



# Thalassaemia International Federation

**Activity Report 2011**

**Plan of Activities 2012**

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## **Foreword**

### **By President of the Thalassaemia International Federation**

On behalf of the Board of Directors and Staff of the Thalassaemia International Federation (TIF), I present to you the Activity Report 2011 and the Plan of Activities 2012.

TIF's activities in 2011, promoted through the slogan "Equal Chance to Life", focused on health inequalities faced by patients, highlighting TIF's ultimate mission for providing equal access to quality healthcare for every thalassaemia patient throughout the world. TIF actively encourages thalassaemia patients, individually and through associations, to fight for their basic human rights and their rights as patients, for their voice to be heard and their struggle to be acknowledged by their governments.

TIF has now successfully made its presence known in 62 countries around the world, most of which are highly affected by thalassaemia. Membership has increased to 108 patient organisations and 114 associate members that represent parties interested in thalassaemia, including medical professionals, researchers, non-thalassaemia related patients' organisations, and industries from 41 countries around the world. We have welcomed into the TIF family three new members from Argentina, Israel and Turkey, and two new Voting Members from Pakistan and Singapore. As a patient-driven organisation, TIF works closely with all its members to promote its ultimate objective of implementing national programmes on thalassaemia for the effective prevention and clinical management of the disorder.

The opportunity to connect and encourage patients' associations and organisations, but also to assess the status of haemoglobinopathies in a country, record the patients' issues and meet with high officials in order to lobby for the improvement of access to quality treatment for all patients with thalassaemia are best enabled through delegation visits. In 2011, TIF visited a number of 'affected' countries, including Cambodia, Indonesia, Laos, Morocco, Vietnam, Albania, and the Russian Federation.

However, such networking was further enabled this year with the organisation of the 12<sup>th</sup> International Conference on Thalassaemia and the Haemoglobinopathies and 14<sup>th</sup> TIF International Conference for Patients and Parents, which took place in May 2011 in Antalya, Turkey, and brought together with great success more than 1300 participants from over 50 countries, across 5 continents. The event was co-organised by the Thalassaemia Federation of Turkey and had the support of the Turkish Ministry of Health. The international conference allowed TIF's Board Officials to meet with and discuss pertinent issues with delegations of countries, thus consolidating collaboration and renewing commitments.

Other highlights of 2011 include the high-level meetings of TIF's President and Executive Director with His Highness the Sheikh Sultan Bin Khalifa Al Nahyan in April 2011 to discuss the establishment of a new, prestigious international award for thalassaemia, and with Her Excellency Yasmina Baddou, Minister of Health of Morocco, in May 2011, followed by the signing of a 3-year Joint Plan of Action with Morocco. TIF has also regularly participated in the Thalassaemia Advisory Committee and the Steering Committee for Rare Diseases of the Cyprus Ministry of Health and, as a founding member and coordinator of the newly-founded Cyprus Alliance for Rare Disorders (C.A.R.D.), organised the 1<sup>st</sup> National Scientific Conference for Rare Disorders, co-organised by C.A.R.D., in March 2011 in Cyprus.

In 2011, TIF also focused its activities on three main areas, the first being the creation and consolidation of global networks of experts and patients, the second the promotion of haemoglobinopathies on the national, European and international health agendas, and third expanding the framework of our activities in order to place thalassaemia and other Hb disorders in the wider context of Rare Diseases.

TIF's global networks of experts in cardiology, endocrinology and hepatology in the area of thalassaemia are expanding, as are the networks of nurses in thalassaemia, and the networks of patients and parents at the European, Asian, African, and American levels. With TIF's efforts through its members associations, but also European (EPA, EURORDIS, EPPOSI, EMA, ESTM, EHA) and international health organizations (IAPO, WHO), and through meetings with important health officials, thalassaemia is being prioritized more and more on national and international health agendas and incorporated in strategic plans of action for rare diseases and public health. Finally, TIF has been exerting great efforts to participate in conferences on the wider topic of rare diseases in order to promote thalassaemia and insert it in the bigger picture, thus ensuring that attention is paid and initiatives are undertaken to combat this disease.

Despite the progress reported, still a lot remains to be done around the world in order to ensure a quality life for all patients with thalassaemia. Lack of national programmes for adequate prevention, treatment and reimbursement policies remains a grave concern. In 2011 and 2012, TIF reinstates its commitment to work in a targeted and focused way, strengthening networks and stepping up efforts for collaboration with national and international health authorities and organisations to achieve its mission.



Panos Englezos  
President

## 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  $\beta$ -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. The majority of patients are children because without treatment, patients die at an early age and without effective prevention at the national level, affected births are expected to occur every year.

Today, as a result of significant clinical and scientific advances, thalassaemia and other haemoglobin disorders are considered both treatable and preventable in cases where effective national programmes are in place and where there is free access to quality healthcare for every patient. With the right care patients can grow up, lead normal lives, become productive citizens, and integrate into society. Unfortunately however, this is not the case for the majority of patients, who are often born into and live in medium and low-resource countries. To date there is a very wide heterogenous gap between regions, countries and even within countries in the quality of services provided to patients and improving health equity constitutes a long-term goal of TIF.

The treatment of thalassaemia is lifelong, complex and costly, requiring specialised expertise and a multi-disciplinary approach. 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 a disease that has considerable social and economical repercussions.

# 1. Thalassaemia International Federation

The Thalassaemia International Federation (TIF) is a non-profit, non-governmental patient driven organisation that was founded by a handful of mainly parents in 1986 and registered in 1987 under the Cyprus Company Law.

The founding group was from Italy, Cyprus, Greece, UK, and USA. Over the years TIF has grown widely. Today it is a global umbrella federation with 104 member associations and other members from 54 countries across the world and supported by over 200 medical specialists and other health professionals from over 60 countries. TIF functions today from a well structured and staffed office that constitutes its headquarters and is situated in Nicosia, Cyprus.

## Vision

TIF's **vision** is to ensure equal access to quality health care for every patient with a haemoglobin disorder.

## Mission

TIF's **mission** is the establishment of national control programmes, and appropriate prevention and management components, across every affected country.

## Values

TIF respects the language, gender, nationality, culture, religion and other beliefs in a nation, population or individual.

TIF believes in Unity, Knowledge and Equality:

**“Unity is our Strength”**

**“Knowledge is our Power”**

**“Equal access to quality health treatment”**

TIF invests in transparency, honesty and sincerity.

## Key Figures 2011

108 member patient organisations  
62 countries

56 General members  
51 Voting members  
114 Associate members

10 staff members

## 2. Strategic Approach

### Objectives

To achieve its mission and vision TIF has set the following goals and objectives:

**I. Empowerment of patients/parents through the creation of associations.**

This is a pivotal objective and is achieved by uniting patients and parents into organised groups in society through:

(a) the establishment of new patient/parents associations and support groups in affected countries where they do not exist and

(b) the strengthening and support of the already existing patient/parents associations

**II. Awareness, Knowledge, Information and Education.** Spreading knowledge and awareness about all aspects of diagnosis treatment, multidisciplinary care and cure of haemoglobin disorders through a well established educational programme of workshops, seminars, conferences and publication of educational material.

The programme focuses on the needs of patients and parents, the medical professionals and the community at large. The publications are translated and distributed free of charge and are available on TIF's website.

**III. Compilation of information, investigation of prevailing status of chronic diseases, thalassaemia and health system whilst also monitoring progress.**

This is achieved through delegation visits. TIF organises two types of delegation visits:

(a) Fact-finding. This type of visit is organised in countries where insufficient or no information is available, in an effort to identify the current situation and the current status and needs of a country with regards to haemoglobin disorders in particular.

(b) Follow-up/monitoring visits. This type of visit usually includes the (i) organisation of a national workshop for patients/parents and medical professionals takes place; (ii) visits to hospitals/blood banks and (iii) meetings with the national health authorities. These activities are organised in collaboration with the national patients/parents association(s), the medical community and the national health authorities, the objective being to monitor progress and establish joint plan of activities.

**Where possible, TIF requests auspices or participation of local/regional WHO offices. Such visits are usually repeated for follow up on an interval based on needs and progress of the country.**

**IV. Projects.** As a leading patient-orientated organisation TIF is participating in a number of important projects with topics ranging from conducting world wide

thalassaemia epidemiology research to establishing electronic patient records creation of medical specialists and patients/parents networks to establishing or reviewing criteria for building or strengthening reference centres for Hb disorders, to projects focused on improving access and quality to appropriate health care either on TIF's initiative and including its coordination on projects or to which TIF contributes or participates as a major partner.

- V. Conferences.** Organisation of local, regional and international conferences with the aim to spread knowledge on the treatment and prevention of thalassaemia according to international standards, focusing on new research and clinical trials. These are usually organised in a format that address both the patients/parents and the health professionals' needs and serve in addition as an opportunity for networking, sharing and establishing collaborations and friendships.
- VI. Joint Plans of Action.** These are major activities organised by TIF in collaboration with the support of the national health authorities according to the needs of the country. It usually has as a main objective the promotion of effective prevention and control of haemoglobin disorders at the national level – a pre-requisite for effective control and management of the disease.
- VII. Health Policies and Networks of Collaboration.** At the international and European levels, TIF contributes actively in the development of health policies through its membership in and close collaboration with a number of important health institutions, such as World Health Organisation (WHO), International Alliance of Patients Organizations (IAPO), European Organisation on Rare Diseases (Eurordis), European Public Health Alliance (EPHA), European School of Transfusion Medicine (ESTM), European Platform for Patients Organisations, Science and Industry (EPPOSI), European Haematology Association (EHA), European Medicinal Agency (EMA), International Genetics Alliance (IGA), European Genetics Alliance (EGA).

TIF currently participates in the formulation and/or amendment of policies in the areas of Blood Safety, Cross-Border healthcare, Orphan Drugs, Rare Diseases, Counterfeit drugs, Patient's rights and information to patients, pharmacovigilance, clinical trials and others with comments and recommendations on European Commission (EC) consultations, communications and green papers but also on the amendments proposed by the aforementioned health organisations.

At the national level, TIF also contributes actively, in the adaptation of the above mentioned policies and their transposition

## **Problems and Difficulties**

TIF encounters a number of problems and difficulties in promoting its activities, depending on the country of focus:

- the existence of weak or absence of patients/parents' associations;
- education and health illiteracy;
- other health priorities in the country;
- lack of adequate knowledge on the disease on the part of health professionals;
- poor or complete absence of updated reliable epidemiological data;
- under-recognition of haemoglobin disorders as a priority in the country and lack of appropriate services to patients;
- poor resources to build up or strengthen necessary health infrastructure;
- political instability

### **3. Highlights 2011**

#### **Sheikh Sultan International Thalassaemia Award**

A prestigious international award for thalassaemia has been established during the course of 2011 by His Highness Sheikh Sultan Bin Khalifa Al Nahyan of the United Arab Emirates in collaboration with the Thalassaemia International Federation.

The United Arab Emirates present an exemplary picture, both in the area of medical advancements and in the management of thalassaemia. The Sheikh Sultan International Thalassaemia Award has been established for individuals with significant contribution to the field of thalassaemia.

The son of the president of the United Arab Emirates, His Highness Sheikh Sultan Bin Khalifa Al Nahyan, who has and continues to relentlessly fight in favour of the creation and materialisation of effective means of management and control of thalassaemia and against the further spread of the disease, is responsible for the establishment of this unprecedented award.

As the major financial sponsor of the award, His Highness has chosen the TIF to be the award committees' main expert partner and advisor. Indeed, Mr Panos Englezos, President of TIF, has been appointed as Vice-President of the Award's Administrative Board of Trustees.

The award, which will exceed one million US dollars, will be presented every two years to local and international groups, individuals and/or institutions who are actively involved and provide significant contribution in the areas of research, support, prevention and control of thalassaemia. The awardees will be announced during the biennial international thalassaemia conferences organised by TIF, whereas the award ceremony will be held in Abu Dhabi, home of His Highness.

This award constitutes an immense achievement, both on the part of His Highness as well as of TIF, as it will serve to raise public awareness about thalassaemia and other haemoglobin disorders. This award furthermore is expected to constitute a major success in educating the public, creating competitiveness, and providing motivation and encouragement to all essential stakeholders in the field of thalassaemia.

#### **Delegation visits**

##### **Cambodia – February 2011**

TIF, in collaboration with the Department of Preventative Medicines of Cambodia, co-organised a workshop forum for the discussion and exchange of ideas on the 'Cambodian Guidelines for the clinical management of thalassaemia', which have been based on the TIF Guidelines. After a lively, interactive discussion, the final draft of this document was adopted by the quorum. Once they are endorsed by the Ministry of Health, the Guidelines will be printed and distributed across Cambodia.

TIF's delegate, Dr Matheos Demetriades, met with the Director and Vice-director of the Department of preventative medicines to assess progress and plan future steps, including a three-year joint plan of action, a patients' registry and pilot prevention schemes in the big cities, as a starting point. The TIF delegation also met with the Paediatric Medical Association and the Chancellor of Phnom Penh University, as well

as with the local thalassaemia association to strengthen collaboration ties and offer support for thalassaemia patients across the country.

### **Indonesia – March 2011**

TIF's follow-up delegation visit to Indonesia took place on 3<sup>rd</sup> to the 6<sup>th</sup> of March 2011, and in its course, TIF also took part in the WHO/SEARO meeting.

On behalf of TIF, Dr Matheos Demetriades, met with parents and patients as well as with health professionals, and delivered a message from TIF's President. Issues discussed in the meetings included the translation into Bahasa and distribution of TIF reference material at thalassaemia centres across the country and ways to promote a national prevention programme. The delegation also met with Ministry of Health officials and discussed issues of implementation of a national prevention programme for thalassaemia and the need to establish a unified national registry under the hosting of the Ministry of Health. It was agreed that a three-year joint plan of action between TIF and the MOH should be drafted over the next months.

At the WHO/SEARO meeting, TIF's Vice President, Mrs Shobha Tuli, delivered a three-minute intervention statement on 'Health and Development Challenges of Non-communicable Diseases'.

### **Laos – February 2011**

This was TIF's first exploratory delegation visit to assess the situation of thalassaemia and to meet with TIF collaborators there. The TIF delegation, including Dr Matheos Demetriades, met with the medical community and discussed ways of educating health professionals on the prevention and control of thalassaemia, but also with patients/parents. A unanimous vote was taken for the establishment of a Laos Thalassaemia Association before end of the year. 'About Thalassaemia' has already been translated in Lao and is expected to be distributed to patients/parents across the country. Finally, the delegation met with the Vice Minister of Health and it was agreed that a three-year joint plan of activities should be drafted together with TIF over the next year.

### **Morocco – January 2011**

As part of TIF's monitoring of the progress achieved in the countries of the Maghreb region, TIF's delegate Dr Matheos Demetriades, visited Morocco between 27<sup>th</sup> and 30<sup>th</sup> January 2011. In the course of the visit, the delegate met with members of the Steering Committee and evaluated the progress of their activities, and also with the President of MATHED for an update on the progress achieved regarding the establishment of a national control programme for thalassaemia in Morocco. Our delegate also saw patients and parents and discussed in what ways TIF could assist them.

In Rabat, a high level meeting was organised with Ministry of Health officials, and the issues discussed included the current situation of blood transfusion, chelation treatment and reimbursement, but also how TIF can best support national efforts in the implementation of a national thalassaemia control programme.

TIF's delegate also met with the Executive Director of the Princess Lalla Salma Foundation and, in Casablanca, with the President and members of the Haematological Medical Association as well as members of the Paediatric Society of Morocco. Both Societies expressed the wish to collaborate more closely with TIF in organising further educational events, and we as TIF are of course delighted!

### **Russian Federation – February and April 2011**

TIF has exerted great efforts over the past year to open a line of communication with the Russian Federation. Russia constitutes a very significant focal point in TIF's efforts to assess the extent and status of thalassaemia and other haemoglobinopathies in the wider region of the ex Soviet Block. TIF's goal is to establish a solid and productive network of medical experts and patients/parents in the Russian Federation. Dr Michael Angastiniotis, TIF's Medical Advisor visited Moscow on 14<sup>th</sup> and 15<sup>th</sup> February 2011 for two important events: a symposium on the prevention and clinical management of haemoglobinopathies co-organised by our Federation and the Scientific Centre for Child Health of Russia, and for the 15<sup>th</sup> Congress of paediatricians of Russia "Actual problems of paediatrics". He gave presentations designed to present the issue of thalassaemia in all its scope to raise awareness in the medical community. In the course of the visit, Dr Angastiniotis also met with officials and medical experts from the Russian Ministry of Health and Social Development and discussed with them the important issue of thalassaemia and haemoglobinopathies.

TIF also participated in the Second All-Russian Conference on Rare Diseases which took place in April 2011 in St Petersburg. The goal of the conference was the creation and promotion of national programmes for rare diseases and TIF pushed for the inclusion of haemoglobinopathies on the national health agenda.

### **Vietnam – February 2011**

A delegation to Hanoi City in Vietnam on the 11<sup>th</sup> and 12<sup>th</sup> February 2011 was successfully carried out. The delegation participated in the inauguration ceremony for the registration of the Vietnamese Thalassaemia Association, which was also attended by a number of ministers and prominent health professionals and hundreds of patients and parents. This was followed by a series of high level meetings with the national health authorities of this country. Goal of the delegation visit was to assess the current situation and the magnitude of the problem of thalassaemia in this country, to observe any progress that has been made since the last TIF delegation visit in 2007, and to discuss the potential draft of a joint three-year plan of action as well as the necessary steps to be taken in order to materialise this plan of action. Moreover, the TIF delegation sought to evaluate the level of public and professional awareness, and the degree of the health services' involvement.

## **Workshops/Conferences**

### **Course of the European School of Transfusion Medicine in Albania – March 2011**

On 16<sup>th</sup> to 20<sup>th</sup> March, 2011, ESTM organised a course on "Transfusion Medicine: development in Albania and in Europe" in Tirana (Albania). TIF's Medical Advisor and TIF's close collaborator Philip Chircop of the European Federation of Blood Donor Organisations participated with presentations on the role of patients'/parents' support groups in the promotion of voluntary blood donation, the joint promotion of voluntary blood donation and awareness of screening for haemoglobinopathies: feasibility, advantages and results, and the moves towards eradication of homozygous thalassaemia in Cyprus with an analysis of the sequence of different steps to its achievement. Both TIF representatives also met with the national health authorities, government officials, patients/parents and medical experts, assessing the current situation with thalassaemia and SCD in Albania.

### **1<sup>st</sup> National Scientific Conference for Rare Disorders, co-organised by C.A.R.D. and TIF, in Cyprus – March 2011**

In the context of the Cyprus Alliance for Rare Disorders' strategic plan for 2011, the first national scientific conference for rare diseases was organised in Nicosia, Cyprus, on 19<sup>th</sup> and 20<sup>th</sup> March 2011. The event attracted many members of the medical and the patients/parents community of Cyprus, and benefitted from the presence of officials of the ministry of health of Cyprus, and representatives from European health organisations, such as the European Organisation of Rare Diseases (EURORDIS). The latter sent a member of its Board to give a speech on their behalf – Prof Mirando Mrcic, a haematologist with great knowledge and expertise in his own country, Croatia. The conference was very well attended and received excellent comments. We believe that the event was very successful in disseminating knowledge and spreading awareness about rare diseases in general, and thalassaemia in particular, in the country.

The event organised by the Alliance received full mass media coverage. We are happy to see thalassaemia obtain a significant position as a rare disease in Europe, where for a long time it was considered an illness restricted to immigrants and unfortunately, as such, received very little attention.

### **12<sup>th</sup> International Conference on Thalassaemia and the Haemoglobinopathies and 14<sup>th</sup> TIF International Conference for Patients and Parents – May 2011**

More than 1300 participants from over 50 countries, across 5 continents gathered in Antalya to witness by far the most successful conference on thalassaemia and the haemoglobinopathies organised by the Thalassaemia International Federation until now. The event was co-organised by the Thalassaemia Federation of Turkey and had the support of the Turkish Ministry of Health.

Health professionals and thalassaemia patients gathered in the WOW Kremlin Palace Hotel for four days that were jam-packed with exchange of knowledge, ideas and experiences from people of all walks of life. The number of medical scientists and patients was approximately equal thus making interaction more lively and proactive.

The beautiful location of Antalya and the hospitality exhibited by the Turkish people was exceptional, making this year's conference a most memorable occasion.

### **High-Level Meetings and Participation**

#### **Meeting with His Highness Sheikh Sultan Bin Khalifa Al Nahyan, son of the President of the United Arab Emirates – April 2011**

Following an invitation from His Highness Sheikh Sultan Bin Khalifa Al Nahyan, son of the president of the United Arab Emirates, to discuss possible collaboration for the establishment of a prestigious international award specifically for thalassaemia – the “Sheikh Sultan International Thalassaemia Award” TIF's President and Executive Director travelled to the United Arab Emirates in March.

The visit was very successful and a strong relationship has begun between the royal family and TIF. Indeed TIF's President has been invited to be the Vice President of the Award's Board of Trustees of the new International Award. Furthermore, TIF has been asked to act as an expert collaborator and adviser for the award. This is one of

the most impressive and important gestures in recent years in the promotion of haemoglobinopathies worldwide, and will constitute an outstanding tool for raising awareness about thalassaemia.

Specific issues and the legal framework remain to be discussed, but it would appear that this award is of a very high level, approximating the value of a Nobel, yet designed specially for thalassaemia. Therefore, we are very pleased and greatly honoured that His Highness chose TIF for close collaboration on setting up the award.

### **Meeting with Her Excellency Yasmina Baddou, Minister of Health of Morocco and signing of a 3-year Joint Plan of Action- May 2011**

A joint plan of action was signed by the TIF Executive Director, Dr Androulla Eleftherious and Her Excellency Yasmina Baddou Minister of Health of Morocco with the aim to establish national control strategies in Morocco. This plan of action between Morocco and TIF, although limits the activity plan to the period 2011-13 it sets the ground for the creation, materialisation, development and implementation of numerous services which will improve the lives of patients in the country. Close monitoring of the progress will be followed by TIF, especially by TIF's Medical Advisor, Dr Michael Angastiniotis, who accompanies the Executive Director to Morocco for this high-level meeting.

### **Meeting with His Excellency Dr Christos Patsalides, Minister of Health of Cyprus in the context of policy-making committees**

#### **a. Thalassaemia Advisory Committee**

TIF's President, Mr Panos Englezos and Executive Director, Dr Androulla Eleftheriou, are active members of the Thalassaemia Advisory Committee set up by the Cyprus Ministry of Health. Present at meetings the representatives of TIF promote multidisciplinary and holistic healthcare to be provided to thalassaemia patients in the Thalassaemia Reference Centre in Nicosia, Cyprus. Upgrading of services to include psychologists and other specialties have been placed on the agenda in 2011 as have the importance of the establishment of a thalassaemia-specific patient registry.

#### **b. Steering Committee for Rare Diseases**

Initiating work in the field of rare diseases in Cyprus, TIF is a founding member of the Cyprus Alliance for Rare Disorders and was heavily active in bringing about its establishment in 2010. As a patient-driven organisation, TIF's Executive Director, Dr Androulla Eleftheriou, acts as a patient representative in the recently set up Steering Committee for Rare Diseases of the Cyprus Ministry of Health. The Steering Committee seeks to formulate a set of recommendations for the implementation of a national plan for rare diseases in Cyprus by 2013, in accordance to the recommendations of the European Commission (EC 2009/C 151/02).

### **Participation in Executive Meetings of the European Public Health Alliance (EPHA)**

TIF's collaboration with EPHA has become closer since the election of TIF Executive Director Dr Androulla Eleftheriou on EPHA's Executive Board in the summer 2010. Dr Eleftheriou has a close relationship with EPHA thus promoting the public health issues of thalassaemia at a European level. Participating in Executive Meetings of the EPHA, Dr Eleftheriou has repeatedly met with Anne Hoel, Programmes and

Communication Manager of EPHA. In 2011, Ms Hoel provided a training course on the recent European health policies to TIF staff. Collaboration with EPHA is exceptionally important to TIF as it has secured a foothold in Brussels, enabling the continuous flow of information and news on health policy developments, as well as particular interests and state policies whilst lobbying for the further acknowledgment of thalassaemia by policy makers in Europe.

### **8<sup>th</sup> May activities**

#### **Motto: "EQUAL CHANCE TO LIFE"**

In keeping with Rare Disease Day 2011 theme ('Rare but Equal'), and the focus on Health Equity, World Thalassaemia Day 2011 focused on the inequality experienced by thalassaemia patients and their families. Social and financial inequalities go hand in hand with lack of basic awareness and prevention programmes for thalassaemia. Dire working and living conditions are linked to lack of treatment from a young age, thus causing problems in later life. The high cost of treatment, when not reimbursed by the State, and problems of integration deepen the social divide, affecting the psychology of patients and families, leading to isolation and depression.

The idea of the 2011 slogan – "Equal Chance to Life" – was formulated to encourage thalassaemia patients worldwide to fight for their basic human rights and their rights as patients, for their voice to be heard, their struggle to be acknowledged by their governments. TIF ardently fought for 2011 to be a year of positive changes, of empowerment and gaining new ground for every patient with thalassaemia across the world.

Activities for the World Thalassaemia Day 2011 took place in more than 30 countries worldwide in the form of patient/parent workshops, press conferences, compliance workshops, community awareness campaigns, children camps etc, with particular focus on raising awareness about thalassaemia, neo-natal screening, blood donation and blood safety.

## **4. Governance, Organisation and Funding 2011**

### **Board of Directors**

Five new Board members were elected at the General Assembly in 2011. The President, Vice-President and Treasurer were re-elected. The Board is composed of 18 members from 15 countries. According to the WHO region definition, TIF Board Members are represented by 9 of the European Region, 2 of the Pan-American Region, 1 of the Western Pacific Region and 4 of the Eastern Mediterranean Region.

### **Staff Team**

The team comprises of 10 persons as of April 2011. The team is composed of full-time paid staff and several sub-contracting companies. The staff is based in the Nicosia office headquarters.

The following are the main changes in human resources in 2011:

- Position of 'Administrative Assistant' are now held by two individuals – Maria Apostolidou and Michelle Theodoulou
- Position of 'Health Policy Officer' is now held by both Dr Chrystalla Thoma and Lily Cannon



## 6. TIF Members 2011

### Voting members

Country	Member Association
Albania	Albanian Thalassaemics Association (ATA)
Australia	Thalassaemia Australia Inc
Australia	Thalassaemia Society Of New South Wales
Azerbaijan	Azerbaijan Thalassaemia Society INSAN
Azerbaijan	For Association Of Parents Of Children
Bahrain	Bahrain National Hereditary Anaemia Society
Bangladesh	Bangladesh Thalassaemia Samity
Bulgaria	Bulgarian Anti-Thalassaemic Organisation (BATA) -SOFIA
Bulgaria	Thalassaemics' Organization In Bulgaria
Canada	Thalassaemia Foundation of Canada
China	Children's Thalassaemia Foundation Ltd
Cyprus	Cyprus Anti-Anaemia Association
Egypt	Egyptian Thalassaemic Friends Association
Greece	Greek Thalassaemia Federation (EOTHA)
India	Thalasseemics India
Indonesia	Yayasan Thalassaemia Indonesia
Iran	Charity Foundation For Special Diseases
Iran	Iranian Thalassaemia Society
Iraq	Ninavah Thalassaemia Society (Mosul)
Israel	Israeli Association Of Thalassaemia & Sickle Cell Anemia
Italy	Associazione Ligure Talassemici Onlus (ALT)
Italy	Associazione Talassemici E Drepanocitici
Italy	Associazione Veneta Per La Lotta Alla Talassemia (AVLT)
Italy	Fondazione Italiana "L. Giambrone"
Jordan	Jordanian Talassemia & Hemophilia Society
Lebanon	Chronic Care Centre

Malaysia	Federation Of Malaysian Thalassaemia Societies
Maldives	Society for Health Education
Morocco	Moroccan Association Of Thalassaemia
Nepal	Nepal Thalassaemia Society
Pakistan	Pakistan Thalassaemia Welfare Society (Redg)
Pakistan	Thalassaemia Federation of Pakistan
Pakistan	Thalassaemia Society of Pakistan
Palestine	Palestinie Avenir Foundation
Palestine	Thalassemia Patients' Friends' Society (TPFS-Palestine)
Romania	Asociatia Persoanelor Cu Talasemie Majora
Singapore	Thalassaemia Society (Singapore)
South Africa	South African Thalassaemia Association
Sri Lanka	Kurunegala Thalassaemia Association
Syria	Thalassaemia Patients And Hereditary Blood Diseases
Thailand	Thalassaemia Foundation of Thailand
Tunisia	ALPHATT Tunisie
Turkey	Akdeniz Talasemi Dernegi
Turkey	Tadad - Talassemi Dayanisma Dernegi
Turkey	Talasemi Federasyonu (Thalassemia Federation Of Turkey)
United Arab Emirates	Emirates Thalassaemia Society
United Kingdom	North Of England Bone Marrow & Thalassaemia
United Kingdom	United Kingdom Thalassaemia Society (UKTS)
USA	Cooley's Anemia Foundation
Yemen	Yemen Thalassaemia & Genetic Disorders Society

## General members

Country	Association Name
Algeria	Association "El Amani" Des Anemies Hemolytiques Congenitales
Argentina	Asociacion De Talasemia Argentina
Argentina	Thalassaemia Foundation Of Argentina "FUNDATAL"
Bangladesh	Bangladesh Thalassaemia Foundation
Bangladesh	Thalassaemia Welfare Centre Bangladesh (Reg 215)
Belgium	Association Belge De Thalassemie ASBL
Cambodia	Cambodian Thalassaemia Association
Canada	The Vancouver Thalassaemia Society of B.C.
China	Guangdong Thalassaemia Association
China	Guangxi Thalassaemia Federation
France	Association Francaise De Lutte contre la thalassemie
Germany	Thalassaemieverein Ulm E.V.
Germany	Interessengemeinschaft Sichelzellkrankheit
Greece	Sylogos Pashonton Apo Mesogeiki Anaimia NomouKorinthias
India	Federation of Indian Thalassaemics
India	Foundation Against Thalassaemia
India	Indian Association Of Blood Cancer & Allied Diseases
India	Malabar T.H.A.S. Society (Kerala)
India	Mumbai Thalassaemic Society
India	National Thalassaemia Welfare Society (Regd)
India	Nivethan Trust
India	Parents' Association Thalassaemic Unit Trust
India	Research Society Of Bjw Hospital For Children
India	Thalassaemic Children Welfare Association
India	Thalassemia And Sickle Cell Society
India	The Thalassaemia Society of India

Iran	Esfahan Thalassaemia Society
Iraq	Diwanyah Thalassaemia Association
Iraq	Iraqi Thalassaemia Association
Israel	The Galilee Foundation of Thalassaemia & Sickle Cell Anemia
Italy	Associazione Lotta Alla Talassemia Di Ferrara
Italy	Associazione Talassemici Di Torino ONLUS
Italy	Nuova Associazione Talassemici Italiani ONLUS
Luxembourg	Etudier, Combattre Les Maladies De L'hémoglobine
Malaysia	Johor Thalassaemia Society
Malaysia	Pertubuhan Thalassaemia Pulau Pinang
Malaysia	Thalassaemia Association Of Malaysia
Malta	Thalassaemia Awareness Maltese Association (TAMA)
Mauritius	Blood Donors Association (Mauritius)
Netherlands	OSCAR Nederland
Pakistan	Abbotonians Medical Association
Pakistan	Kashif Iqbal Thalassaemia Care Center
Pakistan	Thalassaemia Federation Of Pakistan
Pakistan	Thalassaemia Patients & Parents Society Of Pakistan
Philippines	Balikatang Thalassaemia
Philippines	Mindanao Thalassaemia Foundation Inc
Portugal	Associação Portuguesa De Pais E Doentes
Saudi Arabia	Saudi Friends' Charity Of Thalassaemia & Sickle Cell Anemia Society
Singapore	Club Rainbow (Singapore)
Singapore	Thalassaemia Society (Singapore)
Spain	Alheta (Asociación Española De Lucha contra las hemoglobinopatías y talasemias)
Sudan	The Sudanese Patients And Parents Society For Sickle Cell
Taiwan	Taiwan Thalassaemia Association (TWTA)
Trinidad	The Society For Inherited & Severe Blood Disorders
Turkey	Adana Thalassaemia & Sickle Cell Anemia Patients

	Protection and Solidaty Association(ATODER)
Turkey	Akdeniz Kan Hastaliklari Vakfi (AKHAV)
United Arab Emirates	UAE Genetic Diseases Association
United Kingdom	Oscar Sandwell

### **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.

## 7. 2012 Plan of Activities

### A. EUROPE

#### Current Situation:

Epidemiological data shows that in Europe the carrier rate for  $\beta$ -thalassaemia ranges between 0.1%-15% of the total population, with an estimation of 1,636 affected births annually. The majority of carriers in Europe are from migrant communities. TIF has as voting and general members a total of 32 national thalassaemia associations from 16 European countries including Albania, Azerbaijan, Belgium, Bulgaria, Cyprus, France, Germany, Greece, Italy, Luxemburg, Malta, Netherlands, Portugal, Spain, Turkey and United Kingdom.

#### Objectives:

- Continue to raise awareness about thalassaemia and haemoglobin disorders, their treatment and prevention,
- Further investigation and promoting the quality of the health services available to patients and patients' take-up of and access to those services,
- Support existing patients' associations and encouraging them to become members of TIF,
- Encourage the creation of new associations,
- Collect or update epidemiological data from each European country, extended to eastern and extended Europe, including numbers and location of patients with thalassaemia,
- Strengthen networks of collaboration between and amongst health professionals, patients and parents and other disease organisations,
- Monitor and support EU and WHO efforts towards the development of recommendations and policies relevant to Hb disorders, by extending to Chronic Care Diseases,
- Support patients to acquire expert knowledge on the disease and its management enabling them to have active involvement in development and shaping of policies relevant to improvement of health and quality of life,
- Develop or promote existing National Registries for Hb Disorders.

### PLAN OF ACTION:

#### **A.1. 3<sup>rd</sup> Pan-European Conference on Haemoglobinopathies and Rare Anaemias (September/October 2012)**

Organisation of the 3<sup>rd</sup> Pan-European Conference on Haemoglobinopathies and Rare Anaemias, in Nicosia, Cyprus under the Cyprus Presidency of the European Union (2<sup>nd</sup> half of 2012).

*A.1.1. Purpose:* The purpose of the conference is to monitor progress, changes and existing weaknesses and problems with regards to establishment of effective control, prevention and management of haemoglobin disorders. Following the 1<sup>st</sup> and 2<sup>nd</sup> Pan-European Conferences, its primary objective is to bring together patients, medical professionals, and other stakeholders from across Europe in order to share best practices on patient care, prevention and patient empowerment and to encourage national health authorities to recognise and address the public health burden of Hb disorders.

The status of Hb disorders varies between European countries, which can be broadly categorised into those with indigenous carrier rates of 6-19% where successful control programmes are long-established and serve as models; Those where Hb disorders occur at lower rates and national control services exist to varying degrees; Those where Hb disorders were introduced through migration and appropriate services either exist or must be developed. Even where services exist their take-up can be hampered by low awareness by patients and doctors, lacking data on numbers and location of patients, and cultural/language barriers.

In Europe Hb disorders often fall under the category 'rare diseases'. Sharing best practices and experiences at the European level and between countries, is crucial for reducing inequalities of patient access to appropriate care.

*A.1.2. Objectives:* The general objective is to promote optimal management and prevention of Hb disorders in the context of European policies of rare diseases. Furthermore, reduce inequalities in access to optimal care through the dissemination of good practice techniques and sharing of experiences.

Specific objectives:

1. To continue to update the epidemiology of  $\beta$ -thalassaemia and  $\beta$ -non transfusion dependent thalassaemia, HbH and other Hb syndromes;
2. To extend the knowledge gained in experienced countries to other European countries through sharing experiences and best practices;
3. To enable the development of a nuclei of expert medical specialists at the local level and the formalisation of a plan for existing specialists' knowledge and networking at the national and European level;
4. To strengthen awareness of Hb disorders among national authorities at the European Commission and European Parliament level for its inclusion amongst national agenda priority items;
5. To empower patients and their families through strengthening associations and creating networks of collaboration or joining national associations into national federation;
6. To continue and complete the compilation of information on patient access to quality health care and the reimbursement policies and to investigate patients expectations regarding treatment in the different centres within countries in Europe;
7. To inform medical and patient communities and policymakers of the latest EU-level policies, projects and legislative developments in the fields of rare diseases, medicines, patients' rights and mobility, reference networks, etc;
8. To promote national registries and micro-mapping through the adoption of a standard thalassaemia specific software.

*A.1.3. Impact –Expected Outcomes:* The outcomes should contribute in the long term to improvement in the standards of patient care across Europe and reducing the existing inequalities. Participating health professionals should have improved capacity to diagnose, manage and follow up patients. The outcomes will feed into reports which will be used to inform national governments of the epidemiology and public health burden posed by Hb disorders. Patients' groups will be able to lobby their national ministries of health more effectively using the knowledge gained. The outcomes will also illustrate the specific needs and challenges of patients in different European countries and guide further actions.

Specific expected outcomes are that:

1. Participating health professionals will gain an improved awareness of diagnosis and management of patients as well as prevention and on improving Pan-European networks of collaborations, particularly in the areas of multidisciplinary care and reference centres;
2. National health policy-makers will have an improved awareness of the epidemiology and public health burden posed by Hb disorder;
3. Patients' groups will be better networked across Europe sharing experiences, success and weaknesses;
4. Patients will be empowered through knowledge and information on their condition and its optimal standards of treatment, as well as relevant EU policies and issues such as patients' rights clinical trials and cross-burden health. They should be in a stronger position to lobby their national governments and interact with treating physicians;
5. TIF will have a better awareness of patients' needs and specific challenges faced in various European countries and will be able to focus its future activities accordingly;
6. A better realisation of the control programmes developed and established and on their outcomes;
7. Adoption of disease specific electronic patient records for more appropriate follow-up of the quality of management provided to patients and on the identification of weaknesses and problems on which to focus further resources for further improvements in clinical management;
8. Better identification of the non-transfusion dependent syndromes and their needs.

*A.1.4. Target Participants:* Target participants are patient and health professionals involved in treating Hb disorders – mainly haematologists and paediatricians but also interns, cardiologists, endocrinologists, nurses from at least 16 European countries and possible nearby ones. Moreover, the target audience includes EU-wide and international medical professionals' bodies, EU-level and international NGOs, EU institutions and agencies, and national rare disease platforms and government representatives, as well as industry representatives.

1. Patients with Hb disorders (sickle cell and thalassaemia). This group includes also parents as many patients are under the age of 18. The event will aim to include patient representatives from all affected European countries where Hb disorders are prevalent. Given that patients as a rule do not have the wherewithal to travel to such events, TIF will make available a number of bursaries through its "Patient sponsorship programme" to ensure participation. Recipients will be selected on the basis of balanced geographical representation within the confines of the budget.
2. Health professionals. The conference aims particularly to attract haematologists, paediatricians but will also focus on attracting other specialists involved in the multidisciplinary care of these patients. The aim will be to focus attention on those countries where awareness is particularly low and standards of care and prevention are lacking or suboptimal.
3. National government representatives. The conference aims to attract ministry of health representatives from countries where Hb disorders pose a growing

public health problem. Other possible government stakeholders include ministries of employment and social services.

4. Representatives of European-level NGOs will be among the speakers, but a number are also expected to participate.
5. Representatives of EU institutions (Parliament, Commission) will be invited to be both speakers and participants.

*A.1.5. Expected Attendance:* The attendance of a minimum of 150 patients will be secured through TIF's patient sponsorship programme from the following European countries: Albania, Azerbaijan, Belgium, Bulgaria, Cyprus, Denmark, France, Germany, Greece, Italy, Malta, Netherlands, Poland, Portugal, Romania, Spain, Russia, UK, and Turkey.

It is expected that a minimum of 250 health professionals will attend from the same countries as above.

In the context of the European Presidency, other participants will include representatives of European-level and international NGOs involved in public health, rare diseases or patients' affairs, (already secured: IAPO, European Patients' Forum (EPF), Eurordis, EPHA and the EC). Other organisations such as EMEA and representatives of rare disease platforms will be invited to attend. It is hoped that the conference will attract high-level governmental representatives from the host country Cyprus, as well as possibly from other countries of the region.

Total expected participation: 500-600.

### **A.2. Follow up delegation visit in Germany (March 2012):**

- a) to strengthen the collaboration between the national thalassaemia associations and to further promote the unification of the efforts of patients and parents in the country;
- b) to meet and extend the network of health professionals and to initiate a line of communication with the central and regional health authorities;
- c) to include Hb disorders in the scientific programme of the National Haematological and Paediatric Associations.

### **A.3. Follow up delegation visit in Russia (July 2012):**

- a) to identify and build up a network of health professionals and patients/parents;
- b) to establish a collaboration with the national health authorities;
- c) to integrate thalassaemia into haematology, paediatric and rare disease conferences

#### **A.4. Follow up delegation visit and workshop in Romania (April 2012):**

- a) to promote the establishment of MRI T2\* or Ferriscan for the detection of iron overload in patients with thalassaemia in one hospital of the Reference Thalassaemia Centre to which patients may have free and equal access;
- b) to ensure that appropriate treatment is accessible to all patients across Romania;
- c) to include thalassaemia as a topic in the next national haematology and paediatric conferences;
- d) to expand the network of haematologists and paediatricians in the country and to develop a multidisciplinary group and a reference centre;
- e) to organise a workshop on the prevention and treatment of thalassaemia targeting the participation of health professionals and patients/parents and policy makers. The objective is to establish a joint plan of action with the National Health Authorities.

#### **A.5. Follow up delegation visit and workshop in Albania (month to be confirmed, 2012):**

- a) to promote the establishment of MRI T2\* or Ferriscan for the detection of iron overload in thalassaemia patients in one hospital;
- b) to expand network of health professionals including haematologists, paediatricians, endocrinologists and other medical specialists in the country and create a multidisciplinary working group and a Reference Centre;
- c) to include thalassaemia as a topic in the next national haematology and paediatric meeting;
- d) to organise in collaboration with the national thalassaemia association a national workshop on the prevention and clinical management of thalassaemia for national health authorities and policy makers.

#### **A.6. Activities in Cyprus:**

- a) to promote the use of Ferriscan for the detection of iron overload in the heart and liver for improved monitoring and treatment tailoring;
- b) to apply the patients disease-specific record used in the Nicosia Thalassaemia National Health Authorities Reference Centre for pilot study (See details in Projects). This is a project which upon completion will constitute a service provided by TIF to countries in need of a developed and coherent patient registry.

#### **A.7. European Haematology Association (EHA)**

- a) to secure participation in the 17<sup>th</sup> EHA Congress with a booth and lecture on the topic of thalassaemia (14-17 June 2012);
- b) to extend the knowledge of participants through the distribution of TIF's educational material to European haematologists.

## **B. SOUTH EAST ASIA AND WESTERN PACIFIC REGION**

### **Current Situation:**

Epidemiological data shows that in South Asia the carrier rate for  $\beta$ -thalassaemia ranges between 2.2%-16% of the total population, out of which up to 30% are HbE-thalassaemia intermedia carriers, with the estimation of 41,366 annual affected births. For the Asian Pacific region epidemiological data shows that the carrier rate for  $\beta$ -thalassaemia ranges between 0.4%-6.8% of the total population, out of which up to 30% are HbE-thalassaemia intermedia carriers, with the estimation of 5,945 annual affected births. The majority of carriers in both the South Asian and Asia Pacific region are from the indigenous population. TIF has as voting and general members a total of 43 national thalassaemia associations from 15 countries of the region including Australia, Bangladesh, China, India, Indonesia, Malaysia, Maldives, Mauritius, Nepal, Pakistan, Philippines, Singapore, Sri Lanka, Taiwan and Thailand.

### **Objectives:**

- Strengthen existing and create new associations or federations of patients/parents associations,
- Support patients to acquire expert knowledge on the disease and its management enabling them to have active involvement in development and shaping of policies relevant to improvement of health and quality of life,
- Strengthen TIF's Pan-Asian Network for NGOs and Health Professionals
- Work with health professionals to raise awareness about thalassaemia and haemoglobin disorders, their treatment and prevention,
- Support National Health Authorities towards the implementation of an effective national prevention and clinical management programmes and initiate lines of communication with the NHAs in other countries of the region,
- Strengthen collaboration with Regional WHO and Country representative offices in countries,
- Strengthen collaboration with regional WHOCC's for the purpose of establishing twinning programmes with centres in highly affected countries,
- Development of "Guidelines for Thalassaemia Intermedia" and HbE thalassaemia and  $\alpha$ -thalassaemia syndrome,
- Follow up the progress of the 1<sup>st</sup> Pan-Asian Conference.

## **PLAN OF ACTION:**

### **B.1. Fact-finding delegation visit to Myanmar- first activity in the country (February, 2012):**

- a) to build up a health professionals and patients/parents network;
- b) to identify major treating centres and the epidemiology of the Hb disorders;
- c) to initiate a line of communication with the National Health Authorities;
- d) to map the current situation and availability of services provided to patients – access, availability, standards, reimbursements.

### **B.2. Follow-up delegation visit in Bangladesh (January 2012):**

- a) to monitor the progress of the thalassaemia federation of national associations – an effort to strengthen the voice of patients;

- b) to meet with the existing network of health professionals and expand the network of haematologists and paediatricians in the country;
- c) to focus attention on inclusion of prevention and management in the national agenda as a priority;
- d) to promote and support the development of reference centres across the country;
- e) to organise a workshop on the prevention and treatment of thalassaemia to extend knowledge on screening, prenatal diagnosis and other technologies. The target is the participation of health professionals and patients/parents and policy makers. The objective is to establish a joint plan of action between TIF and the National Health Authorities.

**B.3. Follow-up delegation visit in Indonesia (September 2012):**

- a) to identify centres that provide treatment to thalassaemia patients that are situated outside Jakarta;
- b) to meet with patients/parents that are living outside Jakarta to identify their needs and problems;
- c) to expand the network of haematologists and paediatricians in the country and to develop a multidisciplinary group and a reference centre;
- d) to focus attention on inclusion of prevention and management in the national agenda as a priority;
- e) to ensure that appropriate treatment is accessible to all patients across Indonesia.

**B.4. Follow up delegation visit in China (Nanning and Guangzhou) (month to be confirmed, 2012):**

- a) to monitor progress according to the Joint Plan of Action signed with the National Health Authorities of the country;
- b) to monitor progress of the patients/parents associations;
- c) to expand the network of haematologists and paediatricians in the Southern Region and to develop a multidisciplinary group and a reference centre.

## C. EAST MEDITERRANEAN AND AFRICA

### Current Situation:

Epidemiological data shows that in East Mediterranean region the carrier rate for  $\beta$ -thalassaemia ranges between 1.5%-6% of the total population, with an estimated 8,128 annual affected births. From the African region, the main focus is on Algeria with a carrier rate for  $\beta$ -thalassaemia to be 3% of the total population with an estimation of 123 annual affected births. The majority of carriers are from the indigenous population. TIF has as voting and general members a total of 23 national thalassaemia associations from 17 countries of the East Mediterranean and African regions including Algeria, Bahrain, Egypt, Iran, Iraq, Israel, Jordan, Lebanon, Morocco, Palestine, South Africa, Saudi Arabia, Sudan, Syria, Tunisia, United Arab Emirates, and Yemen.

### Note:

**The activities of TIF in the Eastern Mediterranean region will be confined for 2012 due to the political unrest that exists in many countries of the region. This is especially true of countries such as Syria, Egypt, Iraq and Iran where there is an exceptionally high prevalence of thalassaemia.**

### Objectives:

- Strengthen and capacity-build the already existing national thalassaemia associations,
- Strengthen lines of communication with national health authorities in countries and to develop joint plan of activities,
- Collaborate closely with Regional WHO and Country representative offices of countries,
- Promote and expand the Middle East Network for NGOs and Health Professionals,
- Complete compilation of information on health systems-infrastructure and reimbursement policies in countries of the region for targeted advocacy,
- Support patients to acquire expert knowledge on the disease and its management enabling them to have active involvement in development and shaping of policies relevant to improvement of health and quality of life,
- Distribute educational material in Arabic, French and English languages to patients/parents and doctors,
- Contribute to the development by EMRO of guidelines for the treatment of Hb Disorders.

## PLAN OF ACTION:

### C.1. Delegation visit and workshop in Jordan (July, 2012):

- a) to revisit and reinvestigate the current situation in Jordan following a 2011 visit;
- b) to expand the health professionals network and support more specifically the patients/parents;

- c) to develop a national network of medical specialists and other specialists aiming to develop a multidisciplinary group;
- d) to support and to strengthen the programme of prevention and management protocol according to international guidelines;
- e) to meet with the national health authorities and to develop a joint plan of action for the prevention and clinical management of haemoglobin disorders;
- f) to include thalassaemia as a topic in the next haematology and paediatric conferences.

**C.2. Activities in Morocco (2012):**

- a) monitor the progress of the joint plan of action signed between TIF and National Health Authorities in 2011;
- b) to expand the health professionals network and support more specifically the patients/parents;
- c) to develop a national network of medical specialists and other specialists aiming to develop a multidisciplinary group;
- d) to support and to strengthen the programme of prevention and management protocol according to international guidelines;
- e) to include thalassaemia as a topic in the next haematology and paediatric conferences.

**C.3. Workshop in Algeria (month to be confirmed, 2012):**

- a) to meet with the national health authorities and develop a joint plan of action and follow up progress;
- b) to extend the network of health professionals and develop a network of haematologists and paediatricians;
- c) to monitor progress of the Algerian Federation of Thalassaemia Associations of patients/parents and support its promotion;
- d) to distribute educational material;
- e) to establish and promote a National Registry for obtaining essential data for policy makers' planning and recognition of the magnitude of the problem.

**C.4. Follow-up delegation visit in Saudi Arabia (2012):**

- a) to distribute educational material in Arabic to patients/parents association;
- b) to strengthen the collaboration with the Ministry of Health and to provide an official proposal with recommendations on developing a national prevention plan;

- c) to promote and support the establishment of a national patients' registry.

#### **C.5. Activities in Syria, Egypt, Iran and Iraq (2012):**

The activities of TIF in these countries will be confined for 2012 due to the political unrest that exists in the region.

TIF in previous years has identified that these highly affected countries have ongoing problems in relation to the provision of quality healthcare to patients, supply of services to patients from the National Health Authorities and limited treatment resources. Unfortunately, unstable governments and the general instability that characterizes these countries especially makes it exceptionally difficult to infiltrate the National Health Authorities or to have regular contact with the National Thalassaemia Associations. Nevertheless, TIF remains committed to securing and gathering information on the epidemiology within these countries and about the status quo in so far as thalassaemia treatment, prevention and management is concerned. Syria, Egypt, Iraq and Iran are after all priority- countries in the region of the Eastern Mediterranean and Africa for TIF.

## **D. AMERICAS**

### **Current Situation:**

Epidemiological data shows that in the Americas the carrier rate for  $\beta$ -thalassaemia ranges between 0.4%-1.3% of the total population with an estimation of 614 annual affected births. TIF has as voting and general members a total of 7 national thalassaemia associations from 5 countries region – Argentina, Brazil, Canada, Trinidad and Tobago, United States of America.

### **Objectives:**

- Identify the 'affected' countries of South America in addition to Argentina and Brazil;
- Initiate a line of communication with national health authorities in countries;
- Collaborate closely with Regional WHO and Country representative offices of countries;
- Identify patients/parents and medical specialists in South American countries where no information is available to build a Pan-American Network of medical specialists and patients/parents;
- Compile information on health systems-infrastructure and reimbursement policies in countries of the region for targeted advocacy;
- Support patients to acquire expert knowledge on the disease and its management enabling them to have active involvement in development and shaping of policies relevant to improvement of health and quality of life.

## **PLAN OF ACTION:**

### **D.1. Follow-up of the delegation visit in Trinidad and Tobago, and Venezuela:**

- a) to strengthen the line of communication with the national health authorities and support the promotion of prevention and holistic care;
- b) to identify and build up a network of health professionals and patients/parents.

### **D.2. Activities for Argentina:**

- a) to initiate and strengthen a line of communication with the national health authorities;
- b) to identify and built up a network of health professionals and patients/parents;
- c) to support the activities of the newly formed patients associations and the unification with the existing ones to strengthen the patients voice.

## **E. PROJECTS**

### **E.1. Expert Patients' Programme 2012: Creation of Network**

The creation of a network of expert patients aims to train and enable patients to (i) manage their condition in the best way possible; (ii) discuss their condition with their physician in a competent and informed manner and (iii) discuss and lobby with national health authorities for the implementation or reformation of health policies to improve their quality of life.

#### **Plan of action:**

The second meeting of the extended core expert group of patients following the first one in 2011, will aim to finalise and distribute the expert patients material and extend the network of expert patients to an additional 12 countries. Subsequent examination and certification by medical experts of the capacity and knowledge will allow members of the core group to initiate the expansion of the group to the first twelve countries, according to the plan of action.

### **E.2. MSc Course in Haemoglobinopathies**

Promotion of the course and development of joint fellowship programmes. The course needs to be recognised as a post-graduate course in each country according to national regulation.

#### **Plan of action:**

- a) to target the enrolment of 6 students until the end of 2012
- b) to identify sources of funding
- c) to establish collaboration with NTAs for fellowships
- d) to sponsor 2 fellowships to candidates from highly affected countries – TIF in collaboration with TIF member NTAs and/or other NGOs (50% each partner ~ £7,500)

### **E.3. Guidelines for the development and management of Reference Centres**

Promotion of the concept of reference centres as an important, if not the most vital, feature of a coordinated system of care to be provided to patients, and publication of a relevant booklet comprising of the main criteria set by a variety of organisations for the development of reference centres for thalassaemia and other haemoglobinopathies, constitutes a key objective in 2012. The publication will be formulated with the aim to be distributed to National Health Authorities and National Thalassaemia Associations with the ultimate objective to act as a recommendation text for the developing, materialisation and implementation of reference centres in all countries, based on specific criteria. In 2012, TIF aims to publish the material that has already begun to be compiled in 2011 through participation in high-level EU committees and projects, monitoring of course the progress of recommendations of other institutions in so far as thalassaemia and haemoglobin disorders reference centres are concerned.

**Plan of Action:**

- a) Compile new, and use existing information from the Task Force of Eurordis, Enerca and other sources to prepare a publication, on the criteria required for the development of new haemoglobinopathy expert centres and list the existing ones (based on current criteria) across the world to facilitate networking and sharing of knowledge and expertise in Europe and across the world;
- b) Efforts will be maximised to promote existing and push for the development of new Reference Centres in 5 countries in 2012.

**E.4. MRI**

Promote the development and establishment of a license-free MRI software T2\* for detecting iron overload in heart and liver in thalassaemia patients.

**Plan of action:**

- a) Firstly to identify the countries and centres that use MRI technology and note the type of methodology and protocol used;
- b) Secondly, establish MRI T2\* software in 8 countries worldwide in 2012;
- c) Subsequently develop and publish a booklet on the use and value of MRI T2\* as per the recommended guidelines of experts.
  - i. meeting in Cyprus of experts to develop the aforementioned guidelines,
  - ii. publication and distribution of the material to National Thalassaemia Associations, health communities and National Health Authorities.

**E.6. Thalassaemia Specific Electronic Patients-Record Registry**

Development of an electronic patient registry specific for thalassaemia patients. This project aims to introduce an electronic patient-record specifically adapted to thalassaemia needs. The software will support TIF's efforts significantly to promote patients registries and to enhance clinical support and improve patient care. The software will be developed and piloted in Cyprus and is expected to be finalised by mid-2012.

**Plan of action:**

- a) to develop and install the software as a pilot study in the Nicosia Thalassaemia Centre;
- b) upon the pilots' completion the software will be provided to Thalassaemia Centres across the world between 2012-2015. In 2012, TIF will promote the establishment of the registry in 6 countries.

**E.7. Epidemiology Project**

This project sees the analysis of information already compiled in 2011 from 90 countries globally on the demographics of  $\beta$ - thalassaemia, and HbE thalassaemia.

The information acquired includes carrier rates, number of affected births per year, health systems, contributions to GDP, reimbursement policies, availability and use of chelation, treatment policies, quality of healthcare (comprised of 18 indicies).

**Plan of Action:**

- a) In 2012, statistical analyses will commence on the information gathered during 2011 and will result in a publication and formulation of an epidemiological database to be used by National Health Authorities in addition to regional authorities for tailoring their actions, recognizing the significance of haemoglobin disorders and public health issues and prioritizing them on their national agendas. Moreover, it will promote the improvement of knowledge on the extent and demographics of  $\beta$ -thalassaemia, and HbE thalassaemia globally, which is an essential pre-requisite to any government lobby organisation that seeks to achieve progress in the field;
- b) Furthermore, 2012 will see the embarkment of gathering of similar information across the world in regards to  $\alpha$ -thalassaemia and Hb Intermedia.

**E.8. Specialist Networks: Creation of specialist networks and publication of guidelines in the management of thalassaemia complications**

**1. Endocrine Network**

The need for optimum and quality care for haemoglobin disorders is well established if the aim is to achieve long survival and good quality of life. To achieve this aim in dealing with a multi-organ pathology as encountered in thalassaemia, a coordinated multidisciplinary team of specialists is required. Such a team must include an endocrinologist, preferably experienced in the management of hormonal deficiencies caused early in life by transfusional iron overload.

**Plan of Action:**

Following the establishment of the network of endocrinologists with an interest in thalassaemia and who have extensive knowledge of the complications that occur in patients, in 2012 TIF aims to secure two meetings of these specialists. The meetings will focus on the formulation and publication of consensus guidelines for the management of endocrine complications in thalassaemia patients by the end of 2012.

**2. Cardiac Network**

Heart complications in thalassaemia, mainly due to iron toxicity, are the commonest cause of death in young adults. This fact alone makes the expert monitoring and case management by dedicated cardiologists as members of the multi-disciplinary team necessity which cannot be neglected. TIF in recognition of this need has collaborated with experts in the field to form an international network to promote recruitment and training of cardiologists for thalassaemia, to educate through workshops and other means and also to promote collaborative research.

**Plan of Action:**

In 2012, TIF seeks to secure two meetings with the members of the cardiology network that was established in mid-2011. The discussion in the meetings will seek to produce a publication containing consensus guidelines on how specialists can work to treat and manage cardiac complications in thalassaemia patients.

**3. Liver Network**

Occurrence of Post transfusion viral Hepatitis B and C in the industrialised part of the world has dramatically declined through the years as a result of implementation of voluntary blood donation policies, sensitive and specific blood donor screening and careful donor selection and other public health measures including blood transfusion. On the other hand, in developing regions of the world, (low and medium HDI Countries) transmission of these viruses still occurs and in some parts even at high rates. The carrier rate reflects the quality of National Public Health Policies with regard to blood safety measures and the local or regional prevalence of the two hepatitis viruses.

**Plan of Action:**

The establishment of a liver network in 2011 is to be followed by two meetings of specialist hepatologists in 2012 with the ultimate aim of producing and publishing guidelines of how to deal with liver complications that occur in thalassaemia patients. These consensus guidelines will be completed and published by the end of 2012.

## **F. PUBLICATIONS**

### **F.1. New publications:**

#### **a) Thalassaemia in the Emergency Room**

In view of the often inexistent or suboptimal knowledge about thalassaemia and other haemoglobinopathies in the emergency room, doctors working in the A & E department of hospitals and primary healthcare often come face-to-face with thalassaemia patients in an emergency situation without being familiar with the disorder or its complications. Furthermore, the absence or restricted use of electronic patient records in haemoglobin disorders, there is often considerable delay and misdiagnosis of a patient's condition with severe repercussions on the patient's health. A manual with instructions is needed to avoid the delays and ensure the correct treatment is given.

#### **Plan of action:**

TIF has embarked on such a project, preparing a manual entitled 'Emergency Guidelines', in collaboration with international medical experts in thalassaemia. Two 'core group' meetings and one 'consensus' meeting are scheduled for 2012 to conclude the final draft of the guidelines. We aim to publish this manual by September 2012 and make it available in A & E units across the world. The aim of this new publication is to provide an easily read guide to doctors and the staff of the A & E for the treatment of thalassaemia patients in an emergency situation.

#### **b) Nurses' Guidelines for the Clinical management of thalassaemia**

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 collaboration and providing education for nurses all around 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.

#### **Plan of action:**

Preparation on such a publication, with the collaboration of experienced, specialised nurses has already begun. In 2012, we hope to publish this work which will further emphasize the duties of nurses and the kind of services they should provide to the patient and the family at a very practical level, within the context of a thalassaemia centre.

#### **c) Guidelines for the thalassaemia intermedia, HbE, non-transfusion dependant thalassaemia $\beta$ and $\alpha$**

In recent years much information has been gathered on the differences between thalassaemia intermedia and thalassaemia major in relation to the emerging complications that appear with the increase of age of affected patients. Serious complications such as thrombotic phenomena and pulmonary hypertension have been identified and new evidence-based guidelines are now available for their treatment.

**Plan of action:**

TIF, in collaboration with internationally renowned experts in the field has begun to compile texts for the extension of these guidelines, at a more practical level for patients and doctors alike. It is expected that the text will be ready for publication in early 2012, providing support to caregivers and health professionals who deal with thalassaemia intermedia, HbE, non-transfusion dependent thalassaemia  $\beta$  and  $\alpha$  patients.

**d) Prevention of Thalassaemias and other Haemoglobin Disorders (Vol I & II)**

TIF's mission, the establishment of national prevention programmes in accordance to appropriate prevention and management components across every affected country, is most vividly highlighted in the 'Prevention of Thalassaemias and other Haemoglobin Disorders (Vol I & II)' TIF publication of 2003. Eight years later, a review of this publication, with addition of new information, is deemed appropriate.

**Plan of action:**

The same team of international collaborators and writers have re-united to produce a reviewed and updated version of this publication in 2012, to be used across the world to note the importance of prevention and for the implementation of prevention programmes.

## **G. COMMUNICATIONS**

### **Objectives:**

- a) build more effective communications with our members and partner organisations,
- b) more effective use of existing publications and newsletters of members and collaborating organisations in order to promote our activities and enhance TIF's profile.

### **PLAN OF ACTION:**

#### **H.1. TIF Website**

##### **Plan of Action:**

Upgrade TIF's website to a format that is more user friendly and appealing to visitors. Already, starting in July 2011, a new template for the website will be set in place, allowing members of TIF's Staff to upload documents and update the webpage themselves, thus saving on costs and energy and allowing for fast and easy changes. The e-newsletter is expected to be integrated in the matrix of the website, and there are also thoughts about an online patients' forum where patients can ask questions to be answered by TIF's scientific experts.

Furthermore, TIF envisions an update of the medical focus of the website, with new articles and information in order to conform to criteria of the Health on the Net (HON) site and 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 and looks forward to achieving this in 2012.

#### **H.2. Electronic Newsletter**

##### **Plan of Action:**

Establish an electronic newsletter containing a summary of important events and activities. The purpose of this newsletter is to establish closer communication with our members and give them a sense of being a part of TIF, disseminate information more frequently and allow for quick feedback, and provide essential information on activities, events and medical advances in a number of languages, aiming to reach parts of the community who do not speak English.

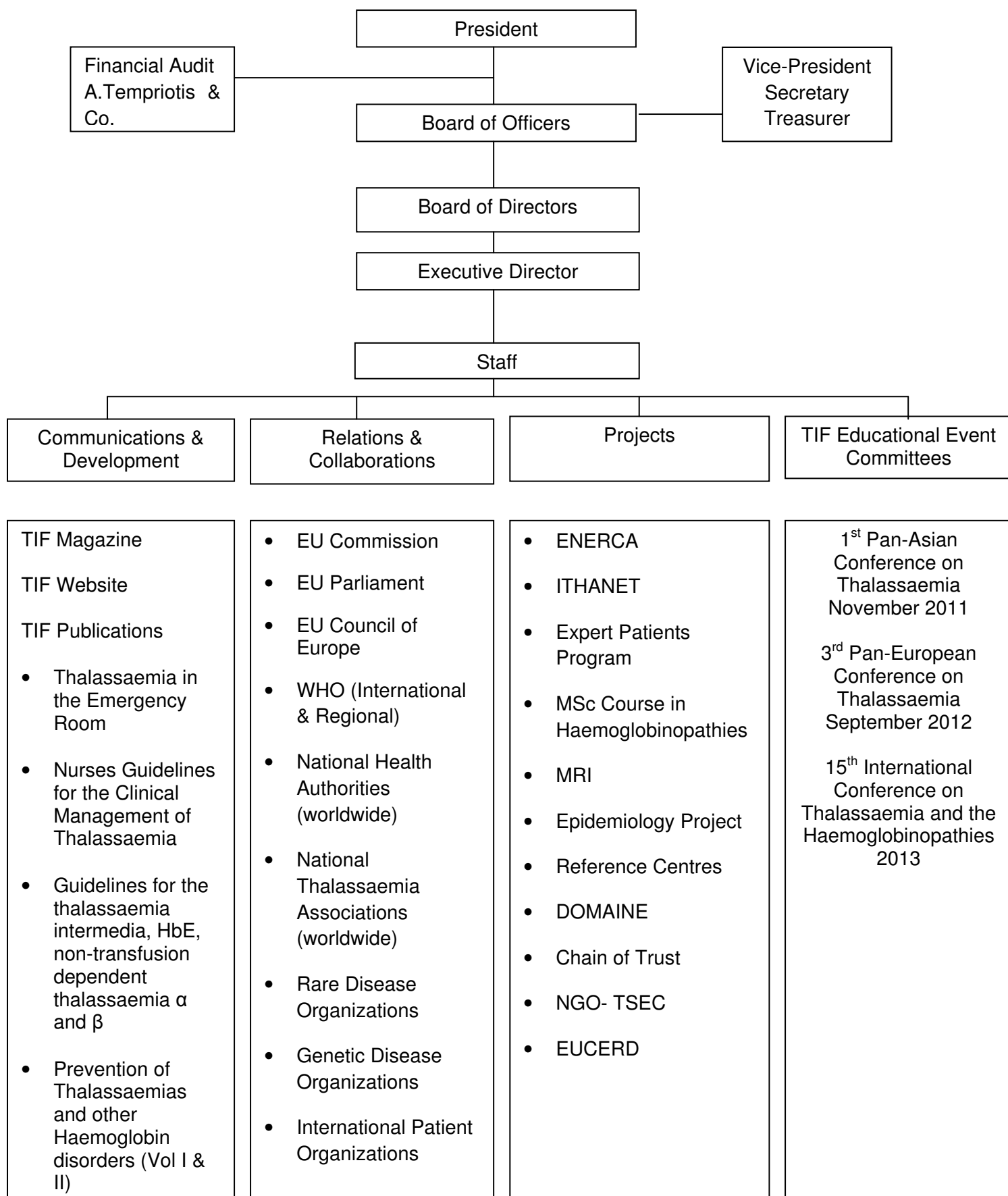
#### **H.3. InfoBase**

The InfoBase is a vital tool for TIF where hundreds of thousands of contacts are stored including member associations (Voting, General and Associate), key people of National Health Authorities in each country, WHO collaborators, associates of each of our regional networks, contacts made on delegation visits etc. These contacts make the work of TIF staff more coherent and productive as they provide focal points for each and every liaison which concerns the treatment, prevention and clinical management of thalassaemia in a region and/or country. The InfoBase also provides a key component to our financial computations.

**Plan of Action:**

In 2012 we hope to be able to upgrade the current InfoBase infrastructure to a more user friendly version, where we can input and deduce more valuable information. The current system has deemed itself inadequate, redundant and often confusing due to the rise in members, associates and contacts of all types that TIF has acquired in recent years. At the present time we are receiving and evaluating tenders for these changes, which we envision to implement in 2012.

## 8.TIF Governance Chart 2011



## 9. TIF Representation in External Organizations 2011

### European and International Non-Profit Organizations

WHO- World Health Organisation

FIODS/IFBDO - International Federation of Blood Donors' Organizations

ISBT- International Society Blood Transfusion

IAPO – International Alliance for Patients' Organizations

EBA- European Blood Alliance

EHA – European Haematology Association

EMA – European Medicines Agency

EURORDIS – European Organization for Rare Diseases

EUCERD – EU Committee of Experts on Rare Diseases

ESTM - European School of Transfusion Medicine

EPHA – European Public Health Alliance

EPPOSI – European Platform for Patients' Organisations, Science and Industry

C.A.R.D. - Cyprus Alliance for Rare Disorders

## 10. TIF Team Chart 2011

