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THALassaemia In Action 2018

JA2015 - GPSD [705038]

START DATE: 01/01/2018

END DATE: 31/12/2018

DURATION: 12 month(s)

CURRENT STATUS: Finalised

PROGRAMME TITLE: 3rd Health Programme (2014-2020)

PROGRAMME PRIORITY: -

CALL: Financial contribution to the functioning of non-governmental bodies
(Operating grants)

TOPIC: Specific Grant Agreements under HP-FPA-2017

EC CONTRIBUTION: 297828 EUR

KEYWORDS: Advocacy, Awareness Raising, Clinical Management, Disease-Specific Policies, Education, Haemoglobinopathies, Migration, Networking, Prevention, Public Health, Rare Diseases, Research, Thalassaemia

Project abstract

Thalassaemia, a previously fatal childhood genetic disease, can today be effectively prevented and appropriately treated, as a result of medical and scientific advances 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 2018 (THALIA2018) focuses on Europe, targeting patients with thalassaemia and other haemoglobinopathies, healthcare professionals and policymakers and aims to attain four general objectives, based on TIF's main pillars of activities:

1. Continue and strengthen the education of patients/parents and healthcare professionals, as well as the patients' capacity, competency and networking within and across countries and regions of Europe. This is to be achieved via the development of e-learning tools and the launching of capacity building courses and training seminars.
2. Raise awareness on thalassaemia and the importance of optimal care amongst the public at large, as well as among THALIA target groups at national and European level. This will be attained using an array of online tools, activities and publications.
3. Prioritise haemoglobin disorders and their control (prevention and management) at European level. This will be accomplished by establishing and training national patients' associations in EU priority countries, creating an EU Electronic Health Record and entering into policy dialogue with policymakers at national and European level.
4. Support research programmes and studies focused on the clinical management of Thalassaemia. This is to be achieved via the publication of guidelines on the clinical management of Thalassaemia, participating in scientific conferences and providing medical specialists in priority countries with fellowships.

Knowledge is our power.

Work package

Work Package 1: Work Programme Management

Start month: 1

End month: 12

Work Package Leader: TIF

WP1 covers all management aspects of THALIA2018 (operational, financial, risk), as well as reporting. The deliverables under this Work packages are an Interim Report in M6 and a Periodic/Annual Report in M12 that will include the Operational Plan of THALIA2018, a quick reference manual for TIF stall members on their annual work.

Work Package 2: Education (Pillar I)

Start month: 1

End month: 12

Work Package Leader: TIF

A number of activities are foreseen under three categories:

- a) online education tools for patients and healthcare professionals across Europe (T2.1.1. Educational Platform for Healthcare Professionals; T2.1.2: Educational Platform for Patients; T2.1.3: TIF Digital Library);
- b) capacity building courses for patients, healthcare professionals and volunteers from France (T2.2.1: Capacity Building Course for newly established association and patients; T.2.2: Capacity Building Course for healthcare professionals; T2.3: Traineeship for ESC volunteers) and
- c) fellowships for EU physicians (T2.4: Renzo Galanello Fellowships).

Work Package 3: Awareness Raising (Pillar II)

Start month: 1

End month: 12

Work Package Leader: TIF

A Dissemination and Awareness Plan (T3.1/WA3.1) will be drafted in M1 with practical tips regarding the implementation of the Dissemination Strategy. TIF website will be translated into French, German, Greek, Italian and Arabic by the end of 2018 (T3.2/WA3.2) and will be enriched with content from the annual Thalassaemia Video Challenge (T3.3). Thalassaemia Patients Connect Platform (T3.4) and THALIA Mobile App (T3.5) will be used to reach EU-based patients, while a Pocket Guide for Healthcare Professionals will be drafted and disseminated.

Work Package 4: Policy Advocacy (Pillar III)

Start month: 1

End month: 12

Work Package Leader: TIF

TIF works in a simultaneous top-down and bottom-up approach, raising awareness among international and European institutions (WA4.5: Information Letter to DG ECHO regarding Syria crisis), creating quality tools for national health systems (WA4.3: Thalassaemia EU Electronic Health Record/ Architecture) and empowering patients through the establishment of associations wherever there are patients (WA4.1: New Thalassaemia national association [France]) and via the exchange of good practices between associations (WA4.2: TIF EU Twinning Programme).

Work Package 5: Research (Pillar IV)

Start month: 1

End month: 12

Work Package Leader: TIF

Through WP5, TIF will inform patients about clinical trials using its educational tools and will invest on the creation of an EU-wide Electronic Health Record. Moreover, TIF Guidelines for the clinical management of thalassaemia will be given further visibility via their publication in peer-reviewed academic journals (WA5.1) and TIF experts will participate in scientific conferences to raise awareness among the research community about thalassaemia and haemoglobinopathies (WA5.2).

Work Package 6: Dissemination of Results

Start month: 1

End month: 12

Work Package Leader: TIF

A number of activities is foreseen to be implemented via a) online media (website, social media pages, newsletters, email blasts), b) traditional media (articles, TV appearances) and c) events (press conferences).

Work Package 7: THALIA2018 Evaluation

Start month: 1

End month: 12

Work Package Leader: TIF

THALIA2018 will be evaluated internally by the Board of Directors and the Executive Director (the "Internal Evaluation Committee") that will draft an Internal

Evaluation Report (WA7.1) by M12. The external evaluation of the work will be assigned to a third independent party that will deliver a comprehensive report in M12.

COORDINATOR



Thalassaemia International Federation (Thalassaemia International Federation)

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PARTNERS

No partners related to the current project

Annual/Periodic Reports

TIF

THALassaemia In Action 2018 (THALIA2018)

Published on: 27/03/2019

This is a document that includes a publishable summary of the entire THALIA2018 work programme (giving an overview of the results, their exploitation and dissemination, and the conclusions about the project and its socio-economic impact), an annual technical report (providing details about work progress, attainment of milestones, delivery of deliverables, shortcomings and mitigation measures) and a comprehensive annual financial report (consisting of details on expenses, budget allocation, timesheets, etc.). The educational, awareness raising, policy advocacy and research work completed by the end of the year and all respective documentation will be attached.

Annual Internal and External Evaluation Report

TIF

THALassaemia In Action 2018 (THALIA2018)

Published on: 19/03/2019

This is an annual evaluation report consisting of an evaluation summary, the internal evaluation report compiled by the Board of Directors and the Executive Director and the external evaluation report, prepared by a third independent party. It aims to assess whether THALIA2018 objectives and impact were achieved at the level described in the proposal, as well as the effectiveness of operational and financial management mechanisms.

Interim Report

TIF

THALassaemia In Action 2018 (THALIA2018)

Published on: 12/03/2019

This is an internal document, representing an accurate description of the work carried out in THALIA2018 for the first half of the implementation period. It is used as a monitoring tool to assess whether the work plan has fully achieved its objectives and technical goals for the period, as described in the original application, or if there are any deviations and shortcomings to be addressed by the team. It consists of a technical and a financial part that provide a detailed picture of work progress and the use of resources. It also lists all pending tasks and deliverables to support internal coordination.

Annual Progress Outline on Research (Pillar IV) Activities

TIF

THALassaemia In Action 2018 (THALIA2018)

Published on: 12/03/2019

This is an annual narrative report outlining TIF's research activities for 2018, their impact and lessons learned. It consists of reports on the participation of TIF expert in the annual conferences of the European Haematology Association (EHA) and the International Society of Blood Transfusion to take place in June 2018, as well as details about the publication of TIF guidelines in peer-reviewed academic journals. Further details and financial information will be provided in the Annual/Periodic Report.

Annual Progress Outline on Education (Pillar I) Activities

TIF

THALassaemia In Action 2018 (THALIA2018)

Published on: 11/03/2019

This is an annual narrative report providing an overview of TIF's annual education activities, their brief description, relevant justification and impact assessment and lessons learned throughout the year. It will consist of sections dedicated on each workflow action, namely the educational platform for healthcare professionals (development of 13 modules and pilot testing with the participation of 50 HCPs), the educational platform for patients (translation into 5 languages: FR, DE, EL, IT, AR), the revision of TIF's Transfusion-Dependent Thalassaemia Guidelines (preparation of new edition), the capacity building course for 20 patients and their families living in France (scheduled to take place in Greece in M9), the educational course for 20 healthcare professionals (living in France), the European Solidarity Corps 2-month Traineeship Programme (for 10 volunteers travelling from France to Cyprus to work in refugee camps) and the Renzo Galanello Fellowship Programme (for 2 EU-based physicians). This report will be utilised for the drafting of the detailed annual/periodic report that will also contain financial details.

Annual Progress Outline on Awareness Raising (Pillar II) Activities

TIF

THALassaemia In Action 2018 (THALIA2018)

Published on: 11/03/2019

This is an annual narrative report providing an overview of TIF's annual

awareness raising activities, their brief description, relevant justification, impact assessment and lessons learned throughout the year. It is a map of annual activities that includes the annual dissemination and awareness plan on thalassaemia and details on its implementation and impact, with a special focus on the translation of TIF website in 5 languages (FR, DE, IT, EL, AR), Thalassaemia Video Challenge (EU participation), Thalassaemia Patients Connect (in EU countries), THALIA Mobile App (design and features) and the pocket guide for healthcare professionals. Further details and financial information will be provided in the Annual/Periodic Report.

Annual Progress Outline on Policy Advocacy (Pillar III) Activities

TIF

THALassaemia In Action 2018 (THALIA2018)

Published on: 11/03/2019

This is an annual narrative report outlining policy advocacy work, especially as regards the 10 delegation visits to 5 countries of priority (2 per country: France M8 & M9, Germany M8 & M9, Austria M8 & M9, Sweden (M6 & M10), Serbia (M9 & M10) to establish national thalassaemia associations, the TIF EU Twinning Programme (10 patients/parents from France to travel to Cyprus), the development of the infrastructure of Thalassaemia EU Health Record and the awareness raising activities of the European Commission and EU Member States on the Syria crisis and how it is related to the rise of thalassaemia in Europe. This Progress Outline will also contain lessons learned and practical tips/ best practices in the policy-making procedures. Further details and financial information will be provided in the Annual/Periodic Report.

Annual Progress Outline on THALIA Dissemination of Results

TIF

THALassaemia In Action 2018 (THALIA2018)

Published on: 11/03/2019

This is an annual narrative report outlining THALIA2018 dissemination activities, their outreach in Europe and lessons learned, with a focus on the use of online media (development of a webpage dedicated on TIF's EU work, creation of a web banner leading to this webpage, promotional micro-campaigns on social media, monthly newsletters, email blasts), traditional media (publication of article on thalassaemia in French and EU Press, participation in TV show broadcasted across Europe) and the organisation of 2 press conferences. Further details, analytics and financial information will be provided in the periodic/annual report.