



Dear friends,

We would like to take this opportunity to send wish you happiness, peace, prosperity and a happy and fulfilling year ahead. This has been another productive year and we look forward to 2014!!

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TIF AROUND THE WORLD

The **Annual Pan-Hellenic Informational Event for Thalassaemia** was successfully organised by the Greek Thalassaemia Federation, under the auspices of TIF, on 29 – 30 November 2013 in Athens and was attended by TIF President, Mr Panos Englezos, and TIF Executive Director, Dr Androulla Eleftheriou. An interactive round-table discussion concerning European Policies for Haemoglobinopathies was coordinated jointly by Dr Eleftheriou and the General Secretary of the Greek Thalassaemia Federation, Mr Vassileios Dimos. In this context, the EU Policy Report on Migration entitled "Haemoglobinopathies on the Move: Is Europe ready? A policy analysis of 10 European countries" was presented. This report was 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 on Migration.

The **2nd Capacity Building Workshop** has successfully taken place in New Delhi, India, on 17-18 December 2013. This workshop covered the States of Delhi, Punjab, Haryana, and Uttar Pradesh, and revisited the States of Maharashtra, Gujarat and Madhya Pradesh, with the objective to create a State Charter of Priorities' for each state. This tool will enable patient/ parent associations to advocate and lobby States governments more effectively with a view to instigating the development of appropriate policies, as well as improving existing ones, for addressing the problem of Haemoglobin Disorders in a holistic manner. This, by extent, will improve the quality of life of patients in India.

Stemming from a parallel workshop organised by TIF in collaboration with 13 other associations representing patients with haematological disorders, during the **18th Annual European Haematology Association Congress**, a new umbrella organisation encompassing patient associations with haematological disorders, malignant and non-malignant is now in the pipeline. The founding of HOPE (Haematologic Organisation of Patients in Europe) has been welcomed by all stakeholders, including TIF. This new initiative, aims to bring together European umbrella organizations which represent patients with haematological diseases, in order to advocate on a European level, with a unified voice, where cross-cutting issues are concerned. Already 15 organizations have expressed interest in joining this new forum.

A stakeholder meeting during ASH 2013 has resulted in moving forward with a situation analysis and a common plan of action.

TIF has welcomed this new forum as a platform to further strengthen the voice of patients with thalassaemia and sickle cell disease to the European medical community, and to the EU governing bodies, including the European Parliament and Commission.

Afghanistan has been on TIF's agenda for many years now, as the need to spread awareness about Thalassaemia and Haemoglobinopathies and to promote knowledge on these disorders has become an absolute necessity to the patient and medical community of the country. In this context, Prof. Mehran Karimi, TIF medical advisor in Iran and Professor of the Paediatric Haematology-Oncology Department at the Haematology Research Centre of Namazi Hospital at the Shiraz University of Medical Sciences, supported by Mrs Fatemeh Hashemi, Chair Person of the Charity Foundation for Special Diseases (CFFSD), will organise an Educational Thalassaemia Symposium for the training of Afghani medical specialists in Shiraz, Iran, on 5-6 February 2014. TIF has been invited to attend and contribute to this Symposium. Iran is a neighbouring country to Afghanistan with much expertise and 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.

4th Pan-European Conference,
Athens, September 2014

2nd Pan-Asian Conference,
Location TBC*, March 2015

2nd Pan-Middle East Conference
Location TBC*, September 2015

* to be confirmed

The **2nd Pan-South China Workshop**, organised by TIF is scheduled to take place on 10-11 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 as 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 promoted into other relevant policies and programmes of the Government and Health Authorities of this vast country. We are confident that TIF's ongoing efforts to that end will make a considerable impact in the future.





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TIF PUBLICATIONS

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 was successfully launched online on 2nd December 2013 and is available at <http://www.ncbi.nlm.nih.gov/books/NBK173968/>



TIF has also submitted the following publications for approval to the NLM Therapeutic and Research Centre, expecting a response in early 2014:

- Prevention of Thalassaemias & Other Haemoglobinopathies, Vol. 1: Principles, 2nd Edition, 2013. (*Old, J., Angastiniotis, M., Eleftheriou, A., Galanello, R., Harteveld, C.L., Petrou, M., & Traeger-Synodinos, J.*)
- Prevention of Thalassaemias and Other Haemoglobin Disorders, Vol. 2: Laboratory Protocols, 2nd Edition, 2012. (*Old J, Harteveld C L, Traeger-Synodinos J, Petrou M, Angastiniotis M, Galanello R.*)
- Guidelines for the Management of Non Transfusion Dependent Thalassaemia (NTDT), 2013. (*Taher, A., Vichinsky, E., Musallam, K., Cappellini, M.D., Viprakasit, V.*)
- Emergency Management of Thalassaemia, 2012. (*Porter J, Taher A, Mufarrij A, Gavalas M.*)

REGIONAL NEWS

The "Lanka Thalassaemia Circle", affiliated to TIF and comprising of around 3000 Thalassaemia patients and parents from across Sri Lanka, has sent cheek swabs taken from Thalassaemic children and their siblings to a Genetic Laboratory in New York, USA, for HLA molecular testing. The fourth assembly for the sending of 100 cheek swabs from children in Colombo was held on the 16th December. The highlight of the day was the participation of Mrs Shirathi Rajapakse, the First Lady of Sri Lanka, in taking cheek swabs from these children.



The 2nd December 2013 was marked by the auspicious 42nd UAE National Day, and Emirates Thalassaemia Society (ETS) has celebrated this special day with Thalassaemia patients, doctors, and medical staff in hospitals all over UAE. Emirates Thalassaemia Society organized a fun filled & colorful workshop for arts & crafts which included an UAE themed pattern art, mirror drawing, and T-Shirt painting, nail art, and traditional competitions. Thalassaemia patients, doctors, nurses, & families participated actively & expressed their desire to hold the workshop on a yearly basis.



Members of the rare disease community will be gathering in Berlin, Germany, on 8-10 May 2014 for the European Conference on Rare Diseases & Orphan Products (ECRD 2014 Berlin). Europe is taking a leading role in fuelling the movement, serving as a model as more Member States adopt their national rare disease strategies and a new EU research funding era begins with the upcoming Horizon 2020 programme.

The Lithuanian Health Forum 2013 entitled "Sustainable Health Systems for Inclusive Growth in Europe" was co-organised by EPHA, the Lithuanian Ministry of Education and Science, the Lithuanian Ministry of Foreign Affairs, the Ministry of Health of the Republic of Lithuania, the European Federation of Pharmaceutical Industries and Associations, and the European Patients Forum on November 19-20 (Vilnius, Lithuania). The main aim of this Conference, which was held under the auspices of the Lithuanian Presidency of the Council of the European Union, was to identify existing evidence on fostering the development of sustainable health systems throughout the entire Europe.

Patients' organizations gathered at IAPO's first multi-stakeholder seminar held in South-East Asia on 17 December 2013. The seminar entitled, 'Meeting patients' needs in South-East Asia – effective strategies for tackling NCDs and improving patient safety', explored relevant issues in healthcare systems and patients' needs from around the region. The seminar brought together patient group representatives, policy-makers, healthcare professionals, civil society and industry representatives from India, Sri Lanka and Thailand. Two key healthcare issues were discussed, namely non-communicable diseases (NCDs) and patient safety

RESEARCH & THERAPEUTIC NEWS

New Acceleron Pharma Inc. announced that its partner Celgene reported new interim data at the 55th American Society of Hematology (ASH) Annual Meeting of sotatercept in patients with beta-thalassaemia. Interim data presented from the ongoing phase 2 trial demonstrate dose dependent increases in hemoglobin in non-transfusion dependent beta-thalassaemia patients (Acceleron 09/12/2013).

Bluebird bio Announces First Patient Transplanted in Phase 1/2 HGB-205 Study for the Treatment of Beta-Thalassaemia and Sickle Cell Anaemia (CAF 02/12/2013)

A late-stage trial showed AbbVie's all-oral hepatitis C regimen cured 96% of patients with genotype 1 virus after only 12 weeks of therapy. (AABB 10/12/2013)

An expert panel has advised the World Health Organization to conduct further studies to monitor the ongoing outbreak of Middle East respiratory syndrome, which has resulted in 163 confirmed cases, including 72 deaths (AABB 05/12/2013).

The FDA has approved Gilead Sciences' Sovaldi, or sofosbuvir, as a once-daily treatment for chronic hepatitis C (AABB 08/12/2013)

DELEGATION VISITS

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