

Dear friends,

Packed with activities, this first TIF Newsletter of 2013, provides a glimpse to the multi-faceted nature of TIF's work and the multitude of projects currently underway.

Happy reading!!!

Editorial Team

TIF Activities

The **European Liver Patients Association (ELPA) Advisory Committee Meeting**, held on 14—16 December 2012 was attended by TIF Board Member, Dr Duru Malyali. This Meeting provided an opportunity for TIF to strengthen its relations with ELPA. The vibrant discussion of participants on issues concerning the prevention and treatment of hepatitis C and B offered a unique platform for the exchange of knowledge, experience and expertise by patients from across the world.

Commencing at the end of 2012 and continuing dynamically into the New Year, TIF has began a productive partnership with the **Association of South East Asian Nations (ASEAN)**, urging Senior Officials to place the issue of haemoglobin disorders on the agenda of the meeting on Health Development.

Closer collaboration with the **WHO Headquarters, Regional and Country Offices** has been initiated with the onset of 2013. Focusing on the implementation of the WHO resolutions EB118.R1 on thalassaemia & other haemoglobinopathies, and WHA59.R20 on sickle cell anaemia, adopted in 2006, TIF is investigating the extent of their implementation across 'affected' countries. Working with the WHO, TIF aims to urge member states to implement national strategies for the prevention and management of haemoglobin disorders.

INTERNATIONAL THALASSAEMIA DAY

8th May

"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

Acknowledging the eerie silence from patient associations and health professionals in **Germany**, TIF has undertaken an assessment of the current situation in the country. The report, submitted by an empowered patient, demonstrates that still there is need for further improvements in the spread of awareness, knowledge and education in the medical but also the patient community across the country. As this Newsletter is being compiled news from a medical collaborator of TIF has raised our hopes and expectations for further improvements in this country, which hosts a few million individuals from countries of high Haemoglobinopathy prevalence.

During an official visit to **Greece** on 20 January 2013, on the occasion of the Greek Thalassaemia Federation's General Assembly, TIF President, Mr Panos Englezos and TIF Executive Director, Dr Androulla Eleftheriou met with patients and parents from across Greece. Congratulations were given to the new Board on behalf of TIF and warm wishes for a successful term. Following the receipt of an official invitation, a formal meeting was held with the President of the Panhellenic Association for the Protection of Thalassaemia Patients, Mr Costas Papageorgiou, who introduced to TIF their initiative of creating network of patient-doctors from across the country. This has served as a stepping stone igniting a stronger

relationship with the Association, whom TIF congratulated on their commitment and new endeavor. In addition, the distribution of the soon-to-be-finalized translated guidelines on the management of Sickle Cell Disease were discussed during a meeting with 'KINISI' Patient Association.

An official TIF delegation visit to **Bulgaria** was conducted on 22 January 2013. TIF Board Member, Mr Ivan Ivanov and TIF Medical Advisor, Dr Michael Angastioniotis along with a team of esteemed health professionals and leading experts met with Deputy Minister for International Relations and Finance, Ms Desisuava Dimitrova, where issues concerning multi-disciplinary care, patients registry and the implementation of a national rare disease plan that includes haemoglobin disorders were discussed. Bulgaria constitutes a country-model for its huge advances in recent years for the promotion of Haemoglobinopathy programmes.

The newly appointed Director of the **Regional Collaborating Office**, Dr Essam Dohair and the Head of Operation of the Regional Collaborating Office, Dr Mohammed Naveed, visited TIF Headquarters in late January 2013 to finalize a joint plan of action. Indeed an investigatory delegation visit/tour of **Kuwait, Qatar & Oman** has been scheduled for September 2013 in the course of which meetings with the Ministry of Health, doctors, thalassaemia centres and patient associations will be conducted. Members of the Regional Office will of course accompany the TIF Delegation. Additionally, members of the Regional Office will also accompany TIF on a follow-up delegation visit to **Morocco**, scheduled for May 2013 to meet with the Ministry of Health, patient associations and health professionals. This delegation will be led by Her Highness Sheikha Sheikha Bint Saif Al Nahyan and TIF President.

The development of a Gulf-region **Thalassaemia Patient Registry**, administered by the Regional Collaborating Office is well underway. Beginning with phase I collection of data (i.e. demographic information) in the United Arab Emirates, the registry will expand throughout the Gulf region, with the ultimate vision to unite all thalassaemia registries of the constituent states. Plans have been made with the Regional Office to integrate, upon completion, the data in an online database developed by TIF in the context of the **e-ENERCA** project. The e-ENERCA project, of which TIF is the leader of the Work Package on European epidemiological surveillance for major rare anaemias, aims to develop a centralized online registry for patients with haemoglobin disorders.

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 March 2013.

20th – 23rd October 2013

Abu Dhabi National Exhibition Centre



Thalassaemia International Federation
World Congress

TIF has embarked on an ambitious quest to develop a [database of Haemoglobinopathy reference centres](#) throughout the world, investigating the services they provide. Furthermore, the investigation will also examine methods or protocols of treatment, and blood safety currently in practice. Expected to commence in February 2013, the survey will be distributed to WHO Collaborating Centres and Reference Centres across the 60 countries in which TIF members are located. The survey, will be open for three months thus chronologically placing analysis and publication in autumn 2013. TIF aims to compile the most comprehensive database of Haemoglobinopathy reference centres with the ultimate objective of supporting their improvement and networking according to ENERCA objectives and EUCERD recommendations.

TIF has been involved in the [Patient Advocacy Group of EHA](#) since its formation in 2010 and has had a fundamental role in previous patient advocacy sessions and this is likely to continue with our participation at the 18th EHA Congress in Stockholm in June.

The Council of Ministers of the Republic of Cyprus in January 2013 has officially announced the creation of the [National Committee on Rare Diseases](#), in which the patient voice is represented by TIF through its Executive Director, Dr Androulla Eleftheriou.

TIF Publications

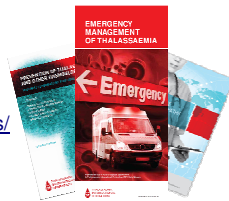
TIF's scientific paper '[The Impact of Migration on the Health Services for Rare Diseases in Europe: The example of Haemoglobin Disorders](#)' (Angastiniotis, M., Vives Corrons, J.L., Soteriades, E.S., Eleftheriou, A.) has been submitted and accepted for publication in The Scientific World Journal. See it [here](#)

The journal, Acta Haematologica, has accepted TIF's scientific article '[Cross-talk between available guidelines for the management of patients with \$\beta\$ -thalassaemia major](#)' (Musallam, K.M., Angastiniotis, M., Eleftheriou, A., & Porter, J. B.) for publication.

Phase III of the ENERCA project (2009-2012) has culminated in the preparation of the [White Book on the creation of Expert Reference Networks for Rare Anaemias](#), expected soon for publication. TIF has been a leading author in this, having previously led the work package on Education & Training.

DOWNLOAD OUR PUBLICATIONS

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



Regional News

Breaking news has reached us regarding the implementation of an official Order issued by the Ministry of Health of [Albania](#), concerning services offered to patients in the country. Read the Order [here](#)

The [132nd WHO Executive Board Meeting](#) has taken place on 21–29 January 2013 in Geneva. High on the agenda were the topics of the WHO Reform and the [Global Monitoring Framework on NCDs](#). Some progress was achieved in defining an action plan on NCDs however, the lack of resources for the implementation by member states remains a serious concern. Resolution EB130.R7 was formally adopted, outlining the process for implementing the global monitoring framework, including targets, indicators and partnerships stated in the UN Political Declaration on NCDs of September 2011. On behalf of its member associations, including TIF, the International Alliance of Patients' Organizations (IAPO) via an intervention made by Jo Groves. IAPO CEO, urged the WHO to better define the role of patients' organizations in the implementation of the action plan for the prevention and control of NCDs (2013-2020). Indeed the potential of civil society and patients' organizations is not adequately explored in the action plan, thus undermining their contribution to society. Moreover, regarding the [WHO Reform](#), IAPO welcomed the further formalization of the active engagement of NGOs in the reform process.

The [work programme of the trio Presidency \(2013-14\)](#) of the Council of the EU, undertaken by Ireland, Lithuania and Greece, has been officially announced. In Health and Consumer Affairs, the three Presidencies will further elaborate on the ongoing 'reflection process' to create modern responsive and sustainable health systems. Furthermore, the proposal for a Directive on the transparency of measures regulating the prices of

pharmaceutical medicinal products and their inclusion in public health insurance systems will also be promoted and the proposal for a Regulation on clinical trials (adopted in 2012) will be finalized during this work programme.

EUPATI, the [European Patients Academy on Therapeutic Innovation](#), has concluded its first year with excellent progress. The project infrastructure has been established and work in all packages has begun. Furthermore, rules on finances, governance and ethics have been defined and agreed by all consortium members, who range from 14 countries. The [EUPATI website](#) has also been launched, providing key information to interested parties.

Therapeutic & Research Centre

A report on [Hemoglobin Sickle Cell Disease in Brazil](#) has been published outlining the importance of neonatal screening for early diagnosis as well as noting numerous co-morbidities in patients. The authors in fact conclude that specific guidelines for the clinical management of haemoglobin sickle cell disease are a necessity. Cabañas-Pedro, A., Braga, J., Camilo-Araújo, R., Silva, R.M., Vicari, P., & Figueiredo, M. (*Haematologica*, January 1, 2013; 98 (1))

The research article '[Towards optimizing the use of deferasirox: potential benefits of combined use with deferoxamine](#)' has shown that supplementing the daily use of deferasirox with 2-3 days of deferoxamine would provide a convenient way to tailor chelation therapy to the individual needs of each patient. Grady, R.W., Galanello, R., Randolph, R.E., Kleinert, D.A., Dessi, C., & Giardina, P. (*Haematologica*, January 1, 2013; 98 (1))

Inovio Pharmaceuticals Inc. has announced that it plans to begin human testing of its [hepatitis C DNA vaccine](#) by the end of the year. (*AABB*, 10/1/13)

[Studies](#) published in the New England Journal of Medicine have stated that experimental treatments for the hepatitis C virus could eliminate the need for interferon therapy in previously untreated patients. (*AABB*, 04/1/13)

Delegation Visits & Workshops

Bahrain, 5-7 February, The International Conference on sickle Cell Disease – Management & Prevention

Lebanon, February, Meeting with Syrian health professionals and patient associations

India, April, Delegation visit & workshop

Yemen, April, Delegation visit

Algeria, 13–19 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, June, Delegation visit & workshop

Philippines, 8-11 September, 43rd Philippine Society of Haematology and Blood Transfusion Annual Convention

Vietnam, October, Delegation visit

Tunisia, December, Delegation visit

China, December, Delegation visit & workshop

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