

HEADQUARTERS

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‘THALassaemia In Action – THALIA’:

Europe’s response to the growing health problem of thalassaemia

***by Dr. Androulla Eleftheriou**

In today’s polarized environment, public discussion about refugees and migrants has become quite heated and muddled. Since 2015, a year that marked the unprecedented arrivals of more than 1 million people in the European Union, mainly fleeing from the war in Syria, the dimensions on this matter highlighted by the European media, have been solidly related to security threats, political and economic implications, but also the remarkable humanitarian support provided by the EU, in consistency with its values and ideals.

However, current and future mobility and migration flows to and within Europe, pose substantial new challenges to its national healthcare systems that have not yet been anticipated. One of the potentially emerging issues, based on the numbers of displaced people from countries with high prevalence in specific genetic blood diseases, is the increase of patients with thalassaemia and sickle cell disease, as well as the degree of readiness of the health systems of the EU Member States to effectively handle such diseases, that have so far been rare or absent in the majority of Central and Northern Europe.

Haemoglobinopathies (thalassaemia and sickle cell disease) are rare genetic blood disorders that, in their severe forms, are associated with chronic, life-impairing and life-threatening consequences that can lead to disability or even death. They impose a significant intrusion in the lives of patients and their families with many effects, sweeping from financial and emotional hardships to social stigmatization and isolation. According to the World Health Organization, they represent a growing health problem in 71% of 229 countries (which



account for 89% of all births worldwide). Whilst Europe has undertaken several initiatives to promote prompt diagnosis, efficacious treatments, and strengthening of research for new orphan drugs and also reduce the psychological and economic impact of rare diseases on patients and society, haemoglobinopathies were for decades considered 'migrants' diseases' and thus were not sufficiently prioritized in national health agendas, even in countries with robust public health infrastructures. A revealing example would be that of Sweden, where only 100 incidents of thalassaemia patients were recorded from 1998 to 2003, whereas from 2003 to 2010 the number of thalassaemia patients incremented to 3.064, due to the Syrian and Iraqi migratory flows, two countries with a high prevalence of the disease.

The Thalassaemia International Federation (TIF) is a Cyprus-based non-governmental, patient-centred organization that has been focusing for more than 30 years on the promotion of effective national programs for the control, prevention and clinical treatment of thalassaemia and their inclusion among the immediate priorities of the national health services of the *affected* countries all over the world. In this context, TIF has evolved through the years to a centre of excellence and a worldwide focal point for the provision of information and education for patients with thalassaemia and haemoglobinopathies. To this end and endeavouring to achieve a better understanding of the needs of countries, in terms of prevention and management of thalassaemia and other blood disorders in Europe, TIF has officially partnered with the European Union for the implementation of a four-year co-funded project entitled "THALassaemia In Action", in abbreviation "THALIA".

In addition to informing and raising public and stakeholder awareness of thalassaemia at both European and national level, TIF's fundamental goals for the systematic life-long education of healthcare professionals, patients and their families, and the reinforcement of their networking and partnerships, extend through THALIA to countries in Europe that have received or are a transit hub for a large number of migrants, such as France, Germany, Sweden, Austria and Serbia. The focus is set initially on these particular countries, since others, such as Greece or Italy, which have taken the strain of dealing with large numbers of immigrants and refugees, already have a longstanding tradition of implementing successful prevention and management programmes for haemoglobin disorders.

Key priorities of THALIA are also providing support to research programmes and studies focused on the clinical management of thalassaemia, as well as entering into policy dialogue with policymakers at national and European level. These objectives will be accomplished by using an array of tools, such e-learning and capacity building courses, online platforms, training seminars, publications, participation in scientific conferences and many more.

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