ITP in Teens
FREQUENTLY ASKED QUESTIONS
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
- Coping with ITP — Frequently Asked Questions
- Cómo Sobrellevar la PTI — Preguntas frecuentes (Spanish)
- Vivre avec le PTI — Questions Fréquemment Posées
- PTI en la adultez — Preguntas frecuentes (Spanish)
- PTI infantil — Preguntas frecuentes (Spanish)
- PTI chez l’adulte — Questions Fréquemment Posées (French)
- PTI chez l’enfant — Questions Fréquemment Posées (French)
- ITP and the Female Lifecycle — Bleeding Issues in the Stages of a Woman’s Life
- La PTI el ciclo de vida femenino — Problemas hemorrhágicos en las distintas etapas de la vida de una mujer (Spanish)

Health Insurance Assistance Programs for ITP Patients
The Role and Function of Platelets in ITP — Frequently Asked Questions
When A Child Has ITP — A Resource Guide for Parents
Parents Resource Packet

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

Platelet Disorder Support Association
133 Rollins Avenue, Suite 5, Rockville, MD 20852
tel 1-877-PLATELET (1-877-528-3538)
fax 301-770-6638
pdsa@pdsa.org
www.pdsa.org

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.

This patient information guide is supported by an educational donation provided by Amgen.

The information in this guide is for educational purposes only. For your child’s unique medical condition, please consult a doctor.
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 chronic when it lasts longer than six months in adults and 12 months in children.

Q What are platelets?
A Platelets are relatively small, irregularly shaped cells in 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 forming a blood clot. If the blood doesn’t have enough platelets, it is unable to clot as rapidly as needed. 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, or bleeding in the brain.

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 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.

Acknowledgments
The Platelet Disorder Support Association (PDSA) would like to thank Dr. Amy Geddis, Rady Children’s Hospital, San Diego and Dr. Michael Tarantino, Bleeding & Clotting Disorders Institute, Peoria, IL, for their medical review of this text.
How do I tell my friends?

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.

Any other advice?


Where can I meet other teens with ITP?

PDSA offers an online discussion forum just for teens. Go to [www.pdsa.org/forum-sp-534/index.html](http://www.pdsa.org/forum-sp-534/index.html) and click on “Teens” to talk with other people like you.

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Talk to your primary doctor (to investigate or explain symptoms before the diagnosis of ITP is made) or a hematologist (once the diagnosis of ITP is made). The Platelet Disorder Support Association (PDSA) has more information. Contact our organization for additional copies.

What causes ITP?

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.

Is my blood type a factor?

None of the blood types have been linked to ITP.

What about underlying diseases?

Some people may have secondary immune thrombocytopenia, meaning that their low platelet count is a result of some other condition. Secondary immune thrombocytopenia can be caused by inherited immune disorders, systemic global 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).

What are the symptoms of ITP?

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 the capillaries. 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.

How do I know I have ITP?

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.

“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.”

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Q What is a bone marrow test and why might I need it?
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A While there is no cure for ITP, 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.

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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., prednisone, prednisolone, methylprednisolone, dexamethasone), cyclophosphamide (Cytoxan®), cyclosporine (Sandimmune®), danazol (Danocrine®), gammaglobulin

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Eltrombopag (Promacta™) is a small molecule (pill) taken daily. Pills must be taken on an empty stomach as food affects its absorption. Possible side effects include mild to moderate headache and elevated liver function. As with other treatments in this class, the FDA is concerned about the development of reticulum in the bone marrow and a drop in platelet count after stopping the drug.

For additional information on all treatments for ITP, visit the PDSA Web site, www.pdsa.org.

Q: Why am I depressed and moody?
A: Many people with ITP report feeling depressed. There are several possible explanations. It has been thought that the level of serotonin (a neurotransmitter that is carried by platelets and delivered to the brain and other parts of the body) may be changed in people with low platelets. Since serotonin helps regulate moods anything that interferes with serotonin processing could contribute to depression. This and other biological effects of having low platelets may affect a person’s mood. 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.

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.

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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 way antibody-coated platelets are eliminated. 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 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, 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. Other treatments — Your doctor may suggest other treatments. You can contact our organization or Web site (www.pdsa.org) for information about these.

Monoclonal antibodies – Rituximab (Rituxan®) — Rituximab is a monoclonal antibody approved by the FDA in November 1997 for treatment of certain kinds of lymphoma, a type of cancer. It is increasingly being used to treat ITP. It reduces the number of B cells in the blood stream, 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 or more to replace the eliminated B cells and have the immune system and antibody production back in 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.

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.

Platelet growth factors romiplostim (Nplate®) and eltrombopag (Promacta®) — 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 unusually 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 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. There is on-going research in the use of this treatment for children younger than 18.

* 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.

“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
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“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 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:

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Q Any other advice?
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Q Where can I meet other teens with ITP?
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A: Normal platelet counts range from 150,000 to 400,000 per microliter of blood. People with platelet counts under 10,000 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.

Acknowledgments

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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
- Coping with ITP — Frequently Asked Questions
- Cómo Sobrellevar la PTI — Preguntas frecuentes (Spanish)
- Vivre avec le PTI — Questions Fréquemment Posées (French)
- PTI en la adultez — Preguntas frecuentes (Spanish)
- PTI infantil — Preguntas frecuentes (Spanish)
- PTI chez l’adulte — Questions Fréquemment Posées (French)
- PTI chez l’enfant — Questions Fréquemment Posées (French)
- ITP and the Female Lifecycle — Bleeding Issues in the Stages of a Woman’s Life
- La PTI el ciclo de vida femenino — Problemas hemorrágicos en las distintas etapas de la vida de una mujer (Spanish)

Health Insurance Assistance Programs for ITP Patients
The Role and Function of Platelets in ITP — Frequently Asked Questions
When A Child Has ITP — A Resource Guide for Parents
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.

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ITP in Teens
FREQUENTLY ASKED QUESTIONS