

# Expert Patients' Programme

**International Thalassaemia Federation**

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# Objective of Presentation

**Present the Expert Patients' Programme to encourage patient knowledge and use of that knowledge for improvement of national and regional legislation**

# **Reach the Patient: Expert Patients' programme**

**A major TIF project initiated in 2007**

**GOAL: To identify and extend quality information to patients with thalassaemia across the world on their disease, its medical care and other forms of care**

**Objective: Empower patients through knowledge to gain control of their treatment and life**

# Information

## **QUALITY INFORMATION:**

**Reliable, validated, accurate, updated information that is derived from consensus of or Guidelines written by international experts in the field**

## **Every Patient:**

**Information to reach the patients directly not through other channels or stakeholders**

# Expert patient programme

Intend to provide patients:

- **In-depth knowledge about their condition, prognosis, complications, treatment options, research, clinical trials, other public health issues**
- **The necessary skills and confidence to effectively self-manage and develop effective partnerships/dialogues with medical specialists and other health and social professionals**
- **The necessary knowledge to EVALUATE AND DECIDE ON CARE AND NEW TREATMENTS**
- **To be able to make accurate presentations, about Thalassaemia to doctors, health professionals and the general public**
- **To support and help other patients to cope and self manage their condition**

# Expert patient programme

An understanding of **IMPORTANT POLICY ISSUES**  
such as:

- **Patients' Safety**
- **Patients' Rights**
- **Cross-border health care**
- **Clinical Trial Directives/ Legal Frameworks  
(ethical and other issues)**
- **Pharmacovigilance/orphan drugs**
  - **Reimbursement policies/models**

# Desired outcome

- 1. Patients have better knowledge first about their condition, but also about research options and developments, wider public health and socioeconomic issues, about available, existing policies, directives, regulations, laws that are relevant to their treatments, health and quality of life.**
- 2. Patients FEEL empowered in their relationship with health care professionals and have higher self-esteem to cope and achieve goals.**
- 3. Patients adhere better to prescribed treatment and take active part in decisions made about their health and life.**
- 4. Patients are more capable of accessing and evaluating the available health and other services and navigating the health system in their own country and settings.**

# Desired outcome

5. **Patients have better health outcomes – better survival and quality of life reflected in:**
  - More patients finishing secondary and tertiary education**
  - Gaining employment**
  - Forming relationships, families of their own**
  
6. **Patients are better equipped to participate and actively contribute their skills and knowledge, for the benefit of their National Thalassaemia Associations – National Services and Health or other-related projects and policies at National , Regional, International level.**

# Conclusion for Expert Patients' Programme

An educated “**EXPERT**” patient (about his condition ) is  
a Patient who:

Knows what he **should have**

Knows what he **must do**

Knows what he **must demand**

Knows what **tools to use to get it**

And so he is not just **SHEEP** to the slaughter

THANK YOU