



PROGRESS OUTLINE 2021



**PILLAR 1:
EDUCATION**

—
Activities
Impact





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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 grassroots 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 2021 and in the framework of THALIA, the educational platform for healthcare professionals was enhanced with the continued provision of quality information on the clinical management of thalassaemia and sickle cell disease through constant content updates, updating of guidelines for clinical management of thalassaemia and launch of a new module (T2.1.1), whereas the learning experience of the educational platform for patients was enhanced with patient-friendly material, content updates to include information on sickle cell disease, while simultaneously maintaining the dynamic momentum of the Thalassaemia Patient Advocates Group (PAG) with a training webinar series and toolkit (T.2.1.2). A key milestone for the success of TIF’s 2021 work was the capacity building course for patients (T.2.2.1) and educational course for healthcare professionals (T.2.2.2) for the respective communities in THALIA countries and across Europe. Contributing to the life-long learning of healthcare professionals focusing on the appropriate clinical management of thalassaemia, as well as new innovative therapies for both thalassaemia and sickle cell disease were highlighted through the personalised Renzo Galanello Fellowship Programme (T.2.4) and Webinars for Healthcare Professionals (T2.1.4). The implementation of the European Solidarity Corps Traineeship Programme (T.2.3) proved challenging in 2021 however relationships with previous volunteers were strengthened.

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

About Us

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

About Haemoglobinopathies

Haemoglobin Disorders, mainly thalassaemia and sickle cell anaemia, are a group of hereditary (genetic) blood disorders. Approximately 7% of the global population is a carrier of an abnormal haemoglobin gene and more than 500,000 children are born each year with these disorders globally, due to the lack of implementation of effective national programmes for their prevention. In Europe, haemoglobin disorders fall within the official EU definition for rare diseases and it is estimated that approximately 44,000 patients with a haemoglobin disorder live in the region. However, the number of patients located in Europe is increasing due to migration flows from high prevalence countries of the Middle East, South East Asia and Africa.

About THALIA

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

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

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

About the impact of COVID-19

The continuing evolution of COVID-19 throughout 2021, resulted in the implementation of the COVID-19 Contingency and Mitigation Plan as described in the THALIA2021 SGA, to ensure the fulfilment of activity objectives whilst simultaneously ensuring the safety of participants (patients, healthcare professionals, policy-makers, TIF Staff and affiliates) at all times. The shift from physical to virtual environments, consequent to travel restrictions, had positive results on the programme's impact, as more people were able to participate in and benefit from all foreseen THALIA activities.

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	T2.1.4	T2.2.1	T2.2.2	T2.3
Target Audience	HCPs	Patients	HCPs	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-ThalEd)

Results: Continued provision of quality information on the clinical management of thalassaemia and sickle cell disease through constant content updates, updating of guidelines and launch of new module.

Impact: KPI met – More than 360 healthcare professionals enrolled in e-ThalEd, exceeding forecast.

Impact Management / Mitigation Measures: N/A

- 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 patient-friendly material, content updates to include information on sickle cell disease, empowerment of Thalassaemia Patient Advocates Group (PAG) with training webinar series and accompanying toolkit, increased engagement with decision-makers to improve policies.

Impact: KPI not met – The late publication of the toolkit prevented its wide accessibility and distribution.

Impact Management / Mitigation Measures: The toolkit will be delivered to members of the PAG based in the EU via a specific email blast in early 2022 and will be made available on TIF's website for the wider patient community.

- 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 Serbia

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

Impact: KPI met - The course took place virtually with the participation of 56 patients (individuals and representatives of existing associations) from THALIA priority countries

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

Impact: KPI met - The course took place virtually with the participation of 150 healthcare professionals from EU Member States including THALIA Priority countries (France, Germany, Sweden and Austria).

Impact Management / Mitigation Measures: N/A

Activity: T.2.1.4: Webinars for healthcare professionals

Results: Provision of up-to-date disease-specific information to healthcare professionals about appropriate treatment of thalassaemia and sickle cell disease through two webinars.

Impact: The webinars on innovative therapies and sickle cell disease were participated by 312 and 94 healthcare professionals respectively.

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: Continued interest from previous ESC volunteers has supported the European advocacy efforts for the prioritisation of thalassaemia as a public health issue among migrant communities.

Impact: KPI not met – COVID-19 safety measures and interest from ESC volunteers fulfilling specific criteria did not allow the materialisation of the programme in 2021.

Impact Management / Mitigation Measures: Continued efforts to stimulate interest, even in a smaller group of volunteers were exerted by to no avail. Consideration for alternative routes of education of European citizens working with migrants about thalassaemia is necessary.

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

Activity: T.2.4. Renzo Galanello Fellowship Programme

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

Impact: Improvement of knowledge about the appropriate treatment of thalassaemia amongst participating healthcare professionals with added value of interacting with an

experienced 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	T2.1: E-Learning Tools T2.1.1: Educational Platform for healthcare professionals
RESPONSIBLE STAFF, SUPERVISING STAFF	Responsible Staff: Communications Officer, Aikaterini Skari (Leader) Medical Advisor, Dr Michael Angastiniotis P.A. to the Executive Director, Maria Peletie Supervising Staff: Executive Director, Dr Androulla Eleftheriou
INDICATORS	<ul style="list-style-type: none"> ▪ Translation of SCD content in 1 language (FR) (MS3). ▪ Number of EU – based healthcare professionals accessing the platform: 50
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ Promotional tools: email banner: May 2021 ▪ Creation of video & poster: Sept 2021 ▪ SCD Module launch: April 2021 ▪ Guidelines for TDT published: June 2021 ▪ Content Updating (based on TDT Guidelines): Jul – Dec 2021
DESCRIPTION OF THE ACTIVITY	
<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 Guidelines¹, authored by international experts in the field of thalassaemia with long-term experience in the prevention and clinical management of the disease.</p> <p>COURSE 1: PREVENTION OF THALASSAEMIA AND OTHER HAEMOGLOBIN DISORDERS</p> <ul style="list-style-type: none"> ▪ 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 	

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/>

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 of high quality scientific content with the contribution and guidance of international experts. The e-ThalEd Platform, available in French and Arabic as a means to overcome linguistic barriers, is annually upgraded with additional technical features and audio-visual content (v. community awareness and the inheritance of thalassaemia) to cover the needs of the target audience. The e-ThalEd has been endorsed by the International Society of Hematology. Furthermore, the continuous engagement of new healthcare professionals through yearly content updating to reflect ongoing scientific advancements, live webinars, the new modules on sickle cell disease as well as the promotion via a specific marketing strategy and campaign have proven instrumental.

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/>

The e-ThalEd Platform serves as an important continuous medical education tool for healthcare professionals in Europe who work with thalassaemia and sickle cell disease 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 2021, further promotion and marketing of the e-ThalEd Platform to medical specialists in THALIA priority countries and across Europe was pursued through the creation of a dedicated video and poster. In addition, the webpage on TIF's website relating to the educational platforms for medical specialists and patients/parents (v. T2.1.2), collectively known as TIF's e-academy has been duly revamped and updated.

The TIF e-academy webpage is available at <https://thalassaemia.org.cy/what-we-do/education/e-academy/>

The updating of the Clinical Guidelines for Transfusion-Dependent Thalassaemia (3rd edition) following the unanimous decision of the authors, international experts in the field of thalassaemia, members of TIF's International Advisory Board and consultants to TIF's Educational Programme, was halted in 2019 as a result of the continuing announcements of ground-breaking research which would have a bearing on the clinical management of the disease. Resuming work in early 2020, the 4th edition of the publication was anticipated to reflect the regulatory approvals of advanced therapies and medicinal products (ATMP's)² for patients with transfusion-dependent thalassaemia (TDT). The extenuating circumstances brought about by the COVID-19 pandemic significantly delayed completion of the publication, which was finalized in June 2021. Subsequently, the content of e-ThalEd has undergone updating to reflect the new edition of the Guidelines. This was completed in December 2021.

The independent module on sickle cell disease, based on internationally accepted treatment guidelines and standards of care (e-SCD for Medical Specialists) was finalized in December 2020 and thereafter underwent a thorough evaluation by a pilot group of international medical experts specialised in the care of sickle cell disease from the Greece, France, UK and the USA. Thereafter actions were taken to improve and extend the contents of the module leading to the endorsement by the European Hematology Association.

A launch event took place on 09 April 2021 with Prof. Dimitris Loukopoulos (Greece) and Dr Anne Yardumian (UK) participating as key speakers on behalf of the authors. In addition, the added-value of the module were voiced by the European Hematology Association, Sickle Cell Disease Coalition (USA), Global Alliance of Sickle Cell Disease Organizations, Panhellenic Association of Sickle Cell Disease and the Pancyprian Association of Sickle Cell Disease.

Following the launch event, the contents of the module have continued to feature additional updates, including clinical case examples. Importantly, the Red Cell Network (a group of hospitals treating patients with SCD in the UK) have expressed interest to incorporating this

module in their staff training resources in 2022. Due to delay in launching, as a result of thorough piloting, the translation to FR (MS3) was postponed.

No. of Medical Specialists accessing the e-SCD module in 2021: 178 of which 36 were EU based.

More information on the e-SCD for Medical Specialists is available at <https://thalassaemia.org.cy/what-we-do/education/e-academy/scd-hcps/>

No. of Medical Specialists accessing the e-ThalEd in 2021: 182 of which 24 were EU-based.

**RESULTS
ACHIEVED**

- Increased awareness about training opportunities to a wider audience.
- Implementation of content updates to facilitate the learning experience.
- Improvement of knowledge about the appropriate treatment of thalassaemia and other haemoglobin disorders (v. Sickle Cell Disease) amongst healthcare professionals.

TASK	<p style="text-align: center;">T2.1: E-Learning Tools T2.1.2: Educational Platform for patients</p>
<p style="text-align: center;">RESPONSIBLE STAFF, SUPERVISING STAFF</p>	<p>Responsible Staff: Communications Officer, Aikaterini Skari (Leader) Medical Advisor, Dr Michael Angastiniotis P.A. to the Executive Director, Maria Peletie Administration Officer, Rawad Merhi Office Administration, Stella Eleftheriou</p> <p>Supervising Staff: Operations Manager, Lily Cannon</p>
<p style="text-align: center;">INDICATORS</p>	<ul style="list-style-type: none"> ▪ Patient Advocacy Group Toolkit (MS4). ▪ Number of EU – based patients accessing the Toolkit: 50
<p style="text-align: center;">CALENDAR OF ACTIVITIES</p>	<ul style="list-style-type: none"> ▪ Thalassaemia Patient Advocates Group (PAG) Consultations: Jan – Dec 2021 ▪ Educational Booklet on Gene Therapy translations (FR, DE, GR &IT): Jan – March 2021 ▪ Educational Brochure on Gene Therapy translations (FR, DE &IT): Jan – March 2021 ▪ Infographic: March 2021 ▪ Development of Content Updates (SCD): Jul – Dec 2021 ▪ Creation of video & poster: Sept 2021 ▪ PAG Training Webinars: Sept 2021 ▪ PAG Toolkit: Sept – Dec 2021
<p>DESCRIPTION OF THE ACTIVITY</p>	
<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 <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</p>	

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 is available free-of-charge in 7 languages (EN, FR, DE, GR, IT, TK & AR) and 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. The learning experience is continuously improved through a series of technical adjustments and content development, including production of content to allow for multimodal learning which also reflect the current developments in the research and policy fields, including publications, videos and webinars. Culminating in the formation of a Patient Advocacy Group in 2020, the Thal e-course constitutes an important educational tool for existing and newly established patient support groups in THALIA priority countries.

In 2021, focus on the Thal e-course has followed two main directions:

i. Content Updating

Considering the new advances in the care and cure of thalassaemia³ (including gene therapy, erythroid maturation agents), in addition to many others that are in the pipeline⁴ (e.g. gene editing, pathogen inactivation etc), content refinement of relevant sections of the Thal e-course have been revised. Patient-friendly educational material on Gene Therapy in thalassaemia have been translated (booklet: FR, IT, GR & DE; brochure: FR, DE & IT) and uploaded on the Thal e-course to overcome the linguistic barriers of thalassaemia patients living in THALIA priority countries. Moreover, an infographic on potentially curative therapies has also been developed to aid the understanding of patients on these complex medical methodologies.

Moreover, additional content (M7 – M12) has been created by expert haematologists and patient advocates on sickle cell disease to contribute to the increase of disease-specific education of patients and caregivers living in EU Member States, who are part of migrant communities and often receive treatment by the same physicians in the same clinics as those with thalassaemia. The content is separated into three parts (Introduction, Clinical

³ REBLOZYL® – first in class innovative medicinal product (EMA approval June 2020) ; ZYNTEGLO® – gene therapy (EMA approval June 2019)

⁴ <https://thalassaemia.org.cy/haemoglobin-disorders/clinical-trial-updates/>

Complications and Treatment Options). The aim is to provide practical guidance to patients, carers and families. Piloting is expected to be initiated in January 2022, with official launching by March 2022.

ii. Thalassaemia Patient Advocates Group (PAG)

The Thalassaemia Patient Advocates Group comprised of Thal e-course graduates from Europe and established in the context of THALIA2020 (SGA No.881566), underwent a series of five training webinars (M9) that enhanced their knowledge in the field of advocacy and communication. The webinars featured prominent speakers with extensive experience in the establishment and development of NGOs, spearheading successful advocacy initiatives, conducting professional and far-reaching communication campaigns and building resilient and sustainable groups. A toolkit (MS4) on practical skills for infrastructure and communication capacities has been amalgamated and published (M12).

The webinars provided the Group with knowledge and skills in order to best support their peers on the ground level in each country. Members of the Group have also provided the patient perspective in consultations with regulatory bodies (M1, M2, M3, M6), industry (M5, M9, M10, M11, M12) and national health authorities (M6, M12). Patients participating in the Group are required to engage in a specific agreement with TIF, encompassing the Terms of Reference of the Group and confidentiality of discussions.

Further promotion and marketing of the Thal e-course to target audiences in THALIA priority countries and across Europe was pursued through the creation of a dedicated video and poster. In addition, the webpage on TIF's website relating to the educational platforms for medical specialists (v. T2.1.1) and patients/parents, collectively known as TIF's e-academy has been duly revamped and updated. The TIF e-academy webpage is available at <https://thalassaemia.org.cy/what-we-do/education/e-academy/> Furthermore, actions were taken increase the impact and usability of the Thal e-course to the patients *met* on virtual delegation visits (See WP4) and educational courses (See WP2 below).

No. of Patients/Parents accessing the Thal e-course in 2021: 198

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 content updates on new advances, complementary material etc.
- Facilitation of peer-to-peer interaction through discussion boards.
- Increase engagement with decision-makers of the Thalassaemia Patient Advocates Group

TASK	<p style="text-align: center;">T2.1: E-Learning Tools T2.1.4: Webinars for Healthcare Professionals</p>
<p style="text-align: center;">RESPONSIBLE STAFF, SUPERVISING STAFF</p>	<p>Responsible Staff: Communications Officer, Aikaterini Skari (Leader) Medical Advisor, Dr Michael Angastiniotis P.A. to the Executive Director, Maria Peletie Administration Officer, Rawad Merhi Office Administration, Stella Eleftheriou</p> <p>Supervising Staff: Executive Director, Dr Androulla Eleftheriou</p>
<p style="text-align: center;">INDICATORS</p>	<ul style="list-style-type: none"> ▪ Invitation to webinar faculty (MS5)
<p style="text-align: center;">CALENDAR OF ACTIVITIES</p>	<ul style="list-style-type: none"> ▪ Webinar on Novel Therapies in SCD: April 2021 ▪ Webinar on the Future of Thalassaemia – Innovative Therapies: May 2021
<p>DESCRIPTION OF THE ACTIVITY</p>	
<p>Experience from delegation visits (v. THALIA2018 – 20, WP4) to THALIA priority countries have fervently demonstrated that treating physicians (mainly haematologists and paediatricians) have many professional commitments that compete for their time, and hence the in-depth understanding of thalassaemia and sickle cell disease – chronic and rare diseases – do not constitute a high priority compared to other malignant blood diseases which they also treat.</p> <p>Hence, physicians require bite-size information on important and essential disease-specific topics, in the form of webinars that can be attended either live or later on demand.</p> <p>To date, a total of 7 Webinars for Healthcare Professionals have been organised (v. T2.1.1.; THALIA2020 SGA No.881566), led by international experts, which have been proven to enhance understanding and to facilitate knowledge acquisition among participants. Following the live webinars, the recordings were uploaded on the e-ThalEd Platform (v. T2.1.1) so participants would have the opportunity to view the discussion in their own time, hence contributing towards the different learning styles and pace of each individual.</p> <p>In 2021, this experience was extended with the organisation of the following two webinars (MS5) that featured a prominent international leader as a key speaker and a multi-stakeholder panel discussion including medical experts and patient advocates.</p> <ol style="list-style-type: none"> 1. Newly authorised drugs and an overview of therapies in the pipeline for sickle cell disease were presented by Dr Androulla Eleftheriou (TIF Executive Director) during a webinar (M4). 2. A scientific retrospective on thalassaemia was presented during a webinar by Prof. J. Porter (M5) where the future of thalassaemia treatment was discussed, including advanced/novel therapies. 	

RESULTS ACHIEVED	<ul style="list-style-type: none"> ▪ Provision of up-to-date disease-specific information ▪ Increase education among healthcare professionals about appropriate treatment of thalassaemia and sickle cell disease ▪ Accommodation of various learning styles and promotion of interaction and engagement through webinars.
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OFFLINE EDUCATION ACTIVITIES

TASK	<h3 style="color: blue;">T2.2: Capacity Building Courses</h3> <p>T2.2.1: Capacity building course for newly established patients' associations (Serbia) and patients with Thalassaemia and haemoglobinopathies</p>
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Medical Advisor, Dr Michael Angastiniotis (Leader) Policy Officer, Eleni Antoniou P.A. to the Executive Director, Maria Peletie Administration Officer, Rawad Merhi Office Administration, Stella Eleftheriou</p> <p>Supervising Staff: Executive Director, Dr Androulla Eleftheriou</p>
INDICATORS	<ul style="list-style-type: none"> ▪ Total number of participants from THALIA priority countries: 20
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ Organisation of Capacity Building Course for newly established patients' associations (Serbia) and patients with Thalassaemia and haemoglobinopathies: Nov 2021 ▪ Course Evaluation by participants (MS6): Dec 2021
DESCRIPTION OF THE ACTIVITY	
<p>The fluctuating evolution of the COVID-19 pandemic, deemed the safety of participants, patients and healthcare professionals, that would attend as attendees and faculty respectively, to be the deciding factor for TIF's Board of Directors and Internal Evaluation Committee in their consideration for organising the Capacity Building Course for Patient Associations and Patients in 2021. Due to these extenuating circumstances, it was decided that the best course of action would be to hold the three-day capacity building course virtually.</p> <p>The Capacity Building Course (MS6) was organized on 19 – 21 November 2021, in the context of TIF's International Conference and TIF's Educational Programme for Capacity Building⁵. TIF's International Conference also incorporated the Educational Course for HCPs (see T2.2.2 below).</p>	

⁵ 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

The Faculty of Speakers comprised of eminent medical specialists and other health professionals, members of the TIF Expert Patient Advisory Panel, and TIF representatives.

The following topics were covered:

- Challenges and Unmet Needs in Europe: the Patients Perspective
- Education, Employment, Social Life
- Building truthful relationships
- Having a family
- Mental Health impact of COVID-19
- New advances in the care and cure of thalassaemia and sickle cell disease

The Course aimed to highlight the importance of patient knowledge, unity, engagement and contribution to the improvement of services, through meaningful and productive participation in decision-making processes at the national, regional and international levels.

A total of 129 persons participated in the Capacity Building Course for Patients and Patient Associations from THALIA Priority countries (v. Sweden, France, Germany, Austria and Serbia) and another 13 EU Member States. 56 participants were from THALIA priority countries.

**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 patient advocacy skills.
- Learning about clinical care management and new advances in the field.

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

TASK	<h2 style="text-align: center;">T2.2: Capacity Building Courses</h2> <h3 style="text-align: center;">T2.2.2: Educational course for healthcare professionals</h3>
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Medical Advisor, Dr Michael Angastiniotis (Leader) Operations Manager, Lily Cannon P.A. to the Executive Director, Maria Peletie Office Administration, Stella Eleftheriou</p> <p>Supervising Staff: Executive Director, Dr Androulla Eleftheriou</p>
INDICATORS	<ul style="list-style-type: none"> ▪ Total number of EU-based participants: 20
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ Organisation of Educational course for healthcare professionals: Nov 2021 ▪ Course Evaluation by participants (MS7): Dec 2021
DESCRIPTION OF THE ACTIVITY	
<p>The fluctuating evolution of the COVID-19 pandemic, deemed the safety of participants, patients and healthcare professionals, that would attend as attendees and faculty respectively, to be the deciding factor for TIF’s Board of Directors and Internal Evaluation Committee in their consideration for organising the Educational Course for HCPs in 2021. Due to these extenuating circumstances, it was decided that the best course of action would be to hold the two-day capacity building course virtually.</p> <p>Seeking to inform the healthcare community working in Europe about the optimal multidisciplinary care required by patients with thalassaemia, an Educational Course for Healthcare Professionals on Thalassaemia & Sickle Cell Disease was organised (MS7) virtually on 19 – 21 November 2021, in the context of TIF’s International Conference. TIF’s International Conference also incorporated the Capacity Building Course for Patients’ Associations and Patients’ (see T2.2.1 above).</p> <p>The Course brought together some of the most prominent scientific personalities active in the field of haemoglobinopathies from the European medical community, as well as physicians of primary care, haematology and paediatrics from France, Germany, Sweden Austria (v. THALIA priority countries) and an additional 13 EU Member States.</p> <p>The Course covered aspects relating to the cornerstones and multidisciplinary clinical management of thalassaemia and sickle cell disease in addition to the new innovative drugs and therapies that have recently been approved by regulatory authorities as well as those in the development pipeline. In addition, the discussion of emerging concerns (e.g. ageing, malignancies) and increased the knowledge-base of attendees.</p>	

The Faculty of Speakers comprised of eminent medical specialists and other health professionals, members of the TIF Expert Patient Advisory Panel, and TIF representatives.

The following topics were covered:

- Guideline recommendations for the clinical management of thalassaemia and sickle cell disease
- Multidisciplinary Care & Case Studies
- Prevention of Haemoglobin Disorders
- New advances in the Care and Cure of Thalassaemia and sickle cell disease

A total of 150 persons participated in the Educational Course for Healthcare Professionals, from THALIA Priority countries (v. Sweden, France, Germany, Austria and Serbia) and another 13 EU Member States.

**RESULTS
ACHIEVED**

- Networking and sharing of information between participants on respective experiences.
- Enhancement of knowledge regarding the importance of the multi-disciplinary care of thalassaemia.
- Understanding the application of new therapeutic advancements in the care & cure of thalassaemia.

TASK	T2.3: European Solidarity Corps
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Administration Officer, Rawad Merhi (Leader) Policy Officer, Eleni Antoniou</p> <p>Supervising Staff: Operations Manager, Lily Cannon</p>
INDICATORS	<ul style="list-style-type: none"> ▪ Total number of participants: 3 from THALIA countries
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ Identification of participants: Sept 2021 (MS8)
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. The Thalassaemia International Federation (TIF) 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 haemoglobinopathies.</p>	
<p>Continuing the volunteering programme in 2020 whilst taking into consideration the COVID-19 pandemic and its impact on travelling and health safety, the programme was conducted in Cyprus in October – December 2020.</p>	
<p>The volunteer programme moved into its third year with TIF initiating the recruitment and selection process for volunteers in September 2021 focusing on candidates from THALIA priority countries (v. Austria, France, Germany and Sweden). Taking into consideration the COVID-19 pandemic and its impact on travelling and health safety, the Internal Evaluation Committee took the decision to conduct the programme in Cyprus in October – December 2021. This decision was employed as a result of feedback received from volunteers of the previous year who had '<i>felt safe (v. COVID-19) in the volunteer programme held at TIF premises</i>'. Thus, the Internal Evaluation Committee decided that the 2021 volunteer</p>	

programme would follow a similar format and be held at TIF premises between October – December 2021.

Interest from possible candidates that met TIF criteria was limited by mid-September and hence the decision was taken by the Internal Evaluation Committee to broaden the call to candidates from other EU-countries too that are impacted by migration (v. Italy, Greece, Spain). The application period was also extended to the end of September 2021. This resulted in the receipt of several applications and a short list of candidates which would proceed to the interview process in early October 2021.

The fluctuating epidemiological situation and its anticipated deterioration across Europe during the programme period (v. Oct – Dec) as well as unresponsiveness on behalf of candidates to arrange interviews, urged the Internal Evaluation Committee to halt the programme for 2021.

A total of four volunteers from EU countries with a high migration influx (namely France, Germany and Italy) have benefitted from this programme (2019 & 2020) and have formally been appointed by TIF as ‘local info points’ whilst stating their readiness to assist in any way they can the migrant communities in their home countries.

In this context and demonstrating the continuity of the programme a *Thalassaemia Ambassador* from Germany who took part in the volunteering programme in 2019 visited TIF premises in September 2021 to discuss current developments and the possible impact of the Afghan crisis on migration flows to Europe and their relation to thalassaemia (Afghanistan has a high prevalence of thalassaemia patients). This Ambassador continues to provide support to migrants in Berlin with an extensive fieldwork humanitarian action. TIF maintains communication with all ESC volunteers who have participated in the programme, noting that their experience with thalassaemia has been instrumental in their professional development and social contribution.

**RESULTS
ACHIEVED**

- Identification of highly capable individuals with an interest to support migrants with thalassaemia
- Continued interest from previous ESC volunteers
- Supported the European advocacy efforts for the prioritisation of thalassaemia as a public health issue

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: Executive Director, Dr Androulla Eleftheriou</p>
INDICATORS	<ul style="list-style-type: none"> ▪ Number of participating healthcare professionals from Europe: 2
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ Communication with experts from Italy: Jan – July 2021 ▪ Completion of selection procedure: Sept 2021 (MS9) ▪ Renzo Galanello Fellowship (virtual): 21 – 22 Oct 2021 ▪ Post-Fellowship Questionnaire: Nov 2021
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 17 healthcare professionals have received further training in the multidisciplinary care of thalassaemia from 15 countries since its initiation in 2014, including 4 EU Member States.</p> <p>The intention to identify international experts from Italy who would lead the Fellowship Programme for EU-based candidates was unfortunately not possible due to their deep involvement in the completion of the Guidelines for Transfusion Dependent Thalassaemia (4th edition) (v. T2.1.1) and in the courses for Patients (v. T2.2.1) and Healthcare Professionals (v. T2.2.2.). Therefore, the Renzo Galanello Fellowship continued to be led by the Joint Red Cell Unit, Haematology Department of the University College London NHS Foundation Trust in London, UK.</p> <p>In 2021, the safety of the participating healthcare professionals in view of the fluctuating evolution of the COVID-19 pandemic, particularly in the United Kingdom (where the Fellowship takes place), necessitated the Internal Evaluation Committee’s decision to organize Renzo Galanello Fellowship in an alternative format.</p> <p>More specifically, the format ensued an interactive and experiential discussion with the Leader of the Fellowship Programme at the Joint Red Cell Unit, Haematology Department of the University College London NHS Foundation Trust and international expert in the field</p>	

of haemoglobinopathies, Prof. John Porter. This tailored approach enabled candidates to directly address their questions to Prof. Porter on specific complex cases and through an intense dialogue to address the clinical management of these patients through a personalised pathway.

The Fellowship Programme as described above took place on 21 – 22 October 2021 and was offered to doctors from EU Member States (Bulgaria, Romania, Cyprus, Italy and Greece) in a virtual environment. For the purposes of improved coordination and in order to be briefed by the TIF field-work team with current unmet needs and challenges in the participating countries, Prof. Porter travelled to TIF's premises in Cyprus.

Three distinct sessions (1. Cyprus, 2. Bulgaria, Romania, Albania, 3. Italy, Greece) were set up to facilitate the discussions, and which also allowed for more in-depth information to be provided by Prof. Porter on the management of thalassaemia and sickle cell disease but also by TIF about current educational opportunities for healthcare professionals offered by TIF (v.T.2.1.1.).

The sessions were:

1. Discussion with Cyprus Thalassaemia Doctors & National Thalassaemia Committee – Topic: New therapies in Haemoglobin Disorders
2. Discussion with HCPs from Bulgaria, Romania and Albania – Topic: Optimal Management of Haemoglobin Disorders
3. Discuss with HCPs from Italy and Greece – Topic: Management of SCD and TIF educational opportunities

The interactive discussion with Prof. Porter contributed to the professional development and lifelong learning of participating medical specialists, and by extension to their knowledge and capacity for providing improved healthcare to their patients with thalassaemia and sickle cell disease.

**RESULTS
ACHIEVED**

- Improvement of knowledge about the appropriate treatment of thalassaemia and sickle cell disease
- Knowledge acquisition in the multidisciplinary thalassaemia patient care
- Networking with colleagues and exchange of experiences

IMPACT ASSESSMENT

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 THALIA 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 e-ThalEd course remains a key component for the provision of accessible and life-long learning to healthcare professionals.	For 2021, the outputs were the continuous engagement of participants through marketing campaigns and content updates (v. SCD module, TDT guidelines updating) which have maintained the interest of the HCP community.	The “inputs” required for the implementation of this task were optimally used, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners.	Content updates ensured that the e-ThalEd keeps up with the needs of healthcare professionals but the downside were the delay in launching to allow for translation.	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. As such new features (v. SCD module) require translation to strengthen the sustainability of TIF’s work and best serve EU efforts to preserve the right of its people to education.
T.2.1.2. Educational platform for patients	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 2021, content for the sickle cell patient community and the empowerment of the Thalassaemia Patient Advocacy Group through webinars and toolkit enabled patients to participate in the decision-making processes, nationally.	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 virtual delegation visits and educational courses 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. The Thalassaemia Patient Advocacy Group participated in consultations and meetings with key stakeholders, influencing the future of thalassaemia in Europe.	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) as well as evolve the Thalassaemia Patient Advocacy Group into an empowered vehicle representing the patients voice.



<p>T2.1.4 Webinars for Healthcare Professionals</p>	<p>The webinars for HCPs fully supports the TIF educational programme objectives for the life-long learning of treating physicians.</p>	<p>The organisation of two webinars in 2021 allowed the continuous engagement of HCPs.</p>	<p>The “inputs” required for the implementation of this task were optimally used, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners.</p>	<p>The topics of the webinars responded to current needs and challenges that HCPs meet on a daily basis, while their virtual format enabled on-demand viewing thus accommodating the schedule of HCPs.</p>	<p>The organisation of further webinars should be pursued by TIF to ensure that queries of HCPs are promptly responded to.</p>
<p>T.2.2.1. Capacity building course for patients</p>	<p>The capacity building course for patients and their associations directly supports 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 across Europe have identified areas where they can take a more active role to best defend the interests of their 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 European region and directly affected its work plan for 2022, 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>T.2.2.2. Educational course for healthcare professionals</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 new advances that will soon impact the clinical management of patients.</p>	<p>Contributing to the life-long learning of healthcare professionals, this activity provided the opportunity to participants to acknowledge national challenges, and to learn from best practices for the further development of services in their country.</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>Closer partnership with participants to see change at the national level will contribute to TIF’s long-term goals in each country for improving the quality of care and life of patients.</p>

<p>T.2.3. European Solidarity Corps</p>	<p>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.</p>	<p>The continuous involvement of ESC volunteers in TIF's migration-related activities was demonstrated.</p>	<p>All resources (in terms of staff, network, financial resources) were utilised to implement this activity albeit its non-materialisation.</p>	<p>N/A.</p>	<p>Expanding the network of thalassaemia ambassadors requires consideration of alternative means in addition to the ESC.</p>
<p>T.2.4. Renzo Galanello Fellowship</p>	<p>This hands-on training for healthcare professionals directly serves the objectives of TIF's educational programme.</p>	<p>Participants were indeed given the opportunity to learn about the importance of multidisciplinary care and gain valuable insights regarding the clinical management of haemoglobin disorders.</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>Participants are ready to provide disease-specific training to their peers in their respective countries. This is expected to improve the quality of care provided to patients.</p>	<p>The programme will be launched again in 2022 providing more healthcare professionals the opportunity to participate.</p>



THALIA
