

ITP in Adults

FREQUENTLY ASKED QUESTIONS





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Q I've just been diagnosed with ITP. What is that?

A ITP, immune (idiopathic) thrombocytopenic purpura, is an autoimmune disease. In autoimmune diseases, the body mounts an immune attack toward one or more seemingly normal organ systems. In ITP, platelets are the target. They are marked as foreign by the immune system and eliminated in the spleen and sometimes, the liver. In addition to increased platelet destruction, some people with ITP also have impaired platelet production.

Q What are platelets?

A Platelets are relatively small, irregularly shaped components of our blood. They are required to maintain the integrity of our blood vessel walls and for blood to clot. Without a sufficient number of platelets, a person with ITP is subject to spontaneous bleeding or bruising.

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. For many, a count of 30,000 is sufficient 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 Can you inherit ITP?

A ITP is not usually considered a disease that can be passed from one generation to another. There are cases in which multiple family members have been diagnosed with ITP, but most researchers consider these a misdiagnosis.

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 is ITP diagnosed?

A ITP is a diagnosis of elimination. 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. There is no accurate, definitive test for ITP.

Q What is a “bone marrow aspiration” and why is it done?

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 Novocain 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.

“I woke up the morning of the 4th of June with blisters in my mouth and red spots on my skin. I also had bruises on my legs and arms. My family doctor acted quickly, and the blood tests confirmed what he thought. I had ITP.”

— GREG



Q Can ITP be cured?

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 lifestyle 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 treatments are available?

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 include (in alphabetical order) anti-D (WinRho SDF®), azathioprine (Imuran®), corticosteroids (ex. prednisone), cyclophosphamide (Cytoxan®), cyclosporine (Sandimmune®), danazol (Danocrine®), gamma globulin (ex. IVIg), mycophenolate mofetil (Cellcept®), rituximab (Rituxan®), splenectomy, and vinca alkaloids (ex. 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 Are there treatment guidelines?

A ITP treatments vary with the severity of the disease, age of the patient, the experience of the hematologist and other factors. Both the American Society for Hematology and the British Society for Haematology have published guidelines for treating ITP. However, there is no consensus on a treatment protocol. ITP treatment is evolving as researchers learn more about the disease.

Q Is there one treatment that is usually recommended?

A An initial course of prednisone is often given to newly diagnosed patients. Prednisone suppresses the immune

"I am one of the lucky ones who, after a five-year struggle (including a brain bleed), have been in remission for two years."

— BARBARA



system. It is hoped that suppressing the immune system will cause the patient's platelet count to increase and remain elevated after the patient stops taking prednisone. Sometimes a short course of dexamethasone, another corticosteroid, is used instead of prednisone.

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 to 48 hours) increase in the platelet count, but any improvement is generally short-lived. 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 to 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

"My platelets have stayed in the mid to high 30,000s since February. Even though that's low, it's safe and I haven't had to have any medical treatments other than blood tests."

— ROSELLYN



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, anemia, and rarely, kidney failure.

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

Q Do alternative treatments work?

A Some people report success with herbs, supplements, energy work, diet changes and other alternative treatments. There are many reported cases of their success but few formal studies. Many of the alternative treatments attempt to correct the underlying problem rather than treat the symptoms of the disease. They tend to take a longer time to be effective and have fewer unwanted side effects. Like the more traditional treatments, the alternative treatments do not have the same results in all who try them.

Q In addition to a low platelet count, I'm tired. Is this a normal part of the disease?

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 dietary changes increase their energy level and reduce fatigue.

Q Is depression a normal part of the disease?

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.

"I have had ITP for five years but the last two years have been the worst. The first three were okay, but for the past two years I have not been able to get my count above 23,000. I am struggling physically and, I must admit, emotionally too."

— DEBRA

* 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.

Since serotonin helps regulate mood, 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.

Q Are aches and pains a normal part of the disease?

A Some patients report these symptoms.

Q Will changing my diet or lifestyle make a difference?

A Some patients report that eating a healthier diet, exercising, meditating, avoiding toxins, etc. have a positive effect on their platelet count and how they feel. It is also important to avoid substances such as alcohol that can harm the bone marrow or substances such as aspirin that interfere with platelet function.

Q Can I still do the things I love?

A This is an individual decision based on your platelet count, your symptoms, your current lifestyle and the amount of risk with which you are comfortable. Your doctor can provide guidelines for you. Some people with ITP use the opportunity to enjoy new activities that do not place them at risk of bleeding.

Q Will I die from ITP?

A A very small percentage of people with ITP die from the disease or the treatments. The large majority of people find treatments that raise their platelet counts or successfully live with a low platelet count.

Q Am I eligible to go on disability?

A This varies. Some people with ITP have been successful in getting assistance. Others have found it a challenge. The severity of this disease and the impact on life-style varies greatly. Your success in getting disability assistance depends on how your case is presented and on the specific difficulties you are experiencing as a result of the ITP. Contact the Social Security Administration for more information.



Q What if I have ITP and want to have a baby?

A Many women with ITP deliver healthy babies, although this is not without some risk. Your decision to have a child and your treatments during pregnancy depend on your count, symptoms, and overall health and should be discussed with your doctor and obstetrician.

Q Can I give ITP to my children?

A If you are a woman with ITP and you become pregnant, some of the anti-platelet antibodies may cross the placenta and your baby may temporarily develop low counts. If this happens, the baby may be treated to prevent bleeding. When the baby's own immune system matures, the platelet count improves.

"I'm looking forward to completely recovering and getting off the meds."

—WAYNE

Q What can family and friends do to help?

A Most people are quite shocked to get this diagnosis. They probably have not heard of the disease before being diagnosed and have no idea what to expect. First reactions may include fear, confusion and stress. It's difficult to assimilate all the new terms and understand the treatment options in a crisis situation. You can ask your family and friends to be extra patient. You can explain that you have so much on your mind. You are learning as fast as possible and dealing with the side effects of some very potent drugs. You can explain that when counts are low, you may feel pretty awful, tired and often sad. Although you may look just fine, your body is waging an incredible war on the inside and this is exhausting work.

Q What else should I as the patient do or know?

A You should learn as much as you can about the disease. Do your homework, learn the benefits and the side effects of the recommended medications, decide how you want to approach the disease and your life, now that it has changed. Keep a copy of every lab report and copies of all blood work. Maintain a log of the medications used, dosages, your platelet count, and how they made you feel. Pay attention to your life-style and see if there is any correlation between your platelet count and the food you eat, the places you visit, noxious chemicals in your environment, etc. Often you are the person paying the most attention to these things. Truly, it is up to you to learn and help heal yourself.



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.



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

ITP in Teens — 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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