



**DE**FERIPRONE  
**E**VALUATION IN  
**P**AEDIATRICS

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# Patients' empowerment and Patients' needs

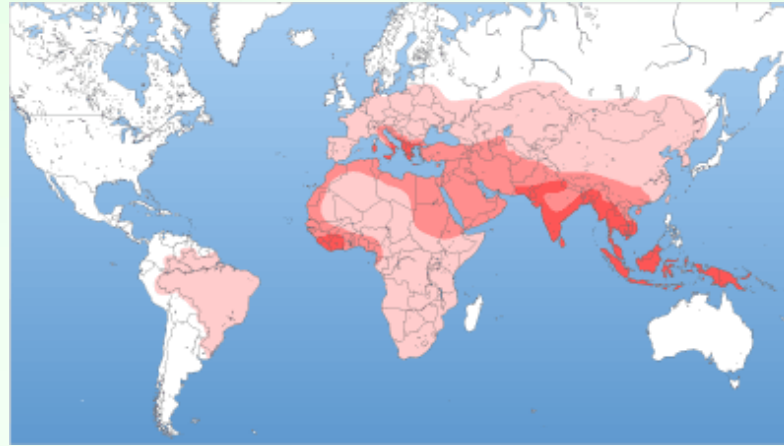
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# Treatment overview



- The world of Thalassaemia and Sickle Cell is divided into two main areas:
- Developed Countries where the treatment is optimal and patients' lifespan is good
- Developing Countries where the access to the treatment is difficult and the QoL is poor



# Treatment overview

The treatment is considered optimal in patient's perspective if:

- Blood Transfusion: high standards of blood quality and safety
- Iron Chelation Treatment: accessible for the whole patients' community and free of charge
- Iron Overload: prevented and monitored with accuracy performing timely MRI on heart, liver and pancreas
- Complications: tackled by a multidisciplinary approach with a close collaboration between a panel of specialists well aware of thalassemia and the thalassemia-specialist
- QoL and lifespan meets the highest standard possible



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# Treatment overview

It's of evidence that

- Developing Countries need to approach this standard that is not achieved yet
- Developed Countries need to implement the international protocols and to maintain the excellence of their thalassemia centers



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# Key Word

in both situations is the same:

## Patients' Empowerment

- Crucial for developing countries to allow the patients to improve their access to the treatment
- Extremely important for developed countries' patients to face the challenges of the future



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# Patients' empowerment

## Developing countries

- To provide them a deep knowledge of their condition to arise their awareness not only about blood transfusion and chelation
- To provide them with tools for facing their condition and for demanding the creation of centers of excellence and to have access to the treatment with a multidisciplinary approach
- To promote the creation of patients/parents associations to claim the respect of patients' rights
- To help them to join the Expert Patients' Program of TIF



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# Patients' empowerment

## Developed countries

- To fill the lack of knowledge on secondary complications, teaching them how to prevent and/or how to manage them
- To become expert in advocacy at national and international level
- To provide them with knowledge about how the regulatory drugs' agencies work, about the clinical trials and ethical aspects, about the access to the new drugs and treatment developments



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# Patients' empowerment

## Developed countries

- The real challenge is for the patients to actively participate to making decision process in every field of the health policy.
- It's pivotal to design a very specific Empowerment Program able to build their capacities in patients' advocacy for promoting through the associations a new vision of the modern patient.
- This is a fact at international level both socially that institutionally





# Patients' needs

A new vision of the patients in Developed countries

- To promote a new vision of the doctor-patient relationship where the patient is considered a **subject** and not anymore an **object** of study
- A partner working side by side for a common aim that for both is the health of patient



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# Historical Notes

## Thalassemia in Italy

- The therapeutic alliance between scientific community and patients/parents associations has been pivotal for achieving important goals.
- The associations have facilitated a lot the developments demanding strongly what the patients needed for improving their health.
- The scientific community had benefited a lot from this strong support
- This alliance has changed, recently, driving the two to run different ways



# New Vision

## Thalassemia

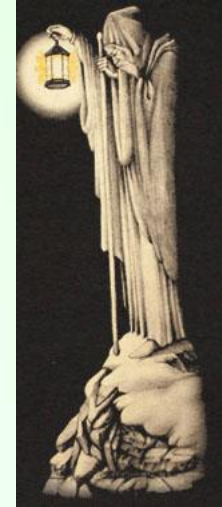
- In times of austerity is pivotal to sign a new agreement between patients' community and scientific community
- It's reliable only if it starts under the new proposed vision of a patient in partnership with doctor at the same level
- Achieving the international funds for clinical research, promoting amongst patients clinical trials and studies are common aims that can be approached from different sides
- Defending strongly the position's privileges means that we won't be able to win the challenge of the future



# Patient-Doctor Relationship



Old Vision of  
paternalistic medicine



New Vision: Doctors  
need to be educated  
to talk with the  
patient.



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# Thank you



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