

# TIF Newsletter

March 2013

Volume 4., Issue 1

Dear friends,

We dedicate this issue to our dearly departed friend Kostas Agathocleous who was a source of strength and inspiration for all of us.

Editorial Team

## TIF Activities

A three-day workshop on the **Emergency Management of Thalassaemia & Sickle Cell Disease** was organized by TIF in collaboration with the Ministry of Health of Cyprus on 6 – 8 March 2013, and gathered more than 200 health professionals. The primary goal of the Workshop was to provide updated scientific information using case studies, to health professionals working in the primary health service on the suitable emergency treatment protocols of patients with haemoglobin disorders.

TIF's Executive Director, Dr Androulla Eleftheriou, actively participated in the **Global Iron Summit** that took place on 16 – 17 March 2013 in Copenhagen, Denmark. The Summit constitutes the single largest congregation of medical specialists and health professionals from across the globe, this year reaching 600 delegates. A highly scientific meeting which focused on new advances in non-transfusion dependent thalassaemias (NTDTs) with excellent sessions dedicated to quality of drugs added to the Summit's ground-breaking format of interactive sessions.

The first meeting of the **Ambassador's Circle** with 14 Ambassadors & Honorary Consuls finally took off on the 20 March 2013 in Nicosia (Cyprus). The meeting was opened by TIF President, Mr Englezos in the presence of members of the Board – Mr Loizos Pericleous (Cyprus) and Mr Anton Skafi (Palestine). The meeting was joined by representatives of the Ministry of Foreign Affairs and Ministry of Health. The huge spectrum of TIF's work was presented by Dr Androulla Eleftheriou (Executive Director) whilst the status quo relating to the prevention and control of haemoglobin disorders was discussed by Dr Michael Angastiniotis (TIF Medical Advisor). This project constitutes one of the most ambitious projects that TIF has undertaken in 2013, as a means to further promote the development and implementation of national control programmes for the prevention and clinical management of thalassaemia worldwide. The objective of developing this prestigious group is to share knowledge on haematological genetic diseases, which in addition to a significant public health burden, carry immense social and economic repercussions. TIF's aims are to underscore the fact that although considerable work has been already achieved in the direction of their control, there are still many gaps and services that need to be promoted worldwide. Already further meetings have been set up to discuss the development of mutual strategies aimed at supporting national authorities to further progress and with the support of the members of the Ambassador's Circle promote protocols for national strategies that secure the provision of quality health care for every patient.

Patient representatives of national thalassaemia associations from 10 countries, including an official TIF representation, met in Zurich for a two day **Advocacy Meeting on Non-Transfusion Dependent Thalassaemias** (NTDTs). The meeting aimed to identify and detect ways to raise awareness about NTDTs and to meet educational & support needs of patients with NTDTs. A comprehensive, and highly enlightening presentation of the multi-faceted nature of NTDTs and their difference in management to  $\beta$ -thalassaemia major was presented by international expert Dr Shahina Daar (Oman). The findings of a pre-meeting survey in addition to the discussion highlighted the fact that for many years NTDTs were ignored and

**2013 Theme:**  
"The right for quality health care  
for every patient with thalassaemia,  
major and beyond"



INTERNATIONAL THALASSAEMIA DAY • 08MAY

marginalized. This was most evident in the lack of awareness and knowledge both amongst patients but also health professionals. The meeting strengthened TIF's commitment, on behalf of the global thalassaemia family, to advocate for the rights of patients with all thalassaemia syndromes.

In our continuous efforts striving for the implementation of WHO resolutions on Thalassaemia and Other Haemoglobinopathies, TIF regularly approaches regional legislative bodies such as the **Association of Southeast Asian Nations** (ASEAN). ASEAN holds Senior Officials Meeting on Health Development (SOMHD) as well as scheduled Health Ministers' meeting after its general summit. TIF has successfully been invited by Malaysia to present a Concept Note on Thalassaemia and Other Haemoglobinopathies specifically for ASEAN countries at the next SOMHD, which is scheduled to be held in August 2013. 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. TIF is in expectance of an invitation to this highly significant health meeting to present TIF's Concept Note urging for the implementation of the WHO resolution for the development of national prevention and control programmes in nations across the region.

Moving forward in our activities in **Algeria**, a series of workshops with invited international medical and patient experts will take place between 14 -16 April in three main cities, namely El-Taref, Annaba & Skikda. The workshop aims to educate health professionals on the state-of-the-art medical care for on thalassaemia and sickle cell disease whilst the afternoon sessions will be dedicated to the education and empowerment of patients/parents. Policy makers and key haematologists are participating and a meeting with the Ministry of Health is scheduled to take place. The development of a joint plan of action for the promotion of a national prevention and control programme will be discussed.

A series of delegation visits and workshops have been scheduled for 2013 in **India**. The first of these is due to take place on 18 – 19 May in the form of a Capacity Building Workshop for patients/parents in Maharashtra state. Patients/Parents are encouraged to attend in order to gain knowledge, exchange experiences and create networks of collaboration as well as form new friendships aiming to strengthen their work and efforts for better health and quality of life. Mrs Shobha Tuli, TIF's Vice President, and a large number of collaborators in the medical and patients community of India are greatly supporting this initiative. More information can be provided by the Federation of Thalassems India.

**20<sup>th</sup> – 23<sup>rd</sup> October 2013**

Abu Dhabi National Exhibition Centre

Thalassaemia International Federation  
World Congress

tif2013.org

**TIF's Sponsorship Program for Patients with  
Haemoglobinopathies Available on our website**

## TIF Publications

### OUT NOW!!!!

A Guide for the Haemoglobinopathy Nurse (Aimiwu, E., Thomas, A., Roheemun, N., Khairallah, T., Nacouzi, N., Georgiou, A., Papadopoulou, C.)



### DOWNLOAD OUR PUBLICATIONS FOR FREE

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

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

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

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

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

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

Guidelines for the Clinical Management of Non-Transfusion Dependent Thalassaemias (Cappellini, M.D., Taher, A., Musallam, K.)

Community Awareness Booklets on  $\alpha$ -thalassaemia,  $\beta$ -thalassaemia & Sickle Cell Disease (Greek). (Eleftheriou, A.)

## Regional News

The Thalassaemia Children Welfare Society – Ulhasnagar, **India** on 17 February organized a Workshop that focused on the "Better Treatment of Thalassaemia". More than 250 children and parents in addition to 70 doctors from the vicinity attended. The importance of adherence to treatment was highlighted. Furthermore, representatives of the Legislative Assembly Govt. of Maharashtra also attended pledging the Governments support.

The award ceremony for 2012 participants in the awareness campaign entitled 'What is Thalassaemia?' of the Emirates Thalassaemia Society in the **United Arab Emirates** took place on 10 January under the patronage of Her Highness Sheikhha Sheikhha Bint Seif Al Nahyan, President of Emirates Thalassaemia Society. The campaign is in its 5<sup>th</sup> year and entails a competition where students from various schools, universities, colleges & institutes submit projects on thalassaemia such as organizing weekly awareness campaigns, designing websites, short films, and research. The campaign involves thousands of individuals in the local community educating and empowering patients and the public on the importance of screening and blood donations.



The **Executive Summary of the Conference on Hepatitis B and C in Mediterranean and Balkan Countries** (05 – 07 December 2012) has been published. Attended by TIF, the Conference focused on advocating for the implementation of WHO resolution (WHA 63.18) on viral hepatitis prevention and control. The heterogeneity of prevalence was highlighted by speakers as well as the rising incidence of HCV in Europe, attributed to population migration. The report can be found at <http://www.hepsummit2012.org/sites/default/files/pdfs/CyprusConfEXECUTIVESUMMARY26.02.2013-1.pdf>

The European Council has announced the agreement of the next **multi-annual budget**. In a press release, President of the Council Herman van Rompuy stated that consensus was reached after the longest meeting but the compromise achieved indicates a 'collective responsibility from Europe's leaders'. The budget which sees an overall increase of nearly 40%, €2.75bn of which will be allocated to health, still needs to be passed by the European Parliament.

The European Commission on the occasion of Rare Disease Day, 28 February, has announced €144 million new funding for 26 **research projects** on rare diseases. Approximately 30 million European live with a rare disease including patients with thalassaemia and sickle cell disease. Indeed amongst the projects, the new THALAMOSS project is included, focusing on the development of personalized therapy for  $\beta$ -thalassaemia.



"The right for quality health care of every patient with thalassaemia: major and beyond"

Find out more on our [website](#) and join us on this day

## Therapeutic & Research Centre

Born with HIV a baby girl has been cured after very early treatment with standard HIV drugs, U.S. researchers reported. This is a potentially groundbreaking case that could offer insights on how to eradicate **HIV infection** in its youngest victims. (AABB, 04/03/2013)

Research at Johns Hopkins University (USA) has found that **red blood cells** stored longer than three weeks begin to lose the flexibility needed to carry oxygen through narrow capillaries. "There's more and more information telling us that the shelf life of blood may not be six weeks, which is what the blood banks consider standard," study leader Dr. Steven M. Frank said. (AABB, 04/03/2013)

An interferon-free treatment for **hepatitis C** is in the pipeline with Phase II clinical trials beginning in the second quarter of 2013, marking the collaboration of Presidio Pharmaceuticals Inc. and Boehringer Ingelheim. (AABB, 14/01/13)

The European Medicines Agency (EMA) has declared approval of Roche's drug Pegasys plus ribavirin for the treatment of **chronic hepatitis C** to children from age five years of age. (AABB, 19/01/2013)

## Delegation Visits & Workshops

**Algeria**, 14—16 April, Workshop

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

**Morocco**, May, Delegation visit

**Afghanistan**, May, Delegation visit

**Russian Federation**, 7-9 June, IV Interregional Conference of National Society of Paediatric Haematologists and Oncologists

**India**, July, Delegation visit & workshop

**Philippines**, 8-11 September, 43<sup>rd</sup> Philippine Society of Haematology and Blood Transfusion Annual Convention

**Oman**, September, Delegation visit

**Kuwait**, September, Delegation visit

**Vietnam**, October, Delegation visit

**Tunisia**, December, Delegation visit

**China**, December, Delegation visit & workshop