

TIF Newsletter

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Dear readers,

The New year is rapidly approaching and with it we are beginning to finalize our plans for 2014, which promises to be another great year filled with new projects, and endeavors.

Editorial Team

TIF Activities



The **Cyprus National EUROPLAN Conference** took place on 14-15 November in Nicosia, Cyprus. The conference was co-organised by TIF and the Cyprus Alliance for Rare Disorders (C.A.R.D.) of which TIF is a founding member. EUROPLAN is an EU-funded project which aims to develop national

plans for rare diseases in accordance with the Council Recommendation on an action in the field of rare diseases (2009/C 151/02).

The findings and conclusions of this Conference will contribute significantly to further promote a national strategic plan in Cyprus but also in gathering relevant information and experience at a European level for other countries. The discussions at the conference focused on issues of development indicators to monitor national plans,



the creation of registries, social welfare, and the accreditation and networking of centres of excellence. The workshops were fruitful, giving new life and impetus for the implementation of the national strategy of rare diseases.

The **5th European Symposium on Rare Anaemias and the First National Conference on Thalassaemia, 15-16 November**, was co-organised by TIF, the ENERCA Project, in collaboration with the Italian National Federation for Thalassaemia, Rare Haemoglobinopathies and Sickle Cell Disease (UNITED). Dr Michael Angastiniotis, (TIF Medical Advisor), actively participated in this workshop strongly supporting the urgent need for the development of a registry and specific policies in European Member States for Hb disorders. This conference gave the opportunity to exchange views on the most important scientific advances in the treatment of hemoglobinopathies, covering therapeutic innovations for medical complications and the new iron chelating therapies.

On **18-19 November 2013, a workshop on the prevention and management of Thalassaemia and Genetic Disorders**, in Guangzhou City, Guangdong province, China, was organised by Guangdong and China provincial health authorities in collaboration with TIF and was hosted by the NHFPC. The workshop aimed at the incorporation and strengthening of prevention programmes for Hb disorders in the context of China's own genetic and birth defects programmes, with a specific emphasis in the Southern part of the country where haemoglobinopathies are most prevalent. Dr Androulla Eleftheriou (TIF Executive Director) and Dr Michael Angastiniotis (TIF Medical Advisor) attended this workshop on behalf of TIF and were joined by representatives of the Central Government

and Provincial officials as well as leading academics and representatives of the WHO. These efforts have culminated in the **signing of a Memorandum of Understanding** in China between Chinese Central Government, state officials and TIF for the promotion of Prevention and Control policies in Southern China.

The "Indian project" is one of the biggest and most ambitious ever undertaken by TIF, in a very large and populous country exhibiting a high frequency and great heterogeneity in the genotype/phenotype character of haemoglobinopathies, a pattern repeated across the sub-continent. As part of this project and following two delegation visits and one workshop this year, TIF will continue its efforts with the organisation of **the 2nd Capacity Building Workshop in India New Delhi, India, 17-18 December**. This workshop will cover Delhi, Punjab, Haryana, Uttar Pradesh, Maharashtra, Gujarat and Madhya Pradesh.

The **2nd Pan-South China Workshop**, organised by TIF, has been scheduled to take place on 10-12 January 2014. This workshop will focus on the specific needs and challenges China faces regarding the management of Hb disorders, in particular Thalassaemia, thus taking forward the previous work done in China. The objective is to support in as many ways possible patients with Hb diseases in the southern provinces of China where β - and α -Thalassaemia syndromes are most prevalent. China has made great advances in recent years and is now entering a critical phase, during which, the integration of national policies on haemoglobin disorders needs to be prioritised and further integrated into other policies and programmes.

Afghanistan has been a high priority on TIF's agenda for many years now, as the need to spread awareness about Thalassaemia and Haemoglobinopathies and promote knowledge on these disorders has become an absolute necessity to the patient and medical community of the country. In this context, TIF and the Charity Foundation for Special Diseases (CFFSD), Iran, presided by Mrs Fatemeh Hashemi, a TIF Board Member, in collaboration with Prof. Mehran Karimi, an esteemed collaborator in Iran, are co-organising an **Educational Thalassaemia Symposium for the training of Afghani medical specialists in Shiraz**, (Iran), on 5-6 February 2014. Iran is a neighbouring country with much expertise with a highly successful prevention and management program. The exchange of knowledge and best practice as well as networking is imperative for the successful outcome of this symposium.



NEW ISSUE OF TIF MAGAZINE!
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TIF Publications

OUT NOW!!!!

TIF's Guidelines for the Management of Thalassaemia (2nd Edition—2008) has been accepted for online publication at the National Library of Medicine (NLM) of the National Institute for Health (NIH) in the USA. The publication is expected to be launched online on 2nd December, 2013.



TIF has also submitted several other publications for approval to the NLM Therapeutic and Research Centre

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...Expected in 2013-2014...

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,

Regional News

Following TIF's excellent work in **India** during the course of 2013, we are proud to announce that as a consequence to the efforts exerted by all stakeholders including TIF, the government of Madhya Pradesh has adopted two new policies on (1) the abolishment of replacement blood donors and (2) the availability of *Desferal* free of charge at government hospitals. The availability and accessibility of free blood and quality treatment for all thalassaemia and sickle cell disease patients reflects the hard work, dedication and devotion of all involved stakeholders. Congratulations!



The launch of the **Chinese Rare Disease Research Consortium** (CRDRC) was formally announced during the 1st Chinese Rare Disease Symposium, in 14 September 2013. It is presided by Prof. Paul Lasko, the President of the International Rare

Disease Research Consortium (IRDIRC), and Prof. Penggen Li, the President of Huazhong University of Science & Technology (HUST). CRDRC, has been accepted as a member of IRDiRC and aims to team up with several other researchers and organisations investing in rare disease research in China.



The **Directive on Cross-Border Healthcare (2011/24/EU) strengthened and further developed** the right to European citizens, to choose where to receive medical treatment across the EU, and to be reimbursed for it, no matter where they live. This law entered into force in on 25 October 2013.

This Directive introduces three major changes focusing on patients' rights: Firstly, citizens have the right to choose and be reimbursed for treatment, either public health care or private health care, anywhere in the EU. Secondly, prior authorisations for cross-border healthcare will become the exception rather than the rule. Finally, citizens have the right to make informed decisions about treatment options.

The new law clarifies patients' rights to access safe and good quality treatment across EU borders, and be reimbursed for it. Patients travelling to another EU country for medical care will enjoy equal treatment with citizens of

the country in which they are treated. This new law will make it easier for patients to access information on healthcare in another EU country, and thus increase their treatment options.

Read more on our website!

Patient Blood Management Awareness Week (4-8 November) provided an opportunity for both patients and providers around the world to become more educated on patient blood management -- an evidence-based, multidisciplinary approach to optimizing the care of individuals who might need a transfusion.

The National Institute for Health and Care Excellence (UK) has released draft **Standards for the Care and Management of inpatients with sickle cell crises**. The document provides guidance to nurses and health professionals regarding the appropriate treatment of pain management in Sickle Cell Disease Patients. To read the standards, click [here](#).



Therapeutic & Research Centre

Scientists at the University of Glasgow (Scotland) are using **stem cells in a bid to end blood shortages**. [Read more here](#).

Dynavax Technologies Corp. plans to launch a 8000-person late-stage trial of a **Heplisav hepatitis B vaccine** early in 2014 in order to support the license application with the FDA. (AABB 7/10/2013)

Merck & Co.'s experimental **hepatitis C combination drug** has obtained "breakthrough therapy" designation from the FDA. (AABB 25/10/2013)

An FDA advisory panel has unanimously endorsed the approval of **sofosbuvir (Gilead)** for treatment of patients with genotypes 2 and 3 Hepatitis C and those with previously untreated genotype 1 and 4. (AABB 28/10/2013)

The **Middle East respiratory syndrome coronavirus has** reached Spain while two new cases were also reported in Saudi Arabia. The syndrome usually infects in the lungs with symptoms being similar to the common

Delegation Visits & Workshops

India, 17 –18 December, Delegation visit & workshop

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

See our next issue for delegation visits that are to take place in 2014!