THALASSAEMIA INTERNATIONAL FEDERATION

TIF advocates for:

The implementation of the Executive Board Decision of the World Health Organisation Thalassaemia and other Haemoglobinopathies (EB118), 2006

HUMAN RIGHTS

The implementation by national health authorities and adherence to the United Nations Declaration on Human Rights (UDHR), particularly the following articles:

1. The right to be free from discrimination (UDHR Art. 2) in terms of access to quality healthcare;

2. The right to education (UDHR Art. 26.1) through policies that facilitate participation in school and further education without contradicting access to healthcare services;

3. The right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment (UDHR Art. 23.1);

4. The right to marry and to found a family (UDHR Art. 16.1);

5. The right to a standard of living adequate for the health and well-being (UDHR Art. 25.1) including having access to safe and quality medication and healthcare.

References: United Nations Declaration on Human Rights, 1948; Preamble of Side Meeting at Human Rights Council to discuss the Human Rights of Thalassaemia Patients, 2017

PATIENT'S RIGHTS

The implementation by national health authorities and adherence to the:

1. United Nations Declaration on Human Rights (UDHR), including:

   "The right of everyone for a standard of living adequate for the health and well-being of himself and of his family, including food, clothing housing and medical care…" (UDHR Art. 25)*;*

2. UN Sustainable Development Goals, particularly Article 3 on Good Health and Well-being;

3. World Health Organisation Constitutional Principles, including:

   "The enjoyment of the highest attainable standard of health is one of the fundamental rights, of every human being...",

"Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.";

4. European Charter of Patients' Rights.

References: Position Paper on 'Patients' Rights', 2012; Patient's Rights, 2009; UN Sustainable Development Goals

SAFE AND ADEQUATE BLOOD

1. Promotion and full dependence on voluntary, non-remunerated blood donation practices in every country worldwide;

2. Strengthening existing, and promoting the creation of new, National Transfusion Programmes, in accordance to internationally accepted Guidelines of the World Health Organisation and other official bodies, and strengthening of national Hepatitis B vaccination programmes;

3. Implementation of state-of-art blood banking practices, including a haemovigilance programme.

References: Position Paper on 'Safeguarding blood safety', 2017; Position Paper on 'Chronic Hepatitis B in Transfusion – Dependent Thalassemia, 2015; Position Paper on 'Liver disease in thalassaemia', 2015.

TREATMENT

1. Integration of TIF's Guidelines for the Clinical Management of Transfusion Dependent Thalassaemia (3rd Edition) into national treatment protocols;

2. Establishment of continuous, life-long education programmes of healthcare professionals for the provision of up-to-date, quality healthcare to patients;

3. Strengthening of research for the continuous improvement and advancement in both the clinical and total/ holistic care and cure of thalassaemia.

MEDICINAL PRODUCTS

1. The provision of free-of-charge access of thalassaemia patients to the three chelating agents and other drugs relating to the clinical management of the disease, as per the relevant international clinical guidelines[1];

2. The adoption of national policies for the identification of counterfeit/ substandard medicinal products;

3. Equitable, prompt and affordable access to essential iron chelating drugs and other drugs necessary for the multi-organ disease and treatment-related complications of thalassaemia, including viral hepatitis;

4. National and regional pricing and reimbursement policies that will facilitate the faster accessibility of novel therapies to patients.

References: Position Paper on 'Counterfeit Medicines & Patients' Safety - A global threat', 2012; White Paper on 'The use of generic drugs in beta-thalassaemia', 2016; Position Paper on 'Chronic Hepatitis C in Transfusion-Dependent Thalassaemia (TDT)', 2014; Position Paper on 'Viral Hepatitis C in thalassaemia', 2015.

MULTIDISCIPLINARY CARE

A holistic, multidisciplinary approach for the optimal clinical management of thalassaemia for the prevention and treatment of medical complications, and ensuring improved survival and quality of life for patients.

References: Position Paper on 'Multidisciplinary care in thalassaemia', 2017

IRON LOAD MONITORING

Universal access of all thalassaemia patients around the world, to free-of-charge, quality assured, validated and appropriately calibrated, effective technologies for the accurate measurement and monitoring of organ iron load, in accordance to the relevant international clinical guidelines[1].

References: Position Paper on 'The importance of cardiac magnetic resonance imaging in the monitoring of heart iron in transfusion dependent patients with haemoglobin disorders', 2013; Position Paper on 'Access to effective monitoring and iron chelation and their contribution to survival and quality of life in thalassaemia patients', 2015

NATIONAL PROGRAMMES / STRATEGIES

1. Comprehensive, national programmes for the prevention and management of thalassaemia integrated in national health policy, tailored to specific socioeconomic and cultural contexts, aiming to reduce incidence, morbidity and mortality and providing a suitable quality of life for patients.

2. The development of national registries for haemoglobinopathies, in order to ascertain epidemiological, demographic and geographic information for the guidance of public policy planning.

References: WHO Executive Board Decision (EB118) on Thalassaemia and other Haemoglobinopathies, 2006; Consensus Document 'The future of Haemoglobin Disorders and Rare Anaemias in Europe: Observations, Key Findings, and Recommendations', 2014

[1] TIF's Guidelines (3rd Edition), 2014 http://thalassaemia.org.cy/publications/tif-publications/guidelines-for-the-management-of-transfusion-dependent-thalassaemia-3rd-edition-2014/

PREVENTION OF THALASSAEMIA

National programmes for the screening and identification of carriers, including provision of genetic counselling services.

References: Consensus Document 'The future of Haemoglobin Disorders and Rare Anaemias in Europe: Observations, Key Findings, and Recommendations', 2014

MIGRATION AND ACCESS TO HEALTHCARE

1. Facilitation of access to existing healthcare services for migrant patients with haemoglobin disorders through the development of specific mechanisms and channels;

2. Development targeted awareness programmes, taking into account the diverse cultural and religious background of migrant groups;

3. Strengthening existing national healthcare services, enabling the continuous provision of quality care to inflated thalassaemia populations in non-endemic countries.

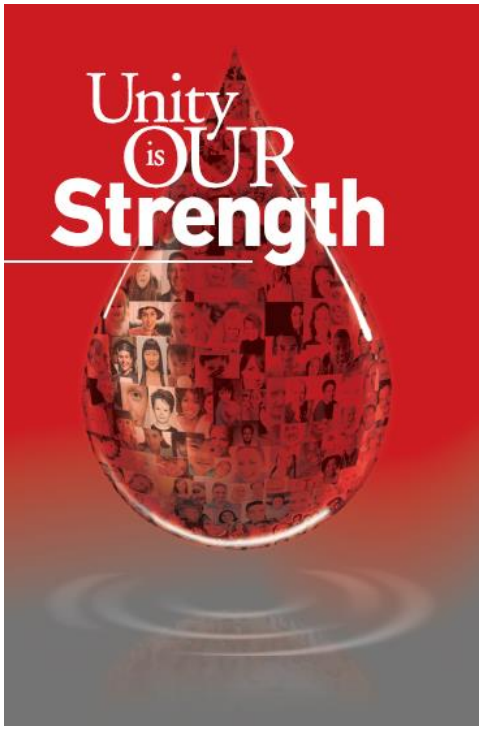
References: Haemoglobinopathies on the Move: Is Europe Ready?, 2013

ADHERENCE TO TREATMENT

1. Empowerment and encouragement of patients through their familial and social network to actively participate in their healthcare and compliance to medical advice provided;

2. Sensitisation of healthcare professionals to the contributing multiple factors and possible solutions for optimising adherence;

3. Adoption by national health authorities of thalassaemia management programmes that will enable patients to have sufficient access to appropriate therapeutic options.



References: Position Paper on 'Adherence to Therapy in patients with β-thalassaemia', 2016; Compliance to Iron Chelation Therapy with Desferrioxamine, 2000

TIF's Position Papers are available at

http://thalassaemia.org.cy/positions-policies/