



PROGRESS OUTLINE 2018



Co-funded by
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PILLAR 1: EDUCATION



Activities

Impact

Lessons Learned



TABLE OF CONTENTS

EXECUTIVE SUMMARY	2
INTRODUCTION.....	3
MATCHING OBJECTIVES TO ACTIVITIES AND IMPACT	4
OVERVIEW OF ACTIVITIES (PILLAR 1 – WP 2).....	6
IMPACT ASSESSMENT.....	16
LESSONS LEARNED.....	20

EXECUTIVE SUMMARY

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 Digital Library. 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 2018 and in the framework of THALIA, the educational platform for healthcare professionals was fully developed in English (T2.1.1), whereas the educational platform for patients was translated in the languages of priority for Europe (French, German, Greek, Italian, Arabic) to ensure that new migrant populations have access to knowledge on thalassaemia (T.2.1.1). Moreover, TIF Digital Library was enriched with different language versions of TIF’s “Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia” (T.2.1.3). A key milestone for the success of TIF’s 2018 work was a capacity building course for patients living in France that took place in Thessaloniki, Greece (T.2.2.1) and re-ignited the patients’ interest in working together for the benefit of the community.

Three activities were not implemented in 2018 as initially planned for compelling and duly reasons. The educational course for healthcare professionals living in France (T.2.2.2) was cancelled, following the on-site situation and needs analysis that indicated the high level of competency of the French healthcare professionals who have agreed to further strengthen TIF’s work with their expertise. The implementation of the European Solidarity Corps Traineeship Programme (T.2.3) and the Renzo Galanello Fellowship Programme (T.2.4) was inhibited by time constraints and had to be postponed for 2019, as their duration is two (2) months. Therefore, there was no adequate time for the selection process to take place and all logistic aspects to be taken care of. This has not of course affected the impact of TIF’s activities that have yielded unparalleled dynamics and a strong interest of EU-based stakeholders in the migration of thalassaemia and the defence of the right to health for all patients.

INTRODUCTION

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.

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

- I.0. Continue and strengthen the education of patients/parents 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	T2.1.3	T2.2.1	T2.2.2	T2.3	T.2.4
Target Audience	HCPs	Patients	HCPs & Patients	Patients	HCPs	Volunteers / General Public	HCPs
KPI Met	✓	✓	✓	✓	✗	✗	✗
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: 14 modules developed in 2018 in English

Impact: KPI not met - Pilot testing was postponed due to development of an additional module (Module 4) and the delayed completion of content revision.

Impact Management / Mitigation Measures: Greater effort will be put forth in early 2019 to ensure that the platform is pilot tested and its content 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: Translation of modules in 5 languages (French, German, Italian, Greek, Arabic)

Impact: KPI not met – 6 EU-base patients passed the online course instead of 50, as anticipated. Language barriers prevented patients from visiting the platform and registering for the course.

Impact Management / Mitigation Measures: Promotional campaign will take place in all platform languages in early 2019 to ensure that target audience is reached.

- I.3. Update and further enrich TIF's Digital Library

Activity: T.2.1.3: TIF Digital Library

Results: Translation of "Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3rd Edition)" into French, German and Arabic; Update of "Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3rd Edition)" – December 2018.

Impact: KPI met – 3 new language versions of TIF’s TDT Guidelines available through TIF Digital Library; At least 200 users accessed the document in 2018.

Impact Management / Mitigation Measures: The Digital Library will continue to exist through the TIF website to increase traffic to/from TIF’s domain and further increase the visibility of TIF’s work.

- 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 France

Results: KPI met - The course took place in Thessaloniki, Greece with the participation of 20 patients (individuals and representatives of existing associations) from France

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: To keep and utilise the momentum, TIF will invite patient representatives from France in its 2019 capacity building workshop, scheduled to take place in Germany.

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

Activity: T.2.2. Capacity building course for healthcare professionals from France

Results: KPI not met. The activity was cancelled due to the excellent coordination and level of knowledge of healthcare professionals in France who manage cases of patients with thalassaemia and sickle cell disease.

Impact: The work of TIF is now known to French doctors who have agreed to strengthen TIF’s EU-based activities.

Impact Management / Mitigation Measures: Healthcare professionals from France will be invited to participate as trainers/speakers in the 2019 workshop for doctors, scheduled to take place in Germany.

- 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 activity was postponed to 2019 due to non-availability of budget and limited time.

Impact: The ground has been prepared to obtain optimal results in 2019.

Impact Management / Mitigation Measures: The 2019 annual plan has been adjusted accordingly for the ESC programme to train volunteers from both Germany and France.

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

Activity: T.2.4. Renzo Galanello Fellowship Programme

Results: KPI not met – There was interest by EU-based doctors but the tight timeframe did not allow them to acquire an extended (2-month) leave from work.

Impact: The Renzo Galanello Programme is now known to doctors who are eager to learn more about the management of thalassaemia and are ready to be trained.

Impact Management / Mitigation Measures: The Programme will be relaunched in early 2019 to allow for authorisation time.

OVERVIEW OF ACTIVITIES (PILLAR 1 – WP 2)

ONLINE EDUCATION ACTIVITIES

TASK	T2.1: E-Learning Tools T2.1.1: Educational Platform for healthcare professionals
RESPONSIBLE STAFF, SUPERVISING STAFF	Responsible Staff: Educational Scientist, Dr Victoria Antoniadou (Leader) Medical Advisor, Dr Michael Angastiniotis Supervising Staff: Operations Manager, Lily Cannon
INDICATORS	<ul style="list-style-type: none"> ▪ Finalize content of 17 modules in English (MS2). ▪ Number of EU – based healthcare professionals for piloting: 50
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ Content Development: June 2018 (MS2) ▪ Content Revision & Finalization: October 2018 (MS3) ▪ Pilot testing: October 2018 (MS4)
DESCRIPTION OF THE ACTIVITY	
<p>The Educational Platform for Healthcare Professionals (hereafter ‘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, forums, quizzes, complimentary references and other material, the content is based on the internationally acclaimed TIF Guidelines¹, authored by international experts in the field of thalassaemia with long-term experience in the prevention and clinical management of the disease.</p>	

¹ Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3rd 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 (2nd 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 (2nd Edition), 2013 Available at <https://thalassaemia.org.cy/publications/tif-publications/prevention-of-thalassaemias-and-other-haemoglobin-disorders-vol-1-2nd-edition-2013/>

Prevention of Thalassaemias and Other Haemoglobin Disorders, Vol. 2: Laboratory Protocols (2nd Edition), 2012. Available at <https://thalassaemia.org.cy/publications/tif-publications/prevention-of-thalassaemias-and-other-haemoglobin-disorders-vol-2-laboratory-protocols-2012/>

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) Preferably have previous experience in the treatment of Haemoglobinopathies. Furthermore, participants have the choice to either take the entire course (i.e. 17 modules) or to take the which module(s) 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 for the continuous life-long learning of the healthcare professionals working in the field of thalassaemia.

In 2018, the ThalEd Platform material was completed, 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 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.

RESULTS ACHIEVED	<ul style="list-style-type: none"> Development of an innovative educational tool for the medical community working in the field of thalassaemia which will continue and strengthen the education of healthcare professionals across Europe.
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TASK	T2.1: E-Learning Tools T2.1.2: Educational Platform for patients
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Educational Scientist, Dr Victoria Antoniadou (Leader) Medical Advisor, Dr Michael Angastiniotis</p> <p>Supervising Staff: Operations Manager, Lily Cannon</p>
INDICATORS	<ul style="list-style-type: none"> Translation of Educational Platform for Patients in 5 languages (FR, DE, GR, IT & AR) (MS5). Number of EU - based patients with thalassaemia accessing the platform: 50
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> Translation of Educational Platform for Patients- Italian: March 2018 Translation of Educational Platform for Patients- French: June 2018 Translation of Educational Platform for Patients- Greek: August 2018 Translation of Educational Platform for Patients- German: November 2018 Translation of Educational Platform for Patients- Arabic: November 2018
DESCRIPTION OF THE ACTIVITY	
<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"> i. Enrich knowledge on optimal treatment ii. Increase adherence iii. Understanding importance of appropriate monitoring to assess treatment effectiveness 	

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 & Organ 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 translated versions Thal e-course was made available and formally launched online in December 2018.

RESULTS ACHIEVED	<ul style="list-style-type: none"> ▪ Development of an innovative educational tool for the thalassaemia patient community. ▪ Improvement of knowledge amongst thalassaemia patients. ▪ Enhancement of the learning experience with interactive quizzes, pop-ups, glossary, complementary audiovisual material etc. ▪ Facilitation of peer-to-peer interaction through discussion boards.
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TASK	T2.1: E-Learning Tools T2.1.3: TIF Digital Library
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Educational Scientist, Dr Victoria Antoniadou (Leader) Medical Advisor, Dr Michael Angastiniotis</p> <p>Supervising Staff: Operations Manager, Lily Cannon</p>
INDICATORS	<ul style="list-style-type: none"> ▪ Number of translated editions of 'Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3rd Edition)': 3 ▪ Number of updated TIF publications: 1 ('Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3rd Edition)') ▪ User base of TIF Digital Library: 100 patients from EU countries

<p>CALENDAR OF ACTIVITIES</p>	<ul style="list-style-type: none"> ▪ Translation of ‘Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3rd Edition)’ into French, German and Arabic within 2018. ▪ Update ‘Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3rd Edition)’ – December 2018.
<p style="text-align: center;">DESCRIPTION OF THE ACTIVITY</p>	
<p>The TIF Digital Library is a mobile application for iOS and Android devices, providing users, including patients and healthcare professionals, with a virtual bookshelf containing all TIF publications and informing them of TIF news and events, through push notifications, alerts and a digital calendar.</p> <p>To date, the main achievements of the TIF Digital Library are a) providing instant access to knowledge and information about thalassaemia via any device (e.g. mobile, tablet, desktop etc) at any time; b) enabling the on-the-go access to guidelines for the clinical care of thalassaemia; c) facilitating the high-pressure and resource-limited work of the emergency department personnel through an easy to use application that allows direct access to the clinical protocol for dealing with thalassaemia-related emergencies, which are often crucial and life-threatening.</p> <p>In 2018, the TIF Digital Library continued to be maintained and the French version of the ‘Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3rd Edition)’ was uploaded (August 2018) for facilitating the work of French-speaking medical specialists across the EU. The Arabic translation begun in March 2018, but due to unforeseen circumstances and challenges in the scientifically-accurate translation of medical terminology the delivery of the final translated version has been delayed.</p> <p>Furthermore, the revision of the ‘Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3rd Edition)’ began in early 2018, reaching a stalemate in October 2018, due to reservations expressed by the authors, international experts in the field of thalassaemia. The authors, members of TIF’s International Advisory Board and consultants to TIF’s Educational Programme, unanimously agreed that the current scientific and research scene in relation to thalassaemia, will bear ground-breaking changes in the clinical management of the disease within the next few months (mid-2019) and thus proposed that it would be more advisable to halt the revision of this publication until early 2020, whence updates and new advances could be included in the publication.</p>	
<p>RESULTS ACHIEVED</p>	<ul style="list-style-type: none"> ▪ Enrichment of TIF Digital Library with ‘Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3rd Edition)’ – French version ▪ Provision of clinical guidelines to French-speaking medical specialists.

OFFLINE EDUCATION ACTIVITIES

TASK	<h3>T2.2: Capacity Building Courses</h3> <p>T2.2.1: Capacity building course for newly established patients' associations (France) and patients with Thalassaemia and haemoglobinopathies</p>
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Medical Advisor, Dr Michael Angastiniotis (Leader) Educational Scientist, Dr Victoria Antoniadou P.A. to the Executive Director, Maria Peletie</p> <p>Supervising Staff: Executive Director, Dr Androulla Eleftheriou</p>
INDICATORS	<ul style="list-style-type: none"> ▪ Total number of participants: 20
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ Identification of patients to participate in Workshop by August 2018 (MS6). ▪ Organisation of Capacity Building Course for newly established patients' associations (France) and patients with Thalassaemia and haemoglobinopathies: September 2018
DESCRIPTION OF THE ACTIVITY	
<p>The first exploratory delegation visit to France in early September 2018 (see Work Package 4), provided a fruitful ground for further strengthening TIF's collaboration with the SOS Globi Federation for Sickle Cell & Thalassaemia (FMDT) which encompasses 13 patient associations across France, including 2 with thalassaemia. As such, members of the SOS Globi were invited to participate in a three-day capacity building course for patients/parents (hereafter 'Train-the-Trainers Capacity Building Workshop') organised in Thessaloniki, Greece in 21 – 23 September 2018.</p> <p>The Train-the-Trainers Capacity Building Workshop, was organized in the context of TIF's Educational Programme for Capacity Building², and comprised of an interactive round-table workshop 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> <p>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.</p>	

² 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.

The venue of Thessaloniki (Greece) was selected for two reasons:

1. The presence of a dynamic local thalassaemia patients' association (Greek Thalassaemia Society – ESTHA) in Thessaloniki. ESTHA members are knowledgeable and active in all national areas of healthcare policy-making, including drug approvals, clinical trials, centres of expertise etc. As such ESTHA constitutes a model patient association, which served as an inspiration to the French patient community during the networking opportunities provided by the Workshop.
2. The wide range of state-of-art services for the prevention and treatment of thalassaemia offered in Thessaloniki and Northern Greece in general. These services congregate the largest cluster of medical experts and researchers working in the field of thalassaemia in Greece. Hence, the scientific session of the Workshop was delivered by high-level experts thus providing participants with accurate and up-to-date knowledge about current issues and new advances being discussed by the global research community focuses on thalassaemia.

The Faculty of Speakers comprised of eminent medical specialists and other health professionals from Greece, members of the TIF Expert Patient Advisory Panel, as well as TIF representatives. The Workshop was organised by TIF in collaboration with the Greek Thalassaemia Society (ESTHA) and under the auspices of the Greek Thalassaemia Federation (EOTHA).

The participation of 20 persons, including patients/parents from France (as per the rationale outlined in the SGA THALIA2018 agreement), Faculty members (medical specialists & members of TIF Expert Patients Panel), and TIF representatives was covered by TIF, including all subsistence expenses, in addition to venue, equipment and travel costs (see FPA pg 20).

The workshop focused on the following topics:

- Patient Organisation Strategy Development
- Creating an Action Plan
- Effective Communication Tools & Skills
- Best Practice Exchanges
- Working with TIF
- Novel developments and strategies in treating thalassaemia and in iron chelation therapy
- Iron Load Monitoring
- Renal Complications
- Liver Disease in Thalassaemia
- Bone disease and Hypercalciuria

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

RESULTS ACHIEVED	<ul style="list-style-type: none"> ▪ 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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TASK	T2.2: Capacity Building Courses T2.2.2: Educational course for healthcare professionals
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Medical Advisor, Dr Michael Angastiniotis (Leader) Educational Scientist, Dr Victoria Antoniadou P.A. to the Executive Director, Maria Peletie</p> <p>Supervising Staff: Executive Director, Dr Androulla Eleftheriou</p>
INDICATORS	<ul style="list-style-type: none"> ▪ Total number of participants: 20
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ Identification of healthcare professionals to participate in Workshop in September 2018 (MS7). ▪ Organisation of Educational course for healthcare professionals: October 2018.
DESCRIPTION OF THE ACTIVITY	
<p>Through the first exploratory delegation visit to France in early September 2018 (see Work Package 4) the high-level expertise of French medical specialists and healthcare professionals working in the field of thalassaemia emerged. Indeed, national guidelines for the clinical management of thalassaemia have been developed, a national registry documents cases of thalassaemia all over the country since the early 2000's and many French hospitals and thalassaemia centres participate in clinical trials for the development of new drugs and therapies in thalassaemia.</p> <p>Furthermore, the healthcare services provided to patients in France are of the highest calibre and quality with an organised national medical community, comprising of paediatric and adult haematologists, laboratory experts and other experts who come together at least four times a year to discuss issues of common concern, challenges, opportunities and ways forward. During the second delegation visit to France in November 2018, (see Work Package 4) TIF delegates had the opportunity to participate in one such meeting.</p>	

Hence, it transpired that the level of knowledge and expertise of healthcare professionals in France is exceptional, and thus an educational workshop was not presently necessary. France has historically welcomed migrants from thalassaemia prevalent countries since the 1960s and hence the accumulation of knowledge and expertise. Thus, it was suggested that the French healthcare professionals could share their expertise and knowledge with other EU countries that are less experienced in the management of thalassaemia.

RESULTS ACHIEVED	N/A
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TASK	T2.3: European Solidarity Corps
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Educational Scientist, Dr Victoria Antoniadou (Leader) Policy Officer, Eleni Antoniou</p> <p>Supervising Staff: Operations Manager, Lily Cannon</p>
INDICATORS	<p>KPI: Number of participating ESC volunteers: 10 from France</p> <p>Status: Not Met (N/A)</p> <p>Justification: No budget available under THALIA2018; no other funding linked to the ESC initiative until October 2018 (new legal base & first call for project proposals published with deadline in February 2019).</p>
CALENDAR OF ACTIVITIES	2-month traineeship to take place in Cyprus for ESC volunteers from France in September and October 2018.
DESCRIPTION OF THE ACTIVITY	
<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. It was announced by the President of the European Commission, Jean-Claude Juncker in September 2016 and was officially launched with a new legal base in October 2018. 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 suggested the launch in 2018 of a 2-month traineeship programme (entitled “THALIA Traineeship”) aiming to 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 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 2018, THALIA Traineeship would take place in Cyprus for 10 ESC volunteers from France (THALIA country of priority) and would include training on how to find information about thalassaemia, how to work for non-governmental and volunteer organisations and assist refugees and migrants with Thalassaemia arriving in the EU, acting as local info points. The activity had to be redesigned and postponed for 2019.</p>	

RESULTS ACHIEVED	N/A
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TASK	T2.4: Renzo Galanello Fellowship
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Medical Advisor, Dr Michael Angastiniotis (Leader) P.A. to the Executive Director, Maria Peletie</p> <p>Supervising Staff: Operations Manager, Lily Cannon</p>
INDICATORS	Number of healthcare professionals from Europe participating
CALENDAR OF ACTIVITIES	Renzo Galanello Fellowship at Joint Red Cell Unit, Haematology Department of the University College London NHS Foundation Trust in London - 15th October – 14th December 2018
DESCRIPTION OF THE ACTIVITY	
<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> <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 10 healthcare professionals have received further training in the multidisciplinary care of thalassaemia from 9 countries since its initiation in 2015.</p> <p>In 2018, applications were opened in June and the application period lasted until the end of August. The Fellowship Programme began on 15th October 2018 and lasted until 14th December 2018.</p> <p>Targeted promotional efforts were made throughout Europe aiming at the participation of health care 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. Interest was received by healthcare professionals in Germany, Sweden, Cyprus and Greece.</p> <p>Candidates however were not able to obtain the necessary permissions for extended study leave in time to participate in the Fellowship Programme. Hence the Fellowship Programme began without any participating healthcare professional from Europe.</p>	

The Internal Evaluation Committee will take this challenge into consideration when planning the activity in 2019 so as to facilitate interested healthcare professionals as much as time as possible for obtaining the necessary permissions.

The Task Team worked towards the development of the Fellowship Programme Agenda, in consultation with Fellowship Supervisors in London, UK as well as in the identification of suitable candidates, including undertaking administrative work in communicating with TIF Members, Ministries of Health and TIF's network of medical collaborators across Europe.

RESULTS ACHIEVED	N/A
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IMPACT ASSESSMENT

Methodology (*The Impact Model*)

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

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

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

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

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

Criteria	Relevance <i>Are the “general objective” and “specific objectives” still meaningful?</i>	Effectiveness <i>Has the objective been achieved? How much contribution did the “outputs” make?</i>	Efficiency <i>To what extent have “inputs” been converted to “outputs”?</i>	Impact <i>What positive or negative, direct or indirect effects have happened?</i>	Sustainability <i>To what extent will TIF be able to maintain the positive results of its activities?</i>
Tasks					
T.2.1.1. Educational platform for healthcare professionals	The eThalEd course remains a key component for the provision of accessible and life-long learning to healthcare professionals.	The pending pilot testing has prevented the team from assessing the platform’s effectiveness in 2018.	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 to priority countries. Healthcare professionals expressed their vivid interest and are ready to sign up. This is the first platform of its kind that is highly welcome by the community and especially young doctors.	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).
T.2.1.2. Educational platform for patients	The Thalecourse 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 2018, the outputs were the different language versions of the platform (French, German, Italian, Greek, 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 to the majority of migrant and indigenous populations with thalassaemia or interest in thalassaemia. The downside is that the different language versions were not launched on time to allow for patients to register and navigate through the platform.	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.
T2.1.3. TIF Digital Library	TIF Digital Library is a unique source of information on thalassaemia and helps	The Digital Library was updated and further enriched in 2018 with new language versions of the TDT Guidelines. The	The “inputs” required for the implementation of this task were optimally used, namely: staff time,	The impact of this task was limited to the education of people who had access to the new publications and	Studies on new advances and novel therapies and medicines in the area of haemoglobinopathies (e.g. gene therapy, gene

	TIF attain its general objective.	specific objective was thus attained.	knowledge base, technology, partners.	subsequently to the better treatment of a number of patients that cannot be defined.	editing, etc) are currently undergoing. To track these advances, maintain TIF publications up-to-date and optimise the use of resources, the Board of Directors has decided to cancel the maintenance of the Digital Library and make TIF's publications available through other channels (mainly TIF's website and platform for HCPs)
T.2.2.1. Capacity building course for patients	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.	Strengthening the voice and involvement of patients in policy making was the ultimate aim of the course that was achieved, as the existing French thalassaemia associations have taken a more active role and have developed their own strategic plans to best defend the interests of the local thalassaemia community.	The "inputs" required for the implementation of this task were optimally used, namely: staff time, knowledge base, technology, financial resources, network contacts, partners.	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.	To maintain the French momentum, TIF decided to promote the creation of a national network of thalassaemia patients that is to be educated and empowered via all TIF's EU-based workshops for patients.
T.2.2.2. Educational course for healthcare professionals	The activity was not deemed meaningful for healthcare professionals in France, specifically, as they provide optimal and	N/A	N/A	Healthcare professionals were invited to support TIF's work in Europe by providing feedback for all educational tools,	A plan of collaboration is to be shared with the national network of doctors treating thalassaemia and sickle

	multid-isciplinary care to patients with haemoglobinopathies across the country.			participating as speakers and trainers in workshops and providing guidance to TIF delegated when visiting other countries. This collaboration expands TIF's network of international experts.	cell disease patients. This will include, among other things, the translation of material on thalassaemia in French and other collaborative projects.
T.2.3. European Solidarity Corps	This traineeship programme links TIF's work to the migration of thalassaemia and the provision of support to migrants and refugees with thalassaemia arriving to Europe.	N/A	N/A	N/A	The programme will be officially launched and promoted in early 2019 for the creation of a network of thalassaemia ambassadors.
T.2.4. Renzo Galanello Fellowship	This hands-on training for healthcare professionals directly serves the objectives of TIF's educational programme.	N/A	N/A	The fellowship programme was promoted in the course of TIF's delegation visits. A pool of doctors interested in participating in the programme was created.	The programme will be launched and promoted in early 2019.

LESSONS LEARNED

TIF's educational programme in 2018:

STRENGTHS	WEAKNESSES
<ul style="list-style-type: none"> ▪ involved all relevant stakeholders (patients, healthcare professionals); ▪ was accessible both online (platforms, publications) and offline (capacity building courses); ▪ was available in key languages, spoken by migrant and indigenous populations; ▪ was kept updated with all advances in the area; ▪ was flexible enough to adapt to the needs of specific audiences; ▪ was comprehensive enough to deal with all aspects of the prevention and management of the disease, as well as policy advocacy and other issues; ▪ focused on one country (France) and at the same time involved all others to achieve optimal results; ▪ provided all EU countries with the tools needed to raise awareness and educate patients and Hb-related audiences. 	<ul style="list-style-type: none"> ▪ was challenged by time constraints, especially as regards to the 2-month commitments of volunteers (ESC traineeship programme) and doctors (Renzo Galanello fellowship) – this stressed the need to promote early and intensively in 2019 both activities; ▪ faced significant delays by the translators of the educational platform for patients and the reviewers of the educational platform for healthcare professionals – this prevented the timely launch and pilot testing of both platforms respectively and the reach of the annual targets/indicators / TIF's strategy had to be adjusted accordingly.
OPPORTUNITIES	THREATS
<ul style="list-style-type: none"> ▪ Healthcare professionals in Europe expressed vivid interest in thalassaemia-related training opportunities; ▪ Communities expressed the need for more informational material translated into their local languages; ▪ TIF's collaborators in Europe (other European and international NGOs in the area of haemoglobinopathies) expressed their readiness to support TIF activities; ▪ Patients embraced TIF's work and showed increased interest in all educational activities. 	<ul style="list-style-type: none"> ▪ The highly demanding management of the volume and complexity of the educational material did not allow us to keep up with the momentum – intensive effort needed to adjust the existing educational material to the needs of the community; ▪ The involvement of patients living in remote areas was limited – the local networks need to be utilised; ▪ Linguistic diversity in Europe was a major challenge, creating barriers for the access of patients to educational material – translation as a key component of communication; ▪ Access to migrant populations, documented or undocumented, was nearly impossible – urgent collaboration with IoM, UNHCR and other organisations working in the field is needed;