
**12° International Conference on Thalassaemia
and the Haemoglobinopathies**
14° TIF International Conference for Patients and Parents
11-14 May 2011
Antalya – Turkey

“Provision of a Thalassemia Center”

Thalassaemia International Federation Promote:

**“Equal Access to quality care to
every patient with thalassaemia”**

Provisions for patients

A General presentation on what kind of services should be available in a Thalassemia Center

Thalassemia Centers worldwide are not at the same level for many reasons:

- ▶ **Different Resources available**
- ▶ **Scarce Physicians aknowledgements about Thal**
- ▶ **No experience in preparing Blood units**
- ▶ **No following international Protocols**
- ▶ **No available diagnostic instruments (MRI)**

We have to focus on two topics

Could we still consider Thalassemia a peditaric disease?

Probably **YES for the undeveloped countries**

No, for the most advanced countries

The main complications rise with increasing of age of patients so Pediatrics or Adults Patients

we have to decide for the future

**Thalassemia should be managed into
Specialized Centres provided with a
Day Hospital for treatment
by specialized staff of doctors and
nurses
Because**

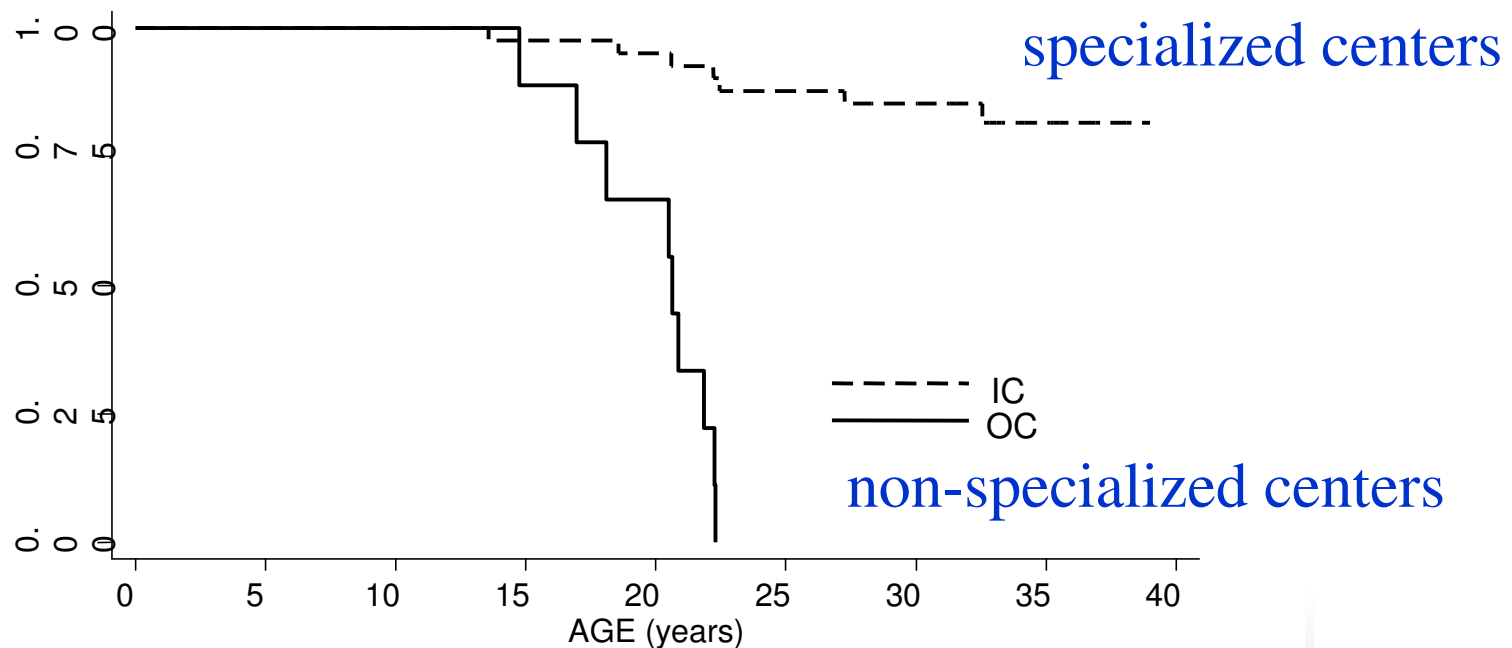
Survival in/out Specialized Center



Am J Hematol. 2009 May;84(5):317-8.

The influence of treatment in specialized centers on survival of patients with thalassemia major

[Forni GL](#), [Puntoni M](#), [Boeri E](#), [Terenzani L](#), [Balocco M](#).



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How should be organized a Thalassaemia Center for a better management

- ▶ **Unity completely dedicated to thalassaemia**
- ▶ **Day Hospital for treatment**
- ▶ **Doctors and Nurses dedicated and limited turnover**
- ▶ **Nurse Coordinator**
- ▶ **Clinical Folder shared by doctors**
- ▶ **Clinical Folder shared by nurses**

Multidisciplinary Approach



Means that a thalassaemia staff should interact with:

Cardiologist

Endocrinologist

Hepatologist

Diabetologist

Specialist in Reproductive medicine

Psychologist

Transplant Unity

In a close teamwork coordinated by a specialist in thalassaemia

Interactions

The Thalassaemia Centre should also interact with:

- ▶ **Blood Bank**
- ▶ **Centralized Laboratory**
- ▶ **If possible, a Laboratory Unit into the TC**

Blood Bank: To provide the blood units of the best quality possible, more appropriated for patients in order to avoid haloimmunization and/or infections

Laboratory Unit: To activate all the specific procedures for diagnosis, follow-up and monitoring of the treatment

Therapy



Day before Blood Transfusion:

- ▶ Evaluation on the clinical situation of patient by testing blood pressure and heart frequency (nurses staff)
- ▶ Execution of blood test for testing the Hb level
- ▶ Report on the personal health perception by patient

Blood Transfusion Day:

- ▶ Administration of blood transfusion
- ▶ Discussion with doctor after blood tests
- ▶ Interview with doctor to decide future aims, specific informations, therapy opportunities
- ▶ Determining the next appointment
- ▶ Discharge after updating the documents

After Discharge:

- ▶ **Provision of drugs for home daily therapy through Hospital Pharmacy**
- ▶ **Discharge paper for Management Program**
- ▶ **Update of medical record**

Controls Program:

- ▶ **Every 10 days: Blood test for WBC counting in case of administration of Deferiprone**
- ▶ **Monthly: Blood tests, Electrophoresis, Serum Ferritin, Transaminase**
- ▶ **Every 3 months: Hormone Assays (TSH, FSH, LH, GnRH)**
- ▶ **1 time/year: Several instrumental examinations**

MRI



Echography



DEXA



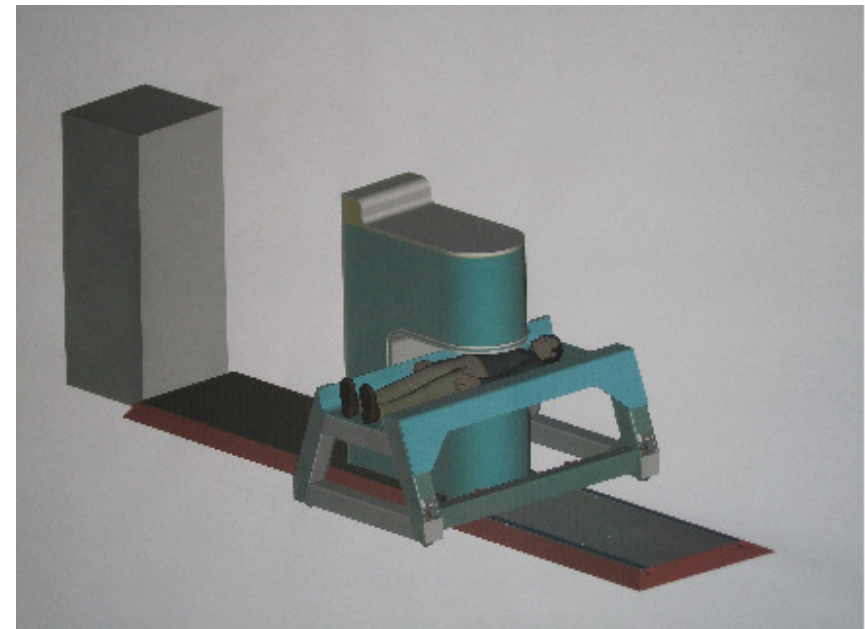
SQUID



MID

Magnetic Iron Detector

- **Non Invasive instruments to detect Liver Iron Overload**
- **Easier management than SQUID**
- **Less expensive**
- **Settled in Thalassemia Center in Genoa**



Provisions

To allow acceptable levels of quality of life of the patients a well Organized Center should also:

- ▶ **Organize the controls program in agreement with patient**
- ▶ **Provide more appointments on the same day**
- ▶ **Organize the transfusion treatment throughout the day**
- ▶ **Give confirm of the controls to the patient the day before**
- ▶ **Provide an adequate space for the treatment to preserve patient's privacy**

To be a Center of Excellence it's absolutely required to reserve part of the activity to the clinical research

For the purpose it's needed:

- **Organize a dedicated staff to compile the research protocols**
- **Respect the ethical issues concerning clinical research directed to patient**
- **Put in action qualified studies to evaluate new drugs or new diagnostic methods**
- **Collect all the data for their publications on specialized issues**

Only through link the clinical research and the therapy it will be possible for a Thalassemia Center to reach those levels of excellence that patients require in order to improve their quality and expectations of life

Conclusions

These provisions are not available everywhere but it should be the mission of every parents/patients association to achieve that by

- **Stimulate our Thalassemia Center by demanding to apply treatment protocols**
- **Support our Center in clinical research**
- **Stimulate the national Government**
- **Constitute a strong group of pressure to influence health policy**
- **No giving up in front of the difficulties keeping in mind that being informed it is the first step to claim our rights**

Thank you

