INFORMATION FROM TIF 27-01-2017

Subject: Organization of a High Level Side Event on the right to health and thalassaemia at the 34th Session of the UN Human Rights Council

We are delighted to inform you that the Thalassaemia International Federation (TIF)[i], is privileged to enjoy the endorsement and support of the Permanent Mission of Cyprus in Geneva, and will jointly organize a Parallel High Level Event on the right to health and thalassaemia[ii] in the course of the 34th Session of the UN Human Rights Council (HRC), scheduled to take place between 27 February – 24 March 2017 at the United Nations Office in Geneva, Switzerland.

The High Level Event focused on the human rights in the area of health, and more specifically on thalassaemia is scheduled to take place on the 17th of March 2017 (the exact time and location will be confirmed soon).

The medical, public health, economic and social repercussions of thalassaemia and other haemoglobin disorders (as for all genetic disorders), coupled with the global rising of inequality of access to quality healthcare and patient-centred healthcare systems, as defined by the UN Sustainable Development Goals 2030, will be discussed by experts of international stature and policy makers at the head of decision-making in countries with high disease prevalence and burden, thus bringing thalassaemia to the forefront of the human rights agenda.

Speakers will include the '*father*' of thalassaemia, Sir Prof. David Weatherall – a distinguished figure in the history of haemoglobinopathies; H.E. the Minister of Health of Cyprus, Dr Georgios Pamporides – representing a country which to-date constitutes a model for the successful control of this disease; the EU Commissioner for Health & Food Safety, Dr Vytenis Andriukaitis – demonstrating the added-value of policy-making for rare diseases, into which thalassaemia is categorized, as means to alleviate the public health burden ; and Mr Dainius Puras, Special Rapporteur of the HRC on the right to health – an eminent human rights advocate whose expertise is crucial for the successful tangible outcome of this event, amongst others.

The anticipated outcome will be the development of a Joint Declaration, by the cross-regional Core Group, that will be subsequently delivered to the General Debate, hoping for a Resolution on this topic.

The relevant Concept Note will be sent to you shortly.

INVITATION FOR COLLABORATION

With the opportunity of this communication, we would like to kindly request your collaboration for informing your Ministry of Health regarding the aforementioned event and its importance.

Please note that we have already sent a letter directly to the Ministry of Health on this subject (please find attached).

As a long-term collaborator of TIF, and healthcare professional working in the field of thalassaemia, your assistance will be invaluable to promote this activity to the appropriate individuals and encourage the Ministry of Health to participate in the cross-regional Core Group on the right to health and thalassaemia.

We look forward to receiving your feedback, at your earliest convenience.

We remain at your disposal for any further information and/or clarifications that you may require.

Sincerely,

Panos Englezos

President,
Thalassaemia International Federation

Honorary President, Pancyprian
Thalassaemia Association

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Thalassaemia International Federation (TIF) awarded with:

- Dr Lee Jong-wook Memorial Prize for outstanding contribution in public health
- the Outstanding Contribution Award of the University of Nicosia, Cyprus

INTERNATIONAL CONFERENCE 2017
Date and venue to be confirmed

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[i] The Thalassaemia International Federation (TIF) is a non-profit, non-governmental umbrella federation, established in 1986, working in official relations with the World Health Organisation (WHO) since 1996.

To-date membership boasts 190 members from 61 countries.

Our mission is to promote optimal quality care for all patients with thalassaemia worldwide.

Most remarkably, TIF has been awarded in the context of the 68th World Health Assembly in May 2015, **'Dr Lee Jong-wook Memorial Prize'** for the Federation's outstanding contribution to public health in our work for promoting the development and implementation of national control programmes (prevention and clinical management) for thalassaemia across the world.

More information about the Federation is available at www.thalassaemia.org.cy

[ii] Thalassaemia (and sickle cell anaemia) belongs to the family of haemoglobinopathies – a group of hereditary (genetic) blood disorders.

Approximately 7% of the global population is a carrier of an abnormal haemoglobin gene, and more than 500,000 children are born each year with these disorders globally, due to the lack of effective programmes for their prevention. Sadly, an equal and even greater number of children and adults die annually as a consequence of poor or lack of appropriate clinical management. A significant number of patients, mainly in developing countries, die at a young age often without diagnosis, treatment and with very poor quality of life.

The inequalities in access to quality healthcare are truly tremendous and are not, in most cases, justified considering that these disorders today can be effectively prevented and appropriately treated, with the life expectancy of patients significantly increased, and the quality of life dramatically improved.