Coping with ITP

FREQUENTLY ASKED QUESTIONS

Platelet
Disorder
Support
Association

Empowering ITP Patients

Coping with ITP

FREQUENTLY ASKED QUESTIONS

When a patient has a chronic disease like ITP, finding means of coping is very important. This booklet provides information about ITP and offers suggestions for how to cope with the disease and with side effects of its treatments. It also offers ways to cope with the psychological aspects of having a chronic illness. Coping means "dealing successfully with something difficult" and "struggling to overcome problems or difficulties." Coping means managing, succeeding, and carrying on. The information in this booklet will help you successfully cope with ITP.

Q **What is ITP?**

A ITP is the abbreviation for immune thrombocytopenia *(THROM-bo-sigh-toe—pee-nee-uh),* a disorder characterized by an abnormal decrease in the number of platelets in the blood.

Immune – meaning the immune system is involved. The immune system is your body's defense against harmful substances and "invaders," such as bacteria and viruses. The immune system is made up of different organs, cells, and proteins that work together to keep you "healthy."

Thrombocytopenia – the medical term for a reduced number of platelets in the blood. Platelets are relatively small, disc-shaped cells in our blood. They are required to maintain the integrity of our blood vessel walls and for blood to clot. Without sufficient platelets, people with ITP are subject to spontaneous bleeding and easy bruising, or they may bleed for a long time if they get a cut. Women may have longer or heavier periods than normal.

ITP is not contagious and is considered rare because it occurs in approximately 9.5 people per every 100,000. You may hear ITP called by its original name of

idiopathic thrombocytopenic purpura. Historically, the term "idiopathic" was used because the cause of the condition was unknown. Today, we know ITP is an autoimmune disease, which means it is caused by the body's immune system mistakenly attacking and destroying healthy platelets.

Q **Who gets ITP?**

A Anyone can get ITP at any age. In children, ITP is most commonly diagnosed between 1 to 6 years of age, with occurrence slightly more common in boys than girls. Previous studies indicate that ITP may be more common in women, but only among those younger than 65 years of age. Newer studies also show that the chance of having ITP increases as people age.

"I hope I can experience a long-term recovery, but one never knows with this illness, so I take one week at a time."
- Sonia

Q **What is a normal platelet count? And what can happen when your platelet count is low?**

A Normal platelet counts range from 150,000 to 400,000 platelets per microliter of blood. Individuals with ITP usually have a platelet count under 100,000. The lower the platelet count, in general, the more risk there is for bleeding, although some people may have very low platelet counts (under 10,000) without any noticeable symptoms. Every person's body responds differently. Deciding what might be a safe platelet count for an ITP patient depends on their individual symptoms and activities and is a personalized decision made in consultation with a hematologist. A hematologist is a doctor who specializes in diseases of the blood and blood components. When deciding if or when to start treatment for ITP, many hematologists will consider not only the platelet count, but also a person's bleeding symptoms, activities and quality of life. Individuals who have few symptoms with a low platelet count do not always need treatment.

The physical symptoms of ITP vary greatly from person to person. Some individuals do not have any symptoms despite a low platelet count while others may have mild bleeding such as bruising under the skin and/or small purple/red pinpoint circles on their skin, called petechiae *(pe-TEEK-ee-eye)*. Petechiae are tiny spots of bleeding under the skin caused by damaged blood vessels. Usually these occur on the feet and lower extremities

but can occur anywhere on the body. Some individuals will experience more bleeding when their platelet count is low. Warning signs of serious bleeding risk include heavy bleeding and blood blisters in the mouth (gums and lips), stomach or intestines, urinary tract, nose, and brain. Women may also experience heavy menstrual bleeding (menorrhagia) and prolonged bleeding with their periods. When platelets are low, bleeding symptoms can happen without injury or may result from simple trauma, such as bumping into a table or toothbrushing.

Fatigue, a feeling of constant tiredness or weakness, is a common experience for those with ITP. This may be caused by the disease itself, or it could be a response to treatment. The underlying cause of fatigue in ITP is not clear but is very real. Many people with ITP also report feeling depressed or anxious.

Q
A

What happens to people with ITP?

While people with ITP may have a lot of the same symptoms, the way ITP progresses and affects an individual is different for everyone. Sometimes symptoms improve, sometimes they fluctuate or remain the same, and sometimes they can worsen. It is important for patients to track symptoms and personal experiences to provide detailed information to their health care team.

Children usually have ITP for a very limited time, often less than a year, whereas in adults, ITP is typically chronic, meaning it lasts longer than a year and is less likely to resolve on its own.

There are three phases of ITP:

Newly diagnosed ITP is ITP that is present for less than 3 months.

Persistent ITP is ITP that is present for 3 to 12 months. During this phase, many individuals with ITP may have spontaneous remission, which means that their symptoms and low platelet count may improve to normal standards on their own, or they may achieve remission after being treated with ITP medications. The majority of children with ITP will have ITP that improves within the newly diagnosed or persistent phases.

Chronic ITP is ITP that is present for more than 12 months. Chronic ITP is more common among adults but can also occur in children.

These time periods are approximations only to help doctors and researchers better understand and treat ITP.

Q A What is primary vs. secondary ITP?

When a low platelet count occurs in the absence of other known causes of thrombocytopenia, the diagnosis of primary ITP is made. For some individuals, the cause of a low platelet count may be a different underlying medical condition with symptoms similar to ITP. These individuals are said to have either secondary ITP or inherited thrombocytopenia. ITP is a diagnosis of exclusion. There is no accurate, definitive test for ITP. As a result, sometimes the true underlying cause of a low platelet count cannot be determined right away. It is possible some people with primary ITP may later be found to have secondary ITP if another cause of the low platelet count is found.

Doctors may do tests to rule out other causes of low platelets depending on symptoms, family history, physical exam, and other blood counts. They should look at a patient's blood cells under the microscope when determining which additional tests may be needed. Under certain circumstances, doctors may test for the presence of anti-platelet antibodies, secondary causes of ITP such as other autoimmune disorders (like lupus), immune deficiency issues (like common variable immune deficiency or CVID), and viral exposure (such as hepatitis, Epstein-Barr virus or, in some cases, HIV), and possibly bone marrow abnormalities. Rarely, quinine, found in tonic water and some anti-malaria drugs, can cause ITP. If you have been exposed to these it is important to let your doctor know.

Doctors might even suggest genetic testing to determine if there is a hereditary (genetic) condition causing low platelets, especially if the ITP is chronic and/or resistant to initial therapies, the patient has never had a normal platelet count, or there is a family history of low platelet counts. For more information on hereditary conditions that could cause a low platelet count, visit *PDSA.org/patients-caregivers/disease-information/genetics.*

Q **Can ITP be treated?**

A Yes. Treatment can improve the platelet count in most individuals with ITP, which decreases problems with bleeding. The difficulty for many people is finding the treatment that works for them without unwanted side effects. This is not easy. Some patients report that changing their diet or lifestyle helps them feel better. While the disease can go into remission for a long time, sometimes for the remainder of the person's life, ITP can also recur. There is currently no way to predict the course of the disease.

Coping with the Physical Symptoms of ITP

Q **Are there ways to minimize bleeding symptoms related to having ITP?**

A Those with ITP should take extra precautions to avoid injury, bumps, cuts, and bruises, and be extra careful when using sharp tools such as knives, razors, and scissors.

While bleeding isn't always related to the platelet count level, in that some can experience very low platelet counts and never experience bleeding, it's a good idea for people with ITP to check their platelet counts and follow them when experiencing bleeding and/or reduced quality of life. Copies of lab work should be kept, and maintaining a log of medications used, dosages, platelet counts, and how a patient feels is a good idea. It is recommended that people with ITP pay attention to their lifestyle, looking for any connection between a low platelet count and the food they eat, places they visit, and possible toxins in their environment.

Diet and lifestyle can influence ITP; therefore it is recommended that those with ITP eat plenty of dark, leafy greens loaded with Vitamin K (a vitamin needed for blood to clot). Alcohol in any but small amounts should be avoided as it can damage the bone marrow and harm the liver where the body makes clotting factors and the protein called thrombopoietin (TPO) that signals platelet production. Know the foods and substances that can interfere with the clotting process or reduce the number of platelets. PDSA maintains a

helpful list on its website at *PDSA.org/diet-lifestyle.* Avoid medications such as aspirin and NSAIDS that may reduce platelet function and increase bleeding.

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

A Even if a person with ITP has been in remission, they should contact their healthcare provider immediately if experiencing new signs of bleeding, including an increasing number or size of bruises and petechiae, nose bleeds, bleeding gums, blood in urine, stool, or vomit, or other signs of severe bleeding, which can indicate a very low platelet count.

A person with ITP should pay especially close attention if they hit their head or have a serious accident. Signs of bleeding in the brain include a headache (even one that may come and go), lack of appetite, dizziness, vomiting, unusual sleepiness, confusion, slurring of speech, weakness, seizures, or other changes in ability to do usual things.

"Educate yourself and take responsibility, both for what you can control and for knowing what you cannot. Mostly, remember that you've got ITP, but ITP doesn't have to have you."

- Lizabeth

Q **How can I stop worrying about platelet count and symptoms?**

A Many people with ITP worry about their platelet count, bruises, or petechiae. When the platelet count goes up it is easy to become elated and when the platelet count goes down, many people become depressed. Staring at bruises and looking for red dots can become habitual.

If you find yourself thinking about your platelet count and ITP for most of the day, consider substituting thoughts about something fun and fulfilling you are planning in the future to divert your attention. Services such as wellness therapy can be highly effective in helping to adjust to living with a rare chronic illness, like ITP.

Try to stay positive. Having a positive attitude, along with a sense of humor, can be helpful in managing the stress of having ITP. You may benefit by joining one of the local support groups sponsored by PDSA, where you can talk with others who have been touched by ITP either as a patient or a family member or caregiver. Find an ITP support group near you at *PDSA.org/support-groups.*

Q **In addition to a low platelet count, I'm often tired. Is fatigue a normal part of the disease? Will anything improve this?**

A Fatigue is a common experience for people with ITP. It may be caused by the disease itself or it could be a response to medications or other treatments. At this time, the cause of fatigue in ITP is unknown. Some people report that changing to a healthy diet (especially adding dark, leafy greens) increases their energy level and reduces fatigue. Be sure to get adequate rest but be careful with using "sleep aids" because of possible side effects. Try to avoid draining, exhausting situations that take up your energy. Include as many activities in your life as you can that energize you and make you happy and get plenty of exercise (check with your doctor for types of exercise appropriate for you).

Q **Should ITP patients wear medical alert jewelry?**

A It is recommended that those with ITP wear some type of medical alert identification. Wearing a medical alert bracelet or necklace can indicate you have ITP, a bleeding disorder, have had splenectomy, and/or are on steroids. This would help emergency medical staff quickly and correctly attend to your needs in an emergency situation. In addition, you should carry an identification card in your wallet with a list of your medications and dosages and a brief note on your illness. It is especially important to wear some type of medical alert jewelry while traveling. PDSA offers free wallet medical cards and has exclusive ITP medical alert jewelry for sale in our online Platelet Store at *PDSA.org/shop*.

Q **As a parent, how can I protect my busy, active child with ITP?**

A Encourage your child to live as active a life as possible. Talk to your child's doctor about activities that may be appropriate. Explain to older siblings the need to avoid rough play with the child with ITP and enlist their help in looking out for their sibling. For more information on what sports would be considered 'safe,' consider looking through our ITP in Children booklet, found at *PDSA.org/booklets*.

Use rubber no-slip mats in the tub or shower. Pad the sides of cribs for small children and for older children who may fall out of bed, put their mattress on the floor, or add a side rail. Clear obstacles such as tables and chairs that they frequently must go around. For small children, pad the corners of furniture and counters where they might run into them.

Q **What else can parents do to help a child cope with the physical symptoms of ITP?**

A Examine your child's skin for unexplained bruises or petechiae regularly at bath time. Check your child's stool or have them report to you any blood in their stool or urine. Blood in their urine may be red or brownish (tea- or cola-colored). Blood in the stool may be black like tar. Be sure your child is eating plenty of fruit, fruit juice, water, and fiber foods to avoid constipation.

Watch for bleeding in the mouth or nose, especially in the dry air season. Encourage only gentle nose blowing. Use a saline nose spray to moisten nasal passages during dry weather to help prevent nosebleeds. In addition, regular application of a Vaseline®-based compound to the child's nasal mucosa helps prevent bleeding.

Using a room or house humidifier can also help. To minimize gum bleeding, have your child use the softest toothbrush possible, using plenty of toothpaste, and avoid using dental floss until their platelet count is up. Use lip balm to keep their lips from drying and cracking. Report to your doctor or hospital immediately any blows or injuries to the child's head, belly, or back.

Avoid giving medications to your child until you have discussed them with their doctor or nurse practitioner. Check to be certain that any medicines recommended by your health care provider do not reduce platelets. Your child's platelet count can be affected by many over-the-counter pain, cold, and cough medicines. To minimize bleeding, aspirin or medicines containing salicylates (such as Pepto Bismol®) should not be used. Also, avoid ibuprofen and other NSAIDS. Usually, acetaminophen products (Tylenol®, Tempra®, etc.) are safe to give your child for a fever or pain while their platelet count is low.

Continue to learn all you can about ITP and its treatment and share more information with your child as they are able to understand it. Try to stay upbeat and avoid transmitting unnecessary anxiety and concern to your child. Explain to them that most children recover completely from ITP. PDSA offers the ITP POKE-R Club, a unique pediatric support program designed to help children manage the fear of injections that often result from treatments and frequent blood draws. The ITP POKE-R Club is a free and exclusive benefit of PDSA membership. Learn more at *PDSA.org/poke-r-club*.

Coping with the Side Effects of Treatments for ITP

Q **What are the main treatments available for ITP? What are the goals of treatment?**

A The main (first line) treatments for ITP are medications (drugs). The main medicinal treatments include corticosteroids (ex., prednisone), and intravenous gamma globulin (IVIG).

If the platelet count remains low or recurs after treatment, or steroids cannot be stopped after 6 weeks without a severe drop in platelet count, second line treatment may be necessary. Second line treatments include medications. In some cases, if low platelet counts persist for a year or more despite medical treatment a splenectomy (surgical removal of the spleen) may be suggested. Treatment for ITP is most often coordinated by a hematologist (a doctor who specializes in blood disorders). The goals of ITP treatment are to ensure a safe platelet count, prevent bleeding complications, and minimize treatment side effects.

All treatment options have different risks and benefits. It is important to understand both the success rate and potential side effects before beginning a treatment. PDSA offers helpful information on conventional ITP treatments, including detailed treatment tables that outline how each treatment works, potential side effects, likelihood of response, and other considerations. Visit *PDSA.org/conventional* to learn more.

"It is so important not to cancel one's life plans when you have ITP, but to rearrange them instead."
- Sue

Q **How can I find out about the latest developments in ITP treatment?**

A The Platelet Disorder Support Association (PDSA) is the go-to resource for the ITP patient community. Become a PDSA member at *PDSA.org/membership* and get connected to the latest on ITP diagnosis, research, and treatments.

Q **What are the side effects of ITP treatments?**

A Each ITP treatment has its own benefits and risks. Side effects have been reported for all available drugs and treatments for ITP. These side effects and their severity will vary from one person to another. You may experience all, some, or none of the side effects. Below is a description of two common first-line (initial) treatments for ITP and their potential side effects.

Common First-Line (Initial) Medicinal Therapies

Prednisone

Q **What is prednisone?**

A Prednisone, in a class of medications called corticosteroids, is similar to cortisone, a natural substance produced in the body's adrenal glands. Cortisone helps the body use carbohydrates, proteins, and fats and helps the body deal with stress.

Q **What are the possible side effects of prednisone?**

A Prednisone is generally given for only a few weeks at a time because it can have serious side effects with long-term use. In fact, professional medical guidelines developed in 2019 suggest using steroids for no more than six weeks to avoid long-term effects of steroid use. Prednisone affects every system in your body. Even when prednisone is given for a short time, you may feel irritable and experience stomach upset, sleep disturbances, headaches, increased appetite, weight gain, puffy cheeks, frequent urination, sugar in the urine, loss of bone density, loss of muscle mass (including the heart muscle), and skin problems. Once the medicine is stopped, most side effects will begin to disappear. As prednisone is tapered, patients may experience extreme fatigue.

This occurs because their adrenal glands haven't resumed their function of producing adrenal hormones, which normally give a person energy and vitality.

Q **Are there dietary changes that can help minimize prednisone weight gain?**

A Taking corticosteroids may cause increased appetite, weight gain, and changes in electrolytes, even when you watch your diet carefully. Seek nutritional advice and counseling. Talk with your doctor about a vitamin/mineral supplement to ensure adequate replacement of lost electrolytes. Following these dietary suggestions may lessen prednisone weight gain: Avoid salt (sodium) to help decrease fluid retention. Don't add salt to food. Find unsalted versions of foods you eat. Avoid salty snacks, such as chips and pretzels. Eat more fresh, unprocessed foods. Avoid fat. Steroids can increase levels of blood fats. A low-fat diet may help. Use good fats, such as cold pressed olive oil, for cooking and avoid fried foods and foods with trans fats. Avoid sugar. Refined white sugar can leach B vitamins, calcium, phosphorus, and iron from our teeth, bones, and tissues. Try alternative sweeteners such as rice syrup or barley malt for baked goods and cereal. Eat complex carbohydrates, which contain more fiber and are less sweet, including whole-grain breads and cereals, beans, brown rice, whole-grain pasta, and root vegetables. To combat increased hunger, snack more frequently on low-calorie fruit, vegetables, low-fat dairy, and low-salt rice cakes.

Q **What else helps in coping with prednisone?**

A Try to avoid stressful situations as much as possible. To cope with the side effects of prednisone, try using stress reduction strategies, including relaxation videos, yoga, and meditation. Also, avoid coffee and other products with caffeine. While taking steroids you may experience personality changes, memory issues, and/or mood swings. Consider getting counseling if the stress of prednisone becomes too difficult. Exercise to minimize muscle loss. See your doctor to monitor your health for signs of osteoporosis (bone thinning), high blood pressure, and diabetes.

PDSA offers a helpful resource booklet, *Coping with Prednisone,* for sale in The Platelet Store. Order your copy today at *PDSA.org/books*.

IVIG

Q **What is IVIG?**

A IVIG (intravenous gamma globulin), which comes in slightly different formulations made by a number of manufacturers, is a liquid concentrate of antibodies purified from the plasma (the liquid portion of the blood that doesn't contain blood cells) of healthy blood donors. IVIG treatment usually results in a rapid (within 24 to 48 hours) increase in the platelet count; however, any improvement is generally short-lived, usually lasting a month or less. IVIG is delivered by intravenous infusion directly into an arm vein for several hours a day over a period of one to five days.

Q **What are the possible side effects of IVIG?**

A Those with ITP treated with IVIG may experience side effects that include headache, fever, local skin reaction or pain at the infusion site, nausea and vomiting, leg cramps, rash, and flu-like symptoms. Rare but more severe side effects can include aseptic (noninfectious) meningitis, abnormal blood clots, or kidney failure. Patients on IVIG treatment should contact their doctors immediately if they experience the following more serious side effects: decreased urination, sudden weight gain, swelling of legs or ankles, chest tightness, or shortness of breath. IVIG is made from a protein extracted from human plasma and carries a small risk of transmittable disease. Because of the difficulty in manufacturing and the extensive screening that it must undergo, the cost of IVIG is quite high, creating a limitation on treatment for some.

Q **What can help in coping with side effects of IVIG?**

A As with any treatment, IVIG infusion has side effects. The key to getting the best treatment results while minimizing adverse effects is working closely with your health care team. Discuss the following tips with your health care team prior to treatment:

- Hydrate well with liquids the day before, of, and after the infusion; avoid caffeine and alcohol.
- Pre-medicate 30 to 60 minutes prior to infusion. Possible pre-meds to discuss with your health care team include diphenhydramine (Benadryl),

acetaminophen (Tylenol), prednisone, hydrocortisone, methylprednisolone (Solumedrol), and Saline IV.

- Decrease the rate of infusion. Do not exceed 4cc/kg/hour infusion rate unless directed by a physician.
- Ask for numbing cream before the intravenous line is inserted.
- Keep a log of infusions, pre-medications, lot numbers, and side effects, and jot down any questions.

Second-Line Therapies

Q **If "first-line" therapies are not effective, what "second-line" medical treatments might be prescribed to raise platelet counts?**

A If first-line therapies are not effective in raising platelet counts to a safe level or the side effects pose problems, a number of second-line treatments may be tried.

The two primary types of second-line treatment are either medical (drugs) or surgical (spleen removal). Second-line treatments include: thrombopoietin receptor agonists (such as Revolade/Promacta®, NPlate® and Doptelet®), antibodies (such as Rituxan®), and Tavalisse®. If the platelet count is still not satisfactorily controlled after more than a year surgical removal of the spleen (splenectomy) may be recommended.

Surgical Splenectomy Option

Another treatment for ITP involves surgery to remove the spleen (splenectomy) in patients whose platelet count remains below 30,000 and who have serious bleeding. Whether or not to undergo splenectomy is a decision that is complex because you must carefully consider the potential risks and benefits depending on your personal medical situation and medical history. The considerations are too many to fully cover in this brochure. Please consult your doctor.

Q **What is splenectomy?**

A Splenectomy is the surgical removal of the spleen, an organ that filters and stores blood, destroys old red blood cells, and produces antibodies to fight infections.

Splenectomy has been performed on thousands of patients over the decades in countries throughout the world with varied success. The long term success rate is approximately 60%. This type of surgery is performed in a hospital with the patient under general anesthesia (asleep). Many patients may be able to have laparoscopic surgery, which uses small incisions and has a faster recovery time.

Q A **How can a splenectomy stop platelet destruction?**

Since the spleen is an internal organ that is a major site for platelet destruction and for the production of autoantibodies in ITP, about two-thirds (or 67%) of ITP patients who remove their spleen will see their ITP go away. Removing the spleen may raise the platelet count by removing the major site of platelet destruction.

It is important to take note that professional medical guidelines developed in 2019 recommend delaying a splenectomy for at least a year following an ITP diagnosis as the disorder may resolve on its own during that time or other treatments may be effective. These same guidelines also suggest that if second-line therapy is required sooner it may be considered in those who have had ITP for longer than three months but suggest trying thrombopoietin receptor agonists and/or rituximab before going on to splenectomy.

It is also important to consider other options apart from splenectomy shortly after receiving an ITP diagnosis because your ITP may not be primary, it may be secondary (see page 4, “What is Primary vs Secondary ITP?”).

Q A **How do you know if splenectomy will work for you?**

There is no sure way to predict whether a splenectomy will resolve your ITP, or not. And there are no guarantees your ITP will not return if it does resolve for a while following splenectomy. There is a test called the splenic-sequestration test using autologous indium-labeled platelets that may be helpful in predicting response, however, this test is not readily available and must be performed by a very experienced medical professional.

ITP patients who do not respond to splenectomy are more often refractory (meaning not responsive) to other first and second-line therapies, however, this is not always the case.

Q **What are the side effects of having splenectomy?**

A Possible short-term complications of splenectomy immediately following surgery may include serious infections, such as sepsis. To minimize the risk of infections following the procedure, vaccination for pneumococci (bacteria) and liberal use of oral antibiotics are often used. The reason for the infection risk is that your spleen filters your blood and produces antibodies to help fight infections. It is very important to receive urgent parenteral (injection of) antibiotics if there are any fever and chills. Other side effects include mild-moderate infection, incisional bleeding, deep vein blood clots, pneumonia, incisional hernia, pancreas inflammation, and pulmonary embolism (a blood clot that travels to the lungs). While general anesthesia prevents pain during the surgery, there may be incision pain for several days after surgery.

Possible long-term complications of this surgical procedure include an increased risk of deep vein clots, severe infection (such as bacterial sepsis), and a possibility of an increased risk for a stroke or pulmonary hypertension.

COVID-19 infection in individuals who have undergone splenectomy may be more severe and more commonly require hospitalization.

Vaccination to prevent infections should be given at least 2 weeks prior to a planned splenectomy for them to be effective. If you have been treated with Rituxan® vaccination may not be effective for 9 months following treatment and splenectomy may need to be postponed until vaccination can be effective.

Q **How can I cope with the side effects of a splenectomy?**

A For incisional pain after surgery, your doctor can prescribe pain medication. You should avoid vigorous activity such as heavy lifting and driving as directed by your doctor.

Over the long term, patients who have had a splenectomy should seek medical attention for fever and major infections, as these may require antibiotics to prevent a more serious infection. In general, the

most common cause of an overwhelming bloodstream infection (sepsis) after splenectomy is the bacteria pneumococcus, which is a type of strep bacteria. The best way to prevent, avoid, and treat it is to a) get the pneumococcal vaccine every five years and check the response to it by having blood sent for antibody levels; b) have antibiotics at home so if high fever occurs they can be started immediately; and c) plan to go to the emergency room immediately at any time there is a fever of 101 degrees or higher no matter how you feel. Do not wait to see if the fever responds to Tylenol and do not wait until the morning. If the fever happens at 3 a.m. you should be leaving home at 3:05 a.m. Part of this means you need to have a thermometer handy and you need to take your temperature whenever you feel ill even if you do not feel very warm.

At the emergency room, a blood culture will be done, a blood count will be drawn, your blood pressure and vital signs including temperature, pulse, and respiration (breathing) rate will be assessed. Ideally, you will get an antibiotic right away. After that you need to be observed closely.

It is important to have information on you or in your wallet that you have undergone splenectomy. Always tell any doctor treating you that you do not have a spleen. When traveling outside the U.S., take special precautions against malaria, babesiosis, and other infections that may cause a threat and talk to your doctor about the benefits of traveling with antibiotics in case you need it while far away from home Talk to your health care provider about the immunizations you may need.

Additional Therapies

Other therapies that may be recommended if second line therapies are not effective include immunosuppressive therapies such as mycophenolate, cyclophosphamide (Cytoxan®), danazol (a hormone), azathioprine (Imuran®) among others. It is sometimes helpful to consult with a hematologist who specializes in ITP to help determine the best therapy to try if second line therapy is not effective. For more information, visit *PDSA.org/treating-itp.*

Alternative Treatments

Q **What about alternative medicine treatments?**

A Some patients report success with herbs, supplements, energy work, diet changes, and other alternative treatments. PDSA offers tips for suggested diet and lifestyle changes to help ease your ITP symptoms at *PDSA.org/diet-lifestyle.* As with more traditional treatments, alternative treatments do not have the same results for all who try them. Be sure to tell your doctor if you decide to use alternative or complementary therapies.

Coping with the Emotional Aspects of Having ITP

Q **Is there a standard solution for coping with ITP?**

A There is no "one size fits all" solution to make coping with ITP easier. People with ITP receive information about medications, treatments, and nutrition from many sources. Situations and coping strategies vary based on a person's genetics, lifestyle, influences, location, allergies, treatments, and available care. Therefore, it is best to explore what works best for you and the symptoms you are experiencing.

Q **How does having ITP change the patterns and relationships of life?**

A We are used to the everyday routines of life, and we struggle with new patterns that arise when we are dealing with a major life stressor like a chronic illness. As you cope with ITP, there may be changes in relationships and patterns in your family that can be unsettling for all involved. Some medications, such as corticosteroids, can cause emotional changes and it is important for other family members and friends to be aware of this. Successful coping means everyone must recognize and adjust to the new reality. Not everyone deals with stress the same way even in the same family, or friendship circle. If you find you are not supported by those around you, PDSA is here to help you navigate and feel supported in your ITP journey.

"I would have to say positive people and positive influences have helped me deal with my ITP. I have a great family and amazing friends. My outlook has totally changed… I believe our thoughts affect our health… I only want to attract positive and healthy things."

- NATALE

Q **How do I cope with feelings of helplessness and dependency?**

A Having ITP can certainly make you feel helpless. You may even worry about asking people for help too much. It's important to talk to those around you and share with them what you need or would like. It may not be obvious to them.

Q **How do I cope with the unpredictability of ITP?**

A The unpredictability of the disease is one of the worst aspects of having ITP. There is a "roller coaster" effect in dealing with this rare bleeding disorder. Understand that some of your plans may not work out. Realize that feeling distress at facing ITP is "normal." It may help to join a support group to meet others who are coping with ITP.

"At first I was afraid, I was petrified… but I tried to educate myself, to stay positive, and as time went by, I felt less afraid and knew that I had to do what a lot of others have to do — live one day at a time."
- SALLY

Q **How can I maintain some control over my ITP treatments?**

A Those with ITP need some element of control, to know in some way they are managing what is happening in their lives. Sometimes adding complementary or alternative approaches to your health care, such as energy therapy, yoga, or stress reduction techniques can offer additional coping strategies to supplement your medical care. It may also be helpful to focus on what you can do rather than things you cannot do at the moment due to your ITP.

Q **What helps children cope with the emotional aspects of ITP?**

A PDSA offers several helpful booklets, including *When a Child Has ITP* for parents and caregivers and *Understanding ITP,* written and illustrated just for children. You can download these and other educational booklets on ITP at *PDSA.org/booklets.* We also have a Parent and Child Teleconference Support group that meets throughout the year so that children can meet others with ITP and see they are not alone in their ITP journey. For information on PDSA ITP support groups, visit *PDSA.org/support-groups.*

Feelings Experienced by Those with ITP

ITP patients may experience many feelings throughout the course of their illness, including anxiety, anger, and depression. These feelings may be caused by the illness itself, from the treatments given, and/or from the process of coping with a chronic illness.

Q **How can those with ITP cope with feelings of anxiety?**

A Anxiety occurs when a person feels something bad is about to happen and they can't control it. Adding new coping skills and knowledge, such as learning to recognize your own signs of stress, keeping a diary of stressful situations that make you feel anxious, recognizing negative thoughts, and making the effort to substitute more helpful thoughts can help you cope with anxiety. Talking about your feelings with a trusted friend, family member, or medical professional is usually helpful. Having some control over medical decision-making also can ease your anxiety. Playing an active role in talking with your doctor and understanding your ITP treatment options can help you in making those decisions.

Q **How can those with ITP cope with anger?**

A Having ITP can make you feel angry for a variety of reasons. You didn't choose to have ITP, and it has caused a major change in your life. It is important to know that you didn't "cause" ITP. It is easy to feel angry and frustrated when you don't think your doctor is listening to you or offering you the best options for care. It can be helpful to learn ways to understand and deal with these feelings. Finding a physician who will respect shared decision-making and collaborate with you may be helpful.

Q **What causes depression in ITP?**

A Individuals dealing with a difficult, possibly chronic, illness may experience feelings of isolation, fear, and anger. Depression can also occur when experiencing a "loss," such as the loss of the healthy person we once were or the loss of relationships with family and friends that may change as a result of ITP. Another potential factor is the treatments for ITP. Many drugs used to treat ITP may bring on depression as a possible side effect.

Q A What can help those with ITP cope with depression?

There are various ways to cope with depression. It can be helpful to know it may be part of having ITP and living with a rare disease and could in part be due to some of the common treatments for ITP, such as a temporary use of corticosteroids.

Ask your doctor about the psychological effects of any medication that you take to treat your ITP Some ways to cope with depression include self-relaxation through podcasts, videos, meditation, prayer, and energy therapy. Coping with depression might include taking an anti-depressant medication or getting psychological counseling for a while. Ask for understanding from your family and friends as you cope with having ITP and the side effects of the treatments. Try to find activities that bring you joy and help you focus on the positive.

Eating a balanced and nutritious diet, eliminating sugar, and getting enough rest can also help in coping with depression.

Talk to your doctor about what medications may be safe to take with your ITP that can help treat depression. ITP patients and those with platelet disorders should be careful about using SSRIs (selective serotonin reuptake inhibitors), such as fluoxetine (Prozac®), paroxetine (Paxil®), sertraline (Zoloft®). These medications treat a variety of anxiety or mood disorders such as depression. Studies found that SSRIs block serotonin uptake into platelets, thus decreasing, reducing, or inhibiting platelet aggregation, adhesion, and agglutination (clumping of platelets). These are important steps in blood clotting. Using SSRIs could lead to bleeding problems for those with ITP.

Q A Why should I join a support group?

Many patients or parents of children with ITP benefit greatly from meeting, talking, or chatting online with others touched by ITP. People who have been through, or are going through, a similar circumstance can do more than sympathize with you — they can relate to what you are going through and keep you from feeling alone. Support groups are a place for people to give and receive emotional and practical

support as well as to exchange information. People with ITP, as well as their friends, families, and caregivers, find support groups to be a valuable resource. You may benefit by joining one of PDSA's 60+ local support groups across the U.S. and Canada. Find an ITP support group near you at *PDSA.org/support-groups*.

Q **How can family members and caregivers support the ITP patient?**

A Patients are often shocked to be diagnosed with ITP. Their initial reactions may include confusion, fear, and stress. It is hard to grasp all the new terms and understand the treatment options all at once or in a crisis situation.

Consider asking family, friends, and other caregivers to be extra patient. Explain to them that when your platelet counts are low, you may feel poorly, tired, moody, and sometimes sad. Side effects of your medications may make you feel bad as well. Even though you may look just fine on the outside, your body is waging an incredible battle inside. This can be exhausting.

"Another way to make it a little easier is to always be honest with yourself and loved ones… making sure that everyone who is important knows what's going on."
- MIKE

Q **As an ITP patient, what do I tell my child, siblings, parents, friends, teachers, and other adults about the disease and what is expected?**

A PDSA has a wide selection of helpful educational resources on ITP – many of which have been translated into multiple languages. These informational resources, including booklets written for adults and children, fact sheets, and a parent/school resource packet, are free and can be downloaded at *PDSA.org/booklets* or ordered directly through the PDSA office at PDSA@PDSA.org or (440) 746-9003.

Oftentimes, family, friends, teachers, and coworkers may not know how to help. These booklets can help them gain understanding. They may also want to proactively help by organizing a PDSA Pump It Up For Platelets! walk/run or fundraiser, or participate in ITP Awareness Month (September) at their school or place of work. PDSA is always happy to help and can provide educational resources for anyone interested.

Q **What can I do to support my caregiver(s) and reduce their stress?**

A Caregivers often suffer from stress themselves, which can lead to mental health struggles and physical health concerns.

Give caregivers credit when they do something that really made a difference for you and recognize their accomplishments in helping you cope with ITP. Remind them to take care of their own health, including keeping their own doctors' appointments, taking their medications, eating right, exercising, and getting enough rest. Encourage them to take a break each day, whenever they need it. Suggest they join a PDSA support group or see a professional counselor to provide an outlet for their concerns, frustrations, and fears. Ask them to learn as much as they can about your illness. And let them know of PDSA's webpage on caregiver support at *PDSA.org/caregiver-support.*

What Else Can I Do to Take Care of Myself?

Q **How can a person with ITP be more effective when interacting with their health care team?**

A Follow up with your health care team on a regular basis. Some important skills to have when talking to your health care providers include writing down important questions/issues before meeting with the doctor, asking the doctor to explain something you do not understand, and not leaving the important questions until the end of your visit when you may run out of time. Bring a list of your current medications and dosages. Before your visit, check with your doctor's office to be sure they have important lab results/ doctor's reports. PDSA has tips for those newly diagnosed at *PDSA.org/newly-diagnosed.*

If you feel unsure of your ability to interact effectively with your doctor, bring a family member or friend with you. It helps to have someone else listening. Take notes or ask the doctor if you can record the session for later review.

Q **What else should those with ITP do to take care of themselves?**

A It is important to learn how to listen to your body. If your body tells you to rest, do that. If you are thirsty, drink. It is also important to set your body up for success by feeding it well and treating it well. Visit the PDSA website, at *PDSA.org/diet-lifestyle,* for a list of substances that may lower platelet counts.

Learn as much as you can about the disease and available treatments. Meet others with ITP through discussion groups, local support group meetings, and the annual ITP Conference hosted by PDSA. Truly, it is up to you to learn and help heal yourself.

Staying Healthy to Cope With ITP

Q **What specific dietary changes should an ITP patient make?**

A To stay healthy as you cope with having ITP, follow as many of the dietary suggestions as possible. Below are some examples. You can also visit *PDSA.org/diet-lifestyle.*

- Eat a wide variety of foods.
- Eat whole foods, including vegetables, fruits, whole grains, nuts, and legumes. Limit white flour, white rice, and processed foods.
- Choose organic foods if available. Avoid those sprayed or treated with fertilizers and pesticides and wash fruits and vegetables carefully.
- Reduce sugar, including fructose, corn syrup, honey, and other sweeteners.
- Limit dairy, reducing or eliminating milk, cheese, ice cream, and yogurt from your diet, based on your reaction to these foods and your dietary needs.
- Use healthy fats and cold-pressed oils, such as olive or canola oil for cooking and baking. Avoid hydrogenated, partially hydrogenated, or trans fats.
- Eat green leafy vegetables such as kale, collard greens, and spinach. They contain calcium, minerals, and Vitamin K to help with clotting. Sea vegetables like seaweed are also beneficial.

- Limit canned and frozen foods and leftovers as the nutritional value of food deteriorates over time.
- Rely on lean, white fish, whole grains and beans, and nuts for protein.
- Limit alcoholic beverages.
- Avoid foods in large quantities that can thin the blood, such as blueberries, red/purple grape products, garlic, onion, ginseng, ginger, and tomatoes.
- Before taking any supplements, such as turmeric, ginger, or garlic check to see if taking these in large quantities can have a negative effect on platelet function.
- Avoid prominent food allergens. If allergic, get tested. Delayed food allergies can produce vague and difficult-to-diagnose symptoms.
- Chew your food well to aid digestion.
- Drink plenty of pure water at room temperature or above. Ice water can slow and hinder the digestive process.
- Strict vegetarians should make sure they get enough vitamin B12.

"The body cannot heal itself without proper nutrition and sleep, but in today's society, we are on a go-go-go schedule, and people forget to sit back and relax."
- Summer

Q **Will regular exercise help those with ITP better cope with their illness and depression?**

A Being physically active is another good way to cope with ITP. Exercise and stretching will give you a measure of power over your body by helping you gain strength, lessen bone and muscle loss, and regulate blood sugar levels. Ask your doctor what restrictions, if any, you may have on physical activity.

More Information

Q **Where can I learn more information about coping with ITP?**

A PDSA is home to the most comprehensive collection of resources on ITP and offers a wealth of information and invaluable support services and programming to help patients and caregivers navigate their ITP journey. Visit *PDSA.org* for hundreds of pages of helpful information, including other free educational booklets like this one. Sign up for PDSA's monthly e-News at *PDSA.org/enews* to receive the most current information on ITP research, treatments, and PDSA activities and events. Better yet, become a PDSA member and receive additional benefits, including our quarterly 28-page publication, The Platelet News, plus special discounted rates for attending the annual ITP Conference, purchases in The Platelet Store, and access to our pediatric support program, the ITP POKE-R Club. Join today by visiting *PDSA.org/membership* or by calling PDSA at (440) 746-9003.

Thank you to PDSA Medical Advisor Terry Gernsheimer, MD, from the University of Washington in Seattle, WA, for her contribution of information and medical review of this free educational booklet.

PDSA Offers the Following Helpful Resources for Managing ITP:

ITP Patient Connect Support Groups by region: *PDSA.org/support-groups*

ITP Helpline: (440) 746-9003 or *PDSA@PDSA.org*

Online discussion group: *PDSA.org/discussion-group*

Medical Emergency Cards and Medical Alert Jewelry for Patients with ITP: *PDSA.org/shop*

ITP POKE-R CLUB℠ Empowering Kids with ITP: *PDSA.org/poke-r-club*

Parents Teleconference Group – kids join in the first 30 minutes to talk with each other about life with ITP; then parents have the chance to talk and learn from one another: *PDSA.org/kids-parents-group*

Depending on your circumstances, one of our other booklets may also be helpful. Find our full inventory of educational booklets at *PDSA.org/booklets.* Many of these booklets are also available in multiple languages at *PDSA.org/translated-publications.*

ITP Pamphlet (perfect for sharing with families)

ITP in Children — Frequently Asked Questions

When a Child has ITP: A Resource Guide for Parents

Understanding ITP: A Story for Kids about Immune Thrombocytopenia

ITP Student Factsheet (perfect for sharing with schools)

ITP in Teens — Frequently Asked Questions

ITP in Adults – Frequently Asked Questions

ITP and the Female Lifecycle: Bleeding Issues in the Stages of a Woman's Life

Living with ITP – Answers to Common Questions

Health Insurance and Assistance Programs for ITP Patients

Who Pays for Drugs in Canada?

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

Platelet Disorder Support Association
8751 Brecksville Road, Suite 150, Cleveland, OH 44141
tel (440) 746-9003 • 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, research, and support.

Membership benefits include our 28-page publication, *The Platelet News,* newsletter, discounts to the ITP Annual Conference, and the good feeling of supporting the ITP community.

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

This patient information guide was supported by an educational donation by **Novartis**.

The information in this guide is for educational purposes only. For your unique medical condition, please consult a qualified medical doctor and/or health care provider.

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❍ I would like to join the Platelet Disorder Support Association (PDSA) to receive an information packet and *The Platelet News* quarterly newsletter for one year, and enclose $25 for membership.

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❍ I would like to raise funds for the PDSA.
Please send me fundraising information.

❍ I would like to receive an *ITP Emergency ID* card (1st one is free)

Please complete:

Name: _____

Address: _____

City: _____ State/Province: _____

Country: _____ Zip code: _____

Please help us update our records by completing this section of the form:

I am: ❍ an ITP patient ❍ parent of an ITP child ❍ family member
❍ friend/other ❍ health professional ❍ industry professional

For additional information about ITP and PDSA visit our Web site:
www.pdsa.org or send email to *pdsa@pdsa.org*

SEND THIS FORM TO: Platelet Disorder Support Association
8751 Brecksville Road, Suite 150
Cleveland, OH 44141

Call the PDSA office if you need assistance or to use a credit card:
877-528-3538 (toll-free) or (440) 746-9003

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