

TIF Newsletter

September 2013

Volume 7., Issue 1

Dear friends,

Winter is slowly approaching but our activities are blossoming. This monthly e-Newsletter provides information on some of TIF's many activities.

Pleasant Reading!!

TIF Activities

As a result of TIF's work in Algeria in recent years, and most notably the meeting held with the Ministry of Health during the last delegation visit in the country in April 2013, a memorandum of understanding regarding the prevention and treatment of haemoglobinopathies in the country was signed on 30 September 2013. TIF was represented by Mr Costas Papageorgiou (President of the Hellenic Society for the Protection of Patients with Thalassaemia & former president of TIF), and Professor Dimitris Loukopoulos, (Emeritus Professor of Haematology & member of TIF's Scientific Advisory Committee). Meetings with the Algerian Thalassaemia Association and the local Rotary Club have also been conducted. This is a milestone achievement and TIF is committed to follow up developments closely.

TIF launched an initiative to support health authorities of seven states in Northern and North-western India. Dr Androulla Eleftheriou (TIF Executive Director), Dr Michael Angastiniotis and Dr Matheos Demetriades (TIF Country Officer) embarked on an official delegation visit to the states of Delhi, Maharashtra, Gujarat, and Madhya Pradesh, on 14–20 September 2013, with the aim to continue to another three states, namely Haryana, Punjab and Uttar Pradesh. Official meetings with State Public Health officials, medical specialists, and patients/parents organisations from each of the aforementioned states were conducted. This initiative is closely supported by the Federation of Indian Thalassemics (FIT) in an effort to promote the prevention and clinical management of these disorders across the country.



Thalassaemia and sickle cell disease have been placed on the official agenda of the Association of Southeast Asian Nations (ASEAN) Senior Officials Meeting on Health Development (SOMHD), at the meeting held in August 2013. TIF had been invited by Malaysia to present a Report on Thalassaemia and Other Haemoglobinopathies specifically for ASEAN countries (including Indonesia, Thailand, Malaysia, Singapore, Philippines, Vietnam, Myanmar, Brunei Darussalam, Cambodia, and Laos), aiming to promote the implementation of the WHO resolutions for the development of national prevention and control programmes for haemoglobin disorders in nations across the region. Issues agreed at the SOMHD will be escalated to the next Health Ministers' Meeting of the ASEAN, which is scheduled to be held in 2014 in Vietnam.

A delegation, headed by Mr Panos Englezos (TIF President), accompanied by Dr Androulla Eleftheriou (TIF Executive Director), supported by Ms Lily Cannon (TIF European Affairs Officer) and Ms Maria Apostolidou (TIF PR & Communications Officer) attended the **18th Annual Congress of the European Hematology Association (EHA)** held in Stockholm on 14–16 June 2013. An

Thalassaemia International Federation
World Congress13th International Conference
On Thalassaemia & Hemoglobinopathies
15th TIF International Conference
For Parents & Patients20th - 23rd October 2013
Abu Dhabi National Exhibition Centre**Join Us in Abu Dhabi!!!!****2nd Pan-Middle East meeting, 20 October, 09.00—12.00**

All patients/parents & medical experts of the Region are invited to attend this open discussion which aims to pave the way to TIF's 2nd Pan-Middle East Conference in September 2015

The Voice of Patients & Parents around the World: Sickle Cell Disease Patients/Parents Programme, 22 October, 08.30—15.30

For the first time in an international conference, an entire day dedicated to Sickle Cell Disease! Come and hear about new advances, share experiences and develop new friendships.

The Global Status of Blood Safety & Viral Hepatitis Control Programmes, with focus on Transfusion Dependent Haemoglobin Disorders, 23 October, 11.00—16.00

New antiviral drugs & technologies to ensure the safety of blood are on the horizon. Hear about them in this session!

active member of EHA's Patient Advocacy Group, TIF had a strong presence in patient program which focused on the inclusion of patients with haematological diseases in clinical studies. Moreover, a parallel workshop for the development of a pan-European voice of patients with haematological disorders was also organized. However, the highlight of the Conference was the mass distribution of the recently published Guidelines of the Clinical Management of Non Transfusion Dependent Thalassaemias (NTDT) as well as other TIF publications to delegates from across the world.

The EU Policy Report on Migration

entitled "Haemoglobinopathies on the Move: Is Europe ready? A policy analysis of 10 European countries" was successfully launched on 26 June 2013 at the European Parliament.

Members of the European Parliament Mrs Antigoni Papadopoulou (Cyprus) and Mrs Marina Yannakoudakis (UK) undertook the task of promoting this Report, compiled by medical experts of the ENERCA project, the International Organization for Migration, and TIF. Dr Androulla Eleftheriou (TIF Executive Director) and Dr Michael Angastiniotis (TIF Medical Advisor) actively participated in the meeting, presenting the findings of the report on behalf of the experts. Mrs Papadopoulou and TIF are currently working on a Written Declaration to be submitted to the European Parliament. You can read the Report on our website!

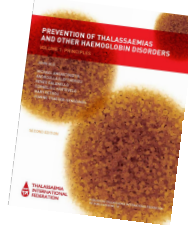


Mr George Constantinou (TIF Board Member) has participated in a **Multi-Stakeholders Meeting** in Brussels that was organised by the European AIDS Treatment Group and the European Liver Patients Association (ELPA). The meeting focused on the timely access to new treatments for hepatitis C, especially for patients who have no alternative opportunities. TIF is committed to continue its active participation in this forum, representing patients with haemoglobinopathies.

TIF Publications

OUT NOW!!!!

Prevention of Thalassaemias and other Haemoglobin Disorders, Vol 1, 2nd Edition (Old, J., Galanello, R., Eleftheriou, A., Traeger- Synodinou, J., Petrou, M., Angastiniotis, M.)



Community Awareness Booklets on α -thalassaemia, β -thalassaemia & Sickle Cell Disease (Greek). (Eleftheriou, A.)

Sickle Cell Disease Guidelines for the Clinical Management of Adults and Children (Greek) . (Translated by Farmakis, D.)

DOWNLOAD OUR PUBLICATIONS FOR FREE

<http://www.thalassaemia.org.cy/list-of-publications/>

...Expected in 2013...

Community Awareness Booklets on α -thalassaemia, β -thalassaemia & Sickle Cell Disease (English). (Eleftheriou, A.)

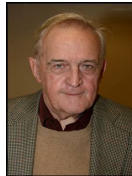
Guidelines for the Clinical Management of Transfusion Dependent Thalassaemias, 3rd Edition (Cappellini, M.D., Cohen, A., Eleftheriou, A., Piga, A., Porter, J., Taher, A.)

Sickle Cell Disease: A booklet for parents, patients and the community, 2nd Edition (Inati-Khoriaty, A)

Emergency Management of Thalassaemia (2012) - (Greek). (Porter J, Taher A, Mufarrij A, Gavalas M)

Congratulations!!!

The American Society of Haematology (ASH) is planning to present the Society's highest honour, the Wallace H. Coulter Award for Lifetime Achievement in Haematology, to Professor Sir David Weatherall during the Annual Meeting & Exposition, to be held on 07–13 December 2013 in New Orleans.



Sir David Weatherall has a career in haematology spanning more than half a century, with a special interest in thalassaemia.

Regional News

World Sickle Cell Day, celebrated on 19 June each year, was honoured by the **Blood Patients Protection Council (BPPC)** in Calicut, India. In collaboration with the Regional Science Centre, the BPPC organised an educational patient/parent meeting on 15th June 2013 on sickle cell disease.



Focused on promoting the rights of patients with thalassaemia in Sri Lanka, the "**Lanka Thalassaemia Circle**" has officially been formed under the patronage of the First Lady of Sri Lanka, Madame Shiranthi Rajapakse. Sri Lanka is a country with many successes in the field of thalassaemia control and its medical and patient communities have shown exemplary strength and commitment.



Iftikhar Muhammad Chaudhary, the Honorable Chief Justice of **Pakistan** received a delegation of patients with thalassaemia on the occasion of Red Letter Day, celebrated on 11 April 2013. The delegation promoted the implementation of screening prior to marriage across the country, as a measure of prevention.



A review of the literature on the burden of liver disease in Europe has resulted in the publication of a **White Paper by the European Association for the Study of Liver (EASL)**. Constituting part of EASL's public policy activities, this White Paper is an important first step to emphasize the importance of liver disease to the European legislative bodies as well as to national health authorities, promoting the development of national programmes for the prevention and management of liver diseases.

Therapeutic & Research Centre

The American Heart Association has issued a consensus statement affirming that **MRI T2* tests** offer the opportunities of early diagnosis and treatment of cardiac iron overload in patients with β -thalassaemia major (AABB, 20/06/2013)

Ischemic stroke has been shown to be a minimal factor in the deaths of children with sickle cell disease from 1988–2007 in the African American community (AABB, 25/06/2013)

It has been estimated that in 2050 approximately 404,200 newborns worldwide will be diagnosed with **sickle cell disease**, in comparison to approximately 305,800 cases diagnosed in 2010 (AABB, 17/07/2013)

A study, published in the New England Journal of Medicine, states the effectiveness of **interferon-free treatment** in a clinical trial involving 362 patients with chronic hepatitis C genotype 1 (AABB, 15/08/2013)

Selexys Pharmaceuticals has announced the initiation of **patient enrollment for a midstage study** of an experimental sickle cell disease drug (AABB, 21/08/2013)

Delegation Visits & Workshops

China, 18–19 November, Delegation visit & workshop

China, 14–15 December, Delegation visit

India, 18–19 December, Delegation visit & workshop

** These Delegation Visits & Workshops are subject to change according to local circumstances **



IN PARTNERSHIP WITH THALASSAEMIA INTERNATIONAL FEDERATION (TIF)



The first successful awardees will be officially announced in the Opening Ceremony of the TIF World Congress on 20 October 2013 in Abu Dhabi

AWARDEES!!

Sultan bin Khalifa Grand International Award for Scientific Achievement

Shared by: Prof David Nathan (USA) ~ Prof Phaedon Fessas (Greece) ~ Prof Prawase Wasi (Thailand)

Sultan bin Khalifa International Award for Leadership in Thalassaemia
Prof Ali Taher (Lebanon)

Sultan bin Khalifa International Award for Innovative Research in Thalassaemia
Prof Michel Sadelain (USA)

Sultan bin Khalifa International Award for Clinical Centre for Excellence
Mahidol Hospital Thalassaemia Centre (Bangkok, Thailand)

Sultan bin Khalifa International Award for Thalassaemia Society of Excellence
Cooley's Anemia Foundation (USA)

Sultan bin Khalifa International Scholarship for Transitional Research in Thalassaemia
Dr Juliano de Lara Fernandes (Brazil)

Congratulations to all and our deepest gratitude to HH Dr. Sheikh Sultan Bin Khalifa Bin Zayed Al Nahyan for this great humanitarian act