

# 14<sup>th</sup> TIF International Conference for Patients and Parents

11-14 MAY, 2011

Antalya - Turkey

## *Service Provision of Thalassaemia Centres*

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# Main factors causing needs of patients with thalassemia

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- ✓ Disease heterogeneity
- ✓ Age
- ✓ Disease complications
- ✓ Special patient request

# The European Chart of Patients' Rights

Every patient has the right

1. to proper services to prevent illness/complications
2. of access to the required health services
3. of information on health, health services and their use
4. to informed -consent
5. to free choice among treatments
6. to privacy and confidentiality
7. to respect patients' time
8. to high quality health services
9. to high safety standards
10. to Innovative procedures
11. to avoid unnecessary suffering and pain
12. to personalised treatment
13. to complain
14. to appropriate compensation

# Services for patients with thalassemia are based on:

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- ✓ Patients needs and rights
- ✓ Centre experience
- ✓ Resources (*human, economic, structural*)
- ✓ Organization
- ✓ Motivation

# Comprehensive clinical care

- + Dedicated clinical staff**
- + Adequate amount and safe blood supply**
- + Monitoring of iron overload and iron chelation**
- + Specialists for complications**
- + Dedicated computerized clinical record**

# Adequate staff/pts ratio



- 1 nurse 33pts
- 1 doctor 50pts
- 1 psych 100pts
- 1 secretary 100pts

# Heart T2\* clinical use

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- Evaluation of heart iron overload
- Prediction of risk of cardiac disease
- Prescription and monitoring of chelation
- Comparison of the myocardial efficacy of chelators
- Accurate assessment of cardiac function

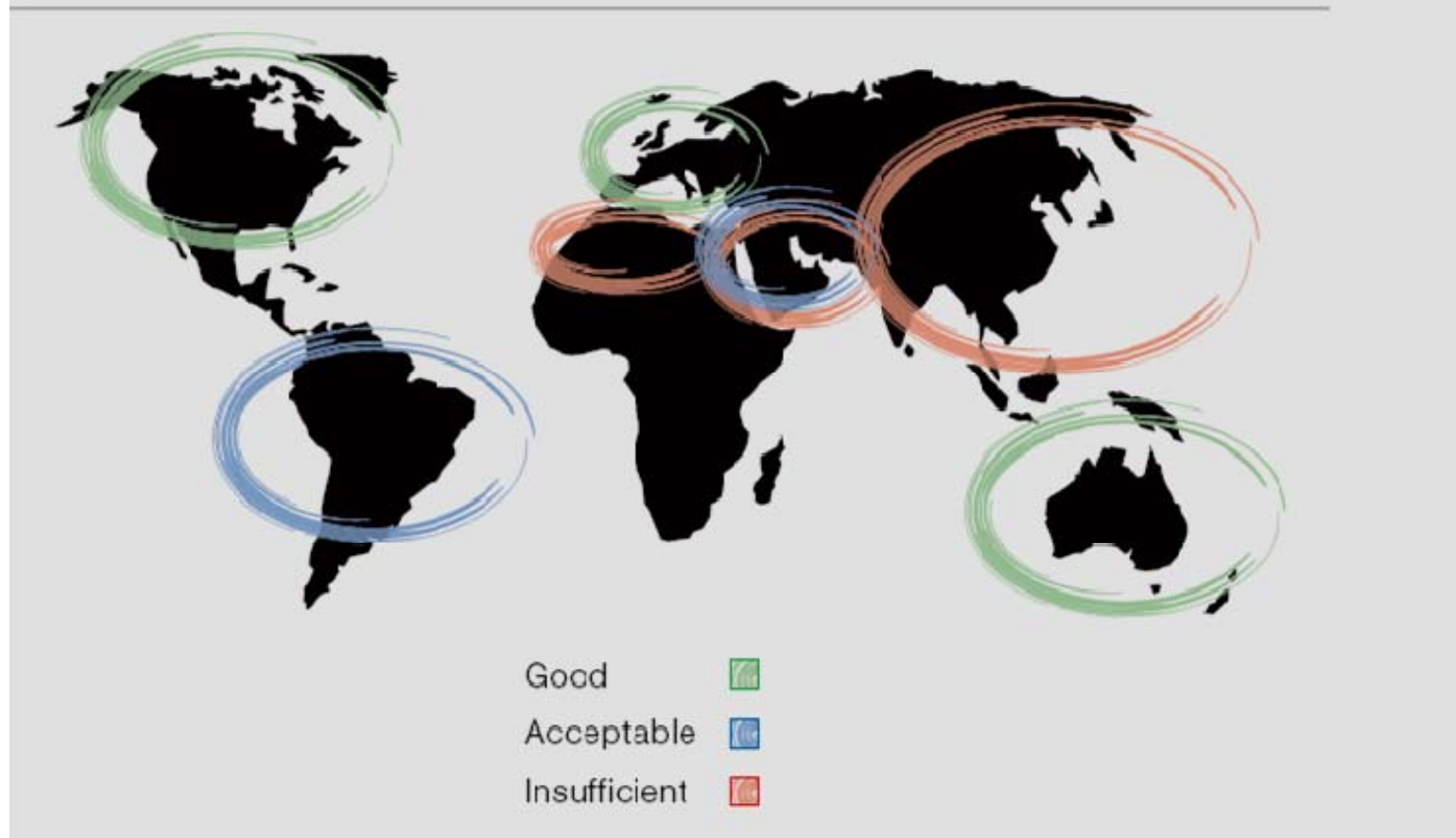
# Role of local thalassemia clinics

- + provide conventional treatment
- + monitoring of iron chelation
- + monitoring of complications
- + interaction with the Reference Centre

# Role of Reference Centre

- + provide regular treatment
- + monitoring of iron chelation
- + monitoring of complications
- + offer consultation for complex cases and annual review
- + offer access to multispecialist team
- + screening (first and second level) and prenatal diagnosis
- + bone marrow transplantation
- + research
- + organization and coordination of clinical trials
- + education and training

**Figure 3:** *Treatment of thalassemia in different parts of the world.*



# **Patient's responsibilities**

**to actively and positively participate to  
the complex management process**

# Clinical research in thalassemia



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- Patients oriented
  - Rationally selected
  - Ethically conducted
  - Unbiased
  - Public sponsorship
  - Patient Association sponsorship

WHO, Hereditary Disease Program 1994