

TIF Newsletter

May 2013

Volume 6. , Issue 1

Dear friends,

This issue is dedicated to a remarkable scientist, dearest friend and long-term collaborator, Professor Renzo Galanello, whose untimely departure has shocked the thalassaemia family to its core.

Editorial Team

TIF Activities

2013 Theme:

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

INTERNATIONAL THALASSAEMIA DAY • 08MAY



Every year, since 1994, on the 8th of May TIF honours the **International Thalassaemia Day**, in the memory of all those patients, parents and families who have fought towards a better future for thalassaemia patients. Even though they are no longer with us, they 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.

A press conference was organized on the 8th of May by TIF in Nicosia, where TIF's Headquarters are based, spreading the message *"It is responsibility of all of us to secure the rights of patients with chronic diseases, even in times of economic crisis"*.

The Mayor of Nicosia, Mr Konstantinos Yioratzis, actively participated in the proceedings, that included an impressive art exhibition of Dr. Michalis Psiloinis (former Head of Limassol Thalassaemia Centre). In conjunction with the press conference and in collaboration with the Cyprus Blood Centre, four blood drives were organised across Nicosia.



Extensive articles regarding activities from around the world on the International Thalassaemia Day will be in the next issue of

TIF Magazine

Submit your articles at
thalassaemia-mp@thalassaemia.org.cy
using the subject title 'TIF Magazine'

- **TIF's Message** was translated into 8 languages
- **Campaign kit** disseminated including a logo, poster and video
- A specially designed **postage stamp** was distributed
- Dedicated **Facebook** page was created at: <https://www.facebook.com/events/525140160860495/>
- Message by **EU Commissioner on Health & Consumers**, Mr Tonio Borg was published 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 science lesson. The highlight of the Day of course was the formation of the '8' shape, as seen in the photo.

Thalassaemia International Federation
World Congress

Mr Riyad Elbard (TIF Treasurer) actively participated in the **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, held in Brazil on 6-10 May 2013. The forum brought together representatives from developed and developing countries, members of WHO Expert Advisory Panel on Transfusion Medicine, WHO Collaborating Centres, key international organizations and WHO professional staff from headquarters and six WHO regional offices. A total of 250 participants participated in the GFBS which aims to foster collaboration, enhance communication & information exchange among key international experts, institutions, organizations and other stakeholders working on blood safety issues.

After several delegation visits to **Morocco**, an official high level follow-up visit took place on 11-12 May 2013. The purpose of the visit was to ensure the effective implementation of the national thalassaemia policy in accordance with the officially co-signed joint plan of action between TIF and the then (2011) Minister of Health. The TIF delegation team was led by H.H. Sheikh Sheikh Bint Saif Al Nahyan (TIF Board Member) and TIF President, Mr Panos Englezos, and Dr Androulla Eleftheriou (TIF Executive Director) who were received by Princess Lalla Salma of Morocco. This delegation visit was organized in collaboration with the TIF Regional Collaborating Office in Abu Dhabi.

**World Blood Donor Day**
Give the gift of life: donate blood 14 JUNE 2013

A series of delegation visits and workshops have been scheduled for 2013 in **India**. The first of these took place on 18 – 19 May in the form of a Capacity Building Workshop for patients/parents across the three states of Maharashtra, Gujarat and Madhya Pradesh attended by approximately 70 participants. Dr Androulla Eleftheriou (TIF Executive Director) and Dr Michael Angastiniotis (TIF Medical Advisor) represented TIF at the workshop which aimed at improving and supporting national and state efforts for better control of thalassaemia and sickle cell disease country-wise. Patients/Parents exchanged experiences and created networks of collaboration as well as formed new friendships. Mrs Shobha Tuli (TIF's Vice President), and a large number of collaborators in the medical and patients community of India greatly supported this initiative. In an official statement Dr Eleftheriou has said that the workshop 'has been a productive and challenging experience with the conclusions, outcomes and ways to move forward in the context of the road map to be drafted soon.'



In the context of the **EU Policy Report on Migration**, which TIF is preparing in collaboration with ENERCA, several successful meetings with Members of the European Parliament were conducted on 28 May 2013. Dr Androulla Eleftheriou (TIF Executive Director) and Dr Michael Angastiniotis (TIF Medical Advisor) met with Mrs Eleni Theodorou (Cyprus), Mrs Antigoni Papadopoulou (Cyprus), Mrs Angelika Werthmann (Austria) and Mr Karl Ryan (Ireland) in an effort to obtain their support for the launching of this important Report. The Report, entitled *"Haemoglobinopathies on the Move: Is Europe ready? A policy analysis of 10 European countries"* is estimated to be published by the end of June, coinciding with a launch event in Brussels and submission for adoption by the EUCERD.



A glance at Red Day

'TIF taught me to be a blood donor. These people inspired me to be kind, loving & supporting to children'

'Thanks to the blood donors & TIF, million of people are saved, healthy & happy. They said, we children write history but I think they are writing history everyday'

'I think mainly the children that have thalassaemia are so incredibly brave & so are their family & parents that encourage them not to give up!'

TIF Publications

OUT NOW!!!!

Guidelines for the Clinical Management of Non Transfusion Dependent Thalassaemia (NTDT) *Taher, A., Vichinsky, E., Musallam, K., Cappellini, M.D., Viprakasit, V.*



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<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.*)

Community Awareness Booklets on α -thalassaemia, β - thalassaemia & Sickle Cell Disease (Greek). (*Eleftheriou, A.*)



IN PARTNERSHIP WITH
THALASSAEMIA INTERNATIONAL FEDERATION (TIF)



INTERNATIONAL AWARD CATEGORIES include:

- Sultan Bin Khalifa Grand International Award | USD 20,000
- Sultan Bin Khalifa International Award for Innovative Medical Research | USD 20,000
- Sultan Bin Khalifa International Award for Clinical Centre of Excellence | USD 20,000
- Sultan Bin Khalifa International Award for Thalassaemia Society of Excellence | USD 20,000
- Sultan Bin Khalifa International Scholarship for Translational Research in Thalassaemia | USD 60,000
- Sultan Bin Khalifa International Award for Leadership in Thalassaemia | Non-Monetary

APPLY NOW - DEADLINE: 15 JUNE 2013

Information available at:

Sultan Bin Khalifa International Thalassaemia Award - www.sita.ae; info@sita.ae
Thalassaemia International Federation - www.thalassaemia.org.cy; thalassaemia@cytanet.com.cy

Regional News

Information has come through regarding the status of haemoglobin disorders in the **Russian Federation**. Sources have indicated that currently a list of 24 life-threatening orphan diseases has been compiled, which are

being however excludes thalassaemia. The guidelines for Standards of Care are mandatory across the country but unfortunately as no funding is provided for their implementation patients often pay out of pocket for diagnostic tests, monitoring and treatment. Nonetheless, we have been informed that efforts are being made for the development of a national registry of haemoglobinopathies in order to ascertain the location and needs of patients. This after all is the only way forward if policy decisions are to be taken on a national basis.

The Thalassaemia Society of **Mauritius**, the National Blood Transfusion Service and the Blood Donors Association in collaboration with and the Municipality of Beau Bassin Rose-Hill, in the context of the International Thalassaemia Day, has organised a Mega Blood Donation on the 11 May 2013. The Thalassaemia Society, founded in 2009, focuses on areas of awareness raising, ensuring blood safety and adequacy, educating and empowering patients, quality of life as well as advocating for prevention and management to the Ministry of Health and WHO.



The European Commission, taking note of the obstacles EU citizens still face in their everyday lives when exercising their right to free movement has announced the publication of the EU Citizenship Report 2013. The Report sets out 12 concrete ways to help Europeans make better use of their EU rights including the development of an **EU disability card**, to be mutually recognised across the EU, making sure that the 80 million disabled people can also take advantage of the benefits that come with national cards when exercising their right to free movement.

The European Organisation for Rare Diseases (Eurordis) has published Guiding Principles for **Specialised Social Services** to integrate people living with rare diseases into the community—<http://www.eurordis.org/sites/default/files/EJA-WP6-Guiding-Principles-Specialised-Social-Services.pdf>

Therapeutic & Research Centre

Combination therapy for HCV of sofosbuvir with ribavirin for patients who cannot take interferon led to a 78% cure rate after three months of treatment, a study published in the New England Journal of Medicine has stated. In addition, the study found that patients unresponsive to interferon, a 73% cure rate was observed after four months of treatment with the two-drug combo (*AABB, 24/04/2013*)

Researchers at the University of Pune in India are conducting a **mutation analysis** of more than 60 patients with β -thalassaemia to identify its primary, secondary and tertiary mutations (*AABB, 09/05/2013*)

West Nile Virus (WNV) deaths in 2012 are the highest on record. Transmitted through blood transfusions, the WNV has become endemic to Europe, Africa, Asia, Australia, the Middle East and the USA, the Centre for Disease Control has stated (*AABB, 14/05/2013*)

Delegation Visits & Workshops

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 ****

World Sickle Cell Day
June 19th!