THALASSAEMIA INTERNATIONAL FEDERATION
In official relations with the World Health Organization

HEADQUARTERS
31 Ifigenias, 2007 Nicosia, Cyprus • P.O.Box 28807, 2083 Nicosia, Cyprus
Tel.: +357 22 319 129, Fax: +357 22 314 552, E-mail: thalassaemia@cytanet.com.cy

68th session of the WHO Regional Committee for Europe
Rome, Italy, 17–20 September 2018

STATEMENT OF THALASSAEMIA INTERNATIONAL FEDERATION (TIF)

Agenda Item 3: Matters arising from resolutions and decisions of the World Health Assembly and the Executive Board - Development of a draft global action plan on the health of refugees and migrants (EUR/RC68/Inf.Doc./9).

The Thalassaemia International Federation welcomes and endorses WHO's efforts to alleviate the many health issues that migrants and refugees may have to face during the migration and resettlement period. Host countries have a humanitarian obligation to assist and support these population groups, in receiving healthcare appropriate to their needs. TIF also endorses 'the framework of priorities and guiding principles to promote the health of refugees and migrants'. TIF, moreover is in full agreement with the 'Progress report on implementation of the Strategy and Action Plan for refugee and Migrant Health in the WHO European Region', reported by the Regional Committee for Europe in Rome in August of this year[1]. In this report, however, it is stated that 'evidence of poor health among refugees and migrants is generally confined to certain infectious diseases, and maternity and mental illness outcomes'. TIF believes that many chronic diseases may have been excluded from this statement, either because of inadequate diagnosis or inadequate reporting. Chronic disorders are often not visible, unless special laboratory tests are performed. This is certainly the case for sickle cell disease (SCD) and also even for a recently transfused thalassaemia patient.

Even though population movements have been a phenomenon known throughout history, the recent increase of population shifts from south to north and east to west, have brought with them with an increase in chronic diseases which are over above the general acute health issues that are expected. The recent migrations are from countries with a high prevalence of hereditary haemoglobin disorders (thalassaemia and sickle cell) to low prevalence areas of north and Western Europe. For example, of the 5.5 million global carriers of the sickle cell gene, about 80% are born in Sub-Saharan Africa[2] from which most refugees entering southern Europe (Italy and Spain mainly) originate. Thus Italian thalassaemia centres are now treating mostly sickle cell patients where beta thalasseamia was mostly endemic. Likewise, migrations from Iraq, Thailand, Syria, Afghanistan and Turkey, entering Europe from the eastern borders of Greece and the Balkans are carriers of thalassaemia genes and HbE. An example is Sweden which between 1998 and 2003 hosted 200 patients with haemoglobin disorders while by 2015 these have exceeded 3000[3]. Another example is that of Germany, where in 2014 only about 1000-1500 sickle cell patients were recorded[4], while in 2016 a neonatal screening study revealed a frequency of SCD in one in 2385 newborns, probably of Sub-Saharan ancestry[5].

Even more worrying is the flow of refugees from war zones to neighbouring countries, which have also a high burden of these disorders. These protracted emergencies have created, a great humanitarian crisis, which has affected Europe to a great extent. Many have gone to Lebanon, which hosts around 1-1.5 million Syrian refugees while Jordan has received around 700000 and Egypt over 100000. These are countries, which have an indigenous haemoglobinopathy problem, a burden with which they are hardly coping for their own population. Yet no knowledge exists about the fate of the refugee patients in these countries. Who is responsible for their care is not really known. In a TIF study (unpublished) of 2015, there were over 200000 Syrian refugees in Europe, of which 10500 are likely to be carriers of beta thalassaemia. From Afghanistan, also from the same study, another 311660 were residing in European countries and around 10000 are likely to be carriers. This is evidence that it is not only affected patients are increasing but also

healthy carriers, who may affect the future birth incidence of these conditions in Europe. This calls for long term policy considerations.

According to the WHO 2016 “Framework” document it is recommended that through information systems there should be analysis and assessment of refugee and migrants health, there should be emphasis on disease prevention and quality of care in particular for patients with disabilities.

It is the concern of the Thalassaemia International Federation that no action is being taken for the survival and welfare of patients with chronic disorders and especially those with hereditary anaemias, who require lifelong and complex treatment, which includes blood transfusions and the need for essential drugs to chelate excess iron. These patients survive best when managed by experienced practitioners. In some developed countries such services are being offered although experience may have not yet developed.

Through this statement, TIF wishes to bring the issue of chronic and hereditary disease to the attention of all host countries in Europe, urging them to identify patients and plan for their treatment in the best possible way, adopting policies for both prevention and optimal care. These are policies which ensure survival in these diseases, which could lead to early death if not well cared for. In contrast, a good quality and productive life may be expected if given optimal care.

These requests constitute the position and consensus of the TIF Board of Directors and are in keeping with the WHA Resolution 70.15, as well as previous resolutions on thalassaemia and sickle cell disease (WHA63.2, WHA63.17, EB118.R1).

Finally, we would like to express our sincere appreciation for the humanitarian efforts of the WHO concerning the health of refugees and migrants. On the basis of TIF’s long collaboration with the WHO we confirm our desire to collaborate in any way possible with WHO for the promotion of the issues raised in a practical and effective way.

REFERENCES:

1. ‘Progress report on implementation of the Strategy and Action Plan for refugee and Migrant Health in the WHO European Region’, EUR/RC68/8(F)
2. Piel FB, Patil AP, Howes RE, et al. Global epidemiology of sickle haemoglobinin neonates: a contemporary geostatistical model-basedmap and population estimates. Lancet 2013; 381: 142-151
3. Hemminki K, Li X, Forsti A, Sundquist J, Sundquist K. Thalassaemia and sickle cell anaemia in Swedish immigrants: genetic diseases have become global. SAGE Open Med 2015 doi: 10.1177/2050312115613097
4. Eber S, Dickeroff R. Anemia and haemoglobin diseases in patients with migration background.Dtsch Med Wochenschr. 2014; 139(9): 434-40
5. Grosse R, Lukacs Z, Cobos PN, Oyen F, ET AL. The prevalence of Sickle cell disease and its implication for newborn screening in Germany (Hamburg Metropolitan Area). Pediatr Blood Cancer. 2016; 63(1): 168-70