

# ITP in Teens

FREQUENTLY ASKED QUESTIONS





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**Q** What is thrombocytopenia?

**A** Thrombocytopenia is a reduced number of platelets in the blood. Thrombocytopenia is defined as a platelet count below 150,000 platelets per microliter (ppm) of blood. Normal platelet count is approximately between 150,000 and 400,000 ppm. A low platelet count does not cause symptoms for most people until it falls below 50,000 ppm, and a few people are asymptomatic (experience no apparent problems) with platelet counts below 10,000 ppm.

**Q** What is ITP?

**A** ITP (Immune Thrombocytopenic Purpura) is a bleeding disorder caused when the body's defense (immune) system mounts an attack and destroys healthy blood platelets thinking they are disease-causing agents.

- **Immune** — the immune system is involved
- **Thrombocytopenic** — the blood doesn't have enough platelets
- **Purpura** — bleeding into the skin or bruising

ITP can be either acute (temporary) or chronic (long lasting).



**Q Which type of ITP do teens have?**

**A** There is no test to tell the difference. The younger you are the more likely your ITP will be acute; the older you are, the more likely it will be chronic. Doctors consider ITP persistent when it lasts longer than 3 months and chronic when it lasts longer than 12 months.

**Q What are platelets?**

**A** Platelets are relatively small, irregularly shaped components of your blood. They are required to keep your blood vessels from leaking and for your blood to clot. Without a sufficient number of platelets, a person with ITP is subject to spontaneous bleeding or bruising (purpura).

**Q Why are platelets so important?**

**A** Platelets are small, sticky components of the blood formed in the bone marrow (the soft, porous tissue found in the long bones of the body). Their job is to maintain the integrity of the blood vessels and seal small cuts and wounds by initiating the process to form a blood clot. If the blood doesn't have enough platelets, it is unable to clot as rapidly as it normally would. The result is excessive bruising and the tendency for people with ITP to bleed for a long time when cut or wounded. Though rare, it is possible, with a very low platelet count, to have spontaneous bleeding, including a cerebral hemorrhage, bleeding in the brain like a stroke.

**Q What is a normal platelet count?**

**A** Normal platelet counts generally range from 150,000 to 400,00 per microliter of blood. People with platelet counts under 10-20,000 have a severe case of ITP. A count of 30,000 is sufficient for many to prevent a catastrophic bleed. Individual reactions to low platelet counts differ. Determining a safe platelet count is a decision to be made in consultation with an experienced treating physician and is based on many factors.



**Q** What causes ITP?

**A** The specific cause of ITP is usually unknown. Some cases appear after a viral or bacterial infection, after immunizations, after exposure to a toxin, or in association with another illness such as lupus or HIV. It is important to recall what was happening in your life before you began having symptoms of low platelets. This information may be useful to your physician in diagnosing and treating your low platelet count.

**Q** Is my blood type a factor?

**A** None of the blood types have been linked to ITP. Being Rh + however allows treatment with IV anti D.

**Q** What about underlying diseases?

**A** Some people may have secondary ITP, meaning that their ITP is a result of some other condition. Secondary ITP can be caused by inherited immune disorders, systemic autoimmunity (the body attacks other cells as well as platelets), ongoing infections (like HIV, Hepatitis C and the stomach bacteria, *H. pylori*) and lymphoproliferative disorders (immune cells multiply without stopping, causing an overactive immune system).

**Q** What are the symptoms of ITP?

**A** The symptoms vary greatly from person to person. Most people with ITP experience spontaneous bruising. Some find they have petechiae (pe-TEEK-ee-ay), tiny red dots on the skin caused by broken blood vessels or leaks in a capillary wall. If your platelet count is very low you may have other bleeding symptoms including blood blisters on the inside of your cheeks or blood in your urine or stool. In general, the more bleeding symptoms you have, the lower your platelet count.

**Q** How do I know I have ITP?

**A** There is no definitive test for ITP. Your doctor will do tests that rule out other causes of low platelets. If no

“We were surprised and scared. It’s like you have cancer, but you won’t die from it.”

— CHARLIE



other cause is found, then the diagnosis is presumed to be ITP. ITP-specific treatment such as IVIg will confirm ITP if there is a good response.

**Q** What is a bone marrow test and why might I need it?

**A** Platelets are produced in your bone marrow. This test is done to confirm that the platelet production process is working properly. The test is typically done at the hip bone. First a shot of novocaine or other numbing agent is given. Then a needle is pushed through the bone and into the marrow. Some of the marrow is then suctioned out and examined. While some people experience little or no pain, others find this test very painful. It, however, provides unique information as to how well the patient can make platelets and if there are other problems in the marrow preventing platelet production.

**Q** Is there a “cure” for ITP?

**A** Many patients find their platelet count improves with one or more of the treatments. Some patients report that changing their diet or life style helps them feel better and improves their platelet counts. The disease can go into remission for a long time, perhaps for the remainder of a person’s life. ITP can also recur. There is currently no way to predict the course of the disease.

**Q** Is ITP contagious? Can it be spread to family and others?

**A** No, ITP is not a contagious disease and it cannot be spread to others like a cold.

**Q** What are the treatments?

**A** There are many treatments for ITP. They all have different risks and benefits and some are very toxic. It is important to understand both the success rate and potential side effects before beginning a treatment. Hematologists may use several treatments at once to increase their success rate.



Treatments for ITP include (in alphabetical order) anti-D (WinRho SDF®), Rhophylac®), azathioprine (Imuran®), corticosteroids (e.g., dexamethasone, methylprednisolone, prednisone), cyclophosphamide (Cytoxan®), cyclosporine (Sandimmune®), danazol (Danocrine®), dapsone, gamma globulin (e.g., IVIG), mycophenolate mofetil (Cellcept®), rituximab (Rituxan®), splenectomy, and vinca alkaloids (e.g., vincristine). Two new treatments for older teens (age 18 and older) and adults with chronic ITP were approved by the FDA in 2008. These treatments are romiplostim (Nplate) and eltrombopag (Promacta). Both are platelet growth factors. Other treatments are in clinical trials.

Some patients report success with complementary therapies such as vitamins, supplements, dietary changes, herbs, and energy work, such as Reiki. There are no controlled trials demonstrating utility or safety with any of these agents.

## **Q** What are the side effects of these treatments?

**A** Side effects have been reported for each of the drugs used to treat ITP. However, side effects will vary from one person to another. You may experience all, some, or no side effects at all. A description and side effects for frequently used treatments are described below.

**Prednisone** — Prednisone is a synthetic medicine (i.e., steroid) similar to cortisone, a natural substance produced in the body's adrenal glands. It is used in the treatment of ITP because it has been shown to increase the platelet count while it is being taken.

**Possible side effects:** Prednisone is generally only given for a few weeks at a time because it can have serious side effects with long-term use. And even when it is given for a short time, you may become more irritable, have stomach upsets, sleep disturbances, increased appetite, weight gain, puffy cheeks, frequent urination, sugar in the urine, loss of bone density, or acne. When the medicine is stopped, these side effects will begin to disappear.

**Intravenous gamma globulin (IVIg)** — IVIg is a liquid concentrate of antibodies purified from the plasma (the liquid portion of the blood that doesn't contain red blood cells) of healthy blood donors. IVIg is believed to work by interfering with the destruction of antibody-coated platelets. IVIg treatment will usually result in a rapid (24–48 hours) increase in the platelet count, but improvement generally lasts only 2–4 weeks. Treatment may be repeated until the platelet count improves permanently. IVIg is delivered by an intravenous infusion directly into a vein in the arm for several hours a day over a period of 1–5 days.

**Possible side effects:** Some patients treated with IVIg experience nausea and vomiting, headaches or fever and rarely, aseptic meningitis (a really bad headache), abnormal blood clots or kidney failure.

**Anti-Rho(D) immune globulin (WinRho®, Rhophylac®)** — Anti-D is also a liquid concentrate of antibodies derived from healthy human plasma. However, this medicine is targeted against the Rh factor\* on red blood cells. It is thought that anti-D binds to red blood cells to such an extent that the spleen is fully occupied eliminating red blood cells and does not have much opportunity to remove the antibody-coated platelets. Like IVIg, the response is usually rapid but temporary. If a hematologist recommends treating you with anti-D, it will be given by intravenous infusion. The procedure takes less than a half hour and can be done during an outpatient visit. Anti-D will generally not work if you are Rh-negative or have had a splenectomy (removal of the spleen).

**Possible side effects:** Temporary side effects from anti-D include fever, headache, chills, nausea and vomiting and anemia, and rarely, kidney failure.

**Monoclonal antibodies** — Rituximab (Rituxan®) is a monoclonal antibody approved by the FDA in November 1997 for treatment of lymphoma, a type of cancer. It is increasingly being used to treat ITP. It

\* Most people have Rh-positive blood. This means they produce the Rh factor, an inherited protein found on the surface of red blood cells. A small percentage of people lack the Rh factor. They are considered Rh-negative.

reduces the number of B cells, a type of white blood cell, in your body as well as changing the character of T-cells (another type of white blood cell). The B cells eliminated are not specific B cells that target cancer or ITP. Rituximab reduces the general population of all B cells with a specific receptor called CD20. After rituximab treatment, the body can take up to a year to replace the eliminated B cells and have the immune system and antibody production back in full working order. Rituximab is given by intravenous (IV) administration. Hypersensitivity reactions do occur in some patients. The manufacturer recommends premedication with acetaminophen (Tylenol®) and diphenhydramine (Benadryl®) before each infusion and prednisone is also helpful.

**Possible side effects:** Side effects that developed following 7% of infusions included headaches, chills, fever, and body aches. For patients with hypersensitivity to blood products there is a remote risk of anaphylaxis (shock response). If any patients experience back pain, chills, fever, changes in urine output, sudden weight gain, fluid retention/edema, or shortness of breath they should report these symptoms to their doctor immediately. A very small number of patients may experience severe anemia, which requires immediate medical attention. For additional information on rituximab for treatment of ITP, visit the PDSA Web site, [www.pdsa.org](http://www.pdsa.org).

**Platelet growth factors** — Platelet growth factors or thrombopoietin (TPO) receptor agonists are a new class of treatments for ITP that stimulate the bone marrow to produce more platelets. TPO, a protein made in the liver, naturally stimulates platelet production in the bone marrow. TPO receptor agonists bind to the same receptor as the TPO produced in the body, which prompts the megakaryocytes in the bone marrow to produce more platelets. While ITP is often considered a disease characterized by platelet destruction, recent research has shown that many people with ITP also have low platelet production. The additional bone marrow stimulation prompted by the TPO receptor agonists creates a sufficient number of platelets to overcome the platelet destruction or platelet production problems in most people who receive

“I have realized that I can’t let this disease take over my life. I’ve got to enjoy it, and all I have to do is be careful. At the beginning I was afraid my life was over, but in all reality, this disease has never held me back. It’s true I’m not able to do cheerleading, but at least I am alive and well.”

— DREYA



the treatments. In 2008 two different platelet growth factors (romiplostim and eltrombopag) received FDA approval for treatment of chronic ITP in teens 18 and older and adults.

The FDA has mandated that both of these new treatments only be available through a risk-assessment program. There is ongoing research in the use of these treatments for children younger than 18. The most common adverse reactions are joint and muscle pain, dizziness, insomnia, indigestion, and ‘pins and needles’ sensations. Potential exists for patients to develop reticulum (fibrous growths) in the bone marrow and also for the platelet count to drop below the pre-treatment count if the treatment is discontinued.

Romiplostim (Nplate®) is a manufactured peptibody (part peptide and part antibody) liquid that is given by subcutaneous injection (under the skin) initially once a week.

Eltrombopag (Promacta™) is a small molecule (pill) taken once daily Pills must be taken on an empty stomach as food, especially calcium-containing (e.g., milk, yogurt) affects its absorption.

For additional information on all treatments for ITP, visit the PDSA Web site, [www.pdsa.org](http://www.pdsa.org).

**Q** Why am I depressed, moody, and/or tired (at least some of the time)?

**A** Many people with ITP report being depressed. There are several possible explanations. One factor might be serotonin, a neurotransmitter that is carried by platelets and delivered to the brain and other parts of the body. Since serotonin helps regulate moods anything that interferes with serotonin processing could contribute to depression. Another factor is simply that you are dealing with a difficult and potentially chronic illness. This can lead to feelings of isolation, fear, and anger that your body has “turned against you”. A third factor is the treatments. Many of them list depression as a potential side effect. This is now a well-described but poorly understood phenomenon.



**Q Why am I so tired?**

**A** Fatigue is a common experience for people with ITP. It may be caused by the disease or it could be a response to your medications. Some patients report that changing to a healthy diet increases their energy level and reduces fatigue.

**Q How will ITP affect my period?**

**A** Heavy or prolonged periods are common in girls with ITP. If the bleeding is too heavy, birth control pills may help control your period. However, Oral Contraceptive Pills (OCP) may worsen the ITP itself. Speak to your hematologist or gynecologist if your bleeding is very heavy or lasts longer than 7 days.

**Q Can I play sports?**

**A** Depending on your platelet count, you may usually be able to play non-contact sports. This may mean that you will learn to be a tennis champ instead of a football quarterback. Talk to your doctor to decide which activities are best for you but don't let yourself be overly restricted.

**Q What symptoms should prompt me to call my health care provider?**

**A** Call your doctor or other health care provider immediately if you hit your head or have a serious accident. Signs of bleeding in the brain include: a headache that won't go away, dizziness, vomiting, unusual sleepiness, confusion, slurring of speech, eyes not moving together, weakness on one side of the body, a stiff neck or back, seizures, and the inability to see or hear. Watch for a large number of bruises and petechiae, or other signs of severe bleeding. This can indicate a very low platelet count. Also notify your doctor about nosebleeds, bleeding gums, or blood in your urine, stool, or vomit. Even if an ITP patient thinks they are in remission, they should watch for these symptoms so they can contact their health care provider immediately if they occur.

*"You mentally have to be stronger than the disease itself. The main thing is you have to take care of your body. Watch yourself daily for signs, and listen to your body. It will definitely help."*

*— Missy*



**Q** What do I do if something goes wrong?

**A** Tell someone. Speak to your parents if something is unusual; they love you and want the best for you. Make sure your doctor knows about all of your activities and any physical problems you experience.

“Tell your parents everything. Don’t hide the facts of bleeding and bruising episodes. This can be deadly.”

**Q** How do I tell my friends?

**A** Your friends might be curious about why you can’t play certain sports or they may wonder why you visit the doctor so often. Don’t be afraid to tell your friends about your disorder. They may want to help or learn more. Here are a few suggestions about how to tell your friends:

*“My body has trouble forming blood clots, so I bleed and bruise easily.”*

Answering why you won’t play football:

*“I need to be careful because my blood doesn’t clot well. If I get cut or bruised, I may not be able to stop bleeding.”*

If you are taking medication you may want to say:

*“Please be patient. The medicine makes me hungry/tired/moody, but I’m still the same person.”*

Feel free to give this booklet to your friends, teachers and family members. Contact our organization for additional copies.

**Q** Any other advice?

**A** Do something fun. Don’t let ITP control your life. Go for a hike. Spend time with friends. Learn something new. Read a good book. Your options are endless.

**Q** Where can I meet other teens with ITP?

**A** PDSA offers a discussion forum just for teens. Go to [www.pdsa.org](http://www.pdsa.org) and click on “Teens” to talk with other people like you.



**Q** Where can I get more information?

**A** The Platelet Disorder Support Association (PDSA) has more information on all of the topics in this pamphlet. There are hundreds of pages of information on the PDSA Web site, **[www.pdsa.org](http://www.pdsa.org)**. The organization publishes a monthly e-news update, a quarterly newsletter, informational booklets, and makes available other publications and articles. Each year, PDSA holds an annual conference and several regional meetings. PDSA has many support groups around the U.S. PDSA continues to expand their programs to offer more services and reach more people. In addition, information about ITP treatments is available through the Web sites of the companies that market them.



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

*ITP in Adults — Frequently Asked Questions*

*ITP in Children — Frequently Asked Questions*

*ITP and Pregnancy — Frequently Asked Questions*

*Coping with ITP*

*PTI en la adultez — Preguntas frecuentes*

*PTI infantil — Preguntas frecuentes*

*The Role and Function of Platelets in ITP*

*Parents Resource Packet*

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

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The Platelet Disorder Support Association is dedicated to enhancing the lives of people with ITP and other platelet disorders through education, advocacy, and research.

Membership benefits include a newsletter, discounts to the ITP Annual Conference, optional participation in the Name Exchange Program, and the good feeling of helping others.

PDSA is a 501(c)3 organization. All contributions are tax deductible.

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

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