

Understanding ITP

A Story for Kids about
Immune Thrombocytopenia (ITP)



**Produced by the Platelet Disorder
Support Association (PDSA)**

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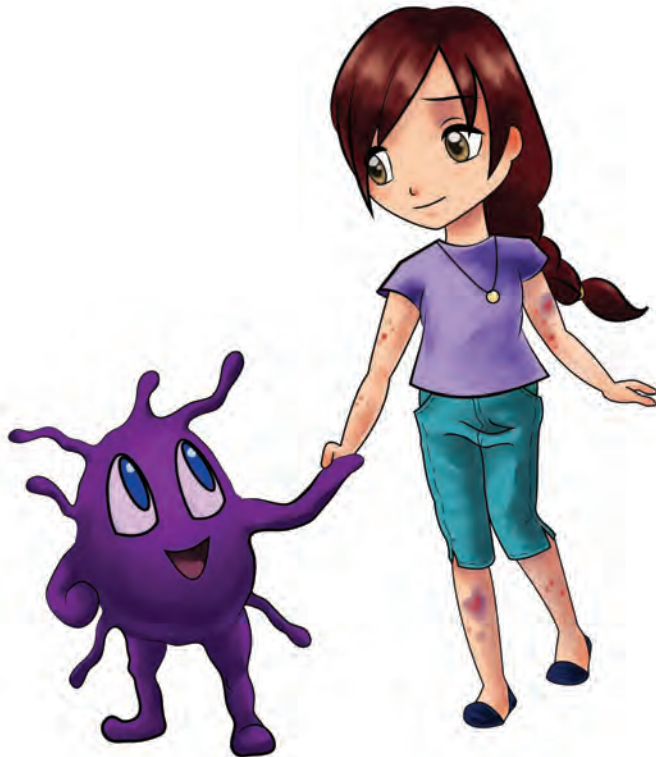
This booklet will help young children who have immune thrombocytopenia (ITP). They will better understand their immune system and their platelet disorder. Their doctors and parents have talked about their platelets, antibodies, and T-cells. The illustrations here show how the immune system works. They 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.

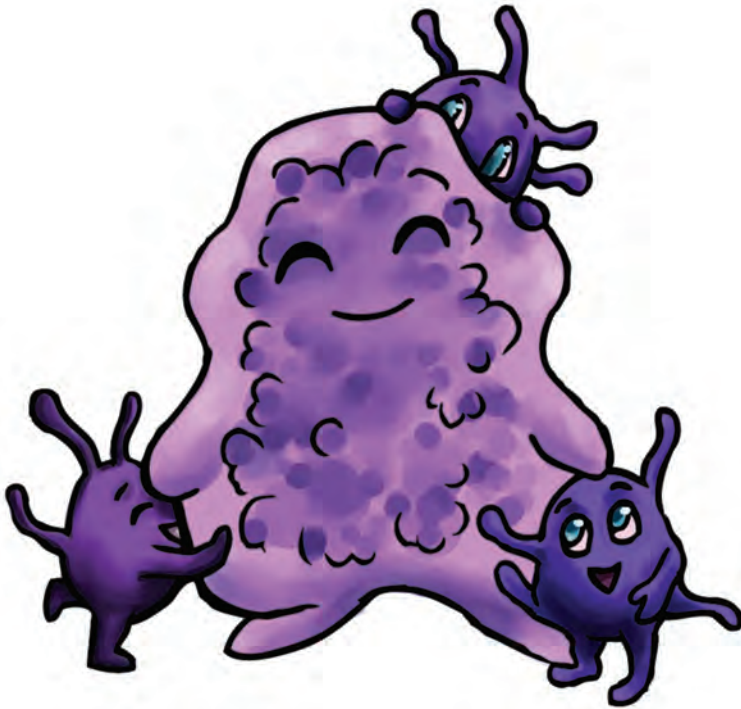
This booklet contains general medical information. It cannot be safely applied to any one case of ITP. There are rapid changes in medical treatment. The information here is not a substitute for professional medical advice.



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.

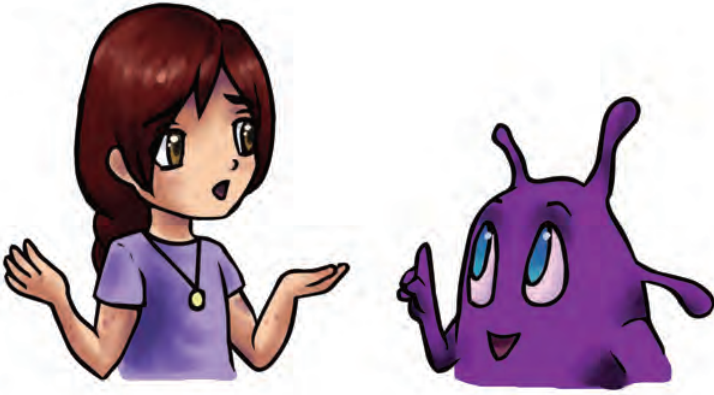




PD Platelet tells Kylee that **platelets** are small cells in our blood. They help us make clots when we get a cut. They are like Band-aids inside of our body. Platelets help stop bleeding and bruising. They come from cells in our bones called **megakaryocytes** (meg-a-carry-oh-sites). Our body makes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





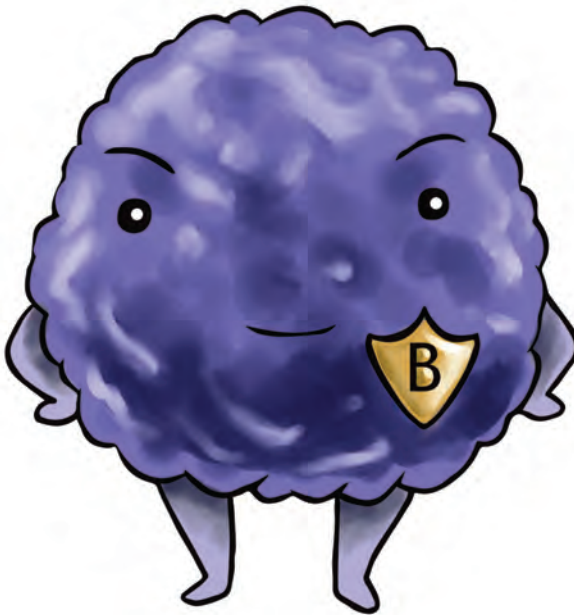
Kylee wants to know why she got ITP. PD Platelet tells her about the immune system. It plays a part in someone getting ITP. He tells Kylee that doctors don't know why some children get ITP. It is not because of anything they did wrong. Also, you can't catch ITP from someone else. The main problem for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

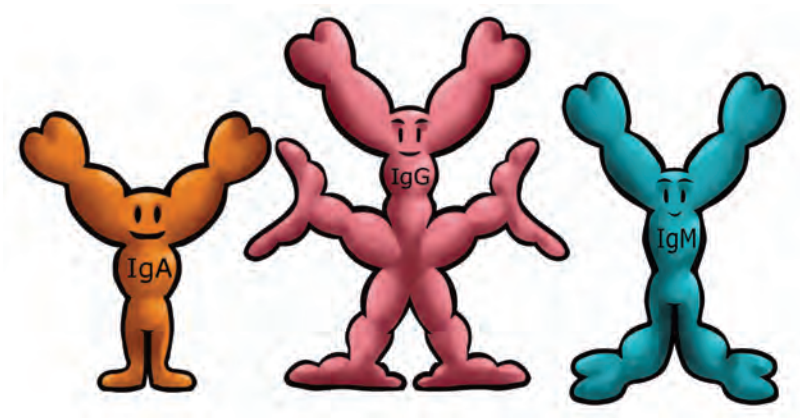
These helpers are part of our immune system.

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.





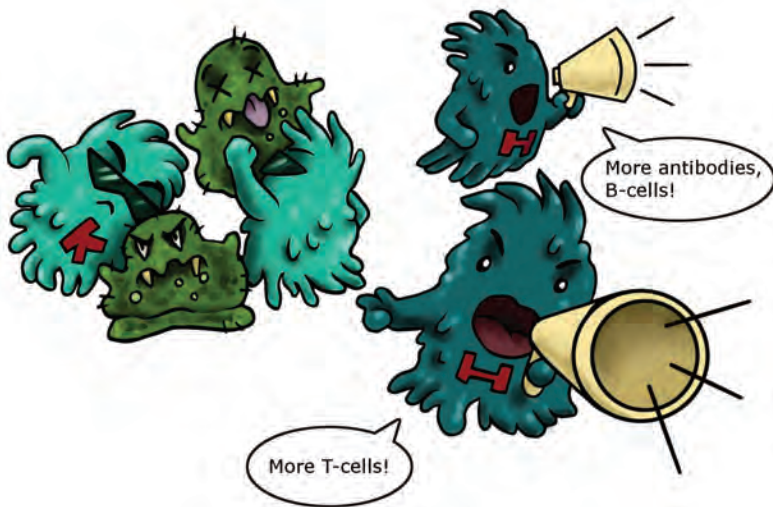
The antibodies or **Igs** in our immune system work together. They help each other fight germs in our body. That is their job.



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

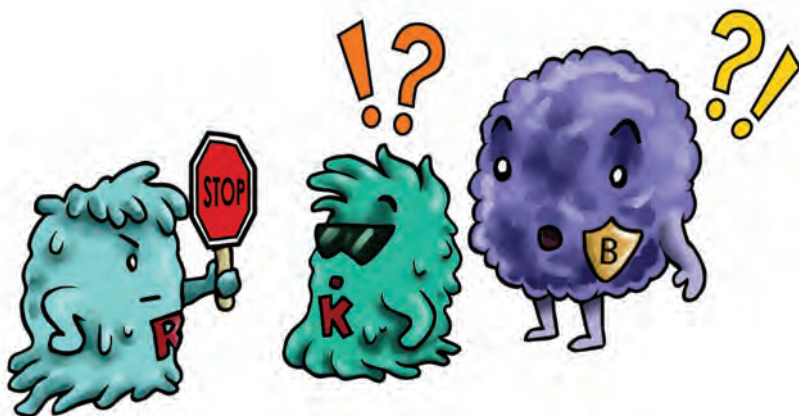
They also go other places in our body. We have three kinds of T-cells: the Helper T-cells, the Killer T-cells, and the Regulatory T-cells.





Killer T-cells kill germs.

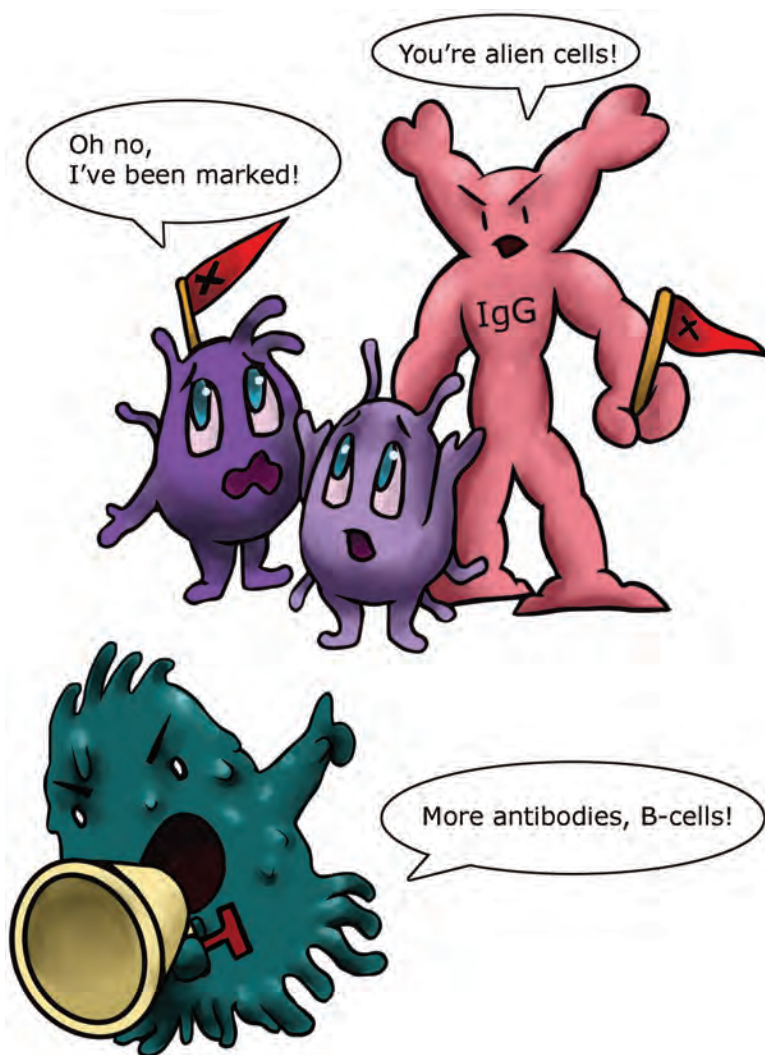
Helper T-Cells call for more Killer T-cells to come help. Helper T-cells also tell B-cells when to make more antibodies.



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.

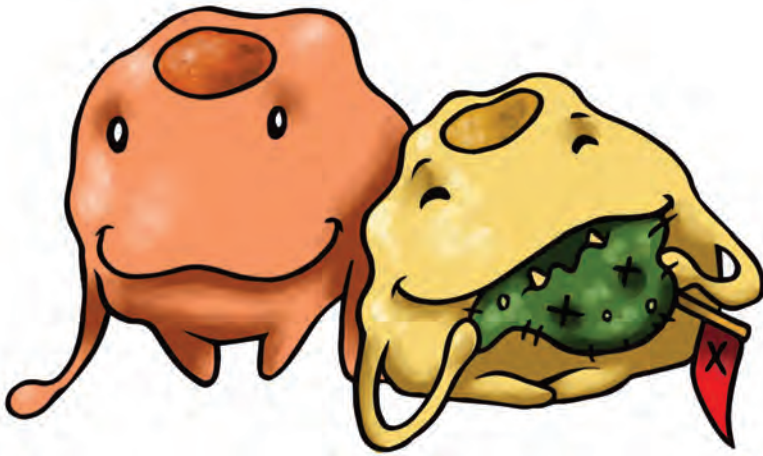
When a child has a cold or flu their immune system cells get rid of germs. But sometimes their immune system gets mixed up. T-cells think the healthy platelets are germs. They send in antibodies to mark the platelets. Then the platelets will be destroyed. When this happens a child can get ITP.







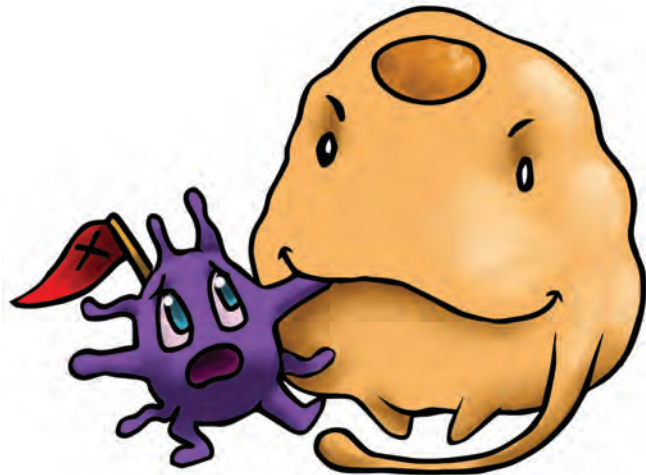
We have other protectors in our immune system. These are called **phagocytes** (fag-oh-sites). They kill germs by eating them! They also send out calls to other phagocytes nearby for extra help. Phagocytes are special blood cells. They hang out in our blood or other organs like our liver and spleen.



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 (purrr-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

RESOURCES

PDSA OFFERS THE FOLLOWING HELPFUL RESOURCES FOR MANAGING ITP:

- **ITP Patient Connect Support Groups by region:**
[PDSA.org/support-groups](https://pdsa.org/support-groups)
ITP Helpline: (440) 746-9003 or PDSA@PDSA.org
- **Online discussion group:** [PDSA.org/discussion-group](https://pdsa.org/discussion-group)
- **Medical Emergency Cards and Medical Alert Jewelry for Patients with ITP:** [PDSA.org/shop](https://pdsa.org/shop)
- **ITP POKE-R CLUBSM Empowering Kids with ITP:**
[PDSA.org/poke-r-club](https://pdsa.org/poke-r-club)
- **Parents of Kids with ITP – kids join in the first 30 minutes to talk with each other about life with ITP; then parents have the chance to talk and learn from one another:** [PDSA.org/kids-parents-group25](https://pdsa.org/kids-parents-group25)

Depending on your circumstances, one of our other booklets may also be helpful. Find our full inventory of educational booklets at [PDSA.org/booklets](https://pdsa.org/booklets).

Many of these booklets are also available in multiple languages at [PDSA.org/translated-publications](https://pdsa.org/translated-publications).

- **ITP Pamphlet (perfect for sharing with families)**
- *ITP in Children – Frequently Asked Questions*
- *When a Child has ITP: A Resource Guide for Parents*
- *Understanding ITP: A Story for Kids about Immune Thrombocytopenia*
- **ITP Student Factsheet (perfect for sharing with schools)**
- *ITP in Teens – Frequently Asked Questions*
- *ITP in Adults – Frequently Asked Questions*
- *Living with ITP – Answers to Common Questions*

- *Health Insurance and Assistance Programs for ITP Patients*
- *Coping with ITP – Frequently Asked Questions*
- *The Role & Function of Platelets in ITP*

For more information about ITP, additional copies of this booklet, or to become a member of PDSA, please contact us: Platelet Disorder Support Association, 8751 Brecksville Road, Suite 150, Cleveland, OH 44141 • tel (440) 746-9003 • PDSA@PDSA.org • PDSA.org

The Platelet Disorder Support Association (PDSA) is dedicated to enhancing the lives of people with ITP and other platelet disorders through education, advocacy, research, and support. Membership benefits include our 28-page publication, *The Platelet News*, and discounts to the annual ITP Conference.

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.

PDSA is a 501(c) 3 organization. All contributions are tax deductible. This patient information guide was supported by an educational donation by **Sobi**.

The information in this guide is for educational purposes only. For your unique medical condition, please consult a qualified medical doctor and/or health care provider.

USE THIS FORM TO:

- MAKE A DONATION TO PDSA
- JOIN PDSA
- REQUEST FUNDRAISING INFORMATION

Please check the appropriate box(es).

All donations to PDSA are gratefully received and will be acknowledged.

(Please make checks payable to: PDSA) (Do not send cash)

☐ I would like to join the Platelet Disorder Support Association (PDSA) to receive an information packet and *The Platelet News* quarterly newsletter for one year and enclose \$25 for membership.

☐ I enclose a donation to PDSA of: \$ _____ .

☐ I would like to raise funds for the PDSA. Please send me fundraising information.

☐ I would like to receive an ITP Emergency ID card (first one is free).

Please complete:

Name: _____

Address: _____

City: _____ State/Province: _____

Country: _____ Zip code: _____

Please help us update our records by completing this section of the form. I am:

☐ an ITP patient

☐ parent of an ITP child

☐ family member

☐ friend/other health professional

☐ industry professional

For additional information about ITP and PDSA, visit our website: pdsa.org or send email to pdsa@pdsa.org

SEND THIS FORM TO:

Platelet Disorder Support Association

8751 Brecksville Road, Suite 150
Cleveland, OH 44141

Call the PDSA office if you need assistance or to use a credit card: (440) 746-9003.

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Association

Empowering ITP Patients

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