

HEADQUARTERS

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The Thalassaemia International Federation (TIF)¹ honours the World Blood Donor Day 14th June 2020

POSITION STATEMENT

Transfusion of blood and blood products helps and save millions of lives. This statement is even more true for individuals whose day to day survival depends on regular blood transfusions. Patients with hereditary blood disorders like thalassaemia, Sickle Cell Disease (SCD), Blackfan Diamond anaemia, other congenital anaemias as well as conditions like the haemophilias and congenital immunodeficiencies, depend on human blood and blood products for both their survival and wellbeing.

The higher the prevalence of transfusion dependent thalassaemia, β - thalassaemia mainly, in a country, the higher the percentage of the donated blood supply needed to address the medical needs of these patients, who often require lifelong 2-3 units of red blood cells every month.

¹ *The Thalassaemia International Federation (TIF) is a patient-oriented non-profit, non-governmental umbrella federation, established in 1986 with Headquarters in Nicosia, Cyprus. TIF's mission is to help ensure equal access to quality health and other care for every patient with thalassaemia and other haemoglobin disorders around the world. To-date membership boasts 232 members from 64 countries across the globe. TIF works in official relations with the World Health Organization (WHO) since 1996 and enjoys active consultative status with the United Nations Economic and Social Council (ECOSOC) since 2017. Moreover, it is a strategic partner of the European Commission under the Third Health Programme since 2018 and a member of the Patients and Consumers Working Party (PCWP) of the European Medicines Agency (EMA) since 2010. In 2019, TIF obtained a participatory status at the Council of Europe, as a Member of the Conference of International NGOs. Moreover, TIF was awarded, in the context of the 68th World Health Assembly in May 2015, the 'Dr Lee Jong-wook Memorial Prize' for its outstanding contribution to public health.*



In the absence of national or international registries for haemoglobin disorders, and based on published and reported figures, which TIF believes are grossly underestimated, some 500,000 patients living across the world with transfusion dependent thalassaemia alone, consume, or should consume if they receive appropriate transfusion care, **about 12 – 18 million units of Red Blood Cells (RBCs) to keep them alive. In addition, an even greater number of patients, anticipated to be some millions across mainly of the developing world, are born and live with ‘milder’ or intermediate phenotypes of thalassaemia (α and β) and/or abnormal haemoglobins including HbE and importantly Sickle Cell Disease (SCD).** A proportion of these, which cannot be predetermined, **become transfusion dependent at some point in their lives, and RBCs transfusion therapy become integrated into their standard medical care protocol.**

One may thus, easily recognise the blood transfusion needs of patients with haemoglobin disorders and consequently the unequivocally great role of the blood donors and immense VALUE of their contribution to the health and quality of lives of these patients.

65% of blood transfusions in low-income countries for example, are given to children under 5 years of age, a good percentage of whom may be transfusion dependent patients with haemoglobin disorders.

Blood transfusion therapy in the early 60s and 70s when provided on a regular basis and in later years with more appropriated processed blood, has literally prevented the early loss of these patients who in their greater majority died prior to reaching their first decade of life. Along with the provision, in later years, of and access to iron chelation therapy and appropriate multidisciplinary care these fatal childhood disorders were transformed to chronic ones and have allowed patients to have an open-ended survival, very satisfactory quality of life and almost full social integration. A phenomenon that is seen in some countries mainly of the West who have developed, since the early 1970s, disease specific control strategies. Sadly, however, only less than 16% of the registered global patient community receive optimal care and less than 25% appropriately processed and adequate quantity of red blood cells for their needs and as recommended in international guidelines [TIF’s Reports].

Voluntary, regular, non-remunerated blood donation practices strongly promoted since 1975² by the World Health Organisation (WHO) and subsequently by other relevant official bodies at national, regional and international level, have been gradually replacing, across the world, family and paid donation practices which have supported the blood supply at national level for many decades.

This change alone, wherever it occurred, contributed significantly to the safety of blood and the role, importance and value of voluntary, regular, non-remunerated blood donors have been unequivocally demonstrated.

From the data of the 2016 Global Status Report of the WHO on Blood Safety and Availability, 74 countries collect more than 90% of their blood supply from voluntary, non-remunerated blood donors. Still however, 72 countries collect more than 50% of their blood supply from family/replacement or remunerated donors. 2020 constitutes the target year for all countries to establish 100% voluntary, non-remunerated donation practices. TIF will be very closely monitoring the achievement of this goal.

In this context, as a patient support organisation, TIF extends its deep gratitude and heartfelt thanks to each and every donor where he or she may live who gives blood on a regular, non-remunerated basis recognising that this is the best and most precious gift of life.

This year's campaign theme, as designated by WHO, "**Safe blood saves Lives**" is in perfect alignment with TIF's position. However, considerable work is still ahead of all of us. Still blood services, in many countries with high prevalence of haemoglobin disorders are facing many and multiple challenges of making sufficient and safe blood available to their patients. Patients' needs

² Since 1975, the World Health Assembly has highlighted the global need for blood safety and availability through the adoption of several resolutions that have given greater priority to the issue within global and national health agendas. Key resolutions include WHA28.72, Utilization and supply of human blood and blood products (1975); WHA56.30, Global health-sector strategy for HIV/AIDS (2003); WHA58.13, Blood safety: proposal to establish World Blood Donor Day (2005); WHA63.12, Availability, safety and quality of blood products (2010); and WHA 67.6, Hepatitis (2014). These resolutions have also identified the guiding principles and essential elements for the development of sustainable national blood systems to meet the transfusion needs of all patients.

include both adequacy – to access blood in sufficient quantities to address their medical condition – and safety to prevent the development of related adverse reactions. The risks of transmitting infection, are always hanging over the vulnerable recipients and it is now, more than ever, well recognised that the goal of reaching zero transmission of pathogens through transfusion may not be plausible. New pathogens, existing ones and other re-emerging at times in a more infectious and/or virulent forms, very much promoted by strong population movements, environmental, political, cultural and other conditions/circumstances, are continually threatening the safety of blood.

Absence of diagnostic tests and/or vaccines and/or therapeutic drugs for many of these pathogens, constitutes a constant threat to the safety of blood transfusion therapy, not only for transfusion dependent patients but also for the ever increasing groups of immunocompromised patients, either transplanted or chemotherapy recipients and others, all related to the dramatic improvements in more accurate and prompt diagnoses and medical care of diseases.

Voluntary Donation remains an unequivocal component contributing to safety and as such the World Blood Donors Day and the 14th of June every year, give us the opportunity to express to all blood donors around the world - known and anonymous individuals – our gratefulness and sincere respect while at the same time provides food for thought and consideration to Governments and all relevant bodies on how to protect and continue to empower these individuals.

The slogan is, for these reasons, **“Give blood and make the world a healthier place”**.

WHO has defined this year’s objectives quite clearly and TIF endorses these objectives, since they are in total agreement with the objectives of the haemoglobinopathy community as whole. These objectives are:

- **celebrate and thank** individuals who donate blood and encourage more people to start donating;

- **raise wider awareness** of the urgent need to increase the availability of safe blood for use wherever and whenever it is needed to save life;
- demonstrate the need for **universal access to safe blood transfusion** and provide advocacy on its role in the provision of effective health care and in achieving universal health coverage;
- **mobilize support** at national, regional and global levels among governments and development partners to invest in, strengthen and sustain national blood programmes.

Almost half of the global blood donations are collected in high-income countries, home to only about 19% of the world's population (<https://media.ifrc.org/ifrc/what-we-do/health/voluntary-blood-donation>) and only 6-7% of beta thalassaemia patients. In these regions/countries of the world it is anticipated to have better organized services, uninterrupted blood donation policies and appropriate, for these patients, blood transfusion therapy and other medical care. In most countries, where more than 80% of the patients' (with hemoglobin disorders) population is born and lives, equitable access to adequate and safe blood transfusion services still does not exist and moreover in many of these, costs are additionally involved.

The medium blood donation rate in middle and low income countries where more than 80% of the patients with haemoglobin disorders live is 11.7 and 4.6 per 1.000 people respectively.

The shortages in blood has been magnified across the world during the 2020 COVID-19 pandemic. The effect of lockdown, fear of blood donors to go to blood donations centres which are usually located in hospitals and can be hubs for SARS-CoV-2 virus, fears that the virus can be transmitted through blood or during donation, concerns about poor social distancing in hospital units, have all helped to reduce donations. In many locations the shortage has been temporary since blood establishments supported greatly also by patient associations took early action to address the issue. TIF issued suggestions and guidelines to help the situation (<https://thalassaemia.org.cy/publications/tif-publications/blood-covid-19-2020/>).

In other locations, which are those where the majority of our patients live however, blood shortages have had almost catastrophic effects on the health and quality of life of the patients and negative social and financial impact on their families. Pre-transfusion Hb, normally kept above 9g/dl, was allowed to fall to levels unacceptable for their condition. In some locations thalassaemia associations have reported to TIF that in order to reduce travel during lockdown, patients, particularly in large countries, were directed to peripheral health centres where, due to lack of facilities, and confined medical expertise, whole blood was transfused instead of red cell concentrates with all anticipated risks and threats to their health.

The concern is that the COVID-19 which may not have itself affected thalassaemia patients more than the general population, according to current information, may in fact as a result of the stress and challenges impacted on the health care systems around the world and the diversion noted from the care of chronic diseases to COVID-19, have long term consequences, on their health some of which may even be irreversible.

It is hoped that one huge relevant lesson learned from the pandemic for all nations across the world, is the need to invest in preparedness programs in case of infectious disease outbreaks and more generally in public health including very importantly blood transfusion services.

To this new global fight, the blood donor continues to have a very substantial and irreplaceable role to perform and the Governments need to continue to empower and safeguard their safety and appropriate management.

**TIF THANKS EACH AND EVERY ONE OF THE 24 MILLION BLOOD DONORS
ACROSS THE WORLD**