, OCTOBER 30TH 2020
15.00 - 16.00 EET | 13.00 - 14.00 GMT

WEBINAR FOR PATIENTS & PARENTS
BLOOD TRANSFUSION IN THALASSAEMIA
THALASSAEMIA INTERNATIONAL FEDERATION

SPEAKERS & TOPICS

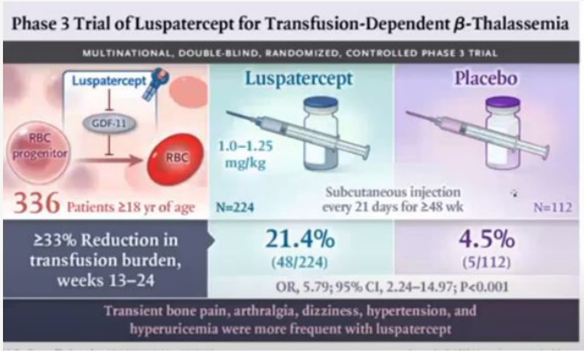
Prof. Constantina Politis
Blood Transfusion Safety

Dr. Farrukh Shah
Blood Transfusion Management

REGISTER FOR FREE AT
https://forms.gle/Jc9pbQXTtFXRmkid7

eThalED Webinars

REBLOZYL - 11/05



Phase 3 Trial of Luspatercept for Transfusion-Dependent β-Thalassemia

MULTINATIONAL, DOUBLE-BLIND, RANDOMIZED, CONTROLLED PHASE 3 TRIAL

336 Patients ≥18 yr of age

	Luspatercept	Placebo
	1.0–1.25 mg/kg N=224	N=112
	Subcutaneous injection every 21 days for ≥48 wk	
≥33% Reduction in transfusion burden, weeks 13–24	21.4% (48/224)	4.5% (5/112)

OR, 5.79; 95% CI, 2.24–14.97; P<0.001

Transient bone pain, arthralgia, dizziness, hypertension, and hyperuricemia were more frequent with luspatercept

GENE THERAPY IN THALASSAEMIA - 05/06

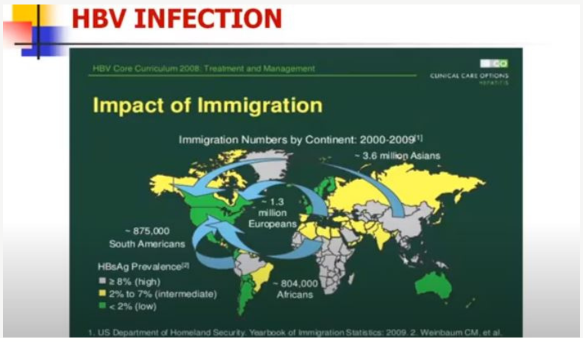
THALASSAEMIA INTERNATIONAL FEDERATION INVITES YOU TO PARTICIPATE IN THE WEBINAR ENTITLED:

PROF. JOHN PORTER

ACCESS TO NEW THERAPIES

eTHALED COURSE FOR MEDICAL SPECIALISTS
SESSION 2
FRIDAY, JUNE 5 - 2020
15.00 CET
16:00 EEST

LIVER DISEASE IN THALASSAEMIA - 31/07



HBV INFECTION

HBV Core Curriculum 2008: Treatment and Management

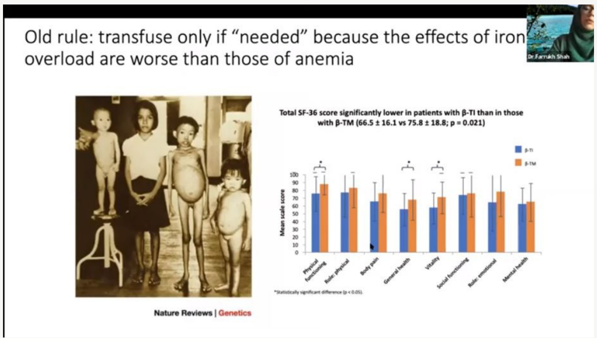
Impact of Immigration

Immigration Numbers by Continent: 2000-2009[1]

HBsAg Prevalence[2]
- ■ ≥ 8% (high)
- ■ 2% to 7% (intermediate)
- ■ < 2% (low)

1. US Department of Homeland Security. Yearbook of Immigration Statistics: 2009. 2. Weinbaum CM, et al.

BLOOD SAFETY & MANAGEMENT - 31/08



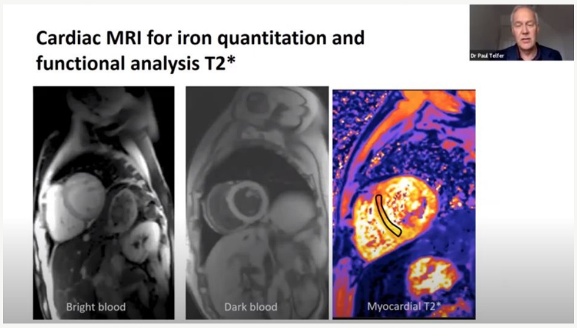
Old rule: transfuse only if “needed” because the effects of iron overload are worse than those of anemia

Nature Reviews | Genetics

Total SF-36 score significantly lower in patients with β-TI than in those with β-TM (66.5 ± 16.1 vs 75.8 ± 18.8; p = 0.021)

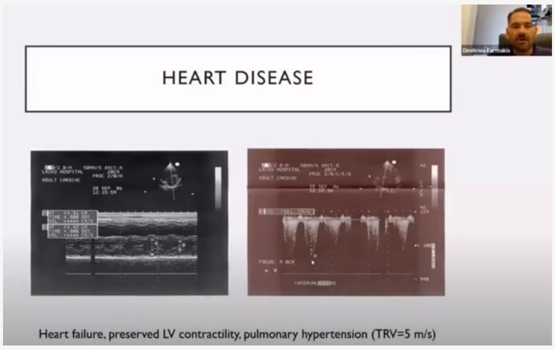
*Statistically significant difference (p < 0.05).

IRON MONITORING IN THALASSAEMIA - 07/09



Cardiac MRI for iron quantitation and functional analysis T2*

HEART DISEASE IN THALASSAEMIA - 23/10



HEART DISEASE

Heart failure, preserved LV contractility, pulmonary hypertension (TRV=5 m/s)

Click Here to Watch Now!

Watch all TIF Webinars here: https://bit.ly/33wTxn3

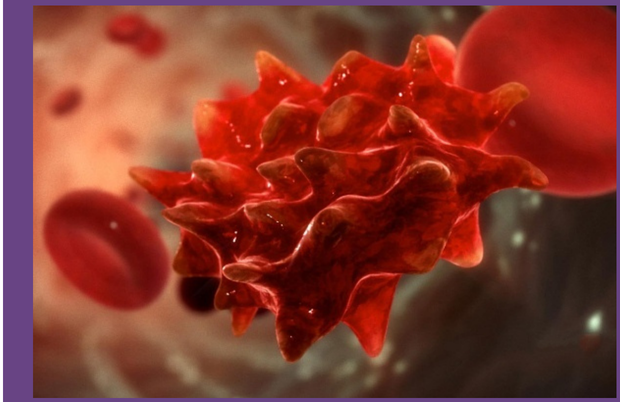
Upcoming TIF Activities for Sickle Cell Disease & Pyruvate Kinase Deficiency

TIF has taken the lead to support patients with sickle cell disease (SCD) through the establishment of the International Active SCD Group (IASG), an informal network of patient-led organisations working in the field of SCD, that advocates for the rights of patients with SCD in a consistent way, and ensure swift and timely access to the new innovative therapies that are currently being developed.

In this context, a special module concerning the treatment of SCD is underway and will be featured by the end of 2020 in our online educational course for healthcare professsionals, the eThalED Course.

Similarly, a TIF online course for SCD patients is already in the process of development, and will very soon be available for use!

Sharing Best Practices With Other Inherited Haemolytic Anaemias: Pyruvate Kinase Deficiency



Thalassaemia and pyruvate kinase deficiency (PKD) constitute inherited haemolytic anaemias; each disorder however has an entirely distinct pathophysiology and clinical needs.

Nonetheless, many PKD patients are members of a number of national thalassaemia ssociations in various countries globally, as both diseases share many common issues, policies and challenges for patients.

TIF has been encouraged by various stakeholders to share its expertise and best practices with the PKD community.

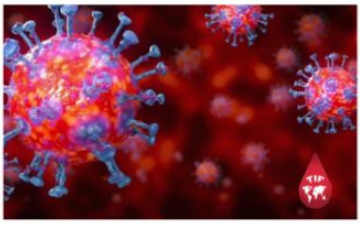
As a result, a dedicated PKD webpage will soon be part of TIF's website containing information about the disease and resources for patients and healthcare professionals!

THANK YOU FOR READING!

Subscribing to our Newsletter will ensure you never miss a chance to get the most out of TIF!

CLICK HERE

Useful Information



TIF material on COVID-19

Other Resources

Don't forget to visit TIF's COVID-19 dedicated webpage for useful resources:
https://bit.ly/2FCDeNB