Learning about chronic immune (idiopathic) thrombocytopenia?

Let's move FORWARD

Not actual patients.

NOVARTIS

MY ITPELIFE
FACING ITP TOGETHER
Learning you have immune thrombocytopenia (ITP), and learning about the disease, can be a complicated and difficult process. This guide is designed to help you get more comfortable talking about the disease and possible treatments with your physicians, friends, and family.

**ON YOUR WAY TO UNDERSTANDING ITP**

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Check out the end of this brochure for:
• A platelet tracker to help you follow your treatment progress
• A refrigerator magnet to keep important contact information handy

Find the definitions of **bolded orange words** in My ITP Dictionary on page 12.
Bruises, Bleeding, Spots... What’s going on with me?

I sometimes experience 1 or more of these:

- Unexplained bruises
- Tiny red or purple dots on my skin (called petechiae)
- Bleeding too easily from my gums, nose, and cuts
- Bleeding that’s hard to stop
- Blood in my stool or urine
- A heavier than usual period flow (females)

Your doctor can help you understand what’s causing this.
WHAT DOES THAT MEAN?

Platelets are part of your blood. They help it clot and keep your blood vessels intact. When platelets are at very low levels, it can cause dangerous internal bleeding. So your doctor will need to measure your platelet count to see how serious your condition may be.1,2

YOUR HEALTH TEAM

There are many health care professionals who can diagnose and/or help you manage your cITP.

PRIMARY DOCTOR

Your first stop on the journey. Talk to your doctor about your symptoms and concerns.

HEMATOLOGIST

A blood specialist. Your doctor may send you or have already sent you to another doctor who specializes in blood and bone marrow: a hematologist, or sometimes a hematologist-oncologist. They are able to rule out other diseases.

NURSING STAFF

Nurses and other health professionals will help you navigate your journey by providing advice for treatments and on symptoms to watch out for.

SOCIAL WORKER/THERAPIST

The impact of a low blood platelet disorder is not only physical. There will be changes to your routine and your day-to-day life. It can really help to have someone to talk to as you adjust to your diagnosis.
SO MANY TESTS, NOT ENOUGH ANSWERS.

SHOULD I BE WORRIED?

Chronic ITP (cITP) is a chronic low blood platelet disorder usually diagnosed by process of elimination: Your doctors need to confirm that it isn’t another disease causing your low platelet count before giving a definitive ITP diagnosis.

Your doctor’s first step is a complete blood count (CBC) test and then a blood smear. A bone marrow aspiration and/or biopsy may also be performed. There may be many appointments with different doctors during the diagnosis and treatment process before the treatment best suited to your specific condition is found.³

You may be scared during this uncertain time. However, it’s important not to jump to any conclusions while your health team narrows down your diagnosis. In fact, it may take several visits over the course of a few weeks. This is all to ensure that you’re getting the right treatment and to help you manage your disease.³
IS IT AS SERIOUS AS IT SOUNDS?

ITP is a rare autoimmune condition that affects 9.5 of every 100,000 Americans. It’s not cancer, and it’s not contagious. People of any gender can have ITP but it’s slightly more common among adult women. Once your doctor has confirmed your ITP diagnosis, you might have 1 of 2 types—acute or chronic. Each has its own potential duration and class of treatments. 

Talk with your doctor about your type of ITP and the treatments they recommend.

ITP is a bleeding disorder in which your body’s immune system mistakenly targets your healthy platelets for destruction.

Platelets might be trapped in your spleen.

Without enough platelets to clot blood and protect your blood vessels, you are at risk for bleeding.

Bleeding may present itself as bruising, spots on the skin, or even a serious bleed in your brain or other vital organs.
GENERAL GUIDELINES TO PLATELET COUNT RANGES:

**450,000-100,000**
A normal range for your platelet count

**>50,000**
Symptoms are rare. This is usually the goal count of your cITP treatment

**50,000-30,000**
Excessive bleeding might occur, but usually only during trauma/surgery

**30,000-20,000**
Your doctor will likely need to get involved to help increase your platelet count.

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*a In patients, treatment is recommended for platelet counts <30,000 mm$^3$ and should be adjusted to maintain counts >50,000 mm$^3$.

*b Primary treatment options for ITP usually include corticosteroids, immunoglobulin therapy, or splenectomy.

Remember that you and your doctor will decide on your own platelet count goals, and you will find that many factors contribute to its level. Everyone’s target count is unique. That’s why it’s important to track your platelet count and think about the impact those levels have on how you feel day to day.
## The Types of ITP: Acute

<table>
<thead>
<tr>
<th>Type of ITP</th>
<th>Acute</th>
<th>TREATMENTS</th>
<th>Steroid pills and/or blood platelet infusions such as intravenous immunoglobulin (IVIG).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration</td>
<td>Up to 6 months.</td>
<td>Actions</td>
<td>If your platelet count and symptoms are stable, your doctor may choose to watch and wait for your ITP to go away. If they’re unstable, or you’re unable to handle the side effects of treatment, it’s time to move on to second-line treatments for persistent ITP. Acute ITP that resolves quickly is more common in children. Once ITP lasts longer than 6 months, it is usually considered chronic.</td>
</tr>
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### The Types of ITP: Chronic

<table>
<thead>
<tr>
<th>TYPE OF ITP</th>
<th>CHRONIC</th>
</tr>
</thead>
<tbody>
<tr>
<td>ITP lasts 6 months or more.</td>
<td></td>
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</table>

| TREATMENTS | Possible switch to platelet growth factors, like a thrombopoetin receptor agonist, immunosuppressants, injections, chemotherapy, or splenectomy (surgery to remove your spleen). |

| DURATION | 6 months or longer. |

| ACTIONS | If a specific treatment is working, and your platelet count and symptoms are stable, you can maintain that course of therapy. If it isn’t, your doctor may recommend a different therapy option. If your chronic ITP is severe, your doctor may consider splenectomy. In chronic ITP, platelets are removed from the blood and then destroyed or trapped in the spleen. By removing the spleen, more platelets remain in the blood. |

In case of an extremely low platelet count, you may need emergency platelet transfusions at a hospital to stabilize your levels.
Finding the right treatment and taking your medicine as prescribed will help you manage your chronic ITP. However, you still may have to deal with symptoms, especially if you undergo different treatments to find the one that best gets your ITP under control. Make sure you keep open communication with your health team and, when in doubt, don’t be shy. Just ask.

You should also pay attention to how your body responds to treatment, as each has different success rates and side effects, and every patient has their own response. Tracking your platelet levels and symptoms can be very useful. Your doctor uses this information to develop your treatment regimen. Once you start writing them down or tracking them in a smartphone app or the tracker included with this brochure, patterns can emerge that can help you and your doctor find a safe zone for success and get a better sense of the impact of your treatment.

**COMMUNICATION:**
- Don’t be embarrassed about being honest with your friends and loved ones about your disease. Let them know why you may have visible bruises or bleeding, and ask for help when you need it.
- Get a Medical Alert bracelet to keep those around you aware of your condition in the event of an emergency.

**COMMUNITY:**
- Stay informed. Review the best practices for managing autoimmune diseases and keep abreast of emerging treatment options. Check medical information about your disease and ways you can keep yourself healthy.
- Find a support group. There are many resources online where you can discuss your disease with people around the world who share the same experience.
- Participate in local meetings and activities with other ITP patients. PDSA.org and its local chapters are a great way to connect with them.
Q: Can I still brush my teeth with a toothbrush?
A: Yes you can!
Brush twice a day using a soft toothbrush. Use interdental brushes to remove plaque and food from between your teeth. They’re softer than dental floss.

Q: Can I move around the house without getting injured?
A: Yes you can!
There are simple ways you can make your living space more ITP-friendly. Cut down on clutter on the floor that might cause you to trip, get a rubber mat for your shower, and avoid rugs that slide around on the floor.

Q: Okay, but what about outside?
A: Yes you can!
Just be more aware of your surroundings. Don’t “text and walk,” make sure you can see around and above any items you might be carrying, and wear helmets and pads when the activity calls for them.

Q: Can I avoid suffering from constant fatigue?
A: Yes you can!
Keep your energy levels up with small snacks throughout the day! Also make sure you don’t suffer from “sleep debt,” where a few nights of bad sleep can cut down on sleep’s effectiveness later in the week. Try going to sleep a half hour earlier each day to catch up.
**Autoimmune condition**
A condition in which the body’s immune system attacks and destroys healthy body tissue.²

**Biopsy**
A procedure that removes cells or tissues from your body so they can be used to test for a disease.¹⁰

**Bone marrow**
The tissue inside some bones which contains stem cells that generate blood components such as red and white blood cells and platelets.¹¹

**Bone marrow aspiration**
A small sample of your bone marrow used for testing.¹⁰

**Chemotherapy**
While usually used to treat cancer, chemotherapy may be effective for some cITP patients, since it can help treat abnormalities in your immune system.³

**Hematologist**
A specialist in the study of blood, blood-forming tissues, and blood disorders.¹⁰

**Immune system**
A network of cells, tissues, and organs that work together to protect the body from disease-causing microorganisms and substances.¹²

**Immune thrombocytopenia (ITP)**
Thrombocytopenia that is caused by the destruction of platelets by the immune system.³

**Immunosuppressant**
A drug that lowers the activity of the immune system.¹⁰
**Infusions/intravenous**
Medicine given through a needle or tube inserted into a vein.\(^{10}\)

**Oncologist**
A physician who treats cancer. He or she may become involved in your treatment while your doctor narrows down your diagnosis.\(^{3,10}\)

**Petechiae**
Small red or purple spots caused by bleeding into the skin.\(^2\)

**Platelet transfusion**
To boost the platelet count, platelets are separated from whole blood and then transfused into the bloodstream. Usually requires more blood drawn than a regular transfusion.\(^{3,10}\)

**Platelet**
A blood cell fragment that helps wounds heal by forming blood clots.\(^{10}\)

**Spleen**
An organ that helps your body fight infection and keeps fluids in balance.\(^2\)

**Steroids**
Steroids known as corticosteroids are drugs that lower stresses and inflammation caused by disease or illness.\(^{15}\)

**Thrombocytopenia**
A blood disorder in which your blood doesn’t clot the way it should because the number of platelets is too low.\(^{3,10}\)

**Thrombopoetin receptor agonist**
An ITP treatment that stimulates platelet production. It is usually used after initial treatments have been unsuccessful.\(^2\)
Keep an eye on your platelets.

By tracking your platelet count, when you see the doctor, you can measure your progress with your health team as they observe your treatment and pick the best courses of action. This tracker can also help you understand how platelet levels affect your body and adapt to your new lifestyle.

Make copies of this tracker so that you will have spare copies for future use. Or you can also download a new copy at MyITPLife.com.

Plot your platelet count after each blood test. Fill in the date of your visit and your current treatment dosage.
YOUR PLATELET TRACKER

Work with your health team to actively keep track of how your platelet counts affect your ITP symptoms over the course of your treatment.
Your ITP journey can be challenging but, at MyITPLife.com, you can find help at every step of the way.

Here you will find more information and plenty of tools to manage your life with ITP. There are real patient stories, links to advocacy and community websites, and medical resources to keep you informed about your condition.