

All about Thalassaemia

by Dr. Androulla Eleftheriou



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Thalassaemia Cartoon for Young Children

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By Dr Androulla Eleftheriou

Thalassaemia International Federation
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ALL ABOUT THALASSAEMIA

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Mrs. Andrea Ioannou, Learning Support Co-ordinator of The Junior School Nicosia, for undertaking the pilot study

The administration, staff and students of The Junior School Nicosia, for their support and comments

Dedication

We dedicate this book to all the children in the world born with thalassaemia – to their indomitable will to survive, their inspiring fight against the disease, their beautiful dreams of a good life and a bright future – with our heartfelt and sincere wishes for a long, healthy, and above all happy life.

Thalassaemia International Federation

Hello! I am Harry and I am your friend -
a tiny friend that lives inside you



Have you ever scraped your knee in the playground?



Did you see a bit of watery, red stuff on your skin?

That is called blood.

Everybody has blood, filled with tiny friends like me.



I belong to a huge family called the Red Cells.

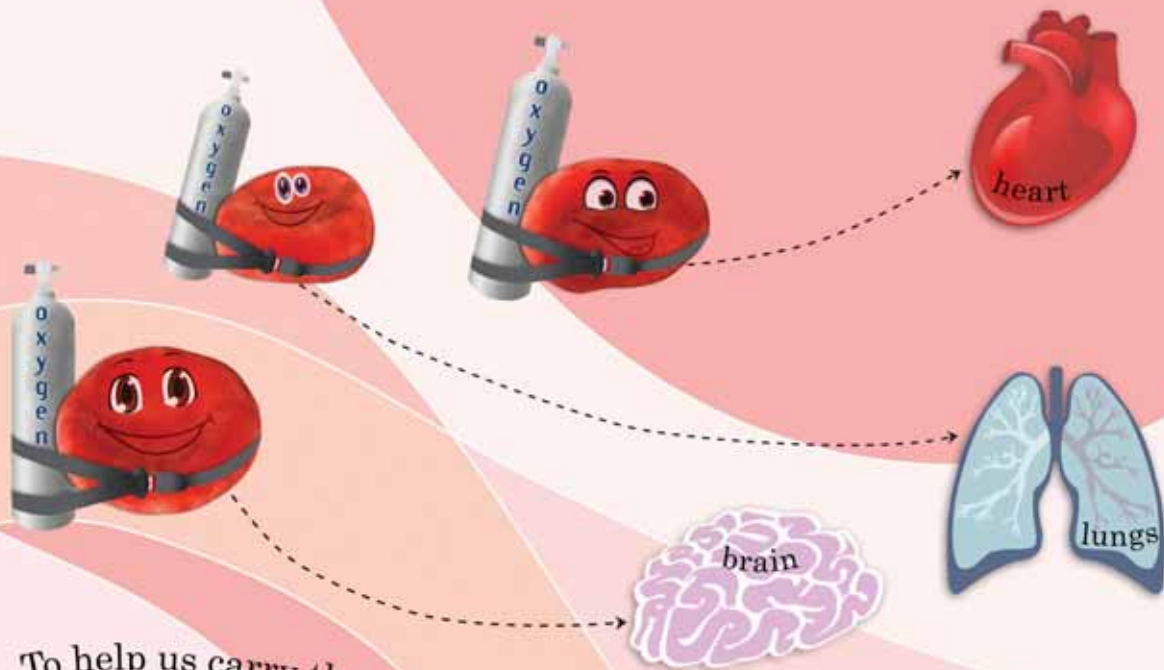


We are all red, and we look like small plates.

Our job is to carry oxygen around your body.
Oxygen comes from the air you breathe,
and it gives energy to each part of
your body - so that you can run,
laugh, jump and play.

xygen oxygen oxygen oxygen oxygen oxygen oxygen
xygen oxygen oxygen oxygen oxygen oxygen oxygen
xygen oxygen oxygen oxygen oxygen oxygen oxygen





To help us carry the oxygen to the different parts of your body, we each have our own little helper, called haemoglobin (hee-mo-glo-bin), and each one of us, the Red Cells, contains a lot of haemoglobin blocks that can carry oxygen.



Haemoglobin block



My family - the Red Cells - is not alone in blood!
Another three families of friends are floating around:
The White Cells family, the Platelets family
and the Plasma family. We all have different
jobs to do, and we also look different!
But we are all working together to keep
your body healthy and strong.

Red Cells



White Cells

Our friends, the White Cells,
are wibbly, wobbly and white.
They act like little soldiers, fighting
off germs to keep you healthy!



White Cells





Platelets

Our friends in the Platelet family look like tiny eggs. If you hurt yourself, they gather and stick together like building blocks to help stop you bleeding.

Platelets



Plasma

And our friend, the Plasma, is the yellow, watery stuff that all of us float in. It also carries many nutrients that your body uses to keep you healthy and strong.

plasma plasma plasma plasma plasma plasma plasma plasma plasma plasma plasma



Do you know where blood, and all of us in it, come from?
Well, all of us come out of a factory
right inside your bones!



But sometimes there is a problem at the
factory, and it can't make Red Cells with
the right helper - the haemoglobin - inside.





When this happens, my family, the Red Cells,
can't carry enough oxygen around your body.
Without its special nutrient, the oxygen, your
body feels tired, and you look weak and pale.
Doctors call this anaemia (a-nee-me-a),
or thalassaemia (tha-la-sea-me-a).



Lots of children around the world have thalassaemia.



If you have thalassaemia, my family, the Red Cells, are weak.
So, we need a bit of help from a doctor.
The best way the doctor can help us is to give us
some new, strong Red Cells. This is called a transfusion.



You can get transfusions at
the hospital, where there are
lots of people who know how to help you!



What happens is that your
doctor or nurse puts a tiny
needle in your arm.

This won't hurt much!



The needle is joined to a plastic
bag of lovely, new, strong,
Red Cells - your tiny friends
who will help you feel better.



At the hospital you will have the time to do some of your favourite things.

Some children like to read stories, or share jokes,
or watch television.

You will make
lots of new friends at the hospital too!





Going to the hospital might seem strange the first time.
But after your transfusion, you will have lots of new
Red Cells to help carry oxygen around your body.
Then, you will feel full of energy!





But... these new Red Cells don't stay long in your blood!

After a short while, they break up, and your body feels tired again. The doctor knows that, so after a few weeks, you will be asked to come

back to the hospital to have some more new Red Cells. This way, your body will feel healthy and strong again.

And this will happen about every month. You will have lots of energy to run, jump,

laugh and play with your friends again!





All of these new Red Cells are a great help.

But your body needs some extra help.

Do you remember Haemoglobin, our friend that helps us - the Red Cells - carry oxygen around your body?

Well, it does so because it has iron bound to it, a special stuff on which the oxygen sticks.



Haemoglobin block

After a few weeks, when the new Red Cells break up, this iron breaks off too, and this happens after every time you get a transfusion.





heart



liver

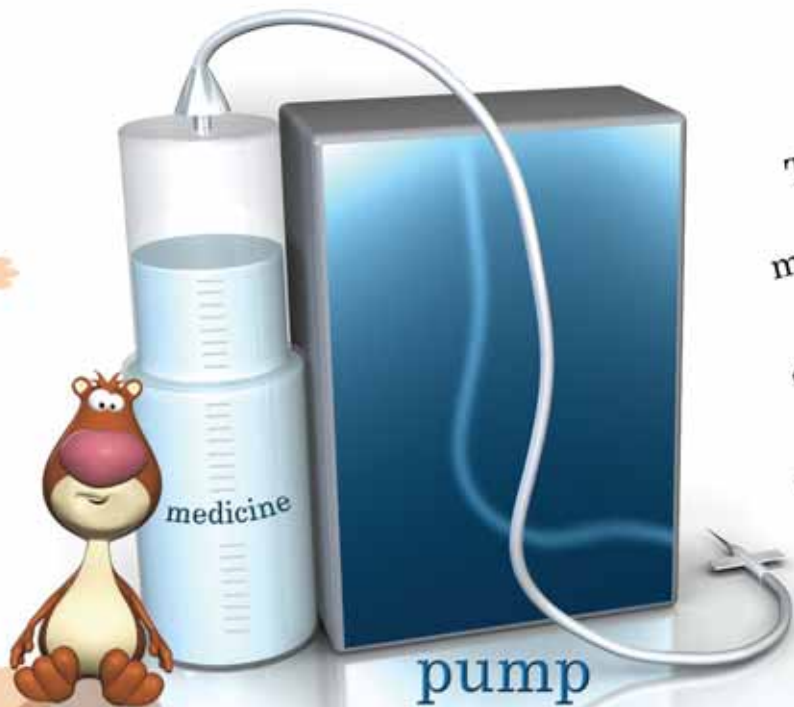
All that extra iron that comes out
when the Red Cells break up
finds a place inside your body to sit and stay.
That can make it difficult for your body to work properly.



Your skin then becomes darker, you feel weak
and don't grow properly. So, now you need
help to take the extra iron out of your body.



Your doctor knows about it, and he or she will give you some special medicine that picks up these pieces of extra iron, like a magnet, and carries the extra iron out of your body when you go to the toilet. This is called iron chelation.



There are different kinds of medicine that can take out the extra iron from your body.

To use one of these medicines,

you will need the help

of a needle and a pump!

And you will have this needle under your skin for many hours every

day or night. This is not always very comfortable. But once you get

used to it, you will feel better and better. You may wear your pump while

you sleep or wherever you are - in the playground, at school, at home

or at a friend's house. Like me, the pump is a good friend of yours!





The other medicines are pills
that can take iron out of your body.

You can swallow them like any
other tablet, with water or juice.





Whichever medicine your doctor gives you, your mum and dad will help you to take it properly until you grow up and learn to do it yourself! Your body absolutely needs the medicine to stay healthy. And don't forget, you are not alone! You have lots of love from your parents and family, lots of care from your doctors and nurses, and lots of help from many, many friends around you.





Now you know all about us, the Red Cells, our other friends in the blood, and about thalassaemia. You can share all this with other kids who also have thalassaemia like you, or who want to learn about it!



About the Publishers:

THALASSAEMIA INTERNATIONAL FEDERATION

Thalassaemia International Federation (TIF) is a non-profit, non-governmental, patient-driven organisation founded in 1986 with headquarters in Nicosia, Cyprus. TIF's mission is to secure equal access to quality health care for every patient with thalassaemia across the world. TIF has been working in official relations with the World Health Organisation (WHO) since 1996, and its educational programme includes a wide range of publications, workshops and conferences at local and international levels for patients, carers, health professionals, and the general public.

This book has been created with a lot of love for the children with thalassaemia who need to understand their condition, accept it, and draw strength from this knowledge to build a better future for themselves.

I liked this story
because when you are
sick your family and your
friends are there to help you.
The story was interesting.



I liked this book
because if you have
Thalassaemia you
can know what to do.



I liked this book
because I learnt
lots of new things
about my body.

I liked it so much
because it was
about our body and
now that I heard the
story I know everything
about our blood.



I loved the illustrations.
I learned that your
red cells are produced
in your bone marrow.
I think the book was
extremely interesting.



I like the story
because I learned
and the doctors
helped the children.



The best of all is
that it was not
fiction. It is easy
to read too.



Comments from the young students who read the book

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