



Thalassaemia
International
Federation

THALASSAEMIA INTERNATIONAL FEDERATION ANNUAL REPORT 2010

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Foreword by the President of the Thalassaemia International Federation

On behalf of the Board of Directors and Staff of the Thalassaemia International Federation, I present to you with great pleasure the Annual Report 2010, which provides a summary of all major activities undertaken during the year and renders transparent the framework, funding, composition and focus of this organisation.

Like previous years, 2010 was an extremely busy but also rewarding year for TIF. It has seen many important educational events across the world, including workshops, conferences and delegation visits in countries such as Morocco, Algeria, Malaysia, Russia, China and Thailand, and support provided to other countries such as Egypt, Pakistan, Cambodia, Afghanistan, Romania, Bulgaria, Saudi Arabia, Trinidad and Tobago, and Venezuela.

Both in Europe and elsewhere, we have worked with our network of partners on monitoring and developing health-related policies, especially on chronic and rare conditions. We have expanded our collaboration with European and international health organisations, such as the World Health Organisation (WHO) and European Public Health Alliance (EPHA), we have met with the new European Health Commissioner to promote haemoglobinopathy issues, and have taken an active role in the establishment of the first national alliance of patients with rare diseases in Cyprus (CARD) of which TIF is also a founding member.

The highlight of the year 2010 was the 2nd European Conference on Haemoglobinopathies which took place in Berlin on 13–14 March 2010, and which brought together more than 500 patients, parents, doctors, and other stakeholders from 34 countries, including 19 EU member states. The conference was a resounding success. In the framework of the conference, new advances in technology, treatment and medicinal research were presented and discussed, and patients' concerns analysed, debated and addressed.

TIF has been involved in numerous delegation visits, workshops and high-level meetings both abroad and in Cyprus, including Bangladesh, Sri-Lanka, Indonesia, Trinidad, Venezuela, and Malaysia, building networks and interconnecting relations and identifying current status leading to more focused action on behalf of TIF.


Furthermore, in the course of this year, TIF has had a number of high level meetings with the Assistant Director General of the WHO, the First Lady of Syria, the European Health Commissioner, the Minister of Health of Thailand, and the Governor of Guangxi.

In addition, in 2010 TIF has participated in and contributed to all Regional WHO meetings with 3-minute intervention statements, and has provided support to many countries around the world, including Egypt, Pakistan, Cambodia, Afghanistan, Romania, Bulgaria, Sri Lanka, Saudi Arabia, with a physical presence whenever possible.

TIF has initiated contact with the Ministries of Health in many European, Asian and Middle Eastern countries in order to prepare for delegation visits and official meetings and to push for the issue of thalassaemia to become a priority on their national health agendas, as per the World Health Assembly (WHA) resolutions adopted in 2007 and more recently in 2010.

Finally, as part of TIF's global educational programme, we have been supporting the translation publication and distribution of many of our publications in many languages. Several new translations and publications have been completed in the course of this year, including a delightful cartoon book for children entitled "All About Thalassaemia", written by TIF's Executive Director.

I would like to extend my sincere gratitude to the Cyprus Government and the Ministry of Health with whom TIF has a longstanding collaboration and from which it receives continuous support and assistance, but also to our collaborators – medical advisors, patients, and friends – and to all our members around the world: You are the reason the Federation exists, and we promise to drive ourselves even harder in our mission to ensure a good life and access to quality health care for every patient with thalassaemia in the world.



Panos Englezos
President

Foreword by TIF's Executive Director

The year 2010 was very busy and exciting as we strove to reach higher goals than ever. The programme of TIF's active involvement in delegation visits, workshops and meetings was rich and multifaceted, ranging from medical conferences to patients/parents' organisations workshops, meetings with health officials on the European and international levels, to conventions of executive committees of health organisations and press conferences. Every act undertaken by TIF aims at improving the life of thalassaemia patients around the world.

TIF has reached and finalised a new, quite successful phase in its history of activities and existence – a phase whereby it has managed to make haemoglobin disorders recognised by official bodies and known to the global community by spreading knowledge, and offering support to their programmes and strategies.

Although each region, each country, even within a country, the status of control programmes is widely heterogeneous, we can today safely say that we have contributed to the promotion of control of these diseases in almost all 'affected' countries with a varying degree of success – in some greatly, and in some to a lesser extent.

Now, we need to move forward to the next phase, one that involves monitoring and ensuring that our commitments are fulfilled and our promises are materialised – that TIF stands up to the expectations and hopes it has raised through the years until today.

This will once again involve a lot of commitment, financial backing, and strong office support, as well as motivated, committed collaborators and partners from the medical, scientific, research and industry communities.

Significant goals have been achieved and even more important projects and programmes have been initiated, including Regional Conferences, networks, new publications and the much awaited Expert Patient programme. Active involvement in new countries has been a real progress.

On behalf of the TIF Office, I would like to extend my sincere thanks to all our esteemed collaborators, partners, members and supporters for your hard work and dedication, and I look forward to another year of close and fruitful cooperation.



Dr Androulla Eleftheriou
Executive Director

About Thalassaemia

Thalassaemia is one of a group of genetic blood disorders referred to as haemoglobinopathies. These disorders, which mainly include thalassaemia and sickle cell anaemia, are among the most common hereditary diseases worldwide: around 7% of the global population carry an abnormal haemoglobin gene, and more than half a million affected children are born each year.

Patients with β -thalassaemia major – the most severe type of thalassaemia – cannot make normal red blood cells and do not produce enough haemoglobin. This leads to severe anaemia with consequences such as retarded growth, bone deformities, reduced energy – and ultimately death at a young age if appropriate medical care is not given. Today, thalassaemia is a treatable though chronic condition, and with the right care patients can grow up to lead almost normal lives.

The treatment of thalassaemia is lifelong, complex and costly, requiring specialised expertise and a multi-disciplinary approach. The majority of patients particularly in low-resource countries are children. This is simply because without treatment, patients die at an early age. In TIF's literature you will often find references to "patients/parents", rather than simply patients, to reflect the importance of parents and families in dealing with all aspects of the disease.

About the Thalassaemia International Federation

The Thalassaemia International Federation (TIF) is a non-profit, non-governmental organisation founded in 1986 and in official relations with the World Health Organization (WHO) since 1996. TIF is an umbrella organisation representing national thalassaemia associations and other members from 56 countries.

Our mission is to obtain equal access to quality care for every patient with thalassaemia across the world. To achieve this, we undertake a wide range of activities.

- We act as the united voice of patients with thalassaemia worldwide, supporting existing patients/parents' associations and encouraging the establishment of new ones.
- We work with national health authorities, supporting their efforts to make appropriate quality treatment available to all patients, as well as in the formulation of effective prevention strategies.
- We prepare and distribute up-to-date, reliable and unbiased information about thalassaemia, its prevention, management and research for cure.
- We educate patients, parents, health professionals, the general public and policy-makers:
 - Our internationally recognised educational programme includes several educational conferences and workshops each year, as well as an extensive range of books and other information materials.
 - Since 1989, our events held at local, national, regional and international levels have benefited over 20,000 participants, and our publications have been translated into more than 20 languages and distributed around the world.

- Our educational programme is supported by an *ad hoc* advisory panel of experts, as well as an extensive international network of around 200 scientific and medical collaborators from over 45 countries.
- We work with health-related organisations and official bodies at national, regional and international levels to promote control programmes in affected countries.
 - Our close collaboration with WHO recently resulted in the adoption of resolutions EB118.R1 on thalassaemia and WHA59.20 on sickle cell anaemia, and we are now working towards the worldwide implementation of these resolutions.

Activities Report 2010

EDUCATIONAL PROGRAMME

I. EUROPE

Bulgaria

Thalassaemia patient/parent seminar, 29th-30th May 2010

The 2nd Thalassaemia patient/parent seminar was organised by the Thalassaemia Organisation of Bulgaria. The event was attended by more than 120 patients/parents and 40 health specialists. The programme included presentations from Prof. Piga on advancements in iron chelation therapy, cardiac complications and the use of MRI in monitoring iron deposition on the heart. TIF was represented by its Board member from Greece, Dr. Christina Stephanidou.

TIF brought both of the existing patients' associations in Bulgaria into contact and established a working party urging in the near future for a national federation and joining forces for a stronger voice.

Romania

Romanian Workshop on Thalassaemia Major, Sinaia, 30 October 2010

TIF's has had a fruitful collaboration with the Romanian Thalassaemia Association, and provided active support for the 2nd Romanian Workshop on Thalassaemia Major organised by this Association on 30 October 2010 in Sinaia, Romania. TIF co-funded the workshop and a welcome message on behalf of the President of TIF was read at the opening ceremony of the workshop by the President of the Association, Costin Radu Ganescu.

Russia

60th Session of the WHO regional committee for Europe, Moscow, 13-16 September 2010

TIF participated in the 60th Session of the WHO regional committee for Europe which took place in Moscow on 13th-16th September 2010, represented by Dr Demetriades, a TIF staff member, and our WHO representative and close collaborator, Dr Victor Boulyjenkov. TIF contributed with a 3-minute intervention statement. Dr Demetriades and Dr Boulyjenkov met with health academics and officials, thus successfully opening a line of communication with the Russian Federation's Ministry of Health (Public Health Office) on the issue of Hb disorders and chronic diseases – a very important first step in establishing ties and organising future joint ventures.

Spain

Spanish Symposium of Thalassaemia patients and professionals, Madrid, 19-20 November 2010

Alheta, the Spanish thalassaemia association with whom TIF has an ongoing and close collaboration, successfully organised together with ENERCA the first Spanish Symposium of Thalassaemia patients and professionals in Madrid, in the framework of the 3rd European Symposium on Rare Anaemias, on 19-20 November 2010. The Symposium was highly successful and well attended. The event was the first one with emphasis on thalassaemia to be organised in Spain, but also the first one with a focus on health professional and patient interaction. The ministry of health of

Spain and the European Commission both sent representatives, and TIF was represented by Mr. George Constantinou, TIF's Secretary. The goals of the Symposium – informing and updating the local medical practitioners, and aiding communication between patients and experts, as well as between international and local experts – were certainly achieved.

Through the activities of Alheta, Spain has made a dynamic move toward better prevention and holistic treatment, one of the issues being lack of consistency in health care provision across the country. Support to Alheta is essential, as is also promotion of awareness about thalassaemia to the doctors and public, the expansion of the network of patients organisations and medical specialists, and the creation of a thalassaemia reference centre in Madrid. TIF must also encourage the Spanish Ministry of Health to push for the creation of a national prevention programme and promotion of multi-disciplinary approach to treatment and psychosocial support to patients.

II. MIDDLE EAST

Algeria

Delegation Visit and workshop for patients/parents and health professionals, 7-9 May 2010

The visit was planned to occur during local activities focused on thalassaemia, so as to place them under the banner of the International Thalassaemia Day, thus providing TIF with the opportunity to meet and interact with as many patients, parents and health professionals as possible. The purpose and specific objectives set by TIF in planning this visit were to understand better the size of the problem, the current situation with regards to the health system involvement, official recognition of Haemoglobin disorders, Thalassaemia and sickle cell disease, as a public health priority, the level of community and health professionals awareness, the existing programmes and services for the management i.e., prevention and medical and social care of these disorders in Algeria. The commitment of TIF as with every other affected country was to identify ways in which it could offer its support and experience through collaboration with health authorities and regional/local WHO towards improving the survival and the quality of life of the patients in Algeria.

Morocco

Delegation Visit and workshop for patients/parents and health professionals, 28-30 May 2010

A Thalassaemia International Federation delegation visited Morocco on the 28th and 29th of May 2010, for the purpose of assessing the prevailing situation in that country, concerning both prevention of haemoglobin disorders and services to patients and to assess the magnitude size of the problem. It was also necessary to understand the level of public but also professional awareness and the degree of health service involvement. Based on the currently known epidemiological information and the status of management of haemoglobin disorders in Morocco, TIF proposed a set of recommendations to the Ministry of Health of the Kingdom of Morocco, as a basis for the development of a national control programme for haemoglobin disorders.

TIF's delegation group was accompanied by the Rotary representatives in their various visits and by Prof Mohammed Khattab, paediatric haematologist/oncologist – a long-term collaborator of TIF with a vast contribution to the thalassaemia problem in Morocco, working in the Rabat Children's Hospital. Prof Khattab, who is also a member of the Middle East Network and President of MATHED, the local patients/parents thalassaemia organisation, coordinated the entire delegation visit.

Maghreb Meeting – 1-2 October 2010

The recognition of the necessity for close follow up on delegation visits paid by TIF to Algeria and Morocco in May 2010 has resulted in TIF's organising of a meeting in Nicosia Cyprus on 1-2 October. To the meeting were invited representatives of the national health authorities, members of the medical community, and patients/parents support groups from Algeria, Tunisia, and Morocco.

The purpose was to further discuss the data and recommendations delivered after the earlier delegation visits to those countries, and to ensure the establishment of solid foundations for the continuation of the activities undertaken in the framework of the joint plans of action. These three countries are heavily affected by thalassaemia. Even though they share some common problems such as geographical proximity, they have widely heterogeneous statuses of control and recognition of haemoglobin disorders as priorities on their health agendas. In particular, Tunisia appears to be the most advanced of the three as regards control of thalassaemia, while unfortunately Algeria lags behind, both in recognition and addressing of the problem.

The meeting was highly productive and detailed reports have been written listing the outcomes and recommendations. Already, materialisation plans of activities are underway.

Syria

Meeting with the First Lady of the Syrian Arab Republic, 5th November 2010

On 5th November 2010, Her Excellency Mrs Asma al-Assad, the First Lady of the Syrian Arab Republic, visited TIF in the context of an official government visit by the President of Syria to Cyprus. TIF's President and Executive Director had already met with the First Lady in May 2009 in the course of the 1st Pan Middle East Conference. Thalassaemia constitutes a grave problem for Syria as well, and Her Excellency is very interested in the topic.

Accompanied by the First Lady of Cyprus, Mrs Elsi Christofia, Mrs Asma al-Assad visited our offices, met with the President and the Executive Director of the Federation, and discussed issues tangent on thalassaemia and ways to support efforts for the effective control of thalassaemia in Syria.

With the opportunity of this visit, Mrs Asma al-Assad was invited to join the Global Circle of Dignitaries project. The First Lady of Syria has shown genuine interest, and we feel confident that she will aid us in achieving our objectives.

Egypt

Ceremony of installation of HPLC instrument, Cairo, 19th December 2010

On 19 December 2010, TIF's Executive Director and Medical Advisor travelled to Cairo, Egypt, to attend the ceremony of installation of an HPLC instrument (BIO-RAD variant) – a significant donation by a UK-based company through TIF's mediation, with the purpose of initiating a population screening programme.

With the opportunity of this visit, the delegation members also met with the medical community, and spoke with the doctors, including Prof. Amal El-Beshlawy, TIF's long-term collaborator in Egypt and other National Health and Cairo University Officials. Problems of treatment and availability of drugs and pumps, as well as issues of compliance on the patients' part and follow up on clinical trials were discussed. TIF's goal for Egypt in 2011 is to expand the network of medical specialists and raise awareness in the public and the medical community.

III. ASIA

Indonesia

Indonesian Paediatric Conference, Medan, February 2010

In February 2010, TIF's Medical Advisor, Dr Michael Angastiniotis, was invited to give a presentation at the Indonesian Paediatric Conference in Medan, North Sumatra. Taking advantage of this opportunity, TIF decided to send one of its members (Mr Michael Michael) to accompany Dr Angastiniotis on a fact finding mission and to gather as much information as possible that will be useful when organising a delegation in this country in the future.

Mr Michael Michael undertook the task of communicating with the local thalassaemia associations and identifying the major issues which concern both treatment and prevention in this large country.

The visit consisted of two parts: The sessions of the Paediatric conference and contacts with doctors managing thalassaemia patients, and the meetings with associations and patients.

Bangladesh

Delegation visit, 22-24 January 2010

TIF, represented by its Secretary Mr George Constantinou, organised a delegation visit to Bangladesh to assess the situation and gather information to guide TIF's activities in this country. He also attended a workshop (also supported by TIF) for nurses and patients, which was organised by long-time TIF medical collaborator Prof. Waqar Ahmed Khan, which was held at Dhaka Shishu Hospital Thalassaemia Centre.

In addition, TIF granted its permission to the Thalassaemia Foundation of Bangladesh to print the TIF Guidelines in English, locally. Moreover, TIF intensified its efforts to initiate a line of communication with the WHO representative country office in Dhaka. To this effect letters were sent to the WHO officials seeking their

collaboration to identify the appropriate Ministry of Health Officials and their guidance in an effort to urge the Ministry of Health to consider the problem of thalassaemia as a health priority in this country.

China

Guangxi Governor and National Health Authorities Visit Cyprus, 26-31 May 2010

It is known that the People's Republic of China and especially the Southern Provinces and Hong Kong, are highly affected regions. Through years of persistent efforts by TIF and as a result of last year's successful TIF delegation visit to China, the Chinese Government is decided to implement all necessary measures to improve the quality of health and care provided to patients with thalassaemia in this country, by implementing a national control programme, using the Cyprus national control programme as a model.

In this context, the Governor of Guangxi and a delegation group consisting of the Director of the National Health Authorities of the Autonomous Zhuang Guangxi region, visited Cyprus. In the course of this visit, the official Chinese contingent visited the Nicosia Thalassaemia Centre and the Population Screening Laboratory – Cyprus WHO Collaborating Centre for thalassaemia, the Institute of Neurology and Genetics, and in particular the Thalassaemia Research Unit, where they had the opportunity to interact and exchange views on all aspects of thalassaemia control with the doctors and scientists and investigate the ways in which Cyprus (based on the Official Memorandum of Understanding between China and Cyprus – 2009) could support, through TIF, the implementation of such a programme in southern China.

The visit culminated with the official signing of an agreement of cooperation between TIF and the Guangxi National Health Authorities for thalassaemia control and management, in the presence of the Cyprus Minister of Health and the Guangxi Governor.

Workshop on haemoglobinopathies and delegation visit – Nanning, Guangxi Province – 3 November 2010

As a follow-up delegation visit to last year's visit in China and as a result of the above-mentioned official high level visit from Guangxi, TIF organised a delegation visit in Nanning Guangxi Province in November 2010.

The most recent visit was the 3rd official visit from TIF with the support of the Cyprus government, through its First Lady Mrs Elsi Christofia, and the Minister of Health. The progress marked by China, since our 1st visit was dramatic in both components of thalassaemia control, i.e. prevention and management of the disease. The type of thalassaemia prevalent in China is mainly haemoglobin E, and at a lower percentage the compound form of E- β thalassaemia. Both types occur mainly, almost exclusively in South/South-Eastern China.

As a follow up actions to the signing of a joint plan of action the between TIF and the regional Guangxi authorities in May 2010, TIF organised this delegation visit and the 1st workshop in Nanning, Guangxi.

The first day of the visit was spent on a meeting with health officials, in the course of which TIF reiterated its interest in the needs of patients and the support required in this part of China. TIF has received detailed information on the progress, decisions, and commitments by the provincial Chinese government on the issue of

thalassaemia, which included a detailed plan of national prevention strategies and improvement of health services provided to the patients. On the following day, TIF engaged in an educational workshop, the first half of which was dedicated to health professionals, and the second half to patients/parents. Ample interactive discussions took place, a fact which pleased us, because providing information and education is one of TIF's core activities.

A detailed report on the outcome of the meeting and future recommendations was drafted. Regional and international experts participating in the faculty and members of the Board of TIF represented the patients' community at the meeting and workshop.

Sri Lanka

Workshop for patients/parents and health professional, Kurunegala, 23 July 2010

TIF's on-going support to Sri Lanka, particularly in educating patients/parents, updating health professionals and raising public awareness about haemoglobin disorders in this country, TIF in collaboration with the College of Paediatrics of Sri Lanka, organised a 1-day workshop in Kurunegala, after having secured financial support of 2,000 USD for this event. TIF invited Prof John Porter to participate as a speaker in this workshop.

Pakistan

2010 saw the reconciliation of established and improved relations between TIF and TFP. Very important also was the completion of the translation of *About Thalassaemia* into Urdu. TIF supported both the printing and distribution of the book in the country. We have launched a rigorous effort to establish a line of communication with the Ministry of Health of Pakistan and have sent relevant letters to the Ministry in order to secure appointments with either the Minister and/or other Ministry of Health officials. If the above-mentioned appointments are secured through the lobbying of the Thalassaemia Federation of Pakistan (General, soon-to-be-Voting member) and the Pakistan Thalassaemia Welfare Society (Voting member), then a future delegation visit will be organised.

Malaysia

This country has made considerable advances through the years, in great part owing to TIF's support and guidance. Our Federation has contributed enormously to the progress made in the area of haemoglobinopathies control, mainly the management component, having succeeded in developing their own national guidelines since 2003, based on TIF's. Malaysia is today a country which together with Singapore has one of the most advanced programmes for patient services in the region of the Western Pacific.

However, considerable work still needs to be done for the establishment of a national prevention plan, further improvements to the clinical management, and very importantly to extend the medical and technological advances to patients across the country. Psychosocial support, as in every place where control progress is made, remains a strong component where more a coordinated focus is required and where NHA's commitment is essential.

The most recent visit to Malaysia on behalf of TIF was effectuated by Mr George Constantinou upon invitation to participate in the annual camps organised by the Pulau Penang Society; An activity which has greatly contributed to the achievement of progress in community awareness, patients/parents education, and their social integration. Mr George Constantinou participated in the 15th Camp and the 5th

Thalassaemia workshop for Doctors and Nurses and Health Professionals on 2-5 October 2010. The course of his visit he met with Officials of the Ministry of Health of Malaysia and members of the Federation, upon Mr Ramli Yunus' coordination. We have recently received the detailed reports on the camp and the meeting with the Ministry of Health officials from Mr Constantinou. Both the workshops and the camp were very successful. Useful contacts were made and significant data collected. Important issues were noted, including the need for further improvement of services to patients, in particular the hospital regulations for arranging transfusions, causing delays and frustration. Excellent recommendations were presented in the above-mentioned reports, especially the need for education of medical experts on the particularities of the needs of thalassaemia patients, but also compliance workshops for the patients and the distribution of *About Thalassaemia* in Malay Bahasa to inform them about their condition.

Thailand

Delegation 9-11 November 2010

November saw the 2nd official visit by TIF to Thailand, after TIF's organisation of the International biennial TIF conference in Bangkok in 1999. We have had a long-term collaboration with the medical community. This visit was extremely productive and informative for us. In the course of the 2-day visit, we met with the Dean of the University and of the Thalassaemia Centre of the Siraraj Hospital and with medical experts involved in the treatment of thalassaemia in Bangkok. TIF visited wards in the day care clinic where patients receive blood transfusions, and had a meeting with the patients/parents of the Thalassaemia Federation of Thailand (TFT) during which TIF was updated on the current situation of health care services for patients.

Thailand is a country heavily affected by haemoglobinopathies; it may have one of the highest rates of carriers in the region. The main thalassaemia type found in the country is haemoglobin E, and combination with β -thalassaemia to a significantly lesser extent. Thailand has made enormous advances in prevention, genotyping, and phenotyping management of patients. The progress in technology and implementation of tools for the monitoring of health and medical complications of patients, including the MRI-T2*, was impressive. TIF is committed to working with the health authorities and the medical community to further support patients' rights and raise the quality of services to patients across the country, including the establishment of a reference centre in Bangkok.

On the second day of the visit, TIF was received by His Excellency the Minister of Health of Thailand. After a detailed discussion, a pledge for further support and more systematic relations with TIF was made by the Minister, who realised the utility of sharing and utilising experience and knowledge in control strategies.

IV. AMERICA

Venezuela/Trinidad/Tobago

Delegation Visit, April-May 2010

As part of expanding its activities and accessing the status of haemoglobin disorders in the West Indies and South America, TIF supported the organisation of a delegation visit to Venezuela and Trinidad and Tobago, by members of the UKTS. Numerous meetings with doctors and other health professionals were conducted thus formulating a network of collaborators in the area.

A series of urgent recommendations for swift actions from TIF have been communicated prior to the finalised report which has already been forwarded to relevant stakeholders in both countries.

V. GLOBAL EDUCATIONAL ACTIVITIES

8th May - World Thalassaemia Day 2010

Theme: “*The informed patient: Knowledge is power!*”

The theme for the 8th May activities in 2010 focused on the power of the **patient’s knowledge and information**. At TIF we believe that an informed patient is an empowered patient: the more you know, the better you can manage your condition and your life. The more you know, the better you can interact with your doctors and other carers. And when a lot of knowledgeable, strong individuals come together and join efforts, their collective voice will be even stronger.

The experience and knowledge held by the patient can greatly benefit patient care and quality of life, something which gradually has become more widely recognised in the medical world. Therefore, today’s knowledgeable patients can make decisions regarding their treatment and work *in partnership* with their doctors, rather than simply being passive recipients of instructions. But in order to do this, the patient needs the power that comes through education and information. This has long been, and still is, one of TIF’s main educational aims.

Hence, we continued through the activities of the 8th May to encourage every patient to become educated, but also to recognise her/his already-existing knowledge, to *use it and share it*.

TIF EDUCATIONAL PUBLICATIONS

“All About Thalassaemia” – a cartoon for young children

TIF has prepared a new delightful cartoon for young children (ages 3-10) about thalassaemia. This book belongs to the range of educational publications of the Federation. It was written with much love for the children with thalassaemia – children who need to understand their condition, accept it, and draw strength from this knowledge to build a better future for themselves.

Page after page of simple explanations, especially designed to educate children and remove fear of treatment is accompanied and illustrated with colourful, attractive characters including Harri, the red cell, who is the perfect narrator for children, in his hat and boots and his down-to-earth storytelling. Sophisticated in its simplicity and with every detail thought out with a young audience in mind, this cartoon is certain to appeal to children and help them understand their condition.

The cartoon was created for and is dedicated to all children in the world born with thalassaemia – to their awe-inspiring will to survive, their ceaseless fight against the disease, and their dreams of a long, healthy, and happy life.

Translation of TIF's publications

The translation of TIF's educational publications into various languages continued in 2010. Translations of TIF's publications with the following titles can be found in Annex I:

- *About Thalassaemia*
- *Guidelines for the Clinical Management of Thalassaemia*
- *Prevention of thalassaemias and other haemoglobin disorders – Chinese.*
- Set of three educational booklets (*About α -thalassaemia, About β -thalassaemia and About Sickle Cell Disorders*)
- *Patients' Rights*
- *Sickle cell disease*

12th International Conference on Thalassaemia And Haemoglobinopathies, and 14th TIF International Conference For Patients And Parents - 11-14 May 2011

TIF is heavily involved in the organisation of the international conference for health professionals and patients/parents – the 12th International Conference on Thalassaemia and the Haemoglobinopathies & 14th TIF International Conference for patients and parents respectively, which will take place between 11-14 May 2011, in Antalya, Turkey.

Following activities in July 2010 in Istanbul, the programme and other organisational details, including fundraising and sponsorship options, were discussed and finalised. The patients/parents programme was put in a broad outline pending the suggestions and refinement of the patients' core group. The programme has been finalised. The final announcement, pending responses from a few speakers, has been posted on TIF's website and announced in TIF Magazine.

TIF's President took particular care to involve a greater number than usual of expert patients in the scientific programme of the conference and has achieved to include seven key patients' lectures during the scientific programme. As regards patients/parents, a core group was formed in the last meeting in June, which undertook to expand and finalise the programme to best meet the patients' needs and expectations. Finalisation of the patients/parents programme is still pending, and we hope by the end of this meeting to place the final touches.

OFFICIAL COLLABORATIONS UPDATE

(Official Partnerships can be found in Annex II)

1. The European Public Health Alliance (EPHA)

TIF's collaboration with EPHA has become closer since the recent election of TIF Executive Director Dr Androulla Eleftheriou on EPHA's Executive Board. She has attended the most recent EPHA meeting in Brussels in September, and had a meeting with Anne Hoel, European Policy Manager of EPHA, in Cyprus on September 24, 2010, to present to Ms Hoel TIF and its activities, and discuss public health policies. Over the past months, Dr Eleftheriou has had several teleconferences and electronic correspondence with EPHA discussing topics relevant to European Health policies and patients' rights. EPHA has secured a foothold for TIF in Brussels, enabling the continuous flow of information and news on health policy developments, as well as particular interests and state policies.

2. The European Organisation for Rare Diseases (EURORDIS)

EURORDIS is a non-governmental patient-driven alliance of patient organisations and individuals active in the field of rare diseases. Thalassaemia International Federation (TIF) maintains a close collaboration with, and is an active member of Eurordis and its Council of National Alliances. Through its executive director, TIF also participates in the DITA Task Force of Eurordis, a drug-orientated group working closely with EMA. Our Federation continues to contribute to Eurordis' policy positions on issues relating to rare diseases. The newly formed Cyprus Alliance of Rare Disorders (CARD) has applied and been accepted by Eurordis as an Associate member and will become a full member of the Council of National Alliances of Eurordis in the course of the next year.

3. The World Health Organisation (WHO)

Following a meeting in May 2010 in Geneva with assistant Director General of WHO, Dr Alaa Alwan, and Coordinator of Chronic Diseases Prevention and Management programme of the WHO (which forms part of the Non Communicable Diseases Programme), Dr Shanthi Mendis, a joint plan of activities 2011-2013 was formulated. The plan was based on (i) the resolutions of the 118th Executive Board in 2006 and the 59th WHA in May 2006, (ii) the outcome of the WHO-TIF Joint Experts meeting on haemoglobin disorders which took place in November 2007 in Cyprus, and (iii) on the objectives set in 2008 by the Non Communicable Diseases Programme of the WHO.

Participation of TIF in WHO Regional Sessions in 2010

(Statements given in Annex II)

On 13-16 September 2010 in Moscow, Russian Federation, TIF participated in the most recent regional meeting of the WHO – the WHO-EURO, the 60th Session of the WHO regional committee for Europe. The session provided TIF with an excellent opportunity to place the haemoglobin diseases firmly on the health agenda of the World Health Organisation and press for an initiative at the international level for better standards and access to health care for every patient with haemoglobin disorder, including thalassaemia, across the world. TIF's three-minute statement, which discusses the management of thalassaemia, was delivered by Dr Victor Boulyjenkov.

WHO Regional Office for Europe (EURO): www.euro.who.int

On 27 September-1 October 2010 in Washington, during the 62nd Session of the Regional Committee for the Americas of the World Health Association (PAHO), TIF Board Member Mr Bob Ficarra, presented the topic of "Management of Haemoglobin Disorders: Chronic multi-organ diseases – A public Health Issue". Mr Ficarra is a founding member of TIF and a past president of the Federation with vast expertise and knowledge in the field.

WHO Regional Office for the Americas (PAHO): www.paho.org

On 3- 6 October 2010 in Cairo, Egypt, during the 57th Session of the Regional Committee For The Eastern Mediterranean of the WHO (EMRO), a three minute intervention statement on behalf of TIF with the topic "Control of Haemoglobinopathies – Prevention and management" was distributed to all present. WHO Regional Office for Eastern Mediterranean (EMRO): www.emro.who.int

On 18-23 January 2010 in Geneva, Switzerland, TIF participated in the Executive Committee of the WHO EB126 with two items on the agenda, statement 4.16 on the "Availability, safety, and quality of blood products", and statement 4.7 "Birth Defects", both presented by Dr Boulyjenkov on behalf of TIF.

4. Meeting with new EU Health Commissioner John Dalli in Brussels

Many of the health policies being developed and promoted at the European level are relevant to the promotion of chronic and rare diseases globally. They form the basis on which other countries can tailor their own national policies to meet their own needs. Therefore, a way to promote the global voice of thalassaemia patients is by advocating their needs to the EU health Commissioner. The post of the EU Commissioner Designate for Health and Consumer Policy was held until the beginning of this year by Androulla Vassiliou. In February this year a new Commissioner was named, Mr John Dalli.

TIF's President Mr Panos Englezos and TIF's Executive Director Dr Androulla Eleftheriou met with the new Commissioner John Dalli in Brussels, Belgium, on 5th October of this year to discuss thalassaemia and TIF's activities in Europe. Attending was also the Adviser and former vice president of FIODS-IFBDO (International Federation of Blood Donors Organisations) and current Vice President of the Malta Blood Donors Association (MBDA), Mr Philip M Chircop.

The Commissioner was updated on the pathophysiology and the developments of clinical management of the disease, as well as on prevention and treatment strategies, but also on the current status of epidemiology and health services and control strategies in Europe.

In the course of the meeting, it was stressed that the health care system in most European countries are of high quality, and therefore with small yet essential alterations and with better coordination of the existing health services, control of thalassaemia and other haemoglobin disorders like sickle cell disease can be considerably improved.

Commissioner Dalli expressed his sincere understanding and interest in the above issues, and made some important commitments to the President of TIF, Mr Englezos, sending a very optimistic message to all patients with thalassaemia both in Europe and the world.

MEETINGS AND CONFERENCES IN 2010

Month	Event	Location
March	TIF Pan-European Conference 2010	Berlin, Germany
	First meeting of the European Network of Patient's Organisations and Health Professionals in the Field of Haemoglobin Disorders	Berlin, Germany
May	Greek Thalassaemia Federation – Pan-Hellenic Thalassaemia Conference	Athens, Greece
	1 st delegation Visit from Guangxi Province – National Health Authorities and Governor representatives	Nicosia, Cyprus
	63 rd Session of World Health Assembly (WHA)	Geneva, Switzerland
June	TIF Board of Directors meeting	Nicosia, Cyprus
July	Meeting with organising committee of 12 th and 14 th International Conferences	Istanbul, Turkey
September	EPHA Executive Committee meeting	Brussels, Belgium
	62 nd Session of the WHO Regional Committee for the Americas (PAHO)	Washington, USA
	60 th Regional Session of World Health Organisation (WHO): WHO-EURO	Moscow, Russia
October	57 th Session of the Regional Committee For The Eastern Mediterranean of the WHO (EMRO)	Cairo, Egypt
	Meeting with new EU Health Commissioner John Dalli	Brussels, Belgium
November	Delegation visit and Workshop on haemoglobinopathies	Nanning, China
	Meeting with His Excellency the Minister of Health of Thailand	Bangkok, Thailand
	Meeting with the First Lady of Syria	Nicosia, Cyprus
	TIF Board of Directors meeting	London, UK

TIF PROJECTS

1. ENERCA – European Network for Rare and Congenital Anaemias

Duration: 3 years

Funding: European Commission co-funding under the Public Health programme – co-ordinated with the University of Spain

ENERCA is a network co-financed by the European Commission (DG-SANCO), in which different experts are working together with the purpose of offering an improved public health service to professional medical practitioners and patients in every aspect of rare anaemias.

TIF leads work package 5 on “Public Health aspects and management of patients with thalassaemia” and is involved in the investigation and establishment of the patients’ perspective with the active participation of patients from all over Europe. Questionnaires have been completed by over 500 patients, and analysis of the data by Dr Eleftheriou and Dr Angastiniotis is currently in progress. The results will be presented at the 3rd European Symposium on Rare Anaemias organised by ENERCA between 26-27 November 2010 in Madrid, Spain, which is supported by TIF.

2. DOMAINE – Donor Management in Europe

Duration: 3 years - finished

Funding: European Commission co-funding under the Public Health programme – co-ordinated with SANQUIN (Netherlands)

DOMAINE was a public health project aiming to increase and maintain a sufficient supply of safe blood across Europe through the promotion of regular 100% voluntary non-remunerated blood donations, facilitate cooperation between blood establishments and build a consensus on good donor management practices across Europe.

TIF led work package 6 on “testing of the manual”. This manual’s purpose is to help harmonise blood donation practices and donor management. The manual has now been completed and published, and it is being distributed to all participating blood establishments who have responded to the survey questionnaire. A training programme for the application of the manual is currently being drafted. Our hope is that the European Commission and the European Council will promote this manual and so help set a quality practice standard in the whole of Europe in the area of donors’ management – an issue which constitutes a gap in the EU blood directives.

3. Expert Patients Programme

Part of the ongoing “Reach the Patient” project, the Expert Patient Programme aims to extend quality information to patients with thalassaemia across the world on their disease, its medical care and other forms of care – the core objective being to empower patients to take meaningful and timely decisions concerning their healthcare and quality of life. Objectives and methodology of materialisation were closely discussed in the course of the 2nd Paneuropean Conference in Berlin 2010 March.

The first official meeting of the core Expert Patients group is took place a day prior to the Board Meeting, in London in November 2010, where the plan of action was discussed and adopted so that this programme would begin to move forward.

4. Global Circle of Dignitaries

The Circle of Dignitaries was initiated in 2009, with the objective of strengthening the work on improving the impact of TIF’s work in promoting awareness for haemoglobinopathies, and the development of national control programmes with the assistance and under the patronage and/or auspices of international dignitaries, including First Ladies. The 1st meeting in early 2010, was organised by TIF and hosted by the Cyprus First Lady, Mrs Elsi Christofia. The First Ladies of Albania and

Lebanon participated, and the First Lady of Greece expressed her interest through a written message. It has been very difficult to achieve any further progress on this, but efforts continue. First Ladies have already set lines of priorities with reports to social/humanitarian work and it is very difficult to change that or integrate Hb disorders into their already heavy schedule of activities. A meeting with the First Lady of Syria took place on 5th November here in Cyprus after expressed interest from Her Excellency and gave TIF new hopes for enlargement of the Circle and establishment of a social basis. TIF again invited Her Excellency to join the project, and we are now waiting for her reply with greater optimism. We move forward to Bulgaria, Romania, Egypt and Morocco, hoping for their First Ladies' participation and looking forward to having a better-attended meeting in 2011.

5. TIF Epidemiology Project

TIF Epidemiology Project is a survey for Haemoglobin disorders and their treatment globally. The project aims to identify and update information on carrier rates of Hb disorders, and calculate the affected births suffering from β -thalassaemia expected to occur every year based on birth rate, population size, carrier rate, in the absence of prevention policies. Finally, TIF Epidemiology Project aims to review and identify the healthcare infrastructure and services for chronic disease patients and more specifically for Hb disorders (such as prevention and management programmes at the national level and reimbursement models used at the moment) in each country. This project is nearing completion, and TIF is preparing a publication on the results with the aim of submitting it to relevant journals and periodicals over the next months. Main outcomes of this project include:

- a) Carrier rates
- b) Anticipated affected births
- c) Actual numbers of affected births
- d) Current prevention/treatment strategies
- e) Current health infrastructure for chronic/Rare/more specific Hb disorders
- f) Comparison of quality of health services in existence and level of success of national prevention programmes
- g) Challenges/difficulties in different Regions/countries/within countries

6. TSEC - Thalassaemia Specific Electronic Communications

TIF has just completed the "Thalassaemia Specific Electronic Communications" (TSEC) project, which was funded through the EEA Financial Mechanism/Norwegian Financial Mechanism 2004–2009 Fund for Non-Governmental Organisations. The project introduces electronic patient records specifically adapted to thalassaemia based on already existing software called JAnaemia. The project has also set up two new tools, building on the existing software but introducing innovative features to enhance clinical support and to improve patient care: these new modules are a serious infections register, and an adverse drug reactions record. TIF is the main coordinator of the grant, together with partners living in the Turkish-occupied Northern Cyprus, and Norway.

The software will first be piloted in Cyprus and refined further based on the outcomes of the pilot phase. It has already been installed in three treatment centres, and data transfer has started.

The project ended with a final press conference on 27 September 2010 which aimed at dissemination of the results to the all interested parties. A close follow up of the practicability, the user-friendly level and other strengths and weaknesses will be reported every three months in the next year. Final objective is for TIF to be able to possess and disseminate worldwide software for the electronic registry of patients with thalassaemia.

NETWORKS UPDATE

1. Regional Networks

The creation of networks of collaboration constitutes another major activity and a most valuable tool for our Federation, to obtain useful information and true facts about the health and other care services for our patients, and of course to promote its mission and objectives. Work on the regional networks is ongoing. Our goal is to materialise the objectives set at the beginning:

- a. to assist with regional meetings and answer to concerns and problems
- b. to have reports and articles written and published by international experts
- c. to have collaboration/partnerships to extend TIF's educational programme
- d. to share and utilise experiences and knowledge successfully in the different Regions

TIF's Office is constantly working on the advancement of these networks, promoting them and tracking their expansion. These networks include both patients/parents and medical specialists and are the European, Asian, American, West Pacific and Middle Eastern Networks of Patients' Organisations and Medical Specialists.

2. Two new networks in the pipeline: Networks of Specialists in Endocrinological and Cardiologial Complications of Thalassaemia

Over the past year, and recognising for some time now the deep need to spread multidisciplinary care for patients with thalassaemia, TIF has been working on forming two core specialists groups, an endocrinologists' and a cardiologists' group, respectively. Purpose of this initiative is to establish networks of collaborators, to identify specialists in the different Regions, to form initially the core groups, and establish specialist educational programmes. Consequently, in each region and within each country of the region, a core group of endocrinologists and cardiologists will exist, specialists who will be fully aware of medical complications existing in thalassaemia and how to address them, and be responsible to undertake the education and training of more such specialists in their country, so that multidisciplinary care for patients is provided.

The first meeting of the two networks is planned to coincide with the 12th International Conference in Antalya next year. TIF's next move will be to expand and develop a third core group of liver specialists, an initiative expected to be launched in 2011.

3. A Global Network of Nurses in haemoglobinopathies

The global network for nurses was initialised in 2009 in recognition of the special role played by nurses in multi-disciplinary thalassaemia care. The nurses' network provides a platform for communication, enabling those in the field to share experiences, ideas and concerns with colleagues from across the world.

A major deliverable of this initiative is to develop a guidelines publication for the clinical management of haemoglobinopathies specifically from the nurses' perspective. The work on this publication is advancing with the collaboration of experienced, specialised nurses who have already joined the network. The number of participants is increasing by the day and we are very happy to see this project grow. TIF is exerting efforts to collaborate on this subject with the American University of Beirut which showed interest in promoting this project, having a solid basis in the framework of its university curriculum on Nursing. Already a first meeting for the Eastern Mediterranean region took place in 2009. Logistics and plans of action for 2011 are in progress between the University Nursing Department and TIF.

COMMUNICATIONS UPDATE

1. TIF Annual report

TIF's annual 2009 report has been published and distributed to the Board and interested, relevant parties. The 2010 annual report will soon be available on the TIF website and upon request.

2. TIF Magazine

Two issues of the TIF Magazine were published in 2010, rich, information-packed editions which covered a wide array of subjects. For 2011, it has been decided that a more streamlined, easier-to-read-and-send version will be promoted. An electronic newsletter is also being planned.

3. TIF Website

The website of TIF has undergone a complete update. Some important additions include biographical notes for the members of the Board and TIF staff, updates of the projects and organisations which are affiliated or collaborating with TIF, the updated Activities Plan for 2010 and the approved Activities Plan for 2011, news and events around the world, policies, publications, position papers, medical and research advances and of course the annual Reports.

TIF Office is working on rendering the website a most reliable and recommended source of information in the domain of thalassaemia, conforming to the strict criteria of the Health on the Web (HON) site, in order to claim accreditation. The Health on the Net Foundation Code of Conduct (HONcode) for medical and health Web sites addresses one of Internet's main healthcare issues: the reliability and credibility of information. TIF considers that it is essential to have such an accreditation which is a badge of professionalism in the area of providing to patients information that is correct, up-to-date and provided by experts.

Governance and Membership

Board of Directors

The Thalassaemia International Federation was founded in 1986 and registered in 1987 as a non-profit non-governmental organisation under Cyprus Company Law. The Federation is governed by an international 18-member Board of Directors, elected for a term of four years. A country can be represented on the Board with a maximum of two members who are elected on the merits of their international contribution in the field and are thus non-country affiliated. The Board has a balanced geographical coverage of the regions of the world affected by thalassaemia. Under the terms of the Constitution, 50% of the directors must be patients with thalassaemia, the Directors are considered volunteers and do not receive any financial compensation for their duties.

In 2010, the Board met twice – in Nicosia, Cyprus, on 26-27 June 2010, and in London on 27-28 November 2010.

Membership

The Federation's membership includes national thalassaemia associations, other disease-specific patients' associations, health-related organisations and institutions, health professionals and interested individuals from around the world. Membership is divided into three categories: General Members include only those patients' associations with an interest in thalassaemia. After completion of one year of membership, general members can become Voting Members. Associate Members can be individuals, commercial or professional groups and disease-oriented patients' associations (other than thalassaemia).

At the end of 2010, TIF had a total of 55 General and 48 Voting Members, making a total of 103 associations representing 54 countries worldwide. Associate Members numbered 114.

TIF welcomed the following new members during 2010:

General members

Nivethan Trust, India
Thalassaemia and Sickle Cell Society, India
Blood Donors Association, Mauritius
Saudi Friend's Charity of Thalassaemia & Sickle Cell Anemia Society, Kingdom of Saudi Arabia
Association "El Amani" Des Annemies Hemolytiques Conginitales, Algeria
The Sudanese Patients and Parents Society for Sickle Cell, Thalassaemia and Other Related Disorders, Sudan
Balikatang Thalassaemia (BA-THA), Philippines

Voting members

Associazione Ligure Talassemici Onlus (ALT), Italy
Thalassaemics Organisation in Bulgaria, Bulgaria
Yemen Thalassaemia & Genetic Disorders Society, Yemen
Thalassaemia Federation of Pakistan, Pakistan

Associate members

South Africa Thalassaemia Association

Office and Staff

The Federation has its head quarters in Nicosia, Cyprus, with an information centre and administrative base as well as conference rooms for educational events and Board meetings.

In 2010, the TIF staff comprised the following members:

Androulla Eleftheriou, BSc, MSc, PhD (Biochemistry, Virology), Dip mgt - Executive Director
Kaisa Immogen-Charalambous, MA (International Relations) – Projects Manager – until June 2010
Matheos Demetriades, BSc, MSc, PhD (Molecular Genetics) – Projects Coordinator
Eliana Iliofotou, MA (European Studies), MBA – European Project Officer – on maternity leave until February 2011
Mikaela Panayiotou, MA (Sociology) – Project Officer
Michael Angastiniotis, MD (Paediatrics) – Medical Advisor
Maria Peletie, BA (Marketing and PR) – Office Administrator and Personal Assistant to TIF's Executive Director
Demetrios Lambrou – Office Assistant
Chrystalla Thoma, BA, MA, PhD (languages, linguistics and translation) - European Health Policy/Country Officer of TIF/Editor of TIF Magazine – onboard since July 2010
Lia Demetriou, BSc (Applied Mathematics), MPhil (Public Health Medicine and Epidemiology) – Public Health and Epidemiology Researcher on contract until February 2011
Michelle Theodoulou, BSc (Health Policy Administration and Speech/Language Pathology), MA (Health Services Research) – coordinating the Thalassaemia Specific Electronic Records project (TSEC)

In addition, the office subcontracts its accounting, IT maintenance and other work to external suppliers.

Board of Directors

Panos Englezos, Cyprus Anti-Anaemia Association, Cyprus (President), Cyprus
 Alliance for Rare Disorders (President)
 Shobha Tuli, Thalassaemics India, India (Vice President)
 Riyad Elbard, Thalassaemia Foundation in Canada, Canada (Treasurer)
 George Constantinou, Non-country affiliated, UK (Secretary)
 Katrina Demetriou, UK Thalassaemia Society, UK (Assistant Treasurer)
 Anton Skafi, Thalassaemia Patients' Friends Society, Palestine (Assistant Secretary)
 Michael Michael, UK Thalassaemia Society, UK
 Loizos Pericleous, Cyprus Anti-Anaemia Association, Cyprus
 Robert Ficarra, Cooley's Anemia Foundation, USA
 Dawn Adler, Non-country affiliated, USA
 Fatemeh Hashemi, Charity Foundation for Special Diseases – Non-country affiliated, Iran
 Mouna Haraoui, Chronic Care Center, Lebanon
 Ramli Mohd Yunus, Federation of Malaysian Thalassaemia Societies, Malaysia
 Christina Stephanidou, Greek Thalassaemia Federation, Greece
 Nailya Guliyeva, Thalassaemia Association "Savab Dunyasi", Azerbaijan
 Musa Zenelaj, Albania Thalassaemics Association, Albania
 Gargi Pahuja, Thalassaemia Action Group, USA
 Manal Safwat Shoukry, Egyptian Thalassaemia Friends Association, Egypt

TIF Members 2010

Voting members

Name	Country
Akdeniz Talasemi Dernegi	Turkey
Albanian Thalassaemics Association (ATA)	Albania
ALPHATT Tunisie	Tunisia
Asociatia Persoanelor Cu Talasemie Majora	Romania
Associazione Ligure Talassemici Onlus (ALT)	Italy
Associazione Talassemici E Drepanocitici	Italy
Associazione Veneta Per La Lotta Alla Talassemia (AVLT)	Italy
Azerbaijan Thalassaemia Society INSAN	Azerbaijan
Bahrain National Hereditary Anaemia Society	Bahrain
Bangladesh Thalassaemia Samity	Bangladesh
Bulgarian Anti-Thalassaemic Organisation (BATA) - SOFIA	Bulgaria
Charity Foundation For Special Diseases	Iran
Children's Thalassaemia Foundation Ltd	China
Chronic Care Centre	Lebanon
Cooley's Anemia Foundation	USA
Egyptian Thalassaemic Friends Association	Egypt
Emirates Thalassaemia Society	United Arab Emirates
Federation Of Malaysian Thalassaemia Societies	Malaysia
Fondazione Italiana "L. Giambrone"	Italy
For Association Of Parents Of Children	Azerbaijan
Greek Thalassaemia Federation (EOTHA)	Greece

Iranian Thalassaemia Society	Iran
Israeli Association Of Thalassaemia & Sickle Cell Anemia	Israel
Jordanian Thalassaemia & Hemophilia Society	Jordan
Kurunegala Thalassaemia Association	Sri Lanka
Moroccan Association Of Thalassaemia	Morocco
Nepal Thalassaemia Society	Nepal
Ninavah Thalassaemia Society (Mosul)	Iraq
North Of England Bone Marrow & Thalassaemia	United Kingdom
Pakistan Thalassaemia Welfare Society (Redg)	Pakistan
Palestine Avenir Foundation	Palestine
Society for Health Education	Maldives
South African Thalassaemia Association	South Africa
Tadad - Talassemi Dayanisma Dernegi	Turkey
Talasemi Federasyonu (Thalassaemia Federation Of Turkey)	Turkey
Thalassaemia Australia Inc	Australia
Thalassaemia Foundation of Canada	Canada
Thalassaemia Foundation of Thailand	Thailand
Thalassaemia Patients And Hereditary Blood Diseases	Syria
Thalassaemia Society Of New South Wales	Australia
Thalassaemia Society of Pakistan	Pakistan
Thalassaemics' Organization In Bulgaria	Bulgaria
Thalassaemia Patients' Friends' Society (TPFS-Palestine)	Palestine
Thalassaemics India	India
United Kingdom Thalassaemia Society (UKTS)	United Kingdom
Yayasan Thalassaemia Indonesia	Indonesia
Yemen Thalassaemia & Genetic Disorders Society	Yemen
Panyprian Antianaemic Association	Cyprus

General members

Name	Country
Abbotonians Medical Association	Pakistan
Akdeniz Kan Hastalıkları Vakfı (AKHAV)	Turkey
Alheta (Asociación Española De Lucha contra las hemoglobinopatías y talasemias)	Spain
Associação Portuguesa De Pais E Doentes	Portugal
Association "El Amani" Des Anémies Hemolytiques Congenitales	Algeria
Association Belge De Thalassémie ASBL	Belgium
Association Française De Lutte contre la thalassémie	France
Associazione Lotta Alla Talassemia Di Ferrara	Italy
Associazione Talassemici Di Torino ONLUS	Italy
Balikatang Thalassaemia	Philippines
Bangladesh Thalassaemia Foundation	Bangladesh
Blood Donors Association (Mauritius)	Mauritius
Cambodian Thalassaemia Association	Cambodia
Club Rainbow (Singapore)	Singapore
Diwanyah Thalassaemia Association	Iraq
Esfahan Thalassaemia Society	Iran
Etudier, Combattre Les Maladies De L'hémoglobine	Luxembourg
Federation of Indian Thalassaemics	India
Foundation Against Thalassaemia	India
Guangdong Thalassaemia Association	China

Guangxi Thalassaemia Federation	China
Indian Association Of Blood Cancer & Allied Diseases	India
Interessengemeinschaft Sichelzellkrankheit	Germany
Iraqi Thalassaemia Association	Iraq
Johor Thalassaemia Society	Malaysia
Kashif Iqbal Thalassaemia Care Center	Pakistan
Malabar T.H.A.S. Society (Kerala)	India
Mindanao Thalassaemia Foundation Inc	Philippines
Mumbai Thalassaemic Society	India
National Thalassaemia Welfare Society (Regd)	India
Nivethan Trust	India
Nuova Associazione Talassemici Italiani ONLUS	Italy
OSCAR Nederland	Netherlands
Oscar Sandwell	United Kingdom
Parents' Association Thalassaemic Unit Trust	India
Pertubuhan Thalassaemia Pulau Pinang	Malaysia
Research Society Of Bjw Hospital For Children	India
Saudi Friends' Charity Of Thalassaemia & Sickle Cell Anemia Society	Saudi Arabia
Syllogos Pashonton Apo Mesogeiki Anaimia Nomou Korinthias	Greece
Taiwan Thalassaemia Association (TWTA)	Taiwan
Thalassaemia Association Of Malaysia	Malaysia
Thalassaemia Awareness Maltese Association (TAMA)	Malta
Thalassaemia Federation Of Pakistan	Pakistan
Thalassaemia Foundation Of Argentina "FUNDATAL"	Argentina
Thalassaemia Patients & Parents Society Of Pakistan	Pakistan
Thalassaemia Society (Singapore)	Singapore
Thalassaemia Welfare Centre Bangladesh (Reg 215)	Bangladesh
Thalassaemic Children Welfare Association	India
Thalassaemieverein Ulm E.V.	Germany
Thalassaemia And Sickle Cell Society	India
The Society For Inherited & Severe Blood Disorders	Trinidad
The Sudanese Patients And Parents Society For Sickle Cell	Sudan
The Thalassaemia Society of India	India
The Vancouver Thalassaemia Society of B.C.	Canada
UAE Genetic Diseases Association	United Arab Emirates

Associate members

The Federation had 114 Associate Members in 2010, representing medical professionals, researchers, non-thalassaemia related patients' organisations, industries and interested individuals from 41 countries around the world.

Financial Statements

THALASSAEMIA INTERNATIONAL FEDERATION NOTES TO THE FINANCIAL STATEMENTS

Year ended 31 December 2010 (audited
accounts)

Revenue	€
Donations Cyprus Government	50000
Donations sundries	65328
Voting members	9034
General members	5069
Associate members	10585
	<hr/>
	140016
Other income	
Interest income	63230
Rate of Exchange profit	40189
Advertising	5131
Sundry Income from projects	738021
	<hr/>
Total Income	986587
	<hr/> <hr/>
	2010
	€
Expenses	
Staff Costs	107254
Depreciation and amortisation expenses	10154
Auditors remuneration	1725
Staff Costs for Projects to generate income	170900
Expenses for Projects to generate income	618600
Other expenses	78413
	<hr/>
Total expenses	987046
	<hr/> <hr/>

TIF Publications Available or Underway in 2010 - Annex I

Title / language	Translated	Printed	Distributed
About Thalassaemia			
- Albanian	✓	✓	✓
- Arabic	✓	✓	✓
- Bengali	✓	✓	✓
- Bulgarian	Completed	In progress	No
- Chinese	✓	✓	✓
- Farsi	✓	✓	✓
- French	✓	✓	✓
- Greek	✓	✓	✓
- Hindi	✓	✓	✓
- Italian	✓	✓	✓
- Khmer	✓	✓	✓
- Laotian	In progress	No	No
- Malay	✓	Completed	Pending
- Portuguese	✓	✓	✓
- Romanian	✓	In progress	No
- Sinhala	✓	✓	✓
- Spanish	Completed	In progress	No
- Turkish	✓	✓	✓
- Urdu	✓	Completed	On-going
- Vietnamese	✓	In progress	No
- German	Completed	In progress	No
- Nepalese	In progress	No	No
Title / language	Translated	Printed	Distributed
Guidelines			
- Arabic	In progress	No	No
- Chinese	In progress	No	No
- Farsi	In progress	In progress	No
- Greek	Completed	Completed	Ongoing
- Italian	Completed	No	No
- Russian	✓	✓	✓
- Skopje	Completed	In progress	No
- Spanish	Completed	Completed	Completed
- Turkish	Completed	On-going	During Antalya
Title / language	Translated	Printed	Distributed
Booklet α-thalassaemia			
- Albanian	✓	✓	✓
- Arabic	✓	✓	✓
- Bengali	✓	No	No
- Bulgarian	Completed	Completed	On-going
- Chinese	✓	✓	✓
- Farsi	✓	✓	✓
- French	✓	✓	✓
- Greek	Completed	On-going	Pending
- Italian	✓	✓	✓
- Khmer	✓	✓	✓
- Nepalese	In progress	No	No
- Sinhala	✓	✓	✓
- Spanish	✓	✓	✓

- Turkish	✓	✓	✓
- Vietnamese	✓	No	No
Title / language	Translated	Printed	Distributed
Booklet β-thalassaemia			
- Albanian	✓	✓	✓
- Arabic	✓	✓	✓
- Bengali	✓	No	No
- Bulgarian	Completed	Completed	On-going
- Chinese	✓	✓	✓
- Farsi	✓	✓	✓
- French	✓	✓	✓
- Greek	Completed	On-going	Pending
- Hindi	✓	✓	✓
- Italian	✓	✓	✓
- Khmer	✓	✓	✓
- Nepalese	✓	No	No
- Sinhala	✓	✓	✓
- Spanish	✓	✓	✓
- Turkish	✓	✓	✓
- Vietnamese	✓	No	No
Title / language	Translated	Printed	Distributed
Booklet Sickle cell			
- Albanian	✓	✓	✓
- Arabic	✓	✓	✓
- Bengali	✓	No	No
- Bulgarian	Completed	Completed	On-going
- Chinese	✓	✓	✓
- Farsi	✓	✓	✓
- French	✓	✓	✓
- Greek	Completed	On-going	Pending
- Hindi	✓	✓	✓
- Italian	✓	✓	✓
- Spanish	✓	✓	✓
- Turkish	✓	✓	✓
Title / language	Translated	Printed	Distributed
Patients' Rights			
- Albanian	✓	✓	✓
- Arabic	✓	✓	✓
- Farsi	✓	✓	✓
- Greek	In progress	No	No
- Vietnamese	✓	No	No
NGO Guide			
- Arabic	✓	✓	✓
- Farsi	✓	✓	✓
- Vietnamese	✓	No	No
Prevention Vol. I			
- Chinese	✓	✓	✓
Prevention Vol. II			
- Chinese	Completed	No	No
Sickle Cell Disease			
Arabic	In progress	No	No
German	Completed	Completed	Completed

Compliance book			
- Arabic	✓	✓	✓
- Farsi	✓	✓	✓
- Greek	✓	✓	✓
- Italian	✓	✓	✓
- Spanish	✓	✓	✓
Thalassaemia & Me (cartoon)	In progress	No	No

Official Partnerships - Annex II

TIF is a member of or has formal partnerships with:

- 1) European Public Health Alliance (EPHA)
- 2) European Organisation for Rare Diseases (EURORDIS)
- 3) The European Medicines Agency (EMA)
- 4) The European Platform for Patients' Organisations, Science and Industry (EPPOSI)
- 5) The Pan-European Blood Safety Alliance (PBSA)
- 6) The International Alliance for Patients' Organisations (IAPO)
- 7) The International Federation of Blood Donors' Organisations (FIODS/IFBDO)
- 8) The World Health Organisation (WHO)
- 9) EE Access to Medicines, and others.

TIF Intervention Statements - Annex III

Request to the Chairman of the Regional Committee for Europe 60th Session (13-16 September, 2010) – Agenda item “f”

Statement of TIF (Thalassaemia International Federation):

“Management of Thalassaemia: A multi-organ disease – A public Health Issue” (by Dr Victor Boulyjenkov)

Mr Chairperson, Ladies and Gentlemen,

TIF is a non-profit organisation comprised of 99 member associations and others from 58 countries – in official relations with the WHO since 1996 as well as other major health-related agencies, institutions and other disease-specific organisations globally. TIF is committed to improving the quality of life and life expectancy for patients with inherited congenital haemoglobinopathies, such as thalassaemia, which fall within the non-communicable diseases, through:

- supporting the activities of existing national patients' and parents' organizations, and establishing new ones, and;
- supporting national health authorities in their efforts to develop effective national control strategies, including prevention and clinical management.

Education of patients/parents and health specialists, and raising awareness about these diseases to the community at large, constitute the 'core' of TIF's educational activities towards achieving the above mission. These include the organisation of conferences, workshops and seminars - at the local, national, regional and international level, as well as publication, translation and distribution of an extensive range of educational materials and books which constitute to-date the reference material for these disorders.

Available epidemiological data, which may be quite underestimated on these diseases in Europe, reflect the significance of these disorders in the national public health burden of every European country. Although, haemoglobin disorders are considered to constitute a major public health problem, mainly in the developing

regions of the world (and more specifically to those endemic or previously endemic to malaria), to date industrialised regions, including Europe are in need to address effectively their control. This becomes a necessity as a result of increasing migration of populations from affected countries and the multiple difficulties faced by health systems in reaching out to these populations because of language, cultural and social heterogeneity and constraints.

TIF was delighted to see two resolutions, WHA59.20 and EB118_R1, adopted by the WHA and EB in 2006, on sickle cell anaemia and on thalassaemia and other haemoglobin disorders, respectively, putting these disorders as priorities on the WHO's health agenda, and facilitating the work of TIF and other NGOs towards encouraging and promoting haemoglobin disorders on national health agendas. In Europe, these disorders, do not occur amongst the indigenous populations and are considered as Rare and the EU address their control and management, in this context.

At present, no national prevention programmes are in place in most of the European countries, and the number of expected affected births, is not yet under control. This number will even increase as the influx, to Europe (particularly to the north) from developing countries continues to increase. As a consequence, in order to address effectively the management of these disorders, national resources will be put under an unbearable strain in many European countries, including blood requirements – where blood transfusion constitutes a major part in the management regime of these diseases.

To this effect, TIF has taken steps towards raising awareness across Europe for these disorders through the organisation of bi-annual Pan-European conferences on haemoglobinopathies since 2007 and has taken an active involvement with the European Commission in formulating, promoting and implementing European policies on 'Rare Disease and Anaemias'.

In this context, TIF wishes to urge the European Regional office to take an equally active role in supporting (i) the promotion of national control programmes in every European country; (ii) the collection and/or promotion (where lacking) of updated and accurate epidemiological data on these diseases; (iii) the adoption of guidelines for consistent management of the disorders across Europe; and (iv) the creation of European Reference Centres and networks of collaboration between the medical and patients' communities and between them in every European country and across Europe.

Thank you.

Request to the Chairman of the 50th Directing Council of the Pan-American Health Organisation (PAHO), 62nd Session of the Regional Committee for the Americas of the World Health Association (WHO), Washington 27th September – 1st October 2010

**Agenda item “8.5F” - “Management of Haemoglobin Disorders: Chronic multi-organ diseases – A public Health Issue” - Statement of TIF (Thalassaemia International Federation)
by Mr Bob Ficarra – TIF Board Member, USA**

Mr Chairperson, Ladies and Gentlemen,

The Thalassaemia International Federation (TIF) wishes to bring to the attention of the Directing Council the need to include Haemoglobin Disorders in the regional Strategy Plan of Action for an Integrated Approach to the Prevention and Control of Chronic Diseases.

Hereditary Haemoglobin Disorders are the commonest major hereditary disorders affecting the world's population. It is estimated that 5-7% are healthy carriers, globally, while around 300000 new affected births occur every year. In the Americas, the countries covered by the PAHO Regional Office, we estimate that 2/1000 live births (range 0-8.2/1000 in Dominica) are affected by these disorders, mainly Sickle Cell Disorders in most countries, but also thalassaemia in North America and Argentina. In Western USA and Canada the HbE syndromes are increasing rapidly because of migration from Asia.

TIF is a non-profit organisation dedicated to improving the quality of life and life expectancy for patients with inherited congenital haemoglobinopathies, such as thalassaemia, which fall within the non-communicable diseases. Our mission is to obtain equal access to quality health care for every patient with thalassaemia, through:

- supporting the activities of national patients' and parents' organizations;
- establishing new associations where they do not yet exist; and
- supporting national health authorities in their efforts to develop effective national control strategies.

Another major focus of TIF's activity is community education through the organization of conferences, workshops and seminars, as well as publication and distribution an extensive range of educational materials. TIF is now comprised of 98 member associations and others from 47 countries and has been working in official relations with WHO about fourteen years.

In its capacity as a patient driven organisation, TIF is concerned that the global burden of non-communicable diseases, including haemoglobinopathies, continue to increase and possibly the magnitude of the problem worldwide is underestimated. In 2006, resolutions WHA59.20 on sickle cell anaemia and EB118_R1 on thalassaemia and other haemoglobin disorders, urge WHO member states to develop, implement and reinforce comprehensive national programmes for the prevention and management of these diseases, including the development of medical genetics services, promotion of community education and training,

A national comprehensive thalassaemia prevention programme may be relatively inexpensive and may be possibly affordable by medium and low-resourced countries. When appropriate prevention services are in place, these disorders can be effectively avoided (diminution of the number of annual affected births), contributing to saving of national resources, which could be redirected and reallocated to improving the health care services and the quality of life of the patients.

Therefore, the experience obtained from countries such as Cyprus, Iran and the UK can serve as models for measuring the effectiveness of such a programmes in terms of national resource savings, appropriate service management and, most importantly, survival and quality of life improvement of affected individuals. In this context, if the world population is to benefit from recent advances in science and medicine, we must seize the opportunity to integrate basic interventions for the prevention and control of genetic and congenital disorders into the national health systems of every affected country.

We reiterate that your council should include these disorders in its strategies and plans for the region and regard them as priorities in the approach to chronic diseases.

Thank you

**Request to the Chairman of the RCM57 (3- 6 October, 2010)
Agenda item 4d “Control of Haemoglobinopathies – Prevention and
management” Statement of TIF (Thalassaemia International Federation)
by Dr Androulla Eleftheriou**

Mr Chairperson, Ladies and Gentlemen

Epidemiology:

Thalassaemia and sickle cell disease are among the world's most common genetic diseases and contribute hugely to the public health burden of affected countries. An estimated 7% of the global population carries an abnormal haemoglobin gene, including thalassaemia. More than 500,000 affected children are born each year, a significant percentage of whom die in affected middle and low-income countries. Despite the medical and technological advances in the field of thalassaemia experienced in recent years, still many hundreds of thousands of patients die undiagnosed, misdiagnosed or sub-optimally, particularly in highly affected developing countries of the world, including this region. The problem is even more accentuated because of the lack of implementation effective national prevention and treatment policies, in many countries of the region.

In the EMRO region, the latest WHO figures illustrate that the overall carrier prevalence for haemoglobin defective gene is 1-4 % - higher for β -thalassaemia (~4%) and lower for sickle-cell disease (~1%). As accurate and/or updated frequency data are still lacking for many countries of the EMRO region, this may still be an underestimation of the real problem. Taking into account the annual birth rates and the population sizes of the countries of this region and based on their moderate carrier rates, the anticipated (or calculated) annual affected births are more than 15,000, confirming the magnitude of the burden on health services that these diseases are already posing and the great need to address their control appropriately.

Thalassaemia International Federation (TIF):

TIF is a non-profit organization dedicated to improving quality of life and life expectancy for patients with inherited congenital haemoglobinopathies such as thalassaemia. TIF is comprised now of 99 thalassaemia member associations and others from over 60 countries and has been working in official relations with WHO since 1996. 29% of its member associations come from this region, e.g. Lebanon, Egypt, Saudi Arabia, Jordan, Syria, Pakistan, Yemen, Tunisia, Morocco, Iraq, Iran, Bahrain and the UAE.

Within its ever-expanding educational activities across the world to spread knowledge on the latest advances on haemoglobinopathies control, including prevention and clinical management, TIF focuses considerable attention to the EMRO region by:

- a) Promoting the medical specialists and other health professionals' education and more importantly patients' education on their disease, its treatment, prevention and other aspects of thalassaemia control, including public health, psychosocial care and patients rights to name but a few.
- b) Promoting patient participation and active involvement in policies and strategies forwarded by national authorities, of each country of the region, ensuring the inclusion of the perspective and experience.

- c) Supporting the participation of patients/parents and health professionals from the EMRO region countries in national, regional and international educational events on haemoglobinopathies, and;
- d) Supporting the translation of TIF publications mainly on aspects of prevention and clinical management, focusing on the needs of health professionals in the region, into Arabic, Farsi, Urdu and Dari.

REQUESTS:

Through this brief statement, TIF takes the opportunity to request from the EMRO Regional committee meeting to:

1. Support national health authorities in the region to place Hb disorders as a priority on their health agenda, to develop and implement national programmes for the prevention and control of these disorders;
2. Encourage and support more updated epidemiological work and research on Haemoglobin (Hb) disorders;
3. Encourage the promotion of regular voluntary non-remunerated blood donation practices as the means for improving adequacy and safety of blood;
4. Support twinning programmes between countries whose haemoglobinopathies' control policies have achieved a measureable level of success with countries that have minimal or no progress achieved, and;
5. Promote the development of partnerships with relevant stakeholders including NGOs at the national and international level.

All above requests constitute the position and consensus of the Board of TIF and fall within the 63rd WHA and WHO Executive Board Resolutions on thalassaemia and other haemoglobin disorders (WHA63.2; WHA63.17; EB118.R1), adopted in May 2010 and 2006, respectively, and within the 5-year plan of action, prepared in the last WHO-TIF joint meeting in Cyprus (November 2007) and fully endorsed by WHO in May 2008.

Finally, we express our deepest appreciation for the ongoing productive collaboration between TIF and the WHO and all the regional offices, including in particular EMRO and reiterate TIF's firm determination and commitment to support their efforts in placing haemoglobinopathies on the priority national health agenda of every country of this region.

Thank you

Request to the Chairman of the 63TH WHA (17-21 May, 2010) – Agenda item “11.9” - “Management of Thalassaemia: A multi-organ disease – A public Health Issue” Statement of TIF (Thalassaemia International Federation) by Dr Victor Boulyjenkov

Mr Chairperson, Ladies and Gentlemen,

The Thalassaemia International Federation (TIF) fully supports the proposed document on prevention and control of NCDs and thanks the Organization for initiating such an important discussion.

TIF is a non-profit organisation dedicated to improving the quality of life and life expectancy for patients with inherited congenital haemoglobinopathies, such as thalassaemia, which fall within the non-communicable diseases. Our mission is to

obtain equal access to quality health care for every patient with thalassaemia, through:

- supporting the activities of national patients' and parents' organizations;
- establishing new associations where they do not yet exist; and
- supporting national health authorities in their efforts to develop effective national control strategies.

Another major focus of TIF's activity is community education through the organization of conferences, workshops and seminars, as well as publication and distribution an extensive range of educational materials. TIF is now comprised of 98 member associations and others from 47 countries and has been working in official relations with WHO about fourteen years.

The global burden of non-communicable diseases, including haemoglobinopathies such as thalassaemia and sickle cell disease, continue to increase and may show an underestimation of the magnitude of the problem worldwide. More specifically, in 2006, resolutions WHA59.20 on sickle cell anaemia and EB118_R1 on thalassaemia and other haemoglobin disorders, urge WHO member states to develop, implement and reinforce comprehensive national programmes for the prevention and management of these diseases, including the development of medical genetics services, promotion of community education and training, A national comprehensive thalassaemia prevention programme may be relatively inexpensive and may be possibly affordable by medium and low-resourced countries. When appropriate prevention services are in place, these disorders can be effectively avoided (diminution of the number of annual affected births), contributing to saving of national resources, which could be redirected and reallocated to improving the health care services and the quality of life of the patients.

Therefore, the experience obtained from countries such as Cyprus, Iran and the UK can serve as models for measuring the effectiveness of such a programmes in terms of national resource savings, appropriate service management and, most importantly, survival and quality of life improvement. In this context, if the world population is to benefit from recent advances in science and medicine, we must seize the opportunity to integrate basic interventions for the prevention and control of genetic and congenital disorders into the national health systems of every affected country.

Thank you.
