



## PROGRESS OUTLINE 2020



Co-funded by the Health Programme of the European Union

### PILLAR 3: POLICY ADVOCACY

*Activities*  
*Impact*



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## EXECUTIVE SUMMARY

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The work of the Thalassaemia International Federation (TIF) can be categorised in four distinct pillars: a) Education; b) Awareness Raising; c) Policy Advocacy and d) Research. For TIF, policy advocacy is all about the rights, choices and capacities of patients and involves delivering messages that are intended to influence thoughts, perspectives and actions of leaders, politicians, policy makers, planners and others in authority. Aiming to prioritise haemoglobin disorders and their control (prevention and management) at European and international levels, TIF acts directly to increase people’s access to information about thalassaemia and other haemoglobinopathies and strives to enhance patients’ capabilities to influence policy processes that affect their lives.

In 2020, the intensive efforts put forward in 2018 and 2019 that yielded a thorough needs analysis of THALIA priority countries, namely France, Germany, Austria, Sweden and Serbia was further strengthened through delegation visits held virtually (on account of travel restrictions in place due to the COVID-19 pandemic) to each of the aforementioned countries (T4.1.). The Delegation visits consolidated partnerships and collaborations in addition to enabled a deeper penetration in making stakeholders aware of the specific challenges that thalassaemia encompasses as a chronic and rare disease across all THALIA target groups: patients (especially migrants and refugees with thalassaemia), healthcare professionals treating thalassaemia and sickle cell disease patients and decision-making bodies.

The empowerment of patients from all THALIA countries that have limited expertise in policy advocacy by patients from Greece, Italy and Cyprus who have a long history of participating in the achieving ground-breaking policy changes was enabled through the THALIA Twinning Programme (T4.2). Moreover, to support evidence-based policy-making, TIF continued the development of an EU Electronic Health Record for thalassaemia and continuing discussions for deployment despite delays encountered due to change in health priorities of authorities to deal with the health crises (T4.3).The distinct challenges faced by thalassaemia patients in accessing quality healthcare, the necessity to further armour the expertise of healthcare professionals in the appropriate multidisciplinary clinical management of the disease, as well as awareness raising among possible carriers (members of migrant communities) through a series of policy changes at the EU and national levels have been driven forward through the publication of an EU Policy Recommendation and Charters of Priorities for each THALIA country, which will act as key advocacy tools (T4.4).

Increased awareness about the impact of migration and thalassaemia on public healthcare infrastructures in Europe was achieved through the organisation of two preparatory with the health authorities in Greece and Cyprus, culminating in a High Level Meeting with the EU Commissioner for Health (T4.6). TIF’s activities in Work Package 4 have capitalised on previous efforts, and have ensured a continued interest of an increased number of EU-based stakeholders in thalassaemia and the need for developing specific policies for this increasing public health issue.



## INTRODUCTION

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### About Us

The Thalassaemia International Federation (TIF) is a patient-oriented, non-profit, non-governmental umbrella federation, established in 1986 with Headquarters in Nicosia, Cyprus. Our mission is to promote access to optimal quality care for all patients with thalassaemia worldwide. To-date membership boasts 232 members from 60 countries across the globe. TIF works in official relations with the World Health Organization (WHO) since 1996 and enjoys active consultative status with the United Nations Economic and Social Council (ECOSOC) since 2017. Most remarkably, TIF has been awarded, in the context of the 68th World Health Assembly in May 2015, the 'Dr Lee Jong-wook Memorial Prize' for the Federation's outstanding contribution to public health. More information about the Federation is available at [www.thalassaemia.org.cy](http://www.thalassaemia.org.cy).

### About Haemoglobinopathies

Haemoglobin Disorders, mainly thalassaemia and sickle cell anaemia, are 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 implementation of effective national programmes for their prevention. In Europe, haemoglobin disorders fall within the official EU definition for rare diseases and it is estimated that approximately 44,000 patients with a haemoglobin disorder live in the region. However, the number of patients located in Europe is increasing due to migration flows from high prevalence countries of the Middle East, South East Asia and Africa.

### About THALIA

Thalassaemia, a previously fatal childhood genetic disease, can today be effectively prevented and adequately treated, as a result of the medical and scientific advances that took place in the last three decades. However, thalassaemia's prioritisation on national health agendas and the development of national plans for its effective control in the EU has been hampered by the many challenges involved, mainly related to its rarity and migration.

"THALassaemia In Action" (THALIA) focuses on Europe, targeting patients with thalassaemia and other haemoglobinopathies, healthcare professionals and policymakers. THALIA has a special focus on:

- 1) countries that receive most refugees and migrants from countries with high prevalence in thalassaemia; namely France, Germany, Sweden;
- 2) major transit countries for migrants; namely Serbia and Austria.

### About the impact of COVID-19

The nature of many of THALIA2020 activities include travel and physical interaction to better assess the community needs and deliver efficient educational and policy-making tools. Therefore, the surgent COVID-19 pandemic required a stringent vigilance throughout 2020 by the Internal Evaluation Committee (IEC) and TIF Board of Directors so as on the one hand to ensure the materialisation of activities, and on the other hand to ensure the safety of involved parties. Close monitoring by the IEC of the evolving epidemiological situation and the measures being taken across EU countries to further inform and revise the mitigation measures for each activity continued through the year, so as to identify new ways to fulfil the objective of the activity (e.g. virtual attendance) or to proceed as planned changing some features (e.g. selecting an alternative venue with the same profile characteristics), aiming to ensure the safety of participants (patients, healthcare professionals, policy-makers, TIF Staff and affiliates) at all times.

## MATCHING OBJECTIVES TO ACTIVITIES AND IMPACT

### General objective

**III.0.** Prioritise haemoglobin disorders and their control (prevention and management) at international/United Nations (UN) and European Union (EU) levels

Task No	T4.1	T4.2	T4.3	T4.4	T4.6
<b>Target Audience</b>	Patients Policy/ decision makers HCPs	Patients	Policy/ decision makers HCPs	Patients Policy / decision makers	Policy/ decision makers
<b>KPI Met</b>	✓	✓	✘	✓	✓
<b>Justification</b>	✓	✓	✓	✓	✓

### Specific objectives

**III.1.** Facilitate the exchange of knowledge and good practices between national Thalassaemia associations.

**Activity: T4.2:** TIF EU Thalassaemia Associations' Twinning Programme

**Results:** Patients from THALIA priority countries (v. DE, AUS, FR, SWE, SRB) virtually met counter-parts from IT, GR, CY for a sharing-of-best-practices meeting focused on COVID-19

**Impact:** Empowerment of patients has led to the adoption of TIF recommendations for the treatment of thalassaemia at the national level with an estimated outreach affecting over 18,000 patients.

**Impact Management / Mitigation Measures:** N/A

**III.2.** Support European countries with no tradition or experience in managing Thalassaemia and haemoglobinopathies and receive a high number of migrants and refugees.

**Activity: T4.1:** Establishment of national associations in France, Germany, Austria, Sweden and Serbia

**Results:** TIF visited albeit virtually all countries of priority (France, Germany, Austria, Sweden, Serbia) and consolidated relationships and partnerships created in 2018 and 2019.

**Impact:** Steps were made for the establishment of thalassaemia patient groups all countries, as grass roots work increased the interest of all target audiences.

**Impact Management / Mitigation Measures:** N/A

**III.3.** Monitor the spread of Thalassaemia and haemoglobinopathies in Europe.

**Activity: T.4.3:** Thalassaemia EU Electronic Health Record

**Results:** The architectural refinements of the software were completed, with discussions regarding licensing and deployment in 4 centres moving forward.

**Impact:** KPI not met – Clinics in Europe suffered unparalleled adjustments in their priorities due to the COVID-19 pandemic. As such, interest in adoption of the Health Record although present, were not shared by hospital administrations who funnelled resources towards the health crises.

**Impact Management / Mitigation Measures:** The interest of clinics will be utilised in 2021 to further promote the tool once the pandemic has subsided. In addition, a targeted literature review of the published relevance of thalassaemia and a subsequent publication will raise awareness among policymakers about the widespread infiltration of thalassaemia across Member States.

#### III.4. Improve EU policies on Thalassaemia

**Activity: T.4.4:** Policy Recommendation and position paper on Thalassaemia in Europe

**Results:** A Policy Recommendation on Thalassaemia in Europe has been prepared to serve as an advocacy tool of patient to improve the healthcare services offered at the national level.

**Impact:** The analysis of data, collected via a validated survey, was delayed due to the teams' resource management during national lockdowns, therefore the desired dissemination has not been achieved.

**Impact Management / Mitigation Measures:** Online and offline dissemination to DG SANTE, National Competent Authorities, WHO and other decision-making bodies will be pursued in 2021.

**Activity: T.4.6:** High-level round table discussion on Thalassaemia in the EU

**Results:** The high-level event was postponed due to the limited availability of Ministers of Health and high-level officials in 2019. Conducted as a high-level virtual meeting in 2020.

**Impact:** The preparatory meetings and high-level event have helped to raise awareness on the migration of haemoglobinopathies among policy makers at EU level.

**Impact Management / Mitigation Measures:** N/A

## OVERVIEW OF ACTIVITIES (PILLAR 3 – WP 4)

TASK	<b>T4.1: Establishment of thalassaemia national associations in Austria and Sweden</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b>            Medical Advisor, Dr Michael Angastiniotis (Leader)            Policy Officer, Eleni Antoniou            Communications Officer, Aikaterini Skari            Administration Officer, Rawad Merhi            Office Administration, Stella Eleftheriou            Operations Manager, Lily Cannon</p> <p><b>Supervising Staff:</b>            Executive Director, Dr Androulla Eleftheriou</p>
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>▪ Establishment of patient associations in Austria and Sweden (MS14)</li> <li>▪ Associations involved: 2</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Alignment meeting (France): Jan 2020</li> <li>▪ Alignment meeting (Germany): Jan 2020</li> <li>▪ Alignment meeting (Austria): Jan 2020</li> <li>▪ Delegation visit (virtual) to France: Sept 2020</li> <li>▪ Delegation visit (virtual) to Germany: Sept &amp; Dec 2020</li> <li>▪ Delegation visit (virtual) to Serbia: Oct 2020</li> <li>▪ Delegation visit (virtual) to Austria: Nov &amp; Dec 2020</li> <li>▪ Delegation visit (virtual) to Sweden: Dec 2020</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>A main constituent of TIF's work globally and at the European level is provide support to local patient and healthcare communities and governments to create robust policy-making for the improvement of patient care. In this context a delegation team from TIF, comprising of medical specialists and patient advocates, travels to various countries every year to offer technical knowledge and experience on key issues touching on thalassaemia prevention and care.</p> <p>These delegation visits serve to establish partnerships with the local communities on the ground, especially in countries where thalassaemia is not found within the indigenous population but rather the result of migration flows from thalassaemia-prevalent areas of the world such as the THALIA priority countries (i.e. France, Germany, Sweden, Austria and Serbia).</p> <p>The TIF delegation team, in collaboration and with the consent of the local medical community and patients association (where one exists), observe a situation analysis through the documentation of (1) epidemiological data (taking into consideration the influence of migration and population movements), (2) the provided medical and other services and (3) unmet patient needs. Together with all stakeholders immediate and long-</p>	

term actions are considered for implementation to advocate for improvement of these.

Where an organised patient association does not exist TIF makes every effort to identify patients and parents who can provide feedback on their unmet needs, and proposes the establishment of a patient association as a priority activity, and provides expert assistance on how to proceed (TIF Publication - 'A Guide to Establishing a non-profit patient support organisation'<sup>1</sup>). Where an association exists then TIF consider ways to strengthen it, providing patient education, and organising capacity building activities.

The foundations for collaboration across the THALIA priority countries was laid in 2018 where two delegation visits (one investigational and one follow up) took place, with a TIF delegation team comprised of an expert TIF Officer or Medical Adviser or Member of TIF's International Scientific Advisory Board and at least one patient from TIF's Expert Group. During the 1st visit, TIF delegation meets with medical specialists, national health authorities and national rare disease association (if exists) to map the situation and tailor the support according and secure the supporting of medical professionals in identifying patients for TIF. During the 2nd visit, TIF delegation meets with patients and parents (where necessary) to ensure support for the establishment of patients' associations with specific goals and timeframes. Further strengthening of relationships and partnerships, while also documenting progress on mutually agreed upon immediate and long-term actions was the focus of delegation visits that took place in 2019.

Seeking to capitalize on the efforts of the previous two years, in 2020 TIF sought to refine the short and long-term goals determined by the stakeholder groups in France, Germany and Austria through the organisation of alignment meetings on 31<sup>st</sup> January 2020 held at TIF Headquarters in Cyprus. These meetings provided the opportunity for discussing progress in each country as well as offering the opportunity lay the foundations for a more structured collaboration with each patient organisation (v. SOS Globi ; France / SAM ; Germany / THALSIFO ; Austria) and deeper understanding of how TIF works. The meetings were participated by Mr Panos Englezos (TIF President), Mr Anton Skafi (TIF Board Member), Dr Androulla Eleftheriou (TIF Executive Director), Dr Michael Angastiniotis (TIF Medical Advisor) and Mr Rawad Merhi (TIF Countries Officer). Additionally, email communication was pursued with partners in Sweden to achieve the same purposes. The alignment meetings concluded in the schedule of delegation visits to each country for 2020.

**COVID-19 Impact:** The travel restrictions, national lockdown measures and fluctuating infection rate across the EU, and most notably in the THALIA priority countries, led the TIF's Board of Directors and Internal Evaluation Committee initially to postpone the planned delegation visits for the second half of 2020, and subsequently as the second wave of the pandemic hit Europe to opt for the organisation of virtual delegation visits. Due to these extenuating circumstances, it was decided that this would be the best course of action that would enable TIF to provide the much-needed support and guidance required by patient communities on the ground as well as to ensure the momentum created through visits and communication is maintained in order to achieve longer term goals that would improve the quality of life of patients.

### Objectives of each Visit

The objectives of these virtual delegation visits, in accordance to the three main stakeholder groups involved in the control of thalassaemia, remain the identical to those of in-person delegation visits, and are:

#### ***Stakeholder Group 1: Healthcare professionals***

- To inform healthcare professionals working in the field of haematology and paediatric haematology about the migration of thalassaemia (how the recent migration flows have led thalassaemia patients and carriers to Europe);
- To ascertain the epidemiology and prevalence of thalassaemia
- To discuss response mechanisms / programmes, including multidisciplinary care and prevention programmes;
- To seek guidance and support on how disseminate knowledge about thalassaemia to the other stakeholder groups (see below) as well as the general public (for community awareness and prevention purposes);
- To involve healthcare professionals in TIF's International Scientific Advisory Committee and;
- To provide information about TIF's tools for this stakeholder group, and how they can become involved (e.g. Healthcare Professionals Educational Platform, Publications – especially Guidelines for the Clinical Management of TDT, Global e-Registry & electronic health record, Preceptorships, Renzo Galanello Fellowship etc).

#### ***Stakeholder Group 2: Patients/Parents***

- To empower and create core groups of patients, promoting the creation of a National Patients' Associations, for providing support (in kind and knowledge-based) to the patients and their families;
- To provide tools and education for the development of the necessary skills and capacities for advocacy and productive participation in decision making at the national level;
- To educate patients/parents on disease-specific knowledge, as well as the latest policies, projects and legislative developments in the fields of Haemoglobin disorders, rare diseases, medicines, patients' rights and mobility, reference networks, etc;
- To invite patients/parents to participate in specific TIF organized activities e.g. Capacity Building Workshop, Twinning Programmes etc;
- To provide information about TIF's tools for this stakeholder group, and how they can become involved (e.g. Thal e-Course, THALIA Mobile app, Publications etc).

#### ***Stakeholder Group 3: Health Authorities***

- To discuss the policies relevant to the prevention and clinical management of haemoglobin disorders;
- To demonstrate the relation between migration and thalassaemia and possible implications for the healthcare system;
- To deliberate regarding possible avenues of collaboration with TIF to increase and

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<sup>1</sup> <https://thalassaemia.org.cy/publications/tif-publications/a-guide-to-establishing-a-non-profit-patient-support-organisation-2007-eleftheriou-a/>



ensure access to optimum care<sup>2</sup> for all patients (e.g. Reference Centres, life-long learning opportunities for healthcare professionals, Global e-Registry & electronic health record etc.) The visits in 2020 have yielded the following notable information (per country):

### Delegation visit to Austria

#### **November 2020**

##### Introduction

A virtual TIF Delegation visit with stakeholders from Austria took place on 26 November 2020. The Delegation Team consisted of Dr Michael Angastiniotis (TIF Medical Advisor) and Mr Rawad Merhi (TIF Countries Officer). The Delegation was accompanied by Dr Eva-Maria Knoll (a Medical Anthropologist & passionate volunteer working with TIF in Austria).

The Delegation Team during the virtual meeting had the opportunity to meet with 53 patients, parents and treating physicians from Austria. The agenda of the meeting focused on social and psychological challenges experienced by patients in their daily life. Experts in the field Dr Roswitha Dickerhoff (Munich), Dr Annette Hoferer (Stuttgart) and Dr Jens Straeudle (Stuttgart) engaged in the discussion also.

During the meeting, the TIF Delegation Team had the opportunity to talk about the challenges that patients face in their everyday lives (including social, occupational and education development) and their quality of life, and discuss with patients and treating physicians collaborative ways forward.

##### Main Findings:

- i. There are prominent language barriers, making communication between doctors and patients rather intricate.
- ii. Patients stated to often feel isolated and marginalized, due to the lack of patient support groups. Hence, the successful establishment of the Thalassaemia & Sickle Cell Forum (THALSIFO) Austria, as a result of the delegation visits in 2018 and 2019 is a huge milestone.
- iii. There is a necessity to strengthen the psychosocial support provided to patients.

#### **December 2020**

##### Introduction

The TIF Delegation Visits in 2018 and 2019, coupled with the maintenance of interest and momentum of volunteer, Dr Eva-Maria Knoll has been pivotal in the establishment of THALSIFO, the first thalassaemia and sickle cell disease patient organisation in Austria, in late 2019. Founded in a uniquely difficult period impacted greatly by the COVID-19 pandemic, on top of the already existing challenges experienced by patients on a daily basis, THALSIFO has managed to unify the patient community to come together to identify

their unmet needs and to provide peer-to-peer support through the organisation of numerous virtual meetings throughout 2020. The current situation in Austria and the efforts of THALSIFO were presented by Dr Eva-Maria Knoll in TIF's European Thalassaemia & Sickle Cell Disease Symposium (see WP2), on 13 December 2020.

#### Main Findings:

- i. The unavailability of a complete patient registry (children and adults) hinders not only the ability of health authorities to create targeted services, but also impacts the peer-to-peer support that can be offered by THALSIFO, thus combating isolation and loneliness among patients and their parents (if applicable).
- ii. Awareness and knowledge about thalassaemia amongst healthcare professionals, patients, carriers, the migrant communities and the society at large is limited.
- iii. Visibility of thalassaemia and sickle cell disease, and their distinct needs as multi-organ non-malignant haematological disorders is limited, as healthcare settings providing care for patients are mostly oncology driven.

#### Delegation visit to Germany

##### **September 2020**

A virtual TIF Delegation visit with stakeholders from Germany took place on 4 September 2020. The Delegation Team consisted of Dr Michael Angastiniotis (TIF Medical Advisor) and Mr Rawad Merhi (TIF Countries Officer). The Delegation was accompanied by Mr Kostas Tsurlis (Vice-President of SAM Deutschland e.V. AM - TIF Member Association; TIF Patient Advocacy Group Member).

The Delegation Team during the virtual meeting had the opportunity to meet with approximately 55 patients, parents and treating physicians from Germany. The agenda of the meeting focused on Gene Therapy with Dr Regine Grosse (Haematologist, Germany) providing an overview of the latest developments. Moreover, partners from Austria, Dr Eva-Maria Knoll (a Medical Anthropologist & passionate volunteer working with TIF in Austria) and Prof. Christian Sillaber (Haematologist, Vienna) also participated in the discussion.

During the meeting, the TIF Delegation Team had the opportunity to further cultivate the environment for the establishment of a national network in Germany (see THALIA2019 Periodic Report) as a result of the closer collaboration with SAM Deutschland e.V. AM and their representative to TIF, Mr Kostas Tsurlis. Since the alignment meeting of January 31<sup>st</sup>, 2020. The increased challenges faced by patients in Germany due to the COVID-19 pandemic have contributed to a strengthened relationship with TIF, who has provided unwavering and regular support and guidance in these trying times, engaging an increasing number of patients from Germany in activities (v.. Thal e-course, translation of COVID-19 materials, surveys for quality of life and gene therapy, webinars, thalassaemia patient advocacy group etc).

1. <sup>2</sup> As per TIF's Guidelines (3<sup>rd</sup> Edition), 2014 <http://thalassaemia.org.cy/publications/tif-publications/guidelines-for-the-management-of-transfusion-dependent-thalassaemia-3rd-edition-2014/>

### Main Findings:

- The value of policy advocacy through a united voice is becoming apparent to the patient groups in Germany, especially highlighted by the acute COVID-19 pandemic crises.
- Participation in educational activities about new therapies is essential for empowerment and knowledge acquisition.
- Knowledge on new therapies is limited and therefore more meetings focused on this topic are needed in order for patients to gain a deeper understanding.

### **December 2020**

#### Introduction

A virtual TIF Delegation visit with stakeholders from Germany took place on 11 December 2020. The Delegation Team consisted of Dr Michael Angastiniotis (TIF Medical Advisor) and Mr Rawad Merhi (TIF Countries Officer). The Delegation was accompanied by Mr Kostas Tsurlis (Vice-President of SAM Deutschland e.V. AM - TIF Member Association; TIF Patient Advocacy Group Member).

The Delegation Team during the virtual meeting had the opportunity to meet with approximately 43 patients, parents and treating physicians from Germany. The agenda of the meeting focused on New Innovative Therapies for the Care and Cure of Haemoglobin Disorders with Dr Regine Grosse (Haematologist, Germany) providing an overview of the latest developments in gene therapy and innovative medicinal products. Mr Tsurlis provided the patient perspective, outlining the daily struggles of patients and expectations for the new therapies before opening the floor for other patients to express their views.

During the meeting, the TIF Delegation Team had the opportunity to talk about the challenges that patients face in their everyday lives (including social, occupational and education development) and their quality of life, and discuss with patients and treating physicians collaborative ways forward.

#### Main Findings:

- Empowerment of patient associations through knowledge is essential in order to engage in effective advocacy.
- Patients unanimously agreed that thalassaemia & sickle cell disease do not only affect the condition of their health, but also education, professional and social opportunities. Therapeutic advances that will allow them to spend less time dealing with hospitals, doctors appointments etc will enable them to focus efforts on the other areas of life.
- Patient Organisations are the most frequent source of information for patients on community news. Therefore, patient organisations are required to have the skills and capacities to provide reliable information.

## Delegation visit to Sweden

**December 2020**

### Introduction

A virtual TIF Delegation visit with stakeholders from Sweden took place on 08 December 2020. The Delegation Team consisted of Mr Panos Englezos (TIF President), Mr George Constantinou (TIF Ass. Secretary), Dr Michael Angastiniotis (TIF Medical Advisor), Ms Lily Cannon (TIF Operations Manager) and Mr Rawad Merhi (TIF Countries Officer).

The Delegation Team during the virtual meeting had the opportunity to meet with approximately 20 patients, parents and treating physicians from across Sweden and to learn about the current status relating to the prevalence, treatment and social integration of patients with haemoglobin disorders in Sweden, as well as introduction of new therapies (Reblozyl and Zynteglo – gene therapy). Moreover, identification of areas for improvement with the support of TIF were also discussed.

The meetings further explored the quality of life of patients with haemoglobinopathies in Sweden, and identified avenues of attaining the support of and closer partnership with TIF. The consensus of all stakeholders focused on the lack of prioritisation by the National Health Authorities to haemoglobin disorders (thalassaemia and sickle cell disease) both in terms of their multidisciplinary management but also concerning the societal integration of patients.

### Main Findings:

- There is no centralised care for thalassaemia and sickle cell disease in Sweden. Therefore patients (scattered across the country) are treated close to their homes. This means over 30 hospitals are provide care to patients without a system for annual referrals to expert centres for more specialised monitoring tests and care plans.
- Paediatric care is more organized and centralised.
- Guidelines for the management of thalassaemia patients exist and are updated regularly. More recently, national SCD recommendations have been developed.
- The exact number of patients in Sweden remains elusive on account of the unavailability of a national haemoglobinopathy register. This impacts the visibility of haemoglobinopathies to national health authorities, as patients are currently registered within the cancer registry.
- Improvement of knowledge and education, both for patients and healthcare professionals is imperative.
- Linguistic challenges are common among patients, who require brochures and information in their native languages or in Swedish.
- Further strengthening of efforts for the creation of a thalassaemia patient community / organization is required to combat isolation and marginalisation.

## Delegation visit to Serbia

**October 2020**

### Introduction

A virtual TIF Delegation visit with stakeholders from Serbia took place on 23 – 24 October 2020. The Delegation Team consisted of Dr Androulla Eleftheriou (TIF Executive Director) and Ms Eleni Antoniou (TIF Policy Officer).

The Delegation Team had the opportunity to participate in the “Caring for Rare” online regional conference of the Serbian Alliance for Rare Disorders (NORBS), and to meet with patients and other stakeholders active in the field in Serbia and across the Eastern European Region. . An array of topics was addressed by the speakers, including access to treatment, the role of patient organisations, how the pandemic affects patients and holistic care.

During the meeting TIF had the opportunity to present the example of thalassaemia, as a multi-organ life-long disease requiring multidisciplinary and holistic care. Furthermore, TIF presented the unmet needs of thalassaemia patients across the European region as identified through work undertaken in the context of the THALIA project. The Conference, allowed the exchange of knowledge and facilitated collaboration between rare disease patient organisations, active in the Eastern European region.

### Main Findings:

- The exact number of patients in Serbia remains elusive on account of the unavailability of a national thalassaemia register. This impacts the visibility of thalassaemia to national health authorities.
- Improvement of knowledge and education, both for patients and healthcare professionals is imperative.
- Further strengthening of efforts for the creation of a thalassaemia patient community / organization is required to combat isolation and marginalisation.

As a result of the meeting, and to further drive momentum for thalassaemia in Serbia, TIF has reached out to the Minister of Health of Serbia and the Ambassador of Cyprus in Serbia requesting virtual meetings to discuss avenues for collaboration.

## Delegation visit to France

**September 2020**

### Introduction

A virtual TIF Delegation visit with stakeholders from France took place on 07 September 2020. The Delegation Team consisted of Dr Michael Angastiniotis (TIF Medical Advisor), and Mr Rawad Merhi (TIF Countries Officer).

The Delegation Team during the virtual meeting had the opportunity to meet with approximately 20 patients, parents and treating physicians from across France and to learn about the current status relating to impact of COVID-19 on the patient community as well as to learn of the progress of introduction of new therapies (Reblozyl and Zynteglo – gene therapy). Moreover, identification of areas for improved social integration and education with the support of TIF were also discussed.

Main Findings:

- Educational material should be developed in French to overcome any linguistic barriers and provide wider access to information amongst French-speaking physicians and patients/parents.
- The lack of peer-to-peer support is a major issue for patients and their families leading to social isolation.
- The establishment of a Thalassaemia Working Group within SOS Globi has enabled the French thalassaemia patient community to be more active and united, noted in the celebration of International Thalassaemia Day in May 2020.
- Adoption of [TIF's Classification of Risk Groups](#) of thalassaemia patients and their vulnerability against SARS-CoV-2 has been adopted by the MCGRE.

**RESULTS  
ACHIEVED**

- Identification of healthcare professionals and patients with thalassaemia in each of the THALIA priority countries (FR, DE, SWE, SRB, & AUS).
- Strengthening of established and building new collaborations with key stakeholders in the medical and patient (where they exist) communities, in addition to other health bodies in each of the THALIA priority countries (FR, DE, SWE, SRB, & AUS).
- Initiating the development of an updated epidemiological mapping of the situation regarding thalassaemia in Europe.
- Empowerment of patients and associations (where they exist) with provision of patient educational material.
- Recognition of the social challenges that patients with thalassaemia in Europe face (isolation and marginalisation) in excess of other discriminations.
- Acknowledgement of 'invisible' patients who are not part of the healthcare systems and the necessity to work with agencies dealing with migrants and refugees in order to find them.
- Dissemination of TIF's educational materials for patients and healthcare professionals as well as other initiatives (e.g. electronic healthcare record, registry, network of collaborating centres etc) to each of the THALIA priority countries (FR, DE, SWE, SRB, & AUS).

TASK	<b>T4.2: TIF EU Thalassaemia Associations' Twinning Programme</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b>            Policy Officer, Eleni Antoniou (Leader)            Medical Advisor, Dr Michael Angastiniotis            Communications Officer, Aikaterini Skari            Office Administration, Stella Eleftheriou</p> <p><b>Supervising Staff:</b>            Executive Director, Dr Androulla Eleftheriou</p>
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>▪ Number of participants: 8</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Identification of participants (MS12): April 2020</li> <li>▪ Twinning Programme: 10 April 2020</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>To facilitate the exchange of knowledge and good practices between patients and associations throughout Europe, TIF has established a Twinning Programme between countries with newly established / inexperienced patient associations (where they exist) or active patients and expert patient associations.</p> <p>TIF's EU Twinning Programme in 2018 served the needs of the patient community in France (THALIA2018 priority country, see FPA No. 785243), and as a result a Thalassaemia Working Party was set up in France (See THALIA2019 Periodic Report). In 2019, the Twinning Programme focused on the building of a relationship between the patient communities of Germany (THALIA2019 priority country, see FPA No. 785243) and Greece, and as a result a focal person was designated to move forward the partnership with TIF and cultivate the ground for the creation of a German Thalassaemia Association Network (see T4.1).</p> <p>Taking into consideration the unique circumstances that quickly unveiled throughout Europe as a result of the COVID-19 pandemic in early 2020, including travel restrictions, national lockdown measures, social distancing etc, the Internal Evaluation Committee decided to initially postpone the Twinning Programme, scheduled for patients from Austria and Sweden with the Cyprus Thalassaemia Association to the second half of 2020. However, increasing reports from patients in all THALIA priority countries of the impact that national measures, especially social distancing and shielding, have had on their mental health, it was decided that a virtual meeting to provide peer-to-peer support was essential. This was further corroborated by ECDC guidance on the risk of COVID-19 vulnerable groups to mental health issues<sup>3</sup></p> <p>Indeed, the mental health of patients with thalassaemia in the THALIA priority countries has already been highlighted as an issue in the THALIA2018 &amp; THALIA2019 Periodic Reports, noting that the rarity of the disease, lack of interaction with other patients (i.e. peers), invisibility by national health authorities (v. tailored services), focus of treating physicians</p>	

<sup>3</sup> <https://www.ecdc.europa.eu/en/covid-19/high-risk-groups>

on more acute malignant haematological diseases as well as the stigmatisation of belonging to migrant communities. Therefore, the social distancing required to stop the spread of the SARS-CoV-2 virus in addition to the exact effects of the virus on patients with thalassaemia (many with multiple and severe comorbidities e.g. heart arrhythmias, liver cirrhosis etc) further exacerbated feelings of isolation and anxiety.

Thus, a wider and extended Twinning Programme between patients from the THALIA countries with newly established / inexperienced patient associations (where they exist) and patients from Greece, Italy, Cyprus with established patient associations since the 1970s and active and expert patients took place on 10 April 2020 in a virtual environment. The Twinning Programme was participated by 18 thalassaemia patients from Austria, Cyprus, France, Germany, Greece, Italy, Sweden and the UK (MS12). Esteemed TIF Board Members Mr Riyad Elbard (TIF Treasurer, Canada) and Mr Anton Skafi (TIF Board Member, Palestine) also attended. The discussion was moderated by Dr Androulla Eleftheriou (TIF Executive Director) and Dr Michael Angastiniotis (TIF Medical Advisor). The virtual meeting sought to provide an opportunity for patients to come together, share information about the national situation concerning COVID-19 (measures taken, concerns, challenges etc), facilitate peer-to-peer support and exchange best practices between advocacy groups.

The Twinning Programme focused on the following topics:

- Challenges in accessing and receiving care during COVID-19
- Impact of social distancing
- The role of a patient association in securing patients rights
- Advocating for high-risk status of thalassaemia and SCD and inclusion in vulnerable persons groups

During the meeting, TIF had the opportunity to inform patients about the numerous [guides and recommendations issued by TIF](#) for patients, healthcare professionals and health authorities about thalassaemia and SCD in the context of the COVID-19 pandemic. Subsequently, more experienced advocacy groups from Cyprus, Greece and Italy were able to share practical tips on how health authorities can implement these recommendations in order to safeguard the health of thalassaemia and SCD patients during the pandemic.

The Twinning Programme provided empowerment to patients in THALIA countries, undermining feelings of isolation and desperation. Moreover, the interaction with more experienced advocacy groups enabled patients to seek adoption of TIF's guides in their own countries, having tangible results in France<sup>4</sup>, Germany and Austria<sup>5</sup> as well as across the healthcare professional community through EUROBLOODNET<sup>6</sup>.

<sup>4</sup> [https://filiere-mcgre.fr/wp-content/uploads/2020/04/COVID19Thalassemie\\_Patient.pdf](https://filiere-mcgre.fr/wp-content/uploads/2020/04/COVID19Thalassemie_Patient.pdf)  
[https://filiere-mcgre.fr/wp-content/uploads/2020/04/COVID19\\_Thalassemie.pdf](https://filiere-mcgre.fr/wp-content/uploads/2020/04/COVID19_Thalassemie.pdf)  
[https://filiere-mcgre.fr/wp-content/uploads/2020/04/InformationCOVID19\\_Patients\\_MCGRE\\_avril.pdf](https://filiere-mcgre.fr/wp-content/uploads/2020/04/InformationCOVID19_Patients_MCGRE_avril.pdf)

<sup>5</sup> <https://www.onkopedia.com/de/onkopedia/guidelines/coronavirus-infektion-covid-19-bei-patienten-mit-blut-und-krebskrankungen/@@guideline/html/index.html>

<sup>6</sup> <https://eurobloodnet.eu/covid/covid-19-information/>



**RESULTS  
ACHIEVED**

- Increase of knowledge amongst patients in THALIA priority countries about COVID-19.
- Mediate the impact on mental health of COVID-19
- Build partnerships between less and more experienced patient organisations for advocacy and empowerment.

<b>TASK</b>	<b>T4.3: Thalassaemia EU Electronic Health Record</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b>            Medical Advisor, Dr Michael Angastiniotis (Leader)            Policy Officer, Eleni Antoniou            Communications Officer, Aikaterini Skari</p> <p><b>Supervising Staff:</b>            Executive Director, Dr Androulla Eleftheriou</p>
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>▪ Data collection from 2 centres (MS11)</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Completion of architectural refinements: Jan 2020</li> <li>▪ Licensing &amp; Deployment procedures for 4 centres in Cyprus: Sept – Dec 2020</li> <li>▪ Targeted literature review: Sept – Dec 2020</li> <li>▪ Drafting of peer-reviewed article: Nov – Dec 2020</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>The development of an EU-wide comprehensive disease-specific database in the form of a thalassaemia-specific electronic health record, which provides data for an EU Thalassaemia Registry, is a pivotal tool for monitoring the spread of thalassaemia and haemoglobinopathies in Europe. This is especially important in the current climate, considering the influx of migrants from thalassaemia prevalent areas of the world to European countries where thalassaemia is not found in the indigenous population and hence there is limited expertise on the management of the disease or understanding of its medical, social and economic repercussions.</p> <p>The need for complex healthcare services for lifelong disorders like thalassaemia, make it essential to understand the real burden of disease; this is an important issue for budgetary and public health planning. Registries, health records and other databases are essential tools for gathering information, which help to define the epidemiology, clinical outcomes and the natural history of these rare conditions. Such information will help to improve quality of care and to plan services, as well as to assist in research initiatives including clinical trials and the recruitment of volunteer patients. Policies concerning reference centres, networking and cross-border health, make the development of registries at healthcare facility, national and international level, necessary tools to facilitate the creation and implementation of these policies.</p> <p>The current lack of reliable and comprehensive national registries for thalassaemia and haemoglobinopathies suggests a gross underestimation of the prevalence of these disorders in Europe. In addition, knowledge and understanding of the distribution of patients and prevalence of the disease in each country is a huge contributing factor to public health planning. Thus, in the effort to assist the development of targeted public health policies for the provision of quality healthcare for thalassaemia patients, TIF has in 2018 developed an</p>	

electronic health record for thalassaemia, with due consideration of EU GDPR<sup>7</sup> legislation in regards to ethical and privacy issues.

The Thalassaemia EU Electronic Health Record was piloted to 6 EU centres in 2019 with further architectural refinements required, thus pushing the official launch into 2020 (See THALIA2019 Periodic Report). Centres in Greece and Cyprus officially declared their interest in adopting the Thalassaemia Electronic Health Record (See THALIA2019 Periodic Report), and procedures were initiated in late 2019 to reach agreements with hospital administrations regarding the installation of the software to ensure safety of data and server security. These procedures continued into early 2020, and a further 2 centres demonstrated interest in the Health Record.

**COVID-19 Impact:** Reprioritisation of hospital administrations and national health authorities in March / April 2020 to deal with the COVID-19 pandemic brought a halt to the discussions. Focus was shifted to promotion of the Health Record to thalassaemia centres in Europe in the interim period until discussions with authorities could resume. Furthermore, national lockdown measures severely impacted the completion of the final architectural refinements and hosting issues thus affecting the installation timeline. Once discussions with hospital administrations in Cyprus resumed in M8, bureaucratic challenges regarding licensing and deployment to 4 centres in Cyprus were met (M9 – M12) involving the the State Health Services Organisation, the Health Insurance Organisation, the National Committee of Electronic Health, the treating doctors and the patients through the Pancyprian Thalassaemia Association. Discussions with health authorities in Greece have not progressed on account of health priority adjustments and more specifically, the treatment of COVID-19 patients in all hospitals. Thus, significant delays have occurred in data entry.

Monitoring the spread of Thalassaemia and haemoglobinopathies in Europe is pivotal to advocating for the improvement of services provided to patients, and tailored to the needs of specific areas/regions. Therefore, entertaining the significant delay in the widespread deployment of the Health Record in Member States, and given the unknown duration of the COVID-19 pandemic which will remain as a health priority for the imminent future, the Internal Evaluation Committee sought to identify alternative ways to ascertain more accurately the epidemiology of thalassaemia in Europe. Thus a targeted literature review of all published information and websites concerning the prevalence of thalassaemia and migrants in Europe was undertaken in M9 – M12. The result, a peer-reviewed article is expected to be published in early 2021.

**RESULTS  
ACHIEVED**

- Architectural refinement of Thalassaemia EU Electronic Health Record completed.
- Licensing & deployment procedures undertaken for 4 centres in Cyprus.
- Literature review on prevalence of thalassaemia in Europe.

<sup>7</sup> General Data Protection Regulation  
<https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32016R0679&from=EN>

<b>TASK</b>	<b>T4.4: Policy Recommendation and position paper on Thalassaemia in Europe</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b>  Policy Officer, Eleni Antoniou (Leader)  Medical Advisor, Dr Michael Angastiniotis  P.A. to the Executive Director, Maria Peletie</p> <p><b>Supervising Staff:</b>  Executive Director, Dr Androulla Eleftheriou</p>
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>▪ Charter of Priorities for each THALIA country (MS13)</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Formation of a multidisciplinary team of experts: Feb 2020</li> <li>▪ Development &amp; distribution of <i>Haemobarometer</i> survey: Mar – Jul 2020</li> <li>▪ Data analysis: Aug – Oct 2020</li> <li>▪ Presentation of unmet patient needs at 2 prestigious conferences: Oct &amp; Dec 2020</li> <li>▪ Compilation of a Policy Recommendation for Thalassaemia in Europe: Oct – Dec 2020</li> <li>▪ National Charters of Priorities for France, Germany, Austria and Sweden: Oct – Dec 2020</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p><b>Overview</b></p> <p>Acknowledging the information compiled by on-site visits to the THALIA priority countries in 2018–19 (FPA T.4.1) in addition to the data concentrated in the Thalassaemia EU Health Record (T4.3), the Haemobarometer and in other interactions with patients, parents, carriers, HCPs and policy-makers, TIF composed in 2020 a Policy Recommendation paper providing an overview of the multiple factors that impact the lives of people with Thalassaemia and Sickle Cell Disease living in the European Union and highlighting specific recommendations addressed to policymakers in order to address key challenges, unmet needs and policy gaps and ultimately improve the patients' health and lives.</p> <p>Although the situation amongst Member States is remarkably diverse and depends on several external and internal factors, including the historic prevalence of the disease, the policy advocacy team identified some recurring concerns that are of interest for the EU bodies and Member States to fill-in the existing policy gaps: the changing epidemiology of these diseases that is due to past and recent migration; the limited number of disease-specific registries; the absence of screening policies across Member States; the limited access of patients to appropriate multidisciplinary care; the social isolation of patients to the detriment of their mental health; the rights of patients that are at stake.</p> <p>The Policy Recommendation paper was subsequently summarised in succinct Charters of Priorities, tailored for the needs of each THALIA country of priority (i.e. Austria, France, Germany, Sweden) to be used as an advocacy tool by patient associations.</p>	

### **Description of Workflow**

A multidisciplinary team of experts was formed in M2 with the purpose to develop a specific survey focusing on the patient perspectives on clinical and social services provided in their respective countries and how these affect their daily lives. The team proceeded to develop the survey, known as '*Haemobarometer*', in M3 and it was subsequently validated (M4) and distributed online and offline in M5 – M7. The data collected was subsequently analysed by the team albeit with some delay on account of disruptions due to COVID-19 (e.g. national lockdown measures, social distancing). The analysis, completed in M10 was presented at the UK Annual Thalassaemia & Sickle Cell Disease Conference and TIF's European Thalassaemia & Sickle Cell Disease Symposium (See WP2) by Dr Androulla Eleftheriou (TIF Executive Director). In parallel (M10–M12), the data collected from the *Haemobarometer*, as well as information compiled from on-site visits to the THALIA priority countries in 2018–19 (see T.4.1) in addition to the data concentrated in the Thalassaemia EU Health Record (T4.3) and in other interactions with patients, parents, carriers, HCPs and policy-makers were amalgamated to compose the Policy Recommendation and Charters of Priorities, tailored to the needs of each THALIA priority country (M12).

Dissemination of all policy documents is planned for Q1 2021, in addition to the translation (FR, DE, SWE) of the Charters of Priorities.

#### **RESULTS ACHIEVED**

- Formation of a multidisciplinary team of experts
- Development & distribution of *Haemobarometer* survey
- Data analysis
- Presentation of unmet patient needs at 2 prestigious conferences
- Compilation of a Policy Recommendation for Thalassaemia in Europe
- National Charters of Priorities for France, Germany, Austria and Sweden.

TASK	<b>T4.6: High-level round table discussion on Thalassaemia in the EU</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b>            Policy Officer, Eleni Antoniou (Leader)            Medical Advisor, Dr Michael Angastiniotis            Communications Officer, Aikaterini Skari</p> <p><b>Supervising Staff:</b>            Executive Director, Dr Androulla Eleftheriou</p>
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>▪ Organisation of 1 event</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Preparatory meeting with Greece: Jul 2020</li> <li>▪ Preparatory meeting with Cyprus: Nov 2020</li> <li>▪ THALIA2019 High Level Meeting: Dec 2020</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>The THALIA2019 Forum is the first informal forum of dialogue aimed at providing EU Member States with the opportunity to informally exchange views and experiences on addressing the multifaceted problem of the migration of thalassaemia. Traditionally an endemic disease of the Mediterranean region, thalassaemia was first addressed in Cyprus, Greece, Italy and the United Kingdom through the establishment of national control programmes. The THALIA2019 Forum would thus provide participants with the opportunity to learn from each other and touch upon a much neglected topic that consists an emerging public health: the rise of thalassaemia in all EU countries.</p> <p>Given that not only affected patients are increasing but also healthy carriers and that these disorders follow a Medelian inheritance pattern (i.e. from parents to children), the phenomenon is expected to greatly affect the future birth incidence of these conditions in Europe. This calls for long term policy considerations and has urged TIF to create a platform of dialogue for EU Member States, as there are no formal prevention policies in place in most countries, while specialised clinical care is only provided in selected centres. Also, there is a general absence of national registries that would allow for better monitoring, planning and resource management.</p> <p>Postponement of the event (see THALIA2019 Periodic Report) due to the limited availability of Ministries of Health and other high-level decision makers to participate has enabled TIF to pursue better planning and coordination for the organisation of the event in 2020. Regretfully the occurrence of the COVID-19 pandemic in early 2020 across EU Member States, led to the reprioritisation of health issues by national competent authorities and the European Commission and other decision-making bodies.</p>	

Seeking to maintain the momentum built throughout 2019, and to continue the discussion with national health authorities, even on an individual basis, two preparatory meetings were organised. The scope of these meetings focused on the recognition of the public health burden of haemoglobinopathies by the respective governments of both countries in the 1970s and the subsequent implementation of national programmes to ensure the appropriate diagnosis and clinical management of patients and screening of carriers. These national programmes constitute global models in the appropriate control of the disorders, and hence can provide best practice examples for other European countries, that have only recently received migrants from high prevalence countries and are facing significant challenges in the provision of appropriate multidisciplinary care across the patient lifespan.

Preparatory meeting with Greece: The virtual round-table discussion chaired by the Ministry of Health of Greece was held on 09 July 2020. A multi-stakeholder affair, participants included the Greek Thalassaemia Federation (including Ms Eleni Michalaki – TIF Board Member), Dr Ersi Voskaridou (Head of Thalassaemia Centre at Laikon Hospital, Athens), Prof. Evagelia Yannaki (Haematologist at G. Papanikolaou Hospital, Thessaloniki), representatives of reimbursement agencies, national health services, Ministry of Health and others. TIF was represented by Dr Androulla Eleftheriou (TIF Executive Director), Dr Michael Angastiniotis (TIF Medical Advisor), Ms Lily Cannon (TIF Operations Manager) and Ms Eleni Antoniou (TIF Policy Officer).

Preparatory meeting with Cyprus: In addition, on 16 November 2020, a meeting with H.E. Mr Nicos Anastasiades, President of the Republic of Cyprus and the Honourable Mr Constantinos Ioannou, Minister of Health was held to discuss the Cyprus Thalassaemia Programme as a best practice model for other EU Member States. Mr Panos Englezos (TIF President) and Dr Androulla Eleftheriou (TIF Executive Director) participated on behalf of TIF.

Taking into account the positive results of the preparatory meetings, coupled with the resurgence of the pandemic in the autumn of 2020, the TIF Board of Directors and Internal Evaluation Committee decided that the THALIA2019 would be organized in a virtual environment.

The high-level virtual meeting took place on 10 December 2020 with the participation of the European Commissioner for Health and Food Safety, Mrs Stella Kyriakides, the Greek Deputy Minister of Health, Dr Vassilis Kontozamanis, and Senior Medical Officer of the Cyprus Ministry of Health, Dr Myrto Azina. The TIF Delegation comprised of Mr Panos Englezos (TIF President), Dr Androulla Eleftheriou (TIF Executive Director), Dr Michael Angastiniotis (TIF Medical Advisor), Ms Lily Cannon (TIF Operations Manager) and Ms Eleni Antoniou (TIF Policy Officer).

Focusing on highlighting connection between migration and thalassaemia, participants unanimously agreed that synergies should be developed between EU Member States, where more experienced countries, such as Cyprus and Greece, could be shared with the competent health authorities in other Member States, which have seen a rise in numbers of patients with thalassaemia recently.

The Commissioner expressed her interest to continue the discussion, so as to find the appropriate solutions to these increasing challenges, in collaboration with her counterpart Mr Margaritis Schinas, Vice-President of the European Commission responsible for migration related issues.

Moreover, TIF continues its efforts with national health authorities across the EU encouraging cross-border collaboration between THALIA priority countries with their counterparts in *more experienced* EU Member States of the Southern Mediterranean.

**RESULTS  
ACHIEVED**

Despite the event's postponement in 2019, and the adjustment of health priorities in 2020 TIF has managed to:

- 1) Raise awareness on the migration of haemoglobinopathies and attract the interest of certain Ministries of Health;
- 2) Emphasize the experience of Cyprus and Greece in development of holistic programmes for thalassaemia that can serve as best practice examples to other EU Member States;
- 3) Initiate and maintain a dialogue at the highest level of the European Commission concerning thalassaemia and migration.



## IMPACT ASSESSMENT

### Methodology (*The Impact Model*)

TIF's Impact Model serves to compile a complete set of questions which, when answered, allows a conclusive and comprehensive impact assessment of the annual activities. Did the activities fulfil the expectation of the THALIA stakeholders? What were the main outputs of THALIA? What effects did THALIA produce, directly and on the long term? These are examples of questions the impact assessment intends to answer. The Impact Model is focusing on the evaluation strand of the Logic Model.

In order to take the whole process of THALIA into account, TIF's Impact Model is structured according to four main stages: (1) inputs, (2) outputs, (3) outcomes and (4) impacts. The first stage (1) consider aspects that can be evaluated before or at the beginning of THALIA, whereas the three others stages (2-4) consider aspects that can be measured conclusively only after the programme has been finished. All have been analysed in the respective THALIA2018 proposal and have been linked to specific indicators. More specifically:

1. Inputs: Inputs include not only financial means but also human resources, equipment, knowledge and ideas.
2. Outputs: Outputs represent the direct results of the activities realised.
3. Outcomes: Outcomes are defined as the effects of the outputs on the target audiences. Outputs may benefit in terms of increased knowledge, improved networking and cooperation skills or access to new markets.
4. Impacts: Impacts are the wider effects of TIF's THALIA activities. These are defined as the benefits for the immediate target audience and users of the outputs. The benefits for the society at large are called relative impacts.

To assess impact, it is important to have a set of basic criteria and compare them against the indicators set in the THALIA annual plan:

	CRITERIA	KEY QUESTIONS
1	RELEVANCE	Are the "general objective" and "specific objectives" still meaningful?
2	EFFECTIVENESS	Has the objective been achieved? How much contribution did the "outputs" make?
3	EFFICIENCY	To what extent have "inputs" been converted to "outputs"?
4	IMPACT	What positive or negative, direct or indirect effects have happened?
5	SUSTAINABILITY	To what extent will TIF be able to maintain the positive results of its activities?

<b>Criteria</b>	<b>Relevance</b>	<b>Effectiveness</b>	<b>Efficiency</b>	<b>Impact</b>	<b>Sustainability</b>
<b>Tasks</b>	<i>Are the "general objective" and "specific objectives" still meaningful?</i>	<i>Has the objective been achieved? How much contribution did the "outputs" make?</i>	<i>To what extent have "inputs" been converted to "outputs"?</i>	<i>What positive or negative, direct or indirect effects have happened?</i>	<i>To what extent will TIF be able to maintain the positive results of its activities?</i>
<b>T.4.1: Establishment of national associations in France, Germany, Austria, Sweden and Serbia</b>	Establishing national associations or networks of thalassaemia patients is key to support EU countries with no tradition in the prevention and management of thalassaemia.	Follow up delegation visits (conducted virtually on account of the COVID-19 pandemic) to the priority countries (FR, DE, AUS, SRB & SWE) allowed TIF to build on partnerships with local thalassaemia-related stakeholders created in 2018 and 2019, and to further enrich TIF's knowledge on the wide and deep implications of thalassaemia in the migrant communities of these countries. This enabled TIF to further encourage patients to join forces and take action to safeguard of their right to health and quality of life in addition to creating avenues for their psychological support and breaking social isolation and marginalisation.	The "inputs" required for the implementation of this task were optimally used, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners, contacts.	THALIA2020 further allowed patients to come together, develop synergies with doctors and participate in disease-specific policy dialogue. The very presence of TIF in all countries reactivated local communities and showed the way forward to more inclusive societies. Moreover, unity against a common <i>enemy</i> (SARS-Cov-2) further solidified relationships and partnerships that for years had been loose collaborations.	To maintain results and the momentum created, follow-up visits in each country were added in the 2021 work programme and regular communication with all stakeholders and local contacts was established. More targeted efforts in collaboration with local health authorities are needed to achieve greater results in Serbia.
<b>T4.2: TIF EU Thalassaemia Associations' Twinning Programme</b>	This task is directly related to the general objective and serves to facilitate the exchange of best practices	The specific objective was achieved as patients were empowered to achieve the implementation of	The "inputs" required for the implementation of this task were optimally used, namely: staff time, planning	Through the Twinning Programme, TIF was able to support the mental health of patients living in	Patients were invited to participate in all 2021 workshops organised by TIF. Associations were encouraged to

	between national thalassaemia associations. The Twinning Programme is a promising tool to bring patients of Europe together and bridge the knowledge gaps between associations.	thalassaemia-specific considerations by professional associations at the national level.	time, financial means, knowledge base, technology, partners.	THALIA countries in the context of the COVID-19 pandemic. The patients who participated in the programme showed interest in furthering their efforts for raising awareness about thalassaemia in their local communities.	maintain communication and also join TIF's Thalassaemia Patient Connect platform in addition to completing the Thal e-course, thus ensuring their access to quality information.
<b>T4.3: Thalassaemia EU Electronic Health Record</b>	This tool is essential for evidence-based policy making and is considered to be the best way to monitor the spread of thalassaemia and haemoglobinopathies in Europe.	The Electronic Health Record underwent architectural refinements, which drove forward the discussions for licensing and deployment.	The "inputs" required for the implementation of this task were used as best as possible, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners.  Impact of COVID-19 pushed timelines back as priorities of hospital administrations focused elsewhere.	A number of clinics from Greece, Cyprus, Sweden, Austria & Germany have expressed their interest in using this tool and will be open to continue the discussion once the pandemic has subsided.	TIF will be sharing news on the tool's development progress to increase visibility.
<b>T4.4: Policy Recommendation and position paper on Thalassaemia in Europe</b>	This document is essential for the European Commission and Member States to recognise the existing policy gaps and address them through targeted measures.	N/A- Activity Ongoing	The "inputs" required for the implementation of this task were optimally used, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners.	Delay in analysis of data, has pushed back dissemination of the Policy Recommendation and Charters of Priorities as well as their translations.	The simultaneous bottom up (with patients) and top down (with decision-makers) approach of TIF has resulted in successful policy changes throughout the years. The maintenance of this continual

<p><b><i>T4.6: High-level round table discussion on Thalassaemia in the EU</i></b></p>	<p>This task serves the need to further inform policymakers about migrant populations with thalassaemia.</p>	<p>This activity was postponed in 2019, and despite other health priorities emerging in 2020 was implemented thus raising awareness among policy-makers at the highest level.</p>	<p>The “inputs” required for the implementation of this task were optimally used, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners.</p>	<p>Increased interest of policy-makers on public health issues pertaining to the migration of thalassaemia.</p>	<p>momentum with both stakeholders is the key. More intensive and systematic efforts will need to be made in early 2021 to further ensure that all Member States are aware of the epidemiological shift that threatens the national health systems, in addition to follow up meetings with other relevant decision-makers to maintain the momentum built.</p>
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