



# THALASSAEMIA INTERNATIONAL FEDERATION



**“In official relations with the World Health Organization”**

## *About Thalassaemia International Federation*

**TIF:-** The Thalassaemia International Federation (TIF) is a non-profit, non-governmental organization, founded in 1987 by a small group of patients and parents representing National Thalassaemia Associations in Cyprus, Greece, UK, USA and Italy – countries where Thalassaemia was first recognized as an important public health issue and where the first programmes for its control, including prevention and clinical management had started to be promoted and implemented.

**MISSION:-** **“Promotion of control programmes and access to quality treatment for every patient with Thalassaemia where ever he or she may live”.**

**OBJECTIVES:-** The objectives of the Federation in addressing effectively the needs of the world Thalassaemia family have since its establishment remained the same and include:

- ✚ Encouraging, motivating and supporting studies and research for further improving prevention strategies, clinical care and for achieving the long-awaited final cure;
- ✚ Extending the knowledge and experiences gained from countries with successful control programmes to those in need.

**GOALS:-** The tools that TIF uses in order to achieve its mission and objectives are noted on the list below which is by no means exhaustive:

- ✚ The establishment of new and the promotion of existing National Thalassaemia Patients/Parents Associations;
- ✚ The organization of field trips and delegation visits to individual countries or regions, enabling TIF to tailor its support and guidance according to specific country or regional needs;
- ✚ Establishment of a network of National, European and International collaboration with:
  - Medical and scientific communities involved in the field;
  - Research Institutes and Medical Centres of Excellence;
  - Health authorities;
  - Pharmaceutical companies;

- Thalassaemia and other disease oriented patients/parents associations;
- Health bodies, health professional organizations/associations;
- Establishment of collaboration with:
  - ❖ World Health Organization (W.H.O.);
  - ❖ Organization of Regional and W.H.O. Collaborating Centres;
  - ❖ European Union (E.U);
  - ❖ Council of Europe (C.o.E.);
- ✚ Establishment of educational programme for the health professionals, patients/parents and the community and includes:
  - The organization of local, national, regional, European and International Workshops, Conferences, Seminars and Meetings, and;
  - The preparation, publication, translation and dissemination of leaflets, books and other informational material, and;
- ✚ Promotion and support of short-term projects related to and targeted at improving, mainly:
  - Epidemiological work;
  - Clinical management and cure;
  - Social integration;
  - Psychological support;
  - Application of new technologies, and;
  - Patients' rights.

## Achievements:-

### “UNITY IS OUR STRENGTH”

- Became an ‘umbrella’ organization participated by 91 Associate, General and Voting Members from 62 countries across the world;
- Entered into official relations with the Non-Communicable Diseases Department (NCD) of the World Health Organization (W.H.O.), since 1996;
- Organized since 1989, 65 Delegation Visits in 35 countries worldwide;
- Organized since 1989, 43 Local, National, Regional, and International Workshops, Seminars and Conferences, participated by 16,800 health professionals and patients and parents from 60 countries of the world;

### EDUCATIONAL PROGRAMME

- Preparation, publication, translation and distribution free-of-charge of educational material such as:
  - ✓ Guidelines to the Clinical Management of Thalassaemia (2000), translated in 6 different languages and distributed 50,000 copies in 60 countries;
  - ✓ Compliance to Iron Chelation Therapy with Desferrioxamine (2001), translated into 4 different languages and distributed 40,000 copies in 45 countries;
  - ✓ About Thalassaemia (2005), translated into 11 languages and distributed 30,000 copies in 25 countries;

✓ Blood Safety Kit (2000), published in English and distributed 6,000 copies in 25 countries;

✓ Prevention of Thalassaemias and other Haemoglobinopathies – Vols I & II (2004 & 2005, respectively), translated into 2 languages and distributed 5,000 copies in 32 countries, respectively;

**3-MONTHLY  
TIF MAGAZINE**

✓ 49 issues of the quarterly published Magazine, distributed to 3,500 subscribers in more than 75 countries across the world;

**LEARN MORE  
ABOUT TIF**

✓ Preparation of a DVD focusing on the activities and work of the Thalassaemia International Federation, and;

**COMING UP –  
TWO MORE  
PUBLICATIONS**

- (i) Patients' Rights, and;
- (ii) A guide to setting up a National Thalassaemia Association, are in press.

## Collaboration in Projects:-

- Electronic Infrastructure for **THA**lassaemia Research **NET**work – **ITHA**net, and;
- PanEuropean Blood Safety Alliance (**PBSA**), and;  
**Visit our web-site or our Headquarters' Offices for more information**

**Contribution:-** TIF contributed to the issue of the W.H.O.'s **Declaration** on '*Thalassaemia and other Haemoglobinopathies*' by the World Health Assembly (W.H.A), in May 2006.

**Visit our web-site for viewing the Declaration**

For any further information, you can contact us directly at:

## **THALASSAEMIA INTERNATIONAL FEDERATION** **“In official relations with the World Health Organization”**

**HEADQUARTERS:**

**P.O. Box 28807, 2083 Strovolos,  
31 Ifigenias, 2007 Strovolos**

**Cyprus**

**Tel: +357-22-319129, Fax: +357-22-314552,**

**E-mail: [thalassaemia@cytanet.com.cy](mailto:thalassaemia@cytanet.com.cy)**

**OR**

**Web-site address: [www.thalassaemia.org.cy](http://www.thalassaemia.org.cy)**