

TIF Newsletter

April 2013

Volume 5., Issue 1

Dear friends,

The role of patient organizations becomes more important in times of global economic and political turmoil as we focus on patients rights for access to quality treatment.

Editorial Team

TIF Activities

2013 Theme:

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

INTERNATIONAL THALASSAEMIA DAY • 08MAY



The **International Thalassaemia Day**, celebrated every year on the 8th of May since 1994, is almost upon us!!!

Each year on this Day we remember and pay respect to all those patients, parents and families who have fought towards a better future for patients with thalassaemia and who are unfortunately no longer with us but indeed have left to the world an immense and invaluable history of altruism, passion and commitment and have paved the way for all of us to continue.

In 2013, under severe economic austerities affecting many countries around the world, it is our responsibility and duty as patients organisations, while continuing the fight for adequately managing β -thalassaemia major, to focus on improving the health and lives of our friends with other forms of haemoglobin disorders.

Unless we, ourselves, become knowledgeable and true ambassadors of these advances, these conditions will continue to remain under-recognised and under-estimated.



Visit the **International Thalassaemia Day** [webpage](http://www.thalassaemia.org.cy/international-thalassaemia-day/) at

<http://www.thalassaemia.org.cy/international-thalassaemia-day/>

Join our efforts and advocate to ensure

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

- Read **TIF's Message** in 7 languages

- **Download** the logo, poster and video

- Be inspired by our **postage stamp**

- Find us on **Facebook**

<https://www.facebook.com/events/525140160860495/>

- Read the message of **EU Commissioner on Health & Consumers**, Mr Tonio Borg on the 8th May (http://ec.europa.eu/commission_2010-2014/borg/)

Red Day

TIF initiated in 2013, in the context of the International Thalassaemia Day, Project 8. Aiming to diffuse knowledge and expertise regarding haemoglobinopathies, to all social levels, particularly amongst young people, TIF has taken steps to establish 'Red Day' as part of Project 8 in schools in Cyprus. Taking place on 09 April with over 150 students aged 10—12 years old actively involved, the children wore red T-shirts and were informed about thalassaemia in the context of their

Thalassaemia International Federation
World Congress13th International Conference
On Thalassaemia & Hemoglobinopathies
15th TIF International Conference
For Parents & Patients20th - 23rd October 2013
Abu Dhabi National Exhibition Centre

TIF's Patients Sponsorship Program is available on our website

Last Application date: 15 May 2013

A series of workshops with international medical and patient experts was organised by TIF in **Algeria** on 14 -16 April. The workshops aimed to educate health professionals on the state-of-the-art medical care for on thalassaemia and sickle cell disease whilst the afternoon sessions were dedicated to the education and empowerment of patients/parents. The workshops were attended with the active participation of more than 100 medical experts, policy makers and patients/parents. Professor Dimitris Loukopoulou, Emeritus Professor of Haematology (Greece) represented TIF during the workshops as well as took part in an official meeting with the Ministry of Health where the development of a joint plan of action for a national prevention and control programme was discussed.

The **International Liver Congress** took place on 24—28 April in Amsterdam and was attended by an official TIF delegation. The Congress, organised annually by the European Association for the Study of Liver (EASL) provides a unique platform for specialists to debate, discuss and analyse the latest developments in the clinical management of liver diseases. Mr George Constantinou (TIF Board Member) and Ms Lily Cannon (TIF European Affairs Officer) met with the Secretary General of EASL, Professor Mark Thursz and Vice-Secretary General, Professor Markus Peck-Radosavljevic to discuss future avenues of collaboration between TIF and EASL. Mr Ivan Ivanov (TIF Board Member), an passionate advocate for the treatment of transfusion dependent patients with chronic hepatitis C in Bulgaria, also attended the Congress.

After several visits to **Morocco**, an official high-level follow-up visit by a TIF delegation is planned for the 12th May. This is to ensure the effective implementation of the national thalassaemia policy that was recently put forward, and also in accordance with the officially co-signed joint plan of action between TIF and the then (2011) Minister of Health. The delegation will visit in collaboration with the TIF Regional Collaborating Office in Abu Dhabi. Her Highness Sheikha Sheikha Bint Saif Al Nahyan will lead this high-level official delegation, which is organised in cooperation with the TIF's Regional Collaborating Office in Abu Dhabi.

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 Thalasseemics India.

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.

TIF Executive Director, Dr Androulla Eleftheriou, participated in an intense **Patient Advocacy Course** at Harvard University in Boston on 21—26 April. The course brought together the elite patient advocates from all fields who with their knowledge and experiences have brought immense success to their respective areas. Taught by professional advocates from the University, the course sought to build capacity and further train advocates. This is a beginning of a new era for TIF for promoting capacity building both with the Federation and by extent to its member associations.

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 α -thalassaemia, β -thalassaemia & Sickle Cell Disease (Greek). (Eleftheriou, A.)

Regional News

Congratulations!!

Dr Constantina Politis, Professor of Haematology at the University of Athens, Head Coordinator of the Haemovigilance Centre and Chairman of the Advisory Committee of the National Blood Bank, has received an award for outstanding and ongoing commitment to the field of haemovigilance, safety and quality of blood from the International Haemovigilance Network in February 2013.

Dr Politis has been a distinguished Member of TIF's scientific advisory Board for many years and her contribution to the field of blood safety and haemovigilance is exemplary and distinguished.



Medical advances in treatment have extended the lives of patients with thalassaemia—previously thought of as a fatal paediatric disorder. This was the impetus for the organisation of a one day workshop on 28 February in Tehran, Iran by the Charity Foundation for Special Diseases, presided by Mrs Fatemeh Hashemi (TIF Board Member). The focus of the workshop was the management of legal, social and welfare issues faced by thalassaemia patients. The workshop concluded that patients are entitled to equal opportunities in areas of education, social and employment. This should be on the priority agenda for health policy makers to ensure patients enjoy a high quality of life with the ability to fulfil all their aspirations.



The Vietnam Thalassaemia Association, in the context of their activities for the International Thalassaemia Day are organising various workshops on the prevention and management of thalassaemia in Hanoi on 3–4 May. There will be dedicated sessions for health professionals as well as others for patients/parents. Efforts to raise awareness about thalassaemia and haemoglobin disorders in Vietnam will be highlighted during a press conference that is expected to gather over 400 participants. TIF will be represented by Professor Suthat Fucharoen (Professor of Haematology, Mahidol University, Thailand) who will also meet with officials from the National Transfusion Centre.

The 14th International Thalassaemia Day Conference is organised by the Egyptian Thalassaemia Association on 8–9 May at the Nile Tower Hotel. Dedicated sessions for patients/parents and health professionals will take place. The Association is offering TIF members a discounted registration fee of 100USD and facilitation for visa purposes. Please contact Professor Amal El-Beshlawy (amalebeshlawy@yahoo.com) for further information.

The Thalassaemia Society of New South Wales is organising a fundraising cocktail on the occasion of the International Thalassaemia Day on 8 May in Sydney (Australia). More information at www.thalnsw.org.au

EPPOSI has published a White Paper entitled 'Building a Workable Model for the Holistic Management of Chronic Conditions in Europe'. This paper represents the contributions and consensus of 49 organisations representing patient organisations, including TIF, health professionals, academics, industry and policy makers. The paper sets out key recommendations for the development of a framework for the holistic management of chronic conditions in Europe—taking into account medical, socio-economic and technological issues. Read the Executive Summary http://epposi.org/images/stories/white_paper_executive_summary.pdf

Therapeutic & Research Centre

Orphan designation has been granted by the FDA for Acceleron Pharma's experimental β -thalassaemia treatment ACE-536. This is an investigational protein therapeutic that increases red blood cells through a novel mechanism, developed by Acceleron as part of a global collaboration with Celgene (AABB, 27/03/2013)

Bristol-Myers Squibb and Vertex Pharmaceuticals have announced their collaboration for Phase II studies of a once-daily combination therapy hepatitis C (AABB, 09/04/2013)

Merck & Co. granted Hawaii Biotech rights to a group of patents involving West Nile virus vaccine technology and a nonexclusive license for associated technologies. The deal will allow Hawaii Biotech to continue work on its West Nile virus vaccine (AABB, 12/04/2013)

Janssen has filed for FDA approval for the use of Simeprevir in combination with pegylated interferon and ribavirin to treat genotype 1 chronic hepatitis C in adults (AABB, 02/04/2013)

The New England Journal of Medicine has published findings of a new drug for hepatitis C that attacks RNA which allows the virus to hide from the immune system. The drug, miravirsin, targets the body's microRNA-122, preventing viral replication (AABB, 29/03/2013)

An international team of researchers says the discovery of two genetic mutations has yielded the possibility of new ways to treat β -thalassaemia. Blocking the macrophages that attach to erythroblasts could reduce red blood cell production, and changing the Tmprss6 gene could halt the body's use of iron. The findings were published in Nature Medicine and the Journal of Clinical Investigation. Professor Stefano Rivella has stated that up to approximately 30 – 40% of β -thalassaemia patients could benefit from this treatment strategy. (AABB, 27/03/2013)

Delegation Visits & Workshops

India, 18– 19 May, Delegation visit & workshop

Morocco, 12 May, Delegation visit

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

Afghanistan, July, Delegation visit

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

India, September, Delegation visit & workshop

Oman, September, Delegation visit

Kuwait, September, Delegation visit

Tunisia, December, Delegation visit

China, December, Delegation visit & workshop

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