THALASSAEMIA INTERNATIONAL FEDERATION

In official relations with the World Health Organization

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Agenda item 5b "European action plan for strengthening public health capacity and services"

Statement of TIF (Thalassaemia International Federation, NGO)

TIF is a non-profit organisation comprised of 108 member associations from 55 countries – in official relations with the WHO since 1996, as well as other major health-related agencies, institutions and other disease-specific organisations, globally. TIF is committed to improving the health, quality of life and life expectancy for patients with inherited congenital haemoglobin disorders, such as thalassaemia (and sickle cell disease), which fall within the non-communicable diseases, through:

- supporting the activities of existing national patients' and parents' organizations;
- establishing new ones, and;
- supporting and encouraging national health authorities in their efforts to develop effective national control strategies, including prevention and clinical management.

Education of patients/parents and health specialists, and raising awareness about these diseases to the community at large, constitute the 'core' of TIF's educational activities towards achieving the above-mentioned mission. These include the organisation of conferences, workshops and seminars - at the local, national, regional and international level, as well as the preparation, translation and distribution of an extensive range of educational materials and books which constitute to-date the reference material for these disorders. TIF's two vital communication and information tools include the quarterly-published magazine and website that are frequently updated and upgraded in order to support more effective service planning and to provide up-to-date information to its web-visitors and members.

Available epidemiological data on these diseases in Europe, which may be quite underestimated, mayreflect the significance of these disorders in the national public health burden of every European country. Although, haemoglobin disorders which have significant social and economic repercussions in addition to being considered a major public health problem, mainly in the developing regions of the world (and more specifically to those endemic or previously endemic to malaria), to date industrialised regions, including Europe are in need to address their control, more effectively. This becomes a necessity as a result of increasing migration of populations from affected countries and the multiple difficulties faced by health systems in reaching out to these populations because of language, cultural and social heterogeneity and other constraints.

TIF was delighted to accept several WHO resolutions (WHA59.20 and EB118.R1), adopted by the WHA and EB in 2006, on sickle cell anaemia and on thalassaemia, respectively, putting

these disorders as priorities on the WHO's health agenda, and facilitating the work of TIF and other NGOs towards encouraging and promoting haemoglobin disorders on national health agendas. In Europe, these disorders, do not occur amongst the indigenous populations and are considered as Rare and the EU address their control and management, in this context.

At present, no national prevention programmes are in place in most of the European countries, and the number of expected affected births, is not yet under control. This number will even increase as the influx, to Europe (particularly to the north) from developing countries continues to increase. As a consequence, in order to address effectively the management of these disorders, national resources will be put under an unbearable strain in many European countries, including blood requirements – where blood transfusion constitutes one of the two major pillars in the management of these diseases, the other one being the iron chelation.

To this effect, TIF has taken steps towards raising awareness across Europe for these disorders through the organisation of bi-annual Pan-European conferences on haemoglobinopathies since 2007, and has taken an active involvement with the European Commission in formulating, promoting and implementing European policies on 'Rare Disease and Anaemias'. In this context, TIF wishes to urge the European Regional office to take an equally active role in supporting within the non-communicable and rare disease programs:

(i) the promotion of national control programmes in every European country;
(ii) the collection and/or promotion (where lacking) of updated and accurate epidemiological data on these diseases;
(iii) the adoption of guidelines for consistent management of the disorders across Europe, and;
(iv) the creation of European Reference Centres and networks of collaboration between the medical and patients' communities and between them in every European country and across Europe.

The 3rd Pan-European conference with support of the WHO/EURO will be held in Cyprus this October. We would be pleased to see you at the Conference (www.thalassaemia.org.cy).

TIF, therefore, deeply appreciates WHO/EURO initiatives for strengthening public health capacity that is in line with TIF's activities and fully supports the presented document, especially in the area of disease prevention. TIF would be pleased to provide WHO/EURO with relevant information and possible actions on the control of haemoglobin disorders at the country level as a part of the NCD's global health burden.