THALASSAEMIA INTERNATIONAL FEDERATION

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HEADQUARTERS

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How Migration Changes the European Health Map:

The increase of Haemoglobin Disorders and the THALIA Project

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Throughout history, poverty, climate change, famine, war, and conflicts have forced people to move from their homeland and, in this context, migration is not at all a recent phenomenon. As such, free population movements have always posed significant challenges to global health.

In the past, the main concern has been the spread of communicable (or infectious) diseases, such as Hepatitis, Ebola or Influenza, often linked to poverty, suboptimal hygiene conditions, and lack of contemporary prevention programs and public health services. The more recent migration process, observed in the end of the 20th and the dawn of the 21st century, continues to contribute to the spread of communicable diseases, but have in addition resulted in dramatic changes in the epidemiology of chronic diseases, previously unknown or of low prevalence in host populations.

This is the case of haemoglobinopathies, mainly thalassaemia and sickle cell disease (SCD), two rare genetic blood disorders which, in their severe forms, are associated with chronic and life-threatening implications that can result in disability or even premature death. According to the World Health Organisation (WHO), 7% of the world global population are carriers of a haemoglobin disorder. More specifically, in Europe the recent migration crisis has led to a striking increase in the estimated migrant carriers of beta thalassaemia from 253,115 in 2012 to 582,128 in 2015 and 647,991 in 2017, according to data collected by TIF.



The most prominent question now is whether European healthcare systems are able to face up to the daunting task of effectively halting further dissemination of these diseases, on the one hand, and ensuring that haemoglobinopathy patients receive appropriate, timely and high-quality health care, on the other.

Prevention and management of haemoglobin disorders is well established and managed in countries where these conditions were traditionally endemic, namely Cyprus, Greece and Italy. Nevertheless, other European countries, that host or are a transit hub for a substantial number of migrants, such as France, Germany, Sweden, Austria and Serbia, need to fill in policy and practice gaps for the extremely vulnerable group of under-diagnosed migrant patients.

Seeking to address this issue, the European Commission has teamed up with the Thalassaemia International Federation (TIF), a global leader in haemoglobinopathies with vast expertise and contribution in educating patients and other relevant stakeholders about thalassaemia for over three consecutive decades, to implement a four-year co-funded project entitled "THALassaemia In Action (THALIA)", with a special focus on Europe.

The THALIA activities touch upon the areas of education, awareness raising, policy advocacy and research and include, amongst others;

- the development and translation of e-learning platforms and capacity building courses for patients and medical specialists,
- the organisation of delegation visits to the countries of priority, mentioned above, aiming to establish new and empower already existing national patient associations,
- the translation and dissemination of TIF's abundant educational materials, guidelines and standards of care and prevention of haemoglobin disorders; and
- the participation of TIF's experts in scientific conferences, for the exchange of related knowledge and best practices

Amongst the key priorities of the THALIA project are also the provision of support to research programmes and studies focused on the clinical management of thalassaemia, as well as the engagement into policy dialogue with policymakers at national and European level. The project is being continued for the 3rd consecutive year with considerably positive results which will be announced upon its completion, always with the support and the cofunding of the

Third Health Program of the European Commission's Consumer, Health and Food Executive Agency (CHAFEA).

We maintain an open line of communication with our patients and the public. Feel free to contact us directly for any query regarding thalassaemia and sickle cell disease at: thalassaemia@cytanet.com.cy

For more information on TIF and the THALIA project, you can visit the following pages:

https://thalassaemia.org.cy/

https://thalassaemia.org.cy/thalassaemia-in-action-the-thalia-project/

https://www.facebook.com/tif.thalassaemia/

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