2019
ANNUALREPORT

...making the patient voice heard globally!

THALASSAEMIA INTERNATIONAL FEDERATION

Front Page photo courtesy of Resala Life Saving Team (Egypt),
taken on the occassion of festivities for the International Thalassaemia Day 2019.

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FOREWORD

BY THE PRESIDENT AND EXECUTIVE DIRECTOR

We are privileged to present to our global patients' and healthcare professionals' communities, collaborators and friends TIF's Annual Report for 2019.

A landmark year, 2019 heralds the beginning of a new era – one that will fundamentally alter the natural history of the disease and fill with hope and optimism the patient/parent and medical communities all over the world. Decades of research have finally produced results that will drastically change the lives of our patients, both in the context of health, but very importantly, in their quality of life.

''Finally, years of research are producing results that will alleviate the yearning and desperation felt and seen in the eyes of patients and their families all over the world for better care and improved survival...'' Panos Englezos, TIF President

The authorisation of two innovative therapies, a drug (REBLOZYL®) and a cure (ZYNTEGLO® - gene therapy) by the two key drug regulatory bodies (European Medicines Agency and US Food and Drug Administration) have given every patient, parent of a child with thalassaemia, and treating physicians important ''weapons'' in their ongoing fight for a better life with quality, independence and social equity.

Many and multiple challenges are still faced by more than 80% of our global patient population, that is born and lives in the developing world, where other health and social priorities, poor health infrastructures and weak economies sadly allow the care of these patients to be suboptimal to extremely basic. Consequently, patients are still struggling to survive, to grow, to access education, to achieve social integration and acceptance, and of course to make families and enjoy what every human being has the right to enjoy. TIF will thus continue to focus with undivided attention on improving the national policies for the prevention and care of thalassaemia across cultures, religions, regions and countries, while at the same time fight for the availability and accessibility of new therapies for our patients across the world.

PANOS ENGLEZOS
PRESIDENT

DR ANDROULLA ELEFTHERIOU
EXECUTIVE DIRECTOR

''Undoubtedly, this is not the end of the road, but merely the beginning. The Federation will continue to advocate, with the same commitment, passion and sensitivity and to collaborate closely and productively with every single involved stakeholder to ensure that such ground-breaking research advances are not only made available but also accessible to patients in need across the world.'' Dr Androulla Eleftheriou, TIF Executive Director

The situation however is quite different in most of the Western world, in comparison to developing countries, with considerably better care and less co-morbidities as well as excellent, in many instances, results in survival, quality of life and social integration. Nevertheless, in both worlds, as grossly presented here, the new innovative therapies will bring new, complicated and different challenges to each setting. In addition, the new therapies may have a different mechanism of action but an important challenge remains common to both – the cost. TIF has closely followed and strongly encouraged through the years the research activity on new drugs and therapies, and had indeed predicted, based on its long term experience, the potential challenges.

In this context, in 2019 TIF has:

- Studied and launched two important initiatives – the TIF Patient Advocacy Group (Community Advisory Board) and TIF. ACCESS;
- Networked with other diseases with common areas of concern (e.g. sickle cell disease and other rare anaemias);
- Strengthened its collaboration with European countries (as a result of the THALIA2019 EU – funded project);
- Enhanced its educational programme through a Patient Capacity Building Workshop, European Healthcare Professionals Summit, Preceptorships (for Clinicians and Nurses), e-educational platform for Patients and Medical Specialists etc.;
- Reinforced communication tools and strengthened its communication strategy;
- Kept abreast of research and clinical developments with monthly updates and
- Maintained partnerships with other health-related organisations (e.g. IAPO, RDI, ISBT, EASL etc).

These, and many more, are activities which you will have the opportunity to read through in this 2019 Annual Report.

Thus, we invite you to go through it, and simultaneously join us in extending our deepest and most sincere appreciation to all our esteemed Board Members for their trust and involvement in the Federation's work, and to TIF Member Associations for their contribution. Moreover, we could not but be grateful to all those individual expert patients, scientific / medical advisors, volunteers, industry partners, and to each and every person, named and unnamed, that supports our work internationally, not forgetting of course the TIF Office Staff for their enduring efforts, hard work and dedication to the global thalassaemia family. The realisation of TIF's mission, and the materialisation of the Federation's activities contained herein, is the product of genuine commitment by all partners and collaborators.

We look forward to another year of close and productive collaboration, focusing efforts on improving the lives of patients worldwide.

ABOUT THE THALASSAEMIA INTERNATIONAL FEDERATION

The Thalassaemia International Federation (TIF) is a non-profit, non-governmental umbrella organisation working to improve the lives of patients with thalassaemia in all affected countries.

Together with patient/parent organisations, the medical community as well as international, regional and national health bodies/authorities, TIF promotes the establishment of new, and the strengthening of existing policies that aim to provide the highest quality of care for all.

220
members

131	National Thalassaemia Associations
62	Countries
100+	Volunteers
198	International Patient Advocates
27	International Medical Advisors
9	Staff members

1986
Founded

2015
Awarded 'Dr Lee Jong-Wook Memorial Prize' of the WHO for outstanding contribution to public health

1996
Official Relations with WHO

2017
Consultative Status of UN ECOSOC

2018
European Commission partner in the field of Health

Mission

The development and implementation of National Control Programmes, including both prevention and management, in every affected country

Vision

The establishment of equal access to quality health, social and other care for all patients with thalassaemia globally, in truly patient-centred healthcare systems

PILLARS OF WORK

The work of the Federation in addressing effectively the needs of the world thalassaemia family and achieving its mission has been based on 5 pillars:

1. The establishment of new and promotion of existing National Thalassaemia Patient/ Parents Associations, across the world, aiming to transform patients and parents into knowledgeable, productive and equal partners in the fight to achieve progress through education and building their capacities and competences;

2. The development and continuous updating and upgrading of an educational programme based on four components:
   - Organisation of educational events at the national, regional and international level;
   - Organisation of educational events in the course of Delegation visits;
   - Preparation, publication, translation and distribution of educational/ awareness-raising/community material, and;
   - Promotion of academic courses/fellowship preceptorships;

3. Collaborations/Networks/Partnerships with National Health Authorities and other relevant health-related institutions or medical/scientific associations or other disease-specific other than thalassaemia at the national, European and international level;

4. The undertaking or contribution to projects that aim to further improve existing policies or develop innovative ones, as well as expressing its position through the development and promotion of Position papers on critical issues and topics relevant to the quality of health, other care, life and safety of the patients, and;

5. Supporting and contributing to research and scientific programmes for further improving existing and development of new treatment procedures and aiming towards the final cure.

Communication Channels

WWW

43,468 new website users

VISITORS

Top 10 visiting countries:
India, USA, UK, Malaysia, Kingdom of Saudi Arabia, Pakistan, Greece, Cyprus, Indonesia & Bangladesh

f	🐦
10,190	2,107

TIF Magazine

TIF Newsletter

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STAKEHOLDER MEETINGS

Meeting Mr Costas Mavrides,
Member of the European Parliament, Cyprus

Meeting Dr Neelam Dhingra-Kumar, Coordinator, Patient Safety and Risk Management, Service Delivery and Safety, World Health Organization

Meeting Dr Junping Yu, Technical Officer, Blood & Transfusion Safety (BTS), HQ/HIS/SDS/SCI, World Health Organization

Meeting Dr George Kassoulides, Ambassador Extraordinary and Plenipotentiary of Cyprus, Permanent Representative to the United Nations office in Geneva and other International Organizations in Switzerland

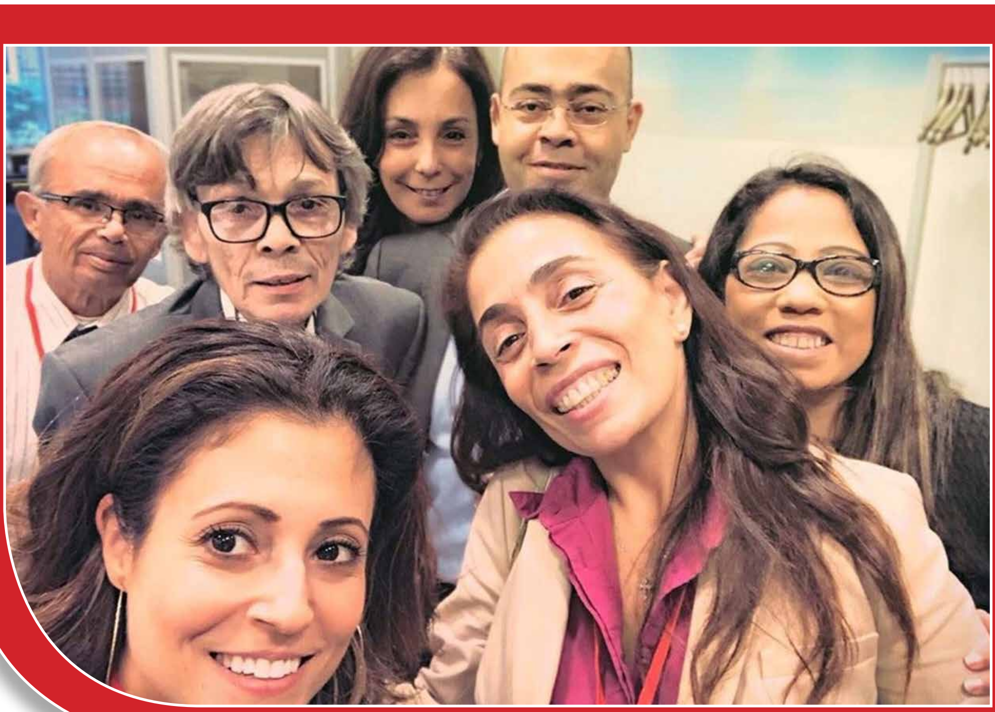
Meeting Mr Kevin Loth (Vice President, Corporate Affairs and Policy, Worldwide Markets) and Ms Anita Atema (Executive Director, Patient Advocacy, Worldwide Markets), Celgene Corp

Meeting Bluebird Bio Inc. Global & European Patient and Medical Affairs Team

Meeting Bluebird Bio Inc. European Access Team

Meeting Dr Anne Yardumian and Dr Anastasios Yiakoumis, Members of TIF's International Scientific Advisory Board

HIGHLIGHTS IN 2019



Capacity Building Workshop for Patients' Associations & Patients

The Thalassaemia International Federation (TIF) organised a Capacity Building Workshop entitled 'Capacity, Competence & Confidence: Building the Three C's for Patient Organisations' on 12 - 13 October 2019 in Hamburg, Germany.

The Workshop gathered more than 100 representatives of patients' associations & patient leaders with thalassaemia and haemoglobinopathies from 30 countries.

Featuring a wide array of interesting topics, the Workshop aimed to highlight the value of patient contribution to the improvement of services, through meaningful and productive participation in decision-making processes at the national, regional and international levels. This however can only be achieved through the development of strong patient-led associations and patient advocates who are 'experts' not only in disease-specific issues but also policy areas too. The Workshop Programme thus include sessions focused on disease-specific issues and new advances in the field, delivered by regional and international experts from Germany, Greece and the UK in addition to sessions on key elements that patients and patient associations should be striving to fulfil, delivered by members of TIF's Thalassaemia Patient Advocates Programme.

Capacity, competence & confidence:
building the three CS
for patient organisations

Kapazität, kompetenz & zuversicht:
aufbau der drei eckpfeiler
für patientenorganisationen

12 - 13 October 2019
Dorint Hotel Hamburg-Eppendorf
Martinistrasse 72
20251 Hamburg Eppendorf
Germany

THALASSAEMIA INTERNATIONAL FEDERATION

In collaboration with Verein für Seltene Anämien Deutschland (SAM)

THALIA

Co-funded by the Health Programme of the European Union

TIF's Patient Advocates Programme officially launched!

Seeking to facilitate the productive and meaningful discussions of patient advocates with decision-makers, healthcare professionals and research community, at the national, regional and international levels, the Thalassaemia International Federation (TIF) has officially announced the launching of TIF's Patient Advocates Programme in 2019.

This constitutes an extension and refinement to the Expert Patients Panel, established over 20 years ago by the Federation, and encompasses patient advocates from over 62 countries, who are able to voice the patient perspective for thalassaemia and sickle cell disease.

The "TIF's Patient Advocates Programme" consists of 2 components:

I. **Educational & Capacity Building opportunities** for becoming an Expert Patient (TIF Educational Programme - Publications, Conferences, Workshops and most importantly the Thal e-course)

II. **TIF Patient Advocacy Group** (T-PAG) - Global, Regional and National (Community Advisory Board)

Find information on the T-PAG structure & criteria for participation at https://thalassaemia.org.cy/projects/pap-patient-advocacy-programme/

THE MAIN ROLE OF T-PAG MEMBERS: To provide their opinion / perspective as patients, and participate in consultations by policymakers, industry, researchers or other stakeholders on aspects and issues related to prevention, care and research and the development of news drugs and therapies in the field of haemoglobinopathies always being in alignment with TIF's positions.

THE ONLY INTERNATIONAL THALASSAEMIA PATIENT ADVOCACY GROUP!!!

International Active SCD Group established!

A significant number of Member - Associations of the Thalassaemia International Federation (TIF) globally have repeatedly in recent years requested the Federation to further strengthen and expand its activities concerning sickle cell disease (SCD), to reflect the diversity of their membership base comprised of both thalassaemia and SCD patients.

Therefore, in 2019 the Federation has taken the lead to support patients with sickle cell disease (SCD) through the creation of a dedicated SCD Working Group, entitled as 'International Active SCD Group - IASG). The first meeting of the IASG Executive Committee took place in Athens, Greece on 5 June 2019.

IASG Mandate

In many countries, thalassaemia and SCD patients have the same:

- Centres/ Clinics
- Treating physicians
- Patient/parent associations

But, there is no dedicated truly global umbrella patient organisation to represent SCD, protecting and safeguarding the rights of patients for equal access to quality medical and other care as well as emerging therapies and drugs, free-of-charge in the context of universal access healthcare systems to decision-makers.

The IASG constitutes a network of patients and patient-led organisations working in the field of SCD in collaboration with TIF, 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.

Throughout 2019, the IASG, drawing upon the Federations' expertise, experience, infrastructure and resources, has achieved the following milestones:

- Partnership with World Health Organisation (WHO) in the field of SCD,
- Patronage of Mrs Maria Vamvakinou, Member of the Australian Parliament
- Collaboration of the Diplomatic Mission in Zambia and Miss Congo.
- SCD Patient Advocacy Group (See page 12 for more information),
- Capacity Building Workshop for SCD from Europe and beyond (See page 11 for more information),
- Conference on SCD for European healthcare professionals (See page 55 for more information),
- Established patient-led initiatives in the Democratic Republic of Congo and Cyprus
- Scientific Update on global SCD drug developments, distributed to IASG members monthly,
- SCD-specific modules in TIF's Thal e-course for Patients and e-ThalEd course for Medical Specialists (to be launched in 2020),
- Webpage on SCD incorporated in TIF's website, viewed by **14,896 users**,
- SCD Social media campaign, sharing news and developments to over **9,000 followers**.

Membership
21 Patient Associations
11 Patients / Parents
16 countries globally

Work on the Global Thalassaemia Report begins...

The Thalassaemia International Federation (TIF) in collaboration with its International Scientific Advisory Board comprised of renowned international medical experts in the field of thalassaemia have taken the first steps towards the development of a Global Thalassaemia Report. The Report will encompass the information gathered by TIF in the last 30 years during delegation visits and communication with national stakeholders (v. patients, doctors and healthcare authorities at the national level) regarding Epidemiology, Unmet Needs, Prevention, Management (Blood Transfusion, Iron Chelation, Monitoring Practices, Multidisciplinary Care), Social Care thus assessing the Disease Burden in more than 60 countries worldwide.

Envisioned to be a key advocacy tool for all patients worldwide and a reference source for the wider community of thalassaemia, the Report will be compiled using a rigid methodology and is expected to be published in late 2020.

TIF INTERNATIONAL RELATIONS

World Health Organisation
In official relations since 1996

- Member of Global Coordination Mechanism for Noncommunicable Diseases (GCM/NCD)

United Nations Economic and Social Council
Consultative Status since 2017

European Commission
Official Partner in the field of Health since 2018

New!

Conference of International Non-Governmental Organisations of the Council of Europe
Encourages dialogue of Members of European Parliament and local and regional authorities with associations on major social issues.

Association of Southeast Asian Nations

European Medicines Agency

- Observer of Patients & Consumers Working Party
- Patient Representative in Committee for Orphan Medicinal Products

NGO Committee for Rare Diseases
Forum of interested parties promoting multi-stakeholder collaboration and actions for rare diseases within the United Nations system.

European Hematology Association

Rare Diseases International
A global body advocating at the international level for rare diseases to be a public health priority.

European Association for the Study of Liver

European Organisation for Rare Diseases

International Association of Patient Organisations

New!

European Bone Marrow Transplantation Society

World Health Organisation

Knowledge Action Portal

The Knowledge Action Portal (KAP) is a flagship online community-driven platform launched by the WHO Global Coordination Mechanism on the Prevention and Control of Noncommunicable Diseases (WHO GCM/NCD), in which TIF officially participates since 2018.

TIF educational resources (e.g. publications, reports, leaflets etc) are uploaded on the KAP thus contributing to the wider dissemination of reliable information on thalassaemia globally.

144th Session of the WHO Executive Board

Statements calling for the prioritisation of thalassaemia by Member States and equal access to quality healthcare services for all patients were delivered by Dr Victor Boulyjenkov on behalf of the Thalassaemia International Federation (TIF) at the 144th Session of the WHO Executive Board, which convened on Thursday, 24 January 2019.

72nd World Health Assembly

A strengthened and expert TIF Delegation attended the 72nd World Health Assembly, held on 21 - 24 May 2019 - in Geneva, Switzerland comprising of Dr Androulla Eleftheriou (TIF Executive Director), Mr George Constantinou (Ass. Secretary of the TIF Board of Directors & Expert Patient), Ms Eleni Antoniou (TIF Senior Policy & International Relations Officer), Ms. Lily Cannon (TIF Operations Manager), Prof. Evangelia Yannaki (Haematologist; Member of TIF's International Scientific Advisory Board; Greece), and Ms. Maria Hadjidemetriou (Member of TIF Patient Advocates Group; USA).

Statements

Statements regarding the following issues were made by TIF:

- Universal Health Coverage
- Access to Medicines
- Prevention
- Migration
- Patient Safety

Watch TIF's statements at https://thalassaemia.org.cy/media-centre/videos/

Side Events

"Health for all: Gene and Cell Therapies in Universal Health Coverage (UHC)"

Organized by the Thalassaemia International Federation (TIF), the International Alliance of Patients' Organizations (IAPO), and the International Federation of Pharmaceutical Manufacturers & Associations (IFPMA).

This Side Event, held on 22 May 2019 and attended by over 60 representatives of Member States, industry and patient organisations, aimed to shed light on the science behind gene and cell therapies, highlight the challenges that need to be addressed to ensure access and uptake of these innovative cures and therapies and assess the practical impact that gene and cell therapies are having and will have on patients' lives. The renowned faculty of speakers coming from academia (Prof. Evangelia Yannaki, University of Washington), international bodies (Dr. Ivana Knezevic, World Health Organization), industry (Dr Mareike Ostertag, IFPMA) and patient associations (Dr Ratna Devi, IAPO; Ms. Maria Hadjidemetriou and Mr. George Constantinou, TIF) sought to discuss the possibilities offered by these therapies to chronic genetic disorders.

"How transformational digital technologies can contribute to leave no one behind in UHC: the case of rare diseases"

Seeking to show the potential of digital health in order to achieve Universal Health Coverage (UHC), using rare diseases as an example, this official Side Event, held on 23 May 2019 at the UN Palais des Nations, was co-sponsored by the Permanent Missions of the EU, Romania, Kuwait, Malta, Cyprus and Colombia.

Dr Androulla Eleftheriou (TIF Executive Director) conveyed the Federations' concerns regarding the role of digital transformation in low- and middle- income countries for achieving UHC. Dr Eleftheriou showcased the example of thalassaemia, as a chronic disorder with significant prevalence in such countries, to demonstrate how non-targeted healthcare service planning and provision contributes to remarkable out-of-pocket expenses being borne by families. Thus leading not only to poor clinical outcomes but also to financial difficulties and the social isolation of patients and their families.

Attendance, exceeding expectations reached approximately 130 delegates, many of whom were representatives of Member States, Permanent Missions and health attaches of other Diplomatic Missions and Bodies.

"Universal Health Coverage: Including Rare Diseases to leave no one behind"

Organised by Rare Diseases International (RDI) in collaboration with TIF, EURORDIS and Orphanet

Promoting awareness and knowledge about rare diseases and attempting to unite the international patient community and all relevant stakeholders to address the unmet needs of this largely ignored and vulnerable population within UHC, was the focus of this Side Event that took place on 23 May 2019. The daily challenges faced by people living with a rare disease, were discussed through an interactive case study session featuring thalassaemia.

The contribution of the Federation to the improvement of diagnosis, reduction of misdiagnosis and promotion of thalassaemia in UHC systems across the globe were the focus of Dr Androulla Eleftheriou's (TIF Executive Director) presentation. Delving into pathology, epidemiology and showcasing thalassaemia success stories from across the globe, Dr Eleftheriou left a mark on the event and proved that amongst rare disease groups, thalassaemia and TIF remains a pioneer.

International Society for Blood Transfusion

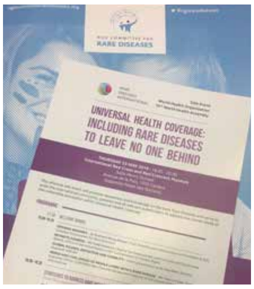
The Thalassaemia International Federation (TIF) in collaboration and with the assistance of Prof. Constantina Politis (Haematologist, Member of TIF's International Advisory Board; Greece) continues to exert efforts for the establishment of a specific Working Group on Haemoglobinopathies within the ISBT, to discuss issues arising from chronic blood transfusion further and promote actions to ensure blood safety and availability.

Seeking to draw attention to the specific needs of multi-transfused patients, TIF was represented at the Annual Congress of the International Society of Blood Transfusion (ISBT) held on 22 - 26 June 2019 in Basel, Switzerland by Prof. Politis who delivered a presentation entitled 'Safeguarding Blood Safety for Patients with Thalassaemia' in the plenary session and Dr Georgios Kaltsounis (Member of TIF Patient Advocates Group; Greece) who presented a poster abstract on gene therapy in thalassaemia. The Congress gathered approximately 8,000 participants.

An article on 'Blood Transfusion in Thalassaemia', authored by Mr Panos Englezos (TIF President), Dr Androulla Eleftheriou (TIF Executive Director), Dr Michael Angastiniotis (TIF Medical Advisor) and Prof. Constantina Politis (Haematologist, Member of TIF's International Advisory Board; Greece) has been published in the ISBT Transfusion Today Journal!

Rare Diseases International

TIF has co-authored the Position Statement "Rare Diseases: Leaving no one behind in Universal Health Coverage" with Rare Diseases International, which following extensive and persistent advocacy efforts has led to the **adoption by UN Member States of a historical Political Declaration on UHC, including a commitment to strengthen efforts to address rare diseases.** This is the first time rare diseases have been included within a UN declaration adopted by all 193 Member States.



NGO COMMITTEE FOR RARE DISEASES

UNIVERSAL HEALTH COVERAGE:
INCLUDING RARE DISEASES
TO LEAVE NO ONE BEHIND

European Medicines Agency

The Thalassaemia International Federation (TIF) has been working closely with the European Medicines Agency (EMA) for many years now, and has been involved in many EMA activities, including participation in multiple consultations, workshops and meetings, providing the patients perspective regarding thalassaemia-specific medicines.

In 2019, TIF's application to officially become a member of the Patients and Consumers Working Party (PCWP) of the European Medicines Agency (EMA) has been approved!

TIF's representatives have participated in 2 PCWP meetings held on 26 June 2019 and 24 - 25 September 2019, bringing the voice of patients with thalassaemia to the forefront of discussions, raising topics of accessibility, availability, adequacy and safety, as a number of novel therapies for thalassaemia are in the pipeline for EMA approval.

European Solidarity Corps

Expanding TIF's network of volunteers!

With the aim to equip volunteers of the European Solidarity Corps with the knowledge and know-how on how to support migrants and refugees with thalassaemia and other haemoglobinopathies arriving in EU Member States, the Thalassaemia International Federation (TIF) offered a two-month volunteering opportunity in Cyprus for EU volunteers. The opportunity was open to individuals from the THALIA countries of priority (France, Germany, Austria, Serbia, Sweden) and other countries that also host a large number of refugees (Greece, Italy, Spain, Belgium, the Netherlands).

The volunteering programme implemented between October - December 2019 in collaboration with the European Asylum Service Office and the Asylum Service of the Republic of Cyprus was provided to three volunteers (2 from France and 1 from Germany), who were informed about thalassaemia (its clinical manifestation, genetic and hereditary origin, distribution across the world, and the increasing public health issues in Europe due to migration).

Moreover, the volunteers were able to get hands-on experience regarding the provision of support to the thalassemia community in Europe (1) through their placement at the Headquarters of TIF, and most importantly (2) through interaction with refugees and migrants at the Kofinou Reception & Accommodation Centre, many of whom were from the Middle East, Asia and North Africa, where thalassemia is highly prevalent. Moreover, the volunteers had the opportunity to visit the Thalassaemia Centres in Cyprus and engage with the medical staff and meet patients, thus enriching their knowledge on the disease and its implications. Debriefing sessions were arranged as required. In addition, the Federation's advocacy efforts for the establishment of a thalassaemia screening policy for refugees, asylum seekers and migrants and for the free-of-charge provision of all necessary healthcare and other services to migrant patients were strenghthened by the volunteers as they participated in meetings with other NGO's focused on the provision of care for migrants.

The volunteers have formally been appointed by TIF as 'local info points' in their respective countries, and have stated their readiness to assist in any way they can the migrant communities in their own countries.

European Association for the Study of Liver

The International Liver Congress of European Association for the Study of Liver (EASL) takes place on an annual basis gathering around 10,000 delegates and 250 media representatives from all over the world.

In 2019, the Thalassaemia International Federation (TIF) represented by Mr George Constantinou (Ass. Secretary of the TIF Board of Directors & Expert Patient) and Dr Anne Yardumian (Consultant Haematologist; Member of TIF' International Scientific Advisory Board, UK) participated in the Congress, which took place in Vienna, Austria on 10 - 14 April.

Actively contributing to the Multi-transfused Patient Forum Discussion, which focused on the development of clinical guidelines for the appropriate treatment of liver-related issues for patients with other underlying disorders such as thalassaemia, Mr Constantinou was able to present the work of the Federation emphasizing the importance of developing partnerships with members of the scientific community and showcasing the new educational tools for healthcare professionals (e.g. e-Thal-Ed platform). In addition, Mr Constantinou made reference to TIF's involvement in the field of hepatology for many years now, most notably with the dedicated chapter in TIF's Guidelines for the Clinical Management of Transfusion Dependent Thalassaemia and its Position Paper regarding Viral Hepatitis C.

Liver complications constitute one of the commonest organ complications of thalassaemia and thus discussion on the development of disease-specific guidelines to manage liver complications are of particular interest to the patient community and TIF.

European Organisation for Rare Disorders

EURORDIS Social Policy Action Group

Officially participating in the EURORDIS Social Policy Action Group (SPAG), TIF has extended its outreach of advocating for holistic and integrated care for thalassaemia patients and their families through the development of specific policies to address these unmet needs. Moreover, the exchange of best practices and wider dissemination of positions and policies, broaden the Federation's collaboration network for effective patient-centred advocacy.

EURORDIS Foresight Study - Rare2030

Rare2030
Foresight in Rare Disease Policy

Acknowledging the pioneering strides of the Federation and the expertise of Dr Androulla Eleftheriou (TIF Executive Director), TIF is an active participant in the Panel of Experts of Rare2030, a foresight study of EURORDIS.

Targeting an aspirational and long-term future of people living with a rare disease in Europe, including people with thalassaemia, the foresight study will create recommendations on the policy priorities of the rare disease community for the next decade.

EURORDIS Membership Meeting

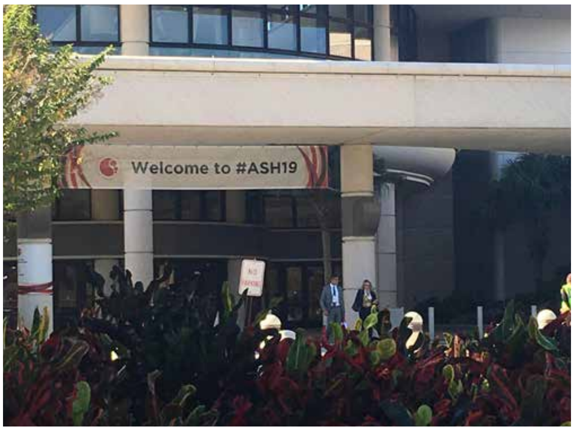
The Thalassaemia International Federation (TIF) participated in the annual EURORDIS Membership Meeting (EMM) which took place on 17 - 18 May 2019 in Bucharest, Romania. Mr. Angelo Loris Brunetta (TIF Board Member & Expert Patient), Ms. Lily Cannon (TIF Operations Manager) and Ms. Eleni Antoniou (TIF Senior Policy & International Relations Officer) represented the Federation and actively participated in all sessions.

American Society of Hematology

The 61st Annual Meeting of the American Society of Hematology (ASH) that took place on 7 - 10 December 2019 in Orlando, Florida constituted a unique opportunity for TIF to learn about the most recent scientific advances in the field of thalassaemia and sickle cell disease as well as to distribute TIF's publications to the haematologists in attendance from the Americas and beyond.

The Federation in 2019 was represented by Ms Lily Cannon (TIF Operations Manager), complementing the annual delegation of the Cooley's Anemia Foundation, including the pivotal participations of Mr Robert Ficarra (TIF Board Member and founding member of the Federation; USA) and, Ms. Maria Hadjidemetriou (Member of TIF Patient Advocates Group; USA).

During the Congress, the TIF delegation had the opportunity to meet with key opinion leaders and other stakeholders to explore possibilities of strengthening partnerships with TIF and the wider thalassaemia community.



Global Globin 2020 Challenge: Human Variome Project

Mr Angelo Loris Brunetta (TIF Board Member & Expert Patient) represented the Thalassaemia International Federation (TIF) in the annual Conference of the Global Globin 2020 Challenge (GG2020) held on 28 - 30 October 2019 at the UNESCO Headquarters in Paris, France.

GG2020, constitutes part of the Human Variome Project, focused on the systematic collection of genome data for identifying and mapping thalassaemia and sickle cell disease in low- and middle-income countries. More than 30 stakeholders from 19 countries, including TIF, have come together in this initiative which is expected to yield important information for future therapeutic approaches to haemoglobinopathies.

The Conference, focused on enhancing partnerships in genomic capacity towards achieving equitable healthcare, constituted an excellent platform for the active participation of Mr Brunetta, with a presentation showcasing the role of NGO's in empowering patients thus highlighting TIF's efforts, activities and contribution globally for the improvement of the quality of life of patients.

ChangeMakers Patient Group

Dr Androulla Eleftheriou (TIF Executive Director) and Dr Michael Angastiniotis (TIF Medical Advisor) participated in the ChangeMakers Steering Committee Meeting in Brussels on 22 January 2019.

The ChangeMakers initiative aims to bring more patient involvement in clinical trial design and development, promoting that study protocols include endpoints that meaningfully enhance patient quality of life and consider patient-relevant outcomes.

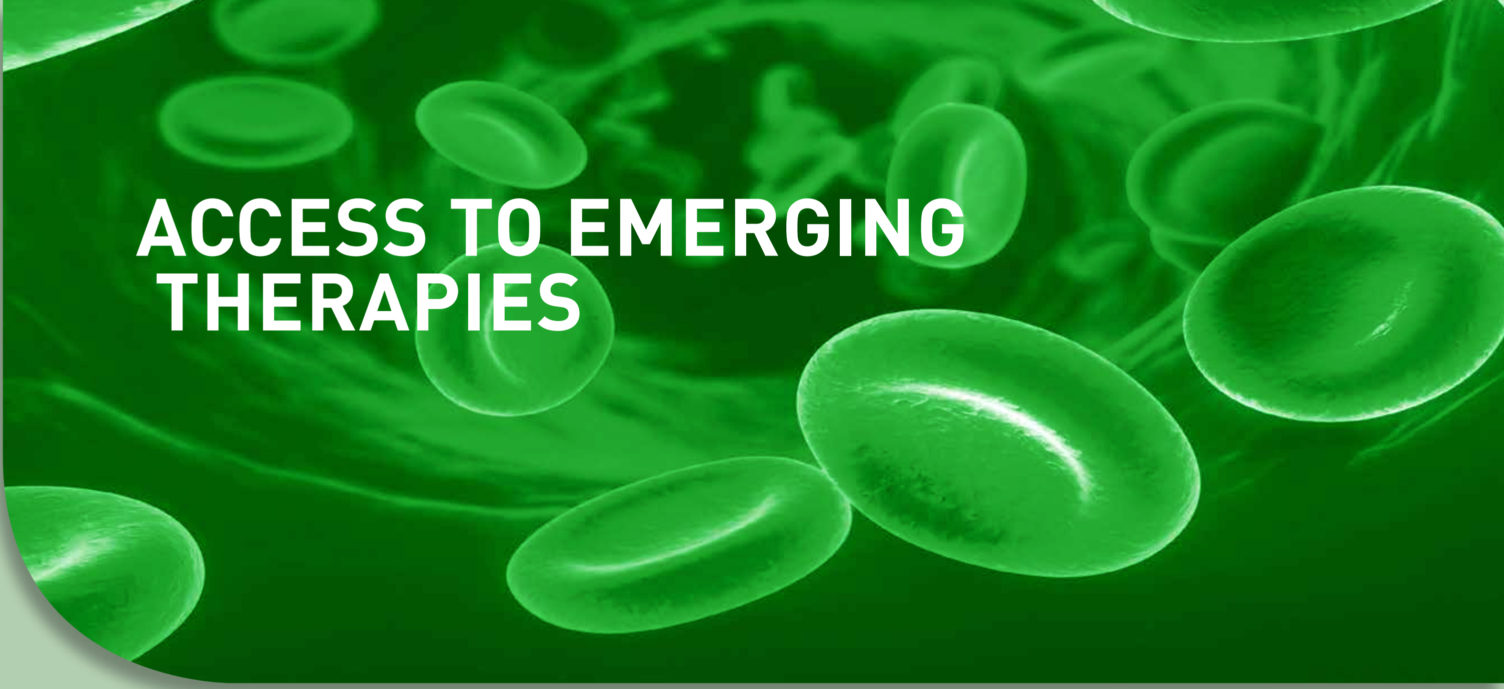
As a result of TIF's continual involvement, a "Clinical Trials Toolkit", empowering patients to include holistic needs assessment in protocols for clinical trials has been created.

International Network of Clinicians for Endocrinopathies in Thalassemia and Adolescence Medicine

The International Network of Clinicians for Endocrinopathies in Thalassemia and Adolescence Medicine (ICET-A), of which the Thalassaemia International Federation (TIF) is a founding member, celebrated its 10th anniversary on 08 November 2019.

The ICET-A, coordinated by international experts on endocrine complications in thalassaemia Dr Vincenzo De Sanctis (Paediatric Endocrinologist and Member of TIF's International Scientific Advisory Board; Italy) and Ashraf Soliman (Paediatric Endocrinologist and Member of TIF's International Scientific Advisory Board; Qatar). Initially comprised of representatives from 10 countries, ICET-A membership now spans across 30 countries globally.

ICET-A plays a pivotal role in publishing research on the endocrine complications of thalassaemia and in organizing scientific forums for exchanging knowledge and experiences.



ACCESS TO EMERGING THERAPIES

Launching of TIF.ACCESS for Advanced Therapies

The recent regulatory approvals of new innovative drugs and therapies in the EU and USA has deemed the understanding and navigating the complexities of market access and the introduction of innovative and advanced therapies in national healthcare systems and formularies imperative. Therefore, it is fundamental to provide information to policy-makers in order to make informed decisions about introduction of these new scientific advanced therapies into national formularies and make them accessible to patients. Thus, the accessibility of these therapies relies heavily on the initiation of an early dialogue with governments, and discussions around the issues of affordability, pricing models, added-value, public health, long-term cost effectiveness etc.

On this premise, TIF has launched the TIF's **I**nternational **F**orum on **ACC**essibility, **E**ffectiveness and **S**ustainability of Therapie**S** for Haemoglobin Disorders (TIF.ACCESS) that encompasses the following activities:

1. Global Thalassaemia Report (See page 13 for more information)
2. Educational Material for Patients/Parents, Healthcare Professionals & Decision-Makers (See page 61 for more information)
3. Organization of and/or participation in events focused on new & innovative therapies (See page 16 for more information).

TIF.ACCESS has been placed under the **patronage of Mr.Dimitiris Syllouris, President of the House of Representatives of the Republic of Cyprus,** who has provided his unwavering support to ensuring the timely and universal access of haemoglobinopathy patients to innovative, life changing and life-saving therapies!

Side Event at 72nd World Health Organisation: "Health for all: Gene and Cell Therapies in Universal Health Coverage (UHC)" organized by the Thalassaemia International Federation (TIF) in collaboration with its international partners, made possible an open discussion with participating stakeholders (i.e. decision-makers, NGOs, industry, healthcare providers) on the possibilities and challenges offered by these therapies to genetic disorders such as thalassaemia. TIF was represented by Dr Androulla Eleftheriou (TIF Executive Director), Mr George Constantinou (Ass. Secretary of the TIF Board of Directors & Expert Patient), Ms Maria Hadjidemetriou (Member of TIF Patient Advocates Group; USA), Prof. Evangelia Yannaki, (Haematologist; Member of TIF's International Scientific Advisory Board; Greece), Ms Lily Cannon (TIF Operations Manager) and Ms Eleni Antoniou (TIF Senior Policy & International Relations Officer). (See page 16 for more information)

The **‘1st Informational Forum on New & Innovative Therapies for Haemoglobinopathies’** organised by the Thalassaemia International Federation (TIF) was held on 12 December 2019 at the Federation’s Headquarters in Nicosia, Cyprus. The multi-stakeholder event brought together more than 50 key opinion leaders, including patients with thalassaemia and sickle cell disease, parents, doctors, nurses, reimbursement agencies, Ministry of Health, state pharmaceutical services, academics, representatives of political parties and researchers. The participants engaged in a lively discussion regarding the newly authorized (by the FDA and EMA) advanced therapies for thalassaemia and SCD and how they will be integrated into the national health system, pricing, and how the patient/parent and medical community can contribute to the negotiations/discussions with reimbursement agencies and Ministries of Health to ensure accessibility to these new innovative therapies that will radically change the lives of patients.

IAPO’s monthly online newsletter publishes TIF’s **article on Gene Therapy for β-thalassaemia** authored by Dr Carsten Werner Lederer (Molecular Scientist, Member of TIF’s International Scientific Advisory Board; Cyprus).

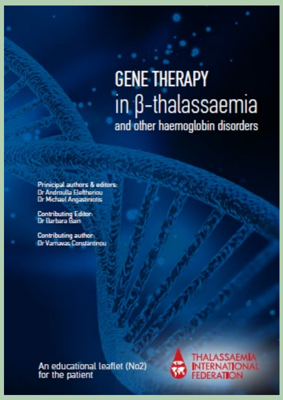
Gene Therapy for β-Thalassaemia Approaches European Market Approval

Gene therapy continues to evolve with new emerging treatments finally reaching its promised potential: providing a one-time lifelong cure for even the rarest and most severe of genetic disorders. IAPO member Thalassaemia International Federation explores this topic by highlighting the significant conditional approval for the first universal cure for the clinically most important type of thalassaemia, β-thalassaemia.

The need for a cure

The Thalassaemia International Federation (TIF), represented by Ms Eleni Antoniou (TIF Senior Policy & International Relations Officer) together with representatives of other EU-based leading patient organisations, such as EURORDIS, participated in a **Closed meeting on Access to and Pricing of Innovative Therapies for Rare Diseases** held in Brussels (Belgium) on 28 November 2019. The meeting focused on the alignment of policy advocacy efforts regarding access to innovative therapies and presented an opportunity for all participants to discuss current challenges, ways to overcome them and draft a collaboration plan for 2020.

Increasing Patient Education and Access to Reliable Information on Emerging Therapies (See page 61 for more information)



GENE THERAPY
in β-thalassaemia
and other haemoglobin disorders

Prinicipal authors & editors:
Dr Androulla Eleftheriou
Dr Michael Angastiniotis

Contributing Editor:
Dr Barbara Bain

Contributing author:
Dr Varnavas Constantinou

An educational leaflet (No2)
for the patient

THALASSAEMIA
INTERNATIONAL
FEDERATION

PATIENT INFORMATION LEAFLET
ON REBLOZYL®

A BREAKTHROUGH IN THALASSAEMIA
MANAGEMENT!

December 2019

THALASSAEMIA
INTERNATIONAL
FEDERATION

Joining forces with EURORDIS and RDI, the Thalassaemia International Federation (TIF) participated in a **Round Table on Access to Therapies for Rare Diseases in Lower and Middle Income Countries** dedicated to discussing access to appropriate care for rare diseases, including haemoglobinopathies. The Round Table took place in Geneva (Switzerland) on 04 December 2019, and was mainly attended by disease-specific NGOs and representatives of industry. Industry presented programmes to support treatments in low resource countries in partnership with NGOs. The TIF Delegation, comprised of Dr Androulla Eleftheriou (TIF Executive Director) and Dr Michael Angastiniotis (TIF Medical Advisor) supported that equality in access can only be achieved through universal healthcare coverage and disease-specific strategies / policies / programmes that cover both the prevention and management of each disorder.


THALASSAEMIA
INTERNATIONAL
FEDERATION


The patients' perspective - Patient questions
5. The challenges that countries of the developing world are facing in the treatment of thalassaemia are different and perhaps patients in the developing world will benefit more from such an innovative treatment. But
it? But what are the criteria for inclusion?
6. What are the criteria for inclusion? Are age and clinic
eligibility/inclusion criteria? A large percentage of pa
world have poor health, consequent to suboptim
MANY WILL BENEFIT?
7. Will there be ongoing research for further devel
minimize or even ensure ZERO off-target effects?


SPEAKER


High-Level
Thalassaemia & Sickle Cell
Disease Healthcare Professionals
Summit
GRAND HOTEL PALACE


disease drug development
Patient engagement in research: a systematic review
GRAND HOTEL PALACE
THALASSAEMIA
INTERNATIONAL
FEDERATION

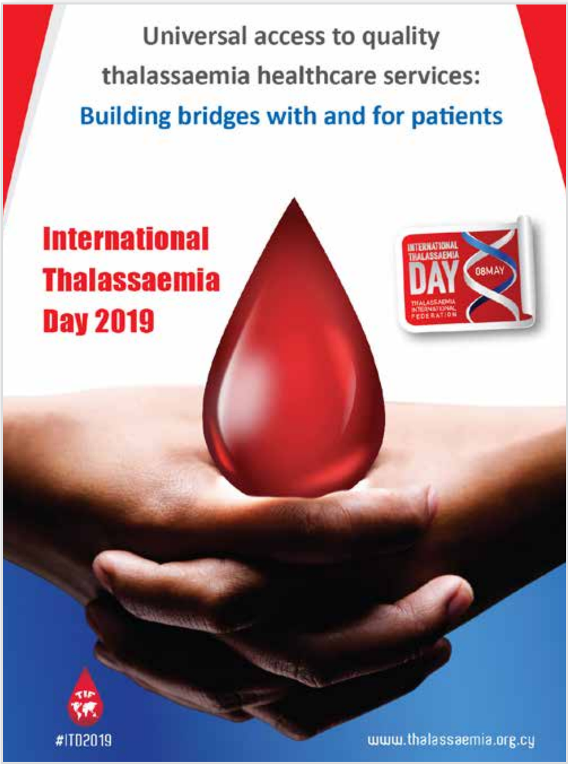
INTERNATIONAL THALASSAEMIA DAY

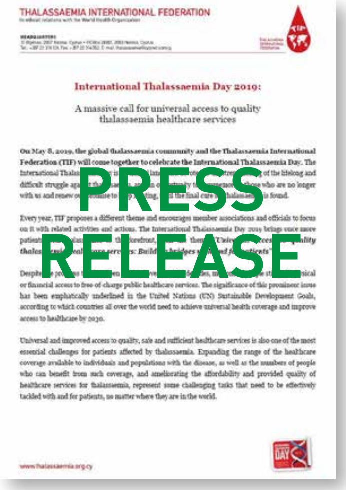
For the global thalassaemia family, the 8th of May constitutes a very special day as it is dedicated to both commemorate the thalassaemia patients who are no longer with us but are always close in our heart and to celebrate all those patients who are alive and fighting every day for their right to a better quality of life.

2019 Theme: Universal access to quality thalassaemia healthcare services: Building bridges with and for patients

This theme accentuates a substantial challenge for patients affected by thalassaemia, because regardless the progress that has been attained over the past decades, millions of people still lack physical or financial access to free-of-charge, safe and sufficient public healthcare services.

Expanding the range of the healthcare coverage available to individuals and populations with the disease, as well as the numbers of people who can benefit from such coverage, and ameliorating the affordability and provided quality of healthcare services for thalassaemia, represent some challenging tasks that need to be effectively tackled with and for patients, no matter where they are in the world.





THALASSAEMIA INTERNATIONAL FEDERATION

International Thalassaemia Day 2019:

A massive call for universal access to quality thalassaemia healthcare services

PRESS RELEASE

Universal and improved access to quality, safe and sufficient healthcare services is also one of the most essential challenges for patients affected by thalassaemia. Expanding the range of the healthcare coverage available to individuals and populations with the disease, as well as the numbers of people who can benefit from such coverage, and ameliorating the affordability and provided quality of healthcare services for thalassaemia, represent some challenging tasks that need to be effectively tackled with and for patients, no matter where they are in the world.

www.thalassaemia.org.cy

The past, present, and future of monitoring and treating thalassaemia and other and haemoglobinopathies were discussed in a dedicated webinar organized by BioRad Laboratories and TIF entitled **"Test2Control"**. Dr. Michael Angastiniotis, (TIF Medical Advisor) discussed global strategies for the control of these severe haemoglobin disorders and the necessity to further improve awareness and education through carrier screening. Moreover, participants from all over the world engaged in a dedicated Q&A session with the speakers.

> *I am confident that the message of today, «to build bridges with and for patients», is stressing the need to create long-lasting bonds of collaboration between all stakeholders and ensure the political commitment of our governments which without doubt will facilitate processes, for the benefit of our People and our Society.*
>
> Constantinos Ioannou, Minister of Health, Cyprus

> *TIF has pushed hard to have safe, quality, acceptable, accessible, affordable and equitable healthcare for patients in many countries and its efforts for safe blood transfusion services and accessible and affordable iron chelation medicines have gone a long way.*
>
> Kawaldip Sehmi, Chief Executive Officer, International Alliance of Patients' Organizations (IAPO)

> *The International Thalassaemia Day on the 8th of May is a valuable opportunity to showcase and share individual experiences with all parties, so that they can work together to improve the lives of those affected with thalassaemia. I'd like to reiterate EMA's continued support for all the work TIF does for the sake of public health.*
>
> Guido Rasi, Executive Director, European Medicines Agency (EMA)

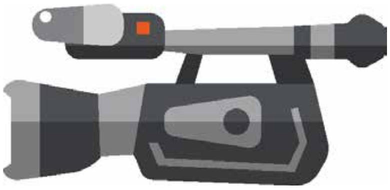
> *The European Commission acknowledges TIF's valuable work and dedication in helping patients with thalassaemia across in Europe and worldwide and is proud to support the Federation through an operating grant for the "THALassaemia In Action" (THALIA) project.*
>
> Roser Domenech Amado, Head of Unit, European Commission. Directorate-General for Health and Food Safety

Three online competitions (a video challenge, a photography contest, and a story challenge), were organized by TIF, inviting the global thalassaemia community to submit videos, stories and photographs (or collages), about the selected theme.

The participation was wide and heart-warming, with **250 entries from 18 countries including more than 700 photos, 50 stories and 15 videos.**

Participating countries: Pakistan, India, Sri Lanka, USA, Canada, Australia, Brazil, Maldives, Mauritius, Indonesia, UK, Italy, Germany, Egypt, Lebanon, Iran, Bangladesh, Ghana.

The International Selection Committee determined the winners of the Global Competitions for 2019.



Video Challenge

1

1st Place: Fadel Nooriandi, Indonesia
Video available at https://www.youtube.com/watch?v=NM2DDJ4wjGc

2

2nd Place: Monica Rockwell, USA
Video available at https://www.youtube.com/watch?v=V8XPlkh3AU4&feature=youtu.be

3

3rd Place: Navdeep Singh, USA
Video available at https://www.youtube.com/watch?v=4wx4q13brCc&feature=youtu.

Photography Contest

1

1st **Place:** Amitava Chandra, India

Photo title: "Daily Medication"

2

2nd **Place:** Sourav Karmakar, India

Photo title: "Give me the colours"

3

3rd **Place:** Sana Atiq, Pakistan

Photo title: "Blood Transfusion"

Story Competition

1

1st Place: Linda Brown, USA
Story title: "The Bridge to a Cure"
https://thalassaemia.org.cy/patients-stories/patient-story/

2

2nd Place: Diana Abou Hamia, Lebanon
Story title: "Life With and Without Thalassaemia"
https://thalassaemia.org.cy/patients-stories/patient-story-2/

3

3rd Place: Bidhan Sarkar, Bangladesh
Story title: "Fighting with Hope"
https://thalassaemia.org.cy/patients-stories/patiet-story-3/

Celebrating International Thalassaemia Day 2019 around the world!
Hundreds of thalassaemia associations' as well as individual patients around the world organised events, activities, and initiatives to spread the message for universal access to quality healthcare services, while helping increase the public's understanding of the current and future challenges faced by the thalassaemia community.


INTERNATIONAL THALASSEMIA DAY 2019
Safe Blood Transfusion Programme


INTERNATIONAL THALASSAEMIA DAY 2019
Building Bridges With And For Patients


TEAM SAREAAM RAWALPINDI SOUTH


معكم
أمل


ශ්‍රී ලංකා இலங்கை 15.00
SRI LANKA
INTERNATIONAL THALASSAEMIA DAY


08.5.2019

COUNTRY ACTIVITIES

AFRICA REGION

Mauritius

A delegation visit to Mauritius took place for the first time in 2019. TIF International and Regional Scientific Advisory Board members Prof Antonio Piga (Italy) and Dr Mohammed Naveed (UAE), as well as TIF Medical Advisor, Dr Michael Angastiniotis, were invited to share their expertise in the provision of optimal clinical care services for thalassaemia patients in their respective countries during a Conference organised by the Thalassaemia Society of Mauritius (TSM), with participation of the Ministry of Health. During the Conference, held on 7 - 10 February 2019, the TIF Delegation had the opportunity to discuss numerous issues with the TSM Committee and treating physicians, thus providing feasible suggestions for more effective advocacy for policy changes regarding the prevention and multidisciplinary treatment of thalassaemia, including the opportunity for further training of nursing staff through TIF's preceptorships (See page 52-53 for more information).

The expert contribution of the TIF Delegation has been pivotal in the updating of the national clinical management guidelines to reflect current evidence-based scientific practices. Following review by Prof. Piga, Dr Naveed, Dr Angastiniotis and Dr Dimitris Farmakis (TIF Medical Advisor), the guidelines have been adopted by the Ministry of Health during a dedicated Workshop in the presence of Dr Naveed, attending on behalf of TIF.

EASTERN MEDITERRANEAN REGION

Iraq

The Ministry of Health of Iraq has initiated a multi-stakeholder process to review the national policy for haemoglobin disorders. Following an invitation from His Excellency, the Minister of Health of Iraq, Prof. Alaa Al-Alwan (former WHO Director of the Easter Mediterranean Regional Office and long-standing interest in thalassaemia), TIF has played an active role throughout the process, including the organisation of a consultation meeting with relevant national stakeholders in 2018. Now in the final stages of review, the Ministry of Health has made efforts to secure WHO Consultancy through TIF - an NGO in official relations with the WHO since 1996.

Jordan

The Thalassaemia International Federation (TIF) has successfully participated in the Haemophilia, Thalassaemia and Sickle Cell Disease Conference organised by the Jordanian Thalassaemia and Haemophilia Society and the Thalassaemia Palestinian Friends Society (TPFS) on 26 - 27 September 2019 in Amman, Jordan.

The Conference held under the patronage of H.E Minister of Health of the Kingdom of Jordan, with the auspices of the World Federation of Haemophilia (WFH) and TIF, brought together doctors and patients from Jordan and neighbouring countries (e.g. Lebanon, Iraq, and Palestine) to discuss issues regarding the clinical management of these haematological diseases.

TIF was represented by Mr Anton Skafi (TIF Board Member and Expert Patient, Palestine) and Dr Michael Angastiniotis (TIF Medical Advisor) who led the discussions in the 1st Meeting of the Thalassaemia Arab Associations Forum which took place in parallel to the Conference.

Kuwait

The Thalassaemia Advisory Committee of the Ministry of Health of Kuwait having received support from the Ministry and Parliament, invited TIF to visit Kuwait for a Delegation Visit on 08 - 09 September 2019. The TIF Delegation Team comprised of Mr Abdul Baset Mohd Merdas (TIF Board Member), Ms Maria Hadjidemetriou (Member of TIF Patient Advocates Group; USA), Dr Michael Angastiniotis (TIF Medical Advisor) and Mr Rawad Merhi (TIF Countries Officer).

The Delegation Team had the opportunity to visit medical facilities and the Ministry of Health IT Department to understand the present situation and provide technical expertise for the improvement of the quality of services provided. Indeed, discussions focused on identifying ways to upgrade the services of the medical facilities, the development of a national guideline for the clinical management of thalassaemia and the necessity of creating a multi-disciplinary team. The Delegation furthermore met with patients from two thalassaemia support groups, namely the Thalassaemia Patients League and the Soroptimist International Club Kuwait.

Oman

A TIF Delegation Visit to Oman took place on 10 - 11 September 2019 as a follow up to the 2017 visit, which was conducted at the request of the Ministry of Health for the provision of technical expertise for the development of a comprehensive national control programme for thalassaemia (clinical management and prevention). The Delegation Team comprised of Mr Abdul Baset Mohd Merdas (TIF Board Member), Ms Maria Hadjidemetriou (Member of TIF Patient Advocates Group; USA), Dr Michael Angastiniotis (TIF Medical Advisor) and Mr Rawad Merhi (TIF Countries Officer).

During the visit the Delegation Team had the opportunity to visit the Sultan Qaboos University Hospital and Royal Hospital (adult and paediatric care) and meet with treating physicians to discuss issues pertaining to the clinical management of thalassaemia. Most notable is the state-of-art electronic health record at the Sultan Qaboos University Hospital including both primary and hospital care. Moreover, the Delegation Team visited the Genetic Centre where the national prevention programme is being regulated.

The Genetic Centre demonstrated the most impressive development since the 2017 visit, in the implementation of specialised training programme of genetic counsellors. This is almost unique across the world where counselling is usually offered by doctors, nurses and laboratory scientists. Already 8 counsellors have been trained in the first course, and 13 in the second course. These counsellors cover the needs of prevention across Oman.

EUROPEAN REGION

Austria

A TIF Delegation Visit to Vienna, Austria took place on 11 - 13 April 2019. The Delegation Team comprised of Mr. George Constantinou (Ass. Secretary of the TIF Board of Directors & Expert Patient), Dr. phil Eva-Maria Knoll (Medical Anthropologist, Austria ; TIF National Advisor) and Dr. Anne Yardumian (Consultant Haematologist, UK; Member of TIF's International Scientific Advisory Board).

The Delegation Team had the opportunity meet with patients and doctors at the Department of Haematology & Hemostaseology (Vienna General Hospital - AKH), and St. Anna's Children's Hospital and to discuss issues of concern following TIF's exploratory visit in 2018. Moreover, the Department of Haematology and Oncology at Hanusch Hospital and Labors Medical Lab & Diagnostic Services were also visited in order to obtain an overall view of the ground-level situation concerning thalassaemia in the country. As a result of discussions held during the visit, steps have been made to further enhance monitoring of adult patients through the installation of MRI T2*.

THALASSAEMIA & SICKLE CELL FORUM - THALSIFO AUSTRIA

The momentum created by the TIF delegation visits in 2018 and 2019, have culminated in the establishment of a patient support group for haemoglobinopathy patients in Austria, called "Thalassaemia & Sickle Cell Forum" (THALSIFO)!

The first meeting of THALSIFO took place on 17 May 2019, with 16 attendees (patients, parents and family members of thalassaemia and sickle cell disease patients). The establishment of the Forum and the meeting gone a long way to combat the social isolation and marginalisation felt by patients and has enabled the exchange of experiences with peers. Not a single of the participating patients had contacts with other patients before this meeting!

The initiative was undertaken by Dr. Phil Eva-Maria Knoll (Medical Anthropologist, Austria ; TIF National Advisor) as a result of the synergy witnessed in the patient community, and attended Prof. Christian Sillaber (Haematologist; Dept Haematology & Hemostaseology, Vienna General Hospital).

Azerbaijan

The 1st International Congress of Azerbaijani Haematology Specialists, held on 22 - 24 May 2019 in Baku, Azerbaijan was organized by the Republican Thalassaemia Centre, with the support of the Heydar Aliyev Foundation and was attended by over 900 healthcare professionals and patient representatives. Covering the entire spectrum of haematology, thalassaemia and sickle cell disease were at the forefront of discussion at the keynote scientific session.

TIF was invited to attend the Congress and participate with presentations on the Quality of Services (Dr Michael Angastiniotis, TIF Medical Advisor) and the Patients Perspective (Mr Ahmet Varoğlu ; Member of TIF Patient Advocates Group; Cyprus).

During their stay in Baku, the TIF representatives had the opportunity to visit the Thalassaemia Centre and to meet with patients from the Savab Dunyasi Association and the Azeri Thalassaemia Federation to discuss the situation in Azerbaijan following a previous visit of TIF in 2017. Concerns regardin g treatment were raised, in addition to the understaffing of the Thalassaemia Centre.

In addition, TIF representatives joined a visit by Ms Leyla Aliyeva (daughter of the President of Azerbaijan and Vice - President of the Heyder Aliyev Foundation) to the Haematology Institute, which includes the National Blood Bank.

Cyprus

The National Thalassaemia Committee, chaired by Mr. Panos Englezos (TIF President), has officially submitted to the Minister of Health in the presence of His Excellency President of the Republic of Cyprus and the Minister of Foreign Affairs on 6th of June 2019, a proposal for the updating of the National Strategy for Thalassaemia and Other Haemoglobinopathies.

The updated Strategy has been drafted after a period of extensive deliberation by national and international experts in the field and in consideration of the role that Cyprus, as a global reference point, has demonstrated in the effective prevention and management of thalassaemia throughout the years.

Following a period of consultation, the National Strategy for Thalassaemia and Other Haemoglobinopathies is expected to be ratified by the Council of Ministers prior to implementation.

France

The Thalassaemia International Federation (TIF), represented by Ms Lily Cannon (TIF Operations Manager) and Ms Eleni Antoniou (TIF Senior Policy & International Relations Officer) actively participated in the 7th National Meeting of the MCGRE Network on 01 February 2019, in Paris, France.

During the course of the Meeting, the TIF Delegates had the opportunity to present an overview of its work to the gathered audience (doctors, healthcare professionals and patients). The presentation, jointly delivered by the TIF Delegates was translated into French to facilitate the understanding of the audience.

The Delegation held follow-up meetings with the thalassaemia patients who participated in TIF's Twinning Programme (Dec. 2018; France/ Cyprus) as well as with the leadership of SOS Globi (Federation of Haemoglobin Disorders Patient Associations), to discuss the further strengthening and empowerment of the thalassaemia patients' community in France. In addition, the Delegation had the opportunity to meet and discuss issues of concern with clinicians and other healthcare professionals regarding specific matters pertaining to the management of thalassaemia and policy/service planning tools.

The French Federation of Haemoglobin Disorders Patient Associations 'SOS Globi' in collaboration with TIF organized a Thalassaemia Conference on 03 - 05 May 2019 in Marseille, France. Over 60 thalassaemia patients and parents attended the Conference; the first of its kind.

The TIF Delegation, comprised of Mr George Constantinou (Ass. Secretary of the TIF Board of Directors & Expert Patient) and Dr Maria Sitarou (Cyprus), had the opportunity present an overview of the Federation's work to the gathered audience (doctors, healthcare professionals and patients) as well as the experience of Cyprus in the effective management of thalassaemia. Moreover the motivational presentation serves as an inspiration to the gathered patients and parents, providing details of societal and professional integration, thus reaffirming the importance of good clinical care for achieving a good quality of life.

Sensitive to linguistic challenges, a leaflet of the educational opportunities and services which TIF provides in French was distributed by the TIF Delegates.

THALASSAEMIA INTERNATIONAL FEDERATION

Mai 2019

Salutations chers amis !

La Fédération Internationale de Thalassémie (TIF) accorde une importance particulière au renforcement de la communauté des parents / patients thalassémiques en France, un besoin réel démontré par nos trois visites en France l'année dernière (en avril, septembre et novembre), où nous avons eu l'occasion de rencontrer quelques-uns d'entre vous.

En outre, nous avons organisé un atelier de renforcement des capacités de deux jours à Thessalonique, en Grèce, en septembre 2018, où nous avons été ravis de voir plusieurs patients / parents français participer et partager leurs expériences avec nous.

Au cours des derniers mois, nous avons développé un partenariat avec la Fédération des Malades Drépanocytaires et Thalassémiques SOS Globi. En effet, au sein de la Fédération, un groupe de travail pour la thalassémie a été formé avec le soutien de la TIF, coordonné par Mme Yolande Adjibi (Présidente de la Fédération) et MM. Ali Sattarpour et Taklun Cheung.

Nous aimerions travailler avec vous pour qu'ensemble nous puissions surmonter les obstacles et atteindre tout patient vivant en France !

La TIF aimerait soutenir vos efforts et partager avec vous et votre famille son immense expérience acquise auprès de patients d'autres pays. Nous aimerions travailler avec vous pour essayer d'améliorer chaque jour !

Vous habitez dans un pays doté de l'un des systèmes de santé les plus performants et les plus robustes et de personnes formidables qui vous soutiennent à la fois en qualité de médecins et d'excellents amis ; néanmoins **l'importance des relations entre pairs et des échanges d'expériences entre patients et familles ne peuvent pas être ignorées. La TIF reconnaît que ce sens de la communauté est un outil précieux pour améliorer la qualité de vie et notre vision du présent et de l'avenir.**

Ainsi, la TIF investit grandement dans la traduction de la majeure partie de son matériel pédagogique et de sa correspondance, afin qu'ils soient plus accessibles à vous. En ce moment, les publications suivantes sont disponibles **en français** et de nombreux autres sont à venir.

1. Site Web de la TIF http://thalassaemia.org.cy/fr/
2. À propos de la β-thalassémie – Livret court
3. À propos de la α-thalassémie – Livret court
4. À propos de la drépanocytose - Livret court
5. Tout sur la thalassémie – Un livre pour les enfants de 4 à 15 ans
   ** **Bientôt disponible** **
6. À propos de la thalassémie
7. Recommandations pour la prise en charge des thalassémies dépendantes des transfusions (TDT)

Germany
A TIF Delegation Visit to Germany took place on 04 - 05 July 2019. The Delegation Team comprised of Mr. George Constantinou (Ass. Secretary of the TIF Board of Directors & Expert Patient), Dr. phil Eva-Maria Knoll (Medical Anthropologist, Austria ; TIF National Advisor). The Team was accompanied by Mr. Zabihullah Safai (Board Member of SAM Deutschland e.V. AM - TIF Member Association).

The Delegation visited Dusseldorf and Ulm for an exploratory visit, aiming to strengthen TIF's presence throughout Germany, building relationships with patients and healthcare professionals, identifying challenges and discussing opportunities. During the visit, the Delegation Team had the opportunity to meet with representatives of the Paediatric Clinic for Oncology, Haematology and Clinical Immunology, at the University Hospital of the Heinrich Heine University Duesseldorf, the patient group IST (Interessensgemeinschaft Sichelzellkrankheit und Thalassämie e.V) and the Clinic of Paediatric and Adolescent Medicine at the University of Ulm. In addition, meetings were held with individual patients.

The importance of building the capacity and knowledge of the patient community through uptake of TIF's educational tools was a recurring theme in all discussions. Indeed, as patients are scattered across the country, many feel socially isolated, thus necessitating the creation of a support network to facilitate education and advocacy opportunities. Moreover, targeted service planning on behalf of the national health authorities remains challenging as a result of an absent national registry, as well as frequent shifting of positions of healthcare professionals making continuity of care difficult to achieve.

Greece
The Thalassaemia International Federation (TIF) successfully participated in the Annual Pan-Hellenic Conference on Thalassaemia organised by the Greek Thalassaemia Federation (EOTHA) in collaboration with the Epiros Thalassaemia Association. The Conference was held on 20 - 22 September 2019 in Ioannina under the auspices of a number of eminent health-related organisations and bodies, most notably the Ministry of Health of Greece and TIF.

TIF was represented by Ms Elena Mylona (Secretary of the TIF Board of Directors), who delivered a Welcome Message on behalf of Mr Panos Englezos (TIF President) highlighting the importance of the new scientific advances in the field of thalassaemia and the dawning of a new era in the care and cure of the disease.

Italy
A Symposium on the Diagnosis and Treatment of Chronic Liver Disease and Disturbances in Heart Rhythm in Haemoglobinopathies was organised by the Associazzione per la Lotta alla Talassemia di Ferrara - Rino Vullo and took place in Ferrara (Italy) on 15 December 2019. The Symposium was held in collaboration with the International Network of Clinicians for Endocrinopathies in Thalassemia and Adolescence Medicine (ICET-A), under the patronage of UNITED Onlus and the Thalassaemia International Federation (TIF).

Presentations on the patient journey through liver transplantation and new approaches in the management of liver disease in thalassaemia were presented by TIF Delegates, Mr George Constantinou (Ass. Secretary of the TIF Board of Directors & Expert Patient) and Dr Michael Angastiniotis (TIF Medical Advisor). The Faculty of Speakers, mainly experts from across Italy, including Prof. Vincenzo de Sanctis (an international expert, founding member and driving force of ICET-A and member of TIF's International Scientific Advisory Board, Italy) discussed all the issues and controversies that surround liver complications, with particular emphasis on hepatocellular carcinoma, its early diagnosis and treatment modalities.

TIF continues to work with a leading hepatologists and thalassaemia specialists from around the world to better understand and identify causes and prognostic markers for preventing the development of liver disease in thalassaemia patients.

Sweden
A TIF Delegation visit to Sweden took place on 23 -25 March 2019. The Delegation Team consisted of Dr Androulla Eleftheriou (TIF Executive Director), and Dr Michael Angastiniotis (TIF Medical Advisor).

Meetings with the Dept. of Hematology Uppsala University Hospital, Capio Saint Göran's Hospital, the Swedish Blood and Cancer Association NGO and individual patients & parents were held to further explored the quality of life of patients with haemoglobinopathies in Sweden, and to identify avenues of a closer partnership with TIF.

The consensus of all stakeholders focused on the lack of prioritisation by the National Health Authorities to haemoglobin disorders (thalassaemia and sickle cell disease) both in terms of their multidisciplinary management but also concerning the societal integration of patients. Steps to empower the patient community with knowledge and capacity building to facilitate more effective advocacy were agreed upon.

Turkey
The Thalassaemia International Federation (TIF) participated in the 2nd Blood Disease Conference held on 03 - 05 April 2019, in Antalya, Turkey. The TIF Delegation comprised of Dr Michael Angastiniotis (TIF Medical Advisor), Mr Rawad Merhi (TIF Countries Officer) and Mr Ahmet Varoglu (President of Turkish Cypriot Thalassaemia Association ; Member of TIF Patient Advocates Group). Dr Angastiniotis delivered a presentation highlighting the importance of multidisciplinary care of patients with thalassaemia.

The visit to Antalya provided the opportunity for the TIF Delegation to meet with several patient groups including the (1) Blood Disease Federation to discuss ways of strengthening collaboration with TIF, (2) A Drop of Blood Thalassemia Society (Urfa, Easter Turkey) focusing on the difficult conditions of patients which include a number of Syrian refugees, (3) Talasemi Derneği Sadece (Antalya Finike) to review issues of concern for patients and

(4) Mevlana Talasemi Derneği - Konya to converse on challenges patients face daily. The heterogeneity in the quality and accessibility of services across the country constitutes a major issue of the patient community.

Moreover, the TIF Delegation met with numerous treating physicians including Dr Yurdanur Kilinc (Head of the Adana Thalassaemia and Sickle Cell Disease Clinic), Dr Dilek Yazman (North Cyprus Thalassaemia Centre), and medical fellows working with Dr Zeynep Karakas (Istanbul). Discussions focused on the translation of TIF's educational opportunities (publications and platform) to Turkish to facilitate the learning of doctors and patients alike.

TIF Delegates, Mr Anton Skafi (TIF Board Member) and Mr Rawad Merhi (TIF Countries Officer) attended the activities organised by ATODER (thalassaemia patient association) for the occasion of International Thalassaemia Day 2019 on 03 - 05 May 2019, in Adana, Turkey. An appreciation award to the Thalassaemia International Federation was presented by the Mayor of Adana to Mr Skafi who accepted on behalf of the Federation.

The visit to Adana, presented the opportunity for the TIF Delegates to visit the local thalassaemia centre, laboratories and blood bank at Adana City Hospital Complex and to meet with local physicians to discuss numerous issues including (1) applying for TIF Certification and being part of TIF's International Network of Collaborating Reference Centres for Thalassaemia; (2) participation in the Renzo Galanello Fellowship; (3) establishment of a dedicated Thalassaemia Centre (currently the clinic is located within the Oncology Department).

SOUTH EAST ASIA REGION

Bangladesh
The Thalassaemia International Federation (TIF) participated in a Conference on Patient Care and Prevention, co-organised by the Bangladesh Thalassaemia Samity organisation and the Ministry of Health of Bangladesh held in Dhaka on 28 - 31 January 2019.

The Conference aimed to gather all relevant and involved stakeholders in order to achieve consensus regarding a national policy for the prevention and management of thalassaemia in Bangladesh.

Members of TIF's International & Regional Scientific Advisory Boards, Dr Paul Telfer (UK), Dr Mary Petrou (UK) and Prof. Maitreyee Bhattyacharya (India) actively participated in the event with presentations on clinical care and prevention.

India

TIF has continued to develop and strengthen its collaboration with the Thalassaemia Patients Advocacy Group (PAG) formed under Thalassemics India, through the provision of guidance and expert advice. Indeed, the PAG has initiated a project to promote NAT testing in India with TIF contributing as an advisor. Members of this PAG constitute an integral part of TIF's Patient Advocacy Group (See page 12 for more information) contributing to consultations and participating in meetings at the national, regional and international level. Moreover, TIF is delighted to see the maturation of the patient community in India, evident in the formation of another group of young adult patients based in Mumbai forming a patient support group known as Youth Thalassaemic Alliance (YTA). The establishment of adult patient groups across India, significantly contributes to effective advocacy for appropriate service planning on behalf of the health authorities for the multidisciplinary care of thalassaemia.

Indonesia

A TIF Delegation Visit to Indonesia took place on 19 - 20 September 2019. The Delegation Team comprised of Mr Michael Michael (former TIF Board Member and Member of TIF Patient Advocates Group; UK), Mrs Aggie Michael (parent and wife of thalassaemia patients') and Dr Farrukh Shah (Consultant Haematologist ; Member of TIF's International Scientific Advisory Board, UK). The Team visited treatment centres in Jakarta, meeting with treating physicians, as well as the Ministry of Health for discussions with officials. Most importantly the Team met a delegation of patients from the distant province of Aceh to understand the level of care for patients living outside the capital.

WEST PACIFIC REGION

China

In the context of the Framework for Collaboration that TIF holds with official bodies from China for the past decade, a high level delegation, consisting of representatives from the Maternal and Child Health, National Health Commission, the Normal University of Beijing and the Birth Defects Intervention and Aid Foundation visited TIF's Headquarters in Cyprus between 21 - 25 October 2019.

During their stay in Cyprus, the delegation had the opportunity to visit relevant thalassaemia services (including the Thalassaemia Centre, Population Screening Laboratory, Karaiskaeio Foundation - Bone Marrow Registry, Cyprus Institute of Neurology & Genetics - Thalassaemia Laboratory) and to hold high level discussions with the leaders of the services, agencies and departments visited. Moreover, the delegation met with Mr Panos Englezos (TIF President), Dr Androulla Eleftheriou (TIF Executive Director) and Dr Michael Angastiniotis (TIF Medical Advisor) with whom discussions were held on the next steps to be taken in China.

Upon departure from Cyprus, the delegation continued its journey to Genoa (Italy), where TIF Board Member, Mr Angelo Loris Brunetta, facilitated their visits to a number of institutions and high level meetings with the objective to strengthen best practice exchanges and learn more about thalassaemia service building.

Malaysia

The Thalassaemia International Federation (TIF) has successfully participated in the 1st Malaysian National Conference for Patients with Thalassaemia, organized by the Federation of Malaysia Thalassaemia Societies on 14 - 15 September 2019 in Sabah, Malaysia. The Conference brought together over 360 patients and parents from across Malaysia, as well as neighbouring countries. TIF was represented by Mr George Constantinou (Ass. Secretary of the TIF Board of Directors & Expert Patient) and Dr Farrukh Shah (Consultant Haematologist ; Member of TIF's International Scientific Advisory Board, UK), both of whom delivered inspirational presentations in the course of the Conference Programme. The visit to Malaysia presented the opportunity to meet with patients and parents, and to discuss issues of concern and provide guidance and support.

Vietnam

The 3rd South East Asia Thalassaemia Forum (SEATHAF) was organised on 24 - 25 April 2019, in Hanoi, Vietnam in the context of activities relating to International Thalassaemia Day 2019. TIF was represented at the meeting by Dr Michael Angastiniotis (TIF Medical Advisor) and Prof. Suthat Fucharoen (Haematologist and Member of TIF's International Scientific Advisory Board; Thailand).

SEATHAF was attended by representatives of national health authorities and healthcare professionals from 9 countries (Vietnam, Thailand, Myanmar, Cambodia, Laos PDR, Philippines and Indonesia). Dr Michael Angastiniotis delivered a presentation highlighting the benefits of national prevention and treatment programmes and their pivotal role in healthcare planning and improving quality of life of patients. Moreover during their stay in Hanoi, TIF Delegates had the opportunity to visit the Thalassaemia Centre at the National Institute of Haematology and Blood Transfusion (NIHBT) and meet with the Director and treating physicians as well as representatives of the Vietnamese Thalassaemia Association (ViTA), with the aim of being updated about the current situation in Vietnam. Reaching almost universal coverage, the Vietnamese health insurance system covers treatment for most thalassaemia patients albeit prevention is not included.

TOPICS-IN-FOCUS: ADVOCACY FOR SAFE & ADEQUATE BLOOD CONTINUES

On 22 January 2019, Mr Panos Englezos (TIF President), Mr George Constantinou (Ass. Secretary of the TIF Board of Directors & Expert Patient), Dr Androulla Eleftheriou (TIF Executive Director) and Dr Michael Angastiniotis (TIF Medical Advisor) participated in an EU policy event, organized by the European Blood Alliance (EBA) hosted by MEP Françoise Grossetête and MEP Guillaume Balas, entitled **"Safeguarding equal access to safe and high-quality blood supply in Europe"** at the European Parliament.

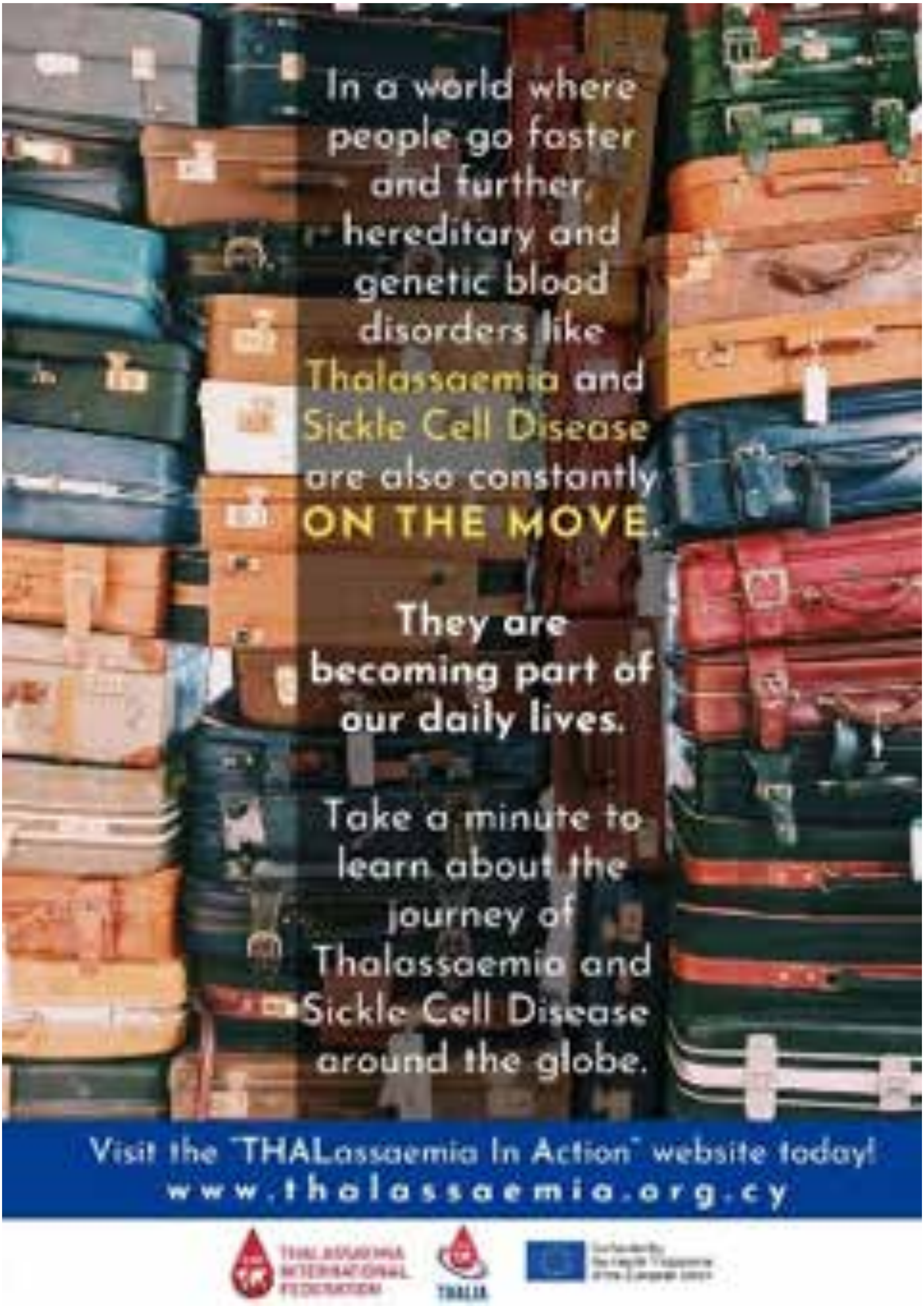
The event served as a platform to discuss the issues in relation with the EU Blood Directive and its potential revision, for enhanced EU action on blood components safety, quality, and donorship, starting the advocacy on a potential new Directive, in preparation of the changing EU political leadership in 2019 (elections of new European Parliament, and new European Commission entering into office). It was also an occasion to discuss further the EU Blood Directive with MEPs and stakeholders.

Mr. George Constantinou, Ass. Secretary of the TIF Board of Directors & Expert Patient, represented TIF and delivered a very successful presentation with the topic "Lifesaving blood supply: Patient cases with focus on rare blood groups and blood supply in recent major incidents". Mr. Constantinou stressed that blood is a key treatment for several chronic diseases, be them of genetic origins or not and that patients with rare diseases such as sickle cell disease and thalassemia rely on blood donations to maintain their health. Therefore, ensuring a constant and safe supply of blood and its components is a mission every country must uphold to the highest level. Referring to his own experiences as a thalassaemia patient, Mr Constantinou pointed out the difficulties and dangers of life long blood transfusions, including the exposure to pathogens and serious allo-immunisations. He also noted how such a programme interferes with education, employment and social integration especially where hospital routines take precedence over patient need for a normal life.

The Thalassaemia International Federation (TIF) participated in a **Multi-stakeholder Round Table Meeting on Blood Transfusion** held on 26 September 2019 in Brussels. Constituting part of a new initiative, the Round Table brought together medical specialists, nurses, health economists, representatives of multi-transfused patients (i.e. thalassaemia, myelodysplasia, multiple myeloma etc), policy-makers (European Commission) to discuss the wider issue of Blood Transfusion (not just for thalassaemia), seeking to identify possible overlooked areas of prioritisation.

TIF was represented by Dr Androulla Eleftheriou (TIF Executive Director) and Ms Lily Cannon (TIF Operations Manager), in addition to the largest majority of patient representatives present being from the thalassaemia patient communities of Greece, Italy, France and Germany. Dr Eleftheriou delivered a presentation highlighting the realities of blood transfusion for thalassaemia patients and conveying the position of the Federation regarding the paramount importance of safety and adequacy of blood.

Following the meeting Dr Androulla Eleftheriou (TIF Executive Director) actively participated in the compiling of the **meeting report and subsequent policy document** on the wider issue of Blood Transfusion, seeking to prioritise the issue on the EU Health Agenda, due to be published in 2020.



In a world where people go faster and further, hereditary and genetic blood disorders like Thalassaemia and Sickle Cell Disease are also constantly **ON THE MOVE**.

They are becoming part of our daily lives.

Take a minute to learn about the journey of Thalassaemia and Sickle Cell Disease around the globe.

Visit the “THALassaemia In Action” website today!
www.thalassaemia.org.cy

THALASSAEMIA
INTERNATIONAL
FEDERATION

THALIA

PROJECTS

THALassaemia In Action (THALIA2019)

The Thalassaemia International Federation (TIF) is an official partner with the European Commission for the period 2018-2021. In this context, the project THALIA: THALassaemia In Action" co-funded by the European Commission, is already underway with numerous activities focusing on thalassaemia patients and families, migrant communities and healthcare professionals in Europe.

More information is available at [https://thalassaemia.org.cy/projects/thalassaemia-in-action-the-thalia-project/.](https://thalassaemia.org.cy/projects/thalassaemia-in-action-the-thalia-project/)

INITIAL RESULTS OF THE PROJECT, stemming from the first year of activities (2018) have been announced in a dedicated Press Conference was held on 21 December 2018 at the Ministry of Health in Nicosia, Cyprus.

TIF's bottom-up approach in THALIA2018 & THALIA2019 and especially the active involvement of the grassroots is considered a major achievement, despite the challenge of linguistic diversity evident in Europe, creating barriers in the access of target audiences to TIF's informational and educational material and activities.

Attended by 32 journalists and other stakeholders, including the Minister of Health of Cyprus, the Permanent Secretary of the Ministry of Health, the Representation of the European Commission in Cyprus, the International Organisation of Migration (IOM) - Cyprus, the Office of the United Nations High Commissioner for Refugees (UNHCR), the National Blood Transfusion Services, the Cyprus Blood Bank, TIF Board Members, patients/parents from the Cyprus Thalassaemia Association, medical experts from the Cyprus Thalassaemia Centre, the National Committee for Thalassaemia, the National Rare Disease Committee, and the Cyprus Alliance for Rare Disorders in addition to other interested stakeholders from university medical schools.

Additional perspectives on migration flows and the health of migrants were presented by Mr. George Ailiotis (representative of the UNHCR's Office in Cyprus), and Mrs. Abdi Nasiyo Mohammed, (representative of the IOM in Cyprus). Migration remains a priority of the European Commission, a position expressed and extrapolated by Mr. Michael Stylianou, Political Analyst of the Representation of the European Commission in Cyprus. Welcome addresses were provided by Mr. Panos Englezos, TIF President and Dr. Christina Yiannaki, Permanent Secretary of the Ministry of Health.

The **ANNUAL PROGRESS OUTLINES 2019** comprising of detailed analysis of activities undertaken in each Work Package are available on TIF's website https://thalassaemia.org.cy/projects/thalassaemia-in-action-the-thalia-project/.

The strategic partnership with the European Commission was showcased during the EU Health Programme High Level Conference held on 30 September in Brussels, Belgium. Attended by more than 300 participants from national health authorities of EU Member States and beyond, the conference was organised by the Consumers, Health, Agriculture and Food Executive Agency, with the support of the European Commission Directorate-General for Health and Food Safety. The TIF Delegation comprised of Dr Androulla Eleftheriou (TIF Executive Director) and Ms Eleni Antoniou (TIF Senior Policy & International Relations Officer) had the opportunity to disseminate information about the THALIA project, and TIF publications to participants.

Haemoglobinopathy e-registry
In view of fact that very few centres and countries maintain a patient registry and knowing the many benefits of replacing paper based records for these lifelong disorders, the Thalassaemia International Federation (TIF) has proceeded to the development of a state-of-art Haemoglobinopathy e-registry and electronic healthcare record. The comprehensive, web-based disease-specific tool will be provided free-of-charge to interested national health authorities, or individual Thalassaemia Centres across the world, storing data on the hospital server, thus adhering to EU regulations for Data Protection.

Treating centres in Cyprus, Greece, Bulgaria, Romania, Turkey and Kuwait have expressed interest in obtaining the software license, with the first three already providing authorisations from hospital authorities.

Are you interested in the Haemoglobinopathy e-Registry? Contact us at thalassaemia@cytanet.com.cy with your query!

Thalassaemia-specific Patient-Reported Outcomes Measures
The Thalassemia International Foundation (TIF) in an effort to document the patient perspective on health, treatment, feelings and quality of life has teamed up with experts at the London School of Economics (LSE) and the University of Nicosia for the development of Thalassaemia-specific Patient-Reported Outcomes Measures (Thal-PROMs).

To this effort, initial exploratory steps to determine and evaluate patient views and experiences on the social care and quality of treatment and care offered to patients with thalassaemia were taken via the dissemination of relevant surveys online and during the Patient's Capacity Building Workshop (see page 11 for more information).

The data collected will be analysed, in the view of creating a validated survey in 2020, entitled *'Haemobarometer'*, which will form the basis of the Thal-PROMs.

Haemobarometer
BY TIF

THALassaemia In Action

THALASSAEMIA INTERNATIONAL FEDERATION

THALIA

Co-funded by
the Health Programme
of the European Union

ABOUT

GLOBAL EPIDEMIOLOGY

According to the World Health Organization (WHO), **7%** of the global population are carriers of a haemoglobin disorder:

- **4%** of which are carriers of Sickle Cell Disease and
- **3%** are carriers of Thalassaemia.

BETA THALASSAEMIA

- **Affects** the production of the normal adult haemoglobin component of red blood cells;
- **Leads** to the excessive destruction of red blood cells;
- **Is characterised** by severe anaemia and other major complications;
- **Requires** lifelong frequent blood transfusions, iron chelation therapy and multidisciplinary care for complications consequent to the disease pathology and treatment including managing iron overload.

SICKLE CELL DISEASE

- **Affects** the structure of the haemoglobin component of red blood cells;
- **Leads** to blocking of the blood flow causing pain and organ damage ("Sickle Cell Crisis");
- **May require** blood transfusion and iron chelation treatment;
- **Requires** early detection, lifelong health monitoring to prevent/ reduce the number of life-threatening Sickle Cell Crises and infections (which may result in death).

THE PROBLEM

THE MIGRATION OF HAEMOGLOBIN DISORDERS TO EUROPE

Historically, Thalassaemia and Sickle Cell Disease have been introduced in the indigenous population of every country globally through population movements.

Indeed, a considerable number of migrants moved to the Western world, with the UK, France, Germany and North America receiving the greatest majority of people from countries around the world with a high prevalence of haemoglobin disorders.

The recent European migration crisis has added to these numbers, especially in France and Germany, while healthy carriers and patients were literally introduced to very low prevalence areas of Europe, including Sweden and Austria.

Estimated migrant carriers of beta thalassaemia in Europe

	Country of Origin of Migrants	% thalassaemia carriers in the indigenous population
1	Albania	5%
2	Afghanistan	3%
3	Algeria	2%
4	Azerbaijan	8%
5	Bangladesh	10%
6	Cyprus	14.5%
7	Egypt	5.3%
8	Greece	8%
9	India	4.9%
10	Indonesia	10%
11	Iran	4%
12	Iraq	4.8%
13	Italy	4.3%
14	Lebanon	2.3%
15	Morocco	1.7%
16	Pakistan	6%
17	Syria	5%
18	Turkey	2.2%

WHAT DID WE DO?

HOW DID WE WORK?

EDUCATION

- Educational platforms for patients and healthcare professionals
- Revision of TIF Guidelines
- Capacity building courses for patients and healthcare professionals
- ESC Traineeship Programme
- Renzo Galanello Fellowship

AWARENESS RAISING

- Translation of TIF Website in EN, FR, DE, EL, IT, AR
- Thalassaemia Video Challenge
- Thalassaemia Patients Connect
- THALIA Mobile App
- Pocket Guide for healthcare professionals

POLICY ADVOCACY

- Establishment of new thalassaemia national associations
- TIF EU Twinning Programme
- Thalassaemia EU Electronic Health Record

RESEARCH

- TIF Guidelines in peer-reviewed academic journals
- Participation of TIF experts in scientific conferences

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THALIA ("THALassaemia In Action") is co-funded by the Third Health Programme 2014-2020 of the European Union under Framework Partnership Agreement (FPA) No 785243 (2018-2021).
For more information, visit https://thalassaemia.org.cy/thalassaemia-in-action-the-thalia-project/ or write us at thalassaemia@cytanet.org.cy

TIF EDUCATIONAL PROGRAMME

Short-term Courses for Healthcare Professionals

Renzo
Galanello
Fellowship
Programme

TIF Renzo Galanello Fellowship Programme

The TIF Renzo Galanello Fellowship Programme 2019 took place between 14 October - 13 December 2019 at the Joint Red Cell Unit, Haematology Department of the University College London NHS Foundation Trust in London, UK.

Following assessment of more than 50 applications from healthcare professionals across 32 countries, the Selection Committee (comprised of 2 members of TIF's Scientific Advisory Board on behalf of TIF and 2 medical specialists on behalf of the training centre) accepted the nominations of two young healthcare professionals from Austria and Greece.

The Fellowship Programme is run under the supervision of Prof. John Porter (Prof. of Haematology and Member of TIF's International Scientific Advisory Board, UK), the coordination Dr Perla Eleftheriou, (Consultant Haematologist and Member of TIF's International Scientific Advisory Board, UK) with the participation of distinguished medical specialists across different relevant disciplines comprising the multi-disciplinary care team for thalassaemia patients.

> "...joining in the ward rounds where we can see how to manage patients with acute crisis...as we could hear from many patients, [the excellent team of the red-cell unit] is making such a difference in their lives..."

“…The hospital is very impressive and all facilities are state-of-the-art…opportunity to observe the excellent work that is being done by the Red Cell Unit. We have a weekly schedule that includes ward rounds, where we observe the treatment of hospitalised patients with acute problems, as well as the red cell/thalassaemia clinic, where we observe the long term management of patients with haemoglobinopathies”

“The multidisciplinary team meetings is another particularly interesting feature of the function of the Red Cell Unit. Experts from all implicated specialties offering their input in a professional and fruitful discussion is very educational, especially for young doctors”

Preceptorships

Held at leading thalassaemia treatment centres, under the leadership of prominent expert physicians in 5 countries, TIF's preceptorships provided on-site training to 17 healthcare professionals in 2019!

Cyprus

A Preceptorship for the training of two nurses from the **Maldives** at the Thalassaemia Centre in Nicosia has been completed on 18 July - 02 August 2019, in the context of the 3-year Strategic Collaboration Plan between the Ministry of Health of the Maldives, Ministry of Health of Cyprus and TIF, established in 2017.

Malaysia

A Preceptorship on the Clinical Management of Thalassaemia has been organised on 17-20 September 2019 in collaboration with the Women & Children's Hospital Kuala Lumpur, under a team led by Prof Mohammed Hishamshah. Participants included 7 treating physicians from **Malaysia**, 1 from **Nepal** and 1 from **Bangladesh.** The programme included a variety of learning opportunities including lectures by TIF representatives Mr George Constantinou (Ass. Secretary of the TIF Board of Directors & Expert Patient) and Dr Farrukh Shah (Consultant Haematologist, and Member of TIF's International Scientific Advisory Board, UK).

Mauritius

A Preceptorship for the training of two nurses from **Mauritius** at the Fujairah Thalassaemia Centre (TIF Certified Collaborating Centre) in the United Arab Emirates has been completed on 10 - 21 November 2019 following a TIF Delegation Visit in early 2019.

Morocco
A Preceptorship on the Clinical Management of Thalassaemia was successful completed with the training of 2 doctors from Algeria at the Children's Hospital in Rabat, Morocco. The Preceptorship took place on 08 - 12 April 2019 and was led by Prof Mohammad Khattab (Morocco) and Prof Amal El-Beshlawy (Egypt).

In the context of the preceptorship the participants had the opportunity to have extensive discussions with treating physicians and other healthcare professionals as well as to meet with patients and parents. Moreover, the participants visited the laboratories at the University Hospital of Rabat and the Institute of Health and visited the National & Regional Blood Bank of Rabat.

United Kingdom
Two nurses from the **Nepal** Thalassaemia Society (NTS) Thalassaemia Centre participated in a preceptorship training at the Whittington Hospital Thalassaemia Unit, as part of the partnership established in 2018 between the NTS, TIF and the UKTS for supporting the care of thalassaemia patients in Nepal.

Peer-to-Peer Learning

Twinning Programme for Patient Associations: Greece - Germany

The Thalassaemia International Federation (TIF) in pursuit of strengthening of the support provided by the Federation to patients/parents and their associations at the ground level has organized a Bilateral Twinning Programme for Patient Associations for Greece and Germany on 11 - 14 October 2019, in Hamburg, Germany.

The Greek Thalassaemia Federation was able to share its experiences with members of the German patient community, focusing on topics concerning effective advocacy, education and policy changes. It is notable that the Greek Thalassaemia Federation hosts 25 local associations, many of which have been amongst the first thalassaemia patient associations created globally, and has a long and vast array of actions and achievements at the national and international levels including (1) the establishment and monitoring of 36

designated thalassaemia centres across Greece, (2) strong advocacy presence leading to retaining of the provision of free-of-charge treatment and laboratory tests even in times of economic crises, (3) achieving an array of state benefits to facilitate social, educational and professional integration, (4) active educational role with events for patients/parents and healthcare professionals on an annual basis as well as raising awareness about thalassaemia in the community thus contributing to the national prevention programme, (5) founding member of the Thalassaemia International Federation with continuous involvement in global activities.

Based on this, the Twinning Programme facilitated the exchange of knowledge and good practices and created a meaningful and long-lasting peer-to-peer learning experience.

Thalassaemia Patients Connect (TPC)

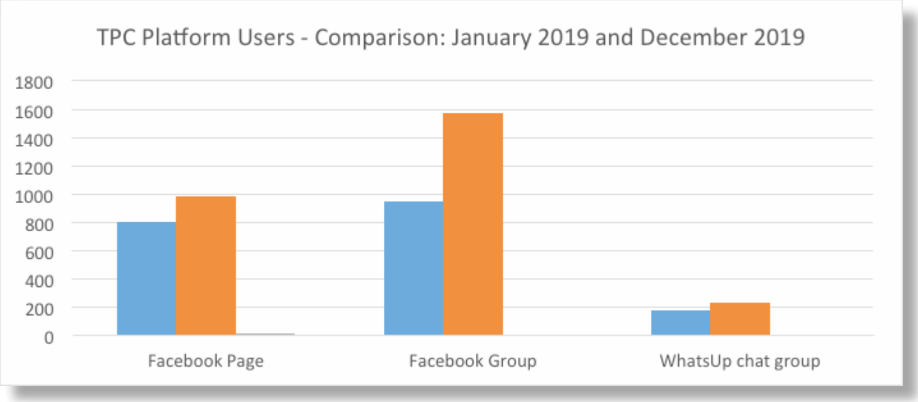
A platform of online communication tools that provides the opportunity for patients and parents to interact, ask for and share information on thalassaemia.

Who responds? Members of TIF's Expert Patients Core Group and International Scientific Advisory Board

Reliable, evidence-based responses! Alignment with TIF's Guidelines (authored by international experts in the field of thalassaemia with long-term experience in the prevention and clinical management of the disease) and TIF's policies and positions

The Platform includes the following tools:

Website:	http://thalassaemiapatientsconnect.weebly.com/
Discussion Board:	http://thalassaemia-connect.proboards.com/
Facebook Page:	Thalassaemia Patients Connect
Facebook Group:	Thalassaemia Patients Connect Group
Twitter:	thalassaemiaTPC
YouTube Channel:	Thalassaemia Patients Connect
WhatsApp chat group:	Thalassaemia Connect



Expert Volunteers respond to queries in real time!

Participants in the WhatsApp Group and Discussion Board are able to ask medical questions about a large scope of thalassaemia-related topics, responded to by an extensive, multi-stakeholder, global network of volunteer patients experts and healthcare professionals (see complete list below, in alphabetical order) in order to ensure accuracy of the information given to the patients and consequently patients' safety.

- Dr Jawad Abboud (TIF Collaborator - Iraq)
- Dr Michael Angastiniotis (TIF Medical Advisor - Cyprus)
- Mr Angelo Loris Brunetta (TIF Board Member - Expert Patient - Italy)
- Mr Madan Chawla (TIF Collaborator - Expert Patient - India)
- Dr Muhammad Darwesh (TIF Collaborator - Iraq)
- Mr Riyad Elbard (TIF Board Member - Expert Patient - Canada)
- Dr Perla Eleftheriou (TIF Collaborator - UK)
- Dr Dimitrios Farmakis (TIF Collaborator - Greece)
- Dr Mahammad Farnouch (TIF collaborator - Iran)
- Ms Maria Hadjidemetriou (TIF Collaborator - Expert Patient - USA)
- Dr George Kaltsounis (TIF Collaborator - Greece)
- Ms Ayesha Mehmood (TIF Collaborator - Expert Patient - Pakistan)
- Dr M. Naveed (TIF Collaborator - UAE)
- Dr Antonio Piga (TIF Collaborator - Italy)
- Mr Anton Skafi (TIF Board Member - Expert Patient - Palestine)
- Mr Ahmet Varoglu (TIF Collaborator - Expert Patient - Cyprus)

Educational Events

Thalassaemia & Sickle Cell Disease Summit

The Thalassaemia International Federation (TIF) organised the first Thalassaemia & Sickle Disease Summit for Healthcare Professionals on 1 - 2 November 2019 in Thessaloniki, Greece. The Summit was organized in collaboration with the Greek Thalassaemia Association and under the auspices of the Greek Thalassaemia Federation (EOTHA).

The Summit brought together 45 Key Opinion Leaders and Medical Specialists (Haematologists and Paediatricians) from 12 European countries to exchange best practices in the management of thalassaemia and the challenges they are faced with daily. An esteemed faculty consisting of international experts in the field of thalassaemia and sickle cell disease as well as expert patients conveyed important messages for the delivery of quality care to patients. Moreover, the importance of multi-disciplinary care of haemoglobin disorders was highlighted, as polyorgan disease require specialist treatment from a range of disciplines. New advances in the care and cure of the disorders indicate that we are living in changing times and continuous life-long learning for healthcare professionals is imperative. Concomitantly, the Summit provided the opportunity for attendants to to visit the Hippokrateion Hospital Thalassaemia Centre which encompasses state of art blood donation unit, blood transfusion services, haemoglobinopathy screening laboratory, and adult and paediatric wards meeting with treating physicians and patients.

Considerable emphasis was placed on inspiring doctors from Austria, Sweden, Germany and France who have seen an influx of haemoglobinopathy patients in recent years due to movement of populations through a keynote session drawing parallels between the past (1970s), the present and the future. The participation of Mr Panos Englezos (TIF President), Mr George Constantinou (TIF Ass. Secretary of the Board & Expert Patient), Mr Angelo Loris Brunetta (TIF Board Member & Expert Patient), Dr Androulla Eleftheriou (TIF Executive Director) and Dr Michael Angastiniotis (TIF Medical Advisor) were imperative to the success of the event, providing knowledge and inspiration to the participants!

TIF E-ACADEMY FOR PATIENTS & MEDICAL SPECIALISTS

Comprised of two separate online, interactive, disease-specific comprehensive electronic courses (namely, Thal e-course for Patients and eThalEd for Medical Specialists), TIF's e-Academy seeks to increase the knowledge of patients, parents and healthcare professionals on thalassaemia facts, past and current advances.

Written and reviewed by medical professionals and expert patients, members of TIF's International Scientific Advisory Board and TIF Patient Advocates Group respectively, the content is adapted by educational scientists, instructional and graphic designers to enhance the acquisition of knowledge through multimodal learning, including text, video, games, quizzes etc. The content of this course has been very carefully formulated to relay complex scientific terms into widely accessible language to facilitate learning for all levels of knowledge.

Thal e-course for Patients

Aiming to empower patients with thalassaemia globally through the attainment of a better understanding of their disease, upcoming or recently approved advanced therapies and medicinal products, as well as the international advocacy landscape on patient rights and policies which directly or indirectly are related to patient quality of life, the Thal e-course for Patients is a unique learning tool, created by the Thalassaemia International Federation (TIF).

A free-of-charge, interactive and self-paced online course, the Thal e-course provides patients skills, confidence and motivation to constitute a key role in decision-making, at the national level. ***Successful graduates are eligible for membership of TIF's Patient Advocacy Group (see page 12 for more information).***

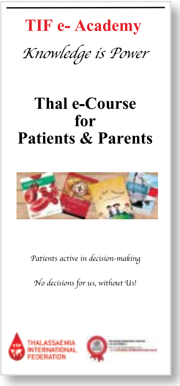
Participants are provided with a Certificate upon completion of the course.

The Thal e-course can be accessed at http://academy.thalassaemia.org.cy/

> *TIF's Thal e-course is truly empowering, highlighting the importance of self-management and taking responsibility for our own health to improve the quality of our lives. I highly recommend it for all thal warriors, their caretakers and policy makers.*
>
> *HbS/ß-thalassaemia Patient, Maldives*

Languages


English


TIF e- Academy

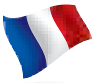
Knowledge is Power

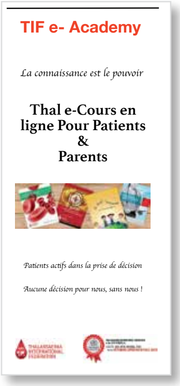
Thal e-Course
for
Patients & Parents

Patients active in decision-making

No decisions for us, without Us!

THALASSAEMIA INTERNATIONAL FEDERATION


French


TIF e- Academy

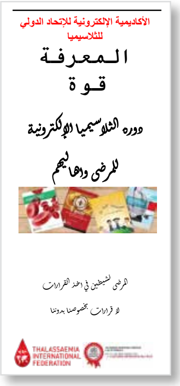
La connaissance est le pouvoir

Thal e-Cours en
ligne Pour Patients
&
Parents

Patients actifs dans la prise de décision

Aucune décision pour nous, sans nous !


Arabic


الأكاديمية الإلكترونية للإتحاد الدولي للثلاسيميا

المعرفة
قوة

دوره الثلاسيميا الإلكترونية
للمرضى واهاليهم

المرضى نشيطين في اخذ القرارات

لا قرارات بخصوصنا بدوننا

THALASSAEMIA INTERNATIONAL FEDERATION


German


TIF e-Akademie

Wissen ist Macht

Thal e-Kurs
für
PatientInnen
&
Eltern

PatientInnen aktiv an Entscheidungen beteiligen

Keine Entscheidungen für uns, und ohne uns!


Italian


TIF e- Academia

Sapere è potere

Thal e-Course
per
pazienti
&
genitori

Pazienti con un ruolo attivo nel processo decisionale

Nessuna decisione per noi, senza di noi

THALASSAEMIA INTERNATIONAL FEDERATION


Greek


Ηλεκτρονική Ακαδημία ΔΟΘ

Η Γνώση είναι Δύναμη

Thal e-Course για
Ασθενείς
&
Οικογένειες

Ενεργός συμμετοχή των ασθενών στη λήψη αποφάσεων

Καμία απόφαση για εμάς, χωρίς εμάς!

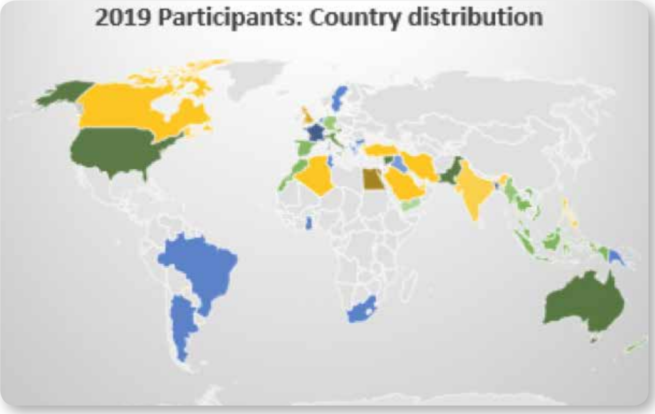
THALASSAEMIA INTERNATIONAL FEDERATION

Meet our 2019 Graduates!

409 GRADUATES

56 COUNTRIES

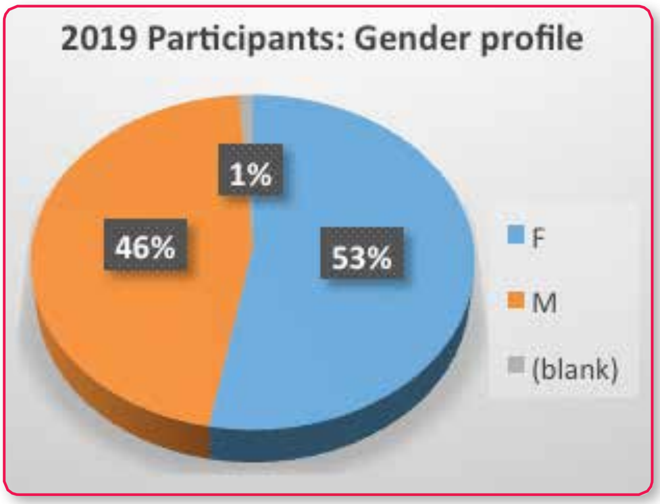
The Thal e-course can be accessed at http://academy.thalassaemia.org.cy/
Participants are provided with a Certificate upon completion of the course.


2019 Participants: Country distribution

Age Range:
14 - 35 years old

Medical Profile:
β-thalassaemia major, thalassaemia intermedia, Parent, Non-Transfusion Dependent, Sickle Cell Disease

Equal male: female ratio


2019 Participants: Gender profile

What they said

Feedback from patients/parents who have completed the Thal e-course:

It is one of the best and easiest platforms to learn about Thalassaemia it’s proper treatments and the promising scientific advances. Patient, Indonesia

The Thal e-course for patients is extremely informative, well -structured and enriching. The three modules span the landscape of the global thalassemia scene, tracing the history to where we stand today and where we hope to reach in the future. Patient, Italy

The course is substantive, provides medical information in an undiluted way, so that we can use the knowledge for advocacy. Thank you TIF for this wonderful exposure.

Patient, India

I was able to co-relate many sections of the Module with my past experiences being thalassaemic...” Patient, USA

I love it, its great service of humanity, as a father am feeling determined to fight and will give a healthy life to my son.

Parent, Pakistan

Very good course!! All Thalassemics must go for it. It will help them manage themselves better, spread knowledge in community, be more informed, take up advocacy issues. Patient, France

The Thal e-Course is very comprehensive and user friendly. It provides various tools and well-structured information that helped me as a patient, to have an overall better understanding of my condition and coping mechanisms. I would definitely encourage any patient to participate in the course because it not only helps you but also other patients and affected persons as it provides forums to interact and build networks with people around the world. It was a great experience... Patient, Trinidad & Tobago

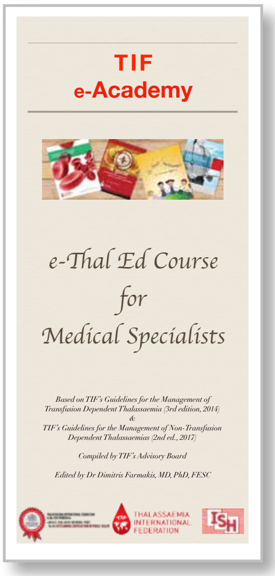
e-ThalEd for Medical Specialists

The Educational Platform for Medical Specialists, e-ThalEd is the first, global innovative online, interactive educational tool for the continuous life-long learning of the healthcare professionals working in the field of thalassaemia.

Developed by the Thalassaemia International Federation (TIF) e-ThalEd comprises of a variety of learning-conducive features including visuals, forums, quizzes, complimentary references and other material, the content is based on the internationally acclaimed TIF Guidelines, authored by international experts in the field of thalassaemia with long-term experience in the prevention and clinical management of the disease.

Participants have the choice to either take the entire course (i.e. 17 modules) or to take the which module(s) they are most interested in.

Certificates are provided upon completion of each module.



TIF
e-Academy

e-Thal Ed Course
for
Medical Specialists

Based on TIF's Guidelines for the Management of Transfusion Dependent Thalassaemia (3rd edition, 2014)
&
TIF's Guidelines for the Management of Non-Transfusion Dependent Thalassaemias (2nd ed., 2017)

Compiled by TIF's Advisory Board

Edited by Dr Dimitris Farmakis, MD, PhD, FESC

THALASSAEMIA INTERNATIONAL FEDERATION

ISH

Languages

English French Arabic

144 Certificates obtained!

63% of participants are Haematologists

25 countries

Endorsed

THE INTERNATIONAL SOCIETY OF HEMATOLOGY INTERNATIONAL HAEMOGLOBINOPATHY EXPERTS

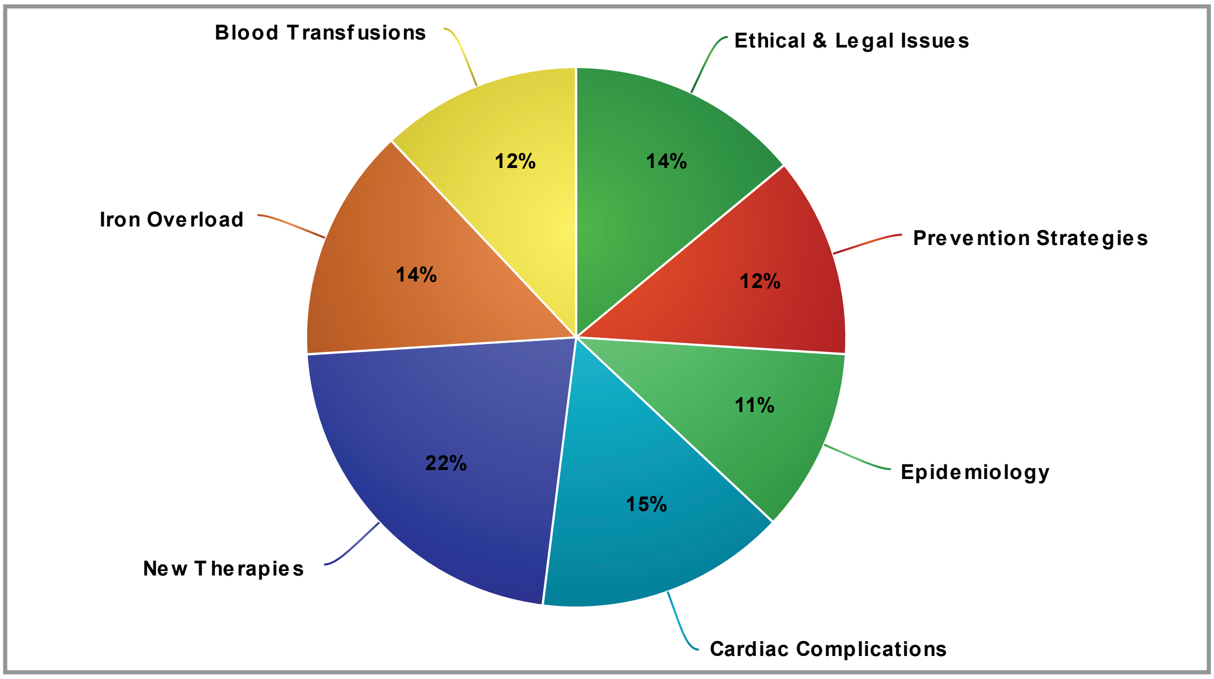
e-ThalEd Course Modules

PREVENTION OF THALASSAEMIA AND OTHER HAEMOGLOBIN DISORDERS	CLINICAL MANAGEMENT OF THALASSAEMIA AND OTHER HAEMOGLOBIN DISORDERS	
Why prevention Epidemiology supporting prevention Strategies for National Prevention Programmes Practical aspects of effective prevention programmes-Screening Ethical and legal issues	Introduction to thalassaemia: genetic basis, pathophysiology and diagnosis Blood transfusions Iron overload and chelation Cardiac complications Liver and spleen Infections	Endocrine disorders and osteoporosis Fertility and pregnancy Thalassaemia emergencies Lifestyle and psychological support Hematopoietic stem cell transplantation and novel therapeutic approaches Organisation of thalassaemia care

Do you have a medical degree and specialisation in Internal Medicine, or Paediatrics, Haematology, preferably with previous experience in the treatment of Haemoglobinopathies?

Register for the e-ThalEd for Medical Specialists today!
https://thalassaemia.org.cy/education/elearning/courses-professionals/

Top Modules



What they said

Feedback from medical specialists who have completed the e-ThalEd:

> *The courses made me feel more confident knowing that the knowledge TIF provides is always authentic and reliable.*
>
> Haematologist, Pakistan

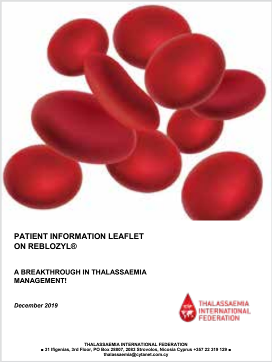
> *The course covers all subjects regarding the Hemoglobinopathies and will be very useful for any physician to treat patients with these diseases.*
>
> Haematologist, Greece

> *This forum is so so beneficial for many people like me who want to seek knowledge but do not find one complete forum with excellent information of each and every aspect of Thalassemia.*
>
> Internal Medicine, Algeria

> *Excellent course, every health personnel should take it.*
>
> Paediatrician, India

PUBLICATIONS

New TIF Publications 2019

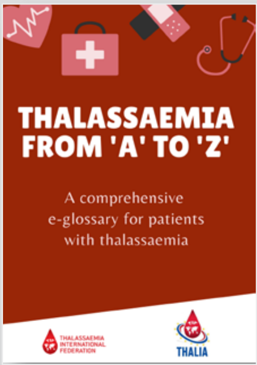


PATIENT INFORMATION LEAFLET
ON REBLOZYL®

A BREAKTHROUGH IN THALASSAEMIA
MANAGEMENT!

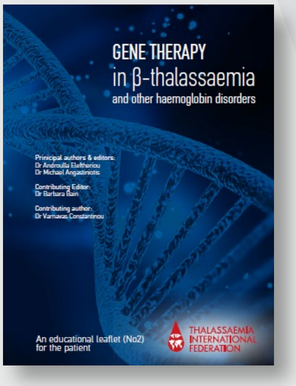
December 2019

THALASSAEMIA INTERNATIONAL FEDERATION
■ 31 Ifigenias, 3rd Floor, PO Box 28807, 2083 Strovolos, Nicosia Cyprus +357 22 319 129 ■
thalassaemia@cytanet.com.cy



THALASSAEMIA
FROM 'A' TO 'Z'

A comprehensive
e-glossary for patients
with thalassaemia



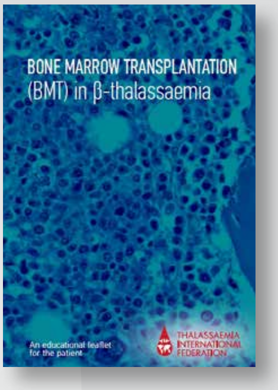
GENE THERAPY
in β-thalassaemia
and other haemoglobin disorders

Principal authors & editors:
Dr Androulla Eleftheriou
Dr Michael Angastiniotis

Contributing Editor:
Dr Barbara Bain

Contributing author:
Dr Varnavas Constantinou

An educational leaflet (No2)
for the patient



BONE MARROW TRANSPLANTATION
(BMT) in β-thalassaemia

An educational leaflet
for the patient

Audiovisual Publications

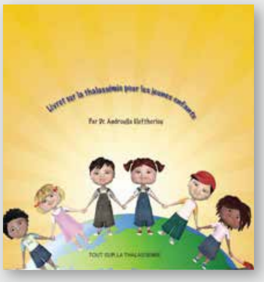
Watch on TIF's YouTube channel!

COMMUNITY AWARENESS ON
THALASSAEMIA CONTROL

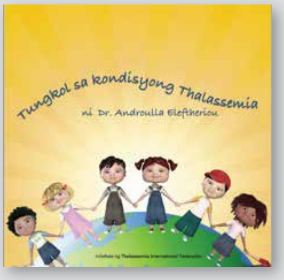
with very encouraging results for patients with thalassaemia and sickle cell disease

On behalf of the Thalassaemia International Federation,

Translations 2019

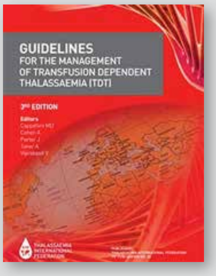


French



Tungkol sa kondisyong Thalassemia
ni Dr. Androulla Eleftheriou

Filipino

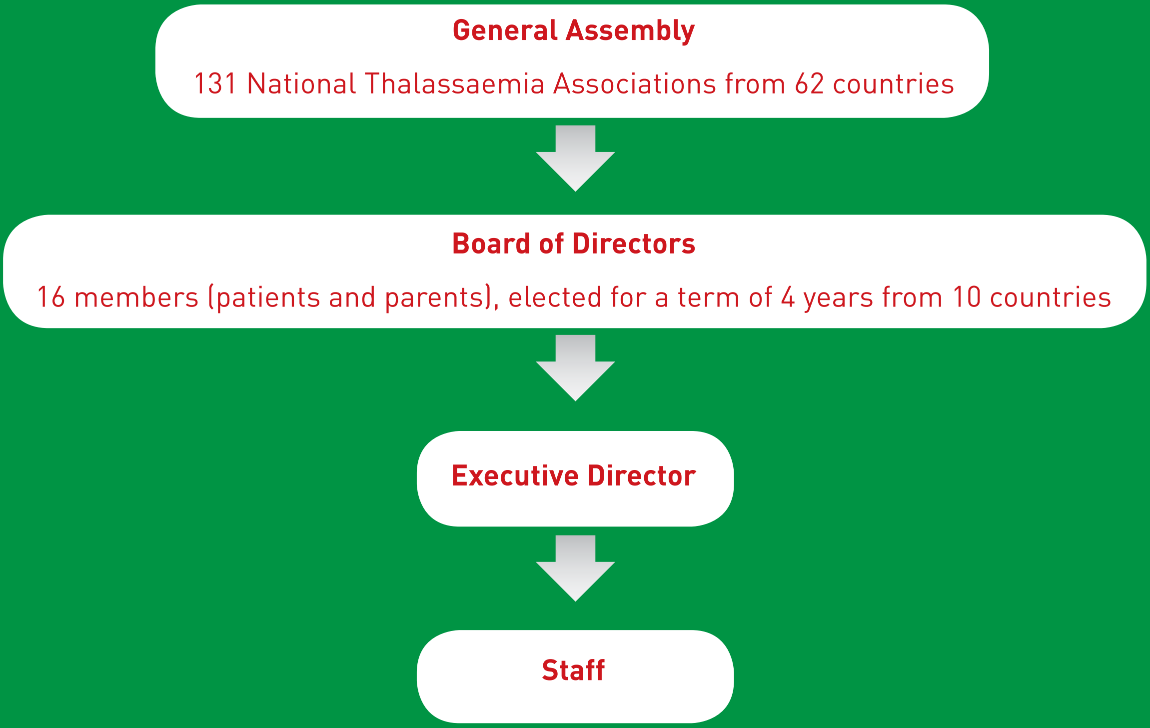


GUIDELINES
FOR THE MANAGEMENT
OF TRANSFUSION DEPENDENT
THALASSAEMIA (TDT)

3rd EDITION

Arabic & Chinese

TIF GOVERNANCE



General Assembly

131 National Thalassaemia Associations from 62 countries

Board of Directors

16 members (patients and parents), elected for a term of 4 years from 10 countries

Executive Director

Staff

The Board met twice in 2019, once on 7 - 8 April in Fujairah, United Arab Emirates and another time on 29 - 30 November in London, UK.

Finally, in the course of 2019, the TIF Office prepared and distributed 5 Briefing Reports to its Board of Directors, keeping them informed of all proceedings.

TIF BOARD OF DIRECTORS


Panos Englezos President (Cyprus Thalassaemia Association, Cyprus)


Shobha Tuli Vice President (Thalassemics India, India)


Elena Mylona Secretary (Cyprus Thalassaemia Association, Cyprus)


George Constantinou Ass. Secretary - Non-country affiliate


Riyad Elbard Treasurer (Thalassemia Foundation of Canada, Canada)


Saeed Jafaar Al-Awadhi Ass. Treasurer (Emirates Thalassaemia Society, UAE)


HH Sheikha Sheikha Bint Seif Al-Nahyan (Emirates Thalassaemia Society, UAE)


Loris Angelo Brunetta (Associazone Ligure Thalassemici Onlus, Italy)


Robert Ficarra (Cooley's Anemia Foundation, USA)


Michelle Abi Saad (Chronic Care Centre, Lebanon)


Fatemeh Hashemi (Charity Foundation for Special Diseases, Iran) Non-country affiliate


Romaine Maharaj (UK Thalassaemia Society, UK)


Abdul Baset Mohd Merdas (Emirates Thalassaemia Society, UAE)


Anton Skafi (Thalassaemia Patients' Friends Society, Palestine)


Eleni Michalaki (Greek Thalassaemia Federation, Greece)


Gabriel Theophanous (UK Thalassaemia Society, UK)

STAFF MEMBERS


Dr Androulla Eleftheriou
TIF Executive Director


Dr Michael Angastiniotis
Medical Advisor

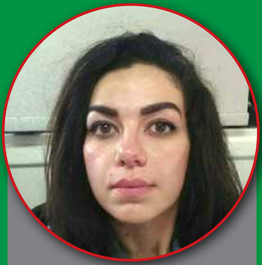

Ms Maria Peletie
PA to the Executive Director


Ms Lily Cannon
TIF Operational Manager


Katia Pelides
TIF e-Academy Officer


Stella Eleftheriou
Administration Assistant


Ms Eleni Antoniou
Senior Officer
Policy & International Relations


Catherine Skari
Senior Officer
Communications


Mr Rawad Merhi
Countries Officer

STAFF IN ACTION

TIF MEMBERSHIP

The Federation's membership includes national thalassaemia associations, other disease-specific patients' associations, health-related organisations and institutions, health professionals and interested individuals from around the world. Membership is divided into three categories:

General Members include only those patients' associations with an interest in thalassaemia. After completion of one year of membership, General Members can become Full Members. Individuals, commercial or professional groups and disease-orientated (other than thalassaemia) patients' associations can become Associate Members.

At the end of 2019, TIF had **78** General, **53** Full Members, and **89** Associate Members, totalling to **220** associations and representing **62** countries worldwide.

TIF New Members 2019

TIF welcomed the following members in 2019:

General Members

NAME	COUNTRY
THALASSEMIA FOUNDATION OF GHANA	GHANA
UNLIMITED HEALTH HUMANITARIAN ORGANIZATION	IRAQ
DURGAPUR SOCIETY FOR PREVENTION OF THALASSAEMIA AND AIDS	INDIA
ZAINABIA BLOOD BANK & THALASSAEMIA CENTRE	PAKISTAN
THE SWEDISH BLOOD CANCER ASSOCIATION	SWEDEN

Associate Members

NAME	COUNTRY
MAKSUDA BEGUM	BANGLADESH
ALI SATTARPOUR	FRANCE
TAKLUN CHEUNG	FRANCE
RANIA ABU SEIR	PALESTINE
ASSOCIATION POUR LE DEVELOPPEMENT DES FRANCOPHONES	CONGO

TIF MEMBERS 2019

FULL MEMBERS

NAME	COUNTRY
ALBANIAN THALASSAEMICS ASSOCIATION (ATA)	ALBANIA
JORDANIAN THALASSEMIA & HEMOPHILIA SOCIETY	JORDAN
THALASSAEMIA AND SICKLE CELL AUSTRALIA	AUSTRALIA
CHRONIC CARE CENTRE	LEBANON
THALASSAEMIA SOCIETY OF NEW SOUTH WALES	AUSTRALIA
FEDERATION OF MALAYSIAN THALASSAEMIA SOCIETIES	MALAYSIA
SAVAB DUNYASI THALASSAEMIA ASSOCIATION	AZERBAIJAN
SOCIETY FOR HEALTH EDUCATION	MALDIVES
AZERBAIJAN THALASSAEMIA SOCIETY INSAN	AZERBAIJAN
MOROCCAN ASSOCIATION OF THALASSAEMIA AND HEMOGLOBIN DISEASES (MATHED)	MOROCCO
BAHRAIN NATIONAL HEREDITARY ANAEMIA SOCIETY	BAHRAIN
NEPAL THALASSAEMIA SOCIETY	NEPAL
BANGLADESH THALASSAEMIA SAMITY (SOCIETY)	BANGLADESH
THALASSAEMIA FEDERATION OF PAKISTAN	PAKISTAN
LAB ONE FOUNDATION OF THALASSAEMIA	BANGLADESH
THALASSAEMIA SOCIETY OF PAKISTAN	PAKISTAN
BULGARIAN ANTI-THALASSAEMIC ORGANISATION (BATA) - SOFIA	BULGARIA
PALESTINE AVENIR FOUNDATION	PALESTINE
THALASSAEMICS' ORGANIZATION IN BULGARIA	BULGARIA
THALASSEMIA PATIENTS FRIENDS SOCIETY (TPFS PALESTINE)	PALESTINE
THALASSEMIA FOUNDATION OF CANADA	CANADA
ASOCIATIA PERSOANELOR CU TALASEMIE MAJORA	ROMANIA
CHILDREN'S THALASSAEMIA FOUNDATION LTD	HONG KONG
AL-MADINA HEREDITARY BLOOD DISORDER CHARITY SOCIETY	SAUDI ARABIA
ΠΑΓΚΥΠΡΙΟΣ ΑΝΤΙΑΝΑΙΜΙΚΟΣ ΣΥΝΔΕΣΜΟΣ (PANCYPRIAN THALASSAEMIA ASSOCIATION)	CYPRUS
THALASSAEMIA SOCIETY (SINGAPORE)	SINGAPORE
EGYPTIAN THALASSAEMIC FRIENDS ASSOCIATION	EGYPT
KURUNEGALA THALASSAEMIA ASSOCIATION	SRI LANKA
GREEK THALASSAEMIA FEDERATION (EOTHA)	GREECE
THALASSAEMIA PATIENTS AND HEREDITARY BLOOD DISEASES	SYRIAN ARAB REPUBLIC
THALASSEMICS INDIA	INDIA
THALASSAEMIA FOUNDATION OF THAILAND	THAILAND
YAYASAN THALASSAEMIA INDONESIA	INDONESIA
THE SOCIETY FOR INHERITED & SEVERE BLOOD DISORDERS TRINIDAD AND TOBAGO LIMITED	TRINIDAD AND TOBAGO
CHARITY FOUNDATION FOR SPECIAL DISEASES	IRAN
ALPHATT TUNISIE	TUNISIA
IRANIAN THALASSAEMIA SOCIETY	IRAN
(ATODER) ADANA THALASSAEMIA & SICKLE CELL ANEMIA	TURKEY
THALASSEMIA ASSOCIATION IN NINIVA	IRAQ
AKDENIZ TALASEMI DERNEGI	TURKEY
ISRAELI ASSOCIATION OF THALASSAEMIA & SICKLE CELL ANEMIA	ISRAEL

TIF MEMBERS 2019

FULL MEMBERS

TADAD - THALASSEMI DAYANISMA DERNEGI	TURKEY
ASSOCIAZIONE LIGURE THALASSEMICI ONLUS (ALT)	ITALY
TALASEMI FEDERASYONU (THALASSEMIA FEDERATION OF TURKEY)	TURKEY
ASSOCIAZIONE TALASSEMICI E DREPANOCITICI LOMBARDI ONLUS (ATDL)	ITALY
EMIRATES THALASSAEMIA SOCIETY	UNITED ARAB EMIRATES
ASSOCIAZIONE VENETA PER LA LOTTA ALLA TALASSEMIA (AVLT)	ITALY
NEBATA (NORTH OF ENGLAND BONE MARROW & THALASSAEMIA ASSOCIATION)	UNITED KINGDOM
UNITED ONLUS	ITALY
UNITED KINGDOM THALASSAEMIA SOCIETY (UKTS)	UNITED KINGDOM
FONDAZIONE ITALIANA "L. GIAMBRONE" PER LA GUARIGIONE DALLA THALASSEMIA	ITALY
COOLEY'S ANEMIA FOUNDATION	UNITED STATES OF AMERICA
YEMEN THALASSAEMIA & GENETIC BLOOD DISORDERS SOCIETY	YEMEN

GENERAL MEMBERS

NAME	COUNTRY
SOCIAL AND HEALTH ORGANIZATION FOR AFGHANISTAN(SOA)	AFGHANISTAN
UNLIMITED HEALTH HUMANITARIAN ORGANIZATION	IRAQ
ALBANIAN ASSOCIATION OF THALASSAEMIA AND HAEMOGLOBINOPATHIES	ALBANIA
SICKLE CELL AND THALASSAEMIA IRELAND	IRELAND
ASSOCIATION “EL AMANI” DES ANEMIES HEMOLYTIQUES CONGENITALES	ALGERIA
THE GALILEE FOUNDATION OF THALASSAEMIA & SICKLE CELL ANEMIA	ISRAEL
ASOCIACION DE TALASEMIA ARGENTINA	ARGENTINA
ASSOCIAZIONE LOTTA ALLA TALASSEMIA DI FERRARA	ITALY
THALASSAEMIA FOUNDATION OF ARGENTINA - FUNDATAL	ARGENTINA
ASSOCIAZIONE THALASSEMICI DI TORINO ONLUS	ITALY
BANGLADESH THALASSEMIA FOUNDATION	BANGLADESH
KUWAIT THALASSAEMIA SOCIETY	KUWAIT
THALASSAEMIA WELFARE CENTRE-BANGLADESH	BANGLADESH
ETUDIER, COMBATTRE LES MALADIES DE L’HEMOGLOBINE	LUXEMBOURG
ASSOCIATION BELGE DE THALASSEMIE ASBL	BELGIUM
JOHOR THALASSAEMIA SOCIETY	MALAYSIA
CAMBODIAN THALASSAEMIA ASSOCIATION	CAMBODIA
PERTUBUHAN THALASAEMIA PULAU PINANG	MALAYSIA
THE VANCOUVER THALASSAEMIA SOCIETY OF B.C.	CANADA
THALASSAEMIA ASSOCIATION OF MALAYSIA	MALAYSIA
GUANGDONG THALASSAEMIA ASSOCIATION	CHINA
MALDIVIAN THALASSAEMIA SOCIETY	MALDIVES
GUANGXI THALASSAEMIA FEDERATION	CHINA
THALASSAEMIA AWARENESS MALTESE ASSOCIATION (TAMA)	MALTA
THALASSAEMIA CHINESE FEDERATION	CHINA
BLOOD DONORS ASSOCIATION (MAURITIUS)	MAURITIUS
THALASSEMIA PATIENTS FRIENDS ASSOCIATION	EGYPT
THALASSEMIA SOCIETY OF MAURITIUS	MAURITIUS
ASSOCIATION FRANCAISE DE LUTTE CONTRE LES THALASSAEMIES (AFLT)	FRANCE
ASSOCIATION MAROCAINE DE THALASSAEMIE ET DREPANOCYTOSE	MOROCCO
INTERESSENGEMEINSCHAFT SICHELZELLKRANKHEIT UND THALASSAEMIE E.V. (IST E.V.)	GERMANY
OSCAR NEDERLAND	NETHERLANDS
THALASSAEMIE VEREIN ULM E.V.	GERMANY
SICKLE CELL / THALASSAEMIA ASSOCIATION OF NIGERIA	NIGERIA
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* *in alphabetical order*

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