

February 2013

Dear friends,

The winter is slowly disappearing but our activities are blossoming. We present here a full months work.

Enjoy!!

Editorial Team

## TIF Activities

The **International Conference on Sickle Cell Disease (SCD)** took place on 5–7 February 2013 in Bahrain and was attended by an official TIF delegation. The Conference, organised by the Ministry of Health of the Kingdom of Bahrain in response to the high prevalence of the condition in Bahrain and the whole of the Arab Peninsula brought together regional and international experts in the field of SCD, haematology and genetics. A wide range of topics were covered including reports on national programmes from 5 countries of the European, African, and the Middle Eastern regions, in addition to epidemiology, prevention and extensive deliberations on the complications of the disease. The TIF delegation met with thalassaemia and SCD patients who are members of the Bahrain Society for SCD Patient Care and completed the visit with a formal meeting with EMRO Regional Director, Dr Ala Alwan, to discuss the inclusion of genetic disorders on the NCD Programme of the WHO.

Possessing the highest  $\beta$ -thalassaemia carrier rate globally, the **Maldives** constitute a priority for TIF. In this spirit, and following following a formal request by the Maldivian Thalassaemia Society, an official TIF delegation visit was conducted on 10–13 February 2013, comprised by Mr George Constantinou (TIF Board Member) and Dr Michael Angastiniotis (TIF Medical Advisor). The delegation met with representatives of the Society, medical community and industry, where they were briefed on the current situation in the country. The visit culminated with an official meeting with the Maldivian Minister of Health. The constructive meeting touched on many issues including the national control programme and the implementation of legislative decisions ratified last year for the development of services and protection of patients rights.



A first investigatory visit was conducted by a representative of TIF on our behalf. Received by the Chairman of the **Yemen** Society for Thalassaemia and Genetic Blood Disorders, the representative met with patients and the medical community in order to provide an accurate assessment of the situation. Visiting centres in Sanaa, where thalassaemia and SCD patients are treated in the same clinic, the severe needs for awareness and thirst for knowledge came through. The creation of a national federation of patients was discussed in order to empower the patient community. The over-reliance on foreign aid and inequity in access to treatment were profound as patients are mismanaged with blood inadequacy and absence of monitoring tools all resulting in low life expectancy (<15 years). All these issues were discussed in the course of a meeting with Deputy Minister of Health, who pledged his support towards any actions taken by TIF in Yemen.

In our efforts to support the creation of a strong patients voice in **Germany**, TIF has proceeded to authorize Mr Nicola De Niittis, an empowered patient who has had a long-standing relationship with the Federation for this task. In addition, following information

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



INTERNATIONAL THALASSAEMIA DAY • 08MAY

regarding the unequal access to various specialized services of the healthcare system. More specifically, TIF has contacted the Federal Ministry of Health in Germany concerning the routine monitoring of thalassaemia patients using MRI T2\* technology. Highlighting the importance of the effective and accurate monitoring of iron load in the heart of patients with transfusion dependent thalassaemia, TIF has advocated that it is essential to provide all patients, irrespective of geographical location, access to this technology and its use free of charge.

The WHO Regional Office for South-East Asia organized a **Regional Consultation Meeting** to develop a Regional Strategic Action Plan with Indicators and Targets for Prevention and Control of Non-Communicable Diseases in the South-East Asian Region on 25 - 27 February, in New Delhi, India. TIF Medical Advisor, Dr Michael Angastiniotis, actively participated with a 3-minute statement at this important meeting. This initiative is a landmark for the SEARO region and constitutes a reward for TIF's long-term efforts in the development of an action plan to reduce the public health burden of NCDs.

The next **WHO Global Forum for Blood Safety (GFBS)**, organized by the WHO Blood Transfusion Safety Program in collaboration with the WHO Regional Office for the Americas, the WHO/PAHO Country Office in Brazil and the government, will convene in Sao Paulo, Brazil on 6-8 May 2013. The GFBS aims to foster collaboration, enhance communication & information exchange among key international experts, institutions, organizations and other stakeholders working on blood safety issues. TIF will be represented in this meeting by Mr Riyad Elbard, TIF's Treasurer.

A three-day workshop on the **Emergency Management of Thalassaemia & Sickle Cell Disease** is being organized by TIF in collaboration with the Ministry of Health of Cyprus on 6 – 8 March 2013. The primary goal of this Workshop is to provide updated scientific information to health professionals working in the primary health service on the suitable treatment protocols of patients with haemoglobin disorders.

Approval has been secured for a project regarding the **analysis of clinical data on cardiac and liver complications of  $\beta$ -thalassaemia in Cyprus** by the Commissioner for the Protection on Personal Data and the Bioethics Committee. Work on the project is expected to commence in June 2013. The purpose of the project is to provide a better understanding of the factors which result in cardiac and liver complications in thalassaemia population of Cyprus. Furthermore the study, which is expected to generate the publication of two peer-reviewed articles, will examine treatment responses to chronic hepatitis with conventional management protocols aiming at the use of new drugs for unresponsive cases, particularly those with genotype 1 HCV.

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

Abu Dhabi National Exhibition Centre



Thalassaemia International Federation  
World Congress

Amongst the grandest 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 is the **Ambassador's Circle**. The objective of this prestigious group is to share ideas and knowledge on haematological genetic diseases, which in addition to a significant public health burden, carry immense social and economic repercussions. TIF's aims to highlight 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. TIF is committed to supporting national authorities for further progress and with the support of the members of the Ambassador's Circle to promote protocols for national strategies that secure the provision of quality health care for every patient. Indeed, a first official working meeting has been scheduled for the 20th March 2013.

## TIF Publications

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.

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

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.)



approximately 11 million carriers exist in Pakistan, with an annual rate of 6,000 new patients being born each year . The activities of the Foundation support the patients in four highly populated districts providing blood units, screening services, counseling and medical treatment free of charge.

**Vietnam** Thalassaemia Association (VITA) has published its Annual Report 2012 and projected Action Plan for 2013. Achieving substantial progress in a short time, VITA notes that the knowledge of the wider public on thalassaemia is limited. However, an investigation of the current situation with regards to thalassaemia throughout the country is still underway. Furthermore, the President of the Association, Prof. Nguyen Anh Tri participated actively in the 63rd WHO WPRO Regional Meeting. Plans for this year include the organization of workshops for patients/parents to develop knowledge as well as the development of multi-disciplinary service complete with experts on hepatitis and endocrinology.



"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

December 2012 marked a milestone in the field of **stem cell transplantation** as the world's millionth hematopoietic stem cell transplant was performed. The first transplant was performed in 1957 as an innovative method to treat leukemia. The advancement of medical knowledge since then has resulted in an exponential rise in transplants, totaling nearly 50,000 per year worldwide, treating both malignant and non-malignant diseases. (AABB, 1/2/13)

A new **experimental drug** for the treatment of naïve patients with chronic hepatitis C has successfully achieved its goal in two late-stage trials. Gilead Sciences plans to apply for marketing authorization in the USA this year. (AABB, 5/2/13)

**Acceleron Pharma** has initiated two studies on patients with  $\beta$ -thalassaemia and thalassaemia intermedia. More information at [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

## Regional News

Disappointment over the lack of implementation of the official Order issued by the Minister of Health of **Albania** concerning services offered to patients with thalassaemia in the country due to staff shortages. This Order constituted a giant leap forward for Albania, formally stating that clinical guidelines for treatment must be followed and extending the working hours of thalassaemia centres.

TIF's position paper—'Chronic Hepatitis C in Transfusion Dependent Thalassaemia' — and subsequent meetings with key public health officials in **Bulgaria** have gone a long way to support the hard work of the Thalassaemics Organisation in Bulgaria (TOB) and the medical community, in their efforts to secure better treatment conditions for thalassaemia patients infected hepatitis viruses. These combined efforts have resulted in the development, by the Ministry of Health of Bulgaria, of a specific treatment protocol for the treatment of chronic hepatitis C for transfusion dependent patients, including thalassaemia patients. *Congratulations and we hope this constructive action will bring many positive results!*

A seminar entitled 'Thalassaemia, Awareness and Prevention' was organized by the Rifah Welfare Foundation at the University of Central Punjab Sheikhpura in **Pakistan**. The seminar focused on raising awareness about thalassaemia amongst medical students. Issues covered both the clinical management and prevention of thalassaemia, especially given the fact that

## Delegation Visits & Workshops

**Greece**, 29—30 March, Delegation visit

**Algeria**, 12—17 April, Delegation visit & workshop

**India**, 20—22 April, 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