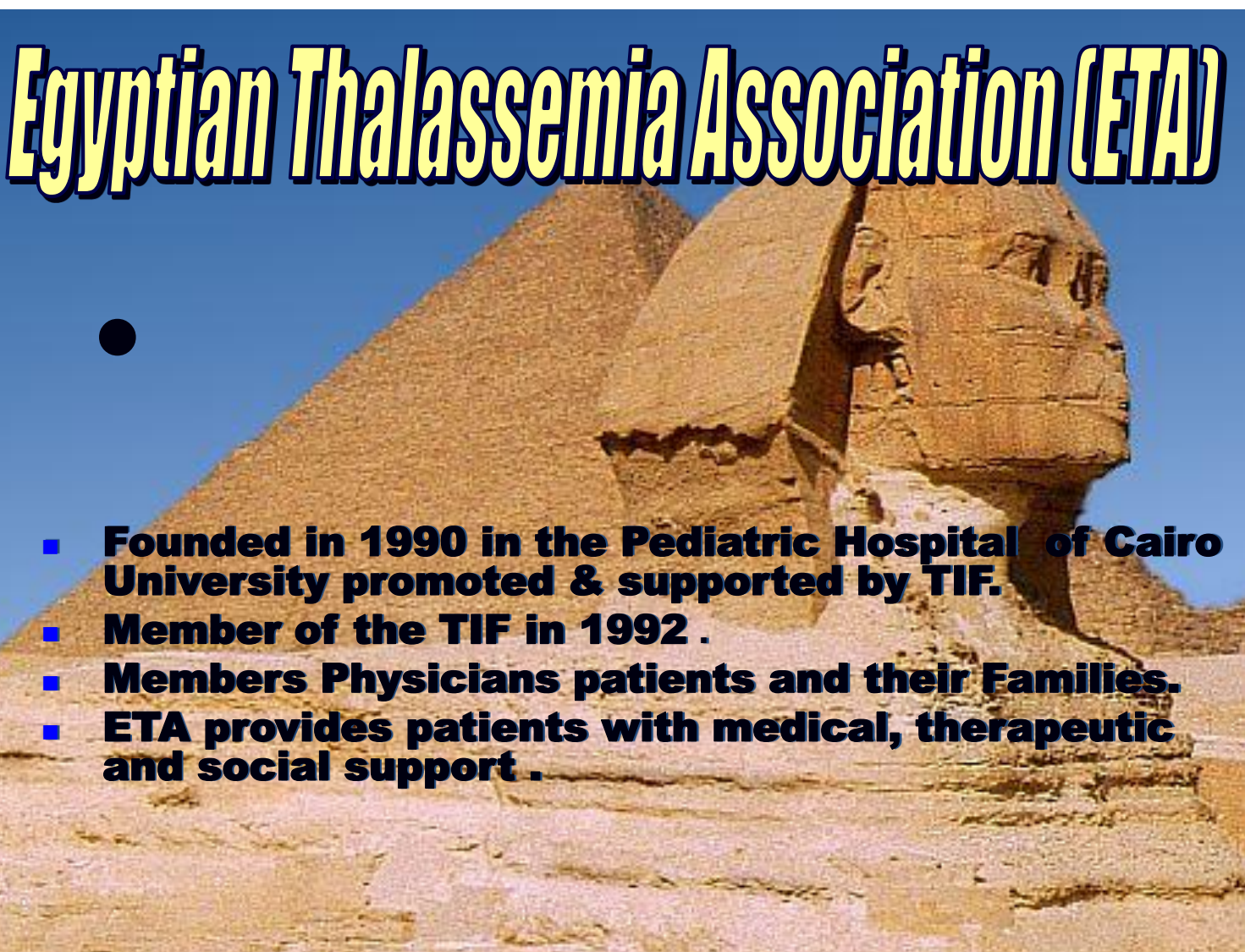




The Egyptian Thalassaemia Association(E.T.A.)

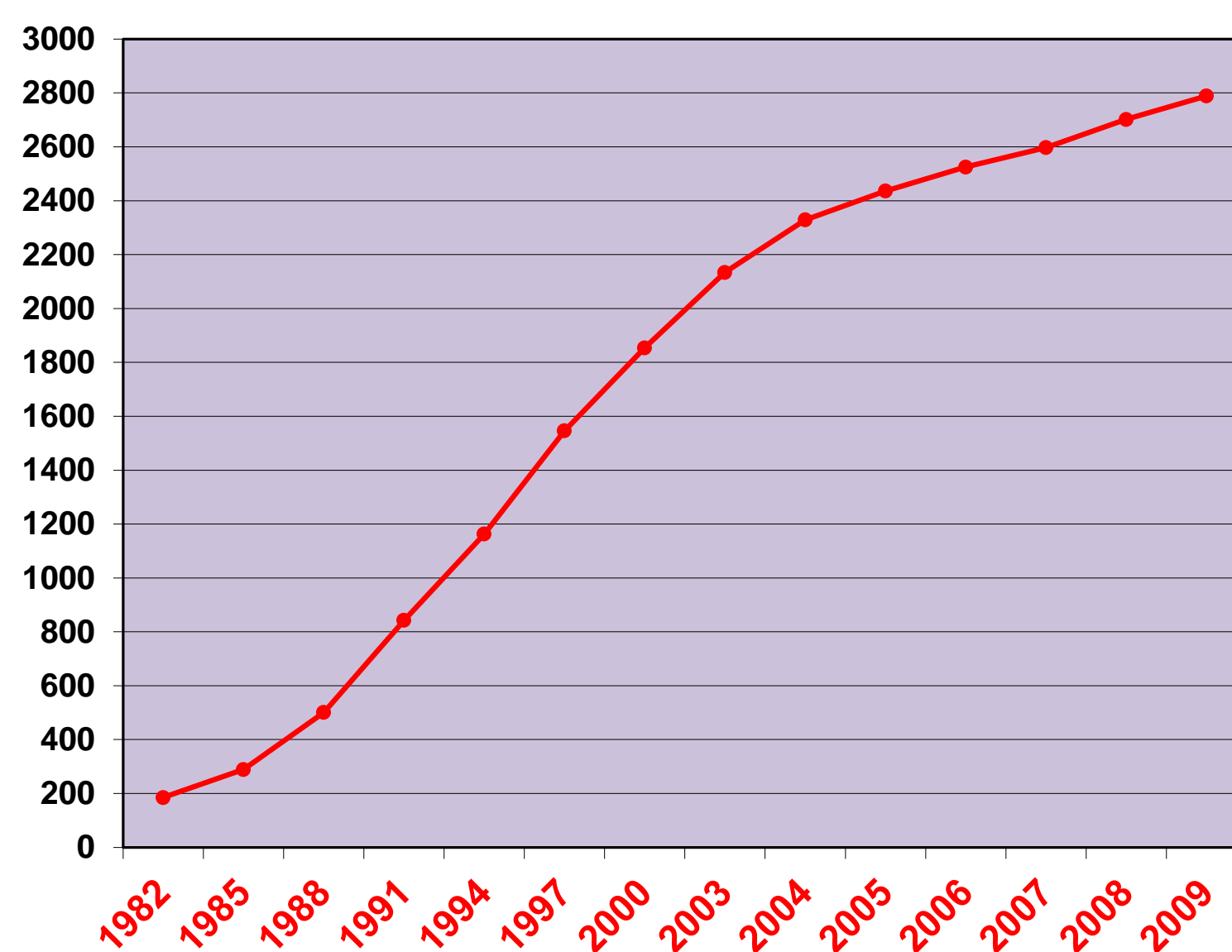


President and Founder; Prof. Amal El Beshlawy
Prof. of Pediatric Hematology , Cairo University



Why the idea came from our Cairo University Center ?

- Thalassemia Patients present the highest number in our center .
- The numbers are increasing continuously.
- Our studies showed a very high carrier rate (5.5 > 9%) in Egypt.
- 1000/1.5 million live birth/yr are born with thalassemia .
- Lack of population, physicians and government awareness to the disease.
- Lack of sufficient resources to support the medication , blood and needs of the patients.
- Motivation and support of TIF on their visit to our center in 1990.



So We Decided to Establish ETA

Goals:

- To improve the quality of life and survival of our patients by
 - Medical support by improving the availability of blood and all essential medications.
 - Social support to their education and employment.
 - Financial support in social events and religious occasions
- Improvement of the population awareness to the disease .
- Increase the physician awareness to the diagnosis, management and prevention of thalassemia.
- Support the medical and research activities in the domain of thalassemia



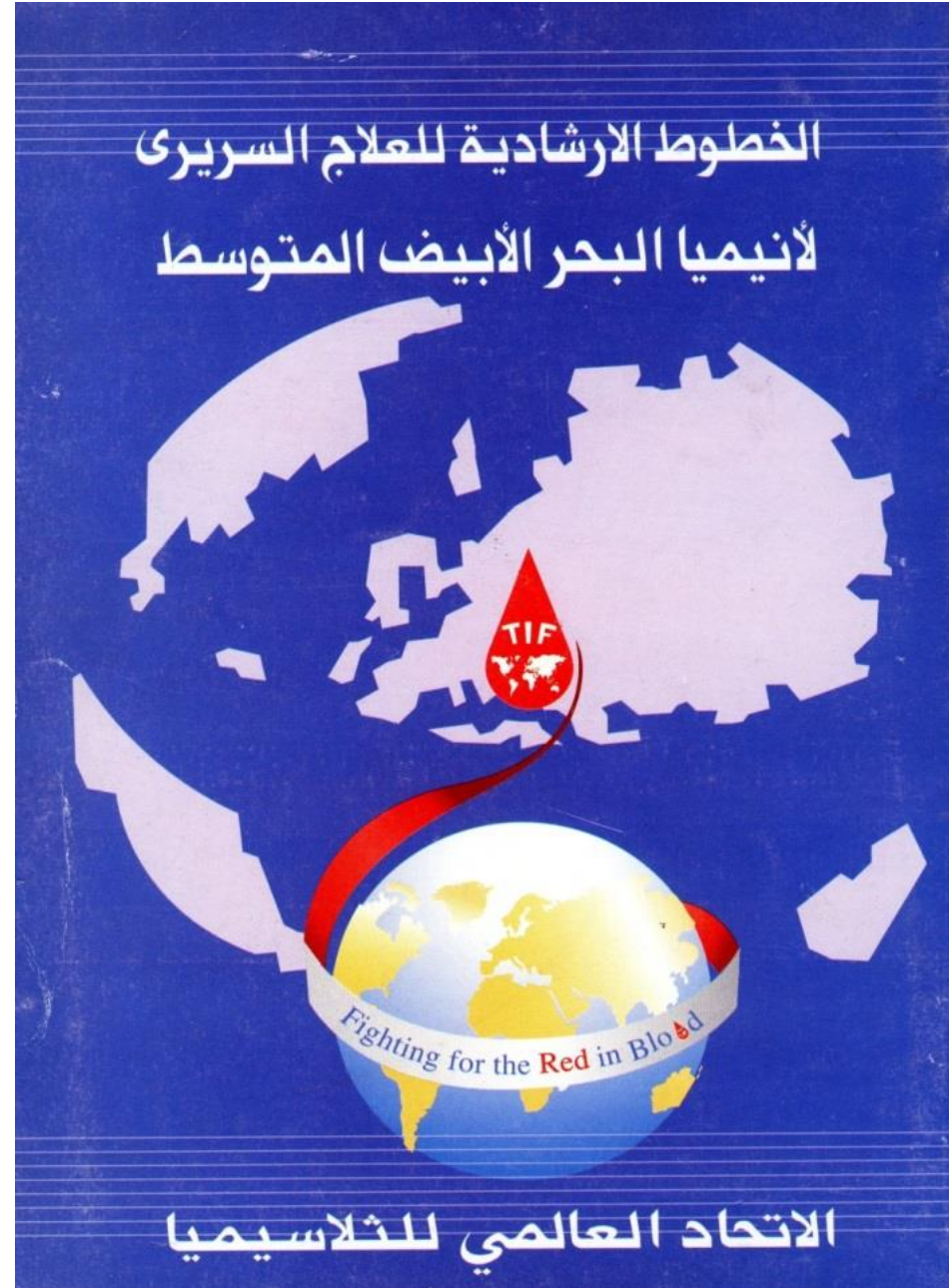
Achievements

- Supporting the availability of medications and motivation for blood donation. motivate the government to support their treatment including oral iron chelators and all interventional procedures including Bone Marrow Transplantation .
- Regular meetings annually in the international thalassemia day since 1999 for all the physicians and patients in special session to meet the International and national expertise in the domain of their disease.
- Printing and distributing booklets to the patients and young physicians on thalassemia.
- Supported the establishment of thalassemia centers in different governorates of Egypt



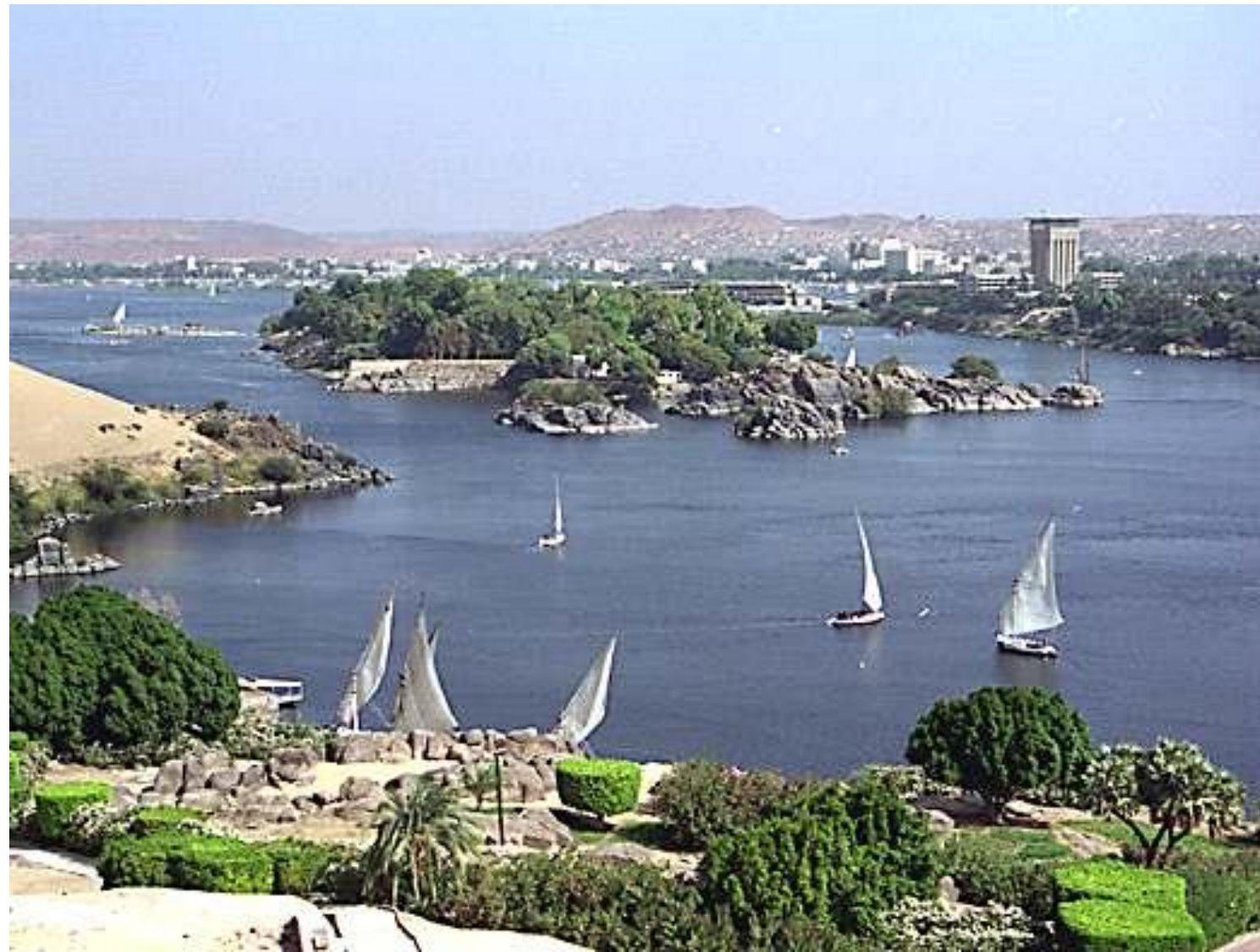
Achievements in The Domain of Education and Employment

- We initiate and support the issue of the ministerial decree No 60 in 1999 for the employment of patients graduated or not in the governmental or nongovernmental jobs (by 5%) (50 certificate issued / yr from ETA).
- We initiate and support the issue of the ministerial decree for the right of the patient to go to the school or the University convenient to them beside their residence disregarding the graduation level.
- Financial support to the patient to complete their education



Achievements for Prevention of Thalassaemia

- Establishment of Prenatal diagnosis center in the pediatric hospital of Cairo University working with the genetic counseling center.
- Designing and implementing a project for screening of thalassemia for students in Cairo University.
- Establishment of stem Cell transplantation center for Thalassemia in pediatric hospital of Cairo University.



Old

Renovated

Mrs Manal Safwat Board Member

Renovation of Transfusion center by CIB Bank Donor



Struggles

- For Screening of thalassemia on a national basis.
- To implement a compulsory law for premarital screening (Not yet in Egypt).
- Minimize the number of thalassemics born yearly in Egypt..

Plan of Action (Present and Future)

- Continuous meetings and negotiation with the minister of Public Health Supported by the mass media and push of TIF and WHO to realize our future goals.
- Patients Against Thalassaemia (PAT) to increase awareness and promote blood donation through the face book and special messages the idea supported by A board member .



Ministerial Decree No. 60 in 20/3/1999.

- Employment of Graduated and non-graduated after rehabilitation thalassaemics and SCD patients in Governmental and Private Jobs by 5% of the total needed for the Job.



Financial Resources

- Personal through the activities of the board members , physicians, patients and parents
- Nongovernmental organizations.
- Through advertising in the national banks in the religious events (Ramadan for Muslims).
- Egyptian and International banks through the activities and contact of the patients and parents in ETA board.
- The financial balance of the society is 1000,000 EP/year (200,000 USD) mostly for medications, filters others.



ETA Board Members

Prof / Amal El-Beshlawy	President
Prof / Normin Kaddah	Vice President
Mr / Selim Negm	Secretary of ETA (Parent)
Consultant Aly Makhloof	Treasurer
Prof / Mona El Tagui	Drug Affair
Prof / Mona Hamdy	Pharmacy Director
Prof / Elham Yossry	
Prof / Lamis Ragab	
Prof / Somia El Gowhary	
Consultant Magdi El Ekiaby	Transfusion Affair
Consultant Naglaa Omar	Pharmacy Affair
Consultant Khaled Abd El Azim	
Mr Kromer Beshara	Parent
Mrs Manal Safwat	Patient
Mrs Manal Zaatar	Parent



www.thalass-eg.org