



Thalassaemia
International
Federation

DRAFT
Plan of Activities
2011

I. Educational programme 2011

The following pages outline TIF's planned activities for 2011 in the context of its Educational Programme (delegation visits and workshops) around the world.

1. Europe

Objectives:

- Raising awareness about thalassaemia and haemoglobin disorders, their treatment and prevention
- Investigating the health services available to patients and patients' take-up of and access to those services
- Supporting existing patients' associations and encouraging them to become members of TIF
- Encouraging the creation of new associations with TIF's support
- Collecting epidemiological data from the country, including numbers and location of patients with thalassaemia
- Strengthening of networks of collaboration between and amongst health professionals, patients and parents
- Monitoring and supporting EU and WHO efforts towards the creation of recommendations and policies relevant to Hb disorders.
- Supporting patients to acquire knowledge and active involvement in development and shaping of policies relevant to improvement of health and quality of life.

TIF's 2011 plan of action for Europe includes the following activities:

1. Follow up activities following the 1st and 2nd Pan-European Conferences on Haemoglobinopathies (September 2007 in Lisbon and March 2010 in Berlin, respectively).
Materialisation of an impact study which will include one year after the 2nd and three years after the 1st Pan-European conference (1 year, January – December 2011) and promotion of the European Network of doctors and patients
2. Completion of the following translations of the 2nd edition of the book "Guidelines for the Clinical Management of Thalassaemia": French, Romanian and German (1 year, January – December 2011)
3. Participation with a booth at the next European Haematology Association conference (April 2011)
4. Satellite meeting on Haemoglobin disorders in the context of the European Paediatric meeting in Vienna, Austria, in May 2011
5. 12th International Conference on Thalassaemia and the Haemoglobinopathies. 14th TIF International Conference for Patients and Parents, in Antalya, Turkey (May 2011)
6. Meeting with Health Commissioner, Brussels, September 2011
7. Delegation visits and official meetings in Netherlands, Romania, Belgium, Germany, Spain (September 2011)

8. National workshop in Bulgaria (September / October 2011)
9. Expert Patients Program
 - (i) Expert Patients Panel 1st meeting of the core group
 - (ii) Publication of Expert Patients' educational material
 - (iii) Capacity building advocacy workshop for European patient associations in Nicosia, Cyprus (October 2011)
10. Exploratory visit and establishment of official contacts in wider Europe: Federation of Russia, October/November 2011
11. Participation in 2 meetings with each of TIF's European partners: Eurordis, EPHA, EMA and EPPOSI (2 meetings in Geneva, Switzerland, May/September 2011). 4 meetings in Brussels (to be confirmed), 2 in Paris (to be confirmed) and 2 in London (to be confirmed)

2. Asia

Objectives:

- Strengthen existing patients' associations and encourage them to undertake more activities to increase public awareness of Hb disorders
- Encourage patients' associations to become actively involved in TIF's Pan-Asian Network for NGOs and Health Professionals
- Work with health professionals towards the implementation of an effective national prevention programme and consistent treatment protocol, including multidisciplinary approach.
- Initiate a line of communication with National Health Authorities (NHAs) in countries where communication exists, while strengthen the collaboration with NHAs in countries that communication has been established
- Strengthen collaboration with Regional WHO and Country representative offices in countries
- Strengthen collaboration with regional WHOCC's for the purpose of establishing twinning programmes with centres in highly affected countries
- First Delegation Visits to countries like Myanmar and Laos
- Translate, Print and distribute of educational material:
 - (i) *About Thalassaemia*: Urdu, Vietnamese, Lao, Myanmar, Nepalese, Filipino
 - (ii) *Set of 3 Booklets*: Urdu, Vietnamese, Lao, Myanmar, Nepalese, Filipino
 - (iii) *Guidelines* in Vietnamese, Urdu and Bengali.

TIF's 2011 plan of action for Asia focuses on five key areas:

1. National Workshop in China (follow-up of 2010 programme, Nov. 2011)
2. Delegation visits in Bangladesh, Indonesia (follow up work of 2010, May 2011)
3. Workshop in Philippines, Cambodia, Vietnam and Laos (September 2011)
4. Delegation visits in Myanmar and Nepal (September 2011)
5. Participation of TIF in workshops organised in India and Sri-Lanka (to be confirmed)
6. Indonesia/Bangladesh follow up workshops/delegation visits

3. Middle East

Objectives:

- To strengthen and capacity-build the already existing NTAs
- To initiate a line of communication with NHAs in countries
- To collaborate closely with Regional WHO and Country representative offices of countries
- To promote and expand the Middle East Network for NGOs and Health Professionals
- To complete compilation of information on health systems-infrastructure and reimbursement policies in countries of the region for targeted advocacy
- To promote patients' rights
- To further educate patients and parents
- Translate, Print and distribute of educational material:
 - *Guidelines* in Arabic
 - *Children's Cartoon Book* in Arabic

TIF's 2011 plan of action for the Middle East focuses on these key areas:

1. Delegation visit and two workshops and follow up activities in the context of 2010 follow up plans with NHA's, the medical community and patients/parents one in Algeria and one in Morocco/Tunisia
2. Workshop in the kingdom of Saudi Arabia
3. 2nd Pan-Middle East conference in September 2011 (venue to be confirmed)
4. Delegation Visit Egypt/Syria

4. Latin America

Objectives:

- To initiate a line of communication with NHAs in countries
- To collaborate closely with Regional WHO and Country representative offices of countries
- To compile information on health systems-infrastructure and reimbursement policies in countries of the region for targeted advocacy
- To promote patients' rights
- To further educate patients and parents

TIF's 2011 plan of action for the Americas focuses on these key areas:

- a. Participation of TIF in a booth in ASH meeting
- b. Participation of TIF delegates in the next Pan-American conference in Brazil or Argentina – organisation of representatives and patients from Latin American countries
- c. Follow-up the delegation visit follow-up in Trinidad and Venezuela

6. Global Activity: e-MSc in Haemoglobinopathies

Objectives:

- To promote the course to NHAs in affected countries
- To promote the course for endorsement by WHO-Regional Offices

TIF's 2011 plan of action for the e-MSc Course focuses:

- To target the enrolment of 10 students until the end of 2011
- To identify sources of funding
- To establish collaboration with NTAs for fellowships
- To sponsor 2 fellowships to candidates from highly affected countries – TIF in collaboration with TIF member NTAs and/or other NGOs (50% each partner ~ £7,500)

II. TIF Membership Activities

Objectives:

In 2011, TIF will continue to reinforce and extend its membership base by:

- Recruiting **10 new general members** amongst existing thalassaemia associations, **15 new associate members** and **5 new voting members**.
- Encouraging the creation of new associations with TIF's support
- Develop incentives for members to encourage them to become more actively involved in events and projects, highlighting the mutual benefits and added value of being part of TIF's global network.
- TIF will endeavour to sponsor 1–2 patients per year to attend appropriate capacity-building and training sessions

TIF's 2011 plan of action for Membership focuses:

- To waive the membership fees for 6 member associations, globally.

III. Communications

Objectives:

- Building more effective communications with our members and partner organisations
- More effective use of existing publications and newsletters of members and collaborating organisations in order to promote our activities and enhance TIF's profile.

TIF's 2011 plan of action for upgrading communication between membership focuses:

1. TIF Magazine - 3 issues per year
2. E-Newsletter – Development of an e-newsletter with a view to have it translated in 2 more languages preliminarily for 2011
3. Web-site – Continuous upgrading with a view to making the web-site more user-friendly.

IV. Publications

Five new publications:

1. Criteria for Reference Centres for Haemoglobin Disorders.
2. Cartoon book for β -thalassaemia.
3. Counterfeit Medicines
4. Nurses' Guidelines for the clinical management of thalassaemia
5. Patients-friendly Guidelines