HAPPY LIFE FOR ALL

I Am Well Transfused

and well Chelated

I am Enjoying Childhood Life

E - T - A -

With the Complement of

The Egyptian Thalassemia Association (ETA)

Especially for those whom

I love the most

My dearest thalassaemia patients in Egypt and all over the world, I would like to dedicate this book to you, a hand-out that explains in a simple way what is thalassaemia, how to treat it; and how to prevent it.

The many years that I have spent with you so closely, living your ups and downs; made me only certain that you deserve nothing less than happiness and accomplishment of your goals in life. You have taught me that the key to reach out to your aspirations is Hope and Commitment to therapy.

Sincerely, I have learned that these are your tools for the life you are looking for; whatever your choice is, being a doctor, an engineer, an artist, a mother or a husband.

May you blossom in a prosperous future!

By you, and with you always.

Prof. Amal EL Beshlawy
Professor of Haematology – Cairo University
President of the Egyptian Thalassaemia Association ETA

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This Book is Designed and Prepared by

Prof. Amal EL Beshlawy

Professor of Pediatric Haematology – Cairo University
President of the Egyptian Thalassaemia Association ETA

&

Dr. Hisham Sedky Abdou

The Egyptian Thalassemia Association (ETA)

Introduction

Thalassemia is a common problem in Egypt. Carrier rate varies between 6 to 10%. It was estimated that more than 1000/1.5 million live birth /year are born with thalassemia in Egypt.

The number of patients in pediatric Hematology clinic of Cairo University hospitals the biggest hematology clinic in Egypt (Abou- El - Rish) is more than 2500.The Egyptian Thalassemia Association (ETA) was established in 1990 motivated and supported by The Thalassemia International Federation (TIF) in the Pediatric Hospital of Cairo University.

The members are the medical staff of our center together with doctors and professor from other Egyptian centers - patients and their parents .

Founder and president of ETA is Professor ***Amal El-Beshlawy,*** ***Prof. of pediatric Hematology in Cairo-University***.

Honorary president Her Excellency

Mrs Suzan Mubarak

First Lady of Egypt

Goals of ETA

- To improve quality of life and survival to thalassemia patients and support of their families in Egypt.
- To increase the population awareness and doctors awareness to thalassemia in Egypt through lectures, scientific meetings and conferences.
- Help in creating thalassemia centers in Cairo and other governerates in Egypt.
- Social and medical support to the patients and their families.
- Support the medical and research activities in the domain of thalassemia

Resources :

Mainly personal and non governemental organizations donations.

Achievements and activities

- Medical support to the new and follow up patients with financial cost of 200,000 US Dollars/ year.
- Social and financial support to the patients and parents in the religious and social events.
- Delivery of certificates to support the education and employment of our patients (50 / years).
- Held the annual international thalassemia conferences in the 8th of May (International Thalassemia day) which are attended by more than 900 Physicians from Egypt and the Arab countries also attended by our patients in a special session with the international experts.
- Support the sending of our thalassemia patients for bone marrow transplantation in Italy (Dr. Lucarelli center). According to agreement which support the BMT for 50 patients from Egypt free of charge.
- Initiating and supporting the training programs on thalassemia for Egyptian and Arab countries physicians (Iraq and Jordan...etc).
- Initiation and establishment of the Bone Marrow Transplantation Center in the Pediatric Hospital of Cairo University for cure

Special achievements

- Motivate and support the issue of the Ministerial Decree in 1998 for the employment and education of the patients.

Future Plans

- Activates Bone Marrow Transplantation for our thalassemia patients who has a donor.
- Prevention of Thalassemia by premarital screening and prenatal diagnosis.
- Increasing the population awareness to thalassemia and its prevention.
- Promoting patients compliance to chelation therapy by the availability of the oral easy taken drugs.

Our Mission

- To prevent the increasing No. of new cases of thalassemia in Egypt.
- To secure the cure and good quality of life for our patients.

The Egyptian Thalassemia Association Board of Directors

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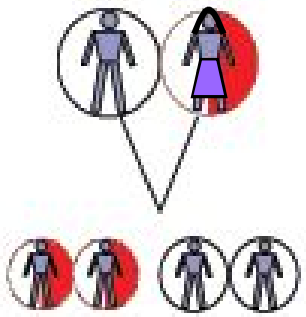
Mrs Gihan Farouk
Mr EhabAbd Allah

Contact information:
Egyptian Thalassemia Association(E.T.A.):
6 El Marees Street El Mounira in front of Abou El Rich Pediatric Hospital
Cairo university Tel: 5314533 - 0123124674
WebSite of ETA :- www.thalass-eg.com
President : Professor Amal El-Beshlawy
Email: amalelbeshlawy@yahoo.com
Mobile: 2012-312-4674

Thalassaemia

Mediterranean Anemia



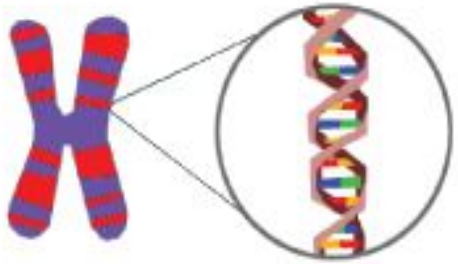
It is a hereditary disease

That causes chronic anemia

and continuous destruction of red blood cells

Is it an infecting disease ?

NO



What are its causes?

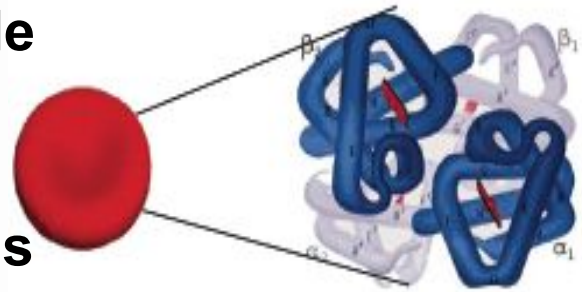
It is transmitted by the genes

that form hemoglobin inside

the red blood cells

leading to a shortage of this

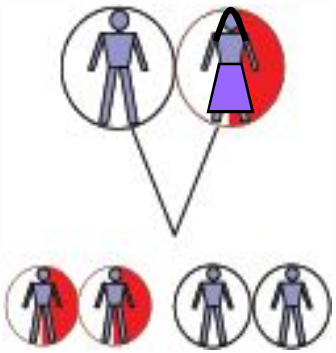
important substance



How Thalassemia Is inherited?

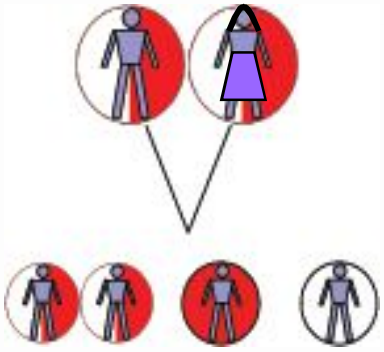
By the genes which transfers hereditary characters from a generation to a generation. The genes could be normal or carry the characters of a disease as thalassemia and it is transferred from the parents to their children.

Normal Parent Carrier Parent



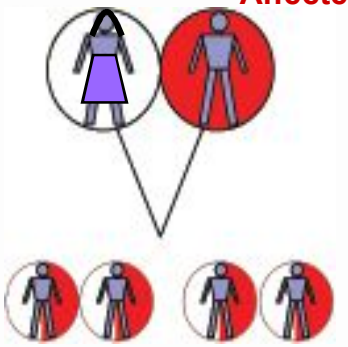
50% Carrier 50% Normal

Both Parents are carriers



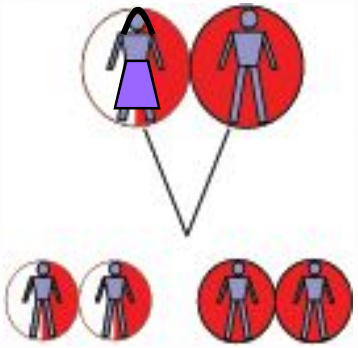
50% Carrier 25% Affected 25% Normal

Normal Parent Affected Parent



100% Carrier

Carrier Parent Affected Parent

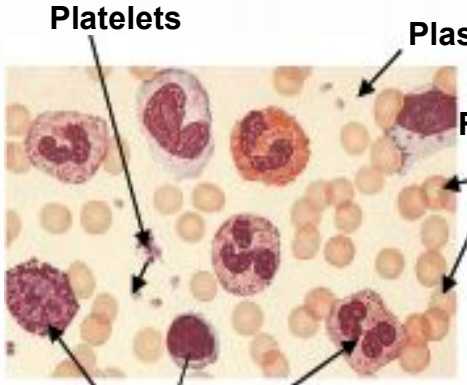


50% Carrier 50% Affected

What are the contents of blood ?

Plasma

It is the yellow fluid that transfers the important substances in the body as minerals, hormones, salts ……etc.

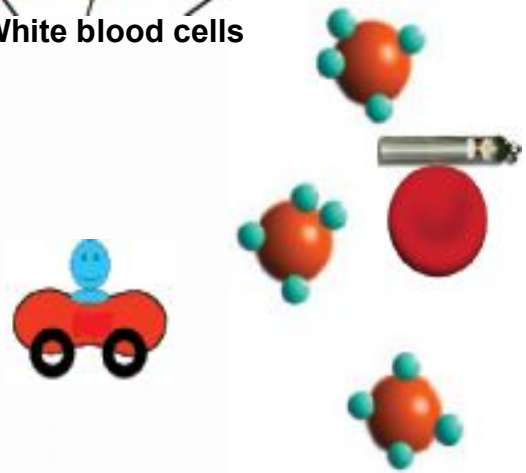


White blood cells attacks the microbes

Cells and platelets swim inside the plasma as

White blood cells

which defend the body against microbes.



Red blood cells

which contain Hemoglobin and is responsible for the carrying the oxygen from the lungs to other cells in the body to generate energy for the important organs.

Blood Platelets

They are very important to stop bleeding when it happens...

There are grades of Thalassemia?

YES

Thalassemia minor

Patients are in good health they are normal people but they are carries of the character.

Thalassemia major

These are persons affected by the disease and the symptoms are severs and are in need for continuous treatment, symptoms and signs usually appear in the first year of life.

Thalassemia Intermedia

These are people affected by the disease but the symptoms are moderate. The signs and symptoms appear later in life and they need treatment and constant medical care.

What are the symptoms and signs that appear on a child affected by thalassemia?

In case of thalassemia major it starts with anemia and facial pallor that increases gradually during the first year of life

The patient does not respond to normal anemia treatment and it is accompanied later with abdominal distention due to enlargement of the liver and spleen and in some cases there is facial changes with frequent affection with flue and diarrhea.

What is the treatment of thalassemia?

Thalassemia minor: the patient dose not need treatment but he must put it in consideration when he gets married.

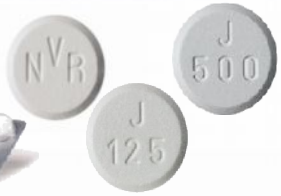
Thalassemia major: ordinary classic treatment Red blood cells transfusion every 3 to 4 weeks to maintain suitable hemoglobin levels for growth and living a normal life.

Taking the medication that helps the body to get rid of the iron that accumulates in the body from the repeated blood transfusion and the increased iron absorption

What are these Medications ?

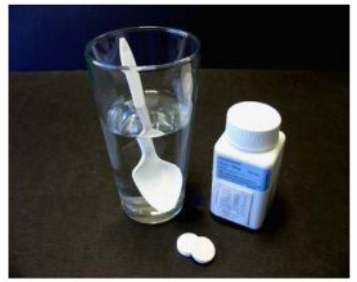
- EXJADE (Tablets)
- L1 (Tablets) 500mg
- Desferal (Injection)

EXJADE (Tablets)

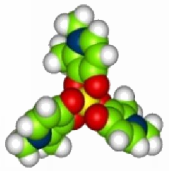


EXJADE which is taken by mouth once daily and its action lasts for 24 hours

- It dissolves in water or orange juice using a glass cup and a plastic spoon
- It is available in three concentrations 125 mg, 250mg and 500 mg tablets
- It could be given to a child starting from the age of two years
- It should be given half an hour before breakfast daily
- it is used now in most countries.

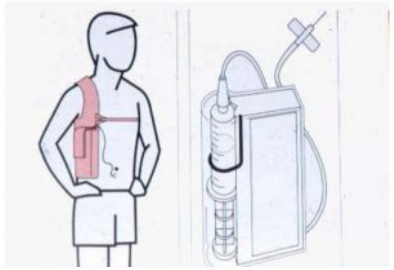


Deferiprone L1 (Tablets) 500mg



The deferiprone - iron complex

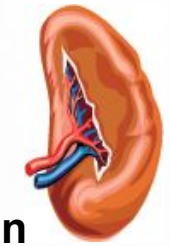
It should be taken after the age of 4 years three times per day by mouth. Monitoring the liver function and the white blood cells regularly as complications rarely occur



Desferal (Injection)

The oldest and most famous drug to remove iron from the body it is given by an electronic pump that inject the drug along 8 -12 hours via a needle under the skin in the arm, the thigh or the belly of the patient 5 to7 days a week. It is effective but annoying to some patients

Surgical removal of the spleen for patients not regularly maintained on an appropriate Hb level



Giving the child the important vaccines **before** the operation (as pneumococcal, HIB and menengococcal), penicillin monthly intramuscular or orally daily after the operation

Taking the suitable **vitamins** as folic acid and vitamin D according to the physician instructions

Radical treatment.

Bone marrow trans-plantation from a suitable compatible brother or sister.

Bone marrow donation does not affect the normal brother or sister health.

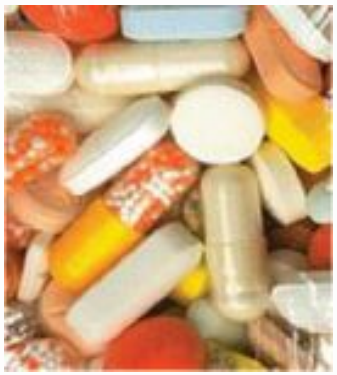
Only 30% of the brothers and sisters of the thalassemia patients have compatible tissues for donation

Treatment by genetic engineering.

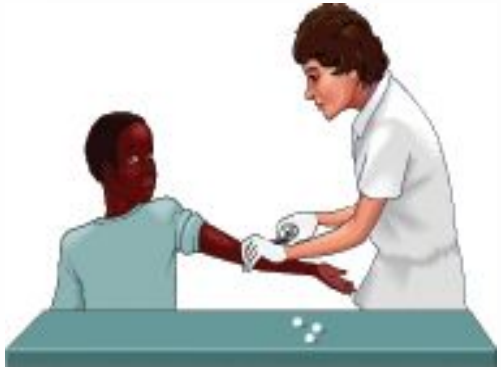
is still under research and development

Thalassemia Intermedia

Treatment is according to the condition of the patient they may need



Some vitamins

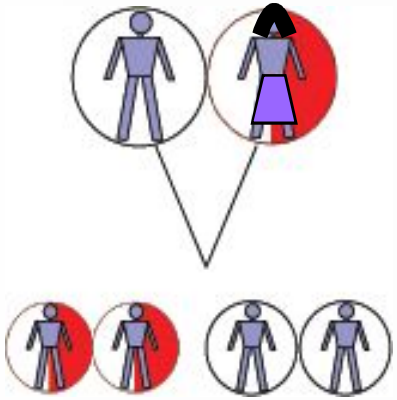


And medical supervision only

Or may need blood transfusion over a long periods of time.

Can we protect our future generations from Thalassemia ?

Yes by doing premarital test to know if we are carries or not and carriers should not marry carriers or thalassemia patients.



This is done by a simple blood test called **Hb-electrophoresis** present in most of the thalassemia centers, in the university hospitals, the ministry of health hospitals or the ETA.

Or by examining the faetal cells in the early weeks of pregnancy to know if the faetus is a carrier or affected by the disease.

I am a Thalassemia patient, what is my future?

The affected patient with thalassemia is a normal person that can live a normal life if he follows the treatment instructions and blood transfusions according to the specialist's recommendations.

There are patient that graduated and became physicians, lawyers, engineers, and others who work in different specialties in our community.

With the Complement of
The Egyptian Thalassemia Association (ETA)