

ITP in Teens

FREQUENTLY ASKED QUESTIONS





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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 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, the more likely it will be chronic. Doctors consider ITP chronic when it last longer than 6 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 What is a normal platelet count?

A Normal platelet counts range from 150,000 to 400,000 per microliter of blood. People with platelet counts under 10,000 are more prone to bleed. 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.

Q What causes ITP?

A The specific cause of ITP is 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.

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), infections (like the 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 other cause is found, then the diagnosis is often ITP.

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 painful.

Q Is there a cure for ITP?

A While there is no cure for ITP, many patients find their platelet count improves following treatment. What proves difficult for many ITP patients is finding the treatment that works for them without unwanted side effects. Some patients report that changing their diet or life style helps them feel better. 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 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.

"We were surprised and scared. It's like you have cancer, but you won't die from it."

— CHARLIE



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

Treatments for ITP include (in alphabetical order) anti-D (WinRho SDF®), azathioprine (Imuran®), corticosteroids (e.g., prednisone), cyclophosphamide (Cytoxan®), cyclosporine (Sandimmune®), danazol (Danocrine®), gammaglobulin (e.g., IVIG), mycophenolate mofetil (Cellcept®), rituximab (Rituxan®), splenectomy, and vinca alkaloids (e.g., vincristine). Additional treatments are in clinical trials.

Some patients report success with complementary therapies such as vitamins, supplements, diet changes, herbs and energy work.

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. 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.

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, most 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 overwhelming the spleen with antibody so that it cannot recognize the antibody-coated platelets. IVIG treatment will usually result in a rapid (24–48 hours) increase in the platelet count, but any improvement is generally shortlived. Treatment may be repeated until the platelet count improves. 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, abnormal blood clots or kidney failure.

Anti-Rho(D) immune globulin (WinRho®) — WinRho 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 WinRho 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 WinRho, it will be given by intravenous infusion. The procedure takes less than a half hour and can be done during an outpatient visit. WinRho 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 WinRho include fever, headache, chills, nausea and vomiting and anemia, and rarely, kidney failure.

Other treatments — Your doctor may suggest other treatments. You can contact our organization or web site (www.pdsa.org) for information about these.

Q Why am I depressed and moody?

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.

“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

* 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.

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

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 menstrual period?

A Heavy or prolonged menstrual periods are common in girls with ITP. If the bleeding is too heavy, birth control pills may help control your period. 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 still 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.

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.

Q How do I tell my friends?

A Your friends might be curious about why you can't play 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 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. The organization publishes a monthly e-news update, a quarterly newsletter and makes available other publications and articles. Each year, PDSA holds an annual conference and regional meetings. PDSA continues to expand their programs to offer more services and reach more people.

“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





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

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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