

# TIF Newsletter

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Dear friends,

Each International Conference reminds all of us how big our thalassaemia family actually is. Returning from Abu Dhabi, we keep close to our hearts the sentiment expressed by TIF's President and father-figure of our family that *'we need to work together, to join hands in order to find a way for all those children born with thalassaemia to live!!'*

Editorial Team

## TIF Activities



Thalassaemia International Federation  
World Congress

13th International Conference  
on Thalassaemia & Haemoglobinopathies  
15th TIF International Conference  
for Patients & Parents  
20th - 23rd October 2013  
Abu Dhabi National Exhibition Centre

The **2013 twin conferences on thalassaemia and the haemoglobinopathies**, held in Abu Dhabi, United Arab Emirates, were the most successful yet, attracting more than 1,300 participants from over 50 countries across five continents.



The three-day event was co-organised by TIF and the TIF Regional Collaborating Office, in cooperation with the Humanitarian Scientific Foundation «HH Dr. Sheikh Sultan Bin Khalifa Al Nahyan » and the Emirates Thalassaemia Society.

The Conferences were officially inaugurated by H.H. Sheikh Zayed Bin Sultan Bin Khalifa Al— Nahyan and H.H. Sheikha Sheikha Bint Saif Al-Nahyan, who have offered their unwavering support to the thalassaemia family in the region and across the world.



The parallel scientific and patients/parents programmes covered a huge range of topics, presented by more than 60 internationally renowned experts in the field of haemoglobin disorders.

A notable feature of this year's patients/parents conference was the materialisation of the first ever **International Patients/Parents Association's Capacity Building Workshop**, which sought to empower patient advocates, in order to enhance their engagement in active and productive dialogue with national health authorities and other health-related stakeholders aiming at policy development and reforms at the national, regional and international level.



Furthermore, several **satellite meetings** were held by TIF in the context of this grand event—most notably a meeting of the Middle East Network, a patients/parents session dedicated to Sickle Cell Disease and a patient-orientated workshop on blood safety and global hepatitis.

TIF President, Mr Panos Englezos, TIF Executive Director, Dr Androulla Eleftheriou and TIF Medical Advisor, Dr Michael Angastiniotis **met with representatives** of the following countries during the course of the Conferences:

- Turkey
- Bangladesh
- Vietnam
- Morocco
- Maldives
- Sudan
- Iran
- Russian Federation
- Kingdom of Saudi Arabia
- Trinidad & Tobago
- Afghanistan



جائزة سلطان بن خليفة العالمية للثلاسيميا  
Sultan Bin Khalifa International Thalassaemia Award

IN PARTNERSHIP WITH  
THALASSAEMIA INTERNATIONAL FEDERATION (TIF)



### Award Ceremony

The official Award Ceremony of the Sultan Bin Khalifa International Thalassaemia Award took place on 20 October 2013, in a majestic and grand event hosted by H.H. Dr. Sheikh Sultan Bin Khalifa Al Nahyan . The 2013 Award winners had already been announced during a press conference in Abu Dhabi last month, and their names published in the September issue of TIF's e- newsletter.

*The Higher Scientific Committee, comprised of international experts in the field of haemoglobin disorders, remains dedicated to its cause for the selection of the next award-*



### New Beginnings!!



Exciting new partnerships were developed with Mrs Antoinette Sassou Nguesso—First Lady of the Democratic Republic of the Congo, with regards to TIF's work with Sickle Cell Disease, and with Her Excellency Dr Aishath Shehanaz Ada, Ambassador of Republic of Maldives to the

United Arab Emirates, concerning the situation on the islands which have amongst the highest thalassaemia carrier rates in the world.



ees in 2 years time.

TIF has actively participated in the **5th Romanian Workshop on Thalassaemia Major**, organised in the context of the Romanian National Congress of Haematology, on 12 October 2013 in Sinaia, Romania. Dr Duru Malyali (Turkey), TIF Board Member, has represented TIF at this workshop.

TIF along with the China National Health and Family Planning Commission (NHFPC) will be hosting the **International Seminar on Prevention and Control of Thalassaemia** (Mediterranean Anaemia), on 18-19 November 2013, in Guangzhou, Guangdong Province, China. This event is organized by the Family Planning and Reproductive Health Research Society and the Guangdong Provincial Health and Family Planning Commission. The aim of the seminar is to provide information about the Prevention and Control of Thalassaemia.

A video projecting the history of thalassaemia throughout the years, created by the President of the **Pan-Hellenic Association for the Protection of Thalassaemia Patients**, Mr Costas Papageorgiou, former President of TIF, was shown during the Opening Ceremony of the biennial International Conferences in Abu Dhabi. Conveying the message of patient empowerment, and demonstrating what patients can achieve with their determination and will to take life in their own hands, the video officially launched the Greek Network of Patient—Doctors. TIF has congratulated Mr Papageorgiou for his initiative to create this video but also for having formed this network of patients-doctors in Greece. The establishment of this network has served as a stepping stone to ignite a stronger relationship with the Association. TIF has applauded the members of the network for their



The **Greek Thalassaemia Federation**, who has under its umbrella all associations for Thalassaemia in Greece, is organizing a Pan-Hellenic Informational event about Thalassaemia on 29-30 November 2013, in Athens. TIF has placed this event under its auspices and a representative from TIF headquarters will participate in this event. Furthermore, TIF has been invited to coordinate a round table discussion in the course of this event on the topic of access to medicines in Europe, and to present the EU Policy Report on Migration entitled "Haemoglobinopathies on the Move: Is Europe ready? A policy analysis of 10 European countries" officially launched at the European Parliament in June 2013. The Report has been drafted by TIF in collaboration with the ENERCA medical experts and the International Organization for Migration.

## 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  $\alpha$ -thalassaemia,  $\beta$ -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/educational-programme/publications.shtml>

### ...Expected in 2013...

Community Awareness Booklets on  $\alpha$ -thalassaemia,  $\beta$ -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)

## Regional News

**Germany** has joined the growing list of EU Member States to adopt a dedicated strategy for rare diseases. The German plan includes Measures to Improve the Health Situation of Persons with Rare Diseases containing 52 distinct proposals for action. Nationally recognised centres of excellence for diseases or groups of diseases that collaborate nationally and internationally are the cornerstone of the German plan, which aims to provide patients with the best, targeted care available.

The European Public Health Alliance (EPHA) has launched a briefing entitled '**Access to Medicines in Europe in Times of Austerity**'. In this paper, EPHA concludes that there are three key determinants to ensuring universal access to medicines—affordability, availability, and innovation. Read EPHA's statement here: [http://www.ephah.org/IMG/pdf/FINAL\\_EPHA\\_Briefing\\_on\\_Access\\_to\\_Medicines.pdf](http://www.ephah.org/IMG/pdf/FINAL_EPHA_Briefing_on_Access_to_Medicines.pdf)

In addition the EPHA has called for urgent and concentrated action among all relevant actors to close the huge, persistent and growing **health divide** between the rich and poor in our societies following the publication of two major reports reviewing trends and progress on health inequalities in Europe by the European Commission and the WHO Regional Office for Europe.

The European Parliamentary Committee on the Environment, Public Health and Food Safety (ENVI) has fought for the implementation of a series of

measures to improve **Patient Safety** in the EU. In particular, the progress report of the Council Recommendation 2009/C 151/01 has called for the creation of European guidelines on patient safety standards and the compilation of a second progress report in June 2014.

The **European Liver Patients' Association, (ELPA)**, has taken a leading position in placing patients at the centre of public healthcare policies throughout Europe by carrying out multiple projects and participating in various policy initiatives. Indeed, the Euro Hepatitis Care Index in 2012 proved to be an impactful instrument; as a result, a number of countries have committed to the development of national hepatitis strategies (Bulgaria, Croatia, Greece, Italy and Germany). The work of ELPA was presented during the satellite session on blood safety and hepatitis during the TIF World Congress 2013 in Abu Dhabi by ELPA President Dr Tatjana Reic.

The **European Medical Technology Industry Association (Eucomed)** has expressed disappointment and strong concern about the outcome of a vote in the European Parliament's Committee for Environment, Public Health and Food Safety (ENVI) on medical devices legislation. The Committee voted in favour of an extreme heavy bureaucratic procedure process based on a case-by-case centralised pre-marketing authorization system. Eucomed, supports that this proposed regulatory system will unnecessarily delay patient access by three years.

**4<sup>th</sup> Pan-European Conference,**  
Athens, September 2014

**2<sup>nd</sup> Pan-Asian Conference,**  
Location TBC\*, March 2015

**2<sup>nd</sup> Pan-Middle East Conference,**  
Location TBC\*, September 2015

\* to be confirmed

## Therapeutic & Research Centre

The **quality of life** of 109 patients' receiving hematopoietic stem cell transplants for the treatment of beta-thalassaemia, has been measured and found to be comparable to that of the general population (AABB, 22/10/2013).

U.S. researchers are investigating a new genetic therapeutic target for **sickle cell disease** called an enhancer, which regulates BCL11A in red blood cells (AABB, 12/10/2013).

An analysis of blood samples showed **that children with low vitamin D levels** had an almost twofold increased risk of having anaemia, (AABB, 22/10/2013).

## Delegation Visits & Workshops

**China**, 18–19 November, Delegation visit & workshop

**China**, 15–16 December, Workshop

**India**, 18 –19 December, Delegation visit & workshop

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