



## PROGRESS OUTLINE 2020



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## PILLAR 1: EDUCATION

*Activities*  
*Impact*

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## EXECUTIVE SUMMARY

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The work of the Thalassaemia International Federation (TIF) can be categorised in four distinct pillars: a) Education; b) Awareness Raising; c) Policy Advocacy and d) Research. Education lies at the heart of the Federation's activities, as it is indispensable to fill in the knowledge gaps of the key target audiences: patients, their families and healthcare professionals.

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

In 2020 and in the framework of THALIA, the educational platform for healthcare professionals was enhanced with continuous content updates anticipating the needs of medical specialists through the organisation of topic-specific webinars, the development of a sickle cell disease module and updating the guidelines for clinical management of thalassaemia (T2.1.1), whereas the educational platform for patients was enriched with content development for an improved learning experience of users and provided additional empowerment to patients through the creation of the Thalassaemia Patient Advocates Group (PAG) (T.2.1.2). A key milestone for the success of TIF's 2020 work was the joint 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. The necessity for the multidisciplinary care for thalassaemia was highlighted through the Renzo Galanello Fellowship Programme (T.2.4) which provided participants with an in-depth experience of the role portrayed by a holistic haemoglobinopathy centre. The implementation of the European Solidarity Corps Traineeship Programme (T.2.3) with the training of a smaller number of volunteers than planned, enabled more focus and structured work.

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

## INTRODUCTION

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### About Us

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

### About Haemoglobinopathies

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

### About THALIA

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

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

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

### About the impact of COVID-19

The nature of many of THALIA2020 activities requires travel and physical interaction to better assess the community needs and deliver efficient educational and policy-making tools.

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

## MATCHING OBJECTIVES TO ACTIVITIES AND IMPACT

### General objective

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

Category	E-Learning Tools		Capacity Building Courses			
Task No	T2.1.1	T2.1.2	T2.2.1	T2.2.2	T2.3	T.2.4
Target Audience	HCPs	Patients	Patients	HCPs	Volunteers / General Public	HCPs
KPI Met	✓	✓	✓	✓	✗	✓
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:** Implementation of a focused marketing campaign to promote uptake among the healthcare professional community, maintaining high quality standards with continuous content updates, anticipating educational needs of medical specialists through the development of a sickle cell disease module and updating the guidelines for clinical management of thalassaemia.

**Impact:** KPI met – More than 130 healthcare professionals enrolled in e-ThalEd.

**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 content development and empowerment of patients by the creation of the Thalassaemia Patient Advocates Group (PAG).

**Impact:** KPI met – 50 EU-based patients in the PAG.

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

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

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

**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 20 patients (individuals and representatives of existing associations) from Sweden

**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

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

**Impact:** KPI not met – The number of volunteers had to be reduced due to COVID-19 safety measures and to meet the standards defined in the 2019 European Solidarity Corps Guide, which were anticipated by all volunteers participating in the programme.

**Impact Management / Mitigation Measures:** The 2021 annual plan has been adjusted accordingly for the volunteering (ESC) programme to train volunteers with meaningful mentorship anticipating longer term interest in supporting migrants from high prevalence countries arriving in the EU.

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

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

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

**Impact:** Improvement of knowledge about the appropriate treatment of thalassaemia amongst participating healthcare professionals with added value of 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	<b>T2.1: E-Learning Tools</b> <b>T2.1.1: Educational Platform for healthcare professionals</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<b>Responsible Staff:</b> Communications Officer, Aikaterini Skari (Leader) Medical Advisor, Dr Michael Angastiniotis P.A. to the Executive Director, Maria Peletie <b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>Marketing Strategy for Educational Platform for HCPs (MS4).</li> <li>Number of healthcare professionals accessing the platform: 50</li> <li>Number of EU – based healthcare professionals accessing the platform: 25</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>Marketing strategy &amp; campaign implementation: Jan – Oct 2020</li> <li>SCD Module: Mar – Dec 2020</li> <li>TDT Updating: Mar – Dec 2020</li> <li>Webinars: May – Oct 2020</li> <li>Content Updating: Aug 2020</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>The Educational Platform for Healthcare Professionals (hereinafter ‘e-ThalEd Platform’) is an online interactive educational platform tool which aims to contribute to the continuous education of healthcare professionals working in the field of haemoglobinopathies, and in particular thalassaemia. Comprising of a variety of learning-conducive features including visuals, fora, quizzes, complimentary references and other material, the content is based on the internationally acclaimed TIF Guidelines<sup>1</sup>, authored by international experts in the field of thalassaemia with long-term experience in the prevention and clinical management of the disease.</p>	

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

The e-ThalEd Platform serves as an important continuous medical education tool for healthcare professionals in Europe who work with thalassaemia patients and carriers, members of the migrant communities that have developed throughout the EU, facilitating



the procurement of in-depth knowledge regarding the disease, hence contributing to the improvement of the quality of care provided to these patients.

In 2020, emphasis on the targeted and specific promotion of the e-ThalEd Platform to medical specialists in THALIA priority countries was pursued through a dedicated and specific marketing strategy and campaign devised in M1 (MS4). The marketing strategy focused on increasing the engagement of medical specialists with the authors (international experts in the field) of the e-ThalEd Platform and interaction in the form of webinars. Proven to enhance understanding and to facilitate knowledge acquisition, 7 webinars were organised between M5 – M10. Following the live webinars, the recordings were uploaded on the e-ThalEd Platform 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.

Ensuring the information provided to participants is up-to-date, the content of the eThalEd is continually updated, taking into account feedback from participants and medical experts. Thus, content updates have been applied to Module 4 (Practical Aspects for Effective Prevention) of the Prevention Course and Module 11 (Hematopoietic stem cell transplantation and novel therapeutic approaches) of the Clinical Management Course.

Furthermore, the development of an additional independent module on sickle cell disease, based on internationally accepted treatment guidelines and standards of care, has been initiated (M3) and completed (M12). The content has been developed and reviewed by a team of international medical experts specialised in the care of sickle cell disease from the Greece, France, UK and the USA. Launching is expected in early 2021.

The updating of the Clinical Guidelines for Transfusion-Dependent Thalassaemia (3<sup>rd</sup> 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 4<sup>th</sup> edition of the publication will reflect the regulatory approvals of advanced therapies and medicinal products (ATMP's)<sup>2</sup> for patients with transfusion-dependent thalassaemia (TDT). The extenuating circumstances brought about by the COVID-19 pandemic has delayed completion of the publication, which is expected to be finalized in Q1 of 2021. Thereafter, the content of e-ThalEd will be updated to reflect the new edition of the Guidelines.

No. of Medical Specialists accessing the e-ThalEd in 2020: 137 of which 23 were EU-based.

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<sup>2</sup> REBLOZYL® – first in class innovative medicinal product (EMA approval June 2020) ; ZYNTGLO® – gene therapy (EMA approval June 2019)

**RESULTS  
ACHIEVED**

- Accommodation of various learning styles and promotion of interaction and engagement through webinars.
- 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	<b>T2.1: E-Learning Tools</b> <b>T2.1.2: Educational Platform for patients</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<b>Responsible Staff:</b> Communications Officer, Aikaterini Skari (Leader) Medical Advisor, Dr Michael Angastiniotis P.A. to the Executive Director, Maria Peletie <b>Supervising Staff:</b> Operations Manager, Lily Cannon
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>Creation of Thalassaemia Patient Advocacy Group (MS6).</li> <li>Number of EU - based patients with thalassaemia in PAG: 50</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>Educational Leaflet on Gene Therapy: Jan 2020</li> <li>Thalassaemia Patient Advocates Group (PAG) establishment: Feb 2020</li> <li>Promotional poster in 4 languages: Feb - Apr 2020</li> <li>PAG Consultations: Feb – Dec 2020</li> <li>Educational Leaflet on Prevention of Inherited Disorders: Mar 2020</li> <li>PAG Webinars: April – June 2020</li> <li>Promotional videos in 7 languages: May – June 2020</li> <li>Content Updates ‘New Advances’ module: May – Dec 2020</li> <li>Content updates (real-life case scenarios): Aug – Sept 2020</li> <li>Webinars: Sept – Oct 2020</li> <li>Course content revision: Dec 2020</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>The Educational Platform for Patients (hereafter ‘Thal e-Course’) is an online interactive educational platform tool which aims to provide scientifically accurate disease-specific and policy information to patients with thalassaemia, taking into account the variability of learning styles, so as to facilitate knowledge acquisition and retention of knowledge in the long run.</p> <p>The content of the course has been very carefully formulated by a team of medical professionals, patients and education specialists in order to relay complex scientific terms into widely accessible language to facilitate learning for all.</p> <p><u>Anticipated Participant Outcomes:</u></p> <ol style="list-style-type: none"> <li>Enrich knowledge on optimal treatment</li> <li>Increase adherence</li> <li>Understanding importance of appropriate monitoring to assess treatment effectiveness</li> </ol> <p>The Thal e-Course includes content in the following modules and units: A. Module I: Introduction to Thalassaemia and to the Thalassaemia International Federation: Unit 1: An Introduction to Thalassaemia (history, genetic causes and inheritance pattern, epidemiology, prevention and treatment, complications); Unit 2: The establishment of TIF: A</p>	

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 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.

In 2020, focus on the Thal e-course has followed three main strands:

i. Content Updating

Considering the new advances in the care and cure of thalassaemia<sup>3</sup> (including gene therapy, erythroid maturation agents), in addition to many others that are in the pipeline<sup>4</sup> (e.g. gene editing, pathogen inactivation etc), content refinement of relevant sections of the Thal e-course have been revised. Updates will be applied in December 2020. Moreover patient-friendly educational material on Gene Therapy in thalassaemia and Prevention of Inherited Disorders has been completed and uploaded on the Thal e-course. To facilitate the learning experience, real-life case scenarios that highlight issues such as blood transfusion safety, adherence to treatment, interaction with health care professionals and advancements in treatment have been developed. These scenarios enabled participants to role play and make decisions regarding the outcome of specific scenarios, thus contributing to the consolidation and assimilation of knowledge acquisition. A review of the entire course content is expected to be initiated in December 2020, with a view of completion in 2021. A total of 4 webinars (M9 – M10) on blood transfusion, iron monitoring, heart and liver disease were organized in order to increase engagement as they provided the opportunity for interaction between participants and international experts in the field.

## ii. Creation of a Thalassaemia Patient Advocates Group

The early identification of Thal e-course graduates from Europe to participate in the newly established Thalassaemia Patient Advocates Group (M2; MS6) enabled their further training through a series of webinars (M4 – M5) on the numerous concerns occurring as a result of the COVID-19 pandemic. 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 (M5, M11), industry (M2, M6, M11) and national health authorities (M2, M7, M9, M11). 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.

## iii. Marketing & Promotion

The marketing of the Thal e-course continues through the development and roll-out of promotional video testimonials in a number of languages (EN, FR, DE, IT, GR, AR & TR) in order to broaden impact and increase participation. In addition, the brochures (developed in 2019 and available in EN, FR, DE, IT & GR) continue to be disseminated in France (via the Fédération française des associations de Malades, Drépanocytaires et Thalassémiques), Germany (via Seltene Anaemien Deutschland) and Austria (via THALSIFO Austria). The online promotion of the Thal e-course through TIF's online communication channels (v. website and social media) has been further strengthened through the creation and translation of a promotional poster (available in EN, FR, DE & GR). 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).

**Additionally, technical refinements have also been applied in order to make the content of the Thal e-course available offline through the Moodle App.**

No. of Patients/Parents accessing the Thal e-course in 2020: 142

### 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, webinars, complementary material, real-life scenarios etc.
- Facilitation of peer-to-peer interaction through discussion boards.

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

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

## OFFLINE EDUCATION ACTIVITIES

<b>TASK</b>	<b>T2.2: Capacity Building Courses</b> <b>T2.2.1: Capacity building course for newly established patients' associations (Sweden) and patients with Thalassaemia and haemoglobinopathies</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<b>Responsible Staff:</b> Policy Officer, Eleni Antoniou (Leader) P.A. to the Executive Director, Maria Peletie Office Administration, Stella Eleftheriou <b>Supervising Staff:</b> Operations Manager, Lily Cannon
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>Total number of participants: 20</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>Organisation of Capacity Building Course for newly established patients' associations (Sweden) and patients with Thalassaemia and haemoglobinopathies: Dec 2020</li> <li>Course Evaluation by participants (MS8): Dec 2020</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<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 2020. 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 (MS8), entitled 'TIF's European Thalassaemia &amp; Sickle Cell Disease Symposium', was organized on 11 – 13 December 2020, in the context of TIF's Educational Programme for Capacity Building<sup>5</sup>, and under the auspices of the Cyprus Ministry of Health. The Symposium was organized jointly with the Educational Course for HCPs (see T2.2.2 below).</p>	

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

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

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



The Symposium 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) and empowerment through sharing of best practices and presentation of TIF tools & resources for advocacy (e.g. Thal e-course, THALIA Mobile App etc.) increased the knowledge-base of attendees. The Symposium 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.

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 workshop focused on the following topics:

- Innovative Educational Tools
- Peer-to-Peer Support
- Best Practice Exchanges
- Fundamentals of clinical management of thalassaemia and sickle cell disease
- New developments in treating thalassaemia and sickle cell disease
- National Challenges in Addressing Haemoglobin Disorders
- Improving Quality of Life of Patients: Expectations of new advanced therapies
- Treatment Beyond the Haematologist & Paediatrician
- Living with Thalassaemia & Sickle Cell Disease
- Achieving Healthcare Reforms through Patient Advocacy

A total of 270 persons participated in the Symposium<sup>6</sup>, including patients/parents and healthcare professionals, Faculty members (medical specialists & members of TIF Expert Patients Panel), and TIF representatives from THALIA Priority countries (v. Sweden, France, Germany, Austria and Serbia) and other 12 EU Member States.

#### **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.

<sup>6</sup> T2.2.1 & T2.2.2 organized jointly.

TASK	<b>T2.2: Capacity Building Courses</b> <b>T2.2.2: Educational course for healthcare professionals</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<b>Responsible Staff:</b> Medical Advisor, Dr Michael Angastiniotis (Leader) P.A. to the Executive Director, Maria Peletie Administration Officer, Rawad Merhi Office Administration, Stella Eleftheriou <b>Supervising Staff:</b> Operations Manager, Lily Cannon
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>▪ Total number of participants: 20</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Organisation of Educational course for healthcare professionals: Dec 2020.</li> <li>▪ Course Evaluation by participants (MS5): Dec 2020</li> </ul>
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 2020. 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, a European Symposium for Healthcare Professionals on Thalassaemia &amp; Sickle Cell Disease was organised (MS5) virtually on 11 – 12 December 2020, under the auspices of the Cyprus Ministry of Health. The Symposium was organized jointly with the Capacity Building Course for Patients' Associations and Patients' (see T2.2.1 above).</p> <p>The Symposium 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 12 EU Member States.</p> <p>The Symposium 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) and empowerment through sharing of best practices and presentation of TIF tools &amp; resources for advocacy (e.g. Thal e-course, THALIA Mobile App etc.) increased the knowledge-base of attendees. The Symposium 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.</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:

- Fundamentals of clinical management of thalassaemia and sickle cell disease
- Multidisciplinary Care & Case Studies
- New advances in the Care and Cure of Thalassaemia and sickle cell disease
- National Challenges in Addressing Haemoglobin Disorders
- Best Practice Exchanges
- Treatment Beyond the Haematologist & Paediatrician

A total of 270 persons participated in the Symposium<sup>7</sup>, including patients/parents and healthcare professionals, from THALIA Priority countries (v. Sweden, France, Germany, Austria and Serbia) and other 12 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.

<sup>7</sup> T2.2.1 & T2.2.2 organized jointly.

TASK	T2.3: European Solidarity Corps
RESPONSIBLE STAFF, SUPERVISING STAFF	<b>Responsible Staff:</b> Administration Officer, Rawad Merhi (Leader) Policy Officer, Eleni Antoniou Office Administration, Stella Eleftheriou <b>Supervising Staff:</b> Operations Manager, Lily Cannon
INDICATORS	<ul style="list-style-type: none"> <li>Total number of participants: 10 from Austria</li> </ul>
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> <li>Identification of participants: Sept 2020 (MS3)</li> <li>2-month traineeship in Cyprus for ESC volunteers from Italy: Oct – Dec 2020.</li> <li>Evaluation of programme by participants: Dec 2020</li> </ul>
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 is authorised to carry out projects under the EU Health Programme, hence an ESC-dedicated activity was added to the annual work plan.</p> <p>Given the low levels of awareness on thalassaemia among refugees/migrants and the volunteers working at refugee camps, TIF successfully launched in 2019 a 2-month volunteering programme, aiming to equip selected volunteers of the ESC with the knowledge and know-how on how to support migrants and refugees with Thalassaemia and other haemoglobinopathies arriving in their respective countries. This ESC support measure would create a network of Thalassaemia ambassadors, able to provide valuable guidance to migrants and refugees with thalassaemia and act as local info points for people wishing to know more about Thalassaemia and hemoglobinopathies.</p> <p>Continuing the volunteering programme in 2020 whilst 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 2020, on account of the epidemiological safety of the country at the time of programme launch (v. July). The nature of the programme had to be revised though, as interaction with refugees and migrants at the Kofinou Reception &amp; Accommodation Centre, was not possible due to visitor prohibition implemented by the Centre Administration as a measure to contain COVID-19 infections.</p>	

Therefore, selected volunteers would work on migration-related issues at TIF premises, following the safety measures imposed by the Cyprus government. The selection process (MS3; M9) was conducted via Skype interviews to ascertain the best fitted candidates, with relevant backgrounds for the placements. Two (2) ESC volunteers were selected from Italy (a country with substantial experience in addressing thalassaemia, but which nonetheless receives huge numbers of refugees annually from other high prevalence countries), were informed about thalassaemia (its clinical manifestation, genetic and hereditary origin, distribution across the world, and the increasing public health issues in Europe due to migration), and were able to get hands-on **experience regarding the provision of support to the thalassemia community in Europe through their placement at the Headquarters of TIF.**

**Through their placement at TIF the volunteers had the opportunity to engage with the medical staff of the Cyprus Thalassaemia Centre, participate in virtual meetings with international experts in the field, interact with thalassaemia patients living across the EU, many of whom are migrants, assist in the advocacy efforts of the Federation through the participation in meetings with the European Commissioner for Health, European Medicines Agency, Council of Europe Conference of INGOs and the World Health Assembly. Finally, the volunteers were able to conduct virtual meetings with a number of NGOs located in Cyprus focused on the daily support of refugees, migrants and asylum seekers.**

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

#### RESULTS ACHIEVED

- Increased awareness about thalassaemia amongst members of the general public
- Transference of knowledge regarding the hereditary nature of thalassaemia and the success of the Cyprus experience in screening and prevention
- Identification of highly capable individuals to assist with ground work in Italy
- 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	<b>Responsible Staff:</b> Medical Advisor, Dr Michael Angastiniotis (Leader) P.A. to the Executive Director, Maria Peletie <b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou
INDICATORS	<ul style="list-style-type: none"> <li>Number of participating healthcare professionals from Europe: 2</li> </ul>
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> <li>Completion of selection procedure: July 2020 (MS7)</li> <li>Renzo Galanello Fellowship (virtual): 14th – 18th December 2020</li> <li>Post-Fellowship Questionnaire: Dec 2020</li> </ul>
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 15 healthcare professionals have received further training in the multidisciplinary care of thalassaemia from 14 countries since its initiation in 2015.</p>	
<p>In 2020, applications were opened in February and the application period lasted until the end of March (See announcement at <a href="https://thalassaemia.org.cy/news/renzo-galanello-fellowship-programme-2020/">https://thalassaemia.org.cy/news/renzo-galanello-fellowship-programme-2020/</a>).</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.</p>	
<p>The Selection Committee (comprised of 2 members of TIF's International Scientific Advisory Board on behalf of TIF and 2 medical specialists on behalf of the training centre) have selected (MS7 ; M7) two (2) healthcare professionals to participate in the Fellowship, 1 from Germany and 1 from Sweden, both THALIA countries of priority.</p>	



The Fellowship Programme, scheduled to take place in October 2020, was unfortunately affected by the fluctuating evolution of the COVID-19 pandemic. The safety of the participating healthcare professionals necessitated the Internal Evaluation Committee's decision to organize Renzo Galanello Fellowship virtually, despite efforts to initially change the venue to the Hippokrateion University Hospital in Thessaloniki, Greece.

Finally, the Fellowship Programme was able to be offered in a condensed format virtually between 14th – 18th December 2020 through the Joint Red Cell Unit, Haematology Department University College London NHS Foundation Trust in London, UK under the supervision of Professor John Porter (Professor of Haematology), the coordination of Dr Perla Eleftheriou (Consultant Haematologist) and the participation of distinguished medical specialists across different relevant disciplines.

#### **RESULTS ACHIEVED**

- Improvement of knowledge about the appropriate treatment of thalassaemia
- Knowledge acquisition in the multidisciplinary thalassemia 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 THALIA2020 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	Effectiveness	Efficiency	Impact	Sustainability
Tasks	Are the “general objective” and “specific objectives” still meaningful?	Has the objective been achieved? How much contribution did the “outputs” make?	To what extent have “inputs” been converted to “outputs”?	What positive or negative, direct or indirect effects have happened?	To what extent will TIF be able to maintain the positive results of its activities?
<b>T.2.1.1. Educational platform for healthcare professionals</b>	The e-ThalEd course remains a key component for the provision of accessible and life-long learning to healthcare professionals.	For 2020, the outputs were the continuous engagement of participants through webinars 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 registration and navigation.	Linguistic diversity/ multilingualism is a major challenge when working for and with EU countries, as language de facto creates barriers to the access of people to knowledge and education. 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.
<b>T.2.1.2. Educational platform for patients</b>	The Thal e-course fully supports the TIF educational programme objectives, as a source of information and promoter of training and personal development.	The platform provides an improved and enhanced learning experience to patients, as well as the knowledge and skills to navigate through the vast wealth of information available on thalassaemia. For 2020, the creation of a Thalassaemia Patient Advocacy Group further empowers 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	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.

				the future of thalassaemia in Europe.	
<b>T.2.2.1. Capacity building course for patients</b>	The capacity building course for patients and their associations directly supports 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 patients in Sweden and across Europe have identified areas where they can take a more active role to best defend the interests of their 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 momentum, TIF decided to further support the education of thalassaemia patients to achieve empowerment and policy changes.
<b>T.2.2.2. Educational course for healthcare professionals</b>	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.	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.	The "inputs" required for the implementation of this task were optimally used, namely: staff time, knowledge base, technology, financial resources, network contacts, partners	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.	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.
<b>T.2.3. European Solidarity Corps</b>	This traineeship programme links TIF's work to the migration of thalassaemia and the provision of support to migrants and refugees	The meaningful participation of ESC volunteers in TIF's migration-related activities was successfully achieved.	All resources (in terms of staff, network, financial resources) were utilised to implement this activity.	The ESC volunteers are now TIF ambassadors in Italy, ready to support migrant populations in their needs and advocate for patients' rights.	The programme will be launched and promoted again in 2021 for the expanding the network of thalassaemia ambassadors.

	with thalassaemia arriving to Europe.				
<b>T.2.4. Renzo Galanello Fellowship</b>	This hands-on training for healthcare professionals directly serves the objectives of TIF's educational programme.	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.	The "inputs" required for the implementation of this task were optimally used, namely: staff time, knowledge base, technology, financial resources, network contacts, partners	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.	The programme will be launched again in 2021 providing more healthcare professionals the opportunity to participate.

