

PROMOTING ACCESS TO TREATMENT FOR PATIENTS WITH HAEMOGLOBIN DISORDERS

- Lack of treatment for haemoglobin disorders persists

“Despite major advances in our understanding of the molecular pathology, pathophysiology, and control and management of the inherited disorders of haemoglobin, thousands of infants and children with these diseases are dying through lack of appropriate medical care. This problem will undoubtedly increase over the next 20 years because, as the result of a reduction in childhood mortality due to infection and malnutrition, more babies with haemoglobin disorders will survive to present for treatment. Although WHO and various voluntary agencies have tried to disseminate information about these diseases, they are rarely mentioned as being sufficiently important to be included in setting health care priorities for the future. It takes considerable time to establish expertise in developing programmes for the control and management of these conditions, and the lessons learned in developed countries will need to be transmitted to those countries in which they occur at a high frequency.”

Sir David Weatherall and J. B. Clegg

The Thalassaemia International Federation (TIF)

Since its establishment TIF has sought to facilitate access to treatment for thalassaemia patients worldwide

▪TIF's Specific Model

Preventive Programs as a *prerequisite* for establishing a basic standard of treatment.

Promotion of **Screening Programs**

Impact of Screening Programs on Cyprus

Screening Program

Introduction of pre-marital certificates

Effects of Screening Program in Cyprus

- Minimization of new births with thalassaemia syndromes
- The standard of care for thalassaemia patients improved dramatically

**Primary
pre-condition for a
good standard of
care and
treatment**

*United and Strong
Patient Voice*

*The creation of a
patient/parent
organization*

In the regions where “a strong patient organization exists” we have observed that there has been a marked improvement in the health care services for haemoglobin disorders



Drawbacks in achieving collective goals

- Lack of strategic planning
- Personality or ego issues within organizations

TIF's Motto:

“Unity is our strength”

