

I'm not a bubble-wrap boy!

A true story of a boy with
immune thrombocytopenia (ITP)



Foreword

I would like to thank Novartis for making this storybook about immune thrombocytopenia (ITP). The book is endorsed in the United Kingdom by the ITP Support Association.

I'm not a bubble-wrap boy! can help children and adults alike to understand what it feels like to live with ITP and describes the different types of treatment by using simple descriptions and compelling storytelling.

The way in which ITP is explained may also help children living with ITP feel more at ease when talking to their healthcare team. It may help them in explaining their symptoms and discussing treatment options available to them. ITP can present in different ways; therefore, different parts of the story may resonate with different children and allow them to share how they feel.

If you have a child either directly affected by ITP or living with a family member or friend affected by the condition, hopefully this book will help them to understand it better and feel more open about discussing ITP when they need to.

I hope you enjoy reading *I'm not a bubble-wrap boy!*

Mervyn Morgan,
Chief Executive, ITP Support Association



Foreword

I'm not a bubble-wrap boy! captures the feelings of a child with ITP. Thankfully, most children with ITP recover or improve quickly enough that any ongoing restrictions to daily life are unnecessary.

Severe bleeding is rare in ITP but many children, families (and doctors!) worry that they could be that rare child. Therefore, knowing how to minimise risk, deal with bleeds and seek help is vital.

The initial period of watching and waiting for recovery is frustrating and some initial changes to lifestyle will be necessary. However, in recent years, there has been real progress in the area of ITP and newer treatments have been developed for those children who do not improve in the first few months.

These newer treatments can boost the platelet levels offering the potential that any ongoing restrictions may be reduced or removed altogether.

I very much welcome this book which will hopefully offer children, families and their friends a way of better understanding ITP and the reassurance to know they are not alone in their journey with it.

Dr John Grainger,

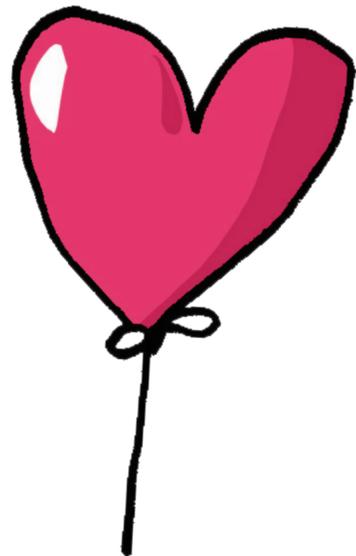
Consultant Paediatric Haematologist at Royal Manchester Children's Hospital, Chair of British Society for Haematology Paediatric Haematology Committee, National Lead for Paediatric ITP, and Medical Advisor for the ITP Support Association

Yesterday was my 7th birthday.

Dad said he'd give me a very special gift when he got home from work. When I heard his car outside our house, I rushed and waited by the door.

When he came in, I was so excited!

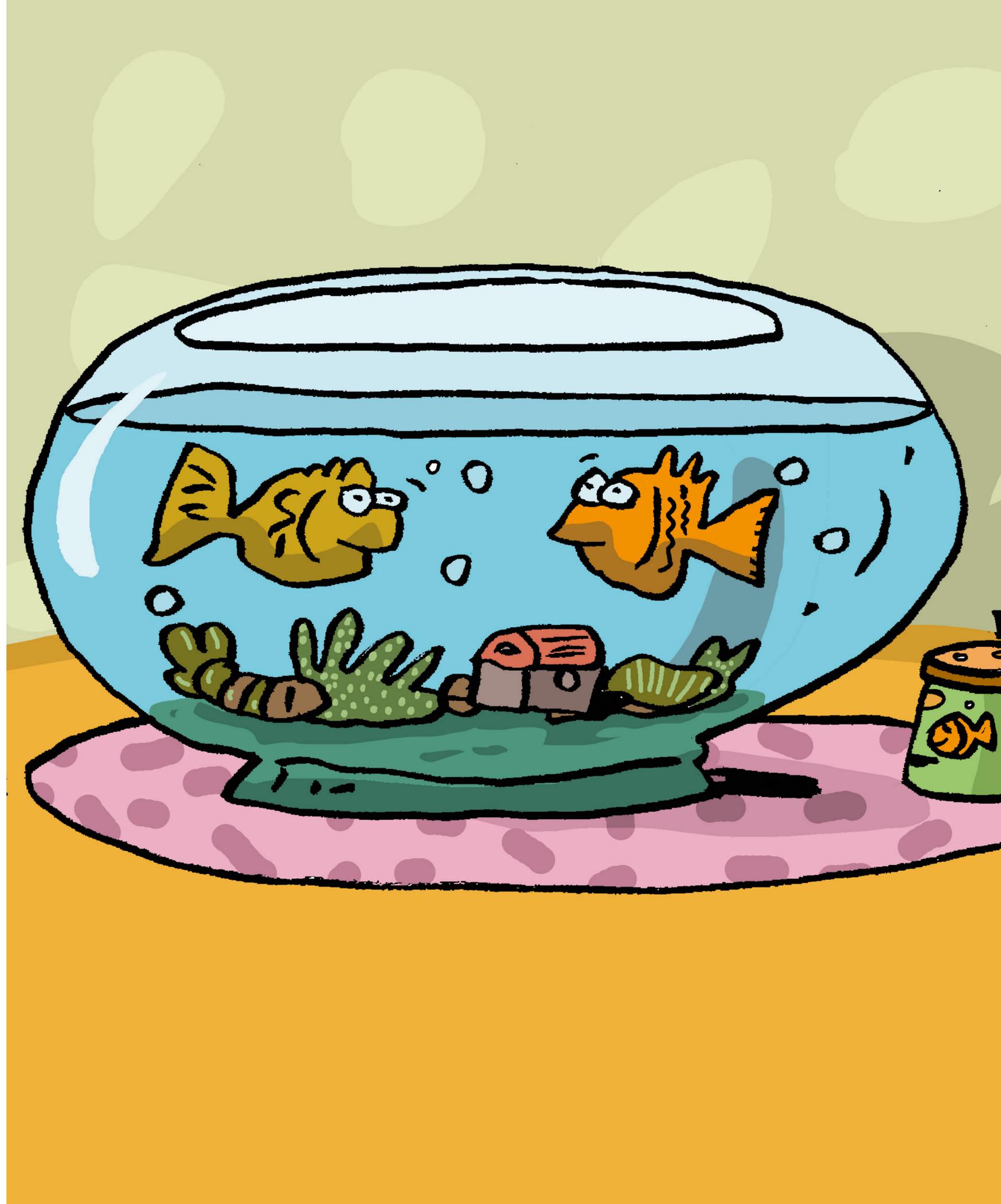
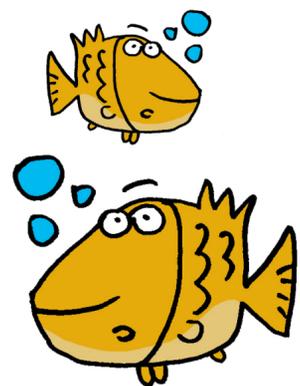
He was carrying a large gift-wrapped box, which he carefully gave to me.



“Don’t shake the box...”

...just open it carefully” said Dad.
I lifted the lid off the box gently.

Inside I saw a round glass bowl wrapped
in bubble wrap, and in it were two goldfish
swimming in water.



Dad helped me take the bowl...

...out of the box, and together we placed it on a shelf next to my bed.

He said that we must be careful with it, just like we're careful not to hurt ourselves.

Even a slight bang could cause the glass to crack, and the water would leak and flow out of the bowl, making quite a mess.

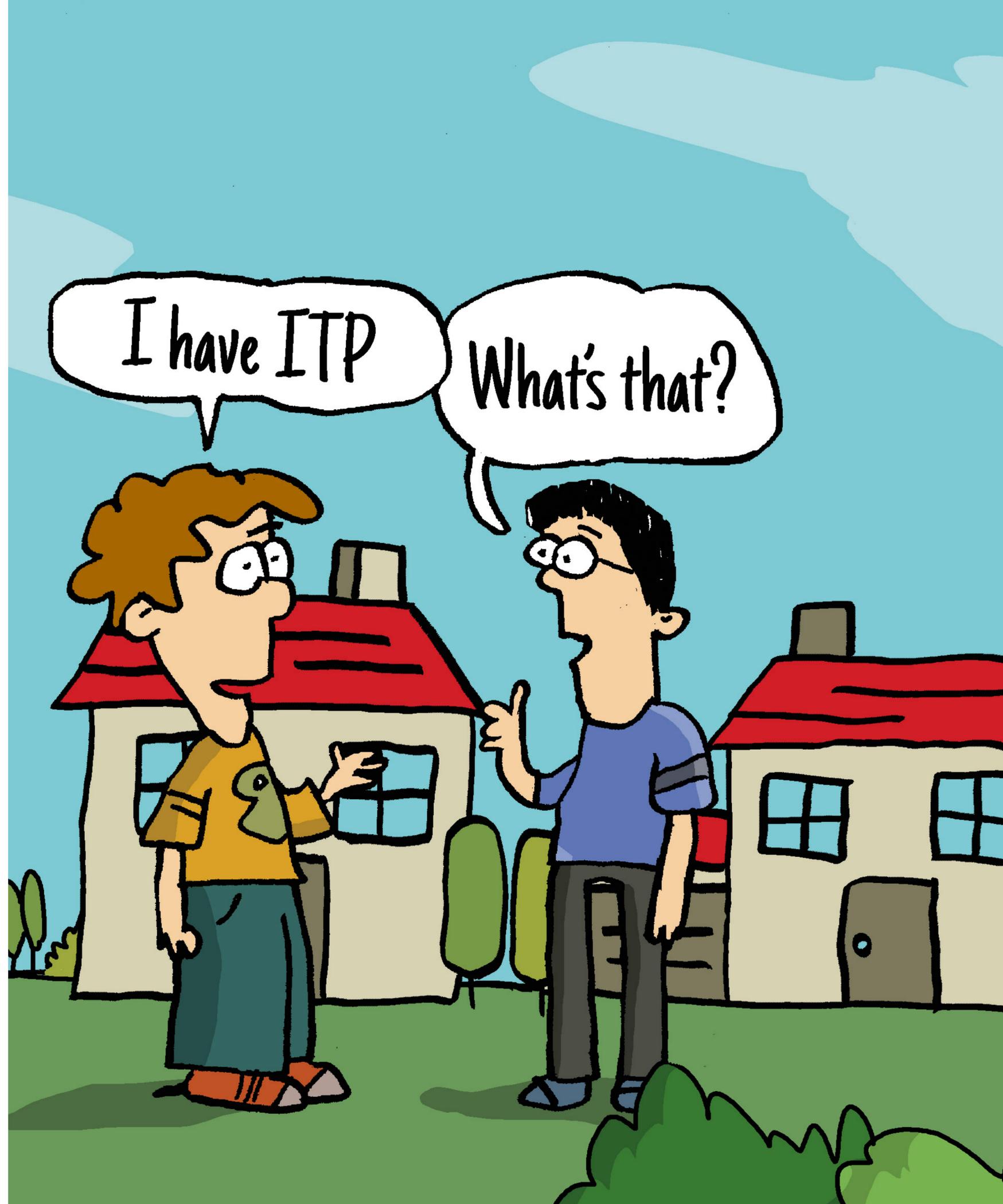


I laughed and reminded my dad,

“This can’t happen to our bodies!”

You see, even though our body has lots of fluids in it, practically like a fishbowl, if we happen to cut ourselves, our body knows how to mend the cut.

How do I know? Because I have a disease called immune thrombocytopenia, also known as ITP, it’s a kind of problem with my blood.

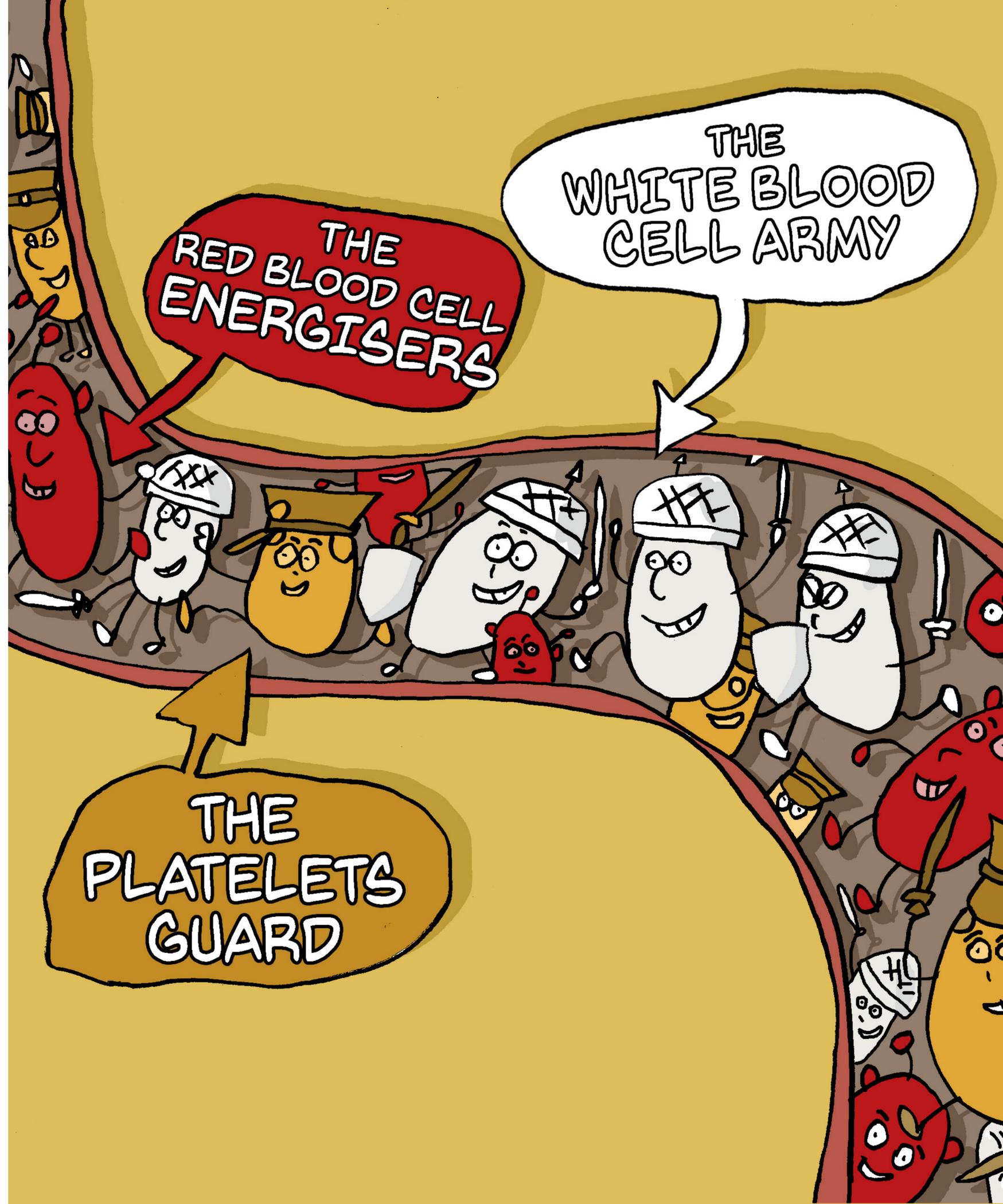
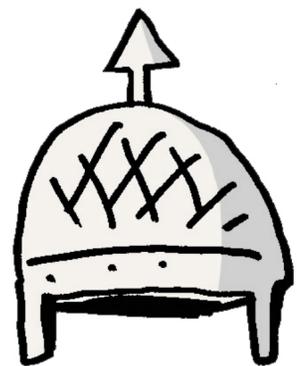


The doctor explained it all to me.

She told me that our bodies have lots of veins and arteries that carry blood.

The blood carries water, food, oxygen, infection fighters and blood clotters to all parts of the body.

In the blood there are lots of tiny bodies called 'cells' that swim there, like fish in a river, and each kind of cell has its own job.

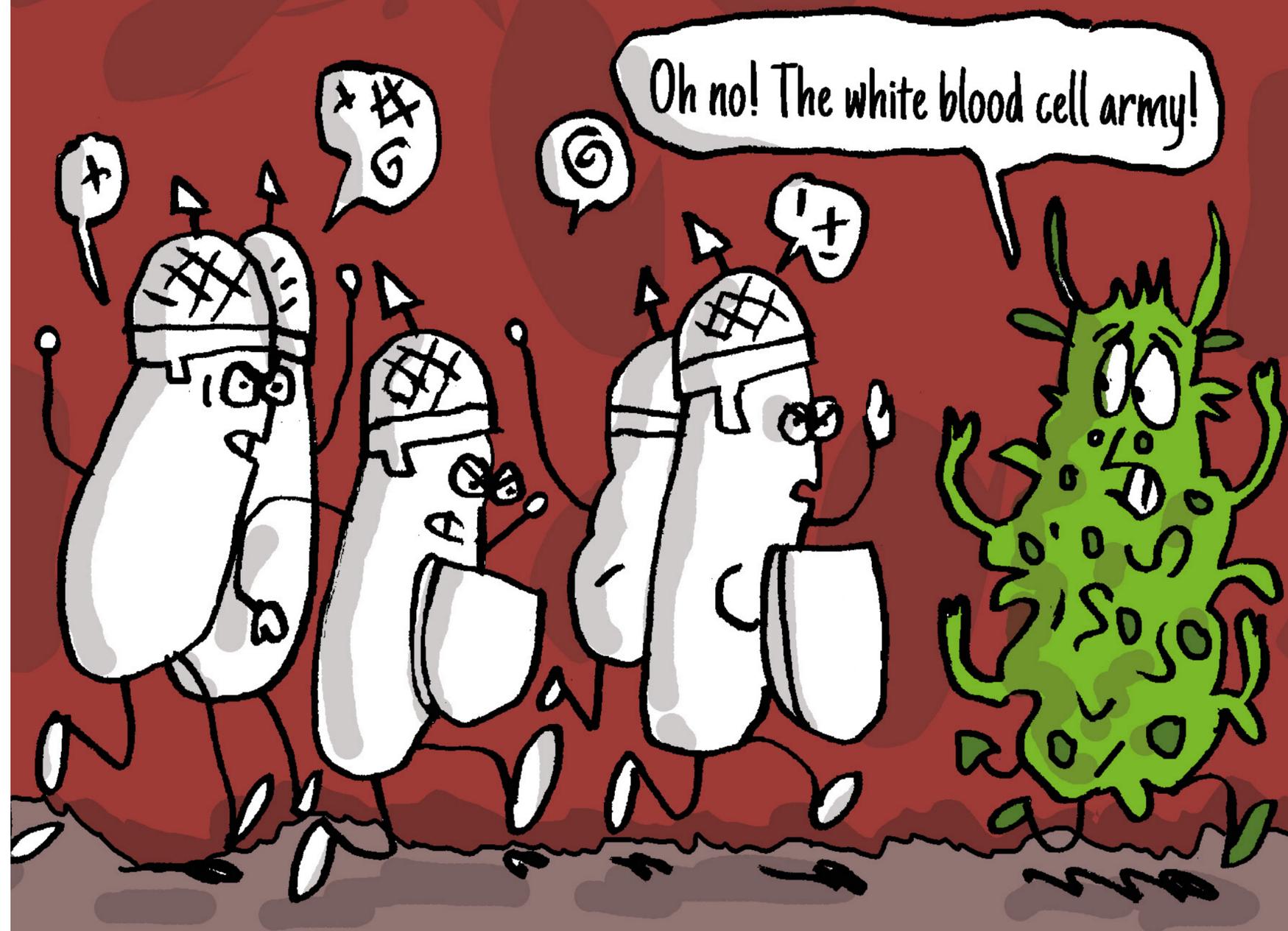
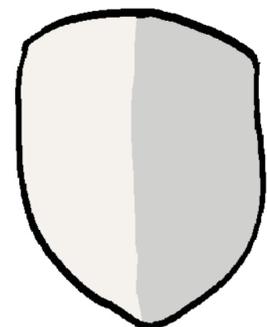


The first kind of tiny bodies...

...are the red blood cells, which bring oxygen and food to all other body cells.

The second kind is the 'army' of white blood cells, whose job is to fight viruses, bacteria and other harmful thingies that invade our bodies.

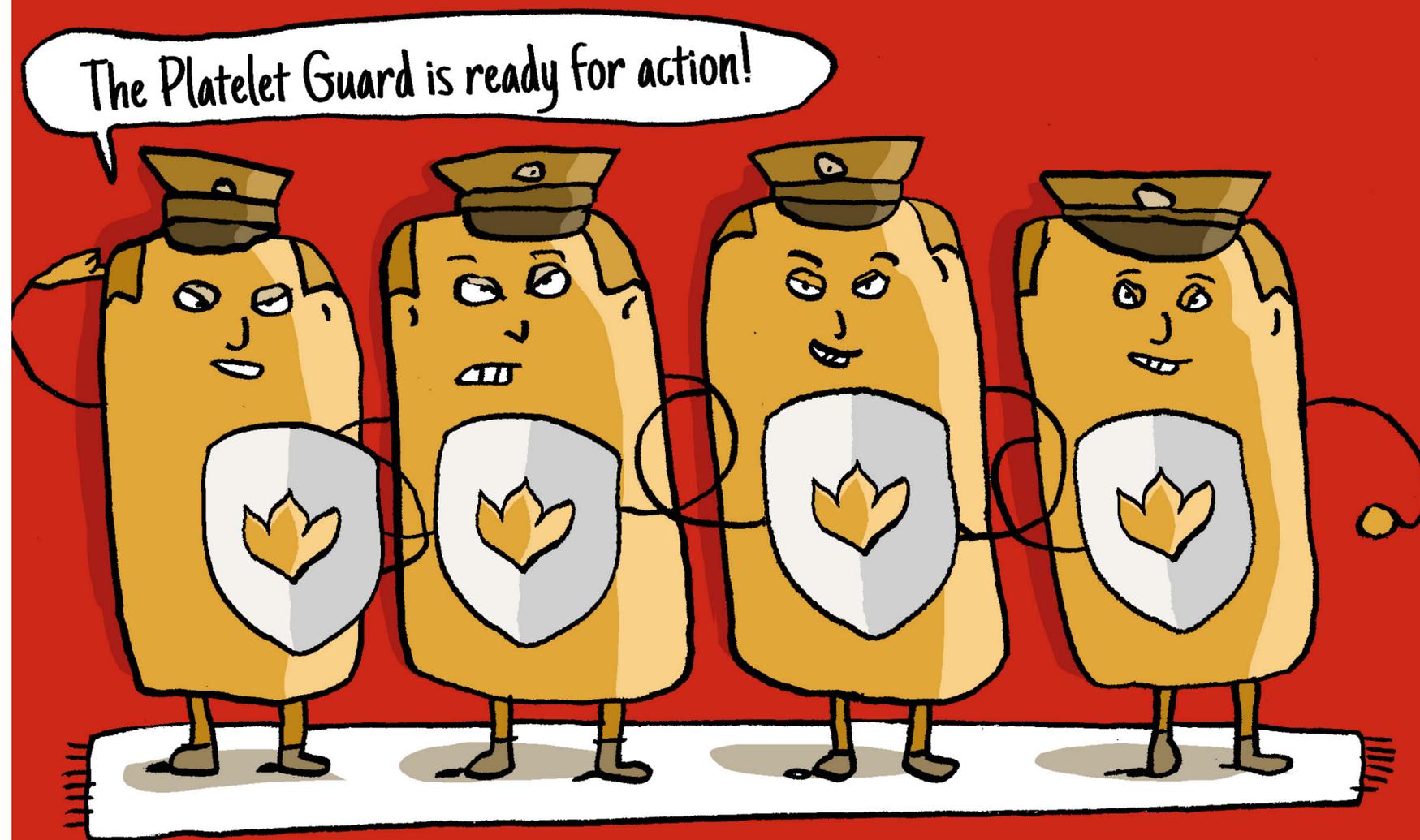
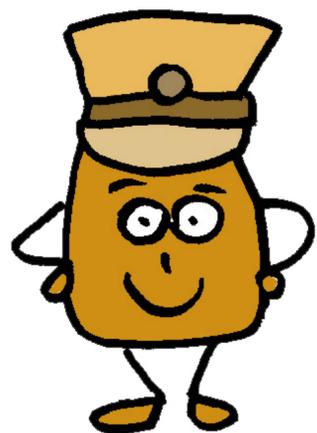
In science, the white blood cells are part of what's called our 'immune system'.



The third kind is The Platelets Guard'.

They are lots and lots of tiny bits, which, as soon as they identify a hole or cut in a blood vessel, they stick to one another and create a barrier, called a 'blood clot', which prevents the blood from leaking out.

"When we say that the blood has clotted", said the doctor, "that means the hard-working platelets have done their job."

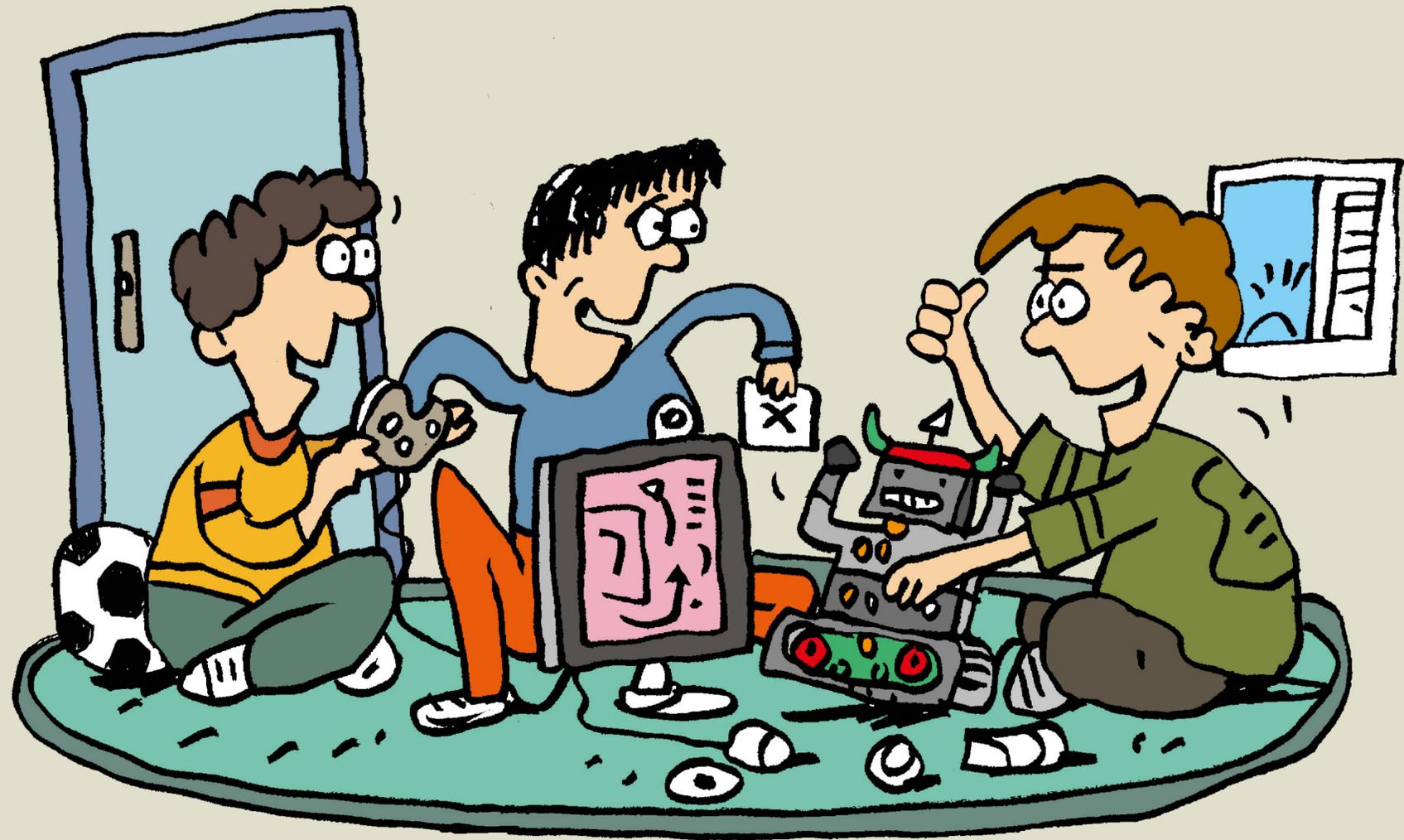
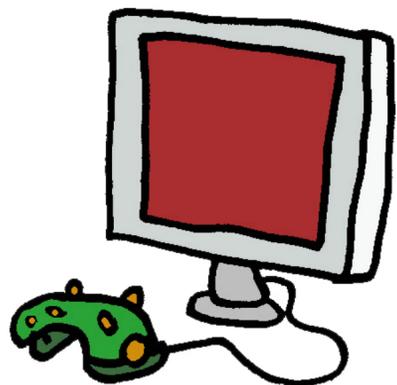


Platelets have a super important job.

Thanks to them we can play, jump, dance, swim, do sports and take part in all sorts of activities without worrying.

Even if we hurt ourselves and bleed, the platelets will immediately spring into action and make sure the bleeding stops.

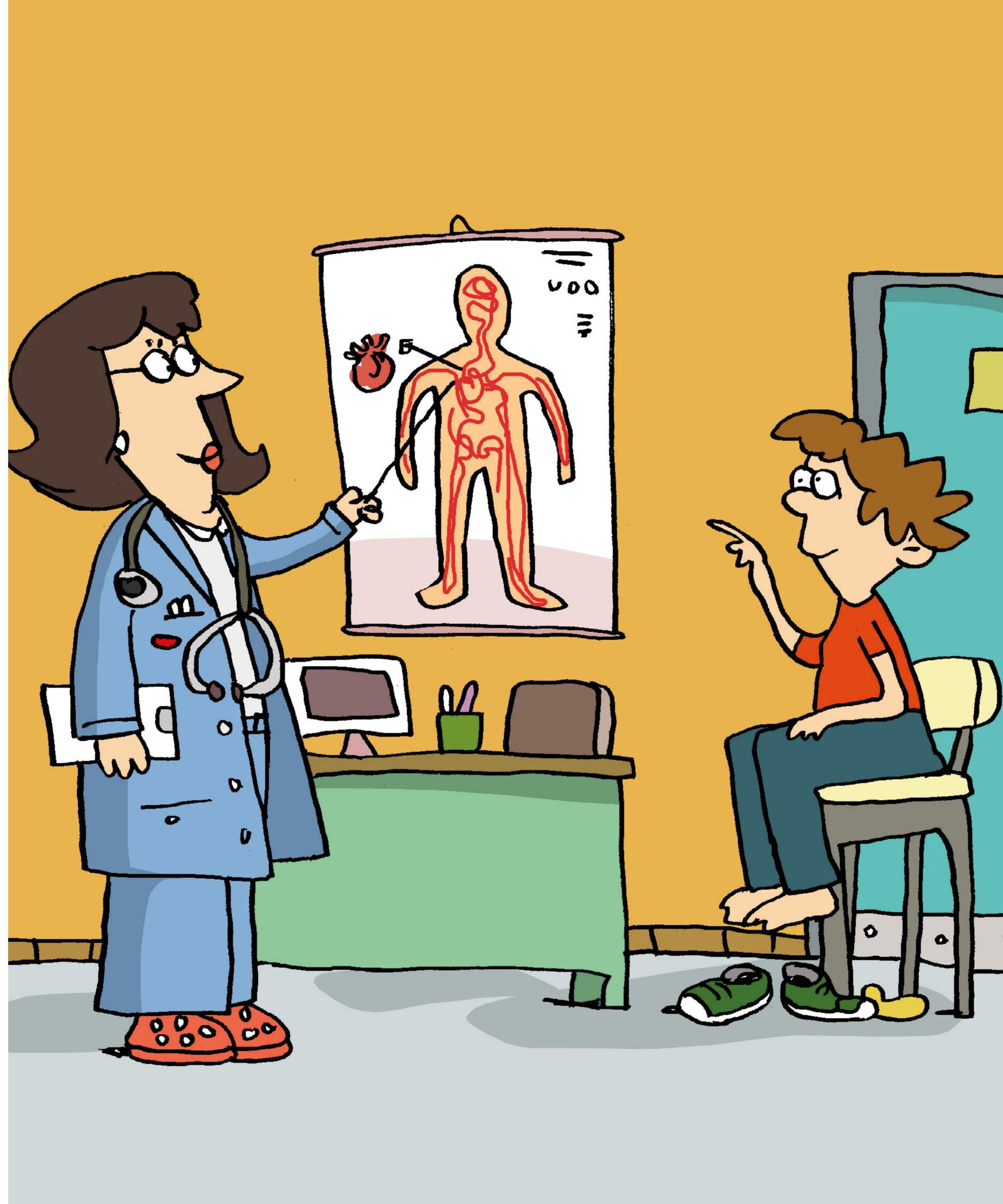
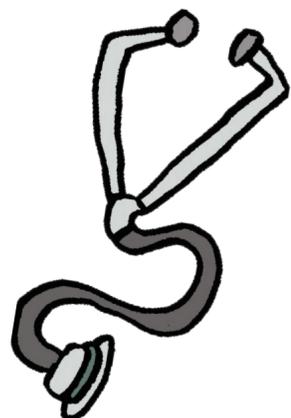
However, in my body, things work a bit differently.



The doctor explained to me.

When a child has ITP, like I do, it means there aren't enough platelets in their blood. It's much more difficult for the 'guards' to plug up holes or cuts in the blood vessels. This is why I sometimes get little red spots on my skin, black and blue bruises, or sometimes a nose bleed.

"This happens," she explained, "when you get a cut somewhere inside your body or on your skin. Since you don't have enough platelets, they have a hard time to stop the bleeding."



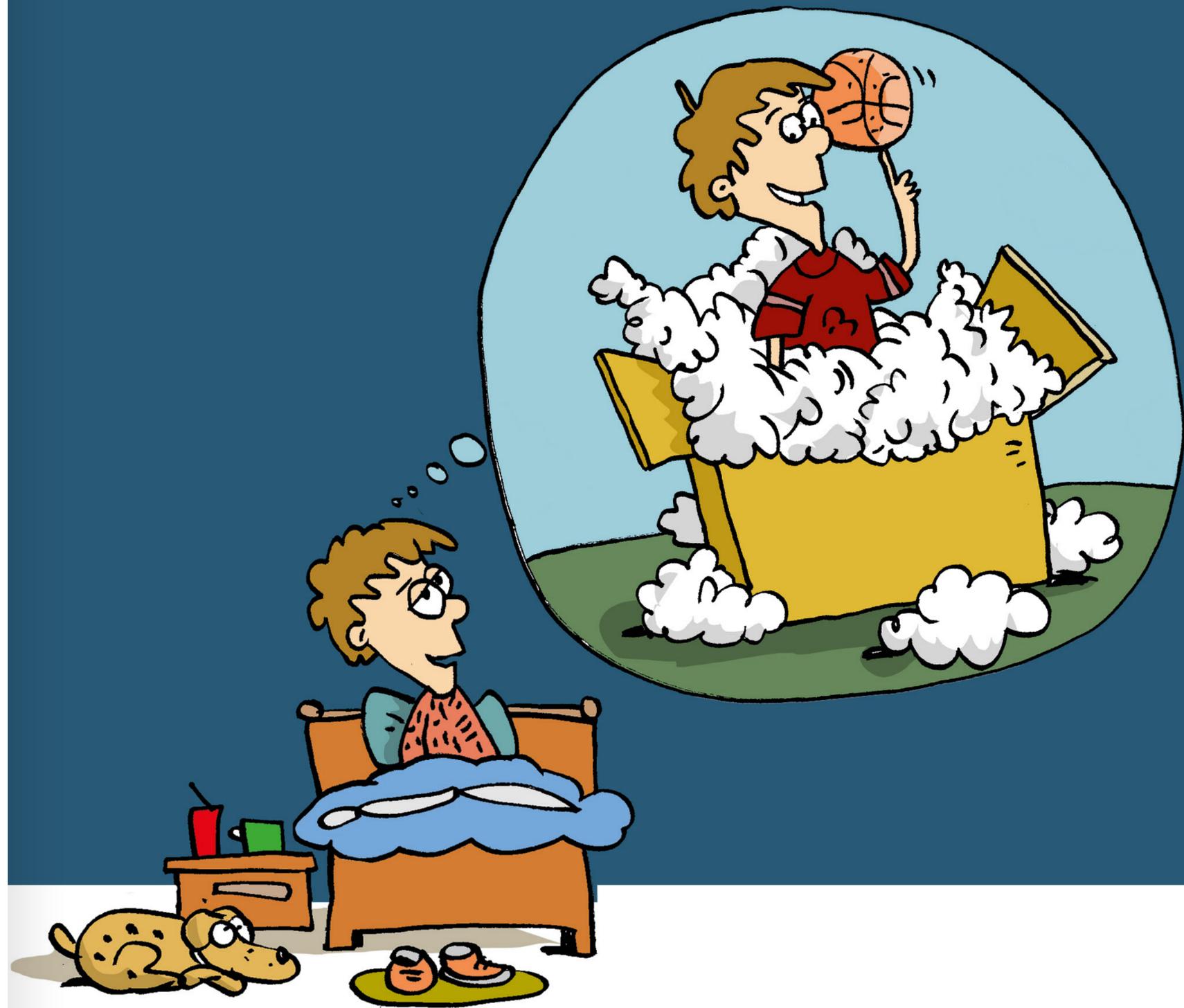
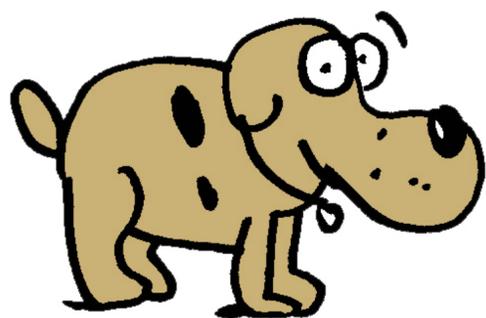
That's why...

...I have to be more careful than other children when I play.

Mum is always reminding Dad that I must not be rough or wild when I'm out with my friends.

Dad always answers, "This doesn't mean we have to keep him in bubble wrap."

I always think that's funny, because I imagine kids that are kept in boxes lined with bubble wrap, to keep them from breaking.



When my platelet count is low,

count is low,

I am not allowed to play ball games, ride a bicycle, skateboard or scooter, or go horse riding. Even if I'm just in the playground, I have to be extra-careful.

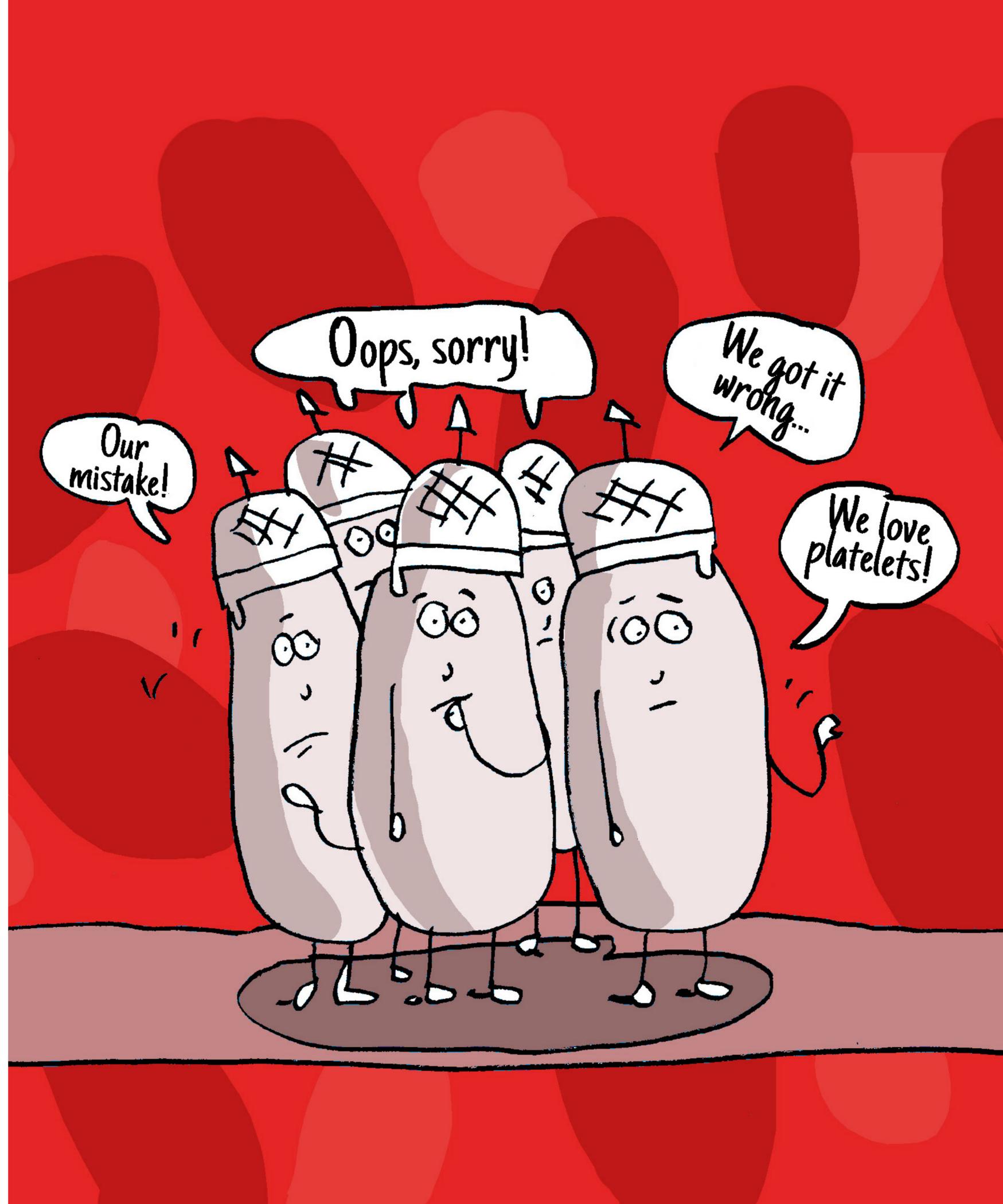
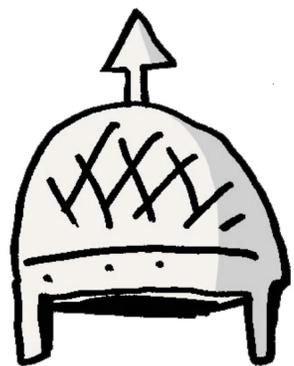
But I do go to school and have fun with friends, because I'm not fragile, and I'm definitely not a bubble wrap boy!



I asked the doctor.

"Why do I have fewer platelets than other children?" She said that it just happens; sometimes the army of white blood cells goes a bit 'crazy' and mistakes the platelets for viruses/bacteria or other harmful pests and they attack them. Or sometimes our bodies don't produce enough of the platelets.

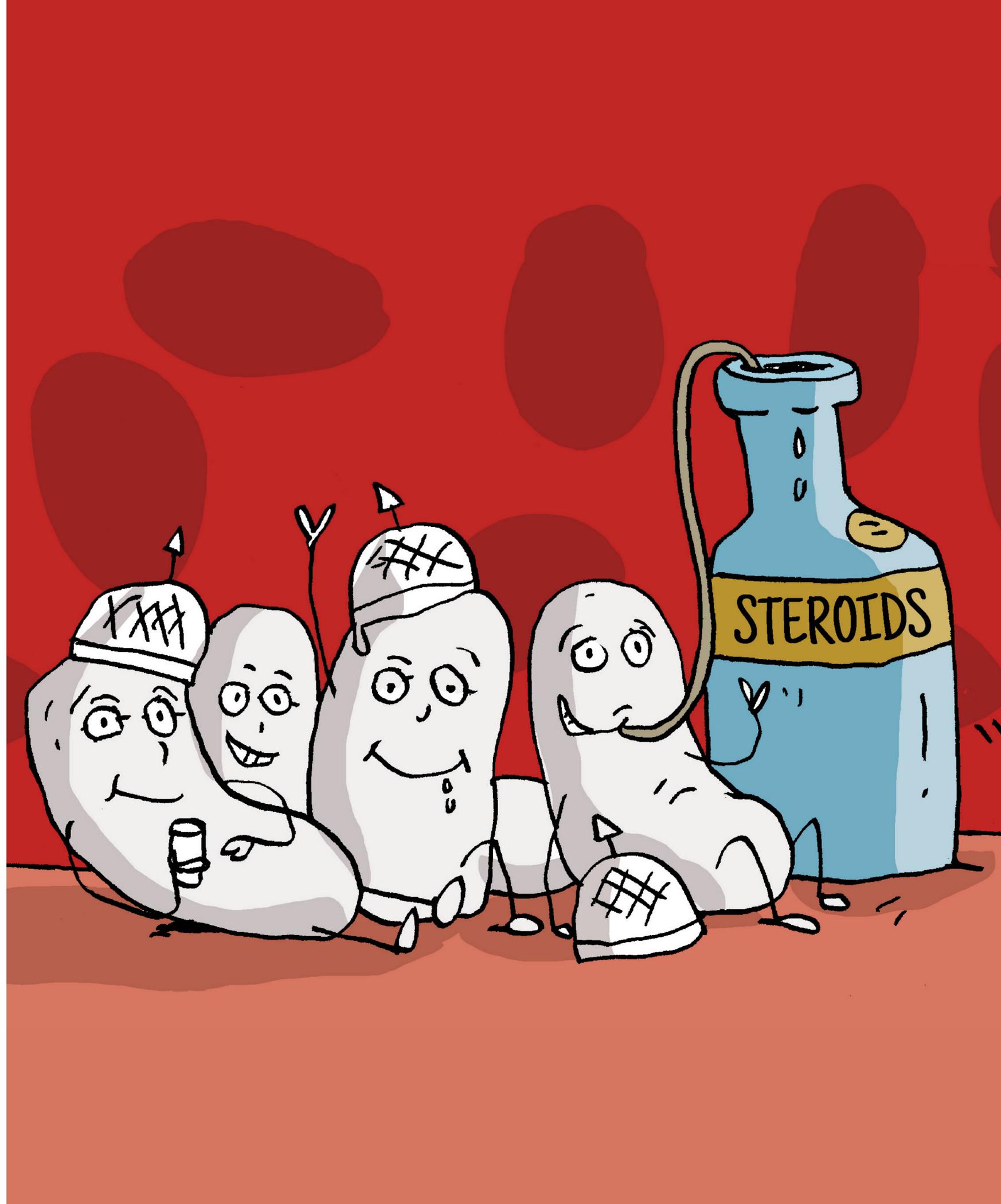
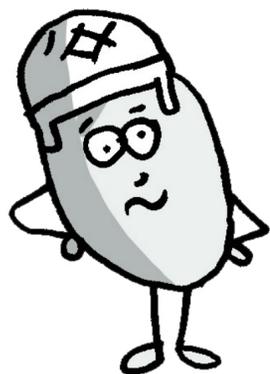
She also said that she hopes that, as I continue to grow, the white blood cells will realise that they were mistaken and will stop fighting the Platelets Guard.



The doctor also told me,

“With the help of certain medicines our bodies can overcome this confusion. Each type of medicine works in a different way.”

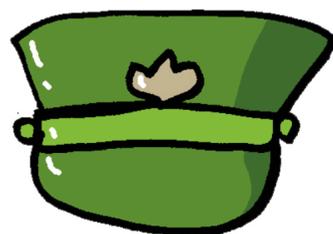
The first type of medicine is called **steroids**. You usually have to take a pill, or syrup, which calms down the army of white blood cells, making them less likely to attack the Platelets Guard.



Another type of medicine is intravenous immunoglobulin,

a funny-sounding name, which is also known as **IVIG**.

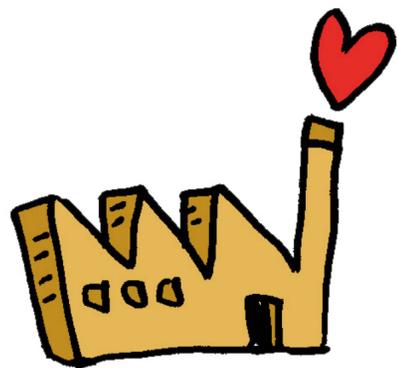
This medicine adds lots of targets for the white blood cell army to attack, then they are too busy, and don't attack the platelets as much.



The third type of medicine...

...is called thrombopoietin receptor agonists,
also known as **TPO-RAs**.

These instruct the body to create lots of
platelets in the bone marrow (the 'platelets
factory'). By creating a lot more platelets,
there's enough of them to stop any bleeding.



Meanwhile...

...I'm having fun with my friends, I enjoy school, and I'm especially happy because I'm celebrating my birthday!



And maybe...

...by my next birthday, my body will no longer be confused, and I will finally be able to ask for a bicycle!



Acknowledgements

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Special thanks to the Hever family.

If you would like further support or information about ITP, the ITP Support Association is here to help:

www.itpsupport.org.uk



I'm not a bubble-wrap boy, is a story about a boy with the rare condition, ITP (immune thrombocytopenia). He describes what it is, how it affects his body and what he does to manage his ITP.

This book has been written to support children with ITP, or to explain to their friends and family what ITP is and that life with ITP doesn't have to mean being wrapped in bubble wrap!

If you or the child/person you care for experiences side-effects with any medication you/they are taking, talk to your/their doctor, pharmacist or nurse. This includes any possible side effects not listed in the information leaflet that comes in the pack. You can report side effects via the Yellow Card Scheme at <http://www.mhra.gov.uk/yellowcard>.
By reporting side effects you can help provide more information on the safety of your/their medication.

The storybook is intended for patient information and education only. It is not intended to be a substitute for professional medical advice, diagnosis or treatment.

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