



Thalassaemia  
International  
Federation

# **Policy on Financial Support 2008**

# 1. INTRODUCTION

## What is Thalassaemia?

Thalassaemia belongs to a family of genetic blood disorders referred to as haemoglobinopathies or haemoglobin disorders. These disorders, which include mainly thalassaemia and sickle cell anaemia, are among the most common hereditary diseases worldwide: around 7% of the global population are carriers of an abnormal Hb gene. Over 500,000 affected children are born each year, more than 75% of them in developing countries.

## About TIF

Thalassaemia International Federation (TIF) is a non-profit, non-governmental patient-driven organisation, founded in 1986 and working in official relations with the World Health Organization since 1996. TIF is an umbrella organisation representing patients from over 60 countries across the world through 98 national thalassaemia associations, as well as other members,

TIF's mission is to promote equal access to quality care for all patients with thalassaemia wherever in the world they may live.

TIF does this through:

- Promoting awareness about thalassaemia, its prevention, medical and other care
- Promoting research into the continuous improvement of prevention and clinical care strategies and for achieving the total cure of thalassaemia
- Disseminating the knowledge, experience and expertise gained from countries with successful control programmes to other countries in the world affected by thalassaemia
- Development of a global network of collaboration with the medical and scientific communities, health-related bodies and organisations including the EU and HO, other patients' organisations, and industry.

TIF's core activities include:

- Establishment of new national thalassaemia associations (NTAs) where they do not exist, as well as supporting existing ones
- Delegation visits and field trips to affected countries
- Participation in projects and involvement in the formulation of policies in the field of public health, chronic/rare diseases, patients' rights and safety, clinical trials, etc. for the benefit of patients
- Educational programme for health professionals, patients and their families, and the general public, including
  - workshops and other educational events at local, national, regional and international levels
  - an extensive range of educational and awareness material published in many languages and distributed globally free of charge

- The International Conference on Thalassaemias & Haemoglobinopathies, organised since 1999 every two years
- The European Conference on Thalassaemias & Haemoglobinopathies, first organised in 2007. This event will take place every 2 years alternating with the International Conference.
- International workshop on the treatment of thalassaemia, held in Cyprus every November except the years when the International Conference is held instead.
- E-MSc degree programme in collaboration with UCL, UK.

For details about TIF's annual programme, see attached Plan of Activities.

# TIF FUNDING

## Background

TIF needs funds to carry out its mission. TIF plays a major role in the development and implementation of control programmes for thalassaemia, including prevention and clinical management, and is widely acknowledged as being the global voice of patients with thalassaemia. In this context it may attract the attention of public and private institutions, foundations and other bodies, as well as companies or industry representative organisations which have a particular interest in the development of drugs, medical equipment, consumables and other medical and healthcare related products and technologies.

The funding of TIF's core operations is independent from any corporate or public funding.

These core operations include governance, policy development and the representation of patient interest, particularly to national health authorities, international and European organisations – such as the European Commission and EMEA – as well as patient organisations and professional forums. TIF's core funding is provided by its members as well as donations from individuals and institutions.

As a patient-driven organisation, TIF is committed to maintaining its independence and will make choices and take positions based solely upon patients' needs and perspectives.

## About the TIF policy on financial support

It is essential to establish rules regarding the terms of collaboration and receipt of financial support from corporates and other bodies, and in particular on what funders may – or may not – expect from TIF in return.

The relationship between TIF and its funders is based on open and meaningful dialogue and partnership, while preserving TIF's independence and integrity. To ensure a successful partnership, each partner must learn to understand and appreciate the other's internal culture and external constraints. The views of each partner need to be heard and acknowledged and the diverse challenges openly discussed, with opportunities to work together on issues of mutual concern.

The purpose of this policy is to provide a clear method which allows TIF and other healthcare stakeholders to interact and collaborate in a transparent, accountable and effective way, while ensuring that the independence of TIF as a patient organisation is protected.

Directors and staff of TIF are expected to adhere to this policy, which will be reviewed if and when considered necessary by the TIF Board. It does not set out to provide a definition of every possible funding possibility, but rather define a set of principles with regard to the relationship between TIF and its funders.

The following principles have been developed to ensure that all funds received from partners, and all collaborative efforts with companies and other bodies, are

consistent with TIF's code of ethics and reflect positively on TIF, its members and the organisations and associations involved.

## **2. POLICY STATEMENTS**

### **Principles to be applied in relationships with funders**

TIF welcomes financial support as long as the relationship between TIF and these companies is based on the following principles:

- a public health objective driven by patient needs
- full independence of TIF
- respect
- mutual benefit
- accountability and transparency.

All sponsorship and collaboration between TIF and its funders must be for the benefit of the development of TIF's mission, as assessed and approved by the TIF Board, must not entail adverse publicity, and can in no way influence TIF's policy, positions or decisions, whether explicitly or implicitly.

- TIF will only accept sponsorship for information and educational services, such as publications, leaflets or the like, when it has full editorial control.
- TIF reserves the right and holds final approval of all uses of its name, logo and any other identifying symbols, as well as its educational materials or any part of them. These can only be used by commercial entities with prior written consent given by the TIF Board.
- TIF will accept funding for events only if the content of the event has been determined by TIF or its chosen or assigned collaborators/organisations who officially represent TIF. Sponsors will not exercise control over the programme content of TIF's events.
- TIF supports equal access for all its patients to the widest range of available drugs, treatments and health services, especially those related to the safety and adequacy of blood, transfusion therapy and iron chelation.
- TIF will not accept advertisements of drugs in any of its publications but will only accept non-promotional information about them when this is considered essential for the patients' education and awareness.

**TIF does not endorse individual medicinal products or treatments.**

**TIF encourages active partnership between patient and health professional, and discussion of all available options to ensure patients can make informed choices.**

## **Limits**

To maintain TIF's independence, financial support by member organisations, public national institutions, the European Commission, commercial companies and other private sources should be balanced.

TIF limits the total annual financial support it receives from commercial companies to an annual maximum which should not be greater than 30% of its annual budget.

To avoid the risks inherent to a relationship with a single company, TIF aims to diversify the types of financial support it receives from multiple sources of funders and to gradually and progressively increase the number and profiles of its supporters.

## **Refusal and exclusion factors**

TIF does not endorse any medicinal product, brand or health service.

TIF refuses financial support from companies or organisations that are a public health risk, or from companies that make unsubstantiated or misleading claims about their products.

A company's motives for profit may evolve over time and come into conflict with TIF's need to maintain its independence. In such situations, financial support from these companies would not be accepted or would be discontinued.

Decisions regarding acceptance of funding are made by the TIF Board and refusals can be decided by TIF on grounds such as breach of the TIF Policy on financial support by commercial companies or the NCC Code of Conduct.

## **3. TYPES OF FUNDING**

### **Funding of projects**

Financial support for a specific project provides TIF with a reliable source of income for a continued period. Project funding covers direct costs, such as personnel, equipment, consultants or suppliers, travel expenses, as well as relevant indirect costs such as telephone or administrative follow-up.

### **Funding of special initiatives or activities within the educational programme**

Special initiatives or activities can include the International Thalassaemia Conference, the European Thalassaemia Conference, national, regional or local workshops, publications and other activities within TIF's educational programme.

## **One-off charitable donations**

One-off charitable donations can be made by organisations and individuals, and they are not linked to any specific project or activity. They do not create any obligation by TIF to publicly acknowledge the financial support, however, this information may be publicised at times such as TIF's General Meetings.

## **Sponsoring the treatment of an orphan child**

Description forthcoming.

## **Membership of the TIF Network of Collaborating Companies**

The Network of Collaborating Companies (NCC) aims to establish a long-term relationship between TIF and those companies who have an interest in drugs, treatments, medical devices and other technologies for patients with thalassaemia. This relationship is driven by the principles outlined in the NCC Code of Conduct, signed by every company before becoming a member.

TIF's Network of Collaborating Companies (NCC) aims to bring together companies committed to forming a long-term relationship with TIF, based on a shared interest in improving the quality and safety of medical care provided to people with thalassaemia. NCC members must be Associate Members of TIF, and their participation is governed by the principles stated in the Code of Conduct as well as the Policy on Financial Support from Commercial Companies.

The goal of the NCC is to provide a pool of untied financial support to be used in establishing and developing activities of common interest and benefit, including:

- improving patient access to drugs, technologies, devices, consumables and services that can support and improve the quality of medical care and quality of life of patients
- raising public awareness about thalassaemia, its prevention and treatment, about the availability of drugs, medical devices and technologies relevant to the care of thalassaemia, and about the need for further research into the disease
- promoting the establishment of national thalassaemia associations and providing capacity building and advocacy support to existing ones.

The NCC is committed to providing a transparent, neutral and unbiased forum for the exchange of information. To this end, the NCC emphasises the role of networking with the global thalassaemia community, including associations, organisations, regulatory agencies and policymakers at national, regional and international levels.

The NCC is committed to encouraging, helping and supporting pharmaceutical and medical companies to improve existing drugs, technologies and devices serving the needs of patients and to develop new ones.

The NCC is committed to educating companies on thalassaemia and its medical care and to building effective partnerships in order to improve working relationships between companies, as well as relationships of companies with patient groups and relevant health professionals.

Ideally, a supporter will be able to commit to the TIF NCC for three years, thus enabling budgeting and effective financial planning. The collaboration may be terminated in case of serious concerns arising on either or both sides which cannot be resolved through discussions.

There are three levels at which funders can become involved in the NCC and sponsor educational events organised by Thalassaemia International Federation – **Silver, Gold, and Platinum**. Detailed information about the benefits in each of these categories is contained in a separate document.

## **4. PROCEDURE**

### **Documentation**

When approaching a commercial company, TIF will request information about the company, including their main business activities, products or services for thalassaemia. TIF will undertake its own research, particularly regarding the company's reputation with patient groups and regulators.

TIF will provide each company with the Policy on Financial Support by Commercial Companies. This document must be read, signed and returned by the company.

When financial support is approved, a contract or an exchange of letters between TIF and the commercial company will take place. These contracts or letters can only be signed by the President of the Board and by an authorised person from the company.

### **Accountability**

Commercial companies that have entered into partnership with TIF during a certain year will receive, if they wish, the annual activity report and financial statements covering that period, once these have been approved by the TIF Board of Directors

When financial support is provided for a project, the company will receive periodical reports and a final report on the project.

When financial support is provided in the context of a specific activity, the company will receive a report or copies of relevant documents about the supported event or other activity.

### **Recognition and visibility of the relationship**

TIF will provide appropriate recognition of an organisation's sponsorship, but this must not be interpreted as an endorsement of products or policies.

All supporters will have the levels of their support fully acknowledged in TIF's financial/funding documents and the relevant publicity materials, where appropriate.

All supporters will be acknowledged on the TIF website within a special area dedicated to supporters, which is transparent and explains the nature of collaboration between the two organisations.

When a commercial company is referring to financial support provided to TIF within their own literature, the wording used and/or the TIF name and logo cannot be published without prior written approval. Any information or statement intended for publication must be approved by the TIF Board of Directors.

### **Transparency Policy**

The relationship between TIF and its funders is based on regular and transparent communications and dialogue. By adopting a transparent policy regarding its relations with commercial companies and being open about its sources of funding, TIF acknowledges that the financial support it receives will never compromise its independence and future policy decisions.

The Annual Financial Statements of TIF will reflect the level of funding received from corporate sponsors and provide fair and reliable information to its members and the public. This information can be obtained upon written official request from the Cyprus Registry of Companies.

Financial support for the funding of projects and any other activities will appear in reports, public presentations and in other relevant documents. Support will also be publicly acknowledged in TIF's Board and General meetings.

## **Exclusions**

The TIF Network of Collaborating Companies (NCC) inclusion and exclusion decisions are made by the TIF Board. Exclusion can be decided by TIF on grounds such as breach of the NCC Code of Conduct, or the TIF Policy on financial support by commercial companies.

## 5. CODE OF CONDUCT

When becoming a member of the TIF Network of Collaborating Companies (NCC), the company accepts the following rules and makes a commitment to adhere to these rules.

1. Discussions should be limited to improvement of mutual understanding and issues of public health, the prevention and medical care of thalassaemia (and other haemoglobinopathies). Any discussion of specific products or services of the company is not permitted.
2. That the NCC is not a platform to attempt to influence the decisions or positions taken by TIF, regulators, public policy makers or any other stakeholders. The NCC may also not be used to attempt to influence public policies that would benefit any company's products.
3. It should be understood that participation in the NCC will have absolutely no influence on the decisions made by TIF's Board of directors or its representatives at the COMP at the EMEA or at any other national, European, or international policy or decision-making body.
4. The independence and integrity of TIF, its representatives and its members should be fully respected.
5. The role of TIF and of its member organisations advocates for the people affected by thalassaemia should be recognised, including TIF's and its member organisations' right to express opinions, comments and criticisms on any relevant matter.
6. The role of patient groups in clinical trials should be recognised, while active partnership between patients, health professionals and industry should be encouraged.
7. Access to quality treatment and other health services by patients, free of charge or at reasonable cost that does not prevent equal access by every patient, should be promoted in every way possible.
8. TIF's Policy on Financial Support by Commercial Companies should be respected and adhered to. In particular, the benefits deriving from membership of the NCC are as stated in the contract/letter of understanding, and no other benefit or advantage - direct or indirect – can be expected.