



Thalassaemia
International
Federation

Internal Regulations

July 2013

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Board Meeting Procedure

Procedure for making a Board meeting productive

All requirements for quorum, agenda, etc. are kept strictly as dictated by the TIF Constitution. For conducting a Board meeting, the following procedures are recommended:

1. The President or Vice President calls out each topic on the agenda and requests from the Board Member who had proposed it to present it (within 6-7 minutes) to the Board in the following format:
 - (i) Subject
 - (ii) Introduction
 - (iii) Reasons for including it in the agenda
 - (iv) Proposed action.
2. After the presentation, the person who had suggested the topic should be ready to answer any questions on the topic posed by the Board Members. The time allocated for discussion and/or further clarifications should be about 20 minutes. Priority to speak should be given to those Board Members who either (i) do not agree with the topic, (ii) do not agree with the proposed action, or (iii) need some further clarification pertaining to the proposed topic.

Efforts should be made by all to allow as many Board Members as possible to express their views. The total question-and-response time should not exceed 40 minutes.
3. The President or the Secretary throughout the meeting addresses each of the non-English-speaking Board Members to ascertain whether they have clearly understood the discussion and to provide further explanation or clarifications where required. Non-English speaking Board Members should be accompanied by a translator according to TIF's internal regulation "Participation of non-Board Members in Board meetings".
4. The President or Secretary reads out the decision taken on the subject, which maybe reached by majority vote.
5. Minutes should be prepared by the Secretary or Assistant Secretary in collaboration with the Executive Director of the TIF office and should contain (i) the topics as shown on the agenda; (ii) proposed actions and (iii) decisions taken. Thereafter the draft version of the minutes should be sent to Board Members for their first comments within a maximum of 3 weeks following the Board meeting. The final draft of the minutes is to be distributed to all Board Members within a maximum of 2 months following the Board Meeting.

Eligibility Criteria to Become a Board Member

- Board Members should be individuals recognised in their country for their contribution in the field of thalassaemia, with experience and knowledge on the disorder, its prevention and treatment, on the promotion of non-governmental organisations, and on lobbying national health authorities and other bodies for support.
- Membership of the Board is considered a voluntary activity, and Board Members do not receive remuneration.
- Board Members should be appointed by National Thalassaemia Associations which are members of TIF with a voting status and have fully addressed their financial membership obligations up to the date of the election.
- Patients with thalassaemia constitute 50% of the Board Members and the rest are non-patients. Parents and other interested non-medical individuals may be candidates for the Board.
- Medical doctors or medical scientists who are not patients with thalassaemia are not eligible for election on the Board of Directors.
- A detailed CV of the proposed Board Member should be presented, together with the application at least 2 weeks prior to the General Meeting and the elections.
- A 5-minute presentation should be made by the proposed Board Member at the General Meeting.
- Board Members should be at least 20 years of age.
- Board Members must not have been convicted of any crime.
- Board Members should have a good understanding of and satisfactory communication skills in the English language.
- The Association represented by the Board Member should be in a financial position to undertake the responsibility of covering the costs of their representation in one or two Board meetings per year, or the Board Member her/himself should be in a position to cover the costs of travel and hotel stay.
- Board Members should spend time and efforts in participating in TIF's activities and promoting TIF's interests, mission, objectives and activities, including fundraising.
- Board Members should have access to email and/or fax, maintained with working account at all times.
- Board Members should adhere to the TIF Code of Conduct in their communications, reporting, other activities and discussions either in the course of Board meetings or outside, and whenever they represent the Federation or discuss the business of the Federation.

Guidance for TIF Board Members

TIF Board Members are expected to adhere to the following principles in their interactions with the Board, as well as in any activity outside the Board where they represent, or may be perceived to represent, the Federation.

1. Board Members should ensure that they are well versed on all issues of concern to TIF as well as all activities and policies promoted by TIF.
2. Board Members should respond to queries by the TIF office promptly and within a reasonable time frame, and to conduct themselves in an appropriate manner in all their communications, including:
 - (i) between Board Members;
 - (ii) between Board Members and health professionals;
 - (iii) between Board Members and industries; and
 - (iv) between Board Members and any other parties or individuals.
3. Board Members who are invited to represent TIF at conferences or delegation visits, or who in the course of their own association's or personal visits are required, or who take the initiative to speak on behalf of TIF or describe its policies, are requested to consult the TIF office beforehand in order to be fully informed about:
 - (i) all available data and information regarding thalassaemia in the particular country, region, city, etc.;
 - (ii) the background of any particular topic(s) to be covered, including TIF's policies on the particular topic(s) or the line it has followed in relation to these; and
 - (iii) what plan of action is being already followed, or is planned regarding the particular country or issue.

Participation of non-Board Members in TIF's Board meetings

Most of the issues regarding Board Members and meetings are fully described in the Constitution. A few issues not described in the Constitution are clarified below.

Individuals attending Board meetings who are not members of the Board cannot vote or be voted.

1. Translators

Translators are not permitted at Board meetings.

2. TIF office staff

Members of TIF staff eligible to participate in Board meetings are:

- (i.) the Executive Director;
- (ii.) those who are directly involved and assigned for taking the minutes of the meeting;
- (iii.) those who have been assigned to present a report or a case; and
- (iv.) any other staff member if specifically requested by the Board.

TIF staff members may be asked to answer any questions and to provide clarifications to any queries by the Board Members with regard to the running of the office or TIF's activities.

The name(s) of the staff that will be present in the Board meeting will be announced to Board Members by the President prior to the Board meeting.

The Board Members have the right to ask TIF staff at any given moment to withdraw from the meeting room.

3. Observers

As per TIF's amended Constitution, observers are not permitted in Board meetings.

4. Alternates

Board Members who are not able to attend Board meetings may wish to be represented by an alternate. According to the Cyprus Company Law, the President of the association which the Board member in question represents should send an official stamped letter to the TIF President and Secretary assigning the name of the individual who is proposed as the alternate. The alternate must be a registered member of the association but not necessarily a member of its Board. The proposed alternate is then registered at the Cyprus Companies Register as officially representing the elected Board Member at the specific Board meeting. After the meeting, his/her name is removed from the Cyprus Companies Register through the same procedure.

The alternate's vote(s), statements and recommendations are fully binding on the Board Member whom he/she represents. A Board member cannot be represented by an alternate (whether the same or different) more than three consecutive times.

A non-country affiliated Board member cannot be represented by an alternate.

Collaboration with Health Professionals for Educational Events – Ad Hoc Involvement of Expert Scientific/Medical Advisors

Introduction

Collaboration with health professionals is an essential part of TIF's worldwide network of international experts, who have contributed significantly to TIF's educational programme during the 20 years since its establishment. TIF aims to strengthen and broaden its global network of collaborating health professionals on an open and transparent basis for the benefit of its patients.

Criteria and Qualifications

TIF's collaborating health professionals should:

- (i) be of recognised academic/scientific calibre, preferably at the level of a Professor in the expertise required;
- (ii) have an extensive list of international publications in the field of haemoglobin disorders; and
- (iii) have at least 10 years' experience in the field of haemoglobin disorders.

Methodology

For each educational activity as described and scheduled in the Plan of Activities every year, one or two international experts are invited by the Board to cover the theme of the particular activity according to their expertise. The following steps will then follow:

1. The one or two leading experts will invite other experts if needed to constitute the faculty, or the group of authors/editors in the case of publication;
2. The group will decide the methodology to be followed for the particular activity (event or publication) and inform the TIF officially in writing;
3. Progress will be monitored closely via tele/videoconferences and emails, and the group will update TIF at regular intervals (weekly/ monthly/bimonthly etc.) depending on the duration of the preparation and of the activity;
4. Meetings of the experts (or the faculty or group of authors) should be avoided due to budgetary constraints. If, however, this is considered essential by the leading expert(s) overseeing the event, TIF will provide sponsorship for the meeting to take place.

Obligations and code of conduct of health professionals working with TIF

Health professionals and scientists collaborating with TIF are expected to adhere to the following obligations and code of conduct:

1. The health professional/scientist will work towards the benefit of patients and the mission and objectives of the Federation.
2. He/she will receive no honorarium for his/her work and involvement. Participation is considered to be a voluntary contribution towards the Federation.

3. He/she will inform TIF of any collaboration with, or any other interests in, any pharmaceutical companies for the last three years and provide a written declaration of conflict of interest.
4. He/she agrees to get involved in all aspects of the execution of the activity, including designing in the case of publications.
5. He/she must be willing to travel to developing regions of the world.
6. All health professionals committed to collaboration with TIF should:
 - a. have access to email and internet,
 - b. respond to correspondence promptly,
 - c. devote sufficient time for meetings, including preparation time, and
 - d. comply with set deadlines.
7. Once a book or other material is published by TIF, its contents become TIF's property jointly with the authors.

The TIF office's responsibilities:

1. To cover the expenses of the collaborating health professionals if required for travel to meetings, including economy air fares, airport transfers, hotel accommodation and food expenses, at reasonable cost;
2. To provide administrative and logistical support on all tasks related to the activity;
3. In the case of publications, TIF reserves the right to submit the final draft to one or two independent reviewers for comments prior to publication.
4. TIF will prepare and provide medical/scientific updates to Board members and other interested parties on a regular basis through its Medical Advisor and Executive Director.

Guidelines for Translations and/or Reprints of TIF Materials

In the event of a translation or reprinting of any TIF publication, we ask that you respect our copyright of these materials by following the guidelines below in preparing the books for printing:

1. The book must be produced in the same size (height & width), shape and colour as the original, with the same title and cover art.
2. Nothing may be added to nor deleted from the text. (i.e., no additions of advertising material, logos of sponsors, etc., and no “partial” translations or reprints of “a selection”).
3. Translations should be made by professional medical translators and ideally checked by a second native speaker of the same language who has a medical background in thalassaemia.
4. A copy of the translation must be sent to TIF for review before printing. TIF will provide written approval for the translation to eliminate the risk of multiple versions of the translated text.
5. TIF books are distributed free of charge upon request. The same should apply to translations and reprints of our materials.

TIF will be happy to provide whatever support or assistance you may need in preparing and distributing translations of TIF books. Your interest and efforts are greatly appreciated.

Travel Policy

The following recommendations are intended for TIF staff, Board Members, health professionals and anyone representing TIF, and should be adhered to when booking travel for TIF's educational events, delegation visits or other purposes.

1. Flight arrangements

- 1.1. Flights should be purchased or reimbursed for economy class only, unless the person traveling wishes to cover the difference between economy and business. Business class tickets may be purchased or reimbursed in exceptional cases at the discretion of the President or the Board, e.g. in consideration of a particularly long and difficult trip, the traveller's age, health or status (e.g. government ministers).
- 1.2. If travellers arrange their own flights they should request reimbursement from the TIF office, enclosing the original invoice.
- 1.3. A direct flight to the destination should be chosen where possible, or if no direct flight is available, the most practical connection should be chosen.

2. Accommodation

- 2.1. Hotels should be booked on a b&b basis.
- 2.2. Hotels should be located as near as possible to the place of work.
- 2.3. Hotels should be 4* or 5* category, however, at rates that do not exceed €250 per person/night.
- 2.4. Travellers should arrive on the day before or the same day, depending on the timetable of the event/work and the convenience of travel (e.g. length of trip, time difference). Departure should be on the evening of the last day or the morning of the next day.
- 2.5. "Extra" nights should not be booked, unless the traveller wishes to cover the cost themselves.
- 2.6. Extra nights can only be considered in cases where there are no convenient flights available, or travelling on the set day would be more expensive than an extra night spent at the destination.

3. Expenses covered by TIF

- 3.1. Per diem. TIF allocates a per diem of €50.00 or \$50.00 per day (according to the destination country) to cover food and other living expenses. The per diem is given for each day of duration of the trip, including travelling dates, and no receipts are required for this.
- 3.2. Other expenses. In addition, fares from and to the airport, as well as other essential expenses such as urgent telephone calls, hospitality or other unforeseen related expenses may be covered by TIF upon presentation of original receipts And permission granted by Executive Director or President of the Board.
- 3.3. The use of public transport should be encouraged whenever this is convenient.

4. Travel / medical insurance for non-patients

- 4.1. Insurance is issued for medical professionals, staff and other (non-patient) individuals travelling on behalf of TIF from Cyprus
- 4.2. Individuals travelling on behalf of TIF from other countries are asked to arrange their own insurance and request reimbursement from the TIF office.
- 4.3. For patients the issue of insurance is very challenging and where it exists the costs are extremely high to purchase it. The Board of Directors unanimously approved the 'Travel Consent Form' during their meeting in November 2011. This document is a standard practice for everyone, including patients, travelling on TIF's behalf to sign this document, until and unless new procedures come to effect.

THALASSAEMIA INTERNATIONAL FEDERATION

“In official relations with the World Health Organization”



HEADQUARTERS:

P.O. Box 28807, 2083 Strovolos; 31 Ifigenias Street, 3rd Floor, 2007 Strovolos, Cyprus
Tel: 357-22-319129, Fax: 357-22-314552, E-mail: thalassaemia@cytanet.com.cy
Website address: <http://www.thalassaemia.org.cy>

Travel Consent Form

THE PARTIES TO THIS AGREEMENT ARE:

TIF Representative / Thalassaemia International Federation (TIF)

THE ORGANISATION

Name of Organization: Thalassaemia International Federation (TIF).....

Address: 31 Ifigeneias Street 2007 Strovolos, Nicosia Cyprus.....

Telephone: + 357-22-319129..... **Fax:** +357-22-314-553.....

Email: thalassaemia@cytanet.com.cy ; tif@thalassaemia.org.cy

(hereinafter referred to as “TIF”)

THE TIF REPRESENTATIVE

Full Name and Surname:

Passport Number/Social Security Identity Number:

Address:

Telephone(s): **Fax:**.....

Email(s):

(hereinafter referred to as "the TIF Representative")

1. I, the TIF Representative agree to travel to the following destination(s):

.....
.....

2. The period of travel shall be from the day of, 20..... until the

..... day of, 20..... .

3. TIF is responsible for making the arrangements and for covering the travelling and accommodation expenses of the TIF Representative for the agreed period of the event(s) (workshop/delegation visit/seminar/training) that the TIF Representative is invited and has agreed to represent TIF. Any additional expenses must be bared by the TIF Representative.

4. In the case that the TIF Representative would like to make his/hers own travelling and accommodation arrangements he/she has to communicate the costs of travelling and accommodation to TIF and after approval by TIF he/she can proceed with finalising arrangements. TIF has the obligation to reimburse the TIF Representative within 2 weeks after the presentation of necessary invoices/receipts.

5. In the case that the TIF Representative is a staff, and in the case that he/she would like or is advised by the management of TIF to make his/her own travelling and accommodation arrangements, he/she has to communicate the costs of travelling and accommodation to TIF and after approval by TIF management, can proceed with finalising arrangements. TIF has the obligation to reimburse the TIF Representative within 3 days after the presentation of necessary invoices/receipts.

6. The TIF Representative is responsible for arranging his/her own medical insurance for the period of travel (including travelling dates). TIF bares no responsibility for the medical expenses in case of an accident or an emergency treatment. TIF will exert every effort , in case of an accident or emergency, to provide remote assistance using its network of collaborators in a country. TIF will provide a focal person (medical) for any emergency problem in a country it sends the TIF Representative.

7. The TIF Representative has the obligation to present between 5 and 10 slides about TIF its mission and activities and relevant information to the country or subject of discussion at the beginning of any presentation he/she is called to make on TIF's behalf. The TIF Representative has to promote the work of TIF according to its mission and vision, serving the best interest of the organisation.

8. Any actions/behaviour or discussion that are not aligned with TIF's mission and vision will be considered as unethical towards the organisation and will be subject to for exclusion of the TIF Representative from future events to represent TIF.

9. TIF has the obligation to provide the 5-10 slides to the TIF Representative and any other additional information available in TIF's archives that will allow the TIF Representative to prepare well for the event.

10. The TIF Representative has to compile and present a report to TIF of the event participated within 15 days of his/her return from the trip. The report is advised to be consisted and relevant to the areas of TIF's interests and to include recommendations and for further actions to be taken by TIF. The format of the report will be provides by TIF.

Signed on this day of.....20.....

SIGNATURE (TIF Representative)

SIGNATURE..... (TIF) **STAMP:**

George and Panos Englezos Awards

Every two years since their adoption in 1997, the Panos and George Englezos Awards have been given to scientists and volunteers in recognition and appreciation of their long and invaluable contribution to the global struggle against thalassaemia.

GEORGE ENGLEZOS AWARD

The George Englezos Award is given to an individual who has made an outstanding evidence-based international scientific clinical, medical or research contribution to the cause of thalassaemia, i.e. publications, WHO involvement, etc, and has retired.

In previous years the following individuals have received the George Englezos Award:

1. **Prof Antonio Cao** for his vast international contribution in developing a prevention model as well as research in basic molecular aspects of thalassaemia diagnosis.
2. **Prof Calogero Vullo** author of the first books on haemoglobin disorders. He is internationally recognized for his contribution in clinical management and issues related to quality of life of patients.
3. **Dr Beatrix Wonke** for her international contribution to the improvement of the survival and quality of life of patients with her innovative clinical research and observational studies.
4. **Prof Bernadette Modell** for her international contribution to the development of control programmes and their integration into national programmes. In addition for her vast contribution to the development of registries and the elucidation of the epidemiology of Hb disorders.
5. **Dr Michael Angastiniotis** for the success of his mission to promote control programmes across the world and collaboration with WHO.
6. **Dr Panos Ioannou** for his high-level scientific research regarding the cure for thalassaemia.
7. **Sir David Weatherall** in recognition of his significant international contribution to the science of thalassaemia
8. **Dr Hans Peter Schnebli** for his discovery and development of the chemical active ingredient (ICL670) for the new oral chelator Exjade.

PANOS ENGLEZOS AWARD

The Panos Englezos Award is presented to an individual who serves as a role model for others in the community and who has contributed in an exceptional way towards the fight against thalassaemia on an internationally recognized basis.

In previous years the following individuals have received the Panos Englezos Award:

1. **Mr Elias Sofianos** activist, pioneer patient and founding member of the 1st Greek Thalassaemia Association and of TIF.
2. **Mrs Shobha Tuli** for her work and commitment in the Indian subcontinent and her invaluable contribution to TIF.
3. **Dr Androulla Eleftheriou** for her contribution in the spread of awareness, knowledge and information to patients and parents through her series of publications and in her capacity as a WHO consultant.
4. **Phedias Soteriou / Mr Mahesh Kotecha** for their invaluable voluntary contributions to their national thalassaemia associations and significant support in the founding of TIF.
5. **Mr Earl “Duke” Brady** for his vast and innovative contribution towards the creation of patients’ training programmes and as a founding member of TIF.
6. **Mr Giovanni Lotta** for the founding of the Italian association with a great national contribution towards the establishment of prevention and management protocols in Italy, which became models followed elsewhere in the world.
7. **Dr Odysseas Platis** for his national and international contribution to the thalassaemia community
8. **Mr Kostas Kountourou** (posthumously) for his invaluable contribution in the promotion of thalassaemia patient support groups
9. **Mr Anastasis Leventis** for his invaluable contribution in the development and launch of the e-MSc course

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Website: www.thalassaemia.org.cy



International Conference on Thalassaemia and Haemoglobinopathies
International TIF Conference for Thalassaemia Patients and Parents
Pan-European Conference on Thalassaemia and Haemoglobinopathies

APPLICATION FORM FOR HOSTING A CONFERENCE

1. Name of country wishing to host Conference/s: _____
2. Thalassaemia and other Hb disorder carrier rate in the country: _____
3. Thalassaemia and other Hb disorder prevalence in the country: _____
4. Name of the Association/Federation proposing to host the Conference/s:

5. Contact person: _____

Address: _____

Tel: _____ Fax: _____

Email: _____

Number of registered patients in the Association/Federation: _____

OR:

6. Name of the academic / medical or health institution proposing to host the Conference/s in collaboration with National Thalassaemia Association/Federation:

7. Contact person: _____

Address: _____

Tel: _____ Fax: _____

Email: _____

8. Thalassaemia Associations or medical/academic institutions in the country that will be involved in addition (please give names, addresses, tel/fax and email details.):

a. Organisation: _____

Address: _____

Tel: _____ Fax: _____

Email: _____

b. Organisation: _____

Address: _____

Tel: _____ Fax: _____

Email: _____

c. Organisation: _____

Address: _____

Tel: _____ Fax: _____

Email: _____

9. Is there expression of official interest or support by the Ministry of Health or other government body for the organisation of the Conference? YES / NO

If yes, please give name, capacity and contact details of the individual representing the Ministry of Health or other government body:

10. Location where Conference/s would be held: _____

11. Approximate dates the Conference/s would be held: _____

12. Will a professional travel agency be used? YES / NO

If yes please state its name: _____

Approximate cost (fee) of the travel agency: _____

13. Please indicate hotel accommodation prices per person per day in 3*, 4* and 5* hotels, and distance from conference venue:

3* Single room: _____ 3* Double room: _____

Distance: _____

4* Single room: _____ 4* Double room: _____

Distance: _____

5* Single room: _____ 5* Double room: _____

Distance: _____

14. What are the visa requirements in the Country? _____

I confirm that the Host Committee is in a position to satisfy the attached Terms & Conditions as a prerequisite for hosting the Conference/s.

Authorised signature

Date

Name:

Position:

Official stamp of institution:

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International Conference on Thalassaemia and Haemoglobinopathies
International TIF Conference for Thalassaemia Patients and Parents
Pan-European Conference on Thalassaemia and Haemoglobinopathies

APPLICATION GUIDELINES

TERMS & CONDITIONS

This document should be used as a guideline for thalassaemia organisations wishing to apply to host a TIF Conference. The Host Committee must be in a position to satisfy the Terms and Conditions below in order to be selected to host the Conference/s.

A. GENERAL GUIDELINES

1. The proposing country must be epidemiologically (based on WHO data) considered a country affected with thalassaemia, having a high carrier and/or prevalence rate.
2. The proposing country must have at least one TIF General Member or Voting Member association.
3. The proposing country must first secure the interest and support of its national health authorities or other relevant government body, and the country's medical professionals involved in the field of haemoglobin disorders.
4. The proposing country must provide 10 copies of the proposal submitted for the Board to review. Proposals must be in the form of an A4 bound document.
5. All proposals must be received by the published closing date and proof of posting must be obtained. The TIF office bears no responsibility for proposals that are lost in the post.
6. Proposals will not be accepted after the published closing date.
7. The selection of the successful proposal is at the discretion of the TIF Board of Directors .
8. TIF may request clarification on any point(s) in the proposals prior to making a final decision.
9. An acknowledgement of receipt of documents will be sent to all candidates.
10. Once the TIF Board has made its decision, the successful candidate will be notified in writing.

B. PROPOSAL DOCUMENT FORMAT

1. All proposals should contain the following information:
 - a. Complete financial proposal, including budget and costs of all aspects of the conference
 - b. Plan of action for securing external funding
 - c. A certified accounting firm selected to keep all accounts
 - d. Information regarding the status of thalassaemia (epidemiology, prevalence, incidence) within the proposed host country
 - e. Proposed conference dates
 - f. Detailed venue information
 - g. Detailed travel information (air and local travel, visa requirements, etc.)
 - h. Hotel accommodation, which should include only hotels of 3*, 4* and 5* standard and give the following information:
 - B&B room rates for single, twin, double and triple rooms
 - Distance to venue
 - Facilities for disabled persons
 - Transportation facilities and costs to and from hotels and venue (metro, taxi, shuttle bus etc.)
 - i. Registration fees for each category:
 - Patient/parent
 - Accompanying person
 - Medical scientific staff
 - Paramedical staff, social workers and other health workers
 - Students
2. Following notification to the successful applicant, TIF Board members will undertake through their Association to:
 - form a local Organising Committee, including TIF and representatives of the local thalassaemia associations; and
 - form an International Committee, including the TIF President and Scientific Co-ordinator, international, regional and local experts involved in thalassaemia, and officials of the local Organising Committee
3. The scientific programme will be prepared by TIF in collaboration with an ad hoc Scientific Advisory Committee, with the involvement of the local host Scientific Committee.
4. The Secretariat of the Conference should be located in the host country and undertakes all local arrangements, working in close collaboration with the TIF office.
5. After successful completion of the programme, the First Announcement will be prepared and distributed, and should include the following information:
 - Location, registration and other fees, travel options, accommodation options
 - Preliminary scientific programme outlining the topics intended to be covered and the panel of selected scientists who are to deliver lectures on these topics
 - Preliminary programme and other details regarding the TIF Patients and Parents' Conference which runs parallel with the scientific programme.

- Official language of the Conference and available translation facilities
 - Availability of fellowships and other awards and bursaries, with application instructions
6. The contents of this document must be approved by TIF and the hosting country, to ensure that any information contained within complies with any national or international pharmaceutical regulatory bodies.
 7. The host organisation and TIF will be jointly responsible for identifying funds to cover all expenses of the Conference, including venue, meals/coffee breaks, social programme, translation facilities, invited speakers and the sponsorship of participants from developing countries.
 8. Complete and accurate records of all income and expenditure relating to the Conference/s should be kept and maintained by the organisers, with the assistance and collaboration of TIF staff.
 9. Thirty per cent (30%) of the income deriving from the total registration fees shall be paid to TIF. The account must be settled within 60 days from the close of the Conference, by which date a full breakdown of attendees and cancellations, as well as accounts, must be sent to TIF.
 10. Two per cent (2%) of the total sum of external commercial funding obtained by the conference shall be paid to TIF as a donation, in addition to income from registrations.

C. TERMS AND CONDITIONS

1. The organisers must have an available budget for organising the event. Evidence must be provided that financial support will be secured from sources other than the association/scientists organising it – such as government, pharmaceutical companies and other private or public sources, prior to the granting of the event.
2. Travel to the host country and conference venue must be convenient and not prohibitively costly. There must be no or minimal restrictions on travel to any participants coming from any country of the world.
3. Both the scientific Thalassaemia Conference and the Patients/Parents' Conference, which run in parallel, must be hosted at the same conference venue. No restrictions shall be placed on patients' participation in the scientific programme or vice versa, unless there are government restrictions that require the two conferences to run separately.
4. The venue
 - a. Must not be in an isolated area and must be easily accessible by regular public transport.
 - b. Must have conference facilities for multiple needs:
 - 1 large hall for 1,200 persons
 - 1 smaller hall for 500 persons
 - 4–5 small meeting rooms
 - c. Must provide free of charge a room for TIF Board meetings and interviewing of Associations at the conference venue, from 1 day prior to the Conference until 1 day after closing.
 - d. Must provide free of charge a storage area for TIF materials for the duration of the Conference.

- e. Must provide free of charge a TIF information desk in the main lobby for the duration of the Conference.
 - f. Must provide free registration for all Board members and at least 2 members of TIF staff.
 - g. Must be wheelchair accessible and have an elevator to the halls, accommodation areas and restaurants.
 - h. Must ensure the availability of a variety of catering facilities which are open until late at night, either at the venue or within easy walking distance.
 - i. Must provide a room or common area for patients to meet in the hotel or Conference venue.
 - j. Must provide a sit-down lunch to all participants
5. Simultaneous translation facilities must be available and provided irrespective of the cost. The number and type of languages should be decided based on registrations.
 6. National airline carrier should be engaged to see if they will provide discounts to conference travellers.
 7. If some accommodation is not close to the conference venue (within 10 minutes' walking distance), shuttle buses must be provided to transfer the participants at no extra charge.
 8. Patients and parents must have free access to the Scientific Conference with no registration fee, or must be offered a nominal registration fee.
 9. The hosts must be able to:
 - a. Provide sponsorship and travel expenses to the invited speakers and to the TIF President (if s/he is not presenting). Travel must be standard fare unless budget allows otherwise. If speakers wish to travel business or first class, they will pay the difference.
 - b. Provide financial support to, or secure sponsorships for, patients to travel to the Conference from poor or developing countries.
 - c. Have enough volunteers to provide assistance during the Conference.
 - d. Make available 24-hour hospital and doctor support if needed for patients and other participants.
 - e. Organise a press conference and press coverage of the event.
 - f. Organise at least 1 social event on a day when the Conference is not in session.
 - g. Organise a gala dinner at a location which can accommodate all participants at the end of the Conference. The cost should be included in the patients/parents' registration fee but not the scientific conference registration fee.
 - h. Ensure that the hotel and Conference Secretariat staff can communicate well in English.
 10. It is preferable that all patients are accommodated in the same hotel.

The Host Committee must be in a position to satisfy the above terms and conditions in order to be selected to host the Conference/s.