



AN ITP CHILDREN'S BOOK

Alex has Chronic ITP



The text for this booklet was written by Shirley Watson, founder of the ITP Support Association, and approved by Dr John Grainger, a leading paediatric ITP specialist based at Manchester Children's Hospital.

The ITP Support Association is most grateful to Harriet Ellis, aged 15, for her illustrations. Harriet has ITP and volunteered her services to our charity as part of the qualification for a Duke of Edinburgh Silver Award.



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Hi,
I'm Alex and I have
chronic ITP.



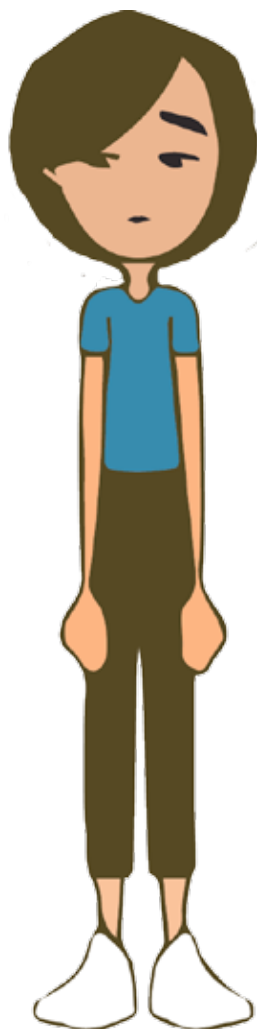
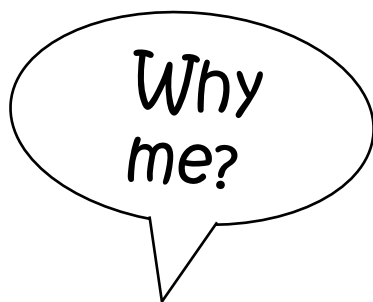
When I first got ITP the doctor said it would probably disappear within a few weeks. But when I still had a low platelet



count after a year he said it was now called a chronic illness. It didn't mean it was bad, it's just a word doctors use when you've had something for a long time.

He told me that only about 1 in 100,000 children have chronic immune thrombocytopenia, so I am very special!

When we got home I moaned to Mummy “why did I have to get this illness with a silly name?” Mummy gave me a big cuddle and explained that most of us have a reason at sometime to ask “why me?” She reminded me about some of my friends who have their own problems – Anika needs an inhaler for asthma, Jake has itchy skin with eczema, Ling is very upset that her daddy has moved away, and Emem finds reading difficult because he has dyslexia.



The next time we went to the hospital Daddy took me for a change. I saw a special doctor called a paediatric haematologist (pee-dee-at-rick hee-mat-ol-o-gist) who knows all about children's blood problems. She felt my tummy, looked at my bruises, and asked if I had nosebleeds, mouth blisters or any other bleeding. She told me that all these were the sort of things that can happen with ITP and they are called 'symptoms'.



The doctor took some of my blood for extra tests to make really sure that my low platelet count wasn't caused by anything else.

Daddy thought I was so brave having my blood taken that he took me to the cafe for a lovely jammy doughnut.



A few days later I woke up with some big black blisters in my mouth so Mummy took me back to the hospital. The doctor thought it was time to try a course of pills called steroids to see if they would make me better. I had to take them every day for a week after breakfast and dinner. They made me feel very hungry, and rather cross.

At my next blood test my platelet count had gone up quite a bit, and Mummy was so pleased she rang Granny from the hospital to share the good news!



After I finished the pills my bruises soon started to come back and when we went saw the doctor again she decided it was probably best for me not have any treatment again unless I get really bad symptoms like a nosebleed that won't stop.

If that happened I could have steroids again, or some liquid made from blood that goes into your arm, and is called immunoglobulin (I laughed at having medicine that sounds like it's made by goblins!)



She said if they didn't work I might be able to have some new drugs called TPOs that would help my body make more platelets.

Now that I've had ITP for quite a long time I don't have to visit the hospital so often, but Mummy can ring up or take me in if I have any problems. I've got used to blood tests now and just look away and think of something nice while it's done.



My teachers hadn't heard of ITP so my Dad ordered two leaflets from the ITP Support Association, one called ITP School Guidelines and another about ITP and sport which he took to my school.



I am quite an expert in ITP now!
I've learnt some very long words,
I know that if I knock myself or fall over
that I am going to get a big bruise,
I know to hold my nose for at least 5
minutes if I have a nosebleed and
I know ITP sometimes makes me feel tired.



I'm not frightened of
blood tests or hospitals
any more, and although
I am sad I can't play in
the football team or do
any sport where I might
fall or get until my ITP
gets better I'm learning
to play drums instead,
which is great fun! I've
got used to having ITP,
and it doesn't bother
me much now.





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