

Understanding ITP

A Story for Kids about
Immune Thrombocytopenia (ITP)



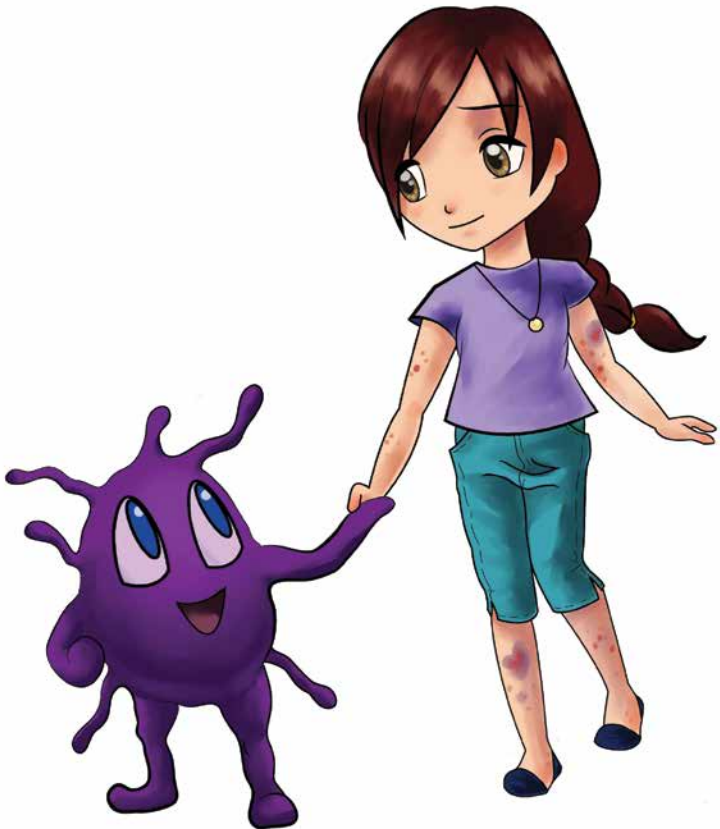
This booklet will help young children who have immune thrombocytopenia (ITP). They will better understand their immune system and their platelet disorder. Their doctors and parents have talked about their platelets, antibodies, and T-cells. The illustrations here show how the immune system works. They show how it gets confused in an ITP patient. Children who have low platelets from ITP will learn some medical treatments they might get. They will also learn good habits to stay healthy. Knowing more about their ITP will help children cope with the challenges of this disorder.

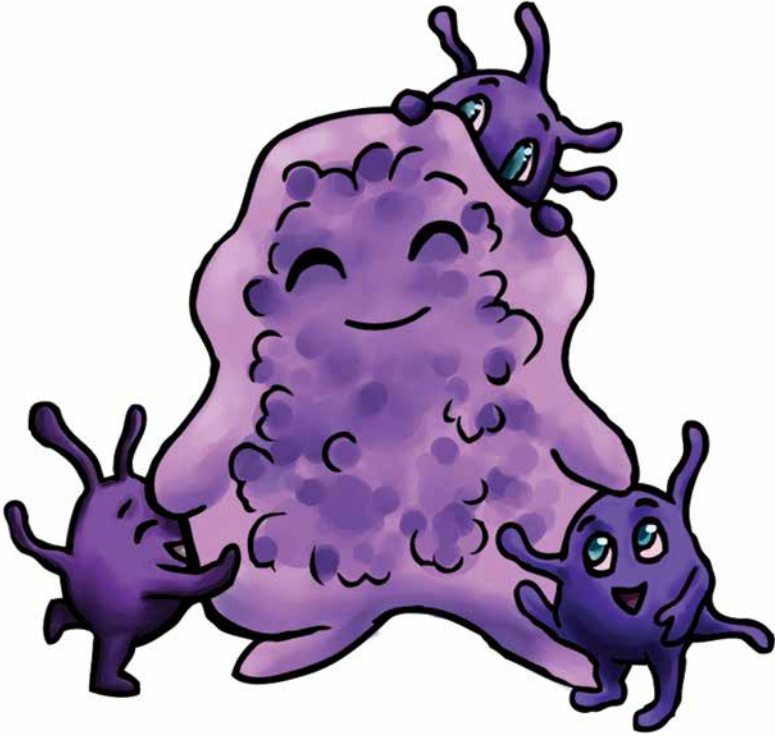
This booklet contains general medical information. It cannot be safely applied to any one case of ITP. There are rapid changes in medical treatment. The information here is not a substitute for professional medical advice.



Seven-year-old Kylee gets bruises, red specks, and purple marks on her arms and legs. She often feels tired. Her doctor and parents said she has a rare platelet disorder. It is called **immune thrombocytopenia** or **ITP**. She has a low platelet count.

Kylee feels scared. She wants to know what ITP is. How did she get it? She hopes she will get better soon. Lucky for Kylee, she meets friendly PD Platelet. He is here to tell her about ITP.





PD Platelet tells Kylee that **platelets** are small cells in our blood. They help us make clots when we get a cut. They are like Band-aids inside of our body. Platelets help stop bleeding and bruising. They come from cells in our bones called **megakaryocytes** (meg-a-carry-oh-sites). Our body makes new platelets every day.

A person with ITP has a very low number of platelets in their blood. They might have bruises. Some have small red specks called **petechiae** (pe-teek-e-ah) on their skin. They may get large purple spots called **purpura** (purr-purr-ah) on their skin. Children who have ITP may feel tired. They need to be careful when playing.





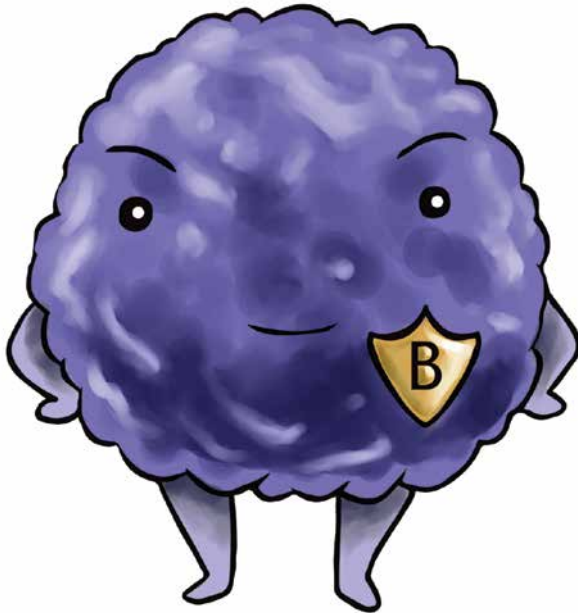
Kylee wants to know why she got ITP. PD Platelet tells her about the immune system. It plays a part in someone getting ITP. He tells Kylee that doctors don't know why some children get ITP. It is not because of anything they did wrong. Also, you can't catch ITP from someone else. The main problem for kids who have ITP is their low platelet counts.



We have special things called cells and organs inside our bodies. They help protect us from getting sick.

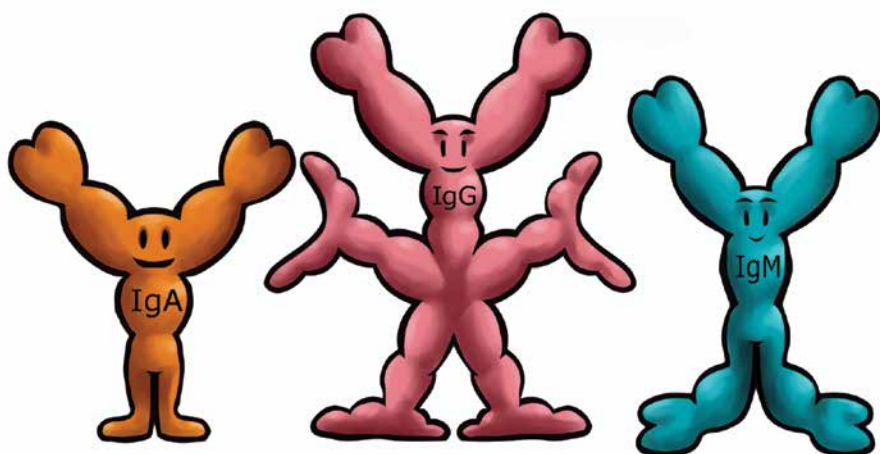
These helpers are part of our immune system.

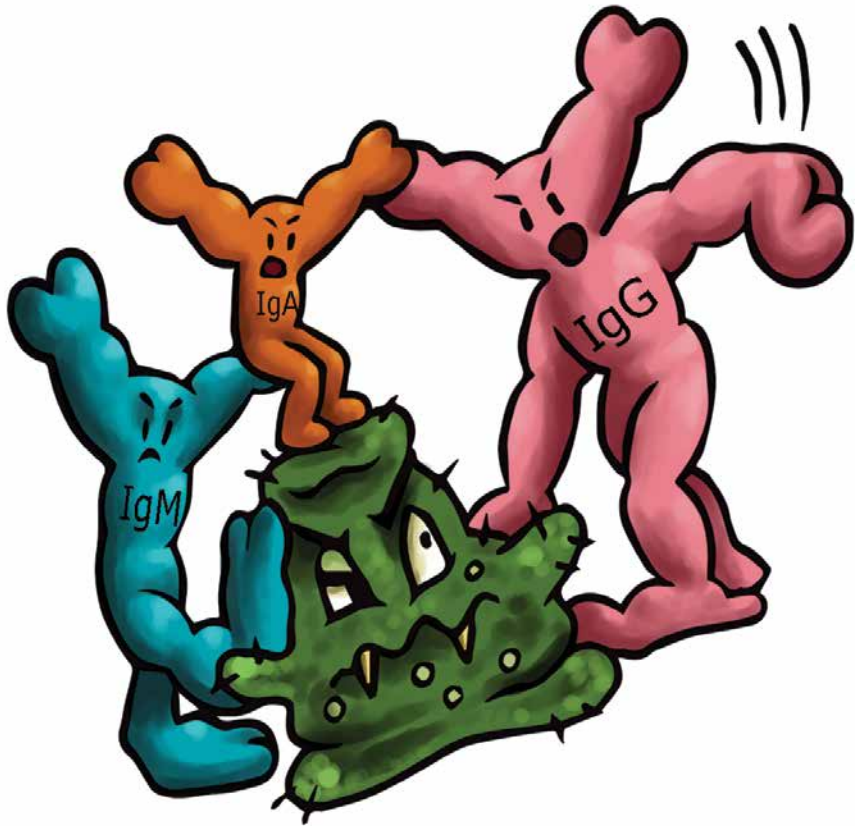
One important helper is the **B-cell**.



B-cells float around in our blood. They also rest in other parts of the body. They are important. They make **immunoglobulins** (im-mu-no-glob-u-lins). These are also called antibodies (an-tee-bod-ees) or **Igs**.

Each antibody has a special job to help keep us well. Antibodies fight **germs**, like bacteria and viruses that get inside us. Germs can make us sick. Three main types of antibodies — IgG, IgA, and IgM — help us.





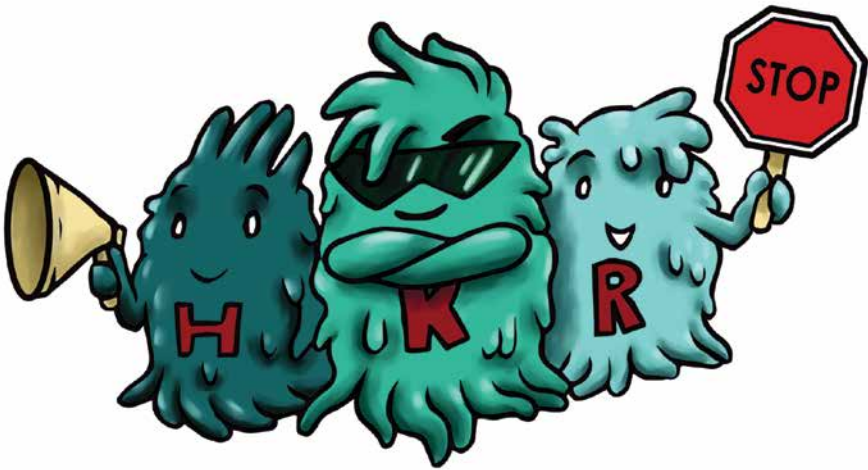
The antibodies or **Igs** in our immune system work together. They help each other fight germs in our body. That is their job.

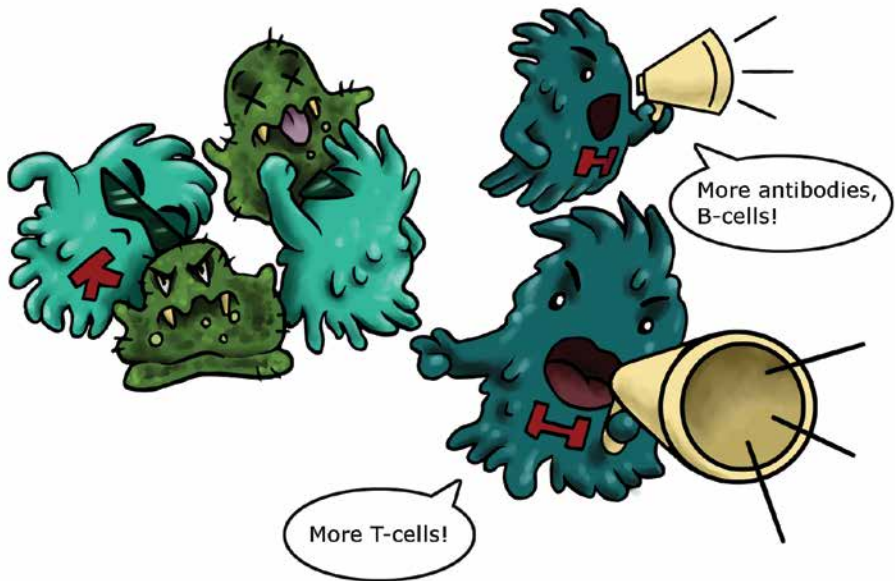


We have an important protector in our immune system. It is called a **T-cell**.

T-cells are found in our blood.

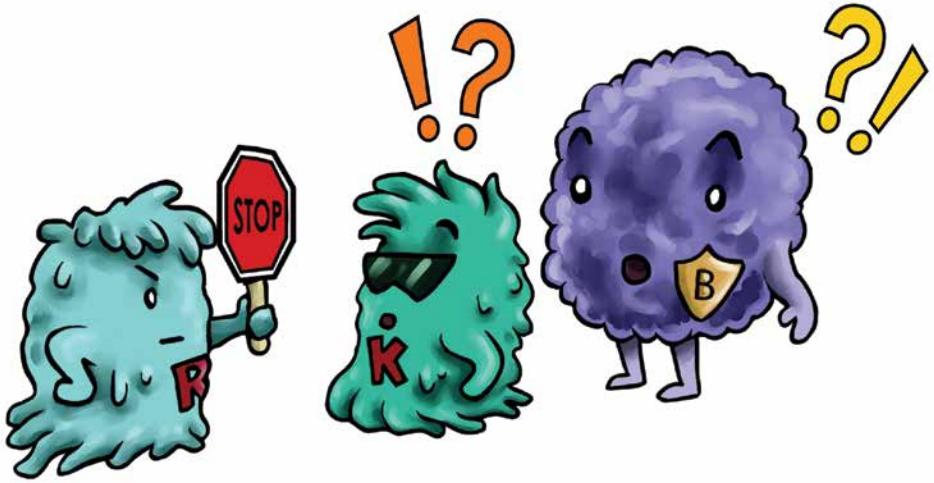
They also go other places in our body. We have three kinds of T-cells: the Helper T-cells, the Killer T-cells, and the Regulatory T-cells.





Killer T-cells kill germs.

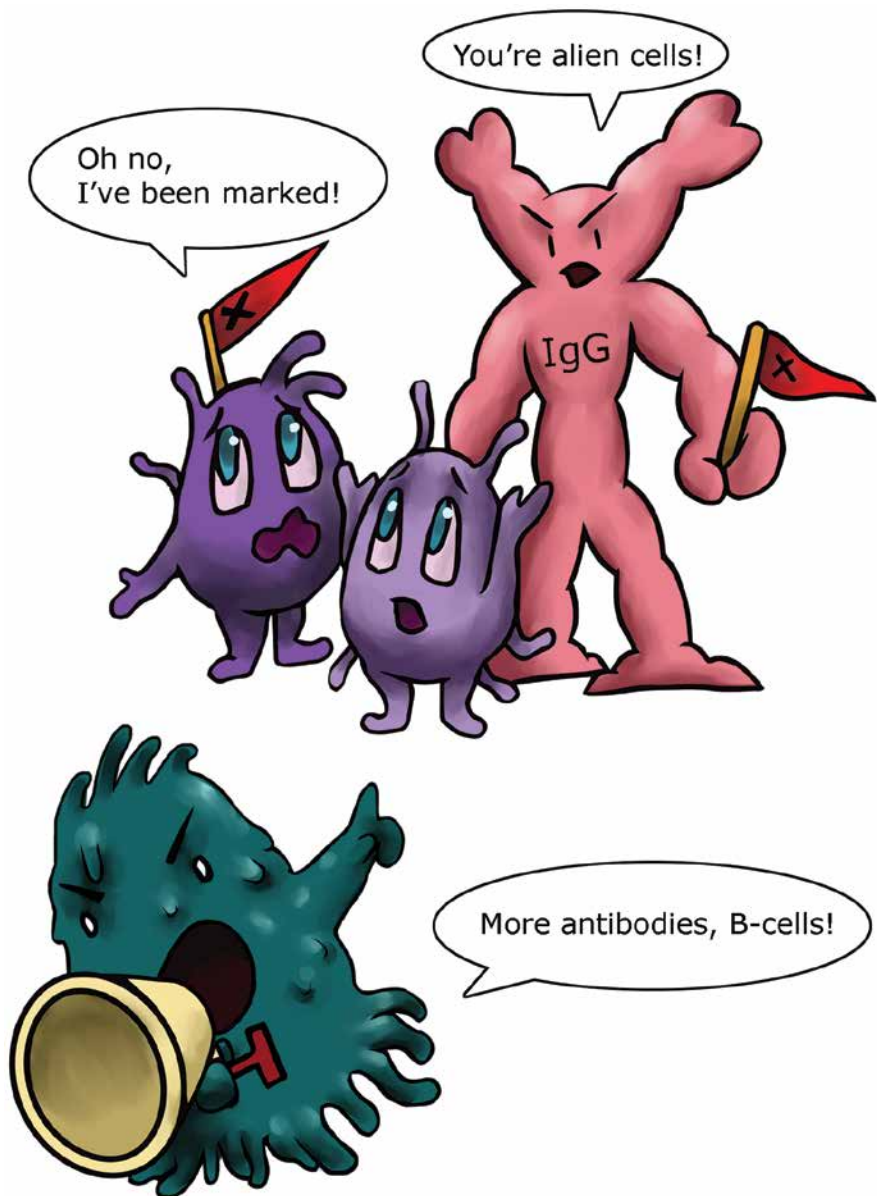
Helper T-Cells call for more Killer T-cells to come help.
Helper T-cells also tell B-cells when to make more antibodies.



The Regulatory T-cells help us. They tell the B-cells when the person is better. They tell other T-cells too. Then the B-cells can stop making more antibodies.

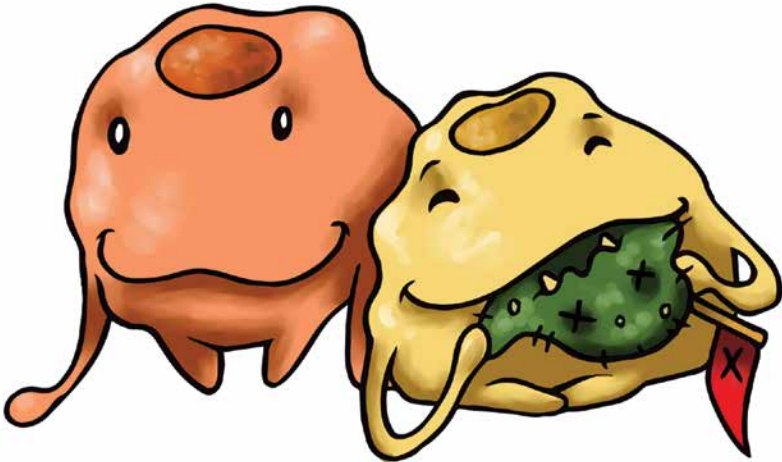
When a child has a cold or flu their immune system cells get rid of germs. But sometimes their immune system gets mixed up. T-cells think the healthy platelets are germs. They send in antibodies to mark the platelets. Then the platelets will be destroyed. When this happens a child can get ITP.







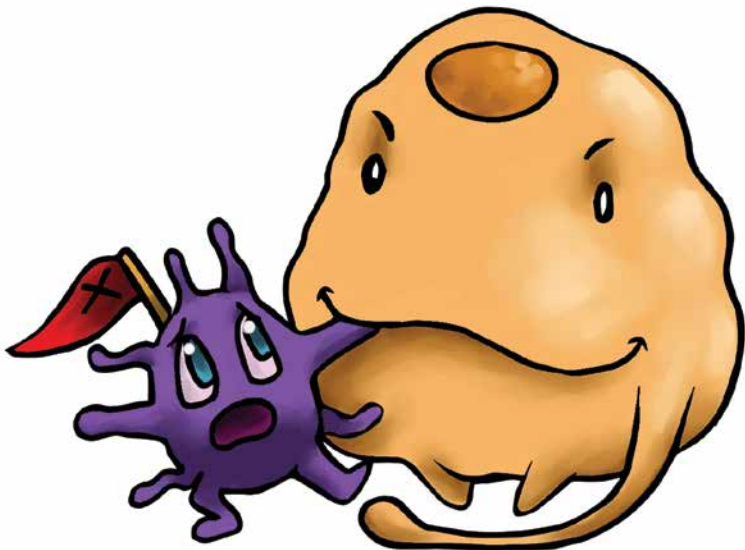
We have other protectors in our immune system. These are called **phagocytes** (fag-oh-sites). They kill germs by eating them! They also send out calls to other phagocytes nearby for extra help. Phagocytes are special blood cells. They hang out in our blood or other organs like our liver and spleen.



In children with ITP, there is a special kind of phagocyte in the **spleen**. It is called a **macrophage**. The spleen is an organ in our body. It helps our immune system. The spleen removes old cells in our blood. Macrophages eat platelets that pass through the spleen. Usually they only eat the old, worn out platelets and other cells.

When a child has ITP the macrophages see platelets that have been marked with antibodies. The child's immune system has gotten 'confused.' It has marked the platelets by mistake. To macrophages this marking makes the platelets look like 'alien' cells. They don't belong. So the macrophages eat them!

If the macrophages eat lots of platelets the child will have a low platelet count. Then they may start showing signs of bleeding. The signs are bruises, petechiae, and purpura. Some children may get nosebleeds and mouth sores.



A doctor can find out if a child has a low platelet count. They do a medical test called a **Complete Blood Count** (or a **CBC**). A little bit of blood is taken from a child's vein. Then the platelets and other cells in the blood are measured.

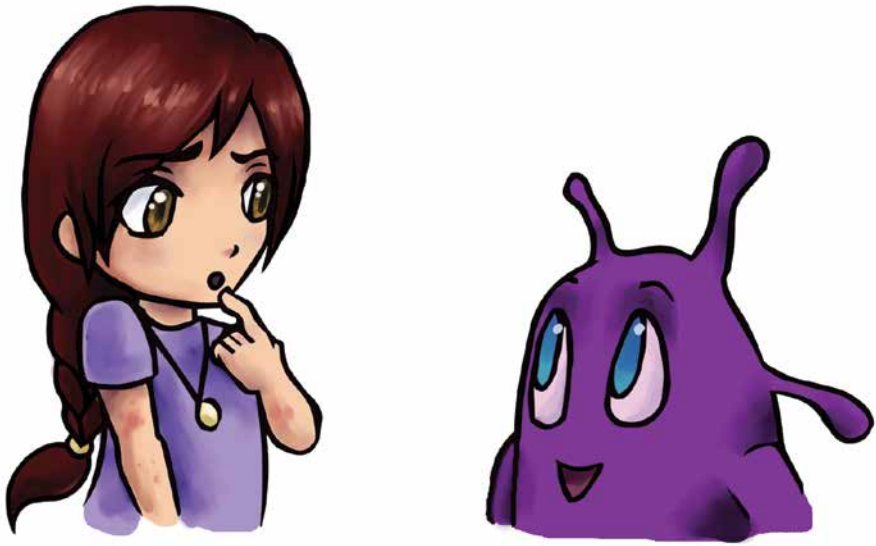
For children with ITP the platelet count is very low.



A doctor who treats blood disorders (called a **Hematologist**) may do other medical tests. A **bone marrow biopsy** may be done. Using a microscope the doctor looks at the blood cells and platelets. Our bone marrow is like a factory for making our new blood cells like platelets. The test shows if the platelets are normal. It helps the doctor pick the best treatment for the child's ITP.



Kylee asked PD Platelet, “How does the doctor know when I need to be treated for my ITP?”



He tells her, “Our normal platelet counts range from 150,000 to 400,000. Someone with ITP may have a very low count such as 10,000. If the child does not have bleeding problems, the doctor may suggest ‘watchful waiting’ to see if the count may go higher on its own.

Luckily most children with ITP get better in a few months. Sometimes their count drops too low or they have bleeding. Then the doctor may decide the child needs medicine. This treatment will help raise their platelet count to a safe level.”

Sometimes our platelet count gets very low. Then we have to go to the doctor. Or we stay in the hospital a little while. Doctors and nurses can take care of us. Some children with ITP receive a treatment with **IVIG**. This is a clear liquid called **intravenous immunoglobulin**. Intravenous means the medicine is given through a needle into a vein. This is usually in the arm or hand.





Here is what happens when you get an IVIG treatment. The nurse puts a small needle into a vein of your hand or arm. This lets the immunoglobulin liquid go into the vein. A little piece of tape holds the needle in place. A special machine slowly drips the clear liquid into the vein. This takes several hours. You can read, watch TV or sleep during the treatment.

Another ITP treatment is called **anti-RhoD immunoglobulin**. It also called **anti-D**.

The clear liquid is given with an IV in the arm.

With anti-D the spleen is busy removing red cells and not platelets. Fewer platelets get eaten in the spleen. This helps a child's platelets go higher. The count may stay at a safer level for several weeks. Now a child can enjoy more days without trips to the doctor. If platelets drop very low again, the child may need another treatment.



PD Platelet tells Kylee, “Sometimes a child with ITP receives medicine called **steroids**. Prednisone is a steroid. This helps raise the platelet count. It will help stop bleeding problems. A child may be given steroids with an intravenous (IV) line. Sometimes steroids are taken as a pill or syrup by mouth.



Steroids help stop the immune system from attacking the platelets. That way more platelets are in the blood to help us.

When taking steroids a child may feel overactive or grumpy. They may have trouble sleeping and feel very hungry. Some children gain weight. These are called ‘side effects.’ All medicines have some side effects. Steroids may have lots of side effects. Most doctors only give steroids to patients for a short time. They lower the dose as soon as possible.

Other treatments are available to children who do not respond well to IVIG, anti-D, or corticosteroids. A newer treatment is platelet growth factors or thrombopoietin (TPO) receptor agonists which prompts cells in the bone marrow to produce more platelets. For additional treatments available to kids with ITP visit <https://pdsa.org/children.html>.”



Kylee says, “Now that I have ITP my parents tell me I must be careful to avoid getting injured. Otherwise I could have bleeding. What things can I do safely for sports and fun?”

PD Platelet tells her, “Kids with ITP and low platelets do have to be careful. There are certain sports where they could get badly hurt. These are football, basketball, and soccer. They can still go to school. ITP kids can enjoy other sports such as running, swimming, snorkeling, and tennis. For some activities kids need to wear a helmet or something to protect hands and knees.”

PD Platelet tells Kylee, “There are many activities ITP kids can safely enjoy. These include music, art, board games, video games, reading, and writing. ITP kids can care for pets, enjoy photography and gardening, and make crafts. Kids and their parents can ask the doctor which activities are okay for them.”



Kylee asks PD Platelet, “Can other things help me feel better while I have ITP?”



PD Platelet says, “First, be sure you eat a healthy diet with a wide variety of foods. These include fruits and vegetables, lean meat, and fish. Make sure you don’t eat a lot of fried and sugary fast food. If you have allergies to foods (like dairy or gluten) talk with your doctor about your diet. Drink plenty of water instead of sugary drinks or sodas.”



PD Platelet added, “Also, be sure to get at least 7-8 hours of sleep each night.”



PD Platelet tells Kylee, “There is a patient support organization for ITP patients. It is called the **Platelet Disorder Support Association** (or **PDSA**). It offers helpful resources, guidance and support to ITP kids and adults.

PDSA has educational booklets and a website with lots of information. They have the Poke-R Club for kids program and a support group for parents of children with ITP where ITP kids talk to one another for the first part of the call. PDSA also offers their Kids’ Kamp at their annual ITP Conference.

Kids’ Kamp has fun programs for children and the conference offers insight for parents and connects ITP families. Families also connect online through the PDSA Discussion Groups available on PDSA.org.

To learn more about PDSA visit their website:
www.pdsa.org”



Every day doctors and other researchers are studying ITP. They are working hard to find new and better treatments.

Most children with ITP get better in six months to a year. A small number of children have ITP that lasts more than a year.

Many treatments can help raise their platelet counts. ITP kids and their families look forward to better treatments. We all hope a cure is found for this rare disorder.

Important Words to Remember

Here are some important words to understand in this booklet.

Antibodies (an-ti-bod-ies) - Also called immunoglobulins, they protect our bodies from germs and are produced by B cells

Anti-RhoD immunoglobulin (Anti-D) - An effective antibody medical treatment that can raise platelets (thrombocytopenia) to a safe level for a patient with ITP but it only works in people with Rh+ blood.

Autoimmune (au-to im-mune) - Your immune system attacks your own cells

B - cells - Cells that make immunoglobulins in the body

Complete blood count (CBC) - Medical test that gives important information about the numbers and kinds of cells in a sample of the patient's blood

Bone marrow (bone mar-row) - Special tissue inside our bones where platelets and other blood cells are created

Bone marrow biopsy (bone mar-row bi-op-sy) - Medical test to see cells in the bone marrow

Corticosteroids - (cor-ti-co-ster-oids), also called 'steroids' Medical treatment given by pill, syrup, or infusion to help raise the platelet count

Germ - A tiny living organism that may make you get sick, such as bacteria or viruses

Immunoglobulins (im-mu-no-glob-u-lins) - These are also called antibodies or Igs

Immune thrombocytopenia (im-mune throm-bo-cy-to-pen-i-a) - An acquired bleeding autoimmune disorder. The patient develops antibodies that attack their own platelets, resulting in a low platelet count

IVIG (i-v-i-g) - Immune globulin liquid that is infused into a vein

Intravenous (in-tra-ven-ous) - This means putting something into a vein

Macrophage (mac-ro-phage) - A type of phagocyte that eats platelets in the spleen

Megakaryocyte (meg-a-carry-oh-site) - The large cells in our bone marrow that make our platelets

Petechiae (pe-teek-e-ah) - Small purple spots that look like a rash, caused by blood leaking under the skin when platelets are low

Phagocyte (fag-oh-site) - Cells in the body that identify germs and then get rid of them by eating them

Platelet Disorder Support Association (PDSA) - Patient support group for people with ITP

Platelets (plate-lets) - Small sticky cells in the blood that are produced in the bone marrow. They help blood vessels stay strong and seal cuts and wounds by making clots

Purpura (purr-purr-ah) - Areas where blood has leaked under the skin from having low platelets, resulting in big, ugly purple marks on the skin

Spleen - A large organ on the left side of the body that works like a filter and removes old blood cells, including platelets

T-cells - These immune system cells identify germs and tell the body how to fight them

Thrombopoietin (throm-bo-po-e-ten) - A protein made in the liver, naturally stimulates cells in the bone marrow to make more platelets

Other helpful resources for children and families managing ITP:



ITP POKE-R CLUBSM: Empowering Kids with ITP – visit <https://bit.ly/2HSe5Lr>

Parents Teleconference Group: kids join in the first 30 minutes to talk with each other about life with ITP – visit: <https://bit.ly/2NxvHTtr>

ITP Student Factsheet

Resource Guide for Parents

Medical Emergency Card for Patients with ITP

PDSA Online Discussion Group

ITP Helpline – 877-528-3538 or PDSA@PDSA.org

Twenty Steps to Better Health

ITP Diet Suggestions

ITP Diet & Lifestyle Resource List

Depending on your circumstances, one of our other booklets may also be helpful:

When a Child Has ITP: A Resource Guide for Parents

ITP in Children — Frequently Asked Questions

(also available in Chinese, French, Finnish & Spanish)

ITP in Teens — Frequently Asked Questions (also available in Spanish)

Understanding ITP: A Story for Kids about Immune Thrombocytopenia

(also available in Spanish, Chinese, Dutch & Finnish)

ITP and the Female Lifecycle: Bleeding Issues in the Stages of a Woman's Life

(also available in Spanish)

ITP in Adults — Frequently Asked Questions

(also available in Chinese, French, Finnish & Spanish)

Coping with ITP — Frequently Asked Questions (also available in Spanish)

Living with ITP: Answers to Common Questions (also available in French)

The Role and Function of Platelets in ITP

Health Insurance and Assistance Programs for ITP Patients

Who Pays for Drugs in Canada? (also available in French)

For more information about ITP, additional copies of this booklet, or to become a member of PDSA, please contact us:



8751 Brecksville Road, Suite 150, Cleveland, Ohio 44141
tel 1-87-PLATELET (1-877-528-3538)
pdsa@pdsa.org • www.pdsa.org

The Platelet Disorder Support Association (PDSA) is dedicated to enhancing the lives of people with immune thrombocytopenia (ITP) and other platelet disorders through education, advocacy, research and support. Patient-founded in 1998 to educate and empower those impacted by immune thrombocytopenia and other rare platelet and bleeding disorders, PDSA is now a powerful force serving and unifying the global ITP community of patients, practitioners, caregivers, advocates and key disease stakeholders. PDSA is committed to building awareness, educating the global community, and providing critical connections and resources that empower patients to take charge of their disease and encourage practitioners to exercise patient-centered medical care.

Membership benefits include a quarterly newsletter, discounts to the annual ITP Conference, and the good feeling of helping others.

The Platelet Disorder Support Association is a 501(c)3 organization and donations are tax deductible to the fullest extent allowed by law.

The information in this guide is for educational purposes only. For your child's unique medical condition, please consult a doctor.

**PDSA thanks Dr. Amy Geddis, Seattle Children's Hospital,
and Dr. Michael Tarantino, Bleeding & Clotting Disorders Institute,
Peoria, IL for their medical review of this text.**

©2019 Platelet Disorder Support Association. All rights reserved. www.pdsa.org.

The PD Platelet name and/or likeness and all images in this publication are the property of and copyrighted by Platelet Disorder Support Association (PDSA). Any unauthorized use and reproduction without express written permission from Platelet Disorder Support Association is strictly forbidden.

PDSA would like to thank Novartis for their assistance in printing this guidebook.

Connect with Us!



PLATELETDISORDER



GROUPS:
PLATELETDISORDERSUPPORTASSOCIATION



PDSA_ITP



PDSA_ITP



PDSAORG



PDSA



8751 Brecksville Road
Suite 150
Cleveland, OH 44141

tel 1-87-PLATELET
(1-877-528-3538)

pdsa@pdsa.org
www.pdsa.org