



## PROGRESS OUTLINE 2018



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### PILLAR 3: POLICY ADVOCACY

*Activities*

*Impact*

*Lessons Learned*

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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 2018, intensive efforts were put to perform a thorough needs analysis of THALIA priority countries, namely France, Germany, Austria, Sweden and Serbia and at the same time reactivate the local associations of France, the year’s country of focus. Delegation visits were organised in all countries (T4.1) to map the situation and assess the needs of all THALIA target groups: patients (especially migrants and refugees with thalassaemia), healthcare professionals treating thalassaemia and sickle cell disease patients and decision-making bodies. This needs analysis was complemented by the launch of the THALIA Twinning Programme (T4.2) that brought together patients from France that have limited expertise in policy advocacy and patients from Cyprus with a long history of participating in the making of ground-breaking policies on thalassaemia prevention and management. To support evidence-based policy-making, TIF developed the infrastructure of an EU Electronic Health Record for thalassaemia and haemoglobinopathies. Moreover, an initial effort was made for the publication of a joint statement on the needs of EU-based patients coming from Syria, in collaboration with the International Organization for Migration and the United Nations Office of the High Commissioner for Refugees.

This pillar’s activities provided TIF with useful insights regarding the current state of affairs in EU Member States, validating THALIA concerns on the increase of the thalassaemia population in Europe and TIF’s decision to focus on EU countries for the years to come.

## 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 204 members from 62 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 Europe. 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.

## 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	T4.5
<b>Target Audience</b>	Patients Policy/ decision makers HCPs	Patients	Policy/ decision makers HCPs	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 France visited Cyprus in 2018 for a face-to-face capacity-building / sharing-of-best-practices meeting

**Impact:** A core group of thalassaemia patients was formed, willing to create a national thalassaemia network in France and empower peers.

**Impact Management / Mitigation Measures:** To maintain the momentum, TIF will support the participation of thalassaemia patients from France in 2019 workshops and conferences and strategically guide the core group to become more active and support patients living in France.

**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 all countries of priority (France, Germany, Austria, Sweden, Serbia), performed a situation/needs analysis and drew a number of conclusions based on findings.

**Impact:** Grass roots work increased the interest of all target audiences in the work of TIF and on the migration of thalassaemia to Europe. It also confirmed TIF's concerns and gave rise to EU-specific challenges that need to be surpassed in the framework of THALIA.

**Impact Management / Mitigation Measures:** To maintain the momentum, TIF shall intensify its efforts in 2019 towards strengthening existing policies, empowering patients and informing healthcare professionals about the prevention and management of the disease.

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

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

**Results:** The infrastructure of this decision-making support tool was developed and a number of specifications were adopted and implemented.

**Impact:** Clinics in Europe expressed interest in participating in the 2019 pilot testing of the Electronic Health Record, given the unavailability of such a tool in their respective countries. This validates the need to complete the development process, test and further disseminate it.

**Impact Management / Mitigation Measures:** The interest of clinics will be utilised in 2019 to pilot test and further promote the tool. The higher the number of participating clinics, the more effective the tool will be in the hands of policymakers.

**III.5.** Raise awareness within Europe about the needs of thalassaemia patients living in and coming from Syria, especially as regards to their access to medical assistance and healthcare.

**Activity: T4.5:** Shedding light on the needs of patients originating from Syria

**Results:** An initial effort to publish a joint statement with the International Organization for Migration and the United Nations Office of the High Commissioner for Refugees was made. A migration-specific awareness campaign on social media was run, yielding encouraging results regarding the levels of interest of the European public on the subject matter.

**Impact:** In 2018, the ground was set to raise awareness among policymakers and develop synergies regarding the migration of thalassaemia.

**Impact Management / Mitigation Measures:** TIF will resume efforts to publish a joint statement in early 2019, while the subject-specific social media campaign will be repeated in the course of 2019.

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

TASK	<b>T4.1: Establishment of national associations in France, Germany, Austria, Sweden and Serbia</b>
RESPONSIBLE STAFF, SUPERVISING STAFF	<p><b>Responsible Staff:</b> Medical Advisor, Dr Michael Angastiniotis (Leader) Policy Officer, Eleni Antoniou</p> <p><b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou</p>
INDICATORS	<ul style="list-style-type: none"> <li>▪ Number of patients identified during the delegation visits to France: 50</li> <li>▪ Number of healthcare professionals identified the delegation visits to France: 20</li> </ul>
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> <li>▪ Delegation visit to France: April, September &amp; November 2018</li> <li>▪ Delegation visit to Germany: November 2018</li> <li>▪ Delegation visit to Sweden: November 2018</li> <li>▪ Delegation visit to Austria: May &amp; September 2018</li> <li>▪ Delegation visit to Serbia: October &amp; December 2018</li> </ul>

## DESCRIPTION OF THE ACTIVITY

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.

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). In this case at least two delegation visits are necessary per year per country: one investigational and one follow-up.

Each TIF delegation team comprises 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.

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-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.

Aiming to ascertain the situation concerning thalassaemia in each priority country of the THALIA project (i.e. France, Germany, Sweden, Austria and Serbia), whilst at the same time establish a thalassaemia patient association in France and/or strengthen the existing ones (if they exist), TIF has conducted a series of delegation visits in 2018.

### Objectives of the Visit

The objectives of these delegation visits, in accordance to the three main stakeholder groups involved in the control of thalassaemia, are:

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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-elftheriou-a/>

### **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, TIF Digital Library, 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. Train-the-Trainers 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, TIF Mobile app, Publications, Thalassaemia Patients Connect 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 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.)

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/>

The visits have yielded the following notable information (per country):

### **Delegation visit to France**

#### **April 2018**

##### Introduction

A TIF Delegation visit to Paris, France took place on 10 -12 April 2018. The Delegation Team consisted of Dr Androulla Eleftheriou (TIF Executive Director) and Dr Michael Angastiniotis (TIF Medical Advisor).

The Delegation Team had the opportunity to participate in the 53<sup>rd</sup> Annual Meeting of the European Association for the Study of Liver, and to meet with physicians working in the field of the thalassaemia in France.

During the meetings, the TIF Delegation Team had the opportunity (1) to present the work of the Federation, sharing best practice examples from across the world, and (2) to discuss the changing epidemiology of thalassaemia in Europe, taking into account the impact of the recent migration influx and the consequent additional pressure on the national healthcare systems and its provision of quality healthcare services.

##### Main Findings:

- Thalassaemia in France is a rare disease, with patients scattered across the country.
- The rarity of the disorder leads many physicians to having limited experience in the management of thalassaemia, and others with accumulated knowledge.
- There is a Federation of Haemoglobin Disorders Patient Associations in existence, namely 'SOS Globi' which encompasses thalassaemia.

#### **September 2018**

##### Introduction

A TIF Delegation visit to Paris, France took place on 13 – 14 September 2018. The Delegation Team consisted of Mr. George Constantinou (Assistant Secretary of the TIF Board of Directors and Expert Patient), and Professor Dimitris Loukopoulos (member of TIF' International Scientific Advisory Board).

The Delegation Team had the opportunity to meet with representatives of the following:

- Haemoglobinopathies Center at Henri Mondor Hospital in Creteil
- Necker- Enfants Malade Hospital
- 'SOS Globi' Federation of patients with sickle cell and thalassaemia
- EURORDIS' Paris Office
- European Commission Office
- French Ministry of Interior
- French Society of Haematology
- Ambassador of Cyprus in Paris



During the meetings, the TIF Delegation Team had the opportunity (1) to present the work of the Federation, sharing best practice examples from across the world, and possible applications for each stakeholder, (2) to discuss the epidemiology of thalassaemia in the country, healthcare service structure and provisions to patients as well as the socioeconomic challenges witnessed, (3) to talk about the challenges that patients face in their everyday lives (including social, occupational and education development) and their quality of life, and (4) to consider the impact of the recent migration influx and the consequent additional pressure on the national healthcare systems and its provision of quality healthcare services. Furthermore, possible avenues of collaboration were discussed with each stakeholder party.

#### Main Findings:

- i. The level of knowledge and expertise of French physicians working in the field of haemoglobin disorders is of outstanding quality, demonstrated by the excellent care provided to patients through a vast network of Reference Centres and Centres of Expertise across the country, the existence of a national registry, nationally developed guidelines for the treatment of thalassaemia, ongoing involvement in clinical research and trials, and regular involvement in continuous medical education activities of the MCGRE network.
- ii. Patients/Parents require more information on the disease and its treatment and consequences, in electronic, printed and face-to-face formats. This was unanimously agreed upon by the 20 patients which the TIF Delegation met with.
- iii. 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.
- iv. Strengthening of SOS Globi infrastructure is necessary in order to promote more tangible and impactful activities for thalassaemia.
- v. In the absence of formal national screening programmes, the number of carriers remain unknown.
- vi. Although the increasing number of patients with thalassaemia is resounded at all levels, it is challenging to obtain accurate figures to measure the magnitude of change.
- vii. French physicians have stated an interest in establishing a closer collaboration with TIF, in mainly in the further training of healthcare staff and provision of information to patients and their families. This was expressed by the physicians which met with the TIF Delegation (6 at Henri Mondor Hospital; 8 at Necker- Enfants Malade Hospital; 2 from French Society of Haematology).

### **November 2018**

#### Introduction

A TIF Delegation visit to Paris, France took place on 09 November 2018. The Delegation Team consisted of Mr. George Constantinou (Assistant Secretary of the TIF Board of Directors and Expert Patient), and Mr. Rawad Merhi (TIF Office Administrator). This was the third delegation visit to France in 2018, which built on the relationships and collaborations developed in the previous 2 delegation visits, and focused on further understanding the patients and their associations.

The Delegation Team had the opportunity to participate in the 2<sup>nd</sup> Associations Meeting of the MCGRE Network, and to meet with representatives of the network. MCGRE is a network of health professionals and patients created in 2014, aiming to promote the care of patients with Haemoglobin disorders. The network works towards the establishment of common guidelines for clinical and laboratory practices as well as to exchange best practices and facilitate the sharing of information and experiences for providing better quality healthcare services. Furthermore, the network works with patient associations to provide information and guidance to patients and their families.

During the visit, the TIF Delegation Team had the opportunity (1) to present the work of the Federation, sharing best practice examples from across the world, and possible applications for each stakeholder, (2) to talk about the challenges that patients face in their everyday lives (including social, occupational and education development) and their quality of life, and (3) to distribute TIF publications and educational material in a dedicated booth in the exhibition area. Furthermore, possible avenues of collaboration were discussed to further strengthen and empower thalassaemia patients and their associations that participate in the Network. This was discussed during a dedicated meeting with members of the patient associations. 34 patients with thalassaemia attended the meeting.

#### Main Findings:

- i. The number of thalassaemia patients in France is considerably lower than those with sickle cell disease, however the two communities often use the same services and visit the same medical teams, as noted by the physicians with whom the TIF Delegation met (a total of 5).
- ii. The medical community in France is well versed in the complications and intricacies concerning the treatment of sickle cell disease, however more in-depth knowledge is required for thalassaemia, especially by nursing staff, emergency departments, cardiac, liver, endocrine specialists etc.
- iii. Although carrier screening is not routinely practised, there is availability for prenatal diagnosis, upon request.
- iv. Strengthening of knowledge and empowerment of patients, through the organisation of a workshop is required.

#### Delegation visit to Germany

##### **November 2018**

#### Introduction

A TIF Delegation visit to Hamburg, Germany took place on 19 – 20 November 2018. The Delegation Team consisted of Mr. George Constantinou (Assistant Secretary of the TIF Board of Directors and Expert Patient), and Dr Michael Angastiniotis (TIF Medical Advisor).

The Delegation Team had the opportunity to meet with representatives of the following:

- Hamburg University Hospital
- Seltene Anämien Deutschland & E.V (SAM) patient organization
- Consulate General of Cyprus in Hamburg

During the meetings, the TIF Delegation Team had the opportunity (1) to present the work of the Federation, sharing best practice examples from across the world, and possible applications for each stakeholder, (2) to discuss the epidemiology of thalassaemia in the country, healthcare service structure and provisions to patients as well as the socioeconomic challenges witnessed, (3) to talk about the challenges that patients face in their everyday lives (including social, occupational and education development) and their quality of life, and (4) to consider the impact of the recent migration influx and the consequent additional pressure on the national healthcare systems and its provision of quality healthcare services. Furthermore, possible avenues of collaboration were discussed with each stakeholder party.

#### Main Findings:

- i. Thalassaemia in Germany is a rare disease, with patients scattered across the country, with limited access to reference centres.
- ii. The rarity of the disorder leads many physicians to having limited experience in the management of thalassaemia, and others with accumulated knowledge. The exchange of expertise in such cases is of great value, especially with other thalassaemia clinics in TIF's Network of Collaborating Centres.
- iii. Development of national guidelines for the treatment of thalassaemia, based on TIF's International Guidelines<sup>3</sup> is imperative.
- iv. Awareness and knowledge about thalassaemia amongst healthcare professionals, patients, carriers, the migrant communities and the society at large is limited.
- v. The unavailability of a complete national registry for thalassaemia hinders the ability of health authorities to make appropriate and targeted service planning. It is noted that a registry was initiated in 2014 but is not yet fully populated.
- vi. Several local/regional associations for thalassaemia patients have formed, maintaining however little contact with each other hence the absence of coordinated and targeted advocacy activities, as expressed by patients who met with TIF both from Hamburg (approx. 15), Göppingen (1 patient) and Drolshagen (1 patient).
- vii. The establishment of a German network of associations would be a powerful vehicle for exchange of knowledge, experiences, promoting advocacy and alleviating isolation and marginalisation.
- viii. The recent migration influx has increased the number of patients however readjustment of services and planning to deal with the growing needs is limited leading to added pressures on the healthcare system.
- ix. Empowerment of patient associations through knowledge (e.g. Thal e-course, workshops, publications in Germany language) and advocacy tools (e.g. registry) is essential.

## Delegation visit to Sweden

November 2018

### Introduction

A TIF Delegation visit to Sweden took place on 15 – 16 November 2018. The Delegation Team consisted of Mr. George Constantinou (Assistant Secretary of the TIF Board of Directors and Expert Patient), and Dr Michael Angastiniotis (TIF Medical Advisor).

The Delegation Team had the opportunity to meet with representatives of the following:

- Department of Clinical Chemistry at the Skane University Hospital, Malmö
- Lund Hospital Children's Day Care Centre
- Karolinska University Hospital in Stockholm
- Swedish Blood and Cancer Association NGO

During the meetings, the TIF Delegation Team had the opportunity (1) to present the work of the Federation, sharing best practice examples from across the world, and possible applications for each stakeholder, (2) to discuss the epidemiology of thalassaemia in the country, healthcare service structure and provisions to patients as well as the socioeconomic challenges witnessed, (3) to talk about the challenges that patients face in their everyday lives (including social, occupational and education development) and their quality of life, and (4) to consider the impact of the recent migration influx and the consequent additional pressure on the national healthcare systems and its provision of quality healthcare services. Furthermore, possible avenues of collaboration were discussed with each stakeholder party.

### Main Findings:

- i. The numbers of patients with thalassaemia in Sweden are steadily increasing due to migrations from the Middle East, mainly from countries, where thalassaemia is most prevalent.
- ii. Awareness and knowledge about thalassaemia amongst healthcare professionals, patients, carriers, the migrant communities and the society at large is limited.
- iii. Thalassaemia is a rare disease in Sweden, with concentrated knowledge about the disease being found in a few number of specialists in main urban hubs, and limited experience found in remoter areas.
- iv. Recognition of the social impact, complications and health risks of thalassaemia is limited.
- v. Patients often feel isolated and marginalized, due to the lack of a respective association advocating for their rights and needs, and providing necessary patient materials for information and education. A position expressed by all patients met by the TIF Delegation (a total of 3).
- vi. Where there are services provided, the knowledge and expertise of Swedish physicians working in the field of haemoglobin disorders is of outstanding quality albeit continuous medical education is always welcomed through electronic, printed and workshop formats.
- vii. There are no dedicated screening programmes for thalassaemia and sickle cell disease.
- viii. The unavailability of a complete national registry for thalassaemia hinders the ability of health authorities to make appropriate and targeted service planning.

- ix. Establishment of a patients association would empower patients, as a means to advocate for the adjustment of to meet the growing needs of the patient population, both medically and socially.

#### Delegation visit to Austria

May 2018

#### Introduction

A TIF Delegation visit to Vienna, Austria took place on 10 – 12 May 2018. The Delegation Team consisted of Dr Androulla Eleftheriou (TIF Executive Director) and Mr. Angelo Loris Brunetta (TIF Board Member).

The Delegation Team had the opportunity to participate in the 9<sup>th</sup> European Conference on Rare Diseases & Orphan Product of the European Organisation for Rare Disorders (EURORDIS), and to meet with representatives of rare disease patient associations from Europe, including the following:

- European Organisation for Rare Disorders
- Rare Diseases International
- National Rare Disease Alliance – Austria (Pro-Rare)
- European Patients Forum
- National Centre of Competence for Rare Diseases – Ågrenska (Sweden)

During the meetings, the TIF Delegation Team had the opportunity (1) to present the work of the Federation, sharing best practice examples from across the world, (2) to discuss the changing epidemiology of thalassaemia in Europe, taking into account the impact of the recent migration influx and the consequent additional pressure on the national healthcare systems and its provision of quality healthcare services and (3) to talk about the challenges that patients face in their everyday lives (including social, occupational and education development) and their quality of life.

#### Main Findings:

A mutual concern considering the readiness and service planning for rare diseases, such as thalassaemia was expressed by all. Hence, TIF, the European Organisation for Rare Disorders, Rare Diseases International, the European Patients Forum, and the National Centre of Competence for Rare Diseases – Ågrenska (Sweden) decided to take common steps towards sensitizing policy -makers at the European and International level regarding the increasing numbers of thalassaemia patients and carriers in Europe and to urge Member States, including the THALIA priority countries to take measures to accommodate the increasing demands on the healthcare system. The results of these efforts were most evidently shown by:

- i. Two Statements at the World Health Assembly (21–26 May 2018, Geneva) on:
  - i.1. 'Promoting the health of refugees and migrants' (Agenda Item 20.3.4.1.K. / Resolution WHA70.15 (2017))
  - i.2. Preparation for the third High-level Meeting of the General Assembly on the Prevention and Control of Non-Communicable Diseases, to be held in 2018' (Agenda Item '11.7).

- ii. Statement at the 38th Session of the Human Rights Council (18 June – 6 July 2018, Geneva) on the ‘The ‘Right to Health in Rare Diseases’.
- iii. Statements at the 68<sup>th</sup> session of the Regional Committee for Europe (18 – 20 September 2018, Rome) on:
  - iii.1. Agenda item 3: Development of a draft global action plan on the health of refugees and migrants (resolution EUR/RC68/Inf.Doc./9)
  - iii.2. Agenda item 5: Action plan for the prevention and control of noncommunicable diseases (resolution EUR/RC66/R11)
  - iii.3. Agenda Item 5 (o): Action Plan to Strengthen the Use of Evidence, Information and Research for Policy- Making in the WHO European Region (resolution EUR/RC66)

September 2018

### Introduction

A TIF Delegation visit to Vienna, Austria took place on 24 – 25 September 2018. The Delegation Team consisted of Mr. Angelo Loris Brunetta (TIF Board Member), and Ms. Lily Cannon (TIF Operations Manager).

The Delegation Team had the opportunity to meet with representatives of the following:

- Hematology & Oncology Department of Saint Anna’s Children’s Hospital
- Hematology & Hemostaseology Department of Vienna General Hospital
- AmberMed (an NGO working to provide free medical care to migrants)
- Austrian Red Cross Headquarters (responsible for the supply of blood and blood products to all hospitals in the country)
- Centre for Public Health of the Medical University of Vienna
- National Coordination Centre for Rare Diseases
- ORPHANET Austria

During the meetings, the TIF Delegation Team had the opportunity (1) to present the work of the Federation, sharing best practice examples from across the world, and possible applications for each stakeholder, (2) to discuss the epidemiology of thalassaemia in the country, healthcare service structure and provisions to patients as well as the socioeconomic challenges witnessed, (3) to talk about the challenges that patients face in their everyday lives (including social, occupational and education development) and their quality of life, and (4) to consider the impact of the recent migration influx and the consequent additional pressure on the national healthcare systems and its provision of quality healthcare services. Furthermore, possible avenues of collaboration were discussed with each stakeholder party.

### Main Findings:

- i. Austria is one of the main entry points into the EU for migrants traveling by land.
- ii. The numbers of patients with thalassaemia in Austria have increased in recent years with most patients being in the capital (Vienna) and fewer dispersed in Innsbruck, Graz and Linz.

- iii. Awareness and knowledge about thalassaemia amongst healthcare professionals, patients, carriers, the migrant communities and the society at large is limited.
- iv. Medical healthcare is provided by a national health insurance system to individuals who are in employment, registered as unemployed or asylum seekers. Persons who do not fit in one of these categories, rare not entitled to healthcare from public hospitals. NGO's (like AmberMed) or specific hospitals (e.g. Caritas) may provide medical care to these persons, many of whom are part of the migrant community.
- v. There are no dedicated screening programmes for thalassaemia and sickle cell disease.
- vi. The rarity of the disorder leads physicians to having limited experience in the management of thalassaemia, however there is earnest interest to learn more about the disorder and its management (including multidisciplinary care ) through continuous medical educational initiatives (e.g. workshops, e-learning, consultations with international experts etc).
- vii. The unavailability of a complete national registry for thalassaemia hinders the ability of health authorities to make appropriate and targeted service planning.
- viii. An organised patient community is not present, although the TIF Delegation had the opportunity to meet with 2 adult patients who expressed their desire to meet with other patients to discuss common issues and challenges, as well as to gain knowledge regarding thalassaemia through TIF's patient educational initiatives (e.g. printed, electronic etc).

### Delegation visit to Serbia

October 2018

#### Introduction

A TIF Delegation visit to Belgrade, Serbia took place on 12 October 2018. The Delegation Team consisted of Mr. Anton Skafi (TIF Board Member), and Dr Michael Angastiniotis (TIF Medical Advisor).

The Delegation Team had the opportunity to meet with representatives of the following:

- The Institute of Molecular Genetics and Genetic Engineering
- The University Children's Hospital
- The National Organization for Rare Diseases of Serbia (NORBS)

During the meetings, the TIF Delegation Team had the opportunity (1) to present the work of the Federation, sharing best practice examples from across the world, and possible applications for each stakeholder, (2) to discuss the epidemiology of thalassaemia in the country, healthcare service structure and provisions to patients as well as the socioeconomic challenges witnessed, (3) to talk about the challenges that patients face in their everyday lives (including social, occupational and education development) and their quality of life, and (4) to consider the impact of the recent migration influx and the consequent additional pressure on the national healthcare systems and its provision of quality healthcare services. Furthermore, possible avenues of collaboration were discussed with each stakeholder party.

### Main Findings:

- i. Thalassaemia in Serbia is found in the indigenous population, especially in the South, in accordance to previous publications<sup>4 5</sup>. Furthermore, as a major transit country for migrants travelling towards the EU from highly prevalent countries of the world, the numbers of patients and carriers could be larger than estimated.
- ii. The epidemiology and prevalence of thalassaemia is unknown due to the absence of a haemoglobinopathy patient registry to identify the number and location of patients. Updating of epidemiological data is necessary.
- iii. There are no dedicated screening programmes for thalassaemia and sickle cell disease.
- iv. The rarity of the disorder leads physicians and laboratories to having limited experience in the diagnosis and management of thalassaemia, hence international collaborations could be pursued.
- v. Development of national guidelines for the treatment of thalassaemia, based on TIF's International Guidelines<sup>6</sup> is imperative.
- vi. The unavailability of a complete national registry for thalassaemia hinders the ability of health authorities to make appropriate and targeted service planning, considering the additional pressures by the migrant influx.
- vii. An organised patient community is not present, hence the TIF Delegation did not meet with patients. Information was provided that more patients are present in Niš (South of Serbia) but further investigation is necessary, as discussed with the National Rare Disease Alliance (NORBS).

### **December 2018**

#### Introduction

A TIF Delegation visit to Belgrade, Serbia took place on 13 – 14 December 2018. The Delegation Team consisted of Ms. Lily Cannon (TIF Operations Manager), and Dr Michael Angastiniotis (TIF Medical Advisor).

The Delegation Team had the opportunity to participate in the Eastern European Conference for Rare Diseases, organized by the National Organisation for Rare Diseases (NORBS), and to meet with patient representatives of rare haematological disease associations in Serbia.

During the visit, the TIF Delegation Team had the opportunity (1) to present the work of the Federation, sharing best practice examples from across the world, and possible applications for each stakeholder, and (2) to talk about the challenges that patients face in their everyday lives (including social, occupational and education development) and their quality of life. Possible avenues of collaboration were discussed with each stakeholder party in order to identify thalassaemia patients in Serbia.

#### Main Findings:

- i. There is a need to develop national policies to deal with rare disorders in Serbia, as there is limited expertise due to the small number of patients with each disease (especially thalassaemia).



- ii. Awareness and knowledge about thalassaemia amongst healthcare professionals, patients, carriers, the migrant communities and the society at large is limited.
- iii. Identification of patients and their doctors is imperative in order to move forward.

**RESULTS ACHIEVED**

- Identification of healthcare professionals and patients with thalassaemia in each of the THALIA priority countries (FR, DE, SWE, AUS & SER).
- Establishment of 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, AUS & SER).
- 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, AUS & SER).

<b>TASK</b>	<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</p> <p><b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou</p>
<b>CALENDAR OF ACTIVITIES</b>	Twinning Programme: France – Cyprus, 4 – 5 December 2018
<b>DESCRIPTION OF THE ACTIVITY</b>	

<sup>4</sup> Efremov GD. Hemoglobinopathies in Yugoslavia: an update. Hemoglobin. 1992; 16(6): 531-54

<sup>5</sup> Pavlovic S, Urosevic J, Poznanic J, Perisic LJ et al. Molecular basis of thalassaemia syndromes in Serbia and Montenegro. ACTA Haematol. 2005; 113: 175-180 doi.10.1159/000084447

<sup>6</sup> 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/>

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.

In 2018, TIF's EU Twinning Programme aimed to serve the needs of the patient community in France (THALIA2018 priority country, see FPA No. 785243).

The Twinning Programme took place on 4 – 5 December 2018 and was participated by 2 thalassaemia patients from France (one who made the trip to Cyprus and one who participated via Skype due to ill health which made him unable to travel), and 4 thalassaemia patients representing the Cyprus Thalassaemia Association.

The thalassaemia patients from France did not belong to a patient association as the thalassaemia – specific patient associations in existence in France are currently inactive. These patients demonstrated interest to revive the activities of these associations or if necessary, create a new one in order to serve the increasing needs of the thalassaemia patient community.

The Cyprus Thalassaemia Association was selected as an appropriate 'role model' for France as it has been amongst the first thalassaemia patient associations created in 1973 with a long and vast array of actions and achievements at the national and international including (1) establishment of the Cyprus Thalassaemia Centre in Nicosia in 1983, (2) establishment of regional thalassaemia centres in the other three largest populated towns in Cyprus, (3) creation of the National Programme for the Prevention of Thalassaemia and the premarital certificate still in place today, (4) awareness campaigns about thalassaemia (1 in 3 Cypriots was a thalassaemia-trait carrier in 1982 and this has been reduced to 1 in 7 in 2016), (5) educational material and events for patients / parents and the community at large, (6) founding member of the Thalassaemia International Federation and (7) establishment of a National Committee for Thalassaemia at the Ministry of Health in 2017.

The Twinning Programme focused on the following topics:

- Social integration and community building
- The role of a patient association
- First steps in building an association – How to attract members
- Effective advocacy methodology
- How to gain respectability and reliability
- Communication Methods
- Relationship building with healthcare professionals
- The importance of obtaining disease-specific knowledge
- Development of patient education materials

In the context of the Twinning Programme, the opportunity to visit the Cyprus Thalassaemia Centre was seized. The patient provided vivid feedback, highlighting the differences between the Centre in Cyprus and the thalassaemia clinics in France. Notably there is a huge contrast as patients in France receive transfusion without contact with other patients (even though they may be in the next room) whereas at the Cyprus Thalassaemia Centre

there is a sense of community and belonging, with patients often knowing each other. Hence, one of the main issues discussed with the Cyprus Thalassaemia Association representatives was that of isolation and social marginalisation.

The Thalassaemia Laboratory at the Cyprus Institute of Neurology and Genetics was also visited.

<b>RESULTS ACHIEVED</b>	<ul style="list-style-type: none"> <li>▪ Establishment of a partnership between patients in France and Cyprus, with the latter providing assistance and guidance to the former in any area required.</li> <li>▪ Increase of knowledge amongst French patients about patient associations and social implications and importance.</li> <li>▪ Dissemination of information and tacit knowledge to their French counterparts by the Cyprus patient community.</li> </ul>
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<b>TASK</b>	<b>T4.3: Thalassaemia EU Electronic Health Record</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b> Policy Officer, Eleni Antoniou (Leader) Medical Advisor, Dr Michael Angastiniotis</p> <p><b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou</p>
<b>INDICATORS</b>	Development of relevant architecture for the Thalassaemia EU Electronic Health Record
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Identification of subcontractors &amp; researchers (MS12): February 2018</li> <li>▪ Initiation of architecture development: March – December 2018</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>	

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.

A Thalassaemia EU Electronic Health Record will facilitate the identification of the geographical distribution of patients throughout the EU and support the improvement of existing, and creation of new, public health policies and legislations by national health authorities. The lack of reliable and comprehensive national registries for thalassaemia and haemoglobinopathies at present 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 initiated the development of an electronic health record for thalassaemia.

In 2018, TIF has proceeded to develop and draft the specifications for the updating of the software architecture and the identification of subcontractors & researchers (MS12) in February 2018.

The initiation of architecture development began in March 2018 and continued until December 2018.

Due consideration of EU GDPR<sup>7</sup> legislation has been taken into account ethical and privacy issues.

**RESULTS  
ACHIEVED**

- A thalassaemia specific electronic database is at an advanced stage of development due to work commenced in 2018. Piloting of the record will be in March 2019 in selected EU centres.

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

TASK	<b>T4.5: Humanitarian aid to thalassaemia patients from Syria (Awareness raising)</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b> Policy Officer, Eleni Antoniou (Leader) Medical Advisor, Dr Michael Angastiniotis</p> <p><b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou</p>
<b>INDICATORS</b>	<p>1. Number of views of online publication of statement sent to DG ECHO: 500 <u>Status:</u> Not Met (N/A) <u>Justification:</u> Joint information statement not submitted</p> <p>2. Number of downloads of online publication of statement sent to DG ECHO: 100 <u>Status:</u> Not Met (N/A) <u>Justification:</u> Joint information statement not submitted</p> <p>3. Number of shares of social media posts regarding migration: 100 <u>Status:</u> Met <u>Justification:</u> Migration-related posts were shared 104 times.</p> <p>4. Number of likes of social media posts regarding migration: 2000 <u>Status:</u> Not Met <u>Justification:</u> 917 likes in total – 23,072 people were reached and 4178 engaged (read/followed/commented on posts)</p>
<b>CALENDAR OF ACTIVITIES</b>	<p>1. Letter to DG ECHO: July 2018 2. Social Media campaign regarding migration in EU: July – September 2018</p>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>This task entails the following actions that target policy makers and the general public: A) send an information statement to the Directorate General for European Civil Protection and Humanitarian Aid Operations, all Ministries of Health of EU Member States, EU and UN bodies; B) run a social media campaign to inform and sensitise the general public about the right of migrants to have access to optimal care, wherever they are.</p> <p>Through this task, TIF aimed to raise awareness among the general public and policymakers regarding the Syrian humanitarian crisis and its link to thalassaemia and develop synergies with the competent authorities of each and every EU Member State to address all issues pertaining to the management of the disease.</p>	

### **A) Information Statement**

Given the very challenge to implement such a stand-alone activity, aiming for substantial impact, the Board of Directors decided to invite two directly relevant international bodies, namely the International Organization for Migration and the United Nations High Commissioner for Refugees, to strengthen this one-off effort via the issue of a joint statement. Invitations were sent to both organisations, along with a first draft of the joint statement, in early July 2018 and no reply was received nor interest expressed until December 2018. Therefore, the International Evaluation Committee decided to resume the effort in 2019.

### **B) Social Media Campaign**

A social media campaign was launched in July 2018 to shed light onto migration-related issues and THALIA activities. A total of 16 posts were published within a 3-month period (July-September), viewed by 23,072 people, liked by 917 and engaging an audience of 4,178 people. The increased interest of TIF followers on the migration of thalassaemia and the difficulties migrants and refugees are facing, further strengthen the evidence basis of THALIA and highlights the need to continue efforts.

#### **RESULTS ACHIEVED**

- Launch of effort for a joint statement on the needs of thalassaemia migrants and refugees coming from Syria;
- Increased visibility on TIF migration-related activities across Europe.

## **IMPACT ASSESSMENT**

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### **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:

	<b>CRITERIA</b>	<b>KEY QUESTIONS</b>
<b>1</b>	<b>RELEVANCE</b>	Are the "general objective" and "specific objectives" still meaningful?
<b>2</b>	<b>EFFECTIVENESS</b>	Has the objective been achieved? How much contribution did the "outputs" make?
<b>3</b>	<b>EFFICIENCY</b>	To what extent have "inputs" been converted to "outputs"?
<b>4</b>	<b>IMPACT</b>	What positive or negative, direct or indirect effects have happened?
<b>5</b>	<b>SUSTAINABILITY</b>	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.	Delegation visits to all countries of priority allowed TIF to identify on the ground the local thalassaemia-related stakeholders, assess their needs and encourage patients to join forces and take action for the defence of their right to health and quality of life. Findings validated TIF’s concerns on the migration of thalassaemia and brought to light a number of EU-specific challenges that need to be communicated to the competent authorities of each Member State.	The “inputs” required for the implementation of this task were optimally used, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners, contacts.	THALIA2018 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.	To maintain results and the momentum created, follow-up visits in each country were added in the 2019 work programme and regular communication with all stakeholders and local contacts was established.
<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 between national thalassaemia associations. The Twinning Programme is a promising tool to bring patients of	The specific objective was achieved as the first core group of thalassaemia patients was formed, inspired by the best practices of their peers in Cyprus.	The “inputs” required for the implementation of this task were optimally used, namely: staff time, planning time, financial means, knowledge base, technology, partners.	Through the Twinning Programme, TIF was able to focus on the specific needs of patients living in France and suggest tailored solutions to address them. The patients who participated in the programme showed interest in creating a	Patients were invited to participate in all 2019 workshops organised by TIF. Associations were encouraged to maintain communication and also join TIF’s Thalassaemia Patient Connect platform.



	Europe together and bridge the knowledge gaps between associations.			national thalassaemia network for patients living in France. The creation of an online French-speaking thalassaemia community on social media platforms was decided in the course of the programme to enable discussion on the needs and needed policies.	
<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 was designed with strict criteria and a number of specifications.	The “inputs” required for the implementation of this task were optimally used, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners.	A number of clinics from Sweden, Austria and Germany expressed their interest in utilising the tool, once developed.	TIF will be sharing news on the tool’s development progress to increase visibility and invite more clinics to join in.
<b>T4.5: Shedding light on the needs of patients originating from Syria</b>	This task serves the need to further inform policymakers about migrant populations with thalassaemia, especially those from Syria.	This activity was partially implemented due to a delay in the responses of partner organisations. The corresponding social media campaign was highly successful.	The “inputs” required for the implementation of this task were optimally used, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners.	Increased interest of the online community on public health issues pertaining to the migration of thalassaemia. The publication of a joint statement is expected to have more substantial impact on the work of the Member States’ health authorities.	More intensive and systematic efforts will need to be made in early 2019 to ensure that all Member States are aware of the epidemiological shift that threatens the national health systems.

## LESSONS LEARNED

TIF's policy advocacy activities in 2018:

STRENGTHS	WEAKNESSES
<ul style="list-style-type: none"> <li>▪ involved all target audiences;</li> <li>▪ shed lights on the specific needs of each target group;</li> <li>▪ re-activated patient associations in countries of priority;</li> <li>▪ encouraged the participation of patients in all disease-specific policy making processes;</li> <li>▪ increased awareness about thalassaemia among healthcare professionals of countries with no tradition in thalassaemia prevention and management;</li> <li>▪ highlighted the need for disease-specific policies across EU Member States;</li> <li>▪ set the ground for evidence-based decision making;</li> <li>▪ provided THALIA2018 with increased visibility.</li> </ul>	<ul style="list-style-type: none"> <li>▪ were affected by delays in correspondence with other organisations (pending joint statement on the migration of thalassaemia);</li> <li>▪ were initially considered project-related with financial interest for TIF, making the arrangement of appointments rather difficult (this was surpassed only after each meeting).</li> </ul>
OPPORTUNITIES	THREATS
<ul style="list-style-type: none"> <li>▪ THALIA2018 created a momentum for thalassaemia in EU Member States and ignited the interest of all stakeholder groups;</li> <li>▪ TIF has a unique opportunity to create bridges of communication between patients within each country and at the same time enable policymakers to address policy gaps regarding the prevention and management of the disease;</li> <li>▪ The increased interest of healthcare professionals to use the Electronic Health Record is promising enough to create a robust tool for the monitoring of epidemiological shifts in Europe.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Delegation visits underlined the need to lift language barriers in order to effectively convey messages;</li> <li>▪ Thalassaemia remains for Europe a rare disease and Member States may not give the necessary attention to its prevention and management;</li> <li>▪ Accessibility to migrants and refugees, documented and undocumented, remains a huge challenge for TIF – synergies need to be developed with stakeholders directly working with them to ensure that they are provided with the support needed.</li> </ul>