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Editorial

International Thalassaemia Day and the Urgent Need for a National Thalassaemia Policy in Pakistan

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Every year, May 8th is observed globally as International Thalassaemia Day, a dedicated occasion to raise awareness among the public and policymakers about thalassaemia. It also serves to acknowledge the strength and perseverance of individuals and families impacted by this lifelong condition. Initiated in 1994 by the Thalassaemia International Federation (TIF), this day commemorates the memory of George Englezos, son of TIF's Founder and President, Mr. Panos Englezos, and of all those who have lost their lives to thalassaemia. George represented a generation of thalassaemia patients who, through access to quality care, could thrive academically and professionally, challenging the limitations once associated with the disease.

In 2025, TIF proudly adopted the theme "Together for Thalassaemia: Uniting Communities, Prioritizing Patients", under the inspiring slogans #WeAre1 and #PatientsFirst. This theme reminds us that behind every statistic lies a personal journey, individuals living with unique challenges that require a more humane, patient-focused approach to care.

First documented in 1960, thalassaemia remains the most prevalent inherited blood disorder in Pakistan, posing a significant public health burden. Approximately 5% of the population carries the beta-thalassaemia trait, and it is estimated that nearly 100,000 individuals are living with thalassaemia major, with around 40,000 cases in Khyber Pakhtunkhwa province alone, primarily due to the high prevalence of consanguineous marriages.[1]

Thalassaemia places an immense emotional, psychological, and financial burden on parents. The constant lifelong need for blood transfusions, medical monitoring, and the fear of complications create ongoing stress and anxiety. Many parents face social stigma and blame, while also struggling to balance caregiving responsibilities with work and other family needs.[2]

Although thalassaemia individuals are often not hospitalized, they are among the largest consumers of blood in the country. This not only places a financial and emotional burden on families but also strains an already fragmented and demand-driven blood transfusion system.[3] Frequent transfusions in thalassaemia can cause alloantibodies, leading to red cell destruction, shorter transfusion intervals, complications, infection risk, and higher costs. This, however, can be reduced by the use of leukocyte filters, especially for chronic recipients, reducing immune reactions.[4]

The safety of blood transfusions remains a significant concern among the public health community. While regular transfusions improve quality of life, they also expose patients to the risk of transfusion-transmitted infections (TTIs) such as hepatitis B and C.[5,6] The risk escalates with age and the cumulative number of transfusions. Furthermore, the use of low-quality rapid diagnostic tests for donor screening exacerbates this problem, contributing significantly to the spread of hepatitis in the country.[7] A 2020 national study by our team in thalassaemia cohort, found an alarming prevalence of 29.79% for HCV and 4.13% for HBV among transfusion recipients.[8]

One promising aspect is the existence of prevention and control laws in Sindh,[9] Balochistan,[10] and Punjab.[11] These laws, however, have not been effectively enforced. Key reasons identified are the absence of clear implementation strategies and a lack of provisions for necessary financial and human resources. Some thalassaemia stakeholders also argue that these laws were formulated without

adequate consultation or input from the thalassaemia community. While the government has taken a positive step by passing these laws, as it aids in raising awareness, stronger efforts are needed to ensure their practical impact and fulfill the commitment to thalassaemia control.

Despite the magnitude of the issue, Pakistan lacks a baseline national survey to determine the actual disease burden. Further, no comprehensive National Policy exists for prevention, control, or management.[1] Consequently, the number of cases continues to rise, even though thalassaemia is a preventable condition.

Countries like Iran,[12] Cyprus,[13] Greece,[14] and Italy[15] have made significant progress in the control and even eradication of thalassaemia through national prevention programmes, premarital screening policies, and strong public awareness initiatives. Pakistan must draw lessons from these success stories and adapt similar strategies to its local socio-cultural context. A National Thalassaemia Policy must include mandatory premarital carrier screening, genetic counseling services, public education campaigns, national registries for patients and carriers, strengthening of safe blood transfusion practices, support for NGO-run and government thalassaemia centers.[16]

Thalassaemia is not just a clinical diagnosis; it represents real lives and complex human stories. A patient-centered approach must go beyond the provision of medical treatment and focus on improving the overall quality of life of patients, socially, psychologically, and economically.

By uniting as a community, we can build a formidable movement for advocacy and reform, one that ensures the needs, rights, and voices of thalassaemia patients are not only recognized but placed at the core of national health planning.

On this International Thalassaemia Day, let us renew our commitment to a future where no child is born with thalassaemia due to preventable causes, and every patient receives the dignified, comprehensive care they deserve.

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