



## PROGRESS OUTLINE 2019



Co-funded by the Health Programme of the European Union

### PILLAR 1: EDUCATION

*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. Education lies at the heart of the Federation’s activities, as it is indispensable to fill in the knowledge gaps of the key target audiences: patients, their families and healthcare professionals.

As educational objectives can only be achieved when working at the grass root level, it is important to use both online and offline educational tools to ensure access to education for all and to maximise impact. TIF has invested in developing two online educational platforms, one for patients (Thal-e-course) and one for healthcare professionals (e-Thal-ed) and in ensuring that all publications are available online via its website. Moreover, great emphasis is given in the organisation of capacity building courses for both patients and healthcare professionals to ensure that all learning styles are utilised.

In 2019 and in the framework of THALIA, the educational platform for healthcare professionals was piloted in English and subsequently translations were initiated and completed together with audio-visual content (T2.1.1), whereas the educational platform for patients was enhanced with technical adjustments and content development for an improved learning experience of users (T.2.1.1). A key milestone for the success of TIF’s 2019 work was a capacity building course for patients living in Germany that took place in Hamburg, Germany (T.2.2.1) and which encouraged patients to take a more active role in decisions that affect their health. Moreover, the knowledge of healthcare professionals from the countries of priority (FR, DE, AUS, SWE) regarding the multidisciplinary care for thalassaemia was deepened through participation in an educational course that took place in Thessaloniki, Greece (T.2.2.2), and the Renzo Galanello Fellowship Programme (T.2.4) which provided on-site, in depth experience of a holistic haemoglobinopathy centre. The implementation of the European Solidarity Corps Traineeship Programme (T.2.3) with the training of a smaller number of volunteers than planned, enabled more focus and structured work.

TIF’s activities in Work Package 2 have yielded unparalleled dynamics and a strong and continued interest of EU-based stakeholders in the migration of thalassaemia and the defence of the right to health for all patients.

## 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 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 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.

## MATCHING OBJECTIVES TO ACTIVITIES AND IMPACT

### General objective

- I.0. Continue and strengthen the education of carriers and patients/parents, found mainly in migrant communities, and healthcare professionals, as well as the patients' capacity, competency and networking within and across countries and regions of Europe.

Category	E-Learning Tools		Capacity Building Courses				
	Task No	T2.1.1	T2.1.2	T2.2.1	T2.2.2	T2.3	T.2.4
Target Audience		HCPs	Patients	Patients	HCPs	Volunteers / General Public	HCPs
KPI Met		x	✓	✓	✓	x	✓
Justification		✓	✓	✓	✓	✓	✓

### Specific objectives

- I.1. Widen access and contribute significantly to the life-long learning of medical specialists and other health professionals.

**Activity: T.2.1.1:** Development of an educational platform for healthcare professionals (e-Thal-Ed)

**Results:** Completion of piloting and implementation of additional features including content updates (audio-visual and other) to facilitate the learning experience.

**Impact:** KPI not met – Pilot testing, creation of new content and translations have been completed to some extent, but accessibility was compromised due to limited dissemination actions.

**Impact Management / Mitigation Measures:** Greater effort will be put forth in early 2020 to ensure that the platform is available and known to as many healthcare professionals as possible.

- I.2. Provide patients with an improved and enhanced learning experience, providing knowledge and skills to navigate through the vast wealth of information available.

**Activity: T.2.1.2:** Educational platform for patients (Thal-e-course)

**Results:** Enhancement of the learning experience through technical adjustments and content development

**Impact:** KPI met – More than 100 patients/parents enrolled in the Thal e-course.

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

- I.4. Strengthen the voice and involvement of patients in policy making via specific education on the treatment and monitoring of their disease.

**Activity: 2.2.1:** Capacity building course for patient associations and patients with thalassaemia and haemoglobinopathies from Germany

**Results:** KPI met - The course took place in Hamburg, Germany with the participation of 40 patients (individuals and representatives of existing associations) from Germany

**Impact:** Activation of patient associations with regard to their functioning and identification of migrants with thalassaemia; encouragement to participate in the decision making processes.

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

- I.5. Educate healthcare professionals in countries with no tradition in Thalassaemia to provide patients with optimal multi-disciplinary treatment.

**Activity: T.2.2.2:** Educational course for healthcare professionals from EU countries

**Results:** KPI met. The course took place in Thessaloniki, Greece with the participation of 36 healthcare professionals from France, Germany, Sweden and Austria.

**Impact:** Enhancement of knowledge regarding the importance of the multi-disciplinary care of thalassaemia

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

- I.6. Equip selected volunteers of the European Solidarity Corps with the knowledge and know-how on how to support migrants and refugees with Thalassaemia and other haemoglobinopathies arriving in their EU Member States.

**Activity: T.2.3.** European Solidarity Corps Traineeship Programme

**Results:** KPI not met – The number of volunteers had to be reduced to meet the standards defined in the 2019 European Solidarity Corps Guide, which were anticipated by all volunteers participating in the programme.

**Impact:** A smaller group of participants allowed more focused and substantial work, with close supervision and meaningful mentorship.

**Impact Management / Mitigation Measures:** The 2020 annual plan has been adjusted accordingly for the ESC programme to train volunteers within budget allowances.

- I.7. Train medical experts from EU Member States in Thalassaemia and haemoglobinopathies.

**Activity: T.2.4.** Renzo Galanello Fellowship Programme

**Results:** KPI met – Two healthcare professionals from Europe have participated.

**Impact:** Improvement of knowledge about the appropriate treatment of thalassaemia amongst participating healthcare professionals with added value of hands-on experience in a multidisciplinary care team and exchange of ideas with colleagues through networking opportunities.

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

## OVERVIEW OF ACTIVITIES (PILLAR 1 – WP 2)

### ONLINE EDUCATION ACTIVITIES

TASK	<b>T2.1: E-Learning Tools</b> <b>T2.1.1: Educational Platform for healthcare professionals</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<b>Responsible Staff:</b> Communications Officer, Aikaterini Skari (Leader) Medical Advisor, Dr Michael Angastiniotis P.A. to the Executive Director, Maria Peletie <b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>▪ Translation of content in 5 languages (FR, DE, GR, IT &amp; AR) (MS4).</li> <li>▪ Number of EU – based healthcare professionals accessing the platform: 50</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Pilot Period: January – March 2019</li> <li>▪ Content revision, finalization &amp; addition of new features based on pilot feedback: March – May 2019</li> <li>▪ Class 1 initiated: April 2019</li> <li>▪ Translation of Educational Platform for Healthcare Professionals in FR &amp; AR: September 2019</li> <li>▪ Production of audiovisual content (video): September 2019</li> <li>▪ Content Updating: December 2019</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>The Educational Platform for Healthcare Professionals (hereinafter ‘e-ThalEd Platform’) is an online interactive educational platform tool which aims to contribute to the continuous education of healthcare professionals working in the field of haemoglobinopathies, and in particular thalassaemia. Comprising of a variety of learning-conducive features including visuals, fora, quizzes, complimentary references and other material, the content is based on the internationally acclaimed TIF Guidelines<sup>1</sup>, authored by international experts in the field of thalassaemia with long-term experience in the prevention and clinical management of the disease.</p>	

<sup>1</sup> Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3<sup>rd</sup> Edition), 2014. Available at <https://thalassaemia.org.cy/publications/tif-publications/guidelines-for-the-management-of-transfusion-dependent-thalassaemia-3rd-edition-2014/>  
 Guidelines for the Management of Non-Transfusion Dependent Thalassaemias (2<sup>nd</sup> Edition), 2017. Available at <https://thalassaemia.org.cy/publications/tif-publications/guidelines-for-the-clinical-management-of-non-transfusion-dependent-thalassaemias-updated-version/>  
 Prevention of Thalassaemias and other Haemoglobin Disorders, Vol 1 (2<sup>nd</sup> Edition), 2013 Available at <https://thalassaemia.org.cy/publications/tif-publications/prevention-of-thalassaemias-and-other-haemoglobin-disorders-vol-1-2nd-edition-2013/>  
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 Emergency Management of Thalassaemia, 2012. Available at <https://thalassaemia.org.cy/publications/tif-publications/emergency-management-of-thalassaemia-2012/>

## **COURSE 1: PREVENTION OF THALASSAEMIA AND OTHER HAEMOGLOBIN DISORDERS**

- Module 1: Why prevention
- Module 2: Epidemiology supporting prevention
- Module 3: Strategies for National Prevention Programmes
- Module 4: Practical aspects of effective prevention programmes- Screening
- Module 5: Ethical and legal issues

## **COURSE 2: CLINICAL MANAGEMENT OF THALASSAEMIA AND OTHER HAEMOGLOBIN DISORDERS**

- Module 1: Introduction to thalassaemia: genetic basis, pathophysiology and diagnosis
- Module 2: Blood transfusions
- Module 3: Iron overload and chelation
- Module 4: Cardiac complications
- Module 5: Liver and spleen
- Module 6: Infections
- Module 7: Endocrine disorders and osteoporosis
- Module 8: Fertility and pregnancy
- Module 9: Thalassaemia emergencies
- Module 10: Lifestyle and psychological support (incl. dental care)
- Module 11: Hematopoietic stem cell transplantation and novel therapeutic approaches
- Module 12: Organisation of thalassaemia care

Participants of the e-ThalEd Platform need to a) hold a Medical degree and specialisation in Internal Medicine, or Paediatrics, Haematology and b) Have at least a 2-year experience in the treatment of Haemoglobinopathies. Furthermore, participants have the choice to either take the entire course (i.e. 17 modules) or to those module(s) in which they are most interested in. Certificates are provided upon completion of each module.

The e-ThalEd Platform can be accessed at:

<https://thalassaemia.org.cy/education/elearning/courses-professionals/>

The main achievement of the e-ThalEd Platform to date is the creation for the first time globally, of an innovative online, interactive educational tool comprising of a total of 17 modules (one more than originally anticipated in the planning process) of high quality scientific content with the contribution and guidance of international experts. The e-ThalEd Platform serves as an important continuous medical education tool for healthcare professionals in Europe who work with thalassaemia patients and carriers, members of the migrant communities that have developed throughout the EU, facilitating the procurement of in-depth knowledge regarding the disease, hence contributing to the improvement of the quality of care provided to these patients.

In 2019, the e-ThalEd Platform was piloted to a total of 7 healthcare professionals to identify and rectify issues related to the technological infrastructure or content. Following a thorough

evaluation by the pilot group, actions were taken to improve the platform and add new features to cover the needs of the target audience, including up-to-date plugins and the installation of necessary plugins to ensure GDPR compliance.

Moreover, the endorsement of the International Society of Hematology (ISH) was obtained with the Society’s seal being visible on the Platform’s home page. In addition, International Experts in the fields of Hematology, Prevention and Genetic Counselling have endorsed the high quality of the Platform’s content, and co-signed the Certificate which participants receive upon completion of each Module.

The translation of the Platform content in Arabic and French has been completed by a professional translation agency. The translation was provided to independent reviewers (e.g. expert healthcare professionals working in the field of thalassaemia), native-speakers of each desired language, to verify the attribution of terminology in the translated text. The reviewers are members of TIF’s International Advisory Board. The translated text has subsequently been provided to the technical administrator of the platform, who had the responsibility of uploading the text to the platform, ensuring workability and functionality.

It is noted that the restriction of the languages from five (FR, DE, GR, IT & AR) to two (FR & AR) represents the result of a cost-benefit analysis, that: a) excluded from initial planning Greek and Italian, given that they are both minority languages; b) removed German from the list of languages, because English is widely spoken in Germany<sup>2</sup>; c) opted for French, taking into account the country’s low score in the EF English Proficiency Index<sup>3</sup>; d) kept Arabic in planning, as it is widely spoken among refugees and migrants<sup>4</sup>. The translated versions of the e-ThalEd in Arabic and French will be available and officially launched in December 2019.

The development of audio-visual content, more specifically on community awareness and the inheritance of thalassaemia has been completed and will be uploaded in combination with other scheduled content updates within December 2019.

No. of Medical Specialists accessing the e-ThalEd in 2019: 39

**RESULTS ACHIEVED**

- Completion of piloting and implementation of additional features based on user-feedback including content updates (audio-visual and other) to facilitate the learning experience.
- Improvement of knowledge about the appropriate treatment of thalassaemia amongst healthcare professionals.

<sup>2</sup> <https://www.ef.com/wwen/epi/>

<sup>3</sup> lb.

<sup>4</sup> <https://translatorswithoutborders.org/wp-content/uploads/2017/04/Putting-language-on-the-map.pdf>



TASK	<p style="text-align: center;"><b>T2.1: E-Learning Tools</b> T2.1.2: Educational Platform for patients</p>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b> Communications Officer, Aikaterini Skari (Leader) Medical Advisor, Dr Michael Angastiniotis P.A. to the Executive Director, Maria Peletie</p> <p><b>Supervising Staff:</b> Operations Manager, Lily Cannon</p>
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>▪ Completion of technical upgrading &amp; development (MS5).</li> <li>▪ Number of EU - based patients with thalassaemia accessing the platform: 100</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Audit of technical infrastructure &amp; content: January – February 2019</li> <li>▪ Technical feature alterations &amp; refinements: March 2019</li> <li>▪ Educational Leaflet on Bone Marrow Transplantation: June 2019</li> <li>▪ Educational Leaflet on Gene Therapy: September 2019</li> <li>▪ Promotional brochures in 6 languages: June – September 2019</li> <li>▪ Translation of Thal e-course into Turkish: December 2019</li> <li>▪ Content Updates: December 2019</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>The Educational Platform for Patients (hereafter ‘Thal e-Course’) is an online interactive educational platform tool which aims to provide scientifically accurate disease-specific and policy information to patients with thalassaemia, taking into account the variability of learning styles, so as to facilitate knowledge acquisition and retention of knowledge in the long run.</p> <p>The content of the course has been very carefully formulated by a team of medical professionals, patients and education specialists in order to relay complex scientific terms into widely accessible language to facilitate learning for all.</p> <p><u>Anticipated Participant Outcomes:</u></p> <ol style="list-style-type: none"> <li>i. Enrich knowledge on optimal treatment</li> <li>ii. Increase adherence</li> <li>iii. Understanding importance of appropriate monitoring to assess treatment effectiveness</li> </ol> <p>The Thal e-Course includes content in the following modules and units: A. Module I: Introduction to Thalassaemia and to the Thalassaemia International Federation: Unit 1: An Introduction to Thalassaemia (history, genetic causes and inheritance pattern, epidemiology, prevention and treatment, complications); Unit 2: The establishment of TIF: A Global Perspective (history, philosophy, membership role and activities); B. Module II: The Thalassaemia blood disorder: Monitoring and Treatment: Unit 1: Blood and Blood Transfusions; Unit 2: Iron Overload and Iron Chelation (Mechanisms, Pharmacological Approaches, Drug Safety and related information); Unit 3: Inadequate treatment &amp; Organ</p>	

complications (primary and secondary prevention, organ function and damage caused by inadequate treatment, adherence to treatment, recommendations); C. Module III: Patients' Lifestyle, Rights & New advances in Thalassaemia cure: Unit 1: New Advances in Thalassaemia and promise for final cure (Bone Marrow Transplantation, HLA matching, Gene Therapy, clinical trial updates); Unit 2: Patients' Lifestyle: Possibilities and Recommendations (nutrition, social habits, physical exercise); Unit 3: Patients' Rights (History, universal and European declarations and current global status).

The Thal e-course can be accessed at <http://academy.thalassaemia.org.cy/>

Participants are provided with a Certificate upon completion of the course.

The main achievement of the Thal e-course is the creation, for the first time globally, of an innovative online, interactive educational tool to facilitate access to information of thalassaemia patients, available free-of-charge in 6 languages (EN, FR, DE, GR, IT & AR).

In 2019, the learning experience and impact of the Thal e-course has been improved through a series of technical adjustments and content development. More specifically, the sign-up methodology has been altered to allow enrolment upon expression of interest in order to accommodate each participant's schedule and life demands. Patients upon request to enrol in the course, are given a set amount of days to complete the course, however if necessary, this timeframe can be adjusted in order to give each participant the opportunity to complete all required modules (so far the Platform had been provided as a virtual classroom – a closed number of participants for a specific time period). Moreover, alternative options for content have been produced in order to allow for multimodal learning (e.g. Bone Marrow Transplantation and Gene Therapy) which also reflect the current developments in the research and policy fields. Such options also allow for the offline access to content. Furthermore, due to demand amongst the thalassaemia patient population in Germany, many of which are of Turkish decent, the Thal e-course has been translated into Turkish and will be accessible in December 2019. Additionally, actions were taken increase the impact and usability of the Thal e-course to the patients met on delegation visits (See WP4) and educational courses (See WP2 below) through brochures, available in 6 languages (EN, FR, DE, GR, IT & AR), sent electronically or disseminated in hard copies (See Annual Progress Outline 2018). Considering the new advances in the field of thalassemia, including gene therapy approval in the EU, clinical trials in gene editing, pathogen inactivation etc, content refinement of relevant sections of the Thal e-course will be completed in December 2019.

No. of Patients/Parents accessing the Thal e-course in 2019: 310

**RESULTS  
ACHIEVED**

- Provision of up-to-date information regarding thalassaemia (about the disease and relevant policy areas)
- Improvement of knowledge amongst thalassaemia patients.
- Enhancement of the learning experience with translated versions of the Thal e-course, complementary audiovisual material etc.
- Facilitation of peer-to-peer interaction through discussion boards.

## OFFLINE EDUCATION ACTIVITIES

<b>TASK</b>	<b>T2.2: Capacity Building Courses</b> T2.2.1: Capacity building course for newly established patients' associations (Germany) and patients with Thalassaemia and haemoglobinopathies
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<b>Responsible Staff:</b> Medical Advisor, Dr Michael Angastiniotis (Leader) Policy Officer, Eleni Antoniou P.A. to the Executive Director, Maria Peletie <b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>▪ Total number of participants: 20</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Organisation of Capacity Building Course for newly established patients' associations (Germany) and patients with Thalassaemia and haemoglobinopathies: October 2019</li> <li>▪ Course Evaluation by participants (MS6): October 2019</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>The exploratory delegation visits to Germany in 2018, provided a fruitful ground for further strengthening TIF's collaboration with the 3 thalassaemia patient associations as well as individual patients located across the country. As such, members of the patient associations and individual patients were invited to participate in a two-day capacity building course for patients/parents organised in Hamburg, Germany on 12 &amp; 13 October 2019.</p> <p>The Workshop, focused on "Capacity, Competence &amp; Confidence: Building the three CS for patients' organizations", was organized in the context of TIF's Educational Programme for Capacity Building<sup>5</sup>, and comprised of educational presentations, sharing best practices, interactive round-table discussions and a scientific session, which provided participants the opportunity to be updated and to understand the recent and/or ongoing developments in the field of thalassaemia.</p>	

<sup>5</sup> TIF Capacity Building Programme:

The Thalassaemia International Federation (TIF) has placed particular emphasis on the capacity building of patients and patient associations, especially in the context of TIF's Expert Patient programme developed in 2012, in order to achieve the development of groups of knowledgeable, empowered and active patients for advocacy in many countries, members of TIF, worldwide. However, considerable work and efforts are still needed to further strengthen these existing nuclei of advocates while at the same time widen the circle of advocates.

Today, it is imperative for patient associations to become more equipped, enabled, empowered, and engaged to work in the advocacy area, as the environment is different, more challenging and demanding compared to some decades ago. Patients (and parents where necessary) need to be more knowledgeable, more informed on every policy, every decision, every recommendation or plan that concerns their health and quality of life and need to be in a position to back or document their requests and demands. The need for the "transformation" of patients in an association into active partners in the healthcare area at national, regional and international level is today a mandate rather than a choice. There is today much and multiple evidence of how successful such involvement and participation has been in promoting, and in reforming existing or in developing new policies and patient-oriented health services across diseases and across countries and regions of the world. Thus, TIF aims to achieve this

The Workshop aimed to increase the capacities and competencies of patients/parents, thus providing empowerment to become valuable partners of the medical community and national health authorities contributing to the strengthening the patients' voice and involvement at decision and policy making bodies at the national, regional and international level, as active and productive partners, which directly or indirectly will contribute to the improvement of their quality of life.

The Faculty of Speakers comprised of eminent medical specialists and other health professionals from Germany, the United Kingdom and Greece, members of the TIF Expert Patient Advisory Panel, as well as TIF representatives. The Workshop was organised by TIF in collaboration with Seltene Anämien Deutschland (SAM) – the thalassaemia patient association based in Hamburg.

The workshop focused on the following topics:

- Patient Organisation Strategy Development
- Effective Communication Tools & Skills
- Innovative Educational Tools
- Peer-to-Peer Support
- Best Practice Exchanges
- New developments in treating thalassaemia
- Improving Quality of Life of Patients
- Patients' Rights and their implementation
- Clinical Trials

A total of 40 persons participated, including patients/parents from Germany, Faculty members (medical specialists & members of TIF Expert Patients Panel), and TIF representatives.

**RESULTS  
ACHIEVED**

- Networking and sharing of information between participants on respective experiences.
- Enhancement of knowledge regarding skills, capacities and competencies required by patient organisations.
- Improvement of targeted and effective communication skills to all stakeholders (e.g. peers, healthcare professionals, decision-makers etc).
- Learning about clinical care management and new advances in the field.

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complex, challenging objective through making available and increase of access of patients to education and capacity building.

TASK	<p style="text-align: center;"><b>T2.2: Capacity Building Courses</b> T2.2.2: Educational course for healthcare professionals</p>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b> Medical Advisor, Dr Michael Angastiniotis (Leader) P.A. to the Executive Director, Maria Peletie 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>▪ Total number of participants: 20</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Organisation of Educational course for healthcare professionals: November 2019.</li> <li>▪ Course Evaluation by participants (MS7): November 2019</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>Seeking to inform the healthcare community working in Europe about the optimal multidisciplinary care required by patients with thalassaemia, a High Level Summit for Healthcare Professionals was organised in Thessaloniki, Greece on 01 – 02 November 2019.</p> <p>The Summit, organized in collaboration with the Greek Thalassaemia Association (ESTHA) and under the auspices of the Greek Thalassaemia Federation (EOTHA), brought together some of the most prominent scientific personalities active in the field of haemoglobinopathies from both the Greek and international medical community, as well as physicians of primary care, haematology and paediatrics from France, Germany, Sweden and Austria.</p> <p>The following topics were covered:</p> <ul style="list-style-type: none"> <li>▪ Optimal Clinical Management</li> <li>▪ Multidisciplinary Care</li> <li>▪ Case Studies</li> <li>▪ New advances in the Care and Cure of Thalassaemia</li> <li>▪ Diagnosis &amp; screening</li> <li>▪ Reference Centres</li> <li>▪ European Reference Networks</li> </ul> <p>Participants had the opportunity to visit the Hippokrateion Hospital Thalassaemia Centre which encompasses state of art blood donation unit, blood transfusion services, haemoglobinopathy screening laboratory, and adult and paediatric wards meeting with treating physicians and patients.</p> <p>A total of 36 persons participated, including medical specialists from France, Germany, Sweden and Austria, Faculty members, and TIF representatives.</p>	

<b>RESULTS ACHIEVED</b>	<ul style="list-style-type: none"> <li>▪ Networking and sharing of information between participants on respective experiences.</li> <li>▪ Enhancement of knowledge regarding the importance of the multi-disciplinary care of thalassaemia.</li> </ul>
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<b>TASK</b>	<b>T2.3: European Solidarity Corps</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b> Administration Officer, Rawad Merhi (Leader) Policy Officer, Eleni Antoniou</p> <p><b>Supervising Staff:</b> Operations Manager, Lily Cannon</p>
<b>INDICATORS</b>	Total number of participants: 20 (10 from France & 10 from Germany)
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Identification of participants: August 2019 (MS8)</li> <li>▪ 2-month traineeship in Cyprus for ESC volunteers from France &amp; Germany: October – December 2019.</li> <li>▪ Evaluation of programme by participants: December 2019 (MS8)</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>The European Solidarity Corps (ESC) is an EU initiative that creates opportunities for young people to volunteer or work on projects that benefit communities across Europe. The Thalassaemia International Federation is authorised to carry out projects under the EU Health Programme, hence an ESC-dedicated activity was added to the annual work plan.</p> <p>Given the low levels of awareness on thalassaemia among refugees/migrants and the volunteers working at refugee camps, TIF successfully launched in 2019 a 2-month volunteering programme, aiming to equip selected volunteers of the ESC with the knowledge and know-how on how to support migrants and refugees with Thalassaemia and other haemoglobinopathies arriving in their respective countries. This ESC support measure would create a network of Thalassaemia ambassadors, able to provide valuable guidance to migrants and refugees with thalassaemia and act as local info points for people wishing to know more about Thalassaemia and hemoglobinopathies.</p> <p>In 2019, the TIF/ESC volunteering activity took place in Cyprus for 3 ESC volunteers from France and Germany (THALIA countries of priority). The ESC volunteers were informed about thalassaemia (its clinical manifestation, genetic and hereditary origin, distribution across the world, and the increasing public health issues in Europe due to migration), and were able to get hands-on experience regarding the provision of support to the thalassaemia community in Europe (1) through their placement at the Headquarters of TIF, and most importantly (2) through interaction with refugees and migrants at the Kofinou Reception &amp; Accommodation Centre, many of whom were from the Middle East, Asia and North Africa, where thalassaemia is highly</p>	

prevalent. Moreover, the volunteers had the opportunity to visit the Thalassaemia Centres in Cyprus and engage with the medical staff and meet patients, thus enriching their knowledge on the disease and its implications. Debriefing sessions were arranged as required.

The volunteers have formally been appointed by TIF as 'local info points' in their respective countries, and have stated their readiness to assist in any way they can the migrant communities in their own countries.

<b>RESULTS ACHIEVED</b>	<ul style="list-style-type: none"> <li>▪ Increased awareness about thalassaemia amongst members of the general public</li> <li>▪ Transference of knowledge regarding the hereditary nature of thalassaemia and the success of the Cyprus experience in screening and prevention</li> <li>▪ Identification of highly capable individuals to assist with ground work in France and Germany</li> <li>▪ Supported the functioning of the Kofinou Reception &amp; Accommodation Centre, including providing suggestions for improvement premises</li> </ul>
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<b>TASK</b>	<b>T2.4: Renzo Galanello Fellowship</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b> Medical Advisor, Dr Michael Angastiniotis (Leader) P.A. to the Executive Director, Maria Peletie</p> <p><b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou</p>
<b>INDICATORS</b>	Number of healthcare professionals from Europe participating: 2
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Completion of selection procedure: June 2019 (MS9)</li> <li>▪ Renzo Galanello Fellowship at Joint Red Cell Unit, Haematology Department of the University College London NHS Foundation Trust in London: 14<sup>th</sup> October – 13<sup>th</sup> December 2019</li> <li>▪ Post-Fellowship Questionnaire: December 2019 (MS9)</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>Thalassaemia is a rare disease in Europe as it is mostly prevalent in areas of South East Asia, Northern Africa and the Middle East – areas from which the majority of migrants currently residing in Europe originate. As such the expertise and experience of medical specialists, especially in European countries which have witnessed the largest influx of migrants in recent years (i.e. France, Germany, Austria, Sweden and Serbia), in the multi-disciplinary care of thalassaemia patients requires strengthening and extension. Hence, TIF considers the further intensive training of healthcare professionals via the Renzo Galanello Fellowship Programme to be imperative.</p>	

The Fellowship Programme, coordinated by TIF takes place each year at the Joint Red Cell Unit, Haematology Department of the University College London NHS Foundation Trust in London and is open to healthcare professionals from around the world. It has a duration of 2 months. Through the Fellowship Programme a total of 13 healthcare professionals have received further training in the multidisciplinary care of thalassaemia from 12 countries since its initiation in 2015.

In 2019, applications were opened in February and the application period lasted until the end of March. The Fellowship Programme takes place between 14<sup>th</sup> October 2019 and 13<sup>th</sup> December 2019.

Targeted promotional efforts were made throughout Europe aiming at the participation of healthcare professionals from European countries. These included a) communication with TIF Members and collaborators across Europe, b) invitation to Ministries of Health of European countries for nominating physicians and c) email blasts to TIF's network of medical collaborators across Europe.

The Selection Committee (comprised of 2 members of TIF's International Scientific Advisory Board on behalf of TIF and 2 medical specialists on behalf of the training centre) have selected two (2) healthcare professionals to participate in the Fellowship, 1 from Greece and 1 from Austria.

**RESULTS ACHIEVED**

- Improvement of knowledge about the appropriate treatment of thalassaemia
- Hands-on experience in the multidisciplinary thalassaemia patient care
- Networking with colleagues and exchange of experiences



## IMPACT ASSESSMENT

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### Methodology (*The Impact Model*)

TIF's Impact Model consists of 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 focuses 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> <i>Are the “general objective” and “specific objectives” still meaningful?</i>	<b>Effectiveness</b> <i>Has the objective been achieved? How much contribution did the “outputs” make?</i>	<b>Efficiency</b> <i>To what extent have “inputs” been converted to “outputs”?</i>	<b>Impact</b> <i>What positive or negative, direct or indirect effects have happened?</i>	<b>Sustainability</b> <i>To what extent will TIF be able to maintain the positive results of its activities?</i>
<b>Tasks</b>					
<b>T.2.1.1. Educational platform for healthcare professionals</b>	The eThalEd course remains a key component for the provision of accessible and life-long learning to healthcare professionals.	For 2019, the outputs were the different language versions of the platform (French and Arabic) that have ensured accessibility to knowledge for non-English-speaking populations living in EU countries.	The “inputs” required for the implementation of this task were optimally used, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners.	The translated version of the platform ensures accessibility to information but the downside is that the different language versions were not launched on time to allow registration and navigation.	Linguistic diversity/ multilingualism is a major challenge when working for and with EU countries, as language de facto creates barriers to the access of people to knowledge and education. The different language versions further strengthen the sustainability of TIF’s work and best serve EU efforts to preserve the right of its people to education.
<b>T.2.1.2. Educational platform for patients</b>	The Thal e-course fully supports the TIF educational programme objectives, as a source of information and promoter of training and personal development.	The platform provides an improved and enhanced learning experience to patients, as well as the knowledge and skills to navigate through the vast wealth of information available on thalassaemia. For 2019, the different language versions of the platform (French, German, Italian, Greek, Arabic) ensured accessibility to knowledge for non-English-speaking populations living in EU countries in addition to the technical and content updates.	The “inputs” required for the implementation of this task were optimally used, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners.	This educational tool was promoted in the framework of delegation visits and educational courses in priority countries to ensure accessibility to information via the translated versions by migrant and indigenous populations with thalassaemia or interest in thalassaemia where English is not their first language.	TIF needs to intensively promote the platform onward and regularly update its content to ensure that it remains a state-of-the-art tool, utilised by its target audience, in view of the advances in the area of thalassaemia and Hb treatment (e.g. gene therapy, gene editing).

<p><b>T.2.2.1. Capacity building course for patients</b></p>	<p>As a face-to-face activity, encompassing blended learning, the capacity building course for patients and their associations directly support the achievement of the TIF's objectives in the area of education.</p>	<p>Strengthening the voice and involvement of patients in policy making was the ultimate aim of the course that was achieved, as the existing German thalassaemia associations have identified areas where they can take a more active role to best defend the interests of the local thalassaemia community.</p>	<p>The "inputs" required for the implementation of this task were optimally used, namely: staff time, knowledge base, technology, financial resources, network contacts, partners.</p>	<p>The course provided patients with the opportunity to express their real problems, pertaining to social isolation and lack of networking at a national level. This completed TIF's needs analysis for the country and directly affected its work plan for the country, as more emphasis had to be given to the quality of life of patients and less to the clinical management of their disease. The course enabled patients to identify ways to communicate their problems to competent authorities and participate in relevant consultations.</p>	<p>To maintain the momentum, TIF decided to further support the education of thalassaemia patients to achieve empowerment and policy changes.</p>
<p><b>T.2.2.2. Educational course for healthcare professionals</b></p>	<p>The activity was meaningful for healthcare professionals as it provided an opportunity to discuss and exchange ideas with colleagues as well as to understand the importance of multidisciplinary care to patients with haemoglobinopathies.</p>	<p>Contributing to the life-long learning of healthcare professionals, this activity provided the opportunity to participants to have hands-on experience of a dedicated thalassaemia centre in a country with long-term tradition in the care of the disease (i.e. Greece) – a take home message for the further development of services.</p>	<p>The "inputs" required for the implementation of this task were optimally used, namely: staff time, knowledge base, technology, financial resources, network contacts, partners</p>	<p>Healthcare professionals were invited to support TIF's work in Europe by providing feedback for all educational tools. This collaboration expands TIF's network of international experts.</p>	<p>A plan of collaboration is to be shared with each national network of doctors treating thalassaemia and sickle cell disease patients. This will include, among other things, the translation of material on thalassaemia and other collaborative projects.</p>
<p><b>T.2.3. European Solidarity Corps</b></p>	<p>This traineeship programme links TIF's work to the migration of thalassaemia and the provision of support to</p>	<p>N/A – Activity Ongoing</p>	<p>All resources (in terms of staff, network, financial resources) were utilised to implement this activity</p>	<p>N/A – Activity Ongoing</p>	<p>The programme will be launched and promoted again in 2020 for the expanding the network of</p>

	migrants and refugees with thalassaemia arriving to Europe.				thalassaemia ambassadors.
<b>T.2.4. Renzo Galanello Fellowship</b>	This hands-on training for healthcare professionals directly serves the objectives of TIF's educational programme.	N/A – Activity Ongoing	The "inputs" required for the implementation of this task were optimally used, namely: staff time, knowledge base, technology, financial resources, network contacts, partners	N/A – Activity Ongoing	The programme will be launched again in 2020 providing more healthcare professionals the opportunity to participate.

